

# **Exploring Hope in People with Aphasia Following Stroke**

Felicity Bright

A thesis submitted to Auckland University of Technology in partial fulfilment of the requirements for the degree of Masters of Health Science

2011

School of Rehabilitation and Occupation Studies

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# Transcription Guide

The abbreviations and conventions given below are used throughout this thesis when excerpts from interview transcripts are provided:

<i>Italics</i>	Indicates the speech of the researcher
... (x s)	Signifies a pause in the participant's speech, length of pause (in seconds) is given in brackets
.....	Indicates words removed from the original transcript
[     ]	Indicates words added by the researcher to clarify the meaning of the quote
{exhalation}	Indicates non-verbal behaviour that contributed to the meaning of the excerpt
“     ”	Indicates a direct quote from a participant or from the literature
‘     ’	Signifies a quotation <i>within</i> a participant's direct quote
/     /	Indicates phonetic transcription using the International Phonetic Alphabet (IPA)

In addition,

- if the participant made phonemic paraphasic errors (sound substitutions), the direct transcription of their speech is provided using the IPA and the target word is identified in square brackets, e.g. /næʃənʊ / [rational]
- if the participant made semantic paraphasic errors (substitution of a related word), these are provided in regular font and the target word is identified in square brackets, e.g. nurse [speech-language therapist]

## Abbreviations

AQ:	Aphasia Quotient
AUT:	Auckland University of Technology
CT:	Computerised tomography
DHB:	District Health Board
IPA:	International phonetic alphabet
LPAA:	Life participation approach to aphasia
MCA:	Middle cerebral artery
MRI:	Magnetic resonance imaging
N:	Number
OT:	Occupational therapist
Psyc:	Psychologist
PT:	Physiotherapist
SAH:	Subarachnoid haemorrhage
sec:	seconds
SLT:	Speech-language therapy or speech-language therapist
SW:	Social worker
TBI:	Traumatic brain injury
WAB-R:	Western Aphasia Battery - Revised



## **Attestation of Authorship**

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

Signed:

Date:

Felicity Bright

## **Publications Resulting From This Research**

### **Publications Directly Emerging from this Research**

Bright, F., Kayes, N., McCann, C. & McPherson, K. (in press). Understanding hope after stroke: A systematic review of the literature using concept analysis. *Topics in Stroke Rehabilitation*.

Bright, F., Kayes, N., McCann, C., & McPherson, K. (31 May, 2011). *Understanding hope in therapy: Implications for practice*. Paper presented at the meeting of the New Zealand Speech-language Therapists' Association Professional Development Seminar, Dunedin.

Bright, F., Kayes, N., McCann, C., & McPherson, K. (21 April, 2010). *Hope: Its role in the journey of recovery*. Paper presented at the meeting of the New Zealand Speech-language Therapists' Association Conference, Wellington, New Zealand.

Bright, F., Kayes, N., McCann, C., & McPherson, K. (23 October, 2009). *The hopes and priorities of people with aphasia following stroke in the post-acute rehabilitation period*. Paper presented at the meeting of the Aphasia Association of New Zealand, Auckland.

### **Publications Influenced by this Research**

Bright, F., & Howe, T. (22 April, 2010). *Goal setting for speech-language therapists*. Workshop presented at the meeting of the New Zealand Speech-language Therapists' Association Conference, Wellington, New Zealand.

# Acknowledgements

This study has only been possible thanks to the involvement, support, and encouragement of a number of people.

To the participants who gave their time to talk about their experience of hope – thank you. I greatly appreciate your willingness to have a stranger come into your home and talk about what was often a very personal subject.

A number of people supported the design, data collection and analysis phases of this study and the writing of this thesis. Dr Huhana Hickey and Dr Ruth DeSouza gave advice regarding recruitment and interview processes involving Māori and Asian participants. Dr David Nicholls and Dr Shoba Nayar assisted me in addressing the methodological challenges that arose during the course of the study. A number of speech-language therapy colleagues helped recruit participants for this study. My sister Dr Viv Anderson – thank you for your help when I was getting stuck; sometimes just being able to talk through the issues was enough to kick-start me and help me keep going.

My supervisors, Dr Nicola Kayes, Dr Clare McCann and Prof Kath McPherson have been a constant source of knowledge and support. You continually challenged me, encouraging me to think critically about my analysis and my writing; the study is all the better for it. Nic, your patience with my questions and interruptions is greatly appreciated; you made the process of completing a Masters as easy as it could be.

My family have borne the brunt of my study. The boys have been very patient and tolerant over the last two years as I've been doing this "jolly Masters". Michael, thank you for all your support, emotionally and practically, for me and for our family. I could not have done it without you. Dan was six months old when the study started; Ben was just over six months when it finished. Thank you both for being good sleepers so I could work during the day! The boys have kept me grounded. Baby cuddles, trips to the zoo, Duplo construction and pretend cooking have been a welcome distraction from the laptop. I am looking forward to spending more time together, not distracted by what needs to be done next.

# **Ethical Approval**

Ethical approval was gained from the Northern Y Regional Health Ethics Committee (NTY/09/07/061) on the 1<sup>st</sup> of September, 2009, and the Auckland University of Technology Ethics Committee (09/022) on the 1<sup>st</sup> of October, 2009.

## Abstract

This study explored the experience of hope in people with aphasia following stroke during the post-acute rehabilitation period. Hope has been suggested to be important for recovery and rehabilitation in other healthcare populations. For example, some studies have found higher levels of hope to be associated with higher levels of quality of life.

A systematic review of hope in people with stroke, completed as part of this thesis, suggested people with stroke consider hope essential for recovery. Hope appeared to be experienced in three different ways – as an inner state, as outcome-oriented and as an active process. It was also related to levels of quality of life and depression. However, the review was limited as there were only a small number of studies that explicitly explored hope after stroke. In addition, people with aphasia were sometimes excluded from these studies despite aphasia being a relatively common consequence of stroke.

This current study drew on an Interpretive Description methodology to explore how hope was experienced by people with aphasia following stroke during the post-acute rehabilitation period, and what factors appeared to influence the experience of hope. Data were collected through multiple semi-structured interviews. Supported communication techniques were used to facilitate full participation of the individuals with aphasia. Data were analysed using a number of methods – coding, thematic analysis, narrative construction, diagramming and memoing.

Five people in the post-acute period of rehabilitation participated in this study. Participants were between two and five months post-stroke at the time of the interviews; all were participating in rehabilitation through outpatient or community-based services. They were aged between 41 and 62 years of age and had varying aphasia severity, as measured by the Western Aphasia Battery – Revised.

The data identified a core theme of “The Simplicity and Complexity of Hope”. Hope was experienced in two ways. *Simply ‘having’ hope* appeared to be the primary form of hope. It was a passive state where participants had a broad sense of hope

about their present state and future possibilities. At times, participants engaged in *actively hoping* – an active, future-oriented form of hope that could involve a process of *identifying hopes for the future* and *working toward hopes*. While this experience of hope appeared simple at face value, analysis indicated it was dynamic and complex. A number of factors appeared to influence how a person experienced hope. These factors were: uncertainty about the future; viewing hope as double-sided; and a sense of disruption. These appeared to be influenced by the participants' past experiences, current situation and perceived future. As a result, different forms of hope were experienced at different times. Sometimes they engaged in *actively hoping* and at other times, they appeared to retreat from *actively hoping*, instead focusing on *simply 'having' hope*.

Based on the findings of this study and on the existing literature on hope after stroke, it appears that hope is a concept that is worthy of consideration by clinicians. As such, a number of suggestions for how clinicians may consider hope in people with aphasia following stroke are discussed. These range from being aware of hope through to actively intervening in order to promote hope. This work contributes to the current knowledge about hope after stroke by exploring hope in people with aphasia during the post-acute period of recovery. It gives voice to a client group who are commonly excluded from research. It enhances understanding of the ways hope may be experienced by this particular population, and highlights the complexities that may be inherent in a person's experience of hope.

# Chapter One: Introduction

This study investigates how people with aphasia following stroke experience hope during the post-acute rehabilitation period. The literature in other healthcare populations suggests hope may be important in people's recovery and rehabilitation. However, to date there has been limited exploration of hope in people with stroke. Because people with aphasia have not been consistently included in studies of hope after stroke, and in fact are sometimes explicitly excluded, the body of knowledge about hope in this population is even more limited. Understanding how people with aphasia experience hope may help therapists better comprehend the lived experience of hope post-stroke and may assist them in considering its role in the journey of recovery of their individual patients.

This chapter provides the background to the study. It discusses the context for this work, describing aphasia and providing details about aphasia rehabilitation services. It then describes the research process, outlining why this topic was of interest, the process behind selection of the research question and methodology, and outlines the focus of inquiry. It also details the assumptions that were present prior to commencement of data collection. Finally, it provides an overview of the structure of the thesis.

## Context for the Study

Aphasia is a language disorder that results from a neurological event such as stroke, traumatic brain injury (TBI) or tumour. Stroke is the leading cause of aphasia (Goodglass, 1993). On admission to hospital, between 15 and 38% of people with an acute stroke present with aphasia (Inatomi, et al., 2008; Kauhanen, et al., 2000; Law, et al., 2009; Pedersen, Jorgensen, Nakayama, Raaschou, & Olson, 1995), while approximately 13-18% still have aphasia on discharge from hospital (Inatomi, et al., 2008; Pedersen, et al., 1995). At six months after stroke, 50-60% of these patients will

have residual aphasia (Pedersen, et al., 1995; Pedersen, Vinter, & Olsen, 2004). Extrapolating these findings suggests approximately 7-10% of people with stroke have aphasia at six months post-stroke. Kauhanen and colleagues (2000) found similar rates of aphasia were present at 12 months post-stroke.

Aphasia can present in a number of ways. At an impairment level, it may include altered auditory and/or reading comprehension and impaired word-finding and sentence construction (written and/or spoken) (Darley, 1982). Aphasia can have a significant impact on a person's functioning, impacting on their ability to communicate with others verbally or non-verbally, to fulfil their roles, to maintain and develop relationships and to participate in society (e.g. Cruice, Worrall, & Hickson, 2006; Dalemans, Witte, Beurskens, Van Den Heuvel, & Wade, 2010; Parr, Byng, Gilpin, & Ireland, 1997; Sjöqvist Nätterlund, 2010). It can also impact on psychosocial functioning (Parr, et al., 1997).

Within speech-language therapy, there has been a move toward participation-based, client-centred therapy focused on areas of importance to the individual with aphasia (LPAA, 2000; Worrall, 2006). Research completed with people with *chronic* aphasia has identified communication, participation in family and social life, contributing to society, dignity and respect, and being able to access information and services are key priorities (Parr, et al., 1997; Worrall, et al., 2011). Although the definition of *chronic* aphasia varies (Luck & Rose, 2007), it generally includes those who are beyond six or twelve months post-stroke (e.g. Barthel, Meinzer, Djundja, & Rockstroh, 2008; Cherney & Halper, 2008; Cruice, Worrall, & Hickson, 2011; Moss & Nicholas, 2006). While the *acute* phase of care and rehabilitation is generally hospital-based and focused on attaining medical stability and restoration of lost skills, the *post-acute* (but *pre-chronic*) phase commonly covers the period of transition from hospital to home and implementation of skills in 'real-world' settings (Buntin, 2007; Evans, 2007). There is a paucity of research investigating what people want, and hope for, during these early phases of rehabilitation.

Studies that considered the *post-acute* phase of aphasia described priorities of demonstrating communicative and cognitive competence, being shown respect and the importance of, and need for, hope (Green & Waks, 2008; Hersh, 2004; Parr, et al.,



1997; Worrall, Davidson, Hersh, Howe, & Sherratt, 2009; Worrall, et al., 2011). Several authors have suggested therapy during the post-acute period may appear unrelated to the person's hopes and priorities (Green & Waks, 2008; Hersh, 2004; Parr, et al., 1997). A limitation of this research is that it is retrospective. This may mean that people's recollections of their hopes at the time period under investigation differed from their actual hopes and needs at that time, based on what happened in the intervening period (Kirkevold, 2002). None of these studies explicitly sought to explore hope, although hope was a theme that emerged in their findings. It is not known whether the views of people with *chronic* aphasia are the same as those with *post-acute* aphasia, who may be in the early stages of adjustment to the stroke and its effects (Alaszewski, Alaszewski, & Potter, 2004; Kirkevold, 2002) and whose communication abilities may be changing (Pedersen, et al., 1995). In addition, there is little known about the processes that underlie a person's experience of hope. There is currently little known about hope in people during the *post-acute* period of rehabilitation despite this being the time when most therapy services are provided (Kirkland, 2008; Sarno, 2004). Therefore, exploring the experience of hope in people with aphasia during the *post-acute* period may further understanding of hope. This discussion will be further expanded in Chapter Two, Literature Review (see page 11).

This study was based in a metropolitan area in New Zealand (see Chapter Three, Methodology, page 51 for more details). Within this area, the majority of rehabilitation services are provided during the post-acute period of recovery. Inpatient and outpatient rehabilitation services are usually offered for short periods of time – the average length of stay in the inpatient service at the main public rehabilitation provider in the region is approximately 30 days; the average length of rehabilitation in the outpatient service is approximately 12 weeks (personal communication). While many patients transfer to community services, the models of service delivery through community services vary significantly – some offer only periodic monitoring while others provide active intervention over an extended period of time. As such, the *post-acute* period is the time that most people access rehabilitation services.

# Research Process

## Researcher's Interest

My interest in exploring hope in people with aphasia arose from a number of sources: my post-graduate rehabilitation study; clinical practice as a speech-language therapist in acute and rehabilitation settings; and my role, at the time of starting this study, as a clinical researcher on a trial of theoretically-informed goal-setting techniques for people with TBI.

As part of my postgraduate rehabilitation study, I researched goal-setting and led workplace projects to improve goal-setting processes. Even with well-designed processes, goal-setting was more complex than it appeared at face value. A person's engagement in goal-setting appeared to be influenced by their hopes and expectations for the future. From a clinical perspective, this was challenging. It appeared many patients hoped to get back to normal and this hope appeared to make it difficult for them to identify other goals. Returning to normal often appeared unrealistic from my perspective but I struggled to know how to address this with them. My next role as a clinical researcher on a TBI goal-setting study (McPherson, Kayes, & Weatherall, 2009) reinforced it was imperative to understand and work with things of importance to people. Taking the time to explore their hopes appeared important for engaging people in goal-setting. Indeed, my reading through the course of that project suggested there is an increasing appreciation of the need to ensure that goals are linked to broader, personally meaningful representations (Emmons & Kaiser, 1996) – this may include their hopes. Understanding the importance of hope often enabled me to work with the person to help them identify a range of personally meaningful goals. It assisted me to work *with* their hopes rather than see them as something that must be changed or challenged. When I looked specifically for information on what was important to people with aphasia, several papers identified priorities of people with aphasia (Green & Waks, 2008; Hersh, 2004; Liechty & Braun, 2006; Worrall, et al., 2009). While these papers identified what was important to people with aphasia in general, I was unable to find research that explored what was important to people

with aphasia (or what their hopes were) at the time they were receiving therapy. As a clinician, I was interested to learn more about this.

## **The Methodological Journey**

The process of identifying and implementing an appropriate methodology for this study was challenging. It appeared to be influenced by two things: the complexities of data collection and analysis which appeared to relate to the presence of aphasia, and the guiding questions for the study. The early methodological issues are discussed here as they provide contextual information about the study and informed subsequent methodological choices. Chapter Three, Methodology and Methods (page 51) discusses the actual methodology and methods adopted for this study.

**Developing the focus of inquiry.** For the reasons detailed above, the research question I was initially interested in exploring was: what are the hopes and priorities of people with aphasia after stroke in the post-acute period of rehabilitation? However, in the process of reviewing the literature for my research proposal it became evident that I had been making an assumption that hopes were synonymous with goals. While they appeared to be related, the literature suggested hope was generally considered a broader concept than goals (see Chapter Two, Literature Review, page 14 for details). As a result, I broadened the focus of inquiry for this study to include exploring the process and experience of hope in people with aphasia. This focus of inquiry guided early data collection and analysis.

**Exploring appropriate methodologies.** The process of identifying an appropriate research methodology for this study was challenging. It was intended that a constructivist grounded theory methodology would underpin the study as it uses a pragmatic, methodical approach to explore process and meaning (Charmaz, 2006). This was consistent with the initial focus of inquiry. Constructivist grounded theory also emphasises the relationship between the participant and researcher and involves the voice of both in the analysis. It was felt this would be beneficial as the participants

all had communication impairment; overt inclusion of the researcher's voice in the interpretation process would add transparency regarding interpretation.

As data collection and analysis proceeded, several methodological challenges emerged. Firstly, coding the responses of the participants was difficult. Initial coding should occur at a line-by-line level and should remain close to the data (Charmaz, 2006). However, there was frequently a need to interpret what the participants were meaning prior to initial coding due to the presence of receptive and expressive aphasia. This was because the aphasia affected the participant's understanding of questions, and their responses to questions. Participants presented with a variety of expressive aphasic errors including paraphasias (word or sound substitutions), altered syntax (sentence formulation) or difficulty producing responses (Davis, 2000). As a result of the lack of clarity in the expressive utterance, coding was necessarily interpretive in nature. Secondly, it appeared reducing data to codes resulted in the voices of the participants being lost. The 'essence' of what they were meaning and the complexity of hope that was apparent in interviews was not reflected in the coding. Thirdly, it felt that the data were being forced into a process model in response to the constructivist grounded theory methodology, which requires a focus on process and meaning (Charmaz, 2006). The forcing occurred because the data were primarily about experience of hope and there were limited data to support the development of a process model. There were several factors that contributed to this: the lack of a clear process-oriented question to inform the study, the questions during the interviews focused on experience rather than process and the difficulty in eliciting process-oriented data. The latter was likely partly because hope is considered a subconscious process and the interview was possibly the first time the participants were specifically thinking about their experience of hope (Cross & Schneider, 2010). In addition, the participant's aphasia (and often co-existing cognitive deficits) may have impacted on their ability to recall and recount the process of hope, if in fact a process was present.

These dilemmas were discussed with several experienced qualitative researchers. They suggested the methodology should be reconsidered, that other research methods may better represent the participants' voices. One possible approach was to support the grounded theory analysis with performance ethnography

to increase the visibility of the participant's voices (Kennedy, 2009). Charmaz and Mitchell (2001) have previously integrated ethnography and constructivist grounded theory, which reinforced this could be an appropriate combination of methods. However, in order to complete a true grounded theory study, the focus would need to return to the basic social process, there would need to be greater theoretical sampling and the processes within the basic social process would need to be further explored (Corbin & Strauss, 2008). The discussions also confirmed that while the interviews had gathered limited process-oriented data, they had gathered rich data about people's experiences of hope. This was lost by focusing on process. As a result, it was agreed exploring another qualitative methodology may help address the issues of forcing data, reduction of data and subsequent loss of participant voice, and would allow for more comprehensive exploration of *experiences* rather than *processes* of hope.

After exploring the methodological literature, Interpretive Description (Hunt, 2009; Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004) was identified as the most appropriate methodology as it aims for analysis at an interpretive, conceptual level and explores patterns and relationships between data, aiming to shed new light on the phenomenon (Hunt, 2009; Thorne, et al., 2004). The richness of the gathered data was evident at this time and it was clear that it could be interrogated in a way that would meet these objectives. Further details of this methodology, a more comprehensive rationale for adopting it for this study and how it was utilised are provided in Chapter Three, Methodology and Methods (page 51).

## **Researcher's Assumptions**

Thorne (2008) stated Interpretive Description studies should be scaffolded by the researcher's clinical background, knowledge about the topic, and by the literature. However, she cautioned that the researcher's knowledge and assumptions may impact on the data analysis process, often unconsciously (Thorne, et al., 1997). One way to illuminate the researcher's knowledge and assumptions about the topic is to specifically identify these prior to commencing the study. It is intended that this would reduce the unconscious influence these assumptions might have during the data

analysis process (Creswell, 1994). This approach is utilised in many qualitative methodologies (Patton, 2002). Prior to data collection, I identified the assumptions I brought to the study through discussion with my primary supervisor and written reflections. These assumptions primarily emerged from my clinical practice and from my personal experiences of hope. Key assumptions identified were: (a) hopes may be unconscious, emerging only when the hope was either realised or dashed; (b) hopes were synonymous with goals; (c) hope was directed at a particular outcome, for example, "I hope to be able to ....."; and (d) the process of hope required action to bring about the particular hope. As has already been discussed on page 5 in this Chapter, the assumption that hopes were synonymous with goals was challenged prior to data collection. Other assumptions were challenged throughout the process of data collection and analysis.

## **Focus of Inquiry**

This study will explore how people with aphasia following stroke in the post-acute period of rehabilitation experience hope, and what factors contribute to their experience of hope. As Chapter Two, Literature Review will demonstrate, there has been limited research into hope after stroke and people with aphasia have been inconsistently included in this research. By involving those with aphasia while they are having therapy, the current body of knowledge about hope after stroke will be enhanced. It is hoped this will assist speech-language therapists to explore hope with their patients with aphasia. Interpretive Descriptive methodology was used to guide this study. Semi-structured interviews were the primary source of data collection. Multiple methods were used for data analysis, as detailed in Chapter Three, Methodology and Methods (see page 61). It is intended that this study will provide insight into the experience of hope in people with aphasia during their rehabilitation period.

## Definitions of Terms

**Hope.** Two definitions of hope were used to guide this study. These definitions are:

“Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future goal which to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380), and

“Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving and a way of relating to oneself and the world” (Farran, Herth, & Popovich, 1995, p. 6).

These definitions were determined after completing a conceptual review of hope after stroke and best reflected how hope was conceptualised after stroke (Bright, Kayes, McCann, & McPherson, in press). Further discussion regarding definitions of hope is provided in Chapter Two, Literature Review (see page 14).

**Post-acute rehabilitation.** The post-acute period of rehabilitation was considered to be the first episode of rehabilitation that followed a person’s discharge from the hospital or inpatient unit, to their living situation in the community, for example, their home or a rest home.

**Working-aged adults.** This study focuses specifically on working-aged adults, as will be discussed further in Chapter Two: Literature Review (see page 12). Working-aged adults are defined as adults between 16 and 64 years of age.

## Structure of the Thesis

Chapter Two, Literature Review, will provide a rationale for exploring hope in people with aphasia following stroke. It will summarise key literature on the concept of hope. It will look specifically at the current state of knowledge about hope after stroke and then focus on what is currently known, and not known, about hope in people with aphasia. Chapter Two provides part of the scaffold for the study, alongside the section on the Researcher’s Interest presented earlier in this chapter (page 4).

Chapter Three, Methodology and Methods, will provide an overview of Interpretive Description, the methodology that underpins this study, and will provide a rationale for using this methodology. It will detail the methods used for data collection, discussing how the study was designed in order to maximise the participation of people with aphasia. It will describe the different techniques used in data analysis. It will outline how key ethical principles, such as informed consent and voluntary participation, were adhered to. Finally, it will detail the steps taken to ensure rigour throughout the study.

Chapter Four, Findings, will identify the primary ways that hope appeared to be experienced by participants in the study and will explore the factors that reportedly impacted on the experience of hope. The findings are presented in a narrative format that incorporates data interpretation. Quotes are used to support these findings and are predominantly within the narrative. This approach was chosen as the presence of aphasia meant that the pertinent data were often in short quotes.

Finally, Chapter Five, Discussion, will discuss the findings, reflecting on these in relation to literature on hope and related concepts. In keeping with Interpretive Description, it has a strong focus on the clinical implications of the findings. It identifies the study limitations, and provides suggestions for future research on this topic.



## **Chapter Two: Literature Review**

This chapter provides a summary of the literature relevant to the research topic of hope after stroke in people with aphasia. It initially discusses stroke recovery and common features of the post-acute rehabilitation period. It discusses why hope may be a factor that influences rehabilitation. The chapter then provides an overview of the concept of hope before exploring the current state of knowledge about it in the stroke population. Finally, it provides a rationale for investigating hope in people with aphasia specifically. This literature review provides the scaffold for the study, framing the research question and study design (Thorne, 2008).

### **Stroke Recovery and Rehabilitation**

Stroke is a relatively common health condition, affecting approximately 7600 people in New Zealand each year (Stroke Foundation of New Zealand, 2003). Stroke can have a number of consequences including aphasia, hemiparesis, cognitive impairment, incontinence, seizures, and depression (Feigin, et al., 2010; Kauhanen, et al., 2000). These impairments may be permanent (Kauhanen, et al., 2000). For example, one study found at five years' post-stroke, 71% of people with stroke had mild neurological impairment, 29% had depression and 9% had seizures (Feigin, et al., 2010). Stroke can also have significant social consequences, including difficulty returning to work, altered family relationships, social isolation, and reduction in leisure activities and community involvement (Daniel, Wolfe, Busch, & McKeivitt, 2009; Haun, Rittman, & Sberna, 2008; Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007; Salter, Hellings, Foley, & Teasell, 2008). These psychosocial sequelae are well recognised in people with aphasia (e.g. Dalemans, et al., 2010; Hilari, 2011; Parr, et al., 1997). Some research indicates people with aphasia may have higher levels of psychosocial sequelae, for example, psychological distress (Hilari, 2011), as interpersonal communication is often a key component in many social activities. Ongoing deficits post-stroke have been correlated with lower levels of activity and participation (Feigin,

et al., 2010). The effects of the stroke for an individual may vary depending on their life circumstances at the time. For example, working-age stroke survivors have been identified as a unique yet diverse group of stroke patients who have age-specific issues (e.g. Bendz, 2003; Daniel, et al., 2009) . 'Working-age' commonly refers to people less than 65 years of age (Anderson, et al., 2005; Bendz, 2003; Islam, et al., 2008). They are more likely to be employed and supporting a family, financially and emotionally (Bendz, 2003) which may impact on their hopes and priorities in life (Nair, 2003).

The post-acute period of recovery has been described as a time of transition (Rittman, et al., 2004). People are often participating in rehabilitation, which helps them maintain hope their situation will improve (Becker & Kaufman, 1995; Kirkevold, 2002). However, this may be countered by the emotional changes that become more evident during the transition between hospital and home. This process can see a growing sense of loss, stress, disruption and uncertainty (Becker & Kaufman, 1995; Rittman, et al., 2004) as a result of a growing awareness of the consequences of the stroke (Doolittle, 1992; Eilertsen, Kirkevold, & Bjørk, 2010; Nilsson, Jansson, & Norberg, 1997). During this post-acute period, many people engage in a process of waiting to get better and for treatment to have an effect, which can result in a sense of passivity about the future (Rittman, et al., 2004; Wallenbert & Jonsson, 2005). This sense of waiting and passivity can be exacerbated because outcomes are often uncertain at this stage (Doolittle, 1992; Eilertsen, et al., 2010).

There are a number of prognostic indicators for broad stroke-related outcomes such as survival, living situation and level of independence. These include: continence, extent of cranial nerve and cortical impairment, size and severity of stroke, presence of dysphagia and cognitive impairment (Frank, Schlote, Hasenbein, & Wallesch, 2006; Massucci, et al., 2006; Meijer, et al., 2003; Teasall, Foley, & Salter, 2009). Social and psychological factors such as depression, social support and pre-stroke activity levels are also associated with outcomes from stroke (Massucci, et al., 2006; Teasall, et al., 2009). Initial aphasia severity is considered a strong predictor of long-term aphasia recovery (Lazar, et al., 2010; Plowman, Hentz, & Ellis, 2011), as are lesion site and size (Plowman, et al., 2011). Clinicians have been shown to be between 61 and 75% accurate at predicting broad outcomes from stroke with accuracy rates higher for short-term outcomes (Frank, et al., 2006; Olai, Omne-Pontén, Borgquist, & Svärdsudd,

2007). Despite knowledge of broad prognostic indicators, it is challenging for clinicians to predict how an individual will recover from the stroke in terms of impairments and functional, personally meaningful recovery (Dam, et al., 1993; Hendricks, Van Limbeek, Geurts, & Zwarts, 2002). It is not uncommon for individuals with similar stroke sequelae who receive similar or identical intervention to have different outcomes from their rehabilitation (e.g. Cramp, et al., 2010), significant at both a functional and statistical level. This suggests that rehabilitation outcomes may be influenced by more than just the specific impairments and subsequent therapy that individuals receive.

Researchers have started to explore some of the factors that may contribute to individual differences in recovery. Factors such as motivation (Cramp, et al., 2010), depression (Barker-Collo, Feigin, Parag, Lawes, & Senior, 2010) and self-efficacy (Brock, et al., 2009) have been hypothesised as possible contributors to this variation. It has been suggested that one direction for future research should include identifying these factors and investigating how they impact on rehabilitation and recovery after stroke (Barker-Collo, et al., 2010; Gillen, 2006).

Hope may be one variable that influences a person's outcomes from rehabilitation and recovery from stroke (e.g. Barker & Brauer, 2005; Bluvol, 2003; Gum, Snyder, & Duncan, 2006). Research in other healthcare populations has suggested that hope is a significant factor in living with and/or recovering from an illness or injury. Qualitative studies of hope in people with spinal cord injury indicated hope is essential for coping and adjustment (Dorsett, 2010) and supports recovery (Lohne & Severinsson, 2004). Kent and La Grow (2007) found hope has a significant role in adjusting to acquired hearing loss. It serves to moderate the sense of loss that results from the hearing impairment. Research with people with terminal illness suggests higher levels of hope are associated with improved coping and quality of life and with lower levels of distress (Herth, 2000; McClement & Chochinov, 2008). Further research into hope after stroke may be useful to explore its role in recovery from stroke.

# Understanding Hope

## Dominant Definitions of Hope

Hope has been studied in a number of healthcare populations such as oncology (Herth, 2000; Little & Sayers, 2004; McClement & Chochinov, 2008; Reynolds, 2008), palliative care (Duggleby & Wright, 2005; Reynolds, 2008), HIV/AIDs (Cutcliffe, 1995; Kylmä, 2005; Kylmä, Vehvilainen-Julkunen, & Lähdevirta, 2001), psychiatric populations (Farran & Popovich, 1990; Schrank, Stanghellini, & Slade, 2008) and spinal cord injury (Lohne & Severinsson, 2004, 2005).

Five primary definitions of hope have been used in the study of hope in healthcare populations. These definitions fall along a continuum. At one end, hope is conceptualised as a way of being; at the other end, hope is conceptualised as goal-oriented. In between the two, hope is conceptualised as a way of relating, a way of acting and a way of thinking. Most of the existing definitions covered several parts of the continuum, as illustrated in Figure 1.

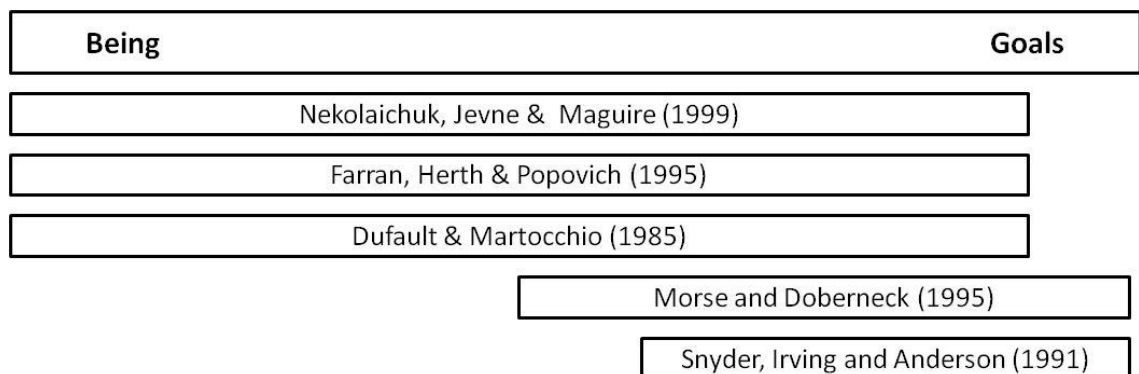


Figure 1. Continuum of definitions of hope

Nekolaichuk, Jevne and Maguire (1999) suggested there are three subjective dimensions of hope. The first dimension, *personal spirit*, focuses on a personal, subjective construction of hope. Its attributes include that it has meaning, is engaging, involves caring and has value. The second dimension, *risk*, focuses on its predictability:

hopes may be relatively certain or expected and boldness is required to hope. The third dimension, *authentic caring*, describes an interpersonal aspect: it incorporates a relational component to holding and working toward hopes. This definition incorporates a sense of hope as a way of being, an internal state, in addition to thinking and acting in order to bring about specific hopes.

Dufault and Martocchio (1985) and Farran, Herth and Popovich (1995) had similar conceptualisations of hope. Dufault and Martocchio defined it as “a multidimensional dynamic life force characterized by a confident expectation of achieving future good which, to the hoping person is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). Farran and colleagues provided more detail of its dimensions within their definition, saying hope was “an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving and a way of relating to oneself and one’s world” (Farran, et al., 1995, p. 6).

Dufault and Martocchio (1985) suggested there are two spheres of hope – generalised and particularised. Generalised hope was described as the presence, or sense of hope, and is not related to a specific state or object. In contrast, particularised hope is linked to specific objects or outcomes. These could be abstract or concrete and reflected the individual’s priorities. They suggested a person’s experience of hope could be influenced by, and comprised of, six factors. The *affective* dimension focuses on the sensations and emotions of the hoping process. The *cognitive* dimension focuses on the processes by which people wish, imagine, interpret and judge in relation to hope. The *behavioural* dimension focuses on the active component of hoping, which may be psychological, physical, religious or social. The *affiliative* dimension relates to the person’s sense of relatedness and connections beyond themselves such as relationships with, or concerns for others. The *temporal* dimension considers the influence of the past, present and future. Finally, the *contextual* dimension related to the life situation surrounding the individual. Farran, Herth and Popovich (1995) considered hope to have four central processes. The *experiential* component referred to the experience of hope at physical, social, psychological and/or spiritual levels. The *spiritual (transcendent)* process links hope and faith – faith in a spiritual sense or faith in one’s abilities. The *rational thought*

process has a number of attributes – goals, resources, active process, control and time. The *relational* aspect acknowledges that hope is often developed and sustained through the presence of others. They described two types of hope – a lower order, basic, unchallenged form and a more specific, high level, challenged form. Unchallenged hopes are often non-specific with a good probability of happening but not necessarily greatly significant. The higher level has a deeper quality and represents a person's deeply held, personal hopes.

These descriptions of hope (Dufault & Martocchio, 1985; Farran, et al., 1995) share a number of common features. They both suggested experiencing hope is an essential part of being human. They consider it to have two components – an internal sense and specific hopes that relate to desired outcomes. They both suggested the experience of hope may have, and may be influenced by, a number of components – cognitive, behavioural, emotional, spiritual, social, psychological and temporal. It appears that hope, by these definitions, starts with a broad sense of hope that can then be focused toward specific hopes.

In contrast to these definitions of hope, Morse and Doberneck (1995) and Snyder, Irving and Anderson (1991) considered hope as a future-focused cognitive process. Their conceptualisations focused on specific hopes which they commonly referred to as goals. Morse and Doberneck suggested it arises in response to a threat and the person's assessment of the threat instigates the process of hoping. This process involves:

“...the setting of a desired goal; the awareness of the cost of not achieving the goal; the planning to make the goal a reality; the assessment, selection and use of all internal resources and supports that will assist in achieving the goals; and the re-evaluation and revision of the plan while enduring, working and striving to meet the desired goal.” (Morse & Doberneck, 1995, p. 284)

Snyder and colleagues (1991) also emphasised the goal-oriented nature of hope, defining it as a “positive motivational state that is based on an interactively derived sense of successful (a) agency (goal directed energy) and (b) pathways (planning to meet goals)” (Snyder, et al., 1991, p. 287). They described the defining characteristic of hope as the *perceived capacity* to work toward goals. This approach emphasises the cognitive element of hope and reflects that Snyder's work originated

from a positive psychology background (Snyder, Rand, & Sigmon, 2002). This approach bears similarities to a number of other psychological concepts such as self-efficacy and self-regulation. Self-efficacy is the belief in one's ability to organise and perform tasks in order to bring about desired outcomes (Bandura, 1995), while self-regulation is the ability to direct thoughts, efforts and action toward goal-attainment (Zimmerman, 2000).

There are a number of commonalities across these five definitions of hope. These include: hope incorporates a focus on particular hopes or outcomes which are meaningful to the individual; there is a degree of uncertainty that hopes may be achieved; hoping requires cognitive engagement; and relationships are significant in the experience of hope. The definitions of hope differ with regard to the existence of a broader, continuous sense of hope. Some view hope as an ever-present state (Dufault & Martocchio, 1985; Farran, et al., 1995; Nekolaichuk, et al., 1999) while one suggested it emerges after an event or a threat (Morse & Doberneck, 1995). Several models are predominantly cognitive in nature (Morse & Doberneck, 1995; Snyder, et al., 1991), while three considered hope to be more holistic and multidimensional (Dufault & Martocchio, 1985; Farran, et al., 1995; Nekolaichuk, et al., 1999). Those that considered it multidimensional propose that the different dimensions could be experienced at different times throughout a person's experience of hope.

The cognitively-oriented approaches to hope (i.e. Morse & Doberneck, 1995; Snyder, et al., 1991) have been criticised for their narrow view of hope. Penz (2008) suggested they are influenced by the authors' philosophical underpinnings, of positive psychology (Snyder, et al., 1991) and anthropology (Morse & Doberneck, 1995) specifically. This may limit the applicability of these models to patient populations. In addition, the development of different models varied significantly. For example, a concept analysis based on an emergency situation depicted in a film formed the basis of Morse and Doberneck's model of hope. Its validity was then assessed in small numbers in specific populations, utilising the identified characteristics of hope as a form of *a priori* coding. In contrast, the conceptualisations of Dufault and Martocchio (1985) and Nekolaichuk and colleagues (1999) were based on empirical investigations of hope and, along with the conceptualisation of hope offered by Farran and colleagues (1995), have been widely utilised in studies of hope in a range of healthcare

populations. Some models, particularly those proposed by Morse and Doberneck (1995), Snyder and colleagues (1991) and Nikolaichuk, Jevne and Maguire (1999) require further empirical testing in order to ascertain their validity in specific populations. The multidimensionality proposed by Farran et al., (1995), Dufault and Martocchio (1985) and Nikolaichuk, et al., (1999) are consistent with many of studies of hope which suggests they offer more to understanding hope.

This summary of the dominant conceptualisations of hope in the healthcare literature indicates there are several ways of considering hope. As will be demonstrated in the next section, this has implications for how it is studied. Within hope after stroke research, it has been approached from several different perspectives; this has influenced the current state of knowledge about hope after stroke.

## **Hope after Stroke**

A review of the hope after stroke literature, drawing on principles of concept analysis (Morse, 2000) and systematic review, was undertaken. The aims and objectives of the review were to explore the current state of knowledge about hope after stroke, specifically:

- (a) the definitions or conceptualisations of hope that underpinned each study;
- (b) the attributes of hope;
- (c) the process of hope, including its development and maintenance, and associated outcomes; and
- (d) the relationship between hope and other constructs.

**Search strategy.** The systematic literature search was completed using the EBSCO (incorporating CINAHL, MEDLINE and PsychINFO), AMED and SCOPUS databases. Search terms included “hope”, “hopelessness”, “wish” and/or “expectation” in conjunction with “stroke” or “cerebrovascular accident”. A manual search of citation lists of retrieved papers and citation searching on SCOPUS identified additional papers relevant to the literature review. In addition, the database of the



Hope Foundation of Alberta (Hope Foundation of Alberta, 2010) was reviewed. This organisation aims to maintain a database of all papers published on hope.

**Inclusion criteria.** Papers were included if they reported an empirical study exploring the perspectives of people after stroke a) that sought to explore hope or b) where hope was identified as a key finding by the authors. Only papers published in English language journals were considered. The titles and abstracts for all papers yielded in the search were screened for relevance and to ascertain if they met the inclusion criteria of the study. Full text copies of the papers were obtained when papers appeared to probably or possibly fit the inclusion criteria and when relevance could not be determined by the title or abstract. These were then reviewed to confirm eligibility for inclusion.

**Quality appraisal.** All papers that fitted the inclusion criteria were included in the analysis, regardless of methodological quality (Morse, 2000). Each article was reviewed for: explanation and appropriateness of study design; inclusion/exclusion criteria and clarity; auditability and evidence for findings of qualitative studies. Each study's contribution to furthering the understanding the concept of hope was also considered.

**Data synthesis.** Each paper was retrieved and read multiple times to develop an understanding of the topic. The papers were initially coded to extract information regarding the definition of hope, attributes of hope identified in the findings, the process of hope and its outcomes. In order to help refine understanding of hope and to delineate it from other similar concepts such as expectations or goals, it was noted how the authors differentiated hope from these other concepts (when these terms were used in a study in conjunction with the term 'hope'). Following initial coding, analytic questioning was used. This involved searching the data in response to questions that the authors felt might reveal more information about hope after stroke. These questions included: Why is hope important after a stroke? How is hope differentiated from similar related concepts? Is hope necessary for recovery from stroke? Does hope change as a result of the stroke? The process of analytic questioning guided deeper analysis of the data with the objective of eliciting new understandings of hope (Morse, 2000; Weaver & Morse, 2006).

**Search results.** Figure 2 illustrates the search process and results. In total, 1093 abstracts were retrieved. Following review of the title and abstract, it was identified that 31 papers possibly or probably met the inclusion criteria of the study. Of these papers, 26 were identified through the initial database searches and an additional five were identified via the alternate search strategies outlined above. After a full reading of the 31 papers, 19 were included in this review. Of the 19 included papers, seven sought to explore hope (Arnaert, Filteau, & Sourial, 2006; Bays, 2001; Bluvol, 2003; Cross & Schneider, 2010; Gum, et al., 2006; Popovich, Fox, & Bandagi, 2007; Popovich, Fox, & Burns, 2003). For the remaining papers, hope was a key finding that was present when related topics were explored, such as recovery or quality of life.

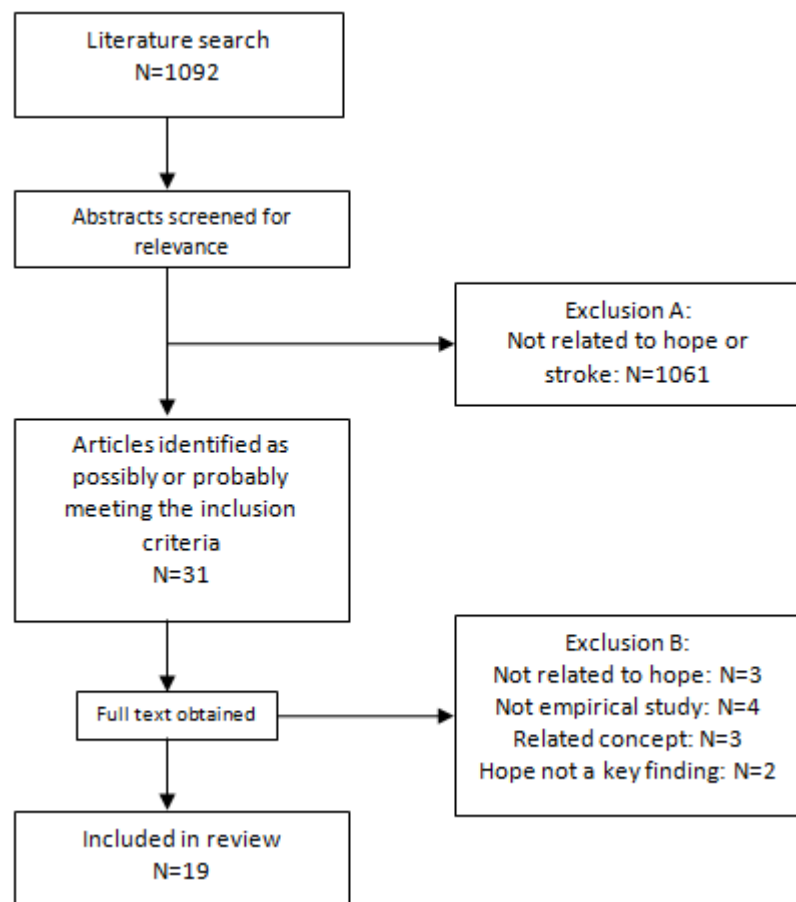


Figure 2. Search results

Of the seven papers that explored hope, four papers were qualitative (Arnaert, et al., 2006; Bays, 2001; Cross & Schneider, 2010; Popovich, et al., 2007) and three

were quantitative (Bluval, 2003; Gum, et al., 2006; Popovich, et al., 2003). Two addressed the acute period (Arnaert, et al., 2006; Popovich, et al., 2007) and three considered the chronic period of recovery (Bays, 2001; Bluval, 2003; Cross & Schneider, 2010). One study measured levels of hope over the acute and post-acute period of recovery (Popovich, et al., 2003) while one compared levels of hope to other constructs such as quality of life, also in the post-acute period (Gum, et al., 2006). This highlighted there has been no explicit exploration of the experience of hope in the post-acute period.

Papers were excluded for several reasons including: the paper was not an empirical study (Bach-Y-Rita & Bach-Y-Rita, 1990; Baldwin, 1996; Dawson, 2000; Western, 2007); the paper was on a topic other than hope (Anwar, 1978; Johnson & Pearson, 2000; Kortte, Veiel, Batten, & Wegener, 2009); the paper was not directly about hope but about a related concept such as expectations of rehabilitation or goal-setting (McClain, 2005; Wiles, Ashburn, Payne, & Murphy, 2002, 2004); or hope was not a key finding of the study and was only mentioned incidentally within the paper (Blijlevens, Hocking, & Paddy, 2009; Marklund, Klässbo, & Hedelin, 2010).

**Quality appraisal and contribution to understanding hope.** The methodological strengths and weaknesses of included papers are summarised in Table 1. There was variation in study quality and in each study's contribution to understanding the concept of hope. The primary issues with qualitative studies were clarity regarding the inclusion/exclusion criteria, inclusion of people with cognitive and/or communication difficulties, provision of adequate detail to support auditability, and provision of adequate data to support study findings. The key issues with quantitative studies were a lack of information about measures used and whether measures had been developed for, or normed on, a stroke population. Many papers, both qualitative and quantitative, were limited in their contribution to this analysis due to their primary purpose. The strongest data were gathered from papers that explicitly sought to explore hope in people after stroke. When hope was not the primary focus of the study, the papers were more limited in their contribution to understanding hope in this population.

**Current knowledge about hope after stroke.** The literature identified hope as conceptualised in three primary ways: as a state of being, as an active process and as being outcome-oriented. This is most similar to the definitions of hope that considered hope a multidimensional concept (Dufault & Martocchio, 1985; Farran, et al., 1995; Nekolaichuk, et al., 1999). Hope was developed through a number of sources. The presence of hope was linked with a number of positive outcomes. Table 1 provides a summary of all the papers that addressed hope after stroke. It summarises the study design (including methods of data collection and analysis, and participant characteristics), key findings and methodological strengths and weaknesses (based on the quality criteria outlined on page 19).

Table 1

*Summary of Papers Exploring Hope After Stroke*

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Arnaert, Filiteau & Souriel (2006)	Explored perceptions of hope during <i>acute phase</i> of stroke	Qualitative case study Semi-structured interviews	N=18 Mean 15 days post-stroke Mixed stroke severity	Hope was essential, futuristic, motivating, involved expectancy and was action oriented. It was a source of energy and comes from the self and others.	Hope was characterised as an inner feeling, involves physical or cognitive action and is commonly outcome-oriented.	Hope was accompanied by times of hopelessness. Hopes changed over time. It was developed through the self, through faith and through others	Hope was a motivator in recovery	Study design appropriate for question and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication difficulties; auditable research method; findings supported by data; strong contribution to understanding hope

<sup>1</sup> Please note that only the measures related to hope are specific in this table; full lists of measures are available in the original papers

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Barker & Brauer (2005)	Explored meaning of recovery and factors that impacted on recovery from patient perspectives	Grounded theory Interviews – Focus groups & individual interviews	N=21 stroke survivors; 9 spouses 3 months-3 years post-stroke Mild-severe upper limb involvement	Not specified as study did not seek to explore hope	Hope was an inner state of being. It was a way of thinking and accompanied by action.	Hope was internally driven but could be developed or shattered through others. It was impacted by stroke severity.	Hope helped people overcome obstacles and helps adjustment. It helped recovery and progress.	Study design appropriate for question and clearly described; people with aphasia included in study; auditable research method; findings supported by data; contribution to understanding hope limited by purpose of study
Bays (2001)	Explored patterns of hope and factors associated with these after stroke	Descriptive qualitative study Individual interviews	N=9 Mean 29.8 months post-stroke Stroke severity not given	Hope was an active, continuous dynamic individualised pattern associated with a person's mutual interaction with the environment	Hope was an inner sense that is essential for life and is future focused. It involved cognitive and active attributes and outcome-oriented hopes	Hope was developed through the self, through achievements others and spiritual sources	Not a focus of this study	Study design appropriate for question and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication difficulties; auditable research method; limited description/ exploration of themes; strong contribution to understanding hope

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Bluvol (2003)	Examined relationship between hope, health-promoting activity and quality of life	Descriptive correlational cross-sectional design Herth Hope Index	N=40 Mean 2.5 years post-stroke Mild-moderate stroke severity	Hope was a multidimensional life force characterised by a confident, yet uncertain expectation of achieving a future good that was realistically possible and personally significant	Not a focus of this study	Not a focus of this study	Hope was positively correlated with quality of life and coping skills that helped healthy living	Study design appropriate for study purpose and clearly described; clear inclusion/exclusion criteria; included people with communication difficulties; appropriate statistical analysis; provided information on clinical implications of hope though limited contribution to understanding hope

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Cross & Schneider (2010)	Explored perceived impact of hope on recovery from stroke in women; explored factors that influenced hope	Qualitative analysis informed by phenomenology Comparison between qualitative and quantitative data Herth Hope Index Geriatric Hopelessness Scale	N=10 Mean 5 years post-stroke Stroke severity not given although majority still experiencing effects	Hope was a multidimensional entity necessary for life and well being. Dimensions included that it was a way of thinking, feeling, behaving and relating to the self and others	Hope was multidimensional. It was usually experienced subconsciously and was considered an unspoken necessity.	Hope was developed through personal support systems, rehabilitation programmes and other stroke survivors. It could be influenced by personal factors such as determination, positive attitude, spirituality, progress, and awareness about stroke	The presence of hope improved quality of life. Hope provided strength and motivation which was necessary throughout the recovery process.	Study design appropriate for study purpose and clearly described; clear inclusion/exclusion criteria; included people with communication difficulties; auditable research method; findings supported by data; further investigation of quantitative data may have enhanced understanding of hope; strong contribution to understanding hope



Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Dowswell, Dowswell, Lawler, Green & Young (2002)	Explored understandings of purpose, expectations and perceived value of physiotherapy	Thematic analysis Semi-structured interviews before and after therapy	N=10 > 1 year post-stroke Severity information n/a	Not specified as study did not seek to explore hope	Hope was outcome-oriented, focused on hopes for therapy and broader recovery.	Hope was reinforced by progress	Not a focus of this study	Limited information provided regarding methods; clear exclusion criteria; people with cognitive impairment excluded; some data provided to support findings; contribution to understanding hope limited by purpose of study
Folden (1994)	Explored how stroke survivors managed the effects of a stroke	Grounded theory Two interviews, 2 weeks post-stroke and 4-weeks post-discharge	N=20 Approx. 2 weeks and 2 months post-stroke Moderate-severe stroke	Not specified as study did not seek to explore hope	Hope was an essential life force	Hope could co-exist with fear about the future	Hope was a key element in recovery and helped improvement	Study design appropriate for study purpose and clearly described; limited information regarding inclusion criteria; appeared to exclude people with cognitive &/or communication impairment; some data provided to support findings; contribution to understanding hope limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Gum, Snyder & Duncan (2006)	Examined the relationship between hopeful thinking, depressive symptoms and participation in meaningful activities and roles after stroke	Correlational and multiple regression analysis Hope Scale	N=110 3 months post-stroke Mix of stroke severities	Hope was a positive motivational state that was based on an interactively derived sense of successful agency (goal-directed energy) and pathways (planning to meet goals).	Not a focus of this study	Not a focus of this study	Levels of hope were correlated with depression, and in combination with impairments, were correlated with participation	Study methods clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication impairment; analysis of large number of categorical variables limit interpretation of findings; provided limited contribution to understanding hope
Haggstrom, Axelsson & Norberg (1994)	Explored the experience of living with stroke sequelae	Hermeneutic phenomenology Meal observation, interview (included photos to elicit data)	N=29 Mean 19 months post-stroke Severity information n/a	Not specified as study did not seek to explore hope	Hope was discussed alongside gratitude and satisfaction	Not a focus of this study	Not a focus of this study	Some information given regarding study design; clear inclusion criteria; people with communication difficulties excluded; findings not well supported by data hope used interchangeably with other terms; provided limited contribution to understanding hope

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Jones, Mandy & Partridge (2008)	Identified personal beliefs about recovery and strategies used to support recovery	Phenomenology Individual interview	N=10 Mean 5.6 months post-stroke Mild-severe stroke	Not specified as study did not seek to explore hope	Hope was similar to optimism and held by all participants. It was future focused and may involve specific hopes.	Hope was maintained through recovery but could co-exist with fear, worry and hopelessness. It was reinforced by progress and staff	Hope supported recovery and thinking about the future	Study design appropriate for study purpose and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication difficulties; auditable research trail; findings supported by data; hope used interchangeably with other terms; contribution to understanding hope was limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Lewis, Dennis, O'Rourke & Sharpe (2001)	Determined if different attitudes toward illness were associated with survival after stroke	Longitudinal correlational study Mental Adjustment to Stroke Scale completed 6 months, and 3-5 years post-stroke	N= 372 Mean 2.5 years post-stroke Mild-moderate stroke	Definition of hopelessness: To be engulfed by the diagnosis, pessimistic and living in fear	Not a focus of this study	Not a focus of this study	Hopelessness was associated with decreased survival at three years, and was correlated with fatalism, depression, anxiety and low fighting spirit	Study design appropriate for purpose and clearly described; clear inclusion criteria though no specific information given re inclusion of those with cognitive &/or communication difficulties; focus is on hopelessness; while results are statistically significant, the focus on hopelessness limits contribution to the review

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Nilsson, Jansson & Norberg (1997)	Explored the lived experience of stroke recovery	Phenomenology Longitudinal interviews, 1 and 3 months post-stroke	N=10 1 and 3 months post-stroke Severity information n/a	Not specified as study did not seek to explore hope	Hope was outcome-oriented	Hopes changed over time as a result of adjustment and insight	Not a focus of this study	Study design appropriate for purpose and clearly described clear inclusion criteria; some exclusion of people with cognitive &/or communication impairment; early imposition of theory may impact on interpretation; limited data supporting findings around hope; contribution to understanding hope was limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Pilkington (1999)	Explored quality of life from the client/patient's perspective	Longitudinal qualitative descriptive Interviews in acute care, 1 and 3 months post-stroke	N=13 Acute-3 months post-stroke Severity information n/a	Not specified as study did not seek to explore hope	Hope was characterised as a state, an active process and being outcome-oriented.	Hopes may have changed as a result of the stroke, and they changed throughout the recovery process. Levels of hope sometimes fluctuated	Hope helped endurance throughout recovery	Study design appropriate for purpose and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication difficulties; auditable research trail; findings well supported by evidence; contribution to understanding hope was limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Popovich, Fox & Burns (2003)	Explored hope as a factor in determining social and functional outcomes after a stroke	Prospective longitudinal design Modified Stoner Hope Scale, Hopefulness Scale, Hope and Coping Questionnaire, Completed 10 days and 3 months post-stroke	N=50 10 days and 3 months post-stroke Severity information n/a	Hope constituted an essential experience of the human condition. It functioned as a way of feeling, thinking, behaving, and relating to one-self and one's world. Hope had the ability to be fluid in its expectations, and in the event that the desired object or outcome did not occur, hope could still be present	Not a focus of this study	Levels of hope fluctuated though the study did not demonstrate statistically significant changes over time	Not a focus of this study	Study design clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication disorders; measures used not readily available; extensive reporting of results though some less relevant to purpose of study; unable to comment on findings as incorrect statistical analysis used; provided limited contribution to understanding hope

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Popovich, Fox & Bandagi (2007)	Explored perceptions of the stroke experience and identified hopes and coping strategies	Qualitative analysis using a priori codes Individual interview	N=60 Mean 7 days post-stroke Severity information n/a	Hope was an inner readiness based on faith and developed through disappointment. It included future goal achievement and was necessary for action. It could be global or specific and involved rational thinking, relationships, spirituality and trial or suffering	Hope was characterised as outcome-oriented, toward broad and specific hopes	Hope was sustained through internal and external forces. Hope did not change over time	Not a focus of this study	Study design appropriate for purpose and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication disorders; predetermined codes/categories may have influence interpretation of data; limited data to support findings; contribution to understanding hope was limited by purpose of study



Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Pound, Bury, Gompertz & Ebrahim (1994)	Described components of physiotherapy valued by stroke survivors	Content analysis Individual interview	N=40 10 months post-stroke Moderate stroke severity	Not specified as study did not seek to explore hope	Not a focus of this study	Therapists were a source of hope and were able to restore hope	Not a focus of this study	Study design appropriate for purpose and clearly described; inclusion criteria given; some exclusion of people with cognitive &/or communication difficulties; limited data to support findings; contribution to understanding hope was limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
Tariah, Hersch & Ostwald (2006)	Explored factors that influenced quality of life following stroke	Mixed methods: Thematic analysis and cross-sectional questionnaire Semi-structured interview	N=9 Mean 2 years post-stroke Severity information n/a	Not specified as study did not seek to explore hope	Hope was perceived to be associated with specific outcomes	Not a focus of this study	Hope helped improve quality of life	Study design appropriate for purpose and clearly described; inclusion criteria given; appears to exclude some people with cognitive &/or communication difficulties; auditable research trail; limited exploration of hope; limited data to support findings; contribution to understanding hope was limited by purpose of study

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope			Strengths and weaknesses	
				Definition	Characterisations	Process		Outcome
White, Magin, Attia, Pollack, Sturm & Levi (2008)	Explored long-term mood changes in the five years post-stroke	Modified grounded theory Qualitative interviews at 1, 3 and 5 years post-stroke	N=12 1, 3 and 5 years post-stroke Mixed stroke severity	Not specified as study did not seek to explore hope	Hope was discussed interchangeably with optimism	Not a focus of this study	Hope helped modulate mood changes	Study design appropriate for purpose and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication impairment; auditable research trail; limited data exploring finding regarding hope; hope used interchangeably with other terms; limited contribution to understanding hope

Author	Purpose of study	Methodology and method <sup>1</sup>	Participant information	Core findings about hope				Strengths and weaknesses
				Definition	Characterisations	Process	Outcome	
Williams, Rittman, Boylstein, Faircloth & Haijing (2005)	Explored the emotional recovery experience following stroke and explored relationship between Geriatric Depression Scale scores and descriptions of emotional recovery	Mixed method study including qualitative descriptive and cross-sectional component Qualitative interview and Geriatric Depression Scale	N=112 One month post-discharge Severity information n/a	Not specified as study did not seek to explore hope	Hope was future oriented and associated with expectations for recovery	Not a focus of this study	Not a focus of this study	Study design appropriate for purpose and clearly described; clear inclusion criteria; some exclusion of people with cognitive &/or communication impairment; auditable research method for qualitative component; reasonable inclusion of data to support themes; hope used interchangeably with other terms; limited contribution to understanding hope

**Definitions of hope.** The studies that explored hope drew on several definitions to guide their study. The vast majority of these papers utilised the definitions of Dufault and Martocchio (1985) and Farran and colleagues (1995), considering hope to be an essential, multidimensional life force (Arnaert, et al., 2006; Bluvol, 2003; Cross & Schneider, 2010; Popovich, et al., 2007; Popovich, et al., 2003). In contrast, one study (Gum, et al., 2006) drew on Snyder's definition of hope (Snyder, et al., 1991) which focused on pathways and agency toward goal achievement.

**Attributes of hope.** The literature suggested hope consists of three dimensions: a broad sense of hope, an outcome-oriented thought process and an active process. Some studies described all three attributes of hope (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Folden, 1994; Williams, et al., 2005). Others addressed only one or two attributes (Cross & Schneider, 2010; Dowswell, et al., 2002; Nilsson, et al., 1997; Pilkington, 1999; Popovich, et al., 2007; Popovich, et al., 2003; Tariah, et al., 2006). This was generally a reflection of the study's purpose and underlying definition of hope.

**Broad sense of hope.** In a number of studies, hope was described as an inner state of being (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001) or inner strength (Arnaert, et al., 2006) that was positive in nature (Cross & Schneider, 2010; Haggstrom, et al., 1994; Jones, et al., 2008). This state was considered to be a life force (Folden, 1994), something necessary for life (Bays, 2001). Participants considered it essential for recovery and living well after stroke (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Cross & Schneider, 2010; Folden, 1994; Lewis, et al., 2001; Nilsson, et al., 1997; Pilkington, 1999). This attribute of hope may be a state that has always been present (Bays, 2001), unaffected by the stroke. Some authors and participants considered it the same as, or similar to, optimism (Arnaert, et al., 2006; Jones, et al., 2008), while another suggested it was interchangeable with positivity (Cross & Schneider, 2010).

**Outcome-oriented hope.** Hope was widely conceptualised as outcome-oriented. In a number of papers, it was the only attribute of hope that was discussed (Dowswell, et al., 2002; Popovich, et al., 2007; Tariah, et al., 2006; Williams, et al., 2005). Outcome-oriented hope was future-focused and centred on broad and/or

specific hopes for the future (Arnaert, et al., 2006; Bays, 2001; White, et al., 2008). Broad hopes included hope for recovery (Arnaert, et al., 2006; Dowswell, et al., 2002) or a hope to not deteriorate (Popovich, et al., 2007). The hopes commonly reflected a desire to return to 'normal' - a normal way of life (Bays, 2001; Pilkington, 1999), normal roles (Dowswell, et al., 2002), normal activities (Popovich, et al., 2007) and to being the same person they were before the stroke (Pilkington, 1999). However, outcome-oriented hope was not always focused on returning to 'normal' – some people reported the stroke was a catalyst for developing new hopes for their future (Pilkington, 1999). Participants also detailed a number of stroke-related specific hopes. In inpatient settings, returning home was a common hope (Jones, et al., 2008). Other hopes included improved mobility (Bays, 2001; Dowswell, et al., 2002; Tariah, et al., 2006), improved cognition, communication and confidence (Dowswell, et al., 2002), and resolution of other deficits that resulted from the stroke and independence (Popovich, et al., 2007). One study suggested that while outcome-oriented may be a part of a person's experience of hope, it was not essential (Cross & Schneider, 2010). Identified hopes were not necessarily accompanied by a sense of certainty that the outcome would be realised. Participants wished or desired that their hopes would eventuate but they did not necessarily expect that this would occur (Dowswell, et al., 2002; Williams, et al., 2005). This illustrates there was a subtle difference between hope and expectations. Other participants described a need to believe that the hope could be realised, saying that individuals should work toward that possibility even if they were not certain it would happen (Barker & Brauer, 2005; Bays, 2001).

*Active process of hope.* Hope had an active, process-oriented attribute which incorporated both a cognitive engagement with hope and process of acting on hopes. This attribute could be present or future-focused. The cognitive aspect included assessment and appraisal about the current situation and the future (Barker & Brauer, 2005; Bays, 2001), comparison with others or self (Bays, 2001), hope-oriented thoughts (Bays, 2001; Pilkington, 1999) and goal-setting (Arnaert, et al., 2006; Bays, 2001). Hope-oriented thoughts could involve positive anticipation, dreams and aspirations about the future and its possibilities (Bays, 2001; Pilkington, 1999), which started the process of identification of specific hopes. Some participants also described a process of evaluating their hopes and modifying them to be 'realistic'

(Dowswell, et al., 2002). This illustrates the interaction between the outcome-oriented and active process attributes of hope.

In several studies, participants discussed how the cognitive aspect of hope must be accompanied by action (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Pilkington, 1999). They proposed this action should be directed at realising outcome-oriented hopes and included participating in rehabilitation and/or activities to maximise recovery (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001). Participants also described active or passive approaches to hope. "Active" hoppers were said to perceive high levels of hope that was personally controlled and converted hopes into actions. "Passive" hoppers were not able to perceive any hope, or perceived that others controlled hope and were unable to act on their hope (Arnaert, et al., 2006). Participants in several studies suggested the responsibility sits with the individual with stroke to take action toward realising their hopes (Barker & Brauer, 2005; Pilkington, 1999).

**The process of hope.** The process of hope was explored in twelve of the studies. Hope after stroke was associated with a journey of recovery (Bays, 2001; Cross & Schneider, 2010) and was experienced throughout recovery at varying levels (Cross & Schneider, 2010; Jones, et al., 2008). Some studies reported periods of hopelessness or loss of hope, particularly during the acute period of recovery (Arnaert, et al., 2006; Jones, et al., 2008; Pound, et al., 1994) although there was limited data exploring this. Popovich, Fox and Burns (2003) measured changes in hope in 50 people over a six month period following stroke. They found no statistically significant change in hope levels over this time, although individual participants reported both positive and negative changes in hope. However, limited information was provided about the measures. Analysis of levels of hope between the two time periods used the incorrect test (specifically, a t-test instead of a McNamara test); this may have influenced the findings.

Several studies suggested hope could co-exist with emotions such as worry, uncertainty (Arnaert, et al., 2006; Jones, et al., 2008) and fear (Folden, 1994; Jones, et al., 2008). Cross and Schneider (2010) found unfulfilled hopes sometimes resulted in the loss of hope and depression. They suggested this was commonly followed by a

process of accepting the changes caused by the stroke. They also suggested that hope diminished as progress slowed. A long-term study of *hopelessness* after stroke reported persistent hopelessness was associated with lower survival rates (Lewis, et al., 2001); it was also found that a lack of, or low levels of hope were associated with depression (Gum, et al., 2006).

Following stroke, a person's outcome-oriented hopes may change (Arnaert, et al., 2006; Bays, 2001; Jones, et al., 2008; Nilsson, et al., 1997; Pilkington, 1999) although the inner state of hope may remain constant (Bays, 2001). Hopes changed as a result of identifying new priorities (Arnaert, et al., 2006), severity of stroke (Arnaert, et al., 2006; Barker & Brauer, 2005; Cross & Schneider, 2010; Gum, et al., 2006; Jones, et al., 2008), the changes brought about by the stroke (Nilsson, et al., 1997; Popovich, et al., 2007; Williams, et al., 2005), or as a result of adjustment and increased insight (Dowswell, et al., 2002; Nilsson, et al., 1997). Nilsson et al. (1997) suggested that while many participants changed their hopes as they became more aware of the 'reality' of stroke, some participants struggled to balance hopes for full recovery with awareness this might not happen. This could cause distress to the individuals concerned if they were aware of this tension; however, others were not aware and the authors considered these people to have unrealistic hopes as they were still hoping for, and expecting a full recovery.

***Development and maintenance of hope.*** The literature identified a number of factors believed to contribute to the development and maintenance of hope. These originated from internal or external sources. Internal sources included personal attitude, progress to date, sense of self and the severity of stroke. External sources of hope included social connections, spiritual beliefs and healthcare professionals. Cross and Schneider (2010) suggested both internal and external factors were required to maintain hope. They suggested three factors were crucial in maintaining hope: a supportive environment, belief in one's self, and a belief that ongoing progress is possible.

A positive personal attitude, willpower, sense of self-responsibility and self-belief were seen as important in maintaining hope and realising specific hopes (Barker & Brauer, 2005; Cross & Schneider, 2010; Jones, et al., 2008; Popovich, et al., 2007;



Pound, et al., 1994). Participants commonly reported gaining hope from their own progress and recovery (Bays, 2001; Cross & Schneider, 2010; Dowswell, et al., 2002; Jones, et al., 2008; Nilsson, et al., 1997; Popovich, et al., 2007). Hope also appeared to be influenced by a person's experiences and perceptions of hope, illness and recovery (Arnaert, et al., 2006; Folden, 1994; Jones, et al., 2008; Pilkington, 1999). The literature was inconsistent regarding the relationship between severity of the stroke and levels of hope. Participants in three studies suggested developing and sustaining hope was more challenging for those with severe stroke (Arnaert, et al., 2006; Barker & Brauer, 2005; Cross & Schneider, 2010). However, Jones and colleagues (2008) found hope was often maintained despite the presence of significant impairment from stroke. One study identified having a sense of purpose and activity could help maintain hope (Cross & Schneider, 2010). Knowledge about stroke and what could be expected was said to be important in helping people manage hope (Cross & Schneider, 2010),

Social connections, including family and friends, were a common source of hope (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Cross & Schneider, 2010; Popovich, et al., 2007). Spiritual beliefs and personal faith helped develop and maintain hope (Arnaert, et al., 2006; Bays, 2001; Cross & Schneider, 2010; Popovich, et al., 2007). The progress of other stroke survivors helped some participants maintain hope (Cross & Schneider, 2010). Health providers could both develop and destroy hope. They were reported to be a common source of hope (Cross & Schneider, 2010; Jones, et al., 2008; Popovich, et al., 2007; Pound, et al., 1994) and were able to restore hope when participants reported having no hope (Pound, et al., 1994). However, participants in one study (Barker & Brauer, 2005) suggested that health providers had the ability to shatter client's hopes. Similarly, Folden (1994) found tensions arose when therapy staff and clients did not share hopes for recovery although two studies found hope could still exist in this situation (Folden, 1994; Jones, et al., 2008). Effort was required to protect oneself from healthcare providers who say there is no hope (Barker & Brauer, 2005). No studies commented on negative influences from other external sources, such as family.

***Outcomes of having hope.*** Eleven studies discussed the outcomes of hope. Most of these identified positive effects of hope. Hope was considered a key element

in the recovery process (Arnaert, et al., 2006; Barker & Brauer, 2005; Cross & Schneider, 2010; Folden, 1994; Jones, et al., 2008; Pilkington, 1999) and was viewed as a source of motivation throughout recovery (Arnaert, et al., 2006; Cross & Schneider, 2010), particularly when progress was slow (Folden, 1994). It helped overcome obstacles (Barker & Brauer, 2005). Hope was said to help modulate mood in the years following stroke (White, et al., 2008) and discussion about hope helped people express their worries and concerns (Arnaert, et al., 2006). It was considered to be a tool that helped adjustment (Barker & Brauer, 2005), coping (Bluval, 2003) and the ability to think about the future (Jones, et al., 2008). People with higher hope had higher participation levels (Gum, et al., 2006). Hope was also associated with quality of life, with both qualitative and quantitative studies associating hope with better perceived quality of life (Bluval, 2003; Cross & Schneider, 2010; Tariah, et al., 2006).

**Related constructs.** Hope has been linked with constructs that are sometimes used interchangeably with hope. Within the literature included in this study, hope appeared to closely overlap with expectations (Dowswell, et al., 2002), goals (Arnaert, et al., 2006; Folden, 1994; Gum, et al., 2006) and optimism (Arnaert, et al., 2006; Jones, et al., 2008; White, et al., 2008). In addition, hope was used alongside terms such as gratefulness and satisfaction (Haggstrom, et al., 1994) and dreams (Pilkington, 1999).

*Expectations* have been described as predicted outcomes (Leung, Silvius, Pimlott, Dalziel, & Drummond, 2009), or “what patients think will happen” (Mondlock, Cole, & Frank, 2001, p. 174). They are said to be specific and relate to a future state or outcome. Expectations bear similarities to the outcome-oriented characteristic of hope outlined above but have higher levels of certainty attached to them. Dowswell et al., (2002) suggested a key difference between hope and expectations was that expectations were focused on improvement of specific functions (e.g., walking quicker) while hopes were broader and more holistic (e.g., getting back to near normal). *Goals* have been described as a desired outcome or future state which involves personal action in order to achieve this desired state (Wade, 2009). As with expectations, they are future focused and outcome-oriented, but also include an active process that enables goal-directed behaviour. This overlaps with both the active process and outcome-oriented attributes of hope outlined above. Goals were explicitly described

as a core component of hope by Gum, Snyder and Duncan (2006), whose definition of hope involved developing goals and developing and implementing pathways to achieve the goals. Specific hopes could be considered to be similar to goals, but unlike goals, they were not necessarily accompanied by a plan of how the hope would be realised. *Optimism* has been defined as “a generalized expectation that good things will happen” (Scheier & Carver, 1987, p. 171). Within the hope after stroke literature, optimism was conceptualised as a general state or specific to a particular goal. Some authors conceptualised it as similar to, if not the same as a state of being (Arnaert, et al., 2006; Jones, et al., 2008). It was also considered a personality trait (Jones, et al., 2008) although White and colleagues (2008) appear to use optimism to refer to purpose in life (e.g. “optimism was centred on ‘living for others’”, p. 1704). Each of these constructs bore similarities to hope as described in this review. They commonly overlapped with one, but not all three attributes of hope – a state of being, outcome-oriented and as an active process.

## **Hope in People with Aphasia**

A key finding from the systematic review was the inconsistent inclusion of people with common stroke sequelae (communication or cognitive impairment) in research on hope after stroke. This may mean that key information about hope after stroke is missing. It is not known if, or how, these impairments could impact on a person’s experience of hope. One such communication impairment is aphasia. Given that approximately one third of people have aphasia after a stroke (Inatomi, et al., 2008; Pedersen, et al., 1995), it is important to understand hope in this population.

The literature retrieved in the systematic review demonstrated significant variability with regard to how people with aphasia were included/excluded in the research. Three studies did not exclude participants on the basis of communication impairment (Barker & Brauer, 2005; Bluvol, 2003; Cross & Schneider, 2010); 15 studies made some exclusions based on communication impairment (Arnaert, et al., 2006; Bays, 2001; Folden, 1994; Gum, et al., 2006; Haggstrom, et al., 1994; Jones, et al., 2008; Nilsson, et al., 1997; Pilkington, 1999; Popovich, et al., 2007; Popovich, et al., 2003; Pound, et al., 1994; Tariah, et al., 2006; White, et al., 2008; Williams, et al., 2005)

while two were unclear whether they included people with aphasia (Dowswell, et al., 2002; Lewis, et al., 2001). The majority of studies appeared to include people with mild aphasia. Some studies offered objective information about their exclusion criteria. For example, several authors (Bays, 2001; Popovich, et al., 2007; Popovich, et al., 2003) included participants on the basis of their scores on the Boston Diagnostic Aphasia Examination, a measure of aphasia severity (Goodglass & Kaplan, 1983). In contrast, other studies included/excluded people based on their ability to communicate with the researcher (e.g. Pilkington, 1999; White, et al., 2008). This somewhat more subjective criterion may reflect the person's communication ability and/or the researcher's ability to facilitate communication with someone with aphasia. Of the papers that included people with communication impairment, little information was available about how the data collection process was modified to maximise participants' abilities to communicate.

In addition to the literature retrieved in the systematic review, a search of databases and Google Scholar identified several other papers relevant to the study of hope after stroke. Two studies provided information about how hope was perceived by people with chronic aphasia (Hopper & Edey, 2007; Worrall, et al., 2009). Hopper and Edey explored hope in five people with aphasia and their significant others. Participants defined hope in two ways: as faith, and as positive expectations for the future. It was influenced by progress, hopeful language from health professionals and by support networks. However, much of the data given to support the themes came from significant others. Hope emerged as a key theme in Worrall and colleagues' (2009) study of goal-setting. They found that developing and maintaining hope is an important component of the goal-setting process. Participants described the need for health professionals to help them maintain hope. They reported devastation could occur if hope was taken away, for example, by health professionals saying goals were unrealistic or could not be achieved. Both studies described hope as an important concept for therapists to be aware of. This reinforces the need to understand how hope is experienced at the time that people are receiving therapy, commonly, the post-acute period of recovery.

People with aphasia have co-authored two papers that discussed hope (Green & Waks, 2008; Liechty & Braun, 2006). Liechty described his experience of recovery

from aphasia (Liechty & Braun, 2006). He stated hope provided motivation to keep going and work toward improvement. The authors suggested a number of factors could help maintain hope, such as being involved in meaningful activities, building trusting relationships, accepting limitations and strengthening social supports. Green and Waks (2008) suggested the stroke and aphasia could result in a loss of hope. Green described gaining hope from talking to people who had been through similar experiences.

Research has indicated that people with aphasia experience recovery differently to people without aphasia (Gialanella, Bertolinelli, Lissi, & Prometti, 2011; Hilari, 2011). It is possible these differences could impact on how people with aphasia experience hope. For example, some studies have found the presence of aphasia was associated with poorer motor and cognitive outcomes and was also predictive of discharge location (Gialanella, et al., 2011). This may impact on a person's experience of hope as several studies exploring hope after stroke suggested the hope may be more difficult, and hopes may be different, for people with more severe stroke (Arnaert, et al., 2006; Barker & Brauer, 2005). Hilari (2011) found some psychosocial consequences of stroke were different for people with aphasia. Three months after stroke, people with aphasia had significantly higher levels of psychological distress, although this reduced by six months. People with aphasia had lower quality of life and increased social isolation at six months post stroke. These findings may influence how people with aphasia experience hope as these factors are associated with hope. For example, the presence of hope is said to contribute to, and improve, quality of life (Bluvol, 2003; Tariah, et al., 2006). Similarly, several studies have suggested a relationship between hope, hopelessness, and depression (e.g. Barker & Brauer, 2005; Lewis, et al., 2001). It may be the early psychological distress experienced by people with aphasia could impact on how they experience hope. Hope is commonly said to be developed and sustained through relationships with others and social interaction (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Popovich, et al., 2007). People with aphasia commonly experience social isolation which may therefore impact on how they experience hope.

In addition to these specific stroke and aphasia-related outcomes, the process of exploring hope in people with aphasia is likely to be more challenging because of

the presence of the language disorder. 'Hope' is a complex word as it can take a number of linguistic functions, serving as a noun (e.g. If there is hope ...), a verb (e.g. I hope that ...), an adjective (e.g. I am hopeful that ...) and an adverb (e.g. Hopefully, ...) (Elliott & Olver, 2002), and it is an abstract term that is not tied to specific objects. People with aphasia have more difficulty retrieving and processing abstract words compared with concrete words (Marshall, 2009). This may make it more challenging for people with aphasia to engage in discussion about hope. In addition, the communicative act of discussing hope requires receptive and expressive language skills. For example, in order to identify specific hopes, one needs to be able to retrieve the words, or other linguistic information, to indicate the outcomes one is hoping for. Research has also indicated that discussion about hope may occur within a broader conversation about the stroke and recovery (Arnaert, et al., 2006). Again, this discussion is language-based. It is unknown whether people with aphasia experience, or report their experience of hope differently because they are not able to express themselves as easily as those without language impairment.

It is clear that the presence of aphasia could impact on how people experience hope in many ways. The literature has identified that a number of outcomes relevant to hope are affected differently in people with aphasia. This provides a rationale for exploring hope in this population.

### **Summary of Current Knowledge on Hope after Stroke and Aphasia**

To date, the literature has suggested hope is multidimensional and that different dimensions of hope are experienced at different times throughout the recovery journey after stroke. Participants in the various studies consider hope important for recovery. It was associated with factors that are important for stroke outcomes such as quality of life and psychological well-being. It was related to concepts that are commonly used in rehabilitation, such as goals. A person's experience of hope was influenced by themselves and other people, including healthcare providers. The fact that hope has been associated with many constructs central to recovery and rehabilitation suggests it is worthy of further investigation.

As this systematic review identified that hope is multidimensional, involving a sense of hope, outcome-oriented hope and an active process, it supports the use of the two definitions that guided this study (see Chapter One, Introduction, page 9) which also conceptualise hope as multidimensional.

The current knowledge about hope after stroke is based on seven studies that have specifically explored hope, and on thirteen studies that have explored related concepts, such as recovery or quality of life. Only three studies explored the meaning and experience of hope and these took place in three distinct populations – people with acute stroke (Arnaert, et al., 2006), women with chronic stroke (Cross & Schneider, 2010) and elderly people with chronic stroke (Bays, 2001). No studies explored the meaning and experience of hope in people while they were undergoing rehabilitation. This would be beneficial given that hope appears to be related to core rehabilitation concepts and outcomes, and healthcare providers are said to have a strong influence on a person's experience of hope. In addition, the post-acute period, when rehabilitation commonly takes place, has been suggested as a unique period in the recovery process after stroke (Becker & Kaufman, 1995; Rittman, et al., 2004). This supports the need to better understand the experience and role of hope at this time. Understanding more about how people with stroke and aphasia conceptualise hope may also help identify which measures of hope may be appropriate for this population, as the measures used in the stroke literature vary in their underlying definitions of hope.

Having a clearer understanding of how hope after stroke is experienced may also assist clinicians to consider and discuss hope with their patients. One study explored how neurological physiotherapists considered hope (Soundy, et al., 2010). Their conceptualisations of hope – as false, realistic, accepting, or no hope – are very different to how hope has been conceptualised by people with stroke. These were centred on specific hopes and they were commonly considered realistic or not based on whether they could be achieved within an intervention period. Having more information about how people with stroke, and specifically those with aphasia experience hope, may help clinicians better understand the lived experience of hope and may guide them in discussions about hope with their clients.

There are a number of reasons why it is important to gather more information about how people with aphasia experience hope. People with aphasia are not consistently included in studies of hope after stroke and, when they are, there is limited information about how, or if, they were supported to maximise their ability to participate in the study. Hope is recognised as a linguistically complex concept which may make it more challenging for people with aphasia to discuss and have their stories heard. It is also important to understand more about hope in this population as the small body of literature that has considered it states that is an important concept to people with aphasia and is linked to participation in rehabilitation. The review has also indicated there are a number of reasons why people with aphasia may experience hope differently to people without aphasia. These factors provide a rationale for exploring hope in people with aphasia following stroke.



## **Chapter Three: Methodology and Methods**

This chapter describes the methodology and methods that underpin this study of how people with aphasia after stroke experience hope. An overview of the Interpretive Description methodology and its core principles is given. The chapter then details the methods used for data collection and analysis and outlines the steps taken to ensure rigour.

### **Interpretive Description: Methodological Overview**

Interpretive Description is an approach to qualitative research that seeks to explore clinically relevant phenomena, shedding light on them in a way that provides new insights and informs clinical practice. This approach emerged from a perceived need to have a nursing-oriented research methodology and from a desire to provide legitimisation for strong qualitative research that did not fit traditional qualitative methodologies (Thorne, 2008).

Naturalistic inquiry (Lincoln & Guba, 1985) provides the philosophical basis for Interpretive Description research. Thorne described the key “epistemological foundations” (Thorne, 2008, p. 74) of Interpretive Description as:

- (a) People’s subjective and experiential knowledge of the subject under investigation are fundamental in providing insight into a phenomenon;
- (b) Both commonalities and variations across people’s experience of the phenomenon are of interest;
- (c) There should be consideration of time and context and how these influence perceptions and experiences. It assumes an individual’s experience is influenced by both psychosocial and biological phenomena. These form some of the context that underpin a person’s experience;

- (d) Knowledge is socially constructed and there are multiple realities of an experience of a phenomenon that may exist. These may be contradictory;
- (e) Both the researcher and the participant construct knowledge. They do this individually through their interpretation of a situation, and together through the interview process; and
- (f) Findings must be grounded in the data, must be considered within their context and should consider the multiple realities that exist. As such, *a priori* coding is not considered appropriate for Interpretive Description studies (Thorne, 2008; Thorne, et al., 2004).

An Interpretive Description study may draw on aspects of phenomenology in exploring a phenomenon, and grounded theory and other qualitative methodologies in analytic methods. However, it does not seek to define the essence of the phenomenon as one would in phenomenology, or to produce a theory, as in grounded theory. Instead, it aims to illuminate it, showcasing patterns, commonalities and relationships. It should provide a comprehensive, contextualised interpretation that is clinically relevant (Hunt, 2009), with findings that delve below the surface that a clinician might ordinarily see. The in-depth exploration should add insight to the phenomenon in a way that clinicians can then apply (Hunt, 2009; Thorne, 2008; Thorne, et al., 2004).

Interpretive Description acknowledges that the researcher comes to the research with a position and with practice-informed questions. In fact, it sees these as crucial aspects of the methodology. The researcher's understandings from clinical practice and from reviewing the literature form a scaffold that informs the study design and early analysis (Thorne, 2008). In the case of the current study, these have been provided in the Introduction and Literature Review (pages 4 and 11). It is not intended that the scaffold remains unchallenged or unchanged as the data collection and analysis process continues. The researcher's biases should be made explicit at the start of, and throughout the study. Sufficient evidence should be provided to support their decisions about data interpretation (for example, through the use of raw data to provide evidence that supports the findings).

Interpretive Description allows the researcher to utilise a range of tools for data collection and analysis (Hunt, 2009; Thorne, 2008; Thorne, Kirkham, & O'Flynn-Magee, 2004), many of which were adopted for this study. They are described in the Methods section of this chapter (see page 54).

### **Applicability of Interpretive Description to This Study**

Interpretive Description was an appropriate methodology for this study for several reasons.

Firstly, this study was driven by a clinical interest in hope and a desire to be involved in research that was overtly clinically meaningful. Interpretive Description is well-suited for this purpose as it intends that the research should result in a report that would allow clinicians to read or hear the findings and easily incorporate them into their clinical practice (Thorne, 2008).

Secondly, this methodology enables the use of multiple approaches to data collection and analysis which can be tailored to the needs of the population group under investigation. This was important given the challenges in data analysis as outlined in Chapter One (see page 6), and the recognised challenges in involving people with aphasia in qualitative research (Dalemans, Wade, Heuvel, & de Witte, 2009; Lloyd, Gatherer, & Kalsy, 2006). For example, while a number of qualitative methodologies recommend unstructured interviews with minimal interruption by the researcher (e.g. Holloway & Wheeler, 2002); this was not possible with the participants in this study due to the presence of aphasia. Questions were frequently semi-structured rather than open-ended to assist participants to understand and respond. Participant responses to questions commonly needed to be co-constructed in order to elicit their meaning. An example of this is the use of clarifying questions, such as “do you mean [researcher’s interpretation]?” or forced choice questions, such as “do you mean x or y?” Multiple semi-structured interviews are recommended as a key source of data collection (Thorne, 2008). While this may be beneficial for all populations regardless of the person’s communicative ability, it is particularly important when the person has a communication impairment as their intent is not always clear and their

expressive language may be open to interpretation. As will be detailed below, multiple interviews with each participant gave the opportunity to gain an understanding of the person, their communication support needs, and to check early interpretation and analysis. Semi-structured interviews are useful with this participant group as they allow the researcher to prepare supported communication material in advance, and can also allow the researcher to prime the participant in advance, highlighting future questions and areas for discussion. Communication impairments such as aphasia can make data analysis challenging as the meaning of the participant's response may be ambiguous at first glance. The use of multiple analytic tools can assist in interpretation. The specific methods of data collection and analysis used in this study are detailed on pages 59 and 61 of this chapter.

Finally, Interpretive Description is an appropriate methodology for an exploratory study (Hunt, 2009; Thorne, 2008; Thorne, et al., 2004). This study is considered an exploratory study as it is one of only two known studies that have sought to explore hope in people with aphasia (Hopper & Edey, 2007). This supports the rationale for using Interpretive Description.

## **Methods**

Interpretive Description draws on a range of methods for data collection and analysis. However, there are some processes that are considered fundamental to Interpretive Description methodology. These are: constant comparison, iterative analysis and concurrent data collection and analysis (Hunt, 2009). They have been incorporated into the study as detailed below.

## Research Questions

This study sought to answer the questions:

- (a) How do people with aphasia experience hope in the post-acute period of rehabilitation?, and
- (b) What factors appear to influence a person's experience of hope?

These questions were consistent with the suggestion that Interpretive Description research questions should be experiential in nature and allow for interpretive explanation of the phenomenon and examination of patterns, commonalities and relationships (Thorne, 2008; Thorne, et al., 2004). It was anticipated that these questions would elicit findings that were clinically significant (Hunt, 2009; Thorne, 2008; Thorne, et al., 2004).

## Sampling

The inclusion criteria for the study were that participants had a left hemisphere stroke resulting in aphasia and were:

- (a) able to communicate with the researcher in some way;
- (b) currently receiving their first episode of outpatient or community based speech-language therapy in one of two rehabilitation services in a large metropolitan area in New Zealand ; and
- (c) aged 16-64 years.

**Rationale for inclusion criteria.** Participants needed to be able to communicate in some way, verbally and/or non-verbally. Some people with global or severe fluent aphasia may be unable to participate in an interview even if non-verbal supported communication methods were used so it was important to only include those who would be able to actually participate in the interview. An individual's ability to communicate in an interview was determined by the referring speech-language therapist, based on their clinical judgement.

As discussed in the literature review, the current knowledge of hope after stroke indicates it to be associated with concepts central to rehabilitation, such as goal-setting. The literature also suggests hope may be influenced by rehabilitation providers. In addition, there has been no study of hope in people with stroke in this period of time, the time when many people with aphasia are receiving rehabilitation services. Working-age adults have specific characteristics which may impact on how they experience hope (see Chapter Two, Literature Review, page 12 for details). Given that no studies have specifically investigated this subset of the population to date and due to the current study being a small, exploratory study, it was decided to focus on working-age adults who were receiving rehabilitation at the time of the study.

**Sampling method.** This study utilised purposive sampling (Holloway & Wheeler, 2002) to identify the first four participants which allowed for recruitment of participants with specific characteristics (Thorne, 2008). Based on clinical experience and the literature, it was anticipated that participants of different gender and different ethnic groups may provide a variety of perspectives on hope after stroke. Gender was considered to be significant as the literature has described gender differences in experience of stroke recovery, hopes and goals (Andersson & Hansebo, 2009; Cross & Schneider, 2010; Kvigne, Kirkevold, & Gjengedal, 2004). Ethnicity was considered a significant variable given the diverse ethnic composition of the region from which the participants were drawn, and that a disproportionate number of Māori, Pasifika and Asian people are affected by stroke (Stroke Foundation of New Zealand, 2010). For example, Māori and Pasifika populations have a higher incidence of stroke and are younger in age at the time of stroke than other ethnicities (Feigin, et al., 2006), while Pasifika and Asian populations have lower levels of functional outcome (McNaughton, et al., 2011). It has been suggested there may be a spiritual component to hope (e.g. Bays, 2001). Given that spirituality is considered important to Māori and Pasifika cultures (e.g. Durie, 1994; Pulotu-Endemann, 2001), it was felt including representatives from these ethnic groups may offer further insight into the experience of hope.

The initial four interviews and co-occurring data analysis informed ongoing sampling. Theoretical sampling was then used to recruit the final participant in order to gain greater variation and depth in the sample and data (Thorne, 2008), focusing on

what the initial findings suggested may be important sample characteristics. At this point, a person with mild aphasia was sought as all other participants had moderate or severe aphasia. While the data gathered to that point were rich and gave a significant amount of information about the experience of hope, the presence of aphasia did pose challenges in fully exploring the concept. It was hoped that talking with someone with mild aphasia would allow for further exploration of the experience of hope but still within the context of aphasia.

Many qualitative studies aim to sample to the point of data saturation (Tuckett, 2004), that is, that there are no new variations or perspectives offered on the phenomenon (Thorne, 2008). This was not the intention of the study as it was a small exploratory study. Thorne (2008) stated that such studies are “justified in having set some arbitrary limits” (p. 98), so long as the researcher is aware of the implications for the findings and acknowledges there is more that could be understood about the phenomena.

**Recruitment.** Participants were initially recruited through a regional rehabilitation service. It was intended all participants would be recruited through this service as scoping prior to commencement of the study suggested there would be sufficient numbers of potential participants from this service alone. However, due to low numbers of eligible consenting participants, another recruitment source was utilised. This was done to enable recruitment of sufficient numbers of participants, and to allow for operationalisation of purposive and theoretical sampling procedures. The second recruitment source was a community-based rehabilitation service.

Recruitment was managed through the supervising speech-language therapist at each locality. They were given the desired participant characteristics that had been identified through purposeful and theoretical sampling decisions. They then discussed these with their therapy staff. Individual therapists approached potential participants who met the sampling criteria during their regular therapy sessions and gave them both verbal and written information about the study (see Appendix A for Participant Information Sheet, page 127). They were given the opportunity to discuss the study with family if they wished. If, after this, they were interested in participating in the

study, the treating speech-language therapist provided their contact details to the researcher.

**Informed consent.** It is recognised that obtaining informed consent can be challenging when conducting research with people with aphasia (Kagan & Kimelman, 1995; Maher, 2002; Penn, Frankel, Watermeyer, & Muller, 2008). While people do not have reduced decision-making capacity as a result of aphasia, the aphasia may mask this capacity (Kagan & Kimelman, 1995). There is an onus on the researcher to ensure that the person is able to understand the information so they can then make an informed decision (Maher, 2002). This often requires the researcher to use a range of methods to maximise the person's comprehension of the material (Kagan & Kimelman, 1995).

A number of techniques were used to seek informed consent in this study. A written information sheet was given to each potential participant by the recruiting speech-language therapist, along with a verbal explanation of the study. The therapists all had some understanding of the study so were able to explain it in detail and answer initial questions from potential participants. The information sheet was designed using the principles of accessible design. These included: simplifying language, using large font, highlighting key words and including significant white space on the page (Brennan, Worrall, & McKenna, 2005; Rose, Worrall, & McKenna, 2003). This was done to make the material easier to comprehend as it was anticipated most, if not all participants would have reading comprehension and/or visual processing difficulties. They were encouraged to review the material and discuss it with family/whānau or friends before deciding to take part.

The researcher also reviewed the information sheet with each participant prior to the initial interview. In addition, the consent form (also designed using principles of accessible design, see Appendix B, page 134) was discussed with the participant prior to completing it. This allowed for clarification and discussion of any points that were unclear. Supported communication techniques such as simplifying language, using diagrams or writing key words were employed to ensure that the participant was able to comprehend the study and to have the fullest possible understanding of what they were consenting to. Following this discussion, written consent was gained from each



participant. In one instance, the Participant Information Sheet and Consent Form were completed at the start of the second interview as the participant, Iosefa, (a pseudonym) wished to engage in a personal exchange of information before fully consenting to take part in the interview process. This initial exchange was not recorded, but notes were taken with the consent of the participant. These notes were not analysed, but provided contextual information.

## **Data Collection**

The primary method of data collection was individual interviews. In addition, a standardised language assessment was completed with each participant.

**Interviews.** Primary data were collected through semi-structured in-depth interviews. In-depth interviews allow the researcher to gain an understanding of the insider perspective on the issue under consideration, through exploring their thoughts, feelings, perceptions and experiences (Johnson, 2002; Taylor, 2005). This enables a better understanding of the perspectives and experiences of the participants (Charmaz, 2006). While Interpretive Description allows for multiple methods of data collection including interviews, observation and focus groups, interviews are the most common method of data collection (Thorne, 2008). For this study, it was felt that individual interviews would allow for each interview to be tailored to the specific communication needs of the individual participant.

One strategy useful in gathering rich data through interviews is the use of multiple interviews (Charmaz, 2002; Thorne, 2008). Three interviews were completed with each participant in this study. There were a number of reasons for this. The initial interview provided an opportunity to identify the communication strategies that would best enable the participant to participate in the interview process. Multiple interviews helped to develop the relationship with the participant and facilitate their engagement in the interviews; adding to the rigour of the research process (Charmaz, 2002; Mills, Bonner, & Francis, 2006; Morse, 2002). They also provided flexibility to respond to participant fatigue which is common after stroke (Staub & Bogousslavsky, 2001). Multiple interviews provided an opportunity to clarify unclear material from previous interviews; they also allowed for the introduction of concepts or questions and allowed participants time between interviews to consider their responses. Finally,

the use of multiple interviews allowed for preliminary analysis between interviews. This facilitated member checking in the third interview, and allowed the opportunity to clarify things that may not have been clear following preliminary analysis of earlier interviews due to the presence of aphasia.

As detailed above, the first interview focused on developing rapport and an understanding of communication issues. The second and third interviews focused on the participant's definition, perception, experience and process of hope in the time since stroke. The third interview also included discussion about the emergent analysis that had been completed to that date. The interview structure had flexibility to ensure the interviews were responsive to the client's needs. This was illustrated by the case described on page 59, where the first interview was replaced by a client-led exchange of personal information, in keeping with his wishes – he felt “it is important that you understand who I am [prior to conducting the interviews]”. Each interview lasted between 45 and 90 minutes. The initial interview was audiotaped, and in the majority of interviews, the second and third interviews were videotaped to allow for analysis of non-verbal communication (Luck & Rose, 2007). The audiotapes were all transcribed verbatim shortly after the interviews. In one instance, the audio recording equipment failed and no video recording had been used; in this instance, the interview was transcribed with as much detail as could be recalled. The videotapes were reviewed if there was a lack of clarity about the participant's meaning or if it was felt reviewing the participant's non-verbal behaviour would support interpretation of their speech.

As all participants had aphasia affecting their expressive and receptive language, the interview process was modified to maximise their ability to fully contribute. While some open-ended questions were asked, for example, “What does hope mean to you?”, many follow-up questions were forced choice (for example, “did you feel more or less hope then?”) or yes/no questions (for example, “did you get hope from that?”). These allowed the researcher to explore what the participant was meaning if it was not clear from their initial response. Non-verbal communication was significant in data collection (Dalemans, et al., 2009; Owens, 2007). A number of supported communication techniques were utilised to support the participant's comprehension and expression (Kagan, 1998). These included simplifying the language used to ask questions; developing picture charts in advance, which allowed

participants to select from various options; use of pictures and diagrams within interviews to support verbal questions and clarify the researcher's understanding of what the participant meant; rephrasing questions to support comprehension; altering pace of presentation; and the use of non-verbal strategies by both conversation partners such as writing, drawing, gesture and facial expression (Kagan, 1998). A number of questions were prepared in advance in order to ensure appropriate supported communication tools were available (Dalemans, et al., 2009; Luck & Rose, 2007)

**Language assessment and medical data.** Each participant completed a language assessment, the Western Aphasia Battery – Revised (WAB-R) (Kertesz, 2006). This was completed to document the severity of aphasia. This language assessment was introduced later into the data collection process after it was identified that such contextual information would be useful when describing the participants. For the first three participants, the WAB-R was completed a number of months after the interviews had taken place (seven-to-twelve months post-interview); for the final two participants, the WAB-R was completed after the final interview had been completed. This may have influenced the severity and type of aphasia indicated by the assessment; it is possible the aphasia had partially resolved by the time of assessment and was less severe, or a different type (Kauhanen, et al., 2000). Informal observations suggested there was little change in the individual's communication patterns between the time of the interview and time of the assessment. In addition, each participant's rehabilitation file was reviewed for demographic information and information about the stroke and its effects (see Appendix C: Data Collection Form, page 137). The language assessment and medical data provided contextual data about the participant, their stroke and its effects.

## **Data Analysis**

Data analysis in Interpretive Description is inductive in nature (Hunt, 2009; Thorne, et al., 2004), and can utilise multiple techniques (Hunt, 2009; Thorne, 2008;

Thorne, et al., 2004). Data analysis commenced as soon as data collection started. The initial process involved prolonged immersion in the data, spending time listening to the interviews, and reading and re-reading the transcripts to gain familiarity with them prior to engaging in structured processes of analysis (Thorne, 2008). There was often an early process of data interpretation that occurred in order to understand what the participant was meaning. This will be illustrated below, before discussing the specific analysis techniques. After the participant's meaning had been identified, questions were asked of the data. These included: What is happening here? What is this saying about hope? What does this mean? (Hunt, 2009; Thorne, et al., 2004). In addition, a number of structured approaches were used for data analysis – coding, narrative construction, identification of core themes, diagramming and memoing. These different methods were used interchangeably throughout the analysis process with coding being the primary form of analysis (Charmaz, 2006). Data analysis was completed in an iterative manner, with data collection and data analysis occurring concurrently, each informing the other (Thorne, 2004). This approach helped to highlight gaps in knowledge, areas where clarification was needed (either by reviewing the data or by questioning new participants), and, commonalities, patterns and differences in experiences and processes (Thorne, 2008; Thorne, et al., 2004). Each of the analytical strategies adopted in this study will be described in more detail below. Microsoft Word was used to manage the data throughout the analysis process.

**Management of aphasic errors.** The data collected through interviews featured a number of aphasic errors, such as semantic and phonemic paraphasias (word and sound substitutions), omissions of words, pauses while the participant searched for words and made revisions. Some of these characteristics are illustrated in this segment from Adrienne:

*Do you ever feel a bit nervous or something, reluctant to dream about the future or have hopes about the future?*

Yes, yes definitely, definitely.

*Can you tell me more about that?*

Um ... (2sec) I just because everything seems to go wrong, but then I'm hopeful in the, ahhh, grandchildren ...(1sec) grandson, that's getting um I just just , but then there's, I'm always always afraid

In order to interpret the data for the purposes of data analysis, the researcher's interpretation of her intent was incorporated into the raw data. This interpretation

was based on accompanying non-verbal material and other data gathered within the context of the interview (for example, just prior to this section of the interview was a discussion about the death of her son, and her relationship with her baby grandson). The interpretation was also checked with Adrienne through further questioning. Thus, the last sentence was interpreted as:

Um ... (2sec) I just because everything seems to go wrong [in the past], but then I'm hopeful in the, ahhh, grandchildren ...(1sec) grandson [I have hope for my grandchildren], that's getting um I just just , but then there's, I'm always always afraid [that something might go wrong]

When interpretation has occurred in this manner, the interpretation is included within the data provided in Chapter Four, Findings. The Transcription Guide (page vi) details the conventions used for transcription and interpretation within this thesis.

**Coding.** Coding was informed by grounded theory methods as described by Charmaz (2006). Drawing on other methodologies for data analysis is in keeping with Interpretive Description (Thorne, 2008). Line-by-line coding was used initially, consistent with Charmaz's approach. As described in Chapter One (see page 6), this was challenging as the presence of aphasia meant it was often not possible to capture the participant's meaning within a single line. Interestingly, Thorne and colleagues (2004) do not recommend coding at the line-by-line level, saying it can cause the researcher to focus on the 'micro' detail, taking away from the 'macro' experiences that may occur within the data and across participants. This was experienced in this study. To manage this, incident-by-incident coding was used instead (Charmaz, 2006). Following initial coding, analysis proceeded to focused coding, looking at larger extracts of data. This resulted in the development of broader codes and categories that emerged from the data. After completing focused coding with each participant, constant comparison *across* participants occurred; this resulted in further refinement of the codes. As each new set of data was gathered and as new codes emerged from the initial and focused coding, they were compared to previously gathered data and codes. The use of constant comparison and iterative analysis have been described as essential components of data analysis in Interpretive Description studies (Hunt, 2009). The final stage of coding, axial coding, utilised the Conditional Relational Guide (Wilson Scott, 2004; Wilson Scott & Howell, 2008) and explored the focused codes, the internal processes of, and relationships between the different codes. This saw the

development of category-level codes, each of which encompassed a number of focused codes. Examples of both the coding structure and the Conditional Relational Guide are provided in Appendix D, page 140 and Appendix E, page 141.

**Thematic analysis.** Thematic analysis was another tool used in the analysis process. It supported a dual focus on both the individual and the group of participants (Hunt, 2009). The themes all emerged from, and were supported by data. The combination of thematic analysis and narrative construction helped to develop intimate knowledge of each person's experience. To give an example, a complete thematic analysis of one participant, Miriam, is provided in Appendix F (page 143) and an overview of the key themes that emerged from each individual participant is also provided (see Appendix G, page 146). Thematic analysis was a useful tool for illuminating commonalities and differences, and helped refine coding. It also ensured analysis was grounded in the data as it involved constantly referring back to the transcripts to ensure that themes truly emerged from the data and reflected the experiences that the participants described.

**Narrative construction.** Narrative construction was used primarily in the early stages of analysis, sometimes before initial coding. Because of the participant's aphasia and cognitive changes, the multiple interviews and semi-structured questioning used within these interviews, the transcripts were often disjointed. Topics could be discussed in multiple places within each interview and were commonly discussed in all three interviews. The construction of narratives enabled data on similar topics to be grouped together within the narrative. This facilitated more intimate knowledge of the data (Hunt, 2009) and supported ongoing analysis. To demonstrate this approach, the full narrative for Iosefa is attached in Appendix H, page 147.

**Diagramming.** Diagramming was incorporated into analysis once focused coding commenced. This supported more detailed exploration of the experience of hope, its processes and the various influences on hope. Diagramming was used to show the relationships between the codes and often identified gaps in the analysis. This resulted in a return to the data and further interrogation of it, in order to better

understand the experience of hope. This served to further develop the analysis. Several diagrams are provided in Appendix I, page 152.

**Memoing.** Memoing was another tool that was used to support analysis. Memos were written throughout data collection and analysis. They captured the researcher's thoughts, questions, concerns and hesitations about the emerging analysis. The act of writing helped identify gaps in analysis, questions that needed to be asked, and links and relationships that were present. It facilitated increasingly complex thinking about the analysis process (Thorne, 2008). An example of a memo is provided in Appendix J, page 154.

**Managing assumptions.** As detailed in Chapter One, Introduction (see page 7), several assumptions about hope were identified prior to commencing data collection. These assumptions were challenged throughout data collection and analysis. Several formal mechanisms were used to try and ensure that the assumptions were not influencing the analysis. These were: using memoing to reflect on the analysis, and using supervision sessions to discuss and defend the emergent analysis. There were several instances where the analysis could have been influenced by the identified assumptions, for example, the category *working toward hopes* could have been influenced by the assumption that hope required action. In these instances, the research supervisors challenged the analysis and the researcher defended it, drawing on raw data.

**Verifying analysis.** The supervisors of this study were closely involved in the analysis process and this helped ensure the analysis was accurate and remained grounded in the data. Their involvement included: reviewing interview transcripts independently, reviewing coding and other analyses, and regularly holding supervisory meetings to debate and come to a consensus on interpretation and the emergent analysis. The supervisors also challenged the emergent analysis when it was possible that the researcher's assumptions about hope may have influenced the analysis, as detailed above.

In addition to the regular discussions with supervisors, member checking was completed with participants through the multiple interviews. This was used to gather more information about the analysis and how it fitted with the individual participant's

experience. The emergent analysis was presented to the last two participants and their feedback was sought. This allowed for expansion of the analysis. It also enabled further exploration of the relationship between the different aspects of the experience of hope (Thorne, 2008).

## **Ethical Considerations**

This study received ethical approval from the local Regional Health Ethics Committee and from the Auckland University of Technology Ethics Committee. Copies of the approval are provided in Appendix K (page 157), although the names of the recruiting localities have been removed to ensure confidentiality for participants. As amendments were made to the study design (for example, addition of the Western Aphasia Battery – Revised), they were approved by both Ethics Committees prior to being implemented in the study.

**Voluntary participation.** Participation in the study was completely voluntary. Potential participants were approached by their treating speech-language therapist who was not involved in the study. They were given the information and given time to discuss the study with their family prior to giving consent or dissent. This was done to allow potential participants the time to independently consider whether they wished to be involved. Participants were informed of their right to withdraw at any time from the study in the information sheet, on the consent form, and during the first interview. The recruitment process was designed to give participants multiple opportunities to withdraw if they wished, including at the time of being approached by the treating speech-language therapist, at the initial phone call from the researcher and at the initial interview. Each participant was also informed of their right to withdraw at any time during the data collection phase of the overall study, even if their three interviews had been completed. In addition, there was a desire to ensure that therapists did not pressure potential participants to participate. This was frequently discussed with the supervising speech-language therapist at each recruiting locality. There was no evidence of participants feeling pressured to participate, and all



participants reported they were grateful for the opportunity to be involved in the study.

**Confidentiality.** The principle of confidentiality was considered paramount in this study. A number of steps were taken to ensure confidentiality: the researcher performed the transcription; computer files related to participants did not include any identifying information and were password protected; emails with participant details from recruiting speech-language therapists were deleted once the information was transferred to a secure source; pseudonyms were used for dissemination purposes (including this thesis and presentations associated with the study); and hard copy files related to participants were stored in locked cupboards.

Some of the information elicited during the interviews was relevant to the clinicians working with the participant and may have been useful to inform the therapy process. On completion of the interviews, the participants were given a summary of the key points from the interviews (in writing and/or on audio-recording as appropriate given their preference and communication abilities) and they were encouraged to share this with their clinicians if they wished. In addition, the ethical approval allowed the researcher to seek consent from the participant to contact the rehabilitation team at the referring service, if there was a concerning emotional response. This was not required.

**Nonmaleficence.** It was considered unlikely this study would have negative physical or psychological effects on the participants although there was awareness that discussing hope may prompt an emotional response from individual participants. There was no evidence of emotional distress in any participants. In several interviews, the opposite response was noted – participants reported discussing their experiences and their hope had been helpful for them. One participant identified that she was able to view some experiences as positive as a result of reflecting on them during the interviews. Before the interviews, she had found those experiences distressing.

It was anticipated that participants may find the interview tiring. They were encouraged to pause or stop the interview if they were feeling fatigued and assured that the interview could be completed at a later date if they wished to cease the interview. This was regularly reinforced throughout the interview process. One

interview was paused for approximately ten minutes to allow the participant a brief break; another interview was terminated early and was completed the next week.

## **Rigour**

Credibility and rigour are essential within Interpretive Description studies (Thorne, 2008; Thorne, et al., 1997; Thorne, et al., 2004). There are four key criteria for assessing rigour within Interpretive Description studies (Thorne, 2008). These are: epistemological integrity, representative credibility, analytic logic and interpretive authority.

*Epistemological integrity* requires that the research question and processes are consistent with the “epistemological foundations” (Thorne, 2008, p. 74) of the study. As demonstrated throughout this chapter, sampling, data collection and analysis were informed by the key underpinning principles of Interpretive Description, as outlined on page 51. *Representative credibility* requires that claims made are consistent with sampling and data collection methods used. Thorne (2008) stated that sampling for variability and data triangulation were preferable, and that prolonged, rather than superficial engagement with the participants was ideal. A number of strategies were used to meet the criteria of representative credibility. Maximum variation (purposive) sampling was initially undertaken; theoretical sampling was used to recruit the final participant. Multiple interviews were completed with each participant. This provided an opportunity to check the interpretation of what they said, ensuring that their ‘aphasic speech’ had been correctly interpreted. The multiple interviews also supported the development of rapport between interviewer and participant; this may have helped them feel more open discussing their experiences. Multiple methods of data analysis were used. Comparing and contrasting the key codes and themes that emerged from each method strengthened the final analysis. Finally, a significant amount of data was incorporated into the final analysis (see Chapter Four, Findings, page 70). This will enable the reader to evaluate the interpretation themselves.

*Analytic logic and interpretive authority* should make the researcher’s reasoning with regard to their interpretation explicit and thereby demonstrate the

results are trustworthy and not constrained by bias (Thorne, 2008). There were multiple methods used to ensure analytic integrity and interpretive authority. Assumptions about how people may experience hope were identified before the study commenced. These were detailed in Chapter One (page 7). As assumptions emerged during the course of analysis, they were documented in memos. Providing data about the participants helps ensure the findings are interpreted in light of the specific context of the study. This data will be provided in Chapter Four: Findings (page 70). All analysis was grounded in the data, that is, no *a priori* codes were used (Thorne, 2008). In addition, records of all coding and analysis decisions were maintained. There were regular supervision meetings where the emergent analysis was discussed and defended. The process of presenting the analysis and the rationale for the findings ensured that decisions about analysis were regularly challenged – this assisted in making the findings robust. Emergent results were discussed with both the participants and with professional colleagues. Finally, a significant amount of data was incorporated into the final analysis, to provide evidence that the analysis emerged directly from the data, and to enable the readers to evaluate the interpretation themselves.

## Summary

This chapter provided an overview of Interpretive Description, the methodology that underpinned this study of the experience of hope in people with aphasia. It illustrated the appropriateness of the methodology for the question and the study population, one that is commonly excluded from qualitative research. Numerous strategies were used to maximise the ability of people with aphasia to participate in the research, along with those used to interpret the data in a way that was consistent with their intent and meaning. These were outlined. The results of this analysis will be presented in Chapter Four: Findings. That chapter will detail how people with aphasia after stroke experienced hope.

## Chapter Four: Findings

### “The Simplicity and Complexity of Hope”

Participants appeared to experience hope in two ways – *simply ‘having’ hope* and *actively hoping*. *Simply ‘having’ hope* was a passive state that provided a level of stability for an individual. It was a prerequisite for *actively hoping*, a form of hope where the individual is engaged in identifying and working toward hopes. However, despite the apparent simplicity of this, the experience of hope appeared dynamic, fluid and complex. That is, a number of factors appeared to influence the experience of hope. This resulted in participants moving between the two forms of hope as they grappled with the tensions inherent within hope.

This chapter will first describe the participants in this study. It will then detail the two primary experiences of hope. The chapter will then discuss the factors that served to make hope complex, detailing how these appeared to impact on the experience of hope. Finally, it will describe the strategies participants used to manage the complexities associated with hope.

### Participant Characteristics

Twelve people were invited to participate in this study. Five declined to be involved at the outset; of these, three stated they were too busy with other commitments such as rehabilitation, family and/or work; the reasons the remaining two declined are unknown. Referring clinicians indicated they did not approach all potentially eligible patients. For example, a number were not advised about the study as their speech-language therapists considered they were too depressed to participate.

Seven potential participants agreed to be referred for the study. Two of these were ineligible. This was discovered prior to data collection for one participant, who was deemed ineligible as they were receiving their third episode of community-based rehabilitation; and following the commencement of data collection for the other participant, who had had a right hemisphere stroke and so despite presenting with similar symptoms, did not have aphasia. The data from this participant were not used in the analysis. In total, five people participated in the study. Details of the five participants are presented in Table 2. The names listed here are pseudonyms to maintain participants' confidentiality.

## The Simplicity of Hope

Participants appeared to experience two forms of hope during the post-acute period of recovery from stroke. *Simply 'having' hope* was a broad sense of hope that was either constant, or developed after the stroke. It was considered essential and gave a sense of hopefulness. It was developed through a range of internal and external sources and participants reported that *simply 'having' hope* gave them a reason for being and a sense that things would improve in the future. *Actively hoping* consisted of two forms of hope – identifying hopes for the future and working toward those hopes. These forms of hope are illustrated within Figure 3 and explained in more detail below.

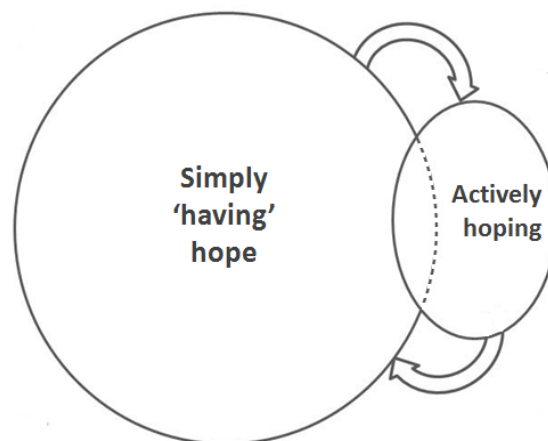


Figure 3. The simplicity of hope: *Simply 'having' hope* and *actively hoping*

Table 2

*Participant Characteristics*

	Gender	Age	Ethnicity	Type of stroke	Time post-stroke <sup>1</sup>	Effects of stroke	Aphasia severity and type <sup>2</sup>
<b>Matthew</b>	Male	41	Pākehā	SAH, left MCA aneurysm	4 months	Aphasia Mild right hemiparesis Cognitive changes – memory, information processing, attention	AQ=83 Anomic aphasia
<b>Iosefa</b>	Male	43	Samoan	Left MCA infarct	3 months	Aphasia Cognitive changes – memory, information processing, attention	AQ=67.3 Conduction aphasia
<b>Miriam</b>	Female	62	English	Left MCA infarct	4 months	Aphasia and apraxia of speech Dense right hemiparesis Neglect	AQ=57.3 Broca's aphasia
<b>Adrienne</b>	Female	57	Pākehā	Left MCA infarct due to left sphenoid wing meningioma	5 months	Aphasia and apraxia of speech Moderate right hemiparesis Limb apraxia Cognitive changes – memory, planning, sequencing Visual perceptual deficits	AQ=80.2 Anomic aphasia
<b>Tony</b>	Male	47	Pākehā	Left MCA infarct Multiple small embolic infarcts	2 months	Aphasia Cognitive impairments – memory, attention, executive functioning	AQ=94.8 Anomic aphasia

<sup>1</sup>Refers to the interval between the stroke and the initial interview

<sup>2</sup>Aphasia severity was measured using the Aphasia Quotient from the Western Aphasia Battery- Revised (Kertesz, 2006) as was the Aphasia type

## Simply 'Having' Hope

*Simply 'having' hope* was the primary form of hope experienced by all participants. It was a passive state where participants reported they felt the presence or a sense of hope. It was a hope that "just is" according to one participant. While all participants experienced this form of hope, there were subtle differences in how it was experienced.

**Developing a sense of *simply 'having' hope*.** *Simply 'having' hope* was a state that was either constant and unaffected by the stroke, or was absent immediately following the stroke but gradually re-emerged during recovery. Two participants, Iosefa and Tony, experienced *simply 'having' hope* throughout recovery; it appeared unaffected by the stroke. Iosefa described this hope as "the life of who I am", something entwined with his sense of self and his faith in God. Miriam's sense of hope was also constant although it felt "out of reach" immediately after the stroke. She became aware of, and drew on, her sense of hope after a few days, stating "all I could do was hope". She did not, or could not, identify what helped her become aware of hope. This sense of hope sustained her during her recovery. She saw hope as positive and essential saying without "positivity, mm ... (3sec) well then I'd [unintelligible] eventually die". When Miriam talked about hope, she commonly referred to it as "positive". This appeared to be a semantic paraphasia, a substitution of a related word. By retrieving "positive" instead of "hope", it suggested that, to Miriam, the two words were related in meaning. Tony also considered hope was synonymous with positivity, saying "my positivity and hopefulness definitely mould into the same thing". He saw these as a key part of his character.

In contrast, immediately after their strokes, Adrienne and Matthew experienced a temporary absence of hope, instead feeling a "state of despair". Both participants had severe strokes and complicated recovery processes. As each person processed what had happened and its implications, they reported feeling grief, despair, and a desire to die. Adrienne described despair saying:

[It] never lets it go. When you're in a despair, in a real despair you always always have it in, just, you don't ... (1sec), really good ... (1sec) you you never ever really um, from the despair.

*You're never free?*

Yes, that's right, it's just really, just there, but hope will quell it.

She said she could "feel that in my mind I have to have to have myself out the window because that's it". She felt there was no hope in the situation: "do you know, in a suicidal lot, there's no hope". Despite an apparent lack of hope, Matthew reported conflicting emotions, saying "in that situation was that I was happy. I was happy as Larry" and "I don't know, just, yeah, I wanted to, wanted to be shot and somebody take me out of there."

Despite an initial despair, both participants developed a sense of *simply 'having' hope* within a relatively short period of time. This happened very suddenly for Adrienne:

Um, all I can say is that I was holding like this {holding self rigid with shoulders elevated} and I and I I looked over at the so-so-so dadada

*Psychiatry nurse?*

Yip, psychiatry nurse and I could I could see myself OK {deep exhalation} OK and I saw myself and I was still exhausted and it was just hope, OK, OK, yes OK. Just that, immediately from despair into hope and that's the truth.

The presence of hope made her feel "just more normal. That's all I can say. More normal." From that point on, she maintained this sense of hope. In contrast, Matthew experienced a gradually developing sense of hope. He thought that it emerged during his time in inpatient rehabilitation but was not certain. He suggested it was developed through particular rehabilitation staff and his children. Sources of hope will be discussed in detail later in this chapter (see page 76).

**Characteristics of *simply 'having' hope*.** *Simply 'having' hope* was experienced as a feeling or way of being. Adrienne described this state of hope as "just hope". It was not something participants had to engage with or act on - they simply needed to have it. This was reinforced by comments such as "it's a good thing to have" and "there is definitely hope there". As a result, they sometimes appeared passive when experiencing this form of hope. This may reflect that people were not always conscious of the presence of hope. Adrienne wasn't always aware of her hope during



her recovery. It only became evident when she was being interviewed – “I’ve never noticed it [hope]”, “I’d never realised that [there was hope there]”.

**“All is nothing without hope”.** All participants considered hope was essential for life and important for recovery. Miriam saw hope as “a matter of /rɪvɪŋ/ [living] or dying”, saying “all is, is nothing without hope”. In her view, she’d “be dead” if she didn’t have hope. After Adrienne re-discovered her sense of hope, it helped her “want to live”. She said that “it’s right to to know it [the time of despair] is over and to now move forward” in the process of recovery. She considered hope crucial in this process. Matthew agreed with these participants, saying “It it’s it’s because you’re gonna gonna need that sort of hope or hope in general as a as a safety rule, as a safety mechanism” and “it’s a hope you’ve got to have.”

Hope was considered reliable and dependable when little else was. It sustained people during recovery as “date by date [day by day] it’s all you can go from”. It appeared to be persistent throughout recovery. Tony was able to maintain his sense of hope even when his friends and family struggled to maintain their hope about his recovery. He attributed this to his positive outlook on life. Miriam considered hope “eternal”. She felt it would persist even if people told her she wouldn’t improve due to her belief that it was “/bɪd mɔt/ [better to have small hope than] no more at all”. This could suggest that viewing hope as an essential quality, “a hope you’ve got to have”, as Adrienne suggested, could help an individual maintain it.

**“Feeling hopeful”.** When participants talked about hope, they commonly used phrases such as “positive hopefulness”, “very hopeful” and “I’m feeling hopeful”. They had a broad sense the future would be good, or “positive” as several participants said, but they did not appear to qualify this further. When asked if hope needed to incorporate specific hopes for the future, Adrienne replied “obviously, it’s your thing that thing ... yeah, I probably never think of it like that”. This illustrates the difference between passive and active forms of hope – *simply ‘having’ hope* and *actively hoping*.

**A place to wait.** This form of hope appeared to allow people to wait and maintain a broad sense of hope when they were not able to engage in *actively hoping*. They appeared to be waiting for a number of things to happen – waiting for unspecified ‘things’ to “work out”, waiting for their recovery to come about, waiting to

get back to normal. Tony said he was waiting to “see what would happen [in the short term]” while Adrienne was waiting until she was “better” before really looking forward to the future. Participants considered themselves passive while they waited for these things to come to fruition, saying “there’s nothing I can do about it”, “I think it always happens out there”, “I think it’s much more happening to me than I am happening” and “I tend to wait to happen”. By providing a sense of stability, *simply ‘having’ hope* appeared to help them maintain hope that improvement was possible while they waited for this improvement to occur.

**Sources of hope.** Other people were the most common source of hope, particularly spouses and children. Matthew reported gaining hope from “listening to my kids tell me what they want to do”, while Miriam identified “[husband’s name] and grandchildren” as her primary sources of hope. Adrienne found the support she got from friends was important. Matthew suggested those who provided hope could also pose a threat to his hope. He felt his sense of hope could be lost if his family took control of his future for him: “My kids and my wife have just have just, they just do something or say something and then it then it would all disappear”.

All other external influences on hope were seen as positive. Iosefa and Adrienne reported God was a source of hope. Iosefa received ongoing hope “because of Him”, while Adrienne felt “it was the Lord. It was God” who moved her “from despair into hope”. The stories and progress of other stroke patients gave participants hope. Tony said, “I look at people like that and think ‘well if those bastards can make it, so can I’”, while Miriam found other people’s stories inspirational: “a little bit of um ... (4sec) a little bit of ... (1sec) um /stɔ stɔ fɔ stɔ/ [stories] um um ... (2sec) a little bit of um um /æpəreɪʃən/ [inspiration]”. Adrienne said talking about her experience of hope gave her more hope as “you [the interviewer] helped me realise there was hope there”.

Rehabilitation staff provided hope for some, with Matthew saying “the service that I got from from the um, the head you know, the honcho at the um rehab, he gave me a whole lot of hope”. The strength of the therapeutic relationship appeared to influence whether they gained hope from their therapy staff. Matthew said he received little hope from one particular therapist. He described their relationship:

“you know, I don’t um I don’t respect her and that’s that’s just as a personal thing really um, I just, I she, I yeah, it’s something about her I just, I can’t relate”. He reported he had a strong relationship with one staff member, saying “he’s good, he’s really good”. The support and attention this person gave helped him think positively about the future which in turn, increased his hope for the future.

All patients found their own progress gave them hope that they would continue to improve. In Tony’s case, this made him feel his potential was limitless: “Within 4 weeks I went from nothing to what I am now. So the hope is ‘my God, I can go from 0’” and “When you’re doing stuff, your hope increases 100 fold cos you’re going ‘wow’”.

Transferring between healthcare services often saw hope increase as the transfer was considered an indicator of progress and recovery; this further reinforced hope.

**Outcomes of *simply ‘having’ hope*.** *Simply ‘having’ hope* was associated with having purpose, a reason for living and unspecified opportunities. When Matthew was asked what it was like for a person to have hope, he replied:

Well, he’ll be over the moon, won’t he? Cos he’s just got everything at his at his door, everything waiting for him. You know. In the, in the, vast, in the you know vast display of God and what have you, it’s he’s, he’s in there somewhere, he’s going to be in there somewhere. And if he’s not, well he’s not but, he’s gonna be you know. And if he tells himself he’s gonna be, well he is gonna be you know.

Tony considered that hope was “about having a chance”. He felt *simply ‘having’ hope* gave people opportunities, “opening up possibilities”. Having hope meant that there was a likelihood that a person would make progress and that “things [would] improve and get better”.

## **Actively Hoping**

The other way participants experienced hope was *actively hoping*. *Simply ‘having’ hope* appeared to be a prerequisite for this. The key distinguisher between these two forms of hope was the active engagement with hope. There were two ways participants demonstrated they were *actively hoping*: explicitly identifying hopes for

the future and working toward hopes. These will be described below. While all participants reportedly experienced this form of hope, it appeared more tenuous than *simply 'having' hope*, and was often experienced intermittently. These factors will be further explored on page 82.

**Identifying hopes for the future.** Hopes for the future appeared hierarchical in nature, ranging from broad, personally meaningful hopes, to more focused hopes, to specific, stroke-related hopes (see Figure 4).

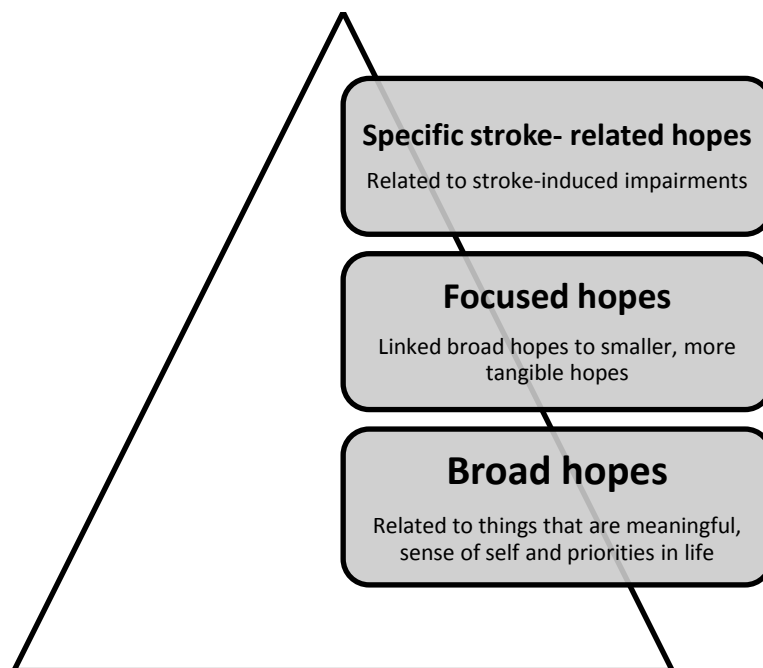


Figure 4. Hierarchy of hopes identified by participants

At the first level, hopes arose from areas of life that were meaningful to the individual and their sense of self. They focused on roles in life, faith, and outlook on life and were broad visions related to the person they would like to be. These hopes appeared easy for some participants to identify and were commonly elicited by the question “what does hope mean to you?” They arose from a process of reflecting on past hopes and ways of being, on the present situation and their possible futures.

Iosefa’s hope was unchanged from those before his stroke: “to be Holy”. He considered this level of hope to be “ethical” and “personal” hopes. Matthew’s hopes

came from reflecting on himself before his stroke. He saw the stroke as a catalyst for change and hoped to do “everything that I wanted to do that I couldn’t do before before this” and “being the best Dad I can be”. He also described another hope: “the inside hope which is [wife’s name] and the girls”. He felt the first hope was “way over” [implying it was out of reach or too difficult] but the latter two hopes acted as a bridge between his current situation and his broadest hope, as they allowed him to “start it from there and just see what happens”. Miriam’s hopes were also broad and non-specific, but were unchanged from before her stroke: “be as as ... (4sec) /bes/ [best] as you can be”. The hopes identified at this level were unique to each individual.

Iosefa suggested there may be a second level of hopes which were more focused, tangible forms of his broad hope. These were: to pass his values and beliefs onto his children, and to continue his theological study. They related to his higher level hope of being Holy: “with the high level with the personal, with this one {points to words written on paper, ‘being Holy’}”. He continually referred to a diagram on a piece of paper when discussing the levels of hope. This is provided in Figure 5 below. He stated:

I’m not um, I link, living, thinking of in with this one [I am thinking of this one] {pointing to middle circle, labeled “broad”}. But we already say this one {pointing to the outer circle, which he had labelled “ethical”}, this is the high level we say. For example for the studying, eh? That what we say the example {points to middle circle}.

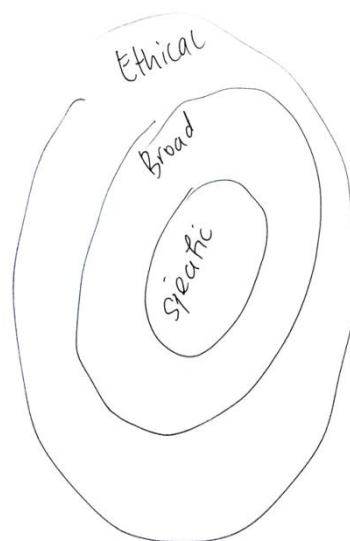


Figure 5. Iosefa’s levels of hope diagram.

All participants acknowledged a final layer of hopes related to the resolution of stroke-related impairments. They were relatively generic and included improving memory, being able to do things independently and being able to work. They were often elicited by closed questions such as “Do you hope your speech will improve?” Matthew identified he wanted to get his speech back because:

... to express my thoughts and then um yeah ... (1sec) I don't know it's just something about you know, having the the ability to to speak for myself you know and and that that that is a huge thing um, but not without you know that um middle set of words you know. They're the poignant models of um, of ohh I don't know, of your personality or something like that.

In addition, most participants expressed an expectation they would return to normal. This was considered an expectation as participants described a high degree of certainty that these would be realised. For example, Iosefa said “I will get it. I will get it remember later, but I'll will go back” while Matthew believed “oh fuck yeah, they'll get completely better”. Adrienne put a timeframe on her expectations, saying “that's the thing that it comes back, it will come back, happen over about six months”. There was some overlap between expectations for recovery (specifically, returning to normal) and their hopes for recovery. The data suggested that the difference between a hope and an expectation was the level of certainty related to the desired outcome. Expectations were accompanied by a high degree of certainty that they would be achieved; hopes had a lower level of certainty attached to them. In addition, expectations had a clear endpoint, were measurable and were commonly stroke-related, while hopes were broader, related to priorities in life and did not necessarily have a measurable outcome, for example, “being the best Dad I can be”.

Attending rehabilitation sessions was perceived to have limited relationship to their broader hopes. Instead, rehabilitation related to their stroke-related hopes. Matthew said:

The the funny thing is, things that are are reliant to me [important] are getting this arm working that's that's that's nothing to do with the kids but that's something I want for you know the future but you know fuck that's such a small thing you know, it's this this this much you know um, but I've gotta do it you know but, I don't know, that's, I don't know, it's a bit weird to me.

Tony did not feel his therapy related to his hopes and was not concerned by this. He felt that therapy was useful to “monitor progress and see what Mother

Nature is doing”. In his view, seeing a therapist once a week was inadequate to help him progress. Iosefa felt his hopes would be realised through God and prayer rather than rehabilitation. He considered therapy might help his stroke-related impairments, but did not see that it linked to his broader hopes.

**Working toward hopes.** Participants suggested there were three steps that would help hopes come about – developing a plan, putting the effort in and taking action. Tony described *developing a plan* as “just [devising] a way to do it”. It was commonly seen as difficult. Participants appeared to struggle with this as many of their hopes were broad and non-specific and didn’t easily lend themselves to developing a plan. The next stage was *putting in the effort*, which Iosefa described as “if you don’t want [if you want it], we have to work”. Miriam said this required an individual to “just gotta /pa:/ [pull] self up”, and “work at it”. The effort may be physical or cognitive, such as “focussing on what you’re working on” or “doing the physio sessions”. Matthew identified this was difficult: “It’s something I want to do, I do want to do it and um, but depending on how much I want to do it, I don’t know”. This suggests that a certain level of motivation and/or volition may be required before starting working toward hopes. The final step participants described was *taking action* to realise the hopes. The only person doing this was Iosefa who had written action plans for two of his hopes. His hopes and his action plan had both been in place before his stroke and had not been affected by the stroke.

While Iosefa was the only one working toward his hopes, all participants reported they should be doing this. Miriam stated “the, the /æspəreɪ/ [aspiration] and /əbɪdɪ:/ [responsibility] both has to be with you”. When Adrienne was asked “Do you think you need to be taking more steps to help your dreams happen?”, she replied: “Yes, yes, I definitely do”. Tony felt that if he didn’t start to work toward realising his hope, it could restrict his potential. Maintaining hopes without action would not help him “in the long run” as it would result in him “just sitting still” and not progressing. He believed that he wasn’t in a position to take action at that point as his hopes were not clear, he had other things to concentrate on and he was waiting for further improvement.

## The Complexity of Hope

While hope was experienced in two primary ways, *simply 'having' hope* and *actively hoping*, the experience of hope was not as straightforward as it appeared at face value. The data suggested that three factors appeared to contribute to the complexity of the hope experience. These were: uncertainty about the future, a perception of hope as double-sided, and a sense of disruption. These factors will be explained in detail and illustrated by data from the interviews.

### **Uncertainty about the Future: “Don’t know the future ... don’t know where it’s going to take me”**

There was a degree of uncertainty about the future for all participants in this study. It appeared there was interaction between a person’s uncertainty and their ability to look toward the future. For example, Adrienne said: “there’s a lot of ‘what will it [what will I] look like at the end [of the recovery period]’, you know?” and “I don’t know where I want to be in three months or a year’s time” while Matthew considered the future was “out there”. Uncertainty could be specific to when the anticipated recovery would occur, or could be broadly related to what the person’s future may look like. A person’s uncertainty about the future appeared to influence how they experienced hope – as a passive form, *simply 'having' hope* or as an active, future-oriented form, *actively hoping*.

As detailed on page 77, *actively hoping* involved thinking about a possible future, identifying specific hopes that the individual would like to realise in the future, and, in one case, working towards these hopes. However, thinking about the future was challenging when the future was considered uncertain or unknown. This uncertainty appeared to result in one of two reactions – acceptance, or fear and vulnerability. One participant, Tony, experienced uncertainty about the future, saying he “[doesn’t] know where life’s going to take me” but he appeared able to sit with the uncertainty as he was content to “go with the flow” and “see how things go”. He felt that he would need to actively engage in thinking about the future at some point, but



he at this point in recovery he was “comfortable with waiting”. In contrast, Matthew and Adrienne appeared to experience some distress as a result of the uncertainty which in turn, appeared to emerge from a sense of fear and vulnerability about the future. One reason for this was that the future was considered outside Matthew’s control; he described himself as “at the mercy of this thing [his brain]” which “will have, you know, all the say [about his recovery]”; he also felt his wife and children may be the ones to determine his future. Adrienne reported:

You know you’ve got something to do that something is better [you have to think about the future] but I just just just /derəfaɪd/ terrified when I terrified, I can you know there /næʃənʊ rɒʊ nəʃənʊ/ [rational] [when I’m terrified, I can’t be rational].

This emotional response seemed to be influenced by her past experience of hope and a sense that “everything seems to go wrong”. As a result, she was taking things “a day at a time”. These examples illustrate the person’s response to the uncertainty (acceptance or fear) appeared to influence their subsequent engagement in thinking about the future – in some cases, simply being passive with regard to the future, or in others, appearing to actively try and avoid thinking about the future due to the perceived negative consequences. Limited thoughts about the future appeared to contribute to a dominant hope experience of *simply ‘having’ hope*.

At various times, all participants had glimpses of a possible future. When participants viewed the future in a positive light and were able to think about what they wanted their future to be like, they were more likely to engage in *actively hoping*. Iosefa had a continually positive view of his future, and had consistent hopes for the future, such as “to be Holy” and was working toward these hopes. When other participants viewed the future as one that had possibilities and could be better than their current situation, it appeared the uncertainty no longer dominated their view of the future. Their view of a possible future facilitated engagement in *actively hoping*. For example, intermittently, Matthew saw the future as one that could be positive, where he could “be the best Dad I can be”. His uncertainty was still present but he appeared able to look past it and see the potential that the future held: “well, I don’t know if it’s ever ever you know, going to be different [from the present situation], but hey, who knows, I can still try”.

It appeared as though there was a tension between hopes and expectations for the future and uncertainty about the future. At times, hopes and expectations for recovery dominated participants' views of the future while at other times, their uncertainty would dominate. When hopes and expectations of recovery dominated, they were positive about the future, expressing a degree of anticipation. However, when uncertainty dominated, their view of the future appeared to become restricted and limited and their focus returned to the present, focusing on "just getting through". This appeared to impact how they experienced hope and instead of engaging in an active, future-oriented form of hope, their dominant experience of hope was *simply 'having' hope*, a passive, more present-focused form of hope.

### **Double-sided Hope: "Hope can be full of, full of joy but hope can be full of grief as well"**

As discussed in the section on *simply 'having' hope*, all participants considered hope was a good thing to have, something essential, life-giving and important for recovery (see page 74). However, two participants reported a co-existing, conflicting view of hope as something bad or negative. Matthew described these competing conceptualisations of hope:

*Is hope necessarily a good thing?*

Yeah I think it is. I think it is a good thing. It's good to have um, and it's also very bad to have but it's it's a hope you've got to have.

*Why do you say it's very bad to have?*

Because because if it's good to have then it's also bad to have. Like there's also um ... (2sec) bad aspects of hope.

*Such as?*

Well, the such as going for a job and not getting it. That's a bad bad hope.

*So kind of the distress that can come from having a hope unfulfilled?*

Yeah, you know, you know, I mean I haven't, I I I haven't been, no I shouldn't say that I I have, I should say that I have had bad hope come my way you know, I I and I've had the bad hope you know linger as well.

This so-called "bad" hope could pose a threat to the individual. For example, Matthew referred to the possibility of emotional distress from unfulfilled hope. It appeared to result from past experiences of having hopes dashed or unrealised which resulted in "my brain, it's more more given up on that word [hope]". This was also

illustrated in Adrienne's experience of hope. She described how she was reluctant to engage too much with hope because of her past experience of things going wrong:

*Do you ever feel a bit nervous or something, reluctant to dream about the future or have hopes about the future?*

Yes definitely, definitely

*Can you tell me more about that?*

Um ...(2sec) I just because everything seems to go wrong [in the past], but then I'm hopeful in the, ahhh, grandchildren ... (1sec) grandson [I have hope for my grandchildren], that's getting um I just just , but then there's, I'm always always afraid [that something might go wrong]

The perception that hope could have both good and bad sides resulted in internal tension for these two participants. It may be that this tension was between intellect and emotions. At an intellectual level, they considered hope was a good thing; there was a strong desire to have hope because participants recognised the positive effects of hope; they appeared to want to believe in hope and the positive things they felt it could bring. However, at an emotional level, this desire was tempered by a fear of unfulfilled hopes – “you can hope for lots of stuff but then half the time it's going to disappear or than half”; a fear of disappointment; a fear they might fail at what they hoped for. This tension was alluded to in Matthew's comments in response to the question “What does hope mean to you?”:

Um, well yeah, um ... (1sec) yeah um ... (2sec), like um, in one sense inspirational. It's just um, yeah, I I I mean, um, the word, the word itself just dic-dictates a whole lot of things but for me it just means um ... (1sec) just um, insanely happier or insanely I don't know, just just blown away by the the situation I'm in you know um, but you know, it's you know, also important to to just let- levitate back and say 'ohhh, hang on' but you know, you you can't say that because ou know something, it might trigger off something but {indrawn breath} yeah well, you know and I think about that.

It was also supported by Adrienne's comments: “There's definitely two sides there. Yes, there's emotion part and a cognitive part you know. It's just the thing, it's horrible really”. This tension and its resultant fears then influenced how the individuals experienced hope.

Both these participants also described a process of judging their specific hopes, suggesting particular hopes could be perceived in different ways. They were measured against an internal sense of what a hope should be: “I don't think that that's, my example [of hope] is true. It's wrong”. These participants, Adrienne and Matthew,

suggested hopes could be considered good, “right” hopes, or could be “not good enough” and they both wondered if they were not hoping for “the right thing”. If their hopes were found lacking, it appeared to make them question their ability to hope at all. Matthew said that he often asked himself “Are you are you are you good at hope or you not good at hope?” and felt that there was “the possibility of fuck, I’m not very good at hope”.

When participants viewed hope as positive, an entity that would assist their recovery, it appeared to promote their engagement with hope through *actively hoping*. However, if they experienced negative thoughts about hope – that it might make them vulnerable, that their hopes weren’t for the “right thing”, or that they weren’t good at it – it was associated with a reduction in active engagement with hope and a retreat from *actively hoping*. Matthew described a process of keeping hope at arm’s length:

It’s like my brain is pushed it and yeah, I I just yeah, I don’t see the need for the hope you know. And and such, for you know, my head is just totally pushed it out of the way so for now, I don’t, I don’t see much of a use for it. I mean, now it’s it’s clinical as it is you know, that that oh that’s nice but it’s not right. For me now, you know.

Even though his sense of hope was at a distance, it was still present at a low level. This suggested that even when participants struggled to maintain a positive view of hope itself, they did, at some level, maintain a sense of *simply ‘having’ hope*.

## **Sense of Disruption**

Another factor that appeared to impact how people experienced hope was the extent of disruption arising from the stroke. Four of the participants reported experiencing differing degrees of disruption to their identity and/or their engagement in meaningful activities as a result of the stroke. Iosefa felt there was a limited disruption: “as I said before, [I] am still the same. Only physically have changed”. His plans for the future were not considered to be affected but were temporarily on hold while he recovered from the stroke, saying “I will get it, I will got is remember maybe later, but I’ll will go back”. He reported his sense of identity was not disrupted– “this is

who I am". Tony also experienced disruption although he did not appear to consider this problematic. He was uncertain whether he would be able to return to his study in the long-term. He appeared to view this as an opportunity to think about the "different possibilities" in front of him. He felt his future would be different because of the stroke, at least in the short and medium term. Because of his view that "what will be, will be", he did not appear concerned by the possible effect of the stroke on his future.

Adrienne and Matthew also experienced significant disruption from the stroke but unlike the other participants, this appeared to pose challenges for them. At one level, the disruption was welcomed as they were dissatisfied with their life before the stroke and it brought new possibilities and the opportunity to "do things differently". Adrienne reported a sense of "relief. Definitely relief. Um, yeah, just relief I think" that she wasn't able to go back to her job: "When I thought that it [the stroke] happened, 'it's gone [her job], it's over' and I was really pleased". Matthew also welcomed the fact things had changed. As he reflected on himself before his stroke, he reported an "unbelievable amount of regret to who I who I I was, the way I was" and identified there were many lost opportunities: "I'm thinking that now, you know. Why didn't I do that, you know". He appeared to have lost his sense of identity and was struggling to regain it. He reported one function of this stage of recovery was "just a just a moment for myself and maybe [wife's name] I suppose as well, to just look at what we've got to do and how we do things you know". The process of moving forward was challenging with Matthew describing a need to "move forward" but "don't know how to do it". He described how this could affect his ability to engage with activities or thoughts about the future:

I sort of thought 'Oh, maybe. Maybe it's me' and then I then I I thought about it you know, again the other night and I thought 'Oh nah, it's not me' and I just, I just I just can't agree whether it's me or not.

Exploration of these participants' experiences of disruption suggested that disruption itself was not automatically problematic. For some participants, it had the potential to be positive as it was an opportunity to move forward in a different way, but rather, it appeared the daunting task of 'where to from here?' in combination with a loss of identity made disruption particularly challenging.

The participant who had low levels of disruption found it easier to engage in *actively hoping* as his hopes were unchanged by the stroke. In contrast, the three participants who had greater disruption between their past and future had more difficulty *actively hoping* as this required them to “move forward” and develop an image of the future. In addition, several of these participants were unsettled by the disruption, despite it being somewhat welcomed. This resulted in their dominant experience of hope being *simply ‘having’ hope*.

### **Moving Between *Simply ‘Having’ Hope* and *Actively Hoping***

As detailed above, the experience of hope was generally fluid and it changed regularly in response to how people perceived their current situation and their future. People demonstrated different aspects at different times, sometimes engaged in *actively hoping* and at other times retreating from *actively hoping*, instead *simply ‘having’ hope*. The data suggested some factors were associated with *simply ‘having’ hope*, while others were associated with a person engaging in *actively hoping*. Factors associated with *actively hoping* were: a positive perception of hope, expectation and positive anticipation about the future, acceptance of uncertainty, a broad unrestricted view of the future and being able to think about their desired future. Factors associated with *simply ‘having’ hope* were: presence of a negative view of hope, tension between expectations and uncertainty, distressing uncertainty, a restricted view of the future, fear of the future and a sense of disruption accompanied by difficulty knowing how to move forward. Participants appeared to fluctuate between *simply ‘having’ hope* and *actively hoping*, sometimes within a short period of time, in response to the presence or absence of these factors.

One example of how these factors influenced a person’s experience of hope was provided by Matthew. He demonstrated many fluctuations in his experience of hope. At times, he reported “I’ve got lots of hope” and with focused questioning, identified hopes such as “to express my thoughts and then um yeah, I don’t know it’s just something about you know, having the ability to to speak for myself”; he had hopes of “[being] truly cured, like 100% cured” and “to be the best Dad I can be”. However, at other times in the interviews, he made comments such as: “I don’t have

much hope for the future”, “I don’t I don’t um know when I last felt hopeful” and “my head is just totally pushed it out” because “I don’t see much of a use for it [hope]”. The fluctuation was confusing for him: “that [hope] is not how I feel at the moment, but you know, well I was good this morning when I woke up so something has happened to me”. These comments illustrate the variability and complexity of hope, highlighting it is a subjective experience subject to a number of contextual factors.

## Managing the Tensions Inherent in Hope

The complex nature of hope and the influence of different factors appeared to result in tension within people’s experiences of hope. Key sources of tension appeared to arise from expectations of the future conflicting with uncertainty about the future; differences between expectations and their hopes; viewing hope as positive *and* negative; and considering the future as good but unknown. It often appeared that participants were in a balancing act, trying to balance the various factors in order to maintain a sense of hope. Participants drew on four different strategies in an attempt to manage the tensions in hope.

“*Hunkering down*” (as described by one participant) occurred when uncertainty dominated thoughts about hope and the future. Participants retreated from *actively hoping*, instead focusing on the present, maintaining a sense of *simply ‘having’ hope*. They did this by moving their focus from their possible future, instead focusing on “getting through”, taking it “a day at a time”. This allowed them to maintain a broad sense of hope while trying to reduce any possible negative influence of hope.

A similar strategy was *limiting engagement with hope* when participants viewed hope as double-sided – something good or bad – or while they waited for their expectations to be fulfilled. If they considered hope could pose a threat to them they tried to minimise its influence on them by reducing their active engagement with hope. They reported they did this by trying not to think about hope. This strategy was also utilised when there were high expectations for the future. Participants gave the impression that they would only start to engage with hope once their expectations had

been fulfilled. For example, Adrienne had high expectations that “everything would will will, come back normal ... (2sec) about six months”. As a result, she said: “and I’m just you know, just just staying, waiting for the thing [the effects of stroke] to go”. In this situation, there was limited *active hoping*, instead she was waiting for things to change and had a dominant hope experience of *simply ‘having’ hope*.

Another strategy used to manage uncertainty was *keeping hopes broad*. By keeping hopes broad and unspecified, such as “/gʊʊt/ [hope] ... (2 sec) you for better times to come [hope for better times to come]”, people weren’t specifying exactly what they hoped to come about. This participant had hopes of not being “too much /ɪŋkəpæstəd/ [incapacitated]” and being able to do things “without too much fuss”. This may provide some protection from disappointment if their hopes were unfulfilled. Another strategy one participant used alongside *keeping hopes broad* was *putting limits on hopes*. Miriam commonly used terms such as “step by step” and “one step at a time” when talking about her hopes for the future. This took the focus away from particular hopes and her long-term future.

While people utilised a number of strategies to try and manage the tensions within hope, these strategies appeared to have the same outcome for the participants’ experiences of hope. Their dominant experience of hope was *simply ‘having’ hope*. They would intermittently engage in *actively hoping* but as this was where the majority of tensions were located, participants moved in and out of this form of hope. The tension could also dominate people’s experience of hope, causing them to lose sight of the future and any hopes they had identified, which resulted in them retreating from this experience of hope. *Simply ‘having’ hope* appeared to act as a stable footing that people needed in order to engage with hope in a more active way. It was also a form of hope that people could come back to when they struggled to actively engage with hope. *Simply ‘having’ hope* was a state that could be relied on or defaulted to when a person was struggling with the complexities of hope. The tensions, strategies and consequences for the experience of hope are highlighted in Table 3.



Table 3

*Tensions, Strategies and Consequences for the Experience of Hope*

Tension		Strategy	Consequence for hope
<b>Hope vs. uncertainty</b>	If uncertainty was stronger than hope, or if there was a fear their hopes would not be realised	“Hunkering down” Keeping hopes broad Putting limits on hopes	Dominant hope experience was simply ‘having’ hope  Sometimes engaged in actively hoping but this was often intermittent and there was limited action toward realising these hopes  Could lose sight of hopes, which in turn limited active engagement with hope
<b>Expectations vs. hopes</b>	If expectations for recovery were high and if individual considered they had limited role in expectations being fulfilled	Limiting engagement with hope while waiting for expectations to be fulfilled	
<b>Hope as good vs. hope as threat</b>	If hope was seen as double-sided	Limiting engagement with hope to protect self from hurt	

### The Simplicity and Complexity of Hope: A Summary

The experience of hope was, at one level, very simple – it was about *simply ‘having’ hope* and *actively hoping*. However, a number of factors appeared to make the process of hope more complex than it appeared at first glance. One reason it was so complex was that a person’s experience of hope was dynamic and strongly influenced by their past experiences, their current reality and their perceived future. Uncertainty about the future could emerge when a person struggled to perceive what their future may be like; they often appeared ‘caught’ in their current reality. Double-sided hope emerged from previous experiences of hope and appeared to influence their current ability to *actively hope*. A sense of disruption could arise if there was a difference between a person’s life pre-stroke and their perceived future. The

hypothesised interaction between temporal and experiential factors influencing hope is demonstrated in Figure 6.

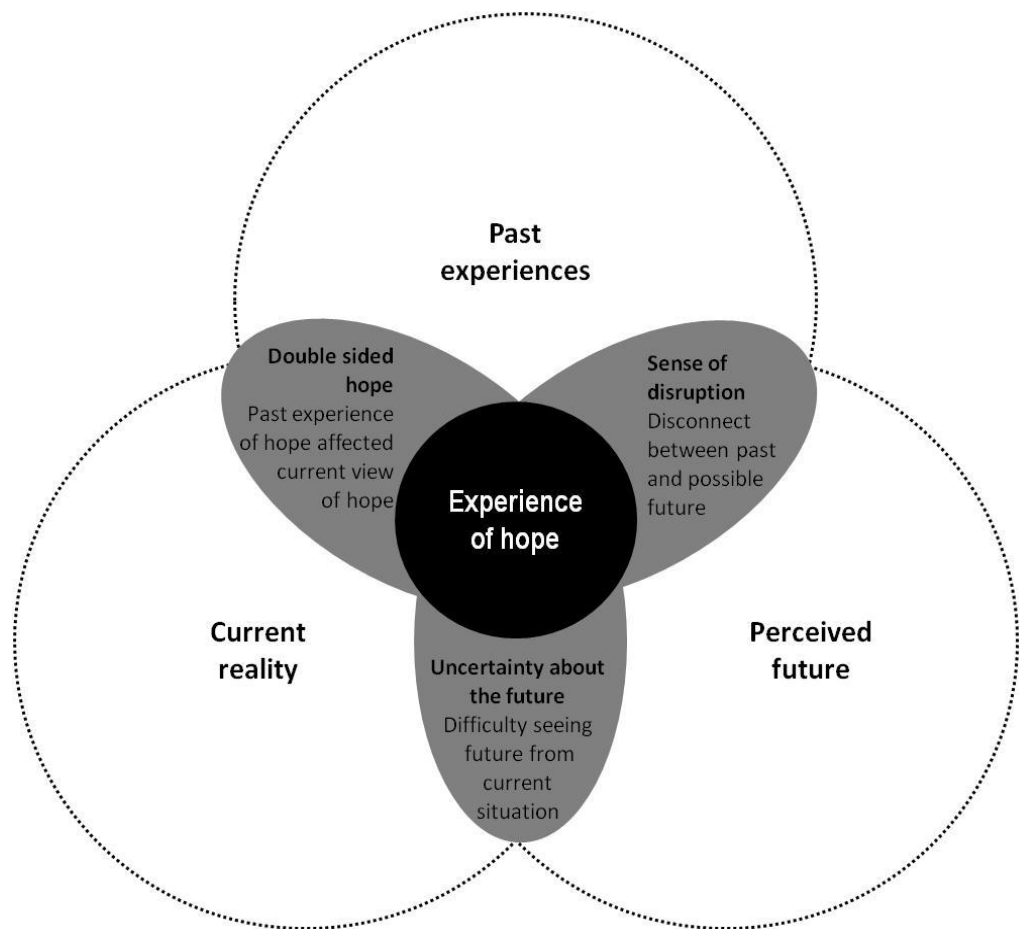


Figure 6. The simplicity and complexity of hope: The hypothesised relationship between temporal and experiential influences on hope

The complexity of hope could result in people engaging with hope, *actively hoping* and looking hopefully to the future, or it could result in them retreating from *actively hoping*, instead maintaining a sense of *simply 'having' hope* while they waited for things to change. The next chapter, Discussion, will position these findings within the context of relevant literature, and will discuss the clinical implications of these findings.

## Chapter Five: Discussion

The aim of this study was to explore how people with aphasia following stroke experienced hope during the post-acute rehabilitation period, and to identify factors that appeared to impact on hope. The core theme that emerges from the findings is “The Simplicity and Complexity of Hope”. The findings suggest hope is experienced in two ways: *simply ‘having’ hope* and *actively hoping*, but the experience is complex and appears to be influenced by three primary factors: uncertainty about the future, double-sided hope and sense of disruption. This chapter will discuss the two ways hope is experienced, in the context of existing literature. The chapter will review the limitations of the study but will demonstrate that in spite of these limitations, the findings are significant and bear a number of implications for clinical practice. These will be detailed, along with suggestions for future research.

### The Simplicity of Hope

*Simply ‘having’ hope* was the primary form of hope experienced by participants throughout the post-acute period. This sense of hope appears to be developed and maintained, or could potentially be reduced, by a number of internal or external sources. In contrast, *actively hoping* was experienced intermittently and appears to involve two processes – *identifying hopes* and *working toward hopes*. Identified hopes were commonly broad hopes related to a person’s priorities in life but also included stroke-related hopes. *Working toward hopes* rarely occurred, despite being described as important by the participants. These findings are discussed below, within the context of relevant literature.

The notion of having different forms, or experiences, of hope is consistent with a number of studies of hope. Marcel, a philosopher on hope, suggested there are two forms of hope which can be differentiated by two statements – “I hope”, referring to a general sense of hope, and , “I hope that”, referring to specific hopes that are directed

at a particular outcome (Marcel, 1962). Studies of hope in stroke and other clinical populations have also suggested there are several forms of hope – an internal sense of hope that is often viewed as essential and motivating, and another focused on specific hopes such as a hope to return to normal. The latter sometimes incorporates action to realise those hopes (Arnaert, et al., 2006; Bays, 2001; Benzein, Norberg, & Saveman, 2001; Lohne, 2008; Popovich, et al., 2007). This supports the finding that hope may have several forms and these may be centred on a state of having hope and an active form of hope.

This study specifically explored the experience of hope in working-age adults. As described on page 12, the literature suggested hope may be influenced by people's particular life stage. The findings from this study suggest that the core experience of *simply 'having' hope*, an inner state of hope and a future-oriented process, may be less influenced by age. These forms of hope have been found in studies of hope after stroke in a variety of age groups (e.g. Bays, 2001; Cross & Schneider, 2010). The participants in Cross and Schneider's (2010) study of hope were aged over 70, ranging from 71 to 100 years of age; they also suggested the dominant form of hope is a central inner sense of hope. Bays (2001) suggested hope is a dynamic process that includes a sense of hope, and specific hopes for the future; the participants in that study were aged over 60.

The current study suggests that *simply 'having' hope* is the dominant form of hope. This is consistent with Cross and Schneider (2010) who found an internal sense of hope to be the primary form of hope in women with chronic stroke. It has been suggested an inner sense of hope is the dominant and most important form of hope for different client groups, including those with chronic illness or suicidal ideation (e.g. Barnard, 2005; Herrestad & Biong, 2010; Kim, Kim, Schwartz-Barcott, & Zucker, 2006). The uncertainty and limitations associated with chronic illness may make a more active, outcome-oriented form of hope more difficult (Kim, et al., 2006). Uncertainty also appears to be a significant factor influencing how people with aphasia experience hope (see pages 82 and 99). This may reflect that the study was completed in the post-acute period of recovery, one that is recognised as a time of uncertainty (Becker & Kaufman, 1995; Burton, 2000; Rittman, et al., 2004). This will be discussed in more detail on page 99.

*Simply 'having' hope* appears similar to generalised hope, a form of hope described by Dufault and Martocchio (1985). They described generalised hope as a general sense of hope, a sense of faith in the future. They suggested it protects against despair and is not tied to a particular timeframe or outcome. It has been suggested that this form of hope gives an individual a sense of what is possible (Nekolaichuk, et al., 1999). It has been described as being:

“... concerned with ‘being’ and is a rather nebulous, personal dimension that provides a sense of something beneficial to come, a positive glow, a global rather than focused component that provides motivation to carry on with life, a way of living in hope.” (Greenstreet & Fiddian, 2006, p. 63)

This broad sense of hope is said to help stroke survivors “[keep] the door open” to recovery (Barker & Brauer, 2005, p. 1213). Based on this study of hope in people with aphasia after stroke, *simply 'having' hope* appears to be the entry point into hope after the stroke and, once established, may be constant throughout the post-acute rehabilitation period. It is a broad sense of hope that the future will be good or better in some way, even though the future is unclear. It appears to function as a springboard that allows people to start thinking about the future when they are able to, albeit in broad terms. It also serves as a ‘safe’ place where people can simply ‘have’ or ‘be with’ hope and not think too much about the future – they can gain respite from the challenges of thinking about the future by reverting to *simply 'having' hope*.

Participants in this study identified a number of sources of hope – family, friends, healthcare providers, other patients. Similar sources of hope have been identified in other studies of hope after stroke (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Jones, et al., 2008; Popovich, et al., 2007; Pound, et al., 1994). Other sources of hope identified in the literature include personal mindset and attitude (Barker & Brauer, 2005; Buckley & Herth, 2004; Jones, et al., 2008; Popovich, et al., 2007; Pound, et al., 1994) and having goals may instil hope. This is supported by Green and Waks (2008); Christopher Green reported meeting another person with aphasia was important in helping him feel there was hope for his situation. This may be particularly important for people with aphasia who may have never heard of aphasia or met anyone else with aphasia and hence have no benchmark for what could happen in terms of progress. The finding that hope may be developed through a number of

sources has further implications for speech-language therapists and other rehabilitation professionals; this will be discussed in more detail on page 104.

Intermittently, participants engaged in *actively hoping*, an active form of hope focused on identifying, and occasionally working toward, specific hopes for the future. It centres on hoping *for* something (Benzein, et al., 2001; Marcel, 1962). Participants identified several forms, or “levels”, of hopes. Identified hopes ranged from broad hopes that related to a person’s priorities in life, for example, “to be Holy”, to specific hopes related to recovery from stroke (see page 78). These hopes bear similarities to Nair’s hierarchy of life goals (Nair, 2003) which suggests there may be five levels of goals: idealised self-image, abstract motivations, personal goals, contextual goals and immediate actions. For example, hopes such as “being Holy” are consistent with idealised self-image, “doing the best you can do” may be similar to abstract motivations and “improving speech” may be contextual goals or immediate actions. Few participants appeared to be working toward these hopes, although most felt they would need to start taking steps toward realising the hopes at some undefined point in the future. *Actively hoping* appears to be a less important form of hope and one that is not essential in order for an individual with aphasia to experience hope after stroke. The fact that few participants were actually taking steps to work toward their hopes despite saying it was necessary, yet were still able to maintain a state of hope, supports this. *Actively hoping* appears vulnerable to intrinsic factors such as the uncertainty present in many people’s experience in the post-acute period of rehabilitation. As a result, participants appeared to move between passive and active forms of hope, something said to be common in those with chronic illness (Barnard, 2005), a finding that also emerged from a study of hope in people with acute stroke (Arnaert, et al., 2006).

*Actively hoping* commonly resulted in the identification of several different forms of hopes. The hopes of the participants in this study contrast with many hopes identified in the stroke literature. The majority of identified hopes in the literature relate to returning to normal (Bays, 2001; Dowswell, et al., 2002; Pilkington, 1999; Popovich, et al., 2007) or to resolution of stroke deficits (Bays, 2001; Dowswell, et al., 2002; Popovich, et al., 2007; Tariah, et al., 2006). In this study, all participants acknowledged these hopes in a third level of hopes that focused on specific stroke-

related hopes (see Figure 4 on page 78). However, the primary level of hopes identified in this study is consistent with other research exploring recovery from stroke, which suggests participants prioritise their engagement in social worlds and personally meaningful activities (Brown, Worrall, Davidson, & Howe, 2010; Haggstrom & Lund, 2008; Wood, Connelly, & Maly, 2010), sometimes over specific physical function (Burton, 2000). The latter is what many of the hopes identified in the stroke literature relate to. The specific, identified hope may have been influenced by the life-stage of the participants, as working-age adults. Nair (2003) suggested the hopes and priorities of people may change depending on the life stage they are in and that a working-age population may be concerned with issues related to family and relationships, careers and income. This was somewhat reflected in the hopes that people identified in the current study, although they also identified hopes that Nair suggested were more likely to be identified by older adults, such as religion and faith.

There may be several reasons why the main identified hopes within this study are broad and relate to what is personally meaningful to the individuals. These include: that people's hopes are primarily about participation and engagement rather than recovery of specific functions; that people expect their impairments to resolve and do not consider they need to hope for these things to come about; that the style of questioning supported participants to identify broad hopes more readily than stroke-related hopes; or that broad hopes were easier for participants to discuss, possibly as a result of the aphasia. Identifying hopes may have been challenging as it is language-based whereas *simply 'having' hope* is primarily a broad sense that one has and does not necessarily involve language. People with aphasia may have a sense of what areas in life are important to them, but may find it challenging to convert this into specific hopes.

All participants in this study indicated they believed they needed to take action to help realise their hopes (*working toward hopes*), although only one was actually engaged in this process. Participants in other studies of hope after stroke also suggested there is a need to work toward realising hopes (Arnaert, et al., 2006; Barker & Brauer, 2005; Bays, 2001; Pilkington, 1999). However, this study of hope in people with aphasia identifies reasons for not taking action including stroke-related fatigue, waiting for further improvement or having other priorities such as attending

rehabilitation. This may reflect the interviews took place during the post-acute period of recovery while other studies of hope after stroke explored the chronic period (Barker & Brauer, 2005; Bays, 2001). As detailed in the Literature Review (see page 12), this period is described as one of uncertainty and change (Becker & Kaufman, 1995; Burton, 2000; Haggstrom, et al., 1994; Kirkevold, 2002; Rittman, et al., 2007; Salter, et al., 2008) and is often a period where people are passive and waiting for their situation to change (Rittman, et al., 2004; Wallenbert & Jonsson, 2005). This stage may last for a year or two (e.g. Carlsson, Moller, & Blomstrand, 2009; Eilertsen, et al., 2010), after which time many people move into a period of recovery that involves more active contemplation of the future and development of meaningful hopes and activities (Brauer, Schmidt, & Pearson, 2001; Eilertsen, et al., 2010; Kirkevold, 2002). It may be that the participants are more likely to engage in working toward hopes later in recovery when they are more likely to be active in thinking about the future. Longitudinal studies with this population may provide more information about this.

Different questions appeared to identify different aspects of the experience of hope. For example, asking “What does hope mean to you?” was a key question in exploring the sense of hope that a person had and their broad, personally meaningful hopes. Asking “How would you describe the word ‘hope’ to someone who didn’t speak much English?” revealed information about the person’s conceptualisation of hope. “What do you want to be doing in six months/one year?” was useful for exploring a person’s uncertainty about the future, desired sense of self and priorities for recovery. More specific, impairment-related hopes were identified in response to more focused questioning such as “What do you hope for?” or closed questions such as “Do you hope to improve your speech?”. A detailed list of questions and their apparent contribution to exploring hope is provided in Table 4. This suggests the way people are asked about their hope may influence their responses. This has implications for how clinicians engage their clients in discussions about hope. This will be discussed in detail on page 105.



Table 4

*Questions and their Apparent Contribution to Exploring Hope*

<b>Question</b>	<b>Information</b>
Do you consider yourself a hopeful person?	General state of hope
What would happen if you didn't have hope?	General state of hope
How has hope changed since your stroke?	General state of hope, patterns of hope
How would you rate your hope out of 10?	General state of hope, patterns of hope, factors that influence hope
What does hope mean to you?	Broad, personally meaningful hopes
What do you hope to be doing in (x) time?	Image of desired self
What do you hope for?	Focused hopes
Do you hope to recover/improve x?	Stroke-related hopes

## **The Complexity of Hope**

The findings of this study suggest that an individual's experience of hope may be influenced by several factors. These are: uncertainty about the future, viewing hope as double-sided, and sense of disruption from the stroke. Uncertainty about the future was a strong theme that emerged from the data. Each person's experience of these factors, and often the combination of the factors, resulted in a different experience of hope, and different patterns of movement between passive and active forms of hope, *simply 'having' hope* and *actively hoping*. These three factors and their influence on hope will be discussed below with reference to relevant literature

### **Uncertainty about the Future**

Uncertainty about the future appears to be a significant factor influencing how people with aphasia experience hope. All participants experienced some uncertainty

but it appeared to influence each person's experience of hope differently. When uncertainty dominated the individual's view of the future, it appeared to limit their ability to think about their possible or desired future and limited their active engagement with hope. As a result, their primary experience of hope was *simply 'having' hope*. However, when uncertainty was present but the individual had a vision of their possible or desired future, they had a stronger sense of *actively hoping*, and experienced a more active form of hope.

Uncertainty about the future is common after a stroke (Becker & Kaufman, 1995; Carlsson, et al., 2009; Hersh, 2009; Hjelmblick & Holmstrom, 2006; Salter, et al., 2008) and may blur the image of a person's possible future (Hjelmblick & Holmstrom, 2006). Participants in this study appeared particularly uncertain about the extent of future recovery and what might happen in the future, similar to sources of uncertainty for other people with stroke (Alaszewski, Alasewski, & Potter, 2006; Becker & Kaufman, 1995; Carlsson, et al., 2009; Salter, et al., 2008). The sense of uncertainty may have been exacerbated as the participants in this study were all in the post-acute period of rehabilitation and had all recently returned home from hospital. Several studies have suggested that each transition point in recovery, such as discharge home, may see an increase in uncertainty (Becker & Kaufman, 1995; Rittman, et al., 2004) and result in some people feeling unsure about the future, and unable to plan for anything in the future (Burton, 2000). The literature suggests that uncertainty may also be exacerbated by health professionals, as they often feel significant uncertainty about the individual's prognosis and are reluctant to commit themselves to a prognosis (Becker & Kaufman, 1995; Wiles, et al., 2002). Given that all participants were receiving rehabilitation, their sense of uncertainty may also have been influenced by their healthcare providers.

By its very nature, there is a degree of uncertainty associated with hope (Miceli & Castelfranchi, 2010; Simpson, 2004), but this does not always influence the person's experience of hope. For example, it has been suggested that if uncertainty is accompanied by a sense of wishing, it can develop a person's sense of hope, while uncertainty combined with fear may result in hopelessness or despair (Kylmä, et al., 2001). Uncertainty has been reported to limit people's ability to hope for things in the future (Corbett, Foster, & Ong, 2007; Giske & Artinian, 2008) and has been found to

contribute to the future being seen as non-existent (Kylmä, et al., 2001). Arnaert, et al.'s (2006) study of hope in people with acute stroke found hope existed alongside worry and concern about the future. Those who were caught in the uncertainty appeared to struggle to recognise hope and were unable to see the future. The authors considered these participants to be "passive hoppers". Others were able to recognise the presence of a broad sense of hope and were able to act on it, even though they had some co-existing uncertainty about what would happen in the future. These participants were considered "active hoppers". These categories bear some similarities to the patterns evident in this study. Those who appeared dominated or paralysed by uncertainty had limited engagement with *actively hoping*; their primary experience of hope was *simply 'having' hope*. In contrast, those who had a vision of their possible future, or were not concerned by the uncertainty, appeared to find it easier to engage in *actively hoping*.

Participants appeared to draw on a number of strategies to manage the uncertainty and to protect themselves from negative consequences. These were: *'hunkering down'*, *limiting engagement with hope*, *keeping hopes broad* and *putting limits on hope*. These are similar to strategies used by people with stroke (Alaszewski, et al., 2006), spinal cord injury (Lohne & Severinsson, 2005) and cancer (Giske & Artinian, 2008). The result of these strategies is a state of living in the present, focusing on *simply 'having' hope*, predominantly passive form of hope. While some studies have suggested uncertainty may contribute to hopelessness or despair (Bolland, McCallum, Lian, Bailey, & Rowan, 2005; Kylmä, et al., 2001; Sällfors, Fasth, & Hallberg, 2002), it was not evident in the participants in this study. It appears the combination of strategies to maintain hope resulted in a sufficient sense of hope (*simply 'having' hope*) which sustained them, even in the face of uncertainty.

The uncertainty that was evident in this study and in the studies outlined above contrasts with Morse and Penrod's (1999) definition of uncertainty. They considered uncertainty occurred "when the person knows where she or he wants to go but cannot identify how to get there" (p. 147). This differs from uncertainty as described in both this study and in much of the literature on hope in healthcare populations. In this study, uncertainty was a broad state related to what might happen in the future. Unlike Morse and Penrod's definition, people did not know where they wanted to go in

the future; the uncertainty and fear about the future appeared to paralyse them and served to return them to a state of *simply 'having' hope* while they waited for more recovery and more information about what might happen in the future.

## **Double-sided Hope**

Participants in this study described two conceptualisations of hope, as being a good thing to have and something that could have a negative side, in that it could result in disappointment if hopes were unfulfilled. The data suggest the negative side of hope could result in a reluctance to engage in hoping, in order to protect oneself from hurt or disappointment, indicating hope may be accompanied by a sense of vulnerability. The literature supports this notion (Barnard, 2005; Simpson, 2004) suggesting vulnerability may emerge from a fear of hope and possible disappointment (Lohne & Severinsson, 2004). The dual conceptualisation of hope is not one that has been discussed in other studies of hope in people with stroke; which have highlighted the positive aspects to hope. Like participants in studies in other healthcare populations (Alaszewski, et al., 2006; Giske & Artinian, 2008; Lohne & Severinsson, 2005), the participants in this study drew on strategies to protect themselves from the vulnerability they considered could arise from hope. The primary strategy was *limiting engagement with hope*, as discussed on page 89.

## **Sense of Disruption**

All participants in this study experienced a sense of disruption. It appears that disruption can impact on a person's experience of hope in several ways. When the disruption affects a person's sense of identity, and/or if the effects of the stroke mean they are unable to participate in activities or roles they held prior to the stroke, they appear more likely to struggle to engage in *actively hoping*. Instead, their focus will be on getting through the present time, hoping things will improve, or waiting for the time when they will be able to think more about their possible future. The dominant experience of hope is *simply 'having' hope*. When disruption does not appear to

impact on sense of identity or on one's perceived ability to participate in activities or maintain roles, it is easier to engage in *actively hoping*. This may be linked with uncertainty about the future, as the future appeared more certain for those who reported less disruption.

It has been proposed that an illness event can result in a sense of disruption to a person's life, often resulting in uncertainty and challenges to a person's sense of self (Bury, 1982). Exploration of disruption within the stroke population suggests disruption may result in changes in how people view themselves and their future. It may also result in uncertainty about the future and a loss of continuity and coherence between the past and the future (Ellis-Hill, Payne, & Ward, 2008; Hjelmblink & Holmstrom, 2006). While this study did not seek to explore disruption, the data suggest that most, if not all, participants experienced disruption to various degrees. It is possible this may be more problematic in the participants in this study due to the presence of aphasia, as language has been proposed to be central to developing and maintaining a person's identity (Shadden, 2005).

The effects of a stroke may mean that priorities and goals need to change; it may also be that the stroke acts as a catalyst, prompting a person to revisit what is important to them and to identify new hopes for the future (Pilkington, 1999). This was evidenced in this study, with a number of participants discussing that the stroke brought new possibilities for them, although they were unable to identify what these might be. This contrasts with much of the stroke literature, which suggests people want to return to previous ways of being (Bays, 2001; Dowswell, et al., 2002; Pilkington, 1999; Popovich, et al., 2007). There may be underlying processes that need to be worked through in terms of constructing a preferred identity or learning how to live in the world in a new mind and body (Guidetti, Asaba, & Tham, 2007) before people are able to explore new possibilities and consistently engage in thinking about the future and *actively hoping*.

## Clinical Implications

There are several reasons why it may be beneficial for clinicians to consider hope in people with aphasia after stroke. Firstly, the participants in this study felt it was important. They viewed it as essential for recovery and something that sustained them throughout recovery. Secondly, the data suggest hope may be related to common components of the rehabilitation process such as goal-setting. Thirdly, clinicians may play a role in supporting or reducing a person's level of hope (whether they mean to or not), so understanding how a person experiences hope may help the clinician be more aware of their potential influence on the individual's hope. This section will focus specifically on how clinicians may consider or explore hope with their clients with aphasia, and will offer a range of suggestions to support clinicians in this process. Some suggestions are directly focused on hope while others relate to associated concepts which appear to influence a person's experience of hope. They also vary in how much action they require from rehabilitation staff. These implications are written predominantly for speech-language therapists, reflecting the professional background of the researcher, although many may be relevant to a range of rehabilitation professionals.

This study suggests that people with aphasia in the post-acute period of recovery from stroke experience hope in two different ways, whereas the literature suggests healthcare professionals commonly consider hope to be aligned with specific hopes for the future, often for recovery (Carter, McKenna, MacLeod, & Green, 1998; Herrestad & Biong, 2010; Soundy, et al., 2010), as do some definitions of hope (Morse & Doberneck, 1995; Snyder, et al., 1991). This study suggests that hopes for recovery are one small component of the meaning and experience of hope in people with aphasia. As people with aphasia appear to experience hope in two ways, clinicians and researchers may find it beneficial to be mindful of this when considering or exploring hope with this population. If they focus only on one form of hope, it may provide limited information about how the person is experiencing hope.

Exploration of hope may be beneficial for the rehabilitation process. A number of identified hopes related to the individual's desired sense of self and to things that

were personally meaningful to the individual, for example, “to be Holy”. It has been suggested that the identification of personally meaningful representations (which may include hopes for the future) that relate to desired identities is important in the selection of lower-order goals (Emmons & Kaiser, 1996; Nair, 2003; Ylvisaker, McPherson, Kayes, & Pellet, 2008). The process of identifying goals is a common component of rehabilitation, but research has indicated that clinicians struggle to engage people in the goal-setting process (Parry, 2004; Wressle, Oberg, & Henrikson, 1999) and it is even more challenging when the client has aphasia (Conneeley, 2004). Factors such as disruption to a person’s sense of identity may impact on their ability to identify broad hopes as these appear to be linked to a person’s current or desired sense of identity. This has implications not only for their experience of hope, but for their ability to engage in identifying personally meaningful goals to address in rehabilitation. It may be beneficial to explore a person’s priorities with them, rather than assuming that their pre-stroke priorities are unchanged. Spending time talking about what is important to a person and exploring possible selves and possible futures may support them in exploring their future and reduce the sense of disruption. It may also be that working with clients to explore hope and hopes is one tool for helping people with aphasia identify desired identities and areas of importance. This in turn may support their engagement in goal-setting (Ylvisaker, et al., 2008).

As identified previously, this study has demonstrated that different questions may identify different aspects of hope – which suggests that the way people are asked about hope may influence their responses. This is significant as a common strategy used to enhance a person’s ability to communicate is to ask closed or forced-choice questions; this strategy may impact on how the person with aphasia communicates what is of importance to them. It may have the potential to limit a person’s ability to talk about what is important to them if clinicians only ask about one form of hope. Asking a range of questions to explore different aspects of hope may help ensure clinicians aren’t ‘forcing’ their conceptualisation of hope onto the client, and aren’t limiting their responses (Smith & Sparkes, 2005). The range of questions used in this study is provided on page 99.

Participants in this study were interviewed three times each, and each interview yielded new information about the person’s experience of hope. This

demonstrates the importance of asking the same question repeatedly, over several sessions. Participants' responses sometimes fluctuated depending on the other factors that impacted their experience of hope. This all provided valuable information about how the person perceived and experienced hope. Asking a variety of questions on multiple occasions may also be beneficial as hope is commonly a subconscious process (Cross & Schneider, 2010). The use of multiple interviews and prolonged engagement in the interview process may have given participants time to think about hope and what it means to them which may have contributed to the final analysis. The fact that people had fluid, changing experiences of hope also supports the argument for discussing it regularly, rather than seeing it as a conversation that needs to be held only once.

This study also suggests there is a need to explore beyond the surface of the hopes that an individual identifies. For example, Adrienne initially reported hoping, and expecting, that she would return to normal in six months. However, further exploration of this comment over the course of three interviews indicated while this may be an expectation, it was based on her understanding of what medical staff had said and was tempered by a fear that it may not happen. This in turn resulted in Adrienne employing strategies to manage this fear, such as '*hunkering down*' and '*limiting engagement with hope*' (see page 89). This illustrates the complexities of hope may not be present at first glance. It also suggests that understanding the person's story, including the motivators for hope in general, and for hopes specifically, along with their response to hope, is important to ensure that the clinician has an accurate picture of the person's view of hope.

Clinicians may have a role in supporting the development, maintenance and reduction of hope in people with aphasia. This study suggests a number of factors contribute to the development and maintenance of hope including family and friends, rehabilitation staff and spiritual sources. Sources of hope differed for each participant, which highlights the importance of exploring sources of hope with each individual. It may be appropriate to consider these when planning intervention. As an example, if family and friends are a source of hope, focusing on facilitating or encouraging the client's ability to communicate and interact with their family or friends may indirectly help them develop or maintain a sense of hope. Many sources of hope are also factors



associated with living successfully with aphasia. For example, Brown, et al., (2010) found meaningful relationships and engaging in personally significant activities are considered important for living successfully with aphasia. These sources of hope commonly feature in socially-oriented, participation-based approaches to speech-language therapy (e.g. Duchan, 2001; Kagan & Simmons-Mackie, 2007; LPAA, 2000). It could be suggested that therapy approaches that incorporate social participation and engagement (Duchan, 2009) may also have the effect of promoting hope.

The relationship between the clinician and the client should also be considered in the context of supporting a person's hopes. The therapeutic relationship has been shown to be significant in fostering a person's hopes, both in this study and in other studies of hope (Cutcliffe, 1995; Simpson, 2004) and people with aphasia have suggested that therapists may remove hope in the goal-setting process (Worrall, et al., 2009). Being mindful of the possible implications of the therapeutic encounter for a person's hopes, both positive and negative, may be beneficial.

Participants in this study suggested that rehabilitation was unrelated to their hopes and the participants appeared to have differing views about the role of rehabilitation; one suggested it was useful for monitoring progress and another thought recovery would come from God, not rehabilitation intervention. This highlights that it may be useful to discuss expectations of rehabilitation with clients, understanding their perceptions and expectations of rehabilitation.

While clinicians may not be able to remove an individual's uncertainty about the future, it would be beneficial for them to be mindful of uncertainty and to be aware of how it may impact a person's ability to engage in thinking about the future. Where possible, it may be appropriate to help a person feel more certainty about the future, for instance, by providing prognostic information. The importance of being mindful of uncertainty is also applicable for the two other factors that appeared to influence hope – *double-sided hope* and *sense of disruption*. Engaging in discussion about hope may raise feelings of vulnerability and uncertainty, and therapists need to consider that this may be challenging for clients and be mindful of how they engage people in these discussions. Clinicians may start by simply acknowledging the uncertainty, vulnerability and/or disruption that the stroke may have brought and the

implications for hope and the rehabilitation process. The data from this study suggests people are more likely to focus on *simply 'having' hope* when there is a problematic sense of disruption as an individual's ability to look at the future appears to be affected.

It may be important for clinicians to consider their responses to the client's experience of hope. There may be different ways that clinicians can respond – by 'just' listening to people's hopes; exploring them to understand their experience of hope and the motivators for their current hopes; or by providing information that may support people's hopes. Being mindful of the potential implications of each response may be important.

The literature also describes tensions therapists may experience with regard to the hopes of their patients. It has been suggested that therapists are motivated to protect a person from disappointment and may utilise strategies to minimise the risk of this and to maintain hope (Wiles, et al., 2004). However, some research has also identified that therapists may feel clients need to focus on accepting the effects of the stroke rather than focusing on hopes for recovery (Worrall, et al., 2009). They may judge hopes as realistic or unrealistic based on what the clinician considers can be achieved within a course of intervention (Soundy, et al., 2010). This contrasts with all of the hopes identified within this study which all extended beyond the formal rehabilitation period, often having an indeterminate time period attached to them. Clinicians may feel less concerned about whether a person's hopes are realistic or not if they focus on how people with aphasia appear to conceptualise hope. Rather than concentrating on specific hopes for recovery and whether they can be achieved within the course of rehabilitation, it may be preferable to consider hope to be comprised of a general sense of hope, and broader personally meaningful hopes for the future. It may also be important to explore the client's expectations of their specific hopes – whether their hopes can be achieved, and if so, within what time period – before classifying them as unrealistic.

This section has offered a range of suggestions of how clinicians may address hope within a rehabilitation setting. These are collated and summarised in Figure 7. These appear to sit along a continuum: some suggestions only require a healthcare

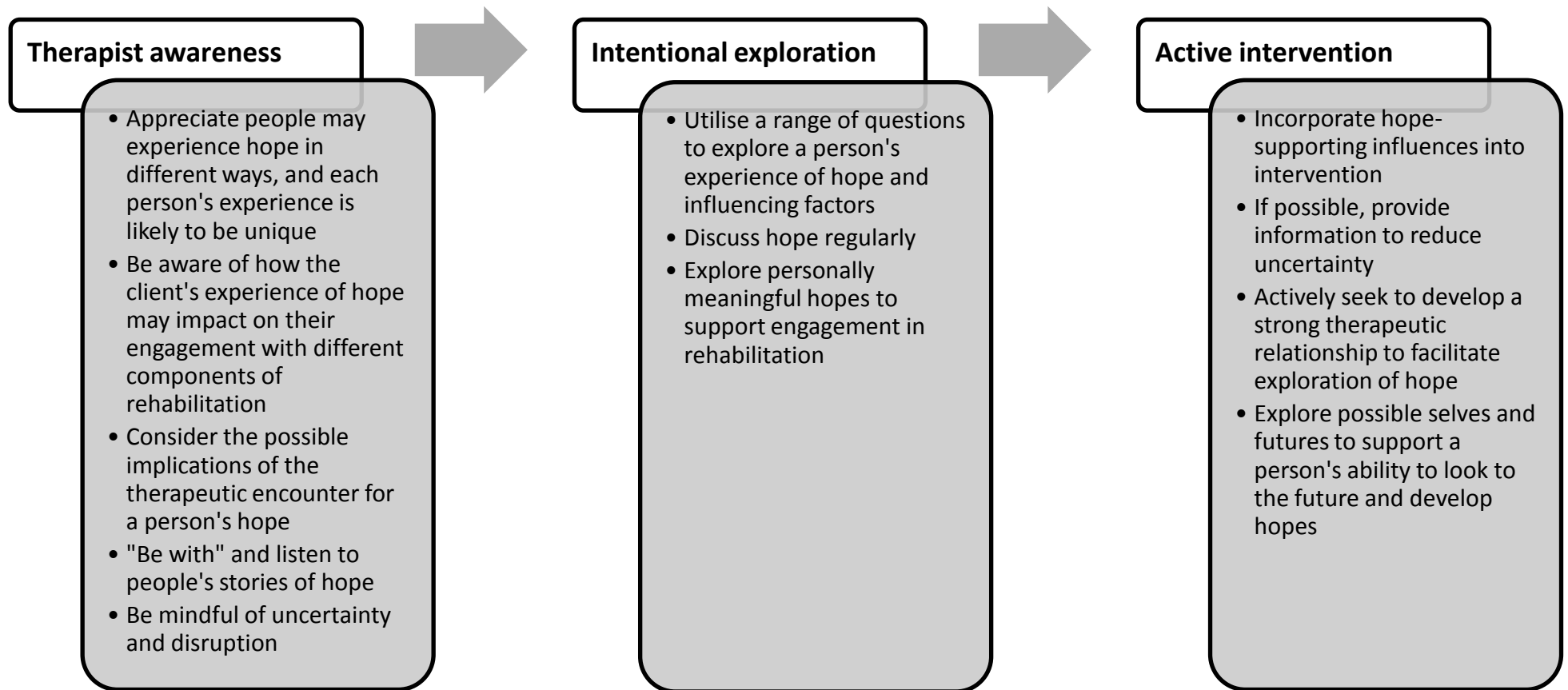


Figure 7. Clinical implications of hope

provider to be mindful of a possible experience while others involve active intervention from the provider. Therapists may choose to address hope at any or all of the levels, depending on what they feel is appropriate for the client and the rehabilitation encounter.

## **Study Limitations**

While this study has contributed to the knowledge of hope after stroke, particularly for people with aphasia, there were some limitations to the study which need to be acknowledged. These are discussed in detail below.

The small number of participants meant that participants with some desired characteristics were not included. An example of this is that, despite best efforts, there were no Māori participants included in the sample. Māori are *tāngata whenua*, the indigenous population of New Zealand. Including a Māori participant may have offered a unique cultural perspective to understanding the experience of hope for people with aphasia in their post-acute phase of rehabilitation that is not currently reflected in the findings. There were significant unexpected challenges in recruiting participants. Several potential participants declined to be involved because they were too busy with rehabilitation, family and/or work. It may be that they would offer different perspectives on hope. In addition, the recruiting therapists identified they did not ask several patients to be involved as they felt they were too depressed; it could be anticipated that they would have offered a different perspective on the experience of hope in the post-acute period of recovery.

The Western Aphasia Battery – Revised (Kertesz, 2006) was completed a significant time after the interview period for three of the participants. Their aphasia severity may have changed between the interview and the assessment. Informal assessment suggested there had been little change in their communication.

Another potential limitation related to data collection is that different questions elicited different responses (see pages 78, 80, 98 and 105) and this may have

impacted on the data that were gathered. While the questions generated a range of responses, it is possible that more or different information may have been gathered had other questions been asked or if the questions were more open-ended. As detailed in Chapter Two (see page 60), the semi-structured interview process facilitated the participants' abilities to participate in the interview process. However, some of the data may be an example of how this may have inadvertently impacted on the data collected. The specific stroke-related hopes may be an example of this. The presence of aphasia may have also limited the information that participants were able to give about their experience of hope; it is possible they may have discussed other aspects of hope had they had stronger language skills.

In addition, the findings may have been influenced by how much the individual had thought about hope in advance of the interviews. It has been suggested that hope is a subconscious process and interviews may be the first time people have consciously thought about it; this may have impacted how they discuss it (Cross & Schneider, 2010). The use of multiple interviews may have supported participants to reflect in more detail on their experience of hope.

The process of data collection was modified to maximise the participation of people with aphasia, their ability to comprehend the study and the questions, and to express themselves and describe their experience of hope (see page 59). Despite this, there were times of misunderstandings when interpretation was required for both parties, with participants trying to understand what the researcher was asking and the researcher trying to interpret what the participant was meaning. It is possible that these possible layers of interpretation may have impacted on the findings. Several steps were taken to try and minimise this risk. Member-checking with the individual participants in the final interview was useful for exploring issues that were unclear. Discussion with the research supervisors, one of whom is an experienced speech-language therapist and aphasia researcher, was beneficial in exploring the data from a number of angles and helped monitor the degree of interpretation. Inclusion of raw data alongside the researcher's interpretation of it was one step to ensure transparency around this process.

In spite of these limitations, the findings have shed light on the experience of hope after stroke for people with aphasia in the post-acute period of rehabilitation. Hope has not been explored in this specific population before, and the findings add to the body of knowledge about hope in people with stroke, highlighting different characteristics of, and influences on, the experience of hope. The findings have a number of implications for clinical practice, as have been detailed in this chapter (see page 104). The study also highlights a number of areas for future research.

## **Directions for Future Research**

Research into hope after stroke is still in its infancy and this study raises a number of questions that required further investigation. These relate to the nature of hope, the role of hope in therapy, types of hopes and hope-related interventions.

There has only been a small number of studies exploring the topic, and these have generally been completed with specific patient populations – acute stroke (Arnaert, et al., 2006; Popovich, et al., 2007), and elderly patients in the chronic period of recovery (Bays, 2001; Cross & Schneider, 2010). It would be beneficial for future research to explore hope in other sub-groups, incorporating participants with a variety of stroke sequelae at various points throughout recovery. Longitudinal studies would be beneficial to understand how, or if, hope changes as people experience recovery and adapt to living with the stroke and its effects, and whether different aspects of hope are emphasised differently as recovery continues. Understanding hope from the perspectives of other people such as family, friends and clinicians, would be beneficial as this research has indicated they have a strong influence on how the individual experiences hope.

While a number of studies have measured hope, examining how it changes with time (Popovich, et al., 2003) or how it relates to other concepts (e.g. Bluvol, 2003; Gum, et al., 2006), further investigation of appropriate measures would be beneficial. A particular focus should be the conceptualisation of hope that underpins the measure as this, and other studies, have indicated that some measures view hope differently to

how patients view hope. While there are a number of different measures of hope available, none have been validated on the stroke population. The development of a more conceptually sound, robust measure of hope will allow further investigation into the relationship between hope and outcome following rehabilitation. This would also facilitate further exploration of the relationship between hope and quality of life and depression. This may be beneficial, as this and a number of other studies have indicated these concepts may be related (e.g. Bluvol, 2003; Gum, et al., 2006; Lewis, et al., 2001).

This study suggests that hope is important for rehabilitation and may support engagement in components of rehabilitation such as goal-setting. As such, it may be beneficial to further explore the role of hope in rehabilitation, for example, whether identification of broad hopes does make it easier for some people to identify rehabilitation goals. It would be useful to investigate this from the perspectives of both people with stroke and clinicians. Given that clinicians consider hopes realistic or unrealistic in light of what they consider may be achievable within the course of an intervention period (Soundy, et al., 2010), focusing on broad hopes could pose challenges for clinicians. The notions of unrealistic hopes, and a tension between acceptance and hope have emerged from research with clinicians (Soundy, et al., 2010; Worrall, et al., 2009), and it appears that some clinicians perceive that hope could be harmful. Some participants in this study identified that hope may be double-sided and may potentially have negative consequences. Questions that could be considered include: What makes hope unrealistic? Are there negative consequences of 'unrealistic' hope, and if so, what are they? Are there positive consequences of 'unrealistic' hope? Can a person simultaneously have hope *and* acceptance of what has happened? This study also suggests that the therapeutic relationship and the therapeutic encounter may be factors in a person's ability or willingness to engage in conversations about their experience of hope. Further exploration of the core components of a positive, facilitatory relationship may support clinicians in modifying their practice to better meet the needs of their clients.

All participants in this study considered hope was essential, supported recovery and was developed and maintained through a number of sources. Research in hope in other clinical populations has identified specific hope-fostering interventions that may

help its development and maintenance (e.g. Buckley & Herth, 2004; Herth, 2000). It may be useful to explore both the applicability and acceptability of hope-fostering interventions for people with stroke and clinicians, along with exploring the effectiveness of these interventions on pertinent outcomes. It may be that participation-based approaches to intervention may support hope, as they often incorporate engagement with a number of sources of hope and relate to personally meaningful hopes. Hope may be a potential outcome to be considered when evaluating these approaches to therapy.

It could be anticipated that a more comprehensive understanding of hope after stroke would better enable clinicians to understand hope in their clients. It may better equip them to investigate and support the individual's hope as they proceed through rehabilitation and recovery. It may also support the development of specific interventions to support people's hope, if research indicates this may be beneficial.

## Summary of Findings

This study has explored the experience of hope in people with aphasia during the post-acute period of rehabilitation. The findings suggest that hope is experienced in two ways – *simply 'having' hope* and *actively hoping*. They also suggest that the experience of hope is complex and impacted by a number of factors. This study of hope, performed at a time in recovery when many people with aphasia are participating in rehabilitation, highlights that hope is an important concept for rehabilitation staff to be aware of as it may have implications for how a person engages in rehabilitation. The literature has identified that this time in rehabilitation is a complex, variable time, and this was reflected in how participants in the current study experienced hope. By using data collection and analysis methods that promote the voice of people with aphasia, it has demonstrated the important contribution that people with communication impairments can make to expanding the body of knowledge about stroke and its consequences. It supports previous research that indicates people with stroke view hope as important and that it is multidimensional.



By considering factors that influence a person's experience of hope, it highlights the complexity of hope in a way that may support clinicians when they are considering how their clients are experiencing hope.

The researcher's pre-assumptions were identified at the start of this thesis (see page 7). These were: (a) hopes may be unconscious, emerging only when the hope was either realised or dashed; (b) hopes were considered synonymous with goals; (c) hope was directed at a particular outcome, for example, "I hope to be able to ....."; and (d) the process of hope incorporated action to bring about the particular hope. The data from this and other studies of hope suggest that hope may be a subconscious process which people may not be aware of until they are specifically asked about it. Contrary to assumptions (b) and (c), people with aphasia experience hope as multidimensional and the primary form of hope is an inner sense of hope, *simply 'having' hope*. While the process of hope incorporated specific hopes and in one instance, action toward these hopes, this was the secondary form of hope and did not appear to be essential for people after stroke.

## Conclusion

This study has demonstrated that hope is an important concept for people with aphasia following stroke in the post-acute period of rehabilitation. It contributes to the body of knowledge about hope after stroke by increasing understanding of the ways in which hope is experienced; demonstrating the experience of hope can be complex and dynamic due to the influence of a number of factors; and highlighting the possible implications of hope for rehabilitation. This study gives a voice to a client group who have often been excluded from research on hope after stroke and has explored hope in a way that has sought to maximise their ability to share their experience.

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## Appendix A: Participant Information Sheet

Research title:

The **hopes and priorities of people with aphasia (language difficulty) following stroke** in the postacute (after hospital) rehabilitation period

Researcher: My name is **Felicity Bright**. I am a **speech and language therapist**. I work as a researcher at AUT. I am doing my **Masters degree** at AUT.

Supervisors: My two **supervisors** are **Nicola Kayes** and **Clare McCann**.

Nicola is a **health psychologist**. She works as a **researcher** at **AUT**.

Clare is a **speech and language therapist**. She is a **lecturer** at the **University of Auckland**.

Our **contact details**:

Felicity Bright	Phone 921-9999 x 7097	Email: <a href="mailto:felicity.bright@aut.ac.nz">felicity.bright@aut.ac.nz</a>
Nicola Kayes	Phone 921-9999 x 7309	Email: <a href="mailto:n.kayes@aut.ac.nz">n.kayes@aut.ac.nz</a>
Clare McCann	Phone 373-7599 x 85221	Email: <a href="mailto:c.mccann@auckland.ac.nz">c.mccann@auckland.ac.nz</a>

Kia Ora,

You are invited to **take part** in a **research project**. We are doing research into **what is important to people with aphasia**.

**You can choose** if you want to take part in the research. **It is your choice**. If you decide to not take part, this **will not affect your therapy** at [rehabilitation provider].

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet will give you **information about the study**. It may **help you decide** if you would like to take part. Please **tell us** if it is **difficult to understand**, or if you have any **questions**.

---

### **The Purpose of the Study**

We are trying to find out **what is important** to people with aphasia. I would like to **interview you** and talk about your **hopes and priorities** for your **therapy, your recovery and your future**.

Research tells us **what is important** to people who had their **stroke a long time ago**. We **don't know what is important** to people who had their **stroke recently**.

## Participant Selection

Up to **six people** with aphasia will be **interviewed**.

People are **eligible** if they are receiving **speech therapy** at [rehabilitation provider].

## The Interviews

I will interview you **three times**.

**Each interview** will take between **45-90 minutes**.

There will be at least **one week between each interview**.

It may take **up to six weeks to complete** the three interviews.

You **do not** have to **answer all the questions**.

You are welcome to have a **family/whānau member** at the interview if you wish.

I would like to **tape the interviews**.

During the **first interview**, I will just use a **taperecorder**.

In the **second and third interviews**, I would like to use a **videorecorder**.

This is so I can record gesture and writing, as well as our voices.

The **interview can take place where you choose**. It might be:

- Your home
- [rehabilitation provider]
- AUT
- Somewhere else

If it **costs** you to **get to the interview**, I will **reimburse you**.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. This is optional.

The interviews are **not speech therapy**.

This study **will not help your communication**.

You will **still have** your **speech therapy** at [rehabilitation provider].

### **Medical Records**

I will ask you for **permission** to review your **medical records that are at [rehabilitation provider]**.

These will give me **information about**

- **what happened**
- **the tests you have had** since your stroke
- the **treatment you are having** with your therapists.



## Confidentiality

What you say is **anonymous**.

I **will not tell anyone** what you say. You **will not be identified** in research findings.

I will **give you a summary** of our discussions.

You can **choose if you want to give this to anyone**. You don't have to.

Your information will be **securely locked**.

The audiotape and videotape **recordings** will be **destroyed at the end of the study**.

The **transcriptions** of the interviews will be **destroyed after 10 years**.

I can give you a **copy of the results** if you want.

These will be **available in 2011**.

## Stopping the Study

You can **withdraw** from the study **at any time** during the interviews.

If you have **finished all the interviews**, you can **completely withdraw** from the study. This needs to happen **before data analysis starts** (about July 2010).

## **Benefits of Being Involved**

### *Benefits for You:*

You **may** find it **helpful to talk about what is important** to you.

This **may help** you **identify goals to work on** in therapy, or by yourself.

### *Benefits for Others:*

You will **help speech therapists** learn more about what is important to people with aphasia.

## **Risks of Being Involved**

There **should not be any risk** to you.

You may find the interviews **tiring**.

**This is common** after a stroke.

If you are tired, we **can take a break**.

Or, we can **finish the interview another day**.

## **More Information**

If you want **more information**, contact **Felicity Bright**.

Your speech therapist can do this for you if you want.

## **Your Rights as a Participant**

Phone 0800 555 050 or email [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz) for a **Health and Disability Advocate**. They can give you **information on compensation** for physical injury.

## **Maori Cultural Support Team**

The Māori Cultural Support Teams are able to be contacted should you want their support: [contact details of Māori cultural support teams]

## **District Health Board (DHB) Research Approval**

This study has been approved by the [name of specific health authorities].

## **Ethics Approval**

This study has been approved by the Northern Y Health Ethics Committee.

## Appendix B: Consent Form

**Project Title:**

The **hopes and priorities of people with aphasia** following stroke in the postacute rehabilitation period

Researcher: Felicity Bright

Supervisors: Nicola Kayes      Clare McCann

<p><b>I have read the information sheet <i>OR</i></b>  someone has read the information to me</p>	<p>YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>
<p>I have been able to <b>ask any questions</b> I have</p>	<p>YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>
<p>I have been able to <b>talk about the study with family or friends</b></p>	<p>YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>
<p>I know that <b>taking part</b> in the study is <b>voluntary (my choice)</b></p>	<p>YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>
<p>I know that I can stop being in the study at any time.  If I decide to stop, this won't affect my rehabilitation at [rehabilitation provider].</p>	<p>YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>  YES <input checked="" type="checkbox"/> NO <input type="checkbox"/></p>

I know that this study is only for <b>research</b> .	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I know I <b>will not receive extra therapy</b> as part of the study.	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I understand that everything I say is <b>confidential</b> .	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I understand I <b>will receive a summary</b> of the hopes and priorities we talk about. I can <b>choose if I give this to anyone</b> (e.g. doctor, therapists).	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I agree that Felicity can <b>review my medical records</b> that are at [rehabilitation provider].	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I have had <b>time to decide</b> whether I take part in the study.	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I know I can <b>contact Felicity or Nicola</b> (supervisor) if I have any <b>questions</b>	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I consent to <b>all my interviews</b> being <b>audiotaped</b> .	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I consent to the <b>2<sup>nd</sup> and 3<sup>rd</sup> interviews</b> being <b>videotaped</b> .	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I consent to <b>completing a short language assessment</b> .	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I consent to Felicity contacting me in 2011 to discuss her findings.	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
I know that if I say no to this, I can still take part in the study.	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>

I know I can change my mind about this at any time.	
I would like a <b>copy of the results</b> of the study.	<b>YES</b> <input checked="" type="checkbox"/> <b>NO</b> <input type="checkbox"/>
I _____ consent to take part in this study.	
<b>SIGNED:</b> _____	<b>Date:</b> _____

This study has been approved by the Northern Y Regional Ethics Committee.

Full name of researchers: Felicity Bright, Nicola Kayes, Clare McCann,  
Kath McPherson

Contact phone number: Felicity Bright – 921-9999 x 7097

Study explained by: \_\_\_\_\_

Project role: Researcher

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix C: Data Collection Form

Participant initials:			
Date of notes review:			
Gender:	Male	Female	
Age:			
Ethnicity:			
Living situation:			
Social supports:			
Pre-stroke employment:			
Date of stroke:			
Presenting symptoms:			
Stroke location:		CT	MRI
Summary of acute hospital admission:			

SLT assessments completed in acute period & results:		
Date of discharge:		
Discharge location:		
Summary of inpatient admission:		
Goals:		Outcome
Other relevant notes:		



Date of Outpatient/Community admission:						
Therapists involved:	SLT	PT	OT	Psyc	SW	Other
Goals:						
SLT assessments completed & results:						
Other relevant notes:						

## Appendix D: Coding Structure

Data	Initial code	Focused code (individual participant)	Focused code (following comparison)	Axial coding	Theoretical coding
Who knows, there'll be something. So I've got hope (Tony)	Seeing possibilities	Seeing new possibilities	Looking to the future		
Maybe that's something I can do and something we can do you know. (Matthew)	Possibility	Considering possibilities		Envisaging possibilities	
I've got to do it for me to show them, look hey, you know, um, you know you guys have put up with heaps and this is, this is the return for it, you know. (Matthew)	Based on motivations	Motivation for future	Focussing on what matters		Looking forward
But because of this one (the stroke) and because of my hope, I hope that I will become doesn't matter what I'm doing but I want to be holy (Iosefa)	Keeping it broad	Desired outcome		Identifying priorities	

## Appendix E: Conditional Relationship Guide

Category	Developing hope
Subcategories	Precursors, [suddenly receiving, gradually developing], gradually realising, searching for more
What	Identifies that hope does not necessarily appear; that it can grow in strength/amount; that it is influenced by a number of factors; that different people develop hope in different ways. The process of developing hope can be part of the transition between hopelessness and hope and can also be a part of the active process of hoping
Who by	Matthew – experienced gradually developing hope during time in rehab. Adrienne – experienced suddenly appearing hope after feeling suicidal. Miriam – experienced throughout recovery, particularly after discharge from rehab. Not experienced by Iosefa – his hope was linked with his faith which was unchanged by the stroke
When (during)	Throughout the process of hope – people come to it as they a) transition out of hopelessness, b) move from having hope to enacting it, c) realise hopes and achievements. One participant denies that he went through this process b/c he always had hope
Where (in)	Internal process of developing one's sense of hope but it is influenced by a number of internal and external variables including sense of identity, a sense of achievement, nurturing, other people, God
Why (because)	In order to develop a state of hope that is not present. To strengthen a state of hope that is currently present. To reinforce hope in times of fluctuation and change?
How (by)	Through a range of sources – internal and external. It may have sudden and/or gradual components. Sources include spiritual, self and others. Self includes through sense of identity, degree of motivation and through specific hopes .
Consequence	Development of a sense of hope or realisation of the presence of hope

Relationships (to other categories/concepts)	<p>Fed into through various routes throughout the process of hope. Through hopelessness (as part of the journey from hopelessness to hope), through the process of working toward hopes (working toward them, realising progress, being in control all leads to further reinforcement/development of hope) and through identification of specific hopes – (e.g. having a hope of wanting to be independent can increase the sense of hope – and possibilities for the future) and can reinforce the desire to engage in hope)</p> <p>Can result in development/presence of sense of hope.</p>
Questions	<p>Do/can suddenly receiving and gradually hoping co-exist? Do the influences on hope relate to influences on the development of hope or influences on having hope? What is the role of ‘developing hope’? (have suggested it relates to further developing an already present state of hope and to reinforce hope in times of fluctuation and change?)</p> <p>How does developing hope relate to the later processes of hope if you already have a sense of hope? Does developing hope only relate to having hope or should it link directly to other processes of hope? How does this relate to the process of constraining hope and helping people move between these different stages in the process of hope?</p>

## Appendix F: Thematic Analysis – Miriam

### Essential hope

Miriam sees hope as essential, something that you need for recovery. Hope is described as *“the only way that you can go”*, and that *“day by day, it’s all you can go on”* and it is essential for life – *“all is, is nothing without hope”*, without it, she would eventually die. She describes the presence of hope as being the difference between *“living and dying”* – in times of despair, hope is the only option. She described it as something she relied on in the first week after the stroke, when there was very little else that she could do. She refers to Emily

"Hope" is the thing with  
feathers—  
That perches in the soul—  
And sings the tune without the  
words—  
And never stops—at all—  
  
And sweetest—in the Gale—is  
heard—  
And sore must be the storm—  
That could abash the little Bird  
That kept so many warm—  
  
I've heard it in the chilliest  
land—

Dickinson’s poem *“Hope is the thing with feathers”*, saying that *“hope is eternal”*, something that never stops at all. She doesn’t attempt to quantify hope or say that you must have lots. When asked what would happen if someone took away her hope, she said she would still have some, as it is *“better to have small than nothing at all”*.

### Hints of a broader future

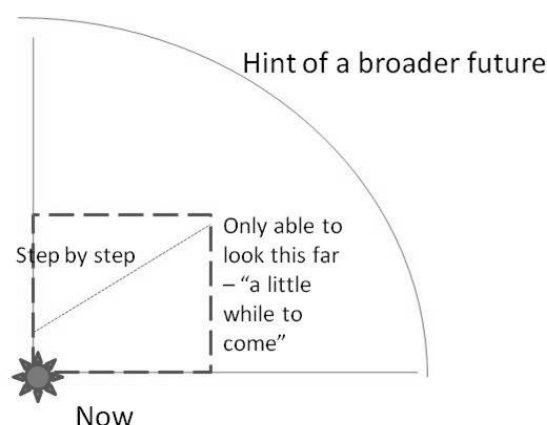
Throughout the interviews Miriam refers to commonly used phrases that her husband describes as her mantras. These appear to be closely held beliefs, centring on *“being the best you can be”* and hope being *“the only way that you can go”*. She describes *“broad aspirations [focused on] special character”*. She also uses the term *“positivity”* in conjunction with, or instead of hope. These words and phrases all paint a view of a positive future comprised of opportunities and possibilities, about a revised version of the self that is focused on strengths while being aware of the uncertainty of the stroke recovery process. Miriam’s non-verbal behaviours during these sections of the interview were open and relaxed and indicated a sense of anticipation about the future.

## Responding to discourses about hope

Miriam was the only participant interviewed while family members were present and seeking to be actively involved in the conversation. Reviewing her transcripts, I was struck by messages of 'should', feelings of limitations and control. When asked what hope meant to her, she replied with broad hopes of "*better times to come*", which gave a message of openness toward the future. Then her husband quickly commented on how she was encouraged to think about small steps, about SMART goals, focusing on the "small things, not the whole thing", and that hope "has got to be SMART. You have to go through the acronyms". This suggests he may play an influential part in goal-setting and translation of hopes. There appears to be a slight tension between her constant, eternal, essential hope and her other form of hope which is limited, bound and guarded. I wonder if this tension arises because of messages received from others, rather than an innate belief that hope should only be focused on one thing at a time?

## Limited hope

On the surface, Miriam appears to have strong hopes and a positive view about the future. She identifies hopes and initially appears to be a model patient – realistic, patient, not looking too far ahead. Then a closer look at the language used suggests a personal protectiveness is in play. A key theme for



Miriam is the notion of limited, guarded hope, possibly due to a fear of the consequences of unrealised hope. She commonly uses terms such as "*step by step*" and "*hopeful. A little*". She talks about taking it "one step at a time" and not focusing too much on the bigger hopes and broader future, instead focusing on the foreseeable future. She does not talk about desired outcomes in terms of her recovery from

stroke, again preferring to focus on qualified hopes such as not being “*too much incapacitated*”, or being able to do things “*without too much fuss*”. These hopes are difficult to measure and as such, she is less likely to experience failure when she works to realise them, possibly making this approach a protective mechanism against disappointment and failure.

### **Inherent tensions and contradictions**

The overarching feeling I have from reviewing Miriam’s interviews is one of inherent tension and contradiction. This is evidenced in the themes above. Hope is seen as essential and there are hopes of a broader, brighter future. But other discourses intervene and serve to limit hopes and refocus her on the here and now, looking step by step at the foreseeable future.

## Appendix G: Thematic Analysis – The Five Core Themes for Each Participant

<b>Matthew</b>	<b>Iosefa</b>	<b>Miriam</b>	<b>Adrienne</b>	<b>Tony</b>
Meaning and layers of hope	Who I am	Essential hope	Losing and finding hope	Positivity
Fluctuations and contradictions	An individual	Hints of a broader future	Belatedly realising hope	Having opportunities
Role of self	The role of faith	Responding to discourses about hope	It's just hope	Multiple influences on hope
Role of the past	Layers of hope	Limited hope	Waiting for normality	Two sides of hope
An uncertain future	Certainty	Inherent tensions and contradictions	Uncertainty and vulnerability	Sense of disruption & continuity



## Appendix H: Narrative Construction - Iosefa

Iosefa is a Pasifika man in his mid-40's, who had a left sided stroke in 2009. He had a short acute inpatient stay in [hospital name] before being discharged home. He has been seeing therapists at [rehabilitation provider] for several weeks.

Iosefa is married to Mele. They have six children ranging from 15 years to three months of age. Iosefa has lived in New Zealand for around 10 years. Prior to his stroke, he was a lay preacher in his local parish and was involved in running Pasifika non-governmental organisations and was involved in the local city council. He has not worked since his stroke. As a result of the stroke, he has mild right sided weakness, significant cognitive impairment and aphasia. He has lost some of his English but his family report his indigenous language is also quite impaired.

### Hope

When initially asked what hope meant to him, Iosefa responded *"It's a word. But it's, I think that hope for me, this is what I ... this is the the life of who I am. You know where I told you before, this is who I am. Why? Because of the hope. We have to do everything"*. When Iosefa talks about hope, he describes hope as something that makes him who he is - *"this is who I am. Why? Because of the hope"* and it is something that will enhance his life - *"and I hope myself it will make my life to be, make it better"*. For Iosefa, hope does not exist in isolation. It closely coexists with concepts such as faith, love, freedom, truth and holiness:

*Hope, this is what can help me to put the faith*

*If I can hope because of those three of this one, if I can faith because my hope and love, they're always go together. And not only that, see the different what I'm saying, cos this one is unending. This one is ending*

*With those three (faith, love, hope), make me back to have those*

Iosefa sees hope as different from these concepts as he sees hope to be finite, something that ends when he dies whereas the other concepts will live on “*when I’m dying this is it for hope*”. He also sees hope as a lower level concept alongside love and freedom (*they are the same*) that supports his faith:

*Hope, this is what can help me to put the faith*

*... this is how my hope, it looks like the things that live in me, the level of understanding and help me to to motivate my faith. This is always going together*

Throughout the interviews, Iosefa identifies a variety of hopes that centre around several distinct levels and objects of hope. Iosefa describes an “ethical” layer that is his primary focus and goal and it is something that he has to work towards. These hopes are developed and inspired by the entwined concepts of hope, faith and love. The ethical level of hope appears to relate to his core sense of self as a man of faith (being holy) and as a father - “*you have to understand that I am a father. See the difference? Even though you are a mother, but myself I am a father. It’s depend my family because I am the father*” . He hopes to “... [*I*] hope for to pass on who I am”, something that is in keeping with his role as a father who is seeking to pass on his values through teaching his children to listen and obey and to spend time in prayer: “... *things what I’m saying for my kids, to pass the good things, the study, the experience and who I am. The values*”.

There is a second layer of hope that is focused more around the broad hope of returning to normal – this includes returning to study – “*one of the things I’d like to concentrate on is my study*” which is important because it relates to his role as a man of God and to his faith: “*It’s because of who I am, who you are. That’s the truth, that’s the truth, who I am*”. Finally, there is a layer of hope related to resolution of specific deficits such as improving physical function, being able to express himself (*To saying something because of this one. I want to say something, I can’t, I can’t, I can’t do that*) and reducing the risk of having a stroke. Iosefa’s specific hopes were only elicited when the interviewer engaged in a process of seeking Iosefa’s thoughts about hopes identified in the literature about stroke. When asked about his hopes, he always referred to the broader, *ethical* levels of hope. When first asked about his specific

hopes, he gave the impression that he did not think about hopes in these terms, that it was not a construct that he related to: what are you saying, *“for myself, this is not the way that I think of what you think”*. It may be that his response to the question about specific hopes may also be influenced by his aphasia – Iosefa recognised that he may have had the hopes and goals but not the ability to express them – *“that’s why I’m asking, also always here (points to head) but I can’t exsolve, how to say?”*. For Iosefa, while these lower levels hopes are important, his main priority is his high level goal of holiness – *“because of my hope, I hope that I will become doesn’t matter what I’m doing but I want to be holy”*.

Iosefa views his different layers of hope in different ways. Hopes that he terms *“ethical”* are value-oriented, non-specific and without a specific point of achievement, for example, to be holy. He considers himself on an ongoing journey toward these hopes. The lower layers of hopes, his role-based and specific hopes share more attributes with goals. Iosefa expresses certainty that he will return to normal and that his specific hopes will be achieved – *“I will get it, I will got is remember maybe later, but I’ll will go back”*. He is not certain when they will be achieved but is certain that they will be. However, at one point in the interviews, he gives the impression that there is some uncertainty about whether they will be achieved due to the effects of the stroke. In contrast, he does not believe that the stroke should affect his ability to strive toward his value-based hopes: *“because of my hope, I hope that I will become doesn’t matter what I’m doing but I want to be holy”*. He sees that hope is something that has an active component and requires his effort – *“we have to work”* and a failure to invest personal effort in working toward his hopes will mean that the hopes *“will not work”*.

Iosefa describes his hope as constant, something that has never changed. When asked if his hope had ever fluctuated, if he had experienced periods of hopelessness, he appeared somewhat surprised that this could happen and was emphatic that his hope had not changed – *“No, that’s not me. I already told you, I said this one before. Never”*. He also views his hopes as constant and unchanged by the stroke *“But um, I hope as I said before, am still the same. Only physically have changed”*.

Iosefa's constant sense of self has parallels with his strong sense of self that he also sees as constant and unchanged by the stroke. When asked whether his sense of self has changed as a result of the stroke, he responds: *"No, not for me. It's always been there. Only physically have changed"* and *"the only way the value, the value of myself never changed that who I am"*. His sense of self was one of the strongest themes that appeared to emerge in the interviews, through constant reference to "who I am" and the need for the interviewer to "get to know me" and to see him as an "individual" and "different". He gives the message that if the interviewer does not understand who he is (which is centred around his faith), then they have failed to understand his hope. The inner sense of who he is is also important in understanding some of the reasons for his hopes such as returning to study - *Why you say "Why do you study"? It's because of who I am, who you are. That's the truth, that's the truth, who I am"*. His hope and his self-identity are entwined and he is clear that they cannot be viewed separately from each other: *"You can't separate the two. We always go together"*

Iosefa appears to focus on what makes him different from others though when asked about specific hopes, he acknowledged the shared experiences with others who have had strokes while also raising his individuality:

*We have some things we can similar, similar, but for myself no one be the same as myself for life*

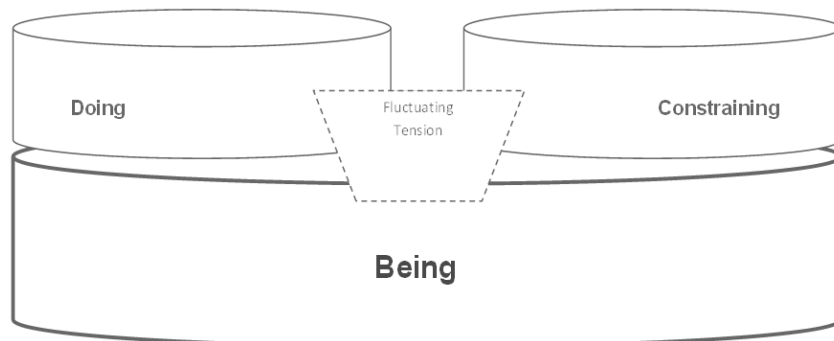
*What you say with even anything for myself what you say, even what you already experience from this one from the other people. They always the same with me*

*Yes, we have the same. That does not mean that I am not a special.*

Iosefa's hope is firmly rooted in his Christian faith. He draws hope from God and sees his faith-related rituals (e.g. evening prayers) as a key factor in maintaining hope – *"I think most of the time I always play (pray), I will just come here"*. In addition, he sees that hope and his ongoing journey toward his hopes is supported by all those around him such as his family, friends and therapy staff: *"It's not only by myself who make myself. The people who are around you and me, what I'm saying"* is post-stroke

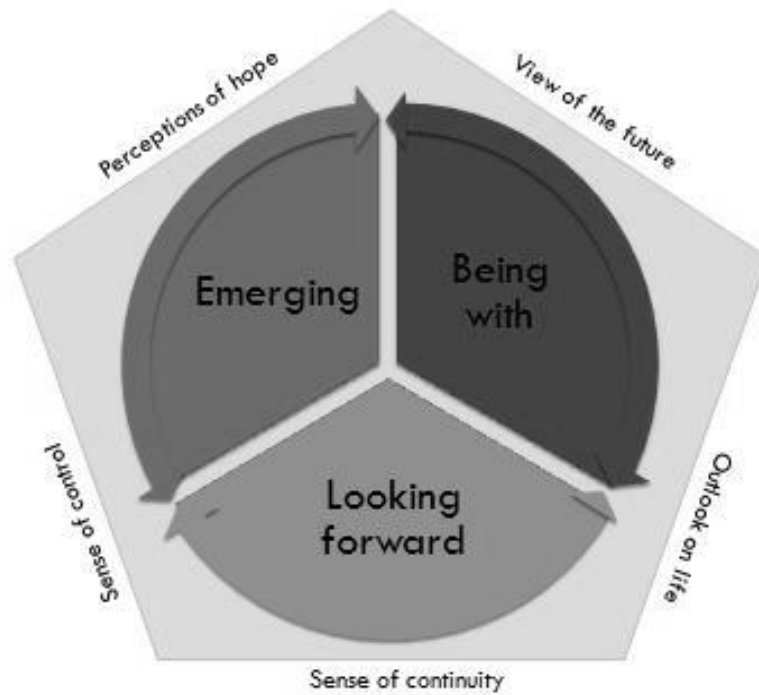
progress to date also reinforces his sense of hope for further improvement: *“You see that after this one, some thing, my experience, it’s very different now. You see it’s getting better and better and better”*.

## Appendix I: Diagramming



Early diagramming, completed after interviews with two participants

The above figure demonstrates a very early conceptualisation of how hope was experienced. This was developed after interviews with the first two participants had been completed. At that point, I queried whether “being” (which became *simply ‘having’ hope*) was the fundamental form of hope that underpinned other experiences of hope. “Doing” developed into *actively hoping*. “Constraining” was an early category that was not continued. At that point, it appeared as though participants were engaged in a process of constraining their hopes in response to the tension. This bears similarities to the strategies that were identified as a result of analysing all the data.



Late diagramming, completed after data collection had ceased

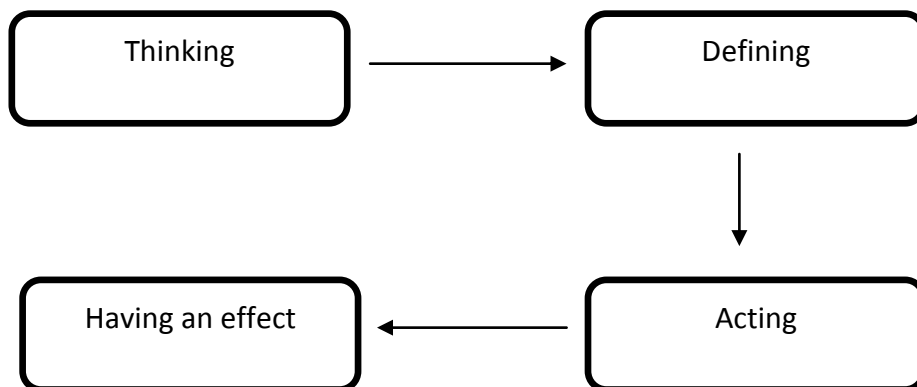
This figure represents a diagram developed after data had been collected from all five participants. The three segments represented possible forms of hope, while the five categories around the outside represented possible influences on the experience of hope. However, discussion of the components of the diagram and supporting data highlighted that there was insufficient evidence to support some categories (e.g. “sense of control”), that some categories could be amalgamated with others (e.g. “outlook on life” and “being”), and that some reflected an early experience of hope (i.e. “emerging” referred to the emergence of hope post-stroke; this occurred in the acute period, not the post-acute period). This resulted in a return to the data and refinement of the findings.

## Appendix J: Memoing

### Memo Title: Doing

13 June 2010

“Doing hope” is a key process within the broader hope experience. It is the one that is easiest for participants to talk about (and is the easiest to ask questions about!). It feels like a big category that encompasses several sub-processes yet there is little information about how people move between the different subprocesses (assuming they move between and don’t coexist).



*Under what conditions does this process develop?*

This process emerges from the presence of a state of hope and from a process of thinking about the future.



*How do(es) the research participant(s) think, feel and act while involved in this process?*

The participants talk about having “hopes” for the future which arise from thinking about the future, and sometimes thinking about the past. Identifying hopes is a multilayered process. Hopes can exist at a number of different levels, from wishes/desires to specific hopes such as “*a little more drawing*”. Participants identify that they can experience these different layers of goals simultaneously. There is not a consistent link between specific hopes and broader wishes/hopes. These broader hopes are often non-specific (e.g. “*a little more sufficient*”) which can be a result of uncertainty about the likely outcome, or a protective mechanism in case the ‘real’ hope can’t be realised – it allows for face-saving. Participants express a degree of expectation that the hopes will be realised although this is they rarely express 100% certainty/belief that it will be realised. Hopes that are identified are unique and personal, though during member checking, participants identified that they shared common hopes with others, with one saying “*yes, we have the same*” which was qualified by the statement “*... but that does not mean that I am not a special*”.

Starting the process of identifying hopes appears to prompt a cognitive process that of “looking forward and back” to past experiences and future hopes, of mentally preparing for how hopes can be realised, and of evaluating one’s skill level and ability to realise the hope. This may help refine the hopes that are identified. Two conflicting experiences of ‘looking back’ are evident in the interviews – for one person, this process made him feel like his ‘previous’ hopes were no longer something he wanted to relate to and his primary overarching hope become “*to do everything that I wanted to do that I couldn’t do before before this*”. His experience of hope in the past also influenced how he felt about hope in the present/future (this is where there are some links with constraining hope), particularly his experience of “*bad hope*”. It also led to a process of reflection on his life pre-stroke, a process that resulted in some grief for lost opportunities and that he had behaved the way he had. For a second participant, the process of looking back confirmed his hopes for the future – his broader hopes were unchanged because they are closely associated with his identity which is unchanged post-stroke. When asked about why he had the hopes he had, he said “*this is who I am ... Why you say “why do you study?”. It’s because of who I am, who you are*”. For him,

his hopes were closely entwined with his identity and this is one reason they were consistent.

The process of identifying and thinking about hope is then followed by action. All participants to date identify that the action stage of hope is essential and that they bear responsibility to ensure that steps are taken to realise their hopes. People with stroke are required to put effort (physical and emotional) into realising their hopes although one did identify that this was more difficult as a result of the effects of the stroke.

*When, why and how does the process change?*

While the process of “doing hope” is evident in all participants, it is stronger in some participants than others. It appears to be mediated by the internal sense of hope, vision/sense of the future, sense of identity, fear of hope and adjustment.

*What are the consequences of the process?*

The outcome of “doing hope” is that it “has an effect” in two primary ways. Firstly, it is seen to **support recovery**, being something that impacts on engagement in rehabilitation (Matthew) and supporting endurance through the recovery process (Miriam). It is also said to work with other processes (Iosefa) through rehabilitation to maximise recovery. Doing hope also has an **internal effect** on the individual with the stroke. It has a number of positive outcomes for the individual, including giving purpose, improving mood, motivating, protecting, supporting and, in general, “*making life better*”. One participant also talked about impact of hope on a person’s ability to “*have a re-re-reject*” (effect) and “*a result*” – which is interpreted to mean, improved outcomes for the individual.

# Appendix K: Ethical Approval



## Northern Y Regional Ethics Committee

Ministry of Health  
3<sup>rd</sup> Floor, BNZ Building  
354 Victoria Street  
PO Box 1031  
Hamilton  
Phone (07) 858 7021  
Fax (07) 858 7070  
Email: [northern\\_y\\_ethicscommittee@moh.govt.nz](mailto:northern_y_ethicscommittee@moh.govt.nz)

1 September 2009

Ms Nicola Kayes  
School of Rehabilitation and Occupation Studies  
AUT University  
PB 92 006  
Auckland 1142

Dear Nicola

**The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.**

**Investigators:** Nicola Kayes, Felicity Bright, Clare McCann, Kathryn McPherson.

**Ethics ref:** NTY/09/07/061

**Locations:** AUT University, [REDACTED]

The above study has been given ethical approval by the Northern Y Regional Ethics Committee.

### Approved Documents

-Interview guide version one: June 2009.

-Data collection sheet version one: June 2009.

-Information sheet and Consent form version two: August 2009.

### Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

### Progress Reports

The study is approved until **30 June 2011**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **1 September 2010**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

### Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

**Please quote the above ethics committee reference number in all correspondence.**

**It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.**

Yours sincerely

Amrita Kuruvilla  
Northern Y Ethics Committee Administrator

Email: [amrita\\_kuruvilla@moh.govt.nz](mailto:amrita_kuruvilla@moh.govt.nz)



## MEMORANDUM

### Auckland University of Technology Ethics Committee (AUTEC)

To: Nicola Kayes  
From: Madeline Banda Executive Secretary, AUTEC  
Date: 1 October 2009  
Subject: Ethics Application Number 09/202 The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.

Dear Nicola

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 14 September 2009 and that I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 12 October 2009.

Your ethics application is approved for a period of three years until 30 September 2012.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 30 September 2012;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics>. This report is to be submitted either when the approval expires on 30 September 2012 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz) or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda  
Executive Secretary  
Auckland University of Technology Ethics Committee

Cc: Felicity Bright [felicity.bright@aut.ac.nz](mailto:felicity.bright@aut.ac.nz), Kath McPherson

From the desk of ...  
Madeline Banda  
Executive Secretary  
AUTEC

Private Bag 92008, Auckland 1142  
New Zealand  
E-mail: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)

Tel: 64 9 921 9999  
ext 9244  
Fax: 64 9 921 9925  
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