

Influences on health-related behaviours following first-ever stroke

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A thesis submitted to
Auckland University of Technology
in fulfilment of the requirements for the degree of
Doctor of Philosophy (PhD)

2018

School of Public Health and Psychosocial Studies

Abstract

Stroke is a health problem that causes high levels of mortality and morbidity. Healthy lifestyle choices to reduce stroke risk factors are an important component of reducing risk of secondary stroke, and include adherence to prescribed medications, smoking cessation, cessation of alcohol consumption, dietary control, and increased physical activity. Yet, uptake of health behaviours following stroke is low. Theories of health behaviour suggest various factors can influence health-related behaviours. While research has focused on different clinical populations, little is known about factors that might influence health-related behaviours in stroke populations.

A literature review explored the factors that might influence health-related behaviour following a stroke. Qualitative and quantitative studies suggested that health-related behaviour following a stroke is a complex process. Health-related behaviours have been found to be influenced by a variety of factors, including physical factors, behavioural factors, and psychosocial factors. Two psychological factors identified in the literature as potentially influencing health behaviours, but where little definitive evidence was identified, were illness perceptions and satisfaction with stroke care.

A mixed methods approach explored the factors that influence health-related behaviour following first-ever stroke in New Zealand. A quantitative study investigated whether an individual's illness perceptions, or satisfaction with their stroke care, influenced their health-related behaviours following first-ever stroke. 386 participants completed questionnaire assessments at 28-days, six-months, and twelve-months post-stroke. In this group of participants, illness perceptions (measured using the Brief Illness Perception Questionnaire) were found to have two dimensions (emotional and practical). Emotional and practical illness perceptions were found to be independent predictors of health behaviours; however, the links were not consistent over time or across health behaviours. Age was the only sociodemographic factor that was significantly related to health behaviour. Satisfaction with stroke care was not significantly related to health behaviour at any time-point.

The qualitative study used an interpretive descriptive approach to explore what influenced stroke survivor health-related behaviours following first-ever stroke. Nine

stroke survivors, six significant others, and six motivational interviewers participated in this study. Stroke survivors and significant others struggled to describe how and why health behaviour change was relevant to them but acknowledged the importance of the broader concept of recovery post-stroke. Four inter-related sub-themes were identified in the data including *Past and present experiences*; *Individuality, beliefs and choice*; *What the stroke means for me*; and *Access, knowledge, and availability of resources*.

The key combined findings from this research were that the emotional aspects of illness are challenging and have a greater influence on health-related behaviour than is currently recognised. Second, health-related behaviour may not be a priority for people following stroke and the practicalities of implementing change into everyday life are challenging. Third, health behaviour advice (from health professionals) may have more relevance for stroke survivors within the community rather than hospital setting. Finally, the results highlighted that individual needs should be addressed by health professionals rather than an 'one-size fits all' approach.

Contents

Abstract	ii
Chapter 1 Introduction.....	1
1.1 Background	1
1.2 Context of the New Zealand health system.....	3
1.3 Context of this doctoral research	4
1.4 Considerations of conducting doctoral research.....	5
1.5 Point of difference for doctoral research	5
1.6 Thesis aims and objectives.....	6
1.7 Positioning this doctoral research and the researcher.....	8
1.8 Mixed methods rationale.....	10
1.9 Thesis structure.....	11
Chapter 2 Literature Review	13
2.1 Overview	13
2.2 Self-management for post-stroke care and stroke prevention	14
2.3 Health behaviour change and health promotion	15
2.4 Factors that influence health-related behaviour in stroke.....	18
2.4.1 Physical factors.....	19
2.4.2 Behavioural and cognitive factors.....	20
2.4.3 Psychosocial factors	21
2.5 Potential influences on health-related behaviour in stroke.....	23
2.5.1 Psychological factors: illness perceptions.....	23
2.5.2 Psychological factors: satisfaction with stroke care	26
2.6 Summary	28
Chapter 3 Quantitative Method.....	30
3.1 Overview	30
3.2 Primary hypotheses	30
3.3 Secondary hypotheses	31
3.4 Design.....	32
3.5 Participants	32
3.6 Procedure.....	33
3.7 Assessment measures.....	34
3.7.1 Illness perceptions	34
3.7.2 Satisfaction with stroke care.....	36
3.7.3 Health behaviour.....	37
3.8 Data analysis	38
3.9 Ethical considerations	40

3.9.1	Informed Consent	41
3.9.2	Confidentiality and Anonymity	41
3.9.3	Participant Burden	41
3.9.4	Cultural Aspects of Participation.....	42
Chapter 4 Quantitative Results		43
4.1	Sample characteristics	43
4.2	Factor Analysis of Questionnaire Measures	46
4.2.1	Brief Illness Perceptions Questionnaire	46
4.2.2	Satisfaction with Stroke Care Questionnaire	48
4.3	Descriptive statistics for predictors	49
4.4	Association between B-IPQ and SASC.....	52
4.5	Health Behaviour Outcomes	52
4.5.1	Use of Alcohol	52
4.5.2	Medication Adherence.....	56
4.5.3	Physical Activity.....	59
4.5.4	Smoking Behaviour	63
4.5.5	Diet behaviour.....	64
4.6	Summary	70
Chapter 5 Quantitative Discussion.....		72
5.1	Summary of findings	72
5.2	Satisfaction with stroke care.....	76
5.3	Illness Perceptions	78
5.4	Link between satisfaction with stroke care and illness perceptions	82
5.5	Other covariates.....	83
5.6	Sample considerations	87
5.7	Health Behaviour Measures.....	89
5.8	Conclusions	91
Chapter 6 Qualitative Methodology and Method		92
6.1	Methodology	92
6.2	Methods	96
6.2.1	Participant sampling and recruitment	96
6.2.2	Recruitment Procedure for stroke survivors and significant others.....	98
6.3	Procedure	99
6.4	Data Analysis	101
6.4.1	Assumptions.....	101
6.4.2	Data Analysis Procedure	102
6.5	Ethical Considerations.....	103
6.5.1	Informed Consent	103
6.5.2	Voluntary Participation	104
6.5.3	Confidentiality and Anonymity	105

6.5.4	Nonmaleficence Or ‘Do No Harm’	105
6.5.5	Rigour	106
Chapter 7 Qualitative Findings.....		108
7.1	Introduction	108
7.2	Participant Characteristics	108
7.3	Main Themes.....	110
7.4	Overarching theme of path-finding	111
7.5	Sub-Theme 1: Past and present experiences.....	113
7.5.1	Need for Change	113
7.5.2	Previous experience of health behaviour change.....	114
7.5.3	Learning from Others	115
7.5.4	Impact of comorbidity.....	116
7.6	Sub-theme 2: Individuality, beliefs and choice	117
7.6.1	I’m different, I’m unique	117
7.6.2	Changing social roles.....	119
7.6.3	Relevance of stroke risk factors to the individual.....	120
7.6.4	Having a choice	122
7.7	Sub-theme 3: What the stroke means for me	122
7.7.1	Confusion	123
7.7.2	Fatigue.....	124
7.7.3	The role of Luck	125
7.7.4	Risk and vulnerability	125
7.7.5	Finding the balance	127
7.8	Sub-theme 4: Access, knowledge, and availability of resources	128
7.8.1	Being supported and motivated	128
7.8.2	External barriers.....	130
7.8.3	Financial Implications.....	132
7.8.4	Finding out what’s available	132
7.8.5	Maintenance of health-related behaviour.....	133
7.9	Summary	134
Chapter 8 Qualitative Discussion		136
8.1	Approach to stroke influences health-related behaviour.....	137
8.2	Impact of past and present experiences related to stroke.....	138
8.3	Influence of individuality, beliefs, and choice.....	139
8.4	What the stroke meant for the individual	140
8.5	Learning what support was available following the stroke	142
8.6	Applying findings to the Health Action Process Approach	144
8.7	Evaluation of Methods.....	146
8.7.1	Sampling and Participants.....	147
8.7.2	Data collection and analysis.....	150

8.8	Original contribution of research	153
Chapter 9 Mixed Method Discussion		154
9.1	Overview	154
9.2	Everyone's post-stroke journey is different.....	155
9.3	Emotional aspects of illness perceptions and health behaviour	157
9.4	Priorities following a stroke	158
9.5	Consequences of stroke go beyond end of healthcare	161
9.6	How findings relate to the HAPA model	165
9.7	Strength and limitations of a mixed methods approach	166
Chapter 10 Conclusion		169
References.....		171
Appendix A: Overview of parent MIST-trial		186
Appendix B: Literature Search Protocol.....		189
Appendix C: Information and Consent Form for MIST-trial (including Caregiver Nomination Form).....		191
Appendix D: Study Questionnaire		201
Appendix E: HDEC Ethics Approval Letter for MIST-trial		222
Appendix F: HDEC Ethics Approval Letter for Quantitative Study		226
Appendix G: Linear Regression for Fruit and Vegetable Consumption at Post-Stroke Time-Points		228
Appendix H: Stroke Survivor Information Sheet and Consent Form for Qualitative Study		231
Appendix I: Significant Other Information Sheet and Consent Form for Qualitative Study.....		238
Appendix J: Motivational Interviewer Information Sheet and Consent Form for Qualitative Study.....		247
Appendix K: Stroke Survivor and Significant Other Interview Schedule for Qualitative Study.....		256
Appendix L: Motivational Interviewer Interview Schedule for Qualitative Study		258
Appendix M: HDEC Ethics Approval Letter for Qualitative Study		260
Appendix N: AUTECH Ethics Approval Letter for Qualitative Study		263
Appendix O: AUTECH Ethics Approval Letter for Qualitative Study		265

List of Figures

Figure 1. Research aims and objectives of thesis.	7
Figure 2. Thesis structure.	12
Figure 3. Associations between illness perceptions, satisfaction with stroke care and health-related behaviour suggested by existing evidence.	30
Figure 4. Hypothesized relationships between illness perceptions, satisfaction with stroke care and health-related behaviour following first-ever stroke.	31
Figure 5. Flowchart illustrating the participant flow over the course of the longitudinal study.	43
Figure 6. Scree plot for the exploratory factor analysis conducted on 28-day B-IPQ.	47
Figure 7. Scree plot for the exploratory factor analysis conducted on 28-day SASC.	48
Figure 8. Findings indicating relationships between satisfaction with stroke care, illness perceptions, and health-related behaviours at the primary time-point of 28 days post-stroke.	73
Figure 9. Findings indicating relationships between satisfaction with stroke care, illness perceptions, and health-related behaviours at the later time-point of six- and twelve-months post-stroke.	74
Figure 10. Relationships experienced by stroke survivors potentially influencing post-stroke health-related behaviours within the context of the MIST-trial.	95
Figure 11: Participant inclusion criteria.	97
Figure 12. Coding framework illustrating themes identified from participants described experiences.	112

List of Tables

Table 1. Participant characteristics of quantitative study.	44
Table 2. Screening criteria for participants in quantitative study.	45
Table 3. Factor (dimension) loadings for B-IPQ.	47
Table 4. Factor (dimension) loadings for SASC.	49
Table 5. Summary statistics for predictors at 28-days post-stroke.	50
Table 6. Summary statistics for use of alcohol at post-stroke time-points.	54
Table 7. Linear regression analysis for frequency of alcohol use at post-stroke time-points.....	55
Table 8. Summary statistics (including crosstabs) for adherence to medication across time-points.	57
Table 9. Logistic regression model for medication adherence at each time-point.	58
Table 10. Summary statistics (including crosstabs) for physical activity by study group.	59
Table 11. Linear Regression Analysis for frequency of physical activity at post-stroke time-points.	60
Table 12. Linear Regression Analysis for frequency of walking at post-stroke time-points.....	61
Table 13. Summary statistics for smoking behaviour at post-stroke time-points.....	64
Table 14. Summary statistics (including crosstabs) for changes to diet across time-points.....	65
Table 15. Logistic Regression Analysis for diet changes at post-stroke time-points.	66
Table 16. Linear Regression for salt consumption at post-stroke time-points.....	68
Table 17. Linear Regression for salt consumption at post-stroke time-points.....	69
Table 18. Participant Demographics	109
Table 19. Significant other Demographics	109
Table 20. Linear Regression for vegetable consumption at post-stroke time-points. .	229
Table 21. Linear Regression for fruit consumption at post-stroke time-points.	230

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.

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Halina Kalaga

15 December 2017

Acknowledgements

I would like to acknowledge and thank the stroke survivors, their significant others, and the team of motivational others, who contributed their time to take part in this research. I am sincerely grateful to the participants who were willing to share their time and experiences with me.

I would also like to thank my supervisors who supported and guided me through this thesis and my development as a researcher. They provided a supportive environment to discuss and develop research ideas, encouragement, and feedback.

Financial support was provided via funding from the Health Research Council, who provided a three-year doctoral stipend. In addition, an AUT doctoral fees scholarship from the Faculty of Health funded my fees for three-years. I would like to thank both these sources of support, which enabled me to complete this thesis and conduct research to improve health outcomes for patients.

I am grateful to my family and friends for their encouragement, support, and patience. My parents have continued to encourage and support me to study towards a PhD. I also want to acknowledge the encouragement I received from my grandparents, especially Dziadek Kalaga. I would like to especially thank my best friend Maggie, for all her support, patience, and for reading through sections of my thesis. Finally, thank you to my husband Pete. Without his love, support, and patience this would not have been possible. Thank you.

Ethical Approval

Ethical approval was obtained from:

- Northern X Regional Ethics Committee for experiments in human subjects (HDEC reference: NTX/10/09/091) on 18/06/2012
- Health and Disability Ethics Committee (HDEC reference NTX/10/09/091/AM04) on 30/07/2014
- Auckland University of Technology Ethics Committee (AUTEC reference 11/298) on 12/08/2014
- Auckland University of Technology Ethics Committee (AUTEC reference 13/342) on 16/12/2013

Chapter 1 Introduction

This thesis presents a mixed methods research approach to explore and understand what might influence health-related behaviours of stroke survivors following a first-ever stroke. This chapter will provide the general context for this doctoral work. This will include a background to the thesis topic, explain the implications of the New Zealand context to this research, the motivations for this research, and my position as a researcher. The chapter will then provide an overview of this thesis, outlining the research questions, how these questions will be addressed, and explain the structure of this thesis.

1.1 Background

Stroke is the second most common cause of death in New Zealand (Stroke Foundation of New Zealand, 2010; Tobias, Cheung, Carter, Anderson, & Feigin, 2007). The majority of people who experience stroke are older adults, with estimated rates of first-ever stroke found to increase exponentially with age (Tobias et al., 2007). Estimates suggest approximately 500 of every 100,000 people live with the consequences of stroke (Donnan, Fisher, Macleod, & Davis, 2008), with up to two-thirds of stroke survivors experiencing some degree of permanent disability (Bronstein, 1991). In addition, the risk of secondary stroke is substantially higher in stroke survivors, with recurrence rates of up to 30% within the first month (Donnan et al., 2008). Approximately 7% of all patients with a history of stroke will have a recurrent event each year (Hankey & Warlow, 1999).

Preventing recurrent stroke (by managing stroke risk) is a key goal of post-stroke care. Improved control of modifiable risk factors has been attributed to the prevention of recurrent stroke (Eames, Hoffmann, Worrall, & Read, 2011; Stuifbergen, Gordon, & Clark, 1998). These modifiable risk factors can be addressed by health promoting behaviours that include: cessation of cigarette smoking, decreased alcohol intake, adequate levels of physical activity, a healthy diet (Eames et al., 2011), and adherence to prescribed medication (Sjolander, Eriksson, & Glader, 2013).

While the key strategies for secondary stroke prevention are well known, their implementation is not always successful. First, health-related behaviour can be

positively or negatively influenced by a variety of factors (e.g. physiological, behavioural, and psychosocial factors) that can change across time. Second, improving post-stroke health-related behaviour can be challenging, as stroke survivors can experience cognitive (e.g. memory loss), physical (e.g. limb paralysis), and psychological (e.g. depression) deficits that can impact on processes associated with health-related behaviour (e.g. motivation, engagement, participation). While health behaviour change has been well documented in healthy populations, as well as other chronic illnesses or conditions (e.g. cardio-vascular disease populations: Akhu-Zaheya & Shiyab, 2017), minimal evidence demonstrates health behaviour change in stroke populations. This might result from differences in the underlying factors that influence health-related behaviour in these populations. To reduce risk of secondary stroke, it is important to investigate what might influence health-related behaviours in populations following first-ever stroke.

Although an existing body of research looks at the different ways health promotion can be influenced, more work is still needed in this area to improve understanding. Current research suggests that the ability of stroke survivors to modify their lifestyle might be influenced by a number of psychosocial factors, including quality of life (Remer-Osborn, 1998), pre-stroke levels of activity (Shaughnessy, Resnick, & Macko, 2006), illness perceptions (Shaughnessy et al., 2006; Sjolander et al., 2013), mood (Dafer, Rao, Shareef, & Sharma, 2008; Remer-Osborn, 1998), self-efficacy (Strecher, DeVellis, Becker, & Rosenstock, 1986; Townend, Tinson, Kwan, & Sharpe, 2006), social (Morris, Oliver, Kroll, & Macgillivray, 2012; Remer-Osborn, 1998) or familial support (Gordon et al., 2004; Remer-Osborn, 1998), support from health care providers (Shaughnessy et al., 2006), and satisfaction with stroke care (Pound, Tilling, Rudd, & Wolfe, 1999). For example, early involvement of the family unit has been strongly correlated with patient adherence to therapy, better understanding between patient and caregiver of achievable outcomes, and improved communication between patient and caregivers (Gordon et al., 2004).

Intervention studies report that behaviour can be successfully modified by physicians' advice and motivational interviewing (MI) (Green, Haley, Eliasziw, & Hoyte, 2007). MI is a client-centred and directive method that aims to improve motivation to change by

focusing on the goals that are relevant to the client (Burke, Arkowitz, & Menchola, 2003). MI makes use of an individual's motivation to achieve a goal using strategies to focus on the individual's readiness to change and integrates relationship-building principles of therapy (Green et al., 2007; Miller & Rollnick, 2002). Although MI has been shown to be effective in helping individuals to modify their risky health behaviours to reduce the risk of secondary stroke (Watkins et al., 2007), there is little evidence to suggest how these interventions might work. In addition, exploring how these individuals might be influenced by psychosocial factors post-stroke holds implications for engagement in interventions such as MI. The barriers to health-promoting behaviour experienced by a stroke survivor might be different to those experienced by a healthy person or for other health conditions because of the acute onset of symptoms and impairments resulting from the stroke.

1.2 Context of the New Zealand health system

Patients with suspected or confirmed diagnosis of stroke should be admitted to hospital under stroke management protocols in New Zealand (Barber, Fink, Gommans, Hanger, & Baker, 2006). Guidelines state that admission to hospital and initial assessments should be completed within three hours of stroke onset. Stroke patients should be admitted to a stroke unit and remain in the unit until acute investigation and treatment have been completed and the patient is medically stable. The average stay of patients within the stroke unit is expected to be between five to seven days (Barber et al., 2006; Taranaki District Health Board, 2010). Active multidisciplinary rehabilitation should be provided for inpatients; however, rest home or hospital level nursing care will be provided for stroke patients who are not able to participate with active treatment and rehabilitation or are experiencing severe co-morbidities.

An estimate of duration of inpatient care should be made within three days of hospital admission by the multidisciplinary team involved in the treatment of the stroke patient (Barber et al., 2006; Taranaki District Health Board, 2010). Inpatient care that involves less than five additional days can allow the patient to be discharged to their residence (taking into consideration their home circumstances). Patients requiring on-going care will be discharged from the stroke unit to alternative options (e.g. Older Peoples Health) within the hospital, where general medical support is provided by the hospital

medical team. Stroke patients requiring on-going rehabilitation extending past the seven days (in the stroke unit) will be transferred to inpatient rehabilitation services, including RehabPlus.

Guidelines also state that during inpatient stay, all stroke patients should be provided with appropriate advice on lifestyle factors and modifiable health behaviours (such as smoking cessation, regular exercise, healthy diet, and reducing salt use). A management plan for the management of risk factors for stroke should also be provided (Barber et al., 2006; Taranaki District Health Board, 2010). Patients with residual impairments following medical investigation and treatment of stroke should be referred to appropriate rehabilitation services (e.g. RehabPlus). Early rehabilitation should involve daily activities that have a physiotherapy component under supervision of a physiotherapist; feedback should be provided to stroke patients involving problems that have been identified, rehabilitation goals, and progress made.

Discharge from hospital should be made in the context of support services available, as well as the needs of the stroke survivor and their informal caregiver. Stroke patients should have access to stroke care and rehabilitation following discharge from hospital. Continuing treatment should be provided by specialist community services or outpatient services. Stroke survivors with reduced activity at six-months post-stroke should be assessed for additional targeted rehabilitation. This overview of stroke management and care provision is outlined by the Ministry of Health, New Zealand.

1.3 Context of this doctoral research

This doctoral research was completed within the context of an externally funded randomised controlled trial (RCT) of motivational interviewing to prevent secondary stroke: the Motivational Interviewing in Stroke Trial (MIST). Funded by the Health Research Council of New Zealand, the MIST-trial was a single blind randomized controlled trial that focused on a population of stroke survivors in Auckland, New Zealand. The methods of the parent study have been described in Appendix A; see also the published methodology of the MIST-trial (Krishnamurthi et al., 2014). The primary objective of the trial was to determine the effectiveness of motivational interviewing (MI) on reducing blood pressure, cholesterol levels and improving adherence to medication for people post-stroke. While all participants received standard care

offered by the New Zealand Health Service, the MIST-trial involved randomising participants to either a control group (usual care) or an intervention group (MI) who received four motivational interviews across twelve-months (Barker-Collo et al., 2015; Krishnamurthi et al., 2014). During the twelve-months of the MIST-trial, all participants completed baseline and follow up questionnaires in addition to objective measures of blood pressure and cholesterol levels.

1.4 Considerations of conducting doctoral research

The implications of exploring the doctoral research questions and objectives within the context of a larger research study (MIST-trial) were considered. This approach had a number of advantages. First, the trial facilitated access to a large sample of stroke survivors using robust case ascertainment methodology reducing sampling bias. The separate recruitment of a similar sample would not have been feasible to implement without extensive funding. Second, the MIST-trial provided the verification of diagnosis of first-ever stroke, which would not have been feasible for the doctoral research if it had been conducted independently. Third, the trial enabled the study of factors that influenced participation with health-promoting behaviours in two separate groups of stroke survivors (people receiving motivational interviewing vs. usual care); this opportunity would not have been available through studying people directly from the general population. Fourth, MIST offered the unique opportunity to directly explore how factors linked to health-promoting behaviours following a stroke were influenced by MI, in a group of people receiving the same mode of administration and duration of the intervention. Consequently, setting this doctoral work within the context of a randomised controlled trial enabled more questions to be answered based on a robust participant sample.

1.5 Point of difference for doctoral research

This programme of doctoral research used a sub-sample of participants from the parent MIST-trial, whilst being a separate research project in its own right. The objective of this doctoral research was to investigate a range of factors that influenced health-promoting behaviours in stroke survivors who had experienced first-ever stroke. This was distinct from the aim of the parent MIST-trial, which investigated the effectiveness of MI to improve physiological outcomes of blood pressure, lipid profiles,

and medication adherence. This doctoral research has a specific focus on behavioural outcomes (such as improvements in health-related behaviours) in stroke survivors, rather than the physiological measures and health outcomes that were the primary objectives of the parent MIST-trial. Whilst this doctoral research has drawn on some data collected as part of MIST, additional and distinct measures were collected to answer the doctoral research objectives. Furthermore, none of the analyses within this doctoral research form part of the analyses of the parent MIST-trial.

1.6 Thesis aims and objectives

Four components make up the mixed methods framework for this thesis and are outlined in Figure 1.

A preliminary literature review was conducted to identify the knowledge base around health behaviour change following a stroke; this knowledge base was used to inform two studies that complemented the overall research objective. The quantitative component of this research was a longitudinal questionnaire-based survey over twelve-months. Stroke survivors were asked about perceptions of their stroke using the Brief Illness Perceptions Questionnaire, B-IPQ; (Broadbent, Petrie, Main, & Weinman, 2006); about their satisfaction with care they had received using the Satisfaction with Stroke Care Questionnaire, SASC-19 (Boter, De Haan, & Rinkel, 2003); and about their health-related behaviours (including questions on diet, smoking, alcohol consumption, physical activity, and medication adherence).

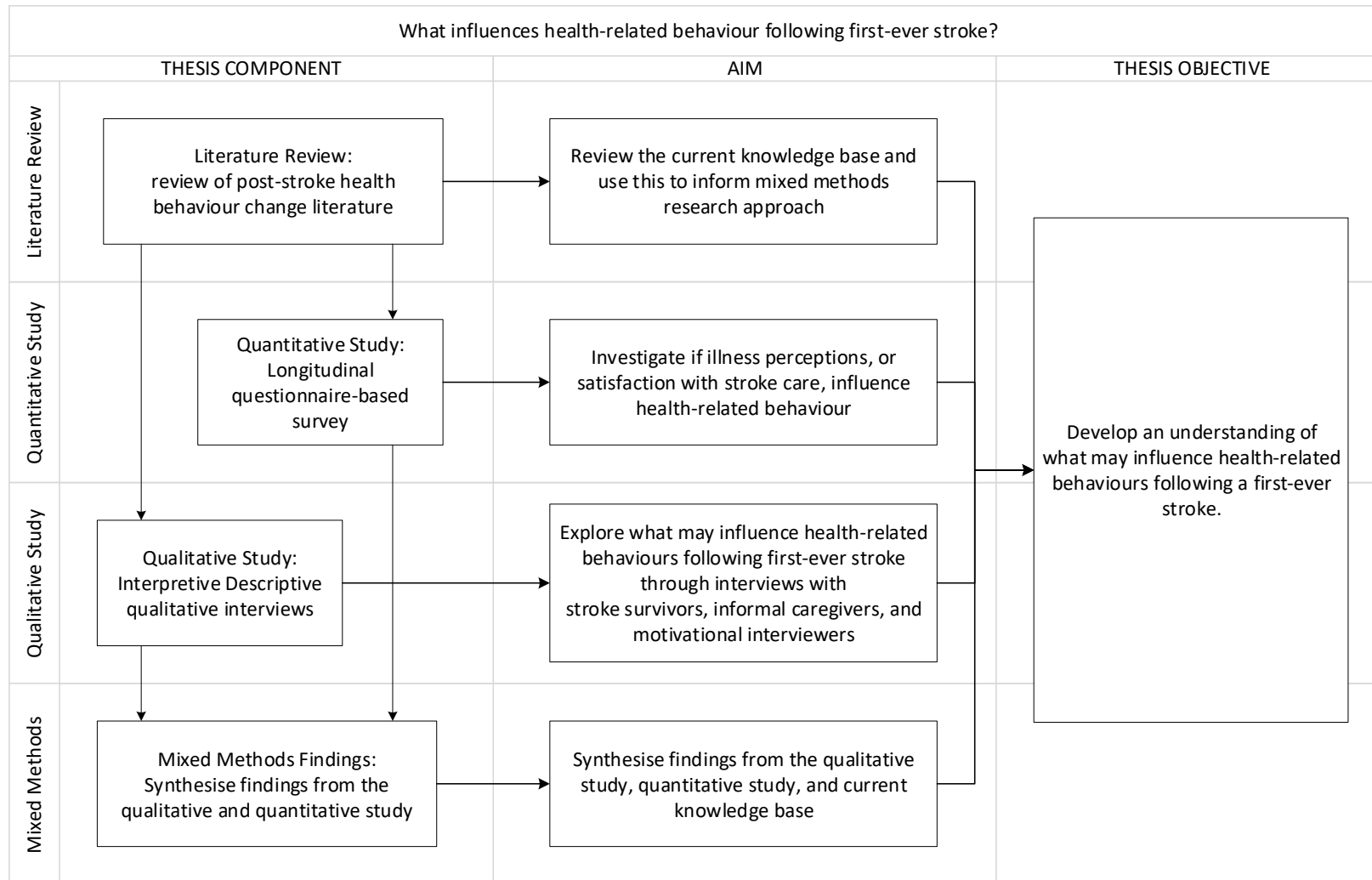


Figure 1. Research aims and objectives of thesis.

The qualitative component of this research used an Interpretive Descriptive qualitative approach to explore what influenced people to participate in health behaviour change following a first-ever stroke to understand the psychosocial factors in this phenomenon. This study augmented the quantitative study by asking stroke survivors, significant others, and motivational interviewers about their perceptions and experiences associated with stroke survivor health-related behaviours following the stroke. The two studies in this thesis were distinct, in that each study had a different objective. However, the two studies augmented each other as they both addressed the overarching research objective using different but complimentary approaches that are well suited to a mixed methods approach. Thus, the final component of this thesis synthesized the findings from the quantitative and qualitative studies using a mixed methods approach.

1.7 Positioning this doctoral research and the researcher

Having provided the background literature to set the scene for this doctoral research, as well as the context of this research being conducted within the MIST-trial, I think it is important to provide a brief overview of the predominant ideas that have shaped this research. By this, I mean to position myself as a researcher, and to position my programme of research.

My interests in health-related behaviour and how a person's perceptions, intentions, and behaviour might be influenced, have been themes present in the majority of my academic work. Over ten years ago, whilst studying towards undergraduate and masters degrees in psychology, my research focused on existing health behaviours and linking this with health behaviour theory to understand elements of health-related behaviour. Although these projects were about human behaviour, they were not about the individual, human story.

I have always felt that why we choose to do things, why we are who we are, why we have got to a certain place at a certain time, is both subjective and incredibly complex. Sometimes I feel that research is not able to, or does not, take that subjectivity or complexity into account when considering real-world or human phenomena. The richness and messiness of real-world experience can seem a barrier to measuring,

describing, understanding, or influencing real-world phenomena. Taking the relevant example of stroke-related research, it can appear that this area of research focuses on aggregated group data. It can also seem that this area of research (and research-related practice) places importance on describing and treating the group—i.e. a group of people who can be thought of, or described as, typical stroke patients—rather than describing, understanding the process of and reasons why something does or doesn't work well, or treating the individual.

With my doctoral research, I feel I have been incredibly lucky to develop a programme of research that has been shaped by my personal and academic research interests. Health-related behaviour, motivation, and decision-making have been themes present in my previous academic work. For this doctoral research, the quantitative method enabled me to quantify the key issues and test out hypotheses that were guided by the previous literature. In addition, throughout my doctoral research I have had the opportunity to acknowledge the importance of the individual voice in my choice of methods and methodology, my approach to analyses, and my findings. For example, my decision to use a mixed methods approach for my doctoral research enabled me to ask questions using a qualitative approach that were not captured by the quantitative methods. My interviews with some of the stroke survivors allowed me to hear their individual experiences, perceptions, and intentions following their stroke. The richness and depth of this data would otherwise have been unsolicited and unheard. My interviews with the significant others of the stroke survivors, and the team of motivational interviewers, allowed me to hear experiences and perceptions relating to the stroke survivor and to explore some of the psychosocial factors that influenced behaviour to understand the processes behind the MI approach. Approaching these two additional groups of people, whose perceptions and experiences were interlinked with the stroke survivors, also provided valuable insights as well as alternative or corroborative data. Finally, the qualitative and quantitative approaches used within the thesis augmented each other and enabled me to answer my research objectives in ways that would not have been possible using either approach in isolation and enabled me to address existing gaps in the research literature.

1.8 Mixed methods rationale

This doctoral research will use a mixed methods parallel approach to make use of both qualitative and quantitative methods at the same time, valuing both equally, to enable the research questions in this programme to be explored fully whilst making use of methods that serve the research aims best (Crotty, 1998). The rationale for conducting mixed methods research lies in combining the strengths of both qualitative and quantitative studies (Pluye, Grad, Levine, & Nicolau, 2009). Typically, qualitative studies provide in-depth and content rich descriptions of complex phenomena that are context specific but might suggest theoretical and methodological lessons that might be transferrable to other contexts. Quantitative studies typically examine observations or causal relationships using statistical inferences that might be generalised. Mixed methods research can be defined as a combination of qualitative and quantitative methods for the broad purpose of gaining breadth and depth of understanding, or corroboration of phenomena, within a single study or closely related studies (Johnson, Onwuegbuzie, & Turner, 2007).

Numerous benefits of mixed method designs have been suggested, such as greater confidence in results, assistance in uncovering unexpected dimensions of a phenomenon, and enriched explanations of psychosocial phenomena to be understood more completely through integrating qualitative and quantitative data (Leahey, 2007). For example, making use of quantitative work to focus on effects that explain relationships between factors of interest, while qualitative work might address interpretive reasons and descriptive mechanisms (Leahey, 2007).

Despite the advantages and popularity of mixed methods, limited guidance exists on the practical application of this approach to research (Leahey, 2007). In addition, the critique of mixed methods (that could contribute to practical guidance) is often overlooked within research that has employed mixed methods (Leahey, 2005). However, some researchers argue that mixed methods research incorporates competing paradigms (Green et al., 2007; Johnson et al., 2007), while others suggest that mixed methods might link competing paradigms, allowing a phenomenon to be socially constructed and real (Hacking, 1999). This thesis is guided by the philosophy of

social constructionism as its epistemological foundation. This philosophy will enable the research to explore health-related behaviour following stroke in terms of 'how things are' and 'what influences behaviour'.

1.9 Thesis structure

The thesis structure consists of ten chapters and is outlined in Figure 2.

- Chapter One presents the background for the thesis and outlines the aims and objectives of this research.
- Chapter Two presents an overview of the literature relevant to this research. The review addresses a number of interlinked questions: What are the experiences of people following a stroke? How do post-stroke experiences effect people? What might influence health behaviour change following a stroke?
- Chapter Three describes the method used for the quantitative measurement of factors that might influence health behaviour following a stroke.
- Chapter Four reports the quantitative findings of this study.
- Chapter Five discusses the quantitative findings.
- Chapter Six describes the methodology and method used for the qualitative exploration of factors that might influence health-related behaviour following a stroke.
- Chapter Seven presents the qualitative findings from this study.
- Chapter Eight discusses the qualitative findings.
- Chapter Nine synthesises the findings of the quantitative and qualitative studies using a mixed methods research approach and addresses the overarching research objective of this thesis. The implications of the research findings are considered in relation to clinical practice and research.
- Chapter Ten presents a summary of the key findings of this doctoral research.
- Appendices, which are referred to within the thesis, follow Chapter Ten.

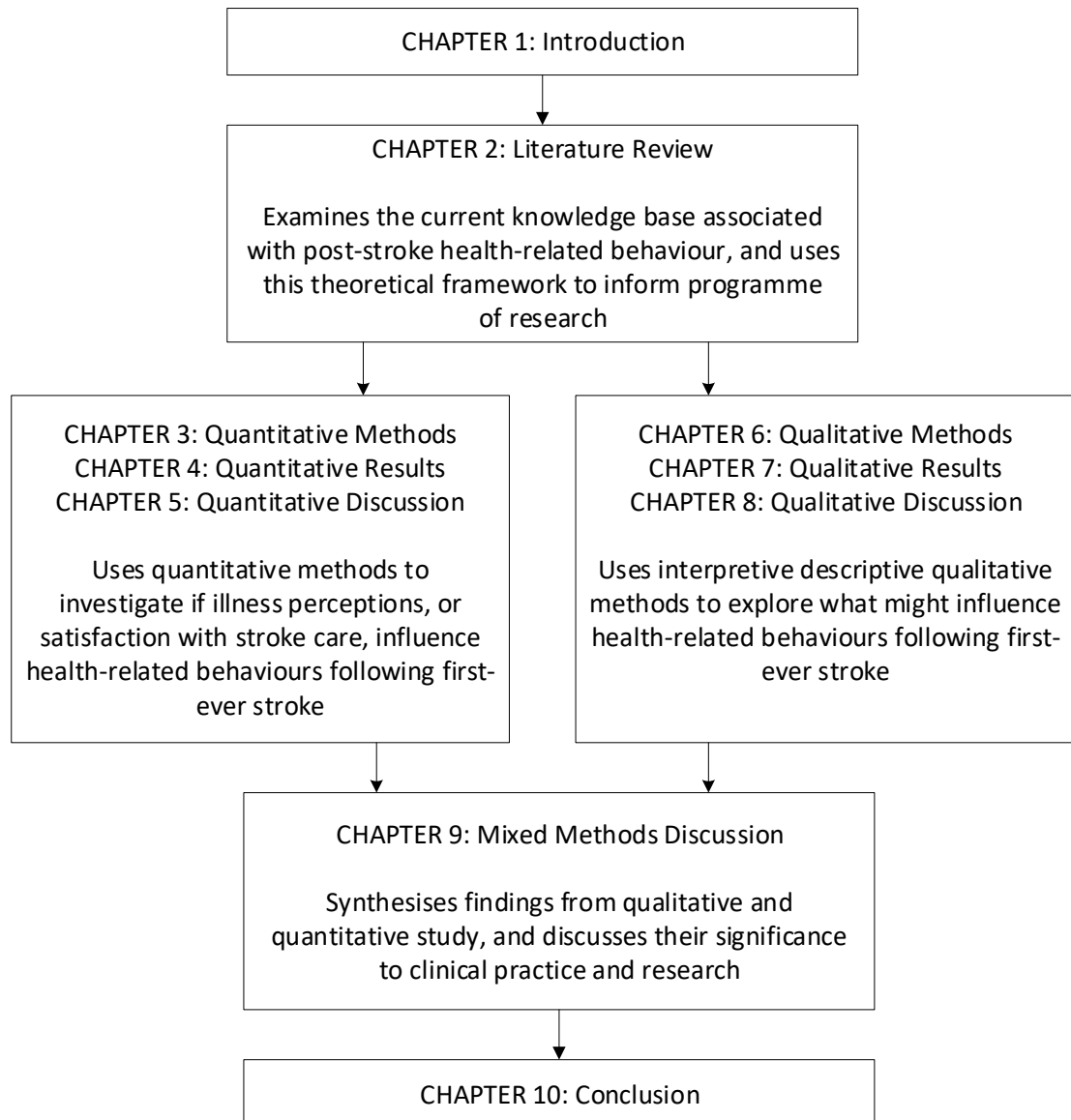


Figure 2. Thesis structure.

Chapter 2 Literature Review

This chapter will review existing literature of what factors might influence health-related behaviours following a stroke. The chapter begins by presenting the findings of a literature review. First, the chapter introduces self-management as part of post-stroke care and secondary stroke prevention; the purpose and focus of self-management will be described and relevant terminology (i.e. *uptake*, *engagement*, and *health-related behaviours*) will be defined. The chapter will then briefly describe what health behaviour theories tell us about health behaviour change. Factors that influence health behaviours following a stroke will then be discussed. Following the initial literature review, the chapter will then present the findings of a structured literature review that focused on the gaps in the literature (i.e. illness perceptions and satisfaction with stroke care). The chapter will conclude by reflecting on the implications of existing literature for this research.

2.1 Overview

This literature review aimed to summarise the scope of literature for what is currently known about factors that might influence health-related behaviours following a stroke. This summary will also outline the current principles of health behaviour change and self-management, to provide some context for the population of interest for this doctoral research. A literature search protocol, with detailed description of search terms for the initial literature review and subsequent structured literature search, can be found in Appendix B.

The purpose of this broad literature review was to provide the context for this research and summarise a large, and complex, amount of information that was relevant to my research question. Thus, this literature review focused on mapping the research area of what influenced health-related behaviours in a population following first-ever stroke. The research question was considered within the broader context of secondary stroke prevention, self-management, and recovery and rehabilitation following a stroke. This approach widened the scope of the literature search to identify evidence relating to post-stroke health-related behaviours (including alcohol use,

smoking cessation, diet choices, physical activity, and medication adherence) whilst considering relevant contexts for this research topic.

2.2 Self-management for post-stroke care and stroke prevention

Self-management is commonly described as the 'ability to manage symptoms, treatment, physical and psychosocial consequences, and life-style changes inherent with living with a chronic disease' (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). While survival following stroke has increased, the process of self-management is important for stroke survivor populations because stroke survivors often experience chronic disability (including physical and cognitive impairments) following stroke. Self-management enables stroke survivors to be independent and manage their health, rehabilitation, and recovery following stroke (Joice, 2012; Lennon, McKenna, & Jones, 2013). The concept of self-management is relevant for this study because first-ever stroke often holds implications for the rehabilitation and recovery of stroke survivors, as well as the prevention of subsequent stroke.

While self-management related to chronic health conditions (such as diabetes and arthritis) has been the focus of healthcare interventions (e.g. Lawn & Schoo, 2010), this process has received minimal focus with stroke populations (e.g. Watkins et al., 2007). Health professionals recognise the need for stroke survivors to manage long-term stroke-related impairments, as well as on-going recovery from stroke (Joice, 2012). Increasingly, the process of self-management has incorporated behaviour change into the management of chronic conditions, with an overarching aim of changing behaviour in those clinical populations (Lennon et al., 2013; Watkins et al., 2007).

Modifying, or changing, health-related behaviours can be regarded as a self-management approach. Within this research, health-related behaviours can be regarded as behaviours that promote health outcomes, and reduce risk of secondary stroke, including behaviours such as smoking cessation, reduced or zero alcohol consumption, healthy diet changes, increased physical activity, and medication

adherence. Increased uptake¹ of health-promoting behaviours has demonstrated improved health outcomes for stroke survivors (e.g. Morris et al., 2012; Weiss, Suzuki, Bean, & Fielding, 2000) and reduced risk of recurrent stroke (Fonarow, 2003). Despite the evidence for reduction of recurrent stroke risk and improved post-stroke outcomes, uptake of health-related behaviours remains low in post-stroke populations. Furthermore, health promotion strategies that aim to improve self-management or increase uptake of health-promoting behaviours have not demonstrated consistent outcomes (Kendall et al., 2007).

2.3 Health behaviour change and health promotion

Behaviour change, and uptake of health-promoting behaviours, is an important component of secondary stroke prevention, with improved control of risk factors (such as smoking and high blood pressure) resulting in a decrease in post-stroke mortality, and the prevention of recurrent stroke (Graham, 2008). A number of social cognition models have been theorised to understand the factors that influence how people manage their health (Byrne, Walsh, & Murphy, 2005).

Numerous theories of health promotion exist, and have been explored with clinical populations to promote better health and outcomes; for example, predicting adherence to medication in chronically ill populations (DiMatteo & Haskard-Zolnieriek, 2011). These models theorise how individuals make sense of an illness (for example, the common-sense model: Leventhal, Meyer, & Nerenz, 1980), while others theorise about how individuals might respond to a perceived health threat (for example, the health action process approach: Schwarzer & Luszczynska, 2008). Understanding adherence to treatment or health behaviour change is important as evidence suggests half of patients with a chronic illness do not adhere to prescribed treatment regimes (DiMatteo, Haskard-Zolnieriek, & Martin, 2012). In addition, understanding how the

¹ The term, *uptake*, encompasses 'motivation, participation, engagement, adherence, and maintenance'. In the context of this thesis, this term behaves as an over-arching term to broaden the scope of this literature review, rather than focusing on individual processes involved with health behaviour change and their technical definitions.

mechanisms for health behaviours (e.g. intention, motivation, action) might be influenced provides opportunities for focused interventions and improved outcomes.

Self-management is an important aspect of post-stroke care and recovery; it is a process that is usually associated with social cognitive theory. Social cognitive theory states that behaviour is the outcome of an interaction between cognitive processes and environmental events (Bandura, 1998). Three elements of social cognitive theory are relevant to health promotion and health behaviour change: the role of expectancies in determining behaviour, the process of vicarious learning, and the motivating influence of good health as a behavioural outcome. It is suggested that motivation for behaviour is related to an outcome that is valued by the individual; this is influenced by the successful ability of the individual to achieve this behaviour. The belief that an action will result in a particular outcome (action-outcome expectancy) and the belief that the individual can achieve the behaviour (self-efficacy expectancy) have been shown to be important influences of health behaviour change (Murphy & Bennett, 2004). Another influence on behaviour is vicarious learning and modelling which is the result of the social context of our previous experiences; through learning, we experience patterns of behaviour which shape our expectancies associated with that and similar types of behaviour. The third main influence on behaviour is the perceived value that is placed on good health. Finding the balance between short-term outcomes versus the long-term outcomes of behaviour can influence health behaviour change. Often, health-related behaviour can be classed as a behaviour that has a long-term reward. This can compete with the short-term rewards associated with unhealthy behaviours (such as smoking, drinking, or eating unhealthily). Evidence supports that cognitive and affective responses to illness and treatment influence health behaviours, such as medication adherence (Phillips, Diefenbach, Abrams, & Horowitz, 2015). Therefore, understanding how these factors may influence adherence to prescribed treatment and health promotion may help improve post-stroke outcomes and secondary stroke prevention.

Another theory that dominates the behaviour change literature is the self-regulatory model of behaviour (SRM, Leventhal et al., 1980) or the “common-sense model”. The SRM provides a theory for understanding and coping with illness where an individual is

actively involved in resolving their health problems (Leventhal et al., 1997) by focusing on an individual's illness perceptions (Cameron & Moss-Morris, 2004). Leventhal and colleagues (1980) defined illness perceptions (or illness representations/ cognitions) as an individual's common-sense perceptions, beliefs, or cognitions about their illness; these can be based on three sources of information. *Lay information* can be provided through previous experiences and social communication with other non-authoritative individuals. External information, is a second source of information, provided through communication with authoritative others (e.g. medical and health professionals). The third source of information can be provided by the individual's current experience of the illness. These illness perceptions vary between individuals and can influence how people perceive and respond to their illness or a perceived health threat (Moss-Morris et al., 2002). While evidence demonstrates the influence of illness perceptions in clinical populations (e.g. medication adherence in diabetic populations: Broadbent, Donkin, & Stroh, 2011), very little evidence investigates how illness perceptions might influence health behaviours in stroke populations.

The Health Action Process Approach (HAPA: Schwarzer & Luszczynska, 2008) is a theory that distinguishes between motivation (including decision-making) and action (which includes planning, action, and maintenance) for health-related behaviour (Schwarzer & Luszczynska, 2008). It was based on the theory that behaviour is the outcome of cognitive processes and environmental events (Bandura, 1998). Motivation may be influenced by a perceived threat to the individual's health, as well as expectancies associated with the health behaviour (such as *action-outcome* and *self-efficacy* expectancies). The HAPA suggests that risk perception influences the motivation phase of behaviour (Schwarzer, Lippke, & Luszczynska, 2011; Schwarzer et al., 2007). Risk perception is the threat a person believes may happen if health behaviour is not initiated; for example, the risk of stroke may be reduced by participating in regular physical activity. The HAPA proposes that motivation for behaviour can result in intention for behaviour. The action stage follows the motivation stage once an intention for behaviour has been formed (Gellert, Ziegelmann, & Schwarzer, 2012; Lippke, Ziegelmann, Schwarzer, & Velicer, 2009; Schwarzer et al., 2007). While the HAPA distinguishes between motivation and action

processes in behaviour, factors that influence motivation may also influence action. The action stage involves a more detailed consideration of goal identification, barriers, and facilitators to the goal, and achieving the goal. While the HAPA has been applied to relevant clinical populations, including cardiovascular and hypertensive populations and supported the generalizability of the HAPA for health promotion (Steca et al., 2013; Steca et al., 2017), limited evidence supports the application of this theory to stroke populations (Tielemans et al., 2014).

In summary, guided by the numerous theories of health behaviour, it is expected that individuals confronted with a life-threatening event (such as stroke), have to decide how to approach their rehabilitation and recovery. For stroke survivors, this will include self-management of health behaviours to reduce their risk of secondary stroke, as well as improve their outcomes following stroke.

2.4 Factors that influence health-related behaviour in stroke

A review of the literature found qualitative and quantitative studies that indicated numerous factors that might potentially influence engagement in health-related behaviour. Factors that influenced health-related behaviours in stroke populations were categorised into three main types. Although these three categories provide a simplistic overview of the numerous factors that may influence health behaviours following a stroke, it should be acknowledged that these three categories are complex and may interact with each other.

First, physical factors (such as physical impairments, physiological factors) were found to influence health-related behaviours following the stroke. Physical factors can be defined as the physiological, or physical, aspects of a person's life that may influence health-related behaviour. For example, prescribed medication to reduce BP may influence health-related behaviours (such as physical activity) following stroke. Second, behavioural factors (such as apathy, depression and anxiety) influence post-stroke health-related behaviours. Behavioural factors can be defined as the behavioural, cognitive, and emotional factors that may influence health-related behaviours following stroke. For example, depression has been associated with low uptake of health behaviour and high rates of depression have been recognised in populations of

stroke survivors. Third, various psychosocial factors (such as social support, quality of life, self-efficacy) have been recognised as factors that influence health-related behaviours. Psychosocial factors can be defined as the psychological factors or social context of an individual's life that may influence health-related behaviour following stroke. For example, changes in self-identity and autonomy have been reported by stroke survivors and these factors can be associated with health-related behaviours.

In addition to discussing existing evidence associated with these various factors, potential factors that have been overlooked, or minimally discussed in stroke populations were also explored and the focus of a subsequent structured literature search. More specifically, the findings from the initial literature review enabled gaps within the stroke-related literature to be identified; two of these gaps informed a structured literature review. While recent research has investigated the influence of relationships between healthcare practitioners and their clients, satisfaction with stroke care has received minimal investigation and has not been associated with health-related behaviours in stroke populations. Similarly, illness perceptions have been associated with health-related behaviours, but this association has not been explored with stroke survivors.

The implementation of health promotion strategies, that aim to improve self-management or increase uptake of health-promoting behaviours, are not always successful. Indeed, self-management following stroke is recognised as being a complex process (Joice, 2012). The ability of stroke survivors to modify their lifestyle or increase uptake of health-related behaviours might be influenced by a number of contextual factors. Three main categories of factors should be considered when advising stroke survivors regarding health-promoting behaviours that might reduce the risk of secondary stroke and improve post-stroke outcomes.

2.4.1 Physical factors

For the primary prevention of stroke, adequate blood pressure reduction has been shown to be effective and is supported by evidence from several randomised controlled trials (e.g. Mant, Hobbs, Fletcher, Roalfe, Fitzmaurice, Lip, & Murray, 2007). Indeed, following initial stroke, medications (including aspirin, warfarin, clopidogrel,

and atorvastatin) are frequently prescribed to prevent secondary stroke (Donnan et al., 2008). Therefore, adhering to medication is an important health promoting behaviour. However, despite evidence of the effectiveness of medication adherence for stroke prevention, non-compliance with medication is a common problem (Chambers et al., 2011). Non-compliance might be intentional or un-intentional (Chapman & Bogle, 2014). For example, non-compliance might result from a physical disability e.g. not being able to access medication stored in a high cupboard or due to memory impairments resulting from the stroke. It might also be the case that people intentionally chose not to take medication because of unwanted side-effects or beliefs or personal values about medication use.

Similarly, increased physical activity has been found to reduce risk of recurrent stroke and improved outcomes following stroke (e.g. Morris, 2016). However, physical impairments or physiological factors might impact a stroke survivor's uptake of health-related behaviour following stroke. Stroke survivors might experience a range of physical impairments (e.g. hemiparesis, spasticity) that cause functional difficulties, which can negatively impact ability to be physically active, or participate in health-related behaviours (Rand, Eng, Tang, Hung, & Jeng, 2010).

2.4.2 Behavioural and cognitive factors

Limited evidence exists for the influence of cognitive impairment on uptake of health-related behaviours following stroke (Morris, 2016). However, cognitive impairments have been identified as barriers to health behaviours (such as physical activity) in long-term neurological conditions (Mulligan, Hale, Whitehead, & Baxter, 2012). Impaired functioning diminishes post-stroke quality of life (QoL: Kaufman, 1988; Mukherjee, Levin, & Heller, 2006). The majority of stroke survivors experience cognitive impairments following stroke, including impairment of intellectual reasoning and memory, neuropsychological deficits (e.g. in speech), and emotional reactions (e.g. mood disturbances, depression, apathy; Kotila, Waltimo, Niemi, Laaksonen, & Lempinen, 1984). In addition, some stroke survivors may not fully understand their post-stroke impairments (Green et al., 2007), or may experience difficulty processing information about stroke (Byers, Lamanna, & Rosenberg, 2010; Ramirez-Moreno,

Alonso-Gonzalez, Peral-Pacheco, Millan-Nunez, & Aguirre-Sanchez, 2015), which may hold implications for their ability to initiate health behaviour change.

Mood disturbances (such as depression, apathy) following stroke are common (Gurr & Muelenz, 2011; Hackett, Yapa, Parag, & Anderson, 2005; White et al., 2008), and might impact rehabilitation and outcomes (Dafer et al., 2008). Furthermore, stroke survivors can experience emotional responses to the cognitive and physical deficits they experience following stroke. For example, becoming frustrated, anxious, or depressed about their inability to do tasks or engage in activities they were able to do before their stroke (Viney & Westbrook, 1981). Post-stroke anxiety and depression are associated with reduced participation in daily activities, poorer post-stroke outcomes, and increased risk of recurrent stroke (Dafer et al., 2008). Post-stroke apathy is also a common complication of stroke, and is associated with functional decline following stroke (Jorge, Starkstein, & Robinson, 2010). While, the experience of negative mood disturbances, and cognitive impairments, following stroke can impact on secondary stroke prevention, these factors might also impact on health behaviours of stroke survivors. For example, depression can reduce participation with dietary control (Perry & McLaren, 2004). Modification of behavioural and cognitive factors, including improvements in quality of life and living standards, improved control of mood disturbances (such as post-stroke depression) might also have some effect on prevention of recurrent stroke.

2.4.3 Psychosocial factors

Despite research that shows that barriers to health promoting behaviour post-stroke are not purely physical, traditional rehabilitative approaches do not typically target psychosocial factors. Psychosocial factors that might influence post-stroke health-related behaviour include: perceived quality of life (Remer-Osborn, 1998), motivation, (Rimmer, Wang, & Smith, 2008), self-efficacy (Shaughnessy et al., 2006), familial support (Gordon et al., 2004; Remer-Osborn, 1998), or wider social support (Damush, Plue, Bakas, Schmid, & Williams, 2007; Morris et al., 2012), and support from health care providers (Damush et al., 2007; Shaughnessy et al., 2006).

Research suggests that psychosocial factors might exert a strong influence on stroke survivor decisions for uptake of healthy behaviour (Morris et al., 2012). For example, common facilitators to stroke survivor physical activity included having a purpose in life and having a place to go to be physically active (Damush, Perkins, Mikesky, Roberts, & O'Dea, 2005), seeing improvements, having control over outcomes and receiving peer support (Courneya, Plotnikoff, Hotz, & Birkett, 2000), providing continuity between the pre-and post-stroke individual (Morris et al., 2015), and receiving physician recommendations (Damush et al., 2007; Damush, Stump, Saporito, & Clark, 2001). In addition, early involvement of the family unit has been strongly correlated with patient adherence to therapy, better understanding between patient and caregiver of achievable outcomes, and improved communication between patient and caregivers (Gordon et al., 2004). In qualitative studies, carers have often reported developing strategies to motivate stroke survivors with post-stroke activities and recovery (e.g. Morris et al., 2015). Although the longevity of such behaviour changes and their relationship to actual behaviour or decreased stroke risk has yet to be fully explored, current evidence suggests that psychosocial factors need to be addressed within health promotion strategies aimed at increasing uptake of health behaviours following stroke.

Health literacy and beliefs about health behaviours are also psychosocial factors that impact health behaviours of stroke survivors. Research suggests stroke survivors have low understanding of modifiable risk factors and a low uptake of health promoting behaviour (Wilkinson et al., 1997). In addition, research reporting overall reductions in risky health behaviour noted that some patients had commenced, or recommenced, risky health behaviours at six and twelve-months post-stroke (Redfern, McKevitt, Dundas, Rudd, & Wolfe, 2000; Shaughnessy et al., 2006). Therefore, it is important to understand why stroke survivors indicate low engagement with health promoting behaviours and how stroke survivors can improve the uptake of their health-promoting behaviour post-stroke.

Following a stroke, survivors are often faced with an unfamiliar sense of self, and have to re-evaluate their abilities, limitations, and future goals (Kaufman, 1988). Impaired psychosocial, cognitive, and physical functioning diminishes post-stroke quality of life,

which in turn reduces uptake of healthy behaviours (Morris et al., 2012). Furthermore, the QOL of each individual will be impacted differently by psychosocial factors. For example, the perception of their abilities (Fraas, 2011) or their illness perceptions (Løchting, Garratt, Storheim, Werner, & Grotle, 2013; Sjolander et al., 2013). Therefore, understanding how psychosocial factors (such as, illness perceptions or satisfaction with stroke care) might influence post-stroke engagement with health promoting behaviour might highlight important implications for increasing engagement with health promoting behaviours.

2.5 Potential influences on health-related behaviour in stroke

Following on from the initial literature review, two separate structured literature searches were conducted (see Appendix B) to identify evidence for how i) illness perceptions, and ii) satisfaction with stroke care, might influence health-related behaviour following stroke. A search limited to 1970 to 2017 was used to ensure original key papers were included (particularly because of the limited evidence base). Studies were included if they were: primary research or reviews of primary research, peer-reviewed, English language, and studies that included adult or older adult populations (recognising that this might range from 20-90+ years old). Studies were excluded if: they were not relevant to an adult population (i.e studies that included children or adolescents were excluded), or the studies were not relevant to clinical populations (the most relevant clinical populations were identified as stroke, neurological, and chronic illness). Titles and abstracts were screened for eligibility, and the full text of relevant articles were obtained and screened. In addition to the structured literature searches, the reference lists of articles were screened (*snowballing*) to identify relevant research not identified by the electronic search.

2.5.1 Psychological factors: illness perceptions

Illness perceptions² are the cognitions, beliefs, or perceptions that an individual has about their illness (Broadbent et al., 2006; Petrie, Jago, & Devcich, 2007). These illness

² Illness perceptions are also referred to as illness representations, illness beliefs, or illness cognitions.

perceptions are important in guiding coping strategies and strategies to manage their illness (e.g. health promoting behaviour; Sjolander et al., 2013). Five components or dimensions of illness perceptions have been proposed (Petrie & Weinman, 2006): identity of illness, causal beliefs, timeline beliefs, beliefs about control or cure, and consequences. *Illness identity* refers to the name associated with the illness and its symptoms. *Causal beliefs* are the individual's beliefs about why they became ill. *Timeline beliefs* refer to how long the individual expects the illness to last, (i.e. acute or chronic illness). Beliefs about *cure or control* are beliefs about how treatable the illness is, and how much the outcome is under their control or other people's (e.g. health professionals). Finally, *consequences* refer to the expected outcome of the illness, and how it will affect their life.

Increasing evidence supports the link between illness perceptions on health outcomes (e.g. well-being, functional outcomes, health behaviour) for clinical populations (e.g. Weinman & Petrie, 1997). Illness perceptions will often influence how an individual responds to their illness or a new threat to their health (Broadbent et al., 2006) and has been linked to important health-related outcomes. Research suggests that when patients hold more threatening illness perceptions about their condition (e.g. a large number of symptoms, severe consequences, longer timeline beliefs) these perceptions are associated with increased future disability and slower recovery. More threatening illness perceptions, in a population experiencing rheumatoid arthritis, were associated with poorer functional outcomes and longer recovery (Scharloo et al., 1999). A study of primary care patients by Frostholm and colleagues (2005) found that patients who reported more threatening illness perceptions used more healthcare resources (Frostholm, Fink, Christensen, et al., 2005). The same research group also found that more threatening illness perceptions were significant predictors of lower patient satisfaction. This evidence has encouraged researchers to investigate how illness perceptions might influence health-related behaviour in clinical populations (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Petrie, Perry, Broadbent, & Weinman, 2012); however, minimal research focuses on stroke populations.

In the wider literature, more threatening illness perceptions have been associated with reduced patient self-management (Damush et al., 2003). Conflicting evidence exists for

the influence on self-management, and in particular adherence to prescribed treatment or lifestyle changes. For example, a systematic review and meta-analysis of illness beliefs predicting adherence to self-management behaviours found that individual illness belief domains did not predict adherence in adults with physical illnesses (Aujla et al., 2016); however, the review reported mixed evidence for the influence of related factors (to illness belief domains) on adherence to self-management behaviours (Aujla et al., 2016). Similarly, illness perceptions have been reported as weak predictors of health-related behaviours for secondary prevention of coronary heart disease (Byrne et al., 2005). In contrast, less threatening illness perceptions have been associated with treatment adherence in diabetic populations (Broadbent et al., 2011; Hemphill, Stephens, Rook, Franks, & Salem, 2013), hypertensive populations (S. Ross, Walker, & MacLeod, 2004), and chronic obstructive pulmonary disease (Krauskopf et al., 2015).

Four cross-sectional studies were identified by the structured literature review that investigate stroke survivor illness perceptions and its influence on treatment adherence. Three studies assessed the influence of illness beliefs on medication adherence in stroke survivors (O'Carroll, Chambers, Dennis, Sudlow, & Johnston, 2014; Phillips et al., 2015; Sjölander, Eriksson, & Glader, 2013); one study focused on a population experiencing hypertension (S. Ross et al., 2004). O'Carroll and colleagues (2014) reported that in a population of stroke survivors, increased adherence to medication was influenced by older age, greater perceived benefit of medication, improved cognitive function, and lower concerns associated with medication. In addition, Sjölander and colleagues (2013) found that adherence to prescribed medication was associated with less threatening illness perceptions. Similarly, Ross and colleagues (2004) reported that medication adherence was associated with perceived necessity of medication, increased age, and low emotional response to illness (e.g. concerns). Finally, Phillips and colleagues (2015) reported that cognitive beliefs (i.e. illness perceptions) predicted adherence to medication following stroke. Interestingly, in addition to measuring illness perceptions, two of these studies (Phillips et al., 2015; S. Ross et al., 2004) used additional emotional measures as predictors for treatment adherence, further acknowledging the difference between cognitive and

emotional aspects of illness. One limitation of these studies is that illness perceptions (e.g. B-IPQ) are often measured on a scale of less threatening to more threatening; this does not capture the varied emotions (e.g. anxiety, apathy) resulting from stroke and the process of recovery.

In addition to the cognitive and emotional aspects associated with illness, other factors may influence the illness perceptions of stroke survivors. Stroke survivors experience cognitive, physical, and psychological deficits post-stroke and these deficits are likely to influence how a stroke survivor perceives their stroke, and their subsequent recovery. Therefore, it is important to consider the implications of illness perceptions in a population of stroke survivors.

2.5.2 Psychological factors: satisfaction with stroke care

Patient satisfaction is an important health outcome (e.g. Jackson, Chamberlin, & Kroenke, 2001), and indicator of the quality of stroke care (Boter et al., 2003), or of risk reduction programmes (Berra, 2003). Patients' perceptions of their care reflect real differences in the provision of care, and have been shown to occur independently of demographic or outcome variables (Jackson et al., 2001; Pound et al., 1999). Research suggests that satisfied patients are more likely to engage with suggested rehabilitation strategies (Boter et al., 2003) and that familial support has been strongly correlated with patient adherence to therapy (Gordon et al., 2004). And while the impact on patient satisfaction on success of health outcomes is increasingly recognised (Clark & Smith, 1998; Frosthalm, Fink, Oernboel, et al., 2005), limited research examines the influence of satisfaction with stroke care on engagement in health-promoting behaviour or on the prevention of recurrent stroke.

Satisfaction with stroke care might be influenced by a number of factors. Relationships between functional independence, good subjective health, and increased satisfaction suggest that stroke survivors with better health outcomes are more satisfied (Hansson, Beckman, Wihlborg, Persson, & Troein, 2013; Jackson et al., 2001; Pound et al., 1999). While functional outcomes and wellbeing have been linked to social support (Gordon et al., 2004), Clark and Smith (1998) suggested that if a positive family environment can improve functional outcomes, it might also influence greater patient satisfaction.

Satisfaction with care has also been linked to patient and informal caregiver quality of life (Cramm, Strating, & Nieboer, 2012). The nature of the relationship between stroke survivors and informal caregivers is a dyadic relationship in which each individual influences the other. Thus, stroke survivors who receive family support might be more satisfied with services than stroke survivors who do not receive familial support (Pound et al., 1999).

Decreased satisfaction with stroke care has been linked to depression and emotional distress (Pound et al., 1999) as well as length of hospital stay and disability at admission (Cramm et al., 2012)—although this does not suggest a causal relationship. This findings contrast with a study into the emotional experience of hospitalisation and satisfaction; this found that the emotional experience of hospitalisation (e.g. trauma of stroke event and admission to hospital) explained a significant proportion of the variance in patient satisfaction (Dube, Belanger, & Trudeau, 1996). However, this study involved a population made up of patients admitted to an acute care hospital, and not solely on stroke survivors.

Patient satisfaction might also be associated with knowledge relating to stroke and expectations of the recovery process (Janse, Huijsman, & Fabbricotti, 2014). For example, unrealistic expectations around recovery following stroke may result in inappropriate goals and impact on a stroke survivor's satisfaction. Stroke survivors and their caregivers have reported feeling that they can be discharged without adequate information about the stroke (Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005). To complement this finding, a review of the literature conducted by Byers et al. (2010) demonstrated that post-discharge education for stroke survivors proves difficult for this population. Self-management (and the active participation) of stroke survivors with their care and rehabilitation has a substantial impact on the individual's adaption to their illness and their outcomes for recovery. Clark and Smith (1998) demonstrated that improved knowledge of stroke has been shown to influence expectations for rehabilitation, which were associated with greater satisfaction with recovery. However, this study focused on functional outcomes, whereas psychosocial outcomes (e.g. motivation, depression) were not considered. However, satisfaction with stroke care might impact how a stroke survivor (and their family/whanau) adjusts

to living with the impact of the stroke and increasing their health-promoting behaviours to reduce risk of secondary stroke.

Greater satisfaction with care can also be associated with continuity of care (Frostholm, Fink, Oernboel, et al., 2005); in addition, satisfaction with care has been associated with staff-patient interactions, perceived quality of care, and confidence in clinician recommendations. Greenlund and colleagues (2002) evaluated physician advice, patient actions, and health-related QOL in a population of stroke survivors who had been prescribed lifestyle modifications (e.g. diet and exercise changes). Although the research noted that advice provision from health professionals was not universal, information provision positively influenced lifestyle change and quality of life (Greenlund et al., 2002). An important theme in the literature suggests that satisfied patients are more likely to continue seeing health professionals and engage in suggested rehabilitation strategies (Boter et al., 2003). In the wider health field, satisfaction with services has been linked with patient satisfaction and use of services. For example, if people are satisfied with a service, they are more likely to engage with it and use it again. However, satisfaction with services has not been explored in stroke populations, and has not been explored with regard to engagement with health promoting behaviour.

2.6 Summary

This review indicates that health behaviours can be influenced by a number of psychosocial factors, and suggests that more research is needed to explore the impact of illness perceptions and satisfaction with care post-stroke. This review has also highlighted the paucity of evidence relating to post-stroke health-related behaviours. Although illness perceptions and satisfaction with stroke care have been identified as potentially important influences by this review, other psychosocial factors might be important to consider for post-stroke health-related behaviour but are outside the scope of this research. Thus, a mixed methods research approach will be employed to investigate the influences on health-related behaviour following first-ever stroke. The identified gaps in the literature will be addressed by this research using a quantitative approach to investigate the influence of illness perceptions and satisfaction with care

on stroke survivor's health-related behaviour. A qualitative study will explore what individuals think might influence health-related behaviours following first-ever stroke.

Chapter 3 Quantitative Method

This chapter outlines the methods used in the quantitative study within this programme of doctoral research. Details of the study design, the research questions, recruitment and data collection, and data analyses will be described.

3.1 Overview

This study investigated whether a stroke survivor's satisfaction with stroke care, and their illness perceptions, influenced their health-related behaviour following first-ever stroke (Figure 3). In this study, health-related behaviours were identified as medication adherence, smoking cessation, reduced alcohol consumption or cessation, healthy diet choices, and increased physical activity. Figure 3 illustrates the associations between the variables of interest based on existing research.

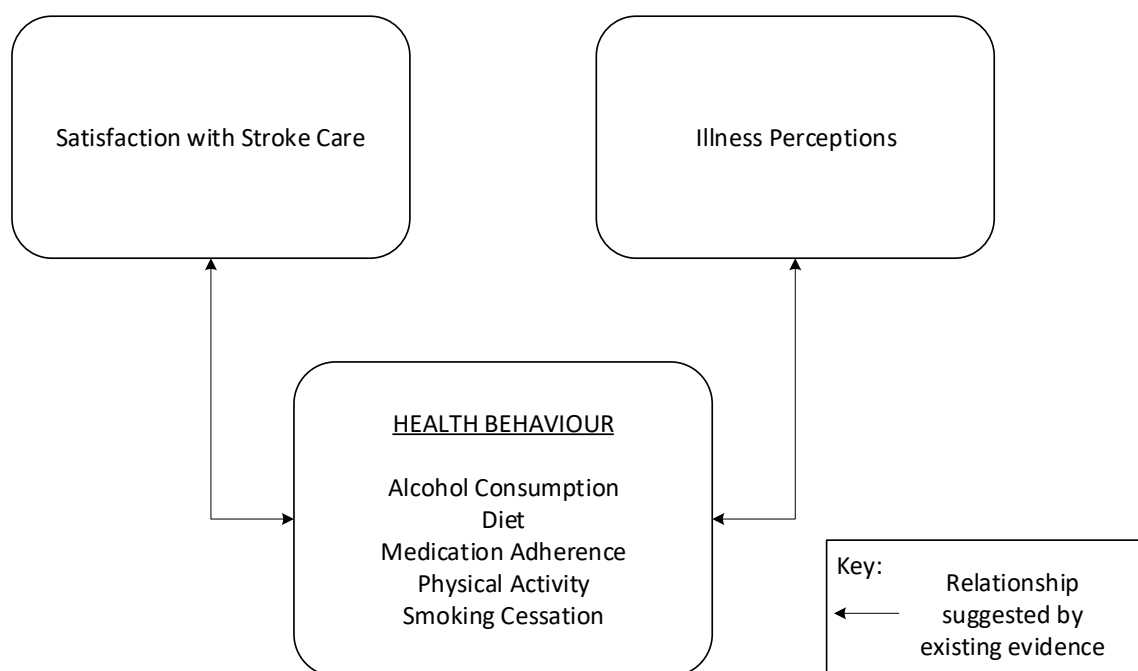


Figure 3. Associations between illness perceptions, satisfaction with stroke care and health-related behaviour suggested by existing evidence.

3.2 Primary hypotheses

Based on research evidence it was hypothesised that:

H₁: Stroke survivors who report higher satisfaction with stroke care at 28-days post-stroke will have improved health-related behaviour at 28-days post-stroke.

H₂: Stroke survivors who report more threatening illness perceptions at 28-days post-stroke will report improved health-related behaviour at 28-days post-stroke.

3.3 Secondary hypotheses

H₃: Stroke survivors who report higher satisfaction with stroke care at 28-days post-stroke will have improved health-related behaviour at six and twelve-months.

H₄: Stroke survivors who report more threatening illness perceptions at 28-days post-stroke will report improved health-related behaviour at six and twelve-months.

H₅: Higher satisfaction with stroke care will be associated with less threatening illness perceptions 28 days post-stroke.

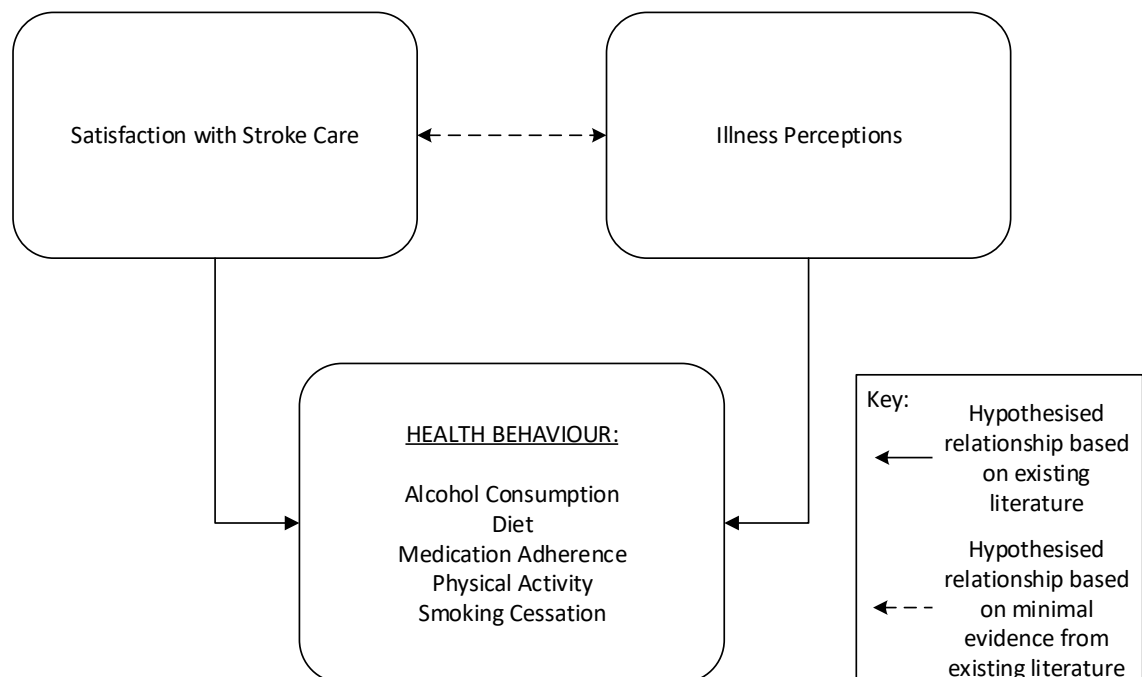


Figure 4. Hypothesized relationships between illness perceptions, satisfaction with stroke care and health-related behaviour following first-ever stroke.

Figure 4 presents the hypothesised influences of satisfaction with stroke care and illness perceptions on a stroke survivor's health-related behaviour. The solid lines represent the primary hypotheses within this study that were supported by research evidence. The dashed line represents a secondary hypothesis that was explored by this study, and that has yet to be explored in the research literature.

3.4 Design

A cross-sectional, telephone questionnaire design was used to explore the association between satisfaction with stroke care, illness perceptions, and health-related behaviours in a population who had experienced first-ever stroke in Auckland, New Zealand. Data for this study were collected between July 2012 and November 2014. The study was conducted within the context of a parent study: the Motivational Interviewing in Stroke Trial (MIST). MIST was a single-blind randomised controlled trial (RCT) that focused on a population who had experienced first-ever stroke (Krishnamurthi et al., 2014). (For MIST design and method, refer to Appendix A or methodology paper.) All participants completed baseline measures (assessing eligibility criteria and demographic information) and post-stroke assessment measures (assessing health behaviours) at 28-days, six-months, and twelve-months.

3.5 Participants

An opportunistic sample of participants were recruited from the parent MIST-trial. Patients who presented with first-ever stroke and resided in the New Zealand region of Auckland were considered for participation in MIST. As part of MIST, stroke cases were ascertained from four Auckland region public hospitals. The inclusion criteria for the parent-trial were: individuals diagnosed with first-ever stroke defined according to WHO criteria, 16 years of age or older, and who were discharged from hospital (Krishnamurthi et al., 2014). Individuals were excluded from the parent-trial if they had significant impairments precluding participation (such as a severe secondary condition or severe cognitive impairment, if they were receiving alternative treatment that could confound the MIST-trial, if they were unable to converse in English or provide informed consent, or were likely to move out of the Auckland region post-discharge); these exclusion criteria were identified as factors that might have impacted the participant's ability to participate in the motivational interviewing intervention. A cut-off of <23 for the MMSE was applied to the MIST sample to ensure that participants were not experiencing significant cognitive impairments precluding participation. In addition, a cut-off of >11 for the HADS was applied to the MIST sample to ensure participants were not experiencing significant depression or anxiety precluding participation; the HADS measure was collected for each time-point during the

longitudinal study. If a participant reported severe depression or anxiety, they were excluded from that time-point, and study protocols followed to refer them to relevant services (Krishnamurthi et al., 2014).

Data for this doctoral study was collected by the MIST researchers between July 2012 and November 2014, providing access to a sample of 376 participants.

A priori power analysis was conducted using G*Power 3.1.6 (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the sample size needed to ensure sufficient power for the planned statistical analyses. Based upon using a multiple regression approach to analyse the data (for two predictors), a medium effect size ($F^2 = 0.15$) was chosen. The alpha level was set at 0.05, as recommended by Cohen (1992), which results in a 5% chance of making a Type I error. This resulted in a Critical F value of 2.32. Power was set at 0.8 (which limits Type II error to 20%). The sample size calculation revealed that a minimum sample size of 92 participants would be required for this study to have sufficient statistical power to test the hypothesis that the variance explained by the model is greater than zero.

A second power analysis was conducted to ensure sufficient power to confirm that the predictors predict more than zero (fixed effects). With the same parameters as the previous power analysis, this resulted in a sample size requirement of 55 participants (for three predictors).

3.6 Procedure

Sociodemographic and diagnostic information for each participant in this study (e.g. age, ethnicity, gender, type of stroke and stroke severity) was extracted from the MIST-trial database with the participant's permission. Participants were sent an information sheet about the study and all participants were asked to provide written informed consent before completing the questionnaires in person or by phone with a researcher. See Appendix C for MIST-trial information sheet and consent form.

Illness perceptions and satisfaction with stroke care were only assessed at 28-days post-stroke to enable influence of acute illness perceptions and satisfaction with stroke care on health behaviour to be explored over time. It is important to identify

potential factors that occur at an acute stage following stroke to enable subsequent interventions to increase health-related behaviours.

Information about post-stroke health behaviours were assessed at 28-days, six-, and twelve-months post-stroke to explore changes over time.

3.7 Assessment measures

An example of the study questionnaire is provided in Appendix D. The choices of assessment measures used within this research were based on a number of criteria. The first criterion considered measures that had been designed to explore the variables of interest in this programme of doctoral research (health-related behaviours, illness perceptions, and satisfaction with stroke care). Where an appropriate measure did not exist (e.g., for specific health behaviours), questions were designed to capture the variable of interest; for example, categorical yes/no questions were developed to determine whether individuals were engaging in health behaviours (e.g. smoking cessation, alcohol consumption, and medication adherence). The second criterion considered measures that were appropriate for use with the population of interest (i.e. stroke population), being guided by published research and the implications associated with stroke, stroke care, and participant burden. The third criterion considered the psychometric properties of the measures: Cronbach's $\alpha > .60$ and test-retest = .70 defined acceptable internal consistency and reliability within this thesis, and reflects the complexity of the constructs (such as illness perceptions or satisfaction) that were being measured (Cronbach, 1951; Gliem & Gliem, 2003).

3.7.1 Illness perceptions

The Brief Illness Perception Questionnaire (Broadbent et al., 2006) was used to measure subjective illness perceptions that the participant held about their illness. This measure consisted of items to assess the dimensions within the cognitive and emotional representations of illness or health threat (e.g. cognitive representations relating to identity, consequences, cause, timeline, and cure or control). These (emotional and cognitive) dimensions were based on the self-regulatory model developed by Leventhal and colleagues (1984) and a subsequent body of work into illness representations (e.g. Weinman, Petrie, Moss-Morris, & Horne, 1996).

In the B-IPQ, the first eight questions measured beliefs about: consequences (how much the stroke affects your life), timeline (how long your illness will continue), personal control (how much control you have over the stroke), treatment control (how much your treatment can help), identity (how much you experience symptoms from the stroke), illness concern (how concerned you are about the stroke), coherence (how well you understand your stroke), emotional representation (how much the stroke affects you emotionally). Three items in this scale were reverse-scored: personal control (B-IPQ3), treatment control (B-IPQ4), and coherence (B-IPQ7). These questions were scored on a ten-point Likert scale (0, not at all; to 10, extremely). The ninth item was the causal item, which asked participants to list up to three of the most important factors they believed to have caused their illness and to rank them in order of importance. Broadbent and colleagues (2006) proposed that items within the B-IPQ measure can be examined individually, or an aggregate score can be computed to represent the degree that the stroke is perceived as threatening or benign. In either case, a higher score reflects a more threatening perception of the stroke.

Although other measures of illness perceptions exist (e.g. IPQ-R: Weinman et al., 1996), the B-IPQ was considered the most appropriate measure to assess the different dimensions of illness perceptions without negatively impacting the participant burden for this group of people. Participant burden was an important factor to consider, due to the fatigue and concentration difficulties commonly experienced by individuals post-stroke. As the B-IPQ takes approximately five-minutes to complete, this questionnaire was chosen over more comprehensive measures that might affect participant responding through fatigue.

Despite being a brief measure the B-IPQ has demonstrated good internal consistency with a Cronbach's $\alpha = .72$ (Løchting et al., 2013). As this questionnaire can be adapted for use with different health conditions, the psychometric properties of the B-IPQ have been assessed with a variety of populations (Broadbent et al., 2015). Relevant to this study, illness perceptions associated with stroke have been tested (O'Carroll et al., 2011; Sjolander et al., 2013) and shown to be a valid and reliable measure of illness perceptions in a stroke population. However, these studies did not report test-retest reliability or internal consistency. This suggests that Exploratory Factor Analysis will be

appropriate to determine if the factor structure of the B-IPQ, suggested by the original authors, applies to this sample of participants.

3.7.2 Satisfaction with stroke care

The eight-item Satisfaction with Stroke Care (Hospital-sub-scale) Questionnaire (SASC) was used to measure stroke survivor satisfaction with their stroke care (Boter et al., 2003). This measure consisted of items to assess aspects of the health care system experienced by stroke patients when in a hospital setting; this was originally developed for use in the United Kingdom, and subsequently revised and investigated in the Netherlands. This study uses the revised Dutch version, which had been translated into English by its authors (Boter et al., 2003).

The eight-item Hospital-sub-scale was used as this study was looking at acute factors predicting health behaviour over time. The eight-items measured beliefs about: respect (kindness and respect from hospital staff), meeting personal needs (staff attended well to my personal needs), approachability (able to talk to staff about any problems), information provision (received information about nature and cause of illness), treatment by doctors (doctors have done everything they can to make me well), recovery level (happy with amount of recovery), treatment received (satisfied with type of treatment received), and provision of therapy (have had enough therapy). Four items in this scale were reverse-scored: meeting personal needs (SASC2), information provision (SASC4), recovery level (SASC6), and provision of therapy (SASC8). The questions were scored on a four-point Likert scale (0, strongly disagree; to 3, strongly agree). Boter and colleagues (2003) propose that items in the SASC can be analysed individually or analysed within the subscale to produce a total score (or aggregate). When analysing the subscale scores, the higher the score, the greater the satisfaction. For example, a score of 24 on the SASC Hospital-sub-scale was equivalent to agreeing with all 8 items, which suggested high satisfaction with the inpatient care received post-stroke (Boter et al., 2003). It is assumed that the intensity of post-stroke services is greatest within the first month post stroke (to achieve the greatest improvement in outcomes following acute stroke); participants completed the SASC Hospital-sub-scale (eight-item) at the 28-day time-point to assess this period of time for stroke survivors.

The SASC has been shown to be a valid and reliable measure of satisfaction with hospital stroke care; it has good test-retest reliability: Hospital-sub-scale = .87, and good internal consistency with a Cronbach's α = .83 for the Hospital-sub-scale (Boter et al., 2003). These statistics suggest that the SASC Hospital-sub-scale is an appropriate measure to assess in-patient satisfaction with stroke care; conclusions based on the data from this questionnaire will be valid and reliable, with findings that will be comparable to other research using this scale.

3.7.3 Health behaviour

Five domains of health behaviour were assessed post-stroke. To enable analysis of the influence of illness perceptions and satisfaction with stroke care over time, data on health behaviours was obtained at 28-days, six- and twelve-months post-stroke.

Research into the health behaviours of clinical populations typically focus on one or two health-related behaviours only; for example, exercise behaviour in stroke survivors (Morris et al., 2012). More recently, research has extended its scope to include multiple health behaviours. Schwarzer and colleagues (2007) investigated a prediction model for the adoption and maintenance of four health behaviours (including dental flossing, seat belt use, diet, and physical activity). However, limited research has explored a range of health behaviours that have been identified as modifiable risk factors for stroke. Five modifiable health behaviours were identified based on recommendations for reducing stroke risk and preventing secondary stroke (Stroke Foundation of New Zealand, 2009). This study aimed to extend previous research through looking at a range of modifiable health behaviours found to be important to stroke prevention; Adherence to Prescribed Medication, Alcohol Intake, Physical Activity, Diet, and Smoking.

Each individual health behaviour domain was assessed in a distinct section of the questionnaire. The main research question was whether people were engaging in health-related behaviour following first-ever stroke. Consequently, engagement in health-related behaviour was assessed by asking participants a categorical yes/no question for behaviours such as smoking cessation, medication adherence, and diet changes. Asking simple questions to assess health-related behaviour were chosen,

rather than asking detailed questionnaires on each health-behaviour domain to minimise participant burden.

Additional aspects of health-related behaviours such as alcohol consumption, diet change, smoking cessation, and physical activity were captured using questions that were measured using a scale. Two existing health behaviour measures, that assessed two of the five domains of health behaviour, were identified: a New Zealand Physical Activity Questionnaire (NZPAQ), and a New Zealand Adult Nutrition Survey (NZANS). To reduce participant burden during the study (an important consideration given this PhD study was part of a larger trial), questions with the highest relevance to the study were identified from these measures to develop shorter measures of physical activity and diet. Please refer to the health behaviour sections of the study questionnaire provided in Appendix D.

3.8 Data analysis

Data from the MIST-trial was extracted from a web-based password-protected database (Krishnamurthi et al., 2014) and merged with data collected as part of this study using SPSS Version 24.0 (SPSS for Windows and Mac, 2016/2017). Participants were allocated an unique registration number that had been generated by the database; this registration number was used to link all study data relating to the participant.

Data cleaning to check the values of each variable were within expected parameters was conducted; data was explored using histograms and estimates of skewness and kurtosis to assess the distribution of the data (as recommended by Tabachnick & Fidell, 2013). Baseline sample characteristics were summarized and descriptive summary statistics including means and standard deviations were provided for data meeting parametric assumptions; median and interquartile ranges were provided for data not meeting parametric assumptions. Two separate issues were considered for the planned analyses: how the missing data in the study would be managed, and the appropriateness for analyses to be conducted.

Missing data in this study could be the result of non-coverage (e.g. a participant not included in that time-point because they were un-contactable), item non-response (e.g. the question wasn't relevant to the participant), or subject non-response (e.g. the participant chose not to answer the questions) (Kalton, 1983). These three reasons for missing data guided the planned analyses. For example, data imputation might be relevant for missing data that results from item non-response (where some items of a questionnaire or measure might be missing) but not for subject non-response (where all items of a questionnaire or measure are missing) (Garson, 2015). The decision to not impute data for participants with missing data was made. This decision was guided by the nature of the participant sample, and the assumption that the diversity of this sample would impact the ability to reliably predict how people would respond.

Participants were not required to have a complete dataset to be included in the analysis. This was because some health behaviours might not have been relevant to all participants e.g. smoking cessation was not relevant to those who did not smoke before their stroke. In cases where standardised questionnaires were used, participants with more than 20% missing data were excluded based on the recommendations from research evidence (Garson, 2015). This decision was made to capitalise on the data available from the collected measures, without imputing data and manufacturing potential findings.

As the psychometric properties of the SASC and B-IPQ have not been explored outside of Europe for people following first-ever stroke, exploratory factor analysis (EFA) was conducted to assess the factor structure of these measures. To conduct this analysis, item-response data was entered into R Version 3.2.3 (R, 2016). The EFA followed the three main steps (determine meaningful factors, rotate, and interpret factor structure) for EFA outlined by Ader (2006). The factor structure of each questionnaire was assessed and compared with the original authors to determine if the original questionnaire was appropriate for use with this group of people. The internal consistency of the subscales was assessed using Cronbach's α to determine how well the items in a measure correlated with each other.

The outcomes of the EFA analysis informed how the measures in this study were scored. In addition, the outcomes of the EFA analysis informed the decision to not exclude participant data or impute data. Primary hypotheses were addressed first to investigate whether illness perceptions and satisfaction with stroke care predicted health behaviours at 28-days. Categorical data was analysed using logistic regression. Continuous data was analysed using linear regression, if the data was normally distributed. Regression analyses were conducted for each individual health behaviour domain where appropriate. If sample sizes were too small, regression analyses were not conducted on the data. For example, only twenty people reported post-stroke smoking behaviour. As approximately ten cases are needed per variable in a regression analysis (Courvoisier, Combescure, Agoritsas, Gayet-Ageron, & Perneger, 2011), and regression analyses would consequently not have sufficient statistical power. Age and treatment condition³ were included in the planned regression analyses as these factors had been identified as factors that could influence health-related behaviour in this group of people.

Secondary analyses investigated if illness perceptions and satisfaction with stroke care predict health behaviours at later time-points (six- and twelve-months); these secondary analyses followed a similar process to that used for the primary hypotheses. Scatter plots and visualisations were used to check assumptions such as homoscedacity and normality of residuals. This process was used to check that the planned analyses were appropriate for the dataset, as major deviations from the assumptions could result in Type I or Type II errors.

3.9 Ethical considerations

This study was granted ethical approval from the (New Zealand) Northern X Regional Ethics Committee for experiments in human subjects (HDEC reference: NTX/10/09/091; see Appendix E and F). Ethical principles for research guided the design of this research and informed the applications for ethical approval for this

³ The two groups in this study were compared because the two groups were different i.e. the MI group had experienced a motivational interviewing intervention and the usual care group acted as a control group.

study. These ethical guidance principles included: informed consent; anonymity and confidentiality; participant burden; and cultural aspects of participation as outlined below.

3.9.1 Informed Consent

The researcher had an awareness of the range of impairments that the stroke survivors may experience (particularly for stroke survivors who may experience cognitive impairments) and how this might impact informed consent. The parent MIST-trial had screened participants to ensure that they were able to provide informed consent and had sufficient levels of cognitive functioning to participate. A cut-off of <23 for the MMSE was applied to the sample to ensure that participants were not experiencing significant cognitive impairments. The study questionnaire (see Appendix D) provides details of the screening measures for all participants. Following the screening process, eligible participants were asked to provide written informed consent before completing the study questionnaires (see Appendix C).

3.9.2 Confidentiality and Anonymity

A number of measures were taken to ensure confidentiality and anonymity in this study. Data from the parent MIST-trial was stored on a web-based password-protected database. For this study, data was extracted and merged with data collected as part of this study. Participants were allocated an unique registration number that had been generated by the database; this removed identifying information about participants from the data. Each registration number was used to link all study data relating to the participant. All data for this study was securely stored on the researcher's laptop and was password protected during the thesis. Data was handed over to the NISAN team at AUT University, NZ (following completion of the thesis), and will be stored securely for the ten-year requirement determined by ethics.

3.9.3 Participant Burden

An awareness of participant burden was an ethical principle that guided the design and practice of this study. To enable participation and reduce participant burden, shorter versions of questionnaire measures were chosen to capture the phenomena of interest i.e. the Brief Illness Perceptions Questionnaire (nine questions) and the

Hospital subscale of the Satisfaction with Stroke Care Questionnaire (eight questions). Furthermore, these questionnaire measures were asked at 28-days post stroke to reduce potential participant burden over the course of the twelve-month study.

3.9.4 Cultural Aspects of Participation

The researcher had an awareness of the cultural aspects for participation in this study. A consultation process was undertaken to acknowledge the suitability of questionnaires for different ethnic groups. This process guided the design and practice of the study. The study also respected individual differences, and offered options for participation (e.g. via telephone or in a public environment).

Chapter 4 Quantitative Results

First, this chapter will describe the participant sample and outline descriptive statistics on the key outcome measures at each time-point. Second, the scale construction of the questionnaire measures will be explored. And third, the relationships between acute illness perceptions, acute satisfaction with stroke care, and health-related behaviour over time will be determined.

4.1 Sample characteristics

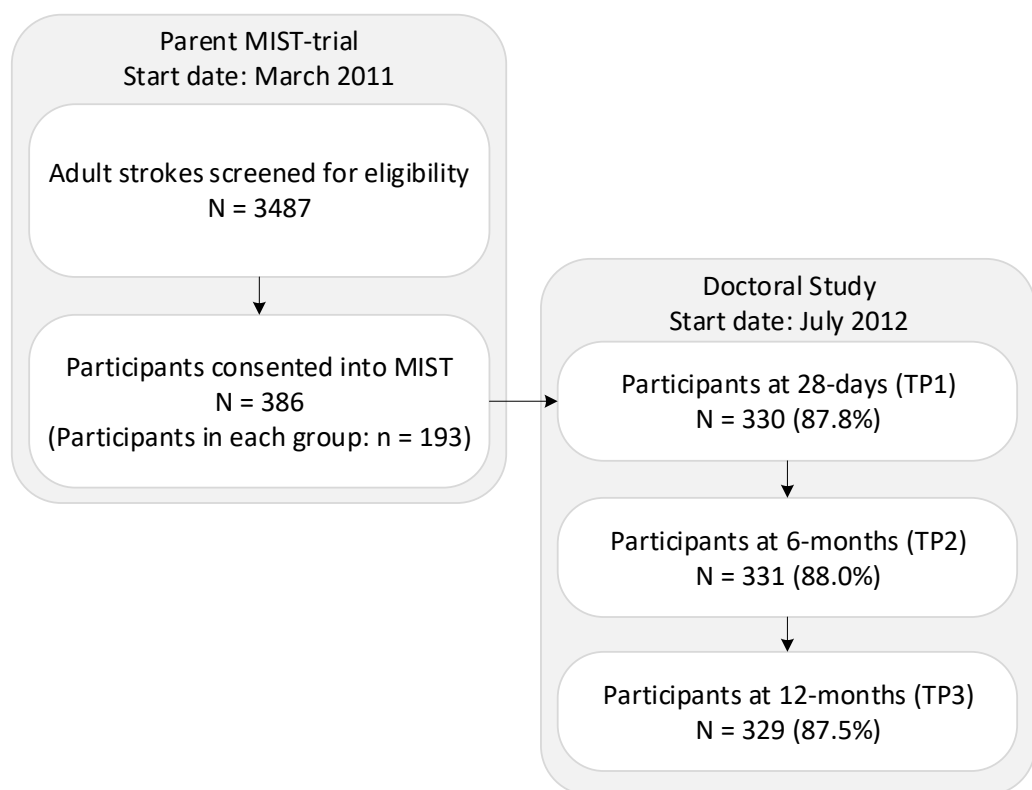


Figure 5. Flowchart illustrating the participant flow over the course of the longitudinal study.

386 participants completed the questionnaire measures for at least one of the three study time-points. As shown in Figure 5, participation (rate) remained stable over-time; however, participants within each time-point did vary due to mortality, loss to follow up, and withdrawal (Barker-Collo et al., 2015). Furthermore, participation rates varied slightly because some people were too unwell to participate at earlier time-points in the study, but were able to participate at later time-points. In this study, there was an overall loss to follow-up of 12.5%.

Table 1. Participant characteristics of quantitative study.

	N (%)	95% CI
<i>Age</i>		
16-64*	170 (44.0)	(38.9; 49.0)
65-74	91 (23.6)	(19.2; 28.0)
75-84	99 (25.6)	(21.5; 30.1)
85+	26 (6.7)	(4.1; 9.3)
<i>Ethnicity**</i>		
Maori	34 (8.8)	(6.0; 11.9)
Pacific Islander	28 (7.3)	(4.7; 9.6)
NZ European/European	243 (63)	(58; 68.1)
Asian/South Asian	7 (1.8)	(0.5; 3.4)
Indian	9 (2.3)	(1.0; 4.1)
Other	88 (22.8)	(18.7; 26.9)
<i>Sex</i>		
Female	152 (39.4)	(34.7; 44.6)
Male	234 (60.6)	(55.4; 65.3)
<i>Marital Status</i>		
Married, Civil Union, Defacto Relationship	275 (71.2)	(66.8; 75.9)
Never Married	19 (4.9)	(2.8; 7.0)
Separated, Divorced, Widowed	92 (23.8)	(19.7; 28.0)
<i>Live with Prior</i>		
Living with partner or family	289 (74.9)	(70.7; 79.0)
Living with others	14 (3.6)	(1.8; 5.4)
Living alone	83 (21.5)	(17.6; 25.6)
<i>Comorbidity***</i>		
TIA	36 (9.3)	(6.5; 12.4)
Cholesterol	200 (51.8)	(46.6; 56.7)
Hypertension	253 (65.5)	(61.1; 70.2)
Diabetes	78 (20.2)	(16.1; 24.1)
Coronary artery disease and angina	73 (18.9)	(15.0; 23.1)
Arrhythmia	100 (25.9)	(21.5; 30.1)
Heart Failure	55 (14.2)	(10.6; 17.9)
Peripheral vascular disease	23 (6.0)	(3.6; 8.5)
Epilepsy	3 (0.8)	(0.0; 1.8)
Migraine	65 (16.8)	(13.0; 20.7)
Head Injury (and loss of consciousness)	39 (10.1)	(7.3; 13.2)
Serious Fall	34 (8.8)	(6.2; 11.7)
Other (any other previous diagnosis)	301 (78.0)	(74.1; 82.1)

*Youngest age in this sample was 27 years; the age range 16-64 enables comparison with other research studies.

**Participants were able to identify with more than one ethnicity.

***Participants were able to report more than one comorbidity.

Table 2. Screening criteria for participants in quantitative study.

	N (%)	95% CI
<i>MMSE Score*</i>		
23	14 (3.6)	(1.8; 5.7)
24	5 (1.3)	(0.3; 2.6)
25	16 (4.1)	(2.3; 6.2)
26	33 (8.5)	(6.0; 11.7)
27	65 (16.8)	(13.2; 20.7)
28	72 (18.7)	(14.8; 22.8)
29	96 (24.9)	(20.5; 29.0)
30	85 (22.0)	(17.9; 26.2)
<i>Barthel Score</i>		
0-17	43 (13.8)	(3.9, 29.5)
18-20	333 (86.3)	(78.7; 93.1)

*Although the cut-off for MIST-trial was +23, newer evidence suggests a MMSE cut-off score of 27 (O'Bryant et al., 2008).

As shown in Table 1, the largest proportion of the sample identified their ethnicity as NZ European/other; this category encompassed people of any European descent. More men participated in this study, with three males for every two females recruited into the study. The largest proportion of the sample was between 16-64 years old at the time of their stroke. The age of participants in the sample ranged from 27-93 years (Median = 67.0, Interquartile Range = 21). This age-range demonstrated a negative skew, with a wide distribution. A large proportion of this sample identified as being married, in a civil union, or defacto relationship. The majority of participants also reported that they were living with their partner or family.

The majority of participants experienced comorbidities that were related to stroke, as shown in Table 1, although comorbidities unrelated to stroke were also observed (e.g cancer). The most common comorbidities reported by this sample were high cholesterol, hypertension, and diabetes, which are all known risk factors for stroke. The least common comorbidities reported by this sample were epilepsy, peripheral vascular disease, or a serious fall.

As shown in Table 2, the majority of participants in this sample had MMSE scores ranging between 27 and 30 (Mean =27.9, SD= 1.8, Median = 28), which suggested that this sample was not experiencing significant cognitive impairments. A Barthel Index

score of 20 (Mean =18.7, SD= 3.4, Median = 20) for the majority of participants in this sample suggested that this sample was able to perform most activities of daily living (see Table 2).

4.2 Factor Analysis of Questionnaire Measures

4.2.1 Brief Illness Perceptions Questionnaire

EFA using maximum likelihood was conducted on the 28-day data (acute) of the B-IPQ ($n_{28\text{-day}} = 177$) to investigate model fit via a range of fit statistics. Eight continuous items in the B-IPQ were entered into the analysis; item nine (in the B-IPQ) measured nominal data, and was not included in the EFA. A two-dimension⁴ model $\chi^2 = 18.52(13)$, $p = 0.14$ was found to best fit the data at 28-days (as identified by the scree plot, eigenvalues, and χ^2 fit statistic; see Figure 6). The significance level of the χ^2 fit statistic was moderate, which suggested a low level of fit for this model. Although the EFA suggested a low fit for the two-dimension model, the one-dimension model proposed by the original authors was rejected based on the poor model fit with this sample ($\chi^2 = 79.72(20)$, $p = 4.38$, with an eigenvalue of 2.31, explaining 29% of the variance).

Based on a varimax rotation, the eigenvalue for a two-dimension measure was 3.41 (explaining 43% of the variance). The first dimension related to the emotional aspects of stroke perceptions, while the second dimension related to the practical aspects of stroke perceptions. Table 3 demonstrates how the individual items in the B-IPQ were loaded on to the two dimensions suggested by the EFA. This was inconsistent with the factor structure proposed by the original authors (Broadbent et al., 2006). However, as the two-dimensions demonstrated the best fit with this data and revealed acceptable Cronbach's alphas of 0.79 and 0.59, the two dimension structure was used in subsequent analyses.

⁴ Please note: the term *dimension* is used (instead of *factor*) to describe the factor structure of the scale. This is to prevent confusion with the use of *factor* to describe the wider influences on health behaviour elsewhere in the thesis.

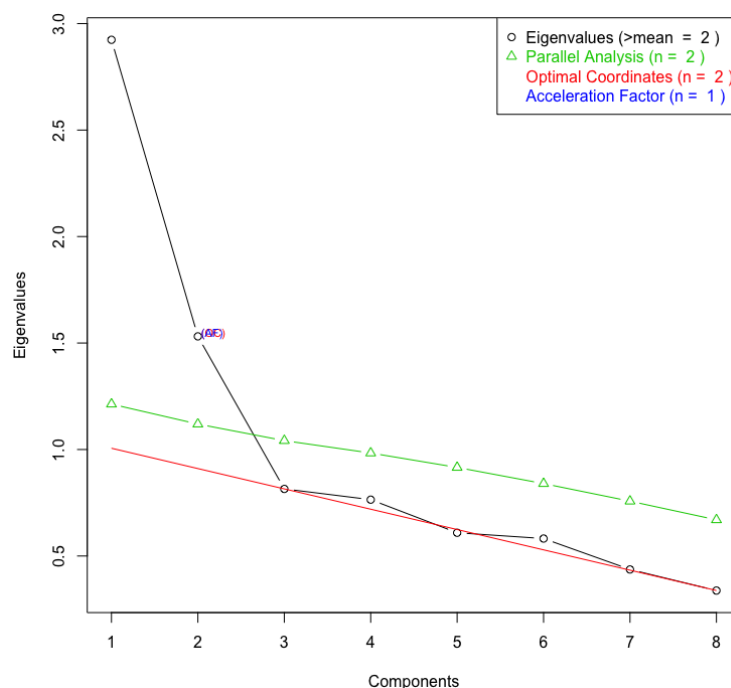


Figure 6. Scree plot for the exploratory factor analysis conducted on 28-day B-IPQ.

Table 3. Factor (dimension) loadings for B-IPQ.

Item #	Item Description	Emotion Dimension	Practical Dimension
B-IPQ 1	How much does your stroke affect your life?	0.81	-
B-IPQ 2	How long do you think your stroke will continue?	0.53	-
B-IPQ 5	How much do you experience symptoms from your stroke?	0.75	-
B-IPQ 6	How concerned are you about your stroke?	0.57	-
B-IPQ 8	How much does your stroke affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?	0.55	-
B-IPQ 3	How much control do you feel you have over your stroke?	-	0.86
B-IPQ 4	How much do you think your treatment can help your stroke?	-	0.48
B-IPQ 7	How well do you feel you understand your stroke?	-	0.44
	SS Loadings	2.16	1.25
	Proportional Variance	0.27	0.16
	Cumulative Variance	0.27	0.43
	Cronbach's alpha	0.79	0.59*

*The Cronbach's alpha increased to 0.63 if B-IPQ-7 was dropped; however, this would leave a factor (dimension) with only 2 items in.

4.2.2 Satisfaction with Stroke Care Questionnaire

An eight-item, one-dimension model (as identified by the eigenvalues, and χ^2 fit statistic, and factor loadings: Table 4) was identified, with an eigenvalue of 2.29 (explaining 29% of the variance). The significance level of the χ^2 fit statistic was very small, $\chi^2 = 48.72(20)$, $p = 0.0003$, which indicated that the hypothesis of acceptable model fit could be accepted. This is consistent with the factor structure proposed by the original authors (Boter et al., 2003) and revealed Cronbach's alphas of 0.73.

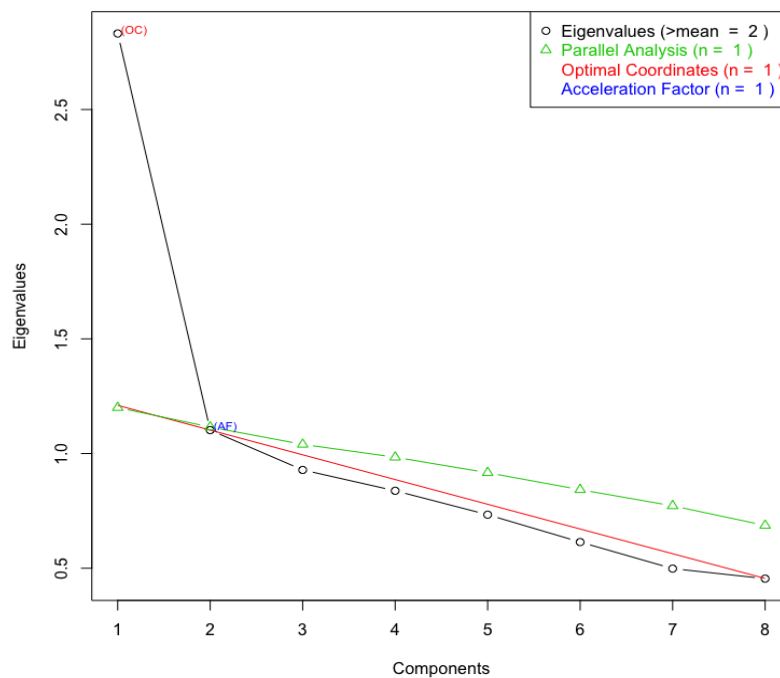


Figure 7. Scree plot for the exploratory factor analysis conducted on 28-day SASC.

Although the scree plot and analysis suggested two different solutions, the χ^2 fit statistic and factor loadings (Table 4) were used in preference to the scree plot (Figure 7). To support use of a one-dimension model, maximum likelihood analysis of a two-dimension model suggested a poorer fit with this sample ($\chi^2 = 21.04(13)$, $p = 0.07$, with an eigenvalue of 3.98, explaining 37% of the variance) when compared to the one-dimension model.

Table 4. Factor (dimension) loadings for SASC.

Item #	Item Description	Model
SASC 1	I have been treated with kindness and respect by the staff at the hospital	0.63
SASC 2	The staff attended well to my personal needs while I was in hospital	0.55
SASC 3	I was able to talk to the staff about any problems I might have had	0.57
SASC 4	I have received all the information I want about the causes and nature of my stroke	0.71
SASC 5	The doctors have done everything they can to make me well again	0.51
SASC 6	I am happy with the amount of recovery I have made	0.45
SASC 7	I am satisfied with the type of treatment the therapists have given me	0.43
SASC 8	I have had enough therapy	0.34
	SS Loadings	2.29
	Proportional Variance	0.29
	Cronbach's alpha (In-hospital Factor: 8-items)	0.73

4.3 Descriptive statistics for predictors

As mentioned previously (refer to sample characteristics), participation rates within each time-point varied in this study. Missing data (N) for this study (see Table 5) occurred because the data collection for this study commenced (16 months) after the parent-MIST trial had commenced data collection. This missing data (N) refers to non-completion of the whole questionnaire and ranged from 37.3% to 58.9%. Furthermore, participation rates (n) for this study varied because of non-completion of items within the questionnaire (see Table 5). Reasons for non-completion of items included non-applicability of item, or the individual was unable to understand or answer the question.

For the B-IPQ, higher scores were an indication of more threatening illness perceptions. Mean and median scores are provided for the B-IPQ summary statistics (Table 5), as some individual items within this scale showed skewed data for this sample. Each item in the practical scale was positively skewed. In contrast, two items in the emotion scale were positively skewed, one item was negatively skewed, and two

Table 5. Summary statistics for predictors at 28-days post-stroke.

	n (%)	Mean (SD)	Median (IQR)	95% CI	Missing data, N (%)
<i>Brief illness perceptions (0-10) n=177</i>					
B-IPQ1: Consequences	177 (100)	4.84 (2.88)	5 (5)	[4.42, 5.27]	139 (44)
B-IPQ2: Timeline	160 (90.4)	3.66 (2.61)	3 (3)	[3.25, 4.06]	156 (49.4)
B-IPQ3: Personal Control	173 (97.7)	3.02 (2.67)	2 (4)	[2.62, 3.42]	143 (45.3)
B-IPQ4: Treatment Control	167 (94.4)	2.28 (2.15)	2 (3)	[1.95, 2.60]	149 (47.2)
B-IPQ5: Identity	176 (99.4)	3.99 (2.69)	4 (4)	[3.59, 4.39]	140 (44.3)
B-IPQ6: Concern	176 (99.4)	5.71 (3.11)	6 (5)	[5.25, 6.17]	140 (44.3)
B-IPQ7: Coherence	175 (98.9)	2.85 (2.79)	2 (5)	[2.44, 3.27]	141 (44.6)
B-IPQ8: Emotional Representation	175 (98.9)	3.79 (3.06)	3 (5)	[3.34, 4.25]	141 (44.6)
B-IPQ Practical Dimension	177 (100)	2.77 (2.04)	2.33 (2.83)	[2.46, 3.08]	139 (44)
B-IPQ Emotion Dimension	177 (100)	4.42 (2.13)	4.60 (3.20)	[4.11, 4.74]	139 (44)
<i>Satisfaction with stroke care (0-3) n = 198</i>					
SASC1: Respect	196 (98.9)	2.76 (0.52)	3 (0)	[2.68, 2.83]	120 (38)
SASC2: Personal Needs	192 (96.9)	2.54 (0.83)	3 (1)	[2.42, 2.66]	124 (39.2)
SASC3: Approachability	187 (94.4)	2.51 (0.76)	3 (1)	[2.40, 2.62]	129 (40.8)
SASC4: Information Provision	197(99.5)	2.23 (0.81)	2 (1)	[2.12, 2.35]	119 (37.7)
SASC5: Treatment by Doctors	193 (97.5)	2.53 (0.68)	3 (1)	[2.43, 2.62]	123 (38.9)
SASC6: Recovery Level	196 (98.9)	2.27 (0.82)	2 (1)	[2.15, 2.39]	120 (38)
SASC7: Treatment Received	143 (72.2)	2.36 (0.77)	2 (1)	[2.23, 2.48]	173 (54.7)
SASC8: Therapy Provision	130 (65.7)	1.91 (0.98)	2 (2)	[1.74, 2.08]	186 (58.9)
SASC Total Mean	198 (100)	2.41 (0.45)	2.43 (0.84)	[2.35, 2.48]	118 (37.3)

*Note: Higher IPQ scores indicate more threatening illness perceptions.

**Note: Higher SASC scores indicate greater satisfaction.

items showed a normal distribution. Visual inspection of the distribution for the practical dimension for B-IPQ suggested that there was positive skew (Skewness = .77, $SE = .18$; Kurtosis = .28, $SE = .36$) in the data, and this was confirmed by using a rule of thumb comparison (dividing the skewness statistic by its standard error). Whereas visual inspection of the emotion dimension indicated a normal distribution, and this was confirmed by skewness ($-.04$, $SE = .18$) and kurtosis ($-.60$, $SE = .36$) statistics for this sample of participants. As shown by the median scores in Table 5, the emotional dimension items reflected a higher perceived threat than the practical items.

One individual item median, B-IPQ6: "Concern" was scored higher than the other items in the scale, suggesting that the sample reported greater concern relating to the stroke, compared to the other items in the measure. The mean for this item was also the highest, with the largest SD, suggesting a wider variability across participants for this item. The lowest scored medians in the scale were for items in the practical scale (personal control, treatment control, and coherence), suggesting that the sample reported lowest perceived threat related to the practical aspects of their illness.

Participants were asked to rank, in order of importance, up to three causal factors for their stroke. For the most important causal factor, the largest proportion of participants identified stress or anxiety (17.9%), followed by smoking (7.2%), and overwork (5.5%); however, the majority of people (20.9%) reported that they had no idea why they had experienced stroke (mentioning luck, that no-one knew, they had no idea, or that there was no causal reason for the stroke). When reporting the second most important causal factor for their stroke, the largest proportion of participants reported stress or anxiety (12.3%), diet (5.5%), or smoking (4.3%). The most common third causal factors were identified as stress or anxiety (6%), drinking alcohol (6%), lack of physical activity (5.5%), and diet (3.8%).

For the SASC, higher scores were an indication of greater satisfaction. The mean and median scores for the SASC suggest that the majority of participants reported that they were happy with the stroke care they had received in the hospital following the stroke (see Table 5). The mean and median scores supported this for the individual item scores and the overall median for the SASC (Table 5). Visual inspection of the

distribution for the in-patient SASC suggested that there was negative skew (Skewness = $-.53$, $SE = .17$; Kurtosis = $.03$, $SE = .34$) in the data, and this was confirmed by using a rule of thumb comparison.

While there was little variance in the individual item medians, a number of individual item means were scored lower than other items in the scale; these items also had larger SD suggesting wider variability for these items. These trends in the data (lower scores for items) suggested that participants reported greater variability in their satisfaction with therapy provision, information provision, recovery level, and the treatment they had received.

4.4 Association between B-IPQ and SASC

Zero order correlations were conducted to investigate the relationship between acute measures of satisfaction with stroke care and the emotional and practical dimensions of illness perceptions. Satisfaction with stroke care was negatively correlated with the emotional dimension of the B-IPQ, $r(176) = -.28$ $[-.41, -.14]$, $p < .001$, and the practical dimension of the B-IPQ, $r(176) = -.28$ $[-.43, -.13]$, $p < .001$.

4.5 Health Behaviour Outcomes

As each health behaviour is distinct, and not all health behaviours relate to every participant, they will be discussed separately. First, for each health behaviour, summary statistics will be described. Second, the relationships between acute illness perceptions and acute satisfaction with stroke care with each health behaviour at 28-days, six-months, and twelve-months post stroke will be presented.

4.5.1 Use of Alcohol

Table 6 outlines the use of alcohol within the sample across all time-points. Trends in alcohol consumption suggested that one in ten participants drank more than five alcoholic drinks per day. There were no significant differences between participants in the usual care group versus the intervention group. In addition, trends suggested that participants drank less frequently at 28-days following the stroke. It was observed that alcohol use (alcohol use during past month and amount per day) gradually increased across the twelve-months following the stroke across both groups. Trends in the data

also revealed significant differences between groups for frequency of alcohol use at six-months ($n_{\text{intervention}}=166$ compared with $n_{\text{usual care}}=164$) and twelve-months ($n_{\text{intervention}}=161$ compared with $n_{\text{usual care}}=167$). No significant differences were observed between groups for alcohol use per day (drinking more than five drinks per day).

Table 6. Summary statistics for use of alcohol at post-stroke time-points.

Alcohol	N (%)	Intervention (%)	Usual Care (%)	χ^2 , p value
<i>28-Days (T1)</i>				
>5 alcoholic drinks/day	14 (9.20)	5 (3.29)	9 (5.92)	0.44, 0.51
<5 alcoholic drinks/day	138 (90.80)	62 (40.79)	76 (48.03)	-
Did not drink during past month	161 (51.44)	87 (27.79)	74 (23.64)	3.10, 0.08
Yes, drank during past month	152 (48.56)	67 (21.41)	85 (27.16)	-
<i>Six-Months (T2)</i>				
>5 alcoholic drinks/day	28 (13.02)	13 (6.04)	15 (6.98)	0.07, 0.80
<5 alcoholic drinks/day	187 (86.98)	82 (38.14)	105 (48.84)	-
Did not drink during past month	115 (34.85)	71 (21.52)	44 (13.33)	9.23, 0.00**
Yes, drank during past month	215 (65.15)	95 (28.79)	120 (36.36)	-
<i>Twelve-Months (T3)</i>				
Drank >5 alcoholic drinks/day	41 (18.55)	15 (6.79)	26 (11.76)	0.73, 0.39
Drank <5 alcoholic drinks/day	180 (81.45)	79 (35.75)	101 (45.70)	-
Did not drink during past month	107 (32.62)	67 (20.43)	40 (12.20)	11.63, 0.00**
Yes, drank during past month	221 (67.38)	94 (28.66)	127 (38.72)	-

*Note: **p<0.01

Summary statistics demonstrated that participant numbers were too small to conduct logistic regression analysis on the variable that assessed if people drank 5 or more alcoholic drinks in a single day. However, participant numbers were appropriate to perform a linear regression analysis on frequency of alcohol use. To address the primary hypotheses that stroke survivors who report higher satisfaction with stroke care, or more threatening illness perceptions, at 28-days post-stroke will have improved health-related behaviour at 28-days post-stroke, linear regression analyses were conducted (Table 7).

Table 7. Linear regression analysis for frequency of alcohol use at post-stroke time-points.

ALCOHOL	Beta	SE	P value	95% CI		Adjusted R ²
				Lower	Upper	
28 Day (T1)						
Constant	-16.95	13.96	0.23	-44.51	10.61	.04*
Treatment Condition	0.62	0.47	0.18	-0.30	1.55	-
Age	0.02	0.02	0.18	-0.01	0.06	-
Practical IPQ	-0.05	0.12	0.66	-0.29	0.18	-
Emotion IPQ*	-0.25	0.12	0.04	-0.49	-0.02	-
SASC	0.33	0.57	0.56	-0.79	1.46	-
Six-month (T2)						
Constant	-18.29	15.43	0.24	-48.77	12.19	.02
Treatment Condition	0.68	0.52	0.19	-0.34	1.70	-
Age	0.02	0.02	0.21	-0.01	0.06	-
Practical IPQ	-0.03	0.13	0.85	-0.29	0.24	-
Emotion IPQ	-0.16	0.13	0.23	-0.42	0.10	-
SASC	0.50	0.63	0.43	-0.75	1.76	-
Twelve-month (T3)						
Constant	-19.82	15.77	0.21	-50.98	11.34	.04*
Treatment Condition	0.69	0.53	0.19	-0.36	1.74	-
Age	0.03	0.02	0.11	-0.01	0.07	-
Practical IPQ	-0.01	0.13	0.95	-0.27	0.25	-
Emotion IPQ	-0.20	0.14	0.16	-0.48	0.08	-
SASC	0.86	0.64	0.18	-0.41	2.12	-

Note: *p<0.05, **p<0.01

Table 7 shows the predicted relationship of emotional illness perceptions at 28-days, and that this independent variable explained 2.8% of variance in alcohol consumption at 28-days post-stroke, $F(5,171) = 2.56$, $p=.029$. The B value indicated that as the score for emotional illness perceptions increased by 1, the score for general alcohol consumption decreased by $-.25$. This suggests that as participants reported more threatening emotional illness perceptions, their general alcohol consumption decreased. No significant relationships between satisfaction and alcohol behaviour were observed.

Linear regression analyses also investigated if acute satisfaction with stroke care, or acute illness perceptions, predicted alcohol consumption at later time-points following a stroke. As suggested by Table 7, these analyses demonstrated that there were no significant relationships between illness perceptions, satisfaction, and alcohol at later time-points for this population. Furthermore, the association between emotional illness perceptions and alcohol use at 28-days was no longer significant.

4.5.2 Medication Adherence

Table 8 presents the summary statistics for the medication adherence scores across all time-points. For adherence to medication scores, questions were categorical (yes or no). No significant trends were observed relating to the increase in adherence to medication over the three time-points post-stroke. However, a non-significant trend suggested that adherence to medication was lowest at six-months, but increased again at twelve-months post-stroke.

Medication adherence was assessed in terms of whether individuals reported if they had taken their medication over the seven days prior to the assessment. To address the primary hypotheses, data provided at 28-days was examined. For this regression analysis, 164 (52.7%) participants had adhered to their medication (at 28-days). Age, Treatment group, IPQ (practical items), IPQ (emotional items), and SASC were entered into a logistic regression model (Table 9).

Table 8. Summary statistics (including crosstabs) for adherence to medication across time-points.

Adherence to medication	N (%)	Intervention (%)	Usual Care (%)	χ^2, p value
<i>28 Days (T1)</i>				
Yes, adhered to medication	294 (94.5)	147 (47)	147 (47)	1.39, 0.24
No	17 (5.5)	6 (2)	11 (3.5)	-
<i>Six Months (T2)</i>				
Yes, adhered to medication	283 (86.5)	148 (45)	135 (41)	1.98, 0.16
No	44 (13.5)	18 (5.5)	26 (8)	-
<i>Twelve Months (T3)</i>				
Yes, adhered to medication	296 (91.4)	148 (45.7)	148 (45.7)	0.13, 0.72
No	28 (8.6)	13 (4.4)	15 (4.6)	-

Table 9 shows that the satisfaction with stroke care and illness perceptions at 28-days did not predict adherence to medication at 28-days post-stroke. Analyses were conducted to investigate if acute satisfaction with stroke care, or illness perceptions, predicted adherence to medication at later time-points following a stroke. No significant relationships between satisfaction or illness perceptions and adherence to medication (at six-months or twelve-months) were noted. This suggests that satisfaction with stroke care and illness perceptions were not able to significantly distinguish between participants who reported medication adherence and participants who had not.

Age was entered into each regression analysis to determine if age was a significant predictor of the different health behaviours for participants in this sample. It was observed that there was a significant relationship between age and medication adherence at six- and twelve-months post-stroke for this sample. Table 9 demonstrates that as age increased by a score of 1, the odds of participants reporting a change in their medication adherence increased by 0.05 at six-months and 0.06 at twelve-months. This suggests that as age increased, participants were more likely to adhere to medication.

Table 9. Logistic regression model for medication adherence at each time-point.

MEDICATION ADHERENCE		Beta	SE	P value	OR	95% CI	
						Lower	Upper
28 Day (T1)							
Constant		19.39	19.83	.33	-	-	-
Treatment Condition		-.59	.66	.37	.554	.15	2.01
Age		.03	.21	.14	1.03	.99	1.08
Practical IPQ		-.04	.16	.79	.958	.69	.132
Emotion IPQ		-.13	.17	.46	.88	.63	1.23
SASC		-.20	.74	.78	.82	.19	3.48
Six-month (T2)							
Constant		11.13	15.11	.46	-	-	-
Treatment Condition		-.48	.51	.35	.62	.23	1.68
Age**		.05	.02	.01	1.05	1.01	1.09
Practical IPQ		-.02	.12	.84	.98	.77	1.24
Emotion IPQ		.21	.14	.12	1.23	.95	1.61
SASC		.48	.62	.44	1.61	.48	5.39
Twelve-month (T3)							
Constant		0.99	19.56	0.96	2.68	-	-
Treatment Condition		-0.10	0.65	0.88	0.90	0.25	3.25
Age**		0.06	0.03	0.01	1.06	1.01	1.12
Practical IPQ		0.06	0.17	0.73	1.06	0.76	1.49
Emotion IPQ		0.05	0.18	0.77	1.05	0.74	1.49
SASC		0.15	0.76	0.84	1.16	0.26	5.15

Note: *p<0.05, **p<0.01

4.5.3 Physical Activity

Table 10 shows the summary statistics for the physical activity scores across all time-points in this study. The mean (M) and median scores for physical activity suggest that the majority of the participant sample reported low to medium levels of activity before and after the stroke. Participants reported higher levels of activity for general activity (how many days a week have you been physically active) compared to walking. While a significant difference between the intervention and usual care group was observed for walking at 28-days (see Table 10), no other significant differences were observed for physical activity at later time-points. Reported walking behaviour and physical activity was shown to increase gradually over time, with greatest levels of walking and physical activity at twelve-months post-stroke; 127 participants (38.6%) reported no walking behaviour for the previous seven days prior to assessment at twelve-months.

Table 10. Summary statistics (including crosstabs) for physical activity by study group.

	n	Mean (SD)	Intervention (%)	Usual Care (%)	χ^2 , p value
WALKING					
<i>28-days (T1)</i>					
Yes	155 (49.68)	2.15 (2.67)	68 (22)	87 (27.9)	3.71, .05*
No	157 (50.32)	-	86 (27.6)	71 (22.8)	-
<i>Six-months (T2)</i>					
Yes	202 (61.03)	2.46 (2.56)	93 (28.1)	109 (35)	2.55, 0.11
No	129 (38.97)	-	71 (21.5)	58 (17.5)	-
<i>Twelve-months (T3)</i>					
Yes	202 (61.4)	2.58 (2.62)	69 (20.9)	58 (17.6)	2.14, 0.14
No	127 (38.6)	-	93 (28.3)	109 (33.1)	-
PHYSICAL ACTIVITY					
<i>28-days (T1)</i>					
Yes	131 (68.23)	2.85 (2.67)	61 (32.1)	70 (36.5)	0.26, 0.61
No	61 (50.32)	-	26 (13.5)	35 (18.2)	-
<i>Six-months (T2)</i>					
Yes	209 (81.32)	3.35 (2.45)	103 (40.1)	106 (41.2)	0.48, 0.49
No	48 (18.68)	-	21 (8.2)	27 (10.5)	-
<i>Twelve-months (T3)</i>					
Yes	225 (84.59)	3.65 (2.44)	108 (40.6)	117 (43.9)	2.34, 0.13
No	41 (15.41)	-	25 (9.4)	16 (6.0)	-

*p<0.05, **p<0.01

Table 11. Linear Regression Analysis for frequency of physical activity at post-stroke time-points.

FREQUENCY OF ACTIVITY	Beta	SE	P value	95% CI		Adjusted R ²
				Lower	Upper	
28 Day (T1)						
Constant	-	14.48	.68	-22.73	34.65	.06*
Treatment Condition	-.01	.49	.92	-.99	.90	-
Age*	-.22	.02	.02	-.07	-.01	-
Practical IPQ	.05	.12	.59	-.17	.29	-
Emotion IPQ*	-.23	.12	.02	-.52	-.05	-
SASC	.13	.54	.17	-.32	1.81	-
Six-month (T2)						
Constant	-	12.03	.44	-14.40	33.21	.04
Treatment Condition	-.02	.41	.84	-.89	.73	-
Age**	-.27	.02	.00	-.08	-.02	-
Practical IPQ	.01	.10	.89	-.19	.21	-
Emotion IPQ	-.17	.11	.09	-.40	.03	-
SASC	.02	.51	.79	-.88	1.14	-
Twelve-month (T3)						
Constant	-	13.74	0.32	-40.89	13.52	.07*
Treatment Condition	0.12	.46	0.16	-0.26	1.55	-
Age*	-0.19	.02	0.03	-0.07	0.00	-
Practical IPQ	-0.09	.11	0.31	-0.33	0.11	-
Emotion IPQ	-0.13	.12	0.16	-0.41	0.07	-
SASC	0.14	.56	0.13	-0.25	1.96	-

Note: *p<0.05, **p<0.01

Table 12. Linear Regression Analysis for frequency of walking at post-stroke time-points.

WALKING	Beta	SE	P value	95% CI		Adjusted R ²
				Lower	Upper	
28 Day (T1)						
Constant	-	14.46	.17	-48.47	8.83	.11*
Treatment Condition*	.18	.48	.04	.03	1.92	-
Age**	-.30	.02	.001	-.09	-.02	-
Practical IPQ	-.06	.12	.50	-.31	.15	-
Emotion IPQ	-.07	.12	.43	-.33	.14	-
SASC	-.14	.54	.14	-1.86	.26	-
Six-month (T2)						
Constant	-	12.46	.39	-35.46	13.84	.06*
Treatment Condition	.13	.42	.12	-.18	1.50	-
Age*	-.18	.02	.05	-.06	.00	-
Practical IPQ	.07	.10	.40	-.12	.29	-
Emotion IPQ**	-.26	.11	.01	-.53	-.08	-
SASC*	-.18	.53	.05	-2.09	.00	-
Twelve-month (T3)						
Constant	-	14.29	0.37	-41.22	15.38	.02
Treatment Condition	0.10	.48	0.25	-0.39	1.49	-
Age	-0.13	.02	0.16	-0.06	0.01	-
Practical IPQ	0.13	.12	0.15	-0.06	0.39	-
Emotion IPQ	-0.13	.13	0.18	-0.42	0.08	-
SASC	0.11	.58	0.26	-0.49	1.80	-

Note: *p<0.05, **p<0.01

Linear regression analyses were used to explore whether acute illness perceptions, or satisfaction with stroke care, explained the variance in the outcomes of physical activity-related health behaviours at 28-days post-stroke (see Table 11 and Table 12).

Table 11 illustrates the predicted relationship of illness perceptions (emotional subscale) with frequency of activity at 28-days, and that the independent variables explained 6.2% of variance in frequency of activity at 28-days post-stroke, $F(5,114) = 2.58$, $p=.03$. The emotional dimension of the B-IPQ was suggested as a significant predictor of frequency of activity during the week prior to assessment at 28-days post-stroke. The B value indicated that as the score for B-IPQ-emotional items increased by 1, the score for frequency of activity decreased by $-.23$. This suggests that as participants reported more threatening emotional aspects of illness perceptions, their frequency of activity decreased. No significant relationships were seen between satisfaction with stroke care and frequency of activity at 28-days post-stroke.

The second aspect of physical activity was assessed in terms of walking behaviour reported in the week prior to the assessment. As suggested by Table 12, there were no significant relationships between satisfaction with stroke care, illness perceptions, and walking behaviour at 28-days post-stroke.

Linear regression analyses were conducted to investigate if acute satisfaction with stroke care, or illness perceptions, predicted physical activity at later time-points following a stroke. This regression analysis (Table 12) demonstrated that no significant relationships were seen between illness perceptions, satisfaction with stroke care, and frequency of activity at six- and twelve-months post-stroke. However, at six-months post-stroke, the independent variables explained 5.7% of variance in walking behaviour, $F(5,130) = 2.62$, $p=.027$, with age at stroke, emotional illness perceptions, and satisfaction emerging as significant predictors. The B value indicated that as the score for B-IPQ-emotional items increased by 1, the score for walking decreased by $.26$; this suggests that as participants reported more threatening emotional aspects of illness perceptions, their walking behaviour decreased. The B value also indicated that as the score for satisfaction increased by 1, the score for walking decreased by $.18$. This suggests that as participants reported greater satisfaction with their stroke care,

their walking behaviour decreased. No significant relationships between satisfaction or illness perceptions and walking behaviour at twelve-months post-stroke were noted.

A significant relationship between age and physical activity was also observed for this sample of participant's at all post-stroke time-points. Table 11 demonstrates that as age increased by a score of 1, the odds of participants reporting a change in their frequency of physical activity decreased by -.22 (28-days), -.27 (six-months), and -.19 (twelve-months). A similar pattern was observed for walking behaviour. Where age increased by a score of 1, the odds of participants reporting a change in their walking behaviour decreased by -.30 (28-days), -.18 (six-months), and -.13 (twelve-months). This suggests that as age increased, participants in this sample were less likely to be physically active following the stroke.

Treatment condition was also entered into each regression analysis to determine if treatment condition was a significant predictor of the different health behaviours for participants in this sample. A significant relationship between treatment condition and walking at 28-days post-stroke was observed. Table 12 demonstrates that for participants in the intervention condition (compared to the usual care condition), the odds of participants reporting a change in their walking increased by -.18 at 28-days post-stroke.

4.5.4 Smoking Behaviour

Table 13 presents the summary statistics for smoking behaviour scores. Smoking behaviour was assessed in terms of whether participants reported post-stroke smoking behaviour or not ($n_{\text{smokers}} = 21$, $n_{\text{non-smokers}} = 365$). A non-significant trend in attempting to reduce smoking was observed across time; fewer participants reported attempting to reduce smoking at six-months post-stroke (55%), however, this increased at twelve-months post-stroke (66.7%). No significant differences were observed between the intervention and usual care group for attempting to reduce smoking or intention to reduce smoking. Summary statistics demonstrated that participant numbers were too small to conduct a regression analyses on variables that assessed smoking behaviours as the small numbers in the outcome would influence the planned analyses and effect sizes for the independent variables.

Table 13. Summary statistics for smoking behaviour at post-stroke time-points.

Smoking	n	Intervention (%)	Usual Care (%)
<i>28 Days (T1)</i>			
Current smoker	19 (6.1)	8	11
Attempted to reduce smoking	17 (89.5)	7	10
Intends to reduce smoking	18 (94.7)	7	11
<i>Six Months (T2)</i>			
Current smoker	20 (6.1)	7	13
Attempted to reduce smoking	11 (55)	4	7
Intends to reduce smoking	17 (85)	6	11
<i>Twelve Months (T3)</i>			
Current smoker	21 (6.4)	5	16
Attempted to reduce smoking	14 (66.7)	4	10
Intends to reduce smoking	18 (85.7)	5	13

Note: samples too small to calculate χ^2

4.5.5 Diet behaviour

Table 14 shows the summary statistics for the final dependent variable in this study across all time-points: diet behaviour scores. At 28-days post-stroke, 112 participants reported that they had made changes to their diet following the stroke. The majority of participants reported that they ate 2 servings of fruit and vegetables per day, they rarely added salt to their food, and sometimes chose low or reduced salt varieties of food. The trends in diet were generally the same across the twelve-months following the stroke.

Table 14 demonstrates that the number of participants who reported making changes to their diet decreased across the twelve-months following the stroke ($n_{28\text{days}}=112$, $n_{6\text{months}}=67$, $n_{12\text{months}}=49$). No significant differences between intervention and usual care groups were observed for diet changes at 28-days post-stroke; however, data suggested that participants who were in the intervention group were more likely to change their diet at six-months and twelve-months following a stroke (Table 14).

Table 14. Summary statistics (including crosstabs) for changes to diet across time-points.

DIETARY CHANGES	n	Intervention (%)	Usual Care (%)	χ^2 , p value
<i>28-Days (T1)</i>				
Yes, made diet changes	112 (35.8)	59 (38.3)	53 (33.3)	0.84, 0.36
No	201 (64.2)	95 (30.4)	106 (33.9)	-
<i>Six Months (T2)</i>				
Yes, made diet changes	67 (20.3)	38 (22.9)	29 (17.7)	17.84, 0.01**
No	263 (79.7)	128 (38.8)	135 (40.9)	-
<i>Twelve Months (T3)</i>				
Yes, made diet changes	49 (14.9)	26 (16.1)	23 (13.8)	15.12, 0.01**
No	279 (85.1)	135 (41.2)	144 (43.9)	-

Regression analyses were used to investigate whether acute illness perceptions or satisfaction with stroke care explained the variance in the outcomes of diet-related health behaviours at 28-days post-stroke. The first aspect of diet behaviour that was assessed examined whether participants reported if they had made changes to their diet following the stroke. To address the primary hypotheses, 177 participants were included in the logistic regression analysis at 28-days. Table 15 shows no significant relationships between satisfaction with stroke care, illness perceptions, and diet change at 28-days post-stroke.

Logistic regression analyses were also conducted to investigate if the predicted relationships emerged at later time-points post-stroke. Table 15 illustrates that the practical dimension of B-IPQ made a significant contribution to reported diet change at six-months post-stroke ($p=.006$). A test of the model, including predictors against the constant only model, was statistically significant $\chi^2(5) = 13.63$, $p=.018$, indicating that practical illness perceptions reliably distinguished between cases and control. The Hosmer-Lemeshow Goodness of Fit test was not significant ($p=.69$) which suggested that the model prediction did not differ significantly from the observed.

Table 15. Logistic Regression Analysis for diet changes at post-stroke time-points.

CHANGES TO DIET	Beta	SE	P value	OR	95% CI	
					Lower	Upper
28 Day (T1)						
Constant	13.41	10.32	.19	-	-	-
Treatment Condition	-.41	.34	.24	.67	.34	1.30
Age**	-.05	.01	.001	.95	.92	.97
Practical IPQ	-.03	.09	.73	.97	.81	1.15
Emotion IPQ	.03	.09	.70	1.03	.87	1.23
SASC	.57	.43	.19	1.76	.76	4.07
Six-month (T2)						
Constant	20.26	12.58	.11	-	-	-
Treatment Condition	-.61	.42	.15	.55	.24	1.25
Age	-.02	.02	.16	.98	.95	1.01
Practical IPQ**	-.37	.14	.001	.69	.53	.90
Emotion IPQ	-.01	.11	.92	.99	.80	1.23
SASC	-.59	.51	.24	.55	.21	1.49
Twelve-month (T3)						
Constant	7.89	13.73	.57	-	-	-
Treatment Condition	-0.16	0.46	0.72	0.85	0.34	2.09
Age	-0.03	0.02	0.09	0.97	0.94	1.00
Practical IPQ	-0.09	0.12	0.46	0.92	0.73	1.16
Emotion IPQ	-0.16	0.13	0.22	0.86	0.67	1.10
SASC	-0.80	0.56	0.15	0.45	0.15	1.34

Note: *p<0.05, **p<0.01

The Wald Criterion suggested that the practical illness perceptions made a significant contribution to prediction of diet change at six-month (Table 15), Wald statistic =7.49, $p=.006$. The analyses illustrate that as the score for the Practical B-IPQ increased by one, the odds of participants reporting a change in diet decreased by .69. This suggests that as participants reported more threatening practical illness perceptions, they were less likely to report a change in diet. No significant relationships between satisfaction, illness perceptions, and diet change were observed at twelve-months post-stroke.

A second component of diet-related health behaviour was assessed relating to portion of fruit consumed, portions of vegetables consumed, salt added to food, and food choice of reduced salt. Analyses demonstrated that no predicted relationships were observed at 28-days for portions of fruit consumed ($n=60$, $R^2=-.06$, $p=.45$), portions of vegetables consumed ($n=52$, $R^2=.09$, $p=.23$), added salt to food ($n=60$, $R^2=.04$, $p=.29$), or reduced salt food options ($n=56$, $R^2=.01$, $p=.04$) (see Appendix G for linear regression of fruit and vegetable consumption).

Analyses investigated if the predicted relationships occurred at later time-points following the stroke. Table 16 demonstrates that emotional illness perceptions were a significant predictor of adding salt to food at six-months post-stroke. At six-months, the independent variables explained 3.6% of the variance; and the model was statistically significant, $F(5,17)=3.49$, $p=.023$. The B value indicated that as the score for emotional illness perceptions increased by 1, the score for adding salt to food increased by .56. This suggests that as participants report more threatening emotional illness perceptions, they are more likely to add salt to their food. However, caution when interpreting this result is needed due to the small sample size ($n=31$).

Similarly, Table 17 demonstrates that practical illness perceptions were suggested as a significant predictor of choosing food that had reduced salt at six-months post-stroke. At six-months, the independent variables explained 2.7% of the variance. However, the model for this relationship was not significant, $F(5,17)=2.62$, $p=.06$. The B value indicated that as the score for emotional illness perceptions increased by 1, the score for choosing food that had reduced salt decreased by -.53. Similarly, this suggests that

Table 16. Linear Regression for salt consumption at post-stroke time-points.

ADDED SALT TO FOOD		Beta	SE	P value	95% CI		Adjusted R ²
					Lower	Upper	
28 Day (T1)							
Constant	-	13.98	.29	-13.08	43.36	.04	
Treatment Condition	-.16	.47	.27	-1.47	.43	-	
Age*	.30	.02	.06	-.00	.08	-	
Practical IPQ	.05	.14	.72	-.23	.33	-	
Emotion IPQ	.13	.12	.38	-.14	.35	-	
SASC	-.15	.57	.34	-1.71	.60	-	
Six-month (T2)							
Constant	-	13.28	.85	-30.51	25.51	.36	
Treatment Condition	-.05	.45	.78	-1.08	.82	-	
Age**	.67	.02	.001	.02	.11	-	
Practical IPQ	-.02	.17	.93	-.36	.33	-	
Emotion IPQ**	.56	.14	.01	.09	.68	-	
SASC	.17	.60	.39	-.74	1.79	-	
Twelve-month (T3)							
Constant	-	21.81	0.73	-54.09	38.89	-.28	
Treatment Condition	0.12	.69	0.67	-1.16	1.76	-	
Age	-0.04	.03	0.92	-0.07	0.06	-	
Practical IPQ	-0.16	.19	0.63	-0.49	0.31	-	
Emotion IPQ	-0.02	.17	0.95	-0.36	0.34	-	
SASC	0.03	.74	0.93	-1.50	1.63	-	

Note: *p<0.05, **p<0.01

Table 17. Linear Regression for salt consumption at post-stroke time-points.

LOW SALT FOOD OPTIONS	Beta	SE	P value	95% CI		Adjusted R ²
				Lower	Upper	
28 Day (T1)						
Constant*	-	14.16	.04	-59.07	-1.90	.10
Treatment Condition*	.33	.47	.02	.17	2.09	-
Age	-.14	.02	.33	-.06	.02	-
Practical IPQ	-.20	.14	.17	-.47	.09	-
Emotion IPQ	-.09	.12	.55	-.32	.17	-
SASC	.08	.58	.61	-.87	1.47	-
Six-month (T2)						
Constant*	-	17.04	.05	71.85	.05	.27
Treatment Condition	-.33	.58	.10	.22	.10	-
Age	-.08	.03	.73	.05	.73	-
Practical IPQ*	-.53	.21	.02	-.11	.02	-
Emotion IPQ	-.16	.18	.46	.24	.46	-
SASC	-.34	.77	.13	.40	.13	-
Twelve-month (T3)						
Constant	-	18.53	0.10	6.59	0.10	.13
Treatment Condition	0.35	.58	0.15	2.14	0.15	-
Age*	0.78	.03	0.02	0.12	0.02	-
Practical IPQ	0.20	.16	0.45	0.46	0.45	-
Emotion IPQ	0.26	.14	0.32	0.44	0.32	-
SASC	0.46	.62	0.11	2.38	0.11	-

Note: *p<0.05, **p<0.01

as participants report more threatening practical illness perceptions, they are less likely to choose food that had reduced salt. Caution when interpreting this result is needed due to the small sample size ($n=29$). No significant relationships between the independent variables and diet-related variables were noted at twelve-months post-stroke.

Finally, a significant relationship was also observed between age and some of the diet variables. Table 16 demonstrates that as age increased by a score of 1, the odds of participants reporting a change in their diet relating to adding salt to their food increased by .67 at six-months, and increased their choice of low sodium options by .78 at twelve-months post-stroke. No significant relationships were observed between age and alcohol use. A significant relationship between treatment condition and choosing low salt food options was also observed at 28-days. Table 17 shows that for participants in the intervention condition, the odds of choosing low salt food options increased by .33 at 28-days for this sample.

4.6 Summary

Trends in alcohol consumption suggested that fewer participants drank more than five alcoholic drinks, and drank less frequently at 28-days post-stroke following the stroke; there were no significant differences between participants in the usual care group versus the intervention group. However, it was observed that alcohol use (alcohol use during past month and amount per day) gradually increased across the twelve-months following the stroke.

The number of participants who reported making changes to their diet decreased across the twelve-months following the stroke. No significant differences between intervention and usual care groups were observed for diet changes at 28-days post-stroke. However, data suggested that participants who were in the intervention group were more likely to change their diet at six-months and twelve-months following a stroke.

Participants reported higher levels of activity for general activity (how many days a week have you been physically active) compared to walking. While a significant

difference between the intervention and usual care group was observed for walking at 28-days, no other significant differences were observed for physical activity at later time-points.

No significant trends were observed relating to the increase in adherence to medication or smoking cessation was observed at the three time-points post-stroke; this could be because of small sample differences between groups and low sample sizes.

Chapter 5 Quantitative Discussion

This chapter discusses the findings from the quantitative study. The quantitative analysis aimed to answer two main hypotheses: Did greater satisfaction with stroke care predict improved health-related behaviour following first-ever stroke? Did more threatening illness perceptions predict improved health-related behaviour following first-ever stroke?

5.1 Summary of findings

This study explored the influence of illness perceptions and satisfaction with stroke care on post-stroke health-related behaviour. Illness perceptions were found to have two dimensions (emotional and practical) in people with stroke. It was revealed that more threatening emotional illness perceptions were linked to lower alcohol consumption at 28 days post-stroke, but this association did not remain at six- and twelve-months post-stroke. More threatening emotional illness perceptions were also linked to reduced physical activity at post-stroke time-points (28-days and six-months), and poorer diet at six-months post-stroke, with no associations at twelve-months. Practical illness perceptions were not found to be associated with health-related behaviour at 28-days (or twelve months) post-stroke. However, an association was indicated for more threatening practical illness perceptions and poorer diet at six-months post-stroke. Satisfaction with stroke care was not associated with significant changes in any health behaviours at 28-days (or twelve-months) post-stroke. However, increased satisfaction with stroke care suggested a reduction in physical activity at six-months post-stroke. Older age was found to significantly influence a reduction in frequency of physical activity and walking; however, these associations only remained significant for frequency of physical activity across all time-points. In contrast, older age improved diet choices at 28-days and six-months post-stroke. Health-related behaviour generally improved over time within this sample with the exception of smoking. Whilst the proportion of current smokers was low, this remained relatively stable over time. This small change in

health-related behaviours suggests the need for a more intensive intervention for this population of stroke survivors.

Figure 8 illustrates the relationships identified between illness perceptions, satisfaction with stroke care, and specific health-related behaviours at the primary time-point of 28-days following stroke. The results provide partial support for the predicted relationships between illness perceptions with health-related behaviours (Figure 8). However, there was no support for any significant relationships between satisfaction with stroke care and health-related behaviour at 28 days post-stroke.

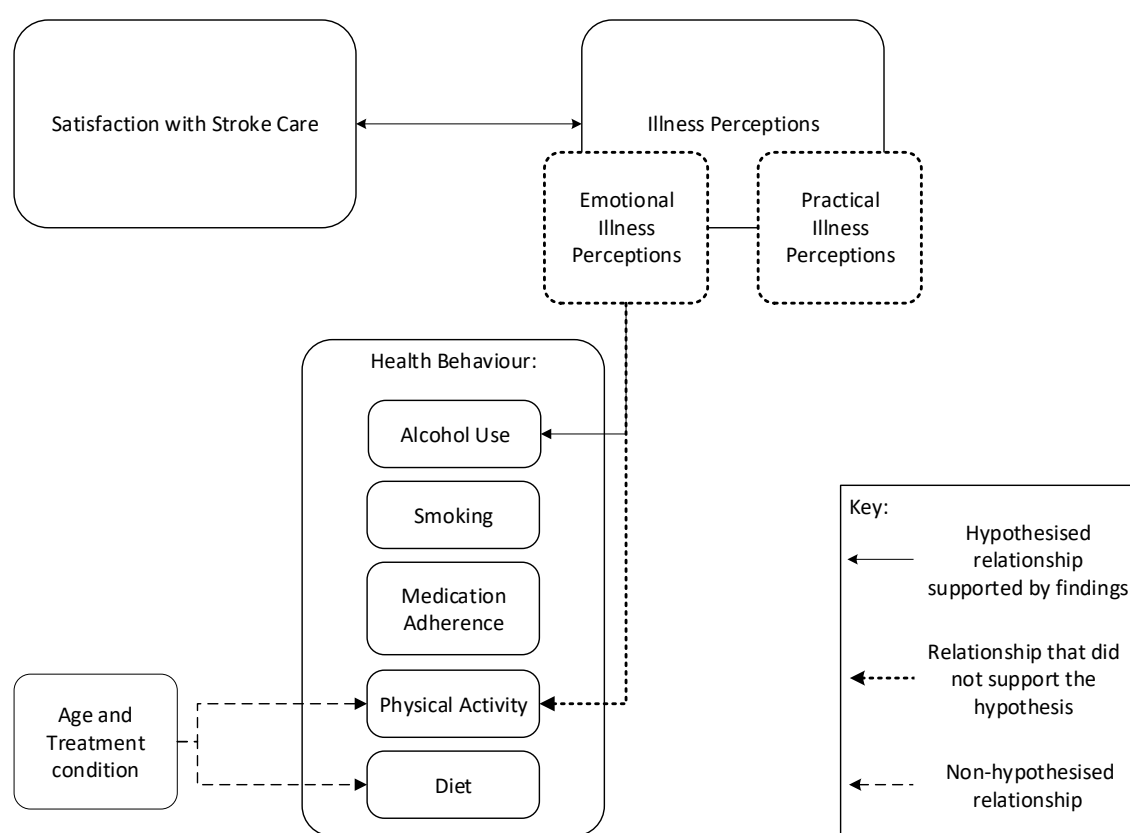


Figure 8. Findings indicating relationships between satisfaction with stroke care, illness perceptions, and health-related behaviours at the primary time-point of 28 days post-stroke.

Figure 9 illustrates the relationships identified between illness perceptions, satisfaction with stroke care, and specific health-related behaviours at the later time-points of six- and twelve-months following stroke. The results do not support the predicted relationships between illness perceptions and satisfaction with stroke care with health-related behaviours (Figure 9). However, the findings do indicate

relationships between these factors (which influence health-related behaviours in the opposite direction to the hypotheses).

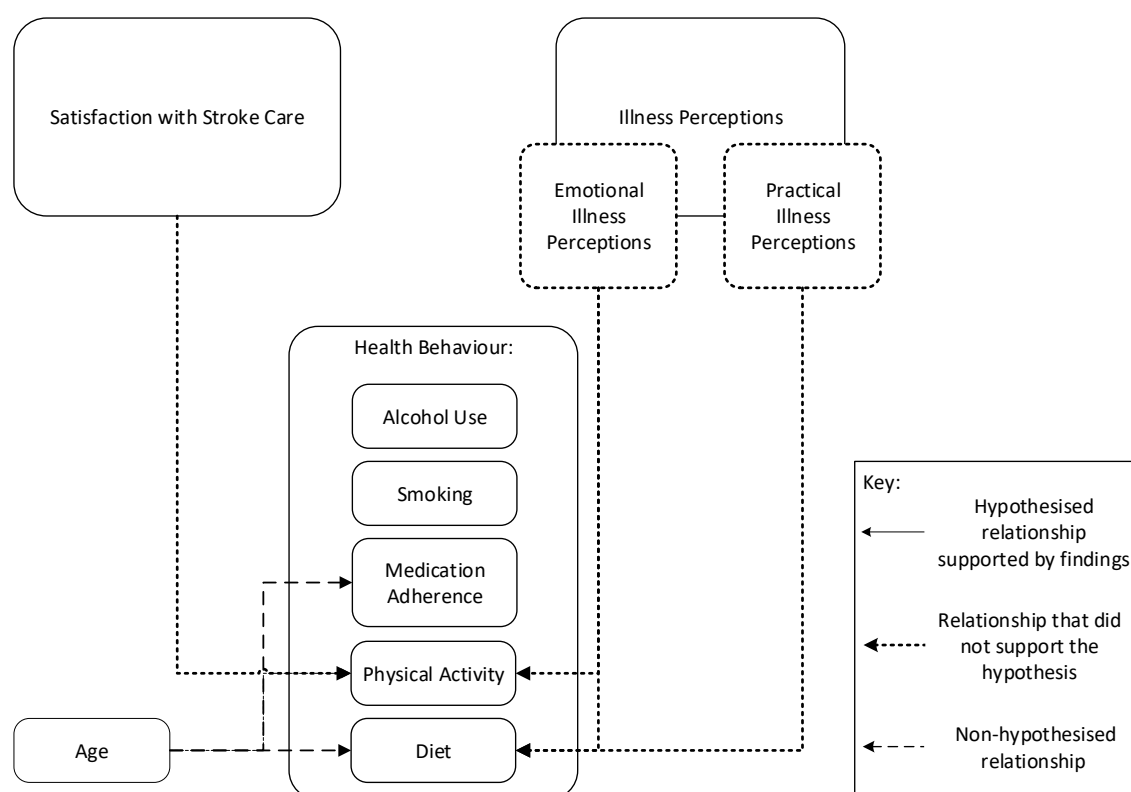


Figure 9. Findings indicating relationships between satisfaction with stroke care, illness perceptions, and health-related behaviours at the later time-point of six- and twelve-months post-stroke.

There were no significant associations between illness perceptions and satisfaction with stroke care with medication adherence at any time-points. This contrasts with previous research studies with clinical populations conducted in this area have shown that greater adherence to medication has been associated with less threatening illness perceptions (Broadbent et al., 2011; Krauskopf et al., 2015). These differences in outcomes might be the result of the differences between the clinical populations. For example, diabetes has a different illness trajectory to stroke, and this might be why illness perceptions influence health-related behaviours differently in these populations. The disparity in current results to previous data might have occurred because of the reduced sample size (from an overall sample $N=386$) for each predictor ($n_{B-IPQ}=177$; $n_{SASC}=198$). Medication adherence is a health-related behaviour that potentially has the greatest association with satisfaction with

stroke care (through memories of earlier interactions with health professionals every time the medicine is taken). This association might be expected to highlight the importance of satisfaction with stroke care for medication adherence. For example, a cross-sectional survey of diabetic patients found that self-care (including medication adherence) was associated with the doctor/patient relationship (Albright, Parchman, & Burge, 2001). The smaller sample size might also reflect a selection bias with cases of non-adherence less likely to participate in a study of this nature. Indeed, adherence to medication was generally high at each post-stroke time-point. High levels of adherence might impact ability to find significant trends in the data (i.e. the sample sizes between adherence and non-adherence were too small to find significant differences). Medication adherence remained relatively stable over time, although declined slightly at six-months. This might suggest that participants at 6-months post-stroke did not adhere to prescribed medication compared with earlier time-points because of improved post-stroke outcomes. Alternatively, non-adherence at six-months might have been associated with medication side-effects, or beliefs that no further improvements were possible.

While smoking has been identified as a modifiable risk factor for stroke (Romero, Morris, & Pikula, 2008), post-stroke rates of smoking in this participant sample were low (5.2%). This study indicated a population with a lower rate of smoking, and stable rate of smoking cessation; forty participants (10% of total sample: N=386) identified as pre-stroke smokers, and twenty participants reporting smoking cessation. This compared to a recent study of TIA or minor ischemic stroke (Brouwer-Goossensen et al., 2016) where 36 participants (36%: N=100) reported as smokers, with nine participants subsequently reporting smoking cessation. This suggests that sample sizes for changes to smoking behaviour tend to be smaller (possibly as the result of numerous campaigns to reduce smoking and increase literacy around risks associated with smoking). The small sample size related to smoking behaviour had implications for analysis, where the sample was too small to conduct the planned regression analyses. These implications around small sample sizes should be considered for future research around smoking cessation and health-related behaviours.

5.2 Satisfaction with stroke care

In contrast to previous literature, the findings did not support any of the hypothesized relationships between satisfaction with stroke care, illness perceptions or any health behaviour at the primary time-point of 28-days posts-stroke. Patient satisfaction with care has been linked to health-related behaviours (Albright et al., 2001), including diet, exercise, and medication adherence in other health conditions. For example, greater satisfaction with care was associated with improved diet in a population of diabetic patients (Albright et al., 2001). The contrast in findings might be due to the nature of the different populations and disease characteristics of the different conditions.

Although it was expected that acute SASC would have the most influence on health-promoting behaviours at the 28-day time-point, this study suggests that SASC scores influence health-related behaviour at later time-points. It was interesting that the only significant association that was observed was between satisfaction with stroke care and physical activity only at the 6-months post-stroke time-point. The direction of this relationship was the reverse of the one predicted; participants, who reported greater satisfaction with their stroke care, reported a decrease in their walking behaviour. It might be the case that disease severity could be influencing this relationship, as those with more severe symptoms and impairment receive more intensive rehabilitation and care. Alternatively, it might be the case that the timeline of illness or recovery influences satisfaction with stroke care. If stroke survivors believed they had been discharged prematurely, this might negatively influence their satisfaction with stroke care. A similar issue could also arise relating to the trajectory of treatment or discharge provided by health-care professionals. Expectations of recovery might also influence satisfaction with stroke care as stroke survivors might hold unrealistic expectations about their stroke outcomes or recovery.

Consequently, future research might benefit from exploring expectations of recovery and timelines of service provision and controlling for stroke severity might assist in understanding this finding. However, it also needs to be considered that this might also be a spurious finding due to the number of statistical comparisons made.

It should also be considered that satisfaction with stroke care in the acute phase (28-days post-stroke) might have been influenced by participation in the MIST-trial. Participants in this study would have experienced initial contact from MIST-trial researchers following their stroke. MIST-trial researchers would have made contact with the participants, consented and recruited them into the trial, and collected questionnaire-based data from them at 28-days. The SASC measure was collected at the end of this process. These participants would have experienced more contact than individuals in the general stroke population, which might have provided benefits to MIST stroke survivors (such as social support or perception of greater healthcare contact) when they were vulnerable following first-ever stroke potentially affecting generalizability of the findings.

The in-patient SASC had not been validated for a New Zealand population who had experienced a first-ever stroke. Exploratory factor analysis (EFA) was conducted on the 28-day data for the SASC (in-hospital subscale) and confirmed the original factor structure (cf. Boter et al., 2003). This suggests that the measure was appropriate for use with this group of people within its original factor structure. The measure also demonstrated good internal consistency (Cronbach's $\alpha = 0.73$), which suggested that the items in the scale measured the same construct. However, the summary statistics for the individual items and aggregated mean for SASC suggested a slightly positive skew, with the majority of people reporting greater satisfaction with their in-patient care, and little variability in this factor. As satisfaction with stroke care was relatively high, this might have prevented detection of the relationship between satisfaction with stroke care and health behaviours.

The independent variables in this study (illness perceptions and satisfaction with stroke care) were both measured at 28-day post-stroke. 28-days was chosen as the time-point that would be most relevant to examine with this group of people and provided an acute measure of each predictor as it was expected most change in health behaviour would be observed in the acute phase following stroke. With regard to satisfaction with stroke care, it was expected that the care participants received within hospital would be more homogenous at 28-days post-stroke, and the

experiences of in-hospital care would be 'freshest' for the stroke survivors; at later time-points, care received would be more diverse. It was assumed that measurement at 28-days would result in greater consistency and coherence between items in the scale. However, the stronger relationship between SASC and exercise health behaviour at six-months suggest that these associations might last longer and requires further investigation.

5.3 Illness Perceptions

While some evidence links illness perceptions to health-related behaviours, findings have not been consistent (Broadbent et al., 2011; Byrne et al., 2005; Krauskopf et al., 2015; Phillips et al., 2015; Yohannes, Yalfani, Doherty, & Bundy, 2007). For example, some studies have found converse relationships with more threatening illness perceptions can be associated with lower adherence to medication (Krauskopf et al., 2015) and poorer diet (Broadbent et al., 2011). In other studies, there has been no significant relationship found with health-related behaviour (Byrne et al., 2005). The findings of this study add to this complexity of findings, providing only partial support for the hypothesized relationship with only emotional illness representations linked to only two (alcohol use and frequency of physical activity) of the five different health behaviours studied. There were no links found between emotional or practical illness perceptions for smoking, diet or medication adherence.

The association between greater emotional concern (relating to their stroke) and a reduction in alcohol use at 28-days might be explained by a greater perceived risk (to health and survival) in the month following the stroke as this link was not sustained in the longer term (at six- and twelve-month follow up) and indeed alcohol use seemed to increase over time. However, this association might be explained by different conditions experienced at 28-days post-stroke: the stroke survivors might have been more dependent on others (limiting their alcohol intake) or their alcohol use might have been influenced by the environment they were in (such as hospital).

In considering illness perceptions, it was expected that the experiences of first-ever stroke at 28-days would provide the greatest contrast between pre- and post-stroke

life. There was an expectation that as time from initial stroke increased, the diversity in illness perceptions would increase. In addition, acute illness perceptions were most likely to measure illness perceptions relating to the stroke, rather than measuring illness perceptions relating to comorbidities or multi-morbidity (Schuz, Wolff, Warner, Ziegelmann, & Wurm, 2014); stroke survivors are highly likely to experience multi-morbidity and co-morbidities (Byles, Francis, Chojenta, & Hubbard, 2015). Measuring each construct (satisfaction and illness perceptions) once at 28-days also enabled the research to examine the duration of acute illness perceptions or satisfaction on health-related behaviours. These factors aimed to increase the coherence and consistency of each measure and guided the decision to measure illness perceptions at 28-days post-stroke. However, future research could measure illness perceptions and satisfaction with stroke care at equivalent time-points to the health-related behaviours they might predict, rather than using the one acute measure of illness perceptions and satisfaction (in this study).

Whilst there were no significant relationships between illness perceptions and diet at 28 days, a link was observed at six-months. More threatening emotional and practical illness perceptions were associated with poorer diet choice. These findings did not support this study's hypothesised relationships between illness perceptions and health-related behaviours; however, these findings do complement previous research findings. For example, less threatening illness perceptions have been found to be associated with poorer diet choices and physical activity in a diabetic population (Broadbent et al., 2011). In this study, more threatening illness perceptions at six-months might be associated with greater anxiety or concern about post-stroke outcomes. A participant's perceptions of poorer outcomes, or perceiving their condition as more severe, might act as a barrier for health-related behaviours (such as healthy diet) as participants might believe there is little they can do to improve their outcomes or reduce their risk of stroke. Alternatively, stroke survivors may not understand risk factors for stroke, and may not identify dietary control as a lifestyle change to reduce secondary stroke. It should be noted that although these effects are statistically significant as predictors, they are all small effect sizes (Cohen, 1992). This finding suggests that more research is needed to investigate if these

findings are representative of stroke survivors, as well as other illnesses. These results suggest that health-care interventions and practice can increase efforts to address the implications of post-stroke illness perceptions, and general awareness of stroke risk factors to facilitate health-related behaviour.

No studies have investigated the factor (dimension) structure of the B-IPQ with stroke populations; and the two-dimension structure identified is a novel finding of my doctoral research. Two dimensions based on the B-IPQ were identified for this sample, and were divided into items that related to aspects of emotional illness perceptions (with five items) and practical illness perceptions (with three items). This analysis did not confirm the factor structure (one dimension) proposed by the original authors (Broadbent et al., 2006). The two dimensions demonstrated good internal consistency (Cronbach's alpha Practical = 0.59, Cronbach's alpha Emotional = 0.79), which suggested that the items in each dimension measured similar constructs. Although the Cronbach's alpha for the practical dimension was low, it was deemed acceptable for a dimension containing three items (Pallant, 2013). This evidence, in addition to the research suggesting that the B-IPQ was not one-dimensional, guided the decision to use the two dimensions of B-IPQ identified for this sample.

Within this sample, emotional illness representations were found to have greater links with health behaviour. The emotional impact of stroke has been the focus of qualitative and quantitative studies. Cognitive and emotional factors have been associated with illness and its treatment (Phillips et al., 2015) and affective state is linked to health promotion. For example, fear or negative affective states can predict intention to change health behaviour following a stroke (e.g. Brouwer-Goossensen et al., 2016). Similarly, mood disturbances (e.g. apathy), or long-term cognitive impairments, resulting from the stroke might impact the affective state of the stroke survivor (Byles et al., 2015; Kotila et al., 1984). This might indicate the importance of the emotional response to the stroke event, residual impairments, and recovery process. Limited evidence exists on this relationship between emotional IPQ items and health-related due to the lack of testing of the underlying factor structure of the

B-IPQ for this population, so no comparable data exists. These findings highlight the importance of recognising emotional aspects of stroke and its influence on health-related behaviours. An awareness of differences in participant illness perceptions have important implications for health-care practice; the majority of health professionals consider the practical factors of illness as priorities for rehabilitation and recovery.

There has been limited research investigating the factor structure of the B-IPQ with different patient populations (Schuz et al., 2014; Timmermans, Versteeg, Meine, Pedersen, & Denollet, 2017). In the two studies identified, neither support the original factor structure of the B-IPQ (Broadbent et al., 2006). In an ageing population experiencing multi-morbidity, three dimensions of the B-IPQ were suggested (Schuz et al., 2014), while two dimensions were suggested for a population experiencing heart disease (Timmermans et al., 2017); both these studies were conducted in Europe. The dimensions of the two studies were different to this study, possibly because of the focus on multi-morbidity, rather than first-ever stroke. The mixed evidence regarding the (original) factor structure of the B-IPQ suggests that the B-IPQ measure might not be psychometrically sound, or that this construct might need to be assessed differently within different populations. With this in mind, application of the scoring method suggested by the original authors should be considered carefully. Broadbent and colleagues (2006) suggest that items within the B-IPQ can be assessed individually, or an aggregate score can be created based on the items in the scale. The chosen method of scoring might hold implications for the data that is provided by the B-IPQ. Further investigation of the B-IPQ with stroke populations should confirm the two-dimension structure proposed within this thesis.

This study did not measure health behaviour 'change' over time, but assessed health behaviours at each time-point following the stroke. This analytic approach was chosen because evidence suggests fewer people continue to make changes to their health behaviours over the course of twelve-months; as time from an event (regarding health) increases, the effects of the stroke (e.g. general health, function, disability, risk or secondary stroke) decrease. The benefit of this analytic decision

meant that the effect sizes for the analyses weren't diminished because of focusing on 'change' between time-points. While this research focused on reported health behaviour at each post-stroke time-point, future research could focus on health behaviour change, including change scores across post-stroke time-points.

Significant relationships between emotional or practical illness perceptions and health-related behaviours were observed across 28-day and six-month time-points for alcohol consumption, physical activity, and diet health behaviours. This trend suggests that the predictors in this study might have greater influence on health-related behaviour in the first six-months following stroke. The shock of the event might help initiate intention to change health behaviour. However, there is also a need to juggle medical appointments, as well as managing prior commitments following a stroke which can make the shift from intention to change more challenging (e.g. Transtheoretical model: Prochaska & Velicer, 1997). Consequently, people might not have the time to consider health behaviour in the acute phase post-stroke. Health professionals should consider the implications of the post-stroke time-line, as it might have consequences for healthcare practice, including when health promotion is discussed. For example, there might be several opportunities to address health behaviour change during recovery. Stroke survivors might not be emotionally ready to participate in health behaviours soon after the stroke. Greater success with secondary stroke prevention might be achieved through identifying when stroke survivors are in a more stable routine to enable them to contemplate health-promoting behaviour and should be a consideration in the months following a stroke. Future research should also consider the implications of the post-stroke time-line for intervention studies, as it might have consequences for success of interventions with stroke populations.

5.4 Link between satisfaction with stroke care and illness perceptions

Illness perceptions can predict patient satisfaction (Frostholm, Fink, Oernboel, et al., 2005); stroke survivors who report greater satisfaction might also report less threatening illness perceptions (Frostholm, Fink, Oernboel, et al., 2005), or better functional status (Jackson et al., 2001). Therefore, stroke survivors who reported

greater satisfaction might not feel they need to exercise as their perceived risk is lower, or they are satisfied with their stroke outcomes or amount of recovery. At 28-days post-stroke, stroke survivors might still be coping with the stroke event and its implications; at six-months post-stroke, individuals who are more satisfied with their stroke care might report less physical activity because they might be satisfied with their post-stroke outcomes and recovery. As shown in Figure 8, illness perceptions were associated with satisfaction with stroke care.

5.5 Other covariates

Possible reasons for the lack of support for the hypothesized relationships between the two predictors, and each of the five health-related behaviours, following the stroke should be considered. The environment, that stroke survivors were in, might have influenced 28-day health-related behaviours. For example, if stroke survivors were in hospital at 28-day assessment, they would be unlikely to drink alcohol, smoke, and their diet would be restricted because of the hospital environment. It is possible that at 28-days post-stroke, stroke survivor diets were managed by healthcare professionals and/or caregivers; the opportunity to change their diet might not arise until later in the post-stroke period, such as at six-months post-stroke. Therefore, it is important to consider what the trends and significant findings in this study actually mean. Second, the health-related behaviour might not have been relevant to the stroke survivor (e.g. they might not consume alcohol, or a comorbidity might prevent them from engaging with physical activity). Third, the hypotheses aimed to answer a simple relationship between a predictor and an outcome; it might be the case that outcomes post-stroke were influenced by factors that weren't captured by this study (hidden moderators) e.g. self-efficacy, quality of life, multi-morbidity, caregiver influence. Future research could explore additional factors that are associated with illness perceptions, satisfaction, and health-related behaviours (to explain more of the variance in outcomes following stroke).

Previous research has suggested that age is a predictor of participation in health behaviours e.g. physical activity and medication adherence. For this group of people, there was a negative skew for age across time; this finding was to be expected, as

older adults are more likely to have strokes (Tobias et al., 2007). In this group of people, age was a significant predictor of mixed diet choices, increased medication adherence, and decreased physical activity at 28-days following a stroke. These findings complement existing evidence that suggests that older adults are less likely to exercise (Jurkiewicz, Marzolini, & Oh, 2011) but more likely to adhere to medication (O'Carroll et al., 2011). Therefore, motivating older stroke survivors to participate in health-related behaviours might be more challenging compared to a population of younger stroke survivors.

Age might also have implications for satisfaction with stroke care. The majority of my sample was aged over 65 years old (56%), with 32.3% of participants aged over 75 years old. Older adults are more likely to be satisfied with care received than younger adults (Jackson et al., 2001; Thi, Briancon, Empereur, & Guillemin, 2002); it is likely that age played a factor in the skewness of the SASC data in my study. This might hold implications for the interpretation of the results; if the sample had a normal distribution of age, more variability in SASC scores might have been reported, and SASC might have emerged as a significant predictor of health-related behaviours.

Older adults are more likely to experience illness and multi-morbidity (Barnett et al., 2012). The majority of participants reported experiencing at least one comorbidity following the stroke, with 78% of the participants in this sample reporting a comorbidity that was not directly relevant to the stroke they had experienced. Comorbidity has been reported to negatively impact self-care behaviours as well as illness perceptions (Bower et al., 2012; Schuz et al., 2014). Limited research has focused on multi-morbidity in older adult stroke populations; however, Schuz and colleagues (2014) highlight the importance of considering multi-morbidity in relation to self-care. Therefore, stroke survivor illness perceptions might not be solely about the stroke, but might relate to their general illness perceptions (including associations they have between the stroke and co-morbidities). These comorbidities might impact on health behaviour directly e.g. a hip replacement could reduce participation in physical activity or result in more threatening illness perceptions and

indirectly reducing stroke survivor participation through fear of consequences. In this study, comorbidity was not entered into the regression models as a predictor because of the limited sample sizes but should be accounted for in future research.

Furthermore, following first-ever stroke, individuals are likely to experience impairments that may impact on their activities of daily living. In this study, the Barthel Index was used to assess activities of daily living which enabled the study to stratify participants (within the parent-MIST trial) and to describe the participant sample in this study. 86.3% participants in this study scored between 18-20 on the Barthel Index indicating that the majority of participants in this study were independent and were able to perform most daily activities. This relatively independent sample of participants enables insight into strokes at the less severe end of the spectrum. While stroke severity has been associated with health-related behaviours following stroke, the Barthel Index was not used as a covariate in the regression models because of the limited sample sizes. The limited sample sizes for the different health behaviours (e.g. physical activity) meant that the power for these analyses would not be enough to infer statistical significance. However, the influence of stroke severity on health-related behaviours, and particularly physical activity, should be considered in future research.

Two further covariates that might be associated with comorbidity or multi-morbidity are the 'hidden symptoms of stroke' and the 'hidden risk of stroke'. These 'hidden' factors might influence illness perceptions or its relationship with health-related behaviours. Common stroke outcomes associated with 'hidden symptoms' of stroke or comorbidity include depression (Chahal, Barker-Collo, & Feigin, 2011), cognitive impairment (Cumming, Brodtmann, Darby, & Bernhardt, 2014), and fatigue (Moran et al., 2014); these factors are likely to influence satisfaction, illness perceptions, and health outcomes. HADS and MMSE were measured by MIST and used as screening criteria for inclusion in the MIST-trial (Krishnamurthi et al., 2014). The use of these measures resulted in a 'relatively well' stroke population, with people experiencing mild anxiety or depression or mild impairment. Future research could investigate the influence of 'hidden symptoms' and comorbidity on illness perceptions and health

outcomes in a representative stroke population. These measures were not able to be included within the scope of this thesis but should be considered in further research.

‘Hidden’ factors might also be interpreted by stroke survivors to mean no lasting effects or risk of stroke and cause the stroke survivors to perceive their stroke as less threatening. Conversely, the hidden symptoms or hidden risk could cause greater feelings of uncertainty and anxiety in stroke survivors, and cause more threatening perceptions associated with stroke. Health literacy might influence this relationship (between hidden factors and illness perceptions). However, a suggestion for future practice (including education) could refer to and focus on ‘stroke’ as a longer-term condition (like CVD). Stroke is often referred to as an event, and ‘hypertension’ is used to refer to the longer-term aspects/condition associated with stroke. The implications of how people understand the differences between ‘stroke’ as an event and ‘stroke’ as a longer-term condition should be considered.

The final covariates to consider were associated with conducting this study within the MIST-trial. The MIST intervention aimed to increase participant self-care and motivation for healthy behaviours following stroke. It was important to consider treatment condition because participants were either experiencing usual-care or a motivational interviewing intervention. The MIST-trial found no significant outcome for blood pressure and lipids in the intervention versus usual-care group (Barker-Collo et al., 2015). However, it was important to include treatment condition as a predictor of outcome in the analyses of this study to consider any potential effects of the intervention on the study data. Indeed, treatment condition predicted an increase in walking behaviour and improved diet choices at 28-days post-stroke and had significantly increased medication adherence at nine-months post-stroke compared to controls. These findings suggest that motivational interviewing did influence these health behaviours. This suggests that motivational interviewing might facilitate acute health behaviour change in stroke survivors; however, the lack of association between the intervention and later time-points suggests that a stronger intervention is needed for longer-term health promotion.

5.6 Sample considerations

When considering the demographics of my sample, it was evident that there was a low uptake of people identifying as Māori (8.8%) and Pacific Islander (7.3%), as well as Asian/South Asian (1.8%) and Indian (2.3%) participants; the largest group of participants were made up of NZ European/European (63%). The NZ population is culturally diverse and the requirement for participants to be English speakers might have reduced participation from other ethnic groups. The low-uptake of participants from different ethnic backgrounds is an issue for representability for the findings to other cultural backgrounds. Cultural differences have been associated with differences in reported illness perceptions and health behaviours in a cross-sectional study of Pacific Islanders, South Asians, and Europeans experiencing diabetes (Bean, Cundy, & Petrie, 2007). Pacific Islanders reported shorter illness timeline perceptions, but more threatening illness perceptions relating to consequences, identity, and emotional representations (Bean et al., 2007); however, illness perceptions were not strongly associated with self-management. Therefore, an awareness of the potential impact of cultural differences on illness perceptions, as well as health-related behaviours, should be considered for this population of stroke survivors.

Data for this study were collected between August 2012 and November 2014 and provided access to 386 participants. There was an overall attrition of 12.5% of participants over time because of participant mortality, loss to follow-up, and non-completion. Of the 386 participants who completed study measures at 28-days, 56% completed B-IPQ measures and 62.3% completed SASC measures. The low numbers of completion for B-IPQ and SASC are an issue for representativeness. However, power calculations indicated that a minimum sample of 92 would be needed with a moderate effect size to test whether the variance explained by the model is greater than zero. An updated power calculation suggested that a sample size requirement of 55 participants would be needed to test the variance explained by the predictors (satisfaction with stroke care, emotional illness perceptions, and practical illness perceptions).

Low sample sizes were a key issue with the study. Low numbers of participants for health behaviour domains might have hindered the analyses e.g. to find trends in certain domains such as medication adherence, because adherence was so high and analyses were unable to compare between adherence and non-adherence. In addition, because this study examined individual health behaviour domains, rather than an aggregate score for all health-related behaviour post-stroke, some participant samples were too small to run regression analyses. For example, only forty people identified as smokers pre-stroke, and twenty people stopped smoking following the stroke; a minimum of ten cases per predictor are needed for regression analyses (Courvoisier et al., 2011). Whilst the small sample sizes are not ideal, the variation in sample size across health-related behaviours are a reflection of conducting research in the real world.

Although issues with sampling were evident (e.g. small sample sizes), conducting this study within the parent MIST-trial provided a number of advantages including access to a large sample of stroke survivors who had experienced first-ever stroke, with demographic data collected systematically at baseline. Additionally, as part of the trial all medical records for participants were extracted providing comprehensive data on stroke type, treatment and medically confirmed diagnosis. Data which would not be accessible without considerable research funding.

The parent MIST-trial applied a number of inclusion and exclusion to the participant sample, which resulted in a relatively 'well' stroke population for the study; the implication of this is that the sample might be not representative of the entire stroke population. The MIST-trial screened for depression, anxiety, and cognitive deficits, which resulted in a population with reasonably mild outcomes. However given that the majority of research focuses on moderate to severe stroke (cf. Barker-Collo et al., 2016) this sample offers a unique insight into strokes at the less severe end of the spectrum which are more common (Barker-Collo et al., 2016; Barker-Collo et al., 2015; Chang et al., 2016; Rutherford et al., 2014). Exploring health-related behaviours in a population who have experienced mild stroke provides greater

understanding about a group of people who are more likely to experience benefits from health-related behaviour and reduce secondary stroke risk and occurrence.

5.7 Health Behaviour Measures

A strength of this study in comparison to previous research was that it looked across five different domains of health-related behaviour (smoking behaviour, alcohol consumption, physical activity, diet, and medication adherence) assessed over time. However, exploring the impact of many different health behaviours proved challenging. A combination of continuous and categorical questions were used to assess each health domain. A number of issues with the questionnaire design were identified. First, questions assessing each health behaviour were not identical or directly comparable. For example, smoking questions asked categorical questions about smoking status, while alcohol use measured the frequency of alcohol use on a continuous scale. Second, questions captured data for health domains if a change in behaviour had occurred; this held implications for missing data and sample sizes at later time-points because data for maintenance of health-related behaviours was not collected. This also meant that questions only captured data for health behaviours that were 'changing'; e.g. a person might have reported positive diet change at 28-days post-stroke which would have been recorded, but if the person only maintained this initial change at later time-points, the positive health behaviour would not be recorded. Third, these questions relied on self-report, which might have been affected by cognitive impairment and social desirability bias. Whilst questions across health behaviours were not directly comparable, trends in the data suggested moderate improvements across post-stroke time-points. Future research could develop comparable questions to investigate the range of health-related behaviours following stroke, with the aim of providing a measure of comparable and relevant questions for health behaviours following first-ever stroke.

Measures in this study were potentially subject to error. Health behaviour constructs and satisfaction with stroke care were assessed using non-linear scoring (i.e. non-linear scales). Sometimes, these scales would have a true zero (e.g. questions for diet that provided 'never' as an option) but the distances between levels (in the scale)

were not equal. With regards to the SASC measure, the scale was a four-point Likert scale and did not have a true zero; each participant and their subjective self-reported SASC would have influenced the measurement and interpretation of this scale. The implications of the non-linear scoring for health-related behaviour items should also be considered when interpreting these findings i.e. does an increase in score of .16 mean much for a non-linear scale. Nonetheless, the understanding gained from this study in relation to health behaviour and influencing factors should not be underestimated. Future research could include a restricted or amended range of responses for some variables. For example, continuous scales could ensure a true zero and linear scale for measurement purposes to increase coherence and consistency.

While the questionnaire measures asked a range of questions relating to the five health domains, the questions focused on actual behaviour but did not assess relevant health-related factors that might have influenced stroke survivor health behaviour. A limitation of the questionnaire was that although health-related behaviours were assessed, the questionnaire did not ask why participants had made a change (e.g. if they had been influenced to change because of doctor recommendation, worried about stroke risk, physically unable to cook for themselves etc.). Neither did the questionnaire assess the health literacy of participants, ask if they understood stroke risk, or if they understood why they should reduce risky health behaviours following a stroke. This might be an issue for health-care practice following stroke. How do people decide which health behaviours to change if they are unsure or unaware of risk? A third consideration noted that the questionnaire did not look at compensatory health behaviours (Amrein, Rackow, Inauen, Radtke, & Scholz, 2017). For example, stroke survivors might choose to change a riskier health behaviour (like smoking) and not feel they need to change other health behaviours. Additionally, the analyses did not assess participants who reported positive behaviour in more than one health domain. Future research could assess more factors that are associated with health-related behaviours, as well as measuring these domains in a comparable way.

5.8 Conclusions

Engagement with health-related behaviours varied over-time for participants within this sample. Four main findings were observed. First, two dimensions of illness perceptions were suggested for this sample; this suggests that emotional illness perceptions and practical illness perceptions are different dimensions for stroke survivors following first-ever stroke. Second, greater satisfaction with stroke care was not demonstrated to have a significant relationship with increased health-promoting behaviours following stroke. Third, more threatening emotional illness perceptions demonstrated a significant relationship with improvements in one of the health-related behaviours (alcohol use) and partially supported the hypothesis. Finally, more threatening illness perceptions demonstrated significant relationships with poorer health-related behaviours (diet and physical activity) at later post-stroke time-points.

Chapter 6 Qualitative Methodology and Method

This chapter outlines the methodology and methods used to answer the question: "What influences health-related behaviour following a stroke?" An overview of the Interpretive Descriptive methodology is given, and details of the methods used for data collection and analysis discussed. The chapter will conclude with an overview of ethical considerations and strategies employed to ensure rigour.

6.1 Methodology

The Interpretive Descriptive Qualitative Approach is an inductive analytic qualitative approach developed by Thorne and colleagues (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997). This qualitative approach can be used to answer health-related questions (e.g. pertaining to health outcomes) and explore how interventions can be delivered more effectively. Interpretive description evolved as a method to generate strong and rigorous grounded qualitative knowledge relating to health-related contexts, with an interpretive or explanatory tone (Hunt, 2009; Thorne, 2008; Thorne et al., 1997). The tone of this approach enables researchers to inform actionable and pragmatic insights to health-related questions and contexts.

Interpretive Description was chosen as an appropriate methodology for this study for several reasons. First, this study was driven by an interest in the participation of stroke survivors with motivational interviewing and its impact on health-related behaviour. The aim was to inform the delivery of motivational interviewing within the stroke context and yield meaningful results for health-related practice. Because interpretive description evolved as a method to develop knowledge about human health and the illness experience it was recognised as an appropriate method to explore this research topic.

Second, as little is known about the factors that influence health-related behaviour following stroke, this was an exploratory study. This study aimed to identify unique factors that were less amenable to measurement. Hunt (2009) and Thorne (Thorne, 2008; Thorne, Kirkham, & O'Flynn-Magee, 2004) have suggested that Interpretive

Description is particularly useful for exploratory studies as it is not restricted by theory or pre-determined coding frames.

Third, Interpretive Description enabled the use of multiple approaches of data collection and analysis to capture the wider experiences of stroke survivors, significant others, and motivational interviewers. Each of these groups have valuable experiences and perspectives relating to the stroke survivor. Some of these experiences will be unique to that group, while other experiences will be shared across groups. Multiple approaches to data collection facilitated exploration of these phenomena. With this in mind, the importance of participant preference for how interviews were delivered was acknowledged (e.g. cultural considerations, as well as being sensitive to different relationship dynamics). Consequently, stroke survivors were offered the option to complete their interviews with their significant other present (as a dyad) or to have separate interviews. Following consultation with the motivational interviewers, it was also considered important to offer the option to complete the interview individually or as a focus group. The impact of multiple approaches of data collection on analysis were taken into account through constant comparison methods to explore the impact of interview modality on analysis. Whilst adding to the complexity of the analysis, successful analysis requires flexibility when using techniques for "comprehending, synthesizing meanings, theorizing relationships, and re-contextualising data into findings" (Thorne et al., 2004, p. 11); this flexibility may therefore assist in adding rigor to interpretive findings.

Guided by the philosophical basis of the interpretive descriptive method, this research draws on social constructionism as its epistemological foundation. The philosophical basis for interpretive description acknowledges the constructed and contextual nature of lived experience (Thorne et al., 1997); these lived experiences can also be shared with (and influenced by) other people. Social constructionism considers how social constructs, and beliefs about them, develop in social contexts (Crotty, 1998). This epistemology is concerned with the nature of knowledge, and how this knowledge is created (Andrews, 2012), with the aim to understand the world of lived experience from the perspective of the people who live in it. It focuses

on everyday human interactions, the language used to construct reality, and the social practices people engage with (Andrews, 2012). Social constructionism allows research to move beyond describing 'what is', and to consider 'what caused this to be?' and 'what does this create?' (Crotty, 1998).

This doctoral study explores health-related behaviour following first-ever stroke in terms of 'how things are' and 'what influences behaviour'. This fits with social constructionism, in that the research explores the social interactions of stroke survivors and how others can influence behaviour, as well as the language used by individuals post-stroke. As outlined below, it is important to consider the social context as part of the post-stroke experience:

Interpretive practice engages both the hows and the whats of social reality; it is centred in both how people methodically construct their experience and their worlds, and in the configurations of meaning and institutional life that inform and shape their reality-constituting activity. (Holstein & Gubrium, 2005, p. 484)

In addition to the 'hows and whats of social reality', how people interpret their social reality and how they react to their reality needs to be considered. Symbolic interactionism provides the ontological foundation for this study as an approach for considering human behaviour, particularly the actions or responses of humans towards stimuli (i.e. the stroke). The principles of symbolic interactionism are "that human beings act towards things on the basis of the meanings that these things have for them" (Blumer, 1969 p.2). These meanings can be influenced by social processes (Oliver, 2012) and through an internalized interpretive process (Blumer, 1969, p.2). *Meaning-making* is an on-going process (Charon, 2010) that helps a person adopt a perspective that fits best with how the person defines themselves in a given situation. Consequently, the meanings people hold towards things, and their perceptions of an experience are not static. Individual perspectives communicate something important about that person's reality, and can provide insight into how something works, whilst contributing to understanding of the phenomenon in a "real world" sense. For research conducted with a symbolic interaction perspective, Charon (2010) proposes that close attention should be paid to the meaningful

objects people attend to, how they interpret these and how they react in response. Attending to people's descriptions around *meaning-making*, their actions, and processes supports the research question of what may influence health-promoting behaviour after a stroke, and also why they participate in health behaviours.

Limited research explores the overarching influence of meaning and interpretation of social context on health-related behaviours following a stroke. Studies have explored the influence of social relationships e.g. influence of caregivers (and significant others) and health professionals, and highlighted the importance of good communication and a supportive relationship with mutually agreed goals (e.g. Morris, 2016). Yet, despite the importance of health behaviour to recovery and risk of recurrent stroke, the meaning of stroke in relation to health-related behaviour, and how social or internalised processes may influence this, has received little attention.

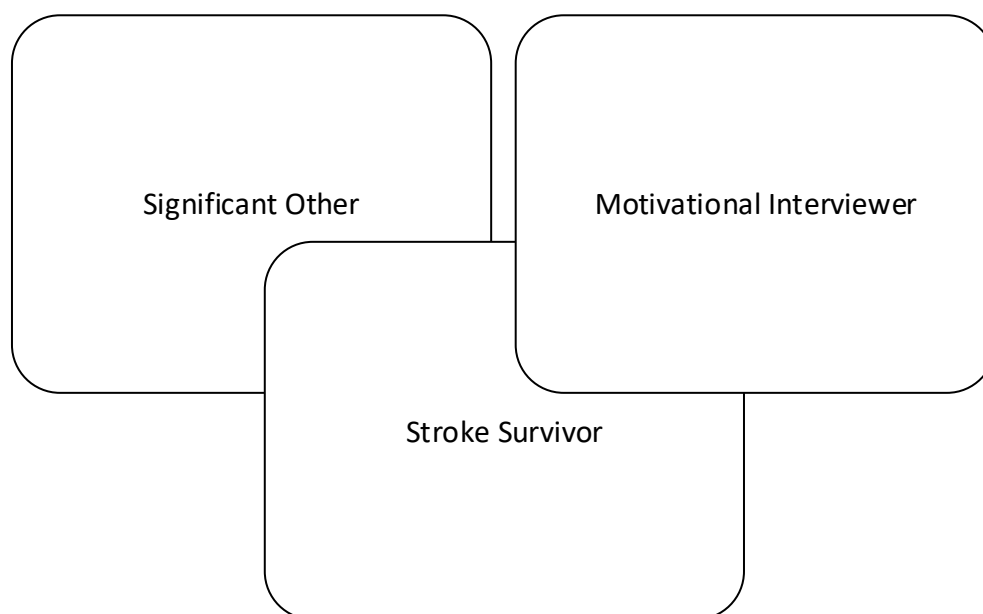


Figure 10. Relationships experienced by stroke survivors potentially influencing post-stroke health-related behaviours within the context of the MIST-trial.

Based on the epistemology and ontology (theoretical framework), the context of this study within a RCT of motivational interviewing, and the potential influence of social processes on health-related behaviours following a stroke were considered. This research aimed to capture the perspectives of three populations that have been

identified to influence post-stroke health behaviour: the stroke survivor, the significant other, and the motivational interviewer (see Figure 10). This multi-perspective approach enabled a holistic approach for exploring the research question with three populations that interact, whilst capturing individual perspectives about the phenomenon of interest.

6.2 Methods

6.2.1 Participant sampling and recruitment

This study drew from a convenience sample of stroke survivors who participated in the parent MIST-trial. Three groups of people (see Figure 10) were asked to describe stroke survivor health-related behaviour and identify factors that may influence engagement in health-related behaviours. This included the person affected by stroke, their significant other and motivational interviewers (who worked on the parent MIST-trial in assisting people to change their health-related behaviours). Stroke survivors and their significant others were recruited into the study from November 2014 until February 2015. The motivational interviewers were recruited into the study from January 2014 until December 2014.

The advantages and limitations of recruiting participants from a convenience sample were considered for this research. The main advantages of this approach were, first, it enabled access to a large population of stroke survivors who had a verified diagnosis of first-ever stroke. Second, participants were recruited at a specific time-point following first-ever stroke. Third, it facilitated exploration of health promotion in this group of people e.g. because of the focus of the parent MIST-trial, all participants (intervention and usual care) were aware of the focus on health behaviours, and therefore were aware of the need for uptake of health-related behaviour.

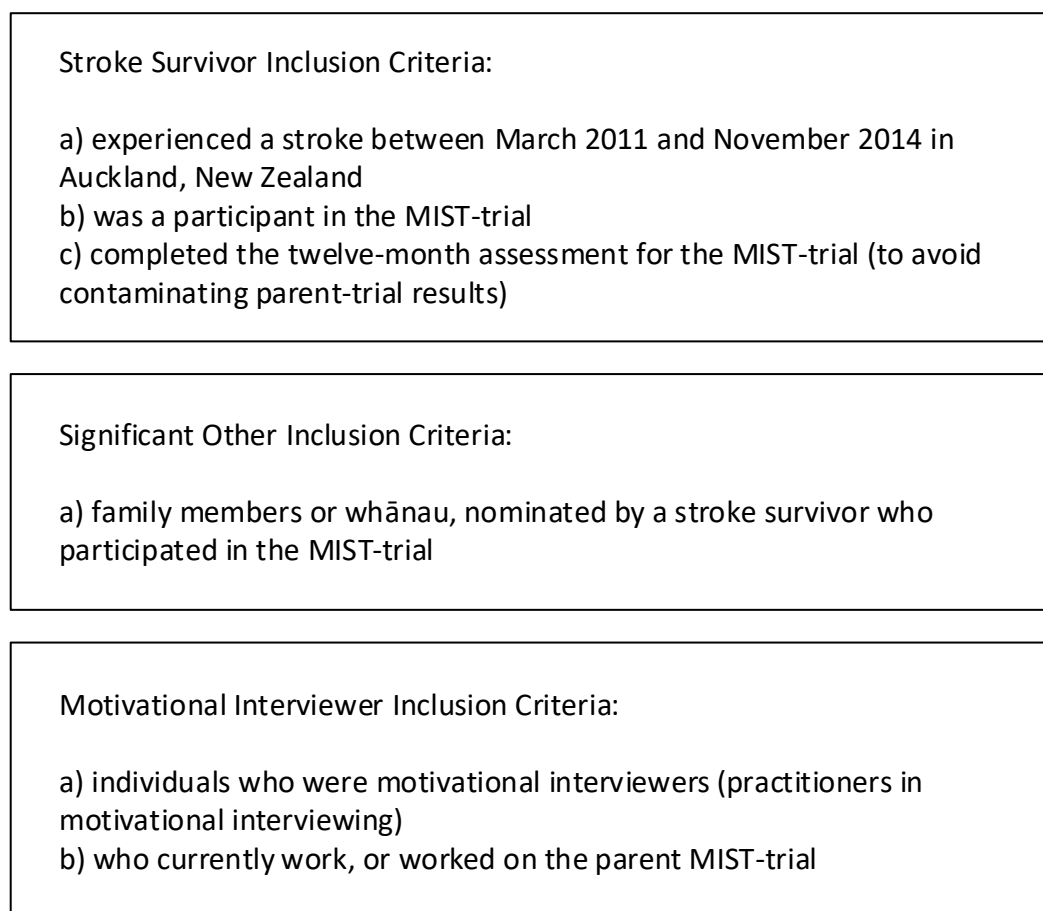


Figure 11: Participant inclusion criteria.

Sampling of stroke survivors

Sampling strategies were used to recruit participants who matched the inclusion criteria⁵ for each of the three participant populations (see Figure 11). Following identification of all potentially eligible participants, purposive sampling (e.g. Holloway & Wheeler, 2002) was applied to the recruitment strategy of this study to capture diversity of experience. This sampling strategy was guided by the participant group (MI vs. UC), age, gender, ethnicity, and stroke severity. The systematic approach to recruitment ensured that participants receiving the MI intervention and participants receiving usual care were represented. This was to allow for the possibility of differences in health outcomes between the two groups, if the MI intervention proved to be effective. Additionally this approach enabled selection of

⁵ Inclusion and Exclusion Criteria for this study match the criteria in Study One.

stroke survivors based on age, gender, ethnicity and stroke severity to achieve maximum variation, to enhance the heterogeneity of the sample, and ensure sufficient variability of experience (Patton, 2002; Ritchie, Lewis, & Elam, 2013; Sandelowski, 2000; Strauss & Corbin, 1990; Thorne et al., 1997; Thorne et al., 2004). For example, gender differences (Feigin et al., 2010), ethnicity (Baskett & McNaughton, 2003), caregivers (e.g. McCarthy & Lyons, 2015) and differences in levels of post-stroke dependency (Barker-Collo, Feigin, Parag, Lawes, & Senior, 2010) may influence stroke recovery and post-stroke goals of stroke survivors. This sampling strategy enabled the recruitment of a range of individuals, who possessed pre-selected variables that had been identified as factors that may have influenced their post-stroke experiences.

6.2.2 Recruitment Procedure for stroke survivors and significant others

Recruitment for this component of the doctoral thesis occurred after stroke survivors had completed all MIST-trial assessments. Following completion of the final twelve-month assessment for MIST, a list of potentially eligible stroke survivor's details were provided to the researcher. This approach was used to reduce confounds to the parent MIST-trial. Recruitment was then driven by the researcher, who identified participants that matched the pre-selected characteristics (age, gender, ethnicity, and stroke severity) identified by the purposive sampling decisions.

The researcher contacted potential participants by telephone and provided them with information about the study over the phone and sent a hard-copy of the information sheet through the mail (see Appendix H-J for Information Sheet and Consent Forms). Stroke survivors were then asked to nominate a primary caregiver or significant other for this doctoral study (see nomination form at end of Appendix C). Significant others were defined as the primary informal caregiver, or person who spent a considerable amount of the day with the stroke survivor. Participants were not required to nominate a significant other in order to take part in the study. If a significant other was identified, they were sent their own information sheet (see Appendix I).

Participants were given the opportunity to read the information sheet, and to discuss the study with family or whānau (extended family). The researcher telephoned the potential participants again (at a pre-confirmed date and time) to confirm an interview time; participants were given the option to have a telephone interview or a face-to-face interview. Participants were also able to decide whether they wanted to be interviewed separately or as a dyad.

Sampling of Motivational Interviewers

The sample of motivational interviewers was a convenience sample of people who had worked on the parent MIST-trial as motivational interviewers. This population was approached to enable a holistic approach to explore the phenomenon of post-stroke health-related behaviour. This holistic approach aimed to capture external perspectives about health-related behaviours of stroke survivors, as well as insights relating to strategies within motivational interviewing that influenced the behaviour of this population. The motivational interviewers were recruited through the MIST-trial. As the team of motivational interviewers had been small, the entire team was invited to participate in this study to capture the range of experiences from this group. Enabling their participation was important, and prior to their interviews, a consultation process with the motivational interviewers was undertaken between November 2012 and October 2013. The purpose of the consultation process was to address any concerns of the team regarding their participation. Options to enable participation were provided to the motivational interviewers: telephone interviews versus face-to-face interviews were offered, and individual interviews versus a focus group were offered.

6.3 Procedure

Time was spent building rapport with participants before commencing the interviews to ensure that participants felt relaxed and comfortable with the interviewer. Participants were provided with another opportunity to ask questions. Participants were informed that they were able to decline participation, and withdraw at any point from the study, without their decision affecting their health-care service provision. The researcher checked that participants understood what

they were agreeing to in the study before asking them to sign the written consent form.

Written consent was obtained from each participant (including stroke survivors and significant others) prior to the interview process. Significant others were also asked sociodemographic questions on their age, gender, and relationship to the stroke survivor to inform the analysis). Following the consent process, participants were informed that the interviews would take between 45 minutes to 75 minutes. Interviews were audio-recorded and transcribed verbatim. Following transcription, accuracy checks were performed on each transcription.

The questions in the semi-structured interviews were initially informed by the research literature, and further developed through an inductive process as participants were interviewed. A semi-structured interview schedule was used to guide the interview, whilst allowing flexibility for the participant to discuss issues relating to post-stroke health behaviour that were important to them (refer to Appendix K and L). The interview explored people's participation in the MIST-trial, processes associated with health-related behaviours, experience of motivational interviewing in the MIST-trial, and experience of services received post-stroke.

The semi-structured interview enabled the researcher to explore the research question with each participant, whilst gaining an understanding of individual's experiences, perspectives, meaning-making, and knowledge development. The interview questions were used flexibly, in conjunction with probing and follow-up questions to ensure the flow of the interview and to fully explore the topic of interest. Probing questions were used to enable the participant to elaborate on responses or to clarify information (Starks & Brown Trinidad, 2007) adding rigour to the research process as well as enabling an inductive process to inform later interviews (Charmaz, 2002; Mills, Bonner, & Francis, 2006; Morse, 2012). Asking questions flexibly also enabled the researcher to respond to individual needs of participants (e.g. participant fatigue, or confusion: Staub & Bogousslavsky, 2001), as well as enabling the introduction of emerging concepts and questions that reflected

the individual experience of each participant. As new themes emerged, new questions were asked of subsequent participants to seek further clarification (Legard, Keegan, & Ward, 2003). Additional qualitative tools were used to promote communication with the participant. Silence, as well as words and noises of encouragement, were used to 'give permission' for the person to continue talking and enable participant to collect their thoughts. Simple reflections were also used by the researcher to confirm a topic the participant had talked about, or to go back to a topic the participant had mentioned earlier. Care was taken by the researcher to be 'present' with each person throughout the interview.

6.4 Data Analysis

6.4.1 Assumptions

An initial search of the literature had informed the analytic framework (or theoretical scaffolding), including the specific research question and sampling and data collection methods for the study. As proposed by Thorne and colleagues (2004), a rigorous analytic process in interpretive description involves exploring within and beyond the original scaffolding (the literature search identifying what may influence health-related behaviour following a stroke) to illuminate this phenomenon in a new and meaningful manner. As with all interpretive research processes, data collection and analysis informed one another iteratively, and the shape and direction of the research evolved as new possibilities were considered (Thorne et al., 2004). The analytic tools (e.g. memoing), as well as strategies to promote rigour and credibility (e.g. constant comparison), were used to manage and challenge these assumptions, to ensure that the findings were data driven as outlined below.

Thorne and colleagues (2004) state that issues of rigor and credibility are an important consideration in the creation of an interpretive description product. Thorne and colleagues (2004) recommend a constructively sceptical process that involves a second reviewer who can conduct an independent audit of the coding process. Consequently, to ensure coding accurately captured the meanings and experiences of the participants, a second coder (AT) independently coded the transcripts. Discussions between the researcher and supervisory team were also

held to challenge and question the analysis conducted by researcher. To support this process, memos, inductive analysis, and examples from the raw data were drawn on to ensure the code names were reflective of the data encompassed within each code. Participants were not asked to verify their transcripts to avoid participant distress or confusion if they were not able to recall the original interview (given the cognitive difficulties experienced post-stroke). However, participants were given the opportunity to comment on the summary of the findings to ensure correct interpretation.

6.4.2 Data Analysis Procedure

Data analysis was concurrent with data collection. Following transcription and accuracy checks, transcripts were read and re-read to gain familiarity and facilitate immersion in the data. To aid understanding of the data, note taking occurred immediately after the interview where the researcher recorded initial thoughts, impressions and interpretations.

Inductive analysis is characteristic of Interpretive Description (Hunt, 2009; Thorne et al., 2004) and can make use of multiple data collection and analysis techniques (Hunt, 2009; Thorne, 2008; Thorne et al., 2004). Following the initial stages of analysis, line-by-line coding and/or incident-by-incident coding was used to establish the initial descriptive codes enabling the researcher to look at both the micro and macro details respectively. The use of memoing, assisted the coding process.

Memoing was also used as an analytic tool to support ongoing analyses. Memos, in the form of notes, were written throughout data collection and analysis to describe the researcher's thoughts and questions about the analytic process. Codes were then refined to incorporate interpretive ideas relating to participation with health-related behaviours. This inductive analytic approach was driven by the data but informed by researcher knowledge and interpretation.

Constant comparison facilitated the refinement of codes to reflect differences in meaning, contexts, and experiences both within participant groups (e.g. stroke survivors) and between (e.g. stroke survivors and motivational interviewers or mild

versus more severe stroke severity). Iterative analysis facilitated the refinement of codes and themes. For example, when commonalities across themes were observed, these commonalities were incorporated into one theme that encompassed these similar aspects. These approaches are consistent with the interpretive descriptive approach used within this study (Thorne et al., 2004). Constant comparison and iterative analysis were strategies that helped to locate the findings within the theoretical scaffolding (of the existing body of knowledge), as well as lending understanding to explanatory factors that arose from the analysis.

6.5 Ethical Considerations

This study received ethical approval from the Health and Disability Ethics Committee (HDEC reference NTX/10/09/091/AM01; see Appendix M), and from the Auckland University of Technology Ethics Committee (AUTEC reference 11/298; see Appendix N) to study stroke survivors and their significant others. Separate ethical approval was granted by AUTEC (AUTEC reference 13/342; see Appendix O) with regards to contacting motivational interviewers for this study. An awareness of the importance of ethical principles for research guided the design of this research, and informed the ethical applications for the study. Ethical guidance principles that were addressed for this study included: participant burden; informed consent (particularly for stroke survivors who may experience cognitive impairments); voluntary participation; anonymity and confidentiality; duty of care and nonmalificence as outlined below.

6.5.1 Informed Consent

Informed consent⁶ can be challenging when conducting research with particular populations; for example, individuals with a range of impairments that reduce decision-making capacity or the ability to understand information (Dunn & Jeste, 2001). The researcher had an awareness of the range of impairments that the stroke

⁶ Informed consent is described by Conneeley (2002) as the voluntary agreement to participate in research based on the understanding and purpose of the research.

survivors may experience, as well as the level of burden that individuals may experience post-stroke. As a result, the study contacted stroke survivors and significant others twelve-months after the stroke with the aim of enabling participation when their level of burden had decreased, or when they had had an amount of time to 'recover' or 'rehabilitate' post-stroke. Stroke survivors and their significant others were encouraged to review the information sheet and consent form prior to the interview, and were given the opportunity to discuss it with each other, or with family or whānau before deciding to participate. Providing participants with the option of having a significant other present for the interview also enabled the significant other to provide support for stroke survivor communication. In addition to this study's consent process, the parent MIST-trial had screened participants to ensure that they were able to provide informed consent and had sufficient levels of cognitive functioning to participate.

6.5.2 Voluntary Participation

Participation in this study was voluntary. However, one concern the team of motivational interviewers voiced when this study was being developed, was about their voluntary participation; in particular, if they (as employees on the MIST-trial) were able to consent or dissent without implication for their roles. The consultation process highlighted the need for these individuals to feel 'safe' as individuals working on a project, and enabling them to feel they had the option to participate or withdraw from the study without any implications for themselves or their employment. The researcher aimed to address the concerns of this group throughout the consultation process by addressing the questions from these individuals, and constructively using their questions and feedback to inform the research question and design. As a result of this consultation process, the motivational interviewers were asked to participate once they felt confident with the outcomes of the consultation process, and were given the option of participating in a focus group or individual interviews. Finally, the motivational interviewers had requested to have access to their transcripts (after de-identification) for confirmation and clarification purposes. Following the consultation process and

refinements of study processed no further questions or comments from the motivational interviewers arose from this process and they all reported feeling freely able to either consent or decline to participate.

6.5.3 Confidentiality and Anonymity

A number of measures were taken to ensure confidentiality and anonymity in this study. First, the primary researcher allocated each participant a pseudonym. Each pseudonym was a name chosen from the top 100 boys' and girls' names from 1954 to 2016 provided by the New Zealand Department of Internal Affairs; for example, Susan. This enabled the transcript to be linked to the participant details but ensure that the participant's names could be removed from the transcript. Second, references to names of other people within the transcript were replaced by a pseudonym or description of the person to protect anonymity e.g the name 'Emily' was replaced with '[physio]'. Third, digital information (i.e. audio-recordings, transcripts, participant information) stored on the researcher's laptop were password protected. Last, hard copies of participant information (e.g. consent forms) were stored in locked filing cabinets separate to the interview transcripts.

Stroke survivor and significant other interviews were transcribed verbatim by the researcher, or by a reputable transcription company. The transcriber at the transcription company was required to sign a confidentiality agreement with the researcher. Audio files for transcription were uploaded to a secure folder on Dropbox. The transcriber was sent the link for the folder, and after transcription of each audio file was completed, the researcher deleted the audio file from Dropbox.

6.5.4 Nonmaleficence Or 'Do No Harm'

This study did not expect to cause harm to participants, although the researcher was aware that discussing post-stroke experiences may have been emotional for some participants. At the beginning of the interview, the participant was made aware that they could stop or pause the interview in the event that the interview caused an emotional response, or distress for the participant. The researcher also monitored

the person throughout the interview so that they could proactively offer a break for the participant if they observed signs of them becoming upset or fatigued.

The researcher was also aware of the importance of being 'present' during the interview to ensure they were able to respond sensitively to the feelings or thoughts of each individual. At times, some participants became tearful and voiced concerns about the stroke, their recovery, or their experiences. In these situations, the researcher acknowledged their emotion, offered the participant time to take a break, and if they remained upset provided the option to stop the interview. All participants who became upset during the interview chose to continue after taking some time out. Information about community services or health agencies was also provided to stroke survivors and caregivers where appropriate in response to concerns about service access or physical or mental health.

An awareness of participant burden was an ethical principle that guided the design and practice of this study. To enable participation and reduce participant burden, the participants were contacted after they completed participation in the MIST-trial (after the final twelve-month assessment). Interviews were scheduled at a time and place of convenience for the participant. All stroke survivors and significant others chose to participate in their own homes. Koha, in the form of refreshments, to acknowledge participants were sharing their experiences and given up their own personal time to take part.

6.5.5 Rigour

Four criteria exist to assess rigor and credibility in Interpretive Descriptive research (Thorne, 2008): epistemological integrity, representative credibility, analytic logic, and interpretive authority as outlined below.

Epistemological integrity requires that the research question, design, and approach are consistent with the “epistemological foundations” of the study (Thorne, 2008). The epistemological foundation and fit with the methodology and methods of this study is discussed at the beginning of this chapter, and the principles underpinning

Interpretive Description are discussed in relation to the study question, design, data collection and analysis.

Representative credibility requires that the findings reflect the sampling and data collection strategies used in the study. Analytic logic and interpretive authority are additional criteria that should provide rigour through a transparency to the research approach, and demonstrate that the findings are trustworthy and confirmable.

Multiple approaches to the data analysis, including analytic tools to support analysis were employed to strengthen the on-going analysis and research findings, as well as providing a transparency to the research approach. Assumptions about the research were identified in the design phase of the study and formed the theoretical scaffolding, and emerging assumptions (in the data collection and analysis phase); these were documented in memos. Analysis was data driven, and coding and analysis decisions were recorded throughout the analytic process. In addition, the supervisory team challenged and questioned analytic processes and findings, which ensured that the findings were robust and data driven. Finally, the final analysis involved reference back to participant quotes to demonstrate the themes and codes that emerged from the data; this provides evidence that the analysis was data driven and indicates the transparency of the analytic process.

Chapter 7 Qualitative Findings

You can't always see through the forest past the trees, but [health professionals] can often see through the trees and not necessarily the path. You've got to set the path, [health professionals] set your steps. (Karen, 57 years old, MI Intervention).

7.1 Introduction

This chapter presents the findings of the interpretive descriptive analysis. This approach was used to explore the question: What influences health-related behaviours following a stroke?

Separate analyses of the three participant groups (stroke survivors, significant others, and motivational interviewers) were conducted to explore the issues of importance to each group. However, because participants had experienced a journey together within the context of the MIST-trial, there was synergy between the identified codes and themes across the groups. Analysis of experience between the three groups was therefore combined. It was also observed that the narratives of the stroke survivors and significant others did not differentiate between the intervention and the usual-care group participants. Of the participants, only one stroke survivor briefly talked about explicit components of motivational interviewing, with all other content focused on health behaviour more generally. Consequently the two groups of participants were combined with unique features (both positive and negative) relating to motivational interviewing, or how participating in the MIST-trial influenced their health-related behaviour encompassed within the themes. This chapter will present the combined findings from the stroke survivors, significant others, and motivational interviewers, highlighting any disparities where apparent.

7.2 Participant Characteristics

Thirteen stroke survivors, eight significant others, and seven motivational interviewers (total N = 28) were invited to participate in this study. Four individuals (two stroke survivors, one significant other, and one motivational interviewer)

Table 18. Participant Demographics

Participant pseudonym	Age	Gender	Ethnicity	Barthel Score	Treatment Group	Nominated a significant other	Type of interview
Karen	57	Female	NZ European	17	Intervention	Yes	Face-to-face interview
Catherine	78	Female	NZ European, Maori	20	Intervention	Yes	Face-to-face interview
Stephen	79	Male	NZ European	14	Intervention	Yes	Face-to-face dyad
Susan	82	Female	NZ European	12	Usual Care	Yes	Telephone interview
Margaret	59	Female	Maori Pasific, British	19	Usual Care	Yes	Telephone interview
Paul	57	Male	British	14	Usual Care	Yes	Face-to-face interview
David	74	Male	NZ European	20	Usual Care	Yes	Face-to-face dyad
Judith	78	Female	NZ European	20	Usual Care	No	Face-to-face interview
Jennifer	83	Female	British	18	Usual Care	No	Face-to-face interview

Table 19. Significant other Demographics

Participant pseudonym	Age	Gender	Relationship to Stroke Survivor	Linked to Stroke Survivor	Living Arrangement	Type of interview
Sarah	34	Female	Niece	Karen	Lives with SS	Face-to-face interview
Mary	74	Female	Wife	Stephen	Lives with SS	Face-to-face dyad
Michael	75	Male	Husband	Susan	Lives with SS	Telephone interview
Robert	64	Male	Husband	Margaret	Lives with SS	Telephone interview
Christine	53	Female	Wife	Paul	Lives with SS	Telephone interview
Elizabeth	71	Female	Wife	David	Lives with SS	Face-to-face dyad

declined to participate without providing a reason, one significant other was unable to participate because of ill-health, and two stroke survivors declined participation because of existing commitments (two stroke survivors declined participation citing existing commitments with family at a busy time of year (just before Christmas 2014)). In total, 21 individuals (75%) consented to participate in this study; this group of individuals was made up of nine stroke survivors, six significant others, and six motivational interviewers. Stroke survivors were aged between 57 and 83 years of age, with a mean age of 71.9 years. Significant others were aged between 34 and 75 years of age, with a mean age of 62 years.

The details of the nine stroke survivors are presented in Table 18 and details of the six significant others are presented in Table 19. To protect the privacy of the motivational interviewers, only generic demographic information will be presented; the motivational interviewers were all female, had on-going training in motivational interviewing during the MIST-trial, and conducted motivational interviewing with stroke survivors during the twelve-months that the stroke survivors participated in the MIST-trial. All participant names presented are pseudonyms to maintain anonymity. As shown in Table 18 and Table 19, diversity in the stroke survivor and significant other samples was achieved in relation to age, gender, Barthel Index (disability), and treatment condition in the trial (those who received motivational interviewing and those who were in the control arm of the study). On two occasions the stroke survivor chose to participate alongside their significant other in a dyad-interview and three of the six motivational interviewers chose to participate in a focus group. The remaining participants completed individual semi-structured interviews.

7.3 Main Themes

It became clear from the data, that health-related behaviour was embedded within the wider context of a person's approach to post-stroke recovery. Overall, stroke survivors and significant others described a post-stroke journey that challenged the life and roles they had originally held; a journey that was emotional, traumatic, and stressful; and a journey that continued to be difficult one year on. The narratives of the motivational interviewers also acknowledged the challenging journeys that stroke survivors had

faced, and often referred to particular individual's stories to illustrate the varying challenges that stroke survivors had experienced pre- and post-stroke and how that affected their engagement with MI. Consequently, it is important to acknowledge the wider context of recovery present in the post-stroke narratives, and the diverse challenges that people experienced. As there is considerable literature on recovery from stroke and for the purposes of answering the research question, information on the wider recovery journey was only included where it influenced health behaviour. Themes and sub-themes focused on the factors influencing health-related behaviours after stroke. A description of the overarching theme following by the subthemes will be presented, supported by participant quotes (specifying pseudonym, age and type of participants) following the quote to provide some context.

7.4 Overarching theme of path-finding

There was diversity in the way that participants approached their post-stroke journey. Some individuals were highly motivated to get back to 'living a normal life':

Recovery, there's no doubt about it. I hated being trapped in the immobility and I saw that the only way out of that was to actually make the effort and I believe that not only would exercises physically strengthen but it would create the neural pathways that were required when I sustained brain damage from the stroke and the way to do it was repetition and actually making the effort to bring about change. (Margaret, 59 years old, Stroke survivor).

In contrast, other participants were ambivalent about making progress or felt that they 'had had their time' and were ready to die.

I do know I'm not as good as I used to be but I'm 78, I don't mind it. I wanna die by the time I'm 80. (Judith, 78 years old, Stroke survivor).

This disparate response to recovery was also observed by the motivational interviewers. The motivational interviewers described how the lack of motivation to recover or improve function after a stroke made it harder to engage people in contemplating making changes associated with healthy behaviours. This contrasted with stroke survivors who had high levels of motivation and were easier to engage in MI to improve their recovery.

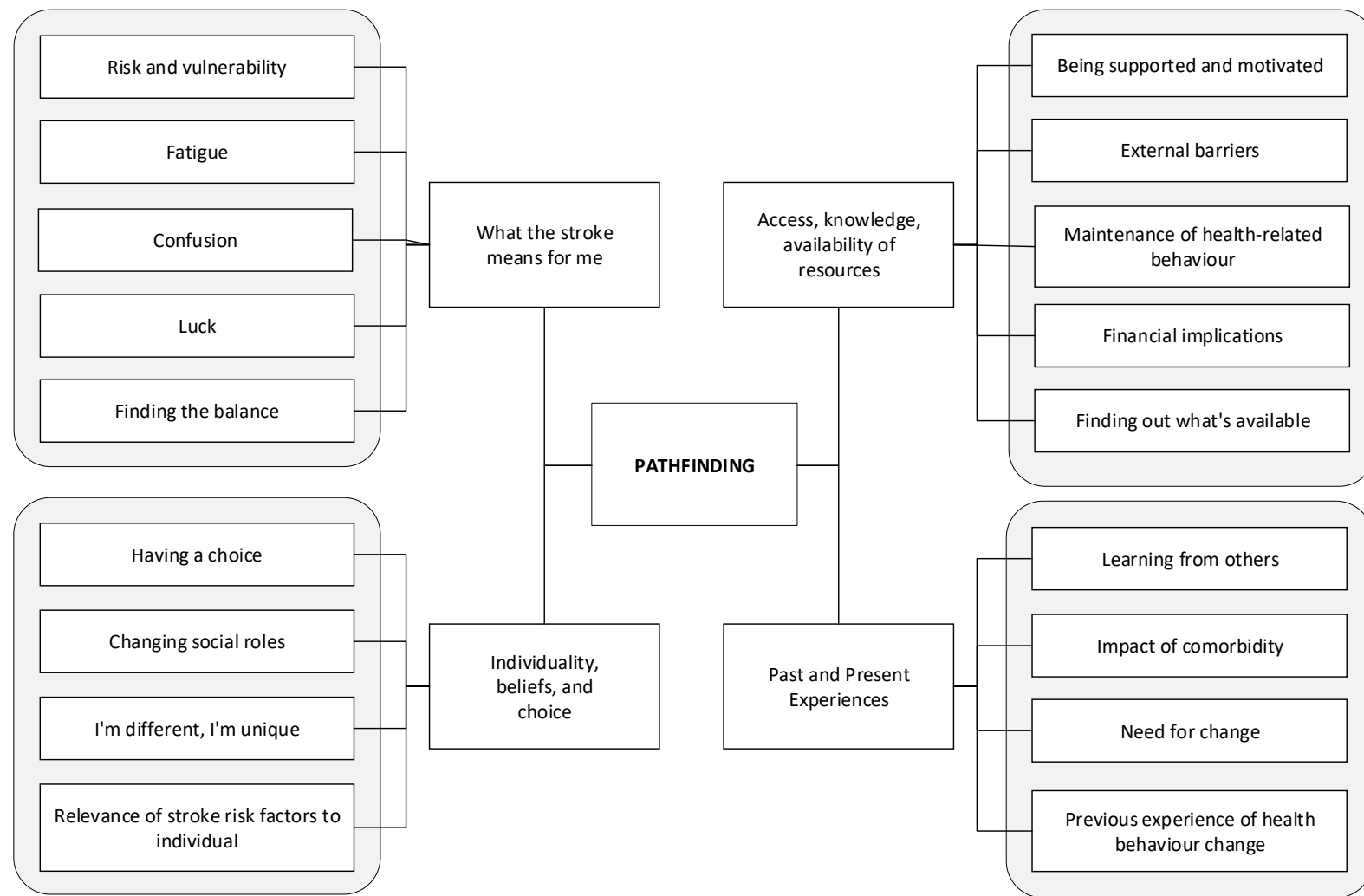


Figure 12. Coding framework illustrating themes identified from participants described experiences.

This overall participant's perspective about their recovery underpinned how they 'chose their path' following stroke and how they engaged with or participated in health-related behaviour post-stroke. This perspective about recovery or *recovery perception* is reflected in the overarching theme of *path-finding*, which influenced how each of the sub-themes was experienced. Four inter-related sub-themes were identified in the data including *Past and present experiences*; *Individuality, beliefs and choice*; *What the stroke means for me*; and *Access, knowledge, and availability of resources* (see Figure 12, for a visual representation of the overarching theme and sub-themes). A description of the data relating to codes within each sub-theme will be presented, with quotes used to illustrate the points made; quotes will be referenced using the participant pseudonym, participant age, and trial group allocation.

7.5 Sub-Theme 1: Past and present experiences

Past and present experiences was a sub-theme that reflected what the person brought to the stroke recovery process. This included whether there was a perceived need to change health behaviour, the influence of past experiences (previous attempts at lifestyle change and experiences relating to health-related behaviour), what they had learnt from observing others' response to stroke, and the impact of pre- and post-stroke comorbidities and how these impacted the post-stroke journey. The importance of these factors for health-related behaviour were described by almost all stroke survivors and their significant others. However, it was noted that the motivational interviewers' did not explicitly identify the influence of these factors for health-related behaviour. Therefore, this first sub-theme only illustrates the subjective perceptions of stroke survivors and significant others.

7.5.1 Need for Change

A key factor that influenced uptake of health-related behaviour was whether an individual perceived a need to change their behaviour. In some cases, participants were already eating healthily, or participating in physical activity, or did not smoke; consequently, no change in behaviour was required. In these cases, the stroke reinforced the need to maintain a healthy lifestyle. Additionally, people looked at

refining other areas of their lifestyle that they thought would be helpful whether these were necessarily related to the stroke or not.

We [Susan and I] don't drink as much as we used too ... we used to have 2 or 3 wines each night and now we don't, maybe once a week or when we've got visitors but we've cut back there. I guess that's probably I think about the only real thing. Food-wise I think we've always did eat quite healthily, and exercise, you can't really live here without getting a fair bit of exercise. I have started walking a bit more lately but that's more because of a circulation problem I've got than anything to do with Susan's stroke ... I don't know, the answer is probably not a lot I guess. (Michael, 75 years old, Significant other).

Other participants expressed that, as they had not been told by a health professional that they needed to make any changes to their lifestyle, they did not change their or uptake health-related behaviours.

Interviewer: So the doctors have told you that you've had a stroke, has that made you think about changing anything in your lifestyle now?

Participant: Well I haven't been told to

Interviewer: Did you get much advice from the doctors or health professionals?

Participant: No, they didn't say I should change anything. (Jennifer, 83 years old, Stroke survivor).

7.5.2 Previous experience of health behaviour change

People's previous experiences relating to lifestyle changes or health-related behaviours in other contexts was a further influence on post-stroke healthy behaviour. Stroke survivors and significant others described how their previous attempts to change health behaviours influenced their current health behaviours. Those who had previously seen positive changes from lifestyle change were more motivated to make lifestyle changes after stroke; conversely, individuals who had struggled with health-related behaviour before the stroke were less motivated to make lifestyle changes post-stroke. For one participant, his previous experiences with health professionals telling him to lose weight, because he had always been larger than average and

unsuccessful with diet changes and weight loss, influenced his decision to not change certain health behaviours following his stroke.

Well I try [to exercise] but people have been telling me to lose weight all my life and I hate it. I've dieted on all sorts of diets. I am what I am by the grace of God, and one of these days I'll fall off the perch and until I do I'm just going to keep working and enjoying life and doing the things I do. (David, 74 years old, Stroke survivor).

7.5.3 Learning from Others

Knowledge of how other people had responded following a stroke, including their outcomes, influenced how stroke survivors and significant others perceived the stroke and their health-related behaviour. Noting the positive progress made by others through increasing physical activity or eating more healthily was highly motivating and gave people hope. Often the stroke survivors and significant others described the supportive relationships that had developed post-stroke; these relationships enabled and supported various health behaviours, and continued to develop as time went on and each person learnt more about stroke and what worked best for them.

My son actually made her an exercise thing. He got a car steering wheel and mounted it on to a frame and we clamped it on to a thing at home so she could stand in front of it and practice turning the steering wheel with her hands and that was excellent exercise because it was a bilateral movement and one hand pulling the other up and moving and perhaps that gave her some confidence as well ... the physiotherapist, actually suggested some exercises. I would go with Margaret and say, "What about this and this?" and [the physio] would say, "If you had a device like this, it would be good," so, we adapted a few things and made a few things for Margaret so she could have that exercise that she needed. (Robert, 64 years old, Significant other).

Observing the decline of others who did not actively try to improve their prognosis after stroke was also a motivating factor for others to engage in health-related behaviour to improve their recovery and quality of life.

Both of us had the opinion that my grandmother gave up, that she basically rolled over and died, albeit that it took years to happen, when your will to live is gone and you stop trying to make your life better, I think that's it you know. You can change your mind, but my

grandmother never did and that influenced Karen's decision. (Sarah, 34 years old, significant other).

This was observed in both personal history (for example, family members who had experienced stroke) and in post-stroke experiences (for example, in rehab with other stroke survivors).

If you don't plan ahead, that I'm going to do this, I'm going to do that, to some extent you're giving up and to some extent you end up one of the people that end up with withered body parts and stuff ... They've accepted it too easily – they've given up. They don't have a plan for the future. If you don't have a plan for the future, you ain't gonna have one. Or, you will have but it will just be severely restricted ... I've seen lots of people who have had strokes a lot longer than me that are probably as physically damaged as I am now. I hope to surpass them. (Paul, 57 years old, Stroke survivor).

7.5.4 Impact of comorbidity

Across all transcripts, it was evident that stroke occurred within the context of a complex life with many competing priorities. Indeed, health-related behaviour was rarely considered in relation to the stroke alone. Further, many participants talked about the influence of pre-stroke or subsequent co-morbidities that influenced their post-stroke health behaviours.

Because of all her other health issues prior to the stroke that she has to deal with anyway, was just kind of like one more obstacle that we kind of work around. So it didn't seem like much of a major, it was just one more thing to deal with. (Sarah, 34 years old, Significant other).

In some cases, managing another medical condition was the person's priority, and the need to consider and uptake health-related behaviour following the stroke became less important to the individual. Managing competing demands (e.g. co-morbidities) used already reduced energy resources, and people felt they couldn't allocate any time or energy to health-related behaviours.

I had to go back and have a full mastectomy in December, that really threw me off everything and I think that set me back quite a bit, so, with the stroke and then that, it's been quite a traumatic year, plus the fact my husband is very sick ... and, as you've seen the list of

appointments we've got to go to, I find it very tiring and very frustrating at times, I get very, very tired ... Like I said, I have my dinner at night-time, I go to bed and I could stay in bed all day. (Catherine, 78 years old, Stroke survivor).

Comorbidities were also seen to influence the feasibility of undertaking health-related behaviour by way of disrupting routines or negatively impacting mobility. On occasion, participants attributed negative health experiences to activities associated with their healthy behaviours.

We [Christine and I] used to go to the swimming pool at Otara, and for the first three or four times one of the nurses came and walked up and down cos I was just walking. We got an eye infection, we both did, so, we put it down to that, that's where it came from, and so we haven't been back. (Stephen, 79 years old, Stroke survivor).

7.6 Sub-theme 2: Individuality, beliefs and choice

This sub-theme illustrates how health-related behaviour could be influenced by an individual's sense of self, how their social identity changed post-stroke, their level of confidence, the importance of feeling that they have a choice, and the relevance of stroke information and how they apply this information to themselves. All participants described experiences of this sub-theme.

7.6.1 I'm different, I'm unique

Stroke survivors and significant others talked about their post-stroke journey as being unique and different to others. They talked about the situations where they felt well supported by professionals which included feeling that their individual needs and motivations had been taken into consideration. This encompassed acknowledging who they were as a person, what their ambitions were and engaging them in health behaviour in a personally meaningful way.

Everybody's different ... We all travel a different road down life ... I am definitely unique, bad unique, good unique, that's for everybody else to decide but I'm unique and I realise that. I differ greatly in the way I function mentally from most of my friends and acquaintances. Most of them are, if I was to be honest, more normal than me and more average. They go along with the set guidelines that everybody goes

along, more or less. I seem to be outside the box. (Paul, 57 years old, Stroke survivor).

Participants described greater uptake of health-related behaviour when it became meaningful to them, and had a 'good fit' with their values and wider perspective of recovery. One participant who still had a strong sense of self as a competitive athlete found that the structure of rehabilitation programmes to facilitate post-stroke physical activity did not align with her competitive nature and consequently she lost motivation to continue.

I'm a gymnast and to do things so slow it didn't seem right. I've always done sport ... I wanted to do it faster but then you find out you can't ... I went to those citizens things ... but to me that was too slow. There was people older than me and, of course, I had to slow down to go with them. (Judith, 78 years old, Stroke survivor).

The motivational interviewers talked about the differences they observed between stroke survivors, and how these individual differences influenced health behaviour. The individual differences commonly described included: age; living arrangements; cognitive ability; personality; effect of the stroke; mood (anxiety or depression); and levels of social support. The motivational interviewers also expressed their awareness that individual differences or circumstances influenced how an individual responded to motivational interviewing, or whether motivational interviewing for lifestyle change was suitable for an individual.

The ones that are not or in my opinion were not suitable to take part ... Whether it's due to mental health issues that were later picked up or due to, it's quite difficult doing an MI with somebody who was bed ridden and not able to do things for themselves so that was quite a challenging one as well. So some of the clients were more challenging than others. (Michelle, Motivational Interviewer).

Participants who experienced motivational interviewing described how one of the most valued aspects of the intervention was that the approach acknowledged and valued their own personal experience. Some participants described how participating in the MIST-trial (and the motivational interviewing) validated their experiences, influenced their self-esteem, and gave the stroke survivors purpose having replaced activities that they were no longer able to participate in. One participant described

how taking part in the trial motivated her during her post-stroke journey and influenced her approach to health-related behaviours by helping to identify ways to be active.

I think it actually helped me. It encouraged me at times when I was down because there was someone there to talk about it and it was my experience that they were learning about. Even if two people have got similar experience, they're not always the same and it was my experience that they wanted to know about and how I felt at that time, why I felt that way, so therefore it became a path that many travelled with me. It was fantastic being able to talk about different ways cos I've got a crook knee, so therefore I had to think of other ways to reach the same effect and that was really good. (Karen, 57 years old, Stroke survivor).

7.6.2 Changing social roles

A changing dynamic became evident between stroke survivors and their significant others following the stroke. Stroke survivors who previously held the role of 'provider' and 'decision maker' often found their role changing within the family unit. These changes often impacted on stroke survivors' perceived self-image, with the majority of participants reporting a loss of confidence, self-worth and independence. Self-concept appeared fundamental to health-related behaviour. A strong sense of self-worth and purpose influenced motivation to 'get back to normal', be healthy and well and maintain a purpose in life. Over time, people reported that their self-concept re-developed and some individuals became more confident in their modified life role; other stroke survivors and significant others continued to struggle with the changes and emotionally described stressful situations, feeling out of control, and not wanting to cause anxiety for their significant other.

Similarly, significant others described how their self-image had changed, described stressful situations, feeling out of control, and not wanting to worry the stroke survivor. In addition, significant others and motivational interviewers often expressed an awareness of how the changing social roles impacted on the stroke survivor and their health behaviour. The majority of participants described how the negative impact of changes in social roles could be moderated by strategies used by people around them; such as, showing interest in progress made by the stroke survivor, teamwork

between the stroke survivor and significant other that helped motivate and facilitate uptake of health-related behaviours, and generally being supported and motivated by others. The following quote illustrates how changing social roles influenced a participant's diet. The significant other took over the cooking role, and their involvement and support for the stroke survivor's decision to eat more healthily was critical to increasing uptake of healthy diet.

The benefit really has been that [Karen] takes it a little more seriously now and realises okay, well she's not useless, 'cos I know sometimes she's felt like that with all her health issues, but that there's things that you have to ask other people to do for you and there are things that you do as much as you can. And I help her realise that and do what she can, and I'm quite happy to leave her to do what she can ... so it just became natural that I took over cooking. It would allow her not to have to stand and test that weakness and now it's become part of our unspoken but formalised arrangement. (Sarah, 34 years old, Significant other).

7.6.3 Relevance of stroke risk factors to the individual

Some stroke survivors and significant others described having a good understanding of risk factors for stroke. This was often linked to the personal research they had conducted to better understand their health and illness. However, there seemed to be a distinction between understanding the general causes of the stroke versus understanding the cause of their own stroke.

I still don't know why I had the stroke or what caused it. (Stephen, 79 years old, Stroke survivor).

This inability to understand or apply general information to their own situation meant that participants often acknowledged that they did not fully understand their own risk factors. This had implications for health-related behaviour such as food choices, medication choices, levels of physical activity, and alcohol consumption because participants expressed ambiguous or conflicting perceptions about health-related behaviour. The ambiguous or conflicting perceptions were observed to reduce participant's healthy lifestyle choices.

I'm not really doing anything to prevent another stroke. I believe that it's down to your luck when you've had one and I've convinced myself,

whether it's right or wrong, that if you don't have one within the first six months, you're less likely to have one. Because the people that have had other minor strokes have tended to have them within six months. That's not to say you're not gonna get another one but it's less likely. And nobody's told me that, it's just my belief from what I've seen. Whether it's factual or not, I've no idea but that's my belief. I'm doing stuff just now which I need to – I need to take the tablets, I need to do the exercise. So, that all helps. It's not stuff that I'm doing because of it or to prevent it – its stuff that I need to do. (Paul, 57 years old, Stroke survivor).

It was often difficult for participants to understand how and why health-related behaviour could help prevent a second stroke. A number of participants expressed that the medical and health professionals were often unable to clearly identify the specific cause of their stroke. Indeed, one participant described the difficulty she experienced when faced with a GP who continued to refute the diagnosis of her stroke. As a result, participants were not clear about how health-related behaviour would impact on their recovery or risk of experiencing a further stroke.

They [motivational interviewers] kept saying that it [health behaviour change] would help them to stop people having stroke but they have no clue what starts them in the first place so, I don't think they were doing much good that way. (Stephen, 79 years old, Stroke Survivor).

For another participant, they felt that they understood what caused their stroke but that it was already too late and that health-related behaviour would have limited effect.

It's probably my own fault, I found out when I was 50 that I had high cholesterol and the doctor wanted to give me tablets for it and I found that if you take the tablets, you're on them for life. So, I elected not to take them and to try and get fitter to get rid of my high cholesterol, which probably worked for 6 months or so, then you get lazy again and I got over-weight-ish and I've got a blocked artery on the right-hand side of my face, a bit of the calcium came off the artery and went into my brain – stroke, so to a big extent, it's my fault but I think probably the blockage was there already. I've got reasons for believing that which I don't really need to go into just now but I think it was already too late by then. (Paul, 57 years old, Stroke survivor).

7.6.4 Having a choice

Participants described feeling a lack of control related to the acute medical treatment that they received following their stroke and they passively trusted the medical professionals. However, they noted it was important they were given the choice about their lifestyle. There seemed to be a fine line between being 'told what to do' and feeling sufficiently informed to be able to make the right choice. When people were self-driven and motivated to research information related to the stroke this appeared to facilitate uptake of health-related behaviour.

They tell you all the time, its non-stop from the day you have your stroke "don't do this" and "don't do that" and "you should do this" and "you should do that... I found it intensely annoying and irritating and it made me angry... Now I choose to ignore it pretty much, I switch off ... I would Google it... I found out that cholesterol which is what they blame for causing my blocked artery... I did all that and read all the foods that I could and shouldn't eat. (Paul, 57 years old, Stroke survivor).

For one participant in the intervention group, they felt the motivational interviewing provided a good opportunity to ask questions that they had about health behaviour change. This provided support to the stroke survivors through a person to talk to about health-related behaviour; this support acted as a sounding board, providing an extra person to problem solve, or assist with developing links and understanding between health-related behaviour and action.

Giving me the tools mentally to be able to fight physically, understanding not what had gone on but what I needed to do to carry on, it wasn't someone telling me you must do this" or anything it was a case of how you felt, where are you falling down, what do you want to do, and giving me the tools to do it. (Karen, 57 years old, Stroke survivor).

7.7 Sub-theme 3: What the stroke means for me

This sub-theme encompasses the impact of stroke symptoms and sequelae related to a person's ability to participate with health-related behaviour. Confusion, luck, fatigue, finding a balance between managing their health and maintaining quality of life, and feelings of vulnerability all impacted on how the person was able to process

information about their stroke and the implications of health-related behaviour; these themes were noted by all three participant groups.

7.7.1 Confusion

The majority of participants talked about the confusion or memory loss they experienced following the stroke. Their impaired memory or confusion influenced their ability to understand medical or health information and why they needed to take certain medication or engage in health-related behaviour post-stroke. It was often unclear whether this was influenced by their cognitive ability to understand information, their ability to remember and recall information following the stroke, or whether this information had not been provided. Some participants described being happy to following advice without full understanding, as they felt this was their patient role and perceived clinicians as the experts.

No, they probably thought I knew. I just do as I'm told when I'm in there [the hospital] ... They know more what you're doing than I do. Well, I hope they do. I take the pills they give me and take the medicine they give me ... I don't know what's wrong with me, I don't know what medications are good for it, so, of course, I do what I'm told. Very obedient child. (Jennifer, 83 years old, Stroke survivor).

However, in other cases cognitive problems were a key barrier to uptake of health-related behaviours. One participant described her short-term memory problems as a barrier to physical activity as she no longer participated in bowls or golf because of her embarrassment when she experienced memory problems.

But if I could get my short-term memory, improve it even. I know I'll never get back to 100% but I'd like to be able to not be embarrassed when I'm out but it is getting worse. (Catherine, 78 years old, Stroke survivor).

The motivational interviewers also recognised that confusion and memory loss influenced the ability of stroke survivors to understand their involvement with the MIST-trial; this, in turn, influenced their involvement with motivational interviewing and health-related behaviour. They described how some stroke survivors found it difficult to understand what they were doing or why they were doing it, which proved

to be a challenge for motivational interviewing. This is revealed in the following quote from a discussion as part of the motivational interviewer's focus group.

Participant 2: I think the difference was whether people really understood why or what they were doing. Even though we really tried to explain in the interview what we were doing. Some people still didn't understand the difference between Form T [questionnaire] and the motivational interview. Or if they were just there to be helpful to us. Sadly some people at the end would say, "Oh I hope I was helpful". (Lisa, Motivational Interviewer).

Participant 3: I would agree with that, and just in terms of it varying person to person. And that there's a huge difference between those who were really switched onto the fact that MI's were a different thing to the Form T's [follow up questionnaire], to the ones who kind of got confused with it. I don't know if that's about where they were cognitively or how it was set up. (Michelle, Motivational Interviewer).

7.7.2 Fatigue

All participants described experiences relating to post-stroke fatigue and its role in precluding health behaviour. Stroke survivors described how they struggled with everyday tiredness and fatigue because of their stroke, or their medication. Some stroke survivors expressed frustration at how their lack of energy was a barrier to activity, and a sense of loss in how their lifestyle had changed because of their reduced ability to participate with activities. This impacted on their health-related behaviours, as their energy resources were often 'used up' by essential daily activities (such as showering or getting dressed). This meant that there was zero or limited energy left to plan or cook healthy meals or be physically active.

I just haven't got the energy to do what I want to do. (Catherine, 78 years old, Stroke survivor).

Significant others expressed an awareness of the fatigue that the stroke survivor experienced. They described various strategies they used to help the stroke survivor and reduce post-stroke fatigue: how they took responsibility for food choices, preparation, and cooking; how they took responsibility for chores and daily household activities; and encouraging and enabling stroke survivors to take it easier and enable healthy lifestyle change and recovery.

A lot of my job is to actually encourage her to take it easy, that it's not so bad ... to go and have a sleep if she needs it. Just to sort of be that person as a backstop I guess, for her, especially as times gone on. She's mostly recovered from the effects of the stroke. I think she [Karen] will always have that slight weakness on that side but the shaking stopped. (Sarah, 34 years old, Significant other).

7.7.3 The role of Luck

Following on from the need to understand the relevance of stroke risk factors to individuals outlined in sub-theme 2, all stroke survivors and significant others described feeling that they didn't have control over whether a stroke occurred or not, and that *luck* played an important role. In some cases, this perception negatively influenced health-related behaviour, as it was perceived to have a limited effect.

Before I got to the phone I realised I'd had a stroke, I knew what the symptoms were but I didn't know what the implications of that was until now. I've known a lot of people that have had strokes now. I've been in the hospital with a lot of people that have had strokes, I've seen them go back in with minor strokes. A great part of it is down to your luck. I know these people that have gone back in have been looking after themselves. Just shit happens, there's some things – you can try and stay fit, try and stay healthy and keep your cholesterol level down, no stress and don't do this and don't do that. But if you do all that, which those people were, they still end up back in hospital, so, preventing another one, yeah, there's steps you can take but it just depends on your luck, really ... I'm not really doing anything to prevent another stroke, I believe that it's down to your luck (Paul, 57 years old, Stroke survivor).

7.7.4 Risk and vulnerability

Perceived risk and vulnerability were strong themes that emerged from the participant's experiences, and were often described as barriers to healthy behaviours. This related particularly to physical activity. Most stroke survivors described the fear of an increased risk of injuring themselves if they participated in particular activities or by being in certain environments. One participant also described being frightened of hurting himself because of being scared by a GP who told him after the stroke that if he fell he would break his hip and wouldn't recover. Consequently, stroke survivors described feeling reluctant to challenge themselves and increase physical activity because of this fear of falling and risk further injury.

And he said you're almost ready to get out of here and I said no I'm not. I'd like a few more days of practice first. The practicalities of it were that he looked after me, I felt safe and we did it. (David, 74 years old, Stroke survivor).

Risk and physical vulnerability were often moderated by health professionals. Following a stroke, the majority of stroke survivors described feeling safe in the presence of medical or health professionals because they would be able to help the stroke survivor if something went wrong during rehabilitation or physical exercise. The notion of needing to feel safe was noted to be a facilitator for health-related behaviour particularly in relation to increase physical activity.

Sometimes you've just got to step back and sometimes you think ... am I being mean or am I encouraging, saying you're doing well, you're independent. It's kinda hard not to know the line. I don't want to mother him and he wouldn't want that either. (Christine, 53 years old, Significant other).

I am far more motivated when somebody's there pushing me I do stuff at home but probably not as much or as often as I do when I'm going to rehab. I probably go through more pain at rehab than I'll inflict on myself ... Because I want to get better. Because I let them because they know what they're doing and they're professionals and I'm in a safe environment and if something goes tragically wrong, there's not too far to go to get it fixed. Plus, there's other people around ... A safe environment is a huge thing for me. (Paul, 57 years old, Stroke survivor).

Significant others demonstrated an awareness of the perceived risk and vulnerability experienced by stroke survivors; this awareness could act as a facilitator or a barrier following stroke. Significant others described a difficult balance between enabling the stroke survivor autonomy, whilst knowing when to take control to reduce the level of physical risk to the stroke survivor. One significant other described initially taking over food preparation and cooking to reduce the risk to the stroke survivor from fatigue with the long periods of standing to cook a whole meal, but then allowing the stroke survivor to undertake specific tasks such as holding and chopping vegetables to assist with regaining motor function and dexterity. The following quotes provide the contrast between the experiences of a stroke survivor wanting support and a significant other knowing how much support to give around finding the balance when supporting and

motivating health behaviours following a stroke. This became an issue regarding supporting a stroke survivor to increase physical activity, which in some cases also came with an increased risk of falls, accidents or fatigue.

7.7.5 Finding the balance

Perceptions about their recovery, and the frustration that went alongside it, could be seen to reduce uptake of health-related behaviours. Following the stroke, participants talked about needing to find a balance between managing their health and focusing on changing their health behaviour or on their rehabilitation, as it was too challenging to prioritise both. Some participants felt so overwhelmed by their rehabilitation that they felt unable to process information about their stroke and the implications of health-related behaviour. While some participants described a journey of getting well and feeling positive about the future, other participants described the limited progress they had made following the stroke. Those who perceived that they were experiencing a positive recovery felt more able to think about and explore health behaviour change. For example, in the quote below, experiencing good physical recovery meant they felt more motivated to increase their levels of physical activity through gardening.

I suppose because of I feel like I've gone a bit backwards physically, but I suppose that's because I also try to do a lot of extra physical work. Like getting out with my trolley in the garden and gardening and pulling weeds. Maybe I try, Michael does the vacuuming. I think I was able to vacuum a bit easier 12 months ago, but I am positive I'll get back to it or hope I'm sure I will. (Susan, 82 years old, Stroke survivor).

For the majority of participants, it was also important to balance the competing priorities between managing their health and maintaining their quality of life following the stroke. Some participants expressed a desire to not have to change their lifestyle, and that returning to their normal pre-stroke life was more important. A few participants described how risk factors for stroke didn't mean much to them and therefore didn't influence lifestyle change. This notion was interrelated with *past and present experiences, relevance of stroke risk factors to the individual*, and *what the stroke meant for the individual*. However, other participants described pragmatic and

realistic expectations for their recovery, which helped them to balance their expectations post-stroke and their health-related behaviours.

Physically there's not that much, although I've regained the ability to walk, I still have to be careful I can't walk for miles and miles. I can't go tramping and stuff like that so you know heavy physical exercise has not happened. I was working with a specific area to try and rehabilitate it, you know like my hand or my elbow or my shoulder. (Margaret, 59 years old, Stroke survivor).

7.8 Sub-theme 4: Access, knowledge, and availability of resources

This final sub-theme reflects the availability and access of resources for health-related behaviour. Stroke survivors and significant others talked about the importance of feeling supported and motivated by the people around them following a stroke. They described that it was often difficult to find out what resources and information were available to them post-stroke. There were often financial implications and external barriers that were encountered in changing health behaviour and influenced both the initial change and maintenance of health-related behaviours following the stroke. This sub-theme was mostly described by the stroke survivors and significant others; however, the motivational interviewers also occasionally acknowledged this sub-theme when describing particular experiences of stroke survivors.

7.8.1 Being supported and motivated

Stroke survivors and significant others described a range of positive ways that they were supported with health-related behaviour post-stroke. For example, family members or health professionals provided ideas or created aides to support physical activity, as well as providing additional motivation through acknowledging the progress made by the stroke survivor. In some cases, the stroke survivor was dependent on others for shopping and cooking; a few stroke survivors described how they were supported by others to eat healthily, even if it was not their choice. In relation to this, some significant others talked about finding balance between providing healthy meals whilst trying to provide meals that the stroke survivor still enjoyed.

I do the cooking partly because for Karen to stand for the length of time that's needed to cook a meal... I know she tends to eat whatever takes her fancy and that maybe going through a whole packet of

crackers, sitting there with margarine and crackers, and that's fine she's an adult, she can choose, but it would be very different meal wise ... I just try to make it so that it's a moderation meal you know and as part of her everyday diet rather than trying to make everything nasty, I also know what Karen likes you know, meat is her main, she's a meat and three veg type of person, that's how she's raised and it's comforting to her, so I change my cooking a bit in that I make sure I follow that for her but also bringing in more vegetables and greens. (Sarah, 34 years old, Significant other).

Significant others often described the challenges of feeling they were being supportive enough whilst enabling the stroke survivor to regain their independence. In addition, stroke survivors demonstrated an awareness of ways people around them tried to reduce the risk and vulnerability they faced. One stroke survivor described how her significant other had found an informal carer to assist her with her rehabilitation exercises at home, and how this facilitated her post-stroke exercise.

When I first came back [home] I had a list of exercises that had been given to Michael from the team at Auckland Hospital, and he suddenly found the young woman living up the road ... and she regularly went through all of those exercises with me and ticked them off in an exercise book and she came regular for 6 months. Unfortunately she's left the Island now but her name was [Ann] and I think that having her here with the list of all the exercises and making sure that I did them, was a great help. I think that was very terrific. (Susan, 82 years old, Stroke survivor).

The strategies that individuals used to motivate the stroke survivor in relation to health behaviours included: grounding the stroke survivor; empowering and validating the stroke survivor by enabling their autonomy such as taking them to swimming pools or out for walks. Significant others felt it helped if they acknowledged the stroke survivors achievements by drawing attention to and celebrating goals they had achieved, or progress they had made.

I think that having her here, with the list of all the exercises and making sure that I did them, was a great help. I think that was very terrific. (Susan, 82 years old, Stroke survivor).

Participants who experienced motivational interviewing also described feeling supported and motivated by the motivational interviewers who could also fulfil the

above roles in terms of providing support, guidance and encouragement as well as monitoring and feeding back progress. This was a key outcome of the intervention, and gave people the opportunity to ask questions and to think about ways of overcoming challenges or barriers they experienced.

Without them [motivational interviewers] I don't think I'd have got so far as I have, simply because of the fact that it would've then just been up to me. In saying that, ultimately it is up to me. The thing is that it encouraged me and kept me going. If I hadn't have had the motivational interviews I wouldn't have done anything. I would've thought, oh, no, I've gotta get up and get moving, I just wouldn't even have thought about what I can or can't do. Whereas it's made me stop and think about what I can and what I can't do, what I'm capable of and what needs work on ... A little bit like your dog always wants to please you and wants to do what you like. It's a little bit like that kind of relationship – you want to please the person who's coming around to check on you, want to make sure you've done what you're supposed to have done and beyond. It's not necessarily something that they caused me to do, it was in talking, it was in sharing, it was in, "What about this?" and "What about that?" "Have you ever thought of doing it this way?" (Karen, 57 years old, Stroke survivor).

The motivational interviewers also described numerous situations where stroke survivors had acknowledged how supportive they perceived motivational interviewing. The different strategies and tools that the motivational interviewer-stroke survivor relationship used to motivate and enable uptake of health-related behaviour were also described.

Somebody said to me "it's good to have somebody ... almost holding them accountable for things that they say that they want" and whether they are walking the walk as well as talking the talk. Something else is signposting with their permission, if there is an issue that they want support with. Although that's not our job to give them that support; we're able to first of all problem solve where they can get that information, and then offer to signpost them towards other services if needed. And they might not be picked up by other services otherwise. (Michelle, Motivational Interviewer).

7.8.2 External barriers

For the majority of stroke survivors and significant others, the transition between services (post-stroke) was described as a barrier to uptake of healthy behaviour.

Participants described feeling that they had lower confidence and motivation about what and how much to do, and how to change things during the transition phase where many things had become uncertain. This was mainly in relation to physical activity following stroke. Participants often expressed frustration and anger about the gap between services, as well as the lack of continuity when transferring between services.

I just felt that when you're making progress, you're into a programme and then suddenly to have that withdrawn is not good ... she [Margaret] was making really good progress and she came home. She had a set of exercises to do and that was good in itself but it's rather hard to be motivated towards that and, also, when you're not a professional in terms of knowing what to look for and how much to stretch things, you did feel somewhat unsupported over that period. (Robert, 64 years old, Significant other).

While stroke survivors and significant others described continuity in terms of influencing their post-stroke progress, the motivational interviewers described continuity in terms of momentum and its impact on working towards goals. The motivational interviewers noted that the three-month time-period between motivational interviews (in the parent MIST-trial) might negatively impact the ability of stroke survivors to work towards and achieve goals they had set themselves; this was described in the following quote from a discussion during the motivational interviewers focus group.

Participant 2: Negative, maybe I think this could have been avoided. You know time; you know how interviews were set up over a three-month period. I'm just wondering because it's not really ideal for people to follow up three months after setting a goal up, it was too long. I don't know if it's actually true, but I'm just wondering because of the un-ideal time period the motivational interviews effect would have been diluted. Maybe for some people they might have set up goals and they didn't achieve it; but maybe they did achieve it, but by the time we talked to them after three-months it felt like they hadn't achieved it because they had done it for a month. So maybe by the time we talk to them, maybe they feel like they haven't actually achieved much. (Lisa, Motivational Interviewer).

Participant 1: Or they had forgotten about... “oh yeah, we talked about that three-months ago”. Yeah it slipped my mind or... (Rachel, Motivational Interviewer).

Participant 2: So maybe that made people lose confidence. But then hopefully we talked about it again to build that up. (Lisa, Motivational Interviewer)

Participant 3: You kind of lose that momentum don't you? (Michelle Motivational Interviewer).

7.8.3 Financial Implications

The majority of participants acknowledged the financial constraints they experienced following the stroke, and its implications for themselves and their significant other. Participants described implications around the cost of on-going post-stroke rehabilitation, the cost of driving to access services (outside of their local area) that would help them be active, and the cost of (private) services that would help them eat healthier. For some participants, in spite of the financial implications of services, they expressed that the benefit to the stroke survivor was more important than the cost.

She [Margaret] has actually been going to a private “Hands On” is the name of it up in Red Beach, who do specifically work on her hand and her arm. That is excellent but, to be honest, we don't have a lot of money to spend on that, so, to pay for that privately is a strain. It's a matter of balancing how much the finance costs versus the benefit. (Robert, 64 years old, Significant other).

However, for some participants, the financial implications resulting from uptake of health-promoting behaviours became a barrier.

I try different foods... I've got on to gluten free, quite expensive, lately I've been a bit naughty, I do cheat now and again but I do endeavour to buy the right food. (Catherine, 78 years old, Stroke survivor).

7.8.4 Finding out what's available

Stroke survivors and significant others often described the additional resources to support their health behaviours that they were able to access through the community (swimming), the additional rehab services (private physiotherapy sessions), and other research studies (e.g. art therapy). The ability of stroke survivors to access these

resources was influenced by how long the service was available, the knowledge about these services, and the cost of services.

In addition to publically available services, participants described conducting personal research (outside of the public health service) for effective ways to understand the nature and cause of their stroke, to reduce their risk of recurrent stroke, stroke rehabilitation, and health-promoting behaviours following the stroke. This personal research provided the stroke survivor with autonomy, a choice in how to approach their post-stroke journey, and information about their stroke on their own terms.

Research about stroke, and stroke rehabilitation, was also conducted by the people around the stroke survivor. Family members, including significant others, often supported the stroke survivor by researching effective exercises for getting well, and to inform aides or equipment associated with post-stroke support. Personal research often provided stroke survivors and their significant others with confidence, and in turn influenced health-related behaviours. Independence and choice was valued by participants.

As a family we're very much into using the internet ... We've done quite a lot of reading about post-stroke activities, exercise, what exercises benefit things, what equipment would benefit recovery. It's centred around the recovery and exercise and research that's been done overseas. We've actually made one or two devices ourselves and sourced some devices. (Robert, 64 years old, Significant other).

In addition to personal research, participants in the control arm of the MIST-trial reported that the questionnaires made them think about aspects of their life and behaviour that they may not have reflected on without having undertaken the study. Some stroke survivors reported that the questionnaires made them think more about their diet, why their diet was important, and about the implications of a *poor* diet.

7.8.5 Maintenance of health-related behaviour

In spite of challenges associated with health-related behaviours, some stroke survivors and significant others recognised the need to maintain the lifestyle changes they had made.

I guess for me the main goal is being consistent and persistent about taking the tablets because I actually find taking tablets extraordinarily hard ... being subject to taking them having no choice so I've had to really be tough with myself that you know, I have to take them. You know there's no option and it's a surprisingly difficult thing for me to submit to that and in some ways its sort of admitting failure because I've tended to believe you can manage almost everything, through your diet ... and so to submit to taking drugs and you know checking my blood sugar regularly and going to see my doctor regularly, is something that I've had to choose to do. (Margaret, 59 years old, Stroke survivor).

A few stroke survivors went on to describe the realisation that their recovery wasn't a quick fix, that it would involve healthy-related behaviour, and that it would involve dealing with the consequences of stroke every day at home.

It was difficult and I didn't think about how difficult it was, I just thought about, I have to, and I think I did pretty well. They all said I did, anyway. But what I wasn't aware of with a stroke was not so much at the actual time of the stroke or being in hospital with a stroke, it was dealing with it in everyday life back home again. That was the thing I found the most difficult was realising that it was a daily thing, not just while you're in hospital but afterwards at home. Two years on, it's been an experience, been a journey, some good and some bad but either way I beat it. (Karen, 57 years old, Stroke survivor).

7.9 Summary

In summary, an overarching theme of path-finding was described by participants; this illustrated the individual journey that people experienced following first-ever stroke. Four main sub-themes emerged from the participant described experiences: *Past and present experiences; Individuality, beliefs, and choice; What the stroke means for me; and Access, knowledge, and availability of resources.* For the participants in this study, health-related behaviour was embedded in the wider context of recovery. The findings highlight that health-related behaviour was not simple and was dependent on numerous and complex internal and external factors. People needed support to help them understand the need for health-related behaviour, and what changes they could incorporate in their life in line with their priorities; access to support and opportunities

helped stroke survivors to make, review, problem solve and maintain positive changes in their life.

Chapter 8 Qualitative Discussion

This chapter will discuss the findings from the qualitative study, which aimed to identify the factors that influence post-stroke health-related behaviour. The chapter begins by exploring the findings in relation to similarities and differences with existing literature, strengths and limitations, and implications for services. Suggestions will be made for future research.

It was identified that health-promoting behaviour was substantially influenced by the person's general approach to recovery following a stroke. This over-arching theme influenced the participant's decision to make relevant changes to health behaviour or not, and also influenced how participants experienced each of the four sub-themes. The findings suggest that past and present experiences of health behaviour influence health-related behaviour following stroke and that the individual needs of stroke survivors need to be identified and addressed by health professionals to facilitate engagement in health-related behaviour. It was also revealed that the symptoms of stroke and sequelae can impact a person's ability to participate with health-related behaviour. Lastly it was found that learning what supports were available following the stroke was seen as a challenge. There is a need for services to actively address these factors to facilitate health-related behaviour following first-ever stroke and reduce recurrent stroke risk.

Overall, in line with previous research (e.g. Eilertsen, Kirkevold, & Bjork, 2010; Greenwood, Mackenzie, Wilson, & Cloud, 2009), the post stroke journey was found to be traumatic, changeable, and people continued to experience difficulties one-year post-stroke. This study has built on previous findings by highlighting that for some stroke survivors, health-related behaviour was not contemplated (e.g. health information was confusing and not engaged with; Lawrence et al., 2010). For other stroke survivors, health-related behaviour was often neglected when challenges became too difficult, or when they felt unable to cope because the post-stroke journey was too traumatic. In contrast, other individuals could clearly see the links between their lifestyle and risk of stroke, which motivated them to participate or continue their health-related behaviours. The findings suggest that health professionals should assess

the priorities of stroke survivors and their significant others to determine what goals should be identified, and what post-stroke rehabilitation should focus on for each individual. Assessing the level of awareness of stroke risk factors, and providing educational material and sources of community support was also important. Health professionals could be encouraged to apply aspects of MI to help identify an individualised strategy to promote rehabilitation, as well as identifying achievable goals and priorities for each stroke survivor.

8.1 Approach to stroke influences health-related behaviour

This study revealed that following a stroke, not all people want to get well, or change their behaviours to reduce their risk. In this study, some stroke survivors were ambivalent about 'getting better' or described being 'happy to die'. Whilst feelings of apathy (lack of interest, enthusiasm or concern) have been described post-stroke, the discrepant approaches to recovery identified in this study have not been previously highlighted in the literature. This notion challenges a commonly held assumption by health professionals that everyone has a desire to get better. It is important for clinicians and families to be aware of these different approaches to stroke recovery so that their response can take this into account. It may be that apathy, which has been found to occur more frequently than other post-stroke symptoms, such as depression (Caeiro, Ferro, & Costa, 2013), could influence a person's approach to recovery. Indeed, apathy has also previously been associated with greater functional decline post-stroke (Jorge et al., 2010). If this is the case, then support to help people to recognise and manage apathy may be an initial step to engaging them in rehabilitation before addressing the need for health behaviour change. Health professionals may also need to consider if there are individual priorities following first-ever stroke. For example, regaining functioning of their arm, preventing another stroke, or being able to spend time with their family that people may need to prioritise before they are ready to think about or engage with health behaviour. It may be helpful to link health behaviour change in with the individual priorities of the stroke survivors. Identifying smaller, achievable goals may help the rehabilitation and recovery process to seem less overwhelming, and focusing on the priorities of that individual may help to motivate people to consider health-related behaviour and lifestyle changes.

8.2 Impact of past and present experiences related to stroke

The findings of this research strongly reflected the subjective nature of the post-stroke journey. An aspect of the social context of what a person brought to the post-stroke recovery process was related to a person's past and present experiences and how these experiences influenced their health-related behaviours following stroke. A key factor related to uptake of health behaviour in this sample was the perceived need to change their health-related behaviour. Some participants reported pre-existing health-related behaviours, such as physical activity or no alcohol consumption, and that they were motivated to maintain these healthy behaviours following the stroke. However, for others this made them feel that although they were trying to be healthy but still experienced a stroke, having another stroke was out of their control. This perceived loss of control reduced their motivation to continue their health behaviour or make further changes. Whereas, participants who were not actively engaged in health behaviour felt they had no need of health behaviour change. This phenomenon may be related to risk perceptions, including unrealistic optimism (Harris & Middleton, 1994) or optimistic bias (Branstrom & Brandberg, 2010). For example, following stroke a person may feel that health-related behaviour is not important because they believe they will fully recover within a short time following their stroke. Likewise, some participants described experiences that could be interpreted as compensatory behaviours (Amrein et al., 2017; Radtke, Scholz, Keller, & Hornung, 2012). For example, participants described how they didn't drink alcohol, or smoke, so they didn't need to change their diet because they were already leading a healthy life.

Competing life demands placed on the stroke survivor meant that stroke recovery and prevention was not always a priority. People often experienced many demands on their time that took them away from focusing on their stroke recovery or making lifestyle changes. For example, in some cases, health-related behaviour (and recovery from stroke) was a lesser priority than managing a separate medical condition such as cancer or dementia, or their partner's or family member's ill-health. The motivational interviewers also highlighted the challenges they experienced when promoting health-related behaviour when the person had wider competing demands. This finding supports previous research by Graven and colleagues (2013), who conducted a

qualitative study of stroke survivor and informal caregiver perspectives of recovery, and reported that a stroke survivor's perspective was often embedded in the wider context of recovery. However, this study revealed that perceptions of recovery differed considerably between people involved in the recovery process (i.e. stroke survivors, informal caregivers, and health professionals). This suggests that health professionals should be aware that perceptions related to health-related behaviour are subjective, and that the different perceptions of the people involved in supporting a person's recovery should be taken into consideration when identifying priorities and goals. This approach would facilitate the support network of the stroke survivor to work towards the same goals and priorities. This may require conversations as part of ongoing healthcare provision, to clarify what everyone considers to be 'healthy behaviour' and to agree what to focus on at that time. This process may help identify and address the individual needs and priorities of each stroke survivor, support families to work together and allow health professionals to develop an individualised strategy to promote health-related behaviour.

8.3 Influence of individuality, beliefs, and choice

The study also illustrated how health-related behaviour could be influenced by an individual's changing self-identity. All participants described the importance of recognising that each individual's post-stroke journey was unique. This need for recognition applied to the healthcare services and rehabilitation that stroke survivors experienced following the stroke. Previous qualitative studies illustrate the importance of individuality, self-efficacy, changing social roles, and independence to post-stroke recovery (Morris, 2016). However, the influence of these participant-level factors impact on the individual's health-promoting behaviour (Murray et al., 2013; Murray, Honey, Hill, Craigs, & House, 2012). The findings from this study found that the individuality, beliefs, and choice of an individual were often interrelated with the other themes in this research, and that the individuals perspective of their recovery influenced how this theme was experienced. This finding complements the findings from Murray and colleagues (2012). Typically, post-stroke rehabilitation can include a combination of physical, cognitive, and occupational therapy in addition to standard medical care (Quinn et al., 2009). As post-stroke rehabilitation involves a range of

interventions, rehabilitation practitioners can flexibly customize interventions to individual patients (DeJong, Horn, Conroy, Nichols, & Heaton, 2005). However, this group of participants described the need for greater recognition of their individuality in relation to all the services they received.

Participants described greater participation with health-related behaviour when it was meaningful, and fitted well with their values and perceptions of recovery. Loss of autonomy and loss of confidence resulting from the stroke and residual impairments often meant that often intentions to change behaviour were difficult to action. In the current study, participants described the importance of being treated as an individual, being able to make their own choices, and having the confidence to say no to health-care options they didn't want. Progress following stroke was often observed when personal goals and values were met, enabling stroke survivors to maintain autonomy and choice in their decisions (Salter, Hellings, Foley, & Teasell, 2008). Therefore, health professionals should be aware of the importance of enabling autonomy in individuals following stroke. Facilitating autonomy will encourage people to make choices about their healthcare and rehabilitation. Facilitating autonomy and building self-efficacy in stroke survivors may also help engage them in their recovery, make their rehabilitation more meaningful to them, and increase their participation in health-related behaviour as a result.

8.4 What the stroke meant for the individual

Many participants in the current study attributed their stroke to (bad) luck and held the assumption that future risk of stroke was also down to luck. Research into health literacy and perceptions of personal risk complements these findings; for example, where high-risk individuals hold a low perception of their personal risk of stroke and don't perceive their risk to be different than other people (Dearborn & McCullough, 2009). The described experiences of participants suggested that perceptions associated with stroke risk factors were often misguided, misunderstood, or unrealistic. Health professionals should be aware of the vulnerability experienced by individuals following stroke. This highlights the importance for practitioners to identify

and address potential concerns and anxiety to enable health-related behaviour, and promote recovery following stroke.

The symptoms and sequelae of the stroke made it harder to implement health-related behaviour. Fatigue, a prevalent post-stroke symptom, was likely to negatively influence health-related behaviour (Young, Mills, Gibbons, & Thornton, 2013). Confusion, memory loss, and difficulties processing information caused by cognitive impairments were also challenges that impacted people's ability to understand the need for health-related behaviour, and its role in preventing a further stroke. This was often exacerbated by how individuals interpreted information. Many participants reported that information about healthy lifestyle changes given to them following the stroke was often confusing, did not relate to them, and was a barrier to their health-related behaviour. This perception associated with health literacy and stroke risk may be related to *action-outcome expectancies* (outlined by the HAPA) as well as the past and present experiences of the individual. Health literacy and risk perception associated with stroke has been a common theme in the qualitative literature (Wellwood, Dennis, & Warlow, 1994). For example, a qualitative Australian study found that stroke survivors reported a need for explanation of rehabilitation exercises they performed in hospital and more information about rehabilitation options following discharge to facilitate their engagement (White et al., 2008). Increasingly, education interventions evaluate the efficacy and effectiveness of stroke education programs to promote health outcomes and stroke prevention (Byers et al., 2010). However, health education for stroke survivors and their whanau is a complex issue with no clear solution.

Perceived risk and vulnerability were reported as substantial barriers to health-related behaviours, particularly physical activity following a stroke (Damush et al., 2007). Many participants reported that there were experiencing anxiety associated with exercise, which complements existing research (Nicholson et al., 2013; Rogerson, Murphy, Bird, & Morris, 2012), and participants in this study were fearful that increasing physical activity could increase their risk of a fall or trigger the onset of another stroke. This suggested that for some individuals, reassurance and information about health risk was needed to enable them to feel more confident to engage in activity (Radcliffe & Klein, 2002; Radtke et al., 2012). Some participants described how interactions with

health professionals had scared them when the health professional had identified potential risk to them (i.e. not using the walker provided and potentially falling and breaking their hip); these types of interaction had decreased their engagement with health-related behaviours, such as walking or other physical activity. This suggests that health professionals should be aware of the nature and their delivery of information they provide to stroke survivors and informal caregivers. Finding the balance between motivating an individual and negatively impacting behaviour is an important consideration for this population.

8.5 Learning what support was available following the stroke

Access to, knowledge of, and availability of resources following stroke were described as barriers or facilitators to health-related behaviour. Participants described a range of ways they were supported and motivated by the people around them, including family members and health professionals. Outside of the healthcare practice environment, family function (Palmer & Glass, 2003) and maintenance of healthy social relationships (Lynch et al., 2008; Murray et al., 2013) are acknowledged to influence stroke outcomes. Furthermore, participants described the support and motivation provided during the motivational interviewing intervention, which facilitated stroke survivors to overcome challenges or barriers related to health-related behaviours. Although participants in this study were part of a motivational interviewing intervention trial, the motivational interviews focused on problem solving rather than educating or signposting people to information and resources. However, motivational interviewers did direct individuals to additional services if this was requested by the participant. Future research could incorporate an educational component (that focused on post-stroke resources) into an intervention and measure subsequent well-being and motivation, and its impact on health-related behaviour, given many participants in this study reported not being aware of their own risk factors and how changing behaviour could reduce their risk of a subsequent stroke.

Additional resources to support health-related behaviours and recovery were valued by stroke survivors and informal caregivers. Participants described community services (swimming), additional rehab services (private physiotherapy), and other research

studies they chose to participate in and how they assisted their health-related behaviours. However, access to these resources was often influenced by availability of the service, appropriateness of the service, and financial implications of the service. Finding out what was available was often a challenge, and participants described needing to find these out for themselves. In addition, family members (including informal caregivers) were often able to support the stroke survivor by researching effective exercises, aides or equipment for rehabilitation purposes, and services to help support the stroke survivor. For example, some caregivers researched local massage therapists to help with physical impairments including muscle atrophy, while another caregiver had bought a spa pool to help the stroke survivor with their tired muscles. However, family members tended to focus on finding support to help with physical difficulties, and less was known about where to go to find support to help with the emotional reactions to stroke, such as risk and vulnerability and uptake of health behaviour. These findings concur with a review of the literature by MacDonald and colleagues (2013) which reported that personalised rehabilitation and person-centred practice, availability and access to knowledge, and a positive therapeutic connection were factors that influenced health-related behaviours following a stroke.

With access to the internet increasing, the capacity for stroke survivors and their families to search for available supports and services has improved. In some cases, individuals have been empowered by technology, whereas, previously people wouldn't have access to comprehensive research and would have been reliant on the health-professionals. This phenomenon suggests a changing arena in post-stroke rehabilitation, with implications for stroke survivor self-efficacy, autonomy, and a changing dynamic between patients and health professionals. The effect of such changes were reflected in the findings of this study. For example, in this study, stroke survivors and significant others described how researching the stroke online, and aspects associated with health-related behaviours (such as, exercises) improved their post-stroke outcomes and their uptake of health-related behaviour. Therefore, health professionals should be aware of this changing dynamic and how it may empower stroke survivors and promote health-related behaviour. In this regard, health

professionals could pre-empt the suggestion of reliable websites as sources of accurate and evidence-based information.

Finally, knowledge of and access to resources and supports also impacted on the maintenance of health-related behaviours. The majority of participants described the poor transition between services as a barrier to their health-related behaviour. This complements the research of (Tholin & Forsberg, 2014) who report the negative impact of poor transition between services. Continuity was a related factor that was described by participants. For stroke survivors and caregivers, continuity was embedded in the wider context of recovery, while motivational interviewers described continuity related to goal setting and achievement. This disparity in the focus of individuals may hold negative implications for health-related behaviour; for example, differences between macro- versus micro-elements of the recovery process may result in conflicting goals and barriers to engagement. This suggests that health professionals should clarify the priorities of stroke survivors, and address how health-related behaviour relates to the macro and micro-elements of recovery. In addition, an awareness of the duration of recovery following stroke should be encouraged; the process and duration of recovery has implications for long-term health-related behaviour of stroke survivors, as well as promoting their engagement and acceptance of the recovery process. This might be achievable through policy change to ensure that continuity of care is provided to facilitate and encourage goal setting for stroke populations (or chronic conditions).

8.6 Applying findings to the Health Action Process Approach

The findings suggested a good fit with the Health Action Process Approach (e.g. Schwarzer et al., 2007). The Health Action Process Approach was chosen as a theory of health behaviour because it had the most synergy with the findings from this study. However, it should be acknowledged that these findings could also be applied to other theories of health behaviour.

The described experiences of participants that were associated with the past and present experiences (sub-theme one) and what the stroke means for the individual (sub-theme three) may involve factors that impact *action-outcome expectancies* and

self-efficacy expectancies; as a result, these sub-themes may influence health-related behaviours following a stroke. For this group of people, it was observed that past and present experiences (sub-theme one) might influence the motivation, as well as volition (action), for behaviour. Participants described the need for change following the stroke, and the impact of their comorbidities in relation to health-promoting behaviours; often, the individuals experienced competing priorities, which impacted their intention for behaviour.

In this study, participants described what the stroke meant for them, and expressed confusion or loss of memory following the stroke, fatigue, risk and vulnerability as barriers to healthy behaviours. However, in this group of people, risk and vulnerability was a key theme throughout participants' described experiences and impacted health-related behaviour. This study suggests that risk and vulnerability influenced motivation and action processes in the HAPA, and played a bigger role in my group of participants that was suggested in the original HAPA (Schwarzer et al., 2011).

The role of self-efficacy was not observed to be as significant in this group of people and didn't emerge from the findings to the degree indicated by the original HAPA. Self-efficacy is a complex construct, and can be difficult to understand. In the context of this study, self-efficacy was raised within the context of perceived risk and vulnerability. In addition, people outside of the health research environment may not use specific terminology associated with self-efficacy. Although participants in this research described concepts related to self-efficacy, they used lay-person language and described small concepts associated with their perceptions to achieve a goal or complete a task. Future research could explore the role of self-efficacy following a stroke on health-related behaviours. Implementing a mixed methods approach would allow exploration of this construct using qualitative methods to provide participant level data, with these findings to augment quantitative data that would provide group level data.

Although the findings suggest a good fit with the HAPA theory, differences in self-efficacy and risk perception were observed. This may be due to the fact that this was an exploratory study on the factors influencing health behaviour rather than explicitly

testing a theory. This research did not test a theory (i.e. HAPA) because little consensus exists relating to health behaviour models in the various clinical populations, and specific to this study, in stroke populations. Instead, this study explored what factors might influence health-related behaviour in stroke survivors. This facilitated information from the population to be interpreted, rather than asking specific questions and fitting the answers into a pre-determined model. Different findings may have emerged if the participants had been asked about health-related behaviour within the context of the HAPA. Limited evidence supports the HAPA in post-stroke populations (e.g. Tielemans et al., 2014). Future research could explore the HAPA theory and investigate if the theory explains health-related behaviour in post-stroke populations to extend these findings.

8.7 Evaluation of Methods

Interpretive Description has been found to be particularly useful in answering clinically relevant questions and exploring how interventions can be delivered more effectively (Thorne et al., 2004). This study explored the factors that influence health-related behaviour following stroke, with an aim to inform future delivery of interventions (such as motivational interviewing) for post-stroke populations. This approach was considered to be most conducive to answer the research question and facilitate clinical interpretation of the findings.

While Interpretive Description was considered to be the most appropriate methodology for this study, an awareness of the complexity of qualitative research process encouraged this method to be used flexibly to explore research phenomena. This flexible approach enabled the researcher to respond to the developing needs of this study (i.e. the participants, data collection, and analysis), which enabled this study to be phenomenon-driven. This phenomenon-driven study captured data that was relevant to the research phenomenon but may not have been accessible using a theory-driven approach, whilst also providing access to a research phenomenon that is unclear and demands further research.

8.7.1 Sampling and Participants

Participants were recruited from a convenience sample who had participated in the parent MIST-trial. The stroke survivors and informal caregivers were recruited for this study after their participation with MIST had finished; the motivational interviewers were recruited towards the end of their involvement with the trial or after their involvement had finished. This approach was used to reduce participant burden and reduce any confounds for MIST or for this study.

It should also be acknowledged that the convenience sample of stroke survivors from MIST had met eligibility criteria specific to MIST. This may hold implications for generalisability and comparison to the general stroke population. For example, the MIST population included people who had experienced first-ever stroke, with mild or minimal cognitive impairment (e.g. Barker-Collo et al., 2016); this may limit the generalisability of these findings to this population. Previous research has focused predominantly on moderate to severe stroke, and neglected mild stroke within the research literature. However, this approach may limit generalisability of the findings to people experiencing more severe strokes.

The majority of stroke survivors (and informal caregivers) were approached approximately one-year post-stroke, but a couple of stroke survivors were further on in their post-stroke journey and had experienced the stroke up to two-years before; the motivational interviewers were recruited during the final year of the MIST-trial. This timeframe enabled participants to look back over a relatively long period of time and reflect on the factors that had influenced their health-related behaviour after the stroke but also may have affected their recall of their experience. As this study highlighted that perceptions and health behaviour change over time, a longitudinal study (during the year following first-ever stroke) would help to explore how health-related behaviours changed over time and highlight the factors influencing uptake of health behaviour post-stroke.

The MIST population of stroke survivors may also have had different experiences following their stroke, compared to the general stroke population. For example, these stroke survivors had participated in a study for one-year post-stroke, during which

time they had received intermittent but regular contact from study researchers for a year post stroke. This was in comparison with stroke survivors from the general population who typically experience continued contact from health professionals for up to six-months post-stroke but with limited follow up after in-patient services had ended (usually between three to six-months post stroke). This difference in duration of continued contact post-stroke may be a potential confound for the findings of this study, because the MIST-trial itself may have acted as an intervention.

The sample in this study broadly met the sampling characteristics (age, gender, study group, ethnicity, and Barthel). However, there was an imbalance between the numbers of stroke survivors recruited into this study by the MIST-intervention group they had been in. As a result of recruitment issues mentioned above, only three participants had been in the MI (intervention) group compared with six participants who had been in the usual care (control group). This reduction in heterogeneity was a potential limitation for the findings. The experiences of the two groups may have differed as the MI intervention group had experienced a greater intensity of contact because of the motivational interviews; the motivational interviews may also have elicited different experiences associated with health behaviours for this group, compared to the usual care group. This imbalance between groups of stroke survivors may have had implications for the findings and may have impacted on the perceived success of motivational interviewing with this group of people. However, MI did not affect the themes in the described experiences of participants, and data was integrated for MI and usual care participants.

New Zealand is a multi-cultural country. Enabling participation of ethnic minorities and indigenous populations provides unique cultural perspectives from these groups. The purposive sampling strategy identified one stroke survivor-informal caregiver couple as Maori, one stroke survivor identified as New Zealand European-Maori, and the remaining participants identifying as New Zealand European⁷. There was only one

⁷ One stroke survivor, who identified their ethnicity as Indian, was approached during recruitment but declined to participate in this study.

participant who identified as being from an ethnic minority group as participants were excluded if they did not speak English. This is likely to limit generalisability of the findings to non-Europeans and further research that captures the perceptions and experiences of health behaviour post-stroke is needed. Within this study, no differences in described experiences were observed across the different ethnicities in this study. However, this may have been different if a broader range of ethnicities had been recruited into this study, or if non-English speakers had been included in this study.

Despite an awareness of issues around participation for certain participant groups, challenges were experienced during recruitment for the study. Some individuals approached during recruitment declined to participate without giving a reason, one significant other was unable to participate because of ill-health, and some stroke survivors declined participation because of existing commitments. This may have contributed to the imbalance between groups of stroke survivors (MI versus usual-care) and may have impacted on the types of described experiences. It is possible that stroke survivors (and informal caregivers) who declined to participate were struggling more with the challenges faced one-year post-stroke; different themes and findings may have been observed in this study if these individuals had chosen to participate.

Finally, during the concurrent recruitment and data collection process, a potential limitation of the study was identified: the sampling strategy had identified stroke survivors who had informal caregivers living with them and had neglected to recruit stroke survivors living on their own. An assumption that had informed the original theoretical framework of this study was that informal caregivers influenced the health-related behaviours of stroke survivors; for example, influencing diet by cooking meals for stroke survivors. To address this potential limitation, four stroke survivors who did not have informal caregivers were approached to participate in the study; two of these stroke survivors consented to participate. The inclusion of these stroke survivors provided perspectives of stroke survivor health behaviour with minimal influence from others. However, these two stroke survivors experienced usual-care and provided minimal perspective about the influence of motivational interviewing for people living on their own following a stroke. It should also be noted that although these stroke

survivors did not identify a significant other living with them, their narratives often identified other family members who looked after them and influenced their health behaviours.

8.7.2 Data collection and analysis

This study approached the research question exploring three separate but related groups about their post-stroke perspectives of health-related behaviour. Stroke survivors, significant other, and motivational interviewers were interviewed in their own right, but provided their own perspectives and personal experiences of what influence health-related behaviours following stroke. This holistic approach to data collection assisted in the identification of themes, including confirming a main finding within the themes. During data collection, it was clear that health-related behaviour was not a priority for stroke survivors. Through the coding process, this was also acknowledged by the significant others and motivational interviewers. This was an example where the information that was provided by the significant other and the motivational interviewers was valuable, particularly in combination with the subjective perspectives from the stroke survivors.

Participants in this study were offered a number of options for their participation: face-to-face interviews, telephone interviews, two-person dyad interviews, or a focus group. These options were offered to meet the different participant needs and enable participation. However, some issues arose as a result of the mode of interview. For example, during the two-person dyad interviews an imbalance in the level of participation often occurred between the stroke survivor and significant other. One person was often observed to be less active during the interview, although they would often speak to contradict or correct the other person. This process would often clarify something that had been said and provide a richer depth to that described experience, which could then be explored. This richer depth provided more specific content about the experiences of the stroke survivor and significant other dyad; however, the researcher was aware that different content (e.g. more emotional content including concerns or anxiety) might have been described if individual interviews had taken place.

Data collection was also impacted by the cognitive ability of participants. For some stroke survivors, they continued to experience cognitive impairments following the stroke, which were apparent through their confusion or lack of memory. For example, the first two consecutive interviews that were conducted in this study highlighted the importance of the comparative analytic process, and the need for awareness of cognitive impairments during the process of data collection and analysis. The first interview suggested that the stroke survivor had a positive approach to health-related behaviour, her post-stroke journey, and importantly that she remembered this journey. The interview with the significant other conveyed his anxiety about his ability to help her, and that she experienced severe memory impairments following the stroke. The contrast in these described experiences highlighted the importance of the holistic approach I was employing, the methodological mechanisms I was using to analyse the participant descriptions, and the personal nature of the research I was conducting. This approach may have enabled me to capture the disparity between stroke survivor and significant other experiences following the stroke, and the interpretive descriptive approach facilitated interpretation of these experiences. Future research could consider exploring stroke survivor and significant other dyads in more depth, particularly in relation to health-related behaviour, using additional qualitative tools (e.g. triangulation, which is an analytic strategy to confirm findings with participants and explore emerging themes) to facilitate this.

Semi-structured interviews were used to ask participants about their experiences and perspectives of health-promoting behaviours following the stroke. The flexibility of this approach enabled me to explore the research question, while accommodating the individual needs of participants (such as cognitive impairments or emotional distress). A potential limitation of this approach was that asking different questions provides different answers (i.e. variability of experience was encouraged during data collection rather than confirmation of experiences). However, as interpretive description acknowledges the subjective nature of described experiences, this could be interpreted as a strength of the research and a strategy to achieve saturation of themes and sub-themes. During the process of semi-structured interviews, it became clear that the broader concept of recovery was embedded within participant

descriptions; this was despite participants being asked about healthy behaviour post-stroke. One observation to draw from this is that recovery emerged as a more important factor for individuals following stroke, compared to health-related behaviour. This prompted the analysis to draw on the wider context of people's experiences, with sub-themes focusing on perceptions of health behaviour and how people participated with health-related behaviours, rather than explicit examples or themes emerging from the data. The flexible nature of the semi-structured interviews enabled this important factor to be captured by the participant descriptions, and provided the participants with a voice to illustrate the factors of importance to their post-stroke journey. Therefore, a recommendation for future research would be to assess the approach used to interview stroke survivors and significant others to ensure that it is appropriate to address the research question.

An initial search of the literature had informed the theoretical framework for this study, including the specific research question; the sampling strategy, and data collection methods. The early stages of analysis in this study involved recognising the nature and shape of the preliminary theoretical scaffolding, and gradually refining this framework as alternative concepts arose. This enabled a data-driven analysis to acquire as much new evidence relating to health-related behaviour following stroke. It became clear that health behaviour change was not as important a factor for this group of people, which conflicted with the overall research question. However, the Interpretive Descriptive method enabled this important factor to be captured by participant descriptions. The key approach for the analysis focused on answering the research question, not becoming side-tracked with themes around recovery, but acknowledging that health-related behaviour took place in the wider context of recovery.

While coding was the primary analytic approach used for the data analysis, this study used a number of structured analytic approaches to support the data-driven findings: memoing, iterative analysis, managing assumptions, and analysis verification. For example, memoing was a useful strategy to note relationships, ideas, and develop concepts (for example, identifying interrelated themes in the data); these memos contributed to the descriptions of themes and sub-themes, as well as the basis of this

study's findings and discussion. Through using Interpretive Description, this method established criteria for a rigorous and credible analytic process in relation to the research design, data collection, and data analysis of this study.

8.8 Original contribution of research

This study has provided several novel contributions to knowledge around health-related behaviours following first-ever stroke. First, this study highlighted that health-related behaviour was embedded within the broader concept of recovery. This illustrated the diversity in how people approached their post-stroke journey. Second, health-related behaviour was not always a priority for people following first-ever stroke. This study demonstrated how complex post-stroke experiences are, and the diverse ways that this complexity impacts on health-related behaviour. Third, this study captured three distinct, but interrelated perspectives on health-related behaviour following stroke, providing a holistic perspective on the overarching research question posed in this study. Fourth, this study explored general health-related behaviours following stroke to look for commonalities across health behaviour that can be used to understand this phenomenon better. Typically, research has focused on one type of health behaviour within at-risk populations, whereas the findings of this study suggest a multi-dimensional approach. The findings suggested partial support for the HAPA although some additional pathways of the influence of beliefs, past and present experience, what the stroke means for the person, and risk perception, are suggested.

Chapter 9 Mixed Method Discussion

This chapter will draw together the findings from the qualitative and quantitative studies to discuss what may influence health-related behaviour following a stroke. The chapter begins with a discussion of the similarities and differences between the qualitative and quantitative findings. Then, the findings will be discussed in relation to strengths and limitations of existing literature, and contribution of this research to the subject area. These findings will then be considered in relation to the HAPA model with an appraisal of the implications for this research and future research. The chapter will conclude by reflecting on the strengths and limitations of a mixed methods approach.

9.1 Overview

This thesis aimed to improve understanding around what may influence post-stroke health behaviours, including alcohol use, smoking cessation, diet choices, physical activity, and medication adherence. Five key findings were identified across both studies in this thesis. First, each individual post-stroke journey is different, and individual needs of stroke survivors need to be identified and addressed by health professionals to facilitate health behaviour. Second, the emotional aspects of illness perceptions were specific significant predictors of health-related behaviours and need to be recognised by health professionals. Third, stroke survivor priorities (in relation to health behaviour uptake) need to be recognised following stroke, as health-related behaviour may not be the biggest priority for an individual at that time. Fourth, the impact of stroke (e.g. impairments, fatigue, mood changes) and need for support with health behaviour change may extend past the timeframe within which current services are provided. Finally, satisfaction with stroke care has minimal impact on longer-term health-related behaviour for this group of people. Findings based on the described experiences of stroke survivors in this thesis suggested a good fit with the Health Action Process Approach (Schwarzer et al., 2011) and suggested some potential modifications for the application of the model to stroke populations.

9.2 Everyone's post-stroke journey is different.

Everyone's post-stroke journey is different. Following stroke, participants were found to experience a range of different impairments, complications, and rates of recovery. Participants described experiences that suggested that the symptoms of stroke made it harder to implement health behaviour changes. For example, some participants described how memory impairments following the stroke reduced health-related behaviours, such as physical activity, because they felt embarrassed or felt more vulnerable. Participants were influenced by the impact of symptoms and sequelae related to the stroke, including confusion and memory loss, fatigue, and other cognitive impairments. Evidence supports that cognitive impairments (such as confusion, memory deficits, dementia, mood changes, visuo-perceptual deficits) can negatively impact outcome following stroke (Barker-Collo et al., 2010; Barker-Collo et al., 2016; Feigin et al., 2010). While comorbidity was not entered as a predictor in the regression analyses, the summary statistics demonstrated the wide range of comorbidity, and the high frequency of comorbidity, experienced following the stroke. Similarly, in the qualitative study, the majority of participants described experiences where fatigue, memory impairments, stress, anxiety, and confusion impacted their post-stroke health-related behaviours. However, the way that these impairments affected participants was often quite varied. This study built on previous findings by revealing that symptoms of stroke directly affect health behaviour. Health professionals should consider the implications of stroke for each patient, and how their individual impairments might impact on their health-related behaviours and post-stroke rehabilitation. Similarly, future research should investigate the implications of impairments and comorbidities following stroke, and their impact on health-related behaviour for this population.

Individual differences were also apparent when the demographics of each person were considered. The quantitative findings demonstrated that age was a significant predictor of reduced physical activity and poorer diet in this group of people. Older adults are more likely to experience multi-morbidity, which is associated with decreased health-related behaviours and self-management (Schuz et al., 2014). Differences in gender, age, socioeconomic status factors (such as education and

occupation) have all been shown to impact post-stroke outcomes (Barker-Collo et al., 2010; Feigin et al., 2010). Sociodemographic factors were also described within the qualitative descriptions of the stroke survivors e.g. participants would often refer to their age, marital status (and living arrangements), and previous occupations while describing how these factors influenced their health-related behaviour following the stroke. For example, one participant described how a family member moved in with her and provided support following the stroke which influenced her health behaviour. The influence of sociodemographic factors supports previous findings that a person's characteristics may predict their psychological reactions to a stimulus or event, such as stroke (Viney & Westbrook, 1981).

Health-related behaviours can also be positively or negatively associated with stress; for example, exercising as a coping mechanism (Park & Iacocca, 2014) or eating unhealthily in response to stress (Carmen et al., 2015). Although coping and stress were not assessed within the current study, future studies should investigate the dynamics within individual demographics that might influence behaviour to understand the complex nature of post-stroke health-related behaviour. For example, one approach could investigate individual trajectories in the quantitative data and construct individual journey maps for participants; employing a mixed methods approach and exploring demographic factors qualitatively to augment the quantitative data would also contribute to understanding how individual differences influence post-stroke health-related behaviour.

A person's identity, including their sense-of-self, level of confidence, and autonomy, were important factors that impacted on health-related behaviour in the qualitative study. Significant others often described the importance of independence for the stroke survivor, and that independence was often associated with increased uptake of health-related behaviours. Furthermore, personal factors guided the choices individuals made about their health-related behaviours following the stroke. For example, some stroke survivors did not want to use physical aides. One stroke survivor described how he avoided using walking sticks to walk around his local area where he often walked alone, whereas he did use them when going to the local shopping area because he felt more vulnerable there. Indeed, stroke survivors and significant others

in the qualitative study identified a specific need for awareness and recognition from health professionals around a stroke survivor's individual requirements. Self-identity has been shown to influence health-related behaviour post-stroke (Morris, 2016; Morris, Oliver, Kroll, Joice, & Williams, 2015; Murray, Ashworth, Forster, & Young, 2003). This combined evidence suggests that health professionals need to develop an approach that takes into account an individual's unique needs and characteristics following stroke to enable health-related behaviours and successful rehabilitation. These factors weren't assessed in the quantitative study because of the lack of psychometrically proven measures. However, future research should also examine personal attributes and characteristics, such as personal identity, self-efficacy, or coping styles, by measuring these constructs with stroke populations and investigating their influence on post-stroke health-related behaviour.

9.3 Emotional aspects of illness perceptions and health behaviour

Within this research, two dimensions of illness perceptions emerged from the quantitative data: emotional illness perceptions, and practical illness perceptions. Quantitative analyses indicated that emotional illness perceptions could positively and negatively influence health behaviours. Furthermore, emotional illness perceptions were significant predictors of more health behaviour domains, compared to the practical dimension of illness perceptions. For example, more threatening emotional illness perceptions were associated with decreased alcohol use as well as poorer diet choices and reduced physical activity. Aspects of emotional illness perceptions also emerged within the described experiences of participants. Individuals described concern around the implications of the stroke, their symptoms, and how much the stroke had affected their life, with these factors impacting health-related behaviours. In addition, the described experiences of participants were often emotionally loaded, and were centred on the stroke and its implications. Most participants voiced fear about the implications of the stroke; this was a source of motivation for health-related behaviours for some stroke survivors, while for others it did not impact their behaviour. This focus on emotions, and the lack of explicit described experiences relating to health-related behaviour, suggested that the emotional factors following

stroke were more important to this group of people during the twelve-months following first-ever stroke (Morris, 2016).

Furthermore, one of the key themes in the qualitative study related to perceived risk and vulnerability as barriers to health-related behaviour. For example, some participants reported anxiety associated with physical activity, and were fearful of potential implications if they did too much or over-challenged themselves (e.g. triggering further stroke). Mixed evidence exists regarding the influence of risk and vulnerability on health-related behaviours. For example, a sample of older adults at risk of stroke demonstrated differences relating to barriers and facilitators for walking (Kwon et al., 2015); concerns for safety were associated with avoidance of physical activity, whilst risk of stroke leading to nursing home placement motivated walking behaviour. Similarly, in a sample of older adults, avoidance of physical activity was based on fears that this might precipitate stroke (Lees, Clark, Nigg, & Newman, 2005). This suggests that emotional aspects of illness perceptions are important to individuals, but might influence people in different ways. It could be suggested that current post-stroke healthcare focuses on the physical implications of stroke, and not enough on the psychological implications such as risk and vulnerability. A practical implication for health professionals based on these findings could develop psychological support to reduce threatening illness perceptions and feelings of risk and vulnerability following stroke. Future research could also explore the emotional implications of the stroke with stroke survivors and significant others, to determine if reducing threatening illness perceptions, and in particular more threatening emotional illness perceptions, would enable health-related behaviours following stroke.

9.4 Priorities following a stroke

An assumption currently held by health professionals is that uptake of health-related behaviour is a priority for stroke survivors after stroke. This programme of work highlighted that this was not necessarily the case for stroke survivors. For example, in the quantitative study, it was evident that not all health behaviours were applicable to all participants (i.e. some participants did not consume alcohol even before their stroke). Augmenting these findings, the qualitative study revealed that some people

saw the link between some health behaviours and risk of subsequent stroke (but not other health behaviours) and were more willing to consider changing their behaviour if the link was clear to them. Whilst the quantitative study only captured information about five pre-determined health behaviours, the qualitative study allowed people to describe a wider range of health-related behaviours (e.g. gardening and housework) that were considered as positive by the participants. This approach enabled a richer, in-depth perspective relating to uptake of post-stroke health-related behaviour, whilst capturing information about healthy behaviours that were relevant on an individual level; these healthy behaviours, which may be considered part of daily life, also provide a perspective of what is achievable or a priority after a stroke. Future research could explore the range of behaviours that people perceive as health-related and what they prioritise following the stroke to determine whether certain behaviours are more likely (compared to others); this could inform the focus of post-stroke interventions.

One of the advantages of a participant-driven qualitative interview rather than following a more structured interview approach, was that it facilitated the identification of areas that were of key importance to our participants. Participants did not talk much about health-related behaviour, but focused more on a desire to return to a normal life, similar to the life they had pre-stroke. Evidence supports this finding, as stroke survivors often identify the desire to return to pre-stroke abilities and the life they had before the stroke (Astrom, Asplund, & Astrom, 1992; Graven et al., 2013; Satink et al., 2013). When health-related behaviour was described by this sample of participants, it was within the context of rehabilitation and returning to pre-stroke life. For health professionals, success in managing the post-stroke journey can be associated with improvement in health-related behaviour to reduce risk of secondary stroke. In contrast, for stroke survivors', success in managing the post-stroke journey might be associated with returning to pre-stroke life and abilities. These contrasting perspectives may cause competing priorities to emerge in relation to health-related behaviour. While uptake of health-related behaviour may be seen as desirable by health professionals, health professionals need to be aware of the priorities that stroke survivors have related to health behaviours and their post-stroke life.

The qualitative sample described perceptions associated with stroke risk factors that were often misguided, misunderstood, or unrealistic. This qualitative finding was supported by the quantitative data from the causal question in the B-IPQ. This question asked participants to list in rank order three factors that they believed had caused their stroke; while some participants provided recognised risk factors for stroke, many stroke survivors stated unrelated stroke risk factors, such as fatigue, headaches, feeling dizzy, etc. Although these factors were often related to stroke, evidence for their causal nature is limited. The lack of health literacy in stroke survivors and their significant others may influence health-related behaviours. Unrealistic risk perceptions can influence health-promoting behaviours (Radcliffe & Klein, 2002; Radtke et al., 2012). In addition, low health literacy is associated with low adherence to self-management in chronic illness (Kale et al., 2015). This study highlights the importance of health literacy in the context of health-related behaviours for this group of people. Health literacy was not part of the intervention, and was not measured by the study. Future research could incorporate an educational component into an intervention, and measure subsequent health literacy and its impact on health-related behaviour. This finding also holds implications for health professionals. Health professionals need to be aware that stroke survivors (and their significant others) may not be literate about stroke risk and secondary prevention; recognising this issue, and incorporating health education into rehabilitation services may improve secondary stroke prevention and health outcomes for stroke survivors.

The social context of health literacy and its implications for health-related behaviour should also be considered for this group of people. First, Auckland has a diverse population, including a large proportion of immigrants from different ethnic backgrounds. Communication about health-related behaviours might differ across ethnicities, and may be an artefact of the country of origin. In New Zealand, health professionals might hold the assumption that people within NZ possess the same information about health-related behaviours. In addition, conflicting and controversial messages about health behaviours should be acknowledged, and their implications for health literacy, illness perceptions, and beliefs about health behaviour should be considered. The current climate of health-related information is constantly changing,

being updated, and sometimes miscommunicated (e.g. press releases that misinterpret research findings). This can result in confusion about whether certain health behaviours are healthy or unhealthy, as well as how health information translates across illnesses; for example, whether a glass of red wine lowers risk for cardiovascular disease or not (Rimm, Klatsky, Grobbee, & Stampfer, 1996; St Leger, Cochrane, & Moore, 1979) and how a glass of red wine might affect stroke risk (Larsson, Wallin, Wolk, & Markus, 2016). For example, Danish women's perceptions of health benefits of alcohol consumption with use of alcohol for medicinal purposes (Aira, Hartikainen, & Sulkava, 2008). Prior knowledge of health-related behaviours should be considered, because the NZ healthcare system might assume cultural invariance, and this may influence how people from different ethnic backgrounds respond to health behaviours and risk of secondary stroke. Future research could determine if cultural variance is considered as part of the healthcare recommendations following stroke, and whether this might be a factor that influences health literacy and health-related behaviours post-stroke.

9.5 Consequences of stroke go beyond end of healthcare

Participants reported a need for on-going support following stroke, with some participants describing how the limited access to or availability of services, or the short duration of service provision, had negative consequences for their health-related behaviours. Literature recognises that stroke can cause chronic disability, with 50-70% of stroke survivors experiencing long-term disability (Barker-Collo et al., 2016). However, as time from the original stroke event increases, less recognition exists that people are able to reduce impairments and disabilities associated with the stroke. As a result, the majority of health services focus on improving outcomes for stroke survivors during the three-months following the stroke. More recently, evidence indicates that some people can improve a disability five years on from a stroke (Dafer et al., 2008). Longer-term healthcare provision (compared with three-month acute services) might promote longer-term health-related behaviours and rehabilitation following stroke by providing services to stroke survivors when they are more able to engage with those services and health-related recommendations.

The findings from this research suggest that although some stroke survivors made changes to health behaviours following stroke, this was not continued or maintained across time for the majority of participants. In this research, the participants described the implications associated with their stroke and the impact this had had on their lives. From the emotional content of these experiences, it may be assumed that most of this group of people were still adjusting to the stroke and its implications, and this may have been why they didn't describe health-related behaviours as expected. Research conducted in parallel with this study found that people experienced a complex adjustment process following stroke that remained evident for up to three-years (Theadom, Rutherford, Kent, & McPherson, 2018). This adjustment process may hold implications for health-related behaviour, as people might be navigating health behaviour decisions at later time-points than expected, and not during the immediate months following stroke when they have access to health professionals and rehabilitation. For example, if people contemplated making diet changes after 6-months but weren't able to discuss this with their rehabilitation team, this might be a barrier to behaviour change. Health professionals should recognise that the process of adjustment for stroke survivors might impact on stroke survivor motivation for health-related behaviour. Identifying coping strategies or services that can support the stroke survivor in coping with the implication of stroke may improve well-being and health outcomes post-stroke.

Limited evidence of role of satisfaction with stroke care on health behaviour

Post-stroke satisfaction with care did not significantly predict uptake of health-related behaviours, or emerge as a main theme within the described experiences for this group of people. However, satisfaction with stroke care was still identified as an important factor for this group of people. It was expected that satisfaction with stroke care would predict uptake of health-related behaviours within the quantitative data, and also emerge from the qualitative data when people described their post-stroke experiences. For example, those having good experiences would be expected to feel more informed about the lifestyle choices that needed to change and more motivated for positive health behaviours. However, the findings were unexpected as acute satisfaction only predicted reduced physical activity at 6-months post-stroke. While in

the qualitative study, satisfaction with stroke care was talked about by participants in terms of how well they felt supported, all participants felt that health care services were out of their control. Where there was dissatisfaction with one particular aspect of care, participants did make changes (e.g. changing their general practitioner). However, none of the participants talked about health care services in connection with health behaviour change. This may indicate that participants did not perceive the link between health care services and their role in supporting health behaviour change and only saw the connection with physical recovery.

Greater satisfaction with stroke care might have been influenced by better functional outcomes in this sample. Eligibility criteria for this study excluded stroke survivors with impairments precluding participation (Barker-Collo et al., 2015; Krishnamurthi et al., 2014) providing a sample who might have experienced milder implications of stroke. Patients who report greater satisfaction are associated with better functional outcomes (Jackson et al., 2001); therefore, satisfied participants might have reduced physical activity because of less need to improve their functional outcomes. Future research could explore the association between satisfaction with stroke care, functional outcomes, and health-related behaviours.

Another factor that may have influenced the lack of association between satisfaction with stroke care and health behaviour, was that service provision was focused within the first few months of recovery, whereas the qualitative interviews were conducted at twelve-months post-stroke. It may be that only the more extreme experiences (very bad vs. very good) were memorable and found to influence long-term behaviour. Some participants described satisfaction with stroke care with an awareness of the healthcare context: services were as good as they could be. However, these participants did not dwell on what could have been, and most had just accepted the experiences with healthcare services that they had received. This study was supported by previous New Zealand stroke survivors who described the individual care they received in an objective manner and acknowledged aspects of healthcare were out of their control (Ahuja et al., 2013). This acceptance may explain why satisfaction did not emerge in the quantitative data as a significant predictor of health behaviour.

Expectations of care may also have influenced the lack of association between satisfaction with stroke care and health behaviour. For example, lower expectations of care might impact how much people engage with health behaviour information or recommendations. Although expectations related to care did not emerge from the qualitative data, and wasn't measured quantitatively, expectations may have influenced satisfaction. Evidence suggests that both expectations and preferences influence satisfaction with healthcare (C. K. Ross, Sinacore, Stiers, & Budiman-Mak, 1990). In addition, the expectations of significant others may guide immediate post-stroke care and subsequent satisfaction. Social support, including informal care from significant others, is associated with improved functional outcomes for stroke survivors and quality of life (Clarke, Marshall, Black, & Colantonio, 2002); stroke survivor and caregiver SASC has been associated with quality of life (Cramm et al., 2012). This was also suggested within the findings: one stroke survivor described her role as a caregiver and how she was motivated in relation to her partner's healthcare; this contrasted with her motivation for her own healthcare. This might suggest that significant others are the driving force behind received healthcare and may influence stroke survivor expectations and subsequent satisfaction. For example, significant others are in a position to complain about unmet expectations of care, whereas stroke survivors have recently experienced a brain injury and expectations of care may not be a priority. Furthermore, older people may have fewer expectations around healthcare than younger people (Jackson et al., 2001; Thi et al., 2002). This holds implications for this research because this group of people were an older adult population, with over a third of the sample aged 75 years and over. Future research could explore the influence of care expectations on satisfaction, either by developing a measure of satisfaction with stroke care that encompassed expectations; the relationship between stroke survivor and significant other (caregiver) expectations and satisfaction could also be investigated and measure and compare the expectations and satisfaction of stroke survivors and their significant others. The longevity of satisfaction with stroke care, it's salience to stroke survivors and significant others, and its implications for health behaviour should be further investigated.

9.6 How findings relate to the HAPA model

'Risk and vulnerability' was a key theme throughout the interviews. All participants described needing to mitigate risk and increased feelings of vulnerability. Risk perception is the threat that an individual believes may happen to their health if health-promoting behaviour is not undertaken. For example, people might believe that participating in physical activity reduces risk of cardiovascular disease (Schwarzer et al., 2011). However, for this group of people, it was observed that risk perception might have acted as a barrier for health-related behaviours as well. For example, while participants associated risk of secondary stroke with luck and chance, risk and vulnerability were described in relation to avoiding health-related behaviours. In addition, the quantitative findings suggested that more threatening emotional illness perceptions were associated with poorer health-related behaviours. These study findings suggest that risk perception may not influence health-related behaviour in the way that is proposed by the HAPA. This holds implications for healthcare practice, with a recommendation that health professionals should be aware that risk perception does not relate solely to risk of second stroke, but extends to risk of harm to the individual.

Risk perceptions played a bigger role in this sample than was suggested in the original HAPA; in contrast, the role of self-efficacy was not found to be as salient as in previous studies. Self-efficacy is the belief an individual has about their ability to succeed with a task or situation (Bandura, 1998). Although participants in the qualitative study described concepts that related to self-efficacy, they did not differentiate between the different types of self-efficacy (task self-efficacy, maintenance, and recovery self-efficacy) in their described experiences. A reason for this finding may be because self-efficacy is a complex construct; in addition, the language that people use with regard to self-efficacy is different between lay-people and academics. For example, when lay-people talk about self-efficacy, they don't use terminology but describe smaller aspects of the construct (e.g. "I don't think I can take control of this" or "I don't think I'm confident in my ability to do this"). Although, the implications of self-efficacy in this research have already been discussed (see Chapter 8), it should be acknowledged that the presence of self-efficacy in the described experiences highlights the importance of language for this construct, as well as partial support for the HAPA. Future research

could use the HAPA as a theory driven approach to guide questions that explore factors that influence post-stroke health-related behaviour. In addition, the association between illness perceptions and self-efficacy following stroke, and its implications for health-related behaviours, should be investigated.

In this mixed research, the findings were data driven rather than theory driven. A data driven method was used to enable the findings to emerge from the data (as recommended by Thorne et al., 2004). This approach may hold implications when considering their applicability to the HAPA. In the qualitative study, the main themes that emerged from participant's described experiences suggested a good fit with the HAPA. In the quantitative study, illness perceptions emerged as predictors of health behaviour, with aspects of illness perceptions described by participants (without the use of specific terminology). Although the study findings suggest a fit with the HAPA, because participants were not talking about the application of theory this fit was the interpretation of the researcher. Different findings may have emerged if the participants had been asked about health-related behaviour specifically guided by the HAPA. Limited evidence supports the HAPA in populations following stroke (Tielemans et al., 2014). Future research could explore the HAPA theory and investigate if the theory explains health-related behaviour in post-stroke populations.

9.7 Strength and limitations of a mixed methods approach

Mixed methods research can combine the strengths of qualitative and quantitative studies (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). For example, during the initial stages of this doctoral research, the mixed methods approach aimed to capture and explain the different factors that could influence post-stroke health behaviour. The quantitative hypotheses enabled identification of the key factors and extent of the issues experienced, and the qualitative findings highlighted nuances in health-related behaviours with examples of how these manifested in everyday life. As the two approaches augmented each other, this provided a greater depth to the research and demonstrated the complexity of post-stroke health behaviour.

As this research evolved, it became clearer that the findings from the qualitative and quantitative research provided a different insight into the research questions that

were asked (e.g. descriptions of health-related behaviours were not explicit, with alternative factors described more frequently). In addition, impairments following stroke might have influenced ability to cope, insight, and self-reflection of stroke survivors. Furthermore, a person's ability to articulate might have been impacted by their stroke severity and residual impairments. Communication deficits might have implications for the mixed methods within this research. For example, in the quantitative study, participants may have understood the questions but experienced confusion around the different response options in the questionnaires. In the qualitative study, some participants demonstrated difficulty in word finding during the interviews. Future research could investigate how poor cognitive function related to information processing and memory influences health-related behaviours following a stroke. The wide-ranging effects of stroke highlights a complex process involved with post-stroke health behaviour (i.e. impairments add an extra layer of complexity to variance in health behaviour).

This programme of mixed methods research aimed to explore the factors that influenced health behaviour from the perspective of two different research methodologies. Research methods within health sciences are often identified as qualitative or quantitative, and are usually considered to be competing paradigms (Creswell & Plano Clark; Pluye, Grad, et al., 2009; Tashakkori & Teddlie, 2003). Qualitative research is usually associated with a constructivist paradigm (i.e. idealism, relativism, and inter-subjectivity) in the form of inductive qualitative studies; whereas, quantitative research is associated with logical empiricism (materialism, realism, and objectivity) in the form of deductive quantitative studies (e.g. Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009). This mixed methods research implemented a parallel method of data collection and analysis (Östlund et al., 2011). While each research method was implemented separately, and was not integrated until the interpretation stage, the findings from the two studies were comparable and could augment each other. Although both the qualitative and quantitative methods had limitations, combining their findings resulted in findings that were stronger than each method used separately, and the combined findings valuable. For example, the quantitative findings related to illness perceptions supported the qualitative findings to do with risk

and vulnerability. Hacking (1999, p. 119) proposes that mixed methods can be “both socially constructed and yet real”; thus, mixed methods may facilitate links between constructivism and logical empiricism, and provide insight to real-world phenomena that are individual and generalisable. While this some programmes of mixed methods research conduct different modes of mixed methods research (e.g. concurrent or sequential data analysis), future directions in research could evaluate the modes of mixed methods research to determine whether the mode of data analysis (i.e. concurrent, sequential, or parallel) provides more rigorous and reliable findings related to post-stroke health behaviours.

Mixed methods enabled this research to consider holistic information in relation to factors that influenced health-related behaviour following stroke. The findings of this research demonstrate that post-stroke health behaviour is a complex phenomenon. Mixed methods research is valuable for this area of research because quantitative data does not capture all the nuances of the around stroke experiences, behaviours, and expectations, and qualitative data provides individual perspectives and descriptions that might not be generalizable to the wider stroke population. Using questionnaires does not unpack that complexity and limits the data to pre-determined questions that may or may not be relevant to the participants; while qualitative interviews provide individual level data and captures information that is relevant to the participants, but may not be explicitly relevant to the research question. Although qualitative and quantitative methods have been combined within research studies (Pluye, Grad, et al., 2009), the concept of mixed methods research has only recently been appraised (O’Cathain & Collins, 2009; Pluye, Gagnon, et al., 2009; Tashakkori & Teddlie, 2003). Furthermore, mixed methods research that examines a single research question is uncommon and continues to be divisive (Clarke, 2009). However, mixed methods research can provide greater understanding of a subject than one method of research alone (Pluye, Gagnon, et al., 2009), and might provide more comprehensive understanding of health conditions and, particularly relevant to this research, of stroke (Clarke, 2009; Östlund et al., 2011). Therefore, future directions in research should aim to conduct mixed methods research to investigate the phenomenon of health-related behaviour following first-ever stroke.

Chapter 10 Conclusion

This research aimed to investigate what may influence uptake of health-related behaviour following first-ever stroke. The key combined findings from this research were that the emotional aspects of illness and recovery (i.e. the shock of the stroke event, and dealing with the emotional aspects resulting from the stroke) are challenging for people following a stroke, and have a much greater influence on their health-related behaviour than is currently recognised. Second, health-related behaviour may not be a priority for people following stroke; people may want to survive, return to normal, or may demonstrate ambivalence about their mortality. Third, people may not be ready for health behaviour advice from health professionals in the months following the stroke; this advice may be more relevant at later time-point in post-stroke recovery. Finally, the results highlighted that individual needs should be addressed by health professionals rather than a 'one-size fits all' approach. Stroke guidelines exist for the general population; however, the combination of people's individual characteristics (personality) and their social context (personal history) mean people may need different approaches for treatment. A person's pre-stroke life is as important as their post-stroke characteristics, and this needs to be taken into account.

Guided by literature within the fields of rehabilitation, associated health professions, and the health promotion and behaviour change literature, the initial direction of this research expected to capture aspects relating to uptake of health-related behaviours in post-stroke populations. However, the findings of this thesis highlighted that the emotional aspects of post-stroke life and the person's individual context may play a more important role in uptake of health behaviour. The majority of participants in this work did not report uptake of health behaviour in the year following their stroke highlighting the complexity and difficulties of implementing health behaviour change. Whilst the study followed people one year post-stroke recovery, for the majority of participants, post-stroke services ended within six-months. This study revealed that the demands placed on the person in the acute phase post-stroke may make it difficult for them to process information, or take action on health-related behaviour because of

other priorities. None of the participants received advice from a health professional on health behaviour after the acute stroke period. Whilst advice on lifestyle changes to reduce risk of recurrent stroke remain important in the acute phase, these findings highlight that people may benefit further advice on health behaviour and risk of recurrent stroke at later time-points in the person's stroke recovery journey.

Finally, this research began with the aim of identifying implications for motivational interviewing in post-stroke populations. This aim had been guided by suggestions from the literature, and the context of the parent-MIST trial. A final finding of this thesis is that the implications of this research are much broader than application to just motivational interviewing. These findings apply to all health professionals working with stroke survivors. Clinical implications for health professionals working with stroke survivors include individualised approaches to post-stroke services, identifying if health behaviour advice is important for that individual, and when it may be relevant (acknowledging the priorities and needs of the stroke survivor). The most significant clinical implication of this thesis is that the emotional aspects of illness and recovery need to be addressed following stroke. Current health practice focuses on the practical aspects of illness and recovery (e.g. physical rehabilitation). However, emotional aspects of illness and recovery (i.e. the shock of the stroke event, and dealing with the emotional aspects resulting from the stroke) are important, and may be a priority, for this group of people. Addressing the emotional aspects of the stroke may facilitate health-related behaviour following a stroke, and aid secondary stroke prevention.

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Appendix A: Overview of parent MIST-trial

Overview of parent MIST-trial

Overview

This doctoral research was completed within the context of an externally funded randomised controlled trial (RCT) of Motivational Interviewing to prevent secondary stroke: the Motivational Interviewing Stroke Trial (MIST). An outline of this wider study will be summarised here to describe the context within which this doctoral work was completed.

The MIST-trial was a single-blind RCT to determine the effectiveness of Motivational Interviewing (MI) on reducing blood pressure and cholesterol levels, and improving adherence to medication for people post-stroke. This study focused on a population of stroke survivors in Auckland, New Zealand (see MIST Protocol: Krishnamurthi et al., 2014). Funded by the Health Research Council of New Zealand, and led by one of my supervisors Professor Valery Feigin, the trial involved an intervention group (Motivational Interviewing; MI) and a control group (usual care/treatment as usual).

Participant Selection & Withdrawal

Patients who presented with first-ever stroke and resided in the New Zealand regions of Auckland and Waikato were considered for participation in MIST. The inclusion criteria for MIST were: individuals diagnosed with first ever stroke (defined according to WHO criteria), 16 years of age or older, who were discharged from hospital (Krishnamurthi et al., 2014). Individuals were excluded from MIST if they had significant impairments precluding participation; for example, a secondary condition that may have impacted the trial, were currently receiving alternative treatment that may have impacted the trial, non-English speaking, unable to provide informed consent, or were likely to move out of the study areas (Auckland or Waikato region) post-discharge. For additional information about eligibility criteria and inclusion/exclusion criteria, refer to the Participant Questionnaire in Appendix D.

Design

Participants were randomly assigned to an experimental group (MI intervention group or usual-care control group) using an online internet randomization service (Krishnamurthi et al., 2014).

Baseline measures were collected at 28-days post-stroke for each participant consented into MIST. All MIST participants completed MIST-trial assessments which included primary outcome measures (blood pressure, cholesterol levels, and adherence to prescribed medication) and secondary outcome measures (health-related behaviours including smoking, alcohol use, diet, and physical activity). These assessments were completed via telephone interview with a MIST-trial researcher. Each assessment took approximately one-hour to complete, at each of the five time-points across twelve-months (28-day, three-month, six-month, nine-month, and twelve-months).

In addition to MIST-trial assessments, participants in the MI-intervention group had four interviews with trained motivational interviewers across twelve-months. The initial interview was face-to-face with the stroke survivor and family caregivers the day before hospital discharge, and remaining interviews were conducted via telephone at three, six, and nine-months. Motivational interviews took approximately one-hour to complete. Participants in the usual-care group received standard care which did not involve an MI intervention.

Intervention

The MIST intervention was based on the principles of MI proposed by Miller and Rollnick (1991). A standardised method for conducting the intervention was developed for the trial and included a MI manual and ongoing training and feedback for the team of motivational interviewers. For additional information about the MIST-trial, please refer to the MIST-trial methods paper (Krishnamurthi et al., 2014) and the MIST-trial outcomes paper (Krishnamurthi et al., 2016).

Appendix B: Literature Search Protocol

stroke OR "cerebrovascular accident" OR cva OR "cerebrovascular disease" OR hemiplegia OR tia OR "transient ischemic attack" OR hypertensi*

AND

"health* behavio*" OR "health* lifestyle" OR "health* practice*" OR "health promote*" OR "behavio* change" OR "lifestyle change" OR "behavio* modification" OR "behavio* intervention" OR "behavio* change" OR participation OR adherence OR compliance or nonadherence or noncompliance or engagement OR adoption OR maintenance OR cessation

AND

influen* OR impact OR effect OR affect OR psychosocial OR barrier* OR facilitat*

For the structured literature searches, additional search terms were included to identify literature relating to illness perceptions or satisfaction with stroke care.

"illness representation*" OR "illness perception*" OR "illness belief*" OR "health belief*" OR "perception* of illness" OR "self-rated health" OR "illness cognition"

OR

Patient* or client OR "service user" OR individual OR hospital* OR inpatient OR inpatient OR rehab*

OR

Satisfaction OR evaluat*

Years included 1970 - 2017

Searches were conducted in the following databases:

- Ebsco (Health) which included Cinahl and Medline
- Scopus
- Web of Science
- PsychInfo

Appendix C: Information and Consent Form for MIST-trial (including Caregiver Nomination Form)

ARCOS IV Part 2: Motivational Interviewing Stroke Trial (MiST)

Participant Information Sheet

An invitation

You are invited to take part in a research study because you have recently had a stroke. This study is coordinated by the National Institute for Stroke and Applied Neurosciences, AUT University, in Auckland.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you choose not to take part, the care or treatment that you are currently receiving will not be affected. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part.

What are the aims of this study?

The purpose of this study is to see whether a new way of providing support and information can help people to understand and follow their GP or physician's advice on medication and lifestyle changes to reduce the risk of further stroke. This is called Motivational Interviewing. If you have experienced a stroke for the first time, you may be eligible to take part.

Why do we need this study?

After a stroke many people are prescribed new medications and have recommendations to change their lifestyle (for example diet, exercise or stopping smoking). It can be difficult for people to follow these recommendations and this can impact their chances of having another stroke. Motivational Interviewing has been successful at increasing patients' ability to stick with lifestyle and medication changes in a range of other medical conditions.

We do not know if Motivational Interviewing will improve adherence in people who have experienced a stroke. This study will examine the effectiveness of Motivational Interviewing by comparing persons who have suffered a stroke and participate in 4 sessions of Motivational Interviewing (1 face-to-face and 3 via telephone) in addition to usual care, with persons who suffer a stroke and receive usual care only.

What is Motivational Interviewing?

Motivational interviewing is a new way to provide support and information to help people to think about the reasons they may or may not wish to make changes in their life. This is accomplished through individual interviews with a skilled interviewer who is non-judgmental, empathic and encouraging. The individual interviews will allow participants an opportunity to share their experience and examine their own behavior change goals.

What types of people can be in the study?

People who have experienced their first ever stroke in the past 28 days and who normally live in the Auckland or Hamilton regions may be eligible to take part in this study.

If you live outside of the Auckland or Hamilton regions or have had a previous stroke you will not be able to take part in this study. Your treating physician or GP will be happy to discuss with you any concerns you may have about recurrent stroke, medication or lifestyle changes.

How many people will be in the study?

We estimate about 604 people from Auckland and Hamilton will be involved in this study.

What happens if I do decide to take part?

If you decide you would like to take part in this study, your participation would be for twelve months only. In total there will be five assessments. These assessments will take place at the start of the study (within 28 days of your stroke) and then at 3, 6, 9 and 12 months after your stroke.

Each assessment will include answering some questions about you and your stroke. This will take approximately 30 minutes and can be conducted over the telephone or in person. You will be asked questions about your stroke, recovery, diet and exercise, mood, treatments, care and services that you have received since your stroke. All researchers have been specially trained for this project. In total, the study interviews should take up to 8 hours of your time over twelve months.

In addition, your medical records will be checked at the time of stroke and 12 months after stroke to record your most recent blood pressure and blood lipid (cholesterol) test results to assess the effectiveness of any stroke prevention interventions prescribed to you by your treating physician. If these results are not available from your hospital or GP, you will be sent a blood test request form to attend a free Labtests clinic to have a fasting blood lipid test conducted. These test results will be accessible by your doctors.

If you are eligible to take part in the study you will be *randomly allocated* to receive either 'Usual Care plus Motivational Interviewing' or 'Usual Care only'. Those who take part in the Motivational Interviewing intervention will be asked to participate in one face-to-face Motivational Interview with a trained researcher, followed by 3 telephone Motivational Interviews conducted 3, 6 and 9 months later, in addition to the follow-up assessment questionnaires. Each interview will take approximately 45 to 60 minutes.

Motivational Interviews will be voice recorded and kept on a computer for this study. Recorded interviews may be used for training purposes and to assess adherence to the principles of Motivational Interviewing. The recording of your interview will be anonymous and only the research team will have access to this data.

What is meant by the term “randomly allocated”?

If you agree to take part in this study you will be randomly allocated to take part in either the 'Motivational Interviewing plus Usual Care' or 'Usual Care only' group. To be randomly allocated is rather like the flip of a coin, you have equal chance of being assigned to either group.

Auckland Region ARCOS IV (March 2011 to February 2012 only)

If you are also taking part in the large study running in the Auckland region called ARCOS-IV (between March 2011 and February 2012) there will be no additional 6 or 12 month follow-up assessments for the MIST study, as these will be completed as part of the ARCOS-IV study follow-up assessments.

What is the time-span for the study?

The MIST study is expected to start on 1 March 2011 and will continue until 28th February 2013. Your involvement will be for just 1 year during this time.

How will the study affect me?

You may not directly benefit from the study, as we do not know if Motivational Interviewing is effective for stroke survivors. However, you will help the people who fund, provide and deliver health services for stroke rehabilitation. This study may be of benefit to the wider stroke population.

What are the potential risks and discomforts?

Taking part in this study will take some time and require you to answer a series of questionnaires. There are no known risks caused by this study or intervention. You will not be asked to do anything that makes you feel uncomfortable. You will continue to receive your usual care from your doctor and other health services. If we request you to have a fasting blood test, you will be given the option of having



a qualified Labtests blood collector visit you at home. Your usual medical care will not be affected in any way by participating in the study, or by declining to participate or withdrawing from the study at any stage.

Withdrawal from the Study

Your participation in the study is entirely voluntary. You may withdraw from the study at any time and you do not have to give a reason for doing so. If you withdraw from the study, you may be asked if you would be willing to answer some questions at the end of the study, but this would also be entirely voluntary. Your doctor may suggest that you withdraw from the study if s/he has any concerns about your participation. You may also be withdrawn if you are not able to participate fully or at the discretion of the study managers. If you do withdraw, this will in no way affect your access or entitlement to any future medical treatment you may require.

Reimbursement/koha

A \$20 food or fuel voucher will be provided to you after completion of the 6 and 12 month follow-up assessments (\$40 in total). There will be no cost to you for participating in the study.

If someone involved in the study experiences a further stroke during the study, they will be asked to continue with the scheduled follow up study appointments as planned and will still receive the vouchers as described.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation, and Compensation Act 2001. ACC cover is not automatic, and your case will need to be assessed by ACC according to the provisions of the Injury Prevention, Rehabilitation, and Compensation Act 2001. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors, such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses, and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, please contact your nearest ACC office or investigator.

You are also advised to check whether participation in this study would affect any indemnity cover you have or are considering, such as medical insurance, life insurance and superannuation.

Confidentiality

All data generated from this study will be treated with utmost confidentiality without reference to your name. The information collected will be used only for the statistical purposes of this study. Your identity will be kept confidential. In the study documents you will only be identified by your initials, date of birth, and a study number. The data will be kept for the duration on the study at Auckland University of Technology and destroyed after 16 years according to national research guidelines. Any information provided will not be acted upon unless there are concerns about the participant's safety or the safety of others.

Your Rights



If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Free phone: 0800 555 050
 Free fax: 0800 2787 7678 (0800 2 SUPPORT)
 Email: advocacy@hdc.org.nz

Contact Details

This study has received Ethical Approval from the Northern X Regional Ethics Committee dated 09.02.2011

If you would like some more information about the study please feel free to contact the ARCOS IV **Study Manager Emma Witt** on email ewitt@aut.ac.nz or telephone (09) 921-9999 ext. 7749.

Alternatively, you can contact:

Professor Valery Feigin, Director, NISAN, AUT University, phone (09) 921-9166 or e-mail vfeigin@aut.ac.nz

Dr Suzanne Barker-Collo, Neuropsychologist, University of Auckland, phone (09) 373-7599 ext 88517 or e-mail s.barker-collo@auckland.ac.nz

Dr Rita Krishnamurthi, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7809 or email: rkrishna@aut.ac.nz

Study Investigators

The principal investigator for this study is **Professor Valery Feigin**, National Institute for Stroke and Applied Neurosciences (NISAN), AUT University, Private Bag 92006, Auckland 1142, phone (09) 921 9166.

***Please keep this brochure for your information.
 Thank you for reading about this study***

Registration Number:	Participant Initials:	Date of Birth:
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CONSENT FORM

- I have read/had explained to me, and understand, the Information Sheet (Version 8, dated 18/07/2012) for participants taking part in the MIST study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview with medical and lifestyle questions, that I may choose not to answer any questions, or to withdraw from the study at any time and this will in no way affect my future health care.
- I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.
- I agree to an approved auditor appointed by either the ethics committee, or the regulatory authority or their approved representative and approved by the Northern Region X Ethics Committee, reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.
- I understand that my GP will be contacted about my participation in this study. A copy of this signed consent form will be sent to your GP, if requested.
- I give my approval for information regarding my present medical condition to be obtained from medical records, including contacting my GP for the results of any recent blood lipid (cholesterol) and blood pressure tests.
- I understand that I may be contacted by the study team and requested to have a fasting blood lipid test after discharge from hospital (at the time of stroke) and/or 12 months after stroke if the routine tests recommended by the *New Zealand Clinical Guidelines for Stroke Management 2010* are not carried out by my treating physician or GP.
- I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- I understand the compensation provisions for this study.
- I have had time to consider whether to take part.
- I know whom to contact if I have any questions about this study.



Registration Number:	Participant Initials:	Date of Birth:
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I am indicating my approval (or otherwise) for the following:

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No
---	----------

I _____ hereby consent to take part in this research.

Signature
(or representative)..... Signature of
witness.....

Date: Name of
witness.....

Project explained by..... Project role
.....

Signature..... Date
.....

Note: A copy of the consent form to be retained by participant and a copy to be stored separately at the study office.

1.0 Stroke Survivor Information

IMPORTANT! Please provide information of the stroke survivor first before completing the information for the caregiver.

Registration Number <div style="border: 1px solid black; width: 100px; height: 20px; margin: 5px;"></div>	Participant Initials <div style="border: 1px solid black; width: 100px; height: 20px; margin: 5px;"></div>	Date Of Birth <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> </div> <div style="display: flex; justify-content: space-around; font-size: small;"> Day Month Year </div>
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Procedure for asking Stroke Survivors to nominate a caregiver or significant other

Would you be happy for a researcher to contact the person who will help you on a regular basis during your stroke recovery?

This could be a significant other (e.g. a husband, wife, or partner), or a relative, friend or neighbour who regularly helps to care for you in some way. This person may live with you, or they may visit you regularly to help you whilst you recover.

- your husband, wife, or partner might drive you to hospital appointments or remind you about your medication
- one of your children might visit you regularly and help you around the house whilst you recover
- a close friend or neighbour might come and help cook dinners for you regularly

We would like to ask this person about their experiences over the next year.

This research won't affect your participation in the MIST study or your stroke care.

2.0 Caregiver Background Information and Contact Details

2.1	Would you like to nominate someone?	<input type="radio"/>	Yes	<input type="radio"/>	No
2.2	Date this form is completed	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> </div> <div style="display: flex; justify-content: space-around; font-size: small;"> Day Month Year </div>			
2.3	First name	<div style="border-bottom: 1px solid black; height: 20px; width: 100%;"></div>			
2.4	Last name	<div style="border-bottom: 1px solid black; height: 20px; width: 100%;"></div>			
2.5	Gender	<input type="radio"/>	Male	<input type="radio"/>	Female
2.6	Date of Birth	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> </div> <div style="display: flex; justify-content: space-around; font-size: small;"> Day Month Year </div>			
2.7	Home phone number	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 40px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 120px; height: 20px; margin: 5px;"></div> </div>			
2.8	Mobile phone number	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 120px; height: 20px; margin: 5px;"></div> </div>			
2.9	Email Address	<div style="border-bottom: 1px solid black; height: 20px; width: 100%;"></div>			
2.10	What is your relationship with the nominated person?	<div style="border-bottom: 1px solid black; height: 20px; width: 100%;"></div> of participant			
2.11	Do you live with nominated person?	<input type="radio"/>	Yes	<input type="radio"/>	No



Appendix D: Study Questionnaire

Patient Registration Birth

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Form A: Case Notification and Eligibility

Answer all questions. DO NOT LEAVE BLANK SPACES. Tick circles, write numbers in boxes.

If the data are unavailable put an asterisk '*'. If the data are not applicable put a dash '-'.

Yes/No Responses: for *each* question, please mark 'Yes' or 'No'.

1.0 Patient Details

Q#	Patient Details	Field format	
1.1	Date of birth	dd/mm/yyyy	
1.2	Gender	Male	
		Female	
1.3	Date of assessment	dd/mm/yyyy	
1.4.	Type of event in <i>this</i> assessment (tick ONE only)	Stroke	
		TIA	
1.5	NHI Number	7 digits	
1.6	Has the participant nominated a caregiver?	Yes	
		No	
1.6.1	If Yes, has the nominated caregiver signed the Caregiver Information and Consent Form?	Yes	
		No	

2.0 Eligibility Screening

3.0 Inclusion criteria for Motivational Interviewing Stroke Trial (MIST)

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Q#	Inclusion Criteria	Field format	
3.1	Usually resident in Auckland region?	Yes	
		No	
3.2	16 years of age or older?	Yes	
		No	
3.3	First-ever Stroke between 1 March 2011 & 28 February 2014	Yes	
		No	

If NO to any, patient is not eligible for the MIST study



Patient Registration

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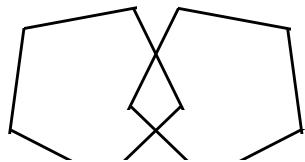
d d m m y y y

4.0 Mini-Mental State Examination

d d m m y y y

Q#	Mini-Mental State Examination	Field Format
Grade answers to each question as 1 (correct) or 0 (incorrect). Sum the total number of correct responses at the end of questionnaire.		
ORIENTATION		
1	What is the date today? (day of the month)	
2	What year is it?	
3	What month is it?	
4	What day of the week is it?	
5	What season is it?	
6	What is the name of this hospital (or name of this street, if home address)?	
7	What suburb do you live in?	
8	What city are we in?	
9	What state are we in?	
10	What country are we in?	
Orientation subtotal		/10
REGISTRATION		
Ask the patient if you may test his/her memory. Then say "apple", "penny", "table", clearly and slowly. After you have said all 3 words, ask the patient to repeat them (up to 6 trials) until the patient can repeat all 3 words. If the patient does not eventually learn all three words, recall cannot be meaningfully tested.		
11	Answered "apple"?	
12	Answered "penny"?	
13	Answered "table"?	
Registration subtotal		/3
ATTENTION AND CALCULATION		
Ask the patient to begin at 100 and count backward by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score one point for each correct number.		
OR		
Also ask the patient to spell the word "world" backwards (D, L, R, O, W). Score one point for each correctly placed letter. Take the highest of the two scores.		
14	Answered "93" or "D"	
15	Answered "86" or "L"	
16	Answered "79" or "R"	
17	Answered "72" or "O"	
18	Answered "65" or "W"	
Attention and calculation subtotal		/5
RECALL		
Ask the patient to recall the three words you previously asked him/her to remember (learned in Registration). Score one point for each.		
19	Answered "apple"?	
20	Answered "penny"?	
21	Answered "table"?	
Recall subtotal		/3

d d m m y y y

LANGUAGE		
Naming: Show the patient a wrist watch and ask “What is this?” Repeat for a pencil. Score one point for each item named correctly.		
22	Answered “watch”?	
23	Answered “pencil”?	
Repetition: Ask the patient to repeat, “No ifs, ands, or buts”. Score one point for correct repetition. Allow only one trial.		
24	Answered “no ifs, ands, or buts”?	
3-Stage Command: Give the patient a piece of blank paper and say, “Take the paper in your right hand, fold it in half and put it on the floor.” Score one point for each action performed correctly.		
25	Patient put paper in right hand?	
26	Patient folded paper in half?	
27	Patient put paper on the floor?	
Reading: On a blank piece of paper, print the sentence “Close your eyes” in letters large enough for the patient to see clearly. Ask the patient to read it and do what it says. Score correct only if the patient actually closes his or her eyes.		
28	Patient closed his or her eyes?	
Writing: Give the patient a blank piece of paper and ask him/her to write a sentence. The sentence should be written spontaneously: It must contain a subject and a verb and make sense. Correct spelling, grammar and punctuation are not necessary.		
29	Patient wrote a sentence?	
Copying: On a clean piece of paper, draw intersecting pentagons, about the same size as below, and ask patient to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Ignore tremor and rotation.		
		
30	Patient drew two intersecting pentagons?	
Language subtotal		/9
Add the subtotals and record the grand total here:		
Total Total		/30



Patient Registration

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5.0 Barthel Index

Instructions to RA: the following section is asking about the participant’s status after this stroke

Guidelines for Completion

d	d	m	m	y	y	y	

- | Barthel Index | | | |
|---------------|------------------------------------|--|--|
| Q# | Label | Field Format | |
| 5.1 | Feeding
(tick ONE only) | 0 = Dependent: Needs to be fed. | |
| | | 1 = Needs help: e.g. with cutting or spreading butter. | |
| | | 2 = Independent: Able to use any necessary device; feeds in a reasonable time; able to cut up food, use condiments, spread butter etc. on his/her own. Food may be placed within reach | |
| 5.2 | Bathing
(tick ONE only) | 0 = Dependent: Needs some help. Includes getting into and out of bath, or shower room | |
| | | 1 = Independent: Able to wash self all over; may be by using shower, a full bath or standing and sponging all over. | |
| 5.3 | Grooming
(tick ONE only) | 0 = Dependent: Needs some help with personal care. | |
| | | 1 = Independent: Doing all personal activities, e.g. washing hands and face, combing hair. (Includes shaving and teeth. Not needing any help. | |
| 5.4 | Dressing
(tick ONE only) | 0 = Dependent: Unable to dress without major assistance | |
| | | 1 = Needs help: Needs minor help verbal or physical managing clothes and balancing. | |
| | | 2 = Independent: Able to dress, includes (buttons, zip, laces) getting clothes out of closet/drawers. No help needed at all, may use rail for stabilising. | |

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5.5	Bowels (tick ONE only)	0 = Incontinent	
		1 = Occasional accident: Rare (under once a week); needs help with enema.	
		2 = Continent: If needs enema, suppository, must manage him/herself.	
5.6	Bladder (tick ONE only)	0 = Incontinent or catheterized and unable to manage.	
		1 = Occasional accident: Maximum once per 24 hours; needs help with catheter	
		2 = Continent: Able to use any device (e.g. catheter) if necessary.	
5.7	Toilet (tick ONE only)	0 = Dependent: Unable to manage without major assistance.	
		1 = Needs help: Able to manage with minor help balancing, handling clothes or toilet paper. However, still able to use toilet.	
		2 = Independent: Able to handle clothes, wipe self, flush toilet, empty commode completely unaided. Able to get on and off alone.	
5.8	Chair/Bed Transfers (tick ONE only)	0 = Dependent: Needs hoist or complete lift by two people. Unable to sit.	
		1 = Major help: Able to sit unaided, but needs much help (two people).	
		2 = Minimal help: Includes verbal supervision and minor physical help such as might be given by a not very strong spouse.	
		3 = Independent: No help; includes locking wheelchair if necessary.	
5.9	Mobility on level surfaces (tick ONE only)	0 = Immobile: Including being wheeled by another	
		1 = Independent in wheelchair: Must be able to negotiate corners alone.	
		2 = Needs help: Verbal or physical supervision, including help up into walking frame or other help standing.	
		3 = Independent: May use any aid; speed is not important. Able to mobilise about house.	
5.10	Stairs (tick ONE only)	0 = Unable: Needs lift (elevator), or cannot negotiate stairs.	
		1 = Needs help: Physical or verbal supervision, carrying aid etc	
		2 = Independent: Must carry walking aid if used.	



Patient Registration

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Form B: Baseline Demographic Information

Complete the following questions for ALL participants at 28-days post-stroke.

1.0 Demographic Information

Patient Registration s irth
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Q#	Demographic Information	Field format	
What ethnic group do you belong to?			
2.1.1	New Zealand European	Yes/No	
2.1.2	Maori	Yes/No	
2.1.3	Samoan	Yes/No	
2.1.4	Cook Island Maori	Yes/No	
2.1.5	Tongan	Yes/No	
2.1.6	Niuean	Yes/No	
2.1.7	Chinese	Yes/No	
2.1.8	Indian	Yes/No	
2.1.9	Other	Yes/No	
2.1.10	If other, specify	text	
2.2	What is your current marital status? (tick ONE only)	Married, civil union, defacto relationship	
		Separated, divorced, widowed	
		Never married	
2.3	Prior to your stroke/TIA who were you living with?(tick ONE only)	Living with partner/family	
		Living with others	
		Living alone	

2.0 Co-morbidities.

d d m m y y y

Form T: Health Behaviour Questionnaire

1.0 General Questions

2.0 Hospital Anxiety and Depression Scale (HADS)

d	d	m	m	y	y	y	

Hospital Anxiety and Depression Scale (HADS)			
Q#	Hospital Anxiety and Depression Scale (HADS)		
2.1	I feel tense or wound up	0-Not at all	
		1-from time to time, occasionally	
		2-a lot of the time	
		3- Most of the time	
2.2	I get a sort of frightened feeling as if something awful is about to happen	0-not at all	
		1-a little, but it doesn't worry me	
		2- Yes but not too badly	
		3-Very definitely and quite badly	
2.3	Worrying thoughts go through my mind	Only occasionally	
		from time to time, but not too often	
		A lot of the time	
		A great deal of the time	
2.4	I can sit at ease and feel relaxed	0-definitely	
		1-usually	
		2-not often	
		3-not at all	
2.5	I get a sort of frightened feeling like 'butterflies' in the stomach	0-not at all	
		1-Occasionally	
		2-Quite often	
		3-Very Often	
2.6	I feel restless as if I have to be on the move	0-not at all	
		1-Not very much	
		2-Quite a lot	
		3-Very much indeed	

2.7	I get sudden feelings of panic	0-not at all	
		1-Not very often	
		2-Quite often	
		3-Very Often	
2.8	I still enjoy the things I used to enjoy	Definitely as much	
		Not quite as much	
		Only a little	
		Hardly at all	
2.9	I can laugh and see the funny side of things	As much as I always could	
		Not quite so much now	
		Definitely not as much now	
		Not at all	
2.10	I feel cheerful	Most of the time	
		Sometimes	
		Not Often	
		Not at all	
2.11	I feel as if I am slowed down	not at all	
		Sometimes	
		Very often	
		Nearly all the time	
2.12	I have lost interest in my appearance	I take just as much care as ever	
		I may not take quite as much care	
		I don't take as much care as I should	
		Definitely	
2.13	I look forward with enjoyment to things	As much as I ever did	
		Rather less than I used to	
		Definitely less than I used to	
		Hardly at all	
2.14	I can enjoy a good book or TV programme	Often	
		Sometimes	
		Not often	
		Very seldom	

d	d	m	m	y	y	y	

3.2 Alcohol consumption

'I am going to ask you some questions about your alcohol consumption during the past month.'

3.3 Smoking

Q #	SMOKING	Field format
3.3.1	Which of these best describes your current smoking status? (tick one only)	<div>Never smoked</div> <div>Ex-smoker; smoked (cigarettes, ready made or roll your own; cigars, cigarillos or pipe) more than once per day for at least one year)</div> <div>Current smoker; currently (smokes cigarettes, ready made or roll your own, cigars, cigarillos or pipe) more than once per day for at least one year)</div>
If Never Smoked or Ex-smoker, Go to Section 3.4 (Medication)		
3.3.2	Within the past month have you attempted to reduce your smoking?	<div>Yes</div> <div>No</div>
3.3.3	If Yes, to what degree has your smoking changed? (tick one only)	<div>I no longer smoke</div> <div>I smoke about ¼ of what I used to</div> <div>I smoke about half of what I used to</div> <div>I smoke about ¾ of what I used to</div> <div>I smoke the same amount</div> <div>I smoke more</div>
3.3.4	Do you intend to reduce your smoking?	<div>Yes</div> <div>No</div>

3.4 Medication

d	d	m	m	y	y	y	

Q#	Label		
3.4.1	Have you been prescribed medication since your stroke?	Yes	
		No	
3.4.2	In the past 7 days have you taken all of your medication as prescribed?	Yes	
		No	
		Unsure	

d	d	m	m	y	y	y	

Q #	DIET	Field format	
3.5.1	Within the past month, did you make changes to your diet?	Yes	
		No	
If No, Go to next section of questionnaire (B-IPQ)			
3.5.2	If Yes, On average how many servings of fruit (fresh, frozen, canned or stewed) do you eat per day? Do not include fruit juice or dried fruit. (tick one only)	Never I don't eat fruit	
		Less than one serving per day	
		1 serving	
		2 servings	
		3 or more servings	
		Don't know	
		Refused	
3.5.3	On average how many servings of vegetables (fresh, frozen or canned) do you eat per day? Do not include vegetable juices. (tick one only)	Never I don't eat vegetables	
		Less than one serving per day	
		1 serving	
		2 servings	
		3 or more servings	
		Don't know	
		Refused	
3.5.4	How often do you add salt to your food after it has been cooked or prepared? (tick one only)	Never	
		Rarely	
		Sometimes	
		Regularly	
		Always	
		Don't know	
		Refused	
3.5.5	How often do you choose low or reduced salt varieties of foods instead of the standard variety? (tick one only)	Never	
		Rarely	
		Sometimes	
		Regularly	
		Always	
		Don't know	
		Refused	

Patient Registration s irth

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4.0 Brief Illness Perceptions Questionnaire (B-IPQ)**ALL PARTICIPANTS** complete this section at **28-DAYS ONLY**.

Q #	Brief Illness Perceptions Questionnaire (B-IPQ)										
The following questions are about how you feel about your stroke. For each question, please give one answer that comes closest to how you feel. (circle one number for each question)											
4.1	How much does your stroke affect your life?										
0	1	2	3	4	5	6	7	8	9	10	
No affect at all											Severely affects my life
4.2	How long do you think your stroke will continue?										
0	1	2	3	4	5	6	7	8	9	10	
A very short time											Forever
4.3	How much control do you feel you have over your stroke?										
0	1	2	3	4	5	6	7	8	9	10	
Absolutely no control											Extreme amount of control
4.4	How much do you think your treatment (e.g. medicines, doctor visits) can help your stroke?										
0	1	2	3	4	5	6	7	8	9	10	
Not at all											Extremely helpful
4.5	How much do you experience symptoms from your stroke?										
0	1	2	3	4	5	6	7	8	9	10	
No symptoms at all											Many severe symptoms
4.6	How concerned are you about your stroke?										
0	1	2	3	4	5	6	7	8	9	10	
Not at all concerned											Extremely concerned
4.7	How well do you feel you understand your stroke?										
0	1	2	3	4	5	6	7	8	9	10	
Don't understand at all											Understand very clearly
4.8	How much does your stroke affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)										
0	1	2	3	4	5	6	7	8	9	10	
Not at all affected											Extremely affected
4.9	Please list in rank-order up to three of the most important factors that you believe caused your stroke. The most important causes for me:- 1. 2. 3.										

d	d	m	m	y	y	y	

Q #	Satisfaction with stroke care (hospital sub-scale)	Field format
These questions are about how you feel about your stroke care at the hospital. For each question, please give one answer that comes closest to how you feel. (tick one option for each question)		
5.1	I have been treated with kindness and respect by the staff at the hospital.	Strongly disagree Disagree Agree Strongly agree Don't know
5.2	The staff attended well to my personal needs while I was in hospital (for example, I was able to get to the toilet whenever I needed)	Strongly agree Agree Disagree Strongly disagree Don't know
5.3	I was able to talk to the staff about any problems I might have had	Strongly disagree Disagree Agree Strongly agree Don't know
5.4	I have received all the information I want about the causes and nature of my stroke.	Strongly agree Agree Disagree Strongly disagree Don't know
5.5	The doctors have done everything they can to make me well again	Strongly disagree Disagree Agree Strongly agree Don't know
5.6	I am happy with the amount of recovery I have made	Strongly agree Agree Disagree Strongly disagree Don't know
5.7	I am satisfied with the type of treatment the therapists have given me (e. g. physiotherapy, speech therapy, occupational therapy).	Strongly disagree Disagree Agree Strongly agree Don't know
5.8	I have had enough therapy (e. g. physiotherapy, speech therapy, occupational therapy).	Strongly agree Agree Disagree Strongly disagree Don't know

Appendix E: HDEC Ethics Approval Letter for MIST-trial



Northern X Regional Ethics Committee

Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

9 February 2011

A/ Professor Valery Feigin
National Centre for Stroke,
Neuroscience & Neurorehabilitation
Auckland University of Technology
PB 92 006
Auckland 1142

Dear Valery

Ethics ref: **NTX/10/09/091** (please quote in all correspondence)
Study title: **ARCOS IV: Measuring and reducing stroke burden in New Zealand. Motivational interviewing stroke trial (MIST)**
Principal Investigator: A/ Professor Valery Feigin
Co-Investigators: Ms Suzanne Barker-Collo, Professor Kathryn McPherson, Professor Max Abbott, Dr Alan Barber, Ms Ruth Bonita, Ms Rita Krishnamurthi, Dr Nicola Starkey, Ms Varsha Parag, Mr Martin Tobias
Localities: Auckland DHB, Counties-Manukau DHB, Waitemata DHB, Waikato DHB

Thank you for letter dated 16 January 2010. Regret delay but this was sent during my leave period.

This study has now been given ethical approval by the Northern X Regional Ethics Committee. A list of members of the Committee is attached.

Approved Documents

- Participant Information Sheet/Consent Form V#4 dated 10 December 2010
- Various Case Record Forms attached to the application
- Flowchart of the programme structure

This approval is valid until 1 September 2014, provided that Annual Progress Reports are submitted (see below).

Access to ACC

For the purposes of section 32 of the Accident Compensation Act 2001, the Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out. Participants injured as a result of treatment received in this trial will therefore be eligible to be considered for compensation in respect of those injuries under the ACC scheme.

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by **9 February 2012**. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A **Final Report** is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

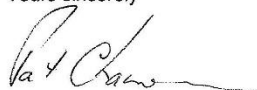
- are *unexpected*.
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, as your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely



Pat Chainey
Administrator
Northern X Regional Ethics Committee
Email: pat_chainey@moh.govt.nz

Cc: ADHB Research Office A+?
CMDHB Research Office – Alison Robertson
Waitemata DHB Research Office, Lorraine Neave
Waikato DHB

NORTHERN X REGIONAL ETHICS COMMITTEE

DATE OF MEETING

7 DECEMBER 2010

Dr Brian Fergus	B.Sc, M.Sc	Consumer Representative	Present
Wayne Miles	MB ChB, MD, Dip (Psychiat Med), FRANZCP	Deputy Chairperson Psychiatrist	Present
Robyn Northey	MA(Hons) Social Welfare & Dev.	Consumer Representative	Present
Joanna Stewart	MSc (Mathematics & Statistics)	Biostatistician	Present
Linda Kaye	M.A.	Lawyer	Present
Jocelyn Byrd	R.N.	Researcher	Present
Paul Tanser	M.D., FRACPC, FRCP(Glasgow)	Cardiologist	Present
Alaina Campbell	BN	Consumer Representative	Present
Rosemary Langham	MPS MNZCP	Pharmacist/Pharmacologist	Present
Ieti Lima	MA (Hons) Development Studies PhD in Sociology	Health Researcher	Present
Marewa Glover		Health Researcher	In attendance

The total Ethics Committee is responsible for the decisions taken. The Committee conforms to ICH GCP Guideline. IRB/IEC No. IRB00004664.

Committee members, who may have a conflict of interest in any of the proposals being considered by the committee, must declare that interest and excuse themselves from any part of the discussion relating to that proposal.

Appendix F: HDEC Ethics Approval Letter for Quantitative Study



18 June 2012

Northern X Regional Ethics Committee

Private Bag 92522

Wellesley Street

Auckland 1141

Phone: (09) 580 9105

Fax (09) 580 9001

Email: northernx_ethicscommittee@moh.govt.nz

A/Professor Valery Feigin c/- Dr Rita Krishnamurthi
National Institute for Stroke and Applied Neuroscience
Auckland University of Technology
PB 92 006
Auckland 1142

Dear Valery/Rita

Re: Ethics ref: **NTX/10/09/091** (please quote in all correspondence)
Study title: **ARCOS IV: Measuring and reducing stroke burden in New Zealand.**
Motivational interviewing stroke trial (MIST): PIS/Cons V#7, 08/09/11
Prot/Amend 08/09/11; Substudy, PIS/Cons (Motivator) V#1 08/06/12
Investigators: Associate Professor Valery Feigin, Ms Suzanne Barker-Collo, Professor
Kathryn McPherson, Professor Max Abbott, Dr Alan Barber, Ms Ruth Bonita,
Dr Rita Krishnamurthi, Dr Nicola Starkey, Ms Varsha Parag, Mr Martin Tobias,
Ms Halina Kalaga

Thank you for your letter received 13 June 2012 (via e-mail) and 18 June (via courier) with proposed amendments to the above study.

The proposed added substudy and documentation were reviewed by the Chairperson of the Northern X Regional Ethics Committee under delegated authority.

Ethical approval is granted to:

- include a study as part of a HRC funded PhD scholarship undertaken by Miss Halina Kalaga
- Satisfaction with Stroke Care Questionnaire (SASC-19)
- Brief Illness Perception Questionnaire
- Caregivers' satisfaction with inpatient stroke care (C-SASC hospital scale)
- change of wording in assessment forms from "caregiver" to "significant other"
- Motivator Information Sheet/Consent Form (version 1, dated 08/06/2012)

The following documents were reviewed with the amendment:

- Halina Kalaga's CV and PhD admission form.

Yours sincerely

Cheh Chua
Administrator
Northern X Regional Ethics Committee

cc: ADHB Research Office
CMDHB Research Office
Lorraine Neave, Waitemata DHB

Appendix G: Linear Regression for Fruit and Vegetable Consumption at Post-Stroke Time-Points

Table 20. Linear Regression for vegetable consumption at post-stroke time-points.

VEGETABLE CONSUMPTION	Beta	SE	P value	95% CI		Adjusted R ²
				Lower	Upper	
<i>28 Day (T1)</i>						
Constant		7.58	0.23	-24.62	5.96	.09
Treatment Condition	0.22	0.25	0.13	-0.12	0.91	-
Age	0.21	0.01	0.16	-0.01	0.04	-
Practical IPQ	-0.21	0.07	0.16	-0.26	0.04	-
Emotion IPQ	-0.17	0.06	0.25	-0.20	0.05	-
SASC	0.07	0.31	0.65	-0.49	0.77	-
<i>Six-month (T2)</i>						
Constant		14.68	0.28	-14.75	47.21	-.20
Treatment Condition	-0.20	0.50	0.42	-1.47	0.63	-
Age	-0.09	0.02	0.76	-0.05	0.04	-
Practical IPQ	-0.07	0.18	0.78	-0.44	0.33	-
Emotion IPQ	-0.14	0.15	0.61	-0.41	0.25	-
SASC	-0.05	0.66	0.86	-1.51	1.28	-
<i>Twelve-month (T3)</i>						
Constant**		9.25	0.00	19.99	59.42	.60**
Treatment Condition**	-0.68	0.29	0.00	-1.89	-0.65	-
Age	-0.06	0.01	0.78	-0.03	0.02	-
Practical IPQ	-0.22	0.08	0.23	-0.27	0.07	-
Emotion IPQ	0.26	0.07	0.15	-0.04	0.26	-
SASC	0.12	0.31	0.52	-0.46	0.87	-

Note: *p<0.05, **p<0.01

Table 21. Linear Regression for fruit consumption at post-stroke time-points.

FRUIT CONSUMPTION		Beta	SE	P value	95% CI		Adjusted R ²
					Lower	Upper	
<i>28 Day (T1)</i>							
	Constant		9.94	0.45	-27.66	12.45	-.06
	Treatment Condition	0.15	0.33	0.32	-0.33	1.01	-
	Age	0.11	0.01	0.49	-0.02	0.04	-
	Practical IPQ	-0.02	0.10	0.89	-0.21	0.18	-
	Emotion IPQ	-0.13	0.08	0.41	-0.24	0.10	-
	SASC	0.04	0.41	0.81	-0.72	0.92	-
<i>Six-month (T2)</i>							
	Constant		14.70	0.60	-23.24	38.77	.03
	Treatment Condition	-0.07	0.50	0.75	-1.21	0.89	-
	Age	0.12	0.02	0.64	-0.04	0.06	-
	Practical IPQ	-0.32	0.18	0.19	-0.63	0.14	-
	Emotion IPQ	-0.21	0.15	0.40	-0.46	0.19	-
	SASC	0.01	0.66	0.98	-1.38	1.41	-
<i>Twelve-month (T3)</i>							
	Constant		17.54	0.28	-17.58	57.18	.08
	Treatment Condition	-0.29	0.55	0.25	-1.84	0.51	-
	Age	0.31	0.02	0.31	-0.03	0.08	-
	Practical IPQ	0.06	0.15	0.83	-0.29	0.35	-
	Emotion IPQ	0.35	0.13	0.19	-0.10	0.47	-
	SASC	0.06	0.59	0.82	-1.12	1.40	-

Note: *p<0.05, **p<0.01

Appendix H: Stroke Survivor Information Sheet and Consent Form for Qualitative Study



Registration Number:

Participant Initials:

Date of Birth:

ARCOS IV Part 2: Motivational Interviewing Stroke Trial (MIST)

Stroke Survivor Information Sheet

Date Information Sheet Produced: 01/08/2014

Project Title: What may influence engagement with health promoting behaviour from a stroke survivor perspective

An invitation

My name is Halina Kalaga, and I am a doctoral student at AUT University. This research study is part of a program of doctoral research being conducted by Halina Kalaga, and is supervised by Dr Alice Theadom and Dr Rita Krishnamurthi at AUT University, Auckland.

You are invited to take part in a research study because within the last year you experienced a stroke and have been involved with the MIST Trial. This research study will investigate what may influence health promoting behaviour (healthy lifestyle changes) in stroke survivors. This doctoral research is part of the MIST Trial, and is coordinated by the National Institute for Stroke and Applied Neurosciences, AUT University, in Auckland. The Health Research Council (HRC) of New Zealand funds this programme of research.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care or disadvantage you in the future. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part. If you require an interpreter this may be arranged.

What are the aims of this study?

The main aim of MIST is to determine the impact of stroke in New Zealand. This doctoral study will add to the findings of MIST through investigating what may influence healthy lifestyle changes in stroke survivors.



Registration Number:	Participant Initials:	Date of Birth:
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We are interested in what may influence healthy lifestyle changes, and would like to explore the experiences of people who participated in the MIST Trial. People who participate in research often have important and insightful ideas about how treatments (or a research study) may be perceived and responded to; therefore, we would like to explore the experiences of people who participated in the MIST Trial.

This study will explore the experiences of stroke survivors, their experience of healthy lifestyle changes, and their perspective of the treatment, services, or care they received. The stroke survivors will also be asked about their experience of being involved with the MIST Trial.

We hope this study will increase the understanding of “real-life” factors that influence healthy lifestyle changes, and how these factors may influence how it can be engaged with most effectively.

The findings from this research will be written up as part of a doctoral thesis, and may result in other academic publications or outputs such as conference presentations, conference posters, and journal articles.

What types of people can be in the study?

People, who have experienced their first stroke, who live in the Auckland area, and who have participated in the Motivational Interviewing Stroke Trial (MIST) can take part. We estimate about 8 to 14 people from New Zealand will be involved in this study.

What happens if I do decide to take part?

If you decide you would like to take part, your participation will involve one telephone interview. If you would prefer a face-to-face interview, this option will be provided.

If you are eligible to take part, the researcher (Halina Kalaga) will contact you to arrange your participation in a telephone interview at the end of the MIST Trial. The interview will be approximately 1 hour long.

You will be asked questions about your experiences post-stroke, about your health behaviours (if you made healthy changes to your lifestyle), and what it has been like to participate in a research study (the MIST Trial).

The interview will be recorded on an audio recorder. All the recording of the interview will be anonymous and confidential. Only the research team will have access to the transcribed and de-identified data. In this instance, the research team is identified as Ms Halina Kalaga, and her supervisors Dr Alice Theadom, and Dr Rita Krishnamurthi.



Registration Number:

Participant Initials:

Date of Birth:

How many assessments will there be?

There will be one interview that will take place after your last assessment in the MIST Trial. The interview will take up to 1 hour to complete. Your information, combined with what others have told us about their experiences of stroke care and recovery (whilst you have participated in the MIST Trial), will help us to look for important issues that can be changed in the future to better help people who have suffered a stroke.

How will the study affect me?

Taking part in this study will take some of your time. There are no known risks caused by this study. Your participation in the study is entirely voluntary. You may withdraw from the study at any time and you do not have to give a reason for doing so. Your participation in this study will be stopped should any harmful effects appear. This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. The results obtained from your participation may help others with stroke through informing how interventions are delivered in rehabilitation.

What are the discomforts and risks of this research?

There are no known risks caused by this study. Participation in this study will be stopped should any harmful effects appear. Participants will be able to take a break any time if this to do so e.g. if they get upset.

At the beginning of the study, the primary researcher and the participants will discuss what to expect during the interview and will agree some boundaries to reduce any potential risks during the interview. The questions will focus on what may influence healthy lifestyle changes from the perspective of a stroke survivor.

Confidentiality

The study files, any notes taken and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for 16 years in a secure place at the central coordinating centre in Auckland. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.



Registration Number:	Participant Initials:	Date of Birth:
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What are the costs of participating in this research?

This research study will take up to 1 hour of your time within the next 6 months.

What opportunity do I have to consider this invitation?

From receiving this invitation, you will have approximately a month to decide if you would like to participate.

How do I agree to participate in this research?

If you would like to participate in this research, please contact the primary researcher, **Halina Kalaga** by telephone **0226447114**.

The primary researcher will organize a time for the interview, and will contact you with the details.

At the beginning of the interview, the researcher will ask if you have any questions about the research.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Alice Theadom, alice.theadom@aut.ac.nz, 09 921 9999 ext. 7805.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 09 921 9999 ext. 6038.

Your Rights

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Free phone: 0800 555 050
 Free fax: 0800 2787 7678 (0800 2 SUPPORT)
 Email: advocacy@hdc.org.nz



Registration Number:

Participant Initials:

Date of Birth:

Contact details

This study has received Ethical Approval from the HDEC Ethics Committee (30/07/2014, HDEC Reference NTX/10/09/091/AM04) and the AUTECH Ethics Committee dated (12/08/2014, AUTECH Reference 11/298).

If you would like some more information about the study please feel free to contact **Halina Kalaga** on email gdg6600@aut.ac.nz or by telephone **0226447114**

Alternatively, you can contact:

Dr Alice Theadom, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7805 or email: alice.theadom@aut.ac.nz

Dr Rita Krishnamurthi, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7809 or email: rkrishna@aut.ac.nz

Study Investigators

The principle investigator for this PhD study is: **Halina Kalaga**
National Institute for Stroke and Applied Neurosciences (NISAN), AUT University,
Private Bag 92006, Auckland 1142.

***Please keep this brochure for your information.
Thank you for reading about this study***

***Approved by the Health and Disability Ethics Committee on 30/07/2014, HDEC
Reference NTX/10/09/091/AM04 and the Auckland University of Technology Ethics
Committee on 12/08/2014, AUTECH Reference 11/298.***



Registration Number:	Participant Initials:	Date of Birth:
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CONSENT FORM

Project title: What may influence engagement with health promoting behavior: a stroke survivor perspective.

Project Supervisor: Dr Alice Theadom

Researcher: Halina Kalaga

I have read/had explained to me, and understand, the Information Sheet for stroke survivors, dated 01/08/2014.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I understand that taking part in this study is voluntary (my choice). I understand that I may withdraw myself at any time during the study without being disadvantaged in any way.

I have had time to consider whether to take part.

I know whom to contact if I have any questions about the study.

I agree to take part in this research.

Yes / No

I _____ hereby consent to take part in this research.

Signature.....

Date.....

Project explained by.....

Note: The Participant should retain a copy of this form.

Approved by the Health and Disability Ethics Committee on 30/07/2014, HDEC Reference NTX/10/09/091/AM04 and the Auckland University of Technology Ethics Committee on 12/08/2014, AUTECH Reference 11/298.

Appendix I: Significant Other Information Sheet and Consent Form for Qualitative Study



Stroke Survivor Reg Number:

Stroke Survivor Initials:

Stroke Survivor DoB:

ARCOS IV Part 2: Motivational Interviewing Stroke Trial (MIST)

Caregiver/Significant Other Information Sheet

Date Information Sheet Produced: 01/08/2014

Project Title: What may influence engagement with health promoting behaviour from a significant other or caregiver perspective

An invitation

My name is Halina Kalaga, and I am a doctoral student at AUT University. This research study is part of a program of doctoral research being conducted by Halina Kalaga, and is supervised by Dr Alice Theadom and Dr Rita Krishnamurthi at AUT University, Auckland.

You are invited to take part in a research study because within the last year a member of your family, or someone close to you, experienced a stroke and have been involved with the MIST Trial. This research study will investigate what may influence healthy lifestyle changes in stroke survivors. This doctoral research is part of the MIST Trial, and is coordinated by the National Institute for Stroke and Applied Neurosciences, AUT University, in Auckland. The Health Research Council (HRC) of New Zealand funds this programme of research.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care or disadvantage you in the future. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part. If you require an interpreter this may be arranged.

What are the aims of this study?

The main aim of MIST is to determine the impact of stroke in New Zealand. This doctoral study will add to the findings of MIST through investigating what may influence healthy lifestyle changes in stroke survivors.

We are interested in what may influence healthy lifestyle changes in stroke survivors, and would like to explore the experiences of people who are close family members, friends, whanau, primary caregivers of stroke survivors who have participated in the MIST Trial. People who are close family members, friends, whanau, caregivers often have important and insightful ideas about how the people they are close to perceive and respond to



Stroke Survivor Reg Number:	Stroke Survivor Initials:	Stroke Survivor DoB:
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treatments (or a research study); therefore, we would like to explore the experiences of close family members, friends, whanau of stroke survivors who participated in the MIST Trial.



Stroke Survivor Reg Number:

Stroke Survivor Initials:

Stroke Survivor DoB:

This study will explore the post-stroke experiences of caregivers, their perspectives about the healthy lifestyle changes of stroke survivors, and their perspectives of the post-stroke treatments, services, or care. The caregivers will also be asked about their perspectives about the experience of being involved with the MIST Trial.

We hope this study will increase the understanding of “real-life” factors that influence healthy lifestyle changes, and how these factors may influence how it can be engaged with most effectively.

The findings from this research will be written up as part of a doctoral thesis, and may result in other academic publications or outputs such as conference presentations, conference posters, and journal articles.

What types of people can be in the study?

Family members/whanau, a close friend, a significant other, or caregivers of people who are in the Motivational Interviewing Study Trial (MIST) can take part. We estimate about 8 to 14 people from New Zealand will be involved in this study.

What happens if I do decide to take part?

The stroke survivor you are close to may have nominated you as their significant other or caregiver. If you decide you would like to take part, your participation will involve one telephone interview. If you would prefer a face-to-face interview, this option will be provided.

If you are eligible to take part, the researcher (Halina Kalaga) will contact you to arrange your participation in a telephone interview at the end of the MIST Trial. The interview will be approximately 1 hour long.

You will be asked questions about your experiences post-stroke, about your perspectives of post-stroke health behaviours, and what you think it has been like for the stroke survivor you are close to to participate in a research study (the MIST Trial).

The interview will be recorded on an audio recorder. All the recording of the interview will be anonymous and confidential. Only the research team will have access to the transcribed and de-identified data. In this instance, the research team is identified as Ms Halina Kalaga, and her supervisors Dr Alice Theadom, and Dr Rita Krishnamurthi.

How many assessments will there be?

There will be one interview that will take place after the last assessment for the stroke survivor who is participating in the MIST Trial. The interview will take up to 1 hour to complete. Your information, combined with what others have told us about their



Stroke Survivor Reg Number:	Stroke Survivor Initials:	Stroke Survivor DoB:
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experiences of stroke care and recovery, will help us to look for important issues that can be changed in the future to better help people who have suffered a stroke.

Stroke Survivor Reg Number:

Stroke Survivor Initials:

Stroke Survivor DoB:

How will the study affect me?

Taking part in this study will take some of your time. There are no known risks caused by this study. Your participation in the study is entirely voluntary. You may withdraw from the study at any time and you do not have to give a reason for doing so. Your participation in this study will be stopped should any harmful effects appear. This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. The results obtained from your participation may help others with stroke through informing how interventions are delivered in rehabilitation.

What are the discomforts and risks of this research?

There are no known risks caused by this study. Participation in this study will be stopped should any harmful effects appear. Participants will be able to take a break any time if this to do so e.g. if they get upset.

At the beginning of the study, the primary researcher and the participant will discuss what to expect during the interview and will agree some boundaries to reduce any potential risks during the interview. The questions will focus on what may influence healthy lifestyle changes from the perspective of the caregiver.

Confidentiality

The study files, any notes taken and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for 16 years in a secure place at the central coordinating centre in Auckland. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

What are the costs of participating in this research?

This research study will take up to 1 hour of your time within the next 6 months.

What opportunity do I have to consider this invitation?

From receiving this invitation, you will have approximately a month to decide if you would like to participate.

How do I agree to participate in this research?

Stroke Survivor Reg Number:

Stroke Survivor Initials:

Stroke Survivor DoB:

If you would like to participate in this research, please contact the primary researcher, **Halina Kalaga** by telephone **0226447114**.

The primary researcher will organize a time for the interview, and will contact you with the details. At the beginning of the interview, the researcher will ask if you have any questions about the research.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Alice Theadom, alice.theadom@aut.ac.nz, 09 921 9999 ext. 7805.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 09 921 9999 ext. 6038.

Your Rights

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Free phone: 0800 555 050
Free fax: 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz

Contact details

This study has received Ethical Approval from the HDEC Ethics Committee (30/07/2014, HDEC Reference NTX/10/09/091/AM04) and the AUTEK Ethics Committee dated (12/08/2014, AUTEK Reference 11/298).

If you would like some more information about the study please feel free to contact **Halina Kalaga** on email halina.kalaga@gmail.com or gdg6600@aut.ac.nz or by telephone **0226447114**

Alternatively, you can contact:

Dr Alice Theadom, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7805 or email: alice.theadom@aut.ac.nz

Dr Rita Krishnamurthi, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7809 or email: rkrishna@aut.ac.nz

Study Investigators

Stroke Survivor Reg Number:	Stroke Survivor Initials:	Stroke Survivor DoB:
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The principle investigator for this PhD study is: **Halina Kalaga**
National Institute for Stroke and Applied Neurosciences (NISAN), AUT University,
Private Bag 92006, Auckland 1142.

Please keep this brochure for your information. Thank you for reading about this study

***Approved by the Health and Disability Ethics Committee on 30/07/2014, HDEC Reference
NTX/10/09/091/AM04 and the Auckland University of Technology Ethics Committee on 12/08/2014,
AUTEC Reference 11/298.***

Stroke Survivor Reg Number:	Stroke Survivor Initials:	Stroke Survivor DoB:
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CONSENT FORM

Project title: What may influence engagement with health promoting behavior: a caregiver perspective.

Project Supervisor: Dr Alice Theadom

Researcher: Halina Kalaga

I have read/had explained to me, and understand, the Information Sheet for caregivers, dated 01/08/2014.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I understand that taking part in this study is voluntary (my choice). I understand that I may withdraw myself at any time during the study without being disadvantaged in any way.

I have had time to consider whether to take part.

I know whom to contact if I have any questions about the study.

I agree to take part in this research.

Yes / No

I _____ hereby consent to take part in this research.

Signature.....

Date:.....

Project explained by.....

Note: The Participant should retain a copy of this form.

Approved by the Health and Disability Ethics Committee on 30/07/2014, HDEC Reference NTX/10/09/091/AM04 and the Auckland University of Technology Ethics Committee on 12/08/2014, AUTECH Reference 11/298.

Appendix J: Motivational Interviewer Information Sheet and Consent Form for Qualitative Study

ARCOS IV Part 2: Motivational Interviewing Stroke Trial (MIST)

Motivational Interviewer Information Sheet

Date Information Sheet Produced: 15/09/2013

Project Title: What factors influence engagement to motivational interviewing from a motivational interviewer perspective

An invitation

My name is Halina Kalaga, and I am a doctoral student at AUT University. This research study is part of a program of doctoral research being conducted by Halina Kalaga, and is supervised by Dr Alice Theadom and Dr Rita Krishnamurthi at AUT University, Auckland.

You are invited to take part in a research study because you are a Motivational Interviewer and you are involved with the MIST Study. This research study will investigate the factors that may influence motivational interviewing (MI) in stroke survivors'. This doctoral research is part of the MIST Study, and is coordinated by the National Institute for Stroke and Applied Neurosciences, AUT University, in Auckland. The Health Research Council (HRC) of New Zealand funds this programme of research.

Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way disadvantage you in the future. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part. If you require an interpreter this may be arranged.

What are the aims of this study?

The main aim of MIST is to determine the impact of stroke in New Zealand. This doctoral study will add to the findings of MIST through investigating the factors that influence motivational interviewing (MI) in stroke survivors.

We are interested in what factors may influence engagement with MI, and would like to explore the experiences of people who deliver the intervention (Motivational Interviewers). People who deliver interventions often have important and insightful ideas about how people perceive and respond to treatments; therefore, we would like to explore the experiences of people who deliver motivational interviewing.

This study will explore the experiences of the Motivational Interviewer and about their perspective of how the stroke survivors' found the intervention. The Motivational

Interviewer will also be asked about their experience of being involved with MI and the MIST Study.

We hope this study will increase the understanding of “real-life” factors that influence motivational interviewing, and how these factors may influence how it can be delivered most effectively.

The findings from this research will be written up as part of a doctoral thesis, and may result in other academic publications or outputs such as conference presentations, conference posters, and journal articles.

What types of people can be in the study?

People who are Motivational Interviewers (practitioners in motivational interviewing) and who are involved with MIST can take part. We estimate that four to seven people from New Zealand will be involved in this study.

You are being contacted because you have previously been involved in consultations about this research study. The primary researcher (Halina Kalaga) has contacted each potential participant directly to ensure confidentiality and participant privacy. Recruitment will involve an email invitation (sent individually to each potential participant); this email will include the information and consent form as an attachment.

The study will focus on the perceptions of Motivational Interviewers who have direct contact with stroke survivors (the participants in MIST). This study is looking specifically at peoples’ experiences of delivering motivational interviewing to stroke survivors’ as part of a research trial (MIST) and therefore external motivational interviewers will not be included in this study.

What happens if I do decide to take part?

If you decide you would like to take part, your participation will involve one focus group. If you are eligible to take part, the researcher (Halina Kalaga) will contact you to arrange your participation in a focus group. The focus group will be approximately 2 hours long; after one hour, the focus group will have a refreshment break for 15 minutes before continuing with the focus group.

You will be asked questions about what you think it has been like for stroke survivors to be involved with MIST, and what you think their experience of MI has been like. You will also be asked what your experience of MIST and MI has been like. In total, the focus group should take up to 2 hours of your time within the next six months.

The focus group will be recorded on an audio recorder. All the recording of the focus group will be anonymous and confidential. The raw data from the focus group will be completely de-identified when transcribed; the primary researcher will allocate each participant a participant code (string of numbers; for example, 0001), which will be used to refer to the conversation of the participant. Only the primary researcher will have access to the raw data (i.e. Ms Halina Kalaga). Only the research team will have access

to the transcribed and de-identified data. In this instance, the research team is identified as Ms Halina Kalaga, Dr Alice Theadom, and Dr Rita Krishnamurthi.

How many assessments will there be?

There will be one focus group discussion. The focus group will take up to 2 hours to complete. The focus group will have a 15-minute break in the middle for refreshments. Your information, combined with what others have told us about their experiences of stroke care and recovery within the context of MIST, will help us to look for important issues that can be changed in the future to better help people who have suffered a stroke.

If you are not able to attend the focus group or would prefer to have an individual interview this can be arranged. If you decide you would like to attend an individual interview, this interview will take approximately 45 minutes.

How will the study affect me?

Taking part in this study will take some of your time. There are no known risks caused by this study. Your participation in the study is entirely voluntary. You may withdraw from the study at any time and you do not have to give a reason for doing so. Your participation in this study will be stopped should any harmful effects appear. This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. The results obtained from your participation may help others with stroke through informing how interventions are delivered in rehabilitation.

What are the discomforts and risks of this research?

There are no known risks caused by this study. Participation in this study will be stopped should any harmful effects appear. Participants will be able to take a break any time if this to do so e.g. if they get upset.

At the beginning of the study, the primary researcher and the participants will discuss the focus group rules and will agree some boundaries to reduce any potential risks during the focus group. As the participants work as Motivational Interviewers at AUT, care will be taken to ensure that the participants feel comfortable with the tone and topic of questions during the focus group. The questions will focus on what factors may influence stroke survivor engagement with MI from the perspective of the Motivational Interviewer.

Confidentiality

The study files, any notes taken and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for 10 years in a secure place at the central coordinating centre in Auckland. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

What are the costs of participating in this research?

This research study will take up to 2 hours of your time within the next 6 months.

What opportunity do I have to consider this invitation?

From receiving this invitation, you will have approximately a month to decide if you would like to participate.

How do I agree to participate in this research?

If you would like to participate in this research, please contact the primary researcher, Halina Kalaga by email.

The primary researcher will organize a time and venue for the focus group, and will contact you with the details. You will be able to attend the focus group during work hours.

At the beginning of the focus group, the researcher will ask if you have any questions about the research, and will witness the consent form by signing and dating it.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Alice Theadom, alice.theadom@aut.ac.nz, 09 921 9999 ext. 7805.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, 09 921 9999 ext. 6038.

Your Rights

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Free phone: 0800 555 050
Free fax: 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz

Contact Details

This study has received Ethical Approval from the AUTC Ethics Committee dated (21 November 2013)

If you would like some more information about the study please feel free to contact **Halina Kalaga** on email halina.kalaga@gmail.com or gdg6600@aut.ac.nz.

Alternatively, you can contact:

Dr Alice Theadom, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7805 or email: alice.theadom@aut.ac.nz

Dr Rita Krishnamurthi, Senior Research Fellow, NISAN, AUT University on 09-921-9999 ext. 7809 or email: rkrishna@aut.ac.nz

Study Investigators

The principal investigator for this study is **Halina Kalaga**, National Institute for Stroke and Applied Neurosciences (NISAN), AUT University, Private Bag 92006, Auckland 1142, halina.kalaga@gmail.com

***Please keep this brochure for your information.
Thank you for reading about this study***

Approved by the Auckland University of Technology Ethics Committee on *type the date*
final ethics approval was granted, AUTEK Reference number 13/342.

CONSENT FORM

Project title: **What factors influence engagement to motivational interviewing from a Motivational Interviewer perspective.**

Project Supervisor: **Dr Alice Theadom**

Researcher: **Halina Kalaga**

I have read/had explained to me, and understand, the Information Sheet for motivational interviewers, dated 15/09/2013.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that the identity of my fellow participants and our discussion in the focus group is confidential to the group and I agree to keep this information confidential.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I understand that notes will be taken during the focus group and that it will also be audio-taped and transcribed.

I understand that I may withdraw myself at any time during the study without being disadvantaged in any way.

If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.

If I request to receive a copy of the transcribed data, I understand that this will be for clarification purposes i.e. if I feel that that something I have said may be misunderstood, or to request for a potentially sensitive topic to be removed prior to analysis. I also understand that this transcript is confidential, and I agree to keep this information confidential.

I have had time to consider whether to take part.

I know whom to contact if I have any questions about this study.

I agree to take part in this research.

I am indicating my approval (or otherwise) for the following:

I wish to receive a copy of the transcribed data. I understand there may be a significant delay between data collection and the transcription of the data.

Yes ☐
 No ☐

I wish to receive a copy of the results. I understand there may be a significant delay between data collection and the publication of the study results.

Yes ☐
 No ☐

I _____ hereby consent to take part in this research.

Signature Signature of witness.....

Name: Name of witness.....

Date Project role

Project explained by Date

Note: The Participant should retain a copy of this form.

Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTECH Reference 13/342.

Appendix K: Stroke Survivor and Significant Other Interview Schedule for Qualitative Study

Interview Schedule for Stroke Survivors and Caregivers

1. What do you feel made the most impact for your recovery from stroke?
2. Did you make lifestyle changes?
 - a. What influenced your lifestyle changes? [Explain]
 - b. Did taking part in a research study help you to make changes to your lifestyle? Explain... Or influence your recovery? [Explain]
3. Could you tell me about your participation in the MIST Trial?
 - a. What was the overall experience of taking part in research like? Can you tell me what it was like to be involved in MIST?
 - b. What was the main thing that you gained from participating in the MIST Trial?
 - c. Were there any positive or negative effects of taking part in the research? Explain
 - d. Can you tell me if you think that you were able to make changes to your lifestyle because of MIST? If yes, how? If no, why not?
 - e. Do you believe that the MIST Trial helped to improve your health or recovery? If yes, how? If no, why not?
 - f. Can you tell me if you noticed any other benefits as a result of participating in the MIST Trial? What were these?
4. Could you tell me about the services you received after the stroke?
 - a. Do you think there are any services you would have benefitted from that you didn't receive?
 - b. What was your overall experience of the services that were provided?
 - c. What were the positive or negative aspects you experienced as a result of receiving particular services?
 - d. What was the main thing that you gained from particular services post-stroke?
 - e. What do you think influenced how you responded to particular services?
 - f. Did you feel you were able to make changes to your lifestyle because of particular services?
 - g. Do you believe that the services provided helped to improve your health or recovery? If yes, how? If no, why not?
 - h. Can you tell me if you noticed any other benefits as a result of receiving particular services? What were these?
 - i. Did your participation in the MIST Trial make you think that you should be receiving any services in particular?
5. Is there anything else you would like to add?

Appendix L: Motivational Interviewer Interview Schedule for Qualitative Study

Interview Schedule for Motivational Interviewers

- Introduce self
 - Check the motivational interviewers have received the information sheet
 - Talk through study and ask if there are any questions
 - Obtain consent
6. Can you tell me what you think it was like for stroke survivors' to be involved in MI? How do you feel that stroke survivors' found participating in MI?
 7. What do you think influenced how people responded to MI? How do you feel participants responded to MI? Were there any differences between participants?
 8. What factors influence a good MI outcome or how an MI is set up? What makes an interview go well?
 9. Can you tell me if you think there any positive or negative effects of being involved with this research for the stroke survivors'? What were these?
 10. Can you tell me if you think that stroke survivors' were able to make changes to their lifestyle because of MI? If yes, how? If no, why not?
 11. Do you feel that MIST/MI improved stroke survivors' recovery from stroke? If yes, how? If no, why not?
 12. MIST focuses on a number of outcome measures; for example, medical outcomes such as bp and lipid profiles. Can you tell me if you noticed any benefits as a result of motivational interviewing? What were these? [Or... Can you tell me what benefits you commonly noticed as a result of MI?]

[Brief Break]

13. Could you tell me what it has been like to work on the MIST study?
14. Can you tell me about your experience of training to learn about motivational interviewing?
15. Can you tell me about the positive experiences when working on the MIST study? Were there any challenges for you whilst working on the MIST study?
16. What were the challenges for you in delivering MI?
17. Are there any things that you would do differently when thinking about your role as a motivator in MIST? Are there any things that you would do differently when thinking about how an MI interview is set up?
18. Is there anything else you would like to add?

Appendix M: HDEC Ethics Approval Letter for Qualitative Study



Health and Disability Ethics Committees
Ministry of Health
C/- MEDSAFE, Level 6, Deloitte House
10 Brandon Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@mh.govt.nz

30 July 2014

Dr Rita Krishnamurthi
NISAN, AUT North Shore
90 Akoranga Drive
Northcote
Auckland 0627

Dear Dr Krishnamurthi

Re: Ethics ref:	NTX/10/09/091/AM04
Study title:	ARCOS IV: Measuring and Reducing the burden of stroke in NE Zealand. Motivational Interviewing in Stroke Trial (MIST).

I am pleased to advise that this amendment has been approved by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

The main issues considered by the HDEC in giving approval were as follows.

— Noting of Ethics Committees in the Caregiver Participant Information Sheet

Non-standard conditions:

1. The Committee notes that the AUTECH Ethics Committee is referred to in the Caregiver Participant Information Sheet but that the Northern A HDEC is not. Please rectify this omission.

Non-Standard conditions must be completed before commencing your study. If you would like to submit your Non-standard conditions please email Non-standard conditions to HDEC@mh.govt.nz. Do not submit Non-standard conditions as a Post Approval form.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Dr Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A

Documents submitted and approved

Document	Version	Date
PIS/CF: Stroke Survivor Information Sheet and consent form	2	14 July 2014
PIS/CF for persons interested in welfare of non-consenting participant: Caregiver Information Sheet and consent form	2	14 July 2014
Survey/questionnaire: Updated Interview Schedule	1	03 July 2014
Letter to HDEC explaining request for amendments.	1	03 July 2014
Post Approval Form	04	16 July 2014

Appendix B

Statement of compliance and list of members

Statement of compliance

The Northern A Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008714) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires
Dr Brian Fergus	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Dr Karen Bartholomew	Non-lay (intervention studies)	01/07/2013	01/07/2016
Ms Susan Buckland	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Ms Shamim Chagani	Non-lay (health/disability service provision)	01/07/2012	01/07/2015
Dr Christine Crooks	Non-lay (intervention studies)	01/07/2013	01/07/2015
Mr Kerry Hiini	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Ms Michele Stanton	Lay (the law)	01/07/2012	01/07/2015

<http://www.ethics.health.govt.nz>

Appendix N: AUTECH Ethics Approval Letter for Qualitative Study



AUTEC SECRETARIAT

12 August 2014

Valery Feigin
Faculty of Health and Environmental Sciences

Dear Valery

Re: Ethics Application: **11/298 Auckland Regional Community Stroke Study (ARCOS IV). Measuring and reducing the stroke burden in New Zealand. Part 2. Motivational interviewing in stroke trial (2010-2014).**

Thank you for your request for approval of an amendment to your ethics application.

I have approved the amendment allowing interviews with patients and caregivers under the approval by the Northern A Health and Disability Ethics Committee – NTX/10/09/091/AM01.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. 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 April 2015;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 30 April 2015 or on completion of the project.

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 responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Alice Theadom; Halina Kalaga, halina.kalaga@gmail.com; Kathryn McPherson, Rita Krishnamurthi

Appendix O: AUTECH Ethics Approval Letter for Qualitative Study

16 December 2013

Alice Theadom
Faculty of Health and Environmental Sciences

Dear Alice

Re Ethics Application: **13/342 What factors influence engagement to motivational interviewing from a motivational interviewer perspective?**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTC).

Your ethics application has been approved for three years until 16 December 2016.

Acting under delegated authority and subject to endorsement by AUTC at its meeting of 3 February 2014, the Executive Secretary approved the satisfactory resolution of AUTC's conditions.

As part of the ethics approval process, you are required to submit the following to AUTC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 December 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 16 December 2016 or on completion of the project.

It is a condition of approval that AUTC is notified of any adverse events or if the research does not commence. AUTC 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 responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Halina Kalaga halina.kalaga@gmail.com

A u c k l a n d U n i v e r s i t y o f T e c h n o l o g y E t h i c s C o m m i t t e e

WA505F Level 5 WA Building City Campus

Private Bag 92006 Auckland 1142 Ph: +64-9-921-9999 ext 8316 email ethics@aut.ac.nz