The Role of Illness Beliefs in Understanding Adjustment after Stroke

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Abstract

Stroke is a highly prevalent condition. It is a principal cause of adult disability and a leading cause of death in the United Kingdom (UK). The lifetime risk of stroke recurrence is also high, particularly for those with specific risk factors (e.g., hypertension). The long-term management of stroke is multi-faceted and complex. Stroke survivors are often responsible for self-managing their secondary preventive treatment (e.g., oral medication(s)) alongside rehabilitation, which is most beneficial in the first six-months. However, patients undergo a period of psychological adjustment after stroke. This is particularly evident in the early days where mood problems, such as depression, are highly common and affect how well people engage with, and adhere to, their rehabilitation and treatment. The present PhD research was interested in further understanding adjustment after stroke, and in particular, by utilising key evidence from the field of Health Psychology (more specifically, the Common Sense Model (CSM)), examining whether survivors' perceptions (or beliefs) about their stroke are influential in determining how well people recover.

The overall aims of this work were to:

- Examine and synthesise the current evidence, through a systematic review and meta-analysis on the CSM in relation to physical illnesses to determine whether individual illness belief domains were important predictors of adherence to self-management in adults with acute or chronic conditions;

- Elicit views regarding an assessment method (the Stroke Illness Perception Questionnaire-Revised (Stroke IPQ-R)) that would be suitable and acceptable to a stroke population for accurately measuring peoples' beliefs in the acute phase (≤three-months post-stroke);
- Apply the CSM (utilising the Stroke IPQ-R) to a population within the acute phase of stroke, to determine whether the model provides a useful framework for understanding survivors' recovery after stroke (e.g., Health-Related Quality of Life (HRQL), disability, and mood).

This research incorporated three standalone though inter-related studies, the first of which was a systematic review and meta-analysis. The key findings from this meta-analysis indicated that the majority of illness belief domains outlined by the CSM significantly predicted (albeit weakly) adherence to a range of self-management behaviours (e.g., attendance; medication adherence; diet; physical activity; and other disease-specific behaviours (e.g., blood glucose self-monitoring)). Pooled effect sizes ranged from 0.04 and 0.13. None of the relationships varied according to acute and chronic illnesses; the type of self-management behaviour; or the duration of follow-up.

A qualitative study was subsequently undertaken. A variety of approaches were employed (including, expert consultation and Think-Aloud interviews) to develop a stroke-specific version of the IPQ-R. Interview findings showed very few problems with completion of the instrument. Where there were problems, these related to the wording of items, specifically abstract, complex and negative wording; the response format for the identity sub-scale; and

questions on the timeline-cyclical and treatment control sub-scales. The revised scale was used in the third and final study.

The final study examined the relationship of illness beliefs, assessed by the Stroke IPQ-R developed in study 2, and measures of post-stroke recovery, including HRQL, disability and mood. This was a longitudinal observational study involving 50 survivors (average age=66.9 years, standard deviation =14.5 years) within three-months of their stroke. The primary outcome for this study, HRQL, was measured using the EQ-5D-5L instrument. The secondary outcomes were: disability, which was assessed using the Barthel Index, Modified Rankin Scale, and Nottingham Extended Activities of Daily Living Scale; and mood, measured using the Patient Health Questionnaire-9. Various statistical approaches were employed in the analyses of these data, the results of which are as follows.

Spearman's correlations indicated that participants who perceived their stroke to have fluctuating effects and considerable distress at baseline (<eight-weeks post-stroke) also reported worse mood one-month later. Multiple mediation analyses were conducted to examine whether baseline mood and coping (follow-up medication adherence, measured using the Medication Adherence Report Scale) mediated any of these relationships. The results indicated that baseline mood rather than coping was a significant mediator in the prediction of worse mood three-months post-stroke. Multiple linear regression analyses were carried out to determine whether baseline illness belief domains explained the additional variance in three-month HRQL, disability and mood,

over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery). The findings indicated that baseline illness belief domains significantly added between 7.4 and 29.9% to the overall variance in models for the majority of the abovementioned outcomes. Last, the results from the study demonstrated that baseline illness belief domains were highly significantly inter-correlated at baseline, and with follow-up illness belief domains. In light of this, cluster analysis was carried out to explore whether stroke survivors in the acute phase could be grouped according to their illness belief schema. Three clusters were identified: 'Low Adjusters;' 'Moderate Adjusters;' and 'High Adjusters.' In contrast to 'High Adjusters,' Low Adjusters' were participants who perceived their stroke to be chronic, with fluctuating effects, associated with a lot of symptoms, serious consequences and considerable distress. While baseline cluster membership was not significantly related to follow-up markers of post-stroke recovery, there were trends to suggest that 'Low Adjusters' had worse HRQL and mood, and greater disability one-month later compared to 'High Adjusters.'

The present research had several important implications. The principal theoretical implication concerns treatment beliefs. The findings from all three studies highlighted that people's beliefs about the effectiveness of their treatment in managing their condition are examined in the CSM in a limited way. There is currently a substantial focus on medication-taking behaviours despite treatments often being more complex (e.g., lifestyle behaviour or surgery). Therefore, the findings indicated that there is scope to further elaborate this

domain, above and beyond what has already been undertaken in the Necessity and Concerns Framework. This examines the cost versus benefits decision-making that patients undergo when taking their medication(s) (Horne and Weinman 1999). In addition, suitable instruments need to be further adapted and validated to accurately measure these treatment beliefs.

There were also several clinical implications of this work. First, it was emphasised that mood assessments should be carried out in patients immediately after stroke. It was shown in this research that even mild depressive symptomatology affected peoples' beliefs about their stroke, and thus how well they psychologically adjust in the acute phase. Second, there is a potential to develop brief belief-based interventions for modifying maladaptive beliefs about stroke. For instance, addressing perceptions around the fluctuating effects of stroke and the considerable distress caused by stroke could form the basis for such interventions. In addition, interventions can be targeted to a particular type of stroke survivor (i.e., 'Low Adjusters'), who are likely to be the people to benefit most from receiving them. However, these findings need to be borne out in a larger sample beforehand. The primary methodological consideration in relation to this work was the logistics of recruiting stroke survivors in the acute phase, which led to issues including: a small sample size; sample non-representativeness; and statistical constraints (e.g., factor analysis).

List of Publications arising from this Thesis

Original Article: Aujla N, Walker M, Sprigg N, Abrams K, Massey A, and Vedhara K (2016). Can illness beliefs, from the common-sense model, prospectively predict self-management behaviours? A systematic review and meta-analysis. Psychology and Health: **(E-publication ahead of print)**

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Aujla N, Walker M, Sprigg N, Abrams K, Massey A, and Vedhara K (2015). The prediction of self-management behaviours using the common-sense model: a systematic review and meta-analysis. **(Poster Presentation: CLAHRC Annual General Meeting, Nottingham).**

Aujla N, Walker M, Sprigg N, Abrams K, Massey A, and Vedhara K (2014). The prediction of self-management behaviours using the common-sense model: a systematic review and meta-analysis. **(Oral presentation: UK Society for Behavioural Medicine Conference, Nottingham).**

Aujla N, Walker M, Sprigg N, Abrams K, Massey A, and Vedhara K (2013). The prediction of self-management behaviours using the common-sense model: a systematic review and meta-analysis. **(Oral presentation: Organisation for Psychological Research into Stroke Conference, Nottingham).**

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Table of Contents

ABSTRACT ..... **I**

LIST OF PUBLICATIONS ARISING FROM THIS THESIS ..... **VI**

ACKNOWLEDGEMENTS ..... **VII**

TABLE OF CONTENTS ..... **X**

LIST OF TABLES ..... **XVI**

LIST OF FIGURES ..... **XIX**

THESIS OVERVIEW ..... **XXI**

CHAPTER 1. CLINICAL BACKGROUND ON STROKE AND INTRODUCTION TO POST-STROKE SELF-MANAGEMENT, ADJUSTMENT AND RECOVERY **1**

1.1 CHAPTER OVERVIEW **1**

1.2 INTRODUCTION TO THE CHAPTER **1**

1.3 PSYCHOLOGICAL ADJUSTMENT AFTER STROKE **6**

1.4 DISEASE ADJUSTMENT AFTER STROKE (COPING) **10**

1.5 FACTORS AFFECTING ADHERENCE AND ENGAGEMENT AFTER STROKE **13**

1.6 SPECIFIC OBJECTIVES OF THE PHD RESEARCH **17**

1.7 CHAPTER SUMMARY **18**

CHAPTER 2. INTRODUCTION TO THE COMMON-SENSE MODEL 20

2.1 CHAPTER OVERVIEW 20

2.2 THEORETICAL FOUNDATION OF THE COMMON SENSE MODEL..... 20

2.3 CORE FEATURES OF THE COMMON SENSE MODEL 25

2.4 STAGES OF THE CSM..... 29

2.5 PATHWAY FOR THE EMOTIONAL REGULATION OF ILLNESS..... ...34

2.6 CHAPTER SUMMARY..... 35

CHAPTER 3. PROSPECTIVELY PREDICTING ADHERENCE TO SELF-MANAGEMENT BEHAVIOURS USING ILLNESS BELIEFS FROM THE COMMON-SENSE MODEL: RESULTS FROM A SYSTEMATIC REVIEW AND META-ANALYSIS 37

3.1 CHAPTER OVERVIEW 37

3.2 BACKGROUND AND RATIONALE..... 37

3.3 AIMS..... 39

3.4 METHODS..... 40

3.5 RESULTS..... 52

3.6 DISCUSSION..... 94

3.7 CHAPTER SUMMARY..... 109

CHAPTER 4. REVIEW OF THE LITERATURE ON THE COMMON SENSE MODEL AND STROKE AND CRITICAL REVIEW OF POST-STROKE OUTCOME MEASURES 110

4.1 CHAPTER OVERVIEW 110

4.2 THE ROLE OF ILLNESS BELIEFS IN PREDICTING OUTCOMES AFTER STROKE 110

4.3 POST-STROKE OUTCOME MEASURES 118

4.4 POTENTIAL ROLE OF ILLNESS BELIEFS IN PREDICTING MARKERS OF RECOVERY AFTER STROKE 136

4.5 INTRODUCTION TO THE CONCEPTUAL MODEL 141

4.6 CHAPTER SUMMARY 142

CHAPTER 5. CRITICAL REVIEW OF MEASUREMENT APPROACHES FOR ENGAGEMENT AND ADHERENCE AFTER STROKE 143

5.1 CHAPTER OVERVIEW 143

5.2 MEASUREMENT OF ADHERENCE TO POST-STROKE SECONDARY PREVENTIVE BEHAVIOURS 143

5.3 MEASUREMENT OF ENGAGEMENT WITH REHABILITATION 148

5.4 CONCLUDING REMARKS 151

5.5 CHAPTER SUMMARY 152

CHAPTER 6. DEVELOPMENT OF A STROKE-SPECIFIC VERSION OF THE ILLNESS PERCEPTION QUESTIONNAIRE-REVISED 153

6.1 CHAPTER OVERVIEW 153

6.2 BACKGROUND AND RATIONALE 153

6.3 PRELIMINARY QUESTIONNAIRE DEVELOPMENT 162

6.4 QUALITATIVE THINK-ALOUD INTERVIEWS 174

6.5 FINAL VERSION OF THE STROKE IPQ-R 205

6.6 STRENGTHS AND LIMITATIONS 214

6.7 CHAPTER SUMMARY 218

CHAPTER 7. THE ROLE OF ILLNESS BELIEFS IN UNDERSTANDING RECOVERY AFTER STROKE 219

7.1 CHAPTER OVERVIEW 219

7.2 STUDY AIMS AND OBJECTIVES 219

7.3 METHODS 225

7.4 STATISTICAL METHODS 236

7.5 RESULTS 240

7.6 APPROACH TO ANALYSIS: RESEARCH QUESTION 1 . 253

7.7 HYPOTHESIS TESTING: RESEARCH QUESTION 1 254

7.8 APPROACH TO ANALYSIS: RESEARCH QUESTION 2..259

7.9 HYPOTHESIS TESTING: RESEARCH QUESTION 2 259

7.10 APPROACH TO ANALYSIS: RESEARCH QUESTION 3..263

7.11 HYPOTHESIS TESTING: RESEARCH QUESTION 3 267

7.12 APPROACH TO ANALYSIS: RESEARCH QUESTION 4 .. 277

7.13 HYPOTHESIS TESTING: RESEARCH QUESTION 4 279

7.14 APPROACH TO ANALYSIS: RESEARCH QUESTION 5A 289

7.15 HYPOTHESIS TESTING: RESEARCH QUESTION 5A ... 289

7.16 APPROACH TO ANALYSIS: RESEARCH QUESTION 5B 292

7.17 RESULTS: RESEARCH QUESTION 5B 295

7.18 APPROACH TO ANALYSIS 5C: RESEARCH QUESTION 5C 301

7.19 HYPOTHESIS TESTING: RESEARCH QUESTION 5C ... 301

7.20 DISCUSSION 302

7.21 CONCLUSION 324

7.22 CHAPTER SUMMARY 325

CHAPTER 8. OVERALL DISCUSSION 326

8.1 CHAPTER OVERVIEW 326

8.2 SUMMARY OF THE OVERALL AIMS AND KEY FINDINGS 326

8.3 THEORETICAL IMPLICATIONS 330

8.4 METHODOLOGICAL IMPLICATIONS 336

8.5 CLINICAL IMPLICATIONS 342

8.6 STRENGTHS AND LIMITATIONS OF THE PRESENT RESEARCH……345

8.7 FUTURE RESEARCH 347

8.8 CONCLUDING THOUGHTS.....349

REFERENCES ……352

APPENDICES.....394

List of Tables

Table 3-1. Eligibility criteria for the review 42

Table 3-2. Summary of studies included in the review 54

Table 3-3. Summary of the meta-analysis results 76

Table 3-4. Summary of the meta-analysis results following exclusion of Lau, Bernard et al. (1989) 79

Table 3-5. Summary of the meta-analysis results for partial correlations 81

Table 3-6. Summary of the meta-analysis results following stratification by the type of self-management behaviour 84

Table 3-7. Summary of the meta-analysis results following stratification by type of physical illness and length of follow-up 86

Table 3-8. Summary of the results from the meta-regression analyses to examine possible confounding factors 90

Table 6-1. Summary of preliminary changes made to the identity sub-scale. 163

Table 6-2. Summary of preliminary changes made to the main sub-scales of the Stroke IPQ-R 165

Table 6-3. Summary of preliminary changes made to the causal sub-scale ... 171

Table 6-4. Characteristics of the Think-Aloud sample 182

Table 6-5. Total problems across sub-scales of the Stroke IPQ-R 188

Table 6-6. Summary of final changes to the identity sub-scale 206

Table 6-7. Summary of final changes made to the main sub-scales of the Stroke IPQ-R 208

Table 6-8. Summary of final changes made to the causal sub-scale 213

Table 7-1. Summary of the outcome data collected at which time-point 234

Table 7-2. Summary of the findings for internal consistency 241
Table 7-3. Descriptive statistics for baseline demographics, family history and clinical information.....246
Table 7-4. Descriptive statistics for recruitment, consent, and data collection 247
Table 7-5. Baseline descriptive statistics for medical history 249
Table 7-6. Baseline and follow-up descriptive statistics for lifestyle.....251
Table 7-7. Summary of the degree of missing values for follow-up clinical variables.....252
Table 7-8. Descriptive analysis for illness belief domains.....256
Table 7-9. Descriptive analysis for markers of post-stroke recovery.....258
Table 7-10. Summary of findings for criteria 1 of mediation for follow-up HRQL (EQ-5D-5L Descriptive System-Index score) 269
Table 7-11. Summary of findings for criteria 1 of mediation for follow-up HRQL (EQ-5D-5L 'Your health today' VAS score) 270
Table 7-12. Summary of findings for criteria 1 of mediation for follow-up disability (Modified Rankin Scale score) 271
Table 7-13. Summary of findings for criteria 1 of mediation for follow-up disability (Barthel Index score) 272
Table 7-14. Summary of findings for criteria 1 of mediation for follow-up disability (Nottingham Extended Activities of Daily Living Scale score).....273
Table 7-15. Summary of the multiple regression results for follow-up HRQL (EQ-5D-5L Descriptive System – Index score) 281
Table 7-16. Summary of the multiple regression results for follow-up HRQL (EQ-5D-5L 'Your health today' VAS score) 282

Table 7-17. Summary of the multiple regression results for follow-up mood (PHQ-9 score).....284

Table 7-18. Summary of the multiple regression results for follow-up disability (Barthel Index score) 285

Table 7-19. Summary of the multiple regression results for follow-up disability (Nottingham Extended Activities of Daily Living Scale score).....288

Table 7-20. Inter-correlations between baseline illness belief domains (N=41) 290

Table 7-21. Inter-correlations between baseline and follow-up illness belief domains (N=41).....291

Table 7-22. Summary of illness belief schema for each cluster.....297

Table 7-23. Summary of the baseline characteristics for each cluster 298

Table 7-24. Relationships between baseline clusters and follow-up markers of post-stroke recovery.....302

List of Figures

Figure 2-1. The CSM, adapted from Leventhal, Nerenz et al. (1984).....26

Figure 3-1. PRISMA flow chart illustrating study selection from searches to final inclusion 53

Figure 3-2. Illness types across all included studies.....69

Figure 3-3. Illness types across studies included in the meta-analysis.....74

Figure 4-1. Conceptual model derived from the CSM 141

Figure 7-1. Conceptual model derived from the CSM 236

Figure 7-2. Participant flow through the study.....244

Figure 7-3. Scatterplot of the relationship between baseline identity beliefs and baseline mood (N=41) 260

Figure 7-4. Scatterplot of the relationship between baseline timeline-cyclical beliefs and baseline mood (N=41).....261

Figure 7-5. Scatterplot of the relationship between baseline consequence beliefs and baseline mood (N=41) 261

Figure 7-6. Scatterplot of the relationship between baseline emotional representations and baseline mood (N=41) 262

Figure 7-7. Scatterplot of the relationship between baseline timeline-cyclical beliefs and follow-up mood (N=41) 263

Figure 7-8. Scatterplot of the relationship between baseline emotional representations and follow-up mood (N=41).....263

Figure 7-9. Illustration of a simple relationship between predictor and outcome 264

Figure 7-10. Illustration of a mediated relationship between predictor and outcome with two mediators.....265

Figure 7-11. Multiple mediation model for baseline timeline-cyclical beliefs and follow-up mood 275

Figure 7-12. Multiple mediation model for baseline emotional representations and follow-up mood.....276

Figure 7-13. Dendrogram to illustrate emergent clusters 296

Thesis Overview

The present PhD thesis is organised as follows:

- Chapter 1 briefly provides the clinical background on stroke, in order to provide a backdrop to the remainder of work presented in this thesis. Chapter 1 also discusses adjustment after stroke and more specifically, highlights the impact of psychological variables (e.g., beliefs and mood) on peoples' adherence to their highly complex post-stroke self-management, and recovery (e.g., disability). In addition, Chapter 1 states the specific objectives of this PhD research.
- Chapter 2 is focused on the Common Sense Model (CSM) (comprising illness beliefs), which is the theoretical framework that the present PhD research is based upon, and provides an introductory discussion of this model.
- Chapter 3 extends the material presented in Chapter 2, reporting on a systematic review and meta-analysis undertaken to synthesise the current evidence on the role of illness beliefs in prospectively predicting adherence to a broad range of self-management behaviours that have relevance to stroke survivors. A version of this chapter has been published (see Aujla, Walker et al. (2016)).
- Chapter 4 is split into two parts. The first part presents a critical review of the literature on stroke where the CSM has been applied, which has thus far been limited to the prediction of specific outcomes (mood and medication adherence). The second part of Chapter 4, therefore, highlights additional and important outcomes that require consideration

after stroke (e.g., disability and Health-Related Quality of Life (HRQL)), and critically reviews their measurement.

- Chapter 5 extends Chapter 4 by providing a brief critical appraisal of the different approaches for measuring adherence to self-management after stroke, in order to inform the selection of measures for the main empirical work that forms this PhD (presented in Chapter 7 of this thesis).
- Chapter 6 reports on research undertaken to develop a suitable method for measuring illness beliefs amongst stroke survivors (the Stroke Illness Perception Questionnaire-Revised (Stroke IPQ-R)).
- Chapter 7 presents findings from a longitudinal observational study involving people early after stroke (≤three-months post-stroke), which examined whether survivors' beliefs about their stroke during the acute phase (as measured by the Stroke IPQ-R) predict indices of post-stroke recovery (HRQL, mood, and disability) measured at three-months post-stroke.
- Chapter 8 summarises the main findings from the research, and discusses the implications of the work and makes recommendations for future research.

The references and appendices are provided at the end of this thesis.

CHAPTER 1. CLINICAL BACKGROUND ON STROKE AND INTRODUCTION TO POST-STROKE SELF-MANAGEMENT, ADJUSTMENT AND RECOVERY

1.1 CHAPTER OVERVIEW

Stroke is the clinical problem at the heart of the present PhD research. The purpose of Chapter 1 is to set the scene for the remainder of chapters in this thesis, and will begin by providing an introductory discussion of stroke, including the definition, types of stroke, and prevalence. This will provide the reader with an understanding of the considerable burden of stroke. Chapter 1 will also highlight the particularly disabling nature of the condition, and high risk of recurrent stroke (briefly considering risk factors for secondary prevention), both of which demand complex and multi-faceted long-term self-management. The chapter will then go on to examine adjustment after stroke, which is an issue that is pertinent to the main focus of this thesis. More specifically, Chapter 1 will consider the importance of two aspects of adjustment in post-stroke recovery: psychological adjustment (or mood); and disease adjustment (or coping), which for the purposes of this thesis is understood in terms of treatment adherence.

1.2 INTRODUCTION TO THE CHAPTER

1.2.1 Definition of Stroke

Stroke is defined as a clinical syndrome, of likely vascular origin, characterised by a sudden onset of symptoms of focal or global disturbance of

cerebral function that typically lasts for more than 24-hours, or is fatal (World Health Organisation 1978, Department of Health 2007).

1.2.2 Types of Stroke

There are two main types of stroke: ischaemic and haemorrhagic (National Audit Office 2010). Ischaemic strokes are the most common, accounting for 85% of all strokes (National Audit Office 2010). They are caused by a clot that narrows or blocks the blood vessels to the brain (cerebral infarction) (National Audit Office 2010), and can be categorised into sub-types based on the location of lesions and associated symptoms (Bamford, Sandercock et al. 1991).

Haemorrhagic strokes (also known as intracerebral haemorrhage) are less common than ischaemic strokes, affecting around 10 to 20% of all people with stroke (Ikram, Wieberdink et al. 2012). Intracerebral haemorrhage is caused by a ruptured diseased blood vessel inside the brain leading to blood leaking into the brain, causing damage (World Health Organisation 1978). Subarachnoid haemorrhage is the least common stroke sub-type, contributing to around 5% of all strokes (de Rooij, Linn et al. 2007). Subarachnoid haemorrhage has a different clinical presentation to ischaemic stroke and intracerebral haemorrhage (World Health Organisation 1978), and is therefore, beyond the scope of this PhD thesis.

1.2.3 Burden of Stroke

Stroke presents a considerable burden globally, and in the United Kingdom (UK) (Intercollegiate Stroke Working Party 2012, Feigin, Forouzanfar et al. 2014). It is the third largest cause of death in England (Intercollegiate Stroke Working Party 2011), and contributes to around 11% of deaths in England and Wales (Intercollegiate Stroke Working Party 2012). Stroke is also a leading cause of adult disability (Intercollegiate Stroke Working Party 2011). The burden of stroke is reflected in the vast annual cost of the condition to the economy, with estimates for England totalling around £7 billion, where almost £3 billion are costs directly incurred by the National Health Service (NHS) (Department of Health 2007).

There are over 900,000 people living in England who have had a stroke (National Institute for Health and Care Excellence 2008). Figures indicate that of people who have had a stroke, around a third will die within one-month, most in the first 10-days, and a further third will have significant long-term disability (Department of Health 2007, Intercollegiate Stroke Working Party 2011). Impairments after stroke are most commonly: physical (e.g., weakness (hemiparesis) or paralysis (hemiplegia)) (Lawrence, Coshall et al. 2001, Intercollegiate Stroke Working Party 2012); psychosocial (e.g., depression, anxiety, and emotionalism) (Hackett, Yapa et al. 2005, Hackett, Yang et al. 2010, Campbell-Burton, Murray et al. 2012, Kneebone and Lincoln 2012); and cognitive (e.g., speech (aphasia), memory, attention, perception, spatial ability, and problem solving) (Sellars, Hughes et al. 2001, Engelter, Gostynski et al. 2006, Reitz, Bos et al. 2008, Kortte and Hillis 2009, Starkstein, Jorge et al. 2010,

Douiri, Rudd et al. 2013). There are around 300,000 people in England living with some form of disability after stroke, leaving them dependent upon others (often members of the immediate family) and needing considerable support with everyday activities (Forsberg-Wärleby, Möller et al. 2001, National Audit Office 2010).

In addition to being a leading cause of death and disability, survivors of a first-stroke are at high risk of further strokes, reportedly around 26% within five-years and 39% by 10-years (Mohan, Wolfe et al. 2011). Recurrent strokes account for around one-quarter of all strokes (Hankey 2005), and survival is even lower than after a first stroke (Samsa, Bian et al. 1999).

1.2.4 Long-Term Management of Stroke

In consequence, patients receive a complex package of long-term care after stroke (Intercollegiate Stroke Working Party 2012). This includes secondary preventive treatment (predominantly oral medication or lifestyle modification e.g., diet, physical activity, smoking cessation) for the management of modifiable (changeable) risk factors for stroke (e.g., hypertension, hypercholesterolemia, diabetes mellitus, atrial fibrillation (irregular heart rhythm), and previous stroke or transient ischemic attack (‘mini-stroke’ (World Health Organisation 1978, Hankey and Warlow 1994)) (Sacco, Benjamin et al. 1997, Antithrombotic Trialists' Collaboration 2002, Rashid, Leonardi-Bee et al. 2003, The Stroke Prevention by Aggressive Reduction in Cholesterol Levels (SPARCL) Investigators 2006, Furie, Kasner et al. 2011, Mohan, Wolfe et al. 2011, Rasmussen, Larsen et al. 2012, Castellano, Chinitz et al. 2014, Kernan,

Ovbiagele et al. 2014, Larsen, Rasmussen et al. 2014, Xian, Wu et al. 2015). Risk factors also often co-exist (e.g., hypertension and hypercholesterolemia), and can lead to an even greater risk of stroke recurrence (Air and Kissela 2007, Amarenco and Steg 2007).

In addition, many stroke survivors receive specialist multidisciplinary rehabilitation after stroke (e.g., physiotherapy, occupational therapy and speech and language therapy), in order to reduce the burden of post-stroke disabilities (Langhorne, Bernhardt et al. 2011). This is usually in the form of intensive hospital (stroke unit) or home-based (early supported discharge) therapy (Langhorne and Legg 2003, Stroke Unit Trialists' Collaboration 2007, Young and Forster 2007, Fearon and Langhorne 2012, Intercollegiate Stroke Working Party 2012, National Institute for Health and Care Excellence 2013, Walker, Sunnerhagen et al. 2013). There is an expectation on stroke survivors to practise exercises outside of formal rehabilitation sessions (self-directed rehabilitation) as a means to enhancing the benefits of therapy as well (Harwood, Weatherall et al. 2012).

With regards to post-stroke long-term management, the onus is mostly on the individual to self-manage well (Lennon, McKenna et al. 2013, McKenna, Jones et al. 2015). Self-management comprises a combination of attitudes, behaviours and skills that are focused on the ability of an individual to manage the symptoms; treatment; physical and psychosocial impact; and lifestyle modifications, which are an important part of living and coping with a chronic illness (McKenna, Jones et al. 2015). However, adjusting well after

stroke is integral to the success of post-stroke self-management and recovery. In order to illustrate why this might be the case, the next part of Chapter 1 will provide a detailed summary of the literature on adjustment as it applies to stroke survivors. Psychological adjustment after stroke will be considered first in the next section.

1.3 PSYCHOLOGICAL ADJUSTMENT AFTER STROKE

Post-stroke recovery is a journey of self-discovery, and can be an on-going process without a specific end-point (Intercollegiate Stroke Working Party 2012). Broadly speaking though, it has been widely acknowledged that the majority of improvement that stroke survivors are likely to achieve is within the first three to six-months after stroke (Kwakkel and Kollen 2013, Stinear, Ackerley et al. 2013). Post-stroke improvements may reach a plateau at six-months (Page, Gater et al. 2004).

The early period following stroke is when survivors undergo a phase of psychological adjustment. Post-stroke impairments can affect how people perceive themselves (identity), leading them to feel lost and no longer themselves (Ellis-Hill, Payne et al. 2000, Mukherjee, Levin et al. 2006). Psychological adjustment after stroke is often gradual and has been likened to the process of grieving, incorporating stages such as, shock, denial, anger and depression, until eventually reaching acceptance (Ch'Ng, French et al. 2008, Lincoln, Kneebone et al. 2012). Some survivors struggle at various points during this process of psychological adjustment (O'Brien, Xian et al. 2014), and this is often reflected in the onset of mood disorders (e.g., depression). Depression is

common after stroke, affecting around one-third of survivors, and presents a considerable burden to patients and their families, especially in the early days post-stroke (Hackett, Yapa et al. 2005, Willey, Disla et al. 2010, Kneebone and Lincoln 2012). Depression is also known to affect peoples' recovery and clinical outcomes after stroke (Gainotti, Antonucci et al. 2001). For example, Parikh, Robinson et al. (1990) found that survivors with depression were more impaired in various aspects of functioning, including physical and language, at two-years post-stroke than non-depressed patients. This was consistent with a further study involving 436 stroke survivors, where it was shown that depressive symptoms were significantly related to poorer functional outcomes, and greater disability at three-months and one-year after stroke (Herrmann, Black et al. 1998). More recent studies have demonstrated similar findings. For instance, Donnellan, Hickey et al. (2010) examined 107 stroke patients at one-month and one-year post-stroke, and found that symptoms of depression early after stroke were significantly associated with worse functional ability and health-related quality of life (HRQL) at one-year.

In order to better appreciate why depression occurs so frequently amongst stroke survivors, an understanding of the complexity of recovery from the perspective of patients is necessary. Qualitative literature has shed some light on this, and thus the process of psychological adjustment after stroke. For example, a study by Hartigan, O'Connell et al. (2011) involved hospital inpatients following a first-stroke. This research found that participants often described themselves as active and healthy prior to stroke, and contrastingly, considered the impact of stroke as being highly detrimental to their health. In

addition, the authors indicated that people generally appeared to be coping better after stroke than was actually the case, and when probed, survivors reported experiencing intense emotions following diagnosis (e.g., shock, fear, frustration, anxiety, and anger). These feelings appeared to be related to a loss of control amongst survivors, particularly in their ability to adapt to their post-stroke impairments, most specifically in the areas of physical and social functioning. These in-patient survivors also noted experiencing a great deal of uncertainty concerning their life after stroke. However, there was a desire amongst participants involved in this research to return quickly to their normal, pre-stroke activities, and regain autonomy, most importantly in their personal care, social functioning, and everyday responsibilities. In addition, this study highlighted the significance of post-stroke mental wellbeing from the perspective of survivors, who suggested that hope, self-belief and confidence were pivotal to the process of recovery at this stage.

A further qualitative study examined the perspectives of people with mild to severe strokes, who had been discharged into the community (Ahuja, Clark et al. 2013). This research comprised interviews, where several themes emerged. The themes encapsulated peoples' personal and on-going journey in finding a new 'self' after their stroke; the highs and lows of living with stroke, including frustration, and acceptance from within the community; attitude towards stroke and motivation to recover; and self-discovery, involving people continually learning how best to adapt and cope after stroke, and work towards accepting their new post-stroke life.

In summary, post-stroke recovery is highly individual and variable. This variability in recovery is influenced by numerous factors (Tilling, Sterne et al. 2001). Clinical variables including, the initial severity of impairment, may explain part of the variability in recovery amongst stroke survivors (Lazar and Antoniello 2008, Prabhakaran, Zarahn et al. 2008). However, some of the variability might also be ascribed to poor psychological adjustment in people following stroke, which can be expressed through emotional problems, such as depression. Depression is common after stroke, and can be detrimental to peoples' post-stroke recovery, leading to worse clinical outcomes (e.g., disability). Poor psychological adjustment importantly influences how well people self-manage following stroke. It is often the case that survivors who adjust well psychologically manage better with their post-stroke demands (i.e., secondary preventive treatment and rehabilitation) than those who struggle with poor psychological adjustment and feel low. Treatment adherence is integral to good self-management after stroke and positive clinical outcomes (e.g., less disability), and can also be regarded as an indicator of how well people are coping with their condition (disease adjustment). It is also affected by mood. The next part of Chapter 1 will further consider this issue of post-stroke treatment adherence. Importantly, adherence is part of a wider construct of engagement, and for stroke survivors, treatment adherence refers to peoples' adherence to their secondary preventive treatment, while engagement is more relevant to how well individuals engage with their rehabilitation. Therefore, the next section will closely consider the evidence related to both treatment adherence and engagement after stroke.

1.4 DISEASE ADJUSTMENT AFTER STROKE (COPING)

1.4.1 Definition and Importance of Adherence and Engagement after Stroke

Adherence is defined as the extent to which a patient's self-management behaviour (for example, tablet-taking and lifestyle modification) is concordant with the advice and recommendations of their medical practitioners (World Health Organization 2003). It can differ among different disease types, including acute or chronic conditions; across different types of behaviours; and deteriorate over time, particularly within the first six-months of therapy (DiMatteo 2004, Osterberg and Blaschke 2005). Furthermore, adherence to self-management becomes more complex when patients experience multiple co-morbidities that require several treatments (Hughes 2004).

The importance of adherence lies in the fact that it is considered to play a central role in treatment effectiveness (Dunbar-Jacob and Mortimer-Stephens 2001, Urquhart 2002). While there is limited evidence on stroke, this has been highlighted more generally across other conditions. For example, a meta-analysis has reported that patients who self-manage effectively are three-times more likely to experience good health outcomes, than those who are non-adherent with self-management (DiMatteo, Giordani et al. 2002). This has been emphasised by a further meta-analysis, which demonstrated that the risk of mortality is halved by good treatment adherence (Simpson, Eurich et al. 2006).

On the other hand, engagement has been defined as a purposeful commitment towards progressing in therapy that is demonstrated by an active involvement in, and maximal effort (or participation) with, rehabilitation and cooperation with therapists, which is often exhibited by patients with a keen interest in reaching therapeutic goals (Lequerica and Kortte 2010). It is generally considered that engagement can be conveyed in several ways, for example: through a patient's body language and other non-verbal communication (such as, facial expressions and gestures); attendance, participation and adherence with rehabilitation sessions; and an open and positive therapeutic relationship (Lequerica and Kortte 2010, Staudt, Lodato et al. 2012, MacDonald, Kayes et al. 2013). Engagement, and within this, adherence and participation, is a key determinant of the effectiveness of rehabilitative treatment, leading to more positive outcomes, including: improved functional recovery and lower levels of depression (Kendall, Catalano et al. 2007, Kortte, Falk et al. 2007, Battersby, Hoffmann et al. 2009, Jones, Mandy et al. 2009, Lequerica and Kortte 2010, Jones and Riazi 2011, MacDonald, Kayes et al. 2013, Bushnell, Arnan et al. 2014, McKenna, Jones et al. 2015).

In spite of the importance of good adherence to, and engagement with, post-stroke treatment and rehabilitation, many stroke survivors struggle to self-manage well after stroke (World Health Organization 2003, Lenze, Munin et al. 2004, Arif, Aijaz et al. 2007, Glader, Sjölander et al. 2010, Paolucci, Di Vita et al. 2012, Engberg and Kofoed 2013). There is an overall paucity of research to illustrate the problem of adherence and engagement after stroke, though the current literature is summarised below.

1.4.2 Problem of Adherence to Secondary Preventive Treatment after Stroke

Most of the research on adherence to post-stroke self-management has focused on adherence to secondary preventive medication, which is considered to be poor, and particularly inadequate compared to other conditions, such as myocardial infarction (Arif, Aijaz et al. 2007, Hedegaard, Kjeldsen et al. 2014). Studies have shown that adherence to medications for the management of various risk factors for stroke recurrence, including anti-hypertensives, statins and oral anticoagulants, is suboptimal, ranging from 20 to 70% (60% on average), with adherence often deteriorating long-term after stroke (Hillen, Dundas et al. 2000, Bushnell, Zimmer et al. 2010, Glader, Sjölander et al. 2010, O'Carroll, Whittaker et al. 2011, Engberg and Kofoed 2013, Xu, Ju et al. 2013). This can lead to worse clinical outcomes, including increased mortality in the first year following stroke and recurrence (Colivicchi, Bassi et al. 2007, Chen, Li et al. 2011). Non-adherence is reportedly especially poor in survivors with an early onset of stroke (<45 years of age) (Choi-Kwon, Kwon et al. 2006). While adherence to anti-coagulation therapy appears to be a greater challenge in older stroke survivors (≥65 years of age), and depends upon the dosage of medication (De Schryver, Van Gijn et al. 2005).

1.4.3 Problem of Engagement with Post-Stroke Rehabilitation

Research exploring engagement with rehabilitation in people with stroke is limited, and has predominantly focused on in-patient settings (for example, Lenze, Munin et al. (2004) and Paolucci, Di Vita et al. (2012)). This evidence has suggested that low participation in rehabilitation is generally

common, with patients frequently disengaging early from physiotherapy and occupational therapy (Lenze, Munin et al. 2004, Paolucci, Di Vita et al. 2012). This can be detrimental to peoples' post-stroke recovery, where it has been emphasised that those who engage well at the beginning of therapy show greater benefits in terms of activities of daily living (elaborated in section 4.3.2 of Chapter 4) and mobility, than those with poor early engagement, who in comparison, are twice as likely to have worse outcomes following rehabilitative treatment (Paolucci, Di Vita et al. 2012). What is less clear in the current literature is how peoples' engagement with rehabilitation changes when they are discharged from hospital and return home (or to a residential facility). There is some evidence that poor engagement with self-directed rehabilitation is common after hospital discharge (Harwood, Weatherall et al. 2012). However, whether this is also the case for home-based formal rehabilitation is presently unknown.

In summary, stroke survivors face a multitude of demands after stroke in relation to their highly complex long-term management, and are responsible for self-managing well. Despite the benefits of good treatment adherence and engagement with post-stroke rehabilitation, the reality is that many survivors commonly struggle to adhere and engage well. However, the precise reasons for this are unclear, though the current literature is briefly reviewed in the next section.

1.5 FACTORS AFFECTING ADHERENCE AND ENGAGEMENT AFTER STROKE

Few studies have examined predictors of adherence to self-management amongst stroke survivors (Sappok, Faulstich et al. 2001, Bushnell,

Olson et al. 2011, Levine, Morgenstern et al. 2013). For example, Sappok, Faulstich et al. (2001) conducted a large prospective study of 347 survivors admitted onto a stroke unit in Germany. This research examined self-reported medication adherence for the treatment of various risk factors for recurrent stroke. The findings indicated that stroke survivors with hypertension showed better adherence compared to those with hypercholesterolemia, where the most commonly reported reasons by patients for their discontinuation of treatment, included the perceived inefficacy of medication and side effects. When examining predictors of adherence, socio-demographic factors, specifically age and stroke severity, emerged to be significant (odds ratios ranging from 1.03 to 1.09). However, the effect sizes were weak, meaning that these factors explained only small amounts of the variance in adherence.

The limitations of this study were threefold. First, the sample may have been non-representative, mostly involving participants with less severe stroke and lower associated disability. Second, the authors did not consider psychological predictors of adherence. Third, where self-reported information on adherence was not collectable from patients via telephone interview, proxy data was gathered from relatives or carers, and as with patient self-report, this can lead to problems with over or under-estimation of adherence (elaborated later in section 5.2.3, Chapter 5).

These findings were broadly consistent with other papers; for example, a large prospective study of 2880 stroke survivors conducted by Bushnell, Olson et al. (2011). This study also collected adherence data for a

range of secondary preventive medications via patient or proxy self-report, though in this paper, the information was verified using hospital records. It emerged from this study that medication adherence for secondary preventive treatment at 12-months was significantly predicted by a range of factors: fewer prescribed medications at discharge; income; stroke severity; being married; discharged home; setting (for example, patient-physician contact); and receiving adequate instructions on the medication regimen and aids (such as, pillboxes). In contrast to Sappok, Faulstich et al. (2001), the effect sizes for these socio-demographic factors were slightly larger, though remained modest. However, this study was also limited by a lack of consideration of psychological factors in predicting adherence.

In summary, the current evidence on predictors of treatment adherence amongst stroke survivors have mostly focused on self-reported medication adherence. Importantly though, studies have often considered socio-demographic variables (e.g., age, income and stroke severity), and demonstrated that while these are independent predictors of adherence, they appear to only account for a small proportion of the variance. Therefore, there is a large amount of variability that is unexplained, and socio-demographic factors are non-modifiable (cannot be changed) (Gellad, Grenard et al. 2011).

In contrast, there is some evidence to date that has suggested that mood, particularly depression, and other modifiable psychological factors (e.g., peoples' beliefs) are predictive of adherence and engagement amongst stroke survivors. For example, O'Carroll, Whittaker et al. (2011) explored self-reported

medication adherence amongst 180 survivors one-year post-stroke, and found that cognitive functioning and medication beliefs significantly predicted adherence. More specifically, increased specific concerns about medications, low perceived benefit of medication, and reduced cognitive functioning predicted poor adherence, explaining around 30% of the variance, which increased following inclusion of emotional distress within the regression model. Similarly, Paolucci, Di Vita et al. (2012) demonstrated that low early participation with therapy amongst stroke survivors was significantly predicted by depression. In addition, the odds ratio to emerge for this factor (3.56) was considerably larger than those that had previously been shown for non-modifiable socio-demographic variables.

This means that psychological variables (e.g., peoples' beliefs and depression) should be measured after stroke in order to better understand how survivors are psychologically adjusting to their condition and thus, adhering to their treatment. This could help to determine who might be most in need of intervention, and these could be targeted towards modifying maladaptive psychological factors to improve post-stroke clinical outcomes.

It is important to note at this stage that the present PhD research is specifically focused on medication adherence, rather than engagement with rehabilitation, for reasons that will be elaborated in later parts of this thesis (Chapter 5). Chapter 1 will close by stating the specific objectives of this PhD thesis.

1.6 SPECIFIC OBJECTIVES OF THE PHD RESEARCH

The study specific objectives of the research were to:

1. Systematically review the relevant literature to:

a. Determine whether individual illness belief domains prospectively predicted adherence to a broad range of self-management behaviours in adults with physical illnesses;

b. Review the evidence on acute and chronic illnesses;

c. Explore whether the relationship between individual illness belief domains and adherence to self-management behaviours varies according to the type of self-management behaviour; or the duration of follow-up.

2. Develop a stroke-specific version of the Illness Perception Questionnaire-Revised (IPQ-R) (the Stroke IPQ-R) (Moss-Morris, Weinman et al. 2002) to measure illness beliefs in people during the acute phase of stroke (≤three-months post-stroke), using a variety of approaches, including expert consultation, and qualitative Think-Aloud interviews.

a. Examine the face and content validity of the Stroke IPQ-R to ensure suitability and acceptability amongst stroke survivors in this group.

3. Conduct a longitudinal observational study of survivors during the acute phase of stroke (≤three-months post-stroke) to examine:

a. Associations between illness belief domains and indices of recovery after stroke (including, HRQL, disability and mood), and whether those at baseline differ significantly from those at follow-up;
b. Whether baseline illness belief domains explain additional variance in three-month post-stroke markers of recovery (HRQL, disability, and mood), over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery);
c. If baseline mood and follow-up coping (three-month post-stroke medication adherence) mediate predictive associations between domains of illness beliefs, and markers of recovery after stroke (HRQL, disability and mood);
d. Whether baseline illness belief domains are related to baseline and follow-up illness belief domains;
e. If stroke survivors can be grouped according to illness belief schema, and whether baseline membership to a particular cluster is associated with follow-up markers of recovery three-months post-stroke (HRQL, disability and mood).

1.7 CHAPTER SUMMARY

Chapter 1 provided the clinical background on stroke, and highlighted the particularly disabling nature of the condition, and concerns about the high risk of recurrent stroke. Further, this chapter emphasised the complexities of long-term care after stroke, and the need for good adherence to post-stroke self-management, especially in the first six-months of the recovery

journey. This is the period in which survivors can expect to achieve the greatest of benefits. However, Chapter 1 indicated that some people struggle with acceptance of their stroke, and depression is particularly prevalent in the early days. Mood problems can adversely affect how well people cope (e.g., treatment adherence) and clinical outcomes (e.g., disability). The chapter subsequently detailed the pertinent literature suggesting that psychological factors are likely to be important contributors to the highly variable nature of post-stroke adjustment and thus recovery. Chapter 1 closed by stating the specific objectives of this PhD research. The next chapter (Chapter 2) will provide additional background into the theoretical framework on which this PhD research is based: the Common Sense Model (CSM).

CHAPTER 2. INTRODUCTION TO THE COMMON-SENSE MODEL

2.1 CHAPTER OVERVIEW

Chapter 2 will further consider the issue of adjustment following stroke. The focus of Chapter 2 is on providing background into the theoretical framework on which this thesis is based: the CSM. The CSM incorporates peoples' perceptions (or beliefs) about their illness (e.g., stroke) as a core component. Chapter 1 emphasised that adjustment (specifically, treatment adherence and mood) varies between patients, and is affected by sociodemographic and psychological (e.g., mood and beliefs about treatment) factors. The CSM has previously shown utility for understanding adjustment in the context of other conditions (e.g., chronic fatigue syndrome), and illness beliefs have been implicated by a wealth of studies in predicting a range of outcomes, including treatment adherence and mood. Based on this premise, the CSM may also be a useful framework to be applied to stroke survivors, in order to better appreciate how people adjust following stroke. However, this requires further examination, and was the purpose of the present PhD research.

2.2 THEORETICAL FOUNDATION OF THE COMMON SENSE MODEL

2.2.1 Origins of the Common Sense Model

The CSM was borne out of Leventhal's original work from the late 1960's and early 1970's (Leventhal, Singer et al. 1965, Leventhal and Watts

1966, Leventhal, Watts et al. 1967). Some of this research examined how threatening communication about a disease (for example, tetanus) provoked fear in people (fear arousal) leading them to adopt a more favourable response (e.g., a better attitude and/or performance of an action) to the prevention or elimination of the threat (such as, having a tetanus vaccination) (Leventhal, Singer et al. 1965, Leventhal, Benyamini et al. 1997). Through this work, Leventhal and colleagues found that different types of fear messages (for example, high or low in fear content) influenced peoples' attitudes towards preventative behaviours, where those receiving a high fear message believed that tetanus vaccinations were more important than did participants receiving a low-fear message (Leventhal, Singer et al. 1965). These findings were replicated in studies examining the impact of fear communications on smoking behaviour and lung cancer (Leventhal and Niles 1964, Leventhal and Watts 1966). However, the performance of preventative actions only seemed to happen when fear arousal (regardless of the content of fear messages, high or low) was combined with a specific action plan, which for the tetanus studies involved asking participants to find a time slot in their daily schedule that would bring them in proximity to the medical centre where tetanus vaccinations were being offered (Leventhal, Singer et al. 1965). Without an action plan, peoples' intentions to perform an action did not translate into the performance of any preventive behaviours (Leventhal and Trembly 1968, Leventhal, Benyamini et al. 1997). Additional research by Leventhal on smoking behaviour showed that by providing participants with specific instructions on how to make changes to risky behaviours (such as, smoking), people were more likely to decrease their actual smoking level (Leventhal, Watts et al. 1967, Leventhal, Brissette et al. 2003).

These behavioural changes were also sustained following exposure, which for this smoking study was one to three-months post-communication (Leventhal and Niles 1965, Leventhal, Watts et al. 1967).

Furthermore, there were certain conditions where Leventhal and colleagues found that people showed resistance to the threatening communications (Leventhal 1970). Studies demonstrated that individuals who were highly vulnerable to a health threat (e.g., those not inoculated for tetanus) were generally more fearful than those with low vulnerability, regardless of whether they had received a high or low fear message, and were least likely to see the value of preventive action (i.e., have a tetanus vaccination) (Leventhal 1970). It also emerged that compliance with recommendations for tetanus vaccinations appeared to be affected by aspects of an individual's personality (e.g., self-esteem to cope), whereby those with low self-esteem agreed to inoculations regardless of a low or high fear message, whereas those with high self-esteem only complied when presented with a high fear message (Dabbs and Leventhal 1966).

2.2.2 The 'Parallel Process Model'

These early findings by Leventhal and colleagues led to the design of the parallel process model (Leventhal 1970). The parallel process model posits that internal (e.g., chest pain) and external (e.g., a loved one who died of a heart attack) stimuli that people gain through exposure or prior experience inform two simultaneous (parallel) and independent problem solving processes, known as fear control and danger control (Leventhal 1970, Leventhal, Brissette

et al. 2003). Fear control refers to the emotional representation of a health threat, where emotional states of fear and distress are generated, with a corresponding need to carry out activities (action plans) to manage these negative emotions (Leventhal 1970, Leventhal, Brissette et al. 2003). Whereas danger control refers to the cognitive representation of the health threat, which is formed in parallel to the emotional processes, whereby people have a corresponding need to activate coping procedures for managing the danger (Leventhal 1970, Leventhal, Brissette et al. 2003). Once the actions of fear control and danger control are undertaken, they are evaluated (or appraised) by the individual for their effectiveness in alleviating the negative emotions evoked by the health threat and reducing the threat itself (Leventhal, Benyamini et al. 1997, Leventhal, Brissette et al. 2003). What people learn from this process of appraisal further feeds into their emotional experience of the health threat and representation of the danger, leading to updated emotional and cognitive representations, and the selection of new coping procedures for management of the fear or danger (Leventhal, Benyamini et al. 1997).

2.2.3 The 'Common Sense Model'

What also emerged through Leventhal's early experiments was that while the processes of fear control and danger control were first considered to be independent (e.g., the parallel process model), further studies demonstrated that these processes can interact with one another (Leventhal, Meyer et al. 1980). For example, Johnson and Leventhal (1974) presented two types of messages to patients receiving an endoscopic examination: one to reduce emotional responses to the procedure (fear control pathway), and the other to encourage

the performance of coping behaviours for danger control. For the former message, a description of the relevant sensory information for the endoscopy was provided, including what would be done to the patient during the examination and the corresponding sensations that they would be likely to experience (e.g., intravenous administration of medicine, so the individual will feel a needle stick and drowsiness). The authors avoided providing patients with information in the sensory descriptions about any of the sensations from the examination that were likely to cause distress or upset. For the behavioural message, specific instructions were given for the appropriate way to breathe during the examination (e.g., rapid mouth breathing to reduce gagging), and also for how the patient should respond during the process of tube insertion (e.g., swallowing motions). Individuals were encouraged to practise these behaviours before the procedure. Each message was presented to participants either singly or in combination. The findings from this study emphasised the interdependence between the fear and danger control processes, whereby the behavioural instruction combined with the sensory description reduced indicators of emotional reaction (e.g., gagging) from the endoscopic examination by evoking less fear and allowing a previously threatening procedure to become non-threatening. In addition, people who received the combined message (sensory and behavioural) were significantly more able to tolerate the endoscopic tube being passed into the stomach. This was shown in this study through the group receiving the combined message allowing a greater mean amount of time for the procedure to be completed (43 seconds), compared to those who received the behavioural instruction and sensory descriptions alone (29.6 and 26.5 seconds, respectively).

These findings led to the extension of the parallel process model, which is now commonly regarded as the CSM, and has several core features that are described in the next section.

2.3 CORE FEATURES OF THE COMMON SENSE MODEL

The CSM suggests that when confronted with a threat to their health people construct mental representations (or illness beliefs) about their illness and treatment, in order to help them to make sense of and manage their condition (Leventhal, Meyer et al. 1980). The formation of illness beliefs is guided by information from peoples' social environment, including doctors or family; cultural knowledge of the disease; and their current perceptions (such as, of symptomatic information) and previous experiences of the illness (Leventhal, Meyer et al. 1980, Leventhal, Nerenz et al. 1984). The CSM is shown in Figure 2-1, and subsequently, the core features of the model are presented.

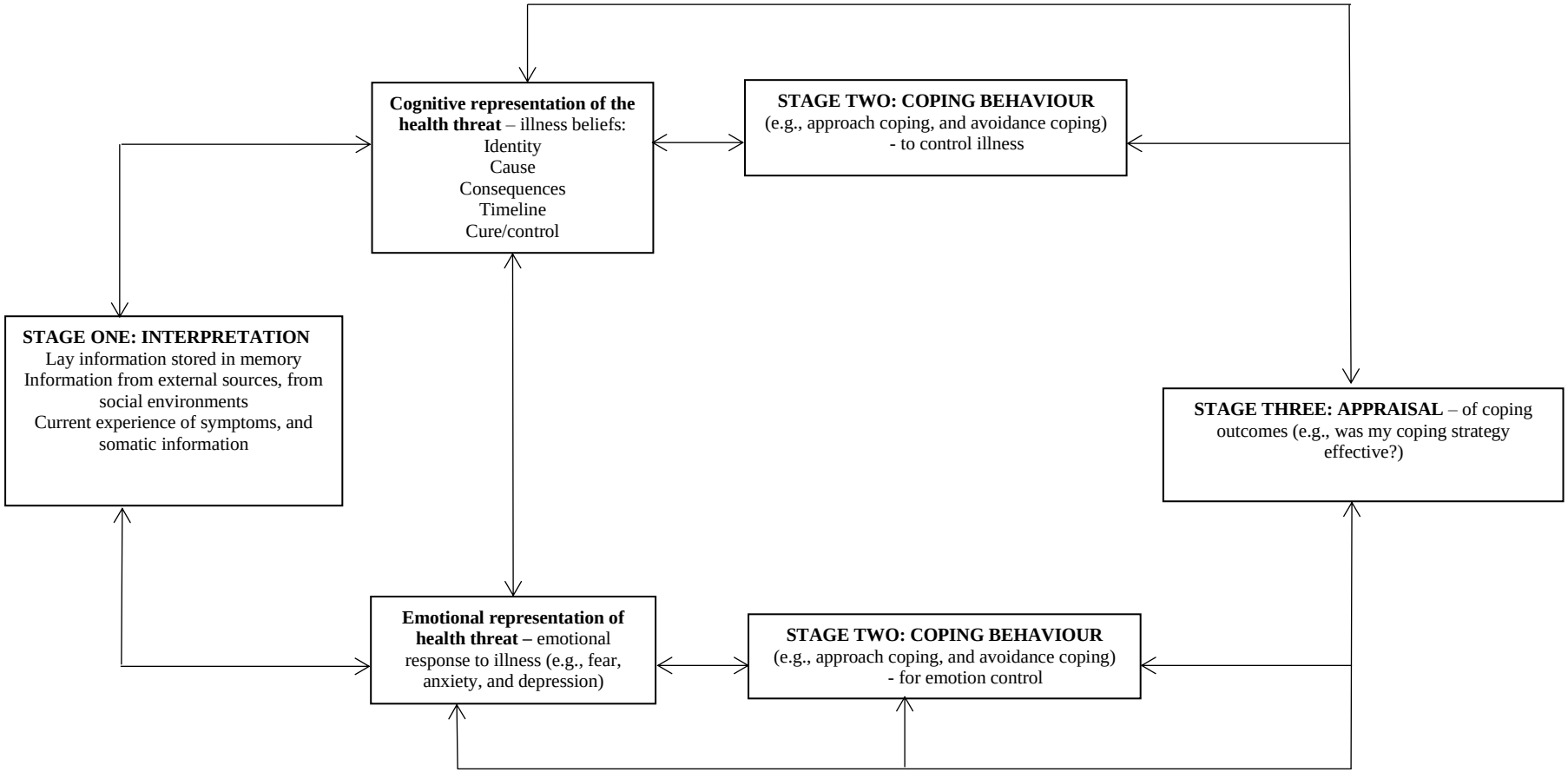


Figure 2-1. The CSM, adapted from Leventhal, Nerenz et al. (1984)

2.3.1 Self-Regulation and Problem Solving

Self-regulation and problem solving are at the heart of the CSM. The theory of self-regulation suggests that given a problem or 'health threat', individuals are motivated to solve their problem or adapt to dangers (for example, through coping procedures), in order to regain a state of equilibrium (Leventhal, Leventhal et al. 1998, Ogden 2007).

2.3.2 Illness Beliefs

Illness beliefs are an integral part of the CSM. Illness beliefs (also commonly referred to as illness representations, illness perceptions or illness cognitions) are the personal, common sense beliefs that patients may have about their illness (Leventhal, Meyer et al. 1980, Leventhal, Nerenz et al. 1984). As illness beliefs are influenced by personality, people hold unique models of their illness that are likely to differ from others (Contrada and Coups 2003, Cameron and Moss-Morris 2004). Whereas some patients may have a full and coherent understanding of their condition, others may hold a more fractured and inconsistent model (Leventhal, Nerenz et al. 1984).

Therefore, illness beliefs provide individuals with a framework for understanding and coping with their illness (Ogden 2007). To emphasise earlier parts of this chapter, the CSM posits that people's beliefs about their illness are cognitive and emotional, formed simultaneously, through a parallel process (Leventhal et al., 1980). Cognitive representations have five core domains (Leventhal, Meyer et al. 1980, Leventhal, Benyamini et al. 1997, Leventhal, Brissette et al. 2003), which have been supported by a wealth of evidence (for

example, Lau and Hartman (1983); Lau, Bernard et al. (1989); Meyer, Leventhal et al. (1985); and Diefenbach and Leventhal (1996)):

'Identity' – describes peoples' beliefs about the label of the illness (e.g., 'I have had a stroke') and associated symptoms (e.g., weakness or paralysis, speech slurring), and sets out the targets for change (such as, to eliminate symptoms);

'Causes' – refers to peoples' own perceptions of possible causes of their condition; these may be internal (e.g., genes) or external (e.g., a germ or virus; stress or overwork; or pollution);

'Consequences' – refers to peoples' beliefs about the seriousness of the disease and impact upon one's daily life, including a short- or long-term impact, and physical (e.g., pain, immobility) and emotional consequences (e.g., isolation, fear);

'Timeline' – refers to people's perceptions of the duration of their illness, including, symptoms and recovery; 'timeline' beliefs may be acute (short-term) or chronic (long-term);

'Cure/control' – refers to peoples' perceptions about the amenability of their illness to being cured, prevented or treated by themselves or powerful others (e.g., healthcare professionals), and also what they can do to recover from the illness (e.g., 'Medicine from my doctor will help me to recover from my stroke').

These five core domains have since been extended (Moss-Morris, Weinman et al. 2002) to incorporate:

'Timeline-cyclical' – referring to beliefs about an episodic nature of the illness;

'Personal control' and 'treatment control' – referring to peoples' perceptions of their own ability, and also that of their treatment, to manage their illness;

'Illness coherence' – referring to peoples' understanding of their illness;

'Emotional representations' – referring to peoples' emotional response to the illness.

Having discussed the theoretical background of the CSM and core features of the model, including domains of illness beliefs, the remainder of this chapter is focused on describing the important stages of the CSM.

2.4 STAGES OF THE CSM

The CSM is comprised of three stages of problem solving (illustrated in Figure 2-1):

2.4.1 Stage One: Interpretation

Peoples' first step towards making sense of their illness and seeking help is by interpreting concrete and abstract sources of information (Leventhal, Meyer et al. 1980, Leventhal, Benyamini et al. 1997, Leventhal, Leventhal et al. 1998, Leventhal, Brissette et al. 2003). There are three sources from which an individual may receive information about a potential health threat, and these will

guide the formation of their illness beliefs (Leventhal, Meyer et al. 1980, Hagger and Orbell 2003, Ogden 2007):

A general 'lay' pool of information that individuals have developed from previous social communication and cultural knowledge of the illness;

Messages from peoples' external social environment (such as, significant others or authoritative sources e.g., 'The doctor has diagnosed my weakness as a stroke');

'Current experience' of the illness (e.g., symptoms), based on peoples' current perceptions and previous experiences of the illness, including successful prior attempts to manage the condition, which will inform their coping strategies.

2.4.2 Stage Two: Coping

In this stage of the CSM, individuals identify and develop strategies for coping with their illness (Ogden 2007). Leventhal (1990) argued that coping procedures can be separated into stages, where an individual first plans and makes decisions about coping, and second, performs particular coping responses or behaviours. Peoples' coping response depends upon their illness beliefs (Hagger and Orbell 2003). For example, Moss-Morris, Petrie et al. (1996) examined relationships between illness beliefs, adjustment and disease outcomes in 223 people with chronic fatigue syndrome. The authors found that patients who perceived a lot of symptoms of their condition, attributed it to stress, and believed it to be uncontrollable with serious consequences had the poorest adjustment, experiencing considerable disability and low psychological

well-being. More specifically, it emerged that the identity and serious consequences illness belief domains were significantly and positively related to coping strategies of planning, venting emotions, and disengagement (behavioural and/or mental). In addition, the cure/control domain was significantly associated with active coping, planning, positive reinterpretation and growth, and behavioural disengagement, whereas seeking emotional support was only characteristic of the consequences domain. Similar findings also emerged in a study by Kemp, Morley et al. (1999) for people with neuroepilepsy, whereby beliefs about controllability were significantly associated with problem-focused coping behaviours, while perceptions of serious consequences and a lot of symptoms were related to avoidance and wishful thinking.

It has been widely acknowledged that a coping response broadly adopts the following forms, comprising particular coping behaviours (Roth and Cohen 1986):

Approach coping is an active coping mechanism, where people attempt to deal with a stressor or health threat by managing the problem directly, often incorporating behaviours, such as: rest, seeing the doctor, and talking to family or friends for social support;

Avoidance coping is a maladaptive coping mechanism, which involves people distancing themselves from the problem, in order to alleviate anxiety, and involves behaviours such as, denial, distraction, and wishful thinking.

It has also been argued that a major component of the CSM is that the relationship between illness belief domains and coping behaviour is causal, whereby illness beliefs will impact upon coping behaviours proportionately to the perceived severity of the illness, and that the relationship with outcomes may be mediated by coping (Hagger and Orbell 2003). This means that coping is likely to be related to both illness belief domains and outcomes, such as psychological wellbeing, forming a link between these CSM dimensions, indicating that the causal relationship described above may happen via coping (Folkman and Lazarus 1988, Hagger and Orbell 2003).

A comprehensive review and meta-analysis added further strength to the abovementioned findings regarding the relationship between illness beliefs with coping strategies and illness outcomes (Hagger and Orbell 2003). The review involved 45 papers, across a range of acute and chronic conditions, where the authors considered adherence to self-management behaviours as a problem-focused coping-specific strategy that included: doctor visits, and medication and dietary adherence. Consistently, medication adherence is operationalised in terms of coping in the present thesis. The review had several important findings.

First, Hagger and Orbell (2003) showed that illness beliefs predicted coping strategies (as predicted by the CSM), and in particular, highlighted the role of several specific illness belief domains. These were: perceptions of a highly symptomatic condition, which were significantly and positively related to avoidance coping and emotional expression; and perceived controllability of

the illness, which was positively associated with problem-focused coping, and other outcomes, including, psychological well-being, social functioning and vitality and negatively related to psychological distress and disease state. Second, the authors demonstrated that illness beliefs are inter-related, and these also showed correlations with coping strategies and illness outcomes. For example, perceptions of the illness as highly symptomatic and chronic with serious consequences were significantly associated with avoidance and emotional expression, and poor psychological well-being, role and social functioning, and vitality. These inter-relationships are consistent with Leventhal's premise for the CSM around the schematic nature of illness beliefs, whereby individual illness belief domains are organised collectively as part of a schema (linked mental representations) rather than in isolation, and stored in peoples' memory, helping them to understand and respond to situations (Leventhal, Meyer et al. 1980, Henderson, Orbell et al. 2009). The literature on illness belief schemas is examined more closely in Chapter 3 (section 3.6.4.2).

An important limitation of the research that was cited by Hagger and Orbell (2003) was the focus on cross-sectional relationships, which unlike examining prospective relationships, cannot provide information on causality. Therefore, when the authors conducted this review, which was indeed over a decade ago, they emphasised the importance of testing causality between illness beliefs, coping and outcomes, and particularly, establishing the direction of causality. In addition, the authors highlighted the need to adequately evaluate the potential role of coping as a mediator in the relationship between illness beliefs and outcomes. This has not yet been evaluated in the literature.

2.4.3 Stage Three: Appraisal

Appraisal is the third stage of the model, and involves evaluation of the effectiveness of peoples' chosen coping strategies (Leventhal, Meyer et al. 1980, Leventhal, Diefenbach et al. 1992, Leventhal, Leventhal et al. 1998). As part of this process, individuals decide whether to continue with their coping approach, or adopt an alternative one that they may deem to be more effective or suitable (Ogden 2007). The CSM incorporates feedback loops, as depicted by the arrows in Figure 2-1, thus emphasising the inter-relationships between different stages of the model, which happen in a dynamic fashion (Ogden 2007). This means that peoples' appraisal may result in changes to their coping strategies, as well as their illness beliefs, and subsequent adaptive behaviours; a process which continues iteratively (Leventhal 1990, Ogden 2007).

2.5 PATHWAY FOR THE EMOTIONAL REGULATION OF ILLNESS

Much of Leventhal's early work on fear and danger control, which was described in prior sections of this chapter (section 2.2), emphasised the importance of an emotional pathway in the CSM (illustrated in Figure 2-1). To reiterate, this pathway recognises that people not only experience an emotional response to their illness, but they also self-regulate to manage the emotions that arise in the face of a health threat, such as fear and anxiety (Leventhal 1990). Further, peoples' emotional reactions are shaped by their cognitive representations, whereby peoples' thoughts about their illness affect how they feel about it, and vice-versa (Leventhal 1990, Cameron 2003). This emphasises earlier discussions regarding the interdependence between the parallel processes of the CSM (section 2.2.2).

In addition to shaping the construction of an individual's illness beliefs, peoples' selection and appraisal of coping strategies is also affected by their emotional reaction to a health threat (Cameron 2003). This premise of the CSM has been supported by previous research; for instance, Jones, Butler et al. (2006). This study showed that medication non-adherence in people with epilepsy was associated with the frequency of seizures, and this was an indicator of the extent to which an individual's condition was well-controlled. The authors demonstrated that poorly controlled patients were generally more anxious, and had stronger beliefs about the chronicity of their condition compared to those who were well-controlled.

2.6 CHAPTER SUMMARY

The present chapter (Chapter 2) introduced the theoretical framework that is central to this PhD research (the CSM), and in particular, highlighted a core component of the model, illness beliefs, which form the basis of this thesis. It was briefly highlighted early in Chapter 2 that the CSM has previously shown utility in understanding adjustment in various conditions. More specifically, there is evidence to suggest that illness beliefs significantly predict treatment adherence, and other outcomes that have relevance to stroke survivors' recovery (e.g., HRQL, disability, and mood). This has been shown for a range of acute and chronic physical health conditions, including stroke, and predominantly informed the decision to adopt the CSM in the present PhD research. While the evidence for the relationship of illness beliefs with these wider markers of post-stroke recovery will be considered in Chapter 4, the next chapter (Chapter 3), which is closely related to Chapter 2, will provide a detailed

examination of the current evidence on the role of illness beliefs in predicting treatment adherence.

CHAPTER 3. PROSPECTIVELY PREDICTING ADHERENCE TO SELF-MANAGEMENT BEHAVIOURS USING ILLNESS BELIEFS FROM THE COMMON-SENSE MODEL: RESULTS FROM A SYSTEMATIC REVIEW AND META-ANALYSIS

3.1 CHAPTER OVERVIEW

Chapter 3 reports on a systematic review and meta-analysis undertaken to synthesise the current evidence on the CSM and adherence to self-management. This work was carried out to begin to examine the utility of the model in the context of stroke. More specifically, whether illness beliefs could enhance the understanding of post-stroke adjustment, including engagement with, and adherence to, self-management following stroke. Therefore, the research presented in this chapter examined whether individual domains of illness beliefs predict the range of self-management behaviours that are pertinent to post-stroke recovery, with a view to explaining some of the variability in recovery that is evident amongst survivors recovering from stroke (as highlighted in Chapter 1). A version of this chapter has been published (see Aujla, Walker et al. (2016)).

3.2 BACKGROUND AND RATIONALE

To date, there have been a number of attempts to synthesise the growing literature using the CSM. As mentioned in Chapter 2 (section 2.4.2), Hagger and Orbell (2003) conducted a comprehensive review and meta-analysis

to examine the inter-correlations between the different dimensions of illness beliefs with coping strategies and illness outcomes. This review found a significant relationship between cure-control beliefs and problem-focused coping-specific behaviours, which incorporated adherence to self-management behaviours (such as, doctor visits, and medication and dietary adherence) (Hagger & Orbell, 2003). However, this review was undertaken over a decade ago; therefore, an update was warranted.

Moreover, Brandes and Mullan (2014) recently conducted a systematic review and meta-analysis that specifically examined the role of illness beliefs in predicting adherence in patients with chronic disease. This systematic review comprised 23 cross-sectional and prospective studies across a diverse range of chronic illnesses, and examined adherence behaviours, including: medication adherence; exercise; diet; and disease-specific behaviours, such as glucose-testing (Brandes and Mullan 2014). Unlike the earlier review, this paper found very weak predictive relationships between individual dimensions of illness beliefs and adherence behaviours, which did not vary according to the type of adherence behaviour (Brandes & Mullan, 2014). Despite the authors reporting a comprehensive review, there were several considerations suggesting that a further review may be necessary.

First, their paper focused on existing chronic diseases, excluding conditions that may have had an acute presentation (such as, stroke) where good adherence to self-management behaviour is necessary for secondary prevention, as well as for supporting post-event rehabilitation and recovery (as highlighted

in Chapter 1 for stroke survivors). Second, the authors excluded attendance behaviours, which are an important component of self-management; as recognised in the meta-analysis conducted by Hagger and Orbell (2003). Last, the authors only examined cross-sectional relationships between dimensions of illness beliefs and adherence behaviours. These did not account for the influence of baseline (time 1) adherence behaviours in the prediction of adherence behaviours at time 2 (follow-up). It has been argued that by measuring behaviour cross-sectionally, studies may be providing information on past or current behaviours rather than the prediction of future behaviours, which is unlikely to be the most appropriate way of examining the utility of a model for predicting behaviour (Weinstein 2007). This was also a limitation of the Hagger and Orbell (2003) paper, and of a further systematic review that has been published which examined illness beliefs and self-management in children and young people (Law, Tolgyesi et al. 2014). Therefore, given that the CSM implies that the relationships between illness beliefs and behaviours may be causal (Leventhal, Meyer et al. 1980), it would be important to consider this formally by focusing only on studies measuring behaviours prospectively.

3.3 AIMS

The aim of the present systematic review and meta-analysis was to determine whether individual illness belief domains prospectively predicted adherence to a broad range of self-management behaviours in adults with physical illnesses. Further aims were to:

- Review the evidence on both acute and chronic illnesses;

- Explore whether the relationship between individual illness belief domains and adherence to self-management behaviours varies according to the type of self-management behaviour; or the duration of follow-up.

3.4 METHODS

To synthesise the literature, a systematic review was undertaken. The systematic review, including: development of the search strategy; literature searching and review; data extraction and collation; and quality assessment, were conducted by the author of this PhD thesis (NA). NA also undertook the meta-analysis and narrative review. However, best practice guidelines from the Cochrane Collaboration were employed for the conduct of the systematic review (Higgins and Green 2011). This included the involvement of additional reviewers at various stages of the review process.

Relevant frameworks have been used for the reporting of this research, including the: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati et al. 2009); and American Psychological Association Meta-Analysis Reporting Standards (Cooper 2010).

3.4.1 Study Selection and Inclusion

3.4.1.1 Search Strategy

Searches were originally undertaken in February 2013, and updated in September 2014. A number of electronic bibliographic databases were searched systematically for relevant literature: MEDLINE (1946 to September 2014, In-Process and Other Non-Indexed Citations); PSYCINFO (1806 to September 2014); EMBASE (1980 to September 2014); CINAHL (1982 to September 2014, Plus with Full-Text), the Cochrane Library (1999 to September 2014), and databases of the CRD York (DARE: 1994 to September 2014; NHS EED: 1994 to September 2014; HTA: 1989 to September 2014). Electronic databases were also searched for the grey literature, including unpublished research, dissertations, and conference abstracts: Open Thesis (1980 to September 2014), ProQuest Dissertations and Theses (1861 to September 2014), Open Grey (1997 to September 2014), and PAIS International (1977 to September 2014).

Important aspects of the review were identified and categorised according to the PICOS approach to ensure that an appropriate and effective search strategy was developed, consistent with best practice guidelines for systematic reviews (Higgins and Green 2011). PICOS refers to Population, Intervention, Comparators, Outcomes and Study design. The PICOS categorisation for the present review is shown in Table 3-1.

Table 3-1. Eligibility criteria for the review

PICOS	Inclusion criteria	Exclusion criteria
P – Population	• Adults ≥18 years old • Acute or chronic physical illness	• Studies involving children • Mental health disorders • General population • People 'at-risk' of illness
I– Intervention*	Illness beliefs, as outlined by the common sense model	Illness beliefs described using other models or where the theoretical framework is unclear, even after detailed review
C – Comparator		
O – Outcomes	• Adherence to self-management behaviours (for example: treatment adherence, help-seeking, healthcare utilisation, and appointment attendance) • Longitudinal, predictive relationships between illness beliefs and adherence to self-management behaviours examined	• Behaviours other than self-management (for example: clinical, psychological or functional outcomes; coping - such as, denial or avoidance; illness behaviour; and return to work). • Descriptive studies where illness beliefs were reported, but no information about predictive relationships with adherence to self-management behaviours
S – Study design	• Observational studies (including: cohort, and case-control designs) • Prospective or longitudinal studies (with a period of follow-up) • Randomised controlled trials (with a period of follow-up)	• Cross-sectional studies • Qualitative studies • Study protocols

* For the purpose of the present review, the 'intervention' refers to the assessment method of illness beliefs

The search strategy used Medical Subject Headings and keywords, which were tailored to individual bibliographic databases. A scoping search of the literature was initially carried out to refine the search strategy. The scoping exercise resulted in the identification of additional search terms relating to self-management behaviours (e.g., help-seeking and care-seeking), which were incorporated into the final search strategy for the main review. Keywords for adherence to self-management behaviours were: recovery OR rehabilitation OR

self-management OR self-care OR medication adherence OR help-seeking OR care-seeking OR treatment OR adherence OR compliance OR health behaviour OR behaviour change OR behaviour modification. The following terms were used for physical illness: disease OR acute disease OR chronic disease OR medical condition OR physical illness. Keywords used for the CSM were: common sense model OR self-regulation OR self-regulation model. Additional keywords for the CSM were also used, consistent with the search strategies employed by key papers (Hagger and Orbell 2003, Brandes and Mullan 2014): illness belief OR illness perception OR illness cognition OR illness representation.

An example search from the MEDLINE electronic database is shown in Box A1-1 (Appendix 1). Searches were combined, and limited to English language papers only, for practical reasons. Searches comprised literature from 1980, when Leventhal's original manuscript on the CSM was published.

All potentially relevant articles, including citations with insufficient detail on which to base a decision, were retrieved. Where studies appeared to meet the inclusion criteria but data were incomplete, authors were contacted for clarification. Papers, such as other published reviews and reference lists of included papers, were hand-searched to identify additional references that may not have emerged from electronic searches. Duplicate references were removed.

3.4.1.2 Eligibility Criteria

The criteria for inclusion and exclusion of studies are summarised in Table 3-1. Titles and abstracts were initially screened by the author to identify studies that met the inclusion criteria. Participants were adults (aged 18 years or over) with any acute or chronic physical illness. Acute was defined in accordance with the King's Fund, which includes rapid onset conditions that are self-limiting (such as, common cold), and acute presentations of existing major illnesses or new chronic diseases (for example, myocardial infarction or stroke) (Jones, White et al. 2010). The latter are conditions often followed by a long period of recovery, involving complex, multi-faceted treatments (such as, secondary preventive therapy and rehabilitation), where self-management is central to the prevention of further events, complications, or death (Bushnell, Arnan et al. 2014, Choudhry, Glynn et al. 2014) (Chapter 1).

Papers were considered only if they used the CSM theoretical framework. This was verified by examining reference lists for citations of CSM research by Leventhal and colleagues. Papers investigating behaviours other than self-management (for example: clinical, psychological or functional outcomes; aspects of coping e.g., denial or avoidance; and return to work) were excluded. Longitudinal studies with any length of follow-up were included to examine prospective relationships between illness beliefs and adherence to self-management behaviours. These included randomised controlled trials (RCTs) with a period of follow-up.

Twenty-percent of the titles and abstracts were randomly selected and assessed for eligibility by a second reviewer. There was a high level of agreement between both reviewers for the initial screening (Cohen's Kappa=0.86). Any instances of disagreement were resolved by discussion between the reviewers, with a third reviewer available where necessary.

3.4.1.3 Data Extraction

Data were extracted from all included articles using a structured evaluation form, based on the eligibility criteria. The form was designed specifically for the present review, and is shown in Appendix 1. The following information was recorded: characteristics of the study population; geographical location; sample size; study design; statistical analysis; method of assessment for illness belief domains; self-management behaviour(s) and method of measurement; and key findings, including effect sizes, where available. The accuracy of extracted data was subsequently checked by a second reviewer.

3.4.2 Analytic Procedure

A meta-analysis was conducted to statistically combine the data. Correlations were the most frequently reported measurement of effect size by included papers for the relationship between individual illness belief domains and adherence to self-management behaviours. Therefore, Pearson's product-moment correlation coefficient (r) was used for the estimate of effect size in the present analysis. Follow-up correlations were extracted from the papers. These referred to baseline (time 1) measurements of illness belief domains correlated with adherence to self-management behaviours at subsequent time points (e.g.,

time 2). Partial correlations, controlling for baseline adherence to self-management behaviours, were also extracted where possible. Further, many of the articles provided multiple datasets; for example, reporting of effect sizes for several illness belief domains across many self-management behaviours. These were included in the meta-analysis as unique datasets (denoted by k). Negative correlations were reversed, where appropriate.

Authors of thirty-five papers that had missing information, such as for correlation coefficients, or where it was unclear from the information provided in the paper whether correlations referred to baseline or follow-up time-points, were contacted via e-mail. This allowed authors the opportunity to contribute relevant data for the meta-analysis, as well as to verify all possible data to be used in the present analysis. Reminders were sent to non-responders two-weeks after the initial mailshot. Twenty-six authors responded with the requested information. A further eligible paper was identified through this correspondence with the authors, and was subsequently included in the review. The remainder of papers where authors did not respond were included in the review but excluded from the meta-analysis. Data from unpublished correlational analyses were provided by authors of eight included papers.

All of the illness belief domains listed in Chapter 2 (section 2.3.2) were examined in this review. The cure-control belief domain from the Illness Perception Questionnaire (IPQ) was analysed separately to personal and treatment control beliefs, to be consistent with the operationalisation in the Illness Perception Questionnaire-Revised (IPQ-R) (Weinman, Petrie et al. 1996,

Moss-Morris, Weinman et al. 2002). The IPQ and IPQ-R are both common methods for assessing illness beliefs outlined by the CSM, which will be covered in Chapter 6 (Weinman, Petrie et al. 1996, Moss-Morris, Weinman et al. 2002). Illness concern was also examined, as per the inclusion of this domain in the Brief Illness Perception Questionnaire (Brief IPQ), which is a further, more recent method for operationalising illness beliefs, and will also be considered in Chapter 6 (Broadbent, Petrie et al. 2006). However, this domain was excluded from the meta-analysis, because of insufficient data for calculation of a valid composite correlation; illness concern was examined by three papers, providing only four unique datasets.

Self-management behaviours were categorised into the following groups: attendance behaviours (including, doctor or therapist visits and other healthcare utilisation); medication adherence; dietary behaviours; physical activity; and other disease-specific behaviours, for example: self-monitoring of blood glucose and foot care.

Twenty different physical illnesses were included across 52 papers. Therefore, it was not possible to group articles in the meta-analysis by specific health conditions; however, papers were categorised according to acute or chronic diseases. The duration of follow-up varied widely across included studies. Thus, for the purpose of the meta-analysis, the median duration of follow-up was calculated, allowing for papers to be grouped according to follow-up of six-months or longer. Further analyses, which are described below (section 3.4.2.1.1), were conducted according to these groupings.

3.4.2.1 Meta-Analysis

The meta-analysis was conducted in STATA 13 (StataCorp LP, College Station, TX, USA). Random effects models were chosen, to allow for the heterogeneity (variability) that was evident across included papers. The alternative would have been to use fixed-effects models. A fixed-effects model assumes that the true effect is the same across all included studies, and the effect size only varies between studies because of random error (Borenstein, Hedges et al. 2010). In contrast, a random effects model assumes that there are other factors, such as the age of participants, which may differ between the studies, and influence the combined effect size (Hedges and Vevea 1998, Borenstein, Hedges et al. 2010).

The pooled effect size reported in the meta-analysis was the average r, computed using the method described by Hedges and Vevea (1998). Each Pearson's correlation coefficient was standardised, using Fisher's Z transformation. The effect sizes were weighted (r+) using the inverse variance, which incorporates a variance component, including the within-study variance and the between-study variance (Tau^2), and depends upon the sample size of each study. A 95% confidence interval (CI) was calculated for each effect size, and an associated p-value was reported. The heterogeneity between studies was also examined. Cochran's Q statistic, which is the classical method for assessing heterogeneity, was used. Cochran's Q uses a Chi-squared distribution with degrees of freedom, allowing for calculation of a p-value. Heterogeneity was also examined using the I^2 statistic, which presents the variability as a percentage. Figures of 75% or greater indicate a considerable problem with

heterogeneity (Higgins, Thompson et al. 2003). In addition, the meta-analysis reported an estimate of the between-study heterogeneity using the Tau^2 statistic, where a low value (<1) indicated little variance between the studies.

3.4.2.1.1 Further Analyses

Sub-group analyses were conducted to further examine the heterogeneity between studies. These were performed according to the: type of self-management behaviour; acute or chronic disease; and duration of follow-up. Sub-group analyses allowed for the investigation of whether any of the predictive relationships were influenced (moderated) by these factors. It is important to note that for a few of the illness belief domains, the sub-groups contained fewer than three studies, which made it impossible to compute the relevant meta-analysis statistics. This did not affect all domains; therefore, meta-analysis was computable for many of the illness beliefs, but fixed effects models were used, provided that more than one of the sub-groups contained three or more studies.

Meta-regression analyses were also conducted to examine whether the abovementioned grouping variables confounded any of the predictive relationships.

3.4.2.1.2 Publication Bias

The risk of publication bias was examined using funnel plots, where asymmetry indicated bias; and Egger's test, which provided a significance test for the asymmetry. The meta-analysis was re-estimated for individual illness

belief domains with asymmetric funnel plots, using the trim-and-fill method (Duval and Tweedie 2000). This is an iterative, non-parametric approach that identifies and corrects asymmetry in funnel plots by removing the studies causing the asymmetry and replacing them with their 'missing' counterpart (Peters, Sutton et al. 2007).

3.4.2.1.3 Sensitivity Analyses

Two sensitivity analyses were conducted. First, one paper involved a disproportionately larger sample size than the other included articles. Therefore, effect sizes for the individual illness belief domains assessed in this paper were re-calculated excluding this article, to determine the extent to which the meta-analysis results were affected by this study. Sub-group analyses were also repeated without this study.

Second, partial correlations were utilised in the meta-analysis for a sub-set of included studies, to examine prospective relationships between individual illness belief domains and adherence to self-management behaviours.

3.4.3 Narrative Review

All included papers were descriptively synthesised. Consistent with the meta-analysis, many of the papers involved in the narrative review also reported on adherence to multiple self-management behaviours for several of the illness belief domains (again denoted by k). The narrative review included articles that examined the illness concern domain.

3.4.4 Quality of Studies

Included papers were assessed for risk of bias in accordance with the PRISMA statement (Moher, Liberati et al. 2009). This assessment of study quality was guided by relevant checklists: the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist (Vandenbroucke, von Elm et al. 2007, von Elm, Altman et al. 2008); and the Delphi list (Verhagen, de Vet et al. 1998) for the reporting of RCTs.

The Delphi list awards papers one mark for reporting of each of the following criteria: method of randomisation; allocation concealment; eligibility criteria; similar groups at baseline; blinding; intention to treat analysis; and effect sizes (Verhagen, de Vet et al. 1998). The total score for any study is nine. Half a mark is awarded for a criterion that is only partially met (Verhagen, de Vet et al. 1998).

An equivalent to the Delphi list for observational studies does not exist; therefore, the STROBE checklist was employed to guide the process of quality assessment for papers adopting these particular study designs. The STROBE checklist allows for the evaluation of key criteria relating to the reporting of observational studies: statement of design and setting; eligibility criteria; definition of variables and assessment methods; sources of bias; sample size; length of follow-up; confounding factors; missing data; sensitivity analysis; and outcome estimates and measures of variability (Vandenbroucke, von Elm et al. 2007, von Elm, Altman et al. 2008).

Where necessary, authors were again contacted via e-mail for clarification of any information relevant to the quality assessment that was not obvious from the paper. Reminders were sent to non-responders two-weeks after the initial mailshot. None of the authors contacted responded with the requested information.

3.5 RESULTS

3.5.1 Identification of Studies

The process of study selection is shown in Figure 3-1.

Searches generated 3352 citations. After the removal of duplicates, 1785 abstracts were screened for eligibility. Six-hundred potentially relevant studies were subsequently identified for full-text retrieval. Fifty-two studies met the pre-defined criteria for inclusion, and are summarised in Table 3-2. From these included papers, 21 studies contributed data for the meta-analysis.

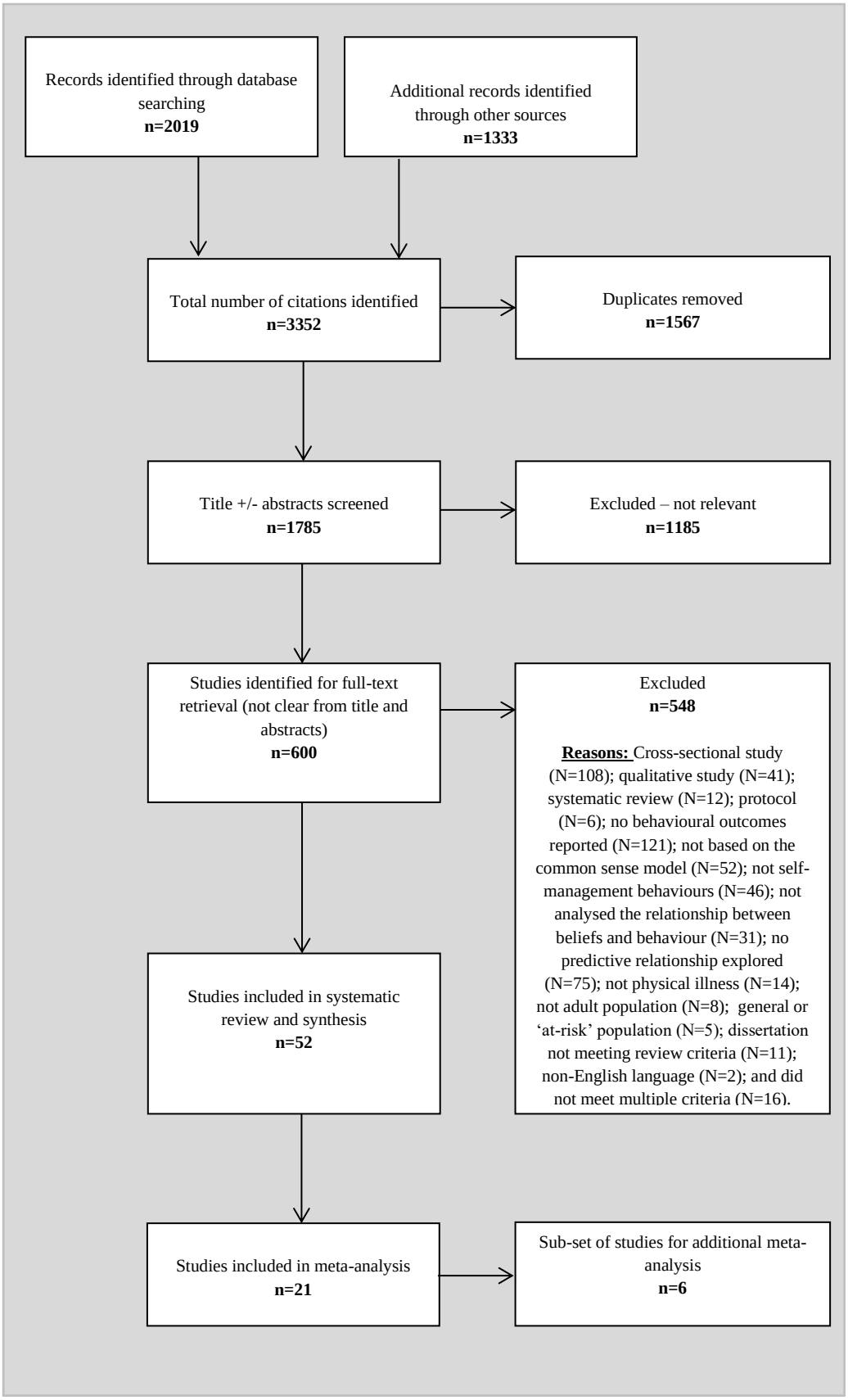


Figure 3-1. PRISMA flow chart illustrating study selection from searches to final inclusion

Table 3-2. Summary of studies included in the review

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
Callaghan, Condie et al. (2008) [1]	Longitudinal (1 and 6-months) *Hospital (Scotland)*	166; 66.7 (10.3)	Peripheral arterial disease amputation	IPQ-R; assisted self-completion	Prosthetic use; self-report questionnaire	Cyclical timeline, treatment control, and causal attributions (risk factors, and emotional-psychological factors) were the strongest predictors of prosthetic use
Clarkesmith, Pattison et al. (2013)[MA] [2]	Randomised trial (1, 2, 6 and 12-months) *Specialist and outpatient clinics (England)*	97; 72 (8.2)	Warfarin-naïve patients with atrial fibrillation	Brief IPQ; self-completion	Medication adherence; objectively measured (time spent within the therapeutic range (INR 2.0 - 3.0))	Illness beliefs were not significantly related to time within therapeutic range
Cooper, Lloyd et al. (1999) [3]	Prospective (6-months) *Hospital (England)*	152; attendees – 58.4 (NR); non-attendees – 64.9 (NR)	Hospitalised for acute myocardial infarction or coronary artery bypass graft surgery	IPQ; self-completion	Attendance at cardiac rehabilitation programme; self-report questionnaire	Control beliefs and causal attributions to lifestyle significantly predicted attendance (regression models adjusted for: belief dimensions, age and knowledge of total cholesterol concentration)
Cossette, Frasure-Smith et al. (2012) [4]	Randomised trial (6-weeks) *Hospital (Canada)*	242; intervention - 59.4 (10.5); control - 59.4 (9.4)	Acute coronary syndromes	IPQ-R; self-completion	Attendance at rehabilitation session; collected from electronic records Physical activity and healthy diet; self-report questionnaires	Illness beliefs were not significantly related to attendance at cardiac rehabilitation, physical activity or healthy diet
Coutu, Dupuis et al. (2003) [5]	Longitudinal (3, 6 and 12-months) *Hospital (Canada)*	214; women – 55.4 (12.5); men – 49.6 (10.7)	Hypercholesterolemia	Cognitive Representation of Hypercholesterolemia Questionnaire; self-completion The Expectancy Questionnaire for	Dietary intake and adherence to lipid-lowering agents; self-report questionnaires	Beliefs about stress and symptoms, and chronicity beliefs significantly predicted 1-year reduction in fat and cholesterol intake (people with low-moderate baseline fat consumption) Accurate baseline representation about hypercholesterolemia (causal and consequence beliefs) significantly predicted improved dietary intake (people with high baseline fat

				Hypercholesterolemic Patients; self-completion, assessing perceived control of the condition		consumption) (regression models adjusted for: perceived self-efficacy, treatment efficacy and BMI)
Author & year [study number]	**Design (follow-up) & setting (country)**	**Sample (N); age (mean and (SD)), unless otherwise stated**	**Illness**	**Illness belief measure; how completed**	**Self-management behaviour(s); how measured**	**Key findings**
Dalbeth, Petrie et al. (2011) [6]	Longitudinal (12-months) *Primary care and hospital clinics (New Zealand)*	142; median=57, range=19-85	Gout	Brief IPQ; self-completion	Adherence to urate-lowering therapy; self-report questionnaire	Illness coherence significantly associated with medication adherence Symptom severity and consequence beliefs significantly associated with non-adherence
Fennessy, Devon et al. (2013)[MA] [7]	Prospective, two-group comparison (30-days post-procedure) *Academic medical centre (USA)*	180; 65.1 (8.3)	Stable coronary artery disease, recruited after coronary angiography and optimal medical therapy (OMT) or after percutaneous coronary intervention (PCI) with initiation of OMT	IPQ-R; self-completion	Adherence to dual anti-platelet therapy, physical activity, and need for emergent care; self-report questionnaire	Chronicity beliefs significantly associated with thienopyridine adherence Chronicity, cyclical timeline, and treatment control beliefs were significantly associated with aspirin adherence, though chronicity beliefs were the strongest predictor of aspirin adherence
Fischer, Scharloo et al. (2009) [8]	Longitudinal (3-months) *Hospital (Netherlands)*	217; 63.4 (9.4)	Chronic obstructive pulmonary disease	IPQ-R; self-completion	Attendance at pulmonary rehabilitation course; collected from medical and therapist records	Treatment control beliefs significantly predicted poor attendance, alongside fat free mass index (regression models adjusted for: living with partner; stopped smoking; and male gender)
French, Lewin et al. (2005) [9]	Prospective (6-months) Hospital (England)	194; 63.3 (10.6)	Myocardial infarction	IPQ; self-completion	Attendance at cardiac rehabilitation programme; verified self-report (hospital records)	Illness beliefs were not significantly associated with attendance at cardiac rehabilitation*

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
French, Wade et al. (2008)¥¥[MA] [10]	Randomised trial (12-months) *General Practice (England)*	339; 65.9 (10)	Non-insulin treated type 2 diabetes mellitus	Adapted IPQ-R *(excluding causal beliefs scale)*; self-completion	Diabetes self-care activities and medication adherence; self-report questionnaires	Consequence beliefs significantly predicted change in self-reported fruit and vegetable consumption (relationship became non-significant with adjustment for group allocation – usual care versus. less and more intensive self-monitoring of blood glucose)
French, Wade et al. (2013)¥ [11]	Randomised trial (12-months) *General Practice (England)*	453; 65.9 (10)	Non-insulin treated type 2 diabetes mellitus	IPQ-R *(excluding causal beliefs scale)*; self-completion	Diabetes self-care activities and medication adherence; self-report questionnaires	Consequence beliefs, emotional representations, symptom severity significantly predicted fruit and vegetable consumption Illness beliefs did not significantly predict: medication adherence, exercise, general dietary behaviours, or consumption of high fat foods
Goodman, Firouzi et al. (2013)[MA] [12]	Longitudinal (2 and 6-months post-hospital-discharge) *Hospital (England)*	88; 70.5 (12.8)	Heart failure	IPQ-R; self-completion	Self-care behaviour; self-report questionnaire	Illness beliefs were not significantly associated with self-care behaviour
Halm, Mora et al. (2006) [13]	Prospective (1 and 6-months) *Hospital (USA)*	198; 49.9 (17.4)	Asthma	Disease beliefs (asthma as a chronic disease or an acute, episodic illness); interview administered survey	Medication adherence and self-management behaviours, including attendance at routine visits; self-reported via interview	'No symptoms, no asthma' belief was associated with significantly lower odds of using inhaled corticosteroids all or most days when asymptomatic (regression models adjusted for age, sex, asthma severity, prior intubation and frequency of oral steroid use)
Hampson, Glasgow et al. (1990) [14]	Prospective (2-weeks) *Outpatient clinics (USA)*	46; 64 (NR) (range=46-79)	Older women with non-insulin-dependent diabetes	Personal Models of Diabetes Interview; interview	Diabetes self-care activities (e.g., dietary intake, physical activity and medication-taking); self-report questionnaire	Beliefs about the importance of treatment significantly predicted dietary self-care, physical activity and glucose testing Beliefs about the seriousness of diabetes predicted dietary self-care

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
Hampson, Glasgow et al. (1994)[MA][15]	Prospective (2-weeks post-interview and 8-months) *Community (USA)*	61; 72 (7.8)	Older adults (>60 years) with osteoarthritis	Personal Models of Arthritis Interview; interview	Self-management (e.g., low-impact activity, medication, rest, range-of-motion exercises, relaxation techniques, heat or cold applied to joints, joint protection, massage, and splinting joints); self-report questionnaire	Symptoms and seriousness significantly predicted typical and worse-day self-management at 2-weeks and 8-months
Hampson, Glasgow et al. (1995)[MA] [16]	Prospective (1 and 4-months) *Community (USA)*	81; 70 (6.5)	Non-insulin-dependent diabetes mellitus	Personal Models of Diabetes Interview; interview	Self-care (e.g., blood glucose testing, dietary intake, physical activity, and medication-taking); self-report questionnaire	Beliefs about treatment effectiveness significantly predicted dietary intake and physical activity at 4-months Personal responsibility for causing diabetes significantly predicted physical activity at 4-months
Hampson, Glasgow et al. (2000)¥¥[MA] [17]	Randomised trial (3, 6 and 9-months) *Outpatient clinics (USA)*	111; 62 (NR)	Diabetes mellitus	Personal Models of Diabetes Interview; self-completion of brief questionnaire	Dietary self-management; self-report questionnaire	Beliefs in treatment effectiveness significantly predicted eating patterns
Hand and Adams (2002) [18]	Longitudinal (1 and 3-months) *General Practice (England)*	44; median=38 years, range=18-55	Asthma	IPQ; self-completion	Inhaler use behaviours; self-report questionnaire	Illness beliefs were not significantly associated with inhaler use*
Harrison, Robertson et al. (2014) [19]	Prospective observational (6-months) *Hospital (England)*	128; 70.8 (8.87)	Acute exacerbation of chronic obstructive pulmonary disease	IPQ-R; self-completion	Uptake, attendance, and completion of pulmonary rehabilitation; collected from hospital records	No significant differences emerged between in control,' 'disengaged,' and 'distressed 'clusters for attendance and adherence to previous pulmonary rehabilitation, or acceptance and uptake of pulmonary rehabilitation

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
Heerema-Poelman, Stuive et al. (2013) [20]	Longitudinal (6 and 12-months) *Rehabilitation Centre (Netherlands)*	60; 61.3 (10.3)	Chronic obstructive pulmonary disease, receiving home-care rehabilitation	IPQ-R *(personal and treatment control sub-scales, only)*; self-completion	Adherence to a maintenance exercise programme; self-reported (early drop-outs - telephone call); and objectively measured (completers - remaining at the end of programme)	Illness beliefs were not significantly associated with adherence to the maintenance exercise programme
Hemphill, Stephens et al. (2013)¥¥[MA] [21]	Longitudinal (6 and 12-months) *NR (USA)*	129 patient-spouse dyads; 66 (7.78)	Patients with type 2 diabetes mellitus and their partners	IPQ-R; interview administered *Disease duration and symptom variability beliefs computed*	Dietary behaviour; self-report questionnaire	Interaction between duration and variability beliefs significantly predicted change in dietary adherence over time Dietary adherence at 12-months was significantly associated with duration beliefs, for people who believed that their symptoms did not fluctuate
Lau, Bernard et al. (1989)[MA] [22]	Longitudinal (3-years) *Community (USA)*	1029 students and 947 parents; students=17 or 18 (NR) (when the study began); parents = 47 (NR)	Common, everyday minor illnesses (e.g., cold)	Illness belief scales; self-completion Lau-Ware Health Locus of Control Scale; self-completed, to assess self-control and provider control over health, chance health outcomes, and general health threat	Number of doctor visits over 1-year; health centre visits over 3-years and recent attendance for a preventative check-up; collected from health centre records	Symptom awareness significantly associated with number of visits to the doctor in 1-year and health centre visits in 1-year and over 3-years Strong curability beliefs significantly related to health-centre visits in 3-years, and a recent preventative check-up
Leung, Ceccato et al. (2007)¥¥ [MA][23]	Longitudinal, (9 and 18-months post-hospital-discharge) *Health centre and hospitals (Canada)*	417; 63.1 (10.2)	Coronary artery disease	IPQ-R *(cyclical timeline, consequences, personal control and cure/controllability sub-scales only);*	Participation in recreational and physical activities; self-report questionnaire	Exercise maintainers were significantly more likely to attribute causes of their coronary artery disease to own behaviour compared to inactive participants (regression models adjusted for gender, exercise history, cardiac rehabilitation

				administered (in-hospital) and self-completion (follow-up)		enrolment, exercise barriers and current/past smoker) Irregular exercisers were significantly more likely to attribute causes of their coronary artery disease to own behaviour compared to exercise maintainers (regression models adjusted for current smoker and diabetes)
Author & year [study number]	**Design (follow-up) & setting (country)**	**Sample (N); age (mean and (SD)), unless otherwise stated**	**Illness**	**Illness belief measure; how completed**	**Self-management behaviour(s); how measured**	**Key findings**
Massey, Tielen et al. (2013) [MA] [24]	Longitudinal (6-weeks and 6-months post-transplant) *Outpatient clinics (Netherlands)*	113; median=53 years, range=19-75	Kidney transplantation	Brief IPQ; interview administered	Adherence to immunosuppressive medication; self-report questionnaire (interview administered)	Timeline perceptions of longevity of graft predicted non-adherence at 6-weeks
Massey, Tielen et al. (2015)[MA] [25]	Longitudinal, 18-months post-transplant Netherlands, outpatient clinics	84; median=53 years, range=19-75	Kidney transplantation	Brief IPQ; interview administered	Adherence to immunosuppressive medication; self-report questionnaire (interview administered)	Illness beliefs were not significantly associated with medication adherence*
Michie, O'Connor et al. (2005) [26]	Longitudinal (2-weeks before attending cardiac rehabilitation, 8-weeks and 8-months after programme) *Hospital (England)*	158; 59 (NR)	Admitted with myocardial infarction or undergone coronary artery bypass graft surgery	IPQ; self-completion	Healthy eating; study specific self-report questionnaire	Illness beliefs were not significantly associated with healthy eating*
Mosleh, Bond et al. (2014) [27]	Randomised trial (8-weeks) *Hospital (Scotland)*	375; 62.5 (11.2)	Admission for myocardial infarction, coronary artery bypass graft surgery, or coronary angioplasty	IPQ *(plus two items for symptom distress);* self-completion	Attendance at cardiac rehabilitation programme; collected from cardiac nurse records	Greater symptom severity significantly associated to cardiac rehabilitation attendance.

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
O'Carroll, Whittaker et al. (2011) [28]	Longitudinal (4-6 weeks) *Hospital (Scotland)*	180; 69 (11.4)	1-year post ischaemic stroke	IPQ-R *(timeline and treatment control sub-scales only)*; assisted self-completion	Medication adherence; objectively measured using opportunistic urinary sample for urinary salicylic acid/creatinine ratio (aspirin adherence); and self-report questionnaire	Illness beliefs were not significantly associated with medication adherence
O'Connor, Jardine et al. (2008) [MA][29]	Prospective (3-weeks) *Hospital (Scotland)*	73; 51.9 (14.7)	End-stage renal disease	IPQ-R; self-completion	Self-care behaviours: objectively measured using pre-dialysis serum phosphate (adherence to phosphate-binding medication); and serum potassium levels (adherence to dietary restrictions)	Emotional representations significantly predicted pre-dialysis potassium and phosphate levels (regression models adjusted for age, gender and ideal weight) Timeline beliefs significantly predicted pre-dialysis phosphate levels (adjusting for the same confounding factors)
O'Rourke and Hampson (1999) [30]	Longitudinal (6-months) *Hospital (England)*	70; hospital 1 – 57.7 (9); hospital 2 – 59.4 (10.4)	Myocardial infarction	IPQ; self-completion	General practitioner contact and hospital admissions; verified self-report (hospital records)	Illness beliefs were not significantly associated with health service utilisation
Olszanecka-Glinianowicz and Almgren-Rachtan (2014) [31]	Prospective (NR) *Outpatient Clinic (Poland)*	Asthma – 3618; 46.7 (15.0), and chronic obstructive pulmonary disease – 2602; 60.0 (13.5)	Asthma and chronic obstructive pulmonary disease	Brief IPQ; interview administered	Medication adherence to the Fantasmino inhaler; self-report questionnaire	Non-adherence was significantly associated with consequence beliefs and emotional representations for chronic obstructive pulmonary disease patients and symptom severity for asthma patients Adherence was significantly associated with chronicity, personal and treatment control beliefs, understanding of disease and interest in knowledge for asthma patients, and personal and treatment control beliefs for chronic obstructive pulmonary disease patients

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
Orbell, Hagger et al. (2006) [32]	Longitudinal (15-months) *Colposcopy Clinics (England)*	660; 33.9 (10.3)	Abnormal cervical screening result	IPQ-R; self-completion	Appointment attendance; collected from medical records	Illness beliefs were not significantly associated with attendance
Petrie, Weinman et al. (1996) [33]	Longitudinal (3 and 6-months) *Hospital (New Zealand)*	143; 53.2 (8.4)	Myocardial infarction	IPQ; self-completion	Attendance at cardiac rehabilitation programme; collected from practitioner records	Attendance was significantly associated with cure/control beliefs, and there was a trend for less serious consequence beliefs and lower distress in attendees
Phillips, Leventhal et al. (2013)[MA] [34]	Prospective (30-days) *Primary care clinic of a research hospital (USA)*	71; 67.9 (12.3)	Hypertension, and on daily pill-form medication	Coherence beliefs, measured using two survey questions; interview administered IPQ-R *(treatment control sub-scale only)* to assess treatment-related health beliefs; interview administered	Adherence to anti-hypertensive medication; objectively measured using electronic monitoring pill bottles; and interview administered self-report questionnaire	Coherence beliefs significantly predicted intentional non-adherence
Poliakoff, Galpin et al. (2013) [35]	Randomised trial (10 and 20-weeks) , *Community (England)*	32; intervention: median=68.6 years (range=48-77); control: median=66.6 (range=49-78)	Parkinson's disease	Brief IPQ; NR	Exercise training (e.g., cardiovascular activity at the gym); assessed using various assessments of motor function	Gym group perceived a low sense of personal control and more serious consequences over the duration of training, but had a reduction in beliefs about illness concern over the intervention period
Powell, McCaffery et al. (2013)¥¥ [36]	Randomised trial (monthly and bi-weekly until 37-weeks gestation)	175; 28.5 (5.4)	Pregnant women with asthma (12 to 20 weeks gestation)	Brief IPQ; administered to patients	Exacerbations (e.g., hospitalisation, emergency visit, unscheduled doctor visit, or oral corticosteroid	Risk of future exacerbations were significantly predicted by beliefs about the controllability of asthma

	Community antenatal clinic (New Zealand)				use for worsening asthma); prospectively assessed at monthly antenatal clinic visits and fortnightly telephone follow-up	
Author & year [study number]	**Design (follow-up) & setting (country)**	**Sample (N); age (mean and (SD)), unless otherwise stated**	**Illness**	**Illness belief measure; how completed**	**Self-management behaviour(s); how measured**	**Key findings**
Rabin and Pinto (2006) [37]	Longitudinal (3 – months) *Hospital (USA)*	Survivors – 61; 56.2 (10); relatives – 31; 46.3 (13.4)	Breast cancer survivors (and their first-degree relatives)	Perceived cause and ability of health behaviour to prevent cancer occurrence/recurrence ; self-completion	Changes in health practices (diet, physical activity, smoking and alcohol consumption); self-report questionnaires	Strong beliefs that a healthy diet overall and consumption of more fruit and vegetables could prevent cancer significantly predicted behaviour change. Borderline significance was found for high-fibre foods Survivors who believed that an unhealthy diet contributed to their cancer were more likely to change their diet, and marginal significance emerged for these causal beliefs and consumption of calories from fatty foods over time
Richardson, Brunton et al. (2013)ł [38]	Quasi-experimental (1 and 3-months) *Ophthalmology clinic (England)*	21; median=69; range=44-89	Glaucoma	IPQ-R; self-completion	Adherence with eye-drops objectively measured using an electronic monitoring container; and self-report questionnaire	Illness beliefs were not reported to be significantly associated with adherence
Sampaio, Pereira et al. (2014) [39]	Prospective (1-2-months and 3-6-months) *Outpatient sleep disordered breathing clinic (Portugal)*	153; 52.2 (10.3)	Obstructive sleep apnoea	Brief IPQ; interview administered	Adherence to automatic positive airway pressure treatment; objectively measured using a five-channel recording device	Illness beliefs were not significantly associated with adherence
Scharloo, Kaptein et al. (2000) [40]	Longitudinal (12-months)	64; 63.8 (7.7)	Chronic obstructive pulmonary disease (minimum illness duration of 1-year)	Illness perceptions *(identity, cause, timeline, consequences, cure,*	Outpatient clinic visits and prescribed medication; collected from patients' medical records	Emotional attributions to others and stress as causes of illness were significantly associated with more visits

	Pulmonology outpatient clinic (Netherlands)			*emotional representations)*; elicited via interview IPQ; self-completion (immediately post-interview)		
Author & year [study number]	**Design (follow-up) & setting (country)**	**Sample (N); age (mean and (SD)), unless otherwise stated**	**Illness**	**Illness belief measure; how completed**	**Self-management behaviour(s); how measured**	**Key findings**
Schuez, Wolff et al. (2014)[MA] [41]	Longitudinal (6-months) *Population-based (Germany)*	215; 73.3 (5.10)	Elderly adults with multi-morbidity (at least 2 physical illnesses)	Adapted Brief IPQ; self-completion	Medication adherence; self-report questionnaire *(single-item)*	Three factors emerged, and significantly predicted medication adherence: consequences (comprising: identity, consequences, coherence, and emotional response); control (including personal and treatment control); and timeline
Searle and Murphy (2000) [42]	Prospective (4-6 weeks) *Community homeopathy clinics (England)*	30; 39 (11.7)	Chronic conditions, including skin complaints, rheumatoid arthritis, respiratory problems, menopause and myalgic encephalomyelitis	IPQ; self-completion Peoples' understanding of their condition; self-completion of study-specific questionnaire	Adherence to practitioners' advice and prescription of remedies; self-report questionnaire	Non-adherence was significantly predicted by causal attributions to one's own behaviour and others and chance, and consequence beliefs Adherence to prescribed remedies was significantly predicted by causal attributions to pollution and poor past care, and symptom severity Adherence to dietary recommendations was significantly predicted by causal attributions to poor past care and chance
Searle, Norman et al. (2007) [43]	Prospective (12-months) *General Practice (England)*	164; patients – 67 (NR); partners – 67 (NR)	Patients with type 2 diabetes mellitus and partners	IPQ-R *(identity sub-scale replaced with sub-scales from the Personal Models of Diabetes Interview)*; self-completion	Self-management behaviours (e.g., diet, physical activity, medication adherence); self-report questionnaires	Patients' beliefs about timeline, partners' treatment control beliefs, and patients' and partners' perceived control of diabetes, significantly predicted engagement with physical activity and fruit, vegetable and fibre intake (mediated by partners' timeline and personal control perceptions)

Searle, Norman et al. (2007)¥[MA] [44]	Prospective (12-months) *General Practice (England)*	134; 67 (NR)	Type 2 diabetes mellitus	IPQ-R *(identity sub-scale replaced with sub-scales from the Personal Models of Diabetes Interview)*; self-completion	Self-management behaviours (e.g., diet, physical activity, medication adherence); self-report questionnaires	Illness beliefs did not predict physical activity, fat and carbohydrate intake Treatment control beliefs significantly predicted medication adherence Consequence beliefs significantly predicted fibre intake Timeline beliefs (regression models adjusted for gender) significantly predicted fruit and vegetable intake, and sugar consumption
Author & year [study number]	**Design (follow-up) & setting (country)**	**Sample (N); age (mean and (SD)), unless otherwise stated**	**Illness**	**Illness belief measure; how completed**	**Self-management behaviour(s); how measured**	**Key findings**
Siemonsma, Stuive et al. (2013) [45]	Randomised trial (18-weeks) *Outpatient Rehabilitation Clinic (Netherlands)*	156; intervention - 45.6 (12,9); control 47.1 (11.1)	Chronic low back pain	IPQ-R; self-completion	Physical activity level; self-report questionnaire	Illness beliefs were not significantly associated with physical activity level
Sniehotta, Gorski et al. (2010)[MA] [46]	Prospective (2-months) *Hospital (Scotland)*	110; 63 (10.3)	Myocardial infarction and underwent percutaneous coronary interventions, had bypass surgeries or other surgeries	Adapted IPQ-R (IPQ-PS); self-completion	Attendance at cardiac rehabilitation programme, verified self-report (medical records); exercise, self-report questionnaire	Illness beliefs were not significantly predictive of physical activity (though post-hoc analyses showed that adding timeline-cyclical into the regression model whilst controlling for past behaviour and perceived behavioural control* added significantly to the prediction of the model) Illness beliefs were not significantly associated with attendance at cardiac rehabilitation
Stafford, Jackson et al. (2008) [MA][47]	Prospective (3, 6 and 9-months post hospital discharge) *Hospital (Australia)*	193; 64.1 (10.4)	Patients hospitalised for percutaneous transluminal coronary angioplasty or coronary artery bypass graft surgery	IPQ-R; self-completion	Adherence to secondary prevention behaviours (e.g., physical activity, taking medications, weight management, alcohol use and smoking); self-report questionnaire	Consequence beliefs coronary artery disease significantly predicted improved adherence (regression models adjusted for: depression, social support, age, educational status, disease severity and social desirability)

Author & year [study number]	Design (follow-up) & setting (country)	Sample (N); age (mean and (SD)), unless otherwise stated	Illness	Illness belief measure; how completed	Self-management behaviour(s); how measured	Key findings
Steed, Barnard et al. (2014)[MA] [48]	Randomised trial (1-week, and 3-and 9-months post-intervention) *Hospital (England)*	124; intervention – 59.2 (8.8); control – 60.3 (8.6)	Type 2 diabetes mellitus	Beliefs about Diabetes Scale (measuring personal models of diabetes e.g., beliefs about seriousness, treatment effectiveness, personal control over diabetes); self-completion	Self-management behaviours (e.g., diet, exercise, blood glucose monitoring); self-report questionnaire	Illness beliefs were not significantly associated with changes in self-management behaviour
Telles-Correia, Barbosa et al. (2012)[MA] [49]	Longitudinal (12-months) *Outpatient Clinic (Portugal)*	62; 57.7 (19.3)	Family amyloid polyneuropathy or chronic liver disease	IPQ-R *(except for emotional representations sub-scale);* self-completion	Adherence (e.g., medication, appointment attendance, treatment compliance, and alcohol consumption); self-report questionnaire	Post-transplant medication adherence was significantly predicted by personal control beliefs adherence (regression model adjusted for adherence to medication before transplant)
Weinman, Petrie et al. (1996)¤[MA] [50]	Longitudinal (3 and 6-months) *Hospital (New Zealand)*	Discharged patients=104¥; 53.8 (8.2)	First-time myocardial infarction	IPQ; self-completion	Recent doctor visits (in the last 3-months); NR	Illness identity and consequence beliefs were significantly related to doctor visits
Yardley, Joseph et al. (2010) [51]	Exploratory Randomised Trial (48-hours and 4-weeks) University (England)	714; NR; range=18-79	Minor respiratory illnesses	IPQ-R *(illness coherence and emotional representations sub-scales only);* self-completion	Health services use; self-report questionnaire	Illness beliefs were not significantly associated with health service use
Yohannes, Yalfani et al. (2007) [52]	Prospective (6-weeks) *Outpatient Clinic (England)*	147; completers – 61.4 (9.2); non-completers – 58.7 (7.2)	Myocardial infarction and enrolled to a	IPQ-R; self-completion	Drop-out from cardiac rehabilitation; collected from medical records	Consequence, personal and treatment control beliefs were significantly predictive of drop-out from rehabilitation (regression models adjusted for age, gender, anxiety and depression)

			rehabilitation programme			

Symbols and abbreviations: BMI: Body mass index; Brief IPQ: Brief illness perception questionnaire; IPQ: Illness perception questionnaire; IPQ-PS: Illness perception questionnaire – psychometrically shortened; IPQ-R: Illness perception questionnaire-revised; OMT: Optimal medical therapy; PCI: Percutaneous coronary intervention; NR: Not reported; * Due to non-significant correlations between beliefs and behaviour, modelling did not include illness belief components; ¤: Validation paper for the IPQ-R; ¥: Based on same data as a study previously reported by the authors (French et al., 2008; Petrie et al., 1996; Searle et al., 2007a); ¥¥: Secondary analysis of a previously reported study (Farmer et al., 2007; Glasgow, Toobert, Hampson, & Noell, 1995; Grace et al., 2007; Iida, Parris Stephens, Rook, Franks, & Salem, 2010; Powell et al., 2011); ł: Feasibility study

3.5.2 Description of Studies Included in the Review

Studies were conducted between 1989 and 2015. Thirty-four studies were undertaken in Europe, where the majority (N=24 studies) were hosted in the UK. A further ten studies were conducted in the United States of America (USA) and Canada, and five studies were undertaken in Australia and New Zealand. The settings included: hospital (N=27 studies); outpatient clinics (N=11 studies); general practice (N=5 studies); and the community (N=6 studies), including a university (N=2 studies). The setting was not reported in one study (Study 21, Table 3-2). The 52 studies involved 15, 828 participants altogether, with sample sizes ranging from 21 to 3618 people. All of the studies included men and women in varying proportions. The average age of participants ranged from around 18 to 73 years. The majority of studies adopted observational designs, with the exception of 12 RCTs. The length of follow-up ranged from 48-hours to three-years. Four of the included papers were based on the same data (Searle, Norman et al. 2007, Searle, Norman et al. 2007, French, Wade et al. 2008, French, Wade et al. 2013). Further, one of the papers included in the review was a questionnaire validation study (Weinman, Petrie et al. 1996).

Studies included participants with a range of physical health conditions, as shown in Figure 3-2. Over three-quarters of the studies (45 out of 52 papers) involved people with chronic diseases. Most of the studies (28 out of 52 papers) either examined populations with heart problems (for example, coronary artery disease and myocardial infarction) (15 out of 52 papers) or metabolic and related disorders (such as, type 2 diabetes mellitus and kidney or liver disease) (13 out of 52 papers).

In terms of self-management behaviours, almost half of the studies assessed medication adherence (23 out of 52 papers). Attendance behaviours were assessed in 14 out of 52 included papers. Around two-thirds of the studies measured dietary behaviours (14 out of 52 papers) and physical activity (14 out of 52 papers). Nine out of 52 studies examined other, disease-specific, self-management behaviours. In addition, there were a proportion of studies (18 out of 52 papers) that assessed adherence to multiple self-management behaviours. Almost three-quarters of the studies measured adherence to self-management behaviours using self-report (34 out of 52 papers). Of these, two studies verified the self-reported data using a different, objective method of assessment (such as, confirmatory checks against medical records). Seven out of 52 papers exclusively used objective measures of adherence to self-management behaviours, and nine out of 52 papers used data collected from medical records. Five out of 52 papers used a mixed approach, including self-report and objective methods of assessment.

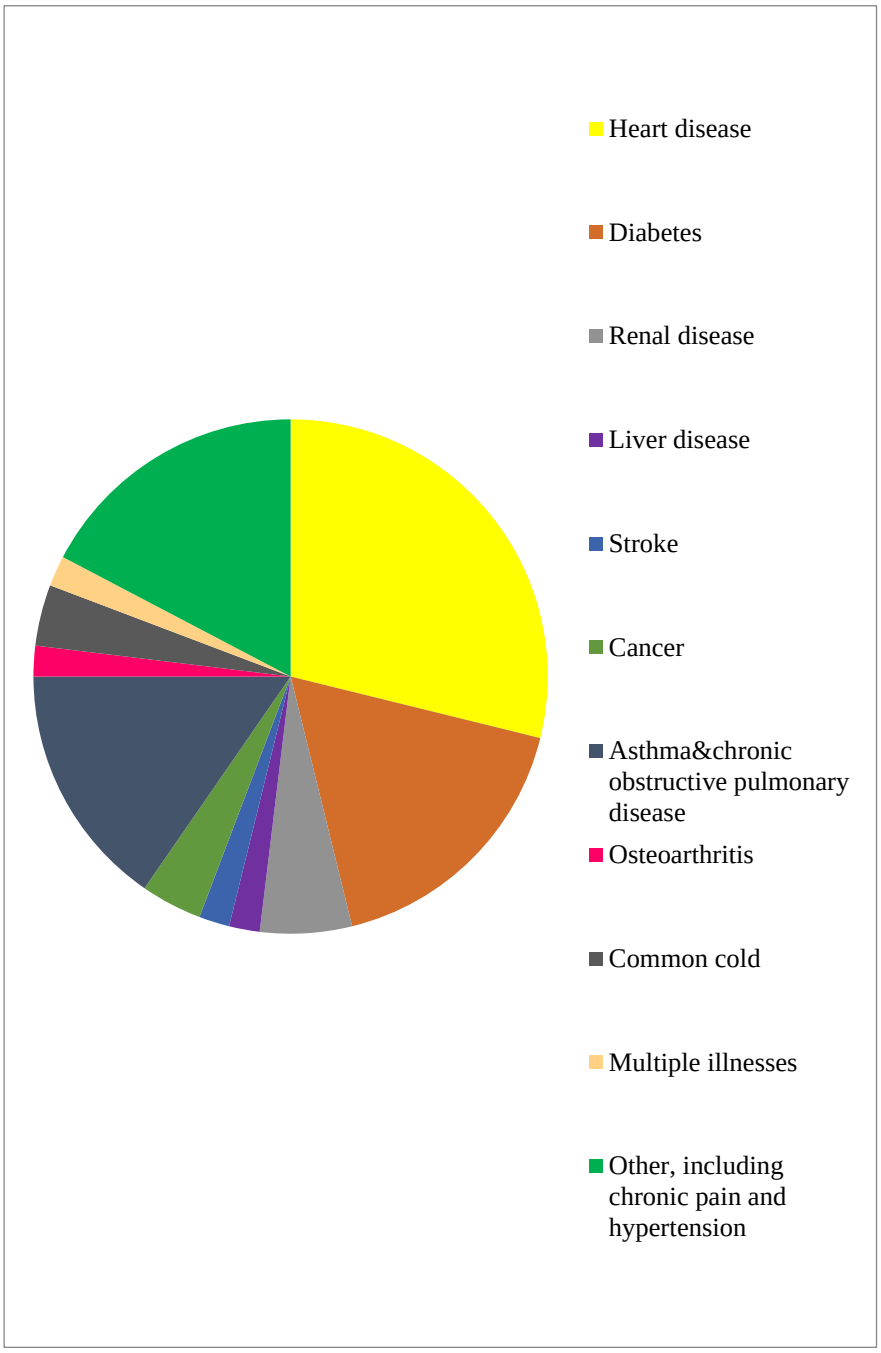


Figure 3-2. Illness types across all included studies

The majority of studies used the IPQ (9 out of 52 papers) (Studies 3, 9, 18, 26, 27, 30, 33, 42, and 50; Table 3-2); the IPQ-R (20 out of 52 papers) (Studies 1, 4, 7, 8, 10, 11, 12, 19, 20, 21, 23, 29, 32, 38, 45, 46, 47, 49, 51 and 52; Table 3-2); or the Brief IPQ (9 out of 52 papers) (Studies 2, 6, 24, 25, 31,

35, 36, 39, and 41; Table 3-2), to measure illness belief domains. The remainder (14 out of 52 papers) used other assessment methods (Studies 5, 13, 14, 15, 16, 17, 22, 28, 34, 37, 40, 43, 44 and 48; Table 3-2), which included: study-specific questionnaires that were tailored to particular diseases, and were self-reported or administered via interviews (8 out of 52 papers); and personal model beliefs (such as, for diabetes), which were again disease-specific and either self-completed by patients, or data were obtained through interviews (4 out of 52 papers). In addition, one study used an interview to elicit people's illness beliefs, using a study-specific interview schedule (Lau, Bernard et al. 1989).

Studies using the IPQ were conducted between 1996 and 2005. Papers using the IPQ-R and Brief IPQ were conducted more recently, between 2007 or 2011 respectively, and 2013. The use of these instruments is likely to reflect the availability of the scales (Weinman, Petrie et al. 1996, Moss-Morris, Weinman et al. 2002, Broadbent, Petrie et al. 2006). The majority of papers using the IPQ (7 out of 52 papers) examined people with acute myocardial infarction, and four of these articles explored attendance behaviours at cardiac rehabilitation (Studies 3, 9, 27, and 33; Table 3-2). The IPQ-R was used more broadly across a range of acute and chronic physical health conditions, including: heart or respiratory diseases, type 2 diabetes mellitus, minor acute illnesses, and cancer. Studies using the Brief IPQ or other assessment methods examined mostly chronic conditions. Papers that used the IPQ-R or other assessment methods examined adherence to a broad range of self-management behaviours. The majority of studies using the Brief IPQ (7 out of 52 papers) measured medication adherence (Studies 2, 6, 24, 25, 31, 39 and 41; Table 3-2).

Over two-thirds of the studies (36 out of 52 papers) used self-completion for the different methods for assessing illness beliefs. The remainder used other response options, including: assisted self-completion (Studies 1 and 28; Table 3-2); interview (Studies 21, 24, 25, 31, 36, 39, 13, 14, 15, 16, and 17; Table 3-2); or self-completion questionnaire plus interview (Studies 23 and 40; Table 3-2).

3.5.3 Quality Assessment

The randomised trials included in the review varied in quality, with Delphi scores ranging from two to 8 ½ for the ten trials; two of which were based on the same data (Studies 10 and 11; Table 3-2). The majority of randomised trials were of adequate to good quality, reporting many of the key criteria from the Delphi list (Studies 2, 4, 10, 11, 27, 35, and 45; Table 3-2). The remainder achieved low scores, omitting many of the Delphi list criteria in the reporting of the studies, including: method of randomisation, allocation concealment, blinding, and details regarding statistical analyses, such as intention to treat analysis (Study 17, 36, 48, and 51; Table 3-2). There were attempts made to clarify this information with the authors, but this was without fruition.

The remainder of included studies (N=41) were observational, and adopted cohort or case-control designs. The majority of these papers satisfactorily reported many of the key STROBE criteria, such as: statement of design and setting; eligibility criteria; and definition of variables and assessment methods. However, there was little consideration by included papers for several of the criteria, particularly with regard to statistical analyses. For example,

confounding factors were examined in just over half of the studies (24 out of 41 papers), and only six of these reported adjustments for relevant psychological variables, such as distress or depression (Studies 7, 21, 26, 29, 47, and 52; Table 3-2). Further, missing data were considered in only three out of 41 papers (Studies 12, 19 and 23; Table 3-2). The majority of studies (29 out of 41 papers) did not report sufficient information regarding effect sizes and measures of variability, with almost three-quarters of these papers (N=21) only providing details about beta coefficients and R^2 changes from regression modelling. In addition, studies were poor at reporting potential sources of bias: only five papers out of 41 (Studies 5, 34, 43, 44, and 47; Table 3-2) described measures that were taken to reduce the effect of bias on the study findings (for example, special recruitment procedures to limit selection bias, which were reported by Study 34 (Table 3-2)).

There were two other important issues that emerged through the assessment of quality for included observational studies. These were: sample sizes and length of follow-up. Around a third of the studies (14 out of 41 papers) involved samples of fewer than 100 participants, which, based on the central limit theorem is the optimal minimum sample size on which to draw statistical conclusions (Altman 1990). There were also nine studies where the length of follow-up was less than three-months.

3.5.4 The Role of Illness Beliefs in Predicting Adherence to Self-Management Behaviours

3.5.4.1 Results of the Meta-Analysis

3.5.4.1.1 Characteristics of the Sample

The sample of 21 studies included in the meta-analysis involved 4049 participants altogether, and sample sizes ranged from 61 to 1029 people (Studies 2, 7, 10, 12, 15, 16, 17, 21, 22, 23, 24, 25, 29, 34, 41, 44, 46, 47, 48, 49, and 50; Table 3-2). Studies were conducted between 1989 and 2015. Eleven studies were undertaken in Europe, with almost half (N=5 studies) in the UK, and the remainder (N=9 studies) were conducted in the USA, Australia and New Zealand. The majority of these studies were undertaken in either hospital (N=9 studies) or outpatient clinic settings (N=5 studies). Participants were aged from 18 to 74 years, but most were between 50 and 70 years old, with men and women in varying proportions.

The sample was comprised of mostly chronic illnesses (18 out of 21 papers), particularly heart disease (6 out of 21 papers) and diabetes (6 out of 21 papers), as shown in Figure 3-3. Most of the studies (3 out of 21 papers) assessed medication adherence. Over two-thirds of the studies measured dietary behaviours (8 out of 21 papers) and physical activity (8 out of 21 papers). Attendance behaviours were assessed in only three studies out of 21, and healthcare utilisation in two out of 21 papers. Nine studies examined disease-specific, self-management behaviours, and 12 out of 52 papers assessed

adherence to multiple self-management behaviours. Self-report was the most commonly utilised method of data collection (17 out of 21 papers).

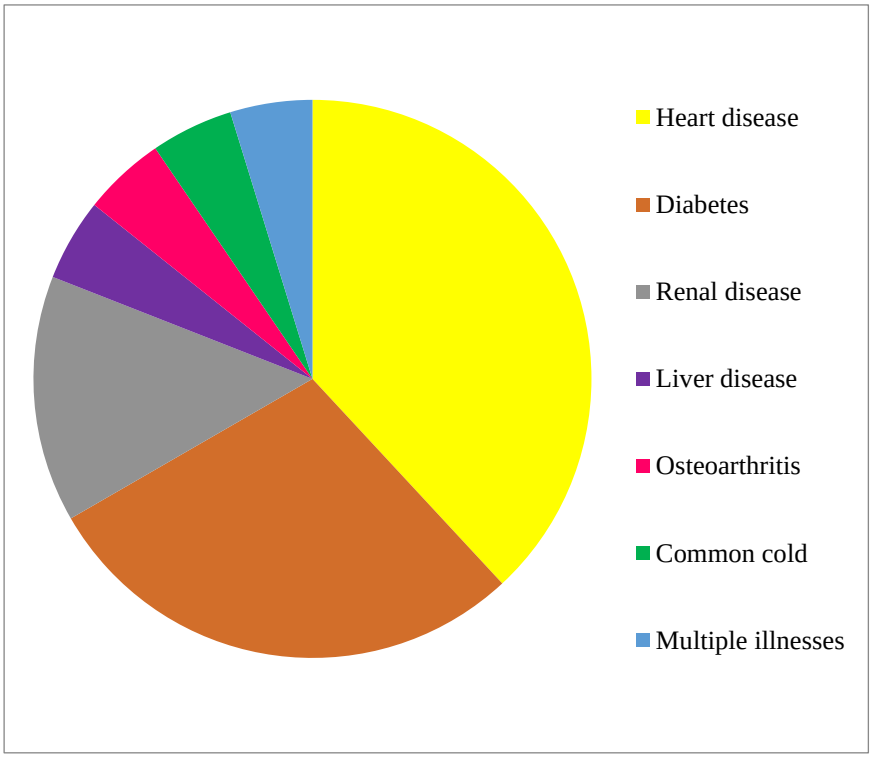


Figure 3-3. Illness types across studies included in the meta-analysis

Studies included in the meta-analysis mostly used either the IPQ-R (10 out of 21 papers); or the Brief IPQ (4 out of 21 papers) to measure illness belief domains, and these were most commonly self-completed (12 out of 21 papers). The majority of studies in the meta-analysis adopted observational designs, with the exception of four papers that were randomised trials (Studies 2, 10, 17 and 29; Table 3-2). Follow-up ranged from 3-weeks to 3-years, but most happened at 6, 9, 12 and 18-months.

3.5.4.1.2 Between-Study Heterogeneity

The findings from the meta-analysis suggested that heterogeneity in the weighted effect sizes was evident, to varying degrees, for many of the individual illness belief domains. A summary of these findings is shown in Table 3-3. The identity and timeline acute-chronic beliefs appeared to be most affected, with I^2 values exceeding the threshold for high heterogeneity of 75%. Several of the other illness belief domains showed moderate heterogeneity: personal control (I^2=50.1%); timeline-cyclical (I^2=56.1%); consequences (I^2=58.9%); cure-control (I^2=59.0%); and emotional representations (I^2=64.3%). Low, but statistically significant, heterogeneity was found for two of the illness belief domains: treatment control (I^2=47.6%) and causes (I^2=33.6%). Illness coherence was the only belief domain to show no evidence of heterogeneity; therefore, it was possible to assume that the studies comprising this domain were homogenous. It is also noteworthy that for all of the illness belief domains, estimates of the variance between studies were small at 0.02 or below.

Table 3-3. Summary of the meta-analysis results

Illness belief domain	Number of studies	k	Correlations		Heterogeneity			Egger's test (p-value)
			r+ (95% CI)	p-value	Q (DF)	I^2	Tau^2	
Identity	10	32	0.08 (0.04-0.12)	<.001	226.71 (31)	86.3***	0.01	0.90
Timeline (acute/chronic)	14	36	0.12 (0.06-0.17)	<.001	269.19 (35)	87.0***	0.02	<0.01
Timeline-cyclical	7	25	-0.01 (-0.05-0.04)	0.83	54.71 (24)	56.1***	0.01	0.81
Consequences	16	67	0.04 (0.01-0.07)	<.01	160.51 (66)	58.9***	0.01	<0.001
Personal control	11	49	0.07 (0.04-0.10)	<.01	96.26 (48)	50.1***	0.01	<0.05
Treatment control	13	65	0.13 (0.09-0.16)	<.001	122.25 (64)	47.6***	0.01	<0.01
Cure-control	6	15	0.07 (0.03-0.12)	<.01	34.15 (14)	59.0**	0.00	0.69
Illness coherence	9	28	0.04 (0.01-0.08)	<.05	31.92 (27)	15.4	0.00	0.19
Emotional representations	9	28	-0.01 (-0.06-0.05)	0.85	75.55 (27)	64.3***	0.01	<0.05
Causes	4	38	0.01(-0.02-0.04)	0.45	55.69 (37)	33.6*	0.00	0.99

Symbols and abbreviations: DF: Degrees of freedom; k: Number of unique data-sets; r+: Weighted correlation coefficient; Q: Between-study heterogeneity (chi-squared); I^2: Between-study heterogeneity (percentage); Tau^2: Estimate of between-study variance; Egger's test: Significance test for funnel plot asymmetry; *: $p<0.05$; **: $p<0.01$; ***$p<0.00$

3.5.4.1.3 Pooled Correlations for Individual Illness Belief Domains

Of the 21 studies that were included in the meta-analysis, several provided multiple datasets. Therefore, the number of unique datasets (k) for each illness belief domain varied, as shown in Table 3-3. Overall, individual illness belief domains did appear to predict adherence to self-management behaviours in adults with physical diseases. However, effect sizes for the individual illness belief domains varied between 0.04 and 0.13, indicating weak, albeit significant predictive relationships with adherence to self-management behaviours. The illness beliefs that emerged as significant predictors of adherence to self-management behaviours were: identity ($r+=0.08$, $p<0.001$); timeline acute-chronic ($r+=0.12$, $p<0.001$); consequences ($r+=0.04$, $p<0.01$); personal control ($r+=0.07$, $p<0.01$); treatment control ($r+=0.13$, $p<0.001$); cure-control ($r+=0.07$, $p<0.01$); and illness coherence ($r+=0.04$, $p<0.05$). Timeline-cyclical ($r+=-0.01$, $p=0.83$), emotional representations ($r+= -0.01$, $p=0.85$), and causal beliefs ($r+= -0.01$, $p=0.45$) were not statistically significant, and showed weak (almost negligible) relationships with adherence to self-management behaviours. A summary of the results is shown in Table 3-3.

3.5.4.1.4 Sensitivity Analyses

One of the included studies by Lau, Bernard et al. (1989) involved the largest sample size of over 1000 people. Therefore, this study held the greatest weight compared to other studies for the following illness belief domains: identity, timeline acute-chronic, consequences, cure-control and causes. Thus, these illness belief domains were most likely to be affected by this study, and were included in the sensitivity analysis. However, with exclusion of

this study, there was very little change in the effect size estimates. These again indicated weak, though significant, predictive relationships of individual illness belief domains with adherence to self-management behaviours. Identity ($r+=0.09$, $p<0.05$), timeline acute-chronic ($r+=0.13$, $p<0.001$), consequences ($r+=0.05$, $p<0.01$), and cure-control ($r+=0.09$, $p<0.001$) remained significant predictors of adherence to self-management behaviours. In addition, the causal belief domain still showed a statistically non-significant and weak predictive relationship with adherence to self-management behaviours ($r+=0.01$, $p=0.56$). A summary of these results is shown in Table 3-4.

Table 3-4. Summary of the meta-analysis results following exclusion of Lau, Bernard et al. (1989)

Illness belief domain	Number of studies	k	Correlations		Heterogeneity		
			r+ (95% CI)	p-Value	Q (DF)	I^2	Tau^2
Identity	9	23	0.09 (0.02-0.16)	<0.05	92.4 (22)	76.2***	0.02
Timeline (acute/chronic)	13	33	0.13 (0.06-0.20)	<0.001	216.2 (32)	85.2***	0.03
Timeline-cyclical							
Consequences	15	64	0.05 (0.02-0.08)	<0.01	149.1 (39)	57.7***	0.01
Personal control							
Treatment control							
Curability/controllability	5	12	0.09 (0.04-0.13)	<0.001	10.7 (11)	0.0	0.00
Illness coherence							
Emotional representations							
Causes	3	35	0.01 (-0.03-0.05)	.56	52.1 (34)	34.8*	0.01

Symbols and abbreviations: DF: Degrees of freedom; k: Number of unique data-sets; r+: Weighted correlation coefficient; Q: Between-study heterogeneity (chi-squared); I^2: Between-study heterogeneity (percentage); Tau^2: Estimate of between-study variance;*: p<0.05; **: p<0.01; ***p<0.001

With regard to the further sensitivity analysis, data for partial correlations were possible to obtain for only six studies. This small number of studies provided data for the calculation of pooled correlations for just a handful of illness belief domains: timeline acute-chronic; consequences; personal control; and treatment control. The findings from this additional meta-analysis are shown in Table 3-5, and highlighted weak prospective relationships between individual illness belief domains and adherence to self-management behaviours that are consistent with the effect sizes in the main meta-analysis (see Table 3-3). With the exception of the timeline acute-chronic domain, the effect sizes for the remainder of illness belief domains were similar to, or became smaller than, the main meta-analysis though retained statistical significance. Therefore, consequence ($r+=0.04$, $p<0.05$); personal control ($r+=0.04$, $p<0.01$); and treatment control ($r+=0.12$, $p<0.001$) beliefs remained significant predictors of adherence to self-management behaviours in partial correlations controlling for baseline (or time 1) adherence to self-management behaviours. Sub-group analyses were not possible to conduct because of the limited data available on partial correlations. In contrast to the main meta-analysis, the timeline acute-chronic domain showed a very small effect size that did not retain statistical significance, indicating a weak (almost negligible) prospective relationship with adherence to self-management behaviours.

Table 3-5. Summary of the meta-analysis results for partial correlations

Illness belief domain	Number of studies	k	Correlations		Heterogeneity	
			r+ (95% CI)	p-value	Q (DF)	I^2
Identity						
Timeline (acute/chronic)	3	8	-0.01 (-0.06-0.05)	0.79	19.92 (7)	64.9**
Timeline-cyclical						
Consequences	4	29	0.04 (0.00-0.07)	<0.05	37.75 (28)	25.8
Personal control	4	29	0.04 (0.01-0.08)	<0.01	39.52 (28)	29.1
Treatment control	5	30	0.12 (0.09-0.15)	<0.001	122.44 (29)	76.3***
Cure-control						
Illness coherence						
Emotional representations						
Causes						

Symbols and abbreviations: DF: Degrees of freedom; k: Number of unique data-sets; r+: Weighted correlation coefficient; Q: Between-study heterogeneity (chi-squared); I^2: Between-study heterogeneity (percentage); Tau^2: Estimate of between-study variance; Egger's test: Significance test for funnel plot asymmetry; *: p<0.05; **: p<0.01; ***p<0.001

3.5.4.1.5 Publication Bias

The majority of the funnel plots were asymmetrical, indicating that publication bias may be present (Figures A1-1 to A1-10, Appendix 1). The number of studies that fell outside of the funnel varied across the illness belief domains. The results of the Egger's test are shown in Table 3-3. Several of the illness belief domains that emerged as significant predictors of adherence to self-management behaviours, and were influenced by high heterogeneity, also appeared to be affected by publication bias: timeline acute-chronic, consequences, personal control, treatment control, and emotional representations. The trim-and-fill technique was applied to these domains, and following re-estimation, the effect sizes were smaller for several of these illness beliefs: timeline acute-chronic ($r+=0.01$, $p=0.80$), consequences ($r+=-0.01$, $p=0.39$), personal control ($r+=0.02$, $p=0.20$), and treatment control ($r+=0.06$, $p<0.001$). The latter was the only illness belief domain to retain statistical significance following application of the trim-and-fill method. In comparison to the main meta-analysis, these estimates were more conservative, with many of the effects sizes showing weaker (almost negligible) predictive relationships of individual illness belief domains with adherence to self-management behaviours, and statistical non-significance. Emotional representations were the exception, which retained a very small effect size that became statistically significant following application of the 'trim and fill' technique ($r+=0.06$, $p<0.01$). This indicated that emotional representations became a significant predictor of adherence to self-management behaviours.

3.5.4.1.6 Further Analyses

3.5.4.1.6.1 Sub-Group Analyses

Significant effect sizes were found for several of the illness belief domains, following stratification according to the type of self-management behaviour, acute or chronic disease, and ≤6-months versus >6-months follow-up (Tables 3-6 and 3-7). However, most of these were fairly similar across the groups (r+ typically around 0.10 to 0.20), which provided weak evidence for any of these factors having a moderating effect in the relationship between individual illness belief domains and adherence to self-management behaviours. It is important to note that in these further analyses, some of the sub-groups within each illness belief domain involved too few studies to allow for a valid comparison to be made, meaning that effect sizes were not possible to compute for the affected groups (highlighted in Tables 3-6 and 3-7).

Table 3-6. Summary of the meta-analysis results following stratification by the type of self-management behaviour

Illness belief domain	Number of studies	k	Correlations		Heterogeneity		
			r+ (95% CI)	p-value	Q (DF)	I^2	Tau^2
Identity	10	32	0.08 (0.04-0.12)	<0.001	226.71 (31)	86.3***	0.01
Attendance	4	12	0.09 (0.08-0.11)	<0.001	130.30 (11)	91.6***	-
Medication	4	5	-0-03 (-0.11-0.04)	0.41	1.88 (4)	0.0	-
Diet	1	4	-	-	-	-	-
Exercise	2	2	-0.07 (-0.17-0.02)	0.12	0.83 (1)	0.0	-
Other	3	9	0.19 (0.13-0.26)	<0.001	29.22 (8)	72.6***	-
Timeline (acute/chronic)	14	36	0.12 (0.06-0.17)	<0.001	269.19 (35)	87.0***	0.02
Attendance							
Medication	3	5	0.00 (-0.07-0.07)	0.99	21.11 (4)	81.1 ***	0.00
Diet	7	10	0.22 (0.09-0.35)	<0.01	65.38 (9)	86.2***	0.04
Exercise	3	11	0.12 (0.04-0.19)	<0.01	28.15 (10)	64.5**	0.01
Other	4	5	-0.02 (-0.14-0.10)	0.75	19.72 (4)	79.7**	0.02
	2	5	0.14 (0.05-0.23)	<0.01	4.56 (4)	12.3	0.00
Timeline-cyclical	7	25	-0.01 (-0.05-0.04)	0.83	54.71 (24)	56.1***	0.01
Attendance	1	1	-	-	-	-	-
Medication	3	4	0.08 (0.01-0.14)	<0.05	16.61 (3)	81.9**	-
Diet	3	11	-0.02 (-0.06-0.02)	0.29	6.07 (10)	0.0	-
Exercise	4	5	-0.02 (-0.08-0.03)	0.38	14.95 (4)	73.3**	-
Other	1	4	-	-	-	-	-
Consequences	16	67	0.04 (0.01-0.07)	<0.01	160.51 (66)	58.9***	0.01
Attendance	4	6	-0.01 (-0.05-0.04)	0.80	9.26 (5)	46.0	0.00
Medication	7	10	-0.04 (-0.09-0.02)	0.20	11.13 (9)	19.1	0.00
Diet	4	24	0.03 (-0.02-0.07)	0.29	43.29 (23)	46.9**	0.01
Exercise	4	10	-0.03 (-0.07-0.02)	0.23	4.64 (9)	0.0	0.00
Other	5	17	0.20 (0.12-0.26)	<0.001	34.25 (16)	53.3**	0.01
Illness belief domains		**k**	**Correlations**		**Heterogeneity**		

	Number of studies		r+ (95% CI)	p-value	Q (DF)	I^2	Tau^2
Treatment control	13	65	0.17 (0.09-0.16)	<0.001	122.25 (64)	47.6***	0.01
Attendance	1	2	-	-	-	-	-
Medication	7	10	0.08 (-0.02-0.17)	0.11	26.49 (9)	66.0**	0.02
Diet	4	25	0.15 (0.09-0.20)	<0.001	64.31 (24)	62.7***	0.01
Exercise	4	7	0.16 (0.10-0.22)	<0.001	5.01 (6)	0.0	0.00
Other	4	21	0.10 (0.05-0.14)	<0.001	21.21 (20)	5.7	0.00
Cure-control	6	15	0.07 (0.03-0.12)	<0.01	34.15 (14)	59.0**	0.00
Attendance	3	6	0.07 (0.04-0.09)	<0.001	27.10 (5)	81.50***	-
Medication	1	2	-	-	-	-	-
Diet	0	0	-	-	-	-	-
Exercise	2	3	0.10 (0.04-0.17)	<0.01	1.78 (2)	0.0	-
Other	1	4	-	-	-	-	-
Illness coherence	9	28	0.04 (0.01-0.08)	<0.05	31.92 (27)	15.4	0.00
Attendance	1	1	-	-	-	-	-
Medication	7	10	0.03 (-0.03-0.08)	0.31	7.58 (9)	0.0	-
Diet	2	10	0.05 (0.01-0.09)	<0.05	3.12 (9)	0.0	-
Exercise	3	3	0.02 (-0.06-0.10)	0.60	5.81 (2)	65.6	-
Other	1	4	-	-	-	-	-
Emotional representations	9	28	-0.01 (-0.06-0.05)	0.85	75.55 (27)	64.3***	0.01
Attendance	1	1	-	-	-	-	-
Medication	7	9	-0.01 (-0.06-0.05)	0.82	20.85 (8)	61.6**	-
Diet	3	11	-0.04 (-0.09-0.00)	<0.05	44.51 (10)	77.5***	-
Exercise	3	3	-0.03 (-0.11-0.05)	0.48	6.24 (2)	67.9*	-
Other	1	4	-	-	-	-	-
Causes	4	38	0.01 (-0.02-0.04)	0.45	55.69 (37)	33.6*	0.00
Attendance	2	4	0.01 (-0.02-0.04)	0.60	3.70 (3)	18.9	-
Medication	1	3	-	-	-	-	-
Diet	2	20	0.03 (-0.01-0.07)	0.16	33.62 (19)	43.5*	-
Exercise	2	5	-0.06 (-0.15-0.02)	0.14	3.10 (4)	0.0	-

Other	2	6	0.07 (-0.03-0.17)	0.17	8.84 (5)	43.5	-

Symbols and abbreviations: DF: Degrees of freedom; k: Number of unique data-sets; r+: Weighted correlation coefficient; Q: Between-study heterogeneity (chi-squared); I^2: Between-study heterogeneity (percentage); Tau^2: Estimate of between-study variance; -: Computation not possible, because analysis not appropriate; *: p<0.05; **: p<0.01; ***p<0.001

Table 3-7. Summary of the meta-analysis results following stratification by type of physical illness and length of follow-up

Illness belief domain	Number of studies	k	Correlations		Heterogeneity		
			r+ (95% CI)	p-value	Q (DF)	I^2	Tau^2
Identity	10	32	0.08 (0.04-0.12)	<0.001	226.71 (31)	86.3***	0.01
Acute	3	12	0.09 (0.04-0.14)	<0.01	132.72 (11)	91.7***	0.01
Chronic	7	20	0.08 (0.01-0.16)	<0.05	78.31 (19)	75.7***	0.02
≤ 6-months follow-up	4	9	0.08 (-0.02-0.18)	0.13	19.27 (8)	58.5*	0.02
> 6-months follow-up	6	23	0.08 (0.03-0.12)	<0.01	207.44 (22)	89.4***	0.01
Timeline (acute/chronic)	14	36	0.12 (0.06-0.17)	<0.001	269.19 (35)	87.0***	0.02
Acute	3	6	0.01 (-0.06-0.08)	0.79	22.52 (5)	86.2***	0.00
Chronic	11	30	0.14 (0.03-0.21)	<0.001	210.81 (29)	77.8***	0.03
≤ 6-months follow-up	4	9	0.12 (0.03-0.20)	<0.01	13.43 (8)	40.4	0.01
> 6-months follow-up	10	27	0.12 (0.05-0.18)	<0.001	251.71 (26)	89.7***	0.02
Timeline-cyclical	7	25	-0.01 (-0.05-0.04)	0.83	54.71 (24)	56.1***	0.01
Acute	1	2	-	-	-	-	-
Chronic	6	23	-	-	-	-	-
≤ 6-months follow-up	3	8	0.03 (-0.11-0.17)	0.67	33.24 (7)	78.9***	0.03
> 6-months follow-up	4	17	-0.02 (-0.05-0.01)	0.27	17.11 (16)	6.5	0.00
Consequences	16	67	0.04 (0.01-0.07)	<0.01	160.51 (66)	58.9***	0.01
Acute	3	6	-0.02 (-0.05-0.02)	0.32	6.85 (5)	27.1	0.00
Chronic	13	61	0.05 (0.02-0.09)	<0.01	144.38 (60)	58.4***	0.01
≤ 6-months follow-up	7	19	0.01 (-0.05-0.07)	0.71	35.46 (18)	49.2***	0.01
> 6-months follow-up	9	48	0.05 (0.02-0.09)	<0.01	124.89 (47)	62.4**	0.01
Illness belief domain		**k**	**Correlations**		**Heterogeneity**		

	Number of studies		r+ (95% CI)	p-value	Q (DF)	I^2	Tau^2
Personal control	11	49	0.07 (0.04-0.10)	<0.01	96.26 (48)	50.1***	0.01
Acute	0	0	-	-	-	-	-
Chronic	11	49	-	-	-	-	-
≤ 6-months follow-up	3	8	0.11 (0.00-0.22)	0.06	20.53 (7)	65.9**	0.02
> 6-months follow-up	8	41	0.06 (0.03-0.10)	<0.001	74.80 (40)	46.5**	0.01
Treatment control	13	65	0.13 (0.09-0.16)	<0.001	122.25 (64)	47.6***	0.01
Acute	0	0	-	-	-	-	-
Chronic	13	65	-	-	-	-	-
≤ 6-months follow-up	5	16	0.14 (0.04-0.23)	<0.01	51.20 (15)	70.7***	0.03
> 6-months follow-up	8	49	0.12 (0.09-0.15)	<0.001	71.05 (48)	32.4*	0.00
Cure-control	6	15	0.07 (0.03-0.12)	<0.01	34.15 (14)	59.0**	0.00
Acute	3	6	0.06 (-0.01-0.13)	0.09	25.21 (5)	80.2***	0.01
Chronic	3	9	0.10 (0.05-0.15)	<0.001	8.00 (8)	0.1	0.00
≤ 6-months follow-up	3	5	0.10 (0.02-0.17)	<0.05	4.32 (4)	7.3	0.00
> 6-months follow-up	3	10	0.07 (0.01-0.12)	<0.05	25.91 (9)	69.5**	0.00
Illness coherence	9	28	0.04 (0.01-0.08)	<0.05	31.92 (27)	15.4	0.00
Acute	1	2	-	-	-	-	-
Chronic	8	26	-	-	-	-	-
≤ 6-months follow-up	5	12	0.06 (-0.01-0.14)	0.10	20.19 (11)	45.4*	0.01
> 6-months follow-up	4	16	0.03 (0.00-0.07)	0.05	11.36 (15)	0.0	0.00
Emotional representations	9	28	-0.01 (-0.06-0.05)	0.85	75.55 (27)	64.3***	0.01
Acute	1	2	-	-	-	-	-
Chronic	8	26	-	-	-	-	-
≤ 6-months follow-up	5	12	0.03 (-0.05-0.11)	0.42	20.85 (11)	47.2*	0.01
> 6-months follow-up	4	16	-0.03 (-0.09-0.04)	0.41	49.22 (15)	69.5***	0.01
Causes	4	38	0.01 (-0.02-0.04)	0.45	55.69 (37)	33.60*	0.00
Acute	1	3	-	-	-	-	-
Chronic	3	35	-	-	-	-	-
≤ 6-months follow-up	1	6	-	-	-	-	-

> 6-months follow-up	3	32	-	-	-	-	-

Symbols and abbreviations: DF: Degrees of freedom; k: Number of unique data-sets; r+: Weighted correlation coefficient; Q: Between-study heterogeneity (chi-squared); I^2: Between-study heterogeneity (percentage); Tau^2: Estimate of between-study variance; -: Computation not possible, because analysis not appropriate; $p<0.05$; **: $p<0.01$; ***$p<0.001$

3.5.4.1.6.2 Meta-regression findings

There was no evidence of a confounding effect of the type of physical illness, acute or chronic, on relationships between individual illness belief domains and adherence to self-management behaviours for any of the individual illness belief domains (Table 3-8). This was also true of the year of publication of included studies; the type of self-management behaviour, apart from the consequences domain; and the duration of follow-up, except for the casual domain. It is also noteworthy that for the type of physical illness, a high correlation between the personal control and treatment control illness belief domains (collinearity) meant that it was not possible to conduct meta-regression analyses for either of these factors. Therefore, whether or not the type of physical illness, acute or chronic, confounded the relationships between personal control and treatment control beliefs and adherence to self-management behaviours was not answerable.

Table 3-8. Summary of the results from the meta-regression analyses to examine possible confounding factors

Illness belief domain	Publication year			Type of self-management behaviour (attendance, medication adherence, diet, exercise or other)			Type of physical illness (acute or chronic)			Length of follow-up (≤6-months or >6-months)		
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
Identity	-0.03	-0.06-0.00	0.08	0.02	-0.02-0.06	0.35	0.01	-0.13-0.12	0.89	0.01	-0.14-0.15	0.93
Timeline (acute/chronic)	0.02	0.00-0.05	0.09	0.01	-0.05-0.04	0.81	0.12	-0.03-0.27	0.11	0.00	-0.14-0.14	0.98
Timeline-cyclical	0.01	-0.03-0.05	0.55	-0.03	-0.08-0.21	0.24	0.12	-0.08-0.32	0.24	-0.06	-0.18-0.05	0.25
Consequences	0.00	-0.01-0.01	0.67	0.04	0.02-0.07	<.01	0.05	-0.06-0.15	0.36	0.05	-0.03-0.12	0.25
Personal control	0.01	-0.02-0.03	0.59	0.00	-0.04-0.03	0.90	-	-	-	-0.04	-0.14-0.06	0.43
Treatment control	-0.01	-0.03-0.01	0.25	0.00	-0.03-0.03	0.88	-	-	-	0.00	-0.08-0.08	0.92
Cure-control	0.00	-.00-0.01	0.41	0.00	-0.03-0.04	0.77	0.03	-0.07-0.13	0.56	-0.02	-0.13-0.09	0.71
Illness coherence	-0.01	-0.04-0.02	0.44	0.03	-0.01-0.06	0.12	0.02	-0.01-0.18	0.84	-0.02	-0.10-0.06	0.59
Emotional representations	0.01	-0.03-0.05	0.68	-0.03	-0.08-0.03	0.34	0.04	-0.17-0.26	0.68	-0.06	-0.17-0.05	0.26
Causes	0.00	-0.03-0.03	0.94	0.01	-0.02-0.03	0.75	0.00	-0.08-0.08	0.97	0.15	0.04-0.27	<0.05

Symbols and abbreviations: β: Point estimate from meta-regression; -: Problems with collinearity, meta-regression results were not computable

3.5.5 Narrative Review

There were several papers (N=31) that did not include sufficient information on effect sizes to allow for inclusion in the meta-analysis. Therefore, the following section of this chapter provides a brief narrative review of all the studies included in the review, in order to give the reader an overall picture of the literature in this area.

Thirty-four out of the 52 papers included in the review showed significant relationships between individual illness belief domains and adherence to self-management behaviours. Of these 34 papers, 16 reported on multiple self-management behaviours, and 21 found predictive relationships for several illness belief domains. Therefore, consistent with the meta-analysis, the number of unique datasets (k) varied for the narrative review. When examining this evidence, two distinct literatures emerged relating to studies investigating acute versus chronic diseases. High variability between studies meant that the literature could not be grouped according to specific types of physical illness or self-management behaviours. This was because too few studies (typically <3) contributed data; therefore, meaningful patterns could not be discerned according to these groupings.

A brief description of the literature according to acute versus chronic disease groupings is provided in this section. There were nine studies out of 34 that involved people with acute conditions. The majority of these papers (5 out of 9) examined patients with myocardial infarction (Studies 3, 27, 33, 50, and 52; Table 3-2), all of which found relationships of illness belief domains

specifically with attendance behaviours. The remaining 25 out of 34 studies involved patients with chronic illnesses, and within this, two distinct groupings emerged to reflect where most of the evidence had assembled. For example, the majority (14 out of 25 papers) comprised people with type 2 diabetes mellitus (N=8 out of 25, Studies 10, 11, 14, 16, 17, 21, 43, and 44; Table 3-2); or respiratory conditions of asthma (N=2 out of 25, Studies 13, and 36; Table 3-2) or chronic obstructive pulmonary disease (N=2 out of 25, Studies 8 and 40; Table 3-2). Study 31 (Table 3-2) examined both asthma and chronic obstructive pulmonary disease conditions. Most of the type 2 diabetes mellitus studies (6 out of 9) assessed multiple self-management behaviours (e.g., diet, physical activity, medication adherence, and other disease-specific behaviours), while those for respiratory disorders tended to examine medication adherence or attendance behaviours.

In terms of significant predictive relationships between illness belief domains and adherence to self-management, the most notable pattern to emerge referred to perceptions of cure/control. Irrespective of whether the condition was acute or chronic or the specific type of illness (e.g., type 2 diabetes mellitus or respiratory disorders), ten papers out of 34 (Studies 3, 8, 14, 16, 17, 31, 33, 43, 44 and 52; Table 3-2) found that beliefs about the amenability of the illness to cure or control significantly predicted all types of self-management behaviour investigated in this review (e.g., diet, physical activity, medication adherence, disease-specific behaviour (e.g., glucose testing) and attendance). However, there was limited reporting of effect sizes in these articles. Correlation coefficients were reported in four papers out of 10 (Studies 16, 17, 31 and 44;

Table 3-2) and these provided information only for the treatment control domain and medication adherence or lifestyle behaviours. On balance, these studies showed positive associations of moderate strength, meaning that beliefs about the effectiveness of treatment to manage peoples' condition predicted adherence to self-management behaviour. Odds ratios were reported by only one study out of 10 (Study 52), which indicated a similar pattern whereby drop-out from cardiac rehabilitation was predicted by weak beliefs around treatment effectiveness and strong beliefs about one's own ability to manage the condition.

Other illness belief domains to emerge as significant predictors of adherence regardless of whether the condition was acute or chronic, and for all self-management behaviours were: identity (N=4 out of 10, Studies 10, 27, 36, and 50; Table 3-2) and consequences (N=5 out of 10, Studies 14, 36, 44, 50, and 52; Table 3-2). However, there were fewer studies that found a significant predictive relationship for these domains compared to the evidence that emerged for cure/control beliefs. Effect sizes were reported for all four of the studies showing significant relationships for the identity domain, and these mostly referred to attendance behaviours. The findings indicated that perceptions of a lot of symptoms predicted greater attendance (e.g., doctor visits and attendance at rehabilitation), with weak to moderate effect sizes. In contrast, three out of the five studies where consequence beliefs emerged as significant predictors of attendance behaviours reported effect sizes (Studies 14, 36, 44, 50 and 52; Table 3-2). These showed relationships of moderate strength, where perceptions of seriousness of the condition predicted greater attendance.

Similarly, causal beliefs (mostly attributions to one's own behaviour, lifestyle, emotions and self-blame) emerged as significant predictors of attendance and lifestyle behaviours in particular (N=4 out of 10, Studies 3, 16, 40, and 44; Table 3-2), and these again emerged irrespective of whether the condition was acute or chronic. Effect sizes were reported in two of these four studies (Studies 16 and 44; Table 3-2), and broadly speaking, indicated that weak attributions to the abovementioned causal factors predicted greater adherence.

In contrast, some interesting patterns emerged only for the chronic disease studies. When reviewing this evidence, timeline (acute, chronic and episodic) (N=4 out of 34, Studies 13, 21, 31 and 44; Table 3-2) and illness coherence beliefs (N=1 out of 34, Study 31; Table 3-2); and emotional representations (N=2 out of 34, Studies 10 and 36; Table 3-2) emerged as predictors of adherence to self-management, specifically medication adherence and lifestyle behaviours. Effect sizes were reported in five out of these six papers (Studies 10, 21, 31, and 44; Table 3-2), and indicated that perceptions of an acute or episodic timeline, poor disease understanding, and considerable distress were all predictive of worse adherence to self-management.

3.6 DISCUSSION

3.6.1 Summary of the Key Findings

This chapter reports on a meta-analysis and narrative review undertaken to determine whether individual illness belief domains, outlined by the CSM, prospectively predicted adherence to self-management behaviours in

adults with physical illnesses. With the exception of timeline-cyclical and causal beliefs and emotional representations, the remainder of illness belief domains emerged as significant predictors of adherence to self-management behaviours. The results from the meta-analysis identified effect sizes ranging from 0.04 to 0.13, indicating weak, but significant, predictive relationships between individual illness belief domains and adherence to self-management behaviours. The meta-analysis also examined whether predictive relationships between individual illness belief domains and adherence to self-management behaviours varied according to acute and chronic illnesses; the type of self-management behaviour; and the duration of follow-up. However, the findings generally indicated that this was not the case, though this may be an artefact of the consistently small effect sizes found in this meta-analysis. The meta-analysis involving partial correlations (controlling for adherence to past self-management behaviours) showed consistently small, and significant, effect sizes ranging from 0.04 to 0.12, for a handful of individual illness belief domains (where this data were available): consequences; personal control; and treatment control. These again indicated weak, though significant, prospective relationships with adherence to self-management behaviours.

The findings from the narrative review were broadly consistent with the results from the meta-analysis, showing significance for the role of several domains of illness beliefs in the prediction of adherence to a range of self-management behaviours. Studies were highly heterogeneous, meaning that patterns according to specific types of physical illness or self-management behaviour were not discernible for the included papers. However, patterns did

emerge when studies were grouped according to acute versus chronic conditions. Beliefs about the amenability of the illness to cure or control, including one's own ability and particularly, that of their treatment to manage their condition, emerged to be the strongest predictors of adherence to a range of self-management behaviours. This was irrespective of the acute or chronic nature of the disease. Perceptions of a lot of symptoms were also found to predict greater attendance behaviour in both acute and chronic diseases. In contrast, weak causal perceptions (e.g., attributions to one's own behaviour, lifestyle, emotions, and self-blame), and beliefs about serious consequences of the condition, predicted greater attendance and adherence to lifestyle behaviours in these patients. Perceptions of an acute or episodic timeline, poor disease understanding, and considerable distress were found to predict worse adherence to self-management (medication adherence and lifestyle behaviours) specifically in people with chronic diseases. The reporting of effect sizes varied in the papers. However, studies that reported effect sizes generally showed significant relationships of moderate strength.

3.6.2 Comparison of Findings with Prior Literature

The findings from the present meta-analysis suggested that predictive relationships between individual illness belief domains, outlined by the CSM, and adherence to self-management behaviours exist, and were significant (albeit weak) for adults with acute or chronic physical illnesses. This is consistent with prior research from Brandes and Mullan (2014) that also focussed on the CSM framework and found similar effects for the role of

individual illness belief domains in predicting adherence in patients with chronic diseases.

It should be noted, however, that the effect sizes observed in the present meta-analysis are consistent with those that have been reported for other non-modifiable predictors of adherence. For example, a meta-analysis by DiMatteo (2004) reported similar small but significant pooled effect sizes for several factors in relation to adherence, including: age (r=0.00); gender (r=0.00); education (r=0.01); and income/socio-economic status (r=0.02). Therefore, both psychological modifiable and non-modifiable socio-demographic factors have similar weak but significant effects on adherence. However, psychological modifiable factors (e.g., peoples' beliefs) are amenable to change, and therefore, have the potential to improve adherence and other clinical outcomes (Petrie, Cameron et al. 2002, Broadbent, Ellis et al. 2009, Cunningham, Swanson et al. 2012, O'Carroll, Chambers et al. 2013).

Further, the small, but significant effect sizes observed in this review can still be clinically relevant, with implications for intervention. Frieden (2010) has argued that even interventions that when tested have shown small effect sizes can still perpetuate meaningful changes and have significant benefit to people when delivered at population level. For example, Lancaster, Stead et al. (2000) demonstrated that clinical public health interventions (e.g., nicotine replacement therapy) for smoking cessation and behavioural and psychological interventions (e.g., individual counselling) have similar modest, but significant effects (odds

ratio=1.71 and 1.55, respectively) and are therefore, analogous in reducing smoking behaviour.

The findings from the narrative review suggested a role for several illness belief domains (identity, cure-control, personal and treatment control, consequences and causes) in the prediction of adherence to a range of self-management behaviours in both acute and chronic conditions. This is consistent with Leventhal's original premise for the CSM, and the evidence that has particularly supported the relevance of these five illness belief domains irrespective of the acute versus chronic nature of the disease (Leventhal, Meyer et al. 1980, Leventhal, Benyamini et al. 1997, Leventhal, Brissette et al. 2003). However, the narrative review also highlighted that several illness belief domains, including timeline beliefs (acute or chronic), and domains added later to the model (illness coherence and emotional representations), were particularly significant in the prediction of adherence to self-management in people with chronic conditions. This is the only finding that is not consistent with the present meta-analysis or prior work by Brandes and Mullan (2014), both of which found that predictive relationships between illness belief domains and adherence did not differ according to acute versus chronic diseases. However, the broader adherence literature suggests that adherence can differ among acute or chronic diseases (DiMatteo 2004, Osterberg and Blaschke 2005). In extension of this, the present findings seem to suggest that patterns of illness beliefs also vary according to the type of physical illness, with some domains being more pertinent than others for acute versus chronic conditions.

Several methodological and theoretical issues were apparent while conducting the present systematic review and meta-analysis, which are worthy of discussion, and may partly explain the small effect sizes found.

3.6.3 Methodological Issues

To begin with, the statistical reporting of included papers was mostly inadequate, particularly in relation to effect sizes. There were many articles that did not report correlation coefficients. While attempts were made to obtain data directly from the authors of included papers, many articles where correlational analyses were not possible to acquire, had to be excluded from the meta-analysis. This meant that the number of datasets available for the meta-analysis, especially for the sub-analysis using partial correlations to examine prospective relationships, was considerably less than anticipated. Therefore, the present statistical analyses were constrained in several ways.

First, additional data on partial correlations would have allowed for a more robust examination of prospective relationships between individual illness belief domains and adherence to self-management behaviours, enabling firmer conclusions to be drawn. Second, a more sophisticated analysis of moderators of the relationship between individual illness belief domains and adherence to self-management behaviours, controlling for baseline adherence to self-management behaviours, would have been ideal to perform. This particular type of analysis, such as hierarchical meta-analysis, would have been viable provided that there were sufficient data on partial correlations available from included studies. McEachan, Conner et al. (2011) provide an exemplar of this

analysis, which supported their evaluation of the efficacy of the Theory of Planned Behaviour, for prospectively predicting health-related behaviours.

Third, given the importance of the emotional pathway in the CSM (highlighted in Chapter 2), and the evidence in Chapter 1 suggesting that mood is a key precursor to poor adherence, it may have also been appropriate to consider the role of psychological distress in the predictive relationships reported in this meta-analysis. However, nearly all of the studies included in the present review did not provide information about this relationship to allow for any statistical examination of the role of psychological distress as a mediator, moderator or confounder in associations between illness beliefs and adherence to self-management behaviours. Nonetheless, several other potential moderators of the predictive relationship between individual illness belief domains and adherence to self-management behaviours were possible to examine statistically: for example, the type of self-management behaviour; acute versus chronic diseases; and the duration of follow-up. However, none of these emerged as important moderators or confounders, which means that predictive relationships were not influenced by any of these factors.

3.6.4 Theoretical Issues

3.6.4.1 Treatment Beliefs

One aspect of the CSM that was not possible to examine thoroughly in this review concerns treatment beliefs. In conducting the review, it became apparent that although peoples' beliefs about their treatment were captured, it was only in a limited way.

While the CSM assesses a dimension of peoples' treatment beliefs (including, medication) within the treatment control domain, there is a considerable body of literature that has extended the CSM (Horne and Weinman 1999). This literature has specifically considered the views that people have that are relevant to taking their medication (but not other aspects of treatment), and has demonstrated that these predict subsequent medication adherence (Gatti, Jacobson et al. 2009, Allen LaPointe, Ou et al. 2011, Horne, Chapman et al. 2013, Sjölander, Eriksson et al. 2013, Jamous, Sweileh et al. 2014, Sweileh, Zyoud et al. 2014). This work has drawn on the 'Necessity-Concerns Framework,' which suggests that people undertake a cost-benefit analysis of their medication, where their own beliefs about the necessity of their medication for improving or maintaining their health are weighed up against their concerns about possible adverse effects (Horne and Weinman 1999). These medication beliefs can be measured using a validated questionnaire: the Beliefs about Medicines Questionnaire (Horne, Weinman et al. 1999).

However, treatment can incorporate much more than simply medication-taking (e.g., lifestyle behaviour and surgery), and it is likely that patients also hold particular beliefs about these treatments that can affect how well they engage or their outcomes. This is an under-researched area at present in relation to the CSM. Thus far, only one study adopting the CSM has examined what patients with coronary artery disease think about their treatments, where the beliefs of people with the same condition receiving diverse treatments (medication or revascularisation surgery e.g., angioplasty or bypass procedures) were compared (Hirani and Newman 2005). This study indicated that

individuals evaluate their treatment based not only on beliefs about the ability of the treatment to cure their condition (as per Leventhal's treatment control domain from the CSM), but also on their concerns and risks of undergoing the treatment (consistent with the Necessity-Concerns framework); the value that they ascribe to their treatment; and their satisfaction with the choice of treatment that they have been offered. Further, and in-keeping with the premise of the CSM, the authors found that this elaboration of treatment beliefs was closely related to peoples' emotional states, where high concern led to more substantial levels of anxiety and depression despite an individual's satisfaction with the choice of treatment. This research also involved the development of a study-specific instrument to measure these wider treatment beliefs, named the 'Treatments Representations Inventory' (Hirani, Patterson et al. 2008).

A related issue is that of inadequate reporting across studies. First, treatment beliefs were not consistently measured by included studies. Second, where treatment beliefs were measured (e.g., N=10 out of 52 papers in the present review), the statistical information that was reported was so limited that it made it impossible to adjust for the effect of treatment beliefs in the present meta-analysis. It is, therefore, recommended that future studies should incorporate simultaneous assessment of treatment beliefs (not just medication beliefs) alongside the more traditional measurement of the treatment control domain of the CSM. In addition, it would be helpful for papers to provide sufficient information (at the very minimum on effect sizes), in order to allow a better appreciation of the role of treatment beliefs in predicting adherence to self-management in future meta-analyses of this literature.

3.6.4.2 Illness Belief Schema

It was highlighted in Chapter 2 (section 2.4.2) that another important feature of the CSM is around illness belief schemas (Leventhal, Meyer et al. 1980, Henderson, Orbell et al. 2009), though this was not considered in the present review. Therefore, it may be that the weak effects that have been reported in this chapter are an artefact of the fact that the CSM was not investigated appropriately (i.e., the model as a whole).

Recent studies have shown that when illness belief domains are examined collectively as part of a schema, such as through cluster analysis methods (further elaborated in Chapter 7, section 7.16), they predict several physical, psychological, coping, and behavioural outcomes, including adherence to self-management (Clatworthy, Hankins et al. 2007, Medley, Powell et al. 2010, Skinner, Carey et al. 2011, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, McCorry, Dempster et al. 2013, Harrison, Robertson et al. 2014, Snell, Surgenor et al. 2014).

For example, one study derived several clusters for people with hypertension based on their beliefs about their illness (Hsiao, Chang et al. 2012). It was observed that where participants had less negative consequence beliefs and emotional representations, and low personal control, medication adherence was optimal. Whereas people clustered on the basis of more negative consequence beliefs and emotional responses to their illness, but high personal and treatment control, fared worse in terms of medication adherence. Similarly, two studies examining patients following traumatic brain injury found three

meaningful clusters to emerge based on their beliefs about their injury, and self-awareness (Medley, Powell et al. 2010) or distress and symptom burden (Snell, Surgenor et al. 2014). These studies showed that 'Low Adapters' and people with low control beliefs or who were ambivalent, had worse coping, and poorer six-month outcomes following injury. In contrast, 'High Adapters' and people with beliefs about serious consequences and greater self-awareness ('High Salience' cluster) coped better and showed a good recovery. A further study identified three clusters in relation to beliefs about mild cognitive impairment: 'Few symptoms and positive beliefs,' 'Moderate symptoms and positive beliefs,' and 'Many symptoms and negative beliefs' (Lin and Heidrich 2012). People in the 'Few symptoms and positive beliefs' cluster were found to cope better with their mild cognitive impairment compared to the other clusters, including the adoption of fewer memory aids and problem-focused, emotion-focused and dysfunctional coping strategies.

Therefore, examining illness beliefs collectively in relation to adjustment (including, coping e.g., treatment adherence) may have greater predictive power than investigating the role of each domain individually. However, whether or not this is the case is not possible to evaluate at the moment from the CSM literature as it currently stands. In consequence, it is recommended that future research considers examining the predictive utility of the CSM as a whole, rather than only the component parts of the model (i.e., individual illness belief domains). In conducting the present review, it was ascertained that this type of analysis would not currently be feasible. This is because papers have not reported sufficient information about inter-relationships

between individual illness belief domains and adherence to self-management behaviours. In light of this, future studies are strongly encouraged to provide these details, even if as a supplementary file, to allow for this evaluation of the predictive utility of the CSM as a whole.

3.6.5 Strengths and Limitations

A particular strength of the present review was its' inclusiveness. This research extended previous reviews (e.g., Brandes and Mullan (2014)) by examining a broader range of self-management behaviours, including attendance, and acute (such as, common cold) as well as chronic conditions (for example, asthma). However, with this inclusiveness, the studies included were heterogeneous, such as for the specific types of physical illnesses examined (e.g., myocardial infarction, type 2 diabetes mellitus etc.), which presented challenges for synthesising the literature. The diversity of the included studies meant that certain analyses were not possible to perform (for example, sub-group analysis by specific illness types). The heterogeneity between studies affected the pooled correlations for particular illness belief domains more extremely than others. Similar problems with heterogeneity were found in the recent paper by Brandes and Mullan (2014). Random effects models were used for the meta-analysis to account for this as much as possible. In addition, further analyses were undertaken in an attempt to explain the heterogeneity; though these findings suggested that there may be factors other than those tested in this meta-analysis (e.g., specific illness types) that may be contributing to the diversity between studies. A further strength of the present review was the reporting of a sub-analysis of prospective relationships (controlling for past

adherence to self-management behaviour) offering valuable information on causality in predictive relationships between individual illness belief domains and adherence to self-management. Previous research has been limited by the assessment of only cross-sectional relationships. Finally, robust methods were employed for the review. This included conduct of the systematic review in accordance with best practice guidelines (e.g., the Cochrane Collaboration (Higgins and Green 2011)), and reporting of the research using relevant frameworks (Moher, Liberati et al. 2009, Cooper 2010).

A limitation of this review was the strict focus on people with physical illnesses. Studies exploring illness beliefs in people with mental health disorders were excluded. The rationale for this was twofold. First, this was the approach that prior (and similar) studies examining the relationship of illness beliefs with adherence/coping have adopted (e.g., Brandes and Mullan (2014); Hagger and Orbell (2003); and Law, Tolgyesi et al. (2014)). Therefore, in order to ensure comparability of the present findings to those from these reviews, it was deemed prudent to restrict the focus to people with physical disorders. Other reviews (such as, Baines and Wittkowski (2013)) have recently done similar by synthesising the evidence for individual illness belief domains and coping amongst people with mental health disorders (including, psychosis, bipolar disorder, eating disorders, depression and adolescents experiencing mood disorders). In consequence, this separation of the literature appears to be a widely advocated approach for systematic reviews in this field. Second, this approach makes particular sense given that there have been suggestions that the relationship of illness beliefs with adherence to self-management likely differs

according to physical versus mental health conditions (Petrie, Broadbent et al. 2008).

There was also some evidence of publication bias found in this review, with many of the illness belief domains showing asymmetric funnel plots, suggesting that not all of the studies that could have been included were actually included in the meta-analysis. Significant efforts were made to obtain relevant research by conducting systematic searches of both the published and grey literature in this area. However, publication bias remains an issue, as it was in the review by Brandes and Mullan (2014). In hindsight, it may be that prominent authors in this field and distribution lists of relevant associations, have literature that was not obtained for this review; future reviews are strongly encouraged to pursue this avenue when conducting searches of this literature.

The problems with publication bias were addressed, as far as possible, statistically (for example, the 'trim and fill' method). The findings following re-estimation of the meta-analysis were broadly similar, albeit more conservative. It should also be noted though that the interpretation of funnel plots be approached with caution, as there may be factors other than reporting bias (for example, delayed publication and selective reporting of outcomes or analyses) that contribute to funnel plot asymmetry (Terrin, Schmid et al. 2003, Sterne, Sutton et al. 2011). For instance, high heterogeneity and poor methodological quality of studies may result in skewed funnel plots: both of these issues were highly relevant to the present study, and have been discussed in earlier sections of this chapter.

3.6.6 Conclusion

The present systematic review and meta-analysis have shown that predictive relationships between individual illness belief domains, outlined by the CSM, and adherence to self-management behaviours (including: attendance, medication adherence, dietary and physical activity advice, and disease-specific behaviours) are significant but weak. The type of physical disease, acute or chronic; the type of self-management behaviour; or the duration of follow-up do not appear to moderate these relationships. Further, prospective relationships, controlling for past adherence to self-management behaviour, are also weak. Therefore, based on the evidence to date, this review suggests that individual illness belief domains may account for a significant but small amount of the variance in patients' adherence to self-management behaviours. Future studies should, however, examine the utility of the CSM as a whole (i.e., using illness beliefs schemas) for prospectively predicting adherence to self-management behaviours, rather than only examining the component parts (i.e., individual illness belief domains). Further research should also carefully consider the role of treatment beliefs (medication and broader aspects of treatment e.g., surgery), as per the Necessity-Concerns Framework, enabling future reviews to examine whether treatment beliefs moderate or independently predict adherence to self-management behaviours.

Finally, in order to improve the robustness of future meta-analyses, studies need to pay careful attention to conducting more comprehensive searches of the unpublished (or grey) literature in this area (though issues around the accessibility of unpublished data may become relevant); and to the reporting of

effect sizes, particularly correlation coefficients. This includes partial correlations, to allow for further examination of prospective relationships; and inter-correlation matrices for relationships between individual illness belief domains, adherence to self-management behaviours, and psychological distress (e.g., depression). All of which would provide data for analyses of illness belief schemas and additional possible moderators.

3.7 CHAPTER SUMMARY

Chapter 3 was closely related to the previous chapter, which provided the background to the CSM and illness beliefs. Here, the relationship of individual illness belief domains with treatment adherence was considered in a systematic review and meta-analysis. The review focused on adherence to self-management in people with a range of acute and chronic physical health conditions. Significant (albeit weak) relationships emerged, and these were discussed in light of several methodological and theoretical issues. The next chapter will extend the work presented here, and further examine the potential utility of the CSM for stroke.

CHAPTER 4. REVIEW OF THE LITERATURE ON THE COMMON SENSE MODEL AND STROKE AND CRITICAL REVIEW OF POST-STROKE OUTCOME MEASURES

4.1 CHAPTER OVERVIEW

Chapter 4 extends the work presented in Chapter 3, and is separated into two parts. Chapter 4 will first consider the existing evidence for the CSM in stroke, highlighting that this literature has mostly examined outcomes of mood and medication adherence. However, there are several other outcomes that also have relevance to recovery after stroke, including HRQL and disability. These will be summarised in the second part of Chapter 4, briefly highlighting pertinent examples from the wider CSM literature where the prediction of these outcomes have been examined in relation to illness belief domains. This part of Chapter 4 will also provide a critical review of the outcome measures for post-stroke recovery, in order to inform the selection of primary and secondary measures for the observational study component of the present PhD research (reported in Chapter 7). Last, the conceptual model on which the research questions and hypotheses to be investigated in Chapter 7 will be introduced.

4.2 THE ROLE OF ILLNESS BELIEFS IN PREDICTING OUTCOMES AFTER STROKE

Eleven studies have thus far been undertaken to examine the CSM in relation to stroke. These have predominantly explored relationships between individual illness belief domains and outcomes of mood and medication

adherence. Of these 11 studies, eight have been published (Johnston, Morrison et al. 1999, Johnston, Bonetti et al. 2007, O'Carroll, Whittaker et al. 2011, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012, O'Carroll, Chambers et al. 2013, Sjölander, Eriksson et al. 2013, Phillips, Diefenbach et al. 2015); two were conference presentations (Joice, Johnston et al. 2002, Joice, Bonetti et al. 2003); and one was a doctoral thesis (Ford 2007).

To summarise the characteristics of these studies: the majority (6 out of 11) were conducted in a hospital setting, either in England (Ford 2007, Twiddy, House et al. 2012), Scotland (Johnston, Morrison et al. 1999, O'Carroll, Whittaker et al. 2011, O'Carroll, Chambers et al. 2013) or Sweden (Sjölander, Eriksson et al. 2013). The remainder took place in a community setting in the USA (Klinedinst, Dunbar et al. 2012, Phillips, Diefenbach et al. 2015) or Scotland (Johnston, Bonetti et al. 2007). The location and setting were not reported by the two studies that were conference presentations (Joice, Johnston et al. 2002, Joice, Bonetti et al. 2003). Four out of the 11 papers were single-centre studies (Johnston, Bonetti et al. 2007, O'Carroll, Whittaker et al. 2011, Twiddy, House et al. 2012, O'Carroll, Chambers et al. 2013), while three out of 11 were conducted across multiple centres (Ford 2007, Klinedinst, Dunbar et al. 2012, Sjölander, Eriksson et al. 2013), and the remainder did not report on this information.

Papers adopted a mixture of study designs, where five out of 11 were longitudinal observational (Johnston, Morrison et al. 1999, Joice, Johnston et al. 2002, O'Carroll, Whittaker et al. 2011, Twiddy, House et al. 2012, Phillips,

Diefenbach et al. 2015); four out of 11 were cross-sectional (Joice, Bonetti et al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Sjölander, Eriksson et al. 2013); and two out of 11 were RCTs (Johnston, Bonetti et al. 2007, O'Carroll, Chambers et al. 2013). As noted in Chapter 2 (section 2.4.2), Hagger and Orbell (2003) argued that a limitation of prior CSM research examining the relationship between illness beliefs and coping has been the disproportionate number of studies adopting cross-sectional designs. This, however, does not appear to be the case for the 11 CSM studies conducted with stroke survivors and reviewed in this section. A large proportion of these (7 out of 11) used longitudinal designs, which is an obvious strength of this literature, most of which has been undertaken recently in the last five-years. The majority of these studies (7 out of 11) recruited survivors within the acute phase of stroke, varying from two to 12-weeks post-stroke, which is again the period of greatest interest to the present PhD research. Consistent with the papers included in the systematic review (Chapter 3), the length of follow-up in these studies varied between two-weeks and six-months post-stroke.

These studies broadly included participants aged between 62 and 75-years, though many of the samples (6 out of 11) comprised older patients around 69-years old (Johnston, Morrison et al. 1999, Joice, Johnston et al. 2002, Johnston, Bonetti et al. 2007, O'Carroll, Whittaker et al. 2011, Klinedinst, Dunbar et al. 2012, O'Carroll, Chambers et al. 2013). None of these studies specifically examined younger stroke survivors (<50 years). Five out of the 11 studies involved patients with a first-ever (mostly ischaemic) stroke. One paper out of 11 (Phillips, Diefenbach et al. 2015) examined recurrent stroke. There

was a lack of clarity with regard to this information from the remaining five out of 11 papers. It was evident from eight out of these 11 studies that participants were only included if they were without significant cognitive or communication problems, and this was formally assessed in these papers using well-established instruments. These are discussed later in section 4.3 of this chapter. In addition, it was apparent that the samples in three out of these 11 papers mostly comprised high functioning participants, with relatively little residual disability following stroke (Johnston, Bonetti et al. 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012). Information of post-stroke disability was not discernible from the remainder of papers.

While the CSM literature undertaken with stroke survivors thus far has employed various approaches for measuring medication adherence and mood, a notable strength has been in the use of validated approaches (e.g., the Medication Adherence Report Scale (section 5.2.2, Chapter 5) or the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983) (elaborated later in section 4.3.1 of this chapter)). A limitation of the literature as it currently stands, however, is that only very few studies (3 out of 11) incorporated stroke-related outcome measures (e.g., disability) alongside measurement of their primary outcomes of interest (e.g., medication adherence and/or mood) (Johnston, Morrison et al. 1999, Johnston, Bonetti et al. 2007, Twiddy, House et al. 2012). These post-stroke outcome measures would have provided supplementary information with regard to the type of participants recruited, and a broader picture of recovery after stroke (e.g., stroke severity), of which medication

adherence and mood are of course a key part. Post-stroke outcome measures are considered in detail in later parts of this chapter (section 4.3).

Sample sizes also varied across the studies, with six out of 11 involving fewer than 100 participants (Johnston, Morrison et al. 1999, Joice, Bonetti et al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012, O'Carroll, Chambers et al. 2013). Of these six studies, four were especially limited by their sample size, with around 40 participants or fewer recruited (Joice, Bonetti et al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012). Comparably, the remainder of studies benefitted from considerably larger samples sizes of between 100 and 600 participants (Joice, Johnston et al. 2002, Johnston, Bonetti et al. 2007, O'Carroll, Whittaker et al. 2011, Sjölander, Eriksson et al. 2013, Phillips, Diefenbach et al. 2015). Carers (informal, unpaid, and generally friends or relatives) were involved in two of the 11 studies (Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012).

The overall findings from these 11 CSM studies are summarised below according to the predominant outcomes that have been measured: mood and medication adherence.

4.2.1 Illness Beliefs and Mood after Stroke

Significant associations between illness belief domains and mood were found in four out of 11 studies (Joice, Bonetti et al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012). Specific illness

beliefs that were implicated in worse mood were: perceptions of a lot of symptoms; serious consequences; chronicity or a fluctuating nature of the condition; inability of treatment to manage the illness; poor disease understanding; and considerable distress.

Beliefs around the cause of stroke being attributed to psychological factors were also significantly associated to worse mood amongst stroke survivors in two of these four studies (Ford 2007, Twiddy, House et al. 2012). Effect sizes were reported by two out of four papers, and showed moderately strong relationships (Spearman's rho or r between 0.3 and 0.5) (Joice, Bonetti et al. 2003, Ford 2007).

4.2.2 Illness Beliefs and Medication Adherence after Stroke

Illness beliefs predicted medication adherence in stroke survivors in only two out of 11 papers (Sjölander, Eriksson et al. 2013, Phillips, Diefenbach et al. 2015). In particular, beliefs about the inability of treatment to manage the illness and considerable distress were implicated in medication non-adherence. Effect sizes were reported by Phillips, Diefenbach et al. (2015), and these showed correlations of weak to moderate strength (r ranging from 0.10 to 0.33). One study was on-going and did not report any findings (Joice, Johnston et al. 2002).

Four out of the 11 studies indicated that there may be a role for wider beliefs about treatment, specifically peoples' beliefs about their medication, in predicting medication adherence (O'Carroll, Whittaker et al. 2011, O'Carroll,

Chambers et al. 2013, Sjölander, Eriksson et al. 2013, Phillips, Diefenbach et al. 2015). This is consistent with discussions emerging from the systematic review and meta-analysis reported in the previous chapter (section 3.6.4.1 of Chapter 3). Effect sizes were reported by Sjölander, Eriksson et al. (2013), and these showed a relationship of moderate strength between treatment beliefs and medication adherence, with significant odds ratios ranging from 0.77 to 1.29.

4.2.3 Concluding Remarks for Section 4.2

In summary, 11 studies have examined the association of illness beliefs with outcomes amongst stroke survivors. This evidence is comparable to other conditions, such as diabetes mellitus. Three key systematic reviews exploring the relationship between illness beliefs and adherence to self-management, which were previously highlighted in Chapter 3, showed that diabetes mellitus has been represented by a majority of studies on the CSM (Hagger and Orbell 2003, Brandes and Mullan 2014, Law, Tolgyesi et al. 2014). For instance, diabetes mellitus contributed 10 out of 30; 12 out of 45; and 7 out of 15 studies in the Brandes and Mullan (2014); Hagger and Orbell (2003); and Law, Tolgyesi et al. (2014) respectively. In comparison to conditions such as cancer (N=1 (Hagger and Orbell 2003)); cystic fibrosis (N=1 (Brandes and Mullan 2014) and N=1 (Law, Tolgyesi et al. 2014)), and coeliac disease (N=1 (Brandes and Mullan 2014)), stroke has been well represented in CSM studies.

However, the studies that have been conducted in stroke have predominantly focused on high functioning older adults, without significant cognitive or communication problems following a first-stroke, and post-stroke

outcomes of mood and medication adherence. Therefore, consistent with the systematic review reported in Chapter 3, there is a lack of evidence examining stroke survivors' adherence to a broader range of self-management behaviours, other than medication adherence (for example, rehabilitation attendance), which are also integral to recovery after stroke. In addition, there are various other aspects of recovery after stroke (e.g., Quality of Life (QOL) and disability) that should also be considered in the CSM literature on stroke. Thus far, there was only one study where functional outcomes after stroke were examined, and showed that better recovery from disability was predicted by survivors' beliefs about the controllability of their stroke (Johnston, Morrison et al. 1999). Therefore, there is a need for additional literature examining the relationship of illness beliefs with a broader range of self-management behaviours (e.g., attendance and lifestyle) that are relevant to stroke. Also, studies should incorporate the diversity of post-stroke recovery outcomes that are usually considered in acute stroke trials (e.g., QOL and disability). Nonetheless, the findings from these 11 studies on the CSM in stroke suggest promise in the application of this model to this patient group, whereby most of the illness belief domains were implicated as predictors of worse mood and medication non-adherence.

To this end, Chapter 4 will now consider the various outcome measures for evaluating recovery after stroke, and will critically review the different approaches. This will provide the reader with an understanding of the rationale for the selection of outcome measures adopted in the observational study (see Chapter 7).

4.3 POST-STROKE OUTCOME MEASURES

The progress of stroke survivors in their recovery journey should be regularly monitored, and where this happens, it is often with questionnaires (National Institute for Health and Care Excellence 2013). It has been recognised that one instrument is insufficient in measuring all of the aspects of post-stroke recovery that need to be charted for an individual, though there has been a lack of clarity in the literature on the optimal instruments to be used (Duncan, Jorgensen et al. 2000, Harrison, McArthur et al. 2013, Bernhardt, Borschmann et al. 2016). It is considered that the ideal instrument would be simple and brief to administer, with sound psychometric properties (e.g., reliability and validity), and responsiveness, which refers to the sensitivity of the instrument to changes in patients over time and can indicate therapeutic effects (Barak and Duncan 2006, Harrison, McArthur et al. 2013).

The International Classification of Functioning, Disability and Health (ICF) is a framework for health and disability from the World Health Organisation (World Health Organisation 2001), which has added some clarity, and suggests that post-stroke recovery outcomes can be assessed at several levels: impairments; activities; and participation (Salter, Jutai et al. 2005, Salter, Jutai et al. 2005, Salter, Jutai et al. 2005). The choice of standardised and valid assessment instruments to evaluate peoples' post-stroke impairments and functional status is vast, many of which also fall within the ICF categories (Duncan, Zorowitz et al. 2005, Barak and Duncan 2006, Harrison, McArthur et al. 2013).

The instruments that are most commonly utilised for stroke survivors, particularly those that are adopted locally, are especially relevant to this PhD thesis and will be critically reviewed in this section.

4.3.1 Impairments

Neurological examination of acute stroke is routinely undertaken upon hospital admission, or as soon as possible thereafter, using the National Institutes of Health Stroke Scale (Duncan, Zorowitz et al. 2005, Jauch, Saver et al. 2013). This is a quick, reliable and valid measure of post-stroke acuity and neurological deficit (Lyden, Brott et al. 1994, Muir, Weir et al. 1996, Goldstein and Samsa 1997, Hinkle 2014). It comprises 11 items examining various aspects of neurological impairment, including: levels of consciousness; vision and gaze; facial palsy; arm and leg drift; limb ataxia (uncoordinated movement); sensory disturbances; aphasia and dysarthria; and neglect (Brott, Adams et al. 1989). The instrument importantly provides information on the severity of stroke, which is an influential factor in post-stroke recovery (Barak and Duncan 2006). It has also shown utility for predicting post-stroke prognosis, including 30-day mortality (Weimar, Konig et al. 2004, Fonarow, Saver et al. 2012).

Post-stroke *cognition* can be assessed using several instruments, though cognitive assessments have often been neglected in stroke research (Lees, Fearon et al. 2012).

The Mini-Mental State Examination has been used more commonly than other cognitive assessment instruments, such as the Montreal Cognitive

Assessment (Barak and Duncan 2006, Lees, Fearon et al. 2012). The Mini-Mental State Examination was originally developed to screen for dementia and delirium, and there is some evidence that the measure has utility for assessing vascular dementia in stroke survivors (Nys, van Zandvoort et al. 2005, Bour, Rasquin et al. 2010, Naco, Dobi et al. 2013). However, with regard to milder cognitive impairment or memory problems after stroke, this instrument performs poorly (Blake, McKinney et al. 2002, Nys, van Zandvoort et al. 2005). The research papers to suggest this have cited problems with cut-points, suggesting that the well-established cut-off value of 24 shows a lack of sensitivity for identifying stroke survivors with impaired cognition (Nys, van Zandvoort et al. 2005). This means that as a screening instrument, the Mini-Mental State Examination is not able to adequately determine which patients require further evaluation for their cognitive impairments (Blake, McKinney et al. 2002), and has a tendency to underestimate the problems with cognition in this group (Pendlebury, Cuthbertson et al. 2010).

The Montreal Cognitive Assessment has been developed more recently, and provides a generalised cognition score of pass or fail (Nasreddine, Phillips et al. 2005). However, there is evidence indicating that this instrument offers a promising alternative to the Mini-Mental State Examination for stroke survivors, particularly when evaluating milder post-stroke cognitive impairment (Hachinski, Iadecola et al. 2006, Popovic, Seric et al. 2007, Pendlebury, Cuthbertson et al. 2010). For example, when compared to the Mini-Mental State Examination, the Montreal Cognitive Assessment identifies a considerably greater number of patients with cognitive problems (greater sensitivity)

(Pendlebury, Cuthbertson et al. 2010, Cumming, Churilov et al. 2013). However, it has also been found that the Montreal Cognitive Assessment has poorer specificity than the Mini-Mental State Examination, meaning that it is worse at accurately identifying people without cognitive problems (Cumming, Churilov et al. 2013). On the other hand, the Montreal Cognitive Assessment has been shown to have utility as an outcome measure in stroke research (Cumming, Bernhardt et al. 2011).

Interestingly, UK clinical guidelines on stroke have emphasised the importance of assessing stroke survivors' cognitive performance across various different domains (e.g., aphasia, visual loss, attention, perception, and reading or writing problems) (National Institute for Health and Care Excellence 2013). However, neither the Mini-Mental State Examination or Montreal Cognitive Assessment comprise any such domain-specific assessment (Demeyere, Riddoch et al. 2015). Furthermore, it has been argued that instruments such as the Montreal Cognitive Assessment demand adequate verbal abilities and would therefore, be highly inappropriate for stroke survivors with aphasia (Demeyere, Riddoch et al. 2015).

In light of these limitations, a further and domain-specific screening instrument for problems with cognition after stroke has recently been developed, called the Oxford Cognitive Screen (Demeyere, Riddoch et al. 2015). This is a brief instrument that is specific to stroke, covering the majority of domains of cognition that are likely to be impaired following stroke, and is suitable for survivors with aphasia (Demeyere, Riddoch et al. 2015). In addition, the Oxford

Cognitive Screen goes beyond a simple pass or fail result, generating domain-specific scores that can be beneficial for guiding peoples' post-stroke rehabilitation (Demeyere, Riddoch et al. 2015). When compared to the Montreal Cognitive Assessment, the Oxford Cognitive Screen has also demonstrated greater sensitivity (Demeyere, Riddoch et al. 2015).

Despite the promise of the Oxford Cognitive Screen, this instrument was not available for use when the present PhD research was undertaken. Rather, the Mini-Mental State Examination and Montreal Cognitive Assessment were the instruments most commonly used locally for cognitive assessments of survivors admitted to hospital following stroke. This is also true of the National Institutes of Health Stroke Scale, which was the local measure of choice for routine post-stroke neurological assessment. Whether or not instruments were used routinely locally was an important pragmatic consideration when selecting the most appropriate measures to be adopted in the observational study reported in Chapter 7.

Psychological outcomes after stroke are difficult to assess, given the complexity of post-stroke impairments (section 1.2.3, Chapter 1), and also the overlap between stroke symptoms and those of common mental disorders, such as depression and anxiety (Kneebone and Lincoln 2012). Individual clinical interviews are the 'gold standard' approach to diagnosis, though there are several screening instruments that have shown utility for identifying symptoms, particularly of depression, in stroke survivors (Bennett and Lincoln 2006, Lincoln, Kneebone et al. 2012). With the exception of the Hospital Anxiety and

Depression Scale, which is described later in this section, there are few instruments available to measure post-stroke anxiety and emotionalism (Kneebone and Lincoln 2012).

Particular instruments for assessing mood in stroke survivors have been utilised more commonly than others, though it has been argued that these have utility for the purposes of screening rather than diagnosis (Lincoln, Nicholl et al. 2003, Barak and Duncan 2006, Bennett and Lincoln 2006, Lees, Fearon et al. 2012, Lincoln, Kneebone et al. 2012, Lees, Broomfield et al. 2014). The most commonly used instruments are briefly described below.

The Centre for Epidemiological Studies Depression Scale is a 20-item self-report instrument that was originally designed to measure depressive symptomatology, according to the formal American Psychiatric Association Diagnostic and Statistical Manual (DSM) criteria for major depressive disorder, in the general population (Radloff 1977). However, the Centre for Epidemiological Studies Depression Scale has since shown reliability and validity for people with stroke, and has recently been advocated as a promising instrument showing high sensitivity in identifying survivors with probable depression (Shinar, Gross et al. 1986, Parikh, Eden et al. 1988, Meader, Moe-Byrne et al. 2013).

Further instruments that are based on the DSM criteria are the 21-item Beck Depression Inventory-I and Beck Depression Inventory-II, both of which assess the intensity of depressive symptoms (Beck, Ward et al. 1961,

Beck, Steer et al. 1996, Beck, Guth et al. 1997). While these instruments have both shown validity and accuracy for measuring depressive symptoms in stroke survivors, recent evidence has indicated that particular items (e.g., crying, changes in sleep, irritability, changes in appetite, and loss of interest in sex) perform poorly in this group (Aben, Verhey et al. 2002, Berg, Lönnqvist et al. 2009, Turner, Hambridge et al. 2012, Lerdal, Kottorp et al. 2014).

An alternative, and shorter, self-report questionnaire is the 14-item Hospital Anxiety and Depression Scale (mentioned in earlier sections of this thesis), which consists of two seven-item sub-scales: one for anxiety and the other for depression, measuring symptoms in the previous week (Zigmond and Snaith 1983). Hospital Anxiety and Depression Scale was originally developed for use in hospital (Zigmond and Snaith 1983). It is currently the only validated screening instrument for post-stroke anxiety (Kneebone, Neffgen et al. 2012). While there is evidence that the Hospital Anxiety and Depression Scale performs well with stroke survivors, it has also been subject to criticism, which has limited the utility of the questionnaire for this group, for example: under-recognition of 'cases' indicating a need for lower cut-points; high misclassification rate with the anxiety sub-scale; and a lack of sensitivity for detecting depression amongst stroke inpatients (Johnson, Burvill et al. 1995, Aben, Verhey et al. 2002, Bennett and Lincoln 2006, Sagen, Vik et al. 2009, Turner, Hambridge et al. 2012, Casal, Finley-Caulfield et al. 2014).

The Hamilton Depression Rating Scale is an interview-administered questionnaire, which has traditionally been regarded as the optimal approach for

measuring symptoms of depression amongst hospital in-patients (Hamilton 1960). The original version consisted of 17-items to measure depressive symptomatology in the seven-days prior, whereas the more recent 21-item version includes a further four-items designed to classify sub-types of depression (Hamilton 1960). While the Hamilton Depression Rating Scale has been evaluated and shown to perform as well as other screening instruments for depressive symptomatology amongst stroke survivors, there is literature that has also raised concerns about this questionnaire (Aben, Verhey et al. 2002, Bagby, Ryder et al. 2004, Meader, Moe-Byrne et al. 2013). For example, Bagby, Ryder et al. (2004) highlighted that the responses to individual items for stroke survivors are summed to generate a total score. However, there are indications that the scale of this instrument may actually be multidimensional, meaning that there may be problems with the underlying factor structure of the questionnaire.

In contrast, a recent meta-analysis has suggested that the Patient Health Questionnaire-2 and Patient Health Questionnaire-9 (PHQ-9) are currently showing the most promise as self-report screening instruments for depressive symptomology amongst stroke survivors (Meader, Moe-Byrne et al. 2013). These questionnaires comprise two and nine-items respectively, and are based on the key DSM criteria for major depressive disorder, including depressed mood and anhedonia (lack of interest or pleasure in activities), where scores are assigned based on the frequency of symptoms (Kroenke, Spitzer et al. 2001, Kroenke, Spitzer et al. 2003). The Patient Health Questionnaire was originally designed for a primary care population, and has shown validity for this group, including the elderly, and has the advantage of brevity (Spitzer,

Kroenke et al. 1999, Kroenke, Spitzer et al. 2001, Kroenke, Spitzer et al. 2003, Phelan, Williams et al. 2010, Turner, Hambridge et al. 2012, Meader, Moe-Byrne et al. 2013).

Instruments for examining speech and language outcomes after stroke are beyond the scope of this PhD thesis, because for practical reasons relating to the completion of interview-administered questionnaires, it was not possible to extend this research to include people with significant communication problems (i.e., aphasia).

4.3.2 Activities

The ICF defines activity as the performance of a task or action (Barak and Duncan 2006). Daily functioning after stroke incorporates 'activities of daily living:' more specifically, basic 'activities of daily living,' which refers only to activities, including functional mobility and personal care (such as, washing and dressing); and instrumental (or extended) 'activities of daily living,' involving complex tasks related to domestic chores and engagement with the community (for example, shopping, cooking, laundry, use of transport, and managing finances) (Rajan, Hebert et al. 2013). Activities are the most commonly reported outcome measure for recovery after stroke, and there are several generic and stroke-specific instruments that have been described in the literature (Barak and Duncan 2006, Harrison, McArthur et al. 2013). This section will examine the instruments that are most frequently used for clinical and research purposes (Barak and Duncan 2006), and that are also the local measures of choice.

The Modified Rankin Scale is a clinician-reported instrument that assesses global disability and dependence, pre-dominantly in the areas of mobility and motor function, with the assignment of scores ranging from 0 (‘no symptoms at all’) to 6 (‘dead’) (Rankin 1957, van Swieten, Koudstaal et al. 1988, Barak and Duncan 2006, Banks and Marotta 2007). The instrument has been most commonly applied to evaluate functional recovery after stroke (Banks and Marotta 2007). The reliability, validity and sensitivity to change in disability of the Modified Rankin Scale has been demonstrated, and the instrument is often regarded as the measure of choice for stroke research, especially for studies taking place in the acute phase (Sulter, Steen et al. 1999, Banks and Marotta 2007, Quinn, Dawson et al. 2009, Quinn, Langhorne et al. 2011). However, a problem with an aspect of the instrument’s reliability, specifically the potential for variability between different raters, has been acknowledged as a limitation of the Modified Rankin Scale (Wilson, Hareendran et al. 2005, Quinn, Dawson et al. 2009). To address this, video-based training resources for the Modified Rankin Scale have been developed, which also involve formal assessment of training and certification, and has been shown to have utility for clinical trials researchers (Quinn, Lees et al. 2007).

Global scales are generally considered less sensitive to changes in disability than other scales, such as the Barthel Index (Dromerick, Edwards et al. 2003). While the Barthel Index is also a clinician-reported scale of global disability, unlike the Modified Rankin Scale, the Barthel Index measures how well patients perform 10 basic ‘activities of daily living:’ self-care (feeding, grooming, bathing, dressing, bowel and bladder care, and toileting); and

mobility (walking and moving about, transfers, and climbing stairs) (Mahoney and Barthel 1965, Granger, Albrecht et al. 1979, Wade and Collin 1988, D'Olhaberriague, Litvan et al. 1996). The Barthel Index was first developed in 1965 (Mahoney and Barthel 1965) and later modified by Granger, Dewis et al. (1979).

The Barthel Index is considered reliable for stroke survivors, and has clinical utility for monitoring the progress of patients with their functional recovery (Granger, Albrecht et al. 1979, D'Olhaberriague, Litvan et al. 1996). Interestingly, while the instrument was not specifically developed for stroke, nor for adoption in clinical trials, it has been widely used for these purposes, and, second to the Modified Rankin Scale, is regarded as the measure of choice for outcomes in stroke research, and is particularly preferred for acute stroke studies (Sulter, Steen et al. 1999, Quinn, Dawson et al. 2009, Quinn, Langhorne et al. 2011). However, an important limitation that has been noted for the Barthel Index is the likelihood of floor and ceiling effects at extremes of disability, where the instrument may lead to an under or over-estimation of disability (Quinn, Langhorne et al. 2011). Further, the Barthel Index has been criticised for its lack of responsiveness to change, referring to difficulties in evaluating the clinical meaning of scores or changes in score, which is important for patient outcomes, and may potentially limit the usefulness of this instrument (Kwon, Hartzema et al. 2004, Harrison, McArthur et al. 2013). The Barthel Index is also primarily an instrument that assesses physical functioning, which is only one aspect of post-stroke recovery and, therefore, does not reflect the burden of

communication and cognitive impairments that commonly affect stroke survivors (section 1.2.3, Chapter 1) (Novak, Johnson et al. 1996).

A further generic assessment instrument for functional recovery after stroke is the 18-item Functional Independence Measure, designed to assess physical and cognitive disability for multiple conditions (Granger, Hamilton et al. 1986, Granger, Hamilton et al. 1993). The Functional Independence Measure is most commonly used clinically for measuring outcomes from rehabilitation during the chronic phase of stroke (six-months onwards) (Duncan, Zorowitz et al. 2005, Schepers, Ketelaar et al. 2006, Chumney, Nollinger et al. 2010). Therefore, this measure is beyond the scope of this PhD thesis.

It has been suggested that measures of instrumental 'activities of daily living' may be more sensitive to functional changes after stroke than those assessing basic 'activities of daily living', with less tendency to underestimate disability, meaning that they have particular utility for stroke research (Ward, Jagger et al. 1998, Duncan, Jorgensen et al. 2000, Dromerick, Edwards et al. 2003, Wu, Chuang et al. 2011). The most frequently used measures of instrumental 'activities of daily living' in stroke rehabilitation research are briefly described below (Wu, Chuang et al. 2011).

The Nottingham Extended Activities of Daily Living Scale is a 22-item stroke-specific self-report questionnaire that measures independence in instrumental 'activities of daily living' amongst survivors, where scores are

assigned for tasks people have managed to complete on their own (Nouri and Lincoln 1987, Gladman, Lincoln et al. 1993, Gompertz, Pound et al. 1994).

The Frenchay Activities Index, which is a further stroke-specific questionnaire, comprises 15-items and is interview-administered, with scores assigned on a four-point scale for the frequency at which individuals have undertaken particular instrumental 'activities of daily living' (Holbrook and Skilbeck 1983, Schuling, de Haan et al. 1993, Piercy, Carter et al. 2000, Post and Witte 2003).

The Nottingham Extended Activities of Daily Living Scale and Frenchay Activities Index have both shown reliability and validity for a population with stroke (Wade, Legh-Smith et al. 1985, Nouri and Lincoln 1987, Schuling, de Haan et al. 1993, Hsueh, S-L et al. 2000, Green, Forster et al. 2001, Schepers, Ketelaar et al. 2006). However, the Nottingham Extended Activities of Daily Living Scale is less affected by floor and ceiling effects, and has been considered superior to the Frenchay Activities Index in terms of responsiveness of the instrument to detecting change from before to after rehabilitation (Wu, Chuang et al. 2011, Sarker, Rudd et al. 2012).

4.3.3 Participation

Participation and activity are closely related (Gray, Hollingsworth et al. 2006). The ICF formally define participation as the involvement of an individual in a life situation (e.g., engagement with the community, hobbies, and return to work) (World Health Organisation 2001). Participation is also central

to peoples' engagement with their post-stroke rehabilitation (section 1.4.1, Chapter 1), and an important component of disability (Gray, Hollingsworth et al. 2006). The ICF suggests that participation is a factor that can, to a certain degree, limit the overall outcome of a person's involvement in areas of life (World Health Organisation 2001). This means that an individual's disability can further manifest when person-environment interactions lead to little or no participation in life events, and vice versa (Gray, Hollingsworth et al. 2006). While ICF participation refers to peoples' involvement in social activities, it has been argued that a specific definition for social participation (e.g., social roles) should be incorporated within the existing definition of participation proposed by the ICF (Piškur, Daniëls et al. 2014).

An important aim of rehabilitation is to help patients with long-term conditions, such as stroke, to re-integrate and participate with their communities (Gray, Hollingsworth et al. 2006). However, there has been uncertainty in the literature on how best to capture participation, and it's associated complexity, with most outcome measures focusing on reducing difficulties in the performance of particular activities (Gray, Hollingsworth et al. 2006). The development of specific measures of participation remains in its' infancy (Gray, Hollingsworth et al. 2006).

The ICF currently considers QOL as a reflection of participation and activity (Barak and Duncan 2006). However, traditional models have defined QOL differently to the ICF, suggesting that it is broad, multidimensional and ubiquitous, meaning that it is widely applicable to everyone, and covers all

aspects of life, including factors that are not related to health (Fallowfield 2002, Osoba 2011). Conversely, HRQL is a term that has recently evolved, and while it has been used interchangeably in the research, HRQL refers to the overall QOL of an individual affecting health, including the physical, functional, social and emotional impact of illness and also that of peoples' treatment (Fallowfield 2002, Osoba 2011). Research has suggested that HRQL is also a multidimensional concept, though it incorporates the following components (de Haan, Aaronson et al. 1993, Carod-Artal, Egido et al. 2000, Salter, Moses et al. 2008):

- Physical health, referring to illness and treatment-related symptoms;
- Functioning, including, self-care, mobility, physical activity level and capacity to carry out family and work roles;
- Psychological health, incorporating cognitive functioning, emotional status (such as, depression) and general well-being;
- Social health, referring to the ability to maintain fulfilling social relationships, such as with family and friends.

Health perceptions and life satisfaction are also considered to be key aspects of HRQL (Barak and Duncan 2006). Therefore, HRQL conceptualises a broad spectrum of disability, alongside patients' own perceptions of their health, life satisfaction and well-being (de Haan, Aaronson et al. 1993).

HRQL is a patient-reported outcome, and thus can lead to a better appreciation of the effect of illness and treatment on peoples' daily lives

(Deshpande, Rajan et al. 2011, Nelson, Eftimovska et al. 2015). These are now considered as having greater importance than other outcomes (Deshpande, Rajan et al. 2011), such as those described in earlier parts of this section (section 4.3.2). This may partly be because HRQL enables an understanding of peoples' personal reactions to their condition (de Haan, Aaronson et al. 1993, Hobart, Williams et al. 2002). Therefore, evaluations of HRQL may provide a richer description of the multi-faceted effects of stroke that are meaningful to survivors themselves, and which would not otherwise be possible to capture as comprehensively, using the traditional impairment and activity measures previously summarised in this chapter (Nichols-Larsen, Clark et al. 2005, Patel, Tilling et al. 2006, Hunger, Sabariego et al. 2012).

However, while HRQL is an important outcome for stroke survivors, it's measurement is often placed secondary to the other, more traditional, post-stroke outcomes (for example, stroke-related disability, basic and instrumental 'activities of daily living') (Carod-Artal, Egido et al. 2000, Ali, Fulton et al. 2013).

4.3.3.1 Measurement of HRQOL

The measurement of HRQL in stroke survivors can be challenging, particularly given the likelihood that HRQL will vary at different time-points following the acute event (Harrison, McArthur et al. 2013). In addition, HRQL relies upon on the person's own experience of their stroke, though this can create problems for individuals with substantial post-stroke cognitive impairments, given that proxy measurements have often been considered to be biased

(Williams, Bakas et al. 2006, Patel, McKevitt et al. 2007, Harrison, McArthur et al. 2013). There are, however, existing HRQL instruments that have been validated for stroke survivors, which are described below (Barak and Duncan 2006).

The Short Form-36 is a generic self-report HRQL instrument that assesses eight domains of HRQL emerging from the Medical Outcomes Study (Ware 2000). While this instrument is validated for people with stroke, the utility of the Short Form-36 is limited because of non-completion bias (particularly with elderly stroke patients), and floor and ceiling effects, which have been common for this questionnaire within this group (Anderson, Laubscher et al. 1996, O'Mahony, Rodgers et al. 1998, Hobart, Williams et al. 2002).

A further generic HRQL instrument is the brief self-reported EQ-5D-5L questionnaire, which is comprised of two parts (The EuroQol Group 1990, Brooks 1996). The first part is termed the 'Descriptive System,' and assesses five domains of HRQL (e.g., mobility, self-care, usual activities, pain/discomfort, and anxiety or depression), and accompanying this is the second part, which is a visual analogue scale (VAS) that examines peoples' own perceptions of their health on the particular day measurement (The EuroQol Group 1990, Brooks 1996). This widely used instrument was developed to aid the calculation of quality-adjusted life years, which are beneficial in informing economic evaluations of health interventions (van Reenen and Janssen 2015). In spite of being validated amongst people with stroke, the EQ-5D-5L compares people to norms for populations, which may not be appropriate for stroke

survivors (Dorman, Waddell et al. 1997, van Reenen and Janssen 2015). In addition, non-completion bias has been a problem for this instrument within this particular group, with people generally needing some support with completion (Dorman, Waddell et al. 1997). However, this can be overcome for the EQ-5D-5L instrument in several ways, including: proxy ratings (e.g., carers) (Whynes, Sprigg et al. 2013), which have shown validity amongst stroke survivors; and telephone or face to face administration, also showing utility (McPhail, Lane et al. 2009, Lozano, Lobos et al. 2016). In contrast, the suitability of the latter approaches has thus far been shown in a non-stroke population; for example, older adults without cognitive impairment, and those with other conditions (e.g., intermittent claudication) (McPhail, Lane et al. 2009, Lozano, Lobos et al. 2016). Nonetheless, one to one delivery of the EQ-5D-5L instrument may still be beneficial for stroke survivors.

A stroke-specific HRQOL instrument has also been developed, the Stroke-Specific QOL scale, which is based on twelve domains of HRQL (Williams, Weinberger et al. 1999). The full 49-item version of this questionnaire has been validated in stroke survivors (Lin, Fu et al. 2011). A shorter 12-item version has also been developed more recently, and early validation studies indicate the promise of this instrument for stroke survivors (Post, Boosman et al. 2011, Chen, Wu et al. 2012, Kerber, Brown et al. 2013).

4.3.4 Concluding Remarks for Section 4.3

In summary, there is a growing appreciation of the value of patient-reported outcomes in assessing recovery after stroke. In particular, measures of

HRQL have become further recognised as a key approach for evaluating how well stroke survivors are recovering; more specifically, peoples' activity and participation after stroke, which are both important aspects of post-stroke disability. While HRQL has traditionally appeared secondary to other research outcomes (e.g., stroke-related disability, basic and instrumental 'activities of daily living'), there has been a shift in the literature, and the adoption of HRQL as a primary outcome measure has been advocated more recently (Ali, Fulton et al. 2013). Furthermore, it has generally been recommended that assessment instruments for outcomes of post-stroke recovery in research are chosen on the basis of the particular research question, and the current psychometric evidence for each measure (Harrison, McArthur et al. 2013). To this end, HRQL was selected as the primary outcome for the present PhD research, and the other, more traditional measures of disability after stroke that have been mentioned above, were assessed secondary to this. A detailed report of this work is provided in Chapter 7.

4.4 POTENTIAL ROLE OF ILLNESS BELIEFS IN PREDICTING MARKERS OF RECOVERY AFTER STROKE

In light of the discussions thus far in Chapter 4, which have focused on the different aspects of recovery after stroke (including, HRQL and disability), the remainder of this chapter will briefly consider examples from the wider CSM literature where the prediction of these outcomes have been examined in relation to illness belief domains. This literature either does not currently exist for stroke, or is limited. For example, earlier parts of Chapter 4 (section 4.2) emphasised that the majority of evidence in stroke has examined

outcomes of mood and medication adherence, with the exception of only one study exploring disability (measured using the Barthel Index) where control beliefs were implicated in the prediction of functional recovery.

However, other studies have also shown that there are several illness belief domains that predict disability across a range of physical health conditions. For example, Dalbeth, Petrie et al. (2011) found that people with gout believed that their condition was chronic and controllable with treatment, viewing it as moderately impacting upon their lives and caused by diet. More specifically, perceptions of a lot of symptoms, serious consequences and an inability of oneself or one's treatment to manage the condition significantly predicted worsening of musculoskeletal disability at one-year. A further longitudinal study in people with hand osteoarthritis also suggested that a strong illness identity and serious consequences were predictors of baseline disability, as were a poor understanding of the illness, more negative emotions, and belief in psychological causes of the condition (Damman, Liu et al. 2014). This study also found that beliefs about chronicity and ineffectiveness of treatment predicted disability at one-year, and more negative perceptions of the illness were generally associated with greater disability in this group (Damman, Liu et al. 2014).

Consistent findings emerged in further cross-sectional studies, which again mostly examined people with arthritis. For instance, Hill, Dziedzic et al. (2007) examined hand and finger function amongst people with musculoskeletal hand problems (e.g., osteoarthritis). Again, this study

implicated perceptions of a highly symptomatic illness; serious consequences; and considerable distress in peoples' overall health and behaviour (e.g., general practitioner (GP) consultations, or medication-taking). Similarly, Moss-Morris and Chalder (2003) found that people with chronic fatigue syndrome attributed more symptoms to their illness, perceived more serious consequences, and also believed that a virus or poor immune function caused their condition, compared to people with rheumatoid arthritis. Further, this negative perception overall of their illness was related to high levels of disability in those with chronic fatigue syndrome. Another example is Graves, Scott et al. (2009), which showed that greater disability was significantly related to: a strong illness identity (r=0.31); and beliefs about serious consequences (r=0.28). In this study, lower disability and improved QOL was related to strong controllability beliefs (r=0.40, and r=0.20, respectively), and all correlations were of moderate strength.

There are also several cross-sectional studies showing relationships between illness belief domains and QOL in people with various chronic health conditions. For example, Scharloo, Kaptein et al. (2007) found that asthma patients with more positive beliefs about their illness, and a lower emotional response had better QOL. Conversely, Rochelle and Fidler (2013) found poor QOL amongst people with inflammatory bowel disease who perceived their illness to have serious consequences, with less belief in their own ability to manage the condition, and considerable distress. Consistent findings also emerged for Borge, Moum et al. (2014), where worse QOL was significantly predicted by a strong perception of symptoms; serious consequences; poor

understanding of the illness; considerable distress; and greater illness concern, for people with chronic obstructive pulmonary disease.

Further studies have also specifically examined HRQL, and showed similar patterns for people with acute or chronic conditions. For example, Mohammed, Nagla et al. (2015) showed that perceptions of a strong illness identity; serious consequences; lack of belief in one's own ability to manage the illness; and distress were significantly related to poor physical HRQL, while greater illness concern was associated with poor mental QOL in people with tuberculosis. A strong illness identity and serious consequence beliefs have also been implicated in poor physical HRQL in people with multiple sclerosis (Spain, Tubridy et al. 2007). In addition, negative beliefs (disease chronicity, and an inability of oneself or one's treatment to manage the condition) were generally found to be related to poor HRQL in people with myocardial infarction (Alsén, Brink et al. 2010).

Therefore, it is apparent from these examples that there is a role for illness beliefs in the prediction of disability and QOL/HRQL amongst people with physical health conditions (acute or chronic), with several domains implicated in the evidence to date. In consequence, it is likely that illness belief domains may also predict these outcomes amongst stroke survivors, though this will be examined more closely in Chapter 7.

4.4.1 Concluding Remarks for Section 4.4

When all areas are considered, what has become apparent in the literature reviewed in the present PhD thesis thus far is that mood and coping (e.g., medication adherence) are both influential in affecting recovery after stroke (covered in Chapter 1). The CSM incorporates coping and emotional pathways, both of which are integral to the formation and maintenance of peoples' beliefs about their illness (Chapter 2). In addition, the literature reviewed in earlier sections of this chapter (section 4.2) has highlighted that illness belief domains are related to mood and medication adherence after stroke. Potentially, there are also relationships that have emerged in the limited literature undertaken in stroke survivors between illness belief domains and other aspects of post-stroke recovery (e.g., disability), which have been further supported in the wider evidence on acute and chronic physical illnesses (Chapter 4). Therefore, these factors (illness beliefs, HRQL, disability, mood, and adherence) may be likely to interact. However, the research as it currently stands has not adequately examined this interplay, and has rather focused on the independent prediction of these outcomes by illness beliefs domains. Given these independent relationships, a mediating effect of mood and/or coping may exist between illness beliefs and outcomes (e.g., HRQL, disability, and mood). Mediation happens when a mediator (e.g., mood and/or coping) is related to both the predictor (e.g., illness beliefs) and the outcome (e.g., HRQL) in the relationship in question, and where the presence of the mediator attenuates the effect of the predictor on the outcome (Baron and Kenny 1986). However, there is currently a lack of CSM studies where this particular relationship has been explored, and certainly, no studies conducted in stroke. Therefore, this potential

mediating role of mood and/or coping is of particular interest to the present PhD research, and will be formally tested in Chapter 7. The final part of Chapter 4 will consider the conceptual model on which the work in Chapter 7 is based.

4.5 INTRODUCTION TO THE CONCEPTUAL MODEL

The CSM was the central theory underlying this research (described in Chapter 2), and the questions and hypotheses to be addressed in the observational study of Chapter 7 are illustrated in the conceptual model below (Figure 4-1).

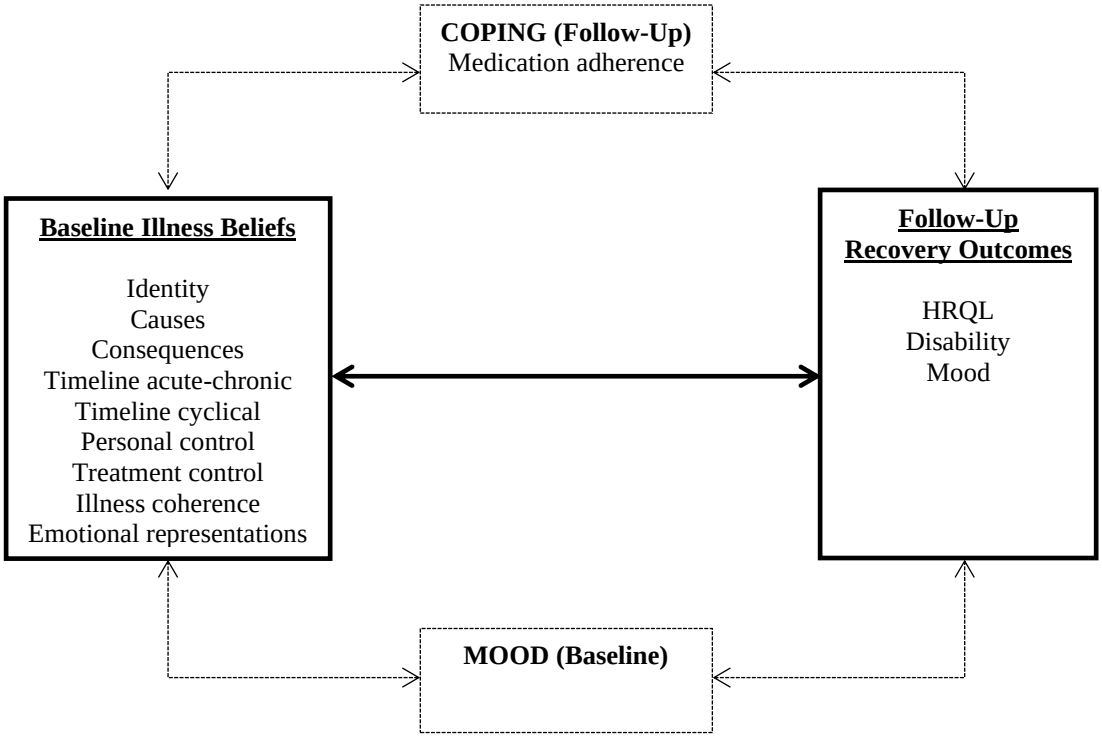


Figure 4-1. Conceptual model derived from the CSM

As can be seen from Figure 4-1, the model indicates that several bidirectional relationships are likely to exist between the key variables of interest (i.e., illness beliefs, HRQL, disability, mood, and medication adherence). The

direct association between illness beliefs measured at baseline and follow-up markers of recovery (HRQL, disability and mood) is highlighted in Figure 4-1 with an emboldened arrow. In addition, it has been postulated in the evidence examined in this and earlier chapters of this thesis that both baseline illness beliefs and follow-up indices of post-stroke recovery have independent and bidirectional relationships with baseline mood and coping. These are denoted by the dotted arrows in Figure 4-1. For the purposes of the present study, coping was understood in terms of medication adherence, which is consistent with the operalisation by Hagger and Orbell (2003) described in Chapter 3.

4.6 CHAPTER SUMMARY

The present chapter (Chapter 4) reviewed the existing evidence for the CSM in relation to stroke, and also examined the wider literature on the CSM and the prediction of other outcomes that have relevance to recovery after stroke (e.g., QOL/HRQL and disability). In light of these findings, the potential for a mediational relationship of mood and/or coping to exist between illness belief domains and outcomes emerged, and will be further investigated in Chapter 7. Chapter 4 also introduced the conceptual model derived from the CSM and underlying the research questions and hypotheses for the main observational study (Chapter 7). In addition, Chapter 4 critically reviewed the various outcome measures for post-stroke recovery, providing a rationale for the selection of the primary and secondary outcomes in the present research (reported in Chapter 7). The next chapter (Chapter 5) extends this material by critically examining the approaches for measuring other outcomes that are important to post-stroke adjustment and thus recovery: engagement and adherence.

CHAPTER 5. CRITICAL REVIEW OF MEASUREMENT APPROACHES FOR ENGAGEMENT AND ADHERENCE AFTER STROKE

5.1 CHAPTER OVERVIEW

Chapter 5 will extend the material covered in the previous chapter. Chapter 4 highlighted the need for acute stroke studies to examine a broad range of outcomes that are relevant to peoples' recovery after stroke (e.g., HRQL, mood and disability). However, given that engagement with rehabilitation and medication adherence following stroke are important indicators of disease adjustment (section 1.4, Chapter 1), the measurement of these factors post-stroke is also necessary. This would provide a clearer picture of how well survivors are coping following stroke. To this end, the present chapter will provide a critical review of the different approaches for measuring engagement with, and adherence to, self-management amongst stroke survivors. This again informed the selection of measures adopted in the observational study (reported in Chapter 7).

5.2 MEASUREMENT OF ADHERENCE TO POST-STROKE SECONDARY PREVENTIVE BEHAVIOURS

A 'gold standard' approach to measuring adherence does not currently exist (World Health Organization 2003). Rather, a variety of subjective and objective measures have been utilised in the stroke literature for measuring

medication adherence and adherence to lifestyle modification, and these are briefly summarised below.

5.2.1 Objective Measures

There are several measures that have been adopted in stroke studies, which on the whole have indirectly examined whether patients have taken their prescribed medication. For example, prescriptions filled over a specific time period usually using pharmacy data (Colivicchi, Bassi et al. 2007, Glader, Sjölander et al. 2010); pill counts, assessing the number of leftover tablets (De Schryver, Van Gijn et al. 2005); electronic monitoring (e.g., Medication Events Monitoring System) (MEMS® Aardex Ltd., Switzerland), recording the time and date at which a pill bottle is opened (O'Carroll, Chambers et al. 2013); and medical records, examined for information about medication (Xu, Ju et al. 2013).

Other methods have included physical assessments and biological markers, which are arguably more superior than those described above, because patients can (and do) dispose of their medication (Horne 2006). Therefore, these alternative objective methods can determine the outcome of taking medication. For example, the measurement of blood pressure for anti-hypertensive medication, where specially designed apparatus (e.g., ambulatory blood pressure recorder) is used, and readings are compared against clinical goals for hypertension (Engberg and Kofoed 2013). A further example amongst stroke survivors is biological markers, such as urinary salicylate levels for determining levels of aspirin adherence (O'Carroll, Whittaker et al. 2011).

5.2.2 Subjective Measures

On the other hand, there are subjective methods that have been used to measure medication adherence, and these rely upon patient self-report. Details of these approaches are briefly elaborated below.

Telephone interviews administered by a healthcare professional using a standardised script or semi-structured approach have dominated the stroke literature (Sappok, Faulstich et al. 2001, De Schryver, Van Gijn et al. 2005, Colivicchi, Bassi et al. 2007, Xu, Ju et al. 2013). Participants in these studies were asked for particular information regarding their medication, including the drug name; dosage and schedule; and dates and reasons for any discontinuation. Studies have also gathered adherence information by proxy (such as relatives and caregivers) or from peoples' medical notes (e.g., GP records) (Sappok, Faulstich et al. 2001, Bushnell, Zimmer et al. 2010). Structured face to face interviews, with some studies using standardised questions, have been most commonly used to gather information from stroke survivors about adherence to lifestyle behaviours (e.g., diet, physical activity and smoking cessation) (Redfern, McKevitt et al. 2000, Bak, Sindrup et al. 2002, Hornnes, Larsen et al. 2010).

Equally dominant are standardised self-report questionnaires, such as the Medication Adherence Report Scale, which has been used for measuring medication adherence in stroke survivors (Choi-Kwon, Kwon et al. 2006, O'Carroll, Whittaker et al. 2011, O'Carroll, Chambers et al. 2013). The Medication Adherence Report Scale comprises five general statements that are

typical of non-adherent behaviour ([questionnaire items]), and respondents answer on a five-point Likert scale ([response options]) (Horne and Weinman 1999, Horne 2004). The Medication Adherence Report Scale is used frequently across various chronic conditions, including stroke, and has shown good reliability and validity for this group (O'Carroll, Whittaker et al. 2011).

In summary, the optimal approach for measuring non-adherence amongst stroke survivors is unclear from the literature as it currently stands. On balance, both objective and subjective measures alike have limitations, and these are considered in the next section of this chapter.

5.2.3 Limitations of Adherence Measures

Specific limitations of the various objective approaches for measuring non-adherence that have been reported, include: inaccurate pill counting, leading to an over or under-estimation of medication adherence; incomplete pharmacy databases for filled or refilled prescriptions, resulting in missing or inaccurate data; and the financial cost of electronic monitoring devices (such as, the Medication Events Monitoring System) (World Health Organization 2003). Further, measurement errors have also been attributed to Medication Events Monitoring System devices through the Hawthorne effect, which suggests that participants tend to alter their behaviour from being studied (Wetzels, Nelemans et al. 2006, O'Carroll, Whittaker et al. 2011). An additional

issue for several of the objective measures (e.g., pill counts and Medication Events Monitoring System (section 5.2.1)) has been whether patients are actually taking their tablets as prescribed or merely disposing of them (World Health Organization 2003). Medication wastage has been shown to be a considerable problem for the NHS, costing around £300 million per year, and some of this wastage is attributed to patient non-adherence (Trueman, Lowson et al. 2010).

In contrast, subjective measures have commonly been criticised for reporting bias, where patients selectively report or withhold information concerning their adherence behaviours; and social desirability, where participants tend to answer questions to appear more favourably to others (World Health Organization 2003, Prince, Adamo et al. 2008, O'Carroll, Chambers et al. 2013). Both of these can lead to inaccurate estimates of adherence. However, while this is a widely acknowledged limitation of self-report data, there are examples of studies showing that carefully selected measures are analogous to, or more superior than, other objective measures of adherence, for various chronic diseases (Buscher, Hartman et al. 2011, Gonzalez, Schneider et al. 2013). For example, Buscher, Hartman et al. (2011) provided people with Human Immunodeficiency Virus Medication Events Monitoring System caps to measure medication adherence, and extracted adherence information from pharmacy records for prescription refill dates. Participants also completed several self-reported measures, including: a four-week recall visual analogue scale; the Adult AIDS Clinical Trial Group four-day recall instrument; and a one-month recall qualitative single-item measure (assessed three-monthly for up

to 18-months). This study demonstrated significant correlations between self-reported and Medication Events Monitoring System and pharmacy medication adherence data, and concluded that these approaches were equivalent in performance. Similarly, Gonzalez, Schneider et al. (2013) recorded adherence to oral medication amongst people with type 2 diabetes mellitus. This study used Medication Events Monitoring System caps versus self-ratings and self-reported information, including prescribed and missed doses and one seven-day recall item from the Summary of Diabetes Self-Care Activities instrument. As before, the authors found significant correlations between self-reported and Medication Events Monitoring System-measured medication adherence, and concluded that these approaches performed equally well.

Further, there has been some attempt to address self-report biases in certain measures, for example: the Medication Adherence Report Scale frames items to imply that non-adherence is a normal behaviour, which can minimise socially desirable responding and encourage more honest answers (O'Carroll, Chambers et al. 2013). In addition, there is recent evidence that patients may find it easier to report their general adherence rather than estimate specific medication adherence information (e.g., number of doses missed) (Garfield, Clifford et al. 2011).

5.3 MEASUREMENT OF ENGAGEMENT WITH REHABILITATION

Consistent with the measurement of medication adherence amongst stroke survivors, there is no ‘gold standard’ approach for assessing patients’ engagement with rehabilitation after stroke. However, evidence from the wider

literature on engagement with single-discipline rehabilitation (e.g., physiotherapy) advocates a multifaceted assessment to better reflect the nature of therapy; for example, measurement of adherence to clinic-based programmes (e.g., attendance behaviours) as well as self-directed therapy at home (Bassett 2003).

Examples of objective assessments of rehabilitation engagement include: healthcare utilisation and record keeping of therapy appointments (for example, appointment bookings and attendance or non-attendance), though these have tended to be used as an adjunct to other, more subjective, methods for assessing patients' engagement with therapy (Roter, Hall et al. 1998).

The two subjective approaches that have been evident from the current stroke literature include, clinician administered versus self-reported measures. The Pittsburgh Rehabilitation Participation Scale is a clinician-rated measure that has shown promising reliability for assessing participation during inpatient rehabilitation amongst stroke survivors (Lenze, Munin et al. 2004, Lenze, Munin et al. 2004, Paolucci, Di Vita et al. 2012). Therapists complete the scale based on their evaluation of patients' participation during therapy sessions, using a six-point Likert scale, which can range from: refusal or no participation in any or at least half of the therapy sessions, to adequate, good or excellent participation with the majority of exercises, including effort and completion of exercises, and active interest in therapy sessions (Lenze, Munin et al. 2004).

However, this scale measures only one aspect of engagement with rehabilitation (participation), and has a strong focus on therapists' perceptions of patient participation during clinic-based therapy. In contrast though, Chapter 1 (section 1.4) highlighted that engagement also broadly includes other adherence behaviours, including unsupervised, self-directed therapies. Further, the previous chapter (section 4.3.3, Chapter 4) emphasised that there is an ever-growing appreciation of the perspective of patients (patient-reported outcomes) in engagement and recovery after stroke.

An on-going study is attempting to address the dearth of evidence with regard to self-report measures for engagement with rehabilitation after stroke (Bollen, Dean et al. 2014, Bollen In Progress). This study is focused on developing the Stroke Rehabilitation Exercise Adherence Measure, and is particularly interested in unsupervised home-based rehabilitation programmes rather than formal rehabilitation. However, as this study is on-going and the findings have not yet been reported, there is currently a lack of information available with regard to the type of stroke patient for whom this instrument would be most suitable. For example, it is unclear whether this self-report instrument has been specifically designed for stroke survivors with any degree of cognitive or communication impairment.

Therefore, there remains a need to examine approaches that are suitable for the purpose of examining engagement with rehabilitation amongst stroke survivors, and which cater for the complex needs of this patient group. Research that was recently completed with stroke survivors, the 'Getting Out of

the House Study,' examined an outdoor mobility rehabilitation intervention, facilitated by occupational therapists (Logan, Leighton et al. 2012, Logan, Armstrong et al. 2014). This study administered novel monthly mobility diaries to patients enabling them to record their own adherence to travel and journeys (e.g., public transport). The findings indicated that the intervention group were a significant 42% more likely to make a journey than those receiving the control (routine care). While it is apparent that this finding referred to the whole intervention, rather than solely the mobility diary component, Logan, Armstrong et al. (2014) specifically advocated the use of monthly diaries as a promising method for assessing adherence (in this case mobility) amongst stroke survivors. Further, the use of self-complete homework diaries has been a long-standing component of cognitive behavioural therapy, not only for enabling therapists to monitor patients' progress with treatment, but also indicate how engaged people are and to maintain their engagement with therapy (for example, Simpson, Marcus et al. (2012); and Funk, Zvolensky et al. (2011)). However, this approach is likely to have issues with regard to whether or not people adhere to completion of the diary. For instance, Stone, Shiffman et al. (2002) suggested that people with chronic pain over-estimated their medication adherence when self-reporting this information using a diary.

5.4 CONCLUDING REMARKS

In summary, various objective and subjective approaches exist for measuring engagement with, and adherence to, self-management after stroke. However, there is no consensus on the optimal or 'gold standard' approach for this group. Objective measures are considered to be arguably more superior to

subjective approaches (e.g., self-report questionnaires). Objective methods are not without their limitations though (e.g., over or under-estimation of medication adherence). Further, efforts have been made to address the most commonly reported criticism of self-report measures: reporting bias. Therefore, questionnaires, such as the Medication Adherence Report Scale, are considered to provide an accurate measure of medication adherence. There is a particular dearth of literature on approaches for measuring engagement with rehabilitation after stroke. Despite this, wider evidence has suggested that extracting attendance data from therapist records and calendars/diaries would be potentially viable in gathering this data for the present PhD research.

5.5 CHAPTER SUMMARY

The present chapter (Chapter 5) provided a brief critical review of the existing literature for measuring engagement with rehabilitation and medication adherence after stroke. This informed the decision to select the Medication Adherence Report Scale for measuring medication adherence, and a calendar/diary for assessing engagement with rehabilitation in the observational study of Chapter 7. The next chapter reports on a qualitative study that was undertaken to develop a suitable method for assessing illness beliefs in a population with stroke.

CHAPTER 6. DEVELOPMENT OF A STROKE-SPECIFIC VERSION OF THE ILLNESS PERCEPTION QUESTIONNAIRE-REVISED

6.1 CHAPTER OVERVIEW

An important part of applying the CSM to a different population is to first, select an appropriate method for assessing illness belief domains, and second, adapt this as necessary to the patient group in question. With this in mind, the present chapter (Chapter 6) reports on a qualitative study of the IPQ-R, which was undertaken to modify this instrument (referred to herein as the Stroke IPQ-R), to ensure that it is suitable and acceptable to survivors of stroke. The chapter begins by explaining the background and rationale to this component of the PhD research, including the options for measuring illness belief domains, and reasons behind the selection of the IPQ-R. The aims and research question of this study will then be detailed, and finally, the research undertaken for this purpose will be reported.

6.2 BACKGROUND AND RATIONALE

6.2.1 Measurement of Illness Belief Domains

Illness beliefs, as outlined by the CSM, have been assessed by a range of methods. These have included: semi-structured and structured interviews (Meyer, Leventhal et al. 1985, Leventhal, Brissette et al. 2003); self-report questionnaires, such as the IPQ and IPQ-R (referred to herein as the original IPQ-R) and Brief IPQ (Weinman, Petrie et al. 1996, Moss-Morris,

Weinman et al. 2002, Broadbent, Petrie et al. 2006); and drawings (Broadbent, Ellis et al. 2006, Petrie, Jago et al. 2007, Reynold, Broadbent et al. 2007, Broadbent, Niederhoffer et al. 2009).

While semi-structured and structured interviews have been a popular approach for measuring peoples' beliefs, there is research that has criticised this method for being laborious and lacking in psychometric validity, and has emphasised the variability in the quantity and quality of responses elicited (Petrie, Jago et al. 2007). Furthermore, semi-structured or structured interviews may not be feasible for stroke survivors with cognitive and communication difficulties, and these are common problems to affect this group (as detailed in Chapter 1). Drawings are a novel and evolving area of illness belief assessment (Petrie, Jago et al. 2007); however, research has not currently been undertaken using this method with stroke survivors. With patients often experiencing unilateral arm paralysis and perceptual difficulties after stroke, the practicalities of drawing is likely to be a significant challenge for these individuals. Therefore, the present chapter is focused on the IPQ-R.

6.2.1.1 The Illness Perception Questionnaire-Revised

The IPQ-R was borne out of several concerns about the psychometric properties of the earlier version of this questionnaire, the IPQ (Moss-Morris, Weinman et al. 2002). The IPQ measured the five core domains of illness beliefs (section 2.3.2 of Chapter 2): identity, causes, consequences, timeline, and cure/control. The problems that emerged for this questionnaire were threefold. First, the internal consistency (Cronbach's alpha (α)) of the

timeline and cure/control sub-scales showed problems. For example, a factor analysis of the cure/control sub-scale indicated that the items actually loaded onto two factors as opposed to one (Moss-Morris, Weinman et al. 2002). These were peoples' own ability to manage the illness (personal control), and beliefs about controllability of their condition through treatment (treatment control) (Moss-Morris, Weinman et al. 2002). For the timeline sub-scale, it emerged that a greater number of items were required overall, including questions to assess cyclical timeline beliefs (section 2.3.2) (Moss-Morris, Weinman et al. 2002). Second, peoples' emotional response to their illness, which is a central feature of the CSM (covered in Chapter 2), was overlooked in the IPQ (Moss-Morris, Weinman et al. 2002). Third, the IPQ did not incorporate measurement of illness coherence beliefs, which were considered important to include by the authors of the IPQ-R. However, the theoretical basis for the inclusion of this and the timeline-cyclical sub-scale has not been detailed (Moss-Morris, Weinman et al. 2002), and remains unclear. A revision of the IPQ (the IPQ-R) was developed to address these concerns (Moss-Morris, Weinman et al. 2002).

The IPQ-R measures the following domains of illness beliefs: identity, causes, consequences, timeline acute-chronic, timeline-cyclical, personal control, treatment control, illness coherence and emotional representations. It is comprised of 38-items, with exception of the identity and causal belief sub-scales, which were also amended alongside the abovementioned sub-scales. This included the addition of two new symptoms (sore throat and wheeziness) to the symptom list for the identity scale, which originally comprised of 12 symptoms; and eight new causal items (18

attributions in total) to the causal sub-scale (Moss-Morris, Weinman et al. 2002). A further notable change for the identity scale of the IPQ-R was the rating of symptom intensity, to ensure that symptoms are appropriately matched to the illness label, rather than the reporting of symptoms in isolation (Moss-Morris, Weinman et al. 2002). This is consistent with Leventhal's original interpretation of the identity domain (Chapter 2). Therefore, in the revised IPQ, patients are first asked to rate whether or not they have experienced each symptom since their illness, using a yes or no response, and then to decide whether or not they perceive that symptom to be related to their illness, again using a yes or no format (Moss-Morris, Weinman et al. 2002).

6.2.1.1.1 Rationale for Selection of the Illness Perception Questionnaire-Revised

The IPQ-R was selected as the method of choice for adaptation to stroke survivors in the present research for two reasons. First, the reliability and validity of the IPQ-R has been established for several illness groups (including those with neurological conditions e.g., multiple sclerosis), with Cronbach's alphas for the sub-scales ranging from 0.79 to 0.89 (Moss-Morris, Weinman et al. 2002). Second, alternative questionnaires such as the Brief IPQ have the advantage of brevity (Broadbent, Petrie et al. 2006), but may be lacking in content validity (van Oort, Schroder et al. 2011). The Brief IPQ is comprised of nine-items, with a single question assessing each domain of illness beliefs (including illness concern), and was designed for a quick assessment of illness beliefs when time is limited, or for specific patients (e.g., people who are very ill, or the elderly) (Broadbent, Petrie et al. 2006). However, van Oort, Schroder

et al. (2011) highlighted that the items comprising the Brief IPQ were developed by "forming one question that best summarised the items contained in each sub-scale of the IPQ-R" (Broadbent, Petrie et al. 2006, p632). van Oort, Schroder et al. (2011) suggested though that in order to fully assess content validity, all aspects of a construct should be examined, which may not be possible to do using a single summary measure (van Oort, Schroder et al. 2011).

6.2.2 Cognitive Interviewing

It has been advocated that items on the IPQ and IPQ-R should be adapted to particular illnesses, such as stroke (Weinman, Petrie et al. 1996, Moss-Morris, Weinman et al. 2002). French and Weinman (2008) argued that a process of interview-based research is necessary to identify items where modification is required. Cognitive interviewing is an approach that has utility for improving the design of questionnaires (Willis 2005). It has traditionally been used to evaluate survey questionnaires, and uncover problems with questions that would have otherwise been unrecognised, allowing for amendments to be made (Willis 2005, Beatty and Willis 2007). Cognitive interviewing has been defined as an approach involving administration of draft survey questions, with simultaneous gathering of verbal information from respondents about their answers to the survey in order to evaluate the quality of their responses, including whether the question is enabling the intended information to emerge (Beatty and Willis 2007). This can consist of obtaining a breakdown from respondents on how they reached their answers; their interpretation of the questions; and any difficulties they experienced in responding (Beatty and Willis 2007).

Cognitive interviewing is based on two paradigms, where one involves verbal probing procedures and the interviewer guides the interview by asking specific, direct questions about how people have formed their responses (Willis 2005, Beatty and Willis 2007). Whereas the other involves instructing respondents to 'think out loud,' while the interviewer remains fairly passive in the interaction, adopting the role of facilitator (Willis 2005, Beatty and Willis 2007). The latter is embedded in the Think-Aloud method. This approach has been used commonly in Psychology, and involves encouraging respondents to verbalise their thoughts, without additional explanations while, for example, answering questions in a questionnaire (van Someren, Barnard et al. 1994, Willis 2005). Therefore, individuals are encouraged to express thoughts that would ordinarily have remained silent (Ericcson and Simon 1993).

It has been argued that any kind of problem that emerges through questionnaire completion, whether re-reading and stumbling, or misinterpretations are all indicative of invalid responding, and wider problems around the validity of measurement and error (van Oort, Schroder et al. 2011). While the Think-Aloud approach does not provide a formal statistical validation of questionnaire items, the technique has shown utility for the development of optimal questions, and examining aspects of validity, including face and content validity of the questionnaire (Willis 2005, van Oort, Schroder et al. 2011).

6.2.2.1 Current Think-Aloud Literature

Several studies have adopted the Think-Aloud method to explore how people respond to items on other commonly used questionnaires, and thus

uncover frequent problems experienced by individuals in relation to these instruments (Boeije and Janssens 2004, French, Cooke et al. 2007, Murtagh, Addington-Hall et al. 2007, French and Hevey 2008, Westerman, Hak et al. 2008, Darker and French 2009). This has included a Think-Aloud analysis of the Brief IPQ (van Oort, Schroder et al. 2011), and a version of the IPQ-R for people with type 2 diabetes mellitus (McCorry, Scullion et al. 2013).

For example, McCorry, Scullion et al. (2013) found few problems with completion of the IPQ-R amongst respondents with type 2 diabetes mellitus (N=36). Where problems were identified, these were in relation to the concept of 'cure' (e.g., 'My treatment will be effective in curing my diabetes') and 'symptoms' (e.g., 'My symptoms come and go in cycles'), whereby participants felt that a cure for diabetes and overt symptoms were not applicable to them. In addition, the negative wording of some items (e.g., 'Nothing I do will affect my diabetes') was also confusing for respondents, and this was particularly relevant to the consequences and personal control sub-scales. Furthermore, the authors highlighted an important pattern in peoples' responses to the consequence items. These beliefs seemed to coincide with peoples' perceived coping response to type 2 diabetes mellitus, and were also contradictory. For example, low scores on the 'My diabetes strongly affects the way others see me' item seemed to suggest that people believed type 2 diabetes mellitus to be a common illness with minimal stigma. However, respondents were also choosing not to disclose their health status to others (coping behaviour), which may have been because people were trying to minimise any chance of others seeing them differently. This suggests that what respondents actually believed was that their condition

would affect others' perceptions of them. This is important information in relation to peoples' responses that would have otherwise remained undiscovered had the Think-Aloud approach not been utilised.

In summary, there is evidence to suggest that there may be problems with the way in which items on the IPQ-R are interpreted by respondents with different medical conditions. Further, there is benefit to utilising cognitive interviewing (specifically, a Think-Aloud approach) to evaluate the problems with these items, and indicate where improvements to the IPQ-R can be made for a particular group. This would be important to improve the accuracy of illness belief measurement amongst specific populations (e.g., stroke survivors).

6.2.2.1.1 Stroke-Specific IPQ-R (Twiddy-Version)

There is only one stroke-specific version of the IPQ-R that has been developed, and this was in an unpublished PhD thesis by Twiddy (2008) (referred to herein as the Twiddy-version). A combination of approaches was used to develop the Twiddy-version, including: a review of the stroke literature, focus groups with stroke survivors, and expert consultation.

The research by Twiddy (2008) demonstrated that many of the sub-scales were reliable for survivors with chronic stroke (α=0.68-0.91) and also those in the acute phase of stroke (α=0.59-0.82). However, from the perspective of the present PhD research, the work by Twiddy was limited in several ways, meaning that a further adaptation of the IPQ-R for stroke survivors was necessary. First, the Twiddy-version was not formally validated for people with

stroke (e.g., through factor analysis). Therefore, the generalisability of the findings may be questionable. Second, Twiddy's work omitted key items from the treatment control sub-scale that may be relevant to the population under study for the present research. For example, two treatment control questions from the original version of the IPQ-R ('The negative effects of my illness can be prevented (avoided) by my treatment' and 'My treatment can control my illness') (Moss-Morris, Weinman et al. 2002) were removed. The focus of the present study is on understanding peoples' beliefs in relation to disease adjustment, of which treatment adherence (and thus beliefs about treatment) are an integral part. Therefore, it would be important to give full consideration to all treatment control items of the original IPQ-R in tailoring this questionnaire to the present study population. Third, Twiddy (2008) did not utilise a cognitive interviewing approach (e.g., the Think-Aloud method) to adapt the IPQ-R to stroke survivors, meaning that important information with regard to the quality of the questions, derived from the way that people respond, may have been missed.

6.2.3 Aim and Research Question

The overall aim of this qualitative study was to develop a version of the IPQ-R (Moss-Morris, Weinman et al. 2002) that is suitable and acceptable for measuring illness beliefs in people during the acute phase of stroke (≤three-months post-stroke). The specific research question to be addressed was: does the Stroke IPQ-R have face and content validity for stroke survivors in this group?

6.3 PRELIMINARY QUESTIONNAIRE DEVELOPMENT

The original IPQ-R (Moss-Morris, Weinman et al. 2002) formed the basis for stroke-specific adaptation. Preliminary development was initially undertaken. This involved: a detailed examination of the stroke literature, including the Twiddy-version of the IPQ-R (Twiddy 2008); and consultation with an expert panel of clinicians and academics with expertise in stroke, stroke rehabilitation and psychology applied to health. The early development also involved consultation with a local patient involvement group, who meet regularly at the University of Nottingham. The Stroke Research Partnership Group is comprised of stroke survivors who have experienced different types of strokes, of varying severity, and are at various stages of post-stroke recovery. The group provided detailed feedback on versions of the Stroke IPQ-R via two meetings held at a meeting room in the University of Nottingham. The meetings were jointly chaired by a senior academic from [University] and a patient representative.

The author of this thesis (NA) attended meetings in November 2012, when the PhD research initially began, and then again in June 2013. The first meeting involved four members of the group and comprised a presentation of the research, and an in-depth discussion of the original IPQ-R, including: relevance to stroke; stroke survivors' needs; and preliminary recommendations for stroke-specific adaptation. In light of this feedback, the author subsequently made changes to this initial version of the Stroke IPQ-R. Then, following consultation with an expert panel and further examination of the stroke literature, this version of the questionnaire was taken to the second meeting with

the Stroke Research Partnership Group, where a detailed discussion of the amendments ensued. This meeting involved five members of the group, and the agenda was specifically focused on three general issues relating to the questionnaire. First, the ordering of the items and in particular whether the questions should be presented in a mixed order or in groups pertaining to each illness belief domain. Second, the response format for the main part of the questionnaire (i.e., all sub-scales except for the identity domain) was considered. Third, the general appearance of the questionnaire and optimal formatting was discussed.

Several changes were made to this initial version of the Stroke IPQ-R following this stage of development. These changes are summarised in Tables 6-1 to 6-3. This preliminary version of the Stroke IPQ-R was then further developed via Think-Aloud interviews, details of which are provided in later parts of this chapter (section 6.4).

Table 6-1. Summary of preliminary changes made to the identity sub-scale

Item	Change(s)	Rationale
Pain	-	-
Difficulty swallowing	Added	Included in Twiddy-version
Sore throat	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Nausea	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Breathlessness	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Weight loss	-	-
Fatigue	-	-
Tight muscles	Added	Considered relevant to stroke by expert panel
Headaches	-	-
Bladder problems	Added	Considered relevant to stroke by expert panel
Bowel problems	Added	Considered relevant to stroke by expert panel
Sore eyes	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Wheeziness	Removed	Not considered relevant to stroke by Stroke Research Partnership Group

Upset stomach	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Sleep difficulties	-	-
Dizziness	-	-
Loss of strength	Removed	Incorporated in 'Paralysis' item
Poor balance	Added	Considered relevant to stroke by expert panel
Paralysis	Added; wording changed to 'Weakness or paralysis in arm or leg'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Poor vision	Added	Considered relevant to stroke by expert panel
Difficulty speaking	Added	Included in Twiddy-version
Forgetfulness	Added	Considered relevant to stroke by expert panel
Difficulty writing	Added	Included in Twiddy-version
Emotionality	Added; wording changed to 'Crying or laughing inappropriately'	Considered relevant to stroke by expert panel; wording subsequently changed following feedback from Stroke Research Partnership Group to improve comprehension by stroke survivors.
Poor concentration	Added	Considered relevant to stroke by expert panel
Difficulty reading	Added	Included in Twiddy-version
What I'm like as a person has changed	Added	Included in Twiddy-version
Getting upset or weepy	Added	Included in Twiddy-version
Clumsiness	Added	Included in Twiddy-version
Hearing difficulties	Added	Considered relevant to stroke by expert panel
Difficulty walking or getting around	Added	Considered relevant to stroke by expert panel
Reduced sensation	Added; wording changed to 'Tingling or numbness'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Stiff joints	-	-

Symbols and abbreviations: Twiddy-version; Stroke-specific version of the IPQ-R developed by (Twiddy 2008)

Table 6-2. Summary of preliminary changes made to the main sub-scales of the Stroke IPQ-R

Item	Change(s)	*Rationale*
Timeline Acute/Chronic		
My stroke will last a short time	Wording changed to 'I believe that the effects of my stroke will last for a short time'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'the effects of my stroke' and 'my condition' for greater relevance to stroke following feedback from Stroke Research Partnership Group; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My stroke is likely to be permanent than temporary	Wording changed to 'I believe that my condition is likely to be permanent than temporary'	
My stroke will last for a long time	Wording changed to 'I believe that the effects of my stroke will last for a long time'	
This stroke will pass quickly	Wording changed to 'I believe that the effects of my stroke will pass quickly'	
I expect to have this stroke for the rest of my life	Wording changed to 'I expect to have these symptoms of my stroke for the rest of my life'	
My stroke will improve in time	Wording changed to 'I believe that the symptoms of my stroke will improve in time'	
Consequences		
My stroke does not have much effect on my life	-	-
My stroke is a serious condition.	Wording changed to 'I believe that my stroke is a serious condition'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My stroke has major consequences on my life	Wording changed to 'I believe that my stroke has major consequences on my life'	
My stroke strongly affects the way others see me	Wording changed to 'I believe that my stroke strongly affects the way others see me'	
My stroke causes difficulties for those who are close to me	Wording changed to 'I believe that my stroke causes difficulties for those who are close to me'	
My stroke has serious financial consequences	Wording changed to 'I believe that my stroke has had serious financial consequences'	
Since my stroke I fear becoming a burden on others	Added	Included in Twiddy-version

Item	Change(s)	*Rationale*
Consequences		
Memory problems since my stroke are affecting my life	Added; wording changed to 'I believe that memory problems since my stroke are affecting my life'	Included in Twiddy-version; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My stroke has strongly affected how I see myself	Added; wording changed to 'I believe that my stroke has strongly affected how I see myself'	
My stroke has badly affected my relationship with my family	Added; wording changed to 'I believe that my stroke has badly affected my relationship with my family'	
Emotional problems since my stroke are affecting my life	Added; wording changed to 'I believe that emotional problems since my stroke are affecting my life'	
Personal Control		
I need to avoid doing too much as this may cause another stroke	Added	Included in Twiddy-version
There is nothing I can do to prevent another stroke occurring	Added; wording changed to 'I believe that there is nothing I can do to prevent another stroke occurring'	Included in Twiddy-version; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
What I do can determine whether my stroke gets better or worse	Wording changed to 'I believe that what I do will determine whether my stroke gets better or worse'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
The course of my stroke depends on me	Wording changed to 'I believe that the course of my recovery from stroke depends on me'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my recovery' for greater relevance to stroke following feedback from Stroke Research Partnership; 'I believe' phrasing added to each statement following discussion with an expert panel
Nothing I do will affect my stroke	Wording changed to 'I believe that nothing I do will affect my recovery from stroke'	
I have the power to influence my stroke	Wording changed to 'I believe that I have the power to influence my recovery from stroke'	

My actions will have no effect on the outcome of my stroke	Wording changed to 'I believe that my actions will have no effect on the outcome of my recovery from stroke'	who considered that making each question more personally relevant would improve comprehension by stroke survivors
There is a lot which I can do to control my symptoms	Wording changed to 'I believe that there is a lot which I can do to control my symptoms'	Retained from original IPQ-R; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
I am confident that I can manage my recovery well	Added	Considered relevant to stroke by expert panel and stroke literature
Item	**Change(s)**	***Rationale***
Treatment Control		
There is very little that can be done to improve my stroke	Wording changed to 'I believe that there is very little that can be done to improve my condition'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my condition for greater relevance to stroke following feedback from Stroke Research Partnership Group
My treatment will be effective in curing my stroke	Wording changed to 'I believe that my medical treatment/rehabilitation will be effective in preventing another stroke from happening'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so item duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation (therapy) e.g., physiotherapy for greater relevance to stroke; wording changed to emphasise stroke prevention to be consistent with Twiddy-version
The negative effects of my stroke can be prevented (avoided) by my treatment	Wording changed to 'I believe that the negative effects of my stroke can be prevented (avoided) by my medical treatment/rehabilitation'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so items duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation e.g., physiotherapy for
My treatment can control my stroke	Wording changed to 'I believe that my medical treatment/rehabilitation can control the symptoms of my stroke'	

		greater relevance to stroke; wording changed to 'symptoms of my stroke' to improve understanding of items by stroke survivors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
Item	**Change(s)**	***Rationale***
Treatment Control		
My treatment will help me to recover	Added; wording changed to 'I believe that my medical treatment/rehabilitation will help me to recover'	Included in Twiddy-version; items duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation e.g., physiotherapy for greater relevance to stroke; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
There is nothing which can help my stroke	Wording changed to 'I believe that there is nothing which can help my recovery from stroke'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so wording was subsequently changed to 'my recovery' for greater relevance to stroke following discussion with an expert panel; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
Illness Coherence		
The symptoms of my stroke are puzzling to me	Removed	Feedback from Stroke Research Partnership Group indicated difficulties with comprehension by stroke survivors
My stroke is a mystery to me	Removed	
I have a clear picture or understanding of my stroke	-	-

I don't understand my stroke	Wording changed to 'I don't understand my recovery from stroke'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my recovery' for greater relevance to stroke following feedback from Stroke Research Partnership Group
My stroke doesn't make any sense to me	-	-
Item	**Change(s)**	***Rationale***
Timeline-Cyclical		
My stroke is very unpredictable	Wording changed to 'I believe that the effects of my stroke are very unpredictable'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'the effects of my stroke,' 'symptoms of my stroke' and 'my condition' for greater relevance to stroke following feedback from Stroke Research Partnership Group; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
The symptoms of my stroke change a great deal from day to day	Wording changed to 'I believe that the symptoms of my stroke change a great deal from day to day'	
I go through cycles in which my stroke gets better or worse	Wording changed to 'I believe that I go through cycles in which my condition gets better or worse'	
My symptoms come and go in cycles	Wording changed to 'I have good days with few or no symptoms and bad days, when I have a lot of symptoms'	Original IPQ-R wording did not make sense to stroke survivors from Stroke Research Partnership Group, so item was subsequently changed for improved comprehension following discussion with an expert panel
Emotional Representations		
I feel embarrassed	Added; wording changed to 'I get embarrassed by the way I am since my stroke'	Considered relevant to stroke by expert panel and stroke literature; wording subsequently changed to be consistent with Twiddy-version
My stroke does not worry me	-	Retained from original IPQ-R with wording amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors

When I think about my stroke I get upset	-	Retained from original IPQ-R with wording amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors
I get depressed when I think about my stroke	Wording changed to 'Since my stroke I get depressed'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently simplified following feedback from an expert panel to improve comprehension by stroke survivors
Having this stroke makes me feel anxious	Wording changed to 'The symptoms of my stroke make me feel anxious'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'this stroke' following recommendations by IPQ-R authors; wording subsequently changed to be consistent with Twiddy-version
My stroke makes me afraid	-	-
My stroke makes me feel angry	-	-
I feel lost since my stroke	Added	Considered relevant to stroke by expert panel
I have lost confidence in myself since my stroke		
I do not feel in control of my emotions	Added	Included in Twiddy-version
My stroke is very worrying to those closest to me		
Those closest to me get very distressed about my stroke		

Symbols and abbreviations: IPQ-R: Illness Perception Questionnaire-Revised; Twiddy-version; Stroke-specific version of the IPQ-R developed by (Twiddy 2008)

Table 6-3. Summary of preliminary changes made to the causal sub-scale

Item	Change(s) made	Rationale
Stress or worry	-	-
Hereditary – it runs in my family	-	-
Diet or eating habits	-	-
Poor medical care in my past	-	-
My own behaviour	-	-
My mental attitude e.g., thinking about life negatively	-	-
Family problems or worries caused my stroke	-	-
Overwork	-	-
My emotional state e.g., feeling down, lonely, anxious, empty	-	-
Ageing	-	-
Alcohol	-	-
Smoking	-	-
My personality	-	-
High cholesterol	Added	Considered relevant to stroke by expert panel
High blood pressure	Added	
Diabetes	Added	
Irregular heartbeat	Added; wording changed to 'Problems with my heart'	Considered relevant to stroke by expert panel; wording subsequently changed in order to improve comprehension by stroke survivors
A germ or virus	-	-
Chance or bad luck	-	-
Inactive lifestyle	Added; wording changed to 'Not taking enough exercise'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Accident or injury	-	-
Pollution in the environment	Removed	Not considered relevant to stroke by expert panel
Altered immunity	Removed	

Important feedback from the [experts] initially suggested that one to one interviews were the preferred option for eliciting survivors' beliefs about their stroke. This informed the decision to collect illness beliefs data from participants in the observational study (reported in Chapter 7) in a face to face visit. The [experts] were also emphatic in their views that drawings would not be an appropriate approach for these patients, primarily because of the physical, cognitive, communication and perceptual difficulties

that commonly affect this population. This corroborated the reasons for selecting the IPQ-R as the method of choice for adaptation in the present research.

There were several modifications that were made to the questionnaire at this stage (Tables 6-1 to 6-3). The most notable amendments are briefly summarised in this section. General modifications will be considered first.

Initially, the phrasing of the items was changed. For example, 'your stroke' and 'my stroke,' were replaced with the 'effects of your stroke,' the 'effects of my stroke,' 'my condition' and 'my recovery' as appropriate. This was because the [experts] considered this wording to better describe the nature of their stroke as an acute event leaving residual short or long-term effects from which they may recover. Second, and relatedly, the words 'I believe' were added as a prefix to each question following discussion with an expert panel, who considered that making each question more personally relevant would improve comprehension by stroke survivors. Third, the wording of the neutral response category was changed from 'neither agree nor disagree' (as per the original IPQ-R) to 'I don't know.' [Experts] made this suggestion in order to minimise any confusion that respondents may feel in answering the questions by ensuring that they had clear and relevant options from which to choose their response.

Fourth, the presentation of the items was modified. Streiner and Norman (2003) suggested that in order to develop a reliable measurement

instrument, the presentation of the items is important. The authors recommended that items should be presented in mixed order to minimise response bias, specifically termed satisficing. This is where respondents provide an answer that is satisfactory rather than optimal (e.g., marking agree for every statement) (Streiner and Norman 2003). However, the [experts] felt that the mixed ordering made the questionnaire more confusing to respond to, and drew attention to the repetitious nature of the questions. Therefore, presentation of the questions was amended to appear in groups pertaining to each illness belief domain (as per the original IPQ-R). In addition, the [experts] suggested that respondents may be more understanding of the repetitious nature of the items (e.g., for accuracy of measurement) if they were initially made aware of the purpose of each batch of questions. In light of this feedback, a preamble (with examples) was included before each set of questions to provide respondents with details regarding the particular illness beliefs domain that the items were assessing. Fifth, the general appearance and formatting of the questionnaire was modified to be consistent with the Twiddy-version, including: a large font; arrows on the identity sub-scale to clearly indicate the order in which people should respond (i.e., symptom first and then the relationship (or not) to stroke); and addition of boxes for each response option that were positioned directly below the item, to make it easier for participants (e.g., those with post-stroke writing problems) to circle their answer (see Appendix 3). Last, items were added throughout the questionnaire for relevance to stroke and to be consistent with the Twiddy-version. Where necessary, questions were also removed for lack of relevance to stroke. See Tables 6-1 to 6-3 for further details of these changes.

There were two noteworthy scale-specific modifications. The first involved the treatment control sub-scale, where items were duplicated and separated according to peoples' medical treatment and rehabilitation. This amendment was made in response to feedback provided by the [experts] who felt that the original questions on this sub-scale did not make sense to them, having received two distinct packages of treatment after stroke (i.e., tablets and rehabilitation). This mirrors earlier discussions in Chapter 1 around the long-term management of stroke. The second change affected the illness coherence sub-scale. Most of these items were abstractly worded (e.g., 'The symptoms of my stroke are puzzling to me' and 'My stroke is a mystery to me'), and were found confusing to the [experts]. [They] emphasised that survivors with post-stroke cognitive impairment (section 1.2.3, Chapter 1) would find it very difficult to understand these items. Therefore, these were removed at this stage.

The preliminary version of the Stroke IPQ-R developed in response to the abovementioned modifications was utilised in the Think-Aloud study, which is reported in the next section of this chapter.

6.4 QUALITATIVE THINK-ALOUD INTERVIEWS

6.4.1 Methods

The Think-Aloud study was carried out and reported in accordance with the recommended guidelines for this approach (van Someren, Barnard et al. 1994).

6.4.1.1 Design and Setting

Qualitative (audio-recorded) interviews were carried out using a Think-Aloud approach in peoples' homes or at a research clinic in Nottingham City and County, UK.

6.4.1.2 Participants

A purposive sample of stroke survivors was recruited to the Think-Aloud interviews to gain insight into a broad range of people with differing experiences of post-stroke treatment and recovery. Participants were recruited over an eight-week period from December 2013 to January 2014.

6.4.1.2.1 Eligibility Criteria

Participants were included if they met the following criteria:

- Adults (aged 18 years or over);
- History of acute stroke;
- Sufficient language and cognitive ability to participate (assessed by NA through liaison with the clinical care team and review of medical notes);
- Residing in Nottingham or Nottinghamshire (UK);
- Provided full written informed consent for an audio-recorded interview.

Participants were excluded according to the following criteria:

- Deemed too unwell by their clinician to be interviewed (e.g., people likely to die within a few days);
- People without sufficient proficiency in English, for practical reasons.

6.4.1.3 Recruitment

The University of Nottingham provided sponsorship and indemnity for this PhD research. Recruitment was performed subsequent to obtaining relevant approvals. Ethical approval was granted from the National Research Ethics Service (NRES) Committee East Midlands – Leicester on 28th November 2013 (Research Ethics Committee (REC) Reference: 13/EM/0392). Research governance approval was obtained on 29th November 2013 from [Hospital] NHS Trust Research and Innovation. Copies of approval letters can be found in Appendix 3.

Recruitment adopted two approaches: 1) from acute stroke and rehabilitation wards, and stroke outpatient clinics at [Hospital]; and 2) from local stroke groups (for example, [example patient advocacy group]). Recruitment was terminated, and further interviews were not conducted, upon reaching theoretical saturation. This is the point at which no new data emerges and is relevant to qualitative research (Glaser and Strauss 1967).

The initial approach about research participation was made by either a member of the usual care team or the lead facilitator of the local stroke group. The author then informed people who were interested in taking part in the study of details pertaining to their participation, which included provision of a Participant Information Sheet (Appendix 2), and a verbal explanation of the research. All initial discussions were completed face to face, and telephone queries were addressed as needed. Where appropriate and necessary, carers were present to facilitate these discussions.

6.4.1.3.1 Informed Consent

Subsequent to initial discussions about participation, those who were keen to be involved in the study were asked by the author to provide full written informed consent prior to being interviewed. This included permission to be contacted to arrange the interview at home or at the research clinic. Participants signed and dated a specially designed Consent Form to record their permission (Appendix 2).

Carers were permitted to be present during interviews as facilitators, or to provide practical support to participants (e.g., circling responses on the questionnaire), where appropriate. However, carers were not consented to this study. Therefore, any responses made by carers during the interview audio-recording were not included in the transcriptions.

6.4.1.4 Materials

Participants completed the preliminary version of the Stroke IPQ-R, developed as described in section 6.3 of this chapter.

6.4.1.5 Procedure

Participants were initially given verbal instructions (see Box 6-1) by the author, adapted from Green and Gilhooly (1996), French, Cooke et al. (2007) and Ericcson and Simon (1993). Further information that was specific to the population under study was also provided, specifically regarding any support that participants required with the actual completion of the questionnaire. Prior to proceeding with the Think-Aloud task, participants were asked to complete a

proforma, which recorded demographic information including their age, sex, ethnicity, type of stroke, and year of diagnosis.

"I have developed a questionnaire to learn more about peoples' beliefs about their stroke, such as what it is, what might have caused it, and how it affects their lives. I have tried to tailor this questionnaire to stroke survivors, and now want to find out whether what I have developed is okay for people, or whether there are ways that I can make it even better. I also want to check that people understand the questions in the way that I had meant them. To do this, I would like you to complete this questionnaire while thinking out loud. So I want you to tell me everything that you are thinking as you read each question and decide how to answer it. There is no right or wrong answer. It is okay if you find some of the questions easy or difficult to answer. I would like you to talk constantly. Please do not plan what you are going to say, just say whatever comes into your head. Do not try to explain to me what you are saying either. Just act as if you are alone in the room. If you remain silent for any long period of time, I will ask you to 'keep talking.' Please try to speak as clearly as possible, as I shall be recording you as you speak. Do you understand what I want you to do?

If you need any help with reading the questions, or indicating your responses (for example, by circling answers or ticking boxes), then I can help you with this. However, I will not be able to explain any of the questions to you. This is because part of the research is around making sure that the questionnaire is really clear for people who have had a stroke to answer.

I would like to first ask you for some information about you. This is so that when I report what I have found from the interviews, I can describe the kind of people that I had spoken to about our questionnaire."

Box 6-1. Verbal instructions provided to participants

The Think-Aloud interview initially involved a practise phase, where participants were asked to complete the first 10 questions of the identity sub-scale of the Stroke IPQ-R as a warm-up task. The purpose of the warm-up task was to allow participants to familiarise themselves with the Think-Aloud method, and clarify any misunderstandings that they had about the requirements

of the task, and also for the author to check that individuals understood the task and were able to think out loud. Any questions or uncertainties that participants had regarding the Think-Aloud task were resolved at this stage. Other studies that have utilised the Think-Aloud approach have assigned different warm-up tasks, and many of these have not been associated with the questionnaire being examined; for example, participants answering questions about their general health (using a five-point Likert scale akin to that used by the IPQ-R) (French, Cooke et al. 2007, Darker and French 2009, van Oort, Schroder et al. 2011). Either option is acceptable, according to the guidelines for the Think-Aloud method (van Someren, Barnard et al. 1994). However, a decision was made to incorporate a warm-up task that was associated to the main Think-Aloud task in this research. This was primarily based on the population under study who often experience difficulties with reading, writing, speaking and cognition (e.g., slowed thinking). Thus, it was considered appropriate to ensure that the burden of completing a lengthy questionnaire was reduced as far as possible. In addition, it seemed more appropriate to engage patients in one task, and minimise any opportunities for confusion that might arise by asking participants to split their focus on two distinct tasks.

Consistent with other Think-Aloud studies, participants were not interrupted once they began completing the questionnaire, unless they were silent for around 10-seconds (French, Cooke et al. 2007, Darker and French 2009, van Oort, Schroder et al. 2011). Audio-recorded Think-Aloud interviews lasted between 30-and 60-minutes, and were transcribed verbatim by the author of this thesis, using standard transcription conventions (Bailey 2008).

6.4.1.6 Analysis

The Think-Aloud interviews were analysed according to the established guidelines for this approach (van Someren, Barnard et al. 1994). The first step involved sectioning the transcripts to obtain episodes of text referring to each illness belief domain (e.g., identity, consequences, personal control etc.) Next, segmenting of the text was carried out (coding), where relevant sections of participants' responses to particular items within each episode were assigned to specific categories (codes), many of which reflected the coding frameworks that have been employed by previous Think-Aloud studies (Tourangeau, Rips et al. 2000, French, Cooke et al. 2007, van Oort, Schroder et al. 2011, McCorry, Scullion et al. 2013):

1. No problems, indicating that participants demonstrated no problems with the item;
2. Missing or insufficient thinking aloud, where a response for a particular item was missing, because of inadequate thinking out loud;
3. Re-read or stumbled in reading (e.g., stammered, stuttered, or repeated the question several times), indicating problems with peoples' understanding of the question;
4. Difficulty generating an answer, where participants expressed that they were not sure of the response that they would provide, which was either because of problems with how well people understood the question, or an item that was not applicable to their current circumstances;
5. Difficulty with the response format, where respondents expressed problems with indicating their answer;

6. Questioned content, suggesting problems with how the question was worded;
7. Confusion or misinterpreted, where participants expressed that they did not fully understand the question, or answered a different question to that being asked;
8. Incongruent response, where respondents' written and verbal responses did not match.

All coding was undertaken by the author. Problems relating to the above mentioned categories were then thematically organised.

6.4.2 Results and Discussion

6.4.2.1 Sample Characteristics

Theoretical saturation emerged following interviews with six participants. Therefore, the study sample comprised six stroke survivors (two males, and four females), whose characteristics are summarised in Table 6-4. The mean age was 58.8 years (standard deviation (SD) =18.9 years; range=31 to 78 years). Over 80% of the sample was of white-British ethnicity, and three out of six participants were educated to University level. The time since acute stroke ranged from one-month to 14-years, meaning that half of the sample comprised people with acute stroke. The majority of participants (five out of six) were hospitalised for an ischaemic stroke, though the sub-type varied.

Table 6-4. Characteristics of the Think-Aloud sample

Participant	Age	Gender	Ethnicity	Type of stroke	Year of diagnosis	Attended University?
1	78	Male	White-British	Ischaemic	1999	✓
2	31	Female	White-British	Ischaemic	1999	✓
3	40	Female	African-British	SAH	2012	✓
4	64	Female	White-British	Ischaemic	2013	×
5	72	Female	White-British	Ischaemic	2013	×
6	68	Male	White-British	Ischaemic	2013	×

Symbols and abbreviations: SAH; Subarachnoid Haemorrhage

6.4.2.2 Summary of Problems with the Stroke IPQ-R

Overall, participants experienced no problems for the vast majority of sub-scales of the preliminary version of the Stroke IPQ-R. The total number of problems that participants encountered while completing the questionnaire was 179. Table 6-5 presents an overview of these problems per sub-scale of the Stroke IPQ-R. Items relating to causes (N=33); identity (n=30); treatment control – rehabilitation (N=22); and treatment control – medical treatment (N=18) yielded the greatest percentage of problems. The remainder of sub-scales showed the fewest problems (Table 6-5). However, the timeline-cyclical sub-scale was the only scale where problems emerged for most of the items (N=12).

6.4.2.2.1 Missing Think-Aloud Data

The main problem identified in the present study was with regard to missing or insufficient Think-Aloud data generated (67 of 179 problems). This consistently affected most of the sub-scales of the Stroke IPQ-R (Table 6-5). For example, missing Think-Aloud data contributed to 10 out of 30 problems on the identity sub-scale; 23 out of 33 problems on the causal sub-scale; and 34 out of 116 problems on the sub-scales for the remainder of illness belief domains. For the identity sub-scale, this was evident for three out of six respondents, and the

most noteworthy example occurred for Participant 4, who did not have Think-Aloud data for various concurrent symptoms: 'bladder problems' and 'bowel problems,' and then again for 'dizziness' and 'poor balance.' However, there were Think-Aloud data for the intermediate item, 'sleep difficulties.' This could have been because the participant was happily responding to these items, and/or they may have forgotten to think-out loud. Indeed, this participant was prompted by the author to 'keep talking' at this point in their interview. Four out of six respondents had missing or insufficient Think-Aloud data for the causal sub-scale, and this was evident for several of the causal attributions. The causal sub-scale appeared last in a lengthy questionnaire. Participant 1 commented at the end of the interview: *"The length is…long…a disadvantage…Quite a few questions."* This pattern was also consistent for the remainder of sub-scales, where again, the majority of problems with insufficient Think-Aloud data happened more frequently for the questions towards the end of the instrument.

These findings are broadly comparable with the study by McCorry, Scullion et al. (2013) where a version of the IPQ-R was developed specifically for respondents with type 2 diabetes mellitus. The authors found that not all participants consistently verbalised their thoughts during the Think-Aloud task, and argued that this is a common problem for studies using this approach. However, the success of the method is highly dependent upon this.

Missing Think-Aloud data may emerge for two reasons. First, participants may not be experiencing any problems at all with the items to which they are responding, and could be happily completing the questionnaire. In spite

of this, peoples' silence is likely to indicate problems with forgetting in relation to the instructions of the Think-Aloud task (i.e., to think out loud). Second, participant fatigue could be implicated. This seemed to be the case for the present study where missing Think-Aloud data tended to happen more frequently for items towards the end of this fairly long questionnaire. Issues regarding fatigue and forgetting are particularly relevant to stroke survivors, and may suggest that the Think-Aloud approach as it currently stands is not suitable for these patients.

6.4.2.2.1.1 Fatigue and Forgetting

Fatigue is common after stroke, affecting people in the acute and chronic phases of the condition, and seriously impairing patients' ability to manage aspects of everyday life (Glader, Stegmayr et al. 2002, Barritt and Smithard 2011). There is currently no research that has specifically examined strain on stroke survivors when completing questionnaires, or equally the suitability of the Think Aloud approach in this group. However, it has been indicated in the literature that respondent fatigue can generally contribute to the burden of questionnaire completion, often leading to problems with poor completion and quality of the data, and this is heightened for particular groups, such as those that are severely ill and older individuals (Rolstad, Adler et al. 2011). Therefore, this is something that is likely to be the case for stroke survivors, and indeed, there were several respondents in the present study (4 out of 6) who fulfilled this particular demographic. Persistent forgetting to think out loud, and therefore, requiring frequent prompts to 'keep talking' could also be attributed to a common difficulty that people often experience after a stroke

(briefly described in Chapter 1): impaired cognition. Memory loss is particularly common amongst stroke survivors (Maud 2006). There is, however, limited literature available on the Think-Aloud approach amongst stroke survivors. Therefore, it is difficult to ascertain whether it is the method that lacks suitability for stroke survivors that should be implicated, or the high cognitive demands that may have been placed on respondents when completing the questionnaire (Rolstad, Adler et al. 2011).

Arguably, the present findings and those from other Think-Aloud studies suggest that the length of the questionnaire (irrespective of the specific patient group) is a likely contributor to the observed problems of missing Think-Aloud data. For example, the study by van Oort, Schroder et al. (2011) was not as affected by absence of responses as the present Think-Aloud research and the work by McCorry, Scullion et al. (2013). van Oort, Schroder et al. (2011) examined peoples' responses to the Brief IPQ, which comprises only nine-items and was developed for brevity. With all of this in mind, it may be that the Think-Aloud approach needs to be altered to ensure that respondents are prompted to 'keep talking' at regular intervals. This is particularly relevant for lengthy questionnaires and respondents with conditions where fatigue may be characteristic. However, the study by van Oort, Schroder et al. (2011) involved adults attending a preoperative exercise programme and those receiving physiotherapy, and respondents were excluded on the basis of problems with cognition (e.g., memory loss). Therefore, the suitability of the Think-Aloud approach for patients with conditions where memory problems are common

(e.g., stroke survivors), remains questionable and cannot be confirmed by the evidence to date.

What was evident in the present Think-Aloud study, however, was that respondents with stroke expressed a natural desire to elaborate on their responses to the questionnaire. Participants seemed keen to share their 'story' about their journey following stroke thus far, and this was evident in many of the quotations that were extracted from the transcripts. Similarly, there was a tendency for individuals to seek reassurance from the interviewer (NA) for their responses. This was less evident for respondents in the present study with a chronic stroke, and has not been found in other Think-Aloud studies either (Boeije and Janssens 2004, French, Cooke et al. 2007, Murtagh, Addington-Hall et al. 2007, French and Hevey 2008, Westerman, Hak et al. 2008, Darker and French 2009, van Oort, Schroder et al. 2011, McCorry, Scullion et al. 2013). However, the Think-Aloud approach is generally not conducive to this kind of elaboration, where the interviewer's role is to remain fairly passive in the interaction, asides from providing instructions to participants to 'think out loud' (Willis 2005, Beatty and Willis 2007). This may provide further support for the argument that the Think-Aloud approach has drawbacks for stroke survivors, particularly those in the acute phase of stroke. Therefore, this finding indicates a need for future studies to investigate the extent to which this method is suitable for people following a recent stroke, and more specifically, whether adaptations to this particular style of interviewing are necessary to enhance its' appropriateness (and thus validity) for this group.

There is indeed another school of thought with regard to cognitive interviewing (mentioned in section 6.2.2 of this chapter) that involves verbal probing and specific, direct questions about peoples' questionnaire responses (Willis 2005, Beatty and Willis 2007). It may be that this approach has better suitability for stroke survivors, or alternatively, a new method that is somewhere between the two extremes of verbal probing versus Think-Aloud. This warrants further elaboration by future research. The beauty of the Think-Aloud approach is that it is a relatively new and evolving method to be used for the development of valid questionnaires; therefore, more work needs to be undertaken before deciding upon the best way to elicit the required information from stroke survivors, as well as other similar patient groups.

Table 6-5. Total problems across sub-scales of the Stroke IPQ-R

	Labels								
	No problems	**Missing, or no sufficient thinking aloud**	**Re-read or stumbled in reading**	**Difficulty generating an answer**	**Difficulty with response format**	**Questioned content**	**Confusion or misinterpreted**	**Incongruent response**	**TOTAL PROBLEMS N (%)**
Identity	*130*	10	2	7	4	2	4	1	30 (17%)
Timeline (acute/chronic)	*31*	1	2	1	2	3	1	0	10 (6%)
Timeline-cyclical	*16*	2	2	0	0	3	5	0	12 (7%)
Consequences	*60*	1	1	3	0	5	3	0	13 (7%)
Personal control	*39*	1	8	3	0	1	3	0	16 (9%)
Treatment control (medical treatment)	*21*	12	3	1	0	1	1	0	18 (10%)
Treatment control (rehabilitation)	*12*	11	3	2	0	2	4	0	22 (12%)
Illness coherence	*13*	0	4	0	0	0	5	0	9 (5%)
Emotional representations	*61*	6	1	4	0	3	2	0	16 (9%)
Causes	*96*	23	0	4	0	1	5	0	33 (18%)

Symbols and abbreviations: IPQ-R; Illness Perception Questionnaire-Revised

Most of the remaining problems with the preliminary version of the Stroke IPQ-R consisted of participants re-reading or stumbling while reading a question (26 of 179 problems); confusion or misinterpretation (31 out of 179 problems); difficulty finding an answer to a question (25 of 179 problems); and the content of items being questioned (21 out of 179 problems). Some, though very few, difficulties with the response format also emerged for the Stroke IPQ-R (6 out of 179 problems), and these are described below.

6.4.2.3 Problems with the Response Format

Problems with the response format mostly occurred when participants were answering questions on the identity sub-scale (4 out of 6 problems), which involved circling of a yes or no response for the experience of a symptom, and indicating (yes or no) whether or not this symptom was related to peoples' stroke (see Stroke IPQ-R in Appendix 3). For example, three participants out of six encountered these difficulties when responding to symptoms that were not specific to stroke (such as, pain, and difficulty seeing things), and rather, symptoms that people may experience daily for other conditions. Therefore, respondents seemed uncertain about how best to indicate their response. For instance:

"Oh pain…Do you want me to circle that?" [Participant 4]

One out of six respondents initially experienced difficulties with the response format for two items from the timeline acute-chronic sub-scale, which appeared first and immediately after the identity sub-scale ('My stroke will last a short time' and 'My stroke is likely to be permanent than temporary'). This

sub-scale involved asking participants to respond on a five-point Likert scale, ranging from strongly agree to strongly disagree, and contributed to two out of six problems with the response format for this questionnaire. For example:

"I believe that the effects of my stroke will last for a short time. I agree. So what do I do with that, circle it?" [Participant 6]

This problem did not recur for the remainder of items on this questionnaire. Therefore, this could reflect a 'run-in' period, while participants became accustomed to this format for responding. Given that the problems with this manner of responding only occurred at the beginning of the questionnaire, the findings seem to indicate that participants quickly got used to this response format.

Therefore, difficulties with the response format mostly affected the identity sub-scale. This response format was added to the revision of the IPQ to be consistent with Leventhal's original conceptualisation of the identity domain. This suggested that people experience a pressure towards symmetry, whereby they have a need to define an abstract concept or label (such as, hypertension) in a concrete manner (e.g., by assigning symptoms) (Meyer, Leventhal et al. 1985, Leventhal, Benyamini et al. 1997, Leventhal, Brissette et al. 2003). Several studies have confirmed this symmetry between labels and symptoms (Schachter and Singer 1962, Bishop and Converse 1986). Further, Easterling and Leventhal (1989) suggested that this process of symptom attribution has an emotional component. For example, higher levels of worry about breast cancer were found in women who considered themselves to be vulnerable to the disease

and who reported symptoms, even those that were not specific to cancer (Leventhal, Benyamini et al. 1997). A further study of people with hypertension showed that this pressure towards symmetry is bi-directional, where patients who are given a disease label seek and find evidence of symptoms (Meyer, Leventhal et al. 1985). For instance, people with hypertension that were new to their blood pressure treatment were more likely to monitor and report symptoms (e.g., heart beating, face warming etc.) the longer that they were receiving treatment (Meyer, Leventhal et al. 1985, Leventhal, Benyamini et al. 1997), and the higher that they considered their blood pressure to be (Baumann, Cameron et al. 1989).

However, some participants in the present study found it difficult to assign a label to symptoms that were non-specific to stroke, and where there was overlap with symptoms that they may experience for other conditions. This finding did not emerge in the work by Twiddy (2008), though affected participants in the present study regardless of when their stroke occurred. The reasons for this pattern are unclear. However, the experience of co-morbidities, which are common amongst stroke survivors (Karatepe, Gunaydin et al. 2008) (e.g., hypertension, atrial fibrillation and diabetes (Chapter 1)) may add to the confusion faced by the present respondents with regard to their stroke and non-stroke-related symptoms. Therefore, some survivors may need support and clarification to aid their completion of this sub-scale. This lends further weight to earlier suggestions by the [experts] (section 6.3) that one to one delivery of the questionnaire would be the most ideal format for eliciting illness beliefs in this group, because it would allow the interviewer to

provide support to respondents as needed. This further indicates a need to modify the Think-Aloud approach to enhance its suitability for stroke survivors and other patient groups with similar needs.

6.4.2.4 Problems with Wording

6.4.2.4.1 Complexity of Wording

Problems with the complexity of wording emerged for several items across the sub-scales. For example, the wording of specific symptoms on the identity sub-scale caused problems (6 out of 30 problems), and these affected two out of six of the respondents.

"What's fatigue?...Now what do you mean by tight muscles?" [Participant 5]

Similar was the case for the 'hereditary' causal attribution, which was another word that was queried by Participant 6: *"What's that word mean?"* In addition, the wording of the 'high cholesterol' item created difficulties for two out of six participants, and for one of these participants, it affected their ability to generate a confident answer:

"High cholesterol…I did have high cholesterol I think, so I'll put that. I don't know cos I never had it checked. I'll just leave that one shall I?...I'm not sure so shall I just put disagree?" [Participant 4]

Further, two out of six participants experienced problems with the word 'consequences' from an item on the consequences sub-scale: *"My stroke has major consequences on my life…What do you mean consequences?"*

[Participant 5]. Participant 5 also struggled with the word 'anxious' from an item on the emotional representations sub-scale: *"Ah, explain a little bit how you mean anxious?"*

In summary, the wording of several items emerged to be too complex for stroke survivors with lower levels of literacy, and therefore, simplifications were necessary. However, this is a problem that is commonly evident for health questionnaires, and is a key consideration in the design of instruments (Mathers, Fox et al. 2007, D'Alonzo 2011). For example, Streiner and Norman (2003) argued that measurement instruments should generally be worded for age 12 reading skills.

6.4.2.4.2 Negative Wording

A particular problem with the wording of questions also emerged for items that were negatively worded, which mostly affected the personal control and illness coherence sub-scales. For example, four out of six participants had problems with a particular item from the personal control sub-scale, and this tended to be demonstrated by people re-reading or stumbling in reading the question:

"I believe that nothing I do will affect my recovery from stroke. (Silence) I believe that nothing I do will affect my recovery from stroke." [Participant 1]

Similarly, two out of six participants had problems with a further item from this sub-scale:

"I believe that my actions will have no effect on the outcome of my recovery. I believe that my actions will have NO effect on the outcome of my recovery…" [Participant 3]

This was also found for two items from the illness coherence sub-scale for two out of six participants, and again resulted in people re-reading or stumbling in reading the questions, and for these items, led to an inability to formulate a response. For example:

"I don't understand my recovery from stroke. (Silence) I don't really understand that one. I don't understand my recovery from stroke…Hmm…(Silence) Not sure what to put for that one." [Participant 4]

"My condition doesn't make any sense to me. (Silence) My condition doesn't make any sense. Any sense to me. What?" [Participant 6]

Problems with negative wording did not generally emerge for the remainder of items on the questionnaire despite the similar way in which these items were worded (e.g., 'My stroke does not have much effect on my life' from the consequences sub-scale, or 'I believe that there is nothing which can help my recovery from stroke' from the treatment control sub-scales). This may perhaps have been because participants became accustomed to this style of wording, and this was particularly relevant for the treatment control questions which appeared last in the questionnaire.

The problems that arose with negative wording of items are consistent with the study by McCorry, Scullion et al. (2013), though for the present research, might be attributable to post-stroke cognitive difficulties. The inclusion of negatively worded items is generally considered to be beneficial in addressing problems with questionnaires relating to biased responding (Streiner and Norman 2003). However, as argued by McCorry, Scullion et al. (2013), the process of agreeing or disagreeing with a negatively worded item increases the cognitive complexity of the task of responding to a questionnaire. Therefore, negatively worded items may not be appropriate for stroke survivors with impaired cognition. In addition, peoples' performance on negatively worded questions is related to age and verbal ability (Marsh 1996), and this was demonstrated in the present study, where several of the older respondents re-read or stumbled in reading many of the negatively worded items of the Stroke IPQ-R.

While it has been argued that negatively worded items should be avoided in the construction of questionnaires (Roszkowski & Soven, 2010), several of these questions from the original IPQ-R were retained in the Stroke IPQ-R, in the interests of reducing response bias. Also, however, the preferred approach for administration of the Stroke IPQ-R as stated by survivors themselves in this research was one to one interviews, where explanations to aid comprehension in this group could be provided as necessary. A similar modified approach has previously been utilised to elicit illness beliefs amongst people with lower limb amputation by Callaghan, Condie et al. (2008). This again

echoes earlier discussions in this section around finding an optimal approach for gathering information on questionnaire suitability amongst stroke survivors.

6.4.2.5 Problems with Specific Items and Sub-Scales

Problems also emerged for several other items on the questionnaire, and these incorporated both individual (i.e., single items) and groups of questions (i.e., whole sub-scales). Issues with the individual items are considered first.

6.4.2.5.1 Item Problems

Most notably, for the identity scale, a specific symptom caused significant problems for four out of six respondents, creating six of the 30 problems for this sub-scale. The problems for this item were varied. For example, re-reading or stumbling while reading this question was evident for Participant 6:

"What I'm like as a person has. What, I'm, like, as a person has changed. What's that mean? What I'm. What. I'm. Like as a person has changed. What does that mean?" [Participant 6]

Whereas, Participants 2 and 5 both struggled to generate an answer for this particular symptom. Participant 2 indicated that the question seemed vague, making it difficult to discern what exactly they were being asked about; their personality or outlook on life:

"What I'm like as a person has changed…that's quite ambiguous because the stroke changed you (silence). My personality hasn't changed, but

the stroke has changed me as a person, in terms of crikey…everything really, my outlook on life, erm my resilience, sensitivity erm…I'm gonna have to put a question mark there, because I think that question is very broad." [Participant 2]

Participant 5 did not provide an answer because of not fully understanding and misinterpreting the question.

Interestingly, and this was also found for questions from other sub-scales (elaborated later in this section), Participant 1 indicated that this question would be best suited to be answered by somebody close to them, and this is likely to be a person who has been there throughout their journey following stroke thus far:

"What I'm like as a person has changed. (Silence). That's a difficult er question to answer, I suppose it must have. Must have changed me. Erm, but that I think is a question for somebody that's close to me and outside of me really." [Participant 1]

Problems arising from this item emphasised several key issues that can affect stroke survivors, including: personality changes; altered outlook on life; and the role of family in the post-stroke recovery journey. For example, several studies have shown that following stroke, patients may demonstrate abnormal behaviours, such as withdrawal, irritability, unpredictability, and rudeness, and these have a tendency to be recognised by carers (e.g., close family) rather than survivors themselves (Anderson, Linto et al. 1995, Stone,

Townend et al. 2004). These changes can impact upon the relationship of survivors with the people that are closest to them (Gillespie and Campbell 2011). It is often peoples' relatives who adopt informal caring responsibilities, and therefore, are the ones who manage the changes to stroke survivors' personalities and mood on a daily basis (Han and Haley 1999, Gillespie and Campbell 2011). However, not all changes in the individual have been regarded as negative (Stone, Townend et al. 2004). For instance, a study has highlighted that after stroke, survivors often develop an awareness of their own mortality, which can affect people in different ways and may influence their outlook on life (Pringle, Drummond et al. 2013). Therefore, asking people about any changes that they have experienced as a person since their stroke is an important and relevant question to ask.

Issues also arose in relation to specific items on the causal sub-scale. For example, one attribution ('accident or injury') contributed to more problems (4 out of 33 problems) compared to the remainder of causes on this sub-scale. In particular, Participant 4 was confused by this question, and was not able to generate an answer: *"Accident or injury…I don't understand that one either." [Participant 4]*

Several other items, particularly those that made people think about the role of psychological factors or their own personality or behaviour in contributing to their stroke, also caused similar problems for participants. Three out of six participants were confused by the 'family problems or worries;' 'my

mental attitude;' 'my own behaviour;' 'my personality' causal attributions. For example:

"Family problems or worries caused…can actual worries then help, cause people to have a stroke? Worries." [Participant 4]

"My personality (silence) my personality? I've got a wonderful personality, so I strongly disagree with that don't I?" [Participant 6]

Respondents who found these items difficult to answer were those with more recent strokes (between one and three-months prior), rather than those with chronic strokes over one-year previously (Participants 1, 2 and 3).

Therefore, respondents in the present study with a recent stroke seemed to experience comparably more difficulties with several of the causal attributions on the causal sub-scale, than those with chronic strokes. Attributions for the role of psychological factors or peoples' own personality or behaviour (some of which were non-specific to stroke) as potential contributors to stroke were particularly problematic. This could indicate that these patients are too early in their recovery journey after stroke to have developed a sound understanding of the possible risk factors for stroke, including that some can be attributed to peoples' own behaviour and lifestyle (as described in Chapter 1). In consequence, these participants may have a lack of knowledge about stroke. In addition, stroke is a medical emergency, which is unexpected and, for the majority of survivors, strikes 'out of the blue' (Chapter 1), without allowing people the opportunity to closely consider early on why it has happened. The

present findings suggested that peoples' understanding of their stroke tends to develop through their recovery journey, and this can continue long-term (Chapter 1). In support of this finding, the concept of 'accident or injury' was generally not well recognised by participants in the present study as a causal factor for their stroke. This could mean that people were aware that something else had caused their stroke, despite some respondents not knowing at the time of being interviewed what exactly that might have been.

6.4.2.5.2 Sub-Scale Problems

Specific problems that emerged for sub-scales of the questionnaire are summarised in this section.

6.4.2.5.2.1 Timeline-Cyclical

There were problems for the majority of questions on the timeline-cyclical sub-scale, particularly around participants not understanding the items. For example, Participant 6 did not understand the questions, 'I believe that the effects of my stroke are very unpredictable' and 'I have good days with few or no symptoms and bad days, when I have a lot of symptoms,' which was reflected in the respondent re-reading or stumbling while reading these items. Further, Participant 5 queried the content of the former question, and again, sought reassurance from the author with regard to their response. For example:

"I believe that the effects of my stroke are very…unpredictable. I believe that the effects of my stroke (silence) I believe that the effects. Of my stroke. Are very unpredictable. What does that mean?" [Participant 6]

Similarly, Participant 4 did not understand the latter item, and more specifically, raised a query with NA in relation to why their stroke has been of an episodic nature for them.

"Yeah they do…I have good days with few or no symptoms, and bad days when I have a lot of symptoms. (Silence) why does that happen then, one day you feel ok, next day, I don't understand that." [Participant 4]

Further, the uncertainty around this question may have contributed to missing Think-Aloud data for the item that appeared intermediate to these questions, 'I believe that the symptoms of my stroke change a great deal from day to day.' This was evident for Participant 6, and also created problems for Participant 5 who may not have fully understood the question, and answered in contradiction to their response for the previous item.

"Symptoms are very unpredictable from stroke…That means it's happening here and there…Yeah, yeah…they change a great deal from day today…No they don't change a great deal er." [Participant 5]

In addition, Participant 5 struggled with their understanding of the final question on the timeline-cyclical sub-scale, 'I believe that I go through cycles in which my condition gets better or worse,' and answered with regard to one particular aspect of their health that was of most concern to them rather than about the stroke

"(Silence) there's, there's days when my eyes is good cos I'm quite happy with myself yes." [Participant 5]

Participants in the present Think-Aloud study may have struggled to answer the questions for the timeline-cyclical domain, because these beliefs may not be applicable to stroke survivors. For example, the later addition of the timeline-cyclical domain to the revision of the IPQ has lacked a strong theoretical basis (Moss-Morris, Weinman et al. 2002). The authors highlighted the need to include these beliefs in the IPQ-R, though did not provide the reasoning for this decision. However, since this revision, there has been some evidence for the importance of episodic disease beliefs in conditions such as asthma (Halm, Mora et al. 2006) and depression (Chilcot, Norton et al. 2013)). This has not been widely acknowledged for stroke, though there is one study cited in Chapter 4 of this thesis (section 4.2) strongly endorsing the role of cyclical timeline beliefs in the prediction of depressive symptoms after stroke (Klinedinst, Dunbar et al. 2012). Rather, a distinction has consistently been made in the stroke literature around an acute or chronic nature of stroke. For example, stroke has been described as having an acute onset (termed clinically as 'acute stroke'), though for many survivors, such as those left with enduring residual disability requiring active long-term management, stroke is considered chronic (Young, Murray et al. 2003). Therefore, acute or chronic timeline beliefs may have greater relevance than cyclical timeline beliefs to stroke survivors in their recovery. This will be further investigated in the observational study of Chapter 7.

6.4.2.5.2.2 Treatment Control

The treatment control sub-scales were generally problematic (40 out of 179 problems overall). As previously noted in the preliminary development

of the Stroke IPQ-R (section 6.3), the sub-scales were separated for medical treatment and rehabilitation, where the former appeared first. Further, as with the other sub-scales, a short preamble was included to support participants' understanding of the questions. However, participants in this Think-Aloud study tended to blur the questions on these two separate sub-scales, becoming confused as to whether they were responding for their medical treatment or rehabilitation. For example, Participant 4 responded to an item from the treatment control – medical treatment sub-scale as though it was asking about rehabilitation:

"I believe there is nothing which…can help my recovery from stroke. Disagree because there's people (silence) people have been really good actually you know, and there's been (silence)…Physiotherapists were good. Getting me out the house, a bit up the road you know. Erm (silence) erm the doctor. I think everybody really you know. Then there was someone around me, I think it was just…just before Christmas or just after, asking me how I was. Somebody called [person's name] someone called…Don't know. It's just someone like rehab I think she said she was yeah." [Participant 4]

A further example was Participant 2, who answered one of the items from the treatment control – rehabilitation sub-scale as though they were answering for their medical treatment:

"I believe there is nothing which can help my recovery from stroke. No. I disagree. Like erm the medication I take is Warfarin, and there are already drug trials being done for an alternative so again you've got to put your faith in research haven't you (laughs)." [Participant 2]

Comprehension problems emerged on this sub-scale for two out of six participants. For example, one item was found difficult to understand by Participants 4 and 5:

"I believe that my rehabilitation (silence) erm, I don't know. Does physiotherapy prevent another stroke from happening?...I don't know with that one." [Participant 4]

The understanding of a further item was also problematic for Participant 4:

"I believe that my rehabilitation can control the symptoms of my stroke (Silence) I don't know, I don't understand that one either. I believe that my rehabilitation can control the symptoms of my stroke." [Participant 4]

These difficulties with comprehension were demonstrated in various ways, including re-reading or stumbling while reading (Participant 4), and being unable to generate an answer (Participants 4 and 5).

The treatment control sub-scale was initially separated following consultation with [experts] in the preliminary development of the Stroke IPQ-R (section 6.3). Following expert feedback, two sets of questions were considered by these sub-scales: one around peoples' medical treatment for stroke, and the other for their rehabilitation. However, this Think-Aloud study has demonstrated that respondents found this confusing, and kept blurring the two sets of questions, responding to questions about

rehabilitation as though they were being asked about their medical treatment, and therefore, repeating their answers.

It is unclear from the findings of the present study as to why exactly these sub-scales caused problems for respondents. Previous research by Twiddy (2008) suggested that participants with chronic strokes did not consider themselves to have received any treatment. In addition, the treatment control sub-scale in the Twiddy-version of the questionnaire showed good internal consistency for survivors with a chronic (α=0.75) or more recent stroke (α=0.80). Whether this also applies to respondents in the present study is not known, and is a limitation of the Think-Aloud approach. As mentioned previously (section 6.2.2), the Think-Aloud method does not allow for any elaboration during the course of the interview (Willis 2005, Beatty and Willis 2007). This further supports the earlier premise that there is value in adopting an alternative approach (e.g., semi-structured interviews) or a modified Think-Aloud method (e.g., verbal probing), in order to gain insight from participants themselves into the reasons behind their difficulties to answer particular questionnaire items. This requires further exploration, and may involve future researchers going back to basics to specifically investigate stroke survivors' understanding of their treatment. This is elaborated in Chapter 8 of this thesis.

6.5 FINAL VERSION OF THE STROKE IPQ-R

Subsequent to the Think-Aloud interviews, a final stage of consultation ensued to produce a version of the Stroke IPQ-R (shown in Appendix 3) to be utilised in the main observational study of this PhD research

(Chapter 7). Consultation involved: a stroke survivor from the Stroke Research Partnership Group; and an expert panel of clinicians and academics with expertise in stroke, stroke rehabilitation and psychology applied to health. The amendments made are summarised in Tables 6-6 to 6-8.

Table 6-6. Summary of final changes to the identity sub-scale

Item	Change(s)	Rationale
Pain	Wording changed to 'Pain (not headaches)	Feedback from one participant in the Think-Aloud interviews suggested that the original wording overlapped too much with the 'Headaches' item
Difficulty swallowing	-	-
Weight loss	-	-
Fatigue	Wording changed to 'Extreme tiredness'	Original wording emerged from Think-Aloud interviews to be too complex
Tight muscles	Wording changed to 'Stiffness in muscles'	Expert feedback suggested that the revised wording would improve comprehension by stroke survivors
Headaches	-	-
Bladder problems	-	-
Bowel problems	-	-
Sleep difficulties	-	-
Dizziness	-	-
Poor balance	-	-
Weakness or paralysis in arm or leg	-	-
Poor vision	Wording changed to 'Difficulty seeing things'	Wording revised to be consistent with other related symptoms (e.g., reading, writing, and hearing)
Difficulty speaking	-	-
Forgetfulness	Wording changed to 'Feeling forgetful'	Expert feedback suggested that the revised wording would improve comprehension by stroke survivors
Difficulty writing	Wording changed to 'Difficulty writing things down'	Wording revised to improve comprehension by stroke survivors
Crying or laughing inappropriately	-	-
Poor concentration	-	-
Difficulty reading	Wording changed to 'Difficulty reading what things say'	Wording revised to improve comprehension by stroke survivors
What I'm like as a person has changed	-	-
Getting upset or weepy	Wording changed to 'Feeling low'	Expert feedback suggested that the original wording overlapped too much with the emotionality symptom ('Crying or laughing inappropriately')

Clumsiness	-	-
Hearing difficulties	-	-
Difficulty walking or getting around	-	-
Confusion	Added	Feedback from one participant in the Think-Aloud interviews suggested that the 'Headaches' item did not adequately capture their post-stroke symptom of fuzzy head/confusion
Tingling or numbness	-	-
Falling over	Added	Expert feedback suggested that falls are particularly common after stroke because of limb weakness/paralysis
Stiff joints	-	-

Table 6-7. Summary of final changes made to the main sub-scales of the Stroke IPQ-R

Item	Change(s)	*Rationale*
Timeline Acute/Chronic		
I believe that the effects of my stroke will last for a short time	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my condition is likely to be permanent than temporary		
I believe that the effects of my stroke will last for a long time		
I believe that the effects of my stroke will pass quickly		
I believe that the symptoms of my stroke will improve in time		
I expect to have these symptoms of my stroke for the rest of my life	Wording changed to 'I will have the difficulties from my stroke for the rest of my life'	Wording changed to enhance relevance to stroke survivors
Consequences		
My stroke is a serious condition.	-	-
I believe that my stroke has major consequences on my life	'I believe' prefix removed; wording changed to 'My stroke has a major impact on my life'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; original wording emerged from Think-Aloud interviews to be too complex
I believe that my stroke has had serious financial consequences	'I believe' prefix removed; wording changed to 'My stroke has seriously affected how much money I have'	
I believe that memory problems since my stroke are affecting my life	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my stroke strongly affects the way others see me		
I believe that my stroke causes difficulties for those who are close to me		

I believe that my stroke has strongly affected how I see myself		
I believe that my stroke has badly affected my relationship with my family		
I believe that emotional problems since my stroke are affecting my life		
My stroke does not have much effect on my life	-	-
Since my stroke I fear becoming a burden on others	-	-
Item	**Change(s)**	***Rationale***
Personal Control		
I believe that there is a lot which I can do to control my symptoms	'I believe' prefix removed; wording changed to 'There is a lot which I can do to manage the effects of my stroke'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; wording changed to enhance relevance to stroke survivors
I believe that there is nothing I can do to prevent another stroke occurring	'I believe' prefix removed; wording changed to 'I cannot prevent another stroke from occurring'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; negative wording emerged from Think-Aloud interviews to be too complex
I believe that what I do will determine whether my stroke gets better or worse	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that nothing I do will affect my recovery from stroke		
I believe that the course of my recovery from stroke depends on me		
I believe that I have the power to influence my recovery from stroke		
I believe that my actions will have no effect on the outcome of my recovery from stroke		

I need to avoid doing too much as this may cause another stroke	-	-
I am confident that I can manage my recovery well	-	-
Item	**Change(s)**	***Rationale***
Treatment Control		
I believe that there is very little that can be done to improve my condition	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my medical treatment/rehabilitation will be effective in preventing another stroke from happening	'I believe' prefix removed; medical treatment/rehabilitation items combined, so wording changed to 'treatment'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; expert feedback suggested to revert sub-scale back to the original version of the IPQ-R, meaning that items appeared only once and referred generically to 'treatment'
I believe that the negative effects of my stroke can be prevented (avoided) by my medical treatment/rehabilitation		
I believe that my medical treatment/rehabilitation can control the symptoms of my stroke	'I believe' prefix removed; wording changed to 'My treatment can control the difficulties from my stroke'; medical treatment/rehabilitation items combined, so wording changed to 'treatment'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; expert feedback suggested to revert sub-scale back to the original version of the IPQ-R, meaning that items appeared only once and referred generically to 'treatment'; wording changed to enhance relevance to stroke survivors
I believe that there is nothing which can help my recovery from stroke	-	-
I believe that my medical treatment/rehabilitation will help me to recover	Removed	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R
Illness Coherence		
The symptoms of my stroke are puzzling to me	Re-added; wording changed to 'The effects of my stroke are confusing to me'	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R; wording changed to

		enhance relevance to stroke survivors and reduce complexity
My stroke is a mystery to me	Re-added	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R
I don't understand my recovery from stroke	-	-
My stroke doesn't make any sense to me	Wording changed to 'The effects of my stroke don't make any sense to me'	Wording changed to enhance relevance to stroke survivors
I have a clear picture or understanding of my stroke	-	-
Item	**Change(s)**	***Rationale***
Timeline-Cyclical		
I believe that the symptoms of my stroke change a great deal from day to day	'I believe' prefix removed; wording changed to 'The difficulties from my stroke change a great deal from day to day'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; wording changed to enhance relevance to stroke survivors
I have good days with few or no symptoms and bad days, when I have a lot of symptoms	-	-
I believe that the effects of my stroke are very unpredictable	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that I go through cycles in which my condition gets better or worse		
Emotional Representations		
I do not feel in control of my emotions	-	-
I get embarrassed by the way I am since my stroke	-	-
My stroke does not worry me	-	-
Since my stroke I get depressed	-	-
When I think about my stroke I get upset		
The symptoms of my stroke make me feel anxious	Wording changed to 'The effects of my stroke make me feel anxious'	Wording changed to enhance relevance to stroke survivors
My stroke makes me afraid	-	-
My stroke makes me feel angry	-	-

I feel lost since my stroke	-	-
I have lost confidence in myself since my stroke	-	-
My stroke is very worrying to those closest to me	Removed	Feedback from Think-Aloud interviews suggested that participants did not know how to answer these questions without asking a carer/loved one
Those closest to me get very distressed about my stroke		

Symbols and abbreviations: IPQ-R: Illness Perception Questionnaire-Revised

Table 6-8. Summary of final changes made to the causal sub-scale

Item	Change(s) made	Rationale
Stress or worry	Wording changed to 'Stress or worry, including family problems'	Item combined with 'Family problems or worries caused my stroke' attribution to avoid repetition
Hereditary – it runs in my family	-	-
Diet or eating habits	-	-
Poor medical care in my past	-	-
My own behaviour	Removed	To avoid repetition
My mental attitude e.g., thinking about life negatively	-	-
Family problems or worries caused my stroke	Removed	To avoid repetition
Overwork	-	-
My emotional state e.g., feeling down, lonely, anxious, empty	-	-
Ageing	-	-
Alcohol	-	-
Smoking	-	-
High cholesterol	-	-
High blood pressure	-	-
Diabetes	-	-
Problems with my heart	Wording changed to 'Problems with my heart, such as an irregular heartbeat'	Considered relevant to stroke by expert panel; wording subsequently changed in order to improve comprehension by stroke survivors
My personality	Removed	To avoid repetition
A germ or virus	Removed	Not considered relevant to stroke following Think-Aloud interviews
Accident or injury		
Chance or bad luck	-	-
Not taking enough exercise	-	-

The most notable modification made at this stage was removal of the 'I believe' prefix from the beginning of each question. Expert feedback considered it to be too abstract, and it was anticipated (based on prior research e.g., Roll, Mårtensson et al. (2012) and Sandberg and Kiran (2014)) to cause problems with comprehension amongst stroke survivors with cognitive difficulties. A further important change was made to the treatment control sub-scale, which in light of findings from the Think-Aloud interviews reverted back to the original (and validated) version of the IPQ-R. This meant that the

questions for medical treatment and rehabilitation that had previously been separated were now combined. Additional items that were included from the Twiddy-version, but were not a part of the original IPQ-R, were removed. Furthermore, a longer preamble providing a more detailed explanation (with examples) of what could be understood by 'treatment' and 'rehabilitation' (termed 'therapy' in this revision) were included to ensure clarity amongst respondents. Where possible and appropriate, Table 6-8 shows that several causal attributions were removed. The reasons for this included to: avoid repetition, enhance suitability to stroke, and shorten this lengthy questionnaire. The wording of items was also simplified as necessary (Tables 6-6 to 6-8). In addition, all negatively worded items that were not incorporated in the original version of the IPQ-R were removed to minimise confusion amongst respondents. However, a decision was made to retain these items from the original IPQ-R, because incorporating a combination of positive and negatively worded questions is considered good practice in questionnaire design. For example, Streiner and Norman (2003) have argued that negative wording minimises response bias by forcing participants to carefully consider their answers, and not simply mark the same response for each question without thinking.

6.6 STRENGTHS AND LIMITATIONS

A major strength of the work reported in the present chapter (Chapter 6) is the comprehensive approach that was adopted to develop a modified version of the IPQ-R for stroke survivors (the Stroke IPQ-R). Given the extensive preliminary development of this questionnaire, the content was already likely to be suitable and acceptable for stroke survivors. However, the

present study was novel in that it further extended this work to incorporate an additional stage of development, which utilised a Think-Aloud method. This provided valuable information with regard to the problems that stroke survivors experience when completing the newly developed Stroke IPQ-R. Consequently, further strengths of this study were that it was the first attempt at applying the Think-Aloud approach to people following stroke, and also, it was one of only two studies that have used this method to examine what people think when completing the IPQ-R. Moreover, modifications that were made to the questionnaire were in direct response to the feedback gained throughout the stages of development.

There are, however, several ways in which the present study was limited, and these are worth noting. First, with regard to the Think-Aloud study, a decision was made to ask participants to complete a warm-up task, though for the purposes of the demographic involved, this was formed by the first part of the questionnaire under examination. It may be that a non-associated task, which has been utilised by prior research (section 6.4.1.5) would have been more appropriate. Additionally, the coding and segmenting of the transcripts was undertaken only by the author of this thesis, who also conducted the interviews, rather than by two independent people, as per the analysis guidance for this particular method (van Someren, Barnard et al. 1994). This was primarily because of the practical constraints in identifying a suitable person that was available to become a second coder for this research. Given the level of subjectivity that is involved in analysing qualitative data, it may have been

helpful to obtain the perspective of an independent person to add to the robustness of the findings, and ensure that the same conclusions were drawn.

Further, a purposive sample of participants was recruited to the Think-Aloud interviews. This means that potential respondents were selected on the basis that they incorporated a range of ages; educational level; types of stroke; stages of recovery; and equally involved males and females. This is the desired approach for recruitment to qualitative research, because it adds to the richness of the data gathered (Palinkas, Horwitz et al. 2015). However, an area in which the present study had not been able to recruit purposively was ethnicity. The present sample was comprised mostly of people from a White-British ethnic background, meaning that the perspectives of people from other ethnicities were not considered. There is research though that has suggested that there are disparities between ethnic groups with regard to responding to questionnaires (Wang, Hempton et al. 2013).

Moreover, given that the aim of the present study was to develop a version of the IPQ-R that was suitable for people within the acute phase of stroke (≤three-months post-stroke), the sample may partly have been non-representative for this purpose. This is because half of the sample was comprised of people within the acute phase, while the other half involved survivors with chronic stroke. Whereas recruiting a broad range of people with stroke was consistent with the requirements of purposive sampling, it may have been of greater value for this study to only focus on interviewing people within the acute phase. This is particularly relevant in light of a further limitation with regard to

recruitment to the study, where one participant with a diagnosis of subarachnoid haemorrhage was engaged. As mentioned in Chapter 1, subarachnoid haemorrhage has a different clinical presentation to ischaemic stroke or intracerebral haemorrhage. Therefore, this participant contributed very little data with regard to problems with the questionnaire in this Think-Aloud study, because many of the items were not relevant to them. As a result, they were excluded from the analysis. These issues emphasise two important points for future research. First, the importance of adequately defining stroke (including sub-types) and other conditions to ensure that items on a questionnaire are specific and relevant to the desired group. Second, recruiting a sample of patients that are representative to address the needs of the research. In this case, the Stroke IPQ-R was being developed to be used in an observational study of stroke survivors in the acute phase following an ischaemic stroke or intracerebral haemorrhage rather than subarachnoid haemorrhage.

In addition to recruiting patients admitted to hospital with a recent stroke, the present Think-Aloud sample also involved [lay experts] that provided input on the preliminary version of the Stroke IPQ-R. Most of the [lay experts] recruited to the interviews had not been present for this early feedback, and therefore, had never seen this questionnaire before. However, there was one participant who volunteered for a Think-Aloud interview that had already seen an earlier version of the questionnaire, and was pivotal in some of the modifications that were made during this initial phase. This may have affected how the participant later responded to the modified version that was

being evaluated using the Think-Aloud approach. However, this particular respondent was keen to help further with the study and provide additional input, and had not previously experienced the Think-Aloud method employed.

6.7 CHAPTER SUMMARY

The purpose of the present chapter was to select and adapt an appropriate method for assessing domains of illness beliefs amongst stroke survivors in the acute phase (≤three-months post-stroke). This is the first step in applying the CSM to a novel patient group. To this end, Chapter 6 reported on work that was undertaken to develop a stroke-specific version of the IPQ-R (the Stroke IPQ-R), which involved various components: a review of prior literature (including the Twiddy-version of the IPQ-R); expert consultation; and qualitative Think-Aloud interviews. Through this research, a suitable and acceptable questionnaire for measuring illness belief domains in survivors within the acute phase of stroke was developed, the accuracy of which will be examined in the next chapter. Chapter 7 reports on the main observational study of this PhD research, which utilised the Stroke IPQ-R developed in the present chapter.

CHAPTER 7. THE ROLE OF ILLNESS BELIEFS IN UNDERSTANDING RECOVERY AFTER STROKE

7.1 CHAPTER OVERVIEW

Chapter 7 reports on a longitudinal observational study conducted to examine whether the CSM provides a useful framework for understanding adjustment after stroke and how well survivors recover. This study was focused on people in the acute phase of stroke (≤three-months post-stroke), which is a crucial period in recovery after stroke (as discussed in Chapter 1). The purpose of this component of the PhD research was to explore whether baseline illness beliefs (measured using the Stroke IPQ-R developed in Chapter 6) predict specific markers of recovery (e.g., HRQL, disability and mood) three-months post-stroke. Chapter 7 will first summarise the research questions and hypotheses for this study, and will subsequently provide a detailed account of the findings.

7.2 STUDY AIMS AND OBJECTIVES

The overall aim for this study was to apply the CSM (utilising the Stroke IPQ-R developed in Chapter 6) to a population within the acute phase of stroke (≤three-months post-stroke), and determine whether the model provides a useful framework for understanding survivors' recovery after stroke, including HRQL, disability and mood.

To address this aim, the specific objectives were to:

- Conduct a longitudinal observational study of survivors during the acute phase of stroke (≤three-months post-stroke) to investigate associations between baseline illness belief domains and baseline and follow-up markers of post-stroke recovery (including, HRQL, disability and mood);
- Explore whether baseline mood and follow-up coping (medication adherence) have a mediating effect on observed associations between baseline illness belief domains and follow-up markers of post-stroke recovery (e.g., HRQL, disability and mood);
- Explore whether baseline illness belief domains explain additional variance in three-month markers of post-stroke recovery (HRQL, disability, and mood), over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery);
- Investigate inter-relationships between baseline and follow-up illness belief domains, and determine whether stroke survivors can be clustered according to their baseline illness belief schema, and whether these clusters differ in terms of three-month markers of post-stroke recovery (e.g., HRQL, disability and mood).

An overview of the specific research questions and hypotheses that were formulated in light of these objectives, and to be answered in this study, is provided below.

7.2.1.1 Study Research Questions and Hypotheses

7.2.1.1.1 Research Question 1

Do illness belief domains and markers of recovery (HRQL, disability and mood) at baseline differ significantly from those at follow-up?

Discussions in Chapter 1 suggested that stroke survivors often improve in relation to their recovery (e.g., functional independence) (Kwakkel and Kollen 2013, Stinear, Ackerley et al. 2013), and develop in their psychological adjustment over time (Ch'Ng, French et al. 2008, Lincoln, Kneebone et al. 2012). Literature by Bijsterbosch, Scharloo et al. (2009) has also indicated that illness beliefs alter over time. In light of this, it was hypothesised that illness beliefs and markers of recovery at baseline would differ significantly from those at follow-up, and these would show improvements over time.

7.2.1.1.2 Research Question 2

Are baseline illness belief domains measured during the acute phase of stroke (≤three-months post-stroke), associated with markers of recovery at baseline and three-months post-stroke (HRQL, disability and mood)?

Based on the literature to date (e.g., Joice, Bonetti et al. (2003); Ford (2007); Klinedinst, Dunbar et al. (2012); Twiddy, House et al. (2012); Sjölander, Eriksson et al. (2013); Phillips, Diefenbach et al. (2015); Damman, Liu et al. (2014); and Mohammed, Nagla et al. (2015)), it was hypothesised that baseline illness belief domains would be associated with baseline and follow-up markers

of recovery after stroke (three-months post-stroke) (HRQL, disability and mood). More specifically, an overall pessimistic impression of stroke at baseline (for example: strong illness identity; serious consequences; chronic timeline; low illness coherence; strong emotional representations; cyclical timeline; and low personal and treatment control) was hypothesised to be inversely related to HRQL, disability, and mood at baseline and three-months post-stroke.

7.2.1.1.3 Research Question 3

Do baseline mood and follow-up coping (three-months post-stroke medication adherence) mediate predictive associations between baseline domains of illness beliefs, and follow-up markers of recovery after stroke (HRQL, disability and mood)?

In view of the current literature (cited in Chapters 1 to 4), it was hypothesised that the relationship between baseline illness beliefs and follow-up markers of recovery three-months post-stroke (HRQL, disability and mood) would be mediated by baseline mood and coping (medication adherence at follow-up).

7.2.1.1.4 Research Question 4

Do baseline illness belief domains explain additional variance in three-month post-stroke markers of recovery (HRQL, disability, and mood), over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery)?

The evidence presented in Chapter 1 suggested that clinical factors (e.g., initial impairment) explain only part of the variability in recovery after stroke (Tilling, Sterne et al. 2001, Lazar and Antoniello 2008, Prabhakaran, Zarahn et al. 2008). The remainder of variability is unexplained (Lazar and Antoniello 2008, Lazar, Minzer et al. 2010). Insights from the wider literature on post-stroke adjustment (described in Chapter 1) suggested that socio-demographic (e.g., age and income) and clinical factors (e.g., stroke severity) are independent predictors of medication adherence (Sappok, Faulstich et al. 2001, Bushnell, Olson et al. 2011). However, these non-modifiable factors appear to only account for a small proportion of the variance, meaning that a large amount of variability in post-stroke recovery remains unexplained (Gellad, Grenard et al. 2011). There is some evidence to date that has suggested that mood, particularly depression (Parikh, Robinson et al. 1990, Gainotti, Antonucci et al. 2001, Donnellan, Hickey et al. 2010), and other modifiable psychological factors (e.g., peoples' beliefs) are also predictive of adjustment after stroke (O'Carroll, Whittaker et al. 2011). In light of this, it was hypothesised that baseline illness belief domains would contribute significantly to the variance in follow-up markers of post-stroke recovery (HRQL, disability, and mood), over and above that explained by socio-demographic and clinical variables.

7.2.1.1.5 Research Question 5A

Are there inter-correlations between baseline illness belief domains, and baseline and follow-up illness belief domains?

It was highlighted in Chapters 2 and 3 of this thesis that a core part of the CSM is that illness beliefs are not generally held in isolation, and rather, are interrelated, interacting with each other and aspects of adjustment (e.g., coping). On this basis, it was hypothesised that baseline illness belief domains, and baseline and follow-up illness belief domains would be inter-correlated.

7.2.1.1.6 Research Question 5B

Can clusters of stroke survivors be identified according to illness belief schema?

There has been a move in recent years for papers in this field to further examine the schematic nature of illness beliefs, and identify groups of similar people (e.g., (Medley, Powell et al. 2010, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, Snell, Surgenor et al. 2014)). These studies were previously described in Chapter 3. Illness belief schema will be examined specifically for stroke survivors in the present study. However, the formation of groups (or clusters) is driven by the data rather than a priori hypotheses. This means that hypotheses cannot be formed for this particular element of Research Question 5.

7.2.1.1.7 Research Question 5C

Is baseline group membership to a particular cluster associated with follow-up markers of recovery three-months post-stroke (HRQL, disability and mood)?

Given the evidence conducted thus far (and cited in Chapters 3 and 4), it was hypothesised that participants classified as 'Low Adjusters' at baseline would fare less well with their recovery after stroke than 'High Adjusters.'

7.3 METHODS

7.3.1 Design

The present study adopted a longitudinal observational design, where data were collected at baseline (<eight-weeks post-stroke), and follow-up (three-months post-stroke). The follow-up time-point of three-months was selected for two reasons: firstly, it allowed assessment of peoples' beliefs well within the acute phase of stroke, which was of primary interest to this PhD research; and secondly, for practical reasons relating to the time by which this work needed to be completed. This chapter is reported in accordance with the guidelines recommended in the STROBE checklist, which was previously described in Chapter 3.

7.3.2 Setting

The study took place in Nottingham City and County (UK) regions, with patients recruited from secondary care acute stroke and rehabilitation wards and outpatient clinics at [Hospital] NHS Trust. People residing in Nottingham City or County with a suspected stroke are taken directly to the acute stroke unit at [Hospital]. From there, people either 1) stay on the acute ward for further medical tests and intervention, depending upon the severity of the stroke, or 2) are discharged home. Patients who are

discharged may or may not require any further support, however for people needing additional services (e.g. in the community), referrals are made to other agencies as necessary. All stroke patients seen at [Hospital] are also invited back to outpatient clinics for follow-up with a stroke specialist at six-weeks post-stroke. Therefore, this setting offered an ideal platform to attempt to capture a representative sample of patients for this study.

7.3.3 Participants

7.3.3.1 Eligibility Criteria

7.3.3.1.1 Inclusion Criteria

The inclusion criteria were*:*

- Adults (aged 18 years or over);
- Confirmed diagnosis of recent stroke (within eight-weeks);
- Sufficient language and cognitive ability to participate (assessed by NA through liaison with the clinical care team and review of medical notes);
- Provision of full written informed consent.

7.3.3.1.2 Exclusion Criteria

People were excluded if they met any of the following criteria:

- Living outside of the research area;
- Patients not deemed well enough by their clinician to complete questionnaires (e.g., people likely to die within a few days);

- People without sufficient proficiency in English making them unable to engage with the researcher;
- People involved in psychological intervention studies.

7.3.4 Sample Size

The [hospital] receives between 1500 and 2000 stroke admissions per year (Intercollegiate Stroke Working Party 2012). However, given the inclusion criteria, only a third of patients may be eligible to participate (around 50 patients per month) and approximately one-fifth may actually agree to take part (around 10 per month). This information informed the sample size calculation for the study.

7.3.4.1 Sample Size Calculation

The sample size calculation was based on detecting a correlation of 0.4 between illness beliefs and outcomes (HRQL, disability and mood), using a power of 80%, significance level (alpha) of 0.05, and allowing for 20% attrition, to acknowledge high drop-out rates in the first three-months following stroke. This yielded a minimum sample of 55 participants.

7.3.5 Sponsorship, Ethics and Research Governance

Details with regard to sponsorship, ethics and research governance for the studies involved in this PhD research were previously provided in Chapter 6 (section 6.4.1.3) (REC Reference: 13/EM/0392). Approval letters can be found in Appendix 3. Recruitment was performed only after relevant approvals had been obtained.

7.3.6 Recruitment

Eligible participants were identified predominantly by review of their medical notes; attendance on ward rounds; and liaison with the clinical care team, all of which provided valuable insight into the suitability of patients for initial approach. The process of participant identification was mostly conducted by the author, though was facilitated by research nurses from the National Institute of Health Research Clinical Research Network.

The initial approach to patient participants about the research was made by a member of the usual clinical care team, and as with the qualitative study reported in Chapter 6, the author provided further details about participation (e.g., Participant Information Sheets (see Appendix 3)). Where appropriate and necessary, carers were present to facilitate these discussions.

7.3.6.1 Informed Consent

Consistent with the qualitative study (Chapter 6), those who wanted to be involved provided full written informed consent prior to taking part and undergoing any study procedures. This included permission to be contacted to arrange research visits at home or at the research clinic; complete baseline and follow-up questionnaires; and for patient participants only, for data extraction to be undertaken by the author from their medical records; and for their GP to be informed of their participation in the research via letter. Participants again signed and dated a specially designed Consent Form (Appendix 3) to record their permission. Consent was also confirmed verbally by the author at each stage of data collection.

7.3.7 Measures

Illness beliefs (predictors) were measured using a stroke-specific version of the IPQ-R (Moss-Morris, Weinman et al. 2002) (the Stroke IPQ-R) developed in Chapter 6. This instrument was shown to be suitable and acceptable for measuring several domains of illness beliefs in stroke survivors: identity, causes, consequences, timeline acute-chronic, timeline-cyclical, personal control, treatment control, illness coherence and emotional representations.

The outcomes examined in this study were selected according to the ICF framework for health and disability (see Chapter 4). The measures employed are briefly summarised below, though further details can be found in section 4.3 of Chapter 4.

7.3.7.1 ICF Participation: HRQL

The primary outcome for this study was HRQL, which assesses participation after stroke. In the interests of brevity and reducing the potential for burden and fatigue amongst participants in completing a battery of questionnaires, the brief and validated EQ-5D self-report instrument (The EuroQol Group 1990, Brooks 1996) was adopted to measure HRQL. This instrument has previously shown utility for stroke survivors (McPhail, Lane et al. 2009, Whynes, Sprigg et al. 2013, Lozano, Lobos et al. 2016). It is comprised of the EQ-5D-5L Descriptive System, measuring mobility, self-care, usual activities, pain/discomfort, and anxiety or depression aspects of HRQL, and the EQ-5D-5L 'Your health today' VAS.

The secondary outcomes were as follows:

7.3.7.2 ICF Impairments: Mood

Post-stroke mood impairments were measured using the validated Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer et al. 2001, Kroenke, Spitzer et al. 2003). The PHQ-9 is a nine-item self-report instrument measuring the frequency of depressive symptomatology, according to the DSM criteria for major depressive disorder. The PHQ was originally designed for a primary care population, though has recently been recommended as a promising mood measure to be used amongst stroke survivors (Spitzer, Kroenke et al. 1999, Kroenke, Spitzer et al. 2001, Kroenke, Spitzer et al. 2003, Phelan, Williams et al. 2010, Turner, Hambridge et al. 2012, Meader, Moe-Byrne et al. 2013).

7.3.7.3 ICF Activities: Disability

An important aspect of ICF post-stroke activities, disability, was assessed using several instruments:

- The Modified Rankin Scale, which is a clinician-reported scale of global disability and dependence that assigns scores ranging from 0 (‘no symptoms at all’) to 6 (‘dead’) for mobility and motor function (Rankin 1957, van Swieten, Koudstaal et al. 1988, Barak and Duncan 2006, Banks and Marotta 2007). It is the measure of choice for disability in acute stroke research (Sulter, Steen et al. 1999, Banks and Marotta 2007, Quinn, Dawson et al. 2009, Quinn, Langhorne et al. 2011);

- Physical functioning was measured using the Barthel Index, which is a further clinician-reported scale and second to the Modified Rankin Scale, a measure of choice in acute stroke research (Sulter, Steen et al. 1999, Quinn, Dawson et al. 2009, Quinn, Langhorne et al. 2011). It assesses 10 basic activities of daily living across domains of self-care and mobility (Mahoney and Barthel 1965, Granger, Albrecht et al. 1979, Wade and Collin 1988, D'Olhaberriague, Litvan et al. 1996);
- Broader post-stroke functioning, including cognitive functioning, was self-reported using the stroke-specific Nottingham Extended Activities of Daily Living Scale (Nouri and Lincoln 1987, Gladman, Lincoln et al. 1993, Gompertz, Pound et al. 1994). This instrument specifically measures independence in performing instrumental activities of daily living (e.g., shopping, cooking, and managing finances).

Some of the data on disability (e.g., Modified Rankin Scale and Barthel Index) was extracted from patients' medical records because this information is collected routinely locally. However, where this data were not available, the author was trained to collect this from participants.

7.3.7.4 Additional Data Collection

Demographic information (e.g., age, gender, ethnicity, disposition and postcode); and medical (including, stroke severity, using the clinician-reported National Institutes of Health Stroke Scale (Duncan, Zorowitz et al. 2005, Jauch, Saver et al. 2013)), and family history (first-degree relative) of

stroke, were also collected from participants. In order to further describe the sample recruited to this study, other information was collected as follows:

- Exercise, self-reported using a single yes/no question which asked whether or not people have engaged in a minimum of 30-minutes exercise per day, with an open response to describe the activities undertaken;
- Diet, self-reported using three-questions regarding peoples' intake of salt, fat, sugar, and fruit/vegetables;
- Smoking status (current smoker, ex-smoker, and non-smoker/never smoked), including where relevant, the number of cigarettes per day. This information was collected from peoples' medical records, and self-reported by participants;
- Drinking habits including caffeine and alcohol consumption (e.g., number of daily cups/units, respectively), which were self-reported;
- Blood pressure, blood glucose, cholesterol and Body Mass Index (BMI), extracted from patients' general practice and hospital medical records;
- Healthcare utilisation, specifically hospital admissions and general practitioner visits, which was extracted from patients' general practice and hospital medical records.

7.3.7.4.1 Medication Adherence and Engagement with Rehabilitation

Information regarding medication adherence and engagement with rehabilitation was collected from participants as follows:

- Medication adherence (coping) was measured using the Medication Adherence Report Scale, which is a five-item questionnaire measuring non-adherent medication behaviour (Horne and Weinman 1999, Horne 2004). The instrument has shown reliability and validity for measuring medication adherence amongst stroke survivors (Choi-Kwon, Kwon et al. 2006, O'Carroll, Whittaker et al. 2011, O'Carroll, Chambers et al. 2013);
- Engagement with rehabilitation (e.g., attendance at formal rehabilitation sessions and self-directed rehabilitation), was self-reported using a diary/calendar. Participants completed this for a minimum of one-calendar month. It had originally been hoped that therapist data on attendance at formal rehabilitation sessions could be extracted from the notes held by community teams to supplement the diary/calendar data. However, permission for this for the purposes of research was not possible to obtain from the lead of these organisations due to patient confidentiality and data protection (further elaborated in Chapter 8).

A summary of the time-point at which data in this study were collected is provided in Table 7-1. Examples of case record forms designed specifically for data collection in the present study can be found in Appendix 3.

Table 7-1. Summary of the outcome data collected at which time-point

	Baseline (≤eight-weeks post-stroke)	**Follow-up (three-months post-stroke)**
Demographics (e.g., age, gender, ethnicity, disposition, postcode)	✓	×
Medical (e.g., first/recurrent stroke, pre-stroke mRS score, stroke severity, previous depression, prior therapy, and co-morbidities) and family history (first-degree relative) of stroke or TIA, heart problems or diabetes	✓	×
Disability (mRS, BI and Nottingham Extended ADL)	✓	✓
Mood (PHQ-9)	✓	✓
HRQL (EQ-5D-5L and EQ-VAS)	✓	✓
Illness beliefs (Stroke IPQ-R)	✓	✓
Lifestyle (e.g., exercise, diet, smoking, caffeine and alcohol)	✓	✓
Clinical data (e.g., blood pressure, glucose, cholesterol, and BMI)	✓	✓
Healthcare utilisation (e.g., general practitioner visits and hospital admissions)	×	✓
Engagement with rehabilitation (e.g., attendance at formal rehabilitation sessions and self-directed rehabilitation)	×	✓ (verified by a sub-sample of carers)
Medication adherence (MARS)	×	✓

Symbols and abbreviations: ADL: Activities of Daily Living; BI: Barthel Index; BMI: Body Mass Index; IPQ-R: Illness Perception Questionnaire-Revised; MARS: Medication Adherence Report Scale; mRS: Modified Rankin Scale; PHQ-9: Patient Health Questionnaire-9; TIA: Transient Ischaemic Attack; VAS: Visual Analogue Scale

7.3.8 Procedure

Following recruitment and informed consent, participants were asked to complete the abovementioned questionnaires at baseline and/or follow-up as necessary (detailed in Table 7-1), and were also given the option of whether or not to provide diary/calendar data.

A flexible approach for questionnaire completion was adopted, which allowed for participants to fill them in on their own or with practical support from a carer (returned by post) and/or the author. For the vast majority of participants, questionnaires were completed with support from the author whilst in hospital, at home or at the research clinic in a one to one visit. Participants were also given the option of completing their questionnaires over two visits instead of one, though the majority of people preferred to do this on a single occasion. The purpose of this flexibility was to minimise any response bias that could have occurred within this population with a recent stroke, where questionnaire burden and fatigue was likely.

All data collection and extraction from hospital records was undertaken by the author. GPs were contacted by the author to provide clinical information for participants at follow-up.

7.3.9 Variables

The predictors, mediators and outcomes for this study are illustrated in the conceptual model on which this research is based (Figure 7-1). This was first shown in Chapter 4 (section 4.5).

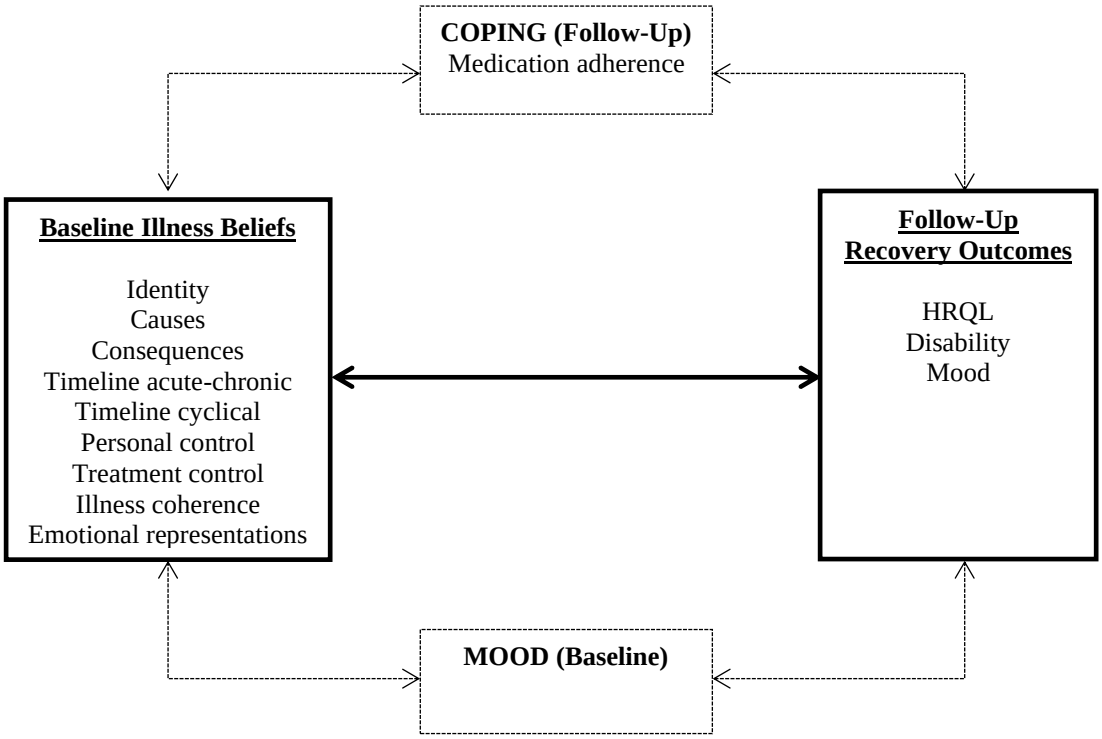


Figure 7-1. Conceptual model derived from the CSM

In summary, baseline illness belief domains were examined as predictors of follow-up markers of recovery (HRQL, disability, and mood) three-months post-stroke. Baseline mood and follow-up medication adherence (coping) were examined as potential mediators of these predictive relationships.

7.4 STATISTICAL METHODS

Broadly speaking, the statistical methods for the present study are detailed according to the specific research hypothesis being addressed, and will be presented alongside the results (sections 7.6 to 7.19).

Scoring of the questionnaires; internal consistency of measures adopted; normality; flow of participants through the study; and descriptive

statistics (including missing data) will be considered first in this section. All statistical analyses detailed in this chapter were conducted using STATA 13 (StataCorp LP, College Station, TX, USA). Statistical significance was assessed throughout the analyses at the 5% level ($p<0.05$). However, a Bonferroni adjustment was applied as appropriate to correct for multiple testing, meaning that adjusted p-values were utilised where necessary in significance testing.

7.4.1 Questionnaire Scoring

Scoring of the Stroke IPQ-R was undertaken in accordance with the established guidelines for the original IPQ-R (Moss-Morris, Weinman et al. 2002). Items were coded as follows: strongly disagree =1; disagree =2; I don't know = 3; agree = 4; and strongly agree = 5. The coding for questions with negative wording was reversed. Scores were then generated for each sub-scale of the Stroke IPQ-R (and thus illness belief domain) by summation of the individual scores for items on each scale. Factor analysis of the causal domain was not possible because of low participant numbers. At least 100 participants is the sample required for statistical validation of questionnaires (Mundfrom, Shaw et al. 2005, Chen, Lenderking et al. 2013). The authors of the original IPQ-R instead recommended analysis of each causal attribution as an individual factor.

Scoring of the remainder of measures (e.g., EQ-5D-5L, PHQ-9, Barthel Index, Nottingham Extended Activities of Daily Living Scale, and National Institutes of Health Stroke Scale was undertaken in accordance with their respective guidelines (Nouri and Lincoln 1987, Wade and Collin 1988,

Horne, Weinman et al. 1999, Kroenke, Spitzer et al. 2001, Horne 2004, van Hout, Janssen et al. 2012, van Reenen and Janssen 2015). With exception of the EQ-5D-5L, total scores on the other questionnaires were calculated by summing the responses to individual questions. High scores on the PHQ-9 indicated more severe depressive symptomatology, while on the Barthel Index and Nottingham Extended Activities of Daily Living Scale; they referred to greater independence. High scores on the Medication Adherence Report Scale indicated better medication adherence. Domain-specific scores were possible to obtain for the Nottingham Extended Activities of Daily Living Scale; however, for the purposes of the present research, total scores for the questionnaire as a whole were utilised instead in order to obtain a global measure of disability. Scores on the Modified Rankin Scale were ordinal, and therefore, dichotomised into two groups according to the median of the data (<2 and ≥2).

Scoring of the EQ-5D-5L differed in that peoples' responses on the descriptive system are understood as health states that are converted to a single index value, which facilitate the calculation of quality-adjusted life years (section 4.3.3.1, Chapter 4). Using a country-specific value set and calculator provided by the Euroqol Group (van Hout, Janssen et al. 2012), index values are obtained and interpreted as: 0=dead; 1=full health; and <0=worse than death (van Reenen and Janssen 2015). The scoring for the EQ-5D-5L VAS involves converting to a percentage the number on the scale that participants marked for their 'health today,' where high scores represent the best health imaginable (van Reenen and Janssen 2015).

7.4.1.1 Deprivation

Deprivation was quantified using participants' postcode data, with the English Indices of Multiple Deprivation (IMD), which provide an overall measure of multiple deprivation that are based on seven domains of deprivation (e.g., employment; health and disability; education, skills and training; crime; barriers to housing and services; and living environment) (Department for Communities and Local Government 2015). IMD enables ranking of neighbourhoods according to their level of deprivation comparative to that of other areas.

7.4.2 Internal Consistency of the Measures

The internal consistency of the instruments adopted in this study was assessed using the Cronbach's alpha statistic. Internal consistency examines the extent to which individual items (or sets of items) in a test measure the same concept or construct (Tavakol and Dennick 2011). Cronbach's alpha is based on the average correlation between sets of items (Field 2013). It was computed for all of the instruments, except for the causal scale of the Stroke IPQ-R and the Modified Rankin Scale, both of which provide ordinal data. In addition, the calculation of Cronbach's alpha was not appropriate for the EQ-5D-5L VAS, which formed only one question.

7.4.3 Normality and Descriptive Statistics

Normality in the distributions of all continuous quantitative variables collected at baseline and follow-up was assessed visually using histograms. However, skewness/kurtosis tests were also conducted for each

variable to confirm departures from normality. For variables where skewed distributions emerged, a logarithmic (base 10) transformation was attempted.

Descriptive statistics for baseline and (where relevant) follow-up data were then computed. The mean and standard deviation (or where data were non-normal, the median and interquartile range) were calculated for all continuous variables, and frequency and percentages for categorical (nominal/ordinal) variables. Relationships between variables at the two-points were examined statistically as appropriate, using non-parametric paired samples t-tests (Wilcoxon signed rank tests) or Chi-squared (specifically, McNemar) tests for proportions. Missing data were also examined descriptively.

Descriptive statistics for demographics, medical and family history, clinical and lifestyle variables will be presented first. Those for the remainder of predictor, mediator, and outcome variables will be reported later in this chapter (section 7.6) alongside the findings from Research Question 1.

7.5 RESULTS

7.5.1 Internal Consistency of the Measures

Internal consistency for the measures used in the present study is reported in Table 7-2. Cronbach's alpha generally showed adequate internal

consistency for most of the instruments. Lower than desired Cronbach's alphas emerged for the treatment control sub-scale of the Stroke IPQ-R (α=0.42), and the Medication Adherence Report Scale (α=0.36). These were well below the accepted range for alpha, and may suggest that the scales are not unidimensional (i.e., more than one construct may be evident). In addition, redundancy of items may have been relevant for the Barthel Index and Nottingham Extended Activities of Daily Living Scale, where both demonstrated alpha values greater than 0.90 (Streiner 2003, Panayides 2013).

Table 7-2. Summary of the findings for internal consistency

Measure	Cronbach's alpha
Stroke IPQ-R	
Identity	0.83
Timeline acute-chronic	0.83
Timeline-cyclical	0.88
Consequences	0.82
Personal control	0.77
Treatment control	0.42
Illness coherence	0.89
Emotional representations	0.77
HRQL	
EQ-5D-5L Descriptive System- Index score	0.84
Mood	
PHQ-9 Total depressive symptomatology score	0.72
Disability	
Barthel Index score	0.90
Nottingham Extended Activities of Daily Living Scale score	0.93
Coping	
Medication Adherence Report Scale score	0.36

Symbols and abbreviations: HRQL: Health-Related Quality of Life; IPQ-R: Illness Perception Questionnaire-Revised; PHQ-9: Patient Health Questionnaire-9

7.5.2 Normality

Normality could only be assumed for a handful of variables. The majority of variables (e.g., illness beliefs, HRQL, disability (Barthel Index and Nottingham Extended Activities of Daily Living Scale), and mood) were skewed. Identity and timeline-cyclical belief domains and emotional

representations were right-skewed. This meant that the mass of the distributions was concentrated on the left of the histogram, indicating that responses were low overall. For example, participants generally endorsed few symptoms of their stroke, had weak beliefs of an episodic nature of stroke, and a low emotional response to their stroke. The distributions for mood were similar, whereby participants generally had mild symptoms of depression. In contrast, several variables were left-skewed. For instance, for illness beliefs, responses to the treatment control and illness coherence domains were concentrated to the right of the histogram. This meant that participants generally endorsed strong beliefs in the ability of their treatment to manage their stroke, and a moderate understanding of their condition. This was also true of scores for the timeline acute-chronic and personal control domains, though these were normally distributed at baseline and left-skewed at follow-up. Left-skewed distributions also emerged for scores for many of the other variables, including: HRQL (EQ-5D-5L Descriptive System-Index and 'Your health today' VAS scores); Barthel Index; Nottingham Extended Activities of Daily Living Scale; and Medication Adherence Report Scale. This meant that participants in the sample generally had high HRQL and medication adherence, and were more functionally independent.

Logarithmic transformations did not normalise the distributions for any of the skewed variables. Therefore, non-parametric methods were used where possible and appropriate for the present analyses.

7.5.3 Flow of Participants through the Study

As can be seen from Figure 7-2, 1085 patients were assessed for eligibility for this study, and of these, 88 were approached for participation. Thirty-eight people declined at this stage, leaving 50 patients that consented to be involved. Attrition (drop-out) was 16% (Figure 7-2). Therefore, baseline data were collected from 46 patients, and follow-up data from 42 patients.

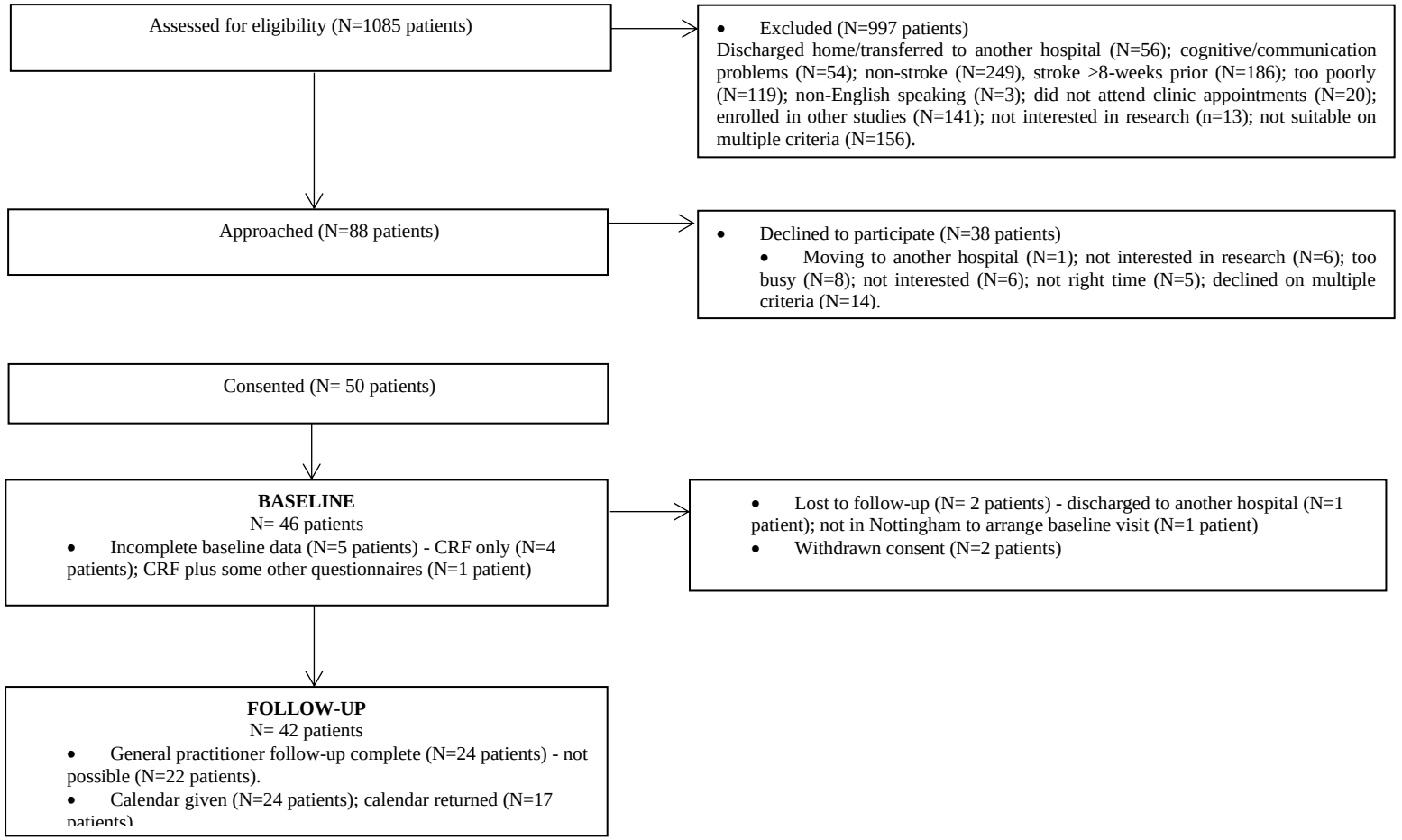


Figure 7-2. Participant flow through the study

7.5.4 Descriptive Statistics

7.5.4.1 Baseline Demographics

Baseline (and where relevant, follow-up) descriptive statistics for the study sample are shown in Tables 7-3 to 7-6. The average age of participants was 66.9 years (SD=14.5 years), with 68% male gender and 98% White-British ethnicity. On average, participants were recruited and consented within six-weeks of their stroke, with baseline data collected around this time (up to seven-weeks post-stroke), and follow-up around three-months after stroke (Table 7-4). The majority of participants (54.4%) were retired, and only a small proportion (20.5%) was university educated. With regard to deprivation, the IMD suggested that on average the present sample were amongst 70% of the most deprived areas in the country.

Table 7-3. Descriptive statistics for baseline demographics, family history and clinical information

	N **Mean (SD)/Frequency (%), unless otherwise stated**
Demographics	
Age	N=50 66.9 (14.5)
Sex-*Male*	N=50 34 (68.0%)
Dominant hand-*Right*	N=50 48 (96.0%)
Ethnic group-*White*	N=50 49 (98.0%)
Age left school	N=45 Median=16 (IQR=1)
University or higher education	N=44 9 (20.5%)
Employment status *Unemployed* *Employed full-time* *Employed part-time* *Self-employed* *Retired*	N=46 6 (13.0%) 7 (15.2%) 3 (6.5%) 5 (10.9%) 25 (54.4%)
IMD rank*	N=44 Median=20706.5 (IQR=17158.0)
IMD decile*	N=44 Median=7 (IQR=6)
National Institute of Health Stroke Scale score ***(Cronbach's alpha=0.79)***	N=44 Median=2 (IQR=4.5)
Pre-morbid Modified Rankin Scale score	N=48 0 (0)
Current disposition *Inpatient* *Home with spouse/carer* *Home alone*	N=50 10 (20%) 30 (60%) 10 (20%)
Clinical data	
Systolic blood pressure (mm/HG)	N=48 147.6 (33.7)
Diastolic blood pressure (mm/HG)	N=48 78.6 (20.0)
Blood glucose (mmol/L)	N=37 Median = 6.6 (IQR=2.8)
Total cholesterol (mmol/L)	N=44 4.74 (1.30)
HDL cholesterol (mmol/L)	N=40 Median = 1.3 (IQR=0.6)
LDL cholesterol (mmol/L)	N=38 Median = 2.7 (IQR=1.9)
BMI (kg/m^2)	N=40 Median = 28 (IQR=9.7)
Family history-first degree relative (mother, father, sibling)	
History of stroke	N=45 15 (33.0%)
History of TIA	N=46 4 (8.7%)

History of hypertension	N=46 11 (23.9%)
History of diabetes	N=44 8 (18.2%)
History of high cholesterol	N=46 5 (10.9%)
History of blood clots	N=45 1 (2.2%)
History of angina	N=46 6 (13.0%)
History of heart attack	N=45 16 (35.6%)
History of atrial fibrillation	N=45 5 (11.1%)
History of other heart problems	N=44 3 (6.8%)

Symbols and abbreviations: *: Computed using postcode data collected from participants; BMI: Body mass index; HDL; High Density Lipoprotein; IMD: Index of Multiple Deprivation; IQR: Interquartile range; LDL; Low Density Lipoprotein; SD: Standard deviation; TIA: Transient Ischaemic Attack

Participants' level of disability prior to stroke (evaluated by the Modified Rankin Scale score) indicated 'no symptoms at all.' Stroke severity was also low and suggested that on average, participants in the present sample experienced a less severe stroke.

Table 7-4. Descriptive statistics for recruitment, consent, and data collection

	N **Mean (SD)/Frequency (%), unless otherwise stated**
Days since stroke (Consent)	N=49 39.6 (20.9)
Weeks since stroke (Consent)	N=49 5.7 (3.0)
Days since stroke (Baseline)	N=46 47.2 (20.5)
Weeks since stroke (Baseline)	N=46 6.7 (2.9)
Days since stroke (Follow-up)	N=42 Median=93.0 (IQR=18)
Weeks since stroke (Follow-up)	N=42 Median=13.3 (IQR=2.6)

Symbols and abbreviations: IQR: Interquartile range; SD: Standard deviation

7.5.4.2 Baseline Medical and Family History

Around 78% of participants at baseline reported their most recent stroke as being their first event, while recurrent stroke was applicable to 18% (Table 7-5). Between 12 and 28% had previously experienced a transient ischaemic attack, and 13 to 18% have had a heart attack. These figures varied for self-reported versus data extracted from medical records, where self-reported figures were generally higher (Table 7-5). Co-morbidities were common in around 70% of participants. A history of hypertension and high cholesterol was particularly relevant for the present sample (Table 7-5). Around 20% of patients had a history of atrial fibrillation and over 24% had diabetes mellitus. A further 24% reported having previously experienced depression, and another 20% have had anxiety problems. Around 50% of participants have received some form of therapy prior to their stroke (e.g., physiotherapy, occupational therapy, or psychological therapy).

A family history (first-degree relatives) at baseline was common for stroke (33%); heart attack (36%); hypertension (24%); and diabetes (18%) (Table 7-3). A family history of transient ischaemic attack (9%), high cholesterol (11%) or atrial fibrillation (11%) was less commonly reported (Table 7-3).

Baseline clinical data are provided in Table 7-3. Average blood pressure for study participants was around 148/79 mm/HG. Blood pressure targets are below 130/80 mmHG for people following stroke (Intercollegiate Stroke Working Party 2012). Systolic blood pressure was on average higher than normal for the present sample. Total cholesterol (4.7 mmol/L) (183.3 mg/dl) and

more specifically, low density lipoprotein (or 'bad') cholesterol (2.7 mmol/L) (104.4 mg/dl) was slightly high (Furie, Kasner et al. 2011). Average BMI suggested that this sample were obese (28 kg/m2), characterised by a BMI of 25 kg/m² or more for males and 30 kg/m² or more for females (Meschia, Bushnell et al. 2014).

Table 7-5. Baseline descriptive statistics for medical history

	N, Frequency (%)	
Medical history	***Medical records***	***Self-reported***
First stroke	-	N=46 36 (78.3)
Previous stroke	N=49 9 (18.4%)	-
Previous TIA	N=49 6 (12.2)	N=46 13 (28.3)
History of hypertension	N=49 29 (59.2%)	N=46 31 (67.4%)
History of diabetes	N=49 13 (26.5%)	N=46 11 (23.9%)
History of atrial fibrillation	N=49 8 (16.3%)	N=46 10 (21.7%)
History of ischaemic heart disease (e.g., angina and heart attack)	N=49 9 (18.4%)	-
History of high cholesterol	N=49 22 (44.9%)	N=46 24 (52.2%)
History of peripheral artery disease	N=49 1 (2.0%)	-
History of blood clots	-	N=46 5 (10.9%)
History of angina	-	N=46 6 (13.0%)
History of heart attack	-	N=46 6 (13.0%)
History of other heart problems	-	N=46 3 (6.5%)
History of depression	-	N=46 11 (23.9%)
History of anxiety disorders	-	N=46 9 (19.6%)
History of other mental health problems	-	N=46 0
Previous therapy	-	N=46 N=23 (50%)
Co-morbidities	N=49 34 (69.4%)	-

Symbols and abbreviations: TIA: Transient Ischaemic Attack

7.5.4.3 Baseline and Follow-Up Lifestyle and Coping

The majority of participants at baseline and follow-up self-reported that they were ex-smokers or non-smokers, and these figures were more than those reported in peoples' clinical records. Between 45 and 52% of participants were ex-smokers at baseline, and this figure rose significantly to almost 93% at follow-up, suggesting that many survivors stopped smoking soon after their stroke. This pattern was also reflected in the figures for current smokers, which reduced significantly from between 9 and 19% at baseline to 7% at follow-up. Current-smokers at baseline and follow-up reported that they consumed around 10 cigarettes daily (Table 7-6). Self-reported caffeine and alcohol intake was minimal for participants, and this did not differ significantly between baseline and follow-up (Table 7-6). Furthermore, a large proportion of the sample (78%) reported undertaking at least 30-minutes of exercise four times per week at baseline, though this figure reduced slightly to 71% at follow-up. A similar pattern was evident for peoples' dietary habits, where a greater proportion reported following a low-fat, low-sugar and low-salt diet at baseline than follow-up data collection (52, 63 and 64% reduced to 44, 51, and 56% respectively). These findings were non-statistically significant after a Bonferroni correction was applied.

Table 7-6. Baseline and follow-up descriptive statistics for lifestyle

	N Median (IQR)/Frequency (%), unless otherwise stated			**Chi-squared (DF), unless otherwise stated P-value***
Lifestyle	***Baseline***		***Follow-up***	
Current smoking status	***Medical records***	***Self-reported***		
Non/never smoked	N=41			
Ex-smoker	17 (36.2%)	18 (39.1%)	14 (34.2%)	52.72 (4) p<0.001
Current smoker	21 (44.7%)	24 (52.2%)	24 (92.7%)	
	9 (19.2%)	4 (8.7%)	3 (7.3%)	
Number smoked daily	N=22			z=0.64 p=0.52
	10 (13)		10 (12)	
Number of cups of tea	N=41			z=-0.13 p=0.89
	4 (5)		3 (6)	
Number of cups of coffee	N=41			z=-0.13 p=0.89
	1 (2)		1 (3)	
Number of cups of decaf coffee	N=41			z=2.24 p<0.05
	0 (0)		0 (0)	
Current alcohol intake (units/week)	N=44 3.5 (14)		-	-
Units of beer	N=41			z=0.82 p=0.41
	0 (7)		0 (4)	
Units of wine	N=41			z=1.08 p=0.28
	0 (2)		0 (0)	
Units of spirits	N=41			z=2.00 p=0.05
	0 (0)		0 (0)	
30-minutes of exercise x4 times a week	N=41			10.60(1) p<0.01
	36 (78.3%)		29 (70.7%)	
Low-fat diet	N=41			4.45 (1) <0.05
	24 (52.2%)		18 (43.9%)	
Low-sugar diet	N=41			4.19 (1) p<0.05
	29 (63.0%)		21 (51.2%)	
Low-salt diet	N=41			3.01 (1) p=0.08
	29 (64.4%)		23 (56.1%)	
Coping				
Medication Adherence Report Scale score	-		N=41 25 (1)	-
Healthcare utilisation				
Number of general practitioner visits	N=41 1 (1)		-	-
Number of hospital admissions	N=42 0 (0)		-	-

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); DF: Degrees of Freedom; IQR: Interquartile range

Participants also reported good medication adherence overall at follow-up, showing on average a perfect score on this questionnaire (25 out of 25).

7.5.5 Missing Data

Missing data were not a problem for many of the variables (Tables 7-3 to 7-6), particularly the predictor and outcomes variables of interest to this research (Tables 7-8 and 7-9) where very few observations were missing. The total proportion of missing values for all of the baseline variables and also some collected at follow-up ranged from 8.7 to 10.9% at baseline to 19.0 to 21.4% at follow-up.

However, follow-up clinical data for participants was very difficult to obtain from general practices (elaborated in Chapter 8), meaning that most of this information was missing (Table 7-7). Imputation of these missing values was considered, though it was decided that this would not to be undertaken, given that the clinical variables were included for descriptive purposes only, and were not the main variables of interest to this PhD.

Table 7-7. Summary of the degree of missing values for follow-up clinical variables

Clinical variable	N (%) missing
Follow-up systolic blood pressure (mm/HG)	N=39 (78%)
Follow-up diastolic blood pressure (mm/HG)	N=39 (78%)
Follow-up blood glucose (mmol/L)	N=47 (94%)
Follow-up total cholesterol (mmol/L)	N=45 (90%)
Follow-up HDL cholesterol (mmol/L)	N=47 (94%)
Follow-up LDL cholesterol (mmol/L)	N=48 (96%)
Follow-up BMI (kg/m^2)	N=45 (90%)

Symbols and abbreviations: LDL; Low Density Lipoprotein; HDL; High Density Lipoprotein; BMI: Body Mass Index

7.5.5.1 Diary/Calendar Data

Data on engagement with rehabilitation was, unfortunately, limited. Of 50 patients recruited to the study, around half agreed to complete the calendar (Figure 7-2), with the remainder refusing for reasons such as being too busy, or not seeing the relevance of completion. Further, only 17 out of these 24 participants returned their calendar (70.8% completion rate), though the usefulness of the data varied. The general pattern was that patients were not involved in any formal rehabilitation sessions upon discharge from hospital, nor were completing self-directed therapy at home. This may partly have been because the sample of participants recruited were those with mild disability after stroke. Given the limited diary/calendar data obtained, no further analyses were conducted using this information.

The next part of this chapter will present the analysis approach for each research hypothesis along with the associated findings.

7.6 APPROACH TO ANALYSIS: RESEARCH QUESTION 1

The computation of descriptive statistics was previously summarised in section 7.4.3. Formal statistical analyses were then undertaken to address Research Question 1: Do illness belief domains and markers of recovery (HRQL, disability and mood) at baseline differ significantly from those at follow-up?

As before, a series of Wilcoxon signed rank tests were conducted in order for this to be examined. Parametric paired sample t-tests were utilised as appropriate for variables where normality could be assumed.

7.7 HYPOTHESIS TESTING: RESEARCH QUESTION 1

It was originally hypothesised that illness beliefs and markers of recovery at baseline would differ significantly from those at follow-up, and would show improvements over time.

This was partly supported by the descriptive analyses undertaken for this research question. The findings for illness belief domains will be considered first.

7.7.1 Baseline and Follow-Up Illness Belief Domains

Findings from the descriptive analysis of illness belief domains are presented in Table 7-8. Scores for the identity domain suggested that at baseline, participants endorsed few symptoms of their stroke (median=9) and symptom burden at follow-up was significantly less in comparison (median=7, $p<0.001$). Scores on the timeline acute-chronic subscale suggested that the majority of patients perceived that their stroke was a chronic condition at baseline and follow-up (mean=15.4 and 16, respectively). Cyclical timeline scores indicated that most of the participants believed that the effects of their stroke were episodic at baseline (median=10). Following Bonferroni correction, these perceptions were not endorsed significantly less at follow-up (median=8). Scores on the consequences sub-scale suggested that participants tended to perceive serious

consequences of their stroke at baseline (mean=30.8) and follow-up (mean=29.8), and the strength of these beliefs did not change significantly over time. Scores on the personal and treatment control sub-scales demonstrated that the majority of participants believed themselves and their treatment to have a large amount of control over their stroke, and this persisted from baseline to follow-up (Table 7-8). Baseline illness coherence scores suggested that participants had a less than satisfactory understanding of their stroke (median=19), and this was not significantly different at follow-up (median=19.5). In addition, scores on the emotional representations sub-scale suggested that the majority of participants believed their stroke to have caused them considerable distress. Following Bonferroni correction, this persisted between baseline and follow-up (Table 7-8).

Scores on the causal sub-scale indicated that the majority of participants did not endorse many of the attributions that were described in Chapter 1 as being potential causes of stroke (e.g., 'Heredity – it runs in family,' 'Diet or eating habits,' 'Not taking enough exercise,' 'Smoking,' 'Diabetes,' and 'Problems with my heart,' such as atrial fibrillation) at baseline or follow-up (Table 7-8). In contrast, Table 7-8 shows that most of the participants seemed to believe that their stroke was caused by ageing or chance or bad luck, and this did not differ significantly at baseline compared to follow-up. Interestingly, for many of the established risk factors for stroke (e.g., high cholesterol and hypertension (described in Chapter 1)), the majority of participants in this study seemed unsure of their relevance in causing their stroke. The median for participants' responses suggested that the majority marked the 'I don't know'

category, and this did not seem to change significantly over time (Table 7-8). There was a further lack of clarity amongst participants on the role of psychological and emotional factors in causing their stroke. For example, median responses to the 'Stress or worry, including family problems;' 'My mental attitude e.g., thinking about life negatively;' and 'My emotional state e.g., feeling down, lonely, anxious, empty' suggested that participants were generally marking 'disagree.' Again, this did not alter with time (Table 7-8).

Table 7-8. Descriptive analysis for illness belief domains

	N Median (IQR), unless otherwise stated		**Z, unless otherwise stated P-value***
Illness beliefs	**Baseline**	**Follow-up**	
Identity	N=42		z=3.83
	9 (7)	7 (8)	p<.0.001
Timeline acute-chronic	N=42		-2.34
	Mean=15.4 (SD=4.2)	16 (8)	p=0.02
Timeline-cyclical	N=42		z=2.72
	10 (6)	8 (4)	p<0.01
Consequences	N=42		t=1.91
	Mean=30.8 (SD=6.5)	Mean=29.8 (SD=5.3)	p=0.06
Personal control	N=42		z=-0.97
	Mean=32.7 (SD=4.4)	34 (3)	p=0.33
Treatment control	N=42		z=0.57
	20 (2)	20 (3)	p=0.57
Illness coherence	N=42		z=-0.97
	19 (4)	19.5 (4)	p=0.33
Emotional representations	N=42		z=2.57
	24 (7)	22 (8)	p<0.01
Cause 1: Stress or worry, including family problems	N=42		z=0.34
	3 (2)	3 (2)	p=0.73
Cause 2: Heredity – it runs in my family	N=42		z=0.15
	2 (0)	2 (1)	p=0.88
Cause 3: Diet or eating habits	N=42		z=1.32
	2 (2)	3 (2)	p=0.18
Cause 4: Poor medical care in my past	N=42		z=-0.37
	2 (0)	2 (2)	p=0.71
Cause 5: My mental attitude e.g., thinking about life negatively	N=42		z=0.14
	2 (0)	2 (0)	p=0.89
Cause 6: Overwork	N=42		z=0.49
	2 (2)	2 (2)	p=0.63
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	N=42		z=-0.63
	2 (0)	2 (0)	p=0.53

Cause 8: Ageing	N=42		z=-1.38
	4 (2)	4 (2)	p=0.17
Cause 9: Alcohol	N=42		z=0.53
	2 (0)	2 (0)	p=0.60
Cause 10: Smoking	N=42		z=-0.37
	2 (2)	2 (2)	p=0.71
Cause 11: High cholesterol	N=42		z=-2.01 p<0.05
	3 (2)	3 (2)	
Cause 12: High blood pressure	N=42		z=0.01
	3 (2)	3.5 (2)	p=0.99
Cause 13: Diabetes	N=42		z=-0.38
	2 (0)	2 (0)	p=0.71
Cause 14: Problems with my heart, such as an irregular heartbeat	N=42		z=-0.91 p=0.36
	2 (0)	2 (2)	
Cause 15: Chance or bad luck	N=42		z=0.22
	4 (2)	4 (2)	p=0.83
Cause 16: Not taking enough exercise	N=42		z=0.33
	2 (2)	2 (2)	p=0.75

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); IQR: Interquartile range; SD: Standard deviation

7.7.2 Baseline and Follow-Up Markers of Post-Stroke Recovery

Table 7-9 provides a summary of the descriptive analyses undertaken for the main outcomes of interest in the present study. As mentioned earlier in this chapter, high scores on the PHQ-9 indicate a greater severity of depression, although this was not the case for study participants, whose mood was generally good and showed only mild depressive symptomatology (median=6). Following Bonferroni correction, mood did not significantly improve over time (median=4). HRQL (EQ-5D-5L Descriptive System) was also high overall, though again following Bonferroni correction, HRQL did not differ significantly between baseline and follow-up (Table 7-9). The EQ-5D-5L 'Your health today' VAS score was well above 50% at baseline, showing adequate HRQL. This markedly increased at follow-up to 70% but was non-statistically significant (Table 7-9). Disability was low in the present sample. For example, Modified Rankin Scale scores categorised the majority of

participants as having 'slight disability' at baseline and follow-up (Table 7-9). In accordance with the guidelines for the instrument, this meant that individuals were unable to carry out all previous activities, but could independently manage their own affairs (Banks and Marotta 2007). In addition scores on the Barthel Index showed that participants experienced very little post-stroke disability. This also improved significantly at follow-up, where on average, people achieved a perfect score on the instrument (20 out of 20) in terms of their independence in basic activities of daily living (Table 7-9). Similar was found in participants' scores on the Nottingham Extended Activities of Daily Living scale. On average, baseline and follow-up scores were high (17 out of 22) indicating greater independence in instrumental activities of daily living, though this was statistically non-significant between baseline and follow-up (Table 7-9).

Table 7-9. Descriptive analysis for markers of post-stroke recovery

	N Median (IQR), unless otherwise stated		**Z P-value***
HRQL	**Baseline**	**Follow-up**	
EQ-5D-5L Descriptive System-Index score	N=46 0.74 (0.44)	N=42 0.77 (0.28)	z=-2.84 p=<0.01
EQ-5D-5L 'Your health today' VAS score	N=46 58.3 (22.7)	N=42 70 (30)	z=-2.05 p=0.04
Mood			
PHQ-9 Total depressive symptomatology score	N=45 6 (6)	N=41 4 (3)	z=3.22 p<0.01
Disability			
Modified Rankin Scale score	N=48 2 (3)	N=42 2 (2)	z=1.80 p=0.07
Barthel Index score	N=47 17 (11)	N=42 20 (0)	z=-4.71 p<0.001
Nottingham Extended Activities of Daily Living Scale score	N=46 17 (9)	N=42 17 (7)	z=-1.81 p=0.07

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); HRQL: Health-Related Quality of Life; IQR: Interquartile range; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale

7.8 APPROACH TO ANALYSIS: RESEARCH QUESTION 2

Subsequent to the normality and descriptive analyses, associations between illness belief domains and outcomes were explored to address Research Question 2, which was: Are baseline illness belief domains measured during the acute phase of stroke (≤three-months post-stroke), associated with markers of recovery at baseline and three-months post-stroke (HRQL, disability and mood)?

The relationship between each baseline illness belief domain and baseline and follow-up marker of post-stroke recovery was examined using Spearman's rho correlation (ρ), which quantifies the strength of any associations between non-normal continuous variables. Scatterplots were also produced to provide a visual representation of any statistically significant relationships to emerge. A Chi-squared test was selected to examine whether baseline illness belief domains were significantly associated with baseline and follow-up Modified Rankin Scale categories.

7.9 HYPOTHESIS TESTING: RESEARCH QUESTION 2

It was originally hypothesised that baseline illness belief domains would be associated with baseline and follow-up markers of recovery after stroke (three-months post-stroke) (HRQL, disability and mood). In particular, an overall pessimistic impression of stroke during the acute phase (for example: strong illness identity; serious consequences; chronic timeline; low illness coherence; strong emotional representations; cyclical timeline; and low personal

and treatment control) would be inversely related to HRQL, disability, and mood at baseline and three-months post-stroke.

This was supported in part by the correlations that emerged through this analysis. Correlations between baseline illness belief domains and baseline markers of recovery will be considered first.

7.9.1 Baseline illness beliefs and baseline markers of recovery

Patients who perceived their stroke to be associated with a lot of symptoms (ρ=0.65, p<0.001), with fluctuating effects (ρ=0.61, p<0.001), serious consequences (ρ=0.51, p<0.001), and considerable distress (ρ=0.53, p<0.001) at baseline also reported worse baseline mood. These relationships are depicted in Figures 7-3 to 7-6. Significant associations did not emerge at baseline between illness belief domains and the remainder of baseline markers of recovery (HRQL and disability).

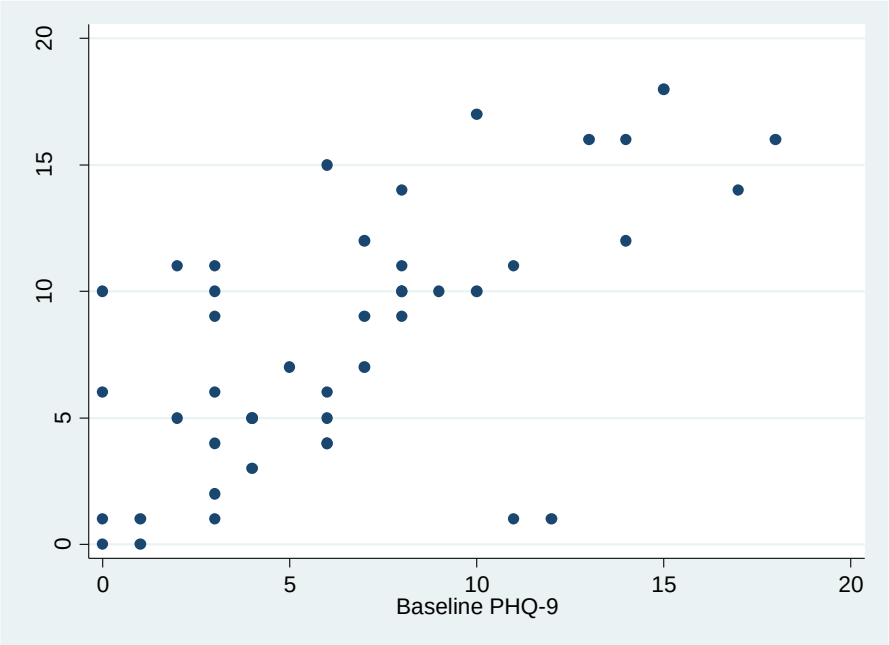


Figure 7-3. Scatterplot of the relationship between baseline identity beliefs and baseline mood (N=41)

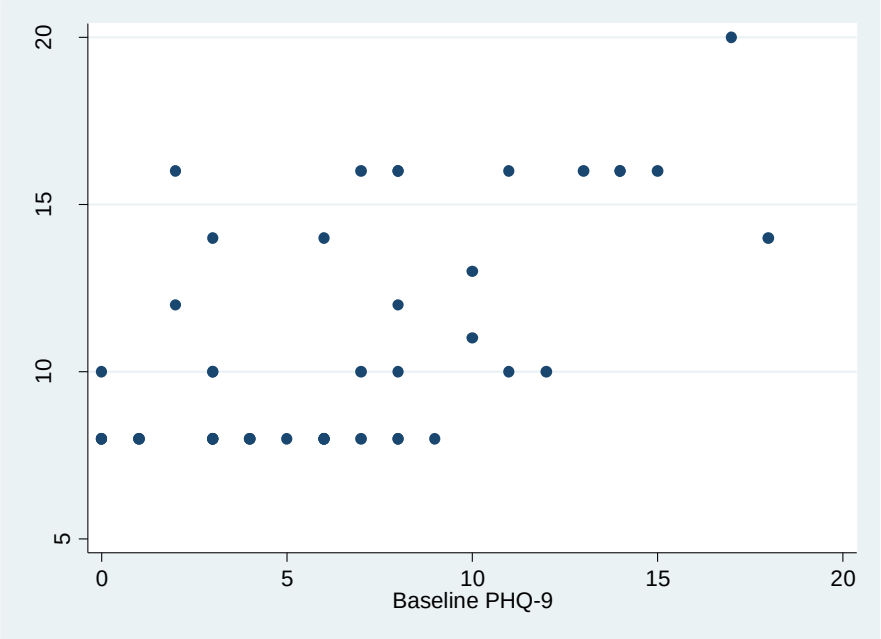


Figure 7-4. Scatterplot of the relationship between baseline timeline-cyclical beliefs and baseline mood (N=41)

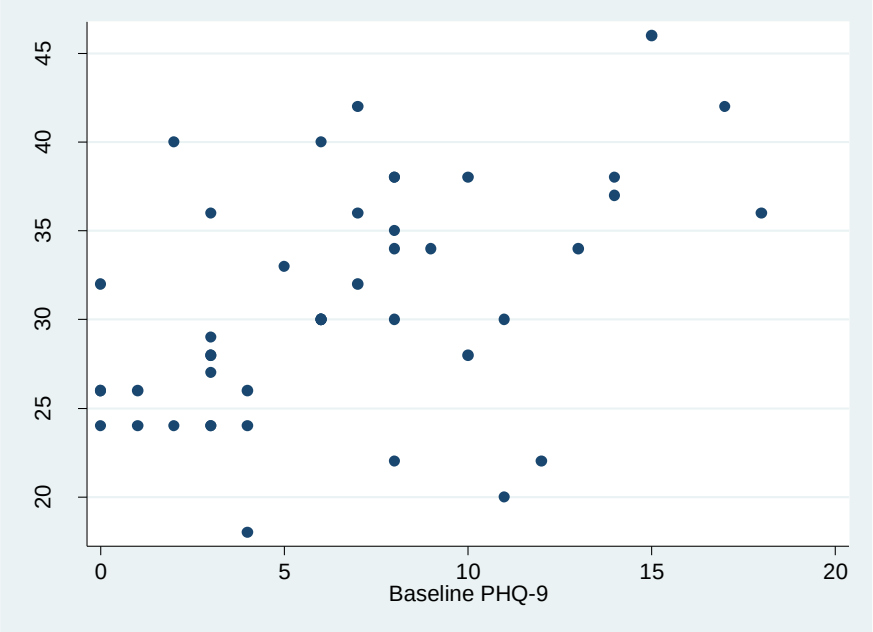


Figure 7-5. Scatterplot of the relationship between baseline consequence beliefs and baseline mood (N=41)

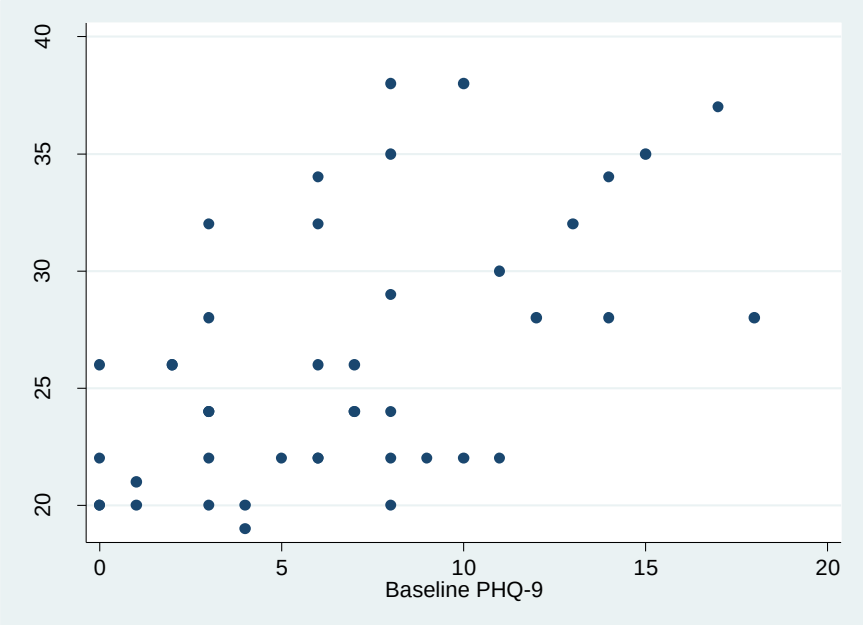


Figure 7-6. Scatterplot of the relationship between baseline emotional representations and baseline mood (N=41)

7.9.2 Baseline illness beliefs and follow-up markers of recovery

Only two of the abovementioned relationships persisted when examining associations between baseline illness belief domains and follow-up markers of recovery. Patients who perceived the effects of their stroke to be episodic ($\rho=0.50$, $p<0.001$), and causing considerable distress ($\rho=0.41$, $p<0.001$) at baseline also reported worse follow-up mood. These relationships are illustrated in Figures 7-7 and 7-8. As before, significant associations did not emerge between baseline illness belief domains and the remainder of markers of recovery (HRQL and disability) at follow-up.

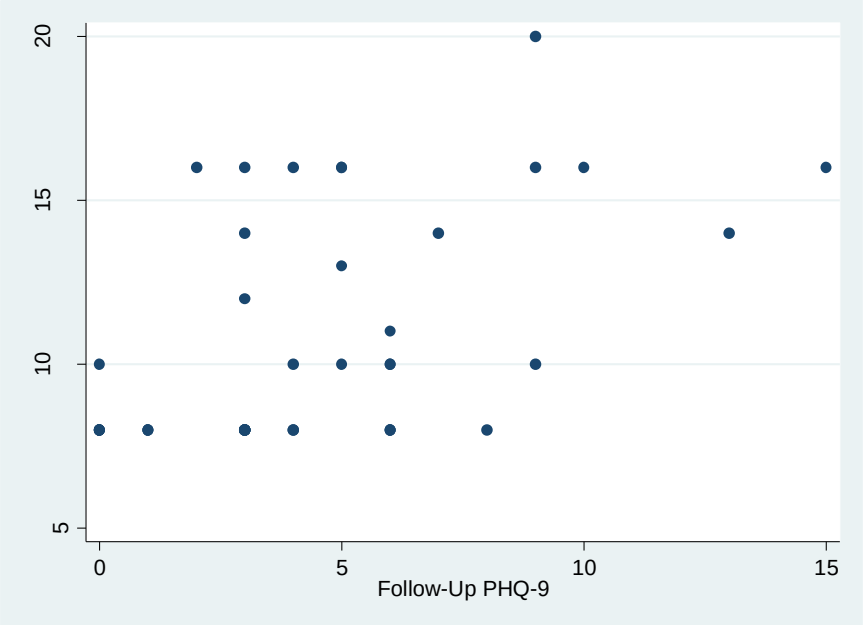


Figure 7-7. Scatterplot of the relationship between baseline timeline-cyclical beliefs and follow-up mood (N=41)

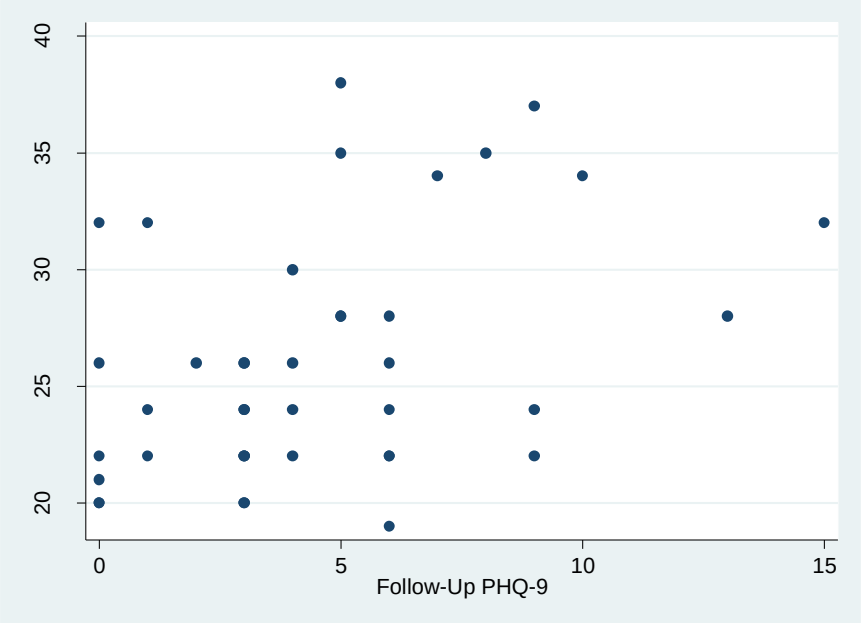


Figure 7-8. Scatterplot of the relationship between baseline emotional representations and follow-up mood (N=41)

7.10 APPROACH TO ANALYSIS: RESEARCH QUESTION 3

Multiple mediation analysis was undertaken to address Research Question 3, which was: Do baseline mood and follow-up coping (three-months post-stroke medication adherence) mediate predictive associations between

baseline domains of illness beliefs, and follow-up markers of recovery after stroke (HRQL, disability and mood)? Given the small sample size, these analyses were undertaken for exploratory purposes only.

Mediation was previously introduced in prior chapters (e.g., Chapter 4), though to reiterate, mediation describes when the relationship between a predictor variable and outcome variable can be explained by a third variable (the mediator) (Field 2013). To illustrate, Figure 7-9 shows a simple relationship between a predictor and outcome, denoted as c.

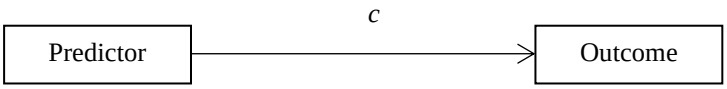


Figure 7-9. Illustration of a simple relationship between predictor and outcome

However, with mediation, these variables are also related to a third variable (Mediator 1) (depicted in Figure 7-10) where the predictor predicts the mediator (denoted by path a1), and the mediator predicts the outcome (denoted by path b1). With inclusion of a mediator, the relationship between the predictor and outcome changes (denoted by path c'). Multiple mediation works in the same way, though includes the effect of a second mediator (Mediator 2), which is also predicted by the predictor (denoted by path a2) and predicts the outcome (denoted by path b2) (Figure 7-10) (VanderWeele and Vansteelandt 2014, VanderWeele 2015, VanderWeele 2016). Paths a, b, c and c' represent the unstandardized regression coefficient (β) between the variables, and therefore, indicate the strength of the relationship, where it is assumed that if the

relationship between predictor and outcome is attenuated with inclusion of the mediator(s) (if β for c' is smaller than c) then mediation has occurred (Field 2013). The multiple mediation models for the present research were captured in the conceptual model of Figure 7-1.

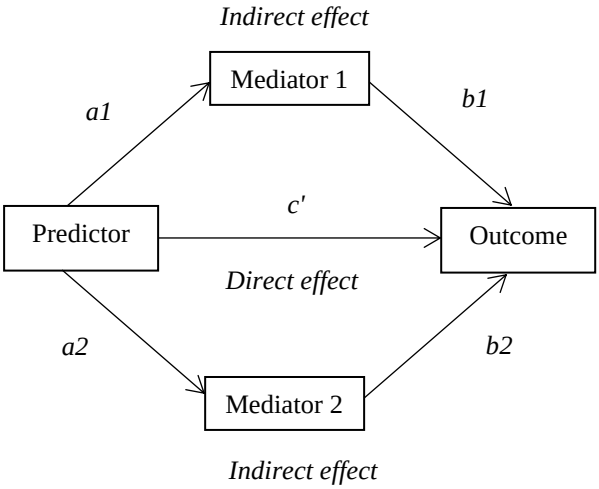


Figure 7-10. Illustration of a mediated relationship between predictor and outcome with two mediators

7.10.1 Mediation using the Baron and Kenny Approach

The traditional approach to examining mediation was proposed in a seminal paper by Baron and Kenny (1986), and involved testing for mediation through three regression models:

1. A regression predicting the outcome from the predictor variable (path c in Figure 7-9);
2. A regression predicting the mediator(s) from the predictor variable (paths a1 and a2 in Figure 7-10);
3. A regression predicting the outcome from both the predictor variable and the mediator(s), where β for the predictor gives the value for path c' and β for the mediator(s) provides the values for paths b1 and b2.

In the Baron and Kenny (1986) approach, it is understood that these regression models assess four conditions of mediation (Field 2013). In the present analyses, these conditions were examined using univariate linear and logistic (where relevant) regression models. Mediation analysis was not pursuable where any of these conditions were violated.

7.10.1.1 Indirect Effects

The final criterion for mediation according to the Baron and Kenny (1986) approach is that the predictor variable must predict the outcome less strongly in model 3 than in model 1. However, it is unclear how much of a reduction in β is necessary for mediation to be inferred (Field 2013). Therefore, it is recommended that indirect effect(s), which are the mediated effect(s) by which the predictor indirectly effects the outcome through the mediator(s) (MacKinnon, Fairchild et al. 2007), are calculated. This can be done using bootstrapping (Preacher and Hayes 2008, Zhao, Lynch et al. 2010, Field 2013).

7.10.1.1.1 Bootstrapping

Bootstrapping is a distribution-free re-sampling method that can be used to estimate parameters of interest (e.g., the mean or 95% CI) by treating the sample data as a good model of the population from which smaller samples can be drawn (Efron and Tibshirani 1993, Field 2013). To elaborate, bootstrapping involves repeatedly drawing samples from the original study data with replacement (putting each score back before a new one is drawn from the sample), which is executed thousands of times, meaning that thousands of parameter estimates are obtained, one from each bootstrap sample (Ajmani

2008). By resampling in this way on a large scale, one can learn about the sampling distribution of the parameter of interest, which for the case of multiple mediation analysis is the β-coefficient (indirect effect), and thus obtain the precision of the statistic (e.g., 95% CI) (Wright, London et al. 2011, Field 2013).

7.10.1.2 Full and Partial Mediation

An important distinction has been made between full and partial mediation (MacKinnon, Krull et al. 2000). Full mediation occurs when path c' (Figure 7-10) is (or approaches 0), which can but often rarely happens, while partial mediation occurs when there is significant mediation as well as a statistically significant path c' (direct effect).

7.11 HYPOTHESIS TESTING: RESEARCH QUESTION 3

It was originally hypothesised that the relationship between baseline illness belief domains and follow-up markers of recovery three-months post-stroke (HRQL, disability and mood) would be mediated by baseline mood and coping (medication adherence at follow-up). This was only partly supported by the mediation analyses undertaken for this research question.

In accordance with the approach advocated by Baron and Kenny (1986), the first criterion for mediation was examined for all outcomes (i.e., follow-up HRQL, disability and mood). However, univariate regression models showed that none of the baseline illness belief domains significantly predicted follow-up HRQL (EQ-5D-5L Descriptive System-Index Score and EQ-5D-5L 'Your health today' VAS score) or disability (Modified Rankin Scale, Barthel

Index and Nottingham Extended Activities of Daily Living Scale scores). These results are shown in Tables 7-10 to 7-14. Therefore, the first criterion for mediation was violated for these outcomes, meaning that further analyses could not be undertaken.

Table 7-10. Summary of findings for criteria 1 of mediation for follow-up HRQL (EQ-5D-5L Descriptive System-Index score)

Baseline illness belief domains Outcome: Follow-up HRQL (EQ-5D-5L Descriptive System-Index score)	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Identity	42	-0.01	0.01	0.55	-0.03-0.01	0.89
Timeline acute-chronic	42	-0.03	0.01	<.05	-0.05-(-0.00)	13.20
Timeline-cyclical	42	-0.01	0.01	0.32	-0.04-0.14	2.51
Consequences	42	-0.01	0.01	0.36	-0.02-0.01	2.10
Personal control	42	-0.00	0.01	0.96	-0.02-0.02	0.01
Treatment control	42	-0.02	0.03	0.52	-0.07-0.04	1.04
Illness coherence	42	0.01	0.01	0.40	-0.14-0.04	1.78
Emotional representations	42	-0.02	0.01	0.05	-0.03-0.00	9.08
Cause 1: Stress or worry, including family problems	42	0.03	0.04	0.57	-0.06-0.11	0.81
Cause 2: Heredity – it runs in my family	42	0.01	0.06	0.84	-0.11-0.13	0.10
Cause 3: Diet or eating habits	42	0.02	0.05	0.72	-0.08-0.11	0.32
Cause 4: Poor medical care in my past	42	-0.01	0.05	0.86	-0.12-0.10	0.08
Cause 5: My mental attitude e.g., thinking about life negatively	42	-0.09	0.06	0.15	-0.22-0.04	5.01
Cause 6: Overwork	42	0.03	0.04	0.51	-0.06-0.11	1.09
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	42	-0.00	0.06	0.99	-0.13-0.13	0.00
Cause 8: Ageing	42	0.04	0.05	0.38	-0.05-0.13	1.93
Cause 9: Alcohol	42	-0.01	0.05	0.88	-0.12-0.10	0.06
Cause 10: Smoking	42	-0.01	0.05	0.84	-0.10-0.08	0.10
Cause 11: High cholesterol	42	0.07	0.05	0.18	-0.03-0.18	4.50
Cause 12: High blood pressure	42	0.08	0.05	0.10	-0.02-0.17	6.69
Cause 13: Diabetes	42	0.05	0.07	0.47	-0.09-0.19	1.30
Cause 14: Problems with my heart, such as an irregular heartbeat	42	0.04	0.05	0.39	-0.06-0.14	1.86
Cause 15: Chance or bad luck	42	-0.05	0.05	0.33	-0.14-0.05	2.42
Cause 16: Not taking enough exercise	42	0.02	0.05	0.68	-0.08-0.13	0.42

Symbols and abbreviations: *: Bonferroni adjusted significance level ($p<0.002$); β: Beta-coefficient; CI: Confidence Interval; HRQL: Health-Related Quality of Life

Table 7-11. Summary of findings for criteria 1 of mediation for follow-up HRQL (EQ-5D-5L 'Your health today' VAS score)

Baseline illness belief domains Outcome: Follow-up HRQL (EQ-5D-5L 'Your health today' VAS score)	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Identity	42	-0.23	0.67	0.74	-1.57-1.12	0.29
Timeline acute-chronic	42	-0.60	0.76	0.44	-2.14-0.95	1.51
Timeline-cyclical	42	-1.47	0.92	0.12	-3.33-0.39	5.99
Consequences	42	-0.21	0.50	0.67	-1.21-0.79	0.45
Personal control	42	0.14	0.74	0.99	-1.48-1.50	0.00
Treatment control	42	-0.10	1.89	0.96	-3.92-3.72	0.01
Illness coherence	42	0.26	0.85	0.76	-1.45-1.97	0.23
Emotional representations	42	-0.94	0.59	0.12	-2.13-0.25	6.04
Cause 1: Stress or worry, including family problems	42	-5.86	2.84	0.05	-11.60-(-0.12)	9.63
Cause 2: Heredity – it runs in my family	42	5.24	3.83	0.18	-2.50-12.97	4.48
Cause 3: Diet or eating habits	42	0.19	3.11	0.95	-6.10-6.47	0.01
Cause 4: Poor medical care in my past	42	6.15	3.38	0.08	-0.68-12.99	7.64
Cause 5: My mental attitude e.g., thinking about life negatively	42	4.76	4.28	0.27	-3.89-13.40	3.00
Cause 6: Overwork	42	1.02	2.74	0.71	-4.52-6.56	0.35
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	42	3.98	4.32	0.36	-4.74-12.71	2.08
Cause 8: Ageing	42	1.82	3.06	0.56	-4.36-8.00	0.88
Cause 9: Alcohol	42	4.17	3.58	0.25	-3.07-11.41	3.28
Cause 10: Smoking	42	-3.37	3.00	0.27	-9.44-2.69	3.06
Cause 11: High cholesterol	42	8.38	3.36	<.05	1.59-15.17	13.45
Cause 12: High blood pressure	42	5.24	3.12	0.10	-1.06-11.55	6.61
Cause 13: Diabetes	42	0.19	4.56	0.97	-9.03-9.40	0.00
Cause 14: Problems with my heart, such as an irregular heartbeat	42	5.54	3.22	0.09	-0.96-12.04	6.90
Cause 15: Chance or bad luck	42	-1.14	3.18	0.72	-7.57-5.28	0.32
Cause 16: Not taking enough exercise	42	4.72	3.46	0.18	-2.27-11.71	4.45

Symbols and abbreviations: *: Bonferroni adjusted significance level ($p<0.002$); β: Beta-coefficient; CI: Confidence Interval; HRQL: Health-Related Quality of Life; VAS: Visual Analogue Scale

Table 7-12. Summary of findings for criteria 1 of mediation for follow-up disability (Modified Rankin Scale score)

Baseline illness belief domains Outcome: Follow-up disability (Modified Rankin Scale score)	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Identity	45	0.10	0.07	0.13	-0.03-0.23	-
Timeline acute-chronic	46	0.24	0.09	<.05	0.05-0.42	-
Timeline-cyclical	45	0.19	0.11	0.07	-0.02-0.40	-
Consequences	46	0.13	0.06	<.05	0.01-0.24	-
Personal control	45	0.03	0.07	0.60	-0.10-0.18	-
Treatment control	45	0.03	0.18	0.86	-0.31-0.37	-
Illness coherence	45	-0.00	0.08	0.95	-0.16-0.15	-
Emotional representations	45	0.11	0.07	0.10	-0.02-0.24	-
Cause 1: Stress or worry, including family problems	46	0.57	0.31	0.06	-0.03-1.17	-
Cause 2: Heredity – it runs in my family	46	-0.14	0.36	0.69	-0.84-0.56	-
Cause 3: Diet or eating habits	46	-0.03	0.29	0.92	-0.61-0.55	-
Cause 4: Poor medical care in my past	46	-0.04	0.34	0.91	-0.70-0.62	-
Cause 5: My mental attitude e.g., thinking about life negatively	46	0.43	0.46	0.35	-0.47-1.33	-
Cause 6: Overwork	46	0.27	0.27	0.32	-0.26-0.80	-
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	46	0.24	0.42	0.57	-0.59-1.07	-
Cause 8: Ageing	46	-0.74	0.32	<.05	-1.37-(-0.11)	-
Cause 9: Alcohol	46	-0.04	0.34	0.91	-0.70-0.62	-
Cause 10: Smoking	46	0.02	0.29	0.95	-0.55-0.59	-
Cause 11: High cholesterol	46	-0.07	0.34	0.84	-0.73-0.59	-
Cause 12: High blood pressure	46	-0.16	0.30	0.59	-0.76-0.43	-
Cause 13: Diabetes	46	-0.10	0.41	0.82	-0.90-0.71	-
Cause 14: Problems with my heart, such as an irregular heartbeat	46	-0.06	0.32	0.85	-0.69-0.56	-
Cause 15: Chance or bad luck	46	0.34	0.30	0.26	-0.25-0.94	-
Cause 16: Not taking enough exercise	46	0.15	0.34	0.66	-0.51-0.81	-

Symbols and abbreviations: *: Bonferroni adjusted significance level ($p<0.002$); β: Beta-coefficient; CI: Confidence Interval

Table 7-13. Summary of findings for criteria 1 of mediation for follow-up disability (Barthel Index score)

Baseline illness belief domains	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Outcome: Follow-up disability (Barthel Index score)						
Identity	42	-0.01	0.06	0.91	-0.14-0.12	0.04
Timeline acute-chronic	42	-0.11	0.07	0.13	-0.26-0.04	5.54
Timeline-cyclical	42	0.01	0.09	0.96	-0.18-0.19	0.00
Consequences	42	-0.04	0.05	0.32	-0.15-0.05	2.50
Personal control	42	-0.05	0.07	0.53	-0.19-0.10	1.00
Treatment control	42	0.01	0.18	0.94	-0.36-0.38	0.00
Illness coherence	42	-0.05	0.08	0.55	-0.22-0.12	0.91
Emotional representations	42	-0.07	0.06	0.23	-0.19-0.46	3.63
Cause 1: Stress or worry, including family problems	42	0.46	0.28	0.11	-0.11-1.03	6.23
Cause 2: Heredity – it runs in my family	42	0.23	0.38	0.55	-0.54-0.99	0.89
Cause 3: Diet or eating habits	42	0.30	0.30	0.32	-0.30-0.91	2.50
Cause 4: Poor medical care in my past	42	-0.08	0.34	0.82	-0.77-0.61	0.13
Cause 5: My mental attitude e.g., thinking about life negatively	42	-0.08	0.34	0.82	-0.77-0.61	0.13
Cause 6: Overwork	42	0.37	0.26	0.17	-0.16-0.89	4.70
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	42	0.09	0.42	0.83	-0.76-0.95	0.12
Cause 8: Ageing	42	-0.16	0.30	0.60	-0.76-0.44	0.70
Cause 9: Alcohol	42	0.17	0.35	0.62	-0.54-0.89	0.61
Cause 10: Smoking	42	0.48	0.29	0.10	-0.10-1.06	6.57
Cause 11: High cholesterol	42	0.03	0.35	0.93	-0.68-0.74	0.00
Cause 12: High blood pressure	42	0.41	0.31	0.19	-0.21-1.03	4.28
Cause 13: Diabetes	42	0.38	0.44	0.39	-0.51-1.27	1.83
Cause 14: Problems with my heart, such as an irregular heartbeat	42	-0.09	0.32	0.78	-0.74-0.56	0.19
Cause 15: Chance or bad luck	42	-0.28	0.31	0.37	-0.89-0.34	1.99
Cause 16: Not taking enough exercise	42	0.59	0.33	0.08	-0.08-1.26	7.29

Symbols and abbreviations: *: Bonferroni adjusted significance level ($p<0.002$); β: Beta-coefficient; CI: Confidence Interval

Table 7-14. Summary of findings for criteria 1 of mediation for follow-up disability (Nottingham Extended Activities of Daily Living Scale score)

Baseline illness belief domains **Outcome: Follow-up disability (Nottingham Extended Activities of Daily Living Scale score)**	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Identity	42	-0.19	0.15	0.22	-0.50-0.12	3.79
Timeline acute-chronic	42	-0.38	0.17	<.05	-0.72-(-0.04)	11.26
Timeline-cyclical	42	-0.03	0.22	0.86	-0.49-0.41	0.08
Consequences	42	-0.08	0.12	0.48	-0.32-0.15	1.24
Personal control	42	0.04	0.17	0.82	-0.31-0.39	0.14
Treatment control	42	-0.40	0.44	0.37	-1.28-0.48	2.05
Illness coherence	42	-0.36	0.19	0.07	-0.74-0.03	8.14
Emotional representations	42	-0.12	0.14	0.38	-0.41-0.16	1.94
Cause 1: Stress or worry, including family problems	42	0.67	0.69	0.34	-0.73-2.06	2.27
Cause 2: Heredity – it runs in my family	42	-0.18	0.91	0.84	-2.03-1.67	0.10
Cause 3: Diet or eating habits	42	0.23	0.73	0.75	-1.24-1.70	0.25
Cause 4: Poor medical care in my past	42	0.23	0.82	0.78	-1.43-1.89	0.19
Cause 5: My mental attitude e.g., thinking about life negatively	42	-1.20	1.00	0.24	-3.22-0.81	3.51
Cause 6: Overwork	42	1.32	0.61	<.05	0.10-2.55	10.65
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	42	-0.38	1.02	0.71	-2.44-1.68	0.35
Cause 8: Ageing	42	0.71	0.71	0.33	-0.73-2.14	2.42
Cause 9: Alcohol	42	-0.19	0.85	0.82	-1.91-1.53	0.13
Cause 10: Smoking	42	0.33	0.71	0.65	-1.10-.176	0.53
Cause 11: High cholesterol	42	0.75	0.84	0.38	-0.94-2.44	1.96
Cause 12: High blood pressure	42	0.57	0.75	0.45	-0.95-2.08	1.41
Cause 13: Diabetes	42	0.14	1.07	0.90	-2.01-2.29	0.04
Cause 14: Problems with my heart, such as an irregular heartbeat	42	0.60	0.77	0.45	-0.97-2.16	1.46
Cause 15: Chance or bad luck	42	-0.51	0.74	0.49	-2.01-0.98	1.19
Cause 16: Not taking enough exercise	42	0.21	0.83	0.80	-1.46-1.88	0.16

Symbols and abbreviations: *: Bonferroni adjusted significance level ($p<0.002$); β: Beta-coefficient; CI: Confidence Interval

In contrast, several baseline illness belief domains emerged from univariate regression analyses to be significant predictors of follow-up mood (PHQ-9 score). These were timeline-cyclical ($\beta=0.51$, $p<0.01$) beliefs; and emotional representations ($\beta=0.28$, $p<0.01$), explaining around 27 and 17% of the variance in this outcome, respectively (Table A3-1, Appendix 3). This meant that participants with baseline perceptions of the effects of their stroke being fluctuating and causing considerable distress significantly predicted worse follow-up mood. When examining the second criterion of mediation, the prediction of Mediator 1 (coping) and Mediator 2 (baseline mood) from each of these illness belief domains, all again emerged to be significant for only baseline mood (Table A3-2, Appendix 3). This meant that these baseline illness belief domains also significantly predicted worse baseline mood. Further, these baseline illness belief domains and baseline mood were significant when examined in a regression model that predicted follow-up mood for the third criterion of mediation (Table A3-3, Appendix 3). Having satisfied all criteria for mediation, indirect effects were estimated, and the findings are summarised in Figures 7-11 and 7-12.

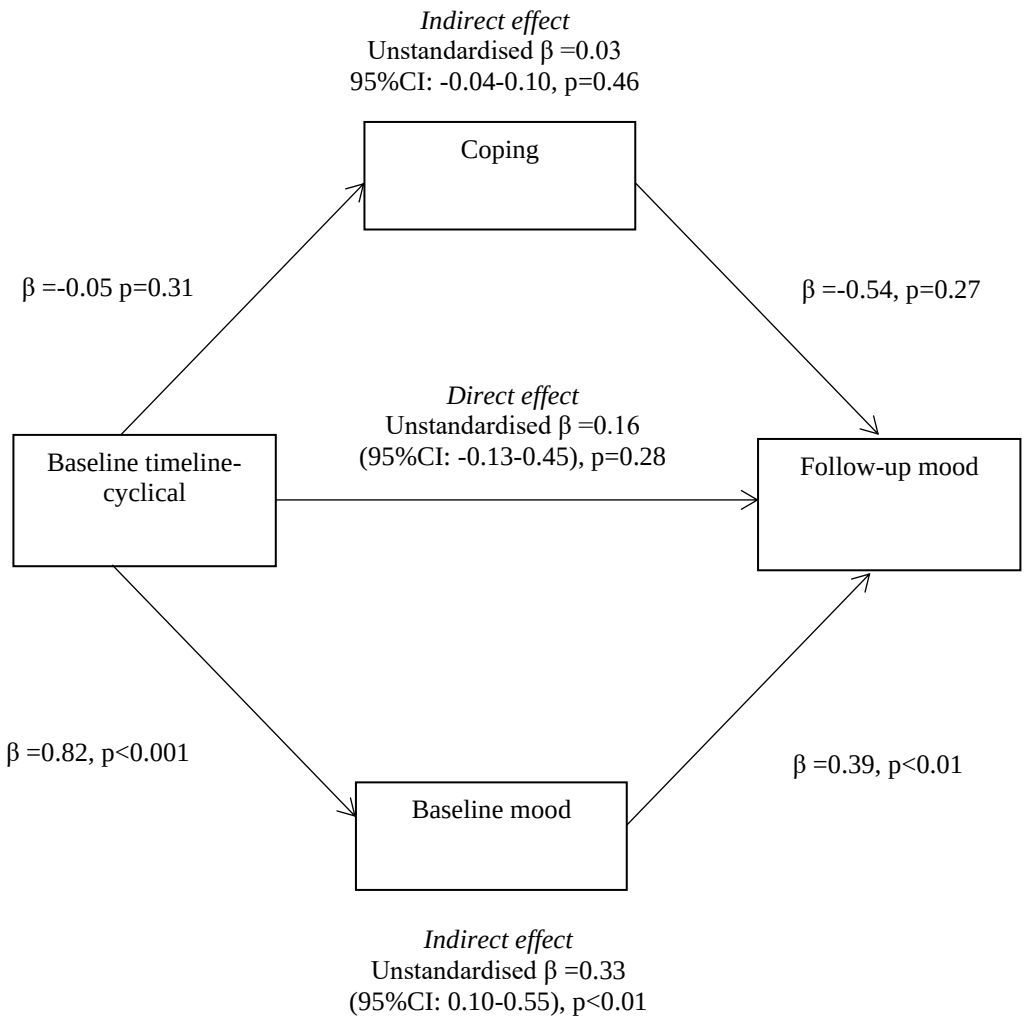


Figure 7-11. Multiple mediation model for baseline timeline-cyclical beliefs and follow-up mood

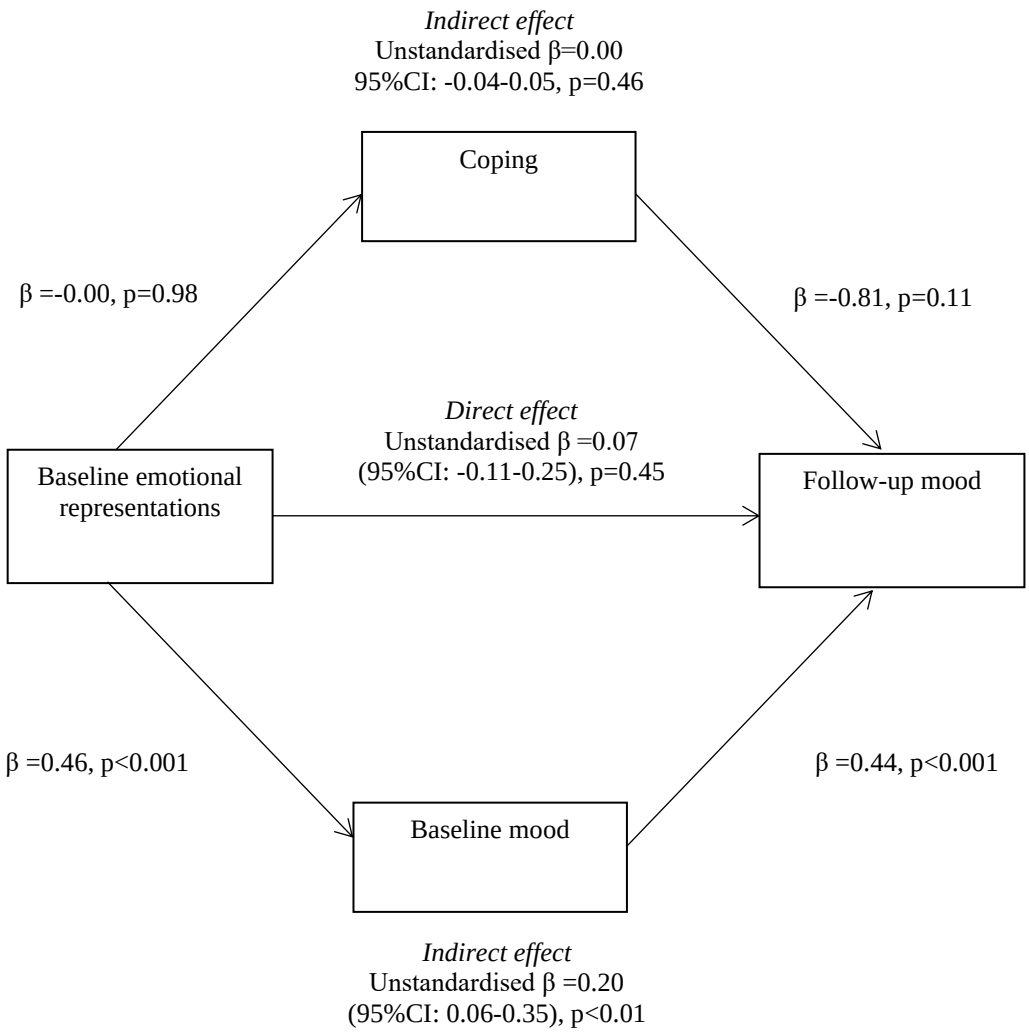


Figure 7-12. Multiple mediation model for baseline emotional representations and follow-up mood

These figures show that statistically significant indirect effects emerged for both baseline timeline-cyclical beliefs and emotional representations predicting follow-up mood, through baseline mood (Mediator 2) (β=0.33, 95%CI: 0.10-0.55, and β=0.20, 95%CI: 0.06-0.35, respectively). There was no evidence of full or partial mediation in either of these models. In addition, evidence of a mediational pathway for follow-up medication adherence (coping) did not emerge for either timeline-cyclical beliefs or emotional representations.

7.12 APPROACH TO ANALYSIS: RESEARCH QUESTION 4

Multiple regression models were fitted to address Research Question 4: Do baseline illness belief domains explain additional variance in three-month post-stroke markers of recovery (HRQL, disability, and mood), over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery)?

In light of the small sample size, these analyses were undertaken solely for exploratory purposes. In order to ensure that the multiple regression models fitted were as robust as possible, only a limited number of variables were included. These were the ones considered to be most key in addressing the research question. In addition, models were only fitted where N was greater than 40 participants. Multiple regression models were not viable for outcomes where there were samples of fewer than 40 people, because of the number of variables being examined (see below). Follow-up disability assessed using the Modified Rankin Scale score was, therefore, excluded from these analyses on this basis.

To begin with, specific socio-demographic and clinical variables were selected as confounding factors from the overall dataset for the observational study. The confounders chosen were those that made intuitive sense to include in light of prior evidence (cited in section 7.2.1.1.4), and were as follows:

- Socio-demographic – age, sex, and deprivation (Index of Multiple Deprivation decile);

- Clinical – baseline co-morbidities, stroke severity (National Institute of Health Stroke Scale score), and markers of recovery (i.e., HRQL, mood and disability).

In these analyses, specific baseline illness belief domains were included as predictors for the following outcomes: follow-up HRQL (EQ-5D-5L Descriptive System - Index score and 'Your health today' VAS score); mood (PHQ-9 score); and disability (Barthel Index, and Nottingham Extended Activities of Daily Living Scale scores). However, it was decided that the causal beliefs domain would be excluded when fitting the present multiple regression models. This was for two reasons. First, there were 16 causal beliefs that would need examination, though the limited sample size for these analyses meant that addition of all of these variables would compromise the validity of any findings to emerge. Second, the univariate analyses conducted to examine the prediction of each of the abovementioned outcomes from baseline illness belief domains in the previous section (7.11) showed that none of the causal beliefs significantly independently predicted any of the outcomes. Therefore, identity, timeline acute-chronic, timeline cyclical, consequences, personal and treatment control, illness coherence and emotional representations measured at baseline were the domains examined in the present analyses.

The order of entry followed an approach similar to that adopted by O'Carroll, Whittaker et al. (2011). Socio-demographic variables were entered at the first step; clinical variables at the second step; and illness belief domains at the third and final step. This was in order to partition out the variance, and

determine the additional variance in each outcome that could be explained at each stage of the analysis, following inclusion of specific variables. In particular, and especially relevant to the present research question, whether baseline illness belief domains added any predictive power to the models, over and above that of socio-demographic and clinical variables. Models were compared using the change in R2 and the likelihood ratio test. The latter provided a p-value, which allowed the significance of the addition of particular variables at each step to be tested. Outliers in each model were also examined.

Post-estimation, the assumptions for linear regression were checked for each model. This included an assessment of multicollinearity, which is where there is a strong correlation between two or more predictor variables. Multicollinearity was examined using the Tolerance statistic (1-R2), and the Variance Inflation Factor (1/Tolerance). Tolerance values below 0.1 and Variance Inflation Factor greater than 10 are considered problematic (Field 2013). Further, normality in the distributions of the models' residuals was assessed visually using Studentised residuals in standardised normal probability (P-P) plots. Last, homoscedasticity (constant variance of residual terms) was examined using scatterplots with a y-line at 0.

7.13 HYPOTHESIS TESTING: RESEARCH QUESTION 4

It was originally hypothesised that baseline illness belief domains would contribute significantly to the variance in follow-up markers of post-stroke recovery (HRQL, disability, and mood), over and above that explained by socio-demographic and clinical variables.

This was generally supported by the present findings, which are summarised in Tables 7-15 to 7-19. Results for the primary outcome, follow-up HRQL, will be considered first. Overall, the final model explained 68.9% of the variance in follow-up HRQL (EQ-5D-5L Descriptive System – Index score) ($F(19, 15) = 1.75$, $p = 0.14$). However, the model was non-statistically significant, and none of the baseline illness belief domains appeared to make a significant contribution to the final model (Table 7-15). In spite of this, regression modelling showed that baseline socio-demographic variables alone explained only 7.3% of the variance in follow-up HRQL. When baseline clinical variables were added, these explained a further 44.1% of the variance, and an additional 17.5% by including baseline illness belief domains, both of which were statistically significant additions to the model. A similar pattern also emerged for the EQ-5D-5L 'Your health today' VAS score, whereby the final model explained 59% of the variance in follow-up HRQL ($F(19, 15) = 1.14$, $p = 0.41$). Inclusion of baseline clinical variables significantly added 45.9% to the variance in follow-up HRQL, respectively, over and above baseline socio-demographic variables (Table 7-16). However, addition of illness belief domains contributed only 7.6% to the overall variance in this outcome, and this was statistically non-significant following Bonferroni correction (Table 7-16).

Table 7-15. Summary of the multiple regression results for follow-up HRQL (EQ-5D-5L Descriptive System – Index score)

Variable	Step 1: β-coefficient (95% CI)*	Step 2: β-coefficient (95% CI)*	Step 3: β-coefficient (95% CI)*	Total R^2	Change in R^2 for the step *(P-value ✕**)*	Tolerance	VIF
Socio-demographics							
+ Age	0.02 (-0.01-0.01)	-0.00 (-0.01-0.01)	-0.01 (-0.02-0.00)	0.073	0.073 *(p=0.39)*	0.93	1.08
+ Gender	-0.22 (-0.51-0.07)	0.07 (-0.28-0.43)	0.36 (-0.09-0.81)				
+ Deprivation	-0.00 (-0.04-0.04)	0.02 (-0.02-0.07)	0.02 (-0.03-0.08)				
Clinical variables							
+ Co-morbidities		0.12 (-0.13-0.37)	0.15 (-0.15-0.44)	0.514	0.441 *(p=0.009)*	0.49	2.06
+ National Institute of Health Stroke Scale score		0.01 (-0.02-0.04)	0.01 (-0.03-0.05)				
+ Baseline EQ-5D-5L Descriptive System- Index score		0.73 (0.15-1.32)	0.65 (-0.07-1.36)				
+ Baseline EQ-5D-5L 'Your health today' VAS score		0.00 (-0.01-0.01)	-0.00 (-0.01-0.01)				
+ Baseline PHQ-9 score		0.00 (-0.02-0.03)	-0.01 (-0.05-0.04)				
+ Baseline Modified Rankin Scale score		-0.00 (-0.25-0.24)	-0.10 (-0.39-0.19)				
+ Baseline Barthel Index score		-0.00 (-0.03-0.02)	0.01 (-0.03-0.04)				
+ Baseline Nottingham Extended Activities of Daily Living Scale score		-0.01 (-0.03-0.03)	0.00 (-0.03-0.04)				
Illness beliefs							
+ Identity			0.03 (-0.01-0.07)	0.689	0.175 *(p=0.003)*	0.31	3.22
+ Timeline acute-chronic			-0.01 (-0.05-0.04)				
+ Timeline cyclical			-0.02 (-0.08-0.04)				
+ Consequences			-0.00 (-0.04-0.04)				
+ Personal control			0.01 (-0.03-0.04)				
+ Treatment control			-0.07 (-0.15-0.01)				
+ Illness coherence			0.02 (-0.02-0.06)				
+ Emotional representations			-0.01 (-0.05-0.03)				

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); **: Bonferroni-adjusted significance level (p<0.02); ✕: Likelihood ratio test; CI: Confidence interval; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale; VIF: Variance inflation factor

Table 7-16. Summary of the multiple regression results for follow-up HRQL (EQ-5D-5L 'Your health today' VAS score)

Variable	Step 1: β-coefficient (95% CI)*	Step 2: β-coefficient (95% CI)*	Step 3: β-coefficient (95% CI)*	Total R^2	Change in R^2 for the step *(P-value ✖**)*	Tolerance	VIF
Socio-demographics							
+ Age	-0.03 (-0.61-0.55)	-0.36 (-1.02-0.31)	-0.26 (-1.18-0.66)	0.055	0.055 *(p=0.52)*	0.94	1.06
+ Gender	-8.13 (-28.0-11.69)	0.20 (-23.13-23.53)	12.00 (-22.05-46.07)				
+ Deprivation	0.80 (-1.88-3.49)	0.85 (-2.12-3.82)	1.57 (-2.51-5.64)				
Clinical variables							
+ Co-morbidities		-8.20 (-24.84-8.43)	-7.87 (-30.36-14.61)	0.514	0.459 *(p=0.007)***	0.48	2.09
+ National Institute of Health Stroke Scale score		0.07 (-2.10-2.23)	0.26 (-2.54-3.07)				
+ Baseline EQ-5D-5L Descriptive System- Index score		8.76 (-29.93-47.45)	8.84 (-45.91-63.57)				
+ Baseline EQ-5D-5L 'Your health today' VAS score		0.55 (0.09-1.00)	0.55 (-0.17-1.12)				
+ Baseline PHQ-9 score		-1.41 (-3.04-0.22)	-2.01 (-5.35-1.33)				
+ Baseline Modified Rankin Scale score		7.74 (-8.42-23.91)	2.08 (-19.80-23.96)				
+ Baseline Barthel Index score		0.47 (-1.55-2.49)	0.88 (-1.80-3.57)				
+ Baseline Nottingham Extended Activities of Daily Living Scale score		-0.84 (2.63-0.94)	-0.59 (-3.22-2.05)				
Illness beliefs							
+ Identity			1.22 (-1.85-4.30)	0.590	0.0763 *(p=0.04)***	0.41	2.44
+ Timeline acute-chronic			-0.17 (-3.59-3.25)				
+ Timeline cyclical			-1.05 (-5.64-3.55)				
+ Consequences			0.95 (-1.81-3.71)				
+ Personal control			0.32 (-2.02-2.67)				
+ Treatment control			-2.64 (-8.87-3.59)				
+ Illness coherence			-0.08 (-2.83-2.68)				
+ Emotional representations			-0.22 (-3.30-2.86)				

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); **: Bonferroni-adjusted significance level (p<0.02); ✖: Likelihood ratio test; CI: Confidence interval; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale; VIF: Variance inflation factor

When analysing follow-up mood, the final model explained 70.5% of the overall variance in this outcome (F (19, 14) =1.76, p=0.14). The model was again non-statistically significant, and none of the baseline illness belief domains appeared to significantly contribute to the final model (Table 7-17). However, baseline socio-demographic variables alone explained only 6.8% of the variance in follow-up mood. After baseline clinical variables were added, a further 40.9% of the variance was explained, though this was statistically non-significant. Addition of baseline illness belief domains significantly contributed 22.8% to the overall variance of the final model (Table 7-17). A similar pattern was also found for one of the disability outcomes: Barthel Index score (Table 7-18). The final model explained 68.8% of the overall variance in follow-up disability (F (19, 15) =1.74, p=0.14). However, baseline illness belief domains significantly added almost 30% to the variance in follow-up Barthel Index score, over and above the contribution by baseline socio-demographic (6.5%) and clinical variables (38.9%) (Table 7-18).

Table 7-17. Summary of the multiple regression results for follow-up mood (PHQ-9 score)

Variable	Step 1: β-coefficient (95% CI)*	Step 2: β-coefficient (95% CI)*	Step 3: β-coefficient (95% CI)*	Total R^2	Change in R^2 for the step *(P-value ✕**)*	Tolerance	VIF
Socio-demographics							
+ Age	-0.02 (-0.11-0.07)	0.04 (-0.08-0.16)	0.03 (-0.12-0.17)	0.068	0.068	0.93	1.07
+ Gender	1.51 (-1.57-4.58)	-0.60 (-4.65-3.45)	-1.43 (-6.44-3.58)		*(p=0.44)*		
+ Deprivation	-0.16 (-0.57-0.26)	-0.20 (-0.70-0.29)	-0.26 (-0.82-0.30)				
Clinical variables							
+ Co-morbidities		0.90 (-1.95-3.74)	-0.52 (-3.67-2.63)	0.477	0.409	0.52	1.91
+ National Institute of Health Stroke Scale score		-0.16 (-0.54-0.21)	-0.26 (-0.69-0.16)		*(p=0.02)*		
+ Baseline EQ-5D-5L Descriptive System- Index score		0.46 (-6.05-6.98)	-0.06 (-7.56-7.43)				
+ Baseline EQ-5D-5L 'Your health today' VAS score		-0.01 (-0.09-0.07)	0.02 (-0.06-0.09)				
+ Baseline PHQ-9 score		0.48 (0.21-0.75)§§§	0.19 (-0.27-0.65)				
+ Baseline Modified Rankin Scale score		0.73 (-1.95-3.41)	1.18 (-1.81-4.17)				
+ Baseline Barthel Index score		-0.07 (-0.41-0.27)	-0.07 (-0.43-0.30)				
+ Baseline Nottingham Extended Activities of Daily Living Scale score		-0.03 (-0.33-0.27)	-0.26 (-0.62-0.10)				
Illness beliefs							
+ Identity			-0.09 (-0.54-0.36)	0.705	0.228	0.30	3.39
+ Timeline acute-chronic			-0.30 (-0.79-0.20)		*(p=0.002)*		
+ Timeline cyclical			0.71 (0.08-1.34)				
+ Consequences			-0.05 (-0.43-0.33)				
+ Personal control			-0.16 (-0.49-0.17)				
+ Treatment control			0.59 (-0.29-1.47)				
+ Illness coherence			0.14 (-0.23-0.52)				
+ Emotional representations			0.11 (-0.37-0.58)				

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); **: Bonferroni-adjusted significance level (p<0.02); §§§: p<0.001; ✕: Likelihood ratio test; CI: Confidence interval; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale; VIF: Variance inflation factor

Table 7-18. Summary of the multiple regression results for follow-up disability (Barthel Index score)

Variable	Step 1: β-coefficient (95% CI)*	Step 2: β-coefficient (95% CI)*	Step 3: β-coefficient (95% CI)*	Total R^2	Change in R^2 for the step *(P-value ✕**)*	Tolerance	VIF
Socio-demographics							
+ Age	-0.01 (-0.07-0.04)	-0.06 (-0.13-0.01)	-0.09 (-0.17—0.01)	0.065	0.065	0.94	1.07
+ Gender	-0.25 (-2.17-1.67)	0.87 (-1.66-3.39)	0.90 (-2.12-3.91)		*(p=0.44)*		
+ Deprivation	-0.14 (-0.40-0.12)	0.02 (-0.31-0.34)	-0.07 (-0.43-0.29)				
Clinical variables							
+ Co-morbidities		1.66 (-0.14-3.47)	2.17 (0.18-4.16)	0.454	0.389	0.55	1.83
+ National Institute of Health Stroke Scale score		-0.13 (-0.36-0.10)	-0.14 (-0.39-0.11)		*(p=0.03)*		
+ Baseline EQ-5D-5L Descriptive System- Index score		1.61 (-2.58-5.41)	0.61 (-4.23-5.45)				
+ Baseline EQ-5D-5L 'Your health today' VAS score		0.00 (-0.05-0.05)	-0.01 (-0.06-0.04)				
+ Baseline PHQ-9 score		0.04 (-0.14-0.22)	0.22 (-0.08-0.51)				
+ Baseline Modified Rankin Scale score		0.20 (-1.55-1.95)	0.65 (-1.29-2.58)				
+ Baseline Barthel Index score		-0.02 (-0.24-0.20)	-0.00 (-0.24-0.23)				
+ Baseline Nottingham Extended Activities of Daily Living Scale score		0.05 (-0.15-0.24)	0.16 (-0.07-0.40)				
Illness beliefs							
+ Identity			0.10 (-0.17-0.37)	0.688	0.299	0.31	3.20
+ Timeline acute-chronic			0.04 (-0.26-0.34)		*(p=0.003)*		
+ Timeline cyclical			-0.15 (-0.55-0.26)				
+ Consequences			-0.13 (-0.38-0.11)				
+ Personal control			-0.12 (-0.32-0.09)				
+ Treatment control			-0.11 (-0.66-0.44)				
+ Illness coherence			0.08 (-0.16-0.32)				
+ Emotional representations			-0.11 (-0.38-0.16)				

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); **: Bonferroni-adjusted significance level (p<0.02); ✕: Likelihood ratio test; CI: Confidence interval; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale; VIF: Variance inflation factor

In contrast, the final model for follow-up Nottingham Extended Activities of Daily Living Scale score showed evidence of multicollinearity, whereby the Tolerance value was 0.07, and Variance Inflation Factor was 14.17. This was not the case for any of the other outcomes. The multicollinearity was further investigated by examining correlations (Spearman's rho) between the baseline and follow-up markers of recovery. It emerged from this analysis that EQ-5D-5L Descriptive System-Index; 'Your health today' VAS; and Barthel Index scores were significantly correlated with Nottingham Extended Activities of Daily Living Scale scores (ρ=0.49, $p<0.01$; ρ=0.32, $p<0.05$; and ρ=0.52, $p<0.001$, respectively). Therefore, the multiple regression analyses were re-run excluding these variables, and the resultant model showed that the problems with multicollinearity were resolved. The final model (shown in Table 7-19) explained 87.2% of the overall variance in follow-up Nottingham Extended Activities of Daily Living Scale score ($F(16, 18) = 7.69$, $p<0.001$), and this model was highly statistically significant. Again, none of the baseline illness belief domains appeared to significantly contribute to the final model (Table 7-19). However, baseline Nottingham Extended Activities of Daily Living Scale score emerged to be a statistically significant predictor of follow-up disability (Table 7-19). Baseline socio-demographic variables alone explained 14.9% of the variance in this outcome, which is larger than that found for the earlier models summarised above. Upon addition of baseline clinical variables, a further 64.9% of the variance was explained, and this was a statistically significant change in R^2. Baseline illness belief domains explained a further and significant 7.4% of the overall variance of the final model (Table 7-19).

Checks were also made for the remaining assumptions of multiple linear regression modelling, including normally distributed residuals; and homoscedasticity. The findings showed that these were generally acceptable for most of the outcomes examined. However, and importantly, a departure of residuals from normality was evident for the final follow-up EQ-5D-5L 'Your health today' VAS score model. As stated earlier in this chapter (section 7.5.2), a logarithmic transformation was attempted without fruition. In addition, heteroscedasticity (i.e., non-random residual terms) appeared to be present for the final model for follow-up Barthel Index score. In light of these findings, assumptions for multiple linear regression modelling were violated for these outcomes, meaning that the results to emerge from these models should be approached cautiously.

Table 7-19. Summary of the multiple regression results for follow-up disability (Nottingham Extended Activities of Daily Living Scale score)

Variable	Step 1: β-coefficient (95% CI)*	Step 2: β-coefficient (95% CI)*	Step 3: β-coefficient (95% CI)*	Total R^2	Change in R^2 for the step *(P-value ✕**)*	Tolerance	VIF
Socio-demographics							
+ Age	0.03 (-0.09-0.16)	-0.04 (-0.12-0.05)	-0.08 (-0.18-0.02)	0.149	0.149	0.85	1.18
+ Gender	-4.52 (8.76-(-0.29)	-1.74 (-4.79-1.30)	-0.89 (-4.61-2.83)		*(p=0.09)*		
+ Deprivation	-0.45 (-1.02-0.12)	-0.20 (-0.59-0.19)	-0.14 (-0.57-0.30)				
Clinical variables							
+ Co-morbidities		2.26 (0.07-4.46)	3.26 (0.75-5.76)	0.798	0.649	0.20	4.96
+ National Institute of Health Stroke Scale score		-0.34 (-0.59-(-0.08)	-0.31 (-0.58-(-0.05)		*(p=0.000)*		
+ Baseline Modified Rankin Scale score		-0.01 (-0.22-0.21)	0.15 (-0.22-0.52)				
+ Baseline PHQ-9 score		1.85 (-0.33-4.04)	1.62 (-0.84-4.09)				
+ Baseline Nottingham Extended Activities of Daily Living Scale score		0.48 (0.30-0.67)§§§	0.51 (0.26-0.77) §§§				
Illness beliefs							
+ Identity			-0.09 (-0.43-0.26)	0.872	0.074	0.13	7.83
+ Timeline acute-chronic			0.13 (-0.24-0.50)		*(p=0.000)*		
+ Timeline cyclical			-0.14 (-0.66-0.37)				
+ Consequences			0.06 (-0.23-0.34)				
+ Personal control			0.05 (-0.20-0.31)				
+ Treatment control			-0.69 (-1.38-0.01)				
+ Illness coherence			-0.07 (-0.37-0.23)				
+ Emotional representations			-0.21 (-0.50-0.08)				

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); §§§: p<0.001; ✕: Likelihood ratio test; CI: Confidence interval; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale; VIF: Variance inflation factor

7.14 APPROACH TO ANALYSIS: RESEARCH QUESTION 5A

Associations were explored to address Research Question 5A: Are there inter-correlations between baseline illness belief domains, and baseline and follow-up illness belief domains?

These relationships were examined using Spearman's rho correlation (ρ).

7.15 HYPOTHESIS TESTING: RESEARCH QUESTION 5A

It was originally hypothesised that baseline illness belief domains, and baseline and follow-up illness belief domains would be inter-correlated.

This was supported in part by the present findings, which are summarised in Tables 7-20 and 7-21. These showed that several baseline illness belief domains (identity, timeline-cyclical, consequences and emotional representations) were inter-correlated, with highly significant effect sizes ranging from 0.54 to 0.69 emerging at baseline, and 0.51 to 0.66 with illness belief domains at follow-up.

Table 7-20. Inter-correlations between baseline illness belief domains (N=41)

	Identity	Timeline acute-chronic	Timeline-cyclical	Consequences	Personal control	Treatment control	Illness coherence	Emotional representations
Identity								
Timeline acute-chronic	0.48 p<0.01							
Timeline-cyclical	0.62 p<0.001	0.22 p=0.17						
Consequences	0.66 p<0.001	0.44 p<0.01	0.33 p<0.05					
Personal control	0.14 p=0.38	-0.12 p=0.46	0.16 p=0.33	0.07 p=0.68				
Treatment control	-0.08 p=0.64	-0.12 p=0.46	-0.07 p=0.68	0.02 p=0.90	0.30 p=0.06			
Illness coherence	0.09 p=0.59	0.03 p=0.85	-0.09 p=0.59	0.07 p=0.66	0.24 p=0.13	0.14 p=0.37		
Emotional representations	0.61 p<0.001	0.33 p<0.05	0.54 p<0.001	0.69 p<0.001	-0.06 p=0.70	-0.23 p=0.16	-0.07 p=0.65	

Table 7-21. Inter-correlations between baseline and follow-up illness belief domains (N=41)

	Identity	Timeline acute-chronic	Timeline-cyclical	Consequences	Personal control	Treatment control	Illness coherence	Emotional representations
Identity								
Timeline acute-chronic	0.47 p<0.01							
Timeline-cyclical	0.62 p<0.001	0.26 p=0.10						
Consequences	0.66 p<0.001	0.45 p<0.01	0.35 p<0.05					
Personal control	0.19 p=0.23	-0.19 p=0.22	0.12 p=0.45	0.06 p=0.73				
Treatment control	-0.04 p=0.78	-0.17 p=0.30	-0.12 p=0.47	-0.00 p=0.99	0.30 p=0.05			
Illness coherence	0.17 p=0.28	0.00 p=0.99	-0.09 p=0.57	0.11 p=0.49	0.30 p=0.06	0.11 p=0.48		
Emotional representations	0.56 p<0.001	0.27 p=0.09	0.51 p<0.001	0.63 p<0.001	-0.07 p=0.65	-0.16 p=0.30	-0.00 p=0.98	

7.16 APPROACH TO ANALYSIS: RESEARCH QUESTION 5B

Cluster analysis was conducted to address Research Question 5B: Can clusters of stroke survivors be identified according to illness belief schema?

Clatworthy, Hankins et al. (2007) have argued that illness beliefs research has traditionally analysed IPQ and IPQ-R data using individual domains of illness beliefs. This may be necessary in examining how best to measure illness beliefs (Clatworthy, Hankins et al. 2007). However, Chapters 2 and 3 emphasised that, according to the CSM theory, people do not usually hold illness beliefs in isolation, rather they form part of an overall schema (Leventhal, Meyer et al. 1980). Therefore, analysis methods that take this into consideration may be more appropriate for these data (Clatworthy, Hankins et al. 2007). To this end, it has been advocated that cluster analysis may be a valuable alternative method for analysing illness beliefs data (Clatworthy, Hankins et al. 2007).

In particular, hierarchical cluster analysis has thus far been considered optimal, and has been used most frequently, for illness beliefs research (Clatworthy, Hankins et al. 2007, Medley, Powell et al. 2010, Skinner, Carey et al. 2011, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, McCorry, Dempster et al. 2013, Harrison, Robertson et al. 2014, Snell, Surgenor et al. 2014).

7.16.1 Hierarchical Cluster Analysis

Hierarchical cluster analysis (agglomerative or divisive) segments data into a particular number of clusters over a series of partitions, rather than

through a single step (Scheibler and Schneider 1985). Agglomerative approaches have been favoured by illness beliefs research (Clatworthy, Hankins et al. 2007). These consider each object to represent an individual cluster, which are fused together sequentially according to how similar they are (Everitt, Landau et al. 2011). This process continues until all of the objects have membership to a single cluster, the results of which are illustrated by a dendrogram (Everitt, Landau et al. 2011). This is a hierarchical tree-like structure that displays the distance at which objects and clusters are combined (Everitt, Landau et al. 2011).

Hierarchical cluster analysis, using the Euclidean distance (e.g., the actual distance between two points if measured with a ruler) as a proximity measure to determine the dissimilarity (or distance) between pairs of objects (Everitt, Landau et al. 2011) was adopted for the present analysis. Clusters were combined using Ward's method, which generates clusters to minimise the within-cluster variability and is a popular linkage rule (Everitt, Landau et al. 2011). In particular, Ward's method has been recommended by Clatworthy, Hankins et al. (2007) as the optimal approach to be used in illness beliefs research.

7.16.1.1 Partitioning Methods

The hierarchical agglomerative analysis described above identifies the centroids (middle of the cluster) and number of clusters, though there are specific non-hierarchical methods that can be utilised to partition n objects into these 'k' clusters, where each object belongs to the nearest cluster (Everitt,

Landau et al. 2011). K-means is the recommended approach for illness beliefs research (Clatworthy, Hankins et al. 2007). This algorithm works by calculating the centroid (mean) of each cluster and relocating an object to a particular group from which it is the least dissimilar, according to a specific proximity measure (e.g., the Euclidean distance) (Everitt, Landau et al. 2011). The centroid is then re-evaluated for another data point, and the above process continues until all objects have been partitioned (Everitt, Landau et al. 2011).

K-means is, however, not well suited to data that are non-normal (Everitt, Landau et al. 2011), such as the highly skewed distributions that are characteristic of the present study. Therefore, an alternative approach (K-medians) has been recommended (Everitt, Landau et al. 2011). This uses the median to calculate mediods (equivalent to centroids) and the squared Euclidean distance as a proximity measure, which places greater importance on objects that are large distances apart (Everitt, Landau et al. 2011).

7.16.1.2 Standardisation

Standardisation of illness beliefs data is considered necessary prior to conducting cluster analysis (Clatworthy, Hankins et al. 2007). This is to ensure that scores across all of the IPQ-R sub-scales are given equal weight in clustering (Clatworthy, Hankins et al. 2007, Everitt, Landau et al. 2011). This would not be the case if the data were not standardised, because the identity sub-scale of the IPQ-R is measured on a different scale (yes/no) to that of the remaining scales (strongly agree to strongly disagree). Therefore, consistent with Clatworthy, Hankins et al. (2007) and further cluster analysis guidelines

(Everitt, Landau et al. 2011), all scores were standardised to Z-scores prior to undertaking clustering.

7.16.1.3 Descriptive Analysis

Following cluster analysis, descriptive statistics were computed for selected variables to examine the baseline characteristics of the people that comprised each group. This followed the same procedure as that previously described for the earlier descriptive analysis in section 7.4.3. Where normality could be assumed, a series of one-way Analysis of Variance (ANOVA) with post-hoc comparisons using Scheffe's method were performed to examine whether any of the continuous variables differed significantly between clusters, and if so, where these differences were. Bartlett's test of sphericity was used to test for homogeneity of variances (homoscedasticity). For non-normal variables, non-parametric ANOVA (Kruskal Wallis) was utilised instead.

7.17 RESULTS: RESEARCH QUESTION 5B

Three clusters emerged from the findings of the hierarchical cluster analysis, which were determined from examination of the dendrogram (Figure 7-13). Specific illness belief schemas were characteristic to each cluster, and these are summarised in Table 7-22.

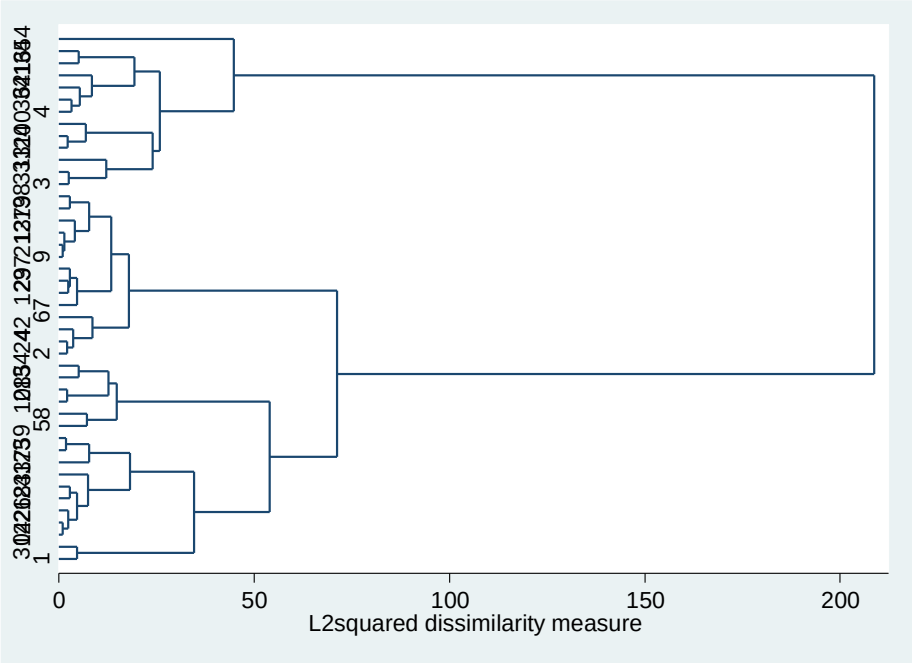


Figure 7-13. Dendrogram to illustrate emergent clusters

As can be seen from Table 7-22, the majority of participants in Cluster 1 perceived that their stroke was a chronic condition, with fluctuating effects, and associated with a lot of symptoms, serious consequences and considerable distress. In contrast, participants in Cluster 3 perceived that their stroke was an acute condition with effects that did not fluctuate, and that was associated with few symptoms, less serious consequences, and little distress. Differences between clusters with regard to personal or treatment control, and illness coherence beliefs were statistically non-significant, and median scores for these domains suggested similarities amongst all participants irrespective of cluster membership.

Table 7-22. Summary of illness belief schema for each cluster

	N Median belief scores (IQR)				
Baseline illness belief domains	**Cluster 1 N=13**	**Cluster 2 N=11**	**Cluster 3 N=20**	**Chi-squared (DF)**	**P-value***
Identity	14 (5)	9 (3)	4 (5)	29.0 (2)	<.001
Timeline acute-chronic	18 (6)	17 (8)	12 (3.5)	16.5 (2)	<.001
Timeline-cyclical	16 (2)	8 (0)	8 (2)	30.2 (2)	<.001
Consequences	37 (4)	34 (8)	25 (4)	30.1 (2)	<.001
Personal control	34 (5)	32 (2)	34 (5)	3.7 (2)	0.16
Treatment control	18 (3)	20 (1)	20 (2)	4.1 (2)	0.13
Illness coherence	19 (4)	20 (2)	18 (6)	1.8 (2)	0.41
Emotional representations	32 (7)	24 (10)	22 (5)	19.8 (2)	<.001

Symbols and abbreviations: *: Bonferroni adjusted significance level (p<0.002); DF: Degrees of freedom; IQR: Interquartile range

In accordance with participants' illness belief schema, clusters were named as follows: Cluster 1 – 'Low Adjusters;' Cluster 2 – 'Moderate Adjusters;' and Cluster 3 – 'High Adjusters.' The demographic and clinical characteristics of participants within each cluster are summarised in Table 7-23. Clusters did not differ significantly in relation to any of these variables. However, there were several trends. First, 'High Adjusters' were older (mean=72.1, SD=15.1) than 'Moderate Adjusters' (mean=69.5, SD=12.3) or 'Low Adjusters' (mean=57.2, SD=13.5). Second, 'High Adjusters' were more likely to be retired; university educated; diagnosed with hypertension; have co-morbidities; a history of stroke or transient ischaemic attack; and a first-degree relative who has had a stroke. Third, 'Low Adjusters' were more likely to have had a first stroke of greater severity (though generally strokes were mild for the present population); high BMI; and a history of depression or anxiety disorders.

Table 7-23. Summary of the baseline characteristics for each cluster

	N Mean (SD)/Frequency (%), unless otherwise stated				
Demographics	**'Low adjusters' N=13**	**'Moderate adjusters' N=11**	**'High adjusters' N=20**	**F (DF), unless otherwise stated**	**P-value***
Age	57.2 (13.5)	69.5 (12.3)	72.1 (15.1)	4.66 (2)	<0.05
Sex-*Male*	11 (84.6%)	7 (63.6%)	12 (60.0%)	Chi^2=2.34 (DF=2)	0.31
University or higher education	2 (16.7%)	3 (27.3%)	4 (21.1%)	Chi^2=0.39 (DF=2)	0.82
Employment status					
Unemployed	4 (30.8%)	1 (9.1%)	1 (5.0%)	Chi^2=11.39 (DF=8)	0.12
Employed full-time	3 (23.1%)	1 (9.1%)	2 (10.0%)		
Employed part-time	1 (7.7%)	2 (18.2%)	0 (0%)		
Self-employed	1 (7.7%)	1 (9.1%)	3 (15.0%)		
Retired	4 (30.8%)	6 (54.6%)	14 (70.0%)		
Index of Multiple Deprivation rank	Median=16401 (IQR=17730)	Median=21243 (IQR=19183)	Median=20835 (IQR=15764)	Chi^2=1.16 (DF=2)	0.56
Index of Multiple Deprivation decile	Median=5 (IQR=6)	Median=7 (IQR=6)	Median=7 (IQR=5.5)	Chi^2=1.31 (DF=2)	0.52
National Institute of Health Stroke Scale score	Median=5 (IQR=10)	Median=2 (IQR=1)	Median=2 (IQR=4)	Chi^2=6.15 (DF=2)	<0.05
Pre-morbid Modified Rankin Scale score	Median=0 (IQR=0)	Median=0 (IQR=1)	Median=0 (IQR=0)	Chi^2=0.73 (DF=2)	0.69
Clinical data					
Systolic blood pressure (mm/HG)	137.7 (21.0)	157.4 (44.0)	150 (35.9)	1.01	0.37
Diastolic blood pressure (mm/HG)	71.7 (18.3)	84.6 (22.2)	80.5 (21.5)	1.26	0.29
Blood glucose (mmol/L)	Median=6.4 (IQR=5.6)	Median=7.3 (IQR=3.3)	Median=6.3 (IQR=2)	Chi^2=0.82 (DF=2)	0.67

Total cholesterol (mmol/L)	4.7 (1.4)	4.7 (1.0)	4.7 (1.5)	0.00	0.99
HDL cholesterol (mmol/L)	Median=1.1 (IQR=0.5)	Median=1.2 (IQR=0.4)	Median=1.4 (IQR=0.70)	Chi^2=1.20 (DF=2)	0.55
LDL cholesterol (mmol/L)	Median=2.2 (IQR=1.5)	Median=3.05 (IQR=1.5)	Median=2.35 (IQR=2.1)	Chi^2=2.46 (DF=2)	0.29
BMI (kg/m^2)	Median=29 (IQR=10.3)	Median=24 (IQR=6)	Median=25 (IQR=5)	Chi^2=1.33 (DF=2)	0.52
Family history-first degree relative (mother, father, sibling)					
History of stroke	3 (23.1%)	4 (36.4%)	8 (40.0%)	Chi^2=1.04 (DF=2)	0.60
History of TIA	1 (7.7%)	1 (9.1%)	1 (5.0%)	Chi^2=0.21 (DF=2)	0.90
Medical history**					
First stroke	3 (23.1%)	3 (27.3%)	3 (15.0%)	Chi^2=0.73 (DF=2)	0.70
Previous TIA	1 (7.7%)	2 (18.2%)	3 (15.0%)	Chi^2=0.61 (DF=2)	0.74
History of hypertension	8 (61.5%)	4 (36.4%)	13 (65.0%)	Chi^2=2.54 (DF=2)	0.28
History of atrial fibrillation	1 (7.7%)	5 (45.5%)	2 (10.0%)	Chi^2=7.36 (DF=2)	<0.05
History of high cholesterol	6 (46.2%)	6 (54.6%)	8 (40.0%)	Chi^2=0.61 (DF=2)	0.74
History of depression	6 (46.2%)	2 (19.2%)	2 (10.0%)	Chi^2=6.98 (DF=4)	0.14
History of anxiety disorders	4 (30.8%)	1 (9.1%)	3 (15.0%)	Chi^2=2.13 (DF=2)	0.34
Previous therapy	8 (61.5%)	4 (36.4%)	9 (45.0%)	Chi^2=1.62 (DF=2)	0.44

Co-morbidities	9 (69.2%)	7 (63.6%)	16 (80.0%)	Chi^2=1.07 (DF=2)	0.59
Lifestyle					
Current smoking status**					
Never smoked	4 (30.8%)	5 (45.5%)	9 (45.0%)	Chi^2=1.95 (DF=4)	0.75
Ex-smoker	8 (61.5%)	6 (54.6%)	9 (45.0%)		
Current smoker	1 (7.7%)	0 (0%)	2 (10.0%)		
Number smoked daily	Median=20 (IQR=10)	Median=17.5 (IQR=17.5)	Median=7.5(IQR=10)	Chi^2=3.64 (DF=2)	0.16
Current alcohol intake (units/week)¥	Median=6 (IQR=10.2)	Median=4 (IQR=21)	Median=0.75(IQR=14)	Chi^2=1.04 (DF=2)	0.59
Units of beer	Median=3 (IQR=11.2)	Median=0.25 (IQR=7)	Median=0 (IQR=3)	Chi^2=2.79 (DF=2)	0.25
Units of wine	Median=0 (IQR=0)	Median=0.25 (IQR=4)	Median=0 (IQR=1.25)	Chi^2=4.15 (DF=2)	0.13
Units of spirits	Median=0 (IQR=0)	Median=0 (IQR=0)	Median=0 (IQR=0)	Chi^2=0.61 (DF=2)	0.74
30-minutes of exercise x4 times a week	10 (76.9%)	7 (63.6%)	17 (85.0%)	Chi^2=1.85 (DF=2)	0.40
Low-fat diet	8 (61.5%)	6 (54.5%)	9 (45.0%)	Chi^2=0.89 (DF=2)	0.64
Low-sugar diet	10 (76.9%)	7 (63.6%)	10 (50.0%)	Chi^2=2.44 (DF=2)	0.30
Low-salt diet	10 (76.9%)	6 (60.0%)	12 (60.0%)	Chi^2=1.14 (DF=2)	0.57

Symbols and abbreviations: *: Bonferroni adjusted significance level (p<0.002); **: Self-reported; ¥: Extracted from medical records; BMI: Body Mass Index; DF: Degrees of freedom; IQR: Interquartile range; HDL: High Density Lipoprotein; LDL; Low Density Lipoprotein; SD: Standard deviation

7.18 APPROACH TO ANALYSIS 5C: RESEARCH QUESTION 5C

After obtaining clusters that suitably represented the sample, further analyses were conducted to address Research Question 5C: Is baseline group membership to a particular cluster associated with follow-up markers of recovery three-months post-stroke (HRQL, disability and mood)?

In order to examine this, further Kruskal Wallis tests were carried out.

7.19 HYPOTHESIS TESTING: RESEARCH QUESTION 5C

It was originally hypothesised that participants grouped in the 'Low Adjusters' clusters at baseline would fare less well with their recovery three-months post-stroke than 'High Adjusters.' However, the hypothesis was not supported by the present data. Statistically significant relationships (following Bonferroni correction) between clusters did not emerge for any of the follow-up markers of post-stroke recovery (Table 7-24). However, there were trends in relation to specific aspects of recovery after stroke. Most notably, 'High Adjusters' had greater HRQL, better mood and lower disability (Modified Rankin Scale score) at follow-up compared to participants in the other clusters.

Table 7-24. Relationships between baseline clusters and follow-up markers of post-stroke recovery

	N Median (IQR)				
	'Low adjusters' N=13	**'Moderate adjusters' N=11**	**'High adjusters' N=20**	**Chi-squared (DF)**	**P-value***
HRQL					
EQ-5D-5L Index score	0.68 (0.18)	0.77 (0.20)	0.88 (0.40)	5.5 (2)	0.06
EQ-5D-5L 'Your health today' VAS score	60 (20)	70 (20)	75 (20)	2.7 (2)	0.26
Mood					
PHQ-9 Total depressive symptomatology score	6 (5)	4 (5)	3 (5)	8.2 (2)	<.05
Disability					
Modified Rankin Scale score	2 (1)	2 (1)	1 (1)	8.4 (2)	<.05
Barthel Index score	20 (1)	20 (0)	20 (0)	0.9 (2)	0.64
Nottingham Extended Activities of Daily Living Scale score	15 (9)	17 (7)	17 (4)	1.8 (2)	0.41

Symbols and abbreviations: *: Bonferroni adjusted significance level (p<0.002); DF: Degrees of freedom; HRQL: Health-related quality of life; IQR: Interquartile range; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale

7.20 DISCUSSION

7.20.1 Summary of Key Findings

This chapter reported on a longitudinal observational study of stroke survivors in the acute phase of stroke (≤three-months post-stroke). This was conducted to examine whether the CSM provides a useful framework for understanding recovery after stroke, including HRQL, disability and mood. More specifically, the study first addressed whether illness belief domains and markers of recovery at baseline differed significantly from those at follow-up three-months post-stroke. Second, whether baseline illness belief domains were associated with markers of recovery at baseline and follow-up. Third, whether

baseline mood and coping (three-months post-stroke medication adherence) mediated predictive associations between baseline domains of illness beliefs and follow-up indices of post-stroke recovery. Fourth, the study examined whether baseline illness belief domains explained additional variance in three-month post-stroke markers of recovery (HRQL, disability, and mood), over and above that explained by socio-demographic (e.g., age, gender, and deprivation) and clinical variables (e.g., co-morbidities, stroke severity, and baseline indices of recovery). Finally, the study examined whether inter-correlations between baseline illness belief domains, and baseline and follow-up illness belief domains existed. Relatedly, whether survivors could be clustered according to illness belief schema, and if particular clusters were associated with follow-up markers of recovery after stroke.

Various statistical approaches were utilised to address these questions, from which some interesting findings emerged. To begin with, it was found that at baseline participants endorsed few symptoms of their stroke, and these significantly lessened over time. In addition, participants' disability (Barthel Index score) showed significant improvement over time. Patients who perceived their stroke to be associated with a lot of symptoms, fluctuating effects, serious consequences, and considerable distress at baseline also reported worse baseline mood. Those who believed in episodic effects of their stroke and considerable distress at baseline also reported worse mood at follow-up. Further, it emerged that the prediction of follow-up mood by baseline perceptions of fluctuating effects of stroke and considerable distress, was significantly mediated by baseline mood rather than coping. The present study also showed

that illness belief domains significantly accounted for between 7.4 and 29.9% of the variance in HRQL (EQ-5D-5L Descriptive System scores), disability (Barthel Index and Nottingham Extended Activities of Daily Living scores), and mood, after controlling for clinical and socio-demographic factors. However, the most influential were still the clinical variables (e.g., baseline co-morbidities, stroke severity, and indices of recovery), which explained between 38.9 and 64.9% of the variance in these outcomes. Finally, the study demonstrated that several baseline illness belief domains (identity, timeline-cyclical, consequences and emotional representations) were highly significantly inter-correlated at baseline and with follow-up illness belief domains. Relatedly, three clusters of stroke survivors emerged: 'Low Adjusters;' 'Moderate Adjusters;' and 'High Adjusters.' In contrast to 'High Adjusters', 'Low Adjusters' were participants who perceived their stroke to be chronic, with fluctuating effects, and associated with a lot of symptoms, serious consequences and considerable distress. Cluster membership was not found to be significantly related to follow-up markers of post-stroke recovery. However, there were trends to suggest that 'Low Adjusters' fared worse in their post-stroke recovery (e.g., worse HRQL and mood, and greater disability) than 'High Adjusters.'

7.20.2 Comparison of Findings with Prior Literature

7.20.2.1 Research Questions 1 and 2: Associations between Illness Belief Domains and Markers of Post-Stroke Recovery

These findings were broadly consistent with prior research in this area. For instance, the CSM studies critically reviewed in section 4.2 (Chapter 4). These examined associations of illness beliefs with mood (Joice, Bonetti et

al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012); and disability after stroke (Johnston, Morrison et al. 1999). The studies found similar illness belief domains to those that emerged in the present study to be implicated in worse post-stroke mood and disability; for example, illness identity, chronicity, cyclical timeline perceptions, and emotional representations. The effect sizes were also analogous, showing moderately strong relationships. In addition, the present findings were consistent with the wider literature on the CSM (reviewed in section 4.4, Chapter 4), where associations of illness belief domains with different aspects of recovery that are pertinent to stroke survivors (including, HRQL and disability) were examined (e.g., Dalbeth, Petrie et al. (2011); Damman, Liu et al. (2014); Hill, Dziedzic et al. (2007); Moss-Morris and Chalder (2003); Graves, Scott et al. (2009);Scharloo, Kaptein et al. (2007); Rochelle and Fidler (2013); Borge, Moum et al. (2014); Mohammed, Nagla et al. (2015); Spain, Tubridy et al. (2007); and Alsén, Brink et al. (2010)). Further, the findings supported the premise by Bijsterbosch, Scharloo et al. (2009), which suggested that illness beliefs change over time. These results also support earlier discussions in Chapter 1 (section 1.3) around post-stroke recovery being a journey, where improvements in functioning and psychological adjustment develop over time (Ch'Ng, French et al. 2008, Intercollegiate Stroke Working Party 2012, Lincoln, Kneebone et al. 2012, Kwakkel and Kollen 2013, Stinear, Ackerley et al. 2013). In the present study though, only the identity beliefs domain and disability (Barthel Index score) showed significant improvements amongst stroke survivors between baseline and follow-up time-points. This pattern was not evident for the remainder of illness belief domains, or markers of recovery

(including, mood). However, this could be explained by methodological issues that were salient in this PhD research; for example, low statistical power to detect significant effects. These will be considered in detail later in this chapter when discussing the limitations of this study (section 7.20.4).

In contrast, the findings reported in this chapter were not comparable to several of the remaining papers examining the CSM and stroke, reviewed in section 4.2 (Chapter 4). For example, Phillips, Diefenbach et al. (2015) and Sjölander, Eriksson et al. (2013) demonstrated a role for weak treatment control beliefs in predicting medication non-adherence. However, medication adherence was not the primary outcome of interest in the present study. Therefore, it may be that beliefs about the effectiveness of treatment in managing the effects of stroke are not pertinent to survivors in their post-stroke recovery (e.g., HRQL, disability and mood). This should be investigated further by future research, and is discussed in Chapter 8.

7.20.2.2 Research Question 3: Multiple Mediation Analysis

With regard to the findings from the mediation analysis, similar research has not yet been undertaken to examine the mediational role of mood and/or coping in the relationship between illness belief domains and markers of post-stroke recovery. Therefore, comparisons could not be made with prior evidence. However, this section will consider these findings in relation to the CSM itself, of which the utility for stroke survivors was being examined as part of this work. This will include methodological and theoretical issues that may explain the results obtained.

7.20.2.2.1 Mediational Role of Baseline Mood

Interestingly, the mediational models that emerged in the present study only showed a mediatory role for baseline mood with specific illness belief domains and the mood aspect of recovery three-months post-stroke. First, and importantly, this added further support to the premise that an emotional pathway exists within the CSM (discussed in section 2.5, Chapter 2). However, given the literature cited previously in Chapters 3 and 4 demonstrating that illness belief domains predict several markers of recovery that are pertinent to stroke survivors (e.g., HRQL, and disability), it is surprising that mediation only occurred for the mood outcome.

This may be a true reflection of the present sample, and indeed, relationships between illness belief domains and mood amongst stroke survivors have certainly been strongly supported by several studies to date (Joice, Bonetti et al. 2003, Ford 2007, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012). However, statistical considerations (e.g., multicollinearity) should be acknowledged for their potential role in the relationships to emerge. Multicollinearity in mediation happens when the mediator is correlated with the predictor and affects the precision of the estimates (Hayes and Preacher 2010). Given that both baseline and follow-up mood in the present study were measured using the same questionnaire (the PHQ-9), multicollinearity was likely to be an issue. It has been argued though that multicollinearity is to be expected in mediation, and is an unavoidable part of the analysis (Hayes and Preacher 2010). Therefore, this problem is likely to persist regardless of the method used for measuring mood.

7.20.2.2.2 Non-Mediational Role of Coping

It was also surprising that a mediational role for coping did not emerge in the present study despite being supported by a wealth of prior research (e.g., Hagger and Orbell (2003)) (section 2.4.2, Chapter 2). However, this may have been because of the way in which coping was operationalised in this analysis, which was in terms of medication adherence and was consistent with the systematic review by Hagger and Orbell (2003). It is noteworthy though that there may have been problems with regard to this in the present study.

7.20.2.2.2.1Measurement of Coping (Medication Adherence)

Firstly, despite the Medication Adherence Report Scale being a widely used instrument, showing good reliability and validity for measuring medication adherence amongst people with various chronic conditions, the psychometric properties for stroke survivors have not been fully reported. One study where Cronbach's alpha for this instrument was reported showed comparably better internal consistency for people 12-months after stroke than what had emerged in the present study for survivors in the acute phase (α=0.36). This indicates problems with the internal consistency of the Medication Adherence Report Scale for this particular patient group, and suggests that the scale may be measuring more than one construct (multidimensional), which warrants further examination.

Importantly, the majority (almost 70%) of the present sample had self-reported co-morbidities alongside their stroke (related e.g., hypertension or unrelated to their stroke e.g., hypothyroidism), and these were likely to require

multiple oral medications that people self-administer concurrently. It has been apparent in the literature that adherence can vary according to the type of medication (e.g., oral anti-coagulants) and dosage (section 1.4, Chapter 1) (De Schryver, Van Gijn et al. 2005). However, the Medication Adherence Report Scale does not differentiate between the type of medications, measuring general medication non-adherence rather than adherence for specific medications. This was unlikely to capture the complexity of medication adherence amongst stroke survivors in the present research. Indeed, participants often asked the author during data collection to which medication the questions on the Medication Adherence Report Scale were referring. Consequently, the reliability and validity of this instrument, including amendments to the scale, should be further examined in future research. This would enhance the suitability of the instrument for stroke survivors within the acute phase who have multiple co-morbidities, and are taking several different types of medication for more than one problem related or not to stroke.

7.20.2.2.2.2Problem-Focused Versus General Coping

A further issue concerns the measurement of only one coping-specific strategy: problem-focused coping (i.e., medication adherence). Heijmans (1999) argued that coping would be best measured in behavioural terms rather than as general coping strategies. It was suggested that in order to provide an accurate picture of coping, the general coping strategies to be measured would need to be exhaustive and represent all of the key coping responses for specific problems (Heijmans 1999). However, this viewpoint does not consider the historical perspective around the importance of individual

differences in the way that people cope, which has been highlighted in the evidence (Parkes 1986, Connor-Smith and Flachsbart 2007, Carver and Connor-Smith 2010). Therefore, there is a tension in the literature with regard to this. For example, a meta-analysis has shown that personality is related to coping, and that particular traits predict specific strategies (Connor-Smith and Flachsbart 2007). Connor-Smith and Flachsbart (2007) showed that extraversion and conscientiousness predicted problem-solving and cognitive restructuring, while neuroticism predicted maladaptive coping strategies (e.g., wishful thinking, withdrawal, and emotion-focused coping). They also showed that where people were particularly stressed, personality was a stronger predictor of coping.

In addition, and as mentioned in Chapter 2 (section 2.4.2), a range of coping strategies exist (e.g., self-blame, venting emotions, and denial). However, these were not evaluated in the present study, though may be relevant to stroke survivors and affect post-stroke recovery. A systematic review of 14 studies previously examined the evidence on coping after stroke, and found conflicting results with regard to the most frequently used coping strategies in this population (Donnellan, Hevey et al. 2006). On balance, the review suggested that problem-focused and emotion-focused coping strategies were most evident amongst stroke survivors, though avoidance-type strategies were also demonstrated. The implications of this to the present research is that by measuring only one specific problem-focused coping strategy, other coping strategies that have relevance to stroke survivors were neglected, meaning that the picture of coping in this study may be incomplete.

7.20.2.2.2.2.1 Measurement of General Coping

A generic coping instrument may, therefore, have been more appropriate to be utilised in the present study. However, there is no consensus on which instrument would be optimal. Donnellan, Hevey et al. (2006) identified ten different coping instruments that have been utilised amongst stroke survivors, and indicated that the self-reported Ways of Coping Questionnaire was most common (employed by five out of 14 studies) (Folkman and Lazarus 1988). The Ways of Coping Questionnaire is based on the Transactional Model of Stress and Coping, which suggests that stress is a two-way process that depends upon the way in which an individual thinks, feels and behaves when confronted by an environmental stressor (Lazarus and Folkman 1984, Folkman, Lazarus et al. 1986). The instrument comprises 66-items assessing five dimensions of coping: problem-focused coping; detachment; wishful thinking; seeking emotional support; and focusing on the positive (Scherer, Luther et al. 1988). The questionnaire has been found to have reliability and validity for various populations, including those with neurological conditions (e.g., multiple sclerosis) (Lundqvist and Ahlström 2006), and has shown adequate internal consistency for stroke survivors (Cronbach's alpha ranging from 0.59 to 0.72) (Donnellan, Hevey et al. 2006). However, studies have tended to use shortened versions of this lengthy instrument (Donnellan, Hevey et al. 2006). A modified version for stroke has also been developed: the Ways of Coping – Cardiovascular Accident Scale, though the psychometric properties of this questionnaire have not been evaluated (Johnson and Pearson 2000).

In consequence, it is recommended that should the present work be replicated in the future, it would be beneficial to measure medication adherence, possibly using a more reliable scale for stroke survivors; and incorporate simultaneous assessment of general coping, using the Ways of Coping Questionnaire for example.

7.20.2.3 Research Question 4: Multiple Regression

The findings from the multiple regression analyses were consistent with prior literature cited in Chapter 1. For example, several studies have shown that clinical factors (e.g., stroke severity and initial impairment) explain around 50% more of the variance in post-stroke recovery, above socio-demographic variables (e.g., age and deprivation) (Sappok, Faulstich et al. 2001, Tilling, Sterne et al. 2001, Lazar and Antoniello 2008, Prabhakaran, Zarahn et al. 2008, Bushnell, Olson et al. 2011).

Importantly though, the findings from the present research indicated that illness beliefs both affect and are affected by peoples' mood after stroke, and these potentially changeable factors contribute significantly to the variability in recovery after stroke. This is consistent with the evidence on disease adjustment after stroke that was noted in Chapter 1, on which the present hypothesis were based (Parikh, Robinson et al. 1990, Gainotti, Antonucci et al. 2001, Donnellan, Hickey et al. 2010, O'Carroll, Whittaker et al. 2011). It is also key in adding to our understanding of the factors, above those that are non-modifiable, that may contribute to the remainder of variability in post-stroke recovery. Prior to the present study, this has been unexplained (Lazar and

Antoniello 2008, Lazar, Minzer et al. 2010, Gellad, Grenard et al. 2011). However, it is highly important in the context of illness beliefs research where several studies to date have shown that interventions, informed by the CSM, can both address maladaptive illness beliefs and promote behaviour change, improving adherence to self-management and other outcomes (e.g., clinical, functional, and psychosocial) amongst people with various conditions (Petrie, Cameron et al. 2002, Broadbent, Ellis et al. 2009, Keogh, Smith et al. 2011, Cunningham, Swanson et al. 2012, O'Carroll, Chambers et al. 2013).

For example, Broadbent, Ellis et al. (2009) conducted an RCT of a brief in-hospital beliefs-based intervention with 103 adults within 10-days of myocardial infarction. The intervention involved four 30-minute sessions delivered by a Health Psychologist. The first session involved an explanation of the intervention and myocardial infarction (e.g., symptoms); exploration of patients' own ideas around causes of their condition; and widening peoples' perceptions to consider other causal factors. The second session involved development of a personal action recovery plan. This involved encouraging participants to think about how causal factors were related to their health behaviours; challenge myths and misconceptions of myocardial infarction and recovery; explore ways to change behaviour, including benefits and problems; set goals; and explore the role of the carer in recovery. Session 3 was specifically focused on participants' spouses, and exploring their causal beliefs about myocardial infarction, and discussing the recovery plan, including recovery timeline; their role as carer; and concerns about returning home. Issues relating to being discharged home were considered in session 4. This included discussion

about medication benefits versus concerns; adherence to the recovery plan; and worry about recurrence. Subsequent to receiving the intervention, this study showed that participants had returned to work more quickly; changed their causal attributions about myocardial infarction; had a greater understanding of their condition; and intended more strongly to attend cardiac rehabilitation. In addition, the intervention group compared to the control (standard care) felt less anxious, exercised more and had lower healthcare utilisation.

The focus of the work by Broadbent, Ellis et al. (2009) on exploring and clarifying problematic causal beliefs may be especially important to stroke survivors given the present findings. These suggested that participants were unclear about the potential causes of their stroke. In particular, they seemed unsure about the role of established risk factors (e.g., hypertension, atrial fibrillation, and smoking), and instead endorsed factors such as ageing or chance or bad luck as the main contributors to their stroke. Further, this lack of clarity with regard to the causes of stroke persisted throughout the first three-months post-stroke.

Similar to the work by Broadbent, Ellis et al. (2009), promising findings also emerged in a further intervention study involving stroke survivors (O'Carroll, Chambers et al. 2013). O'Carroll, Chambers et al. (2013) conducted a pilot RCT involving 62 patients with a first-stroke or transient ischaemic attack. The intervention involved two sessions, delivered two-weeks apart by a trained Research Fellow. The first session involved establishing a better medication-taking routine and preparation of an individually tailored coping

plan. The second session reviewed the effectiveness of the coping plan, including barriers to following it and any necessary modifications, and elicited (through questionnaires) and challenged mistaken beliefs about the illness and/or medication. In comparison to the control group (usual care plus researcher contact), intervention participants were found to take 10% more doses of medication on schedule.

In summary, intervention studies conducted to date have demonstrated that even brief belief-based interventions can successfully modify maladaptive beliefs in people with chronic diseases, including stroke and similar acute onset conditions (e.g., myocardial infarction), to improve adherence to self-management and outcomes of recovery. Therefore, the findings from the present research support the relevance and potential benefit to stroke survivors of future studies focused on developing and piloting a brief belief-based intervention for challenging mistaken beliefs post-stroke to improve mood and other markers of recovery (e.g., HRQL and disability). Arguably, there was some evidence in the present sample that participants were already making changes to their health behaviours following stroke, particularly in relation to smoking cessation. This is promising in that it may suggest that survivors similar to those in the present study may be proactive and open to being supported to make further improvements to their lifestyle after stroke.

7.20.2.4 Research Question 5: Inter-Correlations and Cluster Analysis

The results of the analysis for inter-correlations between illness belief domains were comparable with those emerging from earlier studies, such

as Hagger and Orbell (2003) (section 2.4.2, Chapter 2). For example, Hagger and Orbell (2003) found that perceptions of a highly symptomatic illness were associated with a chronic timeline and serious consequences, and these showed significant relationships with coping strategies and illness outcomes. These interrelationships are also consistent with Leventhal's premise for the CSM around the schematic nature of illness beliefs, previously discussed in section 3.6.4.2 (Chapter 3) (Leventhal, Meyer et al. 1980, Henderson, Orbell et al. 2009).

Further, the results of the cluster analysis were broadly consistent with prior CSM research examining the association of illness belief domains collectively as part of a schema with health and behavioural outcomes in people with hypertension or traumatic brain injury (Medley, Powell et al. 2010, Skinner, Carey et al. 2011, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, McCorry, Dempster et al. 2013, Harrison, Robertson et al. 2014, Snell, Surgenor et al. 2014). Similar research has not yet been undertaken with stroke survivors. However, in accordance with this wider literature, the present study derived three clusters of patients with stroke based on their illness beliefs schema: 'Low Adjusters;' 'Moderate Adjusters;' and 'High Adjusters.' In addition, several of the illness belief domains identified for importance in the present research (e.g., identity, chronicity, and consequence beliefs, and emotional representations) were characteristic of the clusters to emerge in the other evidence to date (Medley, Powell et al. 2010, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, Snell, Surgenor et al. 2014). However, unlike two of these papers, a role for personal control did not emerge in the illness belief schema for the present

sample (Medley, Powell et al. 2010, Hsiao, Chang et al. 2012). Instead, this PhD research found that none of the clusters of stroke survivors differed significantly in terms of their perceptions about their own ability to manage their condition. Again, this may be attributable to methodological considerations that were pertinent to the present research (e.g., low statistical power), which will be considered in the section 7.20.4. In addition though, participants in the present study generally demonstrated high personal control, which may also explain these findings.

A further discrepancy with the other studies was that patients with more negative illness belief schema ('Low Adjusters') in the present research did not fare worse in their recovery after stroke compared to 'High Adjusters.' For example, Medley, Powell et al. (2010) and Snell, Surgenor et al. (2014) examined patients following traumatic brain injury, finding three meaningful clusters based on injury beliefs, self-awareness, distress and symptom burden. These studies showed that 'Low Adapters' and people with poor control beliefs or who were ambivalent, had worse coping and 6-month outcomes following injury. While 'High Adapters' and people with strong consequence beliefs and greater self-awareness ('High Salience' cluster) had greater coping and fared better in their recovery. However, there are again several methodological considerations to bear in mind with the present research that could have contributed to the findings that emerged. These will be discussed later in this chapter (section 7.20.4).

7.20.3 Clinical Implications

On balance, the results from the present study may have important clinical implications, particularly in relation to early psychological intervention amongst stroke survivors in the acute phase. To reiterate, earlier findings from the mediation analysis further emphasised an already recognised need to identify patients with low mood early after stroke. In particular, they showed that psychological adjustment three-months after stroke is affected by specific maladaptive illness beliefs (timeline-cyclical and emotional representations). This was found even where stroke was less severe and depressive symptomatology immediately post-stroke was mild. The findings from the multiple regression analysis then highlighted that illness belief domains significantly accounted for unique variance in markers of post-stroke recovery, after controlling for clinical and socio-demographic factors. Importantly, these psychological variables (illness beliefs) are modifiable. Findings from recent belief-based intervention studies suggested that there is the potential for modifying maladaptive illness beliefs following stroke to improve mood and other aspects of recovery (e.g., HRQL and disability). Further, the results from the cluster analysis demonstrated that there may be a specific type of stroke survivor to benefit most from receiving a belief-based intervention. Grouping people using cluster analysis can establish the types of illness beliefs that particular groups (e.g., well versus poorly-adjusted stroke survivors) may hold in a schema. Most importantly, these groupings can identify which people are most likely to struggle after stroke, cope poorly, and have worse outcomes. This could ensure that any belief-based interventions to be developed for stroke survivors (such as those described previously in this chapter) are ideally targeted

to those people with maladaptive illness belief schema that need to be addressed (Clatworthy, Hankins et al. 2007).

7.20.4 Strengths and Limitations

A particular strength of the work reported in this chapter is that it is the first study to examine the utility of the CSM in relation to how peoples' beliefs about their stroke might affect a broad range of markers of post-stroke recovery (e.g., HRQL, disability and mood). What is also a strength of this research is that robust statistical methods were utilised, the majority of which have not been employed in prior CSM research on stroke survivors. For example, this has been the only study thus far to formally test whether mood and coping mediate predictive relationships between illness belief domains and post-stroke outcomes. A further strength has been the examination of prospective relationships, which was a recognised limitation of prior illness beliefs literature, and offers valuable information of causality that previous cross-sectional studies have not been able to provide. Finally, this study was rigorously conducted and employed established and validated instruments (e.g., EQ-5D-5L), some of which were specific to stroke (e.g., the Nottingham Extended Activities of Daily Living Scale) for measuring key markers of post-stroke recovery. In addition, outcome measures were selected according to the widely acknowledged ICF guidelines.

Despite these strengths, there were several limitations that are noteworthy. First and foremost, the sample size was relatively small. It had originally been anticipated to recruit over 100 participants to this research.

However, this study was affected by significant challenges in recruiting stroke survivors in the acute phase of stroke, which will be elaborated in the next chapter (Chapter 8). The implication of this to the present analyses was predominantly with regard to low statistical power to detect significant effects, resulting in a need to approach some of the findings with appropriate caution. In particular, the small sample size considerably limited the present multiple regression analysis. For example, the Modified Rankin Scale score disability outcome had to be excluded because of too few observations. It is generally accepted that a minimum of 10 participants per predictor in regression is appropriate (Knofczynski and Mundfrom 2008). Given that the overall sample was not large enough (>100) to conduct factor analysis of the causal belief domain (Mundfrom, Shaw et al. 2005, Chen, Lenderking et al. 2013), as recommended by the authors of the IPQ-R (Moss-Morris, Weinman et al. 2002), this also had to be excluded. Examining each causal attribution individually would have included 16 additional predictors to the model, which would have invalidated any findings to emerge. In addition, causal attributions were removed from the cluster analysis for this reason. However, in light of the interesting findings to emerge for the causal beliefs domain amongst stroke survivors in the present study, it may have been relevant to formally explore their role in post-stroke recovery.

In addition, had the sample size been large enough (>100), a more advanced method for multiple mediation could have been utilised (e.g., g formula in STATA (StataCorp LP, College Station, TX, USA)) (VanderWeele 2009, Vansteelandt 2009, Daniel, Stavola et al. 2011). In comparison to the

Baron and Kenny (1986) plus bootstrapping approach employed for the present analysis, these newly evolved techniques would have allowed for more precise estimates of the direct and indirect effects to be obtained, and a detailed examination of potential confounders (e.g., age, gender, deprivation, and National Institute of Health Stroke Scale score) of any emergent relationship(s). It has been indicated in prior literature that factors such as initial impairment and stroke severity are likely to be related to post-stroke recovery and adherence (Chapter 1). This was investigated through multiple linear regression analysis in the present research, of which the findings suggested that inclusion of these confounding variables in mediation analysis may also be worthy of investigation. In addition, limitations in the statistical tests (i.e., non-parametric) meant that these variables could not be controlled for in the post-hoc analyses conducted after clustering for illness belief schema.

There were also specific issues that emerged in relation to the sample recruited and data obtained in the present study. First, sample representativeness may be questionable. This is attributable to widely acknowledged challenges in engaging a broad range of stroke survivors in research (e.g., cognitive/communication impairment, capacity to consent etc.) As before, these issues are discussed in detail in Chapter 8. Second, the present sample was not ethnically diverse, comprising over 90% white-British ethnicity. This is partly a reflection of the ethnic make-up of the population of Nottingham City and County (UK), where this research was conducted. This region is densely populated, though consists mostly of people from a white-British ethnic background (65.4 in Nottingham and 92.6% in Nottinghamshire) (Office for

National Statistics 2011). In addition, where stroke patients of other ethnicities (e.g., south-Asian) were admitted into hospital, participation was only possible where people were English-speakers, for practical reasons. Third, it had been hoped to obtain diary/calendar data with regard to stroke survivors' engagement with, and adherence to, formal and self-directed rehabilitation. However, the majority of participants (one-third) opted not to complete the diary/calendar, for reasons such as being too busy; lack of interest; and not finding it relevant to them. Several participants also reported forgetting to fill in or return the diary/calendar. This poor uptake meant that the diary/calendar data could not be used in the present analyses. Fourth, there was a clear discrepancy between the findings for data obtained via clinical records versus self-report, where self-reported figures were higher than those obtained from clinical records. This could either suggest that participants were over-estimating their self-reported data, or that figures were being under-estimated in their clinical records, both of which are common (Hogan and Wagner 1997) (Chapter 5). This further adds to the lack of clarity in the literature around the optimal way in which to collect data from participants in research (i.e., objective versus subjective) (discussed in Chapter 5), and warrants clarification in future studies.

Additional limitations include the poor internal consistency of the treatment control sub-scale of the Stroke IPQ-R, which may explain the lack of significant findings to emerge for this domain in the present research. This will be further considered in Chapter 8. Further, the use of emotional representations rather than mood as a mediator may have been more consistent with the conceptualisation of the CSM, which involved a fear pathway (operating in

parallel to a cognitive pathway) that is formed primarily from peoples' emotional response to their illness (section 2.2, Chapter 2). It has previously been argued that peoples' emotional representations are distinct from their general mood (Leventhal, Meyer et al. 1980, Moss-Morris, Weinman et al. 2002). Mood was of particular interest to the present research, because of the role of depressive symptomatology in predicting non-adherence, and also in contributing to the variability in recovery after stroke. However, from a theoretical standpoint, it may be interesting for future research to extend the present work by examining the mediatory role of baseline emotional representations instead of general mood in the relationship of illness belief domains with post-stroke recovery.

In addition, an alternative length of follow-up could have been used that was either earlier (e.g., two-weeks) or later (e.g., six-months) after stroke. This is because psychological adjustment tends to develop over time amongst stroke survivors and can continue for many months into the recovery journey (Chapter 1). Illness beliefs also change with time. Given the lack of findings in support of this to have emerged for the majority of illness belief domains in the present research, it may have been that these changes were not adequately captured at the follow-up time-point, which was early following stroke (≤three-months).

Other limitations that have already been considered earlier in this section include, the presence of multicollinearity in mediation models from utilising the same instrument to measure one of the mediators (baseline mood)

and outcome (follow-up mood). In addition, the way in which the coping mediator was operationalised (follow-up medication adherence), and the poor internal consistency of the instrument (Medication Adherence Report Scale) used to measure this variable for the present patient group.

7.21 CONCLUSION

In summary, the present empirical work has demonstrated that the CSM is a potentially useful framework for understanding psychological adjustment in survivors during the acute phase of stroke (≤three-months post-stroke). More specifically, timeline-cyclical beliefs and emotional representations emerged to be particularly important for their relation to worse mood after stroke. In addition, the study showed that baseline mood was influential in affecting these illness belief domains, and their prediction of post-stroke psychological adjustment.

Further, the study highlighted the significance of modifiable psychological factors (i.e., illness belief domains and mood) in explaining variability in recovery after stroke, over and above that explained by non-modifiable socio-demographic and clinical variables. The most notable implication of this being around the potential to develop a brief belief-based psychological intervention to address maladaptive beliefs after stroke to improve adjustment and recovery. Importantly, the study demonstrated that stroke survivors can be grouped according to their illness belief schema, and these groupings can identify which people have maladaptive beliefs (e.g., 'Low

Adjusters'), and would benefit most from early intervention to modify these beliefs.

7.22 CHAPTER SUMMARY

The purpose of the present chapter (Chapter 7) was to report on findings from the main empirical work undertaken as part of this PhD research. The next and final chapter (Chapter 8) will weave together the emergent themes from each component of this PhD (i.e., the systematic review of Chapter 3; the qualitative study of Chapter 6; and the longitudinal observational study of Chapter 7), providing an overall discussion of the work presented in this thesis. More specifically, Chapter 8 will consider the way in which these studies have addressed the overall aims of the research; theoretical, methodological; and clinical implications; strengths and limitations of the whole work; and will present recommendations for future research.

CHAPTER 8. OVERALL DISCUSSION

8.1 CHAPTER OVERVIEW

The present chapter summarises the key results to emerge from the research conducted for this thesis, and provides a synthesis of all of the findings. In addition, Chapter 8 considers the principal theoretical, methodological, and clinical implications of this work, and proposes recommendations for future research.

8.2 SUMMARY OF THE OVERALL AIMS AND KEY FINDINGS

The overall aims of the work were to:

- Examine and synthesise the current evidence, through a systematic review and meta-analysis on the CSM in relation to physical illnesses to determine whether individual illness belief domains were important predictors of adherence to self-management in adults with acute or chronic conditions;
- Elicit views regarding an assessment method (the Stroke Illness Perception Questionnaire-Revised (Stroke IPQ-R)) that would be suitable and acceptable to a stroke population for accurately measuring peoples' beliefs in the acute phase (≤three-months post-stroke);
- Apply the CSM (utilising the Stroke IPQ-R) to a population within the acute phase of stroke, to determine whether the model provides a useful framework for understanding survivors' recovery after stroke (e.g., Health-Related Quality of Life (HRQL), disability, and mood).

To address these aims, three interrelated studies were undertaken, the findings from which are summarised below.

The systematic review and meta-analysis (Chapter 3) showed that the majority of illness belief domains outlined by the CSM significantly (albeit weakly) predicted adherence to a range of self-management behaviours. All expect for timeline-cyclical and causal beliefs, and emotional representations, which emerged to be non-statistically significant. Self-management behaviours included: attendance behaviours (e.g., doctor or therapist visits and other indices of healthcare utilisation); medication adherence; dietary behaviours; physical activity; and other disease-specific behaviours (e.g., self-monitoring of blood glucose and foot care). Pooled effect sizes ranged from 0.04 to 0.13. However, none of the predictive relationships between individual illness belief domains and adherence to self-management behaviours varied according to acute and chronic illnesses; the type of self-management behaviour; or the duration of follow-up. Where data were available, consistent statistically significant though weak prospective associations (controlling for baseline adherence to self-management) were also found for several of the domains: consequences; personal control; and treatment control. Furthermore, the meta-analysis was limited by the quality of the published data, and problems with high heterogeneity and publication bias were evident in this review.

A qualitative study (Chapter 6) was subsequently undertaken, using a combination of methods to develop a stroke-specific version of the IPQ-R (the Stroke IPQ-R). Broadly speaking, this study demonstrated that the Stroke IPQ-

R was suitable and acceptable for measuring illness beliefs in survivors during the acute phase of stroke (≤three-months post-stroke). Think-Aloud interviews showed that stroke survivors generally experienced very few problems for the vast majority of items on the Stroke IPQ-R. Where issues were noted, these mostly referred to the wording of items, specifically abstract, complex and negative wording; the response format for the identity sub-scale; and questions on the timeline-cyclical and treatment control sub-scales. Missing or insufficient Think-Aloud data generated was also noted, though this most usually reflects the absence of a problem and issues such as fatigue and forgetting. Modifications were subsequently made to the questionnaire in response to the Think-Aloud feedback. Despite the benefits of purposively sampling from a broad range of stroke survivors in this study, the focus of this research was on those in the acute phase of stroke. Therefore, the study may have been limited in the potential representativeness of the sample, which was comprised half of people within the acute phase and the other half of survivors with chronic stroke.

The Stroke IPQ-R was then utilised in a longitudinal observational study (Chapter 7), which examined whether the CSM provided a useful framework for understanding recovery after stroke amongst survivors in the acute phase. This study addressed a gap in the current literature on the CSM and stroke, which has mostly focused on post-stroke outcomes of mood and medication adherence, neglecting other pertinent markers of recovery after stroke, such as HRQL and disability. This study used various statistical approaches, and made several important findings. First, Spearman's correlations showed that patients who perceived their stroke to have fluctuating effects, and

cause considerable distress at baseline also reported significantly worse mood at follow-up. Second, multiple mediation analyses demonstrated that baseline mood mediated the significant predictive relationships between these baseline illness belief domains and mood three-months post-stroke. Third, multiple linear regression analyses showed that illness beliefs significantly accounted for between 7.4 and 29.9% of the variance in HRQL, disability and mood, after controlling for socio-demographic (e.g., age, gender, and deprivation) and clinical factors (e.g., baseline co-morbidities, stroke severity and markers of recovery). However, clinical variables remained the most influential, explaining between 38.9 and 64.9% of the variance in these outcomes. Finally, the study demonstrated that baseline illness belief domains were highly significantly inter-correlated at baseline, and with follow-up illness belief domains. In light of this, cluster analysis was carried out and showed that stroke survivors in the acute phase can be grouped according to their illness beliefs schema: 'Low Adjusters;' 'Moderate Adjusters;' and 'High Adjusters.' 'Low Adjusters' perceived their stroke to be chronic, with fluctuating effects, and associated with a lot of symptoms, serious consequences and considerable distress. Whereas, 'High Adjusters' believed that their stroke was an acute condition with effects that did not fluctuate, that was associated with few symptoms, less serious consequences, and little distress. While baseline cluster membership was not found to be significantly related to follow-up markers of post-stroke recovery, there were trends to suggest that 'Low Adjusters' fared worse in their post-stroke recovery, showing poorer HRQL and mood, and greater disability than 'High Adjusters.'

This study was, however, limited in several ways. First, the relatively small sample size constrained the statistical analyses and thus the conclusions drawn. Second, the recruitment of a representative sample of stroke survivors was challenging, meaning that participants were generally highly functioning older adults with little residual disability after stroke. However, sample size and representativeness are both common problems that have emerged in prior literature on the CSM and stroke. Third, the accurate measurement of some of the variables examined in this research was an issue. This particularly affected the treatment control domain of illness beliefs, using the Stroke IPQ-R; and adherence, including rehabilitation engagement and attendance (using a diary/calendar) and medication adherence (using the Medication Adherence Report Scale). Last, the measurement of only one specific aspect of coping (follow-up medication adherence) rather than general coping, may have provided an incomplete picture of coping that was examined in multiple mediation analyses.

The theoretical, methodological, and clinical implications of these findings will be discussed in the next section.

8.3 THEORETICAL IMPLICATIONS

8.3.1 Treatment Beliefs

The issue of treatment beliefs first appeared as a limitation in the systematic review and meta-analysis of Chapter 3, where it was suggested that although people's beliefs about their treatment are examined in the CSM, it is only in a limited way. The CSM captures a dimension of treatment, namely

peoples' beliefs about the effectiveness of their treatment in managing their condition. However, the discussion that ensued in section 3.6.4.1 of Chapter 3 drew upon the considerable body of literature that has extended the CSM by specifically considering peoples' views about medication (the Necessity-Concerns Framework) (Horne and Weinman 1999). This work suggests that people undertake a cost-benefit analysis of their medication, meaning that they weigh their own beliefs about the necessity of their medication for improving or maintaining their health against their concerns about possible adverse effects.

To date, it has been shown by several studies that patients' beliefs about their medication are an important predictor of medication adherence across a range of acute and chronic physical illnesses (Gatti, Jacobson et al. 2009, Allen LaPointe, Ou et al. 2011, Sjölander, Eriksson et al. 2013, Jamous, Sweileh et al. 2014, Sweileh, Zyoud et al. 2014). In addition, Horne, Chapman et al. (2013) recently reported on a systematic review and meta-analysis which supported this premise, showing that beliefs about the necessity of medication predicted greater medication adherence, while concern beliefs about medication predicted non-adherence in people with chronic conditions. Therefore, treatment beliefs would be important to consider alongside illness beliefs, when examining adjustment and other outcomes (e.g., recovery) in this group.

Indeed, numerous studies have demonstrated that together illness beliefs and treatment beliefs are stronger predictors of medication adherence than other factors, including socio-demographic and clinical variables (e.g., Horne and Weinman (2002); Ross, Walker et al. (2004); Mann, Ponieman et al.

(2009); and Rajpura and Nayak (2014)). In particular, illness and treatment beliefs have been found to account for 30% of the variance in medication adherence (Horne and Weinman 2002). This study also demonstrated that illness beliefs alone contributed 13% to this variability, and treatment beliefs 17%. Additional research has supported this premise, indicating that medication beliefs are stronger predictors of medication adherence than illness beliefs. For example, O'Carroll, Whittaker et al. (2011) found that increased specific concerns and low perceived benefit of medication significantly explained an additional 9.5% of the variance in medication adherence. This was compared to beliefs about the effectiveness of treatment (treatment control domain) and perceptions of chronicity, which contributed only 0.2% to the variability in this outcome. Importantly, it has been suggested by Horne and Weinman (2002) that medication beliefs may mediate the relationship of illness belief domains with medication adherence. This has not yet been formally tested in the current evidence on the CSM.

However, the current CSM literature can be criticised for the narrow elaboration of what constitutes a treatment, whereby treatment can incorporate more than simply medication-taking (e.g., lifestyle behaviour and surgery). This is an under-researched area at present, with only one study that has utilised the CSM examining what those with coronary artery disease think about their diverse treatments (medication or revascularisation surgery e.g., angioplasty or bypass procedures) (Hirani and Newman 2005). This study showed that people evaluate their treatment based on their beliefs about the ability of their treatment to cure the condition (as per the treatment control domain of the CSM), as well

as by other factors, including their perceived concerns, risks and value of treatment (consistent with the Necessity-Concerns Framework), and satisfaction with treatment. These treatment beliefs are also closely related to peoples' emotional states.

Therefore, these findings and those from the present longitudinal observational study (Chapter 7), emphasise a need to undertake a further elaboration of the CSM treatment control domain. For example, the present research showed that, despite modification, the treatment control sub-scale of the Stroke IPQ-R demonstrated poor internal consistency, with the results suggesting the presence of multidimensionality. The lack of accuracy in measurement of the treatment control domain in this study may explain why these beliefs did not emerge to significantly predict markers of post-stroke recovery, contrary to other CSM studies in stroke (e.g., Phillips, Diefenbach et al. (2015) and Sjölander, Eriksson et al. (2013)). It might have been that by measuring only one aspect of treatment beliefs (namely, perceptions about treatment effectiveness), a full picture of stroke survivors' beliefs about their treatment was not captured. In consequence, it would be important to further extend this domain, in order to provide information about peoples' beliefs about a broader range of treatments. This would provide a more complete picture of participants' treatment beliefs, which could then be examined in relation to outcomes, such as adherence and recovery.

Subsequently, the accurate measurement of this revised conceptualisation of the CSM treatment control domain is necessary. Only one

disease-specific instrument has thus far been developed and validated to assess beliefs about a broader range of treatments (the Treatments Representations Inventory), and this was undertaken specifically for patients with coronary artery disease (Hirani, Patterson et al. 2008). However, it is recommended that future researchers investigate whether this instrument is also suitable and valid for use in other patient groups. This is with a view to producing a generic measure that could be utilised widely, such as the Beliefs about Medicines Questionnaire (Horne, Weinman et al. 1999) that was developed to measure medication beliefs across various conditions. As with the IPQ-R, the developed instrument could then be adapted as appropriate to be disease-specific, and form the basis of measurement of beliefs in relation to a broader range of treatments in future studies. Further research to examine whether illness beliefs and these treatment beliefs predict adherence and recovery across a range of patient groups would be particularly beneficial in moving this field forward. As would formally evaluating whether treatment beliefs mediate these relationships.

8.3.2 Illness Belief Schema

The systematic review and meta-analysis (Chapter 3) demonstrated that when examined individually, illness beliefs weakly predicted adherence to self-management. However, Chapter 3 (section 3.6.4.2) suggested that this may be an artefact of the fact that the CSM was not investigated appropriately (i.e., the model as a whole), which is more consistent with Leventhal's original theory (Leventhal, Meyer et al. 1980, Henderson, Orbell et al. 2009). Recent studies have shown though that when illness belief domains are examined collectively as part of a schema (e.g., cluster analysis), they predict several physical,

psychological, coping, and behavioural outcomes, including adherence to self-management (Clatworthy, Hankins et al. 2007, Medley, Powell et al. 2010, Skinner, Carey et al. 2011, Hsiao, Chang et al. 2012, Lin and Heidrich 2012, McCorry, Dempster et al. 2013, Harrison, Robertson et al. 2014, Snell, Surgenor et al. 2014). In addition, stroke survivors in the present research were clustered, and there were trends to suggest that those who adjust poorly were more likely to fare worse in their post-stroke recovery (Chapter 7). Therefore, examining illness beliefs collectively in relation to adjustment (including, coping and treatment adherence) and recovery may have greater predictive power than investigating the role of each domain individually. However, none of the studies undertaken thus far have examined whether illness belief schema are more influential in predicting outcomes than individual illness belief domains. Furthermore, this could not be investigated in the present research because of statistical constraints in relation to the small sample size obtained.

There is the potential for the predictive utility of the CSM as a whole in adjustment and recovery to be evaluated in a meta-analysis, provided that papers report sufficient information about inter-relationships between individual illness belief domains and outcomes, even if as a supplementary file. In addition, future observational studies in this field would ideally ensure that they are adequately powered to specifically undertake multiple analyses on the same sample. For instance, multiple regression analyses could be undertaken using individual illness belief domains as predictors of outcomes, and separately using illness belief schemas as explanatory variables derived from cluster analysis. The beta coefficients and variability (e.g., R^2) of these models could then be

compared to determine which is more influential in predicting outcomes. It would also be interesting to examine this for acute versus chronic conditions, to determine whether there are any potential differences to emerge according to the type of illness and patient population.

8.4 METHODOLOGICAL IMPLICATIONS

There are several methodological implications to arise from the present PhD research, which were briefly mentioned in the previous section. First and foremost, a small sample size was a pertinent issue in the observational study (Chapter 7), which limited the statistical analyses undertaken. Primarily, this was due to the logistics of identifying and recruiting survivors in the acute phase of stroke who were eligible for participation in this research.

While undertaking recruitment to the observational study, it became apparent that the main stroke department from which to recruit stroke survivors in Nottingham City and County (based at [Hospital]) for studies was research saturated. There were several studies, including a major psychological study, to which patients were being recruited simultaneously alongside the present research. These studies were unfortunately focused on patients that fulfilled the same or similar eligibility criteria to the present study, meaning that there was in-house competition with regard to recruitment. Further, as the present PhD research did not meet the criteria for adoption on to the National Institute of Health Research Clinical Research Network Portfolio, the priority to recruit to this study was low. The role of the Clinical Research Network is to support the delivery of clinical research in NHS settings, across

all aspects of the research process from study development and set-up, recruitment and data collection, to study closure. In order to be eligible for this support, studies must be portfolio adopted. However, only research studies that are fully-funded by specific sources, including the National Institute of Health Research, UK or overseas governments, overseas charities, and commercial organisations (e.g., pharmaceutical companies) are eligible for adoption. While the Clinical Research Network screening team made considerable efforts to support recruitment to the present research, it still meant that many suitable patients were missed having been enrolled into other higher priority studies. Therefore, studies similar to the present research that are heavily reliant on NHS settings for recruitment should seriously consider portfolio adoption, because this would undoubtedly ensure that a sufficient number of patients as possible can be engaged.

A second issue was that there may have been a selection bias in the present research. It was apparent that people recruited to these studies were generally those who had experienced a mild first-stroke and were highly functioning, without significant cognitive or communication problems. Interestingly, this has also been the case in the other illness beliefs research conducted with stroke survivors, and was previously highlighted as a limitation of this literature (section 4.2.3, Chapter 4). This is likely to be because of several important reasons. To begin with, stroke is a notoriously difficult area from which to recruit participants for research, and in particular, people within the acute phase are a hard to reach group (Newington and Metcalfe 2014). This is commonly because post-stroke impairments (e.g., paralysis, perceptual

difficulties, and impaired cognition) affect peoples' ability to provide informed consent or engage with often complex studies (Newington and Metcalfe 2014). Relatedly, studies examining illness belief domains are naturally complicated because they involve asking people several (often detailed) questions about what they think and feel about their condition. This may be too demanding for, or inaccessible to, those with a more severe stroke and significant post-stroke impairments. Therefore, there is a need for future studies in this area to carefully consider alternative and novel ways to elicit peoples' perceptions about their stroke that may be more appropriate to participants with complex needs.

One approach that could provide a promising framework is 'Talking Mats' (Murphy, Gray et al. 2010). These are a low-technology and inexpensive communication framework developed by the University of Stirling to support people with communication problems to express their views about different topics, including: activities, relationships, and self-care. The framework comprises three sets of picture symbols: topics, involving pictures symbolising the particular issue to be discussed; options, including images specifically related to each topic (e.g., listening to music, visiting friends etc.); and a visual scale for participants to indicate their feelings about each topic and option (e.g., happy, unsure, unhappy). The Talking Mats approach involves asking participants, using open-ended questions, about a particular topic where people are given each option one by one and time to think about how they feel towards it, and then by placing a symbol beneath the appropriate symbol on the visual scale, they can indicate their feelings. The feasibility of using Talking Mats for discussion of various topics, including activities, people, environment, self,

QOL and decision-making, has previously been demonstrated for several groups with complex needs, such as: stroke survivors; people with aphasia; learning disabilities; or dementia (Murphy 2000, Murphy, Tester et al. 2005, Murphy, Gray et al. 2007, Murphy, Gray et al. 2010). To elaborate, one study showed that Talking Mats were helpful in understanding the types of activities that frail, elderly participants with a range of conditions liked or disliked (Murphy, Tester et al. 2005). For example, one respondent with dementia was able to communicate through Talking Mats that they preferred going on bus trips rather than travelling abroad. Similarly, Talking Mats were found to be more effective than both unstructured or structured conversations in supporting people with dementia to express their views (Murphy, Gray et al. 2010). For instance, Talking Mats were associated with significantly better performance in several indicators of communication effectiveness, including: participant and researcher understanding, engagement and keeping on-track, with minimal instances of perseverative behaviour and distraction.

Presently though, the feasibility of this approach has not been examined in relation to what people believe about their illness, though this would be particularly relevant to examine for illness beliefs research. It may enable studies in this field to broaden their eligibility criteria, and engage people with more severe strokes, and cognitive and/or communication impairments, groups which have thus far been neglected.

Finally, there were issues relating to the suitability of current approaches for accurately measuring illness belief domains and some of the

present outcomes (specifically, HRQL and adherence/engagement) amongst survivors in the acute phase of stroke. For example, what emerged from the qualitative component of this research (reported in Chapter 6) was a clear need to develop measurement instruments that are specific to the requirements of stroke survivors. This was attempted with the development of the Stroke IPQ-R. However, in spite of comprehensive adaptation, it was found in Chapter 7 that some aspects of this instrument (e.g., the treatment control sub-scale) still emerged to be problematic for stroke survivors in the acute phase. This emphasises that further development, over and above that conducted in the present work, specifically in relation to the treatment control sub-scale (as noted in section 8.3.1 of this chapter), is necessary to ensure suitability of this instrument for measuring illness beliefs in this and other patient groups in the future.

Similarly, another instruments employed in the observational study showed poor internal consistency for this group (reported in Chapter 7The five-item Medication Adherence Report Scale (Horne and Weinman 1999, Horne 2004) was chosen to be employed in the present research again because of the brevity of its' completion, and psychometric properties for people with chronic conditions. However, the present findings of poor internal consistency suggested that the Medication Adherence Report Scale may be multidimensional, and highlighted a need for further development of this instrument, at least in the context of stroke and in people with multiple co-morbidities, who often take several medications for different problems. Importantly, adherence can vary according to the type and dosage of tablets (De Schryver, Van Gijn et al. 2005).

This suggests that it would be necessary to develop instruments that can differentiate between the types of medications taken, and thus measure adherence to specific medications, as opposed to general medication non-adherence, which is what is assessed by the Medication Adherence Report Scale.

In addition, the development or adoption of alternative and more suitable instruments for measuring other aspects of adherence amongst stroke survivors (e.g., engagement with formal and self-directed rehabilitation) is also necessary. There were two specific challenges that emerged in the present research in relation to the collection of these data. First, the diaries/calendars that were employed to measure engagement had very poor uptake amongst participants, and usable data were not obtained. Future studies should explore other approaches that may have potentially better uptake. Indeed, there is an on-going study developing a self-report instrument for measuring engagement with self-directed rehabilitation after stroke (the Stroke Rehabilitation Exercise Adherence Measure) (Bollen, Dean et al. 2014, Bollen In Progress). Specific details with regard to this study are not currently available. However, the findings would inform the future selection of instruments to measure this aspect of adherence after stroke. Second, record-keeping of therapy appointments is a useful adjunct to other, more subjective, methods for assessing patients' engagement with formal rehabilitation (Roter, Hall et al. 1998). On this basis, permission had been sought to extract this attendance data from records held by local community stroke teams, including the [therapy] teams for Nottingham City and County. However, access was not possible because the author was not clinically trained: this was a pre-requisite for permission to be

granted. This highlights a need to engage with local therapy teams from the outset to explore whether there may be scope to collaborate with therapist colleagues to access and share this information for the purposes of research, in accordance with ethics and regulatory standards, including participant consent. This warrants further investigation, with an important caveat with regard to missing or poor quality of data collected. Both of which emerged as issues in the present research when gathering follow-up clinical data from general practices.

8.5 CLINICAL IMPLICATIONS

Insufficient participant numbers limit the ability to draw conclusions from the present findings. Nonetheless, the results may have important clinical implications. To begin with, the study has further emphasised that clinicians should assess mood in patients immediately after stroke, on the basis that even mild depressive symptomatology (after a less severe stroke) can affect peoples' beliefs and thus their psychological adjustment within the acute phase of stroke (≤three-months post-stroke). As highlighted in Chapter 1, this is the most crucial period in recovery following stroke (Kwakkel and Kollen 2013, Stinear, Ackerley et al. 2013), and low mood can affect how well survivors adhere to their treatment and recover post-stroke (Parikh, Robinson et al. 1990, Gainotti, Antonucci et al. 2001, Donnellan, Hickey et al. 2010).

Importantly, it had originally been envisaged to undertake a formal validation of the Stroke IPQ-R using factor analysis and other methods, including the Rasch model (Tavakol and Dennick 2013). Rasch analysis has recently been used to evaluate the validity of a diabetes-specific version of the

IPQ-R (Rees, Lamoureux et al. 2015). The aim for the present research was to develop a brief version of the IPQ-R for stroke based on the items most pertinent for survivors, which could then be administered at patients' bedsides. However, this was again not possible because of the small sample size. A brief version of this lengthy questionnaire would have undoubtedly improved the clinical utility of this instrument. This is an issue that has also affected prior research (e.g., Twiddy (2008)). Therefore, replicating this study with a larger sample size (>100 participants) would be necessary to enable this instrument to be shortened to obtain a brief measure with greater clinical utility.

The data also indicated that these modifiable psychological variables (i.e., illness beliefs) significantly contribute to the variability in several aspects of post-stroke recovery (e.g., HRQL, disability and mood). In particular, the study highlighted that beliefs about the fluctuating effects of stroke and the considerable distress caused by stroke, were most important in predicting worse mood three-months post-stroke. This was shown even in a sample with mild depressive symptomology and generally beliefs of moderate strength in these domains. Therefore, these specific illness beliefs should be measured alongside mood immediately after stroke, and could form the basis of intervention. Prior literature cited in Chapter 7 (section 7.20.2.3) demonstrated that even brief belief-based interventions, informed by the CSM, can address maladaptive illness beliefs. Furthermore, there is growing evidence that modification of these beliefs can promote behaviour change and improve adherence to self-management and other outcomes (e.g., clinical, functional, and psychosocial) amongst people with a range of chronic conditions (Petrie, Cameron et al. 2002,

Broadbent, Ellis et al. 2009, Keogh, Smith et al. 2011, Cunningham, Swanson et al. 2012, O'Carroll, Chambers et al. 2013). Therefore, stroke survivors in the acute phase may benefit from receiving an intervention that is focused on challenging unhelpful beliefs (e.g., timeline-cyclical and emotional representations) about stroke. This could help to enhance peoples' mood immediately after stroke, with an overall view to perpetuating improvements in other markers of post-stroke recovery (e.g., HRQL and disability). This kind of beliefs-based intervention could be developed in future research and delivered to patients either in hospital or following discharge home. However, in order to engage a broader range of stroke survivors, including those with cognitive and/or communication impairment, consideration would need to be given to ensuring that any interventions developed are suitable for this group. For example, belief-based intervention studies thus far have initially elicited patients' beliefs about their condition using a questionnaire (e.g., the Brief IPQ). The findings of which have generally identified the maladaptive beliefs to be focused on in the intervention. However, given the evidence cited previously (section 8.4) on Talking Mats, picture symbols in this framework could be specifically developed (or adapted as appropriate) for discussion about beliefs about stroke, and utilised as an alternative to pen and paper based assessments that may not be accessible to many stroke survivors with paralysis, for example (section 1.2.3, Chapter 1).

It was particularly interesting to note in the present research that it appeared that there was a specific type of stroke survivor (i.e., 'Low Adjusters') that could benefit most from early psychological intervention. These 'Low

Adjusters' (e.g., perceived stroke to be chronic with fluctuating effects, and associated with a lot of symptoms, serious consequences and considerable distress) may be more likely to struggle after stroke. This group also seemed to hold unhelpful beliefs that need to be addressed, additional to those already found in the earlier statistical analyses of this research (i.e., timeline-cyclical and emotional representations) (sections 7.9 and 7.11). Therefore, a belief-based intervention could be ideally targeted, and be of most benefit, to this group. This would provide a more efficient way of utilising limited NHS resources.

8.6 STRENGTHS AND LIMITATIONS OF THE PRESENT RESEARCH

Study-specific strengths and limitations of the present research have previously been discussed at length (Chapters 3, 6 and 7), and will not therefore, be covered in detail again in this section. However, a reiterated brief summary is provided below.

A particular strength of this research has been that this is the first study, informed by a strong theoretical basis in the CSM, to investigate how survivors' beliefs about their stroke can affect how well they recover immediately post-stroke (≤three-months after stroke). This is particularly important given that the greatest risk of further strokes is during the early period (Samsa, Bian et al. 1999, Hankey 2005, Mohan, Wolfe et al. 2011), and this is also the stage where most functional improvements are noted amongst survivors (Kwakkel and Kollen 2013, Stinear, Ackerley et al. 2013). However, the success of secondary preventive medication and rehabilitation relies upon good adherence and engagement (Dunbar-Jacob and Mortimer-Stephens 2001,

Urquhart 2002) (Kendall, Catalano et al. 2007, Kortte, Falk et al. 2007, Battersby, Hoffmann et al. 2009, Jones, Mandy et al. 2009, Lequerica and Kortte 2010, Jones and Riazi 2011, MacDonald, Kayes et al. 2013, Bushnell, Arnan et al. 2014, McKenna, Jones et al. 2015). Both of which can be affected by poor psychological adjustment (Paolucci, Di Vita et al. 2012). Therefore, this is the first study to have addressed this important problem, and to have extended the current literature on the CSM and stroke.

The present study was also novel in the approaches utilised, including rigorous methods that have neither been employed previously with stroke survivors (e.g., Think-Aloud), nor been considered to date in the current CSM literature on stroke (e.g., mediation and cluster analyses). A further strength is the robust manner in which the study was conducted, according to ethical guidelines (e.g., ICH Good Clinical Practice) and relevant standard operating procedures. In addition, reporting of all components of the research adhered to relevant established guidelines and frameworks (e.g., PRISMA and STROBE).

The most notable limitations of the overall work were the small sample of stroke survivors recruited, and the representativeness of the patients involved. On this basis, the generalisability of the present research to stroke survivors nationally or internationally, across different settings is questionable. However, these issues (particularly, sample representativeness) have also arisen to varying degrees in the prior CSM literature on stroke, and indicate a limitation of the current evidence in this area (Johnston, Morrison et al. 1999, Joice,

Johnston et al. 2002, Joice, Bonetti et al. 2003, Ford 2007, Johnston, Bonetti et al. 2007, O'Carroll, Whittaker et al. 2011, Klinedinst, Dunbar et al. 2012, Twiddy, House et al. 2012, O'Carroll, Chambers et al. 2013, Sjölander, Eriksson et al. 2013, Phillips, Diefenbach et al. 2015). In hindsight, it may have also been worthwhile for the internal consistency of the treatment control sub-scale of the Stroke IPQ-R in particular to have been assessed prior to utilising this instrument in the observational study of Chapter 7. This would have allowed for a further stage of development to ensue, and may have produced a more accurate instrument for eliciting peoples' beliefs about the effectiveness of their treatment for stroke.

8.7 FUTURE RESEARCH

The findings from this research lead to recommendations for future research, particularly in relation to the CSM.

First, there is scope to undertake further systematic reviews and meta-analyses of the current CSM literature, the findings of which would be helpful in further broadening our understanding of the utility of this model for stroke survivors and other similar patient groups. For example, systematic review(s) to examine whether illness belief domains predict broader aspects of recovery after stroke (e.g., HRQL, disability and mood) have not yet been undertaken. These would be timely given the growing evidence in this field in recent years. However, to learn from the findings of the present systematic review (reported in Chapter 3), future studies are recommended to expand their searches of the grey literature. This may help to reduce problems with

publication bias that have also affected other reviews in this field to date (e.g., Brandes and Mullan (2014)). As mentioned in earlier chapters, it would also be helpful for further meta-analyses to consider prospective relationships of illness beliefs with outcomes, and attempt to quantify these. Systematic reviews to examine the relationship of illness beliefs examined collectively with the prediction of relevant outcomes would be particularly interesting. In addition to supporting the current progress of the field towards clustering of illness beliefs and targeted belief-based interventions, this would also provide a better reflection of the CSM. In order to achieve this, it is suggested that authors provide supplementary information with regard to these interrelationships, which could then be examined in future meta-analyses.

Second, it would be beneficial to undertake further development of the treatment control domain of the IPQ-R. Given the findings from the present research, it would be important to examine the exact nature of treatment beliefs amongst people with acute and chronic conditions who are in receipt of treatments that are more complex than simply taking medication (e.g., lifestyle and surgery). This could initially be carried out using qualitative methodology (e.g., semi-structured interviews) to gain an understanding of what people believe about their treatment(s). What would also be of particular interest would be the way in which peoples' beliefs about their treatment are affected by multiple co-morbidities that require patients to juggle often competing demands simultaneously. This can affect outcomes such as adherence (DiMatteo 2004, Hughes 2004, Osterberg and Blaschke 2005, Bushnell, Olson et al. 2011). Recruitment of a purposive sample of stroke survivors fitting these criteria

would aid this exploration. The findings of this could lead to a timely extension of the CSM, in a manner similar to that of the Necessity-Concerns Framework for medication beliefs (Horne and Weinman 1999) (discussed earlier in this and other chapters).

Finally, it would also be highly beneficial for future work to replicate the findings from the present statistical analyses in a larger sample, to examine whether similar illness beliefs are found to be significantly predictive of markers of post-stroke recovery, and whether comparable groupings emerge. This would further support the prospect of developing and piloting a belief-based intervention to target specific maladaptive beliefs amongst stroke survivors. It would also emphasise the relevance and benefit of targeting interventions to those whose illness belief schema suggesting that they are in most need of additional support. It is also recommended that studies undertake multiple regression analyses for individual versus schema of illness beliefs, in order to compare which approach is more influential in predicting outcomes.

8.8 CONCLUDING THOUGHTS

The present PhD research was carried out in light of the considerable burden of stroke to the population in the UK and globally. This work has supported a growing need to further understand adjustment after stroke, and in particular, how survivors' perceptions (or beliefs) about their stroke influence various markers of recovery (HRQL, disability, and mood). Utilising evidence-based theory from Health Psychology (the CSM), the work presented in this thesis addressed a gap in the literature for stroke survivors. It also demonstrated

the promise of applying the CSM in this context, with a view to improving outcomes for these patients in the future. Importantly, the present thesis has indicated the need for other pertinent work to be carried out by future researchers to build upon the foundations provided by this PhD research. This would have relevance, and be of benefit, to both stroke survivors and wider patient groups alike.

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References marked with an asterisk (*) were included in the systematic review of Chapter 3.

Appendices

APPENDIX 1: Supplementary material related to the systematic review and meta-analysis reported in Chapter 3

APPENDIX 2: Supplementary material related to the Think Aloud study reported in Chapter 6

APPENDIX 3: Supplementary material related to the observational study reported in Chapter 7

Appendix 1: Supplementary material related to the systematic review and meta-analysis reported in Chapter 3

- Example MEDLINE search
- Data extraction form
- Supplementary information for the meta-analysis

Database: Ovid MEDLINE(R) without Revisions <1996 to August Week 2 2015>
Search Strategy:
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1 Leventhal#.mp. (79)
2 Disease/ or Acute Disease/ or Disease.mp. (2021422)
3 Chronic disease.mp. or Chronic Disease/ (132351)
4 Medical condition.mp. (3523)
5 Physical illness.mp. (1261)
6 (Common adj sense model).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (129)
7 (Self adj regulation model).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (107)
8 1 or 6 or 7 (259)
9 Illness.mp. (297130)
10 2 or 3 or 4 or 5 or 9 (2206590)
11 "Illness behaviour".mp. or Illness Behavior/ (842)
12 Recovery.mp. (223242)
13 Rehabilitation.mp. or Rehabilitation/ (70938)
14 (Self adj care).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (23295)
15 (Self adj management).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (7544)
16 Medication Adherence/ or Adherence.mp. (73361)
17 Treatment.mp. (2289025)
18 Patient Compliance/ or Treatment adherence.mp. (35825)
19 Illness belief*.mp. (254)
20 Illness perception*.mp. (786)
21 Illness cognition*.mp. (81)
22 Illness representation*.mp. (280)
23 19 or 20 or 21 or 22 (1226)
24 Health Behavior/ or Behavio?r change.mp. (35802)
25 Behavio?r modification.mp. (1024)
26 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 24 or 25 (2574381)
27 8 or 23 (1336)
28 10 and 26 and 27 (792)
29 (Help adj seeking).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (2429)
30 (Care adj seeking).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (1400)
31 26 or 29 or 30 (2576520)
32 28 and 31 (792)
33 limit 32 to (english language and humans and yr="1980 -Current" and ("adolescent (13 to 18 years)" or "young adult (19 to 24 years)" or "adult (19 to 44 years)" or "young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)")) (649)

****

Box A1-1. Example search strategy for the systematic review –MEDLINE

Paper:
Extracted by:
Checked by:

Systematic review of predictive relationships between illness beliefs and adherence to self-management behaviours

Data Extraction Form

ELIGIBILITY CHECKLIST	YES	NO	NOTES
Population aged 18 years or over			If no, exclude
Population with physical illness			If no, exclude
CSM as theoretical framework			If no, exclude
Outcomes include adherence behaviours			If no, exclude
Predictive relationship between beliefs and behaviour reported			If no, exclude
Design is RCT or prospective/longitudinal study with follow-up			If no, exclude

STUDY DETAILS	
First author	
Title of paper	
Journal	
Publication date	
Country of first author	
Important notes (this section is for any significant issues to be recorded e.g. areas of uncertainty).	
POPULATION	
Type of illness	
Setting (e.g. hospital, GP)	
Eligibility criteria	Inclusion: Exclusion:
Sample size (including any sub-groups that participants were categorised into e.g. attendees and non-attendees)	

Number of men	
Number of women	
Mean age (± SD)	
Ethnicity	
Recruitment dates/period	
STUDY DESIGN AND METHODS	
Type of study (e.g. RCT or prospective)	
Length of follow-up	
Method of recruitment	
Other details (e.g. randomisation, allocation concealment, and blinding for RCTs)	
Belief measurement	
How completed?	
Any data reported on measurement properties (e.g. internal consistency and reliability)? If yes, provide details.	
Adherence behaviour(s) assessed	
How was the predictive relationship between beliefs and behaviour analysed, statistically? If an RCT, was analysis by 'Intention To Treat?'	
Any information on missing data and how this was handled?	
RESULTS	
Key findings (including whether groups were the same	

at baseline - for RCTs only)	
Which beliefs were important for predicting behaviour?	
Size of effect(s) (e.g. odds ratio or β-coefficient) and measures of variability (e.g. 95% confidence intervals)	
Any other important data reported regarding this relationship?	
CONCLUSIONS/DISCUSSION	
Authors' key conclusions	
Strengths/limitations of study	
Any strengths/limitations reported around the illness beliefs assessment method	

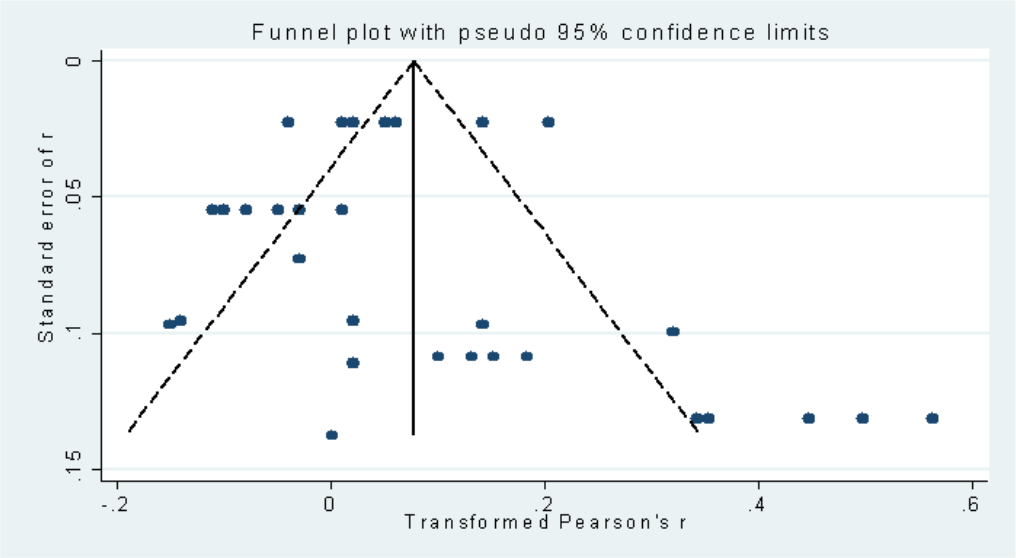


Figure A1-1. Funnel plot for identity beliefs

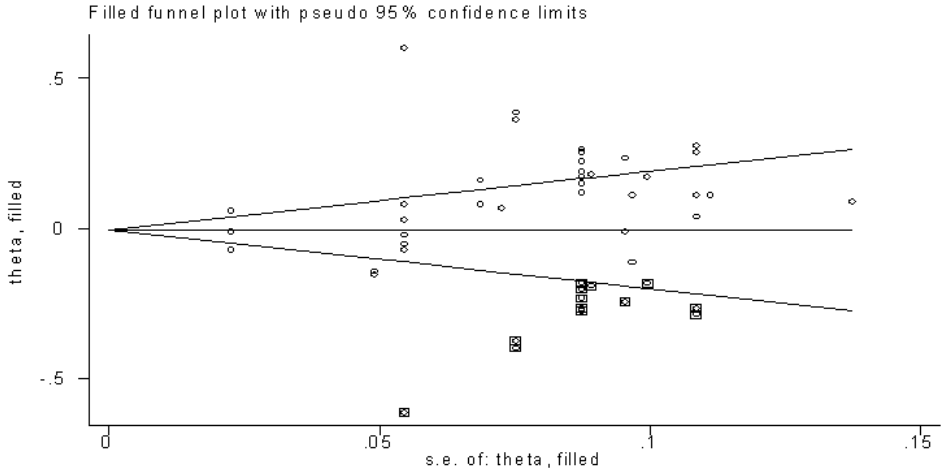


Figure A1-2. Trim and filled funnel plot for timeline acute-chronic beliefs

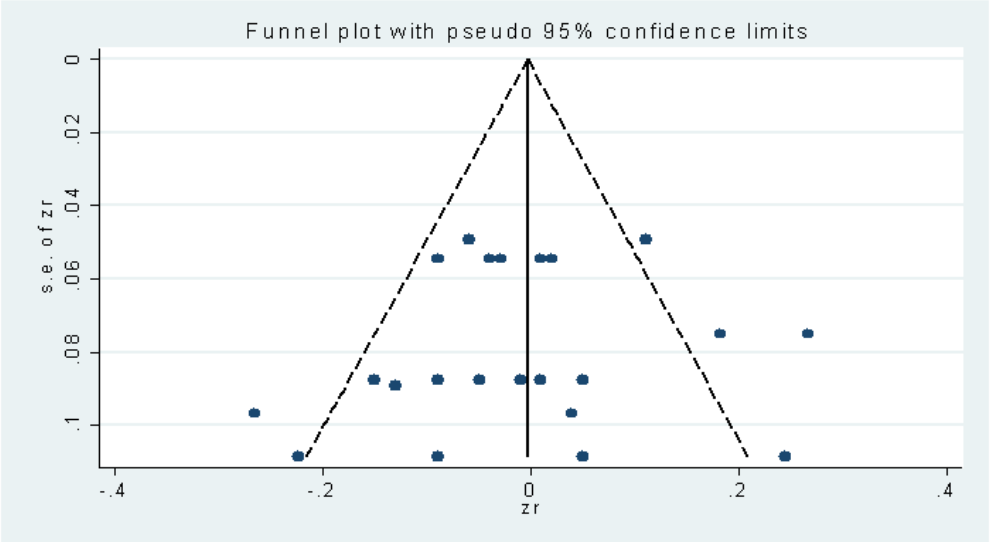


Figure A1-3. Funnel plot for timeline-cyclical beliefs

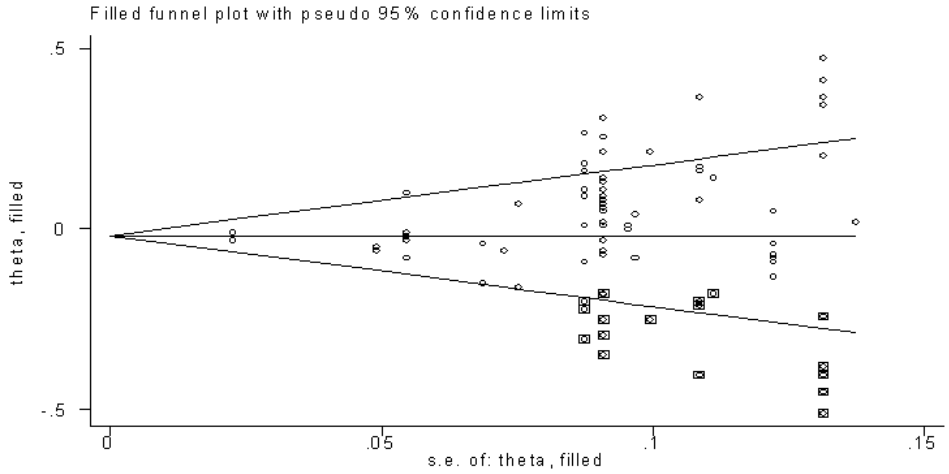


Figure A1-4. Trim and filled funnel plot for consequence beliefs

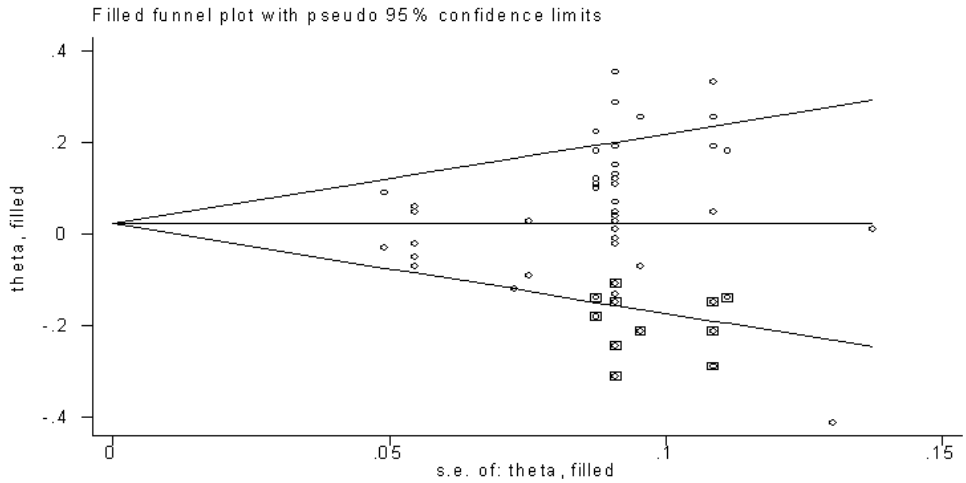


Figure A1-5. Trim and filled funnel plot for personal control beliefs

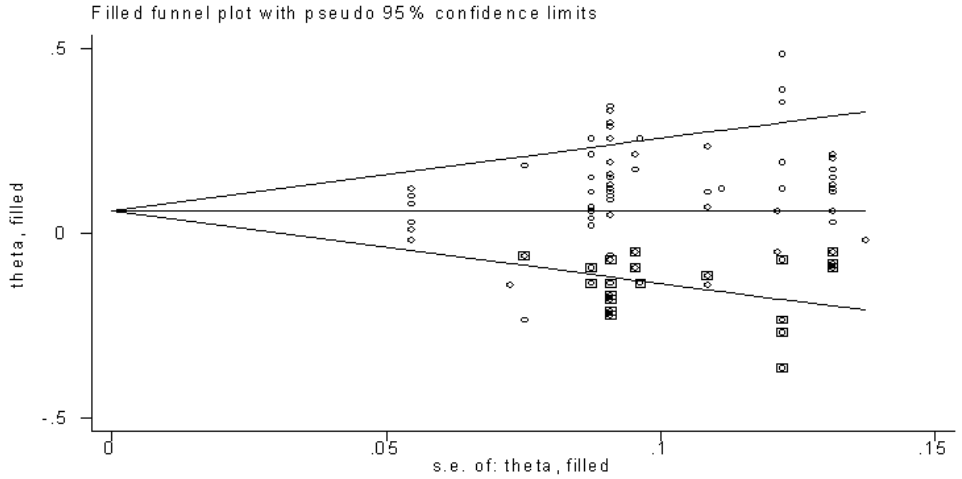


Figure A1-6. Trim and filled funnel plot for treatment control beliefs

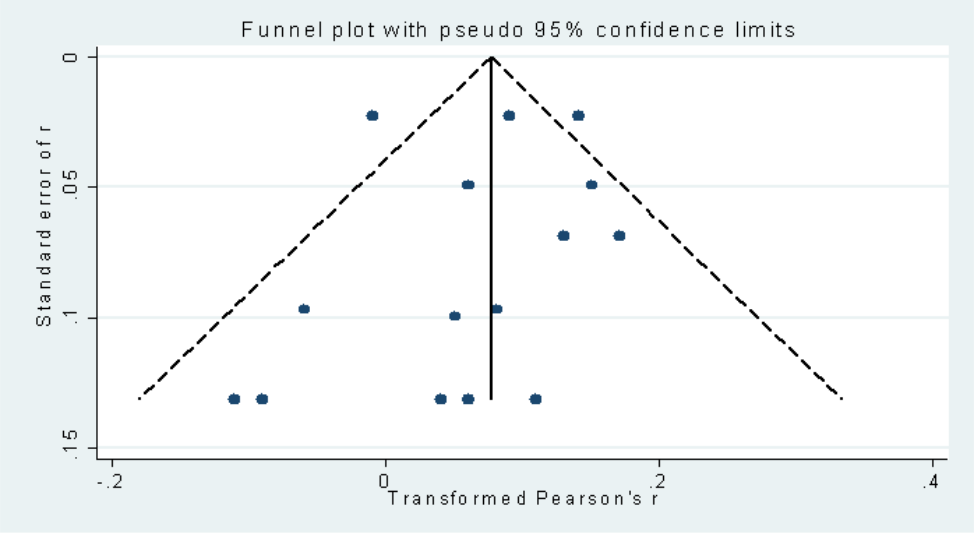


Figure A1-7. Funnel plot for cure-control beliefs

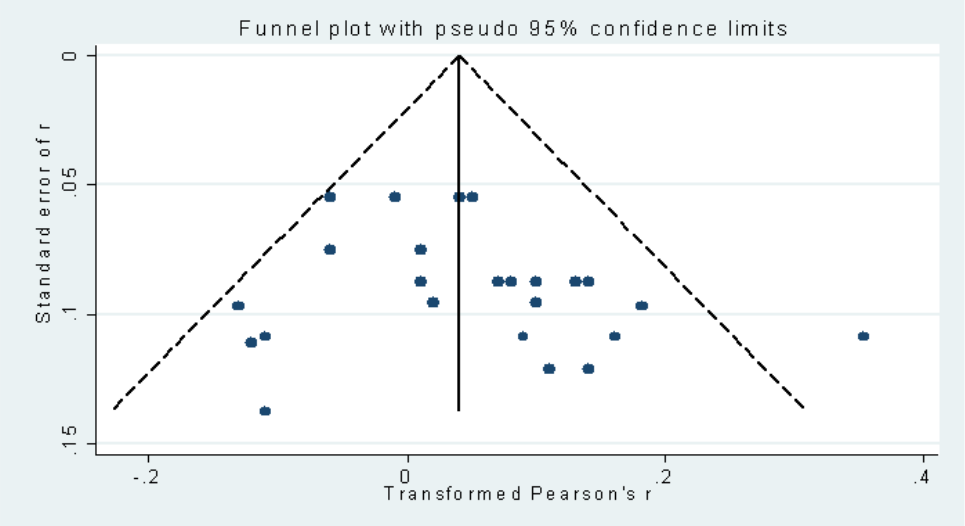


Figure A1-8. Funnel plot for illness coherence beliefs

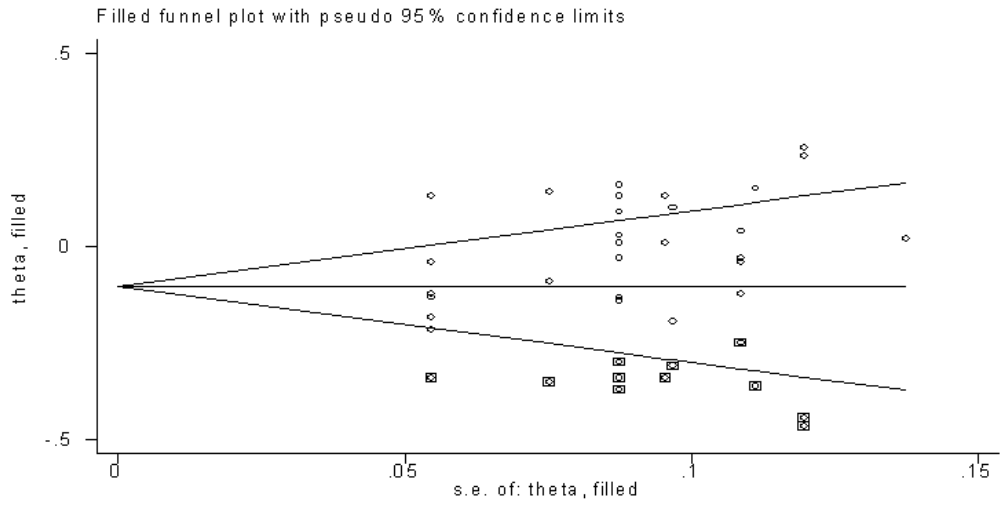


Figure A1-9. Trim and filled funnel plot for emotional representations

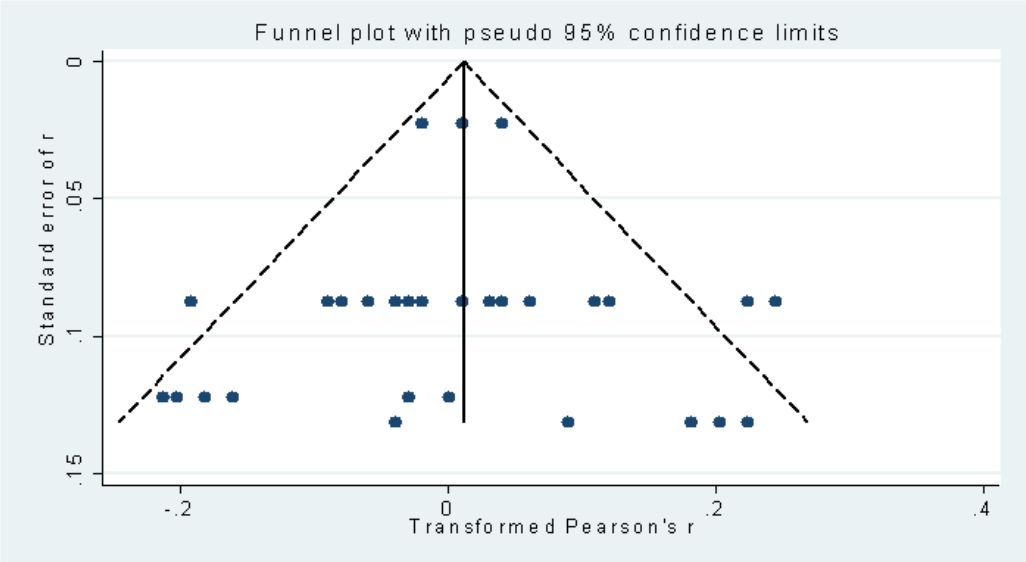


Figure A1-10. Funnel plot for causal beliefs

Appendix 2: Supplementary material related to the Think Aloud study reported in Chapter 6

- Participant documents (i.e., information sheet and consent form).

[Participant information sheet]

[Participant information sheet (continued)]

[Participant information sheet (continued)]

[Blank consent form]

Appendix 3: Supplementary material related to the observational study reported in Chapter 7

- Approval letters (REC and R&I)
- Participant documents (i.e., information sheet and consent form)
- Example case record form/questionnaires and diary/calendar
- Supplementary information for the statistical analyses

[NHS REC approval letter]

[NHS REC approval letter (continued)]

[NHS R&I approval letter]

[NHS R&I approval letter (continued)]

[Participant information sheet]

[Participant information sheet (continued)]

[Participant information sheet (continued)]

[Participant information sheet (continued)]

[Blank consent form]

[Blank baseline case record form]

[Blank baseline case record form (continued)]

[Blank baseline case record form (continued)]

[Blank follow-up patient questionnaire pack]

[Blank follow-up patient questionnaire pack (continued)]

[Blank follow-up patient questionnaire pack (continued)]

[Blank follow-up patient questionnaire pack (continued)]

[Blank follow-up patient questionnaire pack (continued)]

[Blank follow-up patient questionnaire pack (continued)]

[Blank follow-up patient questionnaire pack (continued)]

[Blank baseline beliefs questionnaire – Stroke IRQ-R]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank baseline beliefs questionnaire – Stroke IPQ-R (continued)]

[Blank example diary/calendar]

Table A3-1. Summary of findings for criteria 1 of mediation for follow-up mood (PHQ-9 score)

Baseline illness belief domains	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Outcome: Follow-up mood						
Identity	41	0.24	0.11	<.05	0.03-0.45	11.95
Timeline acute-chronic	41	0.07	0.13	0.57	-0.19-0.34	0.82
Timeline-cyclical	*41*	*0.51*	*0.14*	*<.001*	*0.24-0.79*	*26.60*
Consequences	41	0.14	0.08	0.10	-0.03-0.30	6.84
Personal control	41	0.04	0.12	0.76	-0.21-0.29	0.25
Treatment control	41	-0.05	0.32	0.88	-0.69-0.59	0.06
Illness coherence	41	-0.08	0.14	0.55	-0.37-0.20	0.91
Emotional representations	*41*	*0.28*	*0.10*	*<.001*	*0.08-0.48*	*16.75*
Cause 1: Stress or worry, including family problems	41	0.57	0.50	0.26	-0.44-1.58	3.26
Cause 2: Heredity – it runs in my family	41	0.38	0.65	0.56	-0.94-1.71	0.87
Cause 3: Diet or eating habits	41	-0.30	0.52	0.57	-1.35-0.76	0.82
Cause 4: Poor medical care in my past	41	-0.24	0.59	0.68	-1.44-0.95	0.43
Cause 5: My mental attitude e.g., thinking about life negatively	41	0.91	0.71	0.21	-0.54-2.35	3.98
Cause 6: Overwork	41	-0.21	0.46	0.65	-1.15-0.72	0.55
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	41	1.02	0.71	0.16	-0.42-2.47	5.02
Cause 8: Ageing	41	-0.46	0.51	0.38	-1.50-0.58	2.00
Cause 9: Alcohol	41	-0.26	0.61	0.67	-1.49-0.97	0.47
Cause 10: Smoking	41	-0.17	0.52	0.75	-1.23-0.89	0.26
Cause 11: High cholesterol	41	0.66	0.60	0.28	-0.55-1.88	3.02
Cause 12: High blood pressure	41	-0.32	0.55	0.56	-1.43-0.79	0.87
Cause 13: Diabetes	41	1.40	0.73	0.06	-0.08-2.88	8.55
Cause 14: Problems with my heart, such as an irregular heartbeat	41	0.23	0.56	0.68	-0.90-1.36	0.43
Cause 15: Chance or bad luck	41	0.41	0.53	0.44	-0.66-1.49	1.53
Cause 16: Not taking enough exercise	41	0.09	0.62	0.89	-1.16-1.33	0.05

Symbols and abbreviations: *: Bonferroni adjusted significance level (p=0.002); β: Beta-coefficient; CI: Confidence Interval**;** PHQ-9; Patient Health Questionnaire-9

Table A3-2. Summary of findings criteria 2 of mediation follow-up mood (PHQ-9 score)

Baseline illness belief domains	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Outcome: Coping (Mediator 1)						
Timeline-cyclical	41	-0.05	0.05	0.31	-0.14-0.04	2.69
Emotional representations	41	-0.00	0.03	0.98	-0.06-0.06	0.0
Outcome: Baseline mood (Mediator 2)						
Timeline-cyclical	44	0.82	0.17	<.001	0.49-1.15	37.0
Emotional representations	44	0.46	0.11	<.001	0.24-0.69	29.0

Symbols and abbreviations: *: Bonferroni adjusted significance level (p=0.01); β: Beta-coefficient; CI: Confidence Interval; PHQ-9; Patient Health Questionnaire-9

Table A3-3. Summary of findings criteria 3 of mediation follow-up mood (PHQ-9 score)

Baseline illness belief domains	N	β-coefficient	Standard error	P-value*	95% CI	R^2 (%)
Outcome: Follow-up mood						
Timeline-cyclical Coping	41	0.49 -0.54	0.14 0.48	<.01 0.27	0.21-0.77 -1.51-0.44	28.92
Emotional representations Coping	41	0.28 -0.81	0.10 0.50	<.01 0.11	0.08-0.47 -1.81-0.20	22.19
Timeline-cyclical Mood	40	0.19 0.39	0.15 0.11	0.23 <.01	-0.12-0.51 0.16-0.62	44.44
Emotional representations Mood	40	0.06 0.44	0.10 0.11	0.54 <.001	-0.14-0.26 0.22-0.66	42.78

Symbols and abbreviations: *: Bonferroni adjusted significance level (p=0.01); β: Beta-coefficient; CI: Confidence Interval; PHQ-9; Patient Health Questionnaire-9