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Expectations and experiences following a first ever
transient ischaemic attack or minor stroke

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ABSTRACT

Objectives: to understand how individuals' experiences and perceptions following a TIA or minor stroke change over time, and how far, if at all, they influence recovery. In addition, to investigate whether expectations for recovery of symptoms affect actual recovery.

Methods: three linked methods were adopted. Firstly, a systematic review of negative expectations was undertaken to synthesise the evidence regarding the effect of expectations on negative health outcomes and to review the measures of expectations used.

Secondly, quantitative interviews of an initial sample of N=153 people recruited from NHS Lothian and NHS Fife who had had a first TIA or minor stroke were undertaken. N=143 of these were re-interviewed four to six months later, and N=103 returned postal questionnaires 18 months later. Interviews included questions and questionnaires regarding expectations for recovery, fear of recurrence, illness perceptions, recovery locus of control, medication beliefs, optimism and pessimism, resilience, anxiety and quality of life.

Thirdly, qualitative semi-structured interviews of N=6 participants selected from the larger sample were undertaken, and transcripts analysed using interpretative phenomenological analysis.

Results: a wide range of experiences and expectations were present at baseline interview, with a majority of participants continuing to experience symptoms of their minor stroke or TIA. By the time of the follow-up interviews, quality of life and positivity of outlook had generally improved, although there was an increased belief that the condition was chronic, and a decreased sense of control of one's own recovery. There was a marked deterioration in many aspects by the time of the third interview, especially for the significant proportion of the sample who continued to experience symptoms of their minor stroke or TIA. These findings were broadly corroborated by the qualitative interviews, which for most also revealed difficulty in coming to terms with the aftermath of a minor stroke or TIA, making appropriate lifestyle changes and a need for further intervention.

Conclusions: Recovery from a minor stroke or TIA can be protracted, confusing and distressing, and can negatively affect quality of life, especially if physical symptoms of the event persist. A lack of understanding and/or of clear information on initial diagnosis can lead to unrealistic expectations for a swift and full recovery, and to other beliefs and behaviours which may compound the risk of recurrence.

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CHAPTER 1

GENERAL INTRODUCTION

The aim of this chapter is to provide a background to this research by:

- Providing a brief history to the evolution of this research
- Defining and differentiating between stroke, minor stroke and transient ischemic attacks (TIAs)
- Describing how TIAs and minor strokes are diagnosed and treated
- Giving an overview of the main concepts within this thesis
- Stating the aims of this research

1.1 Evolution of this Research

The original aim of this research was to investigate the effect of negative expectations on recovery of stroke patients after a first ever stroke. During the initial conversations with clinical staff at the first recruitment site (which at the time was planned to be the only site), it became clear that using people who had had a major stroke would not be practical, due to the low number of people who used this particular service and who would fulfil the inclusion criteria.

The clinical staff involved at this early stage of the research suggested using people who had had a TIA or minor stroke instead. After some consideration, it was decided that people who had had a TIA or minor stroke would, in fact, be a more appropriate population for three main reasons. First, they are a more homogenous group. In major stroke there is considerable variation in severity of symptoms and recovery (Grefkes and Fink, 2020) therefore it would be difficult to attribute variations in outcomes to expectations rather than the clinical consequences of the stroke. By contrast, any residual symptoms of a TIA or minor stroke (that is, any symptoms that endure beyond the acute phase) are mild and non-disabling and are expected by clinicians to recover (Albers, Caplan, Easton et al., 2002; Fischer, Baumgartner, Arnold et al., 2010). Second, in major stroke people can often be left with serious problems with communication and /or cognition, which could make the interviews difficult or impossible. Third, the TIA and minor stroke population is larger, meaning that reaching the desired recruitment would be more feasible.

While writing the systematic review (Chapter 2) it became evident that it did not make sense to concentrate only on negative expectations. While it makes sense to measure only negative expectations under laboratory conditions where expectations are manipulated, in longitudinal observational research using Likert scales is problematic because it is very likely that there will be a range of expectations and ignoring the possible effects of positive or neutral expectations risks biasing the research. In addition, measuring only negative expectations assumed that people only had negative expectations for recovery. Once these factors were taken into account it was decided to broaden the research into investigating the overall effects of any expectation for recovery.

Very early on in the interviewing process it became clear that people were seldom thinking in terms of expectations for their symptoms and were often uncertain how to answer questions regarding expectations. It was very common for people to talk about their hopes for recovery, but when they were encouraged to talk about expectations as opposed to hopes, they often became very uncertain. In addition, many people did not have symptoms and did not consider themselves to be in recovery, which meant questions about expectations for recovery were meaningless to them. At this point it was decided to broaden out the research further and although expectations for recovery would remain a central theme, outcomes including quality of life, fear of recurrence and adherence to medication also became central themes. The overarching aim of this research is to understand how individuals' experiences and perceptions following a TIA or minor stroke change over time, and how far, if at all, they influence recovery.

1.2 Stroke - Major, Minor and TIA

Stroke is essentially a disruption in the blood supply to some part of the brain causing corresponding neurological deficits. In 2019, stroke was the second most common cause of death worldwide (WHO, 2019), making it an important area for research. The effects of stroke are extremely varied and can include physical, cognitive and emotional disabilities depending on the area or areas of the brain that are affected. There are over 150 known causes of stroke (Amarenco, Bogousslavsky, Caplan et al., 2009). In the broadest terms, stroke can be classified as ischemic (where a blood clot forms in the brain) or hemorrhagic (a bleed in the brain). In terms of severity, strokes are classified as:

Major stroke - is where the effects are long-term and disabling (Parmar, Sumaria and Hashi, 2011).

Minor strokes - there is no formal definition of minor stroke (Fischer, Baumgartner, Arnold et al., 2010); however, these are broadly classified as strokes where symptoms are minor or non-disabling and last longer than 24 hours (Crespi, Braga, Beretta et al., 2013).

Transient Ischaemic Attacks (TIAs) - are defined as temporary episodes of focal brain dysfunction lasting less than 24 hours and without evidence of cerebral infarction (Kelly, Hunt, Lewis et al., 2018) and are caused by a temporary clot in some part of the brain which resolves itself without treatment. Symptoms are similar to those experienced during a major or minor ischemic stroke; however, they are often milder and traditionally thought to resolve themselves within 24 hours, although this is now being challenged (e.g. Turner, Calvert, Feltham et al., 2016).

Distinguishing between minor stroke and TIA is not always straightforward (Hill and Coutts, 2011). TIAs usually last for 15 minutes or less (Levy, 1988) and where there are persistent signs or symptoms regardless of how insignificant these are, the event is usually classed as minor stroke. Due to the considerable overlap between TIAs and minor strokes, they are often treated as one population in both clinical practice and in research (Hill et al., 2011).

This research is concerned with minor stroke and TIAs only and therefore will not discuss major stroke in any detail except in areas where there is no research using TIA and minor stroke patients. In the UK there are approximately 20,000 TIAs and 23,375 minor strokes per year. However, some estimates suggest the number of TIAs may be as much as 50,000 to 60,000 per year (Giles and Rothwell, 2007). Risk of recurrence after a TIA or minor stroke is estimated at between 12% and 20% within the first three months (Rothwell, Giles, Chandratha, Marquardt, et al., 2007) with the majority of those occurring in the first 48-72 hours (Coutts, Hill, Campos et al., 2008). In addition, one in five people who have a TIA or minor stroke will go on to have a major stroke or heart attack, or to die within one year (Hill et al., 2011).

Treatment and Diagnosis

Treatments for minor ischaemic stroke and TIAs are mainly secondary prevention treatments to reduce the risk of subsequent stroke and myocardial infarction which often include medications to reduce blood pressure and cholesterol and to thin the blood. Surgery to remove plaque build ups in the carotid artery is offered where appropriate. Lifestyle advice

is also normally provided; however, it is unusual for patients to be offered any further specialist contact or rehabilitation (Lam, Blom and Kwa, 2019).

Diagnosis of major stroke is normally done from the patient's presenting symptoms and brain scans are often carried out to identify whether the stroke is ischemic or hemorrhagic and to discover the exact area of the stroke and extent of the damage to the brain.

Diagnosis is more difficult with TIAs and minor stroke because available scanning techniques are not always sensitive enough to pick up very small lesions in the brain (Wardlaw, Brazzelli, Miranda et al., 2014). Diagnosis of a TIA and minor stroke in clinical practice is still frequently based on retrospective reporting of the symptoms experienced and their duration; classification of TIA or minor stroke is carried out according to the duration of the associated symptoms (TIA < 24 hours and minor stroke > 24 hours) (Crespi et al., 2011). This means that TIAs tend to be suspected rather than definite, often leaving patients uncertain about whether they have had a TIA or not. This issue is further complicated by the fact that there are several other conditions that can present with similar symptoms to TIAs. For example, migraine and focal seizures also affect balance or cause sensory loss (Kelly et al., 2001).

1.3 Overview of Main Terms and Variables

This section aims to provide an overview of the variables measured in this thesis. Many of these will be discussed in greater detail throughout this research. Firstly, it will provide an overview of the outcome variables, which are: quality of life; fear of recurrence and symptom severity at baseline (T1), T2 (4-6 months after baseline) and T3 (18 months after baseline) and adherence at T2 and T3. Secondly, it will give an overview of the predictor variables: expectations for recovery; illness perceptions; anxiety; medication beliefs; recovery locus of control; optimism / pessimism; resilience and social support. Because one of the central themes of this research is whether expectations for recovery affect symptom severity, the section on expectations will be more in depth than the sections on the other predictor variables.

Outcome Variables

Health related quality of life.

There are several different definitions of health related quality of life in the literature and multiple texts discussing this concept (Post, 2014). For the purposes of this research, the World Health Organisation's (WHO) definition of quality of life is sufficient. WHO defines quality of life as "a state of physical, mental and social well-being, not merely the absence of disease and infirmity" (WHO, 2019). This definition incorporates: physical health, which includes, somatic sensations, disease symptoms and treatment side effects; functional health, which includes, physical functioning, i.e. mobility, self-care, and physical activity; mental health, which can range from a sense of well-being to psychological distress to diagnosable psychiatric conditions; social health, which includes social contact and social interaction (Aaronson, 1988). Essentially, health-related quality of life is not merely about physical health and mobility, but also mental health and social well-being.

There are a variety of measures of health related quality of life including disease specific measures, which include variables that are relevant to the given disease or treatment. Although there are stroke-specific quality of life measures (e.g. the Stroke Specific Quality of Life Scale), it was decided to use a more general measure in this research because symptoms, particularly in TIAs, may not be severe enough to score on a stroke specific measure.

Fear of recurrence.

Although there is evidence that people who have had a stroke would like more information regarding prevention of recurrence (Townend, Tinson, Kwan et al., 2006) and that recurrence rates are high (see above), there is very little research investigating fear of recurrence in stroke and even less investigating fear of recurrence in TIA and minor stroke patients. Much of the research into fear of recurrence comes from work with cancer patients, where it has been found to be fairly stable over time (Simonelli, Siegel and Duffy, 2016) and is associated with lower quality of life and psychological distress (Hedman, Djarv, Strang et al., 2018; Humphris, Rogers, McNally et al., 2003).

There is no agreed medical definition of recurrent stroke and it has been defined in different ways in research (see Coull and Rothwell (2004) for an overview). For the purposes of this study, fear of recurrence is defined as fear of having another stroke of any type.

Adherence.

Adherence has been defined by the WHO as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (Sabate et al., 2003). In the quantitative section of this research adherence to secondary prevention medications (medications that are prescribed to prevent another stroke) will be examined and adherence to lifestyle changes will be discussed in the qualitative section.

Perceived symptom severity and symptom bother.

Although these are two distinct concepts, they will be discussed together in this section as they are likely to be related to some extent. The more severe a symptom is the more likely it is to cause more bother to the patient; however, this may not always be the case. Studies have found that severity is not always linked to how bothersome a symptom is in cancer (Hong, Blonquist, Halpenny et al., 2016) and in Parkinson's (Backer, 2006) These are important concepts to measure, as perceived severity and the amount of bother that symptoms give to the patient will likely affect other areas of their lives such as quality of life, illness beliefs and expectations for recovery; and one of the main aims of this research is to ascertain whether expectations for recovery can predict symptom severity.

Although no studies in TIA and minor stroke were found looking specifically at this issue, it is not difficult to think of situations where less severe symptoms could cause more bother than more severe ones, for example, fatigue that is rated as more severe than

problems with fine motor control might be less bothersome where hobbies or work rely on dexterity in the hands or fingers.

Predictors

Symptom presence.

Until relatively recently, minor strokes and TIAs were thought to have no lasting symptoms (Moran, Fletcher, Calvert et al., 2014). However, this view is now being challenged and a recent systematic review in the UK found that people who had had a TIA had an increased risk of consulting for fatigue, cognitive impairment and psychological impairment compared to controls (Turner et al., 2016).

In this research, symptoms are defined as any symptom the participants believed were caused by the TIA or minor stroke. It should be noted that this was not always straightforward. Participants often had other conditions that may have accounted for symptoms, for example, pre-morbid mental health disorders, such as depression or anxiety; physical illnesses, for example, arthritis and cancer. Therefore a pragmatic approach was taken to this issue and where a participant believed, on balance, that the symptom was related to the TIA or minor stroke this was scored as such.

Expectations for recovery of symptoms.

Expectations are a complex concept with no agreed definition (Laferton, Kube, Salzmann, et al., 2017). Kube, D'Astolfo, Glombiewski et al. (2016) define them as "cognitions that are future-directed and focused on the incidence or non-incidence of a specific event or experience" (p1). In this definition, there is an implied distinction between what people think will happen and what they want to, or hope will, happen which have been called ideal expectations, value expectations or fantasies (Laferton et al., 2017). There may be some evidence that the latter concept could have a detrimental effect on some aspects of health, for example, in weight loss (Oettingen and Wadden, 1991) and on energy levels (Kappes and Oettingen, 2011). The available evidence regarding the detrimental effect of ideal expectations seems to suggest that people put in less effort to attain their goals when their expectations are overly positive (Kappes et al., 2011). Although this research might not be generalisable to expectations for recovery, it does seem to suggest that expectations and ideal expectations may be two distinct concepts with different outcomes. Expectations can also be

unconscious, for example, in placebo and nocebo effects (Petrie and Rief, 2019). This aspect is discussed in more detail in chapter 2.

Other concepts that have been linked to expectations in health research include self-efficacy, that is, an expectation or confidence that one can or cannot do something (Bandura, 1997); optimism and pessimism, which can be viewed as generalised expectations, i.e. the extent to which a person has positive or negative expectations in any given situation (Carver, Scheier and Segerstrom, 2010); recovery locus of control (Partridge and Johnston, 1989) which is the extent to which future recovery is under the control of the individual or external forces, such as medical professionals or chance; and illness perceptions (Levanthal, Meyer and Nerenz, 1980), which can be seen as a set of beliefs about a particular illness (see below). While none of the beliefs mentioned are explicitly about recovery expectations, they do underlie several of the beliefs, for example, generalised expectations, expectations concerning the length of the illness, expectations regarding control and future consequences.

In this research, the concept of recovery expectations is defined as the belief that the symptom asked about will either get better, get worse or stay the same. However, several of the other concepts mentioned above are also measured.

Illness perceptions.

As was mentioned above, illness perceptions can be thought of as a set of beliefs that shape an individual's understanding of, and reactions to, a particular illness or condition (Levanthal et al., 1980). These beliefs include whether the illness is chronic or acute (timeline acute/chronic), fluctuations in symptoms (timeline cyclical), perceptions about what has caused the illness and symptoms related to it (identity), the consequences of the illness, whether the illness is under the control of the patient or the treatment(s), emotional response to the illness and understanding of the illness (coherence).

In the current research only beliefs about timeline (whether the condition is acute or chronic), emotional response, coherence and consequences of the condition are measured because the other dimensions of this scale (control, identity, fluctuations in symptoms and causes of the condition) were either measured using different measures or were not seen as directly relevant to this research. In addition, it was important to limit the number of predictors as much as possible to achieve the desired power.

Optimism / pessimism.

Optimism and pessimism were briefly introduced and defined above in the section on expectations. In addition, it was felt that this construct may be important as it is a measure of 'general expectancies' and these may be related to specific expectations for symptoms.

Recovery locus of control.

Recovery locus of control is concerned with beliefs about whether recovery is under the control of the individual (internal control) or other factors, such as, healthcare providers or chance (external control). This concept is also related to expectations insofar as it is concerned with beliefs about control over future recovery (Partridge et al., 1989).

Social support.

Social support is defined as the access an individual has to support. There are two main components to social support, which are: firstly, a structural component, that is, frequency of social contact and size of networks; and secondly a functional component, which includes emotional and practical support.

Resilience.

Resilience is defined the ability to bounce back after a stressful event, that is, the ability to recover from a shock or crisis and return to an original state (Kim, Lim, Kim et al., 2018)

Medication beliefs.

As was mentioned above a large number of people who have had a TIA or minor stroke are prescribed medications to help prevent a recurrence. Medication beliefs measure participants' beliefs about the necessity of their medications and concerns about taking them. Concerns about medications have been found to mediate the relationship between symptoms of post-traumatic stress disorder and adherence in people who have had a stroke (Edmonson, Horowitz, Goldfinger et al., 2013) and belief in the necessity of medications has been found to predict adherence (e.g. O'Carroll, Whittaker, Hamilton et al., 2011). Due to the importance of adhering to secondary preventative medications, medication beliefs may be an important

factor in adherence in TIA and minor stroke patients.

Generalised anxiety.

Generalised anxiety is characterised by excessive and persistent unfocussed worrying and anxiety. It is characterised by feelings of threat, restlessness, irritability, sleep disturbance and tension (Tyrer and Baldwin, 2006) and has a prevalence in the general population of around 8% (Wittchen and Hoyer, 2001). There is some evidence that anxiety can be a problem following a TIA or stroke of any kind, with prevalence estimates at 10-29% (Kapoor, Si, Yu et al., 2019).

1.4 Aims of this Research

- 1.** To conduct a systematic review of the literature regarding negative expectations and their effects on recovery or improvement of any health condition (chapter 2).
- 2.** To investigate the extent that the beliefs measured after experiencing a first TIA or minor stroke predict quality of life at baseline, 4-6 months later (T2) and 18 months after baseline (T3) (chapters 3, 4 and 5).
- 3.** To explore whether illness beliefs at baseline predict fear of recurrence at baseline, T2 and T3 (chapters 3, 4 and 5).
- 4.** To investigate the extent that beliefs measured at baseline predict medication adherence at T2 and T3 (chapters 4 and 5).
- 5.** To explore whether expectations for symptoms at baseline predict severity of symptoms at baseline, T2 and T3 (chapters 3, 4 and 5).
- 6.** To investigate differences between those who have symptoms and those who do not at baseline, T2 and T3 (chapters 3, 4 and 5).
- 7.** To investigate change in quality of life between baseline and T2 and T3 and changes in illness perceptions, anxiety, medication beliefs, recovery locus of control, fear of recurrence and symptom presence, severity and bother between baseline and T2 (chapters 4 and 5).
- 8.** To explore how having a TIA or minor stroke affects individuals using qualitative interviews (chapter 6).

CHAPTER 2
A SYSTEMATIC REVIEW OF NEGATIVE EXPECTATIONS

Abstract

Aims: (a) to synthesise the evidence regarding the effect of expectations for negative health outcomes, and (b) to review the measures of expectations used.

Methods: the search strategy was developed by four people and the searches carried out by two. Databases searched: AMED, EMBASE, Medline, Psychinfo, CINAHL, Web of Science and PubMed in May 2012 and June 2013. Results were screened for eligibility and studies that investigated the effect of expectations of a negative outcome and related these to actual outcomes in people with a medical condition were included.

Results: 12,660 titles were identified through searching the databases and 53 through other means. Of these 12, 713 titles, 20 studies were found to meet the inclusion/exclusion criteria. Four studies were identified that manipulated information to influence expectations or analysed the effect of information on outcomes; 15 studies were identified that measured expectations pre intervention and related these to health outcomes post intervention; one study measured expectations of a medical condition and related these to health outcomes; no qualitative studies were identified. The review identified limited support that negative expectations can lead to the development and/or worsening of symptoms. Measurement issues made it difficult to draw many conclusion from the studies that attempted to measure expectations; however, expectations for treatment benefit tended to be high, making their relevance to this review questionable.

Conclusions: Negative expectations can lead to the development and/or worsening of symptoms. In addition, there is a need for testable conceptual frameworks to be developed within which expectations can be understood and measured accurately.

2.1 Introduction

The view that expectations can affect experiences is a widely held belief in health research and clinical practice: one of the reasons for blinding patients to their assigned treatment arm in clinical trials is based on the idea that if people believe they are taking an active substance this belief can lead to reporting of symptom change whether the substance is active or inactive (Peck and Coleman, 1991). The placebo effect, which is where beneficial effects are reported following the administration of an inactive substance (i.e. a placebo) is well known; however, perhaps less well known is the nocebo effect which was originally defined as the development of side-effects after taking a placebo. Evidence for this phenomenon originally came from drug trials where negative side-effects were reported by participants in controls groups of clinical trials (Kennedy, 1961). Meta-analyses of nocebo effects in clinical trials have provided further evidence of this effect (Amanzio, Benedetti and Vase, 2012; Amanzio, Corazzini, Vase and Benedetti, 2009; Papadopoulos and Mitsikostas, 2012). It is claimed that placebo and nocebo effects are caused by the belief that the substance being taken is active and can have beneficial (placebo) or detrimental (nocebo) effects (Sherman et al. 2010).

Although there is some contention surrounding the mechanisms and existence of placebo and nocebo effects (e.g. Kienle and Kiene, 1997); it is generally argued, if they exist, conscious expectations and conditioning both play central roles in their development (Benedetti, 2006). Under experimental conditions pain intensity ratings can be modified by information designed to manipulate expectations about the impending painful event (e.g. Benedetti, Amanzio, Casadio, Oliaro, and Maggi, 1997). Perhaps more dramatically, the analgesic effect of opioids can be eliminated with the information that the drug will increase pain and different regions of the brain are activated under this condition compared to informing participants that the drug will alleviate the pain or do nothing (Bingel et al. 2011).

Research such as this has provided evidence that expectations can affect the experience of pain in laboratory settings; however, there is less evidence regarding how expectations might be important in clinical settings, for example, more long term functional or treatment outcomes in patients with chronic conditions (Sherman et al. 2010).

Much of the research examining whether expectations affect functional and treatment outcomes in patients relies on being able to measure expectations. Accurate measurement of any construct requires, at the very least, a definition of the construct being measured; furthermore, to be able to review the evidence regarding expectations effectively it is

important to be aware of how they are defined and conceptualised in the literature and how this is used to guide measurement in research.

Defining expectations is not straightforward: for example, the dictionary defines them as 'A (strong) belief that something will happen or be the case in the future' (Oxford Dictionaries, Online); whereas (Benedetti and Amanzio, 2011) describe expectations from an evolutionary perspective where they can be thought of as preparing the body so that it can cope with an event better. (Janzen, Silviu, Slaughter, Dalziel, and Drummond, 2006) state that, "broadly speaking, expectancies are stored associations between behaviours and resulting consequences, which then guide subsequent behaviours." (p39). Both Benedetti and Janzen include the possibility of conditioning as part of their definition (although not explicitly stated); conditioning, simply put, is the unconscious association of a stimulus with a response, which is arguably an unconscious expectation. These examples show that expectations can be viewed from different perspectives and that this is not a simple construct.

The most frequently cited conceptual framework for understanding expectations in relation to health is Thompson and Sunol's (1995) model which sets out four types of expectation: predictive (belief about what will happen), ideal (what someone wants to happen), normative (what ought to happen) and unformed (which represents a state where a person is unable to express their expectations as they are gathering information or they are too difficult or painful to express). However, this framework is problematic: ideal and normative expectations do not necessarily include any belief that the outcome will happen and unformed expectations are not actually expectations until they become formed. Another frequently cited framework for understanding health expectations was suggested by Olsen, Roese and Zanna (1996) who argue that expectations come from three main sources: direct experiences, beliefs and other people. These frameworks are descriptive rather than explanatory and do not address how expectations might affect outcomes.

Janzen et al. (2006) developed an explanatory theoretical model of how expectations are formed and how they might affect outcomes. They argue that there are six stages from formulation to post-outcome cognitive processing, which are: a precipitating phenomenon; prior understanding; cognitive processing; expectancy formulation; outcome; post-outcome cognitive processing (see Fig. 1).

In this model, expectations are cyclical as well as longitudinal in nature, i.e. the stages happen in order and because expectations are based on knowledge and experience. As more

knowledge and experience is gained, expectations should change or become strengthened to reflect this.

Although it has not been tested, this is the only convincing model in the literature. However, there are some methodological issues; it was developed using expectations that were only reported retrospectively and, by their nature, expectations are about the future.

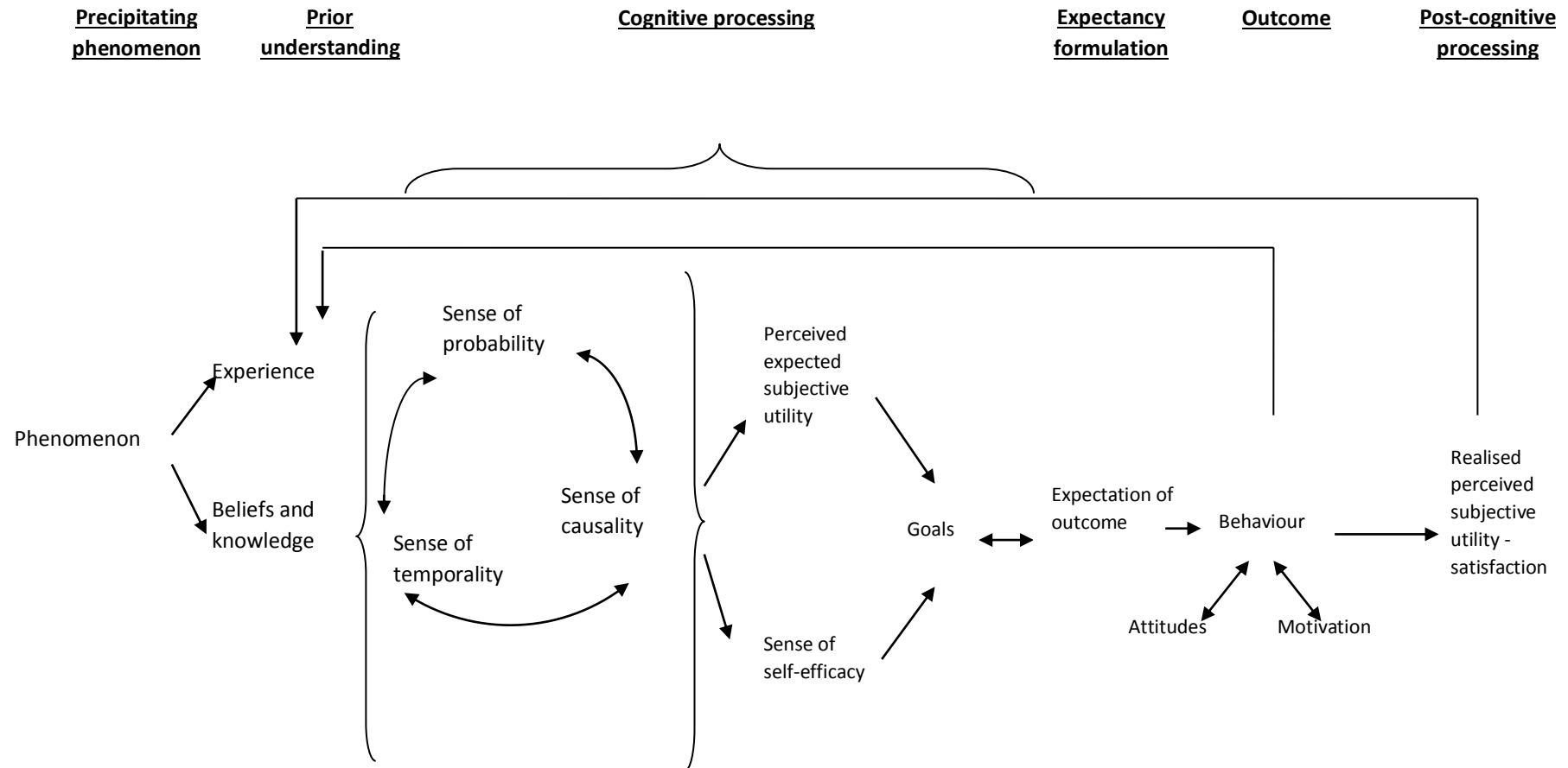


Figure 1.

Janzen et al. (2006) - model of expectation formulation

Although the model is designed to represent how individual expectations are formed and affect outcomes, the quotes that the authors use to illustrate each stage are relating to different types of expectations and come from two different people. Both the retrospective reporting of expectations and the lack of continuity in the examples used to illustrate the stages lead to questions regarding the validity of this model.

In addition to the complexity of expectations and how they might affect outcomes, it is likely that expectations are not stable over time and that they will be affected by new information and experiences; in addition, factors such as disposition and mood state are also likely to be important. If expectations do have an effect on outcomes, it is likely that the interaction between the brain mechanisms involved and behaviour is complex, which means that measuring them may not be straightforward.

Although it seems clear that expectations are not a simple construct and that defining and measuring them is not straightforward, the literature in this area lacks clarity (Haanstra, van den Berg, Ostelo, et al., 2012). Many authors do not provide a definition of what they mean by expectations and, as mentioned, there have been few attempts to develop explanatory conceptual frameworks which explain how expectations might affect outcomes (Janzen, Silviu, Slaughter, Dalziel, and Drummond, 2006). Measurement of expectations is often one or two questions regarding outcomes or interventions or questions extracted from other standardised measures. These problems with definition and measurement lead to the question of what exactly is being measured in this research.

Not only are there problems with defining what expectations are, but also defining what negative versus positive expectations are is not clear-cut; the distinction could be viewed relatively as expectations of a good outcomes versus expectations of a less good outcome or absolutely as in expectations of a good outcome versus expectations of a bad outcome. Moreover, it is arguable that what constitutes a negative expectation as opposed to a positive one depends on the circumstances. In circumstances where improvement would normally be expected, for example, surgery for back pain, expecting to remain the same, or to only improve slightly, could be interpreted as a negative expectation; whereas in circumstances where no or little improvement or, even deterioration, would normally be expected, for example, conditions which cause chronic pain, like arthritis, expecting to remain the same or improve slightly could be interpreted as neutral or positive expectations. In addition,

confidence in the expectation may be important and this will be influenced by a variety of factors, for example, prior knowledge. These issues are rarely discussed in the literature and little is known about how expectations are formed and what it is that is important about them that might affect health outcomes.

It is probable that, in medical populations, expectations interact with outcomes in different ways and at different levels, for example, the evidence from drug trials and pain experiments suggests that expectations affect outcomes directly through some sort of biological mechanism(s); in addition, negative expectations might form unconsciously leading to conditioned responses (e.g. Andrykowski, Jacobsen, Marks, et al., 1988). Moreover, expectations for the efficacy of physical or medical interventions may affect adherence or efficacy itself (e.g. Kalauokalani, Sherman, Koepsell, and Deyo, 2001; Benedetti, Pollo, Lopiano, et al., 2003).

The effect of expectations on health outcomes may be an important area of research for clinical practice and research. If patients who have expectations of negative functional outcomes for chronic conditions have worse actual outcomes than those who expect positive outcomes; or, if expectations of a negative outcome for a medical intervention result in reduced benefit from the intervention, then it is arguable that to be able to accurately identify those with negative expectations, valid and reliable measures would be essential and interventions necessary to modify negative expectations.

2.2 Focus of this Review

This paper will focus on whether expectations of negative health outcomes in people who have a chronic medical condition result in poorer outcomes, including the effects these might have on the efficacy of medications, medical devices, surgery and physical interventions.

2.3 Aims and Objectives

The aim of this paper is to review the evidence concerning what effect negative expectations have on health outcomes in people with physical medical conditions.

Primary Objectives

The primary objectives are to investigate whether expectations of a negative outcome or outcomes in people with a medical condition lead to an increase in

symptom severity or frequency and whether expectations of a negative outcome from an intervention for a medical condition lead to a reduction in benefit or a negative outcome from the intervention.

Secondary Objectives

Secondary objectives are to explore the relationship between expectations, where they come from and how confident participants are in them and how this relates to health or physical outcomes.

2.4 Methods

Research which focused on expectations of a negative health outcome or negative outcome of an intervention in people who have a medical condition and how this is related to health experiences was considered for inclusion. Most designs were considered, including randomised and non-randomised controlled trials, case-controlled studies, cross-sectional research, longitudinal designs and qualitative research.

Inclusion Criteria

Papers which

- either manipulate information or investigate the effects of different kinds of information about a medical condition, device or intervention that could influence expectations and relate this to health outcomes
- measure expectations pre intervention and relate these to negative health outcomes post intervention
- measure expectations of a medical condition and relate these to negative health outcomes
- qualitatively investigate the effect of negative expectations on health or physical experiences

were considered for inclusion.

In addition, only papers using human populations; empirical research; research from peer reviewed journals and papers written in English were included.

Exclusion Criteria

Because this paper is focused on expectations of negative outcomes, studies which compare the effects of inducing or measuring positive and neutral expectations, but not negative expectations were excluded.

A pragmatic definition of negative expectations was employed which defined these as:

- absolute (i.e. expectations asked about ranged from worse to better) where improvement was not necessarily expected from the prognosis (e.g. chronic pain conditions).

- relative (i.e. remain the same to better) where the expectations measured were in a situation where improvement is expected (e.g. expectations of treatment benefit).

As discussed earlier, expectations must include a belief about something occurring in the future. Therefore, studies that define expectations as hopes or desires only, or which ask participants about expectations retrospectively, were excluded. Studies investigating placebo effects in clinical trials were excluded on the basis that there is no measurement of expectations nor manipulation or analysis of information, i.e. it is assumed that negative outcomes are due to expectations. Finally, in an attempt to keep this review focussed and within realistic limits, studies which only measure or report psychosocial outcomes, use only psychiatric populations, or which investigate health behaviours (e.g. addiction) or speech impediments were also excluded.

Additional exclusion criteria for studies that measure expectations.

Studies which measure expectations but do not relate them to outcomes were excluded because this paper is concerned with the affect that expectations might have on outcomes. Studies that do not provide a description of how they measured expectations were excluded because there is no way of knowing whether these were defined as hopes or desires.

Outcomes

Primary outcomes:

1. worsening or development of a medical or physical condition in people with a physical medical condition as defined by the authors
2. reduced efficacy or a negative outcome of a medical or physical intervention

Secondary outcomes:

1. nature and extent of expectations and how these relate to health outcomes

Search Methods

Electronic.

The following databases were searched firstly in May 2012 and again in July 2013:

- AMED
- EMBASE
- Medline
- Psychinfo
- CINAHL
- Web of Science
- PubMed

Other resources.

The reference lists of all identified papers were examined for other possible studies; in addition, the individual journal sites of Spine (Spine) and Health Expectations (Health Expectations: an International Journal of Public Participation in Healthcare and Health Policy) were also searched.

Search Strategy.

The search strategy was developed by four people and the main searches carried out by two people (one who is an expert in search strategies). Because there is no standardised terminology in this area, it was decided to try and keep the searches as broad as possible (see Appendix 1 for the search strategy used); however, this was not sufficient to capture all the literature and searching reference lists of included papers and individual journal sites was also necessary.

Screening for eligibility.

Titles and abstracts were screened for eligibility by the current author according to the inclusion / exclusion criteria, and full papers were obtained for all eligible studies. Screening forms were completed for all full papers and excluded studies are listed with reasons for their exclusion: 36 studies full text articles were excluded (see table 1 below).

2.5 Results

12,660 titles were identified through searching the databases and 53 through other means (reference lists of included papers and searches in individual journals) making a total of 12,713 titles screened. 11,914 were excluded and abstracts for 799 papers were obtained and reviewed for eligibility; 742 of these were excluded and 56 full papers were obtained. Of these 20 (see table 1 for the characteristics of included studies table) were found that met the inclusion/exclusion criteria (see fig. 2 PRISMA diagram).

Table 1

Excluded studies

Reason for Exclusion	No. of Papers
Does not measure or manipulate expectations or is not about expectations	9
Only measures or induces positive expectations or is about the placebo effect	7
Expectations measured are not related to the patient's condition	4
Expectations are only measures retrospectively	4
The population was not described as having a physical medical condition	3
The expectations are not for physical outcomes	3
No description of the scale used to measure expectations	3
The paper measures expectations but does not measure outcomes	3

Table 2*Characteristics of included studies*

Study	Methods	Outcomes	Main results
Andrykowski et al., 1988	Prospective study to identify factors related to anticipatory nausea (AN) in patients undergoing chemotherapy (N=77).	Presence of pre-treatment nausea and / or vomiting.	Higher expectations for development of AN predicted increased chemotherapy-related nausea.
Benedetti et al., 1997	Double blind RCT with 10 conditions to investigate the effects of the CCK antagonist Proglumide on placebo hyperalgesia (N=180). (See app 2 for a full description of all conditions).	Pain intensity rating.	Pain ratings increased significantly with a placebo injection and verbal suggestion.
Benedetti et al., 2003	Experimental design to investigate the role of verbal suggestion on motor performance in Parkinson's patients with deep brain stimulation (N=10).	Movement velocity.	Movement velocity was affected by verbal suggestions regarding whether the stimulator was turned on or off.
Bertisch et al., 2009	Analysis of data from the placebo arm of a RCT to investigate which psychological factors, including expectations of pain, contribute to the placebo effect in patients with persistent distal upper arm pain (N=119).	Pain intensity.	Baseline pain was the only predictor of pain at follow-up.
Boersma et al., 2006	Prospective study investigating the psychological processes underlying the development of chronic pain in people with non-specific back or neck pain (N=141).	Average pain and disability at one year.	The expectation of persistent pain, negative affect and fear avoidance beliefs together predicted future pain.
Cassileth et al., 1985	Prospective study to determine whether expectations of individual side effects were associated with the frequency and severity of actual side effects (N=56).	Chemotherapy related side effects.	No effect of expectations on side effects were found.

Study	Methods	Outcomes	Main results
Henn et al., 2007	Prospective study to evaluate the effect of patients' preoperative expectations about rotator cuff repair on self-assessed outcome at one year post surgery (N=125).	Functional abilities and pain at one year.	Positive expectations predicted better functional outcomes, higher quality of life and less pain.
Kalauokalani et al., 2001	Prospective study designed to investigate whether expectations of treatment outcome were related to actual outcomes in patients with back pain undergoing massage or acupuncture (N=166).	Back pain.	Expectations of treatment benefit predicted functional outcomes.
Lang et al., 2005	Observational study investigating the effects of how descriptions of procedures as painful or unpleasant affect the experience of the procedure. (N=159).	Pain and anxiety ratings.	Negatively loaded suggestions during medical procedures increased pain ratings significantly compared to saying nothing.
Linde et al., 2007	Pooled analysis of four randomized controlled trials of acupuncture for migraine, tension headaches, back pain, and osteoarthritis investigating the influence of expectations on clinical outcome (N=302).	<p>Headaches: no. of days with headaches in the 4 weeks post treatment.</p> <p>Back pain: pain intensity at end of trial (8 weeks).</p> <p>Osteoarthritis: functional abilities at end of trial.</p>	Expectations of treatment benefit were associated with better outcomes.
Mannion et al., 2009	Prospective study of expectations for recovery after lumbar decompression surgery (N=100).	Change in symptoms, functional abilities and ratings of treatment effectiveness at 2 and 12 months.	Expectations did not predict any of the outcomes.

Study	Methods	Outcomes	Main results
McGregor et al., 2002	Prospective study investigating patient expectations of surgery and both short and long term satisfaction with the outcome of decompression surgery in terms of pain, function disability and general health (N=84).	Satisfaction. Functional status and pain at 6 weeks and 6 & 12 months.	No results reported for the effect of expectations. Expectations were significantly higher than outcomes.
Mondaini et al., 2007	RCT assessing whether counselling on sexual side effects of Finasteride has an effect on sexual dysfunction in men with benign prostatic hyperplasia (N=120).	Sexual dysfunction at 6, 12 and 18 months.	Knowledge of potential side-effects affects sexual function at 6 and 12 months but not at 18 months.
Rhodes et al., 1995	Prospective study investigating whether expectations of nausea and vomiting predict actual nausea and vomiting in patients undergoing chemotherapy for the first time (N=239).	Presence of nausea and/or vomiting post chemotherapy.	No effect of expectations on nausea and/or vomiting.
Ronnberg et al., 2007	Prospective study investigating if expectations of surgical results in patients undergoing surgery for lumbar disc herniation predict outcomes (N=183).	Satisfaction, physical functioning and return to work 2 years post-surgery.	Higher expectations predicted better outcomes at 2 years.
Roscoe et al., 2000	Two prospective studies investigating whether pre-treatment expectations for nausea and vomiting predicted post treatment nausea and vomiting in cancer patients undergoing chemotherapy (N=22 & N=69).	Presence of nausea / vomiting post chemotherapy.	No effects of expectations on nausea.
Roscoe et al., 2004	Prospective study examining whether pre-treatment expectations for nausea and vomiting predicted post treatment nausea and vomiting in cancer patients undergoing chemotherapy (N=194).	Presence of nausea / vomiting post chemotherapy.	Expectations predicted severe nausea but not vomiting.
Soroceanu et al., 2012	Prospective study to investigate the relationship between pre-operative expectations and post-operative outcomes and	Post operative satisfaction and functional outcomes.	More positive expectations predicted lower satisfaction but better

Study	Methods	Outcomes	Main results
	satisfaction in lumbar and cervical spine surgery (n=402).		functional outcomes.
Terry et al., 2007	Prospective study which aimed to explore the relationship between patients' expectations, actual pain experiences and retrospective reports of postoperative pain intensity (N=38).	Associations between expected, actual and memory for pain.	Positive correlations between expectations of pain intensity and anxiety ratings and between actual pain intensity and anxiety ratings
Toyone et al., 2005	Prospective study to assess effect of expectations of spinal surgery and how far these are fulfilled (N=100).	Functional status.	Patients were satisfied with surgery had significantly better outcomes for leg pain, usual activities and leg numbness than those who were less satisfied.

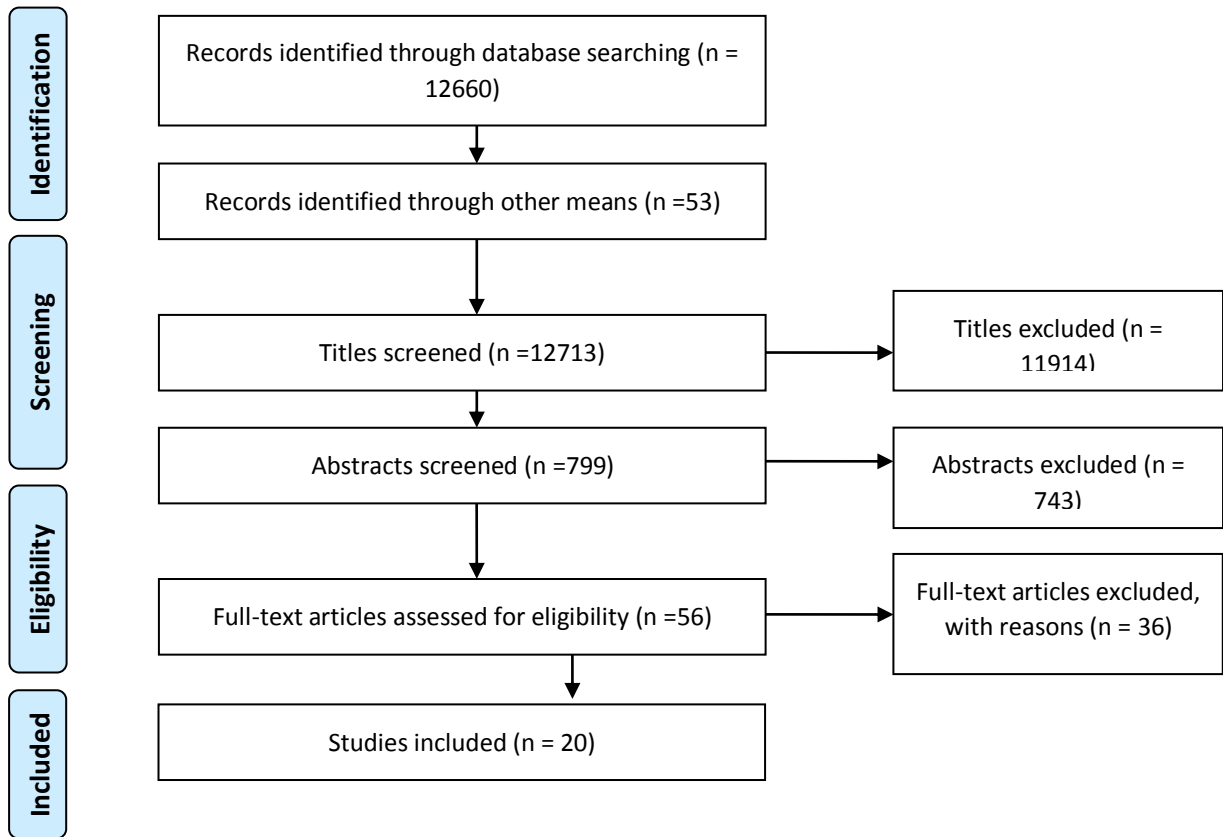


Figure 3. PRISMA diagram

Assessment of Methodological Quality

Methodological quality (see Appendix 2 for the 'Quality Assessment Table') was assessed by the current author and based on methods used by another author in this area (Verbeek, Sengers, Riemens, and Haafkens, 2004). It was assessed on the basis of adequate descriptions of:

- The participants: including inclusion/exclusion criteria, selection of study population and descriptions of participants
- Methods and data collection: including descriptions of measures used and in particular, measures of expectations
- Analysis and results
- Conclusions

Quality Assessment

14 of the 20 studies were considered to be of medium quality and 6 of high quality, none were of low quality.

Study Categorisation

Studies will be categorised using the inclusion criteria for study types as below.

Included studies:

Of the 20 studies included in this review (see table 2):

- 4 studies were identified that manipulated information to influence expectations or analysed the effect of information on outcomes (Benedetti et al. 1997; Benedetti et al. 2003; Lang et al. 2005; Mondaini et al. 2007)
- 15 studies were identified that measured expectations pre intervention and related these to health outcomes post intervention (Andrykowski et al. 1988; Cassileth et al. 1985; Rhodes, Watson, McDaniel, Hanson, and Johnson, 1995; Roscoe et al. 2004; Roscoe, Hickok, and Morrow, 2000; Henn, Kang, Tashjian, and Green, 2007; Kalauokalani, Cherkin, Sherman, Koepsell, and Deyo, 2001; Mannion et al. 2009; McGregor and Hughes, 2002; Ronnberg et al. 2007; Soroceanu, Ching, Abdu, and McGuire, 2012; Terry, Niven, Brodie, Jones, and Prowse, 2007; Toyone et al. 2005; Bertisch et al. 2009 and Linde et al. 2006).
- 1 study measured expectations of a medical condition and related these to health outcomes (Boersma and Linton, 2006)
- no qualitative studies were identified.

Studies that either manipulated information to influence expectations or analysed information given and related it to outcomes: four studies that either manipulated information to influence expectations or analysed information given to patients and related it to outcomes were identified:

- One manipulated information relating to a placebo injection (Benedetti, et al. 1997).
- One manipulated information regarding a medical device (Benedetti et al. 2003).
- One study manipulated information regarding the side-effects of medication (Mondaini et al. 2007)

- One study analysed information given to patients during medical consultations and related this to outcomes (Lang et al. 2005).

In general, these studies found that varying information about an impending event or about possible side-effects of medication can affect the experience of the event or development and severity of side-effects. The research in this category largely fell into three categories: experimental research designed explicitly to induce a nocebo response (Benedetti et al. 1997 and Benedetti et al., 2003); research that was designed to manipulate expectations about a medical intervention that the patients were undergoing as part of their clinical care (Mondaini et al., 2007) and observational research which analysed the effect of language on pain experienced during medical procedures (Lang et al., 2005). This research was quite diverse in terms of the information manipulated, the patient groups and the outcomes measured and therefore will largely be discussed separately

Benedetti et al. (1997) and (2003) found that negative information about an impending event negatively affected the experience of the event. Mondaini et al. (2007) found that negative information about side-effects of a medication impacted on the development of side-effects and Lang et al. (2005) found that use of negative language prior to medical procedures affected the experience of pain intensity during the procedure.

Benedetti et al. (1997) and Benedetti et al. (2003) manipulated information explicitly designed to induce a nocebo response in their patients. Benedetti et al. (1997) conducted a double blind randomised design with 10 conditions and 180 patients to investigate the effects of verbal suggestion on the nocebo response using an injection of saline. In addition, they investigated whether the hormone cholecystokinin (CCK), which can be triggered by anxiety inducing verbal information, is implicated in, and whether endogenous opioids mediate, the nocebo response.

They found that patients who were aware of the injection and were informed that it would increase their pain had significantly higher pain ratings than the no treatment group who were unaware of the injection and had been told nothing ($F(1,34) = 39.69, p = .005$). In addition, their results showed that by administering an increasing dose Proglumide, which is CCK antagonist, the nocebo response was inhibited ($F(3,68) = 16.26, p = .001$) implicating CCK in the nocebo response. Moreover, they found that by administering a hidden injection Naloxone (an opioid antagonist) as well as a hidden

injection of Proglumide (in two conditions) the inhibition of the placebo response remained, shown by the non-significant differences between these groups and the no treatment group ($F(1,34) = 2.77, p = .105$ and $F(1,34) = 2.3, p = .138$). This result suggests that endogenous opioids did not mediate the placebo response observed in this study.

The most relevant result for this review is that pain ratings can be increased significantly with a placebo injection and the information that the injection will cause an increase in pain as it suggests that by inducing a negative expectation of pain, the actual experience of pain is affected negatively. In addition, the results regarding CCK and endogenous opioids are interesting and point to potential mechanisms involved in the placebo effect, including one possible role of anxiety.

Benedetti et al. (2003) investigated whether motor performance (measured using hand movement velocity) in 10 Parkinson's patients, who had all had bilateral subthalamic deep brain stimulation, could be affected by informing them the levels of stimulation had been changed. They found that informing patients that the stimulator had been turned off, when actually no adjustment had been made, resulted in significantly slower hand movement velocity compared to not telling them anything ($F(1,9) = 5.24, p = .04$) suggesting that motor performance in Parkinson's patients can be significantly affected by verbal information alone.

Although both of these studies employed experimental designs and used information and procedures not normally used in health care settings, meaning they may lack ecological validity, their results are probably some of the clearest evidence in the papers included in this review for the possibility of negative effects caused by inducing negative expectations in patients.

Mondaini et al. (2007) attempted to manipulate expectations to investigate the effect they might have on side-effects from medication. They manipulated information about the medication Finasteride used for treating benign prostatic hyperplasia (BPH). 107 patients were randomised to two groups: one group were told that Finasteride was effective for BPH and nothing else (group 1) and the other that it was effective for BPH but that it could also cause sexual dysfunction although this was uncommon (group 2): both groups were blinded to the actual name of the drug. The results at follow-up suggested that the information given did have a significant effect on sexual function: group 2 ($n = 55$) reported a significantly higher proportion of one or more

sexual side effects as compared to group 1 ($n = 52$) (43.6% vs. 15.3%) ($p = .03$). The incidence of erectile dysfunction, decreased libido, and ejaculation disorders were 9.6, 7.7, and 5.7% for group 1, and 3.9, 23.6, and 16.3% for group 2 respectively ($p = .02$, $p = .04$, and $p = .06$ respectively). Follow-ups were at 6 months and 1 year and although the authors do not state this, it appears these results are from the 1 year follow-up.

The results presented in this review were the only inferential analysis reported and were only mentioned in the abstract of the paper with no further details about the tests used or interpretation of the results; the results section only reported percentages. This is unfortunate because not only does it lead to questions about the analysis used and the interpretation of the results, but also because it appears as though there may have been some interesting effects of the information on sexual dysfunction and that these effects had endured for 12 months. If providing information about possible sexual side-effects of Finasteride can have an effect on sexual function, this would have clear implications for clinical practice when prescribing this drug; however, it is not possible to view the results from this paper with any confidence.

Lang et al. (2005) transcribed and analysed 159 videos of medical procedures that were recorded for another study. They analysed the language for 'negatively loaded suggestions' which had been pre-defined and included threatening information about an upcoming procedure (e.g. this will hurt a bit). Pain and anxiety were assessed by self-report every 15 minutes during the procedure.

The results suggested that warning a patient of a potentially painful event with negatively-loaded wording was associated with subsequent increased reported pain than not saying anything before the event (pain scores 3.9 vs. 2.8, $F(1,399) = 4.99$, $p = .0261$). Warning the patient was also associated with subsequent increased reported anxiety (anxiety scores 4.4 vs 3.2, $F(1,399) = 11.75$, $p = .0007$). These results suggest that using negatively loaded suggestions affects pain significantly. This study could be interpreted as providing some support to Benedetti et al's (1997) study that anxiety inducing language can increase CCK and therefore increase pain.

These studies, although diverse in terms of the methods, types of information used and outcomes, provide some support for the claim that information about an event or about possible symptoms can affect the experience of the event or development of symptoms. The two papers investigating the effect of information on the experience of pain (Benedetti et al. 1997 and Lang et al 2005) both provide evidence

that by informing participants that they are going to experience pain or an increase in pain, results in increased pain ratings; in addition, anxiety may play a role in this effect. The evidence provided is strengthened by the fact that the two studies approached the question in different ways: one using experimental techniques and the other observational methods. Benedetti et al.'s (2003) study was small and not described in much detail as the paper reported 3 separate studies, two of which were excluded from this review because they used healthy participants; however, their results did suggest that motor performance in patients with Parkinson's who have deep brain stimulation can be affected by information about the stimulator.

Unfortunately it is difficult to conclude much from Mondaini et al's (2007) study due their lack of detail and clarity regarding their analysis.

Studies that measured expectations of a medical condition over time and related them to outcomes or measured expectations pre intervention and related these to outcomes post intervention. Although these are two categories, they will be discussed together as they both measured expectations and related them to outcomes. 16 studies were identified that measured expectations pre intervention and related these to health outcomes post intervention (Andrykowski et al., 1988; Cassileth et al., 1985; Rhodes, et al., 1995; Roscoe et al., 2004; Roscoe, Hickok, and Morrow, 2000; Henn, Kang, Tashjian, and Green, 2007; Kalauokalani, Cherkin, Sherman, Koepsell, and Deyo, 2001; Mannion et al., 2009; McGregor and Hughes, 2002; Ronnberg et al., 2007; Soroceanu, Ching, Abdu, and McGuire, 2012; Terry, Niven, Brodie, Jones, and Prowse, 2007; Toyone et al., 2005; Bertisch et al., 2009 and Linde et al., 2006). One study was identified that measured expectations of a medical condition and related this to outcomes (Boersma and Linton, 2006).

Measurement of expectations was approached in different ways by different researchers and there are few, if any, validated scales; therefore a description of the measures used is provided in Appendix 3 'Measures Table'. Broadly speaking, there were three main categories of measure; expectations for symptom development before or after a medical procedure, (for example, nausea associated with chemotherapy); expectations for current symptoms becoming worse over time (for example, chronic pain); and expectations for treatment outcomes (for example, functional outcomes following surgery); the studies will be discussed using these categories.

- Five studies measured expectations for symptom development before or after a medical procedure (Andrykowski et al. 1988; Cassileth et al. 1985; Rhodes, Watson, McDaniel, Hanson, and Johnson, 1995; Roscoe et al. 2004; Roscoe, Hickok and Morrow, 2000).
- One study measured expectations of a medical condition over time and related these to outcomes (Boersma and Linton, 2006).
- Ten studies measured expectations for treatment benefit (Henn, Kang, Tashjian, and Green, 2007; Kalauokalani, Cherkin, Sherman, Koepsell, and Deyo, 2001; Mannion et al. 2009; McGregor and Hughes, 2002; Ronnberg et al. 2007; Soroceanu, Ching, Abdu, and McGuire, 2012; Terry, Niven, Brodie, Jones, and Prowse, 2007; Toyone et al. 2005; Bertisch et al. 2009 and Linde et al. 2006) and related them to functional outcomes.

Results in this section were mixed in terms of whether a link was found between expectations and outcomes. In some cases, especially in the expectations for treatment outcomes category, participants had overly positive expectations for outcomes with few or no participants having negative expectations and the papers where this happened tended to focus on this discrepancy and the resulting dissatisfaction, meaning they are not directly relevant to this review.

In addition, links were found in some papers between positive expectations and positive health or functional outcomes, which, although not obviously pertinent to this review, might imply that those with lower or less positive expectations had worse outcomes. These papers were included because they gave participants the option to rate their expectations as negative.

Studies that measured expectations for symptom development: The five studies that measured expectations for symptom development before or after a medical procedure all investigated nausea and vomiting associated with chemotherapy: one study investigated expectations for pre-treatment nausea and vomiting and related this to actual pre-treatment nausea and vomiting. Results suggested that conditioning may be implicated in the development of pre-treatment nausea (Andrykowski et al., 1998); four investigated expectations for post-treatment nausea and vomiting or side-effects in general and related these to actual post-treatment nausea and vomiting or side-effects (Cassileth et al., 1985; Rhodes et al., 1995; Roscoe et al. 2004; Roscoe et al., 2000). Cassileth et al. (1985) and Rhodes et al. (1995) found patients tended to

experience more symptoms than they expected; Roscoe et al. (2004) and Roscoe et al. (2000) found a significant relationship between expectations for post-chemotherapy nausea and actual post treatment nausea, but not vomiting.

Andrykowski et al. (1998) measured expectations for pre chemotherapy nausea in 77 females about to undergo chemotherapy for breast cancer. They found that three variables accounted for 12% of the variance. Patients who developed pre-treatment nausea were characterised by greater severity ($\beta = .19$; $p < .05$) and duration ($\beta = .15$, NS) of nausea following their initial infusion as well as by greater expectations for experiencing chemotherapy-related nausea ($\beta = .17$, NS). The authors suggest that because greater severity and duration of nausea after the initial infusion predicted the development of pre-treatment nausea this implicates conditioning as an integral part of its development. These results do provide some evidence that conditioning is implicated in pre-treatment nausea; however, the questionnaire used was designed to measure expectations of post-treatment nausea and it is unclear from the description in the paper whether this was the purpose, i.e. that expectations of post-treatment nausea predict pre-treatment nausea, or if the questionnaire was adapted for this study.

Cassileth et al. (1985) measured expectations for post-chemotherapy side-effects; Rhodes et al. (1995); Roscoe et al. (2004) and Roscoe et al. (2000) all measured expectations for post-chemotherapy nausea and vomiting. Cassileth et al. (1985) and Rhodes et al. (1995) measured expectations in 52 and 239 patients respectively. Cassileth et al. (1985) measured expectations using a list of 16 toxicities associated with chemotherapy and asked patients to rate how much they expected to experience each one on a Likert scale. The same list was used as the outcome measure where patients were asked to indicate how far they had experienced each toxicity. They found that there was a mismatch between what patients expected to experience and what they actually did experience using chi-square analysis ($p < .01$). This is the only information given about this result and it is the only inferential analysis in this paper relating to expectations and outcomes. All other results were presented as numbers or percentages.

According to the authors, patients in this study tended to experience more side-effects than they expected, although it is difficult to see this from the results reported as they only report matches and non-matches between expectations and experiences with no indication of whether non-matches were between expectations for toxicities and no

experience or vice versa. It is difficult to conclude more from this paper due to lack of clarity in its results section.

Rhodes et al. (1995) measured expectations for post-chemotherapy side-effects by asking patients to list the symptoms they expected to experience. The description of their measure lacked clarity; the authors state that patients were asked to list expected symptoms and the expected distress associated with each; however, the description in their results section suggests they asked participants to list all possible side effects and how far they expected to experience them. Results relating to expectations and experiences were mostly percentages with the exception of two chi-squares: expectations for nausea and expectations for vomiting and occurrence of these ($p=.024$ and $p=.158$ respectively). Other results were that, out of the sample who listed nausea as a symptom ($n = 299$), 49% did not expect to experience nausea and 53% experienced nausea during the 48-hour period after treatment. 29% of the total sample had post chemotherapy total nausea occurrence scores of >9 (representing significant-severe nausea). These results lack clarity and the authors discuss them in terms of a large discrepancy between expectations and experiences; however, examining the above percentages it does not appear as though there was a large discrepancy with almost half expecting nausea and almost half experiencing it. It is impossible to conclude more from this study without further information regarding its results.

Roscoe et al. (2000) and (2004) measured expectations using a two item questionnaire which asked participants to rate how far they expected to experience nausea and vomiting post-chemotherapy. Roscoe et al. (2000) report two studies with 29 in one study and 81 participants in the other. They found that expectations of nausea following chemotherapy to be a significant predictor of post-treatment nausea in both studies. In study 1, patients expecting nausea reported significantly greater nausea severity than patients not expecting nausea at the first treatment ($\bar{x}= 2.6$ versus 1.7), $t(27) = 2.44$, $p = .02$, but not at the second treatment ($\bar{x}=2.1$ versus 1.6), $t(20) = 1.76$, $p = .09$. In addition, after controlling for pharmacological and physiological variables known to predict nausea, expectations for nausea accounted for a significant and unique variance in nausea severity ($p < .04$).

In study 2, patients expecting nausea reported significantly greater nausea severity than patients not expecting nausea at the third treatment ($\bar{x} = 2.6$ vs 1.4, $p = .001$) and for their \bar{x} level of nausea severity ($\bar{x} = 2.2$ vs 1.6, $p = .02$) but not at the first

treatment ($\bar{x} = 2.1$ vs 1.8 , $p = .17$). After controlling for pharmacological and physiological variables known to predict nausea, expectations for nausea accounted for a significant and unique variance in nausea severity ($p < .03$). The results from both studies indicate a significant relationship between pre-treatment expectations for nausea and the development of post chemotherapy nausea; however, using a questionnaire which specifically asks about expectations for nausea may suggest this symptom to the patient and although they may not be expecting to experience it at the time of completing the questionnaire, as expectations are not stable over time, it is possible that an expectation for nausea could develop after completing the questionnaire and therefore any effects of expectations would be lost.

Roscoe et al. (2004) also found that pre-treatment expectations predicted post-treatment nausea ($p = .002$); however, they only found a significant relationship between post-treatment nausea and retrospective expectations: they asked patients to state what their expectations had been before they spoke to their doctor rather than measuring expectations before the patient actually did speak to their doctor. There was no significant relationship between current expectations and post treatment nausea.

The authors explain this discrepancy with the argument that information given by doctors and nurses was overly optimistic. Although the authors' conclusions may be correct, there is no way of knowing whether patients would have answered differently prior to their consultation which leads to questions regarding the validity of these results. In saying that, the results suggest that patients *believed* they had higher expectations for nausea prior to speaking to their doctor.

This evidence taken together provides some fairly limited support for expectations of post chemotherapy nausea having an effect on nausea experienced following treatment and that conditioning may be implicated in pre-treatment nausea. However, there are methodological issues with some of the papers and incomplete descriptions of methods and questionnaires. No study used an instrument that had undergone any reliability or validity testing. Some of the questionnaires had the disadvantage of possibly suggesting nausea to patients, while others asked for retrospective expectations.

Studies that measured expectations of a medical condition and related these to outcomes: one study measured expectations for a medical condition (Boersma and Linton 2006). 141 patients with various chronic pain conditions were recruited and

rated their expectations for their current pain becoming persistent. Follow up was one year and the key finding was that the expectation of persistent pain, negative affect and fear avoidance beliefs had a small (14-15%) but unique predictive value for future pain and disability after controlling for age, gender and average pain at initial assessment. Assessment of expectations in this study relied on only one question about current pain becoming persistent. This makes it difficult to answer if the patient expects their pain to get worse, better, but still there, or intermittent. In addition, this scale may be measuring different expectations in different people, for example, where a patient's pain is already persistent, then they are being asked if they expect it to remain the same, whereas where a patient does not have persistent pain, they are asked if they expect it to get worse.

Studies that measured expectations for treatment benefit: ten studies were identified that came into this category. Of these seven measured expectations for outcomes following surgery (Henn et al. 2007; Mannion et al., 2009; McGregor et al., 2002; Ronnberg et al., 2007; Soroceanu et al., 2012; Terry et al., 2007; Toyone et al., 2005) and related them to functional outcomes. Two studies measured expectations for benefit from real treatments (acupuncture and massage) (Bertisch et al., 2009 and Kalauokalani et al., 2001) and one for placebo treatments (sham acupuncture and a placebo pill) (Linde et al. 2007). Due to the nature of their findings these studies will be discussed in the categories of surgical expectations and expectations of other treatments.

Henn et al. (2007); Mannion et al.(2009); McGregor et al. (2002); Ronnberg et al. (2007); Soroceanu et al. (2012); Toyone et al. (2005) measured expectations for surgical results. All surgeries were for back related problems and the surgery was elective rather than essential. In all of these studies expectations were generally very high for recovery, for example in the study by Ronnberg et al. (2007) 94% had high expectations for recovery from leg pain, 81% from back pain, 71% sensibility and 72% muscle function and in Henn et al. (2007) negative expectations for recovery of functions were 0.8-2.4% of their sample.

The focus of these studies tended to be on the discrepancy between expected and actual outcomes and the resulting dissatisfaction; therefore, none of these papers will be reviewed here. Mannion et al. (2009) found no relationship between expectations and outcome and in all the multivariate regression models the most

significant predictor of treatment effectiveness was the expectations-actuality discrepancy (standardized $\beta = .28$, $p = .013$), which the authors argue is a measure of satisfaction.

Henn et al. (2007) and Ronnberg et al. (2007) found that positive expectations were related to better functional outcomes; for example, Henn et al. (2007) found more positive preoperative expectations correlated with better postoperative outcomes (p values ranging from $<.0001$ to $.03$); Soroceanu et al. (2012) found a relationship between positive expectations and sleep quality; Toyone et al. (2005) and McGregor et al. (2002) only reported descriptive statistics in their analysis of expectations. Although these studies found effects for positive expectations only, it might suggest that those with lower expectations had worse functional outcomes; however, it should be noted that there may be issues with ceiling effects in these studies, with expectations being so high.

Terry et al. (2007) investigated expectations for post-operative pain and pain intensity experienced following surgery. They found little discrepancy between expectations for pain and actual pain.

The results directly relevant to this review were positive correlations between expectations of pain intensity and anxiety ratings and between actual pain intensity and anxiety ratings, suggesting that participants with higher levels of anxiety tended to expect and report experiencing greater levels of pain. This finding is interesting in light of Benedetti et al.'s study (1997) which found that CCK which can be induced by anxiety and is implicated in the nocebo effect.

Expectations for other treatments: three studies measured expectations for treatment benefit other than surgery (Bertisch et al., 2009; Kalauokalani et al., 2001; Linde et al., 2007).

Bertisch et al. (2009) measured expectations of two treatments (a placebo pill and sham acupuncture) in 119 patients with persistent distal upper arm pain. Patients were not aware the treatments were not designed to be effective. They found no effects of expectations apart from a positive correlation between expectations and pain at 6-8 weeks following surgery. Regression analysis found only baseline pain to be a predictor of actual pain at follow up explaining 23% of the variance in the sham acupuncture group and 12% of the variance in the placebo pill group. One possible

explanation for the lack of effects is that they asked for patients' expectations for pain 2 weeks from filling in the questionnaire, which meant they would still be having treatment at the time they were being asked to reflect on. It seems quite possible that if the question had been asked about the end of treatment (when they were actually followed up) the answers would have been different.

Kalauokalani et al. (2001) investigated whether expectations of treatment benefit were related to outcomes in 135 patients with back pain undergoing massage or acupuncture. Using the score from the measure of expectations for treatment benefit the sample was dichotomised into equal sized groups defined as having either a "higher" or "lower" expectations for treatment benefit.

The participants with higher expectations had greater baseline functional disability than those with lower expectations (\bar{x} =13.2 vs 11.1, p = .01). Patients with higher expectations of their assigned treatment group had a significantly better outcome score (p =.01). Adjusting for potential confounders, the relative odds of improvement for a participant with higher expectations as compared with a participant who had lower expectations was 5.3 (95% confidence interval [CI] 1.9 –15.4, p = .002). These results could be interpreted as providing evidence for a reduction in benefit from an intervention due to lower expectations of the intervention.

Linde et al. (2007) investigated acupuncture in patients with migraine (n =302), tension-type headache (n =207), chronic low back pain (n =298), and osteoarthritis of the knee (n =296) investigating the influence of expectations on clinical outcome. Measurement of expectations was items about belief in treatment efficacy and expectations for treatment benefit

In all four trials nearly all patients expected a clear improvement from treatment. After three treatment sessions the majority of patients were highly confident that they would benefit from the treatment they were receiving. There were no patients who expected 'no improvement' from treatment.

Positive attitudes towards acupuncture, high personal expectations and confidence in benefit from treatment were consistently associated with significantly better outcomes both after completion of treatment and at follow-up, both in the univariate and the multivariate analyses.

In all the studies that measured expectations of treatments, expectations for outcomes were high which means that their relevance to this review is limited. However, there may be some relevance, in that, if patients with higher expectations have better functional outcomes than those with lower expectations, it may suggest a reduction in benefit from treatment.

Analysis

There were no studies suitable for a meta-analysis as the outcomes measures were too diverse or the quality of measures was too low.

2.6 Discussion

The research presented above offers some support that negative expectations can have an effect on health outcomes in medical populations. Evidence relating to negative expectations having an effect on the development or worsening of symptoms provided the most support for this view. The studies which used verbal suggestion to induce negative expectations (e.g. Benedetti et al., 1997) were the most successful in showing the effects of negative expectations on the experience of pain. In addition, the studies by Benedetti et al. (1997) and Lang et al. (2005) provide some evidence that anxiety might play a vital role in pain perception.

Boersma et al.'s (2006) study provided some encouraging evidence that negative expectations might be involved in the development of chronic pain; however, there were some methodological issues with their question regarding expectations.

In the research which measured expectations of treatment benefit, where, although participants were given the option of rating their expectations as negative, few if any did, led to problems with discerning any effects of lower expectations. However, there was some evidence that those with higher expectations for treatment benefit had better functional outcomes than those with lower expectations suggesting that lower expectations may result in a reduction in benefit from the treatments.

One serious limitation in the research reviewed was the problems with analyses and reporting only, or predominantly, descriptive results in some of the papers. The lack of clarity in some of the results sections led to questions about the interpretation of results and the validity of any significant findings, for example, Mondaini et al. (2007) who only reported p values in their abstract and did not discuss them. This was particularly unfortunate in the case of Mondaini et al. (2007) as it did appear from the results that they did report that there might have been some interesting effects in their study.

In addition, the measures of expectations reviewed here lacked theoretical foundations and definitions of expectations were often missing meaning that research may not always be measuring the same construct and sometimes what is being measured may not be expectations (e.g. retrospective expectations).

There was little or no discussion or research investigating how expectations are formed, the effect of confidence in expectations or where the specific expectations

measured in the research came from. Although some authors (e.g. Rhodes et al., 1995) asked patients about their knowledge and where their information had come from, these measures often lacked refinement and results were either not reported or presented descriptively.

Problems with defining a negative compared to a positive expectation have highlighted the issue of whether it is possible to discuss one without the other under certain circumstances (e.g. expectations for treatment benefit): if higher expectations of treatment benefit result in better outcomes, then it seems likely that lower expectations will result in worse outcomes, which would make the two intrinsically linked. The failure to include all studies that measured treatment benefit regardless of whether participants were given the option of rating their expectations as negative is arguably a serious limitation of this review.

Another limitation of this review is that as there are no agreed definitions or standardised use of language to describe negative expectations (e.g. nocebo, negative placebo, negative predictions, negative anticipation etc) and therefore it is likely that literature was missed in the searches.

Implications for clinical practice at this stage are few due to the problems outlined with research in this area; however, the results from the studies into the effect of language on pain (Benedetti et al., 1997 and Lang et al., 2005) suggest that warning patients about an impending painful event can significantly increase the pain reported. It is common in clinical practice that patients are warned about painful events, for example, prior to giving injections language such as 'sharp scratch', 'bee sting' or 'this will hurt a bit' are commonplace (Lang et al., 2005) and it is possible that these warnings increase the pain experienced.

Implications for future research into negative expectations include the need for clear definitions and conceptual explanatory frameworks which can be used to guide questionnaire design and help produce standardised measures. However, once reliable and valid questionnaires have been developed it should be possible to measure expectations and investigate possible relationships with negative health outcomes, which may be extremely important for both health research and clinical practice. In so doing this might allow for interventions to be developed to manipulate expectations to improve health outcomes.

CHAPTER 3

BASELINE ANALYSIS

Abstract

Objectives: to describe the population and to investigate variables associated with quality of life and fear of recurrence, to explore symptoms experienced by participants, what these were and their frequency; in addition, whether these symptoms were affected by expectations for recovery. Finally to ascertain whether there were differences between those who had symptoms and those who did not.

Methods: N=153 participants were recruited after a TIA or minor stroke. Correlates of quality of life and fear of recurrence were investigated using hierarchical multiple and logistic regressions where appropriate. Differences between those who had symptoms and those who did not were explored using ANOVA.

Results: lower quality of life was associated with more symptom bother, more concerns about stroke medications, lower understanding of the condition and lower optimism. Higher fear of recurrence was associated with greater understanding of the condition and lower resilience. Ninety-one out of 153 people (60%) had at least one symptom, with fatigue being the most common. People who had symptoms had significantly more negative consequences from their TIA or minor stroke and had lower physical and emotional quality of life.

Conclusions: symptoms 4-6 weeks after a TIA or minor stroke are severe enough to affect quality of life and cause significantly more consequences. Higher coherence scores are associated with a higher quality of life, but in contrast are also associated with higher fear of recurrence, which may be realistic.

3.1 Introduction

This section aims to provide a brief background to:

- the literature concerning quality of life after a TIA or minor stroke
- the literature concerning fear of recurrence after a TIA or minor stroke
- the literature concerning symptoms following a TIA or minor stroke
- the literature concerning expectations for recovery
- the baseline research questions and hypotheses

Quality of Life after a TIA or minor Stroke

Although there is research investigating quality of life after stroke (see Tengs and Luistro (2001) for a review) there is little research looking at quality of life after a TIA or minor stroke. The research that has been published has shown decreases in quality adjusted survival after five years in people who had had a stroke or TIA. The biggest predictors of reduced quality adjusted survival were recurrent stroke and stroke severity at baseline (Luengo-Fernandez, Gray, Bull et al., 2013). Suenkeler, Nowak, Misselwitz et al. (2002) found relatively stable quality of life scores at three, six and twelve months following a stroke or TIA. There was some deterioration in the mental health dimension and the social functioning domain, with predictors of better quality of life being absence of diabetes, being male and absence of depression. However, although both of these studies used TIA patients, they did not differentiate between stroke and TIA in their analyses.

Muus, Petzold and Ringsberg (2010) found no significant differences over time in quality of life in their sample of TIA and minor stroke patients. Stroke specific quality of life and perceived change in quality of life was measured at three and 12 months after a TIA or minor stroke. They found no differences in quality of life between three and twelve months post-stroke, but ratings of change in thinking from pre-stroke were significantly lower at 12 months compared to at three months. Forty-three per cent of their sample rated their overall quality of life at 12 months as lower than at pre-stroke (deteriorated group) and there were significant differences at 12 months on all the quality of life domains between the deteriorated and not-deteriorated groups.

Lam et al. (2019) found that depression and anxiety at baseline predicted lower emotional quality of life one year after the event and older age and being female predicted a lower physical quality of life. A systematic review (Moran et al., 2014)

commented that although the evidence suggests people may suffer from residual symptoms after a TIA or minor stroke which appear to reduce over time and might affect their quality of life, there was not enough good quality research to be able to draw any firm conclusions regarding any aspect of quality of life after a TIA or minor stroke. Further research regarding quality of life following a TIA or minor stroke is clearly needed.

Fear of Recurrence

Fear of recurrence or fear of having a major stroke after a TIA or minor stroke is an area that has largely been overlooked in the quantitative literature despite the fact that patients are usually informed that having a TIA or minor stroke is a significant risk factor for having another one or a having a major stroke. It was only included in this research following discussions with the stroke co-ordinator in NHS Fife who had identified it as a problem that many of her patients had.

There are some studies investigating anxiety after stroke or TIA which might be relevant to fear of recurrence, for example, Chun, Whitely, Dennis, et al. (2018) in their study of anxiety after stroke or TIA found 22% of their sample had an anxiety disorder of some type. The most common sub-type was phobic anxiety followed by generalised anxiety. They comment that in their interviews the most commonly reported stimulus for anxiety was fear of recurrence. However, this research used both stroke and TIA patients (although the authors state that their sample was at the 'milder end of the stroke spectrum') meaning it cannot necessarily be generalised to minor stroke and TIA.

Bruggimann, Annoni, Staub, et al. (2006) found 31% of their sample of 'non-severe' stroke patients had significant posttraumatic stress disorder (PTSD) symptoms; however, they comment that in their opinion, fear of another stroke did not appear to be a factor in whether people had PTSD related symptoms or not because hypochondriacal anguish was not predictive of PTSD symptoms.

There is evidence that a more generalised anxiety may be prevalent following a TIA, for example, Broomfield, Quinn, Abdul-Rahmin, et al. (2014) found evidence of probable or possible anxiety in 29% of their TIA sample as measured by the Hospital Anxiety and Depression Scale (HADS). However, how far this generalised anxiety can be linked to fear of recurrence is unclear.

Fear of recurrent TIA or minor stroke or fear of having a major stroke has emerged as a theme in several qualitative studies of TIA and minor stroke patients (e.g. Croot, Ryan, Read, et al., 2014; Gibson and Watkins, 2011; Spurgeon, Humphreys, James et al., 2012; Townend, et al., 2006); these will be discussed in further detail in the qualitative chapter (chapter 6).

One issue that has arisen from some of the existing research is that fear of having another stroke of any kind can lead to either adaptive or maladaptive behaviours (e.g. Chun et al., 2018; Croot et al., 2014; Gibson et al., 2011). Both Chun et al. (2018) and Croot et al. (2014) comment that heightened fear of having another stroke can result in either avoidance of certain behaviours and situations e.g. travelling alone, crowds, over-exertion, or it can lead to positive changes in health behaviours and better adherence to medications. The research cited above suggests that fear of recurrence and fear of having a more serious stroke may be an important issue to explore further both to help encourage positive health behaviours and to reduce stress and harmful behaviours.

Symptoms following a TIA or minor Stroke

As was discussed previously, TIAs and minor strokes are traditionally thought to leave patients with either no lasting effects or symptoms that are mild and non-disabling (Moran et al., 2014); however, this view is now being challenged and studies have shown that people who have had a TIA or minor stroke are sometimes left with symptoms that negatively affect their quality of life. A recent systematic review found that people who had had a TIA had an increased risk of 43% for consulting for fatigue; 45% for cognitive impairment and 26% for psychological impairment compared to controls (Turner et al., 2016).

Other studies have found problems with communication, cognition and fatigue. Fens, van Heugten, Beusmans et al. (2013) found that 60% of the TIA and minor stroke participants they interviewed had significant fatigue, 44% had problems with their memory, 26% with concentration and 31% had problems relating to speech and language. Coutts, Modi, Patel et al. (2012) found functional impairments in 15% of their minor stroke and TIA cohort (N=499) at 90 days; the biggest predictor of disability was recurrent TIA or stroke.

It seems reasonable to argue that people who have had a TIA or minor stroke may experience more of a decline in their quality of life than previously thought; however, despite the evidence cited above, people who have had a TIA or minor stroke are usually discharged from hospital, assumed to make a full recovery and are not usually offered any treatment other than secondary prevention medications and lifestyle advice (Lam et al., 2019; Croot et al., 2014; Kamara and Singh, 2012).

Expectations for Recovery

Much of the literature concerning negative expectations was covered in the systematic review (chapter 2), therefore this section will give an overview of more recent research and research that includes positive expectations. Only research investigating change in physical health conditions where outcomes were improvement or deterioration of symptoms relating to that condition will be discussed. As far as this author is aware there are no papers investigating expectations for symptoms in people who have had a TIA or minor stroke. Therefore, evidence that expectations may affect outcomes from studies using different patient populations will be discussed.

As was discussed in chapter 2, there is evidence that expectations for recovery might be an important area for health research. In laboratory and clinical settings evidence has been provided that pain may be particularly sensitive to expectations (e.g. Benedetti et al., 1997). There is also evidence that expectations can affect recovery from surgery (Waljee, McGlenn, Sears et al., 2014); recovery from injury (Booth-Kewley, Schmied, Highfill-McRoy et al., 2013; Cole, Mondloch, Hogg-Johnson et al., 2002); and disease progression (Barefoot, Brummett, Williams et al., 2011).

Waljee et al. (2014) carried out a systematic review of the literature investigating expectations after surgery. Out of the 60 studies they included in their review, 36 were concerned with satisfaction (i.e. fulfilment of expectations) and although these are not directly relevant to this research, it is interesting to note that in nine of those studies, where patients had high expectations for recovery and these were not met this led to dissatisfaction.

Nineteen of the 60 studies examined the effect of expectations on quality of life: in 10 studies, more positive expectations for recovery were related to better postoperative quality of life. In 4 studies, fulfilment of pre-operative expectations was related to better quality of life after surgery, which might suggest that, in relation to

patient reported quality of life, it is not only expectations that are important, but also how far these are met.

Fifteen studies found a relationship between positive expectations and better functional outcomes, and five found no relationship. Eight studies found a relationship between more positive pre-operative expectations and post-operative pain. Waljee et al.'s (2014) review does lend considerable support to the notion that expectations are important for recovery from surgery, but also raises the interesting question of the effects on patients when expectations are not met. There is some evidence that dissatisfied patients may adhere less well to treatments, are more likely to have more symptoms and a lower quality of life (Verbeek, Sengers, Riemens, et al., 2004; Waljee et al., 2014; Wang, Zhang, Ma et al., 2015). This could suggest that although positive expectations might be important for recovery they can also be detrimental when they are 'too' positive or unrealistic and therefore not fulfilled.

Booth-Kewley et al. (2013) found that recovery expectations were the strongest predictor of injury outcomes after one year followed by pain severity at baseline and fear avoidance beliefs. In their sample of 134 marines with musculoskeletal injuries, those with high expectations for recovery were five times more likely to have recovered at follow-up compared to those with low expectations. Cole et al. (2002) also found that expectations of returning to normal activities within 3 weeks after soft tissue injuries to the upper or lower extremities or to the back were associated with lower pain levels at 4, 16 and 52 weeks after baseline compared to those who answered that they did not know (N = 1566). In addition, positive recovery expectations were associated with lower reported pain and change in condition compared to those who had negative recovery expectations.

Barefoot et al. (2011) measured recovery expectations using an expectations for coping scale, which measures expectations for returning to normal life, in people with clinically significant heart disease (N=2818). At the one year follow-up, positive recovery expectations predicted better functional status and at the 15 year follow-up, after controlling for clinical and demographic variables, better expectations were significantly associated with longer survival.

In summary, there is evidence that expectations can have an effect on functional outcomes; survival; post-surgery outcomes and healing from injuries. However, how far this research can be generalised to recovery from symptoms relating to TIAs or minor

strokes is unknown. There is also the issue of whether overly positive or unrealistic expectations can affect outcomes detrimentally.

3.2 Baseline Research Questions

Research question 1 - Which Variables are associated with Quality of Life?

Research question 2 - Which Variables are associated with Fear of Recurrence?

Research question 3 - How many People have Symptoms after a TIA or minor Stroke and what are those Symptoms?

Research question 4 - Are Expectations associated with Symptom Severity?

Research question 5 - What are the Differences between Participants with Symptoms and Participants with no Symptoms?

Research question 1 - Which Variables are associated with Quality of Life?

As mentioned earlier, quality of life consists of psychological, physical and social factors. Physical aspects such as symptom presence, symptom severity and symptom bother are all likely to be important to quality of life.

In addition, disease-related psychological variables that might be important in affecting quality of life after a TIA or minor stroke include, factors such as, illness perceptions, recovery locus of control, fear of recurrence and medication beliefs. Furthermore, general dispositional factors like optimism and pessimism, resilience and anxiety may also be important, as well as social factors.

Illness perceptions.

While no research was found in TIA and minor stroke, there are several papers researching illness perceptions in stroke. Illness perceptions have been found to predict quality of life one year post stroke in at least one study, (Dinsmore, 2010), which found lower emotional response, lower belief in the stroke being a chronic condition, high coherence and low consequences predicted better quality of life at one year. A systematic review (Pai, Li, Tsai et al, 2019) of illness perceptions in stroke, which included seven studies, showed that all the constructs, with the exception of personal and treatment control, were associated with depression and anxiety. Illness perceptions have also been found to be associated with quality of life in other conditions such as

coronary heart disease (Foxwell, Morley and Frizelle, 2013), Cushing's syndrome (Tiemensma, Kaptien, Pereira et al., 2011) and prostate cancer (Mickeviciene, Vanagas, Jieveltas et al., 2013).

It is hypothesised that positive illness perceptions will be associated with better overall quality of life.

Recovery locus of control.

Internal locus of control has been found to predict better quality of life (Dinsmore, 2010); better physical functioning in stroke (Zulkifly, Ghazali, Din, Desa et al, 2015); fewer depressive symptoms and less perceived impact from stroke (Zirk and Storm, 2019) and lower levels of fatigue one year post stroke (Schepers, Visser-Meily, Katelaar et al, 2006). In addition, internal locus of control has been found to predict better outcomes in cardiovascular patients (Partridge et al., 1989).

It is hypothesised that internal recovery locus of control will be associated with better overall quality of life.

Fear of recurrence.

No papers were found that investigated the effect of fear of recurrence on quality of life in stroke; although it has been found to affect quality of life in cancer patients (e.g. Hedman et al., 2018). It seems reasonable to hypothesise that heightened fear of recurrence will be associated with lower quality of life in TIA and minor stroke.

Medication beliefs.

There are few, if any, studies in stroke that investigate the effect of medication beliefs on quality of life; most of the research investigating medication beliefs is concerned with adherence. However, medication beliefs have been found to be associated with quality of life in patient with acromegaly (Andela, Biermasz, Kaptein et al., 2015) where negative medication beliefs were found to be associated with lower quality of life.

It is hypothesised that increased belief in the necessity of medications and lower concerns about medications will be associated with better quality of life, but these hypotheses are exploratory due to the lack of research in this area.

Optimism / pessimism.

There is evidence that optimism may reduce the risk of stroke (Kim, Park and Peterson, 2011) and there is also some evidence that it might aid recovery after stroke (Lai, Morales-Scheihing, Blixt et al., 2020). In addition, studies have found relationships between dispositional optimism and pessimism and symptom reporting and quality of life after coronary heart bypass surgery (Ronaldson, Poole, Kidd, Leigh et al., 2014); and risk of mortality from coronary heart disease (Anthony, Silverstein and Barrett-Connor, 2016).

It is hypothesised that higher optimism will be associated with better quality of life.

Resilience.

Resilience, the ability to bounce back after a stressful event, has been found to predict increased symptom reporting in cardiac and chronic pain patients (Smith, Dalen, Wiggins et al., 2002). There is little research in stroke and resilience (Sadler, Sarre, Tinker et al., 2017), but the available evidence suggests that resilience is associated with more positive post-stroke outcomes (Gyawali, Chow, Hinwood et al., 2020) and low resilience in adolescence may increase risk of stroke in later life (Bergh, Udumyan, Fall et al., 2014). Assuming that for many people having a TIA or minor stroke will be a stressful event, it was hypothesised that higher resilience will be associated with better quality of life.

Anxiety.

Generalised anxiety has been found to have a negative effect on quality of life after stroke (e.g. Tang, Lau, Mok et al., 2013) and after TIA and minor stroke (Lam et al., 2019). Therefore it was hypothesised that heightened anxiety will have a negative impact on quality of life.

Social support.

Social support has been linked to survival and recovery following myocardial infarction and in patients with cardiovascular disease (Berg, Barefoot, Berkman, Catellier et al., 2005). Vaglio, Conrad and Poston (2004) found that higher social support was associated with better social functioning, improved symptom control, better general and disease specific quality of life in cardiac patients. In addition, high levels of social

support have been associated with faster and more extensive recovery of functional status after stroke (Glass and Matcher et al., 1993). It was hypothesised that lower social support would be associated with worse quality of life.

Summary.

In summary, the hypothesis 1 for the baseline analysis is that lower overall quality of life will be associated with:

- increased symptom severity and bother
- negative illness perceptions (belief that the condition is chronic, increased consequences, increased emotional response and lower coherence)
- external locus of control
- negative medication beliefs
- heightened fear of recurrence
- pessimism
- low resilience
- heightened anxiety
- low social support

Research question 2 - Which Variables are associated with Fear of Recurrence?

The hypotheses regarding fear of recurrence are all largely exploratory due to the lack of research in this area, so relevant literature from other patient populations will be presented where appropriate.

Symptoms.

No papers were found on this subject in stroke; however, experiencing signs or symptoms related to cancer and increased reporting of physical symptoms in cancer have been linked to greater fear of recurrence (Vandrass, Reinertsen, Kiserud et al., 2020; Hall, Jiminez, Perez et al., 2019). Vandrass et al. (2020) suggest that symptoms can act as a reminder of the cancer and can also be misinterpreted as a relapse. It seems plausible that people who have had a TIA or minor stroke could have similar reactions to having symptoms (i.e. that symptoms could act as reminders of the possibility of another stroke and / or be misinterpreted as signs of another stroke). Therefore it is hypothesised that increased symptom scores (severity and bother) will be associated with higher scores on fear of recurrence.

Quality of life.

No studies were found investigating quality of life and fear of recurrence where fear of recurrence was the outcome variable; however, there is evidence that fear of recurrence in cancer patients affects quality of life one year after diagnosis (Hedmen et al., 2018). It seems reasonable to argue that lower physical and emotional quality of life might be associated with more fear of recurrence. Therefore it was hypothesised that lower emotional and physical quality of life will be associated with more fear of recurrence.

Illness beliefs.

Only one paper was found on illness beliefs and fear of recurrence, which was research investigating cancer patients' views on endocrine therapy (Corter, Findlay, Broom et al., 2013). Fear of recurrence was associated with belief in the condition being more chronic, more negative emotions related to their condition and more negative consequences. In addition, lower coherence correlated with more fear of recurrence.

How far the research cited above can be generalised to TIA and minor stroke is debatable. However, fear of recurrence is about fear of a future event and it makes sense that where people see their condition as longer term rather than an isolated incident that this could result in increased fear of recurrence. Increased negative consequences from the TIA or minor stroke may act as a reminder of the event (like with increased symptoms). Emotional representation is a reflection of how much psychological distress the condition causes and it seems reasonable to suggest that this may be linked to fear of recurrence. Lower perceived understanding of the condition might cause anxiety surrounding the TIA or minor stroke and its implications and thereby increase fear of recurrence.

It is hypothesised that a more chronic timeline; more negative emotions; more negative consequences and lower coherence will be associated with more fear of recurrence.

Recovery locus of control.

No papers were found on this subject, but it seems reasonable to suggest that where a person feels in control of their recovery rather than believing that other people or chance is in control, they will have less fear of recurrence. Therefore it is

hypothesised that internal locus of control will be associated with lower levels of fear of recurrence.

Optimism / pessimism.

Again no papers were found on this subject, but if dispositional optimism and pessimism (defined as generalised expectancies) lead to positive or negative expectations about the future, then it seems possible that higher optimism scores will be associated with lower fear of recurrence.

Resilience.

Lower levels of resilience have been linked to fear of recurrence in cancer patients (Chu, Lim, Chua et al., 2017). There is some evidence that resilience allows people to cope with the psychological distress surrounding fear of recurrence, but it might be less helpful in dealing with other aspects such as triggers (Chu et al., 2017). Depending on how far this is generalisable to TIA and minor stroke there may be an association between lower resilience and more fear of recurrence.

Generalised anxiety.

Generalised anxiety is characterised by incessant worrying and there is some evidence that it may be a problem for some people following a TIA or stroke (Kapoor et al., 2019). Whether generalised anxiety is linked to fear of recurrence, or is a separate concept, is not known, but it seems reasonable to suggest that heightened anxiety may be related to more fear of recurrence. It was hypothesised that fear of recurrence will be associated with generalised anxiety.

Social support.

No papers were found on this topic in stroke, but there is some evidence that low social support may be associated with more fear of recurrence in early stage breast cancer patients (Waters, Liu, Schootman et al., 2013). It is hypothesised that lower social support will be associated with higher fear of recurrence.

Medication beliefs.

No papers were found in this area; however, it was decided to include these variables as the medications used following a TIA or minor stroke are prescribed specifically to prevent recurrence. There is the possibility that belief in the necessity of medications might suggest confidence in the medications and therefore lower fears

about recurrence. More concerns about the medications might suggest a lack of confidence in them. Therefore it was hypothesised that higher score on the necessity of medications scale and lower scores on the concerns scale will be associated with less fear of recurrence.

Hypothesis 2 for the baseline data, higher fear of recurrence will be associated with:

- older age
- symptom presence
- symptom bother
- event type
- negative illness perceptions (IPQ subscales)
- low resilience
- low social support
- heightened anxiety
- external locus of control
- pessimism
- reduced quality of life

3.3 Subgroup Analysis

Research question 3 - How many People have Symptoms after a TIA or minor Stroke and what are those Symptoms?

If this sample recruited are representative of previous research, prevalence of symptoms will be around 40-60% and fatigue will be the most common symptom.

Hypothesis 3 - more people with symptoms will have had a minor stroke as opposed to a TIA.

Research question 4 - Are Expectations associated with Symptom Severity?

The literature and rationale for expectations being associated with symptom severity is presented above. However, in addition to expectations, it is hypothesised that lower physical quality of life, higher IPQ consequences and anxiety will be associated with increased symptom severity.

Hypothesis 4: increased symptom severity will be associated with lower expectations for recovery, lower physical quality of life, higher IPQ consequences and higher anxiety.

Research question 5 - What are the Differences between Participants with Symptoms and Participants with no Symptoms?

Hypothesis 5: that participants with symptoms will have lower physical and emotional quality of life; more negative illness beliefs; higher scores on fear of recurrence; more anxiety and a more external locus of control.

3.4 Baseline Methodology

Design

This was a longitudinal study using structured interviews at baseline (T1), 4 months (T2) and 18 months later (T3) which were administered to patients who had had a TIA or minor stroke for the first time within the previous six weeks. The interviews included standardised measures and questions designed specifically for this study. In addition, a qualitative interview was administered at baseline and T2 to a subset of 6 patients. The baseline chapter focuses in the baseline (T1) data only.

Power: calculated using G*Power -for multiple regression assuming a medium effect size (.15) and 15 predictors, a sample size of 139 is required for 80% power.

Methods

Participants and recruitment: All participants were recruited from NHS Fife and NHS Lothian. NHS ethics and R&D approvals were applied for: NHS ethics was granted on 25th February 2016. R&D approval from NHS Fife was granted in April 2016 and from NHS Lothian in December 2016. NHS Forth Valley R&D approval was also granted; however, no participants were recruited from this site. The study was also adopted by the Scottish Stroke Research Network in December 2016, although no participants were recruited through this service.

A substantial amendment to include the Medications Adherence Scale (MARS) to be included at T2 and T3, to allow for an 1 year follow-up (which was later changed to 18 months due to practical considerations) and to allow invitation letters from the clinicians (sent by the researcher) to be mailed to participants was applied for in November 2016. The amendment was granted in December 2016, but the ethics committee only granted permission for the participants from NHS Lothian to be included in the 18 month follow-up. Recruitment in Lothian had not started and the patients already in the study from NHS Fife had not consented to the follow-up during recruitment (see appendix 4 for all approval letters).

N=153 participants (to allow for attrition), were recruited who had had a TIA (n=69) or minor stroke (n=67) or an event with an uncertain diagnosis (n=17) for the first time that they were aware of within the previous six weeks. n= 4 participants were

found to have had previous strokes from their scan results; however, it was decided that these patients were eligible to take part as they had not been aware of these events at the time they happened.

Recruitment took place between July 2016 and September 2017. Patients were recruited from the TIA clinics in NHS Fife (n=25) and in NHS Lothian (n=128) from the weekly research meetings, clinics, wards and outreach. The patients in NHS Fife were all recruited after speaking to the stroke coordinator who gave them the patient information sheet (PIS) (see appendix 5) and got permission to pass on their contact details to the researcher who phoned them, answered questions and made an appointment to see them where appropriate.

In NHS Lothian n=21 were recruited after having the study introduced to them by a clinician and n=107 were recruited by letter: 308 invitations were sent out by post, meaning there was an uptake of 35% using this method of recruitment.

Ages ranged from 23 to 90 years ($\bar{x} = 69$ (11.7sd)); 68 females and 85 males. Despite the fact that all eligible patients were invited, only one participant who was not Caucasian (self described as mixed race) chose to take part. This underrepresentation of ethnic minorities means that the results of this study may not be generalisable to the whole population. However, this is not an uncommon problem in research, that is, that ethnic minorities are underrepresented (Redwood and Gill, 2013). The reasons for this underrepresentation are not fully understood, but may include societal, doctor or researcher factors (Redwood et al., 2013).

Although it would have been more desirable to interview participants closer to their TIA or minor stroke (ideally the interviews would have taken place within the one week of diagnosis), six weeks was chosen as a compromise between what was practical and keeping the interviews as close to the event as possible. The NHS Lothian TIA clinics typically see patients within approximately 48 hours of a referral from a GP; however, many people do not seek help immediately for a TIA or minor stroke, meaning that it may be days (or even weeks in some cases) since the event that they are seen in the clinic. In addition, the majority of the Lothian sample were recruited by letter after being identified as eligible during the weekly research meeting. Writing to potential participants and waiting for their response led to additional delays in seeing patients.

Moreover, as there was only one researcher on this study doing all the administration, recruitment and interviewing it was not always possible to see participants immediately.

Potential participants were asked if they were interested in taking part in some research by the doctor or specialist nurse during a clinic visit. Those who expressed an interest were given the information leaflet and asked if they were happy for a researcher to contact them. In NHS Lothian (which sees the most patients), whenever possible the researcher was present in the TIA clinics to speak to potential participants about the research after their appointment; however, this was often not possible due to practical considerations. Therefore the researcher attended the weekly research meetings at the Royal Infirmary of Edinburgh where the stroke team reviews all patients who have been seen during the previous week in clinics, wards and outreach and discuss their eligibility for the different research studies taking place. Details of patients who had given their consent for the researcher to contact them in clinic were also passed on by the clinicians during the meeting.

Where potential participants had not been informed about the study, letters from the clinician were sent out by the researcher inviting them to take part in the study. A patient information sheet and tear off slip giving consent to be contacted (see appendix 5 for a copy of the information sheet) was included with the letter as well as an SAE for them to send this back to the researcher if they were interested in taking part. Potential participants were then telephoned by the researcher where they had the opportunity to ask questions about the research and home appointments were made with those who agreed (see fig. 5).

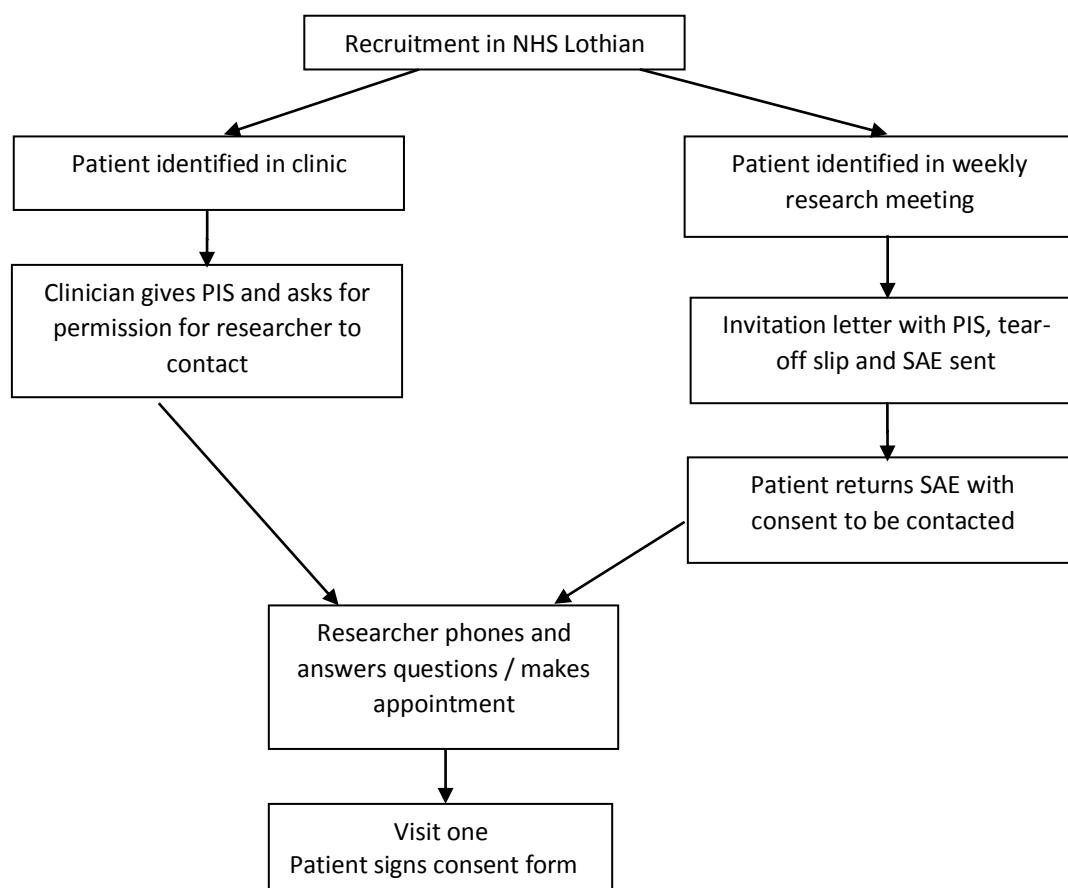


Figure 4: Recruitment procedure in NHS Lothian

Inclusion / exclusion criteria.

Participants were eligible to take part if they were over 18 years old and had had a TIA or minor stroke within the past 6 weeks for the first time that they were aware of. As was discussed earlier in this research, diagnosis of a TIA is frequently not definitive, therefore where there was doubt, patients were only included if there was consensus between the specialist stroke clinicians regarding the diagnosis of a TIA. Minor stroke was defined as a stroke where acute symptoms resolved within 24 hours. Participants were included if they had capacity to give informed consent and were fluent in English.

Potential participants were excluded if they lived too far away to make home visits feasible, if they had a condition that would make taking part in the research too distressing or difficult for them or had communication problems that would make the interview impossible. Patients were not eligible if they were aware of having had a previous TIA or stroke.

Ethical Considerations

It was recognised at the outset that people who had experienced a minor stroke or TIA for the first time could find the process of being interviewed about it distressing. Equally, there was a risk that they might see the interview as an opportunity to ask or seek reassurance about their own condition and prognosis; however, the researcher is not a clinician and has no expertise in such matters.

To mitigate these risks, all potential participants were given an information leaflet and the opportunity to ask questions about the research before giving consent (see appendix 6 for a copy of the consent form). The researcher conducting the interviews was aware of the potential for individual distress or discomfort during interviews and has a long history of working with clinical populations in research, meaning they are knowledgeable about potential causes of distress and how to reassure participants and allow them to express themselves freely without feeling awkward.

In addition, where participants had questions or concerns about their condition, they were encouraged to seek help from their GP. Where there was an apparent need for more specialised information or help, the researcher contacted the Stroke Team in NHS Lothian or the Stroke Co-ordinator in NHS Fife and passed on the participant's information. The participant was then contacted by a medical professional and received the help they needed.

Measures (see appendix 7 for a copy of all measures)

All measures were administered at baseline (T1) and T2 and a reduced battery of questionnaires was sent to participants at T3.

Unstandardised measures

Demographics including age, gender and a brief medical history which asked about whether the participant had had a TIA or a minor stroke, the date of the event, any other medical conditions which affected their quality of life and any medications since the TIA or minor stroke.

Socioeconomic status was measured using the Scottish Index of Multiple Deprivation quintiles (SIMD code) of the participants. Using the software provided by the Scottish Government participants are assigned a code of between 1 and 5, with 1

being the least deprived and 5 the most deprived. This is an approximate measure of socioeconomic status based on the postcode where participants live.

Expectations questionnaire - designed for this study. There are no standardised measures of expectations for health outcomes. Ideally the design of this measure would have been more methodical and reliability and validity testing would have been carried out in advance; however, this was beyond the scope of this research and therefore a pragmatic approach to the design was taken.

To measure expectations for symptoms it is necessary first to identify symptoms that the participant believes are related to the TIA or minor stroke. In addition, symptom severity was felt to be important as this is likely to affect the expected outcome, that is, the more severe the symptom is the more likely the participant is to have negative expectations about that symptom.

The scale then asks about expectations for the symptoms over the next 4-6 months.

Section one: Symptom Identification and severity.

The first section of this scale aimed to identify any symptoms that the patient believed were caused by the TIA or minor stroke. It started by asking the patient to relate their experience of having the TIA or minor stroke. It then asked whether the patient had noticed anything different since having the TIA or minor stroke and included prompts, for example, 'do you feel any more tired than you did before the stroke?'. Symptoms reported were scored on a 1-10 severity scale (with 0 being 'no symptom' and 10 being 'symptom as bad as you can imagine'). Based on the method used in the SCAT 3 (McCorry, Johnston, Meeuwisse et al., 2004) a measure of the severity of concussion, a total symptom severity score was calculated by adding the number of symptoms the participant reported and multiplying that by the sum of the severity scores. At baseline and T2 only the three most severe symptoms were scored, meaning this scale ranged from 0 - 90. This method of scoring takes both the number of symptoms and their severity into account and amalgamates them into one score. It was decided only to include the three most severe symptoms as only 5 participants had four symptoms at baseline. At T3 severity was calculated differently and the reasons for this are given methods section to the T3 study.

Section two: Expectations for symptoms at four months.

The second section asked patients what their expectations were for their three most severe symptoms in four to six months: expectation of the symptom getting better; expectations for no change; and expectation of symptom becoming worse, scored 1-5 (1 being 'strongly disagree' and 5 being 'strongly agree'). Where there were no current symptoms, the scale asks whether the patient expects any symptoms to develop over the next four months.

NB Scoring: while analysis was taking place, it was noted that the Cronbach's alpha was very low (.3) and that this was because 'becoming worse / better' is not part of the same scale as 'staying the same'. This was not an issue that had been considered beforehand. It was decided that instead of scoring the scale out of 15, to score it out of 10 and give those people who expected to stay the same a score of 5. This was not ideal; however, it was felt that to lose these people from the analysis would reduce the power too much and scoring them as essentially 'neutral' on getting better / worse seemed like a reasonable compromise.

Section three: Interference with everyday life.

This section asked about how bothersome the symptom was to the patient and whether it had stopped them from doing anything they wanted to do, scored 1-5 (1 being 'strongly disagree' and 5 being 'strongly agree'). This section aimed to be a basic measure of symptom related quality of life and was included because it is arguable that where symptoms are not bothersome and / or do not interfere daily activities patients will form different beliefs about the symptom compared to people whose symptoms stop them from doing the things they want to do, or who are bothered by the symptom.

Modifications to the measure at T2: At T2 participants were asked whether they had experienced another TIA, minor stroke or major stroke. They were then asked about the symptoms they had had at baseline, interference with daily living and severity of these was measured again. Patients who had not had any symptoms at baseline were asked whether they had developed any in the intervening time. In addition, participants were asked about their expectations for any remaining symptoms in 18 months time.

Fear of recurrence of TIA/ minor stroke and fear of major stroke.

This was measured as it was identified by the clinicians as a common problem for those who have had a TIA or minor stroke. In many cases, patients are often warned about the risk for recurrence following a TIA or minor stroke which could arguably cause

patients to become anxious or distressed. It was measured by asking patients whether they worry about having another TIA or minor stroke and whether they worry about having a more serious stroke both are scored 1-5 (1 being 'strongly disagree' and 5 being 'strongly agree'). The items were summed giving a range of scores from 2-10.

Cronbach's alpha = .83.

Standardised Measures

The Life Orientation Test - Revised (LOT-R) (Scheier and Carver 1985) is a 6 item scale measuring dispositional optimism and pessimism, which is defined as 'generalised positive and negative outcome expectancies'. The scale asks respondents to rate statements about how optimistic or pessimistic they tend to be (e.g. 'In uncertain times I usually expect the best', and 'I hardly ever expect things to go my way') on a 5 point scale with 0 being 'strongly disagree' and 4 being 'strongly agree'. The scale is scored by reversing the scoring of the negatively worded items and the total score is the sum of the 6 items, scores range from 0-24.

Internal consistency is frequently found to be high and in a sample of N=4309, Cronbach's alpha=.82 (Scheier, Carver and Bridges, 1994). In a sample of N=2055 test-retest reliability was acceptable at .68 at 4 months and .6 at 12 months (Scheier, et al., 1994). The scale was tested against several other scales that measure related constructs, including neuroticism, self-esteem and trait anxiety and showed only modest correlations with them (ranging from .32 to.56) suggesting the scale has discriminant validity.

There is some disagreement in the literature regarding whether the construct of optimism / pessimism is one- or two-dimensional . Several factor analyses have found a two factor solution (one for positively worded items and one for negatively worded items e.g. Creed, Patton and Bartrum (2002)); however, the original authors (Scheier et al., 1994) argue that this is because of the item wording and is not due to the fact that there are two dimensions. They found a one factor solution using the revised LOT and argue that optimism and pessimism are opposite poles of the same dimension. For the purposes of this research this scale will be treated as a one dimensional predictor. Cronbach's alpha in this study was .83

The Brief Resilience Scale (BRS) (Smith et al., 2008) - a 6 item scale that measures resilience which is defined as the ability to bounce back or recover from

stressful events. Respondents rate their agreement on a 5 point scale (with 1 being 'strongly disagree' and 5 being 'strongly agree') with statements such as 'I tend to bounce back quickly after hard times' and 'I have a hard time making it through stressful events'. There are three positively worded items and three negative, after reversing the negatively worded items the scale is scored by summing all the responses (range 6-30) and then calculating the mean value.

The BRS was tested on four samples by Smith et al. (2008), factor analysis revealed a one factor solution, suggesting that resilience is a one dimensional construct. Internal reliability was good (Cronbach's alpha ranged from .80 to .91 across the four groups tested). Test-retest reliability was also good (.69 for one month in 48 participants from one sample and .62 for three months in 61 participants from another sample). Cronbach's alpha in this study was .92

The Illness Perceptions Questionnaire (Moss-Morris et al., 2002) - the full measure is made up from eight subscales. Only four of these were used in this study, which are outlined in chapter 1. The decision to use only four of the subscales was made in order to reduce patient load and in an attempt to limit the number of predictors. In addition, it was felt that the four subscales used represented concepts that were not measured by any of the other questionnaires in the research, but were potentially important variables for predicting quality of life. The wording of the questions was changed from 'my illness' to 'my condition' because not everyone considers themselves to be ill following a TIA especially where there are no symptoms that endure. That not everyone consider themselves to be ill or unwell following a TIA became clear early on in the interviewing phase of the study. It was explained to participants that 'my condition' referred specifically to the TIA or minor stroke.

There are 22 items which make up the four subscales used in this study. The respondent is asked to rate their agreement with each item on a scale of 1-5 (1 being 'strongly disagree' and 5 being 'strongly agree').

IPQ-R Timeline acute/chronic: this 5 item subscale aims to measure the extent that respondents believe their condition is permanent or temporary with questions like 'my condition will pass quickly'.

In a large scale study aimed at establishing reliability and validity of the Revised IPQ (Moss-Morris, Weinman, Petrie, Horne et al, 2002) the timeline (acute/chronic)

subscale was found to have good internal reliability (Cronbach's alpha = .89) and test-retest reliability was also acceptable; .76 at three months and .57 at six months, the difference between the test-retest reliability at three and six months is interesting and could be explained by patient perceptions of whether their condition is temporary or permanent changing over time. Cronbach's alpha in this research was .9.

IPQ-R Consequences: 6 item subscale which aims to measure the expected effects and outcome of the illness with questions such as 'My condition has major consequences on my life' and 'My condition is a serious'. Internal reliability was found to be good (alpha = .84) and test-retest reliability was also good (.74 at both three and six months) (Moss-Morris, et al 2002). Cronbach's alpha in this study was .7.

IPQ-R Illness coherence: 5 item subscale aims to measure whether the respondent understands their condition asking questions like 'I do not understand my condition' and 'I have a clear picture or understanding of my condition'. In addition, the differences in scores from baseline to four months will be investigated as this may reflect participants learning more about their condition over the intervening time.

Internal reliability .87 was high and test-retest reliability acceptable: .6 at three months and .53 at six months. The authors argue that the relatively low test-retest results are due to participants gaining a better understanding of their condition as time passes (Moss-Morris, et al 2002). Cronbach's alpha = .82.

IPQ-R Emotional representation: 6 item subscale measures the extent of the emotional impact the respondents condition has caused, using questions such as 'I get depressed when I think about my condition' and 'My condition makes me feel afraid'. Internal reliability was high .88 and test-retest reliability was also good .7 at three months and .81 at six months (Moss-Morris, et al 2002). Cronbach's alpha = .81.

Beliefs about Medications Scale Specific version (Horne, Weinman and Hankins, 1999) - this 10 item scale comprises two factors assessing beliefs about the necessity (specific-necessity) of prescribed medication and concerns (specific-concerns) about prescribed medication. Respondents are asked to rate their agreement to statements medications on a scale of 1-5 (one being 'strongly disagree' and 5 being 'strongly agree'). This scale asks specifically about any secondary prevention medications, that is, medications that are prescribed to help prevent another TIA, minor stroke or major stroke. The scale aims to measure how far the respondent believes that their

medications are necessary to their health with statements such as 'Without my medications I would be very ill' and 'My medications protect me from becoming worse'. The specific-concerns subscale assesses concerns about taking medication with statements like 'Having to take medications worries me' and 'I sometimes worry about becoming too dependent on my medications'.

The BMQ specific necessity subscale was found to have acceptable internal reliability in several different patient groups (Horne et al., 1999) ranging from .55 in the sample of renal patients to .86 in the general medical sample and specific concerns subscale had good internal reliability ranging from .63 in a sample of psychiatric patients to .8 in diabetic patients. Cronbach's alpha in this study for the necessity scale was .82 and for the concerns scale .63.

Recovery Locus of Control (RLOC) (Partridge et al., 1989) - The RLOC scale was developed to measure perceived control over recovery. Five items assess internal beliefs with questions such as 'How I manage in the future depends on me and not what other people can do for me' and four assess external beliefs with questions such as 'I have little or no control over my progress from now on'. Participants respond to statements on a five-point scale from 'strongly disagree' (1) to 'strongly agree' (5). Each item is scored from 1–5 and totalled to give a score between 9 and 45. The total score reflects the strength of the respondent's perception of control, i.e. a high score indicates a high perceived control. In one study of stroke patients this scale had high internal reliability (Cronbach's alpha .90) (Zulkifly et al., 2015). Cronbach's alpha in this study was .74.

ENRICHD Social Support Inventory(ESSI) (Mitchell , Powell, Blumenthal , Norten et al 2003) is a 7 item scale which measures social support by asking respondents about the frequency of the availability of different types of social support (e.g. 'Is there someone available to you whom you can count on to listen to you when you need to talk' and 'Is there someone available to help with the daily chores?') on a 5 point scale, with 5 being 'all of the time' and 1 being 'none of the time'. The last item asks whether the respondent is currently living with a partner (answered 'yes' or 'no'). Scores range from 7 to 35 with a score under 18 being considered low social support.

Vaglio, Conrad and Poston (2004) examined the reliability and validity of the scale in 271 patients with heart disease undergoing treatment. They found that internal reliability was good, Cronbach's alpha = .88 and test-retest reliability showed no significant differences between the two time points and the intra-class correlation was

.94. Concurrent validity was assessed by examining the correlations between the total scores on the ESSI and the social functioning subscale from the SF-36, which showed significant association. Cronbach's alpha in this study was .89.

General Anxiety Disorder Scale (GAD-7) (Spitzer, Kroenke, Williams and Lowe, 2006) - a 7 item scale for assessing anxiety. This scale asks respondents to rate the frequency of anxiety and worrying, for example, 'Feeling anxious, nervous or on edge' and 'not being able to stop or control worrying', in the past two weeks on a scale of 0-3: 'not at all' (0), 'several days' (1), 'nearly half the days' (2) and 'nearly every day' (3). The answers are then summed for a total GAD score. For diagnostic purposes a score of 10 or over is considered the cut off point for general anxiety disorder (sensitivity 89% and specificity 85%) and scores of 5, 10 and 15 as mild, moderate and severe levels of anxiety respectively.

A large study designed to test the reliability and validity of the scale found that internal consistency of the GAD-7 was high (Cronbach's alpha = .92). Test-retest reliability was also good (0.83). In addition, the authors report good criterion, construct, factorial and procedural validity (Spitzer et al 2006). Cronbach's alpha in this study was alpha = .92.

The 36 Item Short Form Health Survey (SF-36).

This scale measures health related quality of life and was chosen as the primary outcome because of its established reputation as a reliable and valid measure of health related quality of life. The scale measures eight health domains: **Physical-functioning** (10 items) - how far physical health limits respondents in a range of activities; **Role-physical** (4 items)- how frequently health limits daily activities and whether those activities were more difficult than previously; **Bodily-pain** (2 items) - asking about severity of bodily pain and how far pain interferes with normal functioning; **General-health** (5 items) - measured by asking participants to rate their health and four questions relating to health beliefs; **Vitality** (4 items) - measures energy levels and fatigue; **Social- functioning** (2 items) which measures how far physical or emotional problems are limiting normal social activities; **Role-emotional** (3 items) - measures the extent to which emotional functioning is limiting normal daily activities; **Emotional wellbeing** - (5 items) assessing anxiety, depression, loss of emotional control and

psychological well being. Factor analysis of the eight health domains revealed a 2 factor solution which were labelled - physical and mental component summary scores (Maruish, 2011), which are essentially, physical health related quality of life and emotional health related quality of life.

There are two main ways to score the SF-36: one method is to convert the scores of the eight subscales to scores out of 100 and average these and then to average the scores for the physical and emotional quality of life subscales. The other way is to use norm based scoring (Jenkinson, Stewart-Brown, Petersen and Paice, 1999). It was decided to use averaged scores for this research.

In addition to the two subscales, some authors (e.g. Alishiri, Bayat, Salimzadehet al., 2011; Keuthen, Dougherty, Franklin, 2004) have also calculated a total score. In the current research, it was decided to use the total score (the average of the physical and emotional quality of life scores) where quality of life was the outcome measure in the regression analyses, but to keep the physical and emotional scores separate for all other analyses. This approach (using the total score) is not ideal (Lins and Carlhalo, 2016); however, it was done in an attempt to reduce the amount of analyses. It should be noted that the regression analyses were also run with the emotional and physical scores as separate outcomes and the results were very similar and therefore it was felt that it was justifiable to only report the results where total quality of life was used. Cronbach's alpha for the physical and emotional subscales was .93 and .9 respectively and .6 for the total score. The SF-36 has been used in thousands of studies across many different patient populations and is viewed as a robust measure with well-established reliability and validity (Maruish, 2011).

As well as the quantitative measures, notes were taken during the interviews recording information regarding participants' experiences of the event and their diagnosis; how they were feeling in general and any other information of interest. Some of these were recorded as direct quotes and others as notes on feelings and how people were responding to the questionnaires. These notes were transferred onto a spreadsheet and are used throughout the quantitative chapters to provide some background to the interpretation of the results.

3.5 Analysis

Data was analysed using SPSS version 25. At baseline there was no missing data because everyone was interviewed by the researcher and at T2 where the postal questionnaires ($n = 7$) were returned with missing data, the researcher contacted the participant and completed the questionnaires over the phone. At T3 where missing data was $> 20\%$ of the questionnaire it was discarded, and if there was $\leq 20\%$ missing, items on the GAD and MARS were prorated using the mean of the reported items on the scale. With the SF-36 missing items within each subscale were not taken into account when calculating the subscale scores, meaning that subscale scores are the average of all items that the participant answered.

All data was checked for normality and transformations were attempted where appropriate.

Differences between those with and without symptoms were calculated using a one-way ANOVAs; differences between baseline and T2 paired t-tests and differences between baseline, T2 and T3 repeated measures ANOVA.

Hierarchical multiple regressions were used to investigate relationships between the predictor and outcome variables, with demographic variables being added first, clinical variables second and psychological variables third. It was decided to use hierarchical regression to ascertain whether the change in R^2 was significant after the inclusion of psychological variables, or if the demographic and clinical variables accounted for the majority of the variance.

As much of this research was exploratory, the models often included 18-20 predictor variables, although this resulted in the significant predictors explaining only small amounts of the variance, it was felt that this was an important first step in identifying psychological variables of interest for further research in this population.

The procedure for carrying out hierarchical multiple regression was followed in accordance with the guidelines set out by the Laerd website (Lund and Lund, n.d) and Tabachnick and Fidell (2001). Bivariate scatter plots were used to check for linear relationships between the dependant and independent variables and were found to be, for the most part satisfactory; however, it was not always clear, but as Tabachnick et al. (2001) point out, "assessing linearity through bivariate scatterplots is reminiscent of reading tea leaves" (p78), therefore regressions were run with all variables.

Regressions were run initially to check the assumptions of collinearity, normality of residuals and homoscedasticity. VIF values were used to check for multicollinearity. Mahalanobis distance scores, studentized deleted residuals, leverage values and Cook's distances were used to check for multivariate outliers, influential points and leverage points. All of these can affect the predictive accuracy of the regression model and can give misleading results (Lund et al., n.d), where there were cases, these were removed and the regression was re-run, both results are reported where they differed. The Durbin-Watson statistic was calculated to check for autocorrelation of the residuals.

3.6 Baseline Analysis

Descriptive Statistics

Table 3 shows the participant demographic and clinical information.

Table 3

Participant Characteristics

Characteristic	n	%	Central tendency
<i>Gender</i>			
Female	68	44	
Male	85	56	
Total	153	100	
<i>Ethnicity</i>			
Caucasian	152	99	
Mixed race	1	1	
Total	153	100	
<i>Age</i>			
20-30	1	1	
31-40	2	1	
41-50	5	3	
51-60	27	18	
61-70	48	31	
71-80	45	29	
81-90	25	16	
91-100	1	1	
Total	153	100	
<i>SIMD code</i>			
1	16	10	$\bar{x} = 3.34 (1.14sd)$ Median = 3
2	38	25	
3	23	15	
4	30	20	
5	46	30	
Total	153	100	
<i>Lives with spouse / partner</i>			
Lives with spouse / partner	99	65	
Lives alone	54	35	
Total	153	100	
<i>Diagnosis</i>			
TIA	69	45	
Minor stroke	67	43	
Unsure	17	11	
Total	153	100	

Characteristic	n	%	Central tendency
<i>Symptoms following event</i>			
Yes	91	60	
No	62	40	
No at BL but Yes at FU	2	1	
<i>Medications</i>			
Anticoagulants	146	95	
Statins	114	75	
BP medication	94	61	
<i>Days from event to baseline</i>			$\bar{x} = 27$ (14.4sd, range = 6-45)

Medications

95% (n=146) of the people interviewed were either recently prescribed, or were already taking, anticoagulant medications. Of the 7 people who were not taking anticoagulants, 3 people had been prescribed them but had chosen not to take them, 1 person had had a hemorrhagic stroke and for the other 3 people it was unclear why they were not taking this medication.

75% (n=114) were either recently prescribed or were already taking Statins. Of the 39 people who were not taking Statins, one person had a haemorrhagic stroke, 12 people had either started taking them and found the side-effects to be too unpleasant to continue or had chosen not to start taking them, and for 26 people either they did not know why they had not been prescribed Statins or their cholesterol levels were not high enough to be prescribed this medication (this included people where cholesterol was not thought to be implicated in the cause of the stroke).

61% (n=94) were taking medication to lower blood pressure. Of the 59 people who were not taking blood pressure medications, 8 people had been prescribed this medication but had chosen not to take it, 15 people thought they would probably, or were definitely going to, be prescribed this medication in the near future, 21 people did not have high blood pressure and for 14 people it was unclear why they were not on this medication.

Descriptives of Standardised Questionnaires

Table 4

Means, standard deviations, ranges and normality tests for all questionnaires

Measure	Mean	SD	Range	Kolmogorov-Smirnov			Shapiro-Wilk		
				Statistic	df	Sig.	Statistic	df	Sig.
IPQ Timeline	11.39	6.69	20	.196	153	.000	.846	153	.000
IPQ Consequences	15.59	5.41	20	.093	153	.002	.966	153	.001
IPQ Emotion	12.46	6.78	24	.195	153	.000	.861	153	.000
IPQ Coherence	20.44	4.86	20	.187	153	.000	.853	153	.000
LOT	16.71	5.29	24	.132	153	.000	.942	153	.000
BMQ Necessity	19.14	4.35	20	.121	153	.000	.945	153	.000
BMQ Concerns	8.56	4	17	.187	153	.000	.832	153	.000
Resilience	24.62	5.75	24	.175	153	.000	.853	153	.000
GAD	3.2	5.2	21	.302	153	.000	.662	153	.000
Social support	30.68	5.34	20	.288	153	.000	.696	153	.000
RLOC	38.79	5.19	21	.135	153	.000	.917	153	.000
Fear of Recurrence	6.27	2.85	8	.159	153	.000	.885	153	.000
SF-36 Physical	66.75	23.41	95	.099	153	.001	.936	153	.000
SF-36 Emotion	71.68	20.1	92.5	.099	153	.001	.913	153	.000

Means, standard deviations and ranges are reported in table 2. All normality tests (Kolmogorov-Smirnov and Shapiro-Wilk) were significant, meaning that the data was not normally distributed. Although normally distributed independent variables are not important for multiple regression (Williams, Grajales and Kurkiewicz, 2013), they will constitute the bulk of the analyses, normality is desirable for the dependent variable and is a basic assumption for examining differences using ANOVAs and paired t-tests (Pallant, 2003).

For these reasons, attempts were made to transform the data using the appropriate methods of transformation outlined by Tabachnick et al. (2001) to investigate whether normality could be achieved. Reflect and square root; reflect and logarithmic; and reflect and inverse transformations were used on positively skewed data where appropriate, and square root, logarithmic and inverse transformations were used on negatively skewed data where appropriate. In addition, a Box and Cox transformation was attempted.

The results of the transformations were, for the most part, unsuccessful and although, for some of the variables, they did improve skewness and kurtosis a little, it was not possible to achieve normality for the majority of the variables and therefore the results of these transformations were rejected as they did not improve the distributions significantly.

In addition, several of the measures were considerably skewed, creating floor and ceiling effects which may have been the reason for the transformations not working. This issue is reported and discussed where relevant.

3.7 Regression Analyses of Baseline Data

As is outlined in the methods section, the power calculation suggested that assuming a medium effect size (.15) and 15 predictors, a sample size of 139 is required for 80% power; final recruitment was 153 (which, based on the above calculation, would allow for 18 predictors); however, when the demographic and clinical variables were included there were sometimes over 18 variables. This is mentioned as it means the

results may lack the desired power and should therefore be interpreted with some caution.

The procedure for carrying out hierarchical multiple regression was followed in accordance with the guidelines set out by the Laerd website (Lund and Lund, n.d) and Tabachnick et al. (2001).

See Table 31 in appendix 9 for the correlation matrix of all baseline variables.

Research question 1: What variables are associated with lower quality of life at baseline?

A hierarchical multiple regression was carried out to see if any of the predictor variables could account for the variance in quality of life. It was hypothesised that lower overall quality of life at baseline would be associated with:

- older age
- lower SIMD code
- increased scores on symptom measures (symptom presence, severity and bother)
- event type
- negative health perceptions (IPQ subscales)
- heightened anxiety
- low resilience
- fear of recurrence
- low social support
- lower scores on the medications necessity scale
- higher scores on the medications concerns scale
- pessimism

Demographic variables were added in step 1, clinical variables in step 2 and psychological variables in step 3. It was decided to use hierarchical regression to ascertain whether the change in R^2 was significant after the inclusion of psychological variables, or if the demographic and clinical variables accounted for the majority of the variance.

Results of regression.

The results of the full model from the hierarchical regression were significant $R^2 = .60$, $F(18, 134) = 10.66$, $p < .01$, adjusted $R^2 = .53$. The addition of clinical variables to the demographic variables (model 2) led to a significant increase in R^2 of .18, $F(3, 146) = 11.63$, $P < .001$. Adding the psychological variables (model 3) led to a further significant increase in R^2 of .33, $F(12, 134) = 8.94$, $p < .001$ (see Table 5).

Table 5

Regression statistics for quality of life

Variable	B	SE B	β	t	sr ²	R ²	Adj. R ²	ΔR^2
Step 1						.082	.064	.082
(Constant)	82.795	10.864		7.621				
Gender	-11.38	3.208	-.28	-3.55***	.08			
SIMD Code	-.638	1.136	-.04	-.561	.00			
Age	.072	.136	.04	.530	.00			
Step 2						.26	.229	.177
(Constant)	81.510	12.409		6.569				
Gender	-8.125	2.972	-.20	-2.734**	.04			
SIMD Code	-.968	1.046	-.07	-.926	.00			
Age	.078	.124	.045	.628	.00			
Event type	2.203	2.195	.073	1.004	.00			
Symptom bother	-.708	.161	-.42	-4.41***	.10			
Symptom presence	.313	3.987	.008	.079	.00			
Step 3						.589	.534	.329
(Constant)	79.072	18.437		4.289				
Gender	-4.321	2.483	-.11	-1.740	.01			
SIMD Code	-.311	.843	-.02	-.370	.00			
Age	-.046	.108	-.03	-.425	.00			
Symptom bother	-.483	.134	-.29	-3.61***	.04			
Symptom presence	-1.129	3.164	-.03	-.357	.00			
IPQ Timeline	.002	.190	.001	.008	.00			
IPQ Cons	-.438	.288	-.12	-1.520	.00			

Variable	B	SE B	β	t	sr ²	R ²	Adj.	
							R ²	ΔR^2
IPQ Emotion	-.027	.301	-.01	-.089	.00			
IPQ Coh	.579	.251	.140	2.308*	.02			
LOT	1.029	.285	.270	3.613***	.04			
BMQ Nec	-1.229	.297	-.26	-4.14***	.05			
BMQ Conc	-.236	.321	-.05	-.734	.00			
BRS	-.385	.278	-.11	-1.381	.00			
GAD	-.647	.357	-.17	-1.809	.00			
Social Support	.480	.252	.123	1.904	.00			
RLOC	.095	.260	.023	.365	.00			
FoR	.240	.439	.034	.547	.00			

Note: N=153; * $p < .05$; ** $p < .01$; *** $p < .001$.

Summary of results for research question 1.

High symptom bother and belief in the necessity of stroke medications, low illness coherence and low optimism were associated with reduced quality of life. There were 4 cases of deleted studentized residuals with a standard deviation greater than ± 3 and 6 cases of leverage points greater than .2. The regression was re-run without these cases and in addition to the significant results reported, greater social support and lower anxiety scores were also significantly associated with high quality of life.

Research question 2: Which variables account for higher fear of recurrence at baseline?

It was hypothesised that heightened fear of recurrence would be associated with:

- older age
- symptom presence
- symptom bother
- event type
- negative illness perceptions (IPQ subscales)
- low resilience
- low social support
- heightened anxiety
- external locus of control

- pessimism
- reduced quality of life

Results: there were no significant predictors of fear of recurrence.

Logistic regression.

Because there may have been some issues with the linearity of the IVs to the DV and because fear of recurrence was measured using two questions only, meaning that to dichotomise it would not lose too much information, it was decided to carry out a logistic regression. Fear of recurrence was dichotomised at the median which was 6. The procedure for carrying out logistic regression was in accordance with the guidelines outlined by Lund, et al. (n.d) and Tabachnik et al. (2001).

Results of the logistic regression.

The results of logistic regression showed that the regression model was not significant $X^2 (18) = 27.47$, $p=.071$ suggesting that the model is not a good fit. However, the Hosmer and Lemeshow test was not significant $X^2 (8) = 79$, $p = .78$, which suggests that the model is a good fit. Due to these conflicting results, it was decided to report the results of the regression, but because of what has been stated the results should be interpreted with caution.

The model explained 21.9% of the variance in FoR (Nagelkerke R^2) and correctly classified 66% of cases. Sensitivity was 64.9% and specificity was 64.5%, positive predictive value was 65.7% and negative predictive value was 62.6%.

Table 6

Logistic regression statistics - fear of recurrence

Variable	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for	
							Lower	Upper
Gender (1)	-.656	.403	2.652	1	.103	.519	.236	1.143
Event			2.711	2	.258			
Event (1)	-.070	.619	.013	1	.910	.933	.277	3.139
Event (2)	-.754	.658	1.313	1	.252	.471	.130	1.708

Age	-.012	.018	.434	1	.510	.988	.955	1.023
SIMD Code	-.008	.136	.004	1	.951	.992	.759	1.295
IPQ Timeline	-.051	.031	2.694	1	.101	.951	.895	1.010
IPQ Cons	.076	.045	2.812	1	.094	1.079	.987	1.179
IPQ Emotion	.030	.042	.535	1	.465	1.031	.950	1.118
IPQ Coh	.085	.043	3.828	1	.050*	1.089	1.000	1.185
LOT	.064	.050	1.636	1	.201	1.066	.967	1.175
BMQ Nec	.004	.051	.008	1	.930	1.004	.909	1.109
BMQ Con	.025	.053	.217	1	.641	1.025	.924	1.137
BRS	-.095	.045	4.407	1	.036*	.910	.832	.994
Social Supp	-.030	.041	.552	1	.458	.970	.895	1.051
RLOC	-.024	.041	.323	1	.570	.977	.901	1.059
SF36 Physical	.012	.013	.857	1	.355	1.012	.987	1.037
SF36 Emotion	-.008	.017	.224	1	.636	.992	.961	1.025
Symp Pres	.335	.422	.630	1	.427	1.398	.611	3.198
Constant	1.268	3.348	.143	1	.705	3.554		

Note: N=153; * $p < .05$; ** $p < .01$; *** $p < .00$; event (1) TIA, event (2) minor stroke

Results for Research Question 2

High fear of recurrence was associated with higher IPQ coherence and low resilience.

However, these results should be viewed with some caution due to the violation of sample size and the model not being significant.

In the event of a logistic regression model not being significant one recommendation from Tabachnick et al (2001) is to reduce the number of variables. A second logistic regression was carried out using variables that were specific to the TIA or minor stroke only which were, symptom severity, symptom bother, the IPQ subscales and RLOC and take variables that measured more general concepts like resilience and optimism / pessimism. The BRS was also included as it was significant in the previous model. The results are presented in table 7 below.

The results of the second logistic regression were that the regression model was significant $X^2(7)=219.4$, $p=.01$. The model explained 15.9% of the variance in FoR

(Nagelkerke R^2) and correctly classified 60% of cases. Sensitivity was 68% and specificity was 65%, positive predictive value was 66% and negative predictive value was 64%.

Table 7

Results of the logistic regression - fear of recurrence

	B	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I. for	
							Lower	Upper
IPQ Timeline	-.049	.029	2.794	1	.095	.952	.899	1.008
IPQ Cons	.048	.040	1.411	1	.235	1.049	.969	1.136
IPQ Emotion	.051	.036	2.041	1	.153	1.052	.981	1.129
IPQ Coherence	.079	.040	3.927	1	.048*	1.082	1.001	1.170
Sym. Sev	.002	.024	.010	1	.921	1.002	.956	1.051
BRS	-.066	.037	3.061	1	.080	.937	.870	1.008
Sym. Both	.002	.034	.005	1	.945	1.002	.937	1.072
RLOC	-.009	.037	.057	1	.812	.991	.921	1.067
Constant	-.514	1.792	.082	1	.774	.598		

Note: N=153; * $p < .05$; ** $p < .01$; *** $p < .001$

Results for research question 2 (fear of recurrence).

Higher scores on IPQ coherence were associated with higher fear of recurrence.

3.8 Sub-group Analysis

Research question 3 - how many Participants have Symptoms and what are they?

60% (N=91) people reported at least one symptom at baseline that they believed was caused by the TIA or minor stroke. Of those 59% (n=54) had a minor stroke, 32% (n=29) had a TIA and 9% (n=8) were unsure see fig. 6.

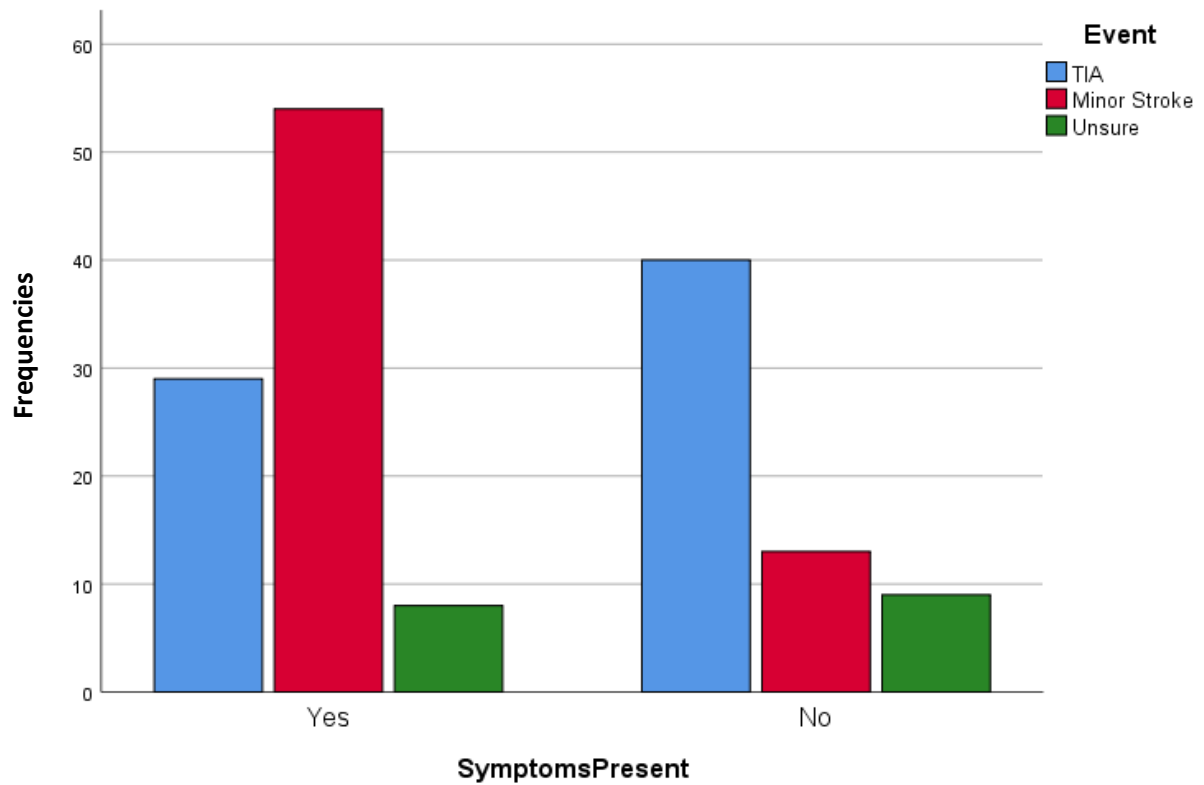


Figure 5: Histogram of symptoms and event type

A 2x2 chi-square test was carried out to investigate the relationship between symptom presence and event type after removing those who were unsure. The results were significant $X^2(1, N=136) = 21.26, p < .001$ suggesting that people who had a minor stroke were more likely to have symptoms than participants who had a TIA.

Table. 8 shows the breakdown of how many symptoms people were experiencing at the time of the interviews.

Table 8

Number of symptoms at baseline

Symptoms	N	% of n	% of N
1 symptom	38	42	25
2 symptoms	33	36	22
3 symptoms	15	16	10
4 symptoms	5	6	3
Total	91	100	60

Tables 9 and 10 show the frequencies of symptom type (note that the percentages add up to more than 100% as some people were experiencing more than one symptom).

Table 9

Baseline frequencies of symptom type

Symptoms	Frequency	% of n	% of N
Fatigue	66	73	43
Limb weakness	26	29	17
Cognitive	17	19	11
Tingling / pins and needles	12	13	8
Balance	8	9	5
Headaches	7	8	5
Eyesight	6	7	4
Light headed	6	7	4
Speech	6	7	4
Mouth drooping	4	4	3
Other	15	16	10

Table 10

Other symptoms

Symptom	n
Co-ordination	2
Fine motor control	2
Hearing	1
Hollowness and heightened irritability	1
Nausea	1
Pain in muscles	2
Pains down right hand side	1
Palpations	1
Sensation of dribbling at side of mouth	1
Strange sensations in body	2
Strange sensations in head	1

Descriptives of Questionnaires relating to symptoms

Means, SDs, range and normality tests for the questionnaires relating to symptoms are presented in table 11.

Table 11

Descriptives of questionnaires relating to symptoms

Measure	Mean	SD	Range	Kolmogorov-Smirnov			Shapiro-Wilk		
				Statistic	df	Sig.	Statistic	df	Sig.
Symptom bother	18.61	11.8	42	.134	91	.00	.902	91	.000
Symptom severity	23.52	18.85	71	.162	91	.00	.83	91	.000
Expectations	7.38	2.19	8	.199	91	.00	.826	91	.000

Research Question 4: What accounts for the Variance in Symptom Severity Scores?

Hierarchical multiple linear regressions were carried out to investigate which baseline variables predicted symptom severity and bother at T2 in participants who had symptoms. The regression models were not significant and there were no significant predictors of either.

Research Question 5: What are the Differences between People who had Symptoms and People who did not?

It was hypothesised that participants with symptoms would have:

- higher scores on IPQ timeline, IPQ consequences and IPQ emotions and lower on IPQ coherence
- higher scores on anxiety
- higher external locus of control
- more fear of recurrence
- lower physical and emotional quality of life

compared to participants who did not have symptoms.

A one-way ANOVA was carried out to investigate differences between those who had symptoms and those who did not (table 12). Although there were only two groups, it was felt that it was necessary to use ANOVA rather than independent t-tests in an attempt to avoid making a Type I error (Coolican, 1999). Due to the fact that the data was not normally distributed, non-parametric tests were also carried out to check the results.

Table 12

Results of the ANOVA and Kruskal-Wallis

		N	Mean	SD	F	Sig.	Eta ²	H	Sig.
IPQ Tim	Y	91	11.66	6.14	.36	.551		1.87	.172
	N	62	11.00	7.47					
	T	153	11.39	6.69					
IPQ Cons	Y	91	16.34	5.59	4.37	.038*	.03	4.09	.043*
	N	62	14.50	4.97					
	T	153	15.59	5.41					
IPQ Emo	Y	91	13.22	6.89	2.87	.092		2.79	.095
	N	62	11.34	6.51					
	T	153	12.46	6.78					
IPQ Coh	Y	91	20.07	5.30	1.32	.253		.195	.66
	N	62	20.98	4.10					
	T	153	20.44	4.86					
Anx	Y	91	3.55	5.52	.96	.328		1.86	.173
	N	62	2.69	4.95					
	T	153	3.20	5.29					
RLOC	Y	91	39.09	5.01	.82	.367		1.52	.22
	N	62	38.35	4.77					
	T	153	38.79	4.91					
FoR	Y	91	6.30	2.96	.01	.908		.095	.76
	N	62	6.24	2.72					
	T	153	6.27	2.85					
QOL	Y	91	61.99	22.90	9.81	.002**	.06	11.24	.001**

		N	Mean	SD	F	Sig.	Eta ²	H	Sig.
Phys	N	62	73.72	22.55					
	T	153	66.74	23.41					
	Y	91	67.05	20.77	12.8	.000***	.08	14.57	.000***
SF-36	N	62	78.46	17.08					
Emo	T	153	71.67	20.10					

Note: N=153; * $p < .05$; ** $p < .01$; *** $p < .001$; T=Total

Summary of results for differences between patients with symptoms and those without

People who had symptoms had significantly higher negative consequences beliefs and had lower physical and emotional quality of life.

3.9 Summary of main findings - baseline analysis

Research question 1: Which variables are associated with lower quality of life?

High scores on symptom bother and beliefs in the necessity of stroke medications, low illness coherence and low optimism were associated with reduced quality of life. When the leverage points were removed lower social support and higher anxiety scores were also significantly associated with lower scores on overall quality of life.

Research question 2: Which variables are associated with higher fear of recurrence?

Higher score on IPQ coherence were associated with a higher fear of recurrence.

Research question 3: How many people have symptoms?

Sixty percent of this sample reported at least one symptom. The most common symptom was fatigue (43% of the full sample). Participants were more likely to have symptoms if they had had a minor stroke as opposed to a TIA.

Research question 4: What variables are associated with high symptom severity

The models were not significant and there were no significant associations.

Research question 5: What are the differences between participants with symptoms and those without?

Participants who had symptoms had higher scores on the consequences scale and significantly lower physical and emotional quality of life compared to those without symptoms.

3.10 Discussion of baseline results

Research Question 1 – Which Variables are associated with Quality of Life?

In relation to the baseline hypotheses, quality of life was not related to event type; symptom presence; IPQ emotion, consequences or timeline; or locus of control. However, high symptom bother and stronger beliefs in the necessity of stroke medications, low illness coherence and low optimism were associated with reduced quality of life. Low social support and higher anxiety were also associated with reduced quality of life once the leverage points had been removed.

IPQ coherence.

Higher scores on the IPQ coherence subscale was associated with increased quality of life at baseline. This finding is in line with previous research which has found that higher coherence / greater understanding of the condition is associated with better quality of life in stroke (Dinsmore, 2010) and in coronary heart disease patients (Foxwell et al., 2013). Any unexpected medical event can be disruptive or even traumatic and usually requires adaptations by the patient to cope with the physical, emotional and behavioural implications of the event (Ben-Sira et al., 1990). Within TIA and minor stroke, these could be residual symptoms, the shock of diagnosis and adhering to medical advice about medications and lifestyle. In order to cope effectively it is, arguably, necessary to have a good understanding of the condition.

It should be noted that the scores on the IPQ coherence scale were heavily positively skewed ($\bar{x} = 20.44$, the highest possible score was 25), meaning the result may be an artefact of the data. The positive skew in the data suggests that this sample had a good perceived understanding of their condition which is in line with previous research (e.g. Groeneveld et al., 2019) who found relatively high levels of coherence in their sample of stroke patients (although not as high as in this research). However, this finding does seem to be in contention with a common finding in qualitative research, which is that some people express a lack of knowledge and a need for further information following a TIA or minor stroke (e.g. Spurgeon et al., 2012; Turner et al., 2019).

In the current sample, from an anecdotal point of view, many people did express a need for further information during the interviews. People frequently indicated that they had a good understanding of what had happened to them insofar as they

understood they had had a blood clot in their brain and that this had caused the symptoms they had experienced or were still experiencing. The types of information that people wanted tended to be more about the more long term implications of what had happened to them, for example, how to reduce the possibility of recurrence, how long symptoms would last for and about medications; these are areas that the IPQ coherence scale does not address. This is an important distinction and research using the IPQ coherence scale may be at risk of drawing flawed conclusions about the level of understanding patients have about their condition.

Symptom bother.

Higher scores on symptom bother were associated with lower quality of life which suggests that symptoms were bothersome enough to affect quality of life between 2 and 6 weeks following the event. This finding is in line with previous research which has found that, not only do symptoms sometimes continue after the acute phase of a TIA or minor stroke, but also that they can be severe enough to detrimentally affect quality of life (e.g. Turner et al., 2016; Fens et al., 2013; Coutts et al., 2012). It should be noted that although it was symptom bother and not severity that was used in the regression analyses, severity and bother were very highly correlated (.90), meaning that it was not possible to use both.

Optimism.

Higher optimism scores were associated with better quality of life. This is in line with previous research that has found that optimism is related to better outcomes after stroke (e.g. van Mierlo et al., 2016).

Necessity of medications.

Higher scores on the necessity of medications subscale were associated with lower overall quality of life. This finding was not in line with the baseline hypothesis that higher scores on the necessity of medications would predict higher quality of life; however, since no papers were found where necessity of medication beliefs were associated with quality of life after TIA or minor stroke, the hypothesis was exploratory. One possible explanation for this finding is that participants who thought of their stroke medications as being more necessary had more co-morbid conditions and therefore more medications in general. Although the scale asks about stroke medications only, it is possible participants were thinking about all their medications when answering.

However, this was not tested in this research and is therefore only a tentative explanation.

Research Question 2 – Which variables are associated with higher fear of recurrence?

None of the hypotheses were upheld. The only significant result was that higher IPQ coherence scores were associated with higher fear of recurrence. Although this was the opposite direction of what was hypothesised, because there is not much research in this area, the analyses regarding fear of recurrence was largely exploratory and the hypotheses were based on what seemed sensible rather than solely on previous research. It is interesting that fear of recurrence was related to greater perceived coherence as this might suggest that the more someone believes they understand what happened during the TIA or minor stroke and the implications of having one, the greater their fear of having another TIA or stroke is. This is not necessarily a negative finding considering that having a TIA or minor stroke is, in fact, a risk factor for having another one and also for having a major stroke, therefore, it may, actually reflect increased understanding of the risk of recurrence.

There is some qualitative evidence that fear of recurrence after a stroke or TIA can lead to better secondary stroke prevention behaviours (e.g. Viprey, et al., 2020 and Chun et al., 2018), which could be related to increased understanding about the benefits of secondary prevention behaviours. In saying that it should also be noted that heightened fear of recurrence can lead to maladaptive behaviours also, for example, Chun et al. (2018) found some evidence of fear avoidance in their sample of TIA, minor and major stroke patients, for example, avoiding social situations, physical exertion and travelling alone. In another study of people who had suffered a major stroke the participants felt they lacked control over the causes of another stroke and their fears were often linked to “idiosyncratic or fatalistic beliefs” (Townend et al. 2006, p747).

The issue of fear of recurrence leading to either adaptive or maladaptive behaviours may be because there is not enough distinction between fear and worry or concern being made. In this research, the scale did not distinguish between fear and concern and some participants commented on the fact that they were not fearful, but realised the possibility of recurrence and were concerned about it, under those circumstances participants would often score themselves as neutral. There is a possibility that concern about recurrence might lead to more adaptive behaviours whereas fear or anxiety could be linked to avoidant behaviours.

Interestingly generalised anxiety was not associated with fear of recurrence, suggesting that these might be two separate concepts. Again this might reflect the fact that the fear of recurrence scale did not distinguish between fear, worry or concerns and that if it had, anxiety may have been associated with fear about recurrence, but not with concern.

Research Question 3: how many people have symptoms and what are they?

Symptoms: ninety-one participants (60%) of this sample had at least one symptom at baseline. The most frequently experienced symptom was fatigue at 43% of the full sample having some fatigue, followed by limb weakness and cognition. These results are in line with previous research which has found that many people have residual symptoms following a TIA or minor stroke (Turner et al., 2016; Fens et al., 2013; Coutts et al., 2012).

Research question 4: What variables are associated with high symptom severity

The models were not significant and there were no significant associations. The possible reasons for this will be discussed in chapters 4 and 7.

Research Question 5: Differences between those with symptoms and those without.

The hypotheses that there would be significant differences in recovery locus of control (external), fear of recurrence, anxiety, IPQ timeline, emotion and coherence were not supported. However, differences were found on both physical and emotional quality of life scales and the IPQ consequences scale, with those who had symptoms scoring significantly lower on quality of life and significantly higher on IPQ consequences. These results suggest that symptoms were serious enough to significantly affect both emotional and physical quality of life two to six weeks after the event. In addition, there were significantly more consequences to the TIA or minor stroke for those who had symptoms. These results are in line with previous research which has found that residual symptoms can be severe enough to affect quality of life as discussed above.

Clinical Implications

The results from the baseline data suggest that coherence/understanding of the TIA and minor stroke could be important for quality of life and it might be useful for clinicians to confirm with patients that they fully understand what has happened to

them and the implications of this. It may also be useful for clinicians to find out from the patient what kind of information they have, want or need. As mentioned above, participants in this study frequently felt that they lacked knowledge about the implications of the TIA or minor stroke.

Although firm conclusions cannot be drawn from the results regarding fear of recurrence, it is interesting that more perceived understanding of the event was associated with heightened fear of recurrence. This may be realistic and adaptive. More research in this area is needed to clarify the relationship between fear of recurrence and behaviours following a TIA or minor stroke.

In addition, clinicians should be aware that people who have had a TIA or minor stroke can experience symptoms that are serious enough to affect their quality of life and that they have significantly more consequences from the event, this is important because traditional definitions of TIA and minor stroke suggest no ongoing symptoms (Moran et al., 2014). These results are in line with previous research (Turner et al., 2016; Fens et al., 2013; Coutts et al., 2012) and might suggest that people who do have symptoms would benefit from further clinical input at an early stage.

Strengths and Limitations

The first limitation to these results is that they are cross sectional and therefore no firm conclusions can be drawn regarding the relationships found between variables. A further limitation is that the fear of recurrence scale was not sensitive enough to distinguish between fear and concern regarding having another stroke. This seems like it could be an important distinction and might help to explain the differences in behaviour found in the research cited earlier in this section. It is recommended that further research in this area makes a distinction between fear or anxiety and concern.

Although co-morbid conditions were recorded, no formal analysis was done on these, which may have been an important oversight. Serious or multiple co-morbid conditions could have significantly impacted on people's quality of life and other illness perceptions. In addition, recent significant life events were not recorded and this may also have affected quality of life.

The strengths of this study were that the sample size was large enough to give the results the desired power. In addition, the number of measures taken was both a

strength and weakness, insofar as it captured the breadth of experiences, but also meant that the variance that was explained in the regression analyses was small.

3.11 Conclusions

Symptoms at 4-6 weeks after a TIA or minor stroke are severe enough to affect quality of life and cause more consequences. Higher understanding of one's condition may contribute to quality of life, but may also be associated with higher fear of recurrence.

CHAPTER 4

ANALYSIS OF FOLLOW-UP DATA

Abstract

Objectives: the primary aims of this chapter were to investigate which baseline variables best predict quality of life, fear of recurrence and adherence 4-6 months after baseline (T2); in addition, whether baseline variables could predict symptom severity and symptom bother in participants who had symptoms. Secondary aims were to investigate change between baseline and T2 and differences between those who had symptoms and those who did not.

Methods: hierarchical and multiple regressions were used to investigate predictors of quality of life, fear of recurrence, adherence, symptom severity and symptom bother. Paired t-tests were calculated to explore change between baseline and T2, and ANOVA was used to calculate differences between those who had symptoms and those who did not.

Results: baseline quality of life predicted higher quality of life at T2; younger age and high baseline fear of recurrence predicted high fear of recurrence at T2; older age, more social support, more belief in the necessity of stroke medications and a higher internal locus of control at baseline predicted better adherence to stroke medications at T2. There were no significant predictors of symptom severity or symptom bother.

At T2 compared to baseline, participants had significantly fewer consequences and less negative emotion relating to the TIA or minor stroke, lower fear of recurrence and better physical and emotional quality of life. In addition, at T2, people saw their condition as significantly more chronic and their recovery locus of control as more external. The results for participants who had symptoms at T2 were the same as in the full sample, for the most part, but symptom severity was significantly lower, expectations for recovery were lower and there was no change in fear of recurrence. Participants who had symptoms believed there were more consequences resulting from their event, had higher fear of recurrence and had

worse physical and emotional quality of life compared to participants without symptoms

Conclusions: Participants' experiences by T2 remain mixed. While there is some evidence of the hypothesised improvements, there is equally evidence of stagnation or deterioration, particularly in those who continued to experience symptoms.

4.1 Introduction

This section aims to provide an introduction to the T2 follow-up analysis. The hypotheses regarding quality of life, fear of recurrence, expectations and symptoms were the same as at baseline (other than the outcome variables were the T2 measures), therefore the justifications for the hypotheses and the literature discussed in the introduction to the baseline analysis applies to this section also. At T2 an adherence to stroke medications scale was included in the interview, therefore the literature regarding adherence will be briefly discussed. In addition, the hypotheses concerning change between baseline and T2 will be discussed.

Adherence

Evidence suggests that among patients with chronic illness approximately 50% do not take their medications as prescribed (Sabate, 2003) and a systematic review reported a pooled non-adherence rate of 30% among stroke survivors (AlShaikh, Quinn, Dunn et al., 2016). Haynes, McDonald and Montague (2002) comment that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments (cited in Sabate, 2003, p61)". Moreover, adherence has been shown to predict better quality of life, fewer disease-related complications and fewer hospital admissions (Khayyat, Mohamed, Khayyat et al., 2018).

Medications for secondary prevention following ischemic stroke and TIAs usually include a combination of antithrombotics (i.e. 'blood thinners', such as clopidogrel or aspirin), statins (for lowering cholesterol) and antihypertensives (for lowering blood pressure) (Flach, Muret, Wolfe, et al., 2020). These medications can reduce the risk of secondary vascular events by 20% to 30% (Lakhan and Sapko, 2009) with some research

suggesting cumulative reductions in relative risk of recurrence by up to 75% (Crayton, Fahey, Ashworth, et al., 2017), making adherence to secondary prevention medications vital.

There is substantial evidence that statin adherence is particularly low. Vonbank, Agewall, Kjeldsen et al. (2017) argue this is primarily due to perceived side effects and safety concerns. One large scale study (Nielsen and Nordestgaard, 2016) found that statin discontinuation increased with negative reports in the media and this discontinuation was associated with increased risk of myocardial infarction. A recent randomised controlled trial (Herrett, Williamson, Brack et al., 2021) investigating the effect of statins on muscle symptoms in people who had previously reported such symptoms from statins and had either stopped taking them or were considering stopping, found that atorvastatin had no effect compared to placebo. The authors reported that most people in their study intended to restart their treatment.

Variables which have been found to affect adherence to stroke medications include knowledge about medications (e.g. why the medications are important, understanding side effects and receiving instructions on how to take them) (Crayton et al., 2017); mental state and doctor-patient communication (Cheiloudaki and Alexopoulos, 2019); social support (Elloker and Rhoda, 2018); younger age (O'Carroll, et al., 2011); older age (Glader, Sjolander, Eriksson, et al., 2010); duration of illness (adherence tends to decline over time) (Glader, et al., 2010); illness beliefs (Ruksakulpiwat, Liu, Yue et al., 2020); stroke severity and medication beliefs (Cheiloudaki et al., 2019); and internal health locus of control (Nafradi, Nakamoto and Schulz, 2017).

As far as this author is aware there are no studies of adherence in TIA and minor stroke specifically, and whether the research investigating stroke of any kind can be generalised to TIA and minor stroke is not clear. For example, several studies found that cognitive impairment was a predictor of poor adherence in stroke survivors (O'Carroll et al., 2011; Coetzee, Andrews, Khan et al., 2008) and although there is some evidence of mild cognitive impairment in some people who have had a TIA or minor stroke (Turner, et al., 2016), it is less likely to be a major issue in this population. Taking the above evidence into account, it is clear that adherence is a complex issue and that research investigating it is important.

4.2 Research questions

Research Question 1: What has changed between Baseline and T2?

Unlike a major stroke where symptoms are frequently long-term and disabling and often require rehabilitation, people are expected to make a full recovery following a TIA or minor stroke without further intervention (Lam et al., 2019). There is some qualitative evidence that this may not be the case and that some people are affected both physically and emotionally (e.g. Kamara et al., 2012), but no quantitative research was found in TIA and minor stroke. In addition, using literature from major stroke studies might not be appropriate, in this instance, because of the expected long-term nature of that condition. People who have had a TIA or minor stroke might well differ in their perceptions of their condition and recovery. Kamara et al. (2012) found that people who had had a TIA thought their TIA was a short-lived event and that they would make a full recovery in time whereas that major stroke was always associated with long-term disability.

If it is the case that TIA and minor stroke patients make a full recovery, then it would be expected that participants' physical and emotional quality of life will have improved, that they will see their condition as less long-term, there will be fewer negative emotions relating to the event and fewer consequences. In addition, lower anxiety and fear of recurrence might be expected where no recurrences have occurred, and locus of control may become more internal where participants are getting better and feeling more in control of their health. There is some evidence that symptom severity reduces over time (Moran et al., 2014), but the effect this might have on quality of life, illness perceptions, fear of recurrence, anxiety and locus of control is unknown.

Hypothesis 1 for T2: that symptom severity and bother will be significantly lower; emotional and physical quality of life will be significantly higher; illness perceptions will be significantly more positive; anxiety and fear of recurrence will be significantly lower and locus of control will be significantly more internal at T2 compared to baseline.

Research Question 2 - What predicts Quality of Life at T2

Hypothesis 2 for T2: that lower overall quality of life at T2 will be predicted by baseline:

- increased symptom severity and bother

- negative illness perceptions (belief that the condition is chronic, increased consequences, increased emotional response and lower coherence)
- external locus of control
- negative medication beliefs
- heightened fear of recurrence
- pessimism
- low resilience
- heightened anxiety
- low social support

Research Question 3 - What predicts Fear of Recurrence at T2

Hypothesis 3 for T2: that fear of recurrence at T2 will be predicted by baseline:

- older age
- symptom presence
- symptom bother
- event type
- negative illness perceptions (IPQ subscales)
- low resilience
- low social support
- heightened anxiety
- external locus of control
- pessimism
- reduced quality of life

Research Question 4 - what predicts Adherence at T2

As mentioned above there is evidence that older age; stroke severity; higher BMQ necessities and lower concerns; internal locus of control; illness perceptions; more social support; less anxiety have all been found to be associated with better adherence in previous research in stroke. In relation to illness perceptions, Ruksakulpiwat (2020) used the brief IPQ, and did not ask about coherence. However, it seems sensible that fuller understanding that an individual has about their condition, the more likely they are to adhere to treatment. No literature was found on fear of recurrence and medication beliefs in stroke or TIAs, but because the medications asked about are

specifically designed to prevent recurrence, it makes sense that higher levels of fear of recurrence will predict better adherence.

Hypothesis 4 for T2: that the following baseline variables will predict better adherence at T2:

- older age
- Having symptoms
- Increased symptom bother
- Event type
- Higher scores on BMQ necessities and lower scores on BMQ concerns
- Higher IPQ coherence, consequences, emotion and timeline
- Higher social support
- Internal locus of control
- Lower anxiety

Research Question 5 - What Proportion of Participants still have Symptoms and what are they?

Coutts et al. (2012) found that 15% of their sample of TIA and minor stroke patients had significant fatigue at 90 days after the event. T2 interviews were conducted 4-6 months after baseline (121 -182 days), going on the basis that people are recovering and using Coutts et al.'s (2012) figures as a guide, it might be expected that around 10-15% of participants will still have symptoms at T2.

Hypothesis 4 for T2: 10-15% of participants will have symptoms at T2

Research Question 6 - What predicts Symptom Severity at T2?

Hypothesis 6 for T2: that increased symptom severity will be predicted by lower physical quality of life, higher IPQ consequences and anxiety at baseline.

Research Question 7 - What has changed between Baseline and T2 for Participants who have Symptoms?

Hypothesis 7 for T2: are the same as with the full sample: that emotional and physical quality of life will be significantly higher; illness perceptions will be significantly more positive; anxiety and fear of recurrence will be significantly lower and locus of control will be significantly more internal at T2 compared to baseline. In addition, it is

also hypothesised that symptom severity and bother will be significantly lower and expectations for recovery will be more positive.

Research Question 8 - What are the Differences between Participants who have Symptoms and those who do not at T2?

For the same reasons as at baseline, hypothesis 8 for T2 is that participants who had symptoms at T2 would view their condition as significantly more chronic; have more negative consequences and emotions relating to the event; have greater anxiety; a more external locus of control; more fear of recurrence and lower emotional and physical quality of life compared those who did not have symptoms.

4.3 Methodology

Participants were contacted 4 - 6 months after their first appointment to arrange another interview. Participants were given the choice between a telephone interview (n = 11), postal questionnaires (n = 7) and another home visit (n = 125). Although home visits were time consuming, participants were given the choice in an attempt to retain as many people as possible in the study.

N = 143 (this number includes postal questionnaires) participants took part in the T2 interviews, of the 10 people who did not complete T2, n = 3 were not contactable (and were sent postal questionnaires, but did not return them); n = 1 had a major stroke and was very ill in hospital; n = 2 did not want to talk about the event again as they found it too distressing; n = 4 did not give a reason for declining (it should be noted that the researcher did not ask for reasons for withdrawal); n = 3 participants not interviewed at T2 were from NHS Fife and n = 7 from NHS Lothian.

Time 2 Measures

All measures were the same as at baseline and an adherence scale was added.

Symptoms and Expectations

Participants were asked again about their symptoms from baseline and whether they had developed any more symptoms. Expectations were asked about any reported symptom for the next 18 months.

Medication Adherence Scale (MARS) (Horne, Reinman and Hankins, 1999). The MARS is a 5 item scale measuring adherence to medications. Although it is a generic adherence scale, there is the option to specify which type of medications are being asked about; and in this study participants were asked about their secondary preventative medications only. It asks participants to rate on a scale of 1-5, with 1 being 'always' to 5 'never', whether they adhere correctly to their stroke medications, and whether they agree with statements such as 'I forget to take them' and 'I alter the dose'.

Analyses

The analyses will take the same form as the baseline analysis. Hierarchical multiple regressions using baseline predictors were used with quality of life, fear of recurrence, adherence and symptom severity at T2 as outcome variables.

Change between baseline and T2 was calculated using paired t-tests. Differences between those with symptoms and those without was investigated using ANOVA.

4.4 Analysis

Research Question 1 - What has changed between Baseline and T2?

N=143 participants completed the T2 interviews. There were 7 recurrences (one of these was a major stroke and the participant did not take part in T2) which is a 5% recurrence rate.

Paired t-tests were used to test for change between baseline and T2. Table 13 shows the means and standard deviations for all measures, and the results from the paired t-tests between baseline and T2. Wilcoxon signed rank tests were also carried out to check the results due to the violation of normality.

It was hypothesised that

- Illness perceptions would be significantly more positive
- recovery locus of control would be significantly more internal
- fear of recurrence and anxiety would be significantly lower
- physical and emotional quality of life would be significantly higher at T2 compared to baseline

Table 13

Means, SDs, paired t-tests, effect sizes and Wilcoxon Z

Measure	Mean	SD	Paired t-test	<i>p</i>	eta ²	Wilcoxon Z
IPQ Timeline						
<i>Baseline</i>	11.39	6.69				
<i>T2</i>	12.22	6.34	2.66	.010*	.04	-1.95
IPQ Consequences						
<i>Baseline</i>	15.59	5.41				
<i>T2</i>	13.34	5.63	5.56	.000***	.18	-5.39***
IPQ Emotion						
<i>Baseline</i>	12.46	6.78				
<i>T2</i>	9.7	5.62	5.27	.000***	.16	-4.92***
IPQ Coherence						
<i>Baseline</i>	20.44	4.86				
<i>T2</i>	21.29	4.88	-1.50	.136		-1.15
LOT						
<i>Baseline</i>	16.71	5.29	-1.05	.296		-1.36

	Mean	SD	Paired t-test	<i>p</i>	eta ²	Wilcoxon Z
<i>T2</i>	16.91	5.17				
BMQ Necessity						
<i>Baseline</i>	19.14	4.35				
<i>T2</i>	18.95	4.62	1.16	.248		-.32
BMQ Concerns						
<i>Baseline</i>	8.56	4				
<i>T2</i>	8.04	3.57	1.01	.312		-1.4
Resilience						
<i>Baseline</i>	24.62	5.75				
<i>T2</i>	24.36	5.17	1.08	.284		-1.24
GAD						
<i>Baseline</i>	3.2	5.2				
<i>T2</i>	2.82	5.06	.55	.585		-.44
Social support						
<i>Baseline</i>	30.68	5.34				
<i>T2</i>	29.52	5.18	3.52	.001**	.08	-4.05**
RLOC						
<i>Baseline</i>	38.79	5.19				
<i>T2</i>	37.15	6	3.52	.001**	.08	-3.49***
Fear of Recurrence						
<i>Baseline</i>	6.27	2.85				
<i>T2</i>	5.32	2.73	3.62	.000***	.08	-3.52***
SF-36 Physical						
<i>Baseline</i>	66.75	23.41				
<i>T2</i>	70.88	23.56	-3.12	.002**	.06	-4.48***
SF-36 Emotion						
<i>Baseline</i>	71.68	20.1				
<i>T2</i>	77.70	18	-3.58	.000***	.08	-3.72***
MARS						
<i>T2</i>	23.97	1.67				

Note: N=143; **p*<.05; ***p*<.01; ****p*<.001; Effect size at .01 = small; .06 = medium; .14 = large

Results of the predicted changes

The hypotheses that participants would have significantly fewer consequences and less negative emotion relating to the TIA or minor stroke, and that they would have significantly less fear of recurrence and higher physical and emotional quality of life, were supported.

The hypotheses relating to anxiety, coherence and stroke medications were not supported and the hypotheses relating to timeline and recovery locus of control went in the opposite direction of what was expected, that is, participants saw their condition as

significantly more chronic and their recovery locus of control as significantly more external.

Research Question 2 - which Baseline Variables predict higher overall Quality of Life at T2?

A hierarchical multiple regression was carried out to see if any of the baseline variables could account for the variance in physical quality of life at T2. It was hypothesised that the following baseline measures would predict decreased overall quality of life at T2:

- older age
- lower SMID code
- increased scores on symptom measures (symptom presence, severity and bother)
- event type
- negative health perceptions (IPQ subscales)
- heightened anxiety
- low resilience
- fear of recurrence
- low social support
- lower scores on the medications necessity scale
- higher scores on the medications concerns scale
- pessimism
- baseline quality of life

Variables were entered in the order of demographics first (Step 1), clinical variables (Step 2), then psychological variables (Step 3). The regression was run initially to check the assumptions of linear regression.

Results of regression

The results of the full model from the hierarchical regression were significant $R^2 = .48$, $F(19, 123) = 5.89$, $p < .001$, adjusted $R^2 = .40$. The addition of clinical variables to the demographic variables (model 2) led to a significant increase in R^2 of .14, $F(3, 136) =$

4.86, $P < .01$. Adding the psychological variables (model 3) led to a further significant increase in R^2 of .30, $F(13, 123) = 5.42$, $p < .001$ (see Table 14).

Table 14

Regression statistics for quality of life at T2

Variable	B	SE B	β	t	sr ²	R ²	Adj. R ²	ΔR^2
Step 1						.088	.069	.088
(Constant)	91.09	11.43		7.967				
Gender	-10.9	3.140	-.28	-3.474**	.08			
Age	1.044	1.098	.077	.950	.00			
SIMD Code	-.063	.146	-.035	-.431	.00			
Step 2						.18	.088	.14
(Constant)	94.39	13.12		7.193				
Gender	-8.15	3.109	-.212	-2.622**	.04			
SIMD Code	1.149	1.069	.085	1.075	.01			
Age	-.076	.141	-.043	-.539	.00			
Event type	1.458	2.261	.051	.645	.00			
Symptom bother	-.563	.170	-.347	-3.314**	.07			
Symptom presence	-2.79	4.086	-.072	-.684	.00			
Step 3						.48	.39	.30
(Constant)	27.13	22.60		1.200				
Gender	-2.59	2.898	-.068	-.895	.00			
SIMD Code	1.448	.926	.107	1.564	.01			
Age	-.038	.130	-.022	-.295	.00			
Event type	-.314	2.006	-.011	-.156	.00			
Symptom bother	-.211	.161	-.130	-1.315	.01			
Symptom presence	-3.56	3.504	-.092	-1.016	.01			
IPQ Timeline	-.287	.221	-.099	-1.299	.01			

Variable	B	SE B	β	t	sr ²	R ²	Adj. R ²	ΔR^2
IPQ Consequence	.423	.334	.117	1.269	.01			
IPQ Emotion	.162	.339	.056	.478	.00			
IPQ Coherence	-.430	.295	-.106	-1.454	.01			
LOT	.010	.342	.003	.031	.00			
BMQ Necessities	.158	.361	.035	.436	.00			
BMQ Concerns	-.118	.381	-.024	-.310	.00			
BRS	.225	.313	.068	.718	.00			
GAD	.035	.406	.009	.086	.00			
Social Support	.333	.285	.092	1.171	.01			
RLOC	.051	.291	.013	.175	.00			
FoR	.003	.488	.000	.006	.00			
Baseline QoL	.580	.099	.620	5.886***	.15			

Note: N=143; *p<.05; **p<.01; ***p<.001

Significant Baseline Predictors of Quality of Life at T2:

Only baseline quality of life predicted quality of life at T2.

There were 14 cases of leverage points above .2 and 2 cases of deleted studentized residuals that were ± 3 standard deviations. Once these were removed and the regression was re-run, in addition to baseline quality of life, higher SIMD code and higher social support predicted higher quality of life at T2.

Research Question 3 - Which Baseline Variables predict Fear of Recurrence at T2?

A hierarchical regression was carried out to investigate whether any of the baseline variables could account for the variance in fear of recurrence scores at T2.

It was hypothesised that the following baseline variables would be associated with heightened fear of recurrence at T2.

- older age
- higher symptom bother

- event type
- negative illness perceptions (IPQ subscales)
- low resilience
- low social support
- heightened anxiety
- external locus of control
- pessimism
- reduced quality of life

Variables were entered in the same order as in the previous regressions.

Results of regression

The results of the full model from the hierarchical regression were significant $R^2 = .35$, $F(20, 122) = 3.23$, $p < .001$, adjusted $R^2 = .24$. The addition of clinical variables to the demographic variables (model 2) did not lead to a significant increase in R^2 ($\Delta R^2 = .03$, $F(3, 136) = 1.5$, $P = .22$). Adding the psychological variables (model 3) did lead to a significant increase in R^2 of $.19$, $F(14, 122) = 2.5$, $p < .01$ (see Table 15)

Table 15

Regression statistics for fear of recurrence at T2

Variable	B	SE B	β	t	sr^2	R^2	Adj. R^2	ΔR^2
Step 1						.131	.112	.131
(Constant)	8.128	1.592		5.106				
Gender	1.241	.437	.227	2.84**	.05			
Age	-.074	.020	-.29	-3.6***	.08			
SIMD Code	.152	.153	.079	.996	.00			
Step 2						.159	.121	.028
(Constant)	8.336	1.891		4.408				
Gender	1.033	.448	.19	2.31*	.03			
Age	-.072	.020	-.29	-3.6***	.08			
SIMD Code	.150	.154	.078	.976	.00			
Event type	-.240	.326	-.06	-.735	.00			
Symptom	.039	.024	.170	1.609	.02			

Variable	B	SE B	β	t	sr ²	R ²	Adj. R ²	ΔR^2
bother								
Symptom presence	.031	.589	.006	.052	.00			
Step 3						.346	.24	.187
(Constant)	9.837	3.618		2.719				
Gender	.580	.464	.106	1.250	.00			
Age	-.068	.021	-.27	-3.3***	.06			
SIMD Code	.035	.149	.018	.237	.00			
Event type	.014	.026	.063	.549	.00			
Symptom bother	-.271	.321	-.07	-.844	.00			
Symp. pres	-.187	.572	-.03	-.327	.00			
IPQ Timeline	.001	.035	.003	.040	.00			
IPQ Consequence	.070	.053	.137	1.317	.00			
IPQ Emotion	.026	.055	.063	.470	.00			
IPQ Coherence	.036	.047	.062	.762	.00			
LOT	.070	.055	.139	1.272	.00			
BMQ Necessities	.093	.058	.148	1.606	.00			
BMQ Concerns	-.056	.061	-.08	-.908	.00			
BRS	-.097	.050	-.21	-1.932	.02			
GAD	-.018	.067	-.03	-.273	.00			
Social Support	-.034	.046	-.07	-.746	.00			
RLOC	-.072	.047	-.13	-1.538	.00			
FoR	.221	.078	.23	2.830**	.04			
SF-36 Physical	-.024	.014	-.21	-1.665	.01			
SF-36	.023	.019	.174	1.228	.00			

Variable	B	SE B	β	t	sr^2	R^2	Adj. R^2	ΔR^2
Emotion								

Note: $N=143$; * $p<.05$; ** $p<.01$; *** $p<.001$

Significant predictors of fear of recurrence at T2

Younger age and higher fear of recurrence at baseline predicted higher fear of recurrence at T2.

Research Question 4 - What predicts Adherence to Stroke Medication at T2?

It was hypothesised that the following baseline measures would predict higher adherence to stroke medications at T2:

- older age
- Increased symptom bother
- Event type
- Higher scores on BMQ necessities
- Lower scores on BMQ concerns
- Higher IPQ coherence, timeline, consequences and emotions
- Lower social support
- Internal locus of control
- Higher fear of recurrence
- Higher anxiety

Results of regression

The results of the full model from the hierarchical regression were significant $R^2 = .25$, $F(18, 124) = 2.36$, $p < .01$, adjusted $R^2 = .14$. The addition of clinical variables to the demographic variables (model 2) did not lead to a significant increase in R^2 ($\Delta R^2 = .032$, $F(3, 136) = 1.24$, $p = .3$). Adding the psychological variables (model 3) did lead to a significant increase in R^2 of $.18$, $F(12, 124) = 2.52$, $p < .01$ (see Table 16)

Table 16

Regression statistics for adherence to medication at T2

Variable	B	SE B	β	t	sr ²	R ²	Adj. R ²	ΔR^2
Step 1						.037	.016	.037
(Constant)	21.72	1.026		21.167				
Gender	-.013	.282	-.01	-.045	.00			
Age	.029	.013	.185	2.199*	.03			
SIMD Code	.081	.099	.068	.817	.00			
Step 2						.068	.027	.032
(Constant)	21.86	1.219		17.937				
Gender	.113	.289	.034	.390	.00			
Age	.027	.013	.172	2.05**	.03			
SIMD Code	.067	.099	.057	.679	.00			
Event type	-.180	.210	-.07	-.856	.00			
Symptom	.215	.379	.063	.567	.00			
bother								
Symptom	-.015	.016	-.11	-.960	.00			
presence								
Step 3						.25	.14	.18
(Constant)	14.64	2.189		6.690				
Gender	.009	.300	.003	.029	.00			
Age	.035	.013	.226	2.612**	.04			
SIMD Code	.037	.097	.031	.379	.00			
Event type	-.328	.207	-.13	-1.588	.01			
Symptom	-.013	.371	-.01	-.034	.00			
bother								
Symptom	-.016	.017	-.11	-.931	.00			
presence								
IPQ Timeline	.019	.023	.07	.830	.00			
IPQ Cons	-.005	.035	-.02	-.142	.00			
IPQ Emotion	.034	.035	.134	.968	.00			
IPQ Coh	.013	.030	.037	.436	.00			
BMQ Nec	.088	.038	.23	2.348*	.03			
BMQ Conc	-.046	.039	-.11	-1.184	.00			
GAD	-.022	.042	-.07	-.515	.00			

Variable	B	SE B	β	t	s_r^2	R ²	Adj. R ²	ΔR^2
Social Sup	.067	.029	.211	2.273*	.04			
RLOC	.058	.029	.173	1.982*	.01			
FoR	.033	.050	.057	.659	.00			

*Note: N=135; *p<.05; **p<.01; ***p<.001*

Significant predictors of adherence to stroke medications at T2

Older age, higher scores on BMQ necessities, higher social support and higher internal locus of control were associated with higher reported adherence.

Logistic regression - predictors of adherence

Due to how skewed the data was, and based on previous research using the MARS scale (O'Carroll, et al., 2011), the MARS scale was dichotomised at the median (which was 24) and a logistic regression was carried out.

Results of the logistic regression: The results of full logistic regression model were significant $\chi^2 (21) = 45.59, p<.01$.

The model explained 36.4% of the variance in MARS scores (Nagelkerke R²) and correctly classified 71% of cases. Sensitivity was 74.7% and specificity was 66.2%, positive predictive value was 71% and negative predictive value was 70%.

Predictors of adherence at T2 (logistic regression)

The significant predictors of adherence to stroke medication at T2 were the same as with the linear regression, except that social support was no longer a significant predictor.

Research Question 5 - Symptoms at T2

52% (n=75) of participants had symptoms at T2 (this was 49% of the full baseline sample). Percentages of those who had a TIA or minor stroke and symptoms were the same as at baseline. Table 17 shows the numbers of symptoms that participants had.

There were 3 participants who had symptoms at T2, but who had not reported any symptoms at baseline.

Table 17

Number of symptoms at T2

Symptoms	n	% of n	% of N
1 symptom	39	52	27
2 symptoms	17	23	12
3 symptoms	16	21	11
4 symptoms	3	4	2
Total	75	100	52

Table 18

T2 frequencies of symptom type

Symptoms	Frequency	% of n	% of N
Fatigue	52	69	36
Limb weakness	22	29	15
Cognitive	13	17	9
Balance	8	11	6
Headaches	5	7	3
Light headed	5	7	3
Speech	5	7	3
Eyesight	4	5	3
Tingling / pins and needles	4	5	3
Mouth drooping	1	1	.01
Other	9	12	6

Table 19

Other symptoms

Symptoms	Frequency
Fine motor	4
Hearing	1
Palpitations	2
'Spasms' in head	1
Strange sensations in leg	1
Total	9

Research Question 6 - Which Baseline Variables predict Symptom Severity and Symptom Bother at 2?

Hierarchical multiple regressions were carried out to investigate which baseline variables predicted symptom severity or bother at T2 in participants who had symptoms. The regression models were not significant and there were no significant predictors of either.

Research question 7 - What are the Differences between Baseline and T2 in Participants who had Symptoms?

Paired sample t-tests were carried out on participants who had symptoms at both baseline and T2 (n=72) investigating whether there were any differences between baseline and T2 in participants who had symptoms. The results are reported in table 20. Due to the violation of the assumption of normality, Wilcoxon signed rank tests were also carried to check the results.

It was hypothesised that symptom bother and symptom severity would be lower; that expectations for recovery would be higher; that participants would view their condition as less chronic; have fewer negative consequences and emotions relating to the event; that anxiety would be lower; and that participants would have a more internal locus of control, less fear of recurrence and a higher quality of life.

Table 20

Paired t-tests

Measure	Mean	SD	Paired		Wilcoxon	
			t-test	P	eta ²	Z
Symptom bother						
<i>Baseline</i>	16.78	11.91	.96	.34		-1.13
<i>T2</i>	15.69	12.24				
Symptom severity						
<i>Baseline</i>	21.4	19.62	2.92	.005**	.11	-3.23**
<i>T2</i>	16.43	17.36				
Expectations						
<i>Baseline</i>	7.6	2.05	2.98	.004**	.11	-2.81**
<i>T2</i>	6.6	2.25				

Measure	Mean	SD	Paired		eta ²	Wilcoxon
			t-test	P		Z
IPQ Timeline						
<i>Baseline</i>	11.72	6.105				
<i>T2</i>	12.94	6.732				
IPQ Consequences						
<i>Baseline</i>	16.25	5.639	2.92	.005**	.1	-2.89**
<i>T2</i>	14.72	5.863				
IPQ Emotion						
<i>Baseline</i>	13.03	7.111	3.16	.002**	.12	-2.92**
<i>T2</i>	10.57	6.360				
IPQ Coherence						
<i>Baseline</i>	20.60	5.065	-1.24	.22		-.80
<i>T2</i>	21.46	4.269				
GAD						
<i>Baseline</i>	3.31	5.65	.125	.90		-.1
<i>T2</i>	3.24	5.61				
RLOC						
<i>Baseline</i>	39.35	39.35	3.69	.000***	.16	3.54***
<i>T2</i>	36.82	36.82				
Fear of Recurrence						
<i>Baseline</i>	6.36	6.36	1.3	.196		-1.39
<i>T2</i>	5.85	5.85				
SF-36 Physical						
<i>Baseline</i>	58.681	23.13	-2.85	.006**	.1	-3.33**
<i>T2</i>	65.068	22.93				
SF-36 Emotion						
<i>Baseline</i>	1.441	.323	2.71	.008**	.09	-2.72**
<i>T2</i>	1.354	.283				

Note: N=72; * $p < .05$; ** $p < .01$; *** $p < .001$; Effect size at .01 = small; .06 = medium; .14 = large

Summary of results for participants who had symptoms

The hypotheses that at T2 symptom severity would be significantly lower, that there would be fewer negative emotions relating to the event and fewer negative consequences and that both physical and emotional quality of life would be higher than at baseline were supported.

The hypotheses that fear of recurrence and symptom bother would be lower and that participants would view their condition as less chronic were not supported.

In relation to the hypotheses that, at T2, participants would have a higher internal locus of control and their expectations for recovery would be higher, these results were in the opposite direction from what was predicted, that is, participants had a higher external locus of control and their expectations for recovery were lower.

Research Question 8 - Differences between Participants who had Symptoms and those who did not at T2

Table 21 below shows the results from the ANOVA and Kruskal-Wallis tests investigating whether there were any differences between participants who had symptoms at T2 and those who did not.

It was hypothesised that participants who had symptoms at T2 would view their condition as significantly more chronic; have more negative consequences and emotions relating to the event; have greater anxiety; more fear of recurrence and lower emotional and physical quality of life compared those who did not have symptoms.

Table 21

Results of the ANOVA and Kruskal-Wallis

		N	M	SD	F	Sig.	Eta ²	H	Sig.
IPQ Time	Y	75	13	6.45	2.32	.13		2.65	.10
	N	68	11.37	6.13					
	T	143	12.22	6.44					
IPQ Cons	Y	75	14.69	5.92	9.65	.002**	.06	8.33	.004**
	N	68	11.85	4.91					
	T	143	13.34	5.63					
IPQ Emo	Y	75	10.40	6.29	2.48	.12		.994	.32
	N	68	8.93	4.70					
	T	143	9.70	5.62					
Anx	Y	75	3.24	5.60	1.09	.30		2.16	.14
	N	68	2.35	4.37					
	T	143	2.82	5.06					
FoR	Y	75	5.75	2.77	3.91	.05*	.03	3.76	.05*
	N	68	4.85	2.62					
	T	143	5.32	2.73					
SF36 Phys	Y	75	65.43	23.13	11.35	.001**	.07	12.76	.000***
	N	68	77.85	20.70					

	N	M	SD	F	Sig.	Eta ²	H	Sig.
T	143	71.34	22.80					
Y	75	1.35	.28	16.39	.000***	.1	17.99	.000***
SF36 Emo	68	1.14	.33					
T	143	1.25	.32					

Note: N=143; * $p < .05$; ** $p < .01$; *** $p < .001$; Effect size at .01 = small; .06 = medium; .14 = large; T=Total

Summary of results – participants who had symptoms at T2 believed there were more consequences resulting from their event, had higher fear of recurrence and had lower physical and emotional quality of life compared to participants without symptoms.

4.6 Summary of T2 Results

Research Question 1 - Change from Baseline to T2

Physical and emotional quality of life were significantly higher at T2 compared to baseline; fear of recurrence, IPQ emotion and consequences were significantly lower. Contrary to the hypotheses, recovery locus of control was significantly lower and IPQ timeline was significantly higher.

Research Question 2 - Predictors of Quality of Life

Only baseline quality of life predicted quality of life at T2.

Research Question 3 - Predictors of Fear of Recurrence

Higher baseline fear of recurrence and younger age predicted higher fear of recurrence at T2.

Research Question 4 - Predictors of Adherence

Older age, higher scores at baseline on BMQ necessity, higher social support and internal locus of control predicted adherence at T2

Research Question 5 - Symptoms at T2

75 participants (52% of T2 sample and 49% of the baseline sample) still had symptoms at T2

Research Question 6 - Predictors of Symptom Severity

The regression model was not significant and there were no significant predictors.

Research Question 7 - Change between Baseline and T2 in People who had Symptoms

Symptom severity, IPQ emotions and IPQ consequences were significantly lower at T2 compared to baseline; physical and emotional quality of life were significantly higher.

Contrary to the hypotheses, recovery locus of control and expectations for recovery were significantly lower at T2 compared to baseline.

Research Question 8 - Differences between Participants with Symptoms and those without

Physical and emotional quality of life were significantly lower in the group that had symptoms and fear of recurrence, and IPQ consequences were significantly higher.

4.7 Discussion of T2 Results

This section will start with a discussion of the results of the T2 analyses, then make some suggestions as to their clinical implications and finally it will discuss limitations.

Research question 1 - What has changed between Baseline and T2?

As was hypothesised, physical and emotional quality of life were significantly higher at T2 compared to baseline and IPQ consequences, IPQ emotion and fear of recurrence were significantly lower at T2 compared to baseline.

IPQ timeline was significantly higher at T2 compared to baseline, which was the opposite of what had been hypothesised. Recovery locus of control was significantly lower, which was also the opposite of the hypothesis.

Physical and emotional quality of life

Both physical and emotional quality of life increased significantly between baseline and T2. As was mentioned in the introduction to the baseline analysis, there is not enough previous research in this area to draw any firm conclusions about quality of life after a TIA or minor stroke (Moran et al., 2014). However, in this sample, both physical functioning and emotional well being improved significantly over a period of four to six months, suggesting that participants were recovering from the physical and emotional impact of the TIA or minor stroke.

Illness perceptions

IPQ Consequences: was significantly lower at T2 compared to baseline suggesting that there were significantly fewer consequences of the TIA or minor stroke at T2 compared to baseline.

IPQ Emotion: was significantly lower at T2 compared to baseline suggesting that there were fewer negative emotions relating to the TIA or minor stroke at T2.

IPQ Timeline: was significantly higher at T2 suggesting that participants saw their condition as more chronic at T2 compared to baseline. This was in the opposite direction from what was hypothesised.

These results are intriguing insofar as people saw their condition as significantly more chronic than at baseline, but also had significantly fewer consequences and less

negative emotion (it is possible that the result is an artefact of the data especially because the means of the IPQ timeline data are quite close and the effect size is small). It seemed intuitively sensible when formulating the hypotheses that where participants were recovering (as would be expected in this population) they would view their condition as being less chronic over time. However, that supposition relied on participants having the perception at baseline that their condition was chronic (at least to some extent).

Anecdotally, especially at baseline, many of the participants saw their TIA or minor stroke as an acute event, something that happened but was now “over and done with”. A substantial minority of participants saw it as a relatively insignificant event in their lives. Some people experience a TIA or minor stroke as transient episode with few, if any, consequences for the future (Croot et al., 2014). Many of those interviewed in this study did not see themselves as unwell to the extent that often they found the questions in the illness questionnaires difficult to answer or irrelevant to them. In addition, people frequently talked about their medications as being temporary and that, in time, they would be able to stop taking them, suggesting that they saw their condition as temporary. However, it is possible that by the T2 interviews people had had time to reflect on their condition and gather more information about it, possibly leading them to the view that the TIA or minor stroke was part of a chronic underlying condition. This is an area that could benefit from more research to ascertain whether these results can be replicated.

Recovery locus of control

The results for recovery locus of control were in the opposite direction from what had been hypothesised, that is, participants had a significantly more external locus of control at T2 compared to baseline. This result, like the result for IPQ timeline, could be an artefact of the data since the means are quite close and the results were positively skewed. In addition, as was mentioned above, many participants were not thinking of themselves as being unwell and therefore did not consider themselves to be in recovery; this meant that the questions in the RLOC scale, especially at baseline, were not relevant to everyone. However, it is more likely this result was due to the group who still had symptoms, and this will be discussed further in the section on the sub group analysis.

Fear of recurrence

Fear of recurrence was significantly lower at T2 compared to baseline, suggesting that fear of having another stroke may reduce over time for some people. This issue will be discussed further in the section on the sub group analysis.

Research Question 2: Predictors of Quality of Life at T2

None of the hypotheses were supported, except that overall quality of life at baseline predicted overall quality of life at T2, meaning that none of the baseline variables accounted for a significant amount of the variance in T2 quality of life scores. It may be worthy of note that the regression analysis without baseline quality of life as a predictor resulted in higher baseline symptom bother being the only significant predictor of lower quality of life at T2.

Research Question 3: Predictors of Fear of Recurrence at T2

Only baseline fear of recurrence and younger age predicted heightened fear of recurrence at T2. There is some evidence that suggests that having a TIA or stroke at a younger age can lead to more anxiety and less adjustment (e.g. Kapoor et al., 2019). It makes some sense that younger age would predict more fear of recurrence given that younger people are more likely to be working and have families depending on them and might fear the loss of independence and inability to work more than older people. In addition, as Kapoor et al. (2019) suggest, it is very possible that the shock of a diagnosis of TIA or minor stroke would be felt more acutely in those of a younger age. Although this study did not record whether participants were still working, 54% of this sample were under 70 years and 23% under 60 years, which would suggest that a considerable number of participants were still working and, anecdotally, it was the younger participants who expressed the most anxiety about their diagnoses.

Research Question 4: Predictors of Adherence at T2

Older age, higher scores on the BMQ necessities scale, higher social support and internal locus of control at baseline predicted adherence at T2. These results are all in line with previous research, although this is the first study that this author is aware of with TIA and minor stroke patients. Older age was found by O'Carroll et al. (2011) to predict higher adherence in stroke patients. They found that younger patients often reported forgetting medications due to not having set up a routine for taking them and having conflicting demands. Although this was not tested in the current research, it

seems reasonable to assume that the younger participants in this study would have similar reasons for non-adherence.

Several studies in adherence to stroke medications have also found that higher beliefs in the necessity of medications predict better adherence (e.g. Cheiloudaki et al., 2019; Crayton et al., 2017; O'Carroll et al., 2011). The finding in this study suggests that these beliefs also predict adherence in TIA and minor stroke and that patients might benefit from emphasis being placed on the importance of secondary preventative medications by both specialists and GPs.

The results for higher social support predicting better adherence is in line with several studies in stroke (e.g. Cheiloudaki et al., 2019; Coetzee et al., 2008). Internal locus of control has also been found to predict better adherence in hypertensive patients (Omeje et al., 2011) and a review article found internal locus of control was associated with better adherence in a variety of conditions (Nafradi et al., 2017). It makes sense that where patients feel that their condition is under their control, they will engage more with treatments and this result provides some evidence of that.

Research Question 5 - Symptoms at T2

Seventy-five participants (52%) had at least one symptom 4-6 months after baseline, with fatigue being the most common followed by limb weakness and problems with cognition. Coutts et al. (2012) found functional impairments in only 15% of their sample at 90 days following a TIA or minor stroke using the Modified Rankin Scale to measure disability, which is a stroke specific scale. This discrepancy may be because Coutts et al. (2012) had a much larger sample (N=499) compared to this study; however, it could also be an indication that stroke specific measures are not sensitive enough to identify all symptoms in TIA and minor stroke.

Research Question 6 - Predictors of Symptom Severity at T2

The regression models were not significant and there were no significant predictors of symptom severity. This finding is the same as at baseline and the possible reasons for this are discussed in the limitations section.

Research Question 7 - what has changed between Baseline and T2 in the Group with Symptoms?

As with the full sample, physical and emotional quality of life were significantly higher and IPQ emotion and consequences were significantly lower at T2 compared to baseline, which was as hypothesised. Recovery locus of control was also significantly lower at T2 compared to baseline which was counter to the hypothesis that locus of control would become significantly more internal.

In relation to the symptom specific measures, symptom severity was significantly lower at baseline compared to T2 as expected, but expectations for recovery were also significantly lower which was in the opposite direction of what had been hypothesised and there was no significant difference in symptom bother.

Quality of life, IPQ consequences and emotions (and timeline)

The results for quality of life, IPQ consequences and emotion are in line with what was expected and the discussion of them earlier is relevant to this section also. It was interesting that IPQ timeline was not significant in the group that had symptoms but was in the full sample. It would be expected that where symptoms endured, participants would view their condition as more chronic; however, this was not the case in this study and, perhaps, lends weight to the argument that the result in the full sample was an artefact of the data.

Symptom severity

Symptom severity was significantly lower at T2 compared to baseline suggesting that symptoms had improved in the four to six months between interviews. Interestingly, there was no significant difference in symptom bother, which suggests that even though symptoms may have been getting better, the bother associated with them had not improved significantly.

Expectations for recovery

Expectations for recovery were significantly lower at T2 compared to baseline which was in the opposite direction to the hypothesis that expectations for recovery would increase. This is interesting especially because symptom severity and IPQ consequences were significantly lower suggesting that symptoms were actually getting better and there were fewer consequences resulting from them. Despite the positive

changes to symptoms the expectations for them to improve further appear to have lowered. However, it is important to stress again that no one in this study rated their expectations for recovery negatively, that is, no participants expected to get worse at either baseline or T2 and participants were given a score of 5 out of 10 when they expected their symptoms to stay the same, it is likely that these results are due to more participants expecting no further improvement or only very small improvements to their symptoms over the next year and a half. This result provides some evidence that expectations for recovery are not static, but that they can change depending on experience (Janzen et al., 2006). In the group that still had symptoms at T2, it is likely that many participants' expectations had not been met (i.e., that they had expected a full or greater recovery by T2) and this might have led to some dissatisfaction with their progress which resulted in a lowering of future expectations.

Recovery locus of control

As with the full sample, this result was in the opposite direction of what was predicted. Participants had a more external locus of control at T2 compared to baseline. The result in the full sample is probably at least partially due to the results for this group. In the full sample the effect size was medium (.08), but in the sub-group analysis there was a large effect size (.16).

There is not much literature in the area of change in recovery locus of control without intervention, and none was found in the area of TIA and minor stroke; therefore the hypothesis was largely exploratory. When the hypotheses were written, it was expected that participants would think of themselves as being in recovery and that there was a possibility that, over time, they would feel more in control of their condition; however, it seems that this may not have the case, and that especially where symptoms persisted, participants may have begun to feel that they did not have control over their recovery.

Given that expectations for recovery were significantly lower, which was probably as a result of more participants expecting their symptoms to stay the same or only expecting small improvements (as was discussed above), it makes intuitive sense that people might start to consider that further recovery is not under their control, but either that it is not going to happen or it is under the control of others or is a matter of chance.

Research Question 8 - what are the Differences between those with Symptoms and those without at T2?

There were significant differences in both physical and emotional quality of life, IPQ consequences and fear of recurrence.

Quality of life

Those with symptoms had significantly lower physical and emotional quality of life, suggesting that symptoms were still severe enough to significantly impact physical functioning and emotional well being quality of life 4-6 months after baseline.

IPQ consequences

People with symptoms felt that they had significantly more consequences resulting from the TIA or minor stroke.

Fear of recurrence

Those with symptoms had significantly higher fear of recurrence than those without symptoms at T2. This result suggests that having symptoms may increase fear of recurrence, as does the fact that there was no difference in fear of recurrence between baseline and T2 in the symptoms group, but there was a significant reduction in the full sample. This is in line with research in cancer where symptoms can increase fear of recurrence (Hall et al., 2019). As Hall et al. (2019) suggests it is possible that symptoms act as a reminder of the possibility of recurrence. In addition, symptoms may be misinterpreted as signs of relapse in cancer (Hall et al., 2019) and it is possible that there is a similar effect in TIA or minor stroke. Possible symptoms of TIAs or minor strokes are wide ranging and, importantly, can be signs of other conditions (Kelly et al., 2001). Symptoms such as pins and needles, numbness, weakness, problems with balance, feeling light headed or dizzy, visual disturbances etc, can be signs of a TIA or minor stroke; however, they can also easily caused by other factors or conditions. Where these symptoms are experienced after a TIA or minor stroke (especially where if they were the symptoms experienced during the actual event), it is understandable that some people will immediately jump to the conclusion that they are having a recurrence. This issue will be discussed more in the qualitative chapter (chapter 6).

4.8 Clinical Implications

In line with the other research in this area, these results suggest that many people have symptoms 4-6 months following a TIA or minor stroke that are affecting their lives significantly. In addition, although symptoms may improve, the interference with everyday life might not improve as much. This suggests that people who have had a TIA or minor stroke may not be part of the same population, that is, some people appear to recover well and do not need further input, but some people may require further support.

Furthermore, having symptoms was associated with a heightened fear of recurrence, a more external locus of control and a lower emotional and physical quality of life. These results suggest that some people who have had a TIA or minor stroke may benefit from further support. The type of support required may not be the same for everyone. Some people might simply require reassurance and encouragement to take control of their condition, whereas others may benefit from specialist rehabilitation.

Younger people who have had a TIA or minor stroke appear to be more at risk of heightened fear of recurrence and to adhere less well to their medications. This may suggest that younger people need different types of information and support following a TIA or minor stroke, for example, support in setting up a routine for taking medications and more tailored information about prevention of recurrence.

As with previous research, the belief in the necessity of secondary preventative medications, having an internal locus of control and more social support improved adherence. These are all areas where intervention is possible (e.g. O'Carroll, Chambers, Dennis et al., 2013 & 2014). Both specialist consultants and GPs could emphasise the necessity of adhering to stroke medications and the role that the person can have in helping self-manage their condition. In terms of social support, wherever possible, significant others (e.g. spouses) could be encouraged by clinicians to help with their medication regime. As was mentioned earlier, in this study some participants who asked about when they would be able to stop taking their medications and discussed them as temporary measures, indicating a perceived acute rather than chronic timeline, suggesting that any messages about the nature of the condition and the importance of these treatments and the expectation that they would be taking them long term may not have been fully received. Increasing internal locus of control might be a more

involved task, but helping patients to feel more in control of their condition and their treatments might be a useful first step.

4.9 Strengths and Limitations

There were some limitations caused by the expectations measure. Choosing to score those who expected to stay the same on the same scale as those who expected to get better, was, in hindsight, probably a mistake. It seems likely that the group that expected their symptoms to stay the same were a distinct group and should have been treated as such in the analyses.

As at baseline and T2, the regression models for symptom severity were not significant and there were no significant predictors. At the time of choosing to how to score the severity scale, it seemed sensible to try to obtain one score which took both the number of symptoms and the severity of each symptom into account; however, in practice, this was not a useful way to measure severity and perhaps using the more simple method of summing the severity scores would have been more successful. There were similar issues with the fear of recurrence scale as there were at baseline, that is, the inability to distinguish between fear and concern.

As well as the strengths that were reported at baseline, the main strength of the follow-up study was the retention of participants. That only ten people chose to withdraw was surprising. One possible reason for the high number of people who chose to stay in the study is the personal contact they had from the researcher and being given the choice of how they wanted to complete the follow-up measures.

4.10 Conclusions

TIA and minor stroke are conditions that are often defined as having no lasting symptoms. A substantial proportion of people who have had a TIA or minor stroke in this sample had symptoms 4-6 months after the event that significantly affect their lives. In addition, although there was evidence of symptomatic improvement, the interference with everyday life did not improve significantly. Furthermore, having symptoms appeared to increase the likelihood of having heightened fear of recurrence, a more external locus of control and a lower emotional and physical quality of life.

The necessity of secondary prevention medications should be emphasised and significant others should be encouraged to support adherence. Clinicians could support patients in self-managing their condition which may help to improve adherence.

Younger people may be more at risk of heightened fear of recurrence and may adhere less well to medications and might benefit from different types of information and support.

CHAPTER 5

PREDICTORS OF LONG-TERM OUTCOME FOLLOWING TIA/MINOR STROKE.

Abstract

Aims: the primary aims of this chapter were to investigate which baseline variables predict quality of life, fear of recurrence and medication adherence 18 months after baseline. In addition, the T3 analysis tested whether baseline variables could predict symptom severity and symptom bother in participants who had symptoms. Secondary aims were to investigate change in quality of life between baseline, T2 and T3 and differences between those who had symptoms and those who did not.

Analysis: hierarchical multiple regressions and logistic regressions were used where appropriate to investigate baseline predictors of quality of life, fear of recurrence and adherence. A repeated measures ANOVA was calculated to ascertain change in quality of life over time and independent t-tests were used to calculate differences in quality of life between those who had symptoms and those who did not.

Results: 42% of participants reported symptoms at T3. Better quality of life at T3 was predicted by better quality of life, lower fear of recurrence and lower resilience at baseline. Higher fear of recurrence at T3 was predicted by lower emotional and physical quality of life, and more negative emotional illness perceptions at baseline. Better adherence to stroke medications at T3 was predicted by lower concerns about medications at baseline.

Quality of life increased significantly between baseline and T2 and decreased significantly between T2 and T3 as well as between baseline and T3. Those without symptoms at T3 had significantly better emotional and physical quality of life than those with symptoms.

Conclusions: there are still a number of people who have symptoms 18 months after a TIA or minor stroke. Fear of recurrence and quality of life were related to each other. Specific concerns about secondary preventative medication are associated with lower long-term adherence and it is recommended that clinicians address concerns that patients may have about their medications.

5.1 Introduction

This section aims to provide an introduction to the T3 follow-up analyses. The hypotheses regarding quality of life, fear of recurrence, adherence, expectations and symptoms were the same as at baseline and at T2 (other than the outcome variables were the T3 measures), therefore the justifications for the hypotheses and the literature discussed in the introduction to the baseline and T2 analyses is relevant to this section also. No new variables were introduced in the T3 analysis; therefore this introduction will start with the research questions.

5.2 Research questions

Research Question 1 - How has Quality of Life changed between baseline, T2 and T3?

Hypothesis 1 for T3: quality of life will increase between baseline and T2.

Research Question 2 - Which Baseline Variables predict Quality of Life at T3?

Hypothesis 2 for T3: the following will predict lower quality of life at T3:

- increased scores on symptom measures (symptom presence, severity and bother)
- event type (TIA or minor stroke)
- negative health perceptions (IPQ subscales)
- heightened anxiety
- low resilience
- fear of recurrence
- low social support
- lower scores on the medications necessity scale
- higher scores on the medications concerns scale
- pessimism
- lower quality of life

Research Question 3 -Which Baseline Variables predict Fear of Recurrence at T3?

Hypothesis 3 for T3: the following will predict higher fear of recurrence at T3:

- older age

- symptom presence
- symptom bother
- event type
- negative illness perceptions (IPQ subscales)
- low resilience
- low social support
- heightened anxiety
- external locus of control
- pessimism
- reduced quality of life

Research Question 4 - Which Baseline Variables predict better Adherence at T3?

Hypothesis 4 for T3: that the following will predict better adherence at T3:

- older age
- Having symptoms
- Increased symptom bother
- Event type
- Higher scores on BMQ necessities and lower scores on BMQ concerns
- Higher IPQ coherence, consequences, emotion and timeline
- Higher social support
- Internal locus of control
- Lower anxiety

Research Question 5 - How many Participants still have Symptoms at T3?

It is hard to hypothesise how many participants will still have symptoms 18 months after baseline. In Muus et al.'s (2010) study, 43% of their sample did not consider their quality of life to have returned to pre-stroke levels after 12 months. However, this is quality of life and not symptom severity, therefore it is unclear whether these results are relevant. For this reason this analysis is purely exploratory.

Research Question 6 - Which Baseline Variables predict Symptom Severity at T3?

Hypothesis 6 for T3: the following baseline variables will predict higher symptom severity at T3:

- lower expectations for recovery
- lower physical quality of life
- higher IPQ consequences
- higher anxiety.

Research Question 7 - Are there Differences in Quality of Life at T3 between those with Symptoms and those without?

Hypothesis 7 for T3: quality of life will be significantly higher in the group that does not have symptoms.

5.3 Methodology for T3 follow-up

T3 Follow-up

A further follow-up at 18 months post baseline was sent to the participants from NHS Lothian with an SAE to post it back. As was mentioned in the methodology section in chapter 3, participants from NHS Fife were not sent the follow-up because when the amendment was sent to NHS ethics to allow for T3 data to be collected, recruitment was already underway in NHS Fife. One reminder was sent to participants if the measures were not returned within one month; no further action was taken after this. N = 125 participants (participants who were not contactable at T2 were included in T3) were invited to take part in T3, of whom n = 103 returned a questionnaire. Of the 22 participants who did not return the questionnaire, n = 4 had died (one as a result of a major stroke), n = 1 withdrew due to terminal cancer and n = 17 did not respond to the invitation. It should be noted that participants were not asked why they had chosen to withdraw; information about the deaths and ill health was given by family members who chose to contact the researcher.

T3 Questionnaires

At T3 participants were sent the SF-36, MARS and the GAD. As well as these, they were asked about whether they had had any other events and the approximate date(s); fear of recurrence was measured again, but only using one question in an attempt to keep the questionnaire as brief as possible; a symptom checklist was also included which asked participants to tick any symptoms they had that they believed were caused by the TIA or minor stroke: it also asked about severity on a 1-10 scale and if the symptom was bothersome to them (see appendix 8).

At baseline and T2 only the three most severe symptoms were scored and this was felt to be justifiable because only 5 participants at baseline and 3 participants at T2 had more than three symptoms and no one had more than 4 symptoms; however, at T3 23 participants reported more than three symptoms and 20 participants reported over four symptoms. Therefore, symptom severity was calculated including all symptoms because it was felt that not doing so would lose too much information. However, this meant that symptom severity at T3 was not comparable with baseline and T2.

Analysis

For the GAD and MARS missing data was dealt with as follows: where <20% of the questionnaire was completed it was discarded, and where there were $\leq 20\%$ missing items, these were prorated using the mean of the reported items on the scale. With the SF-36, missing items within each subscale were not taken into account when calculating the subscale scores, meaning that subscale scores are the average of all items that the participant answered.

Repeated measures ANOVAs were used to investigate any changes in emotional and physical quality of life between baseline, T2 and T3. Hierarchical multiple regressions were used to explore predictors of quality of life and symptom severity. Logistic regressions were used to look for predictors of fear of recurrence and adherence. Independent t-tests were used to investigate differences in emotional and physical quality of life between those who had symptoms and those who did not.

5.4 Time 3 Analysis

One hundred and three participants completed T3 questionnaires. There were 4 further recurrences in between T2 and T3. Three of those were classified as 'uncertain' (i.e. there was no formal diagnosis) and one participant died due to a major stroke. This makes the recurrence rate at eighteen months 7% of the full sample (although clearly it is impossible to say how many participants who had dropped out of the study had a stroke after doing so).

Research Question 1- how does Quality of Life change over Time?

Hypothesis 1 for T3: quality of life will increase between baseline and T2 and further increase between T2 and T3.

A repeated measures ANOVA was calculated to investigate differences in physical and emotional quality of life over the three time points.

Physical quality of life.

N=97 participants completed or provided enough information to produce a score for the SF-36 physical scale at T3. There was a significant effect of time on physical quality of life $F(2, 182) = 18.57, p < .001$. Physical quality of life increased between baseline ($\bar{x} = 67.84, 2.5 \text{ SD}$) and T2 ($\bar{x} = 74.03, 2.67 \text{ SD}$) and decreased between T2 and T3 ($\bar{x} = 63.37, 2.56 \text{ SD}$). Post hoc analysis with a Bonferroni adjustment showed that the

increase between T1 and T2 was significant ($\bar{x} = 6.19, 1.69SD, 95\% CI[2.06, 10.32], p = .001$) and that the decrease between T2 and T3 was significant ($\bar{x} = -10.66, 1.74SD, 95\% CI[-14.9, -6.4], p < .001$). In addition the decrease in physical quality of life between baseline and T3 was also significant ($\bar{x} = -4.46, 1.83SD, 95\% CI[-8.9, 0], p = .05$). See Fig. 7.

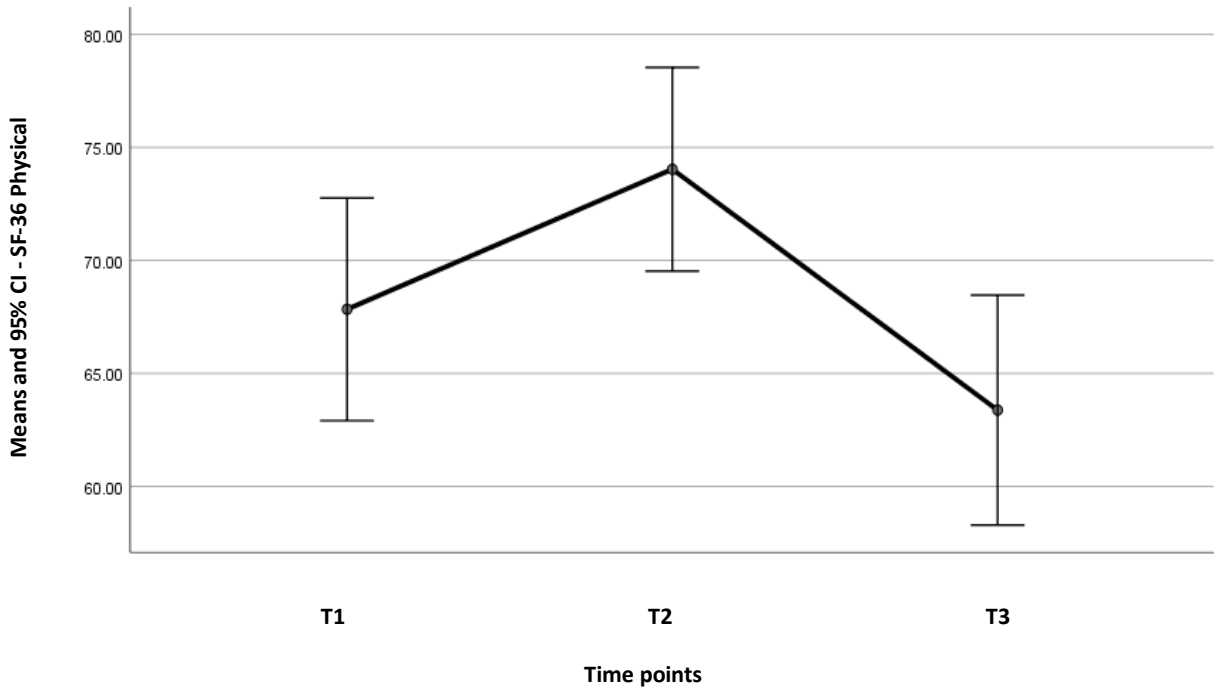


Figure 6: Graph of change in physical quality of life

Emotional quality of life.

N=92 participants completed, or provided enough information to produce, a score for the SF-36 emotion scale at T3. There was a significant effect of time on emotional quality of life $F(2, 182) = 15.15, p < .001$. Emotional quality of life increased between baseline ($\bar{x} = 74.37, 2.05 SD$) and T2 ($\bar{x} = 78.62, 1.79SD$) and decreased between T2 and T3 ($\bar{x} = 69.22, 2.18SD$). Post hoc analysis with a Bonferroni adjustment showed that the increase between T1 and T2 was significant ($\bar{x} = 4.25, 1.72SD, 95\% CI[.06, 8.43], p < .05$) and that the decrease between T2 and T3 was significant ($\bar{x} = -9.4, 1.57SD, 95\% CI[-13.24, -5.57], p < .001$). In addition the decrease in emotional Quality of life between baseline and T3 was also significant ($\bar{x} = -5.16, 1.83SD, 95\% CI[-9.63, .68], p < .05$). See Fig. 8.

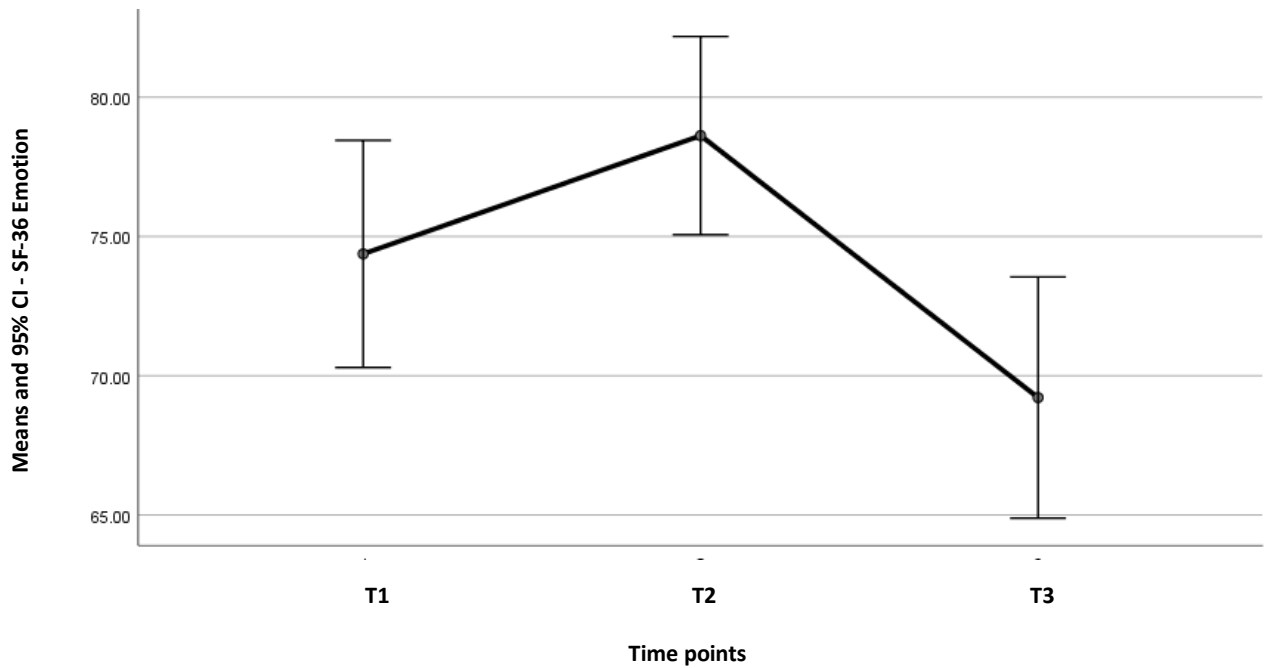


Figure 7: Graph of change in emotional quality of life

Research question 2: Which Baseline Variables predict Quality of Life at T3?

It was hypothesised that the following baseline variables would predict lower quality of life at time 3:

- older age
- lower SMID code
- increased scores on symptom measures (symptom presence, severity and bother)
- event type (TIA or minor stroke)
- negative health perceptions (IPQ subscales)
- heightened anxiety
- low resilience
- fear of recurrence
- low social support
- lower scores on the medications necessity scale
- higher scores on the medications concerns scale
- pessimism
- lower quality of life

The regression was run initially to check the assumptions of linear regression. For the most part these were met; however, there were over 50 leverage points, which

when removed, resulted in the full model not being significant. It was decided to re-run the analysis with fewer predictor variables, removing variables where it was felt this could be justified.

Symptom presence and symptom bother at baseline were removed as these do not apply to all participants, GAD was removed as the SF-36 at baseline includes questions about anxiety, BMQ necessities and BMQ concerns were removed as there was less theoretical justification for these to be included. There were still over 20 leverage points and when these were removed the regression model was not significant.

It was decided to report the results of the regression including the 20 leverage points, however these results should be viewed with some caution.

Table 22

Regression statistics - quality of life at T3

Results of regression.								
Variable	B	SE B	B	t	sr ²	R ²	Adj. R ²	ΔR ²
Step 1								
(Constant)	97.802	15.345		6.374		.065	.035	.065
Gender	-8.997	4.385	-.208	-2.052*	.04			
Age	-.185	.185	-.102	-.999	.01			
SIMD Code	-1.482	1.567	-.096	-.946	.00			
Step 2						.065	.025	.00
(Constant)	96.881	16.217		5.974				
Gender	-9.062	4.422	-.209	-2.049*	.04			
Age	-.184	.186	-.101	-.990	.00			
SIMD Code	-1.488	1.576	-.096	-.944	.00			
Event type	.593	3.219	.019	.184	.00			
Step 3						.612	.545	.546
(Constant)	20.739	22.616		.917				
Gender	.274	3.452	.006	.079	.00			
Age	-.230	.148	-.127	-1.559	.01			

SIMD Code	-1.245	1.105	-.081	-1.127	.00
Event type	1.148	2.312	.036	.496	.00
IPQ Timeline	-.365	.243	-.121	-1.502	.01
IPQ Consequence	.121	.390	.030	.312	.00
IPQ Emotion	.208	.372	.062	.558	.00
IPQ Coherence	.142	.343	.031	.413	.00
LOT	.674	.442	.164	1.525	.01
BRS	-.788	.385	-.195	-2.045*	.02
Social Support	.335	.363	.076	.924	.00
RLOC	.563	.342	.136	1.647	.01
FoR	-1.535	.642	-.192	-2.393*	.02
Baseline QoLTotal	.662	.102	.610	6.48***	.20

Note: N=92; * $p < .05$; ** $p < .01$; *** $p < .001$

The results of the full model from the hierarchical regression were significant $R^2 = .61$, $F(14, 81) = 9.13$, $p < .001$, adjusted $R^2 = .55$. The addition of clinical variables to the demographic variables (model 2) did not lead to a significant increase in R^2 ($\Delta R^2 = .00$, $F(1, 91) = .034$, $p > .05$). Adding the psychological variables (model 3) did lead to a significant increase in R^2 of .55, $F(10, 81) = 11.41$, $p < .001$ (see Table 22).

Significant predictors of quality of life at T3.

Higher quality of life at T3 was predicted by higher baseline quality of life, lower fear of recurrence and, contrary to hypothesis, lower resilience at baseline.

Research question 3 - Which Baseline Variables predict Fear of Recurrence at T3?

Because fear of recurrence was measured using only one question at T3, logistic regression was the most appropriate analysis to use. Fear of recurrence scores were dichotomised at the median, which was 3. Due to the reduced sample size (N=96) and to increase the power of the results it was decided to reduce the number of predictor variables. GAD was removed as the SF-36 emotion asks about anxiety, and BMQ necessities and concerns were removed as there was less theoretical justification for their inclusion than with some of the other variables. There were still too many variables for the model to have the desired power; however, as the other assumptions

for logistic regression were met it was decided to report the results. Regression statistics are presented in Table 23.

Results of the logistic regression.

The results of full logistic regression model were significant $X^2(17) = 36.67$, $p < .01$.

The model explained 44.9% of the variance in fear of recurrence scores (Nagelkerke R^2) and correctly classified 77% of cases. Sensitivity was 64.7% and specificity was 84.5%, positive predictive value was 80% and negative predictive value was 71%.

Table 23

Regression statistics - fear of recurrence at T3

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Gender (1)	-	.714	3.236	1	.072	.277	-1.284	.714
	1.284							
Age	-.051	.031	2.668	1	.102	.950	-.051	.031
SIMD	.095	.221	.186	1	.666	1.100	.095	.221
Event type			3.546	2	.170			
Event (1)	1.935	1.074	3.245	1	.072	6.927	1.935	1.074
Event(2)	2.221	1.242	3.195	1	.074	9.215	2.221	1.242
Symptom presence	-.353	.590	.358	1	.550	.702	-.353	.590
IPQ Timeline	.062	.048	1.630	1	.202	1.064	.062	.048
IPQ Consequence	.042	.072	.344	1	.558	1.043	.042	.072
IPQ Emotion	.176	.081	4.749	1	.029*	1.193	.176	.081
IPQ Coherence	-.019	.065	.082	1	.775	.982	-.019	.065
LOT	.046	.081	.322	1	.570	1.047	.046	.081
BRS	.000	.075	.000	1	.998	1.000	.000	.075
Social support	.012	.068	.030	1	.863	1.012	.012	.068

	95% C.I. for EXP(B)							
RLOC	-.030	.068	.193	1	.660	.971	-.030	.068
FoR	.135	.114	1.394	1	.238	1.145	.135	.114
SF-36 Physical	-.046	.022	4.434	1	.035*	.955	-.046	.022
SF-36 Emotion	-.074	.032	5.237	1	.022*	1.076	.074	.032
Constant	-2.98	4.684	.403	1	.525	.051	-2.975	4.684

Note: N=96; * $p < .05$; ** $p < .01$; *** $p < .001$; Event (1) TIA, Event (2) minor stroke

Significant predictors of fear of recurrence at T3

Fear of recurrence at T3 was predicted by lower emotional and physical quality of life, and more negative emotional illness perceptions at baseline.

Research Question 4 - Which Baseline Variables predict Adherence at T3?

Because the results for the T3 MARS scale were severely skewed in favour of high self-reported adherence, with 64% of the participants who responded scoring a maximum of 25 and only 7 participants scoring under 24, it was decided that the only appropriate analysis was logistic regression. MARS scores were dichotomised at 24 (the median was 25). The results of the full model were not significant. It was possible that this was because of the relatively small sample size and that there were too many variables in the model, therefore it was decided to attempt to reduce the number of predictor variables. Variables were removed from the model in the order of which had the least theoretical basis for inclusion. The model continued to be non-significant until there were only 6 predictor variables. Results are presented in Table 24

Results of the logistic regression.

The results of full logistic regression model were significant $X^2(6) = 12.62, p < .05$.

The model explained 20% of the variance in MARS scores (Nagelkerke R^2) and correctly classified 72% of cases. Sensitivity was 41% and specificity was 90%, positive predictive value was 73% and negative predictive value was 70%.

Table 24*Logistic Regression statistics- adherence*

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Gender (1)	-.632	.555	1.297	1	.255	.532	.179	1.577
Age	-.024	.024	1.031	1	.310	.976	.932	1.023
BMQ Necessities	.067	.075	.798	1	.372	1.069	.923	1.237
BMQ Concerns	-.181	.069	6.879	1	.009**	.834	.729	.955
SF-36 Physical	.015	.018	.735	1	.391	1.015	.980	1.052
SF-36 Emotion	-.031	.022	2.006	1	.157	.969	.928	1.012
Constant	-	4.684	.403	1	.525	.051	-2.975	4.684
	2.975							

Note: N=96; * $p < .05$; ** $p < .01$; *** $p < .001$

Predictors of adherence at T3.

Lower scores on the BMQ concerns scale at baseline predicted higher reported adherence at T3.

Research Question 5 - How many Participants still have Symptoms at T3?

Of the 98 participants who completed the T3 questionnaires, 41 participants reported symptoms relating to their TIA or minor stroke (42% of the T3 sample and 27% of the full baseline sample). There were 9 participants who reported symptoms at T3 but did not at baseline or T2 and an additional 3 participants who did not report symptoms at T2 (or at baseline), but did at T3. Numbers of symptoms and frequencies of symptom types are reported in Tables 25 and 26.

Table 25*Number of symptoms at T3*

Symptoms	n	% of n
1 symptom	6	15
2 symptoms	3	7
3 symptoms	8	20
4 symptoms	3	5
5 symptoms	6	14
6 symptoms	5	12
7 symptoms	4	10
8 symptoms	3	7
9 symptoms	2	5
Total	39	95*

*Note: 2 participants answered 'yes' to having symptoms, but did not provide any further information.

Table 26*T3 frequencies of symptom type*

Symptoms	Frequency	% of n
Fatigue	28	68
Limb weakness	25	60
Cognitive	26	63
Balance	24	58
Headaches	10	24
Light-headedness	19	46
Speech	8	19
Eyesight	11	26
Tingling / pins and needles	17	41
Mouth drooping	1	.02
Other	10	24

Table 27*T3 other symptoms*

Symptoms	Frequency
Clumsiness	1
Hearing	2
Constipation	1
Dribbling	1
Impotence	1
Cramps	1
Lack of strength	1
Choking / swallowing	1
Swollen legs	1
Total	10

Research Question 6 - Which Baseline Variables predict Symptom Severity at 18 months?

A hierarchical multiple regression was run to investigate which baseline variables predicted symptom severity at T3. The full model was not significant and there

were no significant predictors. The regression was re-run with fewer variables; however, the full model was still not significant and there were no significant predictors.

Research Question 7: Are there Differences in Quality of Life at T3 between those with Symptoms and those without?

Independent samples t-tests were calculated to investigate whether there were any differences between those with and those without symptoms at T3.

Table 28

Differences in quality of life between those with symptoms and those without

	Sympt	N	Mean	SD	t-test	Effect size	P value
Physical QoL	yes	40	56.45	24.78	-.322	.7	.001
	no	53	72.12	20.70			
Emotional QoL	yes	40	61.62	21.30	-3.85	.8	.000
	no	53	76.79	16.74			

There were significant differences on both physical and emotional quality of life (see Table 28). Means show that both physical and emotional quality of life were significantly lower in the group that had symptoms.

Summary of T3 results

Research question 1 - how does quality of life change over time?

Both emotional and physical quality life increased significantly between baseline and T2 and decreased significantly between T2 and T3 and between baseline and T3.

Research question 2 - which baseline variables predict quality of life at T3?

Higher baseline quality of life, lower baseline fear of recurrence and lower resilience at baseline predicted higher quality of life at T3.

Research question 3 - which baseline variables predict fear of recurrence at T3?

Higher baseline emotional and physical quality of life and lower scores on baseline IPQ emotion predicted lower fear of recurrence at T3.

Research question 4 - which baseline variables predict adherence at T3?

Higher scores on baseline BMQ concerns predicted lower adherence at T3.

Research question 5 - How many participants still have symptoms at T3?

Forty-two per cent of the participants at T3 had symptoms.

Research question 6 - which baseline variables predict symptom severity at T3?

There were no significant predictors of symptom severity at T3.

Research question 7 - Are there differences in quality of life at T3 between those with symptoms and those without?

Both physical and emotional quality of life was significantly lower in the group that had symptoms at T3.

5.5 Discussion of T3 results

Research Question 1 - How does Quality of Life change over Time?

Both emotional and physical quality of life increased significantly between baseline and T2 and then decreased significantly between T2 and T3 (and also between baseline and T3). This is in the opposite direction from what had been expected. These results are not easy to explain. The rate of recurrence was approximately 7% (n=11), only 4 of those were confirmed diagnoses (the others being possible recurrences, but not confirmed by a clinician) and 7 of those were reported at T2, so is unlikely that the decreases in quality of life were due to recurrent stroke. The rate of recurrence is in line with previous research where recurrence is estimated at 12-20% with the majority of those occurring in the first 48-72 hours (Coutts et al., 2008).

It is possible the participants who still had symptoms at T3 had a disproportionately large effect on the quality of life scores compared to those who did not have symptoms. There were significant differences between both emotional and physical quality of life scores between these groups and the effect sizes were medium and large respectively. It is also possible that the results from baseline and T2 had some element of social desirability responding within them as T3 data was collected by mail whereas baseline and T2 were, for the most part, face to face interviews. There is some evidence that the method of interview administration can affect the way that research participants answer questions and that face to face interviews can lead to more socially desirable responding than other methods. However, the evidence is limited (Bowling, 2005) and it remains unclear why participants' quality of life increased and then decreased so much.

Another possibility is the development or worsening of co-morbid conditions or serious life events in participants, which may have significantly affected quality of life scores; however, this was not possible to test in this research.

Research Question 2 - Which Baseline Variables predict Quality of Life at T3?

At T3 lower quality of life was predicted by higher fear of recurrence and higher resilience scores at baseline.

Resilience: that higher resilience at baseline predicted lower quality of life at T3 is difficult to explain. There is a lot of evidence suggesting that resilience predicts better

quality of life and better adjustment to illness (see Michael, 2014; Stewart et al., 2011 for reviews) and this result appears to contradict previous research, in fact, no papers were found where low resilience predicted better outcomes. It is possible that it is merely an artefact of the data due to the number of predictor variables and therefore not meaningful. One other possibility is that participants who had high resilience scores at baseline did not recover as well as they had hoped and experienced lower quality of life a result of this; however, this is highly speculative and the results of this study would need to be replicated before any conclusions can be drawn.

Fear of recurrence: higher baseline fear of recurrence predicted lower quality of life at T3. Fear of recurrence has been found to be associated with lower quality of life in a variety of cancers (e.g. Simonelli et al., 2017; Sarkar et al., 2014; Mehnert et al., 2013; Hart et al., 2008). More research in TIA and minor stroke is needed to ascertain whether the relationship is robust within this population; however, the two concepts do appear to be closely linked in this study (see below also).

Research Question 3 - Which Baseline Variables predict Fear of Recurrence at T3?

Lower baseline quality of life and higher IPQ emotion predicted higher fear of recurrence at T3. The result regarding IPQ emotions may be in line with Sarkar et al.'s (2014) research which found that higher levels of psychological distress predicted higher fear of recurrence in cancer patients. Although IPQ emotions is not necessarily measuring psychological distress in general (i.e. depression or anxiety), it is measuring psychological distress surrounding the condition.

That lower baseline quality of life predicted higher fear of recurrence is interesting given the results above (i.e. that higher baseline fear of recurrence predicted lower quality of life at T3) and suggests that the two concepts are related in this research. It might also suggest that there is something else mediating the relationship.

Research question 4 - Which Baseline Variables predict Adherence at T3?

Higher scores on BMQ concerns predicted lower adherence at T3. This result is in line with O'Carroll et al. (2011) who found that higher specific concerns about medication predicted lower adherence. This result is discussed further in the clinical implications section.

Research question 5 - How many participants have symptoms at T3?

Forty-one participants reported symptoms relating to their TIA or minor stroke at T3, which is 42% of the T3 sample and 27% of the full baseline sample.

There were several discrepancies in the T3 symptoms data. Twelve participants who reported symptoms at T3 did not report any baseline or T2. Twenty-three participants reported more than 3 symptoms where only 5 participants reported four symptoms at baseline and 3 reported more than four at T2. One possible explanation for these discrepancies is the method of data collection. At baseline and T2 participants were asked to report any symptoms they felt were related to the TIA or minor stroke, while at T3 they were sent a list of ten symptoms (and an 'others' option) and asked to tick any they felt related to their TIA or minor stroke. Whether this method prompted some participants into remembering symptoms that they forgot to mention previously or whether some participants did not see the part of the instructions that said only to tick symptoms relating to the event and ticked all the symptoms they had for any reason is impossible to say.

Many of the symptoms in the list are common, especially in the age group in this study, for example fatigue, weakness in fingers, arms etc, pins and needles, eyesight, and perceived problems with cognition. These could have been caused by other conditions. In this author's opinion the most likely explanation is that some participants were ticking all the symptoms they had regardless of whether they were caused by the TIA or minor stroke. Whatever the reason, the discrepancies in the data make a comparison of numbers of symptoms, symptom severity and bother with those at baseline and T2 impossible. This is an important issue for future research, that is, to consider the implications of different methods of data collection and the possible discrepancies that may result from these.

Research question 6 - Which Baseline Variables predict Symptom Severity at T3?

As with baseline and T2 the regression models were not significant and there were no significant predictors.

Research Question 7 - Are there any Differences in Quality of Life between those who have Symptoms and those who do not at T3?

Participants who had symptoms had significantly lower physical and emotional quality of life. This result has been consistent throughout this research.

5.6 Clinical Implications

Symptoms: despite the fact that there might be issues with the symptoms data, it is likely that, at least, some of the symptoms reported at T3 were related to the original TIA or minor stroke. It has been a consistent finding throughout this research that the participants who have symptoms experience a lower emotional and physical quality of life. It seems likely that this group might benefit from further input from specialists to provide rehabilitation and support where appropriate. In NHS Lothian only three participants in this research were offered any further treatment (other than medications): one participant had a minor stroke in a different NHS trust while on holiday and was offered an appointment for rehabilitation, but was unable to take up the offer; one participant was offered specialised stroke rehabilitation in NHS Lothian (it is not clear why this particular participant received this service); and one participant was offered tailored exercise classes through their GP. All the remaining participants were under the care of their GP practice and had been prescribed secondary preventative medications and most had been offered, at least, some lifestyle advice. It may be worthy of note that many participants expressed dissatisfaction with the lack of follow-up and several commented on feeling like they been left to 'just get on with it'. This is also the finding of some qualitative research (e.g. Croot et al., 2014).

Adherence: the finding that lower baseline concerns about medications predict higher adherence at T3 is important, especially if this is not an immediate effect (the relationship was not found at baseline or T2). It is possible the effects of having more concerns about medications on adherence develop over time, especially if side-effects are experienced. Anecdotally, at baseline and T2, there were participants in this study who expressed discomfort at having been prescribed statins and claimed their concerns were not being addressed by their GPs. Perhaps it would be useful for GPs or practice nurses, to enquire about, and address, any concerns that patients have about their medications, not only immediately after they are prescribed, but also after the patient has been taking them for a period of time.

5.7 Strengths and Limitations

The same limitations regarding the expectations, symptom severity and fear of recurrence measures at baseline and T2 are relevant here also.

There were limitations with the symptoms data that were, probably, caused by the different data collection methods employed at baseline, T2 and T3. It would have been useful to have contacted participants after the data had been returned to check with them about the symptoms they were reporting; however, the NHS ethics approval for the T3 follow-up specifically stated that no further contact with participants was allowed.

As was mentioned in the baseline chapter co-morbid conditions and life events both have the potential to significantly affect quality of life. As these were not recorded formally it was not possible to explore whether these may have had an effect on the results regarding quality of life.

As at T2, a major strength of this study was the retention of participants at long term follow-up. In particular, this allowed the identification of apparent longer-term effects around the impact of experiencing symptoms and adherence to medication which were not, or not as, apparent at T2.

5.8 Conclusions

Many people have symptoms 18 months after a TIA or minor stroke, although whether these symptoms are attributable to TIA/minor stroke cannot be established from this study. People who have symptoms have a significantly lower quality of life than those who do not.

Fear of recurrence appears to be associated with lower quality of life and further research needs to be done in this area to see if this relationship is straightforward or mediated by other variables e.g. low mood.

Specific concerns about secondary preventative medication are associated with lower long-term adherence. Interventions should be attempted where concerns are elicited and addressed where possible (e.g. O'Carroll et al., 2013 & 2014).

CHAPTER 6**QUALITATIVE STUDY****Abstract**

Aims: to explore the impact that having a TIA or minor stroke has on the individual and how this changes over time. In addition, to explore the concept of expectations for recovery of symptoms and whether these change over time.

Methods: semi structured interviews were carried out with six people within eight weeks of a diagnosis of a TIA or minor stroke and again between four and six months later. Interviews were recorded and transcribed verbatim. The transcripts were then analysed using interpretative phenomenological analysis.

Results: The emergent themes were living in a new health reality, and a need for further intervention of some type. Three further themes emerged: the relative importance of the TIA or minor stroke; emotional responses to the TIA or minor stroke; and a general sense of uncertainty. However, these themes could be described as backdrops to the other emergent themes and are discussed throughout the analysis where appropriate.

Conclusions: fear of recurrence was an issue for those interviewed and this fear was mitigated to some extent by individuals taking control over their health and lifestyle. There was a need for more medical and lifestyle advice and emotional support.

6.1 Methodology

This chapter will start by outlining the aims of this research and will provide a discussion of why a qualitative approach was the most appropriate way of addressing some of these aims. In addition, it will provide an overview of the different philosophical underpinnings of qualitative methodologies eventually focussing on the chosen methodology and the reasons for choosing this methodology. Moreover, the methods used in this research will be described, such as sampling, recruitment and consent, data collection, the development of the interview schedule and the process of analysis.

Aims:

1. To explore the perceived impact a TIA or minor stroke has on the individual, including their experience and how they report this; whether it has changed the way they see themselves and their health; what kind of emotional impact it can have and how these factors might change over time.

2. To explore the concept of expectations, including investigating how these might be formed, what people think about them and how far they are conscious processes - i.e. how far are people aware of their expectations, if they change over time and why this might be.

Philosophical and theoretical Underpinnings

This section aims to provide a brief overview of the philosophical and theoretical underpinnings of qualitative research. There are many papers, chapters and complete books written on this subject by experts in the field, and therefore this overview will be brief and by no means exhaustive. However, it will summarise the main concepts in this area and situate the current research within a research paradigm.

The current research was concerned with exploring the experience of having a TIA or minor stroke and what sort of impact these might have; in addition, it aimed to explore the concept of expectations and what people thought about them. To be able to explore these aims it was necessary to explore people's perceptions, thoughts and feelings regarding the TIA or minor stroke that they had; in addition, exploring the concept of expectations required discussions with participants about what their expectations were and what they thought about them. It is arguable that the most appropriate way to address these questions was to conduct face to face interviews with

participants, thereby getting personal accounts of their experiences, which made using a qualitative methodology the best way to approach this aspect of the research.

Qualitative research is concerned with the "subjective world and offers insight into social, emotional, and experiential phenomena" (Giacomini and Cook, 2000, p358). It aims to provide an in depth understanding of the concepts or situation under examination and to explore "the features of settings and culture and to understand the linkages between process and outcomes" (p358).

It is generally agreed that the starting point for any research is to place it within a research paradigm (e.g. Kuba and Lincoln, 1994). Paradigms can be seen as a set of beliefs which represent a worldview. Broadly speaking a research paradigm includes the ontological and epistemological position of the researcher, the methodology and the methods of the research (Kuba et al., 1994).

Ontology refers to the form and nature of reality and what can be known. Epistemology refers to how reality can be known. These two concepts then inform the methodology (i.e. what approach is used for the research) and the methods used to collect data. According to Cresswell (2007) it is also necessary to include the axiological (recognising that research is value-laden and biased and the role of this within research) and rhetorical (this refers to the language used to report the research) positions within a research paradigm.

It is generally accepted that there are four major paradigms (Guba and Lincoln 1994).

- Positivism - is the position the world is external and that there is a single objective reality. This position suggests a "straightforward relationship between the world... and our perception and understanding of it" (Willig, 2013, p2). Positivists believed that the only way to gain knowledge is through objective measurement or observation of a phenomena and in doing this the 'truth' of that phenomena can be discovered. The methodology associated with positivism is primarily quantitative and normally experimental or quasi-experimental (Crotty, 1998).
- Postpositivism - according to Willig (2013) positivism is no longer a widely held research paradigm. Postpositivism grew out of positivism and is now a more

common approach for quantitative (and also, although less commonly, qualitative) researchers. Postpositivism is the position that a single reality exists (like positivism) but that it is not possible to measure it perfectly (unlike positivism). Postpositivists accept that it is not possible to measure reality objectively because observations are affected by the researchers own theories, beliefs and values (Milman, 2010). Objectivity is the (unattainable) aim of postpositivism, but because this is not possible postpositivists look to disprove or falsify hypotheses, usually using quantitative approaches to design and data analysis.

- Critical theory - unlike other research paradigms, critical theory aims to critique and change society rather than understand or explain it (Thompson, 2017). This approach to research assumes that reality is shaped by social, political, cultural, economic, ethnic and gender values and aims to challenge these underlying biases.
- Constructivism - this paradigm holds the position that reality is a construct of the human mind. Honebein (1996), for example, describes the constructivist paradigm as an approach that holds that people construct their own realities through experiencing situations and reflecting on those experiences.

Although these categories are widely used by researchers, other writers in this area have argued for different or additional categories (see Cresswell, 2007, for an overview).

One more category will be considered here as it is the closest research paradigm to the current research, which is pragmatism. Pragmatism is not connected to any particular philosophy or reality and is, in general, less concerned with the philosophical underpinnings of research. While pragmatists do acknowledge these to be important, they are more concerned with the processes and outcomes of the research (Cresswell, 2007). Pragmatists argue that reality and knowledge are based on beliefs and values that are socially constructed. Their epistemological and ontological stance is that reality can be either single or multiple realities that are open to inquiry, that is, that there is an objective reality that is separate from human experiences, but that this reality can only be perceived through human experience, meaning that in actuality there are multiple realities (Kaushik and Walsh, 2019). Pragmatist researchers are not restricted any one approach to research, but utilise the best methodology to answer the research question

at hand (Morgan, 2014). This position is one that fits well with this thesis and author. In this research there is a large quantitative component and a smaller, yet still substantial, qualitative section. The aim is that each approach will complement the other and provide different yet useful and important insights into the experiences of people who have had a TIA or minor stroke and the pragmatic paradigm seems to suit this design well.

Qualitative Designs, Methodologies and Methods

There are multiple classification systems for types of qualitative designs (see Cresswell, 2007 for an overview). According to Cresswell (2007) one popular way of grouping qualitative designs includes five categories, which are summarised in table 29 below:

Table 29

Qualitative approaches

Design	Approach to Research	Data collection methods	Data analysis Methods	Forms of Scientific writing
Narrative	Explores situations, scenarios and processes	Interviews and documents	Storytelling, content review and theme or meaning development	In-depth narration of events or situations
Case study	Examination of episodic events with a focus on answering "how" questions	Interviews, observations and document contents	Detailed identification of themes and development of narratives	In-depth study of possible lessons learned from case or cases
Grounded theory	Theory development	Interviews and questionnaires	Data coding, categorisation of themes and descriptions of implications	Theory and theoretical models
Phenomenological	Understand or explain experiences	Interviews, surveys and observations	Description of experiences, examination of meanings and theme development	Contextualisation and reporting of experience

Ethnographic	Describes and interprets social groupings or cultural situations	Interviews, observations and active participation	Description and interpretation of data and theme development	Detailed reporting of interpreted data
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Table adapted from Chigbu, 2019

Justification for the use of Interpretive Phenomenological Analysis (IPA):

This section will provide a brief summary of the history and theoretical underpinnings of IPA (see Smith et al. 2009 for a more in-depth discussion) and will argue that this approach was the best methodology to use for the analysis of the current research data.

IPA was first introduced in 1996 in a paper by Jonathan Smith (Smith, 1996); it draws on theories of phenomenology and was heavily influenced by philosophers such as Husserl, Heidegger, Merleau-Ponty and Sartre. This approach is phenomenological in that it focuses on exploring experiences. Two other key concepts in IPA are hermeneutics and idiography.

There is a vast and diverse literature on hermeneutics and therefore only a very brief summary will be given here. Hermeneutics is the theory of interpretation; the concept of hermeneutics dates as far back as ancient Greece and was later used as a framework to interpret biblical texts (Sandage, Cook, Hill, Strawn and Reimer, 2008). Hermeneutics was further developed by Heidegger (1962), who saw interpretation as central to the study of any phenomena and that interpretation is necessarily affected by individual pre-conceptions. In addition, Heidegger argued that pre-conceptions will affect analyses and the analyst should therefore attempt to distance themselves from those pre-conceptions, whilst recognising that they exist (known as 'bracketing') (Smith, et al., 2009). Other key philosophers include Gadamer (1960) who continued to develop on these ideas. Gadamer believed that when analysing texts (in his case historical texts) interpretation is a "dialogue between the past and present" (Smith et al, 2009, p27), that is, the interpretation of historical texts is influenced by the context within which it is being interpreted.

Hermeneutic research is designed to explore "meanings and intentions that are, in a sense, hidden in the text." (Crotty, 1998, p91), the word 'texts' in hermeneutics refers to any aspect of the phenomenological world that is being interpreted and in research this could include interview transcriptions, videos, images, actions etc. Hermeneutics is based on the assumption that humans are constantly involved in interpreting the world in order to make sense of it (Sandage, et al., 2008). IPA employs a 'double hermeneutic' which is that the "the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). Therefore interpretations of the text are informed not only by the participant's articulation of their experiences but also by the researcher's skill in interpreting them (Noon, 2018). As Smith et al. (2009) argue this process is necessarily influenced by the researcher's own preconceptions. The process of analysis in IPA is explicitly subjective and reflective (Reid, Flowers and Larkin, 2005).

"Idiography is concerned with the particular" (Smith et al., 2009, p29). Much psychological research is nomothetic, that is, it aims to make statements and predictions about populations and to generate general theories about human behaviour. In contrast, in relation to IPA, an idiographic approach is concerned with detailed in-depth analyses, how people understand the phenomena under investigation within their particular context (Smith et al, 2009); to do this it uses small numbers of people and in-depth interviews which are analysed in a systematic and detailed way.

With these key concepts in mind, IPA is concerned with participants' 'lived experiences' and attempting to make sense of these through a process of interpretation whilst accepting the analysis will be subjective. Inferences in IPA are made cautiously "and with an awareness of the contextual and cultural ground against which data are generated, but it is willing to make interpretations that discuss meaning, cognition, affect and action" (Reid, et al., 2005, p20). The eventual aim is to provide an account which is interpretative whilst grounded in the data and plausible (Reid, et al., 2005).

IPA therefore focuses on people's experiences and how they make sense of these within the context of their own lives whilst recognising that any attempts by a researcher to do this will necessarily include an element of interpretation which usually extends beyond the accounts whilst remaining grounded within them. Smith, Flowers and Larkin (2009) comment that, IPA is "especially interested in what happens when the

everyday flow of lived experience takes on a particular significance... this usually occurs when something important has happened" (p1). So, IPA is particularly suitable for research exploring people's perceptions and feelings about a significant event in their lives. Having a TIA or minor stroke could be seen as 'something important' which may interrupt the flow of everyday life, which makes IPA an appropriate analytical tool for this study.

Sample

In qualitative research there are three broad approaches to sampling, which are purposive, theoretical and convenience (Marshall, 1996).

- Convenience sampling is the least rigorous approach and is where participants are recruited because they are accessible to the researcher, although this is the least rigorous method, it is also the easiest and least costly and many qualitative studies may have some element of convenience sampling due to the practicalities of research (Marshall, 1996).
- Theoretical sampling comes from grounded theory and is "A process in which data gathering is guided by the evolving theory and the aim is to develop categories in terms of their properties and dimensions and integrate those categories (i.e., relate them to each other within the theory being developed)" (Gentles, Charles, Ploeg and MacKibbon, 2015, p1779/1780).
- Purposive sampling is where participants are selected based on the research aims. The aim is to "select information-rich cases for in-depth study. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry." (Patton, 2015, p. 264, cited in Gentles et al, 2015).

This research used a purposive sampling strategy as this was the most appropriate strategy for the research aims and methodology. Participants for this study were selected from the larger quantitative sample. Their selection was an attempt to reflect the major issues experienced by the larger group. The specific sample were chosen for several reasons: firstly whether they had ongoing symptoms or not to reflect the different experiences of having a TIA or minor stroke with or without symptoms that endure; secondly, whether they were experiencing problems with anxiety or fear of recurrence; thirdly, two participants had experienced surgery to unblock their carotid artery, and these were included as this is not an uncommon operation following a TIA or

minor stroke and it was felt that it was important to include the experiences of these patients compared to those who did not undergo surgery.

Six people were interviewed once and five twice (one person dropped out of the follow-up interviews, due to work and personal commitments but extensive notes were taken during a phone interview). Ages ranged from 54 to 75, two females and four males (see Table 30). The baseline interview had to take place within 8 weeks of them having a TIA or minor stroke and the second interview took place between five and six months after that.

Table 30

Participant characteristics

Participant	Age	Diagnosis	Surgery	Symptoms
Frank	72	TIA	No	None
Simon	68	Minor stroke	No	Weakness in hands and problems with balance
Richard	75	Minor stroke	Yes	None
Sarah	57	Minor stroke	Yes	None
Ellen	59	Minor stroke	No	Severe fatigue, problems with cognition and balance
James	65	TIA	No	Strange sensations in head, visual disturbances and weakness in arm

Additional data

Smith et al (2009) comment that using multiple sources of data can help to further contextualise and illuminate the data. Notes were taken during the 153 quantitative interviews regarding people's experiences during the event, and what happened to them afterwards, i.e. where and when they sought medical attention, how they were diagnosed and how they felt about this; in addition where participants expressed other information of interest this was noted down. These notes were then transferred onto a spreadsheet and examined following the qualitative analysis. Any quotes that helped to clarify and contextualise the data were highlighted and a selection of these are used where appropriate in the analysis and discussion.

Recruitment & Consent

Participants were invited to take part in the qualitative interviews after they had completed the baseline quantitative interview. Potential participants were asked whether they would be prepared to take part in an interview about how they were coping and how they felt about having had a TIA or minor stroke. It was emphasised that they did not have to take part and that if they decided not to this would not affect their care or their participation in the larger study in any way. Potential participants were informed that the interviews would be recorded and transcribed by the interviewer and that these recordings and transcriptions would be kept in a secure location that no one except the interviewer had access to.

Where potential participants agreed they were given an information sheet (see appendix 10) and asked if the interviewer could phone them the next day; during the phone call if they agreed to participate, an appointment was made to visit them at home.

Data collection

IPA requires rich, detailed, first person accounts of experiences; in this context 'rich' refers to participants being given the "opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length" (Smith et al., 2009, p56).

The most common method used to collect data for IPA studies is one to one interviews (Reid, et al., 2005). The reasons for this are that one to one interviews allow a rapport to develop between the interviewer and the participant, they are more easily managed than focus groups and give participants space and time to reflect, speak and be heard (Smith et al, 2009). There have been IPA studies using data collection methods such as diaries (e.g. Smith, 1999), focus groups (e.g. Flowers, Knussen and Duncan, 2001), postal questionnaires (e.g. Coyle and Rafalin, 2000) and email dialogue (e.g. Turner, Barlow and Ilbery, 2002). However, it was felt that for this study, one to one interviews would be the best method to collect data because the sample was readily available to the researcher, one to one interviews would provide privacy that might help participants to talk about health and other concerns therefore providing the researcher with fuller and richer accounts.

Participants were interviewed twice, one to two weeks after baseline and at T2. It was decided to carry out two qualitative interviews to complement the quantitative findings and to explore any changes in the way that participants felt about their TIA or minor stroke over time. IPA is a suitable tool to use for longitudinal qualitative research (McCoy, 2017) and there are several papers published using IPA in longitudinal research including one of the first papers published using this methodology (Smith, 1999). It is also recommended by Smith et al (2009) as one way of enriching the data.

Reflexivity

Broadly speaking, reflexivity is the process of self-critique by the researcher (Dowling 2006). It is an awareness by the researcher that their role in the research process will impact not only on the participant but also on the analysis (Shaw, 2010). Being reflexive means the researcher is required to assess and reassess their influence on the research process (Dowling, 2006).

Within IPA it is recognised that the process of interviewing and analysing data is not objective. Pre-conceptions and biases are present even where attempts are made to keep these at a distance (Smith et al., 2009). Moreover, IPA involves the explicitly subjective interpretation of data by the researcher and for this reason requires the interviewer to reflect on their perceptions, biases, preconceptions and general style of interviewing (Reid, et al., 2005).

There are many variables that can influence the participant, the interviewer and the interview process (these include issues such as, the rapport between the interviewer and participant; biases and pre-conceptions: Patnaik, 2013). However, it is also important to take into account the context of the interview, which would include, not only, the setting of the interview (Elwood and Martin, 2000), but also, issues such as how the participant was recruited, the participants' perceptions of the research and the researcher (Kalu, 2018).

Reflexivity and the current research

It is generally recommended that a reflexive statement starts by introducing the researcher and go on to discuss potential influences on the research process.

The interviewer in this study was a 44 year old female with a history of working in clinical research, including of clinical interviewing and neuropsychological assessments for various research studies with patients who had Parkinson's disease and working as an evaluator on an intervention study for cancer patients. Only one of these studies included a (small) qualitative component, meaning that the interviewer was relatively inexperienced in qualitative interviewing and more familiar with the structured style of interviewing required for quantitative research.

The next issue that is worthy of some discussion is that the participants in this study were recruited from the larger sample after they had completed the quantitative interview. This meant that there was already a rapport between the interviewer and participant and a level of trust. It is arguable that because of the previous meeting, participants felt more comfortable to discuss how they were feeling than if the interviewer had been a stranger. Conversely it is also very possible the quantitative interview (and the knowledge that the qualitative interview would cover similar topics in more depth) influenced their feelings and perceptions which they may not have experienced if the previous interview had not taken place for example, asking participants (in the quantitative interview) about their expectations for the future or whether they were anxious about having another TIA or minor stroke, may have influenced their feelings about these issues.

In addition, because the interviewer had already had a reasonably lengthy meeting with the participants and was aware of those who were not coping as well as they might be, it is likely that when these particular participants expressed distress, the interviewer was influenced by this distress and in an attempt to provide reassurance may have inadvertently changed the course of the interview. Moreover, because the interviewer had already interviewed the participants, there were definite preconceptions present about what might come up during the interviews. Although every attempt was made to avoid controlling or manipulating the conversation onto these topics, it is likely that this issue did have some effect, for example, probing more in situations where the participant had spoken in more depth about a topic in the previous meeting.

During analysis the researcher started to feel protective towards the participants and a major concern became not to misrepresent what people said and meant by what they said, although this avoidance of misrepresenting participants is a

central aim of any qualitative research, the feelings of over-protectiveness might have inadvertently influenced the researcher's process of analysis. This was, hopefully, mitigated to some extent by discussion with a colleague (JM) regarding the choice of quotes and the interpretation of these.

Participants were all interviewed at their homes, which was arguably the best place to interview them because it may have helped to redress the power imbalance between the interviewer and participants; in addition, people may feel more comfortable in their own environments (Ellwood et al., 2000). However, this choice was made primarily because there were no other spaces available to the researcher. Participants were recruited in two different locations in Scotland (Fife and Lothian), neither of which were close enough to the institution the researcher was from (Stirling) to make it viable for participants to travel there. In addition, the researcher had, in past work, interviewed participants in their own choice of location and an overwhelming majority chose to be interviewed at home, leading the researcher to believe that, when given the choice, many people do prefer to be interviewed at home.

Participants in this study were recruited via the stroke team at the Royal Infirmary in Edinburgh or the stroke co-ordinator in the Queen Margaret hospital in Dunfermline. Invitations in Lothian (where all the qualitative participants were recruited from), although sent by the researcher, were all signed 'on behalf' of the senior stroke consultant and were written on NHS headed notepaper. This gave the some of the participants the impression that the researcher came from the NHS and, for some, that they were a clinical member of staff. Many participants (including in the qualitative sample) assumed the researcher had in depth medical knowledge of stroke despite being told that the researcher came from a health psychology background and not a medical one. This may have influenced the way in which participants approached the interview and interviewer.

Rigour

The concept of rigour in a qualitative study roughly corresponds to the concepts of reliability and validity in quantitative research (Noble and Smith, 2015). There is a vast amount of literature on this subject and as Sandelowski and Barroso (2002) comment "Yet after all of this effort, we seem to be no closer to establishing a

consensus on quality criteria, or even on whether it is appropriate to try to establish such a consensus" (p74/75). One reason for this is that there are many different approaches to qualitative research and these approaches often have very different theories, methodologies and methods (Rolfe, 2004). Different approaches have naturally emphasised different criteria for assessing quality (Sandelowski et al, 2002) due to the differing nature of qualitative methodologies. This complex discussion on what constitutes high quality qualitative research will not be covered here as it has been written about extensively elsewhere (see Sandelowski, 1993; Sandelowski et al., 2002; Yardley, 2000; Rolfe, 2004; Elliott, Fisher and Rennie, 1999).

When it comes to deciding on which quality criteria should be utilised in any given qualitative research, it should first be recognised that there is not a 'one size fits all' criteria that will make sense in all qualitative methodologies (Yardley, 2000). Different methodologies come from different theoretical perspectives, employ different methods to collect data, analyse the research findings in different ways and have different types of aims (e.g. grounded theory aims to develop theories, whereas phenomenological research aims to explore experiences) (Yardley, 2000). These issues all need to be considered when deciding on a set of criteria that suits the methodology used.

Smith et al (2009) recommend using Yardley's (2000) guidelines with IPA because they are broad-ranging, and within the criteria there a number of ways of satisfying the requirements and also these criteria are applicable to most qualitative methodologies (Smith et al., 2009). There are four main principles in Yardley's criteria, which are, sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (Yardley, 2000).

Smith et al (2009) outlined ways in which Yardley's (2000) criteria are relevant to IPA:

- Sensitivity to context - there are several ways that sensitivity to context can be demonstrated, these include:
 - the choice of methodology, for example, choosing IPA as a research methodology, when the aim of the research and the rationale for choosing IPA is to explore in detail the shared lived experiences of a particular phenomenon.

- Another way to exhibit sensitivity to context is through the appreciation of the complexities of the interview process. As Smith et al. (2009) put it "IPA analysis is only as good as the data it is derived from and obtaining good data ... require(s) ... showing empathy, putting the participant at ease, recognising interactional difficulties and negotiating the intricate power play where research expert may meet experiential expert" (p180).
- Sensitivity to context is also part of the process of analysis. The use of the double hermeneutic, that is, the researcher attempting to make sense of the participant making sense of their experiences (mentioned earlier) involves the researcher immersing themselves in the participant's narrative.

The three ways to exhibit sensitivity to context that are outlined above are difficult to explicitly exhibit and will tend to be judged indirectly through how the research is written up. IPA research should have a substantial number of verbatim quotes from the participants to provide support for the case being made by the researcher, to allow the participant's voice to be heard and for readers to scrutinise the interpretations being made.

- Another more direct ways to show sensitivity to context within IPA research is to demonstrate an awareness of the literature surrounding, not only, the topic being explored, but also the literature relevant to the theoretical underpinnings of IPA.
- Commitment and rigour
 - Commitment refers to the "prolonged engagement of the topic" (Yardley, 2000, p221). Smith et al (2009) suggest that in IPA commitment can be exhibited by the attention paid to the participant during the interview process and "the care with which the analysis of each case is carried out" (p181).
 - Rigour is how thorough a study is. This includes how suitable the sample are for exploring the research topic, how well the interviews are carried out and how thorough the analysis is.

- Transparency and coherence
 - Transparency relates to the clarity of the write-up, that is, how clearly the stages of the research process are described, including the choice of sample, the construction of the interview schedule and how interviews were carried out and the steps used in analysis.
 - Coherence is relatively self-evident as it refers to how coherent the finished report is, that is, is there a coherent argument presented? How well do the themes go together? Are contradictions dealt with? In addition, coherence relates to whether there is a good fit between the research and the underlying assumptions of the methodology (Yardley, 2000); in IPA this would refer to whether phenomenology and hermeneutics are evident (Smith et al., 2009)

- Impact and importance - does the research tell the audience something interesting, important or useful

Smith et al. (2009) also suggest that independent auditing might be useful. Independent auditing can be done on several levels, including having a 'paper trail' that encompasses each stage of the research process finishing with the analysis and having a researcher not involved with the research check for credibility and plausibility, but not necessarily consensus since this is not the aim of IPA. Another, less rigorous way, is to have a peer (again not involved with the research) examine the transcriptions, quotes taken from them and themes to check whether these seem both plausible and credible.

Some of the above criteria can only be judged externally once the research is written up and can be exhibited by showing that there has been careful consideration of the philosophy and theoretical underpinnings of the chosen approach and well described methods and analysis. Every attempt has been made in this research to fulfil these criteria. Although no formal independent audit took place a peer (JM) looked at the transcriptions, themes and quotes to check for researcher bias, credibility and plausibility.

Interviews

Interviews were semi-structured with core questions and probes for those questions; the interviews were designed to be dynamic in nature as advised by Smith et

al (2009), that is, although there were key questions and areas of interest it was not designed to be prescriptive, it was designed to be a guide but was not meant to be followed religiously; in essence, participants led the interviews. The discussion between the interviewer and participant was designed to be fluid to allow for the emergence of novel insights and themes; so often the actual interview would vary from the schedule.

The areas of interest that were discussed in the baseline interview were based on areas of interest that arose during the quantitative interviews and from the existing literature:

1. A description of the event was included as an easy way to start the interview for the participant, to get a little background information about their experience of having a TIA or minor stroke and to explore how they described the event. This description was not meant to be an accurate medical account of their TIA or minor stroke but a description of what they remembered happening and how it made them feel. This was of interest because during the quantitative interviews it became clear that people often gave very detailed accounts of their TIA or minor stroke even where these were not asked for, possibly suggesting this was an event of some importance to many people.

2. What happened immediately after the event, including when they sought medical advice and from whom, their experience of the medical attention they received and how this made them feel. This topic was of interest for several reasons; firstly, as noted in previous chapters, many people do not seek immediate medical attention during following a TIA or minor stroke even if they are aware of what is happening to them, despite the medical advantages of doing so. It was decided that it might be interesting to explore this issue a little and to ask people why they do not seek immediate medical intervention. What happens to people immediately after their event and in the subsequent days or weeks in terms of medical advice, treatment or intervention will likely have a direct bearing on the formation of expectations for the future, i.e. people may be more likely to have positive expectations for any enduring symptoms where they have been told by medical professionals that these are likely to go away in time. In addition, this may have a bearing on how people adjust to life post TIA / minor stroke.

3. Their current symptoms (if any) and what their expectations for those symptoms were for the next few months and why they felt the way they did. This was included to explore the concept of expectations in more detail. As discussed previously, expectations as a concept does not have a standardised definition within the literature and this makes measuring them problematic. Asking people to describe their expectations and why they think the way they do seems a reasonable place to start to define this concept in more detail and to get an idea of what expectations mean to patients. Although this part of the qualitative study is not designed to come up with a standardised definition or a finalised model of expectations, it will hopefully provide an insight into what expectations mean to the participants and perhaps how they are formed and in doing this it might enable the author to make tentative suggestions towards standardising the definition and providing insight into how best to measure them.

4. How having a TIA or minor stroke had impacted on the participants' lives, including any emotional reactions, lifestyle changes, and changes to their sense of their own identity. This area was included to explore how having a TIA or minor stroke impacts on people and their lives and what this means to them. This was probably the most important section of the interviews as it gave a greater insight into how having a TIA or minor stroke impacts on quality of life and provides a more detailed picture of what people experience compared with the quantitative study. This part of the interview allowed participants to speak freely about what mattered to them.

Follow-up Interviews

The interviewer listened to the baseline interviews before seeing the participants for the follow-up interviews. Notes were taken regarding the participant and any major issues they had discussed in the first interview; this varied considerably between participants. The participants who had had symptoms at baseline were asked about those symptoms again and their expectations for those symptoms over the next year or so, this was included to attempt to gain greater insight into how expectations might change over time and what people felt about them. The aims of the follow-up interviews were:

1. to complement the quantitative results by exploring what participants were experiencing at follow-up in relation to their TIA or minor stroke, the content of this section varied depending on what the participant had discussed at the baseline

interview and included areas such as the impact of any remaining symptoms, emotional response to the event and changes to lifestyle.

2. to explore how expectations change over time and how participants felt about these.

6.2 Analysis

Interviews were recorded and full transcriptions were prepared by the author (LD) including pauses and any non-verbal utterances that might have significance to the participant's meaning.

Analysis followed the 6 stages advised by Smith et al. (2009), which are:

1. Reading and re-reading - this stage is the beginning of immersing oneself in the data and involves reading and re-reading the transcript in detail and attempting to get a feel for the flow of the conversation.

2. Note-taking (often merged with step 1) - initial note-taking involves noting down anything of interest. There are no rules to this process other than paying close attention to the text and attempting to keep the focus on the participant's narrative and their experiences; notes at this stage tend to be descriptive. The next stage is to start to comment alongside the notes in a more interpretative way, for example, comments on the type of language used to describe experiences and feelings about these experiences, then attempting to develop more abstract themes which help to shed light on the "pattern of meaning" in their narratives.

3. Development of emergent themes - this process involves moving away from the transcript and working from the notes and comments that were produced in step 2. Developing emergent themes from the notes and comments requires close examination of discrete sections of the comments, it is at this stage that the process becomes more interpretative and starts to move away from the explicit statements made by the participant. The aim at this point is to generate a brief and succinct statement about the various comments regarding the section of the transcription being examined.

4. Looking for connections across emergent themes - this stage is where the researcher attempts to map out how the emergent themes might fit together. There is no prescribed way of doing this and the aim is to bring together the emergent themes in

a structure which makes sense of the interesting or important features of the participant's narrative. Smith et al. (2009) suggest several possible ways to do this, which are:

- Abstraction - development of super-ordinate themes, which is the grouping together of related emergent themes under a super-ordinate title (e.g. psychological distress)
- Subsumption - where an emergent theme becomes a super-ordinate theme and brings together other related emergent themes
- Polarisation - focussing on differences between emergent themes rather than similarities. For example, participants may appear to contradict themselves within an interview and focussing on this issue and exploring why this might be can further deepen the analysis.
- Contextualisation - this is the grouping of emergent themes by key life events. In the context of this study, these might be things such as the TIA or minor stroke occurring, the moment of diagnosis, and telling other people about the TIA or minor stroke.
- Numeration - this refers to the frequency that a particular theme is supported, although Smith et al. (2009) caution against emphasising this too much and that it is not necessarily an indicator of importance.

5. Repeating steps 1-4 for all cases

6. Looking for patterns across cases - this involves examining the themes from all cases and looking for connections between themes or ways in which a theme from one participant might help clarify themes from others. The eventual aim of this stage is to represent not only the individuals and their idiosyncrasies, but also how they share "higher order qualities" (Smith et al., 2009, p101).

Follow-up interviews were analysed in the same way and then themes were compared across the two time points to explore whether there were any similarities and/or differences between the two and whether there were changes in what people were experiencing.

6.3 Results

The results will be split into two sections. Firstly, expectations will be discussed; and secondly, results will be discussed in relation to the emergent themes. Within these sections, the baseline and follow-up discussion will explore any changes between the two time points in the way that participants feel about their TIA or minor stroke and their expectations for symptoms.

There was a range of topics raised by those who were interviewed for this study. People reacted differently to having had a TIA or minor stroke: their concerns depended on their individual circumstances and interpretation of events. For some it was a serious and important event in peoples' lives "I kind of panicked a bit when I realised how serious it was" (*Sarah Interview 1*) and often unexpected "[the TIA] wouldn't be the sort of thing that would happen to me" (*Frank Interview 1*). However, one participant (Simon) did not share these feelings and viewed the TIA as a relatively insignificant event in his life "I don't really think about it, it doesn't affect me much" (*Simon Interview 1*).

Common themes that emerged from the data were grouped into superordinate themes. The analysis attempts to maintain focus on individual experiences whilst balancing this with shared experiences. The emergent themes were living in a new health reality, and a need for further intervention of some type. Three further themes emerged: the relative importance of the TIA or minor stroke; emotional responses to the TIA or minor stroke; and a general sense of uncertainty. However, these themes could be described as backdrops to the other emergent themes and will therefore be discussed throughout the analysis where appropriate (see figure 8).

Figure 8: Themes in the qualitative study



Expectations

Expectations for the progression of symptoms were asked about to see if the answers could provide further insight into how people think and feel about their expectations for specific symptoms. There were three people who had symptoms from their TIAs or minor stroke:

- Ellen had relatively severe fatigue, some minor problems with cognition and some problems with her balance.
- Simon had problems with weakness in his hand and problems with his balance
- James had strange sensations in his head (or, as he described them, 'twinges') and had developed visual disturbances and weakness in his arm which he believed were related to his TIAs by the time of follow-up

Symptoms resulting from participants' TIAs or minor strokes were defined as symptoms that they believed were a result of the event. Such beliefs may or may not have been well-founded. However, as this part of the interview was designed to explore expectations as a concept more fully, it was important only that people believed their symptoms were stroke-related.

Information (and understanding that information), perceived knowledge and experience were important to the forming of expectations for symptom progression. There was a high level of uncertainty expressed about expectations for symptoms and it appeared as though, for the people interviewed, they were not necessarily thinking about their expectations and were sometimes surprised to be asked about them. This was also true of the larger quantitative sample (who were also asked about their expectations for symptoms, but in less detail): people were often surprised by the question and, again, expressed uncertainty about it.

Baseline interviews - expectations: Information

Having information, especially, from healthcare professionals, was important for expectations to form for some of those interviewed:

Int: So what are your expectations for the problems with your thinking over the next little while?

Ellen: That it's going to go away ken? That it'll get better.....

Int: And can you tell me why you think that?

Ellen: ummm.... I... I think because they told me it would... I dinnae ken what else.. (*Ellen Interview 1*)

It seems that Ellen has not really thought beyond what she was told by the rehabilitation services and that her expectations are based only on the information she had received and when she says at the end of the quote "I dinnae ken what else" it appears as though she is expressing uncertainty about what else she could be basing her expectations on. This response seems a like perfectly reasonable one especially considering she is in a situation that she has not encountered before.

When Ellen was asked about her expectations for her fatigue she says:

Ellen: I still get tired but I ken how to rest and when to rest and and things like that, aye.

Int: So how do you think the tiredness will be over the next little while?

Ellen: I think it'll get better, I think as long as I rest a lot it's ok really

Int: So you're still having to rest a lot?

Ellen: Aye, but it's better than it was and if I can sleep at night then... maybe... I dunno do you think it will get better?(*Ellen Interview 1*)

Here Ellen is less certain about recovery. While she seems generally positive, there is still some doubt. Ellen starts off being fairly positive that she will get better, but when asked about whether she is resting a lot she becomes uncertain. The next exchange may shed some light on why:

Int: Did the doctor say anything to you about the tiredness?

Ellen: No not really. We talked more about the memory stuff and that and getting mixed up ken? I didn't think about the tiredness, but I think it's normal.... I don't know.(*Ellen Interview 1*)

So Ellen had not been told anything about the fatigue and she had not really thought about it (probably because she had symptoms that were causing her more

distress). However, not speaking to anyone about it made it difficult for her to form any kind of expectation.

James had also not spoken to anyone about the sensations in his head that he was experiencing:

Int: So, the twinges in your head that you mentioned, do you have any expectations about them?

James: Ummm... Sorry I don't think I know what you mean

Int: No that's me not explaining myself properly. Do you think they might get better or stay the same, or even get worse in the future?

James: oh... I see... ummm I don't know really. I haven't thought about that... ummm... I don't know what to say about that.

Int: No problem. Have you spoken to anyone, I mean a doctor or nurse about them?

James: I cannae remember ... maybe I mentioned them at the hospital, but I don't think anyone said anything about them.

Int: So, do you have any thoughts about how they might progress?

James: Ummm... I don't know. Maybe get better or stay the same... no I don't know really (*James: Interview 1*)

This exchange shows James had not thought about these twinges in terms of expectations and did not remember if anyone had said anything about them, so he did not have any information to base expectations about them on. James appears to feel like he needs to give some kind of answer because of all the questions he was being asked. It seems likely that this was the case for quite a few people in the larger quantitative sample also.

Baseline interviews - expectations: experience

Experience of recovery (or not recovering) was also important for some of those interviewed in how they felt about their symptoms. The quote below from Ellen shows her thinking this through when she was asked about her fatigue:

I don't know. Maybe it's like maybe it's my age as well, ken?
 But no I think it'll get better, now I'm thinking about it, I think definitely.... I mean it's already better so I think it will keep getting better. (*Ellen Interview 1*)

Ellen starts by attributing some of her fatigue to her age, but then becomes more certain that she will continue to improve. After some thought she is able to base her expectations on her experience of what has happened previously. This suggests quite strongly that Ellen has not really thought about her expectations for recovery of her fatigue. She perhaps realises that she has some kind of positive expectation, possibly subconsciously until now. Once she has had a chance to think about it, she realises that she has improved already, so for her, the likelihood seems to be that she will continue to improve.

Simon had some weakness in his hand which meant that he dropped things occasionally. He had positive expectations for recovery for this:

Int: can you tell me what your expectations are for the weakness in your hand?

Simon: It'll come back to normal

Int: okay. Good. And can you think about why you feel that way?

Simon: I don't know really

Int: Ummm.. Ok is there any reasons you can think of?

Simon: I actually don't think about it much, you know, I don't feel like the stroke was anything and I've never really thought about it since, but I suppose ... I guess if you need an answer ... aye well ... it's been getting better a little and it will probably continue to do that(*Simon Interview 1*)

It seems that Simon had not really thought about what his expectations were and although he says at the end that his hand is getting better and therefore will

continue to do that there is a strong feeling that he may have said this for the benefit of the interviewer. Again this exchange suggests that the people interviewed were not thinking in terms of expectations.

So, at baseline there was a lot of uncertainty expressed about expectations for symptoms. There was some suggestion that both information and experience could be important (and the reverse, that is, where people had no information or experience they found forming expectations difficult). There is a high possibility that people were also trying to answer these questions for the interviewer rather than necessarily reflecting their genuine feelings.

Follow-up interviews: expectations - information

The follow-up interviews were more difficult to split up into the categories outlined above; therefore, some of what is discussed below may not fit well into these categories. There was still a lot of uncertainty expressed about expectations, for example, when James was asked about the problems with his eyesight and what his expectations were, he says:

James: Uhhh... probably it won't get better ... but it might stay the same.. I don't know

Int: can you tell me why you feel that way?

James: I don't know really, but I think it will stay the same. Yes, that's what I think

Int: Can you think of any reasons you feel that way?

James: uhhh... I don't know. No one has said anything about it, so I don't know (*James Interview 2*)

James has not spoken to anyone about his eyesight problems, although he does say that he thinks it will 'stay the same', it is very possible that he is saying that (once again) for the benefit of the interviewer. A little later in the interview he was asked about the weakness in his hand and he says:

James: Hmm... well... I dinnae ken

Int: Ok sorry, maybe you're having the same problem with that question as before?

James: I dinnae ken, sorry.

Int: No problem. Maybe we should change the subject a little?

James: Yes please

At this point it did seem as though James did not want to talk about his expectations for symptoms anymore and this is probably because he did not have any and was feeling uncomfortable about being unable to answer the questions.

Follow-up Interviews: Expectations - experience

At follow-up, Simon still had positive expectations for recovery of both the weakness in his hand and his balance, but this time he was more confidently basing his expectations on experience:

Simon: they have changed since the stroke in the way that they've got slightly better. So my balance is still a bit funny, but getting there. So I expect everything to come back to normal

Int: Can you talk about why you feel that way?

Simon: over the next few weeks, I think things will get completely better, yes, because they have got better since the last time, so I think they'll just keep doing that. (*Simon Interview 2*)

Here Simon seems quite clear that his symptoms will continue to get better because they have already changed for the better.

Another factor that may be of more importance to people was how far people were bothered by the symptoms they had. In the follow-up interview Ellen talks about the problems she has with her balance:

Ellen: Oh I dunno I'm used to it now and it doesn't mentally bother me you know? It's just there...

Int: So when you say it doesn't mentally bother you...? Can you explain what you mean by that?

Ellen: well...ummm.. I just mean, it's like, I'm no bothered about it, it's there but I don't think about it, ken? (*Ellen Interview 2*)

Ellen gives the impression here that she does not even really notice this symptom much of the time and they are not on her mind, possibly making expectations for this redundant. When she was asked about her expectations for her balance she says:

Oh oh I'm hoping I'm hoping if I get this exercise class and get some exercises into it... yeah I'm hoping it will get completely better (*Ellen Interview 2*)

Ellen does not express any actual expectations here and talks about her hope that her balance will recover. This was common in the larger sample, that is, talking about hopes when asked about expectations. As discussed in an earlier chapter these are two different concepts which may be related under certain circumstances; however, it is possible that they are less distinct in people's minds. It is also possible that people had not thought much about their actual expectations but more about their hopes for recovery, so when asked about their expectations they resorted to talking about their hopes.

One thing that became apparent during these interviews (and in the larger sample) was that people tended not to think about their expectations for their symptoms; they tended to come up with spontaneous answers, which were often largely positive or neutral. It is impossible to know how far these positive expectations were genuine and it should be acknowledged that the interviewer could well have had an effect on how people were answering this question.

People in this sample (and often in the larger sample) did not always find it easy to talk about their expectations for recovery. This may have been due to their not necessarily thinking about their symptoms in these terms. Many people in the larger sample talked about their hopes for recovery when asked about their expectations and where this was questioned further they would often become less certain about what they thought would actually happen.

Themes relating to the Impact of having a TIA or Minor Stroke

Living with a new health reality

Most of the people interviewed felt that they were living in a new health reality where their health was more uncertain or precarious: "I've realised that if you're going to have any form of a stroke you've got nothing, there's nothing that you can do ..."*(James Interview 1)*; that a recurrence is now a concrete possibility "I mean one has to take the view that it has happened once and it might happen again"*(Frank Interview 1)* and where there was a need to take control of health and lifestyle "It having happened, I'm conscious of trying to help it not happen again" *(Frank Interview 1)*. Living with a new health reality was defined as having feelings, thoughts and behaviours that changed following the minor stroke or TIA.

Baseline - Thoughts about recurrence or a major stroke: good health is now uncertain

Before discussing this subordinate theme, it should be noted it is very likely that for at least some of those interviewed, concerns about recurrence were exacerbated or made more real by the process of being interviewed about them. Attempts are made to recognise this throughout the analysis.

There was a sense that health was now more precarious. For some, thoughts about a recurrence or having a more serious stroke were frequent and sometimes intrusive:

You could be, well you know, I mean it sounds over doing it, but I mean really you could be dead really... or you could be really ill and when you think about that about that kind of thing it's scary. You know before you're just going through life and not thinking about it about those things, but then something like this kind of thing happens and you're thinking about it all the time, you know? *(Sarah Interview 1)*

This suggests that the minor stroke had changed Sarah's perception of her health, and that she was thinking about the stroke or the possibility of having another one 'all the time'. She appears to distinguish an earlier time when health was not something on her mind from the present where thoughts about health and recurrence are always close.

She continues:

I panicked a bit when I realised how serious it all is, it's the kind of thing that makes you realise how easy it is to... ummm ... that you can get ill at any time and sometimes you can't get that out of your head. Those kinds of things can go round in your head and I can't stop thinking about it sometimes ... it's scary when you think about it (*Sarah Interview 1*)

These quotes suggest that Sarah's thoughts about recurrence were quite frequent and could be intrusive. She also gives the impression that things like strokes can just happen: her health has become unpredictable.

James was also preoccupied by thoughts about another stroke, commenting that the possibility:

[is] always there like. It's always at the back of your mind
(*James Interview 1*)

And when talking about 'twinges' or strange sensations he was experiencing in his head he says:

...Well, they worry you, I'd say for the rest of that day, but then things happen and you go out and you forget about it. I suppose that anyone in that situation it's still in the back of their mind, it's still there all the time. I mean imagine a full blown stroke... you're helpless, just totally helpless and to be by yourself, that must be a nightmare. (*James Interview 1*)

James repeats that these thoughts are always there, but also that you 'forget about it', giving the impression that although normal life has resumed, being reminded of the stroke (possibly, not only the sensations in his head, but also by the interview process) makes him realise that his worries about a recurrence are always near. When James says 'it's still in the back of their mind, it's still there all the time' he seems to be normalising his feelings by reasoning that anyone would feel this way. The strength of feeling that James expresses about someone else who is on their own having a major stroke is interesting, he is imagining someone in a much worse situation than he is possibly implying that he is looking for ways to feel better about his own situation.

Talking later in the interview about his confidence he says:

Well I used to go out regular on the bus to Musselburgh or Portobello etc, just after the the thing you know I says to the wife come with me come with me but I gradually got over that, now I just jump on the bus, but it's always there always at the back of your mind, but I've realised now that as I says, that ... I've realised that if you're going to have any form of a stroke you've got nothing, there's nothing that you can do ... (*James Interview 1*)

So James feels that although the worry is there, he can do nothing to stop something catastrophic happening. His confidence is growing but at the same time, he still has thoughts about recurrence. The role of fate is important for James: there is a feeling of fear and uncontrollability about the possibility of a recurrence or major stroke. Like Sarah, he perceives his health to now be more precarious.

Ellen was feeling relatively positive in her first interview; however, when asked about the possibility of a recurrence she says:

Yeah yeah. It's no like it's, it's just that, you know, it's blocked and I ken that a wee bit can break off at any time (*Ellen Interview 1*)

Ellen is referring to her carotid artery being blocked and that a piece of plaque could break off and cause another stroke; she uses very visual language to describe this. Like James and Sarah, she fears another stroke could happen at any time, and feels in a precarious position.

For the other three people interviewed, the thoughts about recurrence were less pervasive. Simon, for example, comments:

Well, I suppose because you hear things everywhere now you know ... it's only what you hear that puts things in your mind, you know, when you hear about someone having a stroke ... So, that kind of thing is on your mind, you know, I've had a stroke, is the second one going to be bad you know. But it's not something I think about, I mean it wouldn't be on my mind the next day (*Simon Interview 1*)

Simon is now noticing whenever he hears about someone having a stroke and relating this to himself; almost as if stroke now has a louder voice. The possibility of having a major stroke is now a concern for Simon (albeit a mild one); it is also interesting that Simon expresses this concern where he says " ... I've had a stroke is the second one going to be bad ..." like he feels like having another stroke is inevitable, although he may also mean that *if* he has one will the second one be worse.

For Frank, having a TIA challenged his view of his own health:

I had what I thought to be a balanced diet and being fairly active that that wouldn't be the sort of thing that would happen to me (*Frank Interview 1*)

Having a TIA was incompatible with Frank's self-perception. His view of himself and his health was challenged by having the TIA. Having had one TIA also made having another one or a more serious stroke a reality for him. When asked about the possibility of recurrence, he comments:

It's on my mind I can't say that it worries me though. I mean one has to take the view that it has happened once and it might happen again (*Frank Interview 1*)

Frank goes on to talk about how treatment ought to lower the risk:

Well, yes, I mean, actually, I'm 71 now and therefore, I'm conscious that, you know, every pain could be something disastrous, yes, that's just the way that it is [...] if I want to go on my own to a remote place fishing where there is no signal for the phone, I'm not sure I'm all that confident about doing that now, because if anything happens ... if it was any worse than that, you know, obviously I could be in a bit of bother. Common sense suggests that that would be the case anyway even if I hadn't had this, you know, should that be any more of a concern? Maybe it should be less of a concern cause now I'm on the medication, which I wasn't on before. But it's made me think along those lines, you know (*Frank Interview 1*)

This quote highlights the fact that having an event like a TIA or minor stroke makes the possibility of something 'disastrous' happening more of a reality. Frank's

actual risk of having another stroke was probably lower than it had been before the first one due to the medications he was now taking and Frank was aware of this. Before having the TIA, thoughts about health were not something that troubled him, but now the possibility of having another TIA or a stroke is very real. This had direct consequences for Frank: he no longer felt confident being alone in remote areas (something which he had enjoyed previously). Again, like the others interviewed there is a sense that Frank feels his health is now more precarious.

Richard, who had had surgery on his carotid artery to remove the build-up of plaques, which are a significant risk factor for stroke, was the only person interviewed who was unconcerned about having another stroke:

it's certainly not going to be on my mind. No, I think that would be the wrong approach. I'm quite a positive person and I think that what I've done is, I don't know, if it will cure you forever and a day but it will give me a new lease of life.

(Richard Interview 1)

This implies that Richard feels he has been 'cured' at least for now. This is not strictly true from a medical perspective; however, it was how Richard chose to interpret his treatment. Richard feels very positive and believes he has been 'given a new lease of life', as though he has been given a blank sheet regarding his health and can start again. So for Richard fear of recurrence was not an issue because he believed that his treatment had removed this threat.

So at baseline, there was a feeling of health being more precarious and unpredictable than it had been before the TIA or minor stroke for most of those interviewed. The event had made having another TIA or stroke a concrete reality. This was a common sentiment in the larger sample also, for example: "I feel like I can't trust my body anymore" (*Participant 024 Quantitative interview*) and "now I know that something serious could happen, I never thought about that before" (*Participant 1035 Quantitative Interview*).

Follow-up interviews - Thoughts about recurrence: good health is now uncertain

Thoughts about recurrence were still present at follow-up for those who were experiencing them at baseline. However, it was not always the same experience. For

those who were still finding these thoughts troublesome, there seemed to be more of a focus on symptoms that were perceived as threatening as opposed to the more generalised worries at baseline.

Ellen, for example, was anxious about a recurrence or major stroke because of symptoms she was experiencing. When asked about how she was feeling in general, she says:

It [thoughts about stroke] just starts going round and round in your head, and then I can hear... ummm ... it's like a noise where they said the blocked bits were ken? Like a ... errr ... a swooshing noise and I know I know that's because it's blocked and when that starts, your brain just starts going and you're thinking 'it's going to happen again now!' and then it's like 'oh God no' and then 'get it together!' ... and ... well... errr... that's it really (*Ellen Interview 2*)

It seems here that Ellen's emotions are in turmoil: she is clearly really very anxious about a recurrence. She is associating the 'swooshing' noise with the blockage in her carotid artery which she believed was causing the noise and would eventually lead to another stroke. It is as though Ellen is describing a progression from her thoughts to the symptoms she sees as threatening. When Ellen thinks about another stroke, she then starts to notice the noise that she finds threatening. This suggests that Ellen might be being hypervigilant about this noise, which could be making it more significant than it actually was. Ellen is clearly struggling to control her fears.

Ellen continued to focus on possibly threatening symptoms later in the interview:

Ellen: Oh yeah yep. I mean every wee bit pain in my head or something like that I'm like 'oh God' and it's awful and I try to calm myself and I'm like oh is it going to get better? Is it going away? Aye, just wee things ken? I mean I try to get my teeth together because that's what they do. When you first have a stroke that's what they say 'try to get your teeth together'. And look for your fingers [laughs]

Int: So are you doing those tests on yourself quite a lot?

Ellen: [Laughs] yeah do you think that's bad? Aye I think that's bad trying to clench my teeth and that. Sometimes I can't stop thinking about it you ken? And testing myself and that. Is that really bad? I shouldn't be doing that should I? (*Ellen Interview 2*)

Here Ellen again shows how anxious she is and how frequently she has thoughts of another stroke. In the first passage she is very expressive in describing her fear and how much her thoughts are in turmoil when she has any possible sign or symptom of a stroke. She tests herself frequently and seems embarrassed about it. Her asking questions implies that she is very uncertain of herself and seeks reassurance from the interviewer. By the time of the follow-up interviews, fear of recurrence was becoming a serious problem for Ellen. She feels as though her health is very precarious and another stroke is on the horizon. Although she does say she sometimes feels better, she gives the impression of being tormented by her worries. It does seem clear from these passages that Ellen was in need of further support.

James, like Ellen, was focussing on symptoms he perceived as threatening, which was a change from the more generalised anxiety he experienced at baseline. In the meantime, he had developed visual disturbances which he felt were related to his TIA; he was also still experiencing sensations he described as 'twinges' at the side of his head. Some of his fear of recurrence was directly related to these symptoms. When he was asked early in the interview whether he was worried about another TIA he simply replied "no", but some of what he says later seems to contradict this. When asked about the visual disturbance he says,

James: yeah, sometimes when that happens it's like you're worried that maybe it's time....[long pause]

Int: time?

James: aye, but it's nothing, but it makes you think about it.

And about the sensations in his head:

James: Oh aye, when that happens, it's like ... you feel like maybe it's going to go again and it could be bad this time, ken?

Int: so maybe... can you expand on those feelings?

James: Aye, maybe I'm a ... maybe .. umm ... it's like I could be, it might happen again, but I don't like to think like that, I'm quite a positive person (*James Interview 2*)

James appears quite reluctant to disclose any worries about recurrence; however, it is very possible that (as mentioned earlier) the interview process was bringing these thoughts to the surface and that in 'normal' life, he could forget about these concerns but that by talking about them, it brought them to the surface of his mind where he had to deal with them.

When asked again about the visual disturbances and whether they had any effect on him, he says:

James: it not really... it's annoying when it happens, but ... uhh... not really. It's just that it makes you think ... ken?

Int: think about what?

James: that it could happen again ... aye ... then I feel a bit kind of panicky ken?

Int: Ok, so you feel a bit panicky about it happening again sometimes?

James: Oh aye, because it could be bad this time ken?

Int: I see, so you feel a bit panicky when....

James: Aye that's it. When that happens or the feeling in my head ken? That's when I think about it, but not at other times. (*James Interview 2*)

As can be seen by this and the previous exchanges, James needed some prompting to talk about his concerns. He was perhaps not certain about the kind of information the interviewer was looking for; however, it appears that his worries about having another TIA or a more serious stroke are brought to the surface only when he experiences what he perceives as threatening symptoms.

For others thoughts about recurrence at follow-up were less significant. Frank still found that having a TIA was something that challenged his view of health:

it makes you realise that these things can happen, that even... it can happen to anyone, even me. I guess I have changed that way, before I never really thought about those things (*Frank Interview 2*).

When asked about whether he thought about the possibility of having another TIA Frank says:

Frank: Well, like I said it's at the back of my mind, so I suppose on one level I might be worried, or concerned is maybe a better word to use, but it's there at the back of my mind. I think I have to be realistic about it

Int: so being realistic means?

Frank: Oh well that it can happen and it could happen at any time, but I don't think about it much (*Frank Interview 2*)

Frank is expressing some level of concern about a recurrence or a more serious stroke, but it did not seem to be an issue that consumed him in any way. It may be relevant that Frank was a fairly literal and (self-confessed) unemotional person; when he states that he does not think about it much, but has some concerns, this is likely to be the case. While he recognised that he could have another TIA, he was dealing with that possibility in quite a constructive way.

Richard had not been concerned about recurrence at baseline because of the surgery he had undergone. At follow-up, he was feeling even more positive than the others interviewed about having had the TIA. When asked about how he was feeling about the TIA, he states that:

Well, there was nothing negative whatsoever. I mean I'm only too pleased to know that something was discovered and given immediate attention. (*Richard Interview 2*)

This more positive outlook was also common for people in the larger study (albeit not always quite so positive) following surgery. Simon had no concerns about his health or recurrence (or anything else related to the stroke) at follow-up.

The feeling that health was precarious and thoughts of a recurrence or a more serious stroke were present at follow-up. However, except for Ellen, these did not seem

as significant as at baseline suggesting that these feelings may reduce over time for some people. In addition, some of concerns had become more focused on symptoms perceived as threatening rather than the more generalised concerns at baseline. In the larger quantitative sample it was common for people to respond in a similar way, for example, "I get scared now whenever I get pins and needles and think it's going to happen again" (*participant 1047 Quantitative Interviews*) and "I'm getting bad dizzy turns and headaches which frighten me, I think it's happening again" (*participant 1032 Quantitative Interviews*).

Baseline - Taking control

Taking control was important for people in alleviating worries about recurrence, and not doing so exacerbated anxieties. 'Taking control' was defined as actions that people took that they believed would improve their health and reduce their chances of having another TIA or stroke, or, failing to take actions that they believed would reduce their chances of a recurrence or major stroke.

Both positive and negative changes to the way people thought, felt and behaved were evident. All of the people interviewed had changed (or tried to change) their lifestyles in positive ways. At baseline Simon was more careful about his diet "I mean you realise you've had a stroke and you do tend to watch food wise and stuff like that, I'm probably eating slightly healthier now" (*Simon Interview 1*); Sarah had stopped smoking and was trying to reduce the stress in her life "Yeah yeah I stopped smoking and that's making me feel good" and "I'm trying to take time for myself more now" (*Sarah Interview 1*); James had reduced his alcohol intake significantly and had lost weight "aye it's no like I was a big drinker before, but now I only have a few cans of beer a week and cut out the vodka" and "I've lost quite a bit of weight and I'm feeling great" (*James Interview 1*); Frank was trying to exercise more and was trying to eat better "I try to get in my 10 000 steps a day, I'm not saying I always manage it, but I get off the bus a few stops earlier now and things like that" and "I've cut out things like crisps and cheese" (*Frank Interview 1*); Richard was exercising more: "I used to be really quite fit with the golf and shooting I did and I kind of let that go over the last few years, but now I'm trying to do more and walk more everyday" (*Richard Interview 1*). Ellen was struggling with stopping smoking although she was feeling hopeless about ever being able to stop.

Taking or being given options over treatment was important for some of those interviewed. As discussed above, both Richard and Sarah had undergone surgery on their carotid arteries. This surgery is very effective in preventing recurrence in patients who have a significant build-up of plaques in their artery. This placed both Richard and Sarah in a different position to the others interviewed. Richard felt that the surgery meant he should not have another TIA or a major stroke, "Well, you know, it was explained to me that it shouldn't happen again. It was removed." And when asked about whether he worried about having another one, he comments that, "I feel that the potential worry has been removed" (*Richard Interview 1*): the worry has been removed along with the blockage.

Sarah felt that she had done everything she could and therefore the worry would go away:

I guess I think I was lucky it could have been a lot worse ... it is scary when you think about it, but I think that will pass because I know I've done the right thing so that will pass (*Sarah Interview 1*)

So Richard was relatively unconcerned about recurrence and Sarah believed that her fears would alleviate in time. When Sarah mentions 'doing the right things' in the quotes above she is referring to having surgery and stopping smoking, which she believed would reduce the risk of recurrence and her worries about it.

Sarah also realised that she needed time to process everything that had happened:

I've kind of slowed down with the visiting and stuff like that because I think it was just too much, it was kind of false because you weren't coming to terms with events [...] I think I needed time for me, you know, to come to terms with things instead of trying to do other things and being too busy. (*Sarah Interview 1*)

At first, Sarah did not give herself time to think about the stroke and having surgery. She tried to carry on regardless, but realised that she needed time to reflect. She continues:

I hadn't thought about looking after myself, but now I'm doing that you know resting and being quiet I think I'm feeling lots better, but I'm looking forward to being normal again. (*Sarah Interview 1*)

Sarah had not considered looking after herself and tried to act as though nothing had happened; but by realising that she needed to give herself time and to look after herself, she was beginning to feel better. This was a common reaction within the larger sample. Participants started realising during the quantitative interviews that they might need to take some time to reconcile themselves with what had happened. That Sarah was also looking forward to being normal again, suggests she was not feeling 'normal' at the time of being interviewed.

Both Richard and Sarah expressed strong feelings about the possibility of a recurrence or a major stroke between diagnosis and surgery (about a week for both). Richard commented that it was "the most miserable time of my life" (*Richard Interview 1*) and Sarah said she was "absolutely petrified" (*Sarah Interview 1*). Their use of dramatic language to describe this period of time might suggest that there was an immediacy and time limit to their fear that intensified it. Moreover, having a time limit to the fear, could have allowed both Richard and Sarah to surrender to the fear that they felt, whereas those who were not offered surgery needed to find more adaptive ways of coping with their longer-term anxieties.

Taking control was also important for the others interviewed For example, James commented:

between the [loss of] weight and the tablets that's where you get the confidence from" (*James Interview 1*).

James' confidence in preventing recurrence was, at least, partly reliant on taking control of his lifestyle (he had also cut down his alcohol intake significantly) and trusting that the medications were working.

He goes on to say:

Aye. What with the tablets and losing the weight, I feel great, I mean I've virtually lost about a stone in weight and that's what? That's about two months and no drastic [it was actually about 5 weeks] ... I mean I'm no starving myself, I'm just

basically watching what I'm eating, I just cut the rubbish out. So, like I says before, between losing the weight and the pills that's where you get the confidence from (*James Interview 1*)

James is feeling good about the changes he had made, he commented earlier in the interview that "I actually feel better now than... I'm actually fitting into clothes that [laughs] ... so I feel good aye" (*James Interview 1*). James had taken control over his health: this helped him to come to terms with what had happened and gave him the confidence to move on.

Frank was also taking control, although he was uncertain regarding the actions he should take:

It having happened, I'm conscious of trying to help it not happen again in spite of medication and that so... diet, well as far as that goes, I think I was on a reasonably balanced diet before, I've cut out things like crisps and cheese and all that sort of thing which was probably a complete over-reaction and I hope I'll be able to not continue on that.... So, I mean I think it's moderation is probably what's called for, but at the moment I'm feeling aware of that and a wee bit frightened of the chocolate biscuits and things like that I'll just have to I suppose what I need to do is to find out from somebody (*Frank Interview 1*)

This quote from Frank shows a willingness (or even desire) to take control and improve his lifestyle to reduce his chances of a recurrence. Frank, is of course, right when he says that a healthy diet is all about moderation and balance, but that at the time of being interviewed, he was feeling intimidated by the things he saw as unhealthy, like chocolate biscuits.

So for most of the people interviewed it seems as though taking control was important. However, for Ellen *not* doing the right thing was causing her anxiety, as she says, "Okay so it's bye bye if I don't stop smoking" (*Ellen Interview 1*). When asked about how that makes her feel, Ellen says

I think about how stupid I am, I'm still smoking and still and still no paying attention to it and there's no solution. You know it's

my own fault. But somebody said to me, that it could happen to someone who has never smoked in their life, so if you smoke it might happen, but if you don't smoke it might happen as well, so I've got to stop beating myself up about it, you know? But every time I light a cigarette I feel guilty about it, but I still smoke the bloody thing (*Ellen Interview 1*)

This quote shows Ellen rationalising and counter-rationalising; she begins by blaming herself for her failure to stop smoking and therefore increasing her risk of having another stroke. She then goes on to rationalise that strokes can happen to anyone, including non-smokers, in an attempt to alleviate her guilt. Overall, it appears she is aware that smoking is a problem, but one she feels she has no control over. Ellen was more positive in her baseline interview compared to the follow-up but she still blamed herself for the stroke she had had and any future stroke.

At baseline the feeling of taking control over health, lifestyle and treatments was important for most of those interviewed insofar as it lessened anxieties about recurrence. Conversely not managing to take control was a problem for Ellen: it heightened her anxieties surrounding recurrence and made her feel badly about herself.

In the larger study, the issue of taking control was also important. Those who had succeeded in changing their lifestyles tended to feel better about themselves and their chances of recurrence, for example, "I stopped drinking and am trying to eat more healthily. I feel good, really good" (*participant 1024 Quantitative Interview*) and "I started exercising again, I'd kind of let that go in recent years, but now I'm really enjoying it and feeling great, I'm not really thinking about the stroke anymore" (*participant 1112 Quantitative Interview*).

Follow-up: taking control

Taking control was also a subordinate theme at follow-up. For most, it remained a way of alleviating concerns about a recurrence or a bigger stroke, James, for example, had maintained the changes he had made to his lifestyle at baseline:

Oh aye, I stopped drinking so much and have changed what I eat and so I'm feeling great that way, aye. My heath I'm feeling better in myself ken? Healthier, I've lost weight and am feeling great for it. (*James Interview 2*)

James had taken control over his health and had maintained this, which helped him to come to terms with what had happened and gave him confidence to move on. This quote from James may give some insight into the conflicted accounts earlier regarding his fear of recurrence. Although James is concerned about a recurrence and is sometimes anxious especially when he experiences 'twinges' that remind him of the TIAs, he had also taken some control over his health and made positive changes to his lifestyle which meant he was feeling healthier than he had for a while.

Sarah had also moved on from the minor stroke and was beginning to put it behind her:

I'm really not thinking about it now you know? I feel I did everything I could at the time, though obviously I don't want that to happen again but.. so... I'm still trying now to be healthy and not to get too busy and things like that again"
(Sarah interview 2 - phone interview).

Sarah is no longer thinking about the stroke; she feels she has done and continues to do all that she can to prevent a recurrence. This seems to have given her the ability to return to her normal life.

There were also positive changes for Frank and Richard. Frank was trying, largely successfully, to exercise daily. He had not maintained the changes to his diet that he reported at baseline. This may have been because those changes were an unsustainable overreaction; this was common amongst the larger sample where participants would make drastic changes to their lives all at once and then find these difficult to sustain. Richard was also exercising more and had a personal trainer by the time of the follow-up interview.

By contrast, Ellen did not feel more in control of her health at follow-up. At baseline Ellen had been attending rehabilitation at a specialist unit which had helped her a great deal, but once this stopped, her mood began to go down and she was losing confidence

Aye, aye it's like after I stopped going to, umm you know [rehabilitation], I felt rubbish again you know? Like it all started coming back and... well, you know how I feel about it, I

feel really bad again and it's going around in my head ken? You know, what happened and that it could happen again ... or no... not even that, like like ... ummm ... it's going to happen again and then I get scared and.. but, it's not all the time like, I think I'm getting better that way.. but yeah... umm [long pause]. (*Ellen interview 2*)

This passage sums up a lot of what Ellen was feeling six months after her baseline interview. She is clearly scared of a recurrence, but hesitant about expressing this. She gives the impression that her thoughts and emotions about the minor stroke are still in turmoil. Her emotions appear to be out of control and her fear of having another stroke is quite intense. Like in the baseline interviews there is a sense of health being uncontrollable. She continues:

"... it's rubbish and you feel stupid because you're not doing the right things" (*Ellen Interview 2*)

Ellen is referring to her inability to stop smoking and has begun to feel hopeless that she will ever manage to, but she is also aware of the risks that continuing to smoke bring. While taking control of health and lifestyle had alleviated others' concerns regarding recurrence, Ellen's failure to do so left her feeling badly about herself, and that something catastrophic could happen.

She goes on to say:

Oh aye, it's like it just depends on the day ken? Sometimes I think it's better but other days ... it's just ... well ... it's rubbish and you feel stupid because you're not doing the right things.
(*Ellen Interview 2*)

The hesitation that is evident in these quotes may reflect how difficult it is for Ellen to talk about how she is feeling, and/or that she may not know exactly how she is feeling. Although she states she is 'sometimes' feeling better, she does seem uncertain about this herself. Ellen uses the word 'rubbish' frequently throughout the interviews, often when talking about herself and this does seem to be a reflection of how she is feeling about herself: she had not managed to stop smoking and has been told that this is a major risk factor for having another stroke. She is feeling stupid and arguably worthless like a piece of rubbish because she has failed to take the advice she had

received. This was preoccupied Ellen: in both interviews she returns to her inability to stop smoking and that this might lead to another stroke.

She continues:

I don't care about it. I don't want to stress myself out about it anymore. The more I stress the more I smoke and the worse it gets, so no. (*Ellen Interview 2*)

Ellen is clearly struggling and has decided that the stress of failing to stop is worse than the stress of continuing to smoke. Ellen had perhaps tried to change too much too soon; and that attempting to stop smoking while she was in a state of heightened anxiety was necessarily challenging. She had managed to cut down; perhaps at this time in her life taking small steps towards her goals was the best way for her to gain some control and give her something positive to focus on.

Those who felt that they had done what they could to reduce the risks of another stroke were still concerned and sometimes anxious, but felt more confident and able to cope better with their worries than Ellen. Ellen's worries increased between the first and second interviews, which was not the case for the other participants interviewed. This could be partly due to her perceived failure to gain control over her lifestyle.

A Need for further Intervention

There was a general need for more reassurance, advice or information, although this did not reflect any dissatisfaction with the treatment they received immediately following the TIA. Everyone interviewed except Simon expressed a need for some kind of further intervention. The types of intervention required varied and can be divided into lifestyle advice, medical information and emotional support.

Baseline Interviews: lifestyle advice / support

The baseline interviews revealed a need for more lifestyle advice for Ellen and also, albeit less so, for Frank. Frank (as mentioned above) was unclear how to improve his diet and whether it was necessary:

I probably need to ask someone about that [diet], but I don't know who really. I mean I have asked the GP and nurse, but I don't feel I know more than I did before. I asked the

consultant at the hospital whether I could ever have another sausage again and he said 'Oh so don't go on a bland diet, you can easily have another sausage, just don't have them all the time'. So I suppose it's about balance, but I mean, I don't know ... I don't know if I'm right or whether I need to worry about it.

(Frank Interview 1)

It seems as though Frank could not get the kind of advice he was looking for. However, it is possible that his uncertainty was irresolvable: during the quantitative interview he had commented that he wanted to know what the precise risks of eating different unhealthy foods were.

Ellen's requirements for support in changing her lifestyle were more serious. As discussed above she was distressed about her inability to stop smoking and the possibility that this would cause a recurrence or a more serious stroke. But she found the thought of quitting caused her more anxiety which was making her smoke more. When asked if she had cut down at all she says:

No, I'm smoking more, I'm actually smoking more, just with the anxiety, I think about it [stopping smoking] and I have to have one, ken? *(Ellen Interview 1)*

Ellen felt like she was stuck in a vicious circle that whenever she thought about stopping smoking or even cutting down, it caused her heightened anxiety which made her want to smoke more. She was feeling hopeless and felt the hospital did not want to help her further because she smoked:

Ellen: They might have put a stent in my neck if I hadn't been a smoker, I was like, ok, cos there's nothing they can do for you and I was like, what do you mean there's nothing they can do for me? What about my tablets? they must be helping because... oh God.. ok, so why haven't I stopped smoking then? Okay so it's bye bye if I don't stop smoking. They won't do anything for me if I don't stop, but I can't, so why am I stressing about it? What's the point in that?

Int: So you feel like they might have done something else if you didn't smoke?

Ellen: Yeah yeah I mean that's what they said to [husband] about the stent and that but because I smoke it was like nothing, there's nothing they can do.

Int: So the way it was at the hospital, how did that leave you feeling?

Ellen: Rubbish really, like I don't matter but angry, and scared as well. Angry because every time you try to speak to someone ... well...all of the above really ... but yeah yeah mostly angry you know (*Ellen Interview 1*)

Ellen was feeling hopeless and anxious that she would ever be able to stop smoking and that she might have been offered further treatment at the hospital if she had not smoked. She was feeling judged by the medical professionals and that she did not matter. Her GP had referred her to the smoking cessation service, but was not finding this helpful:

Oh aye, I mean, he's very nice and that [smoking cessation service] but it doesn't help, it's no good. I ken I need to stop, but I dinnae ken what to do... how to ... I've tried, but it's no good ... it's just no good (*Ellen Interview 1*)

It is unclear what kind of support, if any, would have worked for Ellen at this stage; however, it seems likely that she needed some help with her anxiety surrounding the thought of stopping before she could make progress.

At baseline there were some requirements for lifestyle advice. For Frank these were fairly minor needs, but his situation does highlight the problem for people who are already living a healthy lifestyle and who have a TIA or minor stroke: it can be difficult to find things in their life to change so as to reduce the risk of recurrence.

For Ellen, the need for support to stop smoking was a more serious concern, and her failure to quit was causing her significant distress. She found that the more she thought about stopping the more she was smoking and this added to her anxiety making her smoke more.

Follow-up interviews: need for lifestyle advice

Requirements for lifestyle advice at follow-up were less significant than at baseline. Frank had resolved his concerns about his diet; and although Ellen had not managed to stop smoking she had decided to stop worrying about it.

As mentioned above, by the time of the follow-up interviews, Frank had resolved the issues mentioned above regarding his diet:

[...] So I tried to speak to people and look at websites and you get lists of what is a healthy diet, but that wasn't really my question, you know, I wanted to know how often you can have something unhealthy, or should you never have something unhealthy? But I've come to the conclusion that there isn't really an answer to that, so I have decided to just continue with the kind of reasonably balanced diet I have always had
(*Frank Interview 2*)

So, Frank had gone back to his previous diet and had (it seems) stopped being concerned about his what he was eating. He had also increased the amount of exercise he was taking and was feeling good for it.

Ellen was feeling differently about smoking by the time of the follow-up interviews; she had not managed to stop and had decided to stop thinking about it:

Pt: I dinnae care about it. I don't want to stress myself out about it anymore. The more I stress the more I smoke and the worse it gets, so no.(*Ellen Interview 2*)

Ellen had decided to try and stop worrying about her smoking, which might have been the best approach for her at this time since her anxieties around the thought of stopping smoking were hindering her attempts and seemed to be making her smoke even more. In fact she had managed to cut down the amount she was smoking:

Pt: Oh yes yes a lot. I've cut down a lot.

Int: And how do you feel about that?

Pt: Really good. I feel proud of myself. Even my husband must be proud because he buys the cigarettes and when I first had the stroke he wouldn't entertain me. He was like nope nopenope and now he knows that I'm only smoking the 20 he he ... so I think he must be a bit proud. *(Ellen Interview 2)*

Ellen had succeeded in cutting down how much she smoked and this gave her a boost in her confidence. She felt proud of herself instead of the shame and self-recriminations she had experienced at baseline. Ellen was feeling almost fatalistic about whether she would ever stop smoking and that the support that she had been offered was not for her:

Pt: No I don't want to stress anymore, if it's going to happen it's going to happen and it's no through the lack of trying. I've tried and probably more than the doctors have you know, once they ... they dinnae even care and I know I know they don't have the resources or whatever, but it's just like it's like there's just nothing you know?

Int: Okay. So do you feel like there's been a bit of a lack of support over stopping smoking or ..?

Pt: no not with the stopping smoking he [smoking cessation officer] was really really good with me he was really good. You know and if I phoned up now he would probably say come and see me but really I hate talking about trying to stop smoking. I think when you talk about it it gets worse you know?

Int: Does it make you think about having a cigarette?

Pt: exactly! *(Ellen Interview 2)*

Ellen gives the impression that she feels left alone to cope, she feels like the doctors do not care about her and do not appreciate how hard she is trying to stop

smoking. She does say later that the smoking cessation service tried to support her, but that their methods did not work for her. Perhaps Ellen required a more complex approach to her smoking, one which dealt with her anxieties before she attempted to quit smoking; however, this was not something which had been offered to her.

By the time of the follow-up interviews there was less need for lifestyle advice. Frank had resolved his issues surrounding diet and was exercising frequently. Ellen had chosen to stop worrying about her smoking and had, at least, succeeded in cutting down, which had increased her confidence.

Baseline interviews: need for further medical information

There was a need for further medical information for some of those interviewed. There were questions regarding diagnosis "no one said to me that that's what it was, so I don't know" (*James Interview 1*). There was uncertainty regarding follow-up appointments, for example, James comments: "so I don't know what happens now. Do they test you again later on? Or... I don't know what happens" (*James Interview 1*). The implications of having had a TIA and what that means for the future "it would be nice for somebody to say it's very unlikely or yes, it could happen again" (*Frank Interview 1*) and a more general need for further information, "I never knew because no one explained it to me, not to me, exactly what had happened" (*Ellen Interview 1*).

James was not completely convinced he had had a TIA and when he was discussing his experiences of what happened after he sought medical attention, he commented:

Well he [the GP] put me on these statin tablets and I was on the blood pressure tablets so I just assumed it was a ...a ..aye a TIA, but now I'm sitting here and I'm saying to myself was it? was it? but what else could it be? Quite confusing like. (*James Interview 1*)

Later he says:

Well well she [doctor at TIA clinic] probably said it a few times sort of saying well we might be suspecting a TIA so we're going to put you through these tests but after it we never seen her again. I mean we never never went to meet her again and she never says of the scan it shows you've had TIA that just didnae

happen, just go and see your doctor, go to the GP. As I said you're just sitting there and things are going round and round in your head and after a wee while, like a week or so that's when I started thinking, well have I had these things or...? And I feel great now like. (*James Interview 1*)

As was discussed in a previous chapter, diagnosis of a TIA is rarely definitive. It tends to be based on reported symptoms and medical history of the patient, so James had been told that the episodes he had experienced were probably TIAs. However, this lack of certainty gave him some pause for thought. In addition, all the positive changes he had made to his lifestyle made him feel better than he had in a while, which may have added to his doubts.

James was uncertain about his diagnosis, but this did not prevent him behaving as though he had had a TIA: he was living a healthier lifestyle and taking his medications. James may have needed further medical information but it is also possible that nothing would have given him complete certainty. Because he was complying with all the treatments and advice this was largely an academic question for James: when asked about how he felt about the lack of certainty over his diagnosis he says "it doesn't bother me ken, like I said I feel great" (*James Interview 1*).

For the others interviewed, there were further issues regarding the need for additional medical information at baseline. Frank wanted to understand more about his condition, but only realised he had questions some time after his appointment at the TIA clinic:

I just feel that I suppose what was missing was, you know, was I in the minority? Or do a lot of people have it, was it likely to happen again, how likely ... all that kind of thing ... these are the kind of things I began to worry about afterwards. (*Frank Interview 1*)

It is not uncommon for patients to realise they have questions following medical appointments, and the lack of follow-up for people who have had a TIA or minor stroke might be an issue in this regard. He says later:

The doctor told me I have a condition called significant subclavian stenosis, and he said, well that's quite common,

debris can build up at this particular place and what I'm not certain about is whether this will get worse or stay the same. That's a question which I'd like to ask someone. (*Frank Interview 1*)

And later he set out his understanding of what had happened was:

If I understand it correctly it was caused by little blood clots or something which were presumably trapped behind rough cholesterol, it had broken loose and the cholesterol had broken loose and the pills I'm on they prevent blood clotting I'm not sure whether any existing blood clots will dissolve but that would be quite nice to know as well but if... provided the blood clotting isn't an issue then it hopefully it won't happen again, and if these Statins smooth the cholesterol plaque, so there's nothing to stick behind, then I'm reasonably satisfied that the chances of it happening are... well you can't say zero but reduced ... it would be difficult for it to happen again if that's that's the case, but I don't know, it would be nice for somebody to say it's very unlikely or yes, it could happen, you know, nobody can guarantee things but I'm kind of a black and white person (*Frank Interview 1*)

Most of what Frank says here he had worked out for himself from what he had been told and his own research. His understanding is fairly good, but he still had some concerns which he wanted to discuss. Frank's uncertainty about what exactly happened during the stroke and how the medications affect his chances of having another stroke in the future was not uncommon in the larger sample. Many people were more anxious about this issue than Frank, for example, "the thought of it happening again or something worse terrifies me, but maybe the tablets mean it won't? Is that right? I don't think anyone said anything about that" (*participant 1123, quantitative study*). Most (if not all) patients were probably told something about their chances of recurrence at the TIA clinic, but some may have been unable to process that information at the time. This lack of certainty led some people to look for information from other sources, which was not always helpful. For example, Frank talks below about looking for information online:

Well, I mean, I've been on the web and have managed to sort of worry myself on several accounts, because of course you do that on the web. (*Frank Interview 1*)

This highlights the problem of people looking at information which they may not know how to interpret correctly or which may not apply to them. Again this was relatively common in the larger sample also: people frequently looked online for information that sometimes left them feeling worse than before.

When Sarah was asked about how she felt about the information she had received following her surgery she says that:

Definitely not enough for that. I got nothing nothing at all. I'm sure they did give me a leaflet prior to going in and there was a Heart and Stroke number on it but no I just felt you got your discharge papers and that was it. I think because I was looking well and they knew I had family back up you know what I mean. So yeah I think that had a lot to do with it (*Sarah Interview 1*)

Sarah felt like she did not get sufficient information following her surgery. Although she had been given a Chest, Heart and Stroke leaflet before her surgery (which most patients receive at the TIA clinic), she felt that she needed more information afterwards.

Many of Ellen's requirements for further intervention were for lifestyle and emotional support (discussed in the sections above and below). However, parts of her baseline interview highlight the benefits of further intervention. Ellen was feeling very positive about the rehabilitation she received from a specialist hospital (she was the only person in the study, including the larger sample, who had been offered this service) and having this service had helped her understand her condition better:

well when I was at the hospital [rehabilitation hospital] you were explained everything you were told why the exercise was good for you and why they test things Yeah that kind of help. I've no got anything but praise for them you know. Even the follow-ups put my mind at rest, you know, they explained that just because I've no physical difficulties that doesn't mean

that I'm no ... no up there and that, my memory and that because that's just as bad as what a physical one is. (*Ellen Interview 1*)

For Ellen the reassurance and support from the rehabilitation service was important: it helped to normalise her symptoms, and to understand that just because her symptoms were not physical this did not mean they were not as serious. Later in the interview she says:

Int: So how are you feeling now about the problems with your thinking?

Ellen: I feel better, it's getting better, or I don't know, maybe because I understand it better it doesn't bother me as much ken?

Int: So understanding was important?

Ellen: Oh aye. I didnae ken what to think at first. Didnae ken it was normal and would go away, but they explained all that at [rehabilitation service] and I ken now it should get better.

(*Ellen Interview 1*)

This suggests that part of Ellen's distress surrounding her symptoms was caused by a lack of information about them (she had commented earlier in the interview that no one had spoken to her at the hospital about the minor stroke). Ellen makes an important observation that perhaps it is her understanding that is better and therefore the symptoms do not worry her as much as previously making them feel less severe and less threatening. The fact that she has been told that it is likely she will recover makes a lot of difference to Ellen and to how she is experiencing and coping with her condition.

At baseline some of those interviewed expressed a need for further medical information regarding their diagnosis, the implications of having a TIA and more general information following surgery. The majority of people in this study including the larger sample were very complimentary about the TIA clinic and the stroke team. However, the lack of follow-up was an issue for many people and many felt that their GP was not always able or had time to give them the specialised information that they were looking for.

Follow-up Interviews: need for further medical information

There was still some uncertainty expressed about medical information at follow-up; however, whether there was a need for this information is debatable. Frank, however, still had significant doubts about the stenosis in his arteries:

Well, no not really. I don't think they'd tell you much more, what I'd like to do is, wait till the year is up and have another scan to see if it's the same, worse, I don't know whether the GP or the NHS would allow this to happen, but I think it's important enough from my perspective that I'd probably pay to have it done if necessary, just because I'd like to know (*Frank Interview 2*)

Here, Frank does seem to be expressing curiosity rather than need, but it was important enough for him at this time to consider paying for the answers.

James was still unclear about his diagnosis at the second interview and, it is possible that he had had another TIA as he had new symptoms which he felt were related to the TIAs:

James: Well... as I said before I don't think so, I dinnae ken that it happened before, no one told me I had had one so I dinnae ken [...] Aye, but what else was it if it wasn't that ... what do you call it? [...] Aye a TIA. I mean what else could it have been?

Int: Can you remember what the doctor said to you at the hospital?

James: That it could have been that... that it probably was one, but they never said definitely. So I don't know. (*James Interview 2*)

James still wants a definitive diagnosis before he can completely believe that he had had a TIA. This is interesting because, as discussed above, James was concerned about recurrence, which might suggest that he is more convinced by his diagnosis than the above quote implies. There is also a good possibility that James' doubts were

brought to the surface by the interviewer and interview process. When asked about how the lack of certainty makes him feel he says:

James: I dinnae ken really. I mean it doesn't really matter does it?

Int: So you feel that it doesn't matter?

James: Well, aye, I mean it matters, but I cannae change it now, but it's annoying not to know when I think about it. I dinnae ken I don't think about it much, so I don't know. (*James Interview 1*)

It is possible that it did not actually matter much to James but that he felt that it ought to matter, or that he should not admit to it not mattering, because of the questions he was being asked. So James may not have needed further information about his diagnosis, but the interview maybe made it appear as though he did. During the conversation with James a different but related issue arose, which was that merely asking about what people know can make them aware of what they do not know. This is exemplified by the exchange below:

Int: do you feel like you got enough information to understand what happened?

James: Yes, yes ... well maybe I don't know. I don't really understand it, but I know there was a blood clot that blocked part of the brain. But I don't know anything else much sorry

Int: no that's great. Would you have wanted more information do you think?

James: well, now I would want to know more, maybe not at the time, not when it happened, but now. Maybe talking like this, with you asking all those questions, I see I don't know much, maybe I should know more ... so, yes, now I want more information (*James Interview 2*)

In the above exchange James begins to realise that there are holes in his knowledge and that he now wants more information. It is impossible to say whether he would have felt this way had he not gone through the interview process, but it seems

possible that these questions would not have occurred to him had he not taken part in this research. It seems that for James this realisation was not a negative realisation:

Int: Sorry if all those questions made you uncomfortable

James: no no it's fine, it's good actually you ken? to realise you don't know, don't understand (*James Interview 2*)

Although for James realising what he did not know was, apparently, a good thing this does not mean that that was true for everyone and it is likely that the interview process (both for the qualitative and quantitative samples) brought up questions and concerns for people that they had not thought about previously. In the larger sample there were several participants who expressed high levels of uncertainty and, sometimes, distress or anxiety when asked about their condition. This is clearly an ethical issue and interviewer attempted as far as possible to provide reassurance and encouraged participants to speak to their GPs or to phone the number provided on the Chest, Heart and Stroke booklet.

Baseline interviews: need for emotional support

Sarah expressed a need for further emotional support at baseline. She felt let down by her follow-on care:

Well, I do feel a bit disappointed I do yeah I just felt the GP would do your umm basically the follow on thing. You know looking after. Whereas I feel there it's mainly, and obviously they have to check your cholesterol, your bloods and all that, but that's all they're kind of doing. It's not your wellbeing, you know what I mean, and I feel that bit lacks ... but I still feel that there should be another one there just to make sure of the wellbeing part certainly. It's like I've just been left on my own (*Sarah Interview 1*)

Here Sarah is expressing her need for some reassurance following her experience, she is feeling left alone to cope with her emotions:

As I said I feel like I've been left on my own to just get on with it, it can be a bit scary, definitely [...] But yeah, I think it's, it's a wee bit like .. it's quite hard for someone .. like I've never

experienced it, you know, because they don't understand how to deal with ... and that could cause me more problems and you could just be testing blood and bits and before you know it you're testing for depression sort of thing, you don't want to go down that route. You know what I mean? (*Sarah Interview 1*)

Although this passage might seem a little confused, Sarah is talking about how she feels let down by her follow-on care. She is in a new situation and she feels that those involved in her medical care are only interested in running tests and not providing the reassurance that she needs.

Sarah fears that she may end up feeling lower than she already is without the support she feels she needs. As she says:

but that's something that's been suggested - to go on anti-depressants, you know, I mean, I thought, I don't want that I just wanted the reassurance of what's going to happen next type of thing (*Sarah Interview 1*)

It was difficult for Sarah to get the reassurance she was looking for. Her quote above suggests she feels that her low mood has been medicalised in a way that is not compatible with her own feelings. She feels like if she had someone to speak to about how she is feeling and to get some reassurance she would not need to be medicated for her low mood. Although it would be impossible to actually know what is 'going to happen next', it is likely that Sarah needs reassurance that she is doing well following her surgery and to be reminded that her risk of another stroke is significantly lower.

Sarah was expressing emotions that were common in the larger quantitative sample, that is, the feeling of being left alone to cope. Most of the people in this study (including the larger quantitative sample) saw a stroke specialist either in the TIA clinic or on the ward and underwent tests. Normal practice is then for a patient to see their GP for the results of the scans and to get their prescriptions for any new medications; they do not see a stroke specialist again unless the scans indicate a need for that. This left some people feeling like they had been left alone to cope with any residual symptoms. Follow-on care was not offered to patients in Lothian; however, patients in

Fife all saw a stroke nurse a few weeks after their diagnosis which gave them the opportunity to ask any questions that may have occurred to them.

Follow-up Interviews - need for emotional support

Sarah was feeling a lot better emotionally by the time of the follow-up interviews and felt that her life had got back to normal.

Ellen spoke at length about her experiences in rehabilitation at her first interview and how much it helped restore her confidence. Unfortunately by the second interview (she had been discharged from the rehabilitation service by that time) she was struggling and feeling low despite having been prescribed anti-depressants by the GP:

I ...well... I think I was on a bit of a... of a ... sort of high when I saw you before ... I think I'd just been to the [rehabilitation services] and it was ... I felt good after that because they helped me... ken? They made me feel more normal kind of thing. I think I went down after that, when that stopped you know? (*Ellen Interview 2*)

Much of what was affecting Ellen's mood has been discussed in previous sections; she had significant distress relating to thoughts about recurrences or more serious strokes; she felt let down by the experiences she had in hospital and was blaming herself for her situation (mostly) because she was a smoker and was finding it impossible to stop. However, Ellen was also finding returning to 'normal' life difficult, when she was asked about whether she was feeling anxious, she says:

Ellen: That's before going out, that's... I don't know if it's anxiety... Aye well it will be because I get all sort of... when I cannae go out I get anxious. And I get all sort of I don't know, if I'm going out and I don't know where I'm going, going out for the sake of going out, I get all sort of [loud intake of breath] and I don't know why that happens because I wander about the shops and that, but I don't like doing it myself. If I'm with [husband] or [daughter] then I'm better you know, it's just being on my own, being on your own, I think that's what it is.

Int: So being on your own. Does that make you feel...

Ellen: Yeah, I hate being on my own

Int: right.

Ellen: [sighs] But then I hate being with a lot of people (*Ellen Interview 2*)

Ellen was feeling anxious about not getting out but was also experiencing anxiety about the thought of going out. She hates being on her own, but then goes on to say that she also does not like being with other people. She goes on to say:

Ellen: No, I think I'm not used to meeting people anymore and that, I'm not that good at it now, not as good as I used to be. I used to be more up front and I could talk to anybody about anything and I used to be like I got all their problems and things like that

Int: And do you have any ideas of why that might have changed?

Ellen: No, I think maybe even if it's just with working there and things like that. And everybody seems more involved with me and that. I hate when I'm made to talk about myself, everybody is like how are you feeling? And I'm like I'm fine I'm fine you know? (*Ellen Interview 2*)

It seems as though Ellen feels like having the minor stroke has affected her identity: she now interacts with other people differently. It appears as though she is feeling like she is getting too much attention focussed on her and how she is doing and this is making her uncomfortable. Later in the interview she says:

Int: Yeah. Right, so, does it make you uncomfortable to talk about your health?

Ellen: I dunno. Yes, I hate talking about myself. I hate it more now, I think maybe it reminds me you know?

Int: Yes. I see, it reminds you that...?

Ellen: Yeah yeah about the stroke ken? I hate talking about it. (*Ellen Interview 2*)

From these exchanges it seems as though Ellen finds talking about the stroke and how she is getting on distressing and that avoiding situations where she has to talk about herself is easier than facing them. The stroke affected both how she sees herself and her behaviour. During her first interview Ellen came across as a cheerful outgoing person (despite the distress she was experiencing), by the second interview it did seem to the interviewer that she was beginning to be at risk of becoming depressed and withdrawn. When she was asked about her mood she says:

Aye aye, I've got to do something for to try and get myself out of it [...] it's the same thing constant you know, there's no change, there's no.... everything's just the same. Like there's nothing right and there's nothing I can do (*Ellen Interview 2*)

This gives the impression that she is really quite low and is feeling like she does not know what to do to make herself feel better. She is experiencing despair and it seems as though she could have benefitted from some further intervention to support her.

To summarise, there was a need for further emotional support for, at least, two of the participants interviewed. For Sarah some reassurances that she was doing well after her surgery may have been sufficient. Ellen perhaps required more involved help and may have benefitted from some counselling to help her sort through her feelings about what had happened and to support her in changing her lifestyle.

6.3 Discussion

This section will start by discussing the results relating to expectations and then the emergent themes: living in a new health reality and a need for more intervention.

Expectations

Before discussing expectations for symptoms, it should be noted that, as previously discussed, there is very little clarity or agreement in the literature regarding the definition of expectations and there is a scarcity of explanatory models of how expectations are formed and how they might affect health (Bowling et al., 2012).

Participants in this study generally found talking about their expectations for recovery difficult and spoke more in terms of their hopes for recovery. It was argued earlier in this research that hopes and expectations were two distinct concepts that possibly have different outcomes; however, it seems possible that these two concepts are difficult for people to distinguish between in practise. Wiles, Cott and Gibson (2008) describe expectations as a particularised hope and argue that hope as an expectation is distinct from hope as a want or desire. This may be a useful way to think about expectations in health, where hope as an expectation has a higher level of certainty about the outcome than hope as a want (which might have no certainty attached to it).

Uncertainty about expectations for symptoms was high in the people interviewed which was similar to White, Barrientos and Dunn's study (2014) where feelings of uncertainty and unpredictability about recovery emerged as a theme in their sample of people who had had a major stroke. Expectations were largely positive, but with the high levels of uncertainty expressed it seems likely that people felt the need to give some kind of answer to the interviewer which may have been expressions of hope rather than actual expectations.

There was very little change in expectations for symptoms between baseline and follow-up, therefore both interviews will be discussed together.

Expectations –information

There was some suggestion that people might find forming expectations about their symptoms easier when they have information about the likelihood of recovery, for example, Ellen saying "ummm.... I... I think because they told me it would... I dinnae ken what else.." about her reasons for thinking her cognitive problems would get better.

However, there is a lack of information and understanding about TIAs and minor strokes within the general public (Jagadesham, Aparajita and Gough, 2008) and in people who have had one (Maasland, Koudstaal, Habbema et al, 2007) which was mirrored in the people interviewed for this study. Expectations need to be based on something, whether it be perceived information, experience or beliefs and where none of these are present it is reasonable to assume that expectations will be expressed in terms of hopes rather than what people think will actually happen. This was backed up by people stating that they did not have any expectations for symptoms because they had not been given any information about them “I don’t know, I don’t think anyone has said anything about that” (*James Interview 2 talking about his symptoms*).

Expectations –experience

There was also some evidence that experience might affect the development of expectations. Where symptoms had already improved people felt more confident in their expectations for recovery, Ellen’s comments on the fatigue she is experiencing highlights this “I mean it’s already better so I think it will keep getting better”. Some literature in this area that suggests expectations are not stable insofar as new information or experiences can modify them (Janzen et al., 2006). This did seem to be the case with some of the participants interviewed for this study.

Summary

Generally speaking participants in this study found it difficult to talk about expectations for recovery; this was true of the larger sample also. It seemed as though many people had not really thought about the recovery of their symptoms and sometimes seemed surprised by the question and uncertain how to answer it. A substantial number of participants in the full study talked about their hopes for recovery and when prompted about how confident they were that their hopes would be realised they became hesitant and frequently responded that they did not know.

Living in a new Health Reality

Most of the people interviewed felt that they were living in a new health reality to varying degrees including those who had little or no emotional response to the event: good health was no longer something that people could take for granted. This finding was similar to Gibson et al.’s (2011) finding that having a TIA changed peoples’ perceptions of their health and Croot, et al.’s (2014) TIA study where uncertainty about

the future emerged as theme. One of the most important aspects of living in a new health reality was fear of recurrence or fear of having a major stroke.

Thoughts about recurrence – good health is now precarious

There is very little literature in the area of fear of recurrence or having a major stroke in people who have had a TIA or minor stroke. Much of the literature in this area is concerned with risk perception and behaviour change to prevent recurrence (e.g. Boden-Albala, Carman, Moran et al, 2011; Brouwer-Goosensen, van Genugten, Lingsma, et al., 2016) and tends not to look at whether people are worried or frightened about recurrence. One study (Townend et al., 2006) found fear of recurrence was reported by more than half of their sample of 89 people who had suffered a major stroke and it emerged as a theme in a study by White et al. (2014).

One study investigating anxiety following a stroke of any kind (including TIAs) (Chun et al., 2018) found relatively high levels of fear of recurrence. They found that this fear could lead to either positive health behaviours, for example, medication adherence and stopping smoking or to maladaptive coping behaviours, for example, avoidance. This was true for the people interviewed for this study also. James had stopped going out on his own after his TIAs because he was afraid of a recurrence, although was beginning to feel better about being on his own by the time of the baseline interviews. Ellen was afraid of being on her own also and was avoiding unfamiliar situations. Frank had stopped going to remote areas by himself, which was not necessarily a maladaptive response. He had realised that if something were to happen to him when he was far away from help, he might be in serious trouble. However, this concern about recurrence also led participants to change their lifestyle, for example, James had lost weight and was gaining confidence from this and from his medications. Frank and Richard were exercising more and Sarah had stopped smoking.

At follow-up concerns and anxieties about recurrence or a major serious stroke were more focussed around symptoms that participants felt were threatening rather than generalised anxiety. There was some suggestion that people were being hypervigilant about symptoms that were perceived as threatening. Similar to hypervigilance are the concepts of health competence (Horlick-Jones, 2011) and somatosensory amplification (Barsky, Goodson, Lane et al, 1988), that is, the ability to appraise and react to bodily sensations in an appropriate way. This was true of some of the people interviewed for this study, for example, Ellen's reaction to the 'swooshing'

noises could be considered to be, not only hypervigilant, but also it seems likely she was not appraising this experience appropriately and in so doing this was leading to significant distress.

Research investigating fear of recurrence in cancer has found that physical symptoms can trigger fear of recurrence and / or fear of relapse (e.g. Hall et al., 2019). It is interesting that the results of the qualitative interviews suggest that there may be similar reactions in people who have had a TIA or minor stroke. For example, both Ellen and James talked about being physical symptoms leading them to think they were about to have another stroke.

This is an under-researched area in stroke and in this study there were definite fears and concerns regarding recurrence or major stroke which, for some, resulted in significant anxiety in both the qualitative participants and the larger sample “it’s [minor stroke] changed everything for me, I don’t even want to have a bath unless my husband is in the house” (*participant 1075 quantitative interview*) and “I just can’t face going outside in case it happens again” (*participant 1083 quantitative interview*).

One important question in relation to fear of recurrence is how far anxiety surrounding recurrence is rational. As was outlined earlier, having a TIA or minor stroke is a risk factor for having another one and for having a major stroke or heart attack. Therefore some level of fear, worry or concern seems like a reasonable response and might have prompted some participants to change their lifestyle, whereas for others the fear can be overwhelming and in some cases this can lead to psychological distress and avoidance. This is an important area for further research to attempt to disentangle the relationship between fear of recurrence and subsequent behaviours.

Taking control

Taking control of health behaviours and treatment helped people in this study to reduce their anxieties about recurrence or major stroke and not succeeding in taking control heightened anxieties. Spurgeon, Humphreys, James, et al., (2012) found that constructive optimism emerged as a factor in their Q-methodology study of people who had had a TIA. They argue that this is an adaptive coping mechanism that allows people to reconstruct the TIA as a positive event and to consider lifestyle changes to improve their health, which is similar to the theme of taking control that emerged in this study.

Jones, Mandy and Partridge (2008) likewise found that taking control over recovery emerged as a theme in their study looking at major stroke patients.

The idea of taking control over health behaviours is related to the concept of health locus of control, which is the belief that health is determined by internal factors or external ones, which has been discussed in previous chapters. There is some evidence that better outcomes following stroke is related to internal locus of control (van Mierlo et al., 2013; Thomas and Lincoln, 2010; White, Magin, Attia et al., 2012).

At follow-up people had mostly maintained the lifestyle changes that they were engaged in at baseline, although for one person (Ellen) the failure to take control of her smoking had left her feeling hopeless that she would ever manage to stop. However she had managed to cut down the amount she was smoking which had given her a boost to her confidence.

This may be an important area for clinicians to focus on, that is, encouraging patients to take control of their health thereby increasing their confidence and reducing concerns about recurrence.

A Need for further Intervention

There was a need for further intervention expressed by several people in this study. This is not an unusual finding in studies looking at TIAs, minor and major stroke (e.g. Croot et al., 2014). In addition, the overall levels of uncertainty conveyed during the interviews might suggest that there was more of a need than was openly acknowledged.

Lifestyle advice

In general the people interviewed were making changes to their lifestyles to help reduce their chances of recurrence; however, there was some uncertainty regarding diet and exercise although in this case, Frank, at baseline, was perhaps becoming a little too preoccupied with his diet. This was similar to the finding by Croot et al (2014) that people can become “slightly obsessive ... in relation to reasserting control over their bodies” (p179). However, by follow-up, Frank had more or less resolved the issues with his diet.

For one participant (Ellen) there was a significant requirement for help to stop smoking. Not only was she increasing her risk of a recurrence or a more serious stroke,

her failure to stop was causing her considerable distress. There is some evidence that failure to stop smoking can cause psychological distress (e.g. van der Deen, Carter, Wilson et al., 2011) and that people with mental health issues are less likely to succeed in quit attempts (e.g. Dube, Carabello, Dhingra, et al., 2009) given this evidence and the fact that Ellen was not only still smoking, but also was being treated for low mood at follow-up it seems likely that she required more specialised help with smoking cessation than she was being offered.

There is evidence that people who have had a TIA, minor or major stroke need more detailed information about modifiable risk factors for recurrence. Lawrence, Kerr, Watson et al. (2010) state that in their study people may have been given information about lifestyle at the time of diagnosis but had forgotten and therefore diagnosis may be the wrong time to provide such information. In the quantitative sample many of the people interviewed said that they had not been given any information at the TIA clinic; however, it is possible that people had forgotten that they had been given information leaflets as it is normal practice for the stroke team to provide such information to patients.

Medical Information

There was need expressed for further medical information for some of the people interviewed. For example, James was not convinced that he had had a TIA “I just don’t know if that’s what it was, no one has told me”, at baseline or at follow-up because he had not been given a definitive diagnosis. Croot et al. (2014) also found patients in their qualitative study doubted their diagnosis. As discussed, James was behaving as though he had had a TIA: he was adhering to his medication regime and had significantly improved his lifestyle. However, this was not true of everyone in this study. In the larger sample there were participants who did not believe they had had a TIA or minor stroke and were not adhering to their medications because of this. The researcher always encouraged anyone who was in this position to speak to their GP; however, this suggestion was frequently rejected.

In addition, Frank was curious about whether his condition would improve with the medication he was on and was planning to pay for answers if necessary. This was not an uncommon reaction in the larger sample, where people would frequently ask the interviewer about their medications and what they were for. In addition, many people wondered whether they would be able to come off their medications in time suggesting

that further information was needed from medical professionals to discuss these issues and what their medications actually did.

Emotional support

Both Ellen and Sarah expressed a need for more emotional support. Systematic reviews investigating depression after stroke (Hackett, Yapa, and Anderson, 2005) and anxiety after stroke (Rafsten, Danielsson and Sunnerhagen, 2018) found high levels of both post stroke; however, there is far less research investigating mood after a TIA or minor stroke. One large scale study investigating anxiety and depression in patients who had had either a stroke or a TIA (Broomfield, Quinn, Abdul-Rahim, et al., 2014) found 29% of the TIA patients had anxiety and 21% were depressed. In the larger quantitative sample it was common for participants to talk about their distress at their diagnosis and their feelings of being abandoned by the professionals, many people felt like they had been 'left to just get on with it'. Considering the lack of follow-up for people who have had a TIA or minor stroke this problem is not being addressed.

6.4 Conclusions

In summary the themes that emerged from the qualitative study were living with a new health reality and the need for further intervention. Some of the people interviewed were distressed and required further support for their distress. Fear of recurrence was a significant problem for two of the people in this study and a third had concerns that had prompted him to change his lifestyle. Participants had requirements for further intervention ranging from medical information to emotional support.

One further issue is worthy of mention and that is that not everyone was impacted by their diagnosis. Simon, for example, had no concerns or worries about his condition. This is an important point because he was not alone in this attitude. There were a substantial number of participants in the larger sample who were not impacted by their diagnosis and did not require any further intervention.

The results from this study compliment the results from the quantitative studies and this will be discussed in chapter 7.

Limitations

Although it is recommended not to use sample size as a limitation to qualitative studies, in this case it might have been. The sample in this study were chosen because

they had all reacted differently to their diagnoses, which was a strength; however, it would, arguably, have been better to have included more participants with symptoms to allow for a more in depth analysis of expectations for recovery and reactions to ongoing symptoms.

CHAPTER 7

GENERAL DISCUSSION

This research set out to investigate the effects of expectations on the recovery from a TIA or minor stroke; and to understand how individuals' experiences and perceptions following such an event change over time, and how far, if at all, they influence recovery. This chapter will focus on some of the more novel findings and attempt to draw together the results from the qualitative and quantitative studies. See figure 8 for a diagram summarising the main findings.

One of the most important points to come out of this research is the tension between the medical definition of a TIA or minor stroke and some people's experiences of having one. The medical definition suggests that these are transient and / or minor events where any residual symptoms are minor and non-disabling (Moran et al., 2014), whereas the results from this study suggest otherwise. Many of the participants in this study were left with symptoms that affected their both their physical quality of life and mental wellbeing. In addition, participants were sometimes distressed by their diagnosis, unclear about the implications of having had a TIA or minor stroke and would have benefitted from further support or advice.

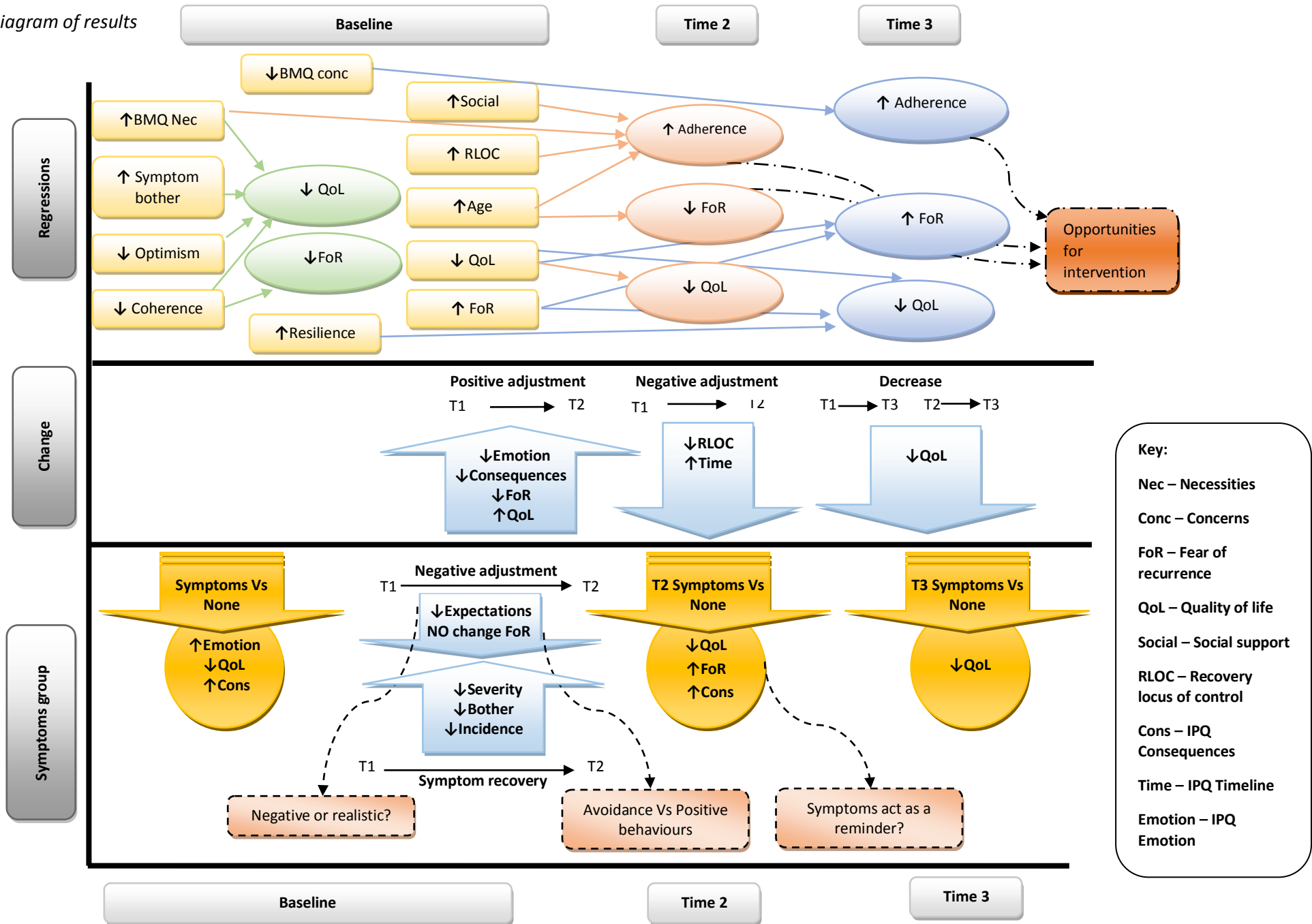
Very broadly speaking, participants in this research fell into two categories. There were those who did not view the TIA or minor stroke as an important event in their lives and those who did. One factor that often led participants to view the event as serious was whether symptoms persisted.

7.1 Symptom Persistence and its Consequences

There were a substantial number of participants at baseline and T2 who had symptoms. At T3 the data is more difficult to interpret; however, it is likely that a number of the symptoms reported were related to the original event. Participants who had symptoms following their TIA or minor stroke had lower physical and emotional quality of life at all time points and the results from the qualitative study showed that, for some, this was distressing and difficult. In addition, by the time of the T2 follow-up, symptoms increased fear of recurrence and tended to lead to an external locus of control. The results from the qualitative study suggest that having symptoms acted as a reminder of the original event, thereby increasing fear of recurrence. Where there was no or little improvement in symptoms this led to the belief that recovery was no longer

Figure 8

Diagram of results



under the control of the individual. In addition, where symptoms persisted, expectations for recovery decreased. It was as though expectations were initially for a swift recovery from a minor or transient event, in line with the medical understanding; but the persistence of symptoms confounded such expectations. Such expectations may have been greater among those who saw themselves as generally more resilient; but so may the sense of being confounded when symptoms persisted.

Furthermore, where recovery of symptoms did not improve significantly, participants' locus of control became more external. This might suggest that they were not engaging as much in lifestyle changes that would help to prevent recurrence. Anecdotally, in this study, at baseline many participants were determined to change their lifestyles, for example, having a healthier diet, taking more exercise and stopping smoking, but by the follow-up, although some had maintained these changes, many had reverted back to their previous habits. In that sense, the greater fear of recurrence associated with the persistence of symptoms may risk becoming self-fulfilling. Individuals may indeed be at greater risk of a further TIA or minor stroke, or for that matter a major stroke, if the persistence of symptoms leads them towards an external locus of control and a lack of commitment to lifestyle changes which mitigate that risk.

As Croot et al. (2014) comment, the principal aim of both primary and secondary care for minor stroke and TIA is on prevention of recurrence particularly through medication, which although vital, is not always enough. The majority of patients in this research saw a specialist once and were then discharged and advised to make an appointment with their GP, sometimes without even being told their diagnosis. This treatment risks giving the impression to patients that having a TIA or minor stroke is not an important event and one that they are expected to recover from quickly. Added to that is the issue that a TIA is rarely a definitive diagnosis, meaning that once discharged patients can be left confused by their diagnosis, and some may not even believe that they have had a TIA at all.

It is thus not hard to see why patients' initial beliefs may be that recovery will be swift and complete: if the situation were more serious, they might reasonably believe they would have received more and longer-term care. Symptoms which persist and which substantially affect people's physical quality of life and mental well-being are basically inconsistent with such beliefs, and can lead to confusion and despair. That was

apparent both from the data, which show a reduced quality of life among those with symptoms, and from the qualitative study, in which several participants were clearly struggling with the persistence of symptoms which they had not expected.

These results taken together suggest that people who have symptoms after a TIA or minor stroke are a different population from those who do not have symptoms. In particular, there may be adverse consequences of persistent symptoms, both in terms of immediate physical and mental well-being, and the longer-term risk of a further TIA or stroke arising from the associated behaviours. If so, that would have obvious clinical implications, although more research is needed to further understand the effects of symptoms on individuals and their longer-term prognoses.

This is not to suggest that those without symptoms should be ignored. There is a possibility that not having symptoms could give people the impression that they do not have to take the TIA or minor stroke or the advice they have been given seriously. These people may not require much in the way of further support; however, it is vital that the importance of adhering to secondary preventative treatments is emphasised.

7.2 Supporting Adherence to Medication and Lifestyle Change

As has been discussed, adherence to secondary preventative medications is vital and the results from this study replicate findings from research in major stroke. However, this is the first study that this author is aware of where these results have been found in TIA and minor stroke. It is perhaps unsurprising that belief in the importance of medications, a lack of concerns surrounding the medications and their side-effects, having a more internal locus of control and having social support all tend to lead to greater adherence to a regime of medication. These are all areas which can and should be addressed by medical professionals during routine consultations; particular attention should perhaps be paid to younger patients, who in this study clearly tended to adhere less well to their medication.

However, many people in this study of all ages were not aware of how important their medications were and/or thought they would be taking them only in the short term. Some were also reluctant to take them, and some chose not to take them at all. Again, this may suggest dissonance as between a belief that a minor stroke or TIA does not have lasting consequences, and the reality that preventative medication is vital to reduce the risk of recurrence. In addition, participants were often reluctant to discuss

these issues with their GP, which may mean that many GPs are not aware of the concerns and misapprehensions that their patients might have. If patients have accurate and understandable information regarding the importance and safety of these medications it may also help to alleviate fears surrounding recurrence.

In relation to adherence to lifestyle advice, there was some evidence, especially from the qualitative study, that suggested that adhering to lifestyle advice gave people confidence and made them feel generally healthier. Conversely, where attempts at adherence failed, this could lead to distress. This was not only a finding in the qualitative study but was also observed in the larger sample. Participants who succeeded in their attempts to change and maintain their habits often commented on how well they felt in themselves and how it had helped them to get over the TIA or minor stroke. This issue goes back to internal locus of control, in that taking control over one's health can lead to better outcomes, less fear of recurrence and increased confidence. This is an area where people could be supported through receiving more individualised information.

7.3 Expectations for recovery

Because this was a central theme of this research it is worthy of some discussion. As was mentioned above expectations for recovery decreased over time in this study. However, there were serious problems with the way that expectations were measured, as was discussed earlier. Separating those with positive expectations from those who expect to stay the same and people who do not know what to expect is important and being able to do this could yield some interesting results.

Anecdotally, there was a feeling at baseline that people's expectations may have been overly positive and that by T2, where these had not been met, there was a sense of hopelessness that the symptoms would improve further. This is corroborated to some extent by the findings that at T2 expectations were lower than at baseline. Again, this may suggest unrealistic initial beliefs about the nature and consequences of a minor stroke or TIA, in particular among those who experienced persistent symptoms. If so, it underlines the need for clarity and transparency in the initial diagnosis, and for continuing support after that.

Perhaps an intriguing area for further research is how far expectations for recovery not being met affects people. This issue has been looked at in surgery and

dissatisfaction with surgical results can lead to non-adherence to medical advice and not seeking medical care when it is needed (e.g. Aharony and Strasser, 1993). There equally is some evidence in this study, albeit tentative, that participants were equally disappointed with the level and pace of their recovery; and that adherence to medication was variable. Adherence is particularly important for those who have suffered a minor stroke or TIA, further research to identify and understand any such tendency would be valuable.

7.4 Limitations and strengths of this research

The major strengths of this research include that the gathering of rich evidence about the actual lived consequences of an under-researched condition using a large sample and a combination of quantitative and qualitative techniques; that it has identified several potentially important factors influencing both immediate quality of life and, potentially, long-term prognosis; and that, if substantiated by further research, some of these findings could have clinical benefits for those suffering a minor stroke or TIA.

On the other hand, many of the findings are tentative and some of the hypotheses were falsified in ways that do not have obvious explanations. In addition, the core concept of expectations and their effects on recovery remains elusive, including to the participants in this study.

7.5 Recommendations for future research and clinical implications

Many of these have been discussed in previous chapters, therefore this will be a summary of the main recommendations.

More research is needed on fear of recurrence in TIA and minor stroke to disentangle the relationship between fears and subsequent behaviours. In addition, even at this early stage in the research, it might prove useful for clinicians to discuss with their patients what their fears are and how they are coping with them.

It seems likely from this research that people who have symptoms following a TIA or minor stroke are a different population from those who do not, especially where those symptoms endure for more than four to six months. This group may benefit from further specialist input, including emotional support and physical rehabilitation. This further input does not necessarily have to be extensive. For example, in NHS Fife all patients who have had a TIA or minor stroke see a stroke co-ordinator (who was a stroke

nurse specialist) within a few weeks of diagnosis to discuss any concerns and ask questions, and in some cases, were referred for further support where necessary. Anecdotally, the participants that were recruited from NHS Fife did seem to have adjusted better to their condition and had fewer questions and concerns during the interviews. Unfortunately there were not enough of them to allow sub group analyses to be conducted.

In relation to expectations for recovery, a reliable measure needs to be designed and tested, a measure that is capable of distinguishing between those who have positive (or negative) expectations, those who expect their symptoms to stay the same and those who do not know what to expect. In addition, research into the effects of overly positive expectations at an early stage after diagnosis might help to explain later attitudes and behaviours.

The importance of adhering to secondary preventative medications needs to be emphasised and concerns surrounding the safety of these medications need to be discussed with patients. These are not novel findings, but a high level of misunderstanding about how important these medications are and the belief that they were causing side-effects was observed in this study. In many cases, these misapprehensions could have been relatively easily dealt with by a variety of clinicians (e.g. both doctor and nurse stroke specialists, GPs and practice nurses).

7.6 Conclusion: neither minor nor transient

The traditional medical view of minor strokes and TIAs sees them as significant but not exceptionally serious conditions. In physiological terms, and relative to the potentially disabling or fatal consequences of a major stroke, that is undoubtedly so.

However, this study has shown that the lived experience of recovery from a minor stroke or TIA is often anything but minor or transient. While some individuals seem able to put the event behind them, and possibly to make a full recovery, for others the effects are persistent and can be both physically and mentally debilitating. This is particularly true for those who continue to experience symptoms of the minor stroke or TIA, and who may find their initial expectations for recovery confounded in a confusing and distressing way. That might lead to something of a sense of despair: a loss of control over one's own health and wellbeing, a greater fear of recurrence, and a failure

to adhere to preventative medication or beneficial changes in lifestyle. In turn, that may enhance the already well-known risk of a minor stroke or TIA leading to another such event or a major stroke, although evaluating that is beyond the scope of this study.

At the same time, this study has also identified factors which may lead individuals to feel this way; and, subject to further research, means by which these risks can be managed and mitigated. Underlying many of them is possibly a need for clarity around the diagnosis and the seriousness of the minor stroke or TIA, transparency about the prognosis and continued support during recovery. While that might well lead to lower initial expectations about the prospects for a swift and full recovery, it might also mean more realisable expectations, and a more positive and sustainable state of health, in the longer term.

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APPENDIX 1: SEARCH TERMS

- 1 nocebo.mp.
- 2 expect\$.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 4 *"Anticipation, Psychological"/
- 5 negative anticipation.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 7 (negative expect\$).mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 8 harmful placebo.mp.
- 9 negative placebo.mp.
- 10 exp Placebo Effect/
- 11 exp Placebos/ae [Adverse Effects]
- 12 expected harm.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 14 Perceived harm.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 15 1 and 4
- 16 negative outcome\$.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 17 (placebo or nocebo).m_titl.
- 18 placebo.mp. or nocebo.ab. [mp=ti, ab, ot, nm, hw, ps, rs, ui, sh, tn, dm, mf, dv, kw]
- 19 17 or 18
- 20 16 and 19
- 21 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 20
- 22 limit 21 to yr="1902 - 2013"
- 23 remove duplicates from 22

Search Strategy used in CINAHL and PsychInfo

- | | |
|------------|--|
| S15 | Remove duplicates |
| S14 | S1 or S2 or S3 or S5 or S6 or S8 or S9 or S10 or S11 or S12 or S13 |
| S13 | TX prior expect* |
| S12 | TX nocebo |
| S11 | TX induc* expecta* |
| S10 | "harm* placebo" |
| S9 | expect* harm |

S8	S4 and S7
S7	TX placebo or nocebo
S6	(MH "Placebo Effect/AE/DE/EI/PF/TU")
S5	negative expect*
S4	"negative outcome*"
S3	"Perceived harm"
S2	"negative placebo"
S1	"negative anticipation"

APPENDIX 2: QUALITY ASSESSMENT OF INCLUDED STUDIES

Study ID	Andrykowski 1985	Benedetti 1997	Benedetti 1993	Bertisch 2009	Boersma 2006	Cassileth 1985	Hartfield 1981	Henn 2007	Kalauokalani 2001	Lang 2005	Linde 2007
Participants											
1. description of inclusion, exclusion and selection of study population is described	2	1	1	1	2	1	1	2	2	1	1
2. Description of the participants in detail (age, gender, social position, diagnosis etc)	1	0	0	2	2	1	1	2	2	2	2
Methods and data collection											
3. Method of data collection is described in detail	2	2	1	2	2	2	1	2	2	2	2
4. Measure of expectations is described in detail and is valid and reliable	1	NA	NA	1	1	1	1	2	1	NA	1
5. Measure of expectations is described as having theoretical basis	0	NA	NA	0	0	0	0	1	0	NA	0
6. Other measures are described and are valid and robust	1	2	2	2	2	0	2	2	1	2	2
7. Intervention (where applicable) is described	NA	2	1	NA	NA	NA	1	NA	NA	2	NA

Study ID	Andrykowski 1985	Benedetti 1997	Benedetti 1993	Bertisch 2009	Boersma 2006	Cassileth 1985	Hartfield 1981	Henn 2007	Kalauokalani 2001	Lang 2005	Linde 2007
Analysis and Results											
8. Power calculation is reported	0	0	0	0	0	0	0	0	2	0	0
9. Analytic methods described/justified and appropriate?	2	2	2	1	1	1	1	2	2	2	2
10. Controlled for confounding?	2	2	2	2	2	0	0	1	2	1	2
11. Results reported in sufficient detail?	2	2	1	2	2	1	1	2	2	2	2
12. Conclusions supported by the results	1	2	1	1	1	1	1	2	2	2	2
Total score	14/22	15/20	11/20*	14/22	15/22	8/22	10/22	18/22	18/22	16/20	16/22
Conclusion quality	M	H	M	M	M	M	M	H	H	H	H

Key: 0=no, 1=partial or unclear; 2=yes

0-7=Low; 8-15 = Medium; 16-22=High (out of possible score of 22): 0-6=Low; 7-14=Medium and 15-20=High (out of a possible score of 20)

Study ID	Mannion 2009	McGregor 2002	Mondiani 2007	Rhodes 1995	Ronnberg 2007	Roscoe 2000	Roscoe 2004	Soroceanu 2012	Terry 2007	Toyone 2005
Participants										
1. description of inclusion, exclusion and selection of study population is described	1	2	2	2	1	1	1	2	1	2
2. Description of the participants in detail (age, gender, social position, diagnosis etc)	2	2	1	2	1	2	1	1	0	1

Study ID	Mannion 2009	McGregor 2002	Mondiani 2007	Rhodes 1995	Ronnberg 2007	Roscoe 2000	Roscoe 2004	Soroceanu 2012	Terry 2007	Toyone 2005
Methods and data collection										
3. Method of data collection is described in detail	2	2	2	2	2	2	2	2	1	2
4. Measure of expectations is described in detail and is valid and reliable	1	1	1	1	1	1	1	2	1	1
5. Measure of expectations is described as having theoretical basis	0	0	0	0	0	0	0	1	0	0
6. Other measures are described and are valid and robust	1	1	2	1	2	2	1	2	1	2
7. Intervention (where applicable) is described	NA	NA	2	NA	NA	NA	NA	NA	NA	NA
Analysis and Results										
8. Power calculation is reported	0	0	0	0	0	0	0	0	0	0
9. Analytic methods described/justified and appropriate?	2	1	0	1	1	2	2	2	1	2
10. Controlled for confounding?	2	0	0	0	0	2	2	2	0	0
11. Results reported in sufficient detail?	2	1	0	1	1	2	2	2	2	1
12. Conclusions supported by the results	2	1	1	2	1	2	1	2	2	1
Total score	15/22	11/22	11/24	12/22	10/22	16/22	13/22	17/22	9/22	12/22
Conclusion quality	M	M	M	M	M	H	M	H	M	M

Key: 0=no, 1=partial or unclear; 2=yes. 0-7=Low; 8-15 = Medium; 16-22=High (out of possible score of 22): 0-6=Low; 7-14=Medium and 15-20=High (out of a possible score of 20)

APPENDIX 3: SUMMARY TABLE – MEASURES OF EXPECTATIONS USED

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
Andrykowski	Breast carcinoma	Anticipatory nausea and vomiting pre-chemotherapy.	Side Effects Expectancy Questionnaire (SSEIQ) <ul style="list-style-type: none"> assesses expectancies for experiencing 16 side effects associated with chemotherapy Measure asks respondents to indicate their expectation of experiencing side effects on a Likert scale of 1-5, with 1 = 'I am certain I will not have this' and 5='I am certain I will have this'.	Measure is for side-effects post-chemotherapy. Authors did not comment on this, or whether they changed the instructions.	No significant results
Bertisch 2009	Persistent distal upper arm pain	Pain following two blinded placebo treatments (pill or sham acupuncture)	Expectations measured with the question: <ul style="list-style-type: none"> "Rate how intense you think the pain will be 2 weeks from now if you are assigned to (acupuncture or medication)?" No rating scale provided. 	Outcomes were measured at 6 and 8 weeks not at 2 weeks.	No significant results found.
Boersma 2006	Non-specific back or neck pain	Future pain	The measure of expectations was one item: <ul style="list-style-type: none"> 'In your view how likely is it that your current pain may become persistent?'. Rated on a 0-10 point scale with 0 being 'no risk' and 10 being 'very large risk'. 	People who think their pain may get worse, intermittent or better would find this question difficult to answer. Also asking some people if expectation is for worse situation and some if it is for same situation.	Found expectation of persistent pain, negative affect and fear avoidance beliefs had a small (14-15%) but unique predictive value for future pain and disability after controlling for age, gender and average pain at initial assessment

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
Cassileth 1985	Various cancers	Post-chemotherapy nausea and vomiting	Used the SEEIQ (described above).	Possibility that by using a list of pre-defined toxicities this creates the suggestion of side effects which may develop into expectations and actual symptoms after completing questionnaire.	There were no significant results, i.e. pre-chemotherapy expectations for side-effects was not related to toxicities experienced. In fact, participants tended to experience more side-effects than they expected
Hartfield 1982	Various gastrointestinal diseases	For sensations experienced during a barium enema	Expected sensation inventory: <ul style="list-style-type: none"> a list of 15 sensations which are rated on a 5 point scale with 1 being 'not at all' and 5 being 'very much so'. 	Authors did not provide any examples of the types of sensations on the list	Focus was on congruency between expected and experienced sensations between two groups who had had different information prior to the enema. No analysis of whether expectations for sensations predicted experiencing them
Henn 2007	Patients in need of rotar cuff repair surgery	For functional outcomes following surgery	Musculoskeletal Outcomes Data Evaluation and Management System (MODEMS) <ul style="list-style-type: none"> 6 items: relief from symptoms; activities of daily living; sleep comfort; return to work; exercise; prevent future disability. Response options range from 1-5, with 1 being 'not at all likely' and 5 being 'extremely likely'. 	This is the only scale to have undergone any reliability or validity testing in this review. Expectations in this study were very	After controlling for a range of potential covariates greater expectations were found to be a significant independent predictor of both better performance at one year and greater

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
				high and almost none of the patients had low or negative expectations for recovery.	improvement on the SST, the DASH, each visual analogue scale, and the SF-36 (p values ranging from <0.001 to 0.042).
Kalauokalani 2001	Back pain	For treatment benefit from acupuncture or massage	<p>Measured by asking:</p> <ul style="list-style-type: none"> how helpful participants believed each treatment would be for their current back problems on a scale with choices ranging from 0 (not at all helpful) to 10 (extremely helpful). They also were asked to describe their expectations for improvement of their back pain without regard to treatment using a 7-point Likert scale with choices ranging from “completely gone,” to “much worse.” 	Although the authors asked about expectations without treatment they have not reported the results.	Using logistic regression and adjusting for potential confounders, the relative odds of improvement for a participant with higher expectations for treatment benefit as compared with a participant who had lower expectations was 5.3 (95% confidence interval [CI] 1.9 – 15.4, <i>P</i> 5 0.002).
Linde 2007	Migraine, tension-type headache, chronic low back pain and osteoarthritis of the knee	For treatment benefit from acupuncture	<p>Measured by asking:</p> <ul style="list-style-type: none"> “how effective do you consider acupuncture in general?” response options: “very effective, effective, slightly effective, not effective, don’t know”, “What do you personally expect from the acupuncture treatment you will receive?” Answer options: “cure, clear improvement, slight improvement, no improvement, don’t know”. After the 3rd treatment session: patients were asked, “How confident do you feel that this 	Patients had very high expectations in this study. In all four groups almost all patients expected a clear improvement from treatment.	Positive attitudes towards acupuncture, high personal expectations and confidence in benefit from treatment were consistently associated with significantly better outcomes both after completion of treatment and at follow-up, both in the univariate and the multivariate analyses

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
			treatment can alleviate your complaint?" Response options: 0 = not certain to 6 = totally certain.		
Mannion 2009	Patients requiring lumbar decompression surgery	For treatment benefit from surgery	Modified version of the expectations scale of the North American Spine Society (NASS) Lumbar Spine Questionnaire: asks <ul style="list-style-type: none"> “what changes in the following items do you expect to experience as a result of the operation? (not your hopes and wishes, but realistic expectations!)” in relation to 8 items functional items: response options were: much better (5), better (4), somewhat better (3), unchanged (2), and worse (1); and “I don’t know.” Also asked what would be the single most important change occurring as a result of the operation that would make them say that the operation helped, or was a success. 		No significant results found.
McGregor 2002	Patients undergoing decompression surgery	For treatment benefit from surgery	Unclear from the authors descriptions was asked, but did ask: <ul style="list-style-type: none"> patients to rate the percentage of improvement they expected after surgery at 6 weeks, 6 months, and 1 year on a 5-point scale, ranging from no improvement to 100% full improvement with respect to function, general health, pain, and life satisfaction. It is also possible that the Oswestry Disability Index, SF-36, VASs for leg and back pain and a 	Unclear description of measures	For all variables considered and at all review stages, expected results were significantly higher than actual results (P< 0.001).

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
			satisfaction scale were completed as measures of expectations as well as being outcome measures.		
Rhodes 1995	Various cancers	Post chemotherapy nausea and vomiting.	Symptom Experience and Expectation Interview Schedule (SEEIS): <ul style="list-style-type: none"> measures patient's past experience with nausea and vomiting and their expectations of side-effects post chemotherapy. It asks respondents to list the symptoms they expect to experience post-chemotherapy and how distressed they think these symptoms will make them. Distress is measured on a 0-6 point scale with 0 being 'none' and 6 being 'severe'. 	This questionnaire avoids the problem of suggestion by asking patients to list their expected side effects	There was a discrepancy between expectations and actual experiences of nausea, with some of those who had not expected any nausea actually experiencing severe nausea.
Ronnberg 2007	one-level disc herniation	For treatment benefit from surgery	Measured with the question: <ul style="list-style-type: none"> before surgery, patients were asked about their expectations for surgical results regarding: leg pain, back pain, sensibility, and muscle function. Rated using a non graded line with the following descriptions: "expect to become worse, remain the same or become better." 	The majority of patients had very high expectations for surgery and almost none had low expectations	The level of expectations on changes of leg pain, sensibility, and muscle function were all associated with improvement in physical functions/ symptoms (i.e. high expectations associated with better results 2 years after surgery).
Roscoe 2000	2 studies; 1 ovarian cancer. 2 various cancers	Post chemotherapy nausea and vomiting.	Measured by asking: <ul style="list-style-type: none"> Patients to respond to items on a 5-point Likert scale, with 1 being 'I am certain I will not have this' and 5 being 'I am certain I will have this'. (The items are not described but are presumably nausea and vomiting), 	Description of the measure lacks detail	Study 1: after controlling for pharmacological physiological variables known to predict nausea, expectations for nausea accounted for a significant and unique

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
					variance in nausea severity ($\Delta = .18, p < 0.04$). Study 2: after controlling for pharmacological physiological variables known to predict nausea, expectations for nausea accounted for a significant and unique variance in nausea severity ($\Delta = .05, p < 0.03$). There were no effects for vomiting in either study.
Roscoe 2004	Breast carcinoma	Nausea and vomiting post-chemotherapy	Pre-consultation expectations question, <ul style="list-style-type: none"> • "“Before you spoke to your doctor about possible side effects of chemotherapy, what did you think the chances were that you would have severe nausea from your treatment?”. • knowledge of side -effects. • information given by doctor and nurse. • items asking about expected nausea and vomiting (Likert scale 1-5 from, 'I am certain I will not have this' to 'I am certain I will have this'). 	Pre-consultation item was measured post-consultation. No information regarding how many items there were measuring expectations of nausea and vomiting	Only nausea expectancies reportedly held by patients before speaking to the physician concerning possible side effects of chemotherapy was a statistically significant predictor of severe nausea ($p = .002$). There were no effects of expectancies on vomiting.
Soroceanu 2012	Patients undergoing lumbar spine surgery	For treatment benefit from surgery	Musculoskeletal Outcomes Data Evaluation and Management System's (MODEMS) expectations survey - described above	Patients had predominantly very high expectations of surgical results	Patients with increased expectations of exercise and sleep following surgery had lower satisfaction with

Study ID	Diagnosis	Expectations	Measure	Notes/comments	Results
					outcomes for exercise ($p = .03$), but a better functional outcome for sleep ($p = .0002$).
Terry 2007	patients scheduled for uncomplicated long or short saphenous day surgery	Post-operative pain	<p>Measured using:</p> <ul style="list-style-type: none"> The short form McGill Pain Questionnaire (SF-MPQ) and visual analogue pain intensity scales (VAS) 	The SF-MPQ is a measure of current pain and the authors do not describe the change in instructions to measure expectations	Positive correlations between expectations of pain intensity (VAS ratings) and anxiety ratings and between actual pain intensity and anxiety ratings suggesting that participants with higher levels of anxiety tended to expect and report experiencing greater levels of pain.
Toyone 2005	Patients undergoing spinal surgery	For treatment benefit from surgery	<p>Measured expected post-operative status using:</p> <ul style="list-style-type: none"> questions regarding relief of leg pain, relief of leg numbness, relief of low back pain, walking ability, activity of daily living. Responses were graded on a 4-point scale ranging from no pain/limitation to very painful/limited. Expectations regarding overall success of the surgery and likelihood of lumbar spine related complications were recorded on a VAS ranging from 0 (complete success/no complication) to 100 (no success/definite complication). 	Analysis of expectations was predominantly descriptive. The focus was on satisfaction.	No significant effects found for expectations

APPENDIX4: APPROVAL LETTERS



Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee

Level 3
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Whitefriars
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BS1 2NT

28 November 2016

L Dickinson
Department of Psychology
Cottrell Building
University of Stirling
FK94LA

Dear Lucy Dickinson

Study title: Expectations and Experiences Following minor stroke or a Transient Ischemic Attack
REC reference: 16/SW/0054
Amendment number: 1
Amendment date: 06 October 2016
IRAS project ID: 143737

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee reviewed the following amendment:

1. One year follow-up.
2. Invitations to potential participants.
3. Addition of two questions to the interview.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letters of invitation to participant [EXAMPLE letter of invitation V1 28 10 16]	1	28 October 2016
Non-validated questionnaire [Pre-morbid depression anxiety]	1	28 October 2016

Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmission (1)]	1	06 October 2016
Participant information sheet (PIS) [Information Sheet Version 4]	4	16 November 2016
Research protocol or project proposal [Protocol Version 3]	3	16 November 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/SW/0054: Please quote this number on all correspondence
--

Yours sincerely

pp. *L Roberts*.

Canon Ian Ainsworth-Smith
Chair

E-mail: nrescommittee.southwest-cornwall-plymouth@nhs.net

Copy to: *Amanda Wood, NHS Fife*
Dr Susan Alexander

South West - Cornwall & Plymouth Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 18 November 2016

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Miss Clare Adams	Consultant Colorectal and General Surgeon	Yes	
Canon Ian Ainsworth-Smith	Retired Hospital Chaplain	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Lucy Roberts	REC Manager

Research & Development

Research & Education Centre, Queen
Margaret Hospital, Whitefield Road,
Dunfermline, KY12 0SU



PRIVATE & CONFIDENTIAL

Date 29 April 2016
Our Ref 16-025

Miss Lucy Dickinson
15 Beechwood Terrace
EDINBURGH
EH6 8DE

Enquiries to Aileen Yell
Telephone 01383 623623 Ext 20940
E-mail aileenyell@nhs.net
Website www.nhsfife.org

Dear Miss Dickinson

LETTER OF ACCESS FOR RESEARCH

Project Title : 'Expectations following a minor stroke or TIA'

This letter confirms your right of access to conduct research through NHS Fife for the purpose and on the terms and conditions set out below. This right of access commences on 29 April 2016 and ends on 30 April 2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project. The information supplied about your role in research at NHS Fife has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to NHS Fife premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee. While undertaking research through NHS Fife, you will remain accountable to your employer University of Stirling, but you are required to follow the reasonable instructions of Dr Amanda Wood, R&D Manager in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings. You must act in accordance with NHS Fife policies and procedures, which are available to you upon request, and the Research Governance Framework. You are required to co-operate with NHS Fife in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Fife premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.



You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. As from 26 July 2010, your HEI employer may initiate your Independent Safeguarding Authority (ISA) registration (where applicable), and thereafter, will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You **MUST** stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you. NHS Fife will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Amanda Wood', written over a horizontal line.

Dr Amanda Wood
R&D MANAGER

cc: Stella Turner, Division Administrator, University of Stirling (s.m.turner@stir.ac.uk)



Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee
 Level 3
 Block B
 Whitefriars
 Lewins Mead
 Bristol
 BS1 2NT

25 February 2016

L Dickinson
 Department of Psychology
 Cottrell Building
 University of Stirling
 FK94LA

Dear Dr Dickinson

Study title: Expectations and Experiences Following minor stroke or a Transient Ischemic Attack
REC reference: 16/SW/0054
IRAS project ID: 143737

Thank you for your letter of 23 February 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Georgina Castledine, nrescommittee.southwest-cornwall-plymouth@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering letter on headed paper [Response to ethics]		23 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence from sponsor]		28 January 2016
Interview schedules or topic guides for participants [Qualitative Interview Schedule]	1	05 January 2016
IRAS Checklist XML [Checklist_23022016]		23 February 2016
Letter from sponsor [Letter from sponsor]		28 January 2016
Non-validated questionnaire [Demographics and Brief Medical History]	1	12 January 2016
Non-validated questionnaire [Expectations Measure]	1	12 January 2016
Non-validated questionnaire [Fear of Recurrence]	1	12 January 2016
Other [Summary CV B Williams]		
Participant consent form [Consent form]	2	23 February 2016
Participant information sheet (PIS) [PIS Qualitative Study]	1	09 February 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	23 February 2016
REC Application Form [REC_Form_10022016]		10 February 2016
Research protocol or project proposal [Protocol]	1	15 December 2015
Summary CV for Chief Investigator (CI) [CV L Dickinson]	1	04 February 2016
Summary CV for supervisor (student research) [Summary CV Ronan O'Carroll]		
Validated questionnaire [Brief Resilience Questionnaire]		
Validated questionnaire [Life Orientation Test]		
Validated questionnaire [Illness Coherence Questionnaire]		
Validated questionnaire [Recovery Locus of Control]		
Validated questionnaire [Beliefs About Medications]		
Validated questionnaire [Social Support]		
Validated questionnaire [Short Form Health Survey]		
Validated questionnaire [Generalised Anxiety Disorder Scale - 7]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of

changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/SW/0054

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp. *I Roberts.*

Canon Ian Ainsworth-Smith
Chair

Email: nrescommittee.southwest-comwall-plymouth@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Dr Susan Alexander*

Amanda Wood, NHS Fife

**NHS Lothian –
University Hospitals Division**



25 October 2016

**Miss Lucy Dickinson
15 Beechwood Terrace
Edinburgh
EH6 8DE**

**Research &
Development**

Room E1.16
The Queen's Medical
Research Institute
47 Little France Crescent
Edinburgh
EH16 4TJ

Tel: 0131 242 3330

Dear Miss Dickinson,

Letter of Clinical Research Access – only valid until 25th October 2017 for study number 2016/0302 entitled 'Expectations and experiences following minor stroke or a transient ischaemic attack '

The Research Governance Framework for Health and Community Care outlines the responsibilities of researchers who undertake research in a clinical setting. The framework has been compiled by the Scottish Executive Health Department to ensure all research meets high scientific and ethical standards.

This Letter of Clinical Research Access defines the requirements of Lothian Health Board (the "Board"), subject to which, you are granted rights of Clinical Research Access to carry out Approved Research in the course of your current PhD programme of study at the University of Stirling.

On signature of this letter, subject to the Board undertaking appropriate Disclosure Scotland checks, you will be granted the right of Clinical Research Access which will continue, until such time as permission is withdrawn by the Board, in the circumstances mentioned in the next paragraph, or such time as you cease to be involved in Approved Research activity or your current study programme mentioned above.

In the event that you are in material breach of the requirements regarding Clinical Research Access as set out in this letter, or the Board considers that it is in the best interests of its patients, then in either circumstance the Board may withdraw Clinical Research Access with immediate effect by giving you written notice of this.

1. Definitions

"Approved Research"

means research which has not only been approved by University of Stirling, but has also received the approval of Lothian Health Board i.e. R & D Management approval, the necessary ethical approval and any further statutory approvals.

"Confidential Information"

includes all information which has been specifically designated as confidential by the Board and any information which relates to the commercial and financial activities of the

Board, the unauthorised disclosure of which would embarrass, harm or prejudice the Board.

“Principal Investigator”

means, in relation to a specific unit of research undertaken in a specific location, the researcher responsible for the overall conduct of that research activity.

2. Confidentiality and Disclosure of Information

You must not divulge Confidential Information to any third party during the period of your research or any time thereafter without the proper authority having first been given.

All Confidential Information belonging to the Board, together with any copies or extracts thereof, made or acquired by you in the course of research shall be the property of the Board and must be returned to the Principal Investigator on completion of the research to which they relate or on the termination of your employment whichever is the earlier date. You will be entitled to retain any copies or extracts made or acquired by you in the course of research for references purposes only, provided that such copies or extracts are held and maintained in accordance with the provisions of the Data Protection Act 1988 and Caldicott principles.

3. Protection of Intellectual Property

The protection of intellectual property is an important matter, and you will abide by the requirements of the Board and the University of Stirling in relation to this matter. The Board and University of Stirling deal with intellectual property matters on a case-by-case basis.

4. Obligations Arising from Data Protection Act 1998/IT Security

Particular regard should be given to your responsibility to abide by the principles of the Data Protection Act 1998, a copy of which is available for reference in the Human Resources Department of the Board.

You must comply with the Board's Information Technology Security Policy on computer security, which is available within the Board R & D Department and on the Board Intranet site. Failure to comply with this will be brought to the attention of the University for investigation/action under the appropriate procedures. In addition failure to comply may lead to temporary or permanent withdrawal of permission to carry out research within the Board.

Patients

In the course of your duties you may have access to Confidential Information regarding patients. You must not divulge such Confidential Information to anyone other than authorised persons, for example, medical, nursing or other professional staff as appropriate, who are concerned directly with the care, diagnosis and/or treatment of the patient. Where, in the course of your clinical research activity, new information comes to light that will or may impact on patient care, you will forthwith advise the relevant personnel within the Board.

Staff

You must not divulge Confidential Information concerning individual members of staff to anyone without the authority of the individual concerned and the appropriate Principal Investigator.

If you are in any doubt whatsoever as to the authority of a person or body asking for information on patients or staff, or your own authority to divulge information, you must seek advice from the Principal Investigator and/or the responsible person at your University.

These provisions are without prejudice to the NHS's stated commitments in the NHS Code of Openness. Further information is available from the Board's Human Resources Department.

5. Disclosure of Concerns

If you have any concerns about quality of service, health and safety, use of NHS money, or believe a colleague's conduct, performance or health may be a threat to patient care or to members of staff, you have a responsibility to raise these concerns without prejudice, directly with the Principal Investigator, your line manager or the responsible person at the University. If you are unable to, or wish not to raise these concerns directly with your line manager / Principal Investigator, you are encouraged to seek the advice of the Human Resources Department or University of Stirling as appropriate.

You are protected against any harassment or victimisation resulting from such a disclosure. Therefore in the event that you are subjected to any form of harassment or victimisation, formal action will be taken against the perpetrators.

Concerns related to any research misconduct or fraud should be addressed similarly.

6. Conflict of Interest

As a general principle, you should not put yourself in a position where your official and private interests conflict, nor must you make use of your official/research position to further your private interests.

7. Research Governance

You are required to observe those requirements of the Research Governance Framework which are applicable and binding on you. The Research Governance Framework is available in the R & D Department and on the Intranet under Organisational/R&D. The framework relates to the management and monitoring, ethics, science, finance, health and safety aspects of research.

8. Health and Safety

The Board has a written Health and Safety Policy. The Board has a duty to ensure, so far as is reasonably practicable, the health, safety and welfare at work of all its employees/individuals who work on the site. As an individual who works on the site, you have a duty to observe safe systems of work at all times, to take reasonable care of yourself and others who may be affected by your activities at work and to co-operate with the Board and others in meeting statutory requirements. Additionally, you are required to report all accidents "near misses"/ incidents to the responsible person at the University and to use any safety equipment provided for your protection.

Failure to comply with the provisions detailed above, without reasonable cause, will be brought to the attention of your employer for investigation/action under the appropriate procedures. In addition

failure to comply may lead to temporary or permanent withdrawal of permission to carry out research within the Board.

9. Hepatitis B

For your own protection, you are advised to maintain Hepatitis B immunity status throughout the period during which you have been granted Clinical Research Access rights if your work brings you into contact with blood, other body fluids or fresh tissue.

10. Professional Registration

If your programme of study requires professional registration you must be fully registered with the appropriate professional body and maintain this registration throughout the period during which you have been granted Clinical Research Access rights. Evidence of this must be produced upon request.

11. Personal Property

The Board accepts no responsibility for damage to, or loss of, personal property. You are, therefore, advised to take out an insurance policy to cover your personal property.

If you need any further advice or guidance on any of the paragraphs set out above you should contact the responsible person at the University in the first instance.

If you agree to accept the conditions indicated above, please print this letter and sign the statement of acceptance and return to the Board's R & D Department. Please retain a second signed copy of this letter for future reference as you will be required to provide this for evidence of clinical research access to each Principal Investigator with whom you work.

Yours sincerely



Dr Douglas Young
Principal R&D Manager

cc: Stella Turner, University of Stirling


(DO NOT DETACH)

Form of Acceptance

I hereby accept the conditions set out in the foregoing letter.

Print Name: (Block Capitals)

LUCY DICKINSON

-  _____
Signature

Date 28/10/2016 _____

Employer/Organisation:

Psychology Department _____
Cottrell Building _____
University of Stirling _____
FK9 4LA _____

APPENDIX 5: INFORMATION SHEET

Expectations following a TIA or Minor stroke Patient information leaflet Version 4 16/11/2016



UNIVERSITY OF
STIRLING



Information Sheet

You are being invited to take part in a research study. Before you decide whether you would like to participate or not, it is important that you understand why the research is being done and what it will involve for you.

Please read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take as much time as you need before deciding whether to take part or not.

What is the purpose of the study?

This study is being undertaken as part of a PhD. Past research has shown that the way people think about their health can affect the way they feel and sometimes how quickly they start to feel better after they have been unwell.

We are interested in what people feel and think about after they have had a transient ischemic attack or minor stroke and if this then affects how they feel 4 months and one year later.

Why have I been chosen?

You are being invited to take part in this research because you were identified in clinic as someone who has recently had a minor stroke or transient ischemic attack.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form.

If you decide to take part you are free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the care you receive at any time.

What will happen to me if I take part?

If you agree to take part, the researcher (Lucy Dickinson) will arrange to come out and visit you at home. The visit will last approximately 45 minutes and will involve answering questions about how you are feeling, both physically and mentally. Another appointment will be arranged at your convenience, approximately four months later, this interview will be similar to the first one and will again involve answering questions about how you are feeling. After one year the same questionnaires will be sent to you in the post with an SAE to send them back. If we do not receive these within one month we will send a reminder to you - if you have chosen not to return them, please ignore both the original letter and reminder. If you need any further advice or support after taking part in this study the phone number for the Chest, Heart and Stroke Scotland nurse advice line is provided at the end of this booklet.

What do I have to do?

You do not need to do anything just now. If you have agreed that the researcher can contact you, they will be in touch within the next few days. If you would like to speak to someone about the study before then, please feel free to phone the number given at the end of this booklet.

Will my taking part in this study be kept confidential?

All information collected about you will be kept strictly confidential. Any records will be kept in a locked cupboard, and only those involved in the research will be permitted access. When the results are published, this will be done in such a way that you will not be identifiable.

Who is organising and funding the research?

The Psychology department and the department of Nursing, Midwifery and Allied Health Professionals Research Unit in the University of Stirling

Who has reviewed the study?

The study has been internally reviewed by the psychology department in the University of Stirling and externally by the Cornwall-Plymouth NRES Committee (Ref:16/SW/0054)

Contact for further information about the study

Lucy Dickinson
PhD Student
Department of Psychology
Cottrell Building
University of Stirling
FK9 4LA
Email: Lucy.Dickinson@stir.ac.uk
Phone:

Contact for further information about your condition

Chest, Heart and Stroke Scotland Advice Line: 0808 8010899 (free from landlines)

If you require further information or support, the hospital will have given you the number for a Stroke nurse which you can call.

Thank you for taking the time to read this, and for considering taking part in the study. It is greatly appreciated.

APPENDIX 6: CONSENT FORM

Consent Form



**UNIVERSITY OF
STIRLING**

SCHOOL OF
NATURAL SCIENCES

Expectations Following a TIA or Minor Stroke

Name of researcher:

Please Initial Box

1. I confirm that I have read and understood the information sheet (version 1 dated 15.01.2016) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.
3. I agree to take part in the above study.
4. I understand that the information collected about me will be kept in a secure environment and will be anonymised
5. I understand that I do not have to answer any questions I do not want to
6. I agree to the use of anonymised quotes in publications
7. If invited, I consent to take part in the qualitative interviews
8. I agree to being audio recorded if I take part in the qualitative interviews

Name of Participant Signature	Date	
----------------------------------	------	--

Name of Researcher Signature	Date	
---------------------------------	------	--

APPENDIX 7: MEASURES

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	In uncertain times, I usually expect the best.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	If something can go wrong for me, it will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	I'm always optimistic about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	I hardly ever expect things to go my way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	I rarely count on good things happening to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Overall, I expect more good things to happen to me than bad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	I tend to bounce back quickly after hard times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	I have a hard time making it through stressful events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	It does not take me long to recover from a stressful event.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	It is hard for me to snap back when something bad happens.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	I usually come through difficult times with little trouble.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	I tend to take a long time to get over setbacks in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	My illness will last a short time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	My illness is likely to be permanent rather than temporary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	My illness will last for a long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	My illness will pass quickly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	I expect to have this illness for the rest of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IPQ - Consequences

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
6.	My illness is a serious condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	My illness has major consequences on my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	My illness does not have much effect on my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	My illness strongly affects the way others see me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	My illness has serious financial consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	My illness causes difficulties for those who are close to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
12.	The symptoms of my condition are puzzling to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	My illness is a mystery to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	I don't understand my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	My illness doesn't make sense to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	I have a clear picture or understanding of my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IPQ - Emotional Response

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
17.	I get depressed when I think about my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	When I think about my illness I get upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	My illness makes me feel angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	My illness does not worry me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Having this illness makes me feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	My illness makes me feel afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	How I manage in the future depends on me and not what other people can do for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	It's what I do to help myself that is really going to make all the difference	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	It's up to me to make sure I can make the best recovery possible under the circumstances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Getting better now is a matter of my own determination rather than anything else	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	It doesn't matter how much help you get - in the end it's your own efforts that count	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
6.	It's often best to just wait and see what happens	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	My own efforts are not very important, my recovery really depends on others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	My own contribution to my recovery doesn't amount to much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	I have little or no control over my progress from now on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Worrying too much about different things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Trouble relaxing				
5. Being so restless that it's hard to sit still				
6. Becoming easily annoyed or irritable				
7. Feeling afraid as if something awful might happen				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all

**Somewhat
difficult**

Very difficult

**Extremely
difficult**

MARS - Your stroke medications and how you use them

Many people find a way of using their medicines which suits them: this may differ from the instructions on the label or from what their doctor has said.

Here are some ways in which people have said that they use their medicines. For each of the statements below please tick the box which best applies to you.

Please answer this questionnaire thinking about your **stroke medications specifically** (e.g. blood thinners, like Clopidogrel or aspirin, medication for high blood pressure, Statins for high cholesterol etc).

Your own way of using your stroke medicines	Always	Often	Sometimes	Rarely	Never
I forget to take them					
I alter the dose					
I stop taking them for a while					
I decide to miss out a dose					
I take less than instructed					

Social support

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
1. Is there someone available to you whom you can count on to listen to you when you need to talk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Is there someone available to give you good advice about a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Is there someone available to who shows you love and affection?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Is there someone available to help you with daily chores?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Are you currently married or living with a partner?		YES	<input type="checkbox"/>		NO	<input type="checkbox"/>

Beliefs about Medications Questionnaire

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	My health depends on my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Having to take medications worries me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	My life would be impossible without my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Without my medications I would be very ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	I sometimes worry about the long-term effects of my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	My medications are a mystery to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	My health in the future will depend on my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	My medications disrupt my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	I sometimes worry about becoming too dependent on my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	My medications protect me from becoming worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Yes, limited a lot	Yes, limited a little	No, not limited at all
▼	▼	▼

- a Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports ₁ ₂ ₃
- b Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ₁ ₂ ₃
- c Lifting or carrying groceries ₁ ₂ ₃
- d Climbing several flights of stairs ₁ ₂ ₃
- e Climbing one flight of stairs ₁ ₂ ₃
- f Bending, kneeling, or stooping ₁ ₂ ₃
- g Walking more than a mile ₁ ₂ ₃
- h Walking several hundred yards ₁ ₂ ₃
- i Walking one hundred yards ₁ ₂ ₃
- j Bathing or dressing yourself ₁ ₂ ₃

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b <u>Accomplished less</u> than you would like.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort).....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b <u>Accomplished less</u> than you would like.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c Did work or other activities <u>less carefully than usual</u>	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
	▼	▼	▼	▼	▼	
a	Did you feel full of life?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b	Have you been very nervous?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c	Have you felt so down in the dumps that nothing could cheer you up?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d	Have you felt calm and peaceful?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
e	Did you have a lot of energy?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
f	Have you felt downhearted and low?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
g	Did you feel worn out?.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
h	Have you been happy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
i	Did you feel tired?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
	▼	▼	▼	▼	▼
a I seem to get ill more easily than other people	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b I am as healthy as anybody I know	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c I expect my health to get worse	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d My health is excellent	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Thank you for completing these questions!

Demographics and Brief Medical History

1. Gender **Male / Female**

2. Date of Birth -- / -- / ----

3. Ethnicity

4. were you told at the hospital
what you had? (eg TIA/minor stroke).
If yes, what?

5. Date of TIA / Minor stroke

6. Other medical conditions

7. Medications since TIA

1. Symptoms since TIA

Some people experience symptoms after having a TIA or minor stroke. Have you experienced anything? If yes, what?

List symptoms:

Prompts, if necessary - have you felt more tired? Had any pain? Etc

2. Symptom severity

If you had to rate how bad [*name symptom*] is at the moment on a scale of 1-10, with 1 being not bad at all and 10 being as bad as it could be, what would best describe how bad [*symptom*] is?

Repeat for each symptom.

3. Expectations for symptoms at four months

If the participant has identified more than 3 symptoms, choose the 3 most severe symptoms from above for the following questions:

Response scale for below = Strongly agree (5) - strongly disagree (1)

1. I expect [*symptom*] to get worse

1

2

3

4

5

2. [symptom] will get better

1 2 3 4 5

3. I expect [symptom] to stay the same

1 2 3 4 5

Repeat for worst 3 symptoms

If no symptoms -

Do you think there is any possibility of you developing any symptoms in the next four months? **Yes / No** If yes, what? **List:**

4. Interference with everyday life

1. [symptom] is bothersome to me

1 2 3 4 5

2. I have had difficulty doing the things I want to do because of [symptom]

1 2 3 4 5

3. I am not bothered by [symptom]

1 2 3 4 5

Repeat for worst 3 symptoms

5. Fear of recurrence

1. I worry about having another TIA / minor stroke

1 2 3 4 5

2. I worry about having a major stroke

1 2 3 4 5

APPENDIX 8: T3 MEASURES

Participant ID Number:

Research study: 'Expectations and Experiences following a TIA or Minor Stroke'

Please try to answer **all** the questions below. If there are questions that you do not want to answer or feel like you can't answer, please leave these blank and return the questionnaires.

Date questionnaires completed: _____ / _____ / _____

1. Have you had any TIAs or strokes since I last saw you (around 18 months ago)?

Yes No

1a. Please let us know what you had by ticking one of the boxes below:

TIA Minor stroke Major stroke Not sure

Approximate Date of the TIA or stroke: _____ / _____ / _____

If you have had more than one more TIA or minor stroke, please let us know what you had and approximately when below:

2. How much do you worry about having another TIA or stroke?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I worry about having another TIA or stroke? Please tick one response					

3. Symptoms - On the two next pages you will find a list of symptoms:

Please let us know if you **currently** have any symptoms that you believe are related to the TIA / minor stroke that you had.

If you tick 'yes' to any symptom please rate how bad it is by circling a number between 1 and 10 on the severity scale, where 1 is no symptoms and 10 is the symptom being as bad as you can imagine and rate how bothersome (i.e. how much does it affect your life or interfere with the things you want to do?) the symptom is to you.

If you have no symptoms, please tick the box below and go to **Question 4 on page 4**.

I have no symptoms relating to the TIA or minor stroke I had

3a. Symptoms: let us know if you are currently experiencing any of the following symptoms	Yes	No	If you ticked 'no' please leave this section blank 3b. Rate the severity the symptom by circling one number below								
1. Fatigue (feeling very tired or lacking energy)	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		
			3c. The fatigue bothers me (please tick one box below)								
			Strongly Disagree	Disagree	Neutral	Agree	Strongly agree				
2. Weakness in arms, legs, hands or fingers	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		
			The weakness bothers me								
			Strongly Disagree	Disagree	Neutral	Agree	Strongly agree				
3. Numbness, tingling or pins and needles	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		
			The numbness, tingling etc bothers me								
			Strongly Disagree	Disagree	Neutral	Agree	Strongly agree				
4. Mouth drooping at one side	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		
			My mouth drooping bothers me								
			Strongly Disagree	Disagree	Neutral	Agree	Strongly agree				
5. Problems with your speech (e.g. slurring your words)	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		
			The problems with my speech bother me								
			Strongly Disagree	Disagree	Neutral	Agree	Strongly agree				
6. Problems with thinking, including, finding the right words, forgetfulness or trouble with planning / thinking things through	<input type="checkbox"/>	<input type="checkbox"/>	Mild 1 2 3			Moderate 4 5 6			Severe 7 8 9		

	The problems with my thinking bother me				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree

4. Anxiety - the next questions are all asking about how anxious you have been over the past **2 weeks**. Please tick the boxes that describe you best.

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	Over half the days	Nearly every day
8. Feeling nervous, anxious, or on edge				
9. Not being able to stop or control worrying				
10. Worrying too much about different things				
11. Trouble relaxing				
12. Being so restless that it's hard to sit still				
13. Becoming easily annoyed or irritable				
14. Feeling afraid as if something awful might happen				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all

Somewhat difficult

Very difficult

Extremely difficult

5. Your stroke medications and how you use them

Many people find a way of using their medicines which suits them: this may differ from the instructions on the label or from what their doctor has said.

Here are some ways in which people have said that they use their medicines. For each of the statements below please tick the box which best applies to you.

Please answer this questionnaire thinking about your **stroke medications specifically** (e.g.

blood thinners, like Clopidogrel or aspirin, medication for high blood pressure, Statins for high cholesterol etc).

Your own way of using your stroke medicines	Always	Often	Sometimes	Rarely	Never
I forget to take them					
I alter the dose					
I stop taking them for a while					
I decide to miss out a dose					
I take less than instructed					

APPENDIX 9: CORRELATION MATRIX

Table 31*Correlation Matrix*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Gender	1																			
SIMD	.08	1																		
Age	.11	-.06	1																	
Sym Sev	.08	-.003	-.006	1																
Sym. Bot	.2*	-.04	-.024	.66**	1															
Event	.04	-.02	-.07	.07	.09	1														
FoR	.13	.06	-.09	.1	.05	-.04	1													
IPQ Time	.11	.04	-.13	.12	.15	.02	-.02	1												
IPQ cons.	-.02	.14	-.37**	.32**	.31**	.06	.22**	.31**	1											
IPQ Emo	.23*	.08	-.29**	.27**	.23**	.02	.35**	.3**	.56**	1										
IPQ Coh.	-.04	.11	-.012	-.14	-.18*	.01	.08	-.15	-.18*	-.17*	1									
LOT	-.09	-.09	.08	-.13	-.1	.13	-.19*	-.15	-.22**	-.43**	.19*	1								
BRS	-.13	-.06	.04	-.2*	-.06	.12	-.3**	-.12	-.26**	-.5**	.18*	.59**	1							
GAD	.12	.06	-.22**	.2*	-.19*	-.13	.27**	.26**	.41**	.76**	.19*	-.41**	-.55**	1						
Social	.14	.03	-.07	-.16	-.12	-.08	-.02	-.08	.02	-.14	.2*	.27**	.12	-.19*	1					
RLOC	.05	-.04	-.07	.09	.16*	.06	-.06	-.03	.15	.01	.02	.28**	.19*	-.04	.3**	1				
QoL Phys	-.29**	-.05	-.06	.37**	-.5**	.01	-.05	-.24**	-.24**	-.23**	.26**	.4**	.23**	-.3**	.31**	.09	1			
QoL Emo	-.25**	-.04	.09	.34**	-.4**	.05	-.06	-.32**	-.39**	-.49**	.31**	-.45**	.33**	-.48**	.33**	.08	.28**	1		
BMQ Nec	.24**	-.09	.1	.16*	.17*	.1	.01	.27**	.08	.21*	-.03	-.2*	-.18*	.27**	-.18*	-.06	.45**	-.4**	1	
BMQ Con	.12	-.06	-.06	.17*	.19*	-.04	.18*	.21**	.22**	.27**	-.13	-.28**	-.27**	.22**	-.27**	-.15	-.23**	.31**	-.01	1

APPENDIX 10: QUALITATIVE INFORMATION SHEET

Information sheet - Qualitative Study Version 1. 09/02/2016



UNIVERSITY OF
STIRLING

Information Sheet - Qualitative Interviews

You are being invited to take part in two qualitative interviews. Before you decide whether you would like to participate or not, it is important that you understand why the research is being done and what it will involve for you.

Please read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take as much time as you need before deciding whether to take part or not.

What is the purpose of the Interviews?

The purpose of these interviews is to investigate the experience of having a TIA or minor stroke in depth from your point of view. Little is known about how TIAs and minor stroke affect the individual and how they feel about the future, these interviews aim to discover more about this.

Why have I been chosen?

You are being invited to take part in this research because you were identified in clinic as someone who has recently had a minor stroke or transient ischemic attack.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the care you receive at any time.

What will happen to me if I take part?

If you agree to take part, the researcher (Lucy Dickinson) will arrange to come out and visit you at home. The visit will last approximately 30 minutes and will involve answering questions about how you are feeling. Another visit will be arranged at your convenience, approximately four months later, this visit will be similar to the first one and will again involve answering questions about how you are feeling.

Both interviews will be audio recorded and the interviews will be transcribed and analysed for major themes. However, all quotes used in publications will be anonymised.

Will my taking part in this study be kept confidential?

All information collected about you will be kept strictly confidential. Any records will be kept in a locked cupboard, and only those involved in the research will be permitted access. When the results are published, this will be done in such a way that you will not be identifiable.

Who is organising and funding the research?

The Psychology department and the department of Nursing, Midwifery and Allied Health Professionals Research Unit in the University of Stirling

Who has reviewed the study?

The study has been internally reviewed by the psychology department in the University of Stirling and externally by the Cornwall and Plymouth NRES (REC ref. no. 16/SW/0054).

Contact for Further Information

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