THE PSYCHOLOGICAL SEQUELAE OF TRANSIENT ISCHAEMIC ATTACK: THE DEVELOPMENT OF A PRELIMINARY SCREENING TOOL

by

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ABSTRACT

While much research has been conducted into the psychosocial impact of stroke, rather less attention has been directed to Transient Ischaemic Attack (TIA). Two points are of particular relevance to this thesis: firstly, both TIA and subjective distress are established precursors of secondary stroke; and secondly, treatment that incorporates the patient's perspective is demonstrably more effective. Together, this suggests that early identification of patients' psychological reactions to TIA could inform tailored intervention post-diagnosis, thus potentially reducing the adverse consequences of TIA. This study aimed to develop a psychometrically-robust preliminary screening tool to facilitate early recognition of dysfunctional psychological reactions to TIA. Consistent with orthodox psychometric theory, and to inform test construction, various data-types and methodologies were used to capture patients' subjective experiences. Using three different epistemological approaches (combined qualitative/quantitative Q-methodology, qualitative repertory grid analysis, and quantitative factor analysis) remarkable thematic consistency in patient experiences emerged. These formed the basis of the preliminary screening instrument, which incorporates 21 questions in a forced-choice, paired-comparison format, permitting weighted responses that indicate the significance of each theme to the patient. Early small-scale use indicates its usability and reliability; further work is required to establish its psychometric and clinical value for a larger clinical sample.

DEDICATION

For my Grandfather, who coped with the sequelae of his own TIA with characteristic good humour and dignity.

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Spurgeon, L, Humphreys, G, James, G & Sackley, C (2012).

A Q-methodology study of patients' subjective experiences of TIA.

Stroke Research and Treatment (12) Article ID: 4886261 [online]. Available at

http://www.hindawi.com/journals/srt/2012/486261/abs/

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Spurgeon, L, James, G, & Sackley, C (2013)

Subjective experiences of Transient Ischaemic Attack: a repertory grid

approach. *Disability and Rehabilitation* (in press and available early online at

http://informahealthcare.com/doi/abs/10.3109/09638288.2013.774062).

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Chapter 1

BACKGROUND TO THE STUDY

1: Preamble

The aim of this thesis is the development of a psychometrically robust screening tool to assess the psychological consequences of Transient Ischaemic Attack (TIA). Often referred to as a mini-stroke, there has been an assumption that TIA is an inconsequential episode that requires little intervention (Daffertshofer et al., 2004). However, the mounting body of evidence that has demonstrated its link with secondary stroke means that TIA is now being treated more proactively (Fisher, 2008). Because of the predictive relationship between TIA and full stroke and the clinical similarities between them, the introductory chapter will review the literature on both stroke and on TIA. Word limits preclude a comprehensive review of the very extensive literature surrounding stroke and TIA; therefore, a selective account will be presented here, with the emphasis being on the consequences and implications of stroke and TIA, rather than the causes and aetiology, to reflect the focus of the thesis.

1.2: Stroke

Defined by the World Health Organisation (2013, p1) as 'the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include: confusion, difficulty speaking or understanding speech; difficulty seeing with one or both eyes; difficulty walking, dizziness, loss of balance or coordination; severe headache with no known

cause; fainting or unconsciousness.' The effects of a stroke depend on which part of the brain is injured and how severely it is affected. A very severe stroke can cause sudden death. While stroke incidence has fallen, prevalence has risen to 7.20/1000, though better management has resulted in a reduction in mortality (Lee et al., 2011). While haemorrhagic stroke accounts for 20% of strokes, the more common cause is ischaemic stroke, where blocked blood-flow to the brain results in cell-death and long-term damage to the affected area (Donnan et al., 2008). Blockages can be caused by atherosclerosis or more typically, an embolism originating elsewhere in the body which travels to the brain (Donnan et al., 2008). Symptoms include weakness or paralysis, visual disturbances, numbness, speech disorders and slurring (dysarthria), confusion and severe headache (NICE Guidelines, 2008). Because of the gravity and extent of the problem, considerable resources have been invested in the identification and management of risk factors, with a view to stroke-prevention (Lee et al., 2011). In particular, attention has been paid to vascular risk factors such as hypertension, atrial fibrillation, diabetes, cholesterol and obesity, with some significant success (Lee et al., 2011); lifestyle risk factors such as smoking, alcohol consumption and exercise levels may be modifiable, but known uncontrollable risk factors such as age, gender, race, family history and pre-morbid health status inevitably elude management (Donnan et al., 2008).

It is estimated that in the UK there are currently around 900,000 people living with the results of stroke, of whom half are dependent on others for help with activities of daily living (National Audit Office, 2005). The human cost of stroke is obvious, but the fiscal consequences are also considerable. Mant et al. (2004) estimate the annual cost of stroke to be £7 billion per annum, of which £2.8 billion are direct NHS costs, £2.4 billion are informal care costs and £1.8 billion are due to lost productivity. Unsurprisingly, prevention and effective management of stroke are key health priorities.

1.2.1: Physical Impact of Stroke

The impact of stroke largely depends on the area of the brain affected. For example, cerebellar damage may lead to ataxia, affecting the body's ability to co-ordinate movement, posture and balance (NINDS, 2011) while neural system damage may result in chronic pain and sensory deficits, such as paresthesias. However, the most common disability associated with stroke is paralysis, with over 50% of stroke patients suffering the condition to some degree (Jacobson, 2011). Typically, it impacts on the side of the body contralateral to the brain area affected by stroke. Patients who suffer from paralysis, which may be either hemiplegia (complete inability to move one side of the body) or hemiparesis (limited ability for movement), are likely to be impaired in everyday activities and may struggle with walking and basic tasks, such as reaching and grasping for an object. Moreover, stroke is associated with a number of serious longer-term co-morbidities (Sackley et al., 2008). Sensory deficits occur in around 50-80% of stroke patients (Carey et al., 2011), but while they impact negatively on the patient's quality of life, they are often neglected by clinicians (Winward et al., 1999).

Fatigue is also a common and serious post-stroke complication, and can have deleterious effects on rehabilitation, with motivation, compliance and ability all negatively affected (Snaphaan et al., 2011). Around 40% of stroke survivors are believed to suffer fatigue, with the frequency of post-stroke fatigue at its highest during the first year after the onset of stroke (Naess et al., 2012). Tang et al. (2010) found that fatigue negatively impacts on stroke patients' short-term Health Related Quality of Life (HRQoL) scores, influencing post-stroke recovery and life satisfaction. Flinn and Stube (2009) found that patients felt unprepared for the fatigue and the extent of its impact, which had a detrimental effect on daily and occupational functioning, social participation, return to work, driving and sleeping. Furthermore, post-stroke fatigue has been linked with increased mortality (Naess et al., 2012; Glader et al., 2002).

1.2.2: Cognitive Impact of Stroke

Stroke is associated with a number cognitive impairments and deficits, including problems with attention; executive function, including the planning, organising and execution of actions (Engstad et al., 2007); language; memory; concentration; visual agnosia and spatial neglect (Hoffmann et al., 2010a and b). These problems may be long-lasting. For example, Hofgren et al. (2006) found that one year after discharge, 83% still experienced cognitive dysfunction and 20% were dependent on others for their everyday activities; after three years, only 20% had found gainful employment. Similarly, Bour et al. (2011) found that 2 years post-stroke, 53.3% of patients continued to experience executive dysfunctions. Although there is limited evidence for the effectiveness of rehabilitation for cognitive dysfunction (Langhorne et al., 2011; Hoffmann et al., 2010a), Bour et al. (2011) suggest that these patients still need to be identified at an early stage as they are at a greater risk of chronic depression, cognitive deterioration and an overall negative stroke outcome. The persistence of cognitive disorders and their resistance to rehabilitation may explain why they are considered to be the primary cause of post-stroke morbidity (Gottesman & Hillis, 2010). Furthermore, there is tentative evidence that stroke can lead to changes in brain volume and predispose to dementia (Cumming & Brodtmann, 2011).

1.2.3: Psychological Impact of Stroke

The emotional and psychological consequences of stroke have received rather less research attention, although they may have a significant and negative effect on the patient's quality of life. A range of post-stroke problems have been documented and include apathy, extreme stress, clinical depression, emotional lability, and personality changes including aggression, irritability and withdrawal (Godefroy & Bogousslavsky, 2007).

The association between stroke and depression is well-documented, with the Stroke Association (2011) estimating that around half of stroke sufferers experience significant depression in the first year post-stroke. Robinson and Spalletta, (2010), in a review of the relevant literature, concluded that prevalence of major depression post-stroke was 21.7% and minor depression 19.5%, while Hadidi et al. (2009) reported that prevalence ranged from 25%-79% depending on the definition and assessment measures used, and the time post-stroke. Post-stroke depression can be caused by a number of factors, such as dealing with physical disability caused by the stroke; fear and anxiety of another stroke, especially as they typically occur without warning; frustration and anger over the impact of the stroke and the implications on everyday life; or underlying physical causes, such as chronic pain (Robinson & Spalletta, 2010). Moreover, it is persistent. Bour et al. (2010) found the prevalence of post-stroke depression after one month was 18.8%, and in 44% of patients, the depressive symptoms reoccurred at a later point, typically in older patients and those with more severe disabilities. Further, there is a link between unmanaged post-stroke depression and increased mortality risk (Bueno et al., 2011; Pan et al., 2011; Ellis et al., 2010).

However, despite the mounting body of evidence about post-stroke depression, Kouwenhoven at al. (2011) note that there is still limited awareness of the problem, and that a 'gold standard' for identifying and measuring depressive symptoms is absent. Cinamon et al. (2010) note that screening tools for depression are not stroke-specific, and often fail to measure the extent of the depression. While depression is amenable to treatment, leading to improved outcomes, its detection and diagnosis of depression following stroke is sufficiently inconsistent that many patients do not receive the necessary treatment (de Man-van Ginkel et al., 2010).

Anxiety has long been recognised as a corollary of stroke (Kneebone et al., 2012; Campbell Burton et al., 2011; Donnellan et al., 2010). For example, Burvill et al. (1995) found prevalence levels for anxiety of 9% and 20% for men and women respectively; the anxiety predominantly took the form of agoraphobia, though there were cases of generalised anxiety disorder. Åström (1996) confirmed comparable prevalence of generalised anxiety in a cohort of 80 stroke patients, which persisted for 12-months post-stroke. Langhorne et al. (2000), in a study of hospitalised stroke patients, found anxiety was a complication in 14%, and was still present at the 30-month follow-up. The enduring nature of anxiety has also been reported by Morrison et al. (2005), who noted that unlike depression which tended to improve over the longer-term, anxiety levels were stable 3 years later. Bergersen et al. (2010), in a study of 255 stroke patients 2-5 years after discharge, reported that 36% suffered from anxiety and 28% from depression. Barker-Collo (2007) reported a link between cognitive performance and affective state (in particular, anxiety), that appeared unrelated to physical recovery. The prevalence and persistence of clinical levels of anxiety following stroke are of great significance, especially since they have been linked to an increased likelihood of further stroke (Fiedorowicz et al., 2011; Katan et al., 2011). Such findings add further weight to the need to manage affective disorders as part of post-stroke rehabilitation programmes.

From the foregoing evidence, it is clear that there is an inter-relationship between the psychological and physical sequelae of stroke and their cumulative impact on post-stroke morbidity and mortality. Consequently, treatment and rehabilitation programmes need not only to be aware of this, but also should proactively address the psychological outcomes of stroke.

1.2.4: Impact of stroke on the family unit

The burden of stroke on the care giver and close relatives has been widely acknowledged and can be substantial (Forsberg-Wärleby, 2001). Compared to norm-values, spouses of first-time stroke patients showed significantly lower psychological well-being, with the most severe impact being on the spouse's perception of his or her future life (Forsberg-Wärleby, 2001). Carod-Artal and Egido (2009) found that stroke caregivers have lower Health-Related Quality of Life (HRQoL) scores, greater economic burden, increased stress and depression, and changes in social relationships. Risk factors for adverse outcomes were also identified, with increasing age and anxiety in both patients and caregivers, high dependency and a poor family support network being the three factors most strongly associated with low HRQoL scores. While recommendations for individualised practical support have been made (SIGN, 2008), these tend not to cover the emotional and psychological impact of caring for a stroke patient.

1.2.5: Stroke Treatment

A growing body of evidence has supported primary and secondary interventions, acute intervention and stroke rehabilitation (NICE Guidelines, 2013). The National Stroke Strategy provides a guide for effective and high quality care for the treatment of stroke viz: prompt transfer to a hospital providing specialist care; an urgent brain scan, such as a CT or MRI; early holistic assessment, including screening for swallowing; and immediate access to a high quality stroke unit, with specialised stroke rehabilitation (National Audit Office, 2010). For ischaemic strokes, treatment is aimed at dissolving blood clots (typically alteplase) within the first four hours of the onset of stroke (National Audit Office, 2010). Other pharmacological interventions such as aspirin (which reduces the platelets' affinity for each other), ACE inhibitors (which widen the

blood vessels and thus reduce blood pressure), and statins (which inhibit a cholesterol-producing enzyme in the liver) may also be prescribed. These are, however, preventative measures, designed to reduce the risk of another stroke, but may do little to ameliorate stroke symptoms. Treatment in specialist units has been consistently shown to be more effective than management in general units (Trialists' Collaboration, 2007) though there is a shortfall in specialist provision most notably a shortage of clinical psychologists, social workers and speech and language therapists (RCP, 2011).

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1.2.6: Stroke Rehabilitation

As an estimated 40% of stroke victims suffer moderate to severe impairments which require special care (National Stroke Association, 2011), a significant proportion of stroke treatment is aimed at rehabilitation. Defined as "a reiterative, active, educational, problem-solving process focused on individual needs" (NICE Guidelines, 2010, p2), post-stroke rehabilitation focuses on helping the patient regain as much independence as possible by increasing daily functioning to levels as close as possible to pre-stroke functionality. The aims of rehabilitation include helping patients re-learn basic skills essential for day-to-day living; reducing risk factors for further stroke; providing training for caregivers; regaining the use of stroke-affected limbs by teaching compensatory strategies designed to reduce the effect of the movement deficits; encouraging the repetitive use of impaired limbs to counteract 'learned non-use' and facilitate brain plasticity; ensuring post-stroke safety; and helping patients relearn performance of self-directed activities such as personal grooming (NINDS, 2011). Traditional rehabilitation techniques, such as repetitive, task-oriented training (Wolf et al., 2006) have been found to be beneficial, enabling patients to regain motor function and reduce disability (Langhorne et al., 2011; 2009). However, the implementation of

such rehabilitation measures can often be tedious, resource-intensive and expensive (Teasall et al., 2009).

Physiotherapy- and occupational therapy-led rehabilitation measures have been effective in post-stroke recovery, and focus on promoting independence in all aspects of everyday life (Sackley et al., 2006; Logan, et al., 2004a and b; Jorgenson et al., 1995; Heinemann et al., 1987). Legg et al. (2007), in a systematic review, found that focused occupational therapy, specific to the personal activities of everyday life, improved overall performance and reduced the risk of a negative outcome, such as death or dependency. The researchers' recommendation that post-stroke rehabilitation should be targeted at specific activities of daily living and patient needs has been corroborated by other research (Logan et al., 2004b; Walker et al., 2004).

Successful rehabilitation outcome has been shown to depend on patient and family motivation (Langhorne et al., 2011; Harris et al., 2010), while Prigatano (2011) concluded that patients' subjective experience of their post-stroke impairments and disabilities must be integrated in to their care, and made a central feature of rehabilitation therapy. Addressing patients' primary frustrations enabled therapists and clinicians to focus the therapy in a more meaningful way for the patient, making them more willing to actively engage in their rehabilitation and better equipped to deal with their post-stroke condition. Prigatano (2011) noted that therapists and clinicians may need to facilitate patients' articulation of their psychological experience, and therefore they must be aware of the range of possible subjective experiences post-stroke. Prigatano emphasised the centrality of the patient to the treatment programme, and in particular, the salience of the patient's subjective experiences and psychological disposition. Certainly, exclusively

focusing on physical/clinical functioning is increasingly deemed to be insufficient; and needs to be replaced by a more holistic, patient-centred approach.

It should, however, be noted that stroke-rehabilitation generally is highly complex, involving as it does, a wide range of individual and intervention factors, which make it less amenable to evaluation by RCT protocols (Ali et al., 2010). Evaluation is further complicated by the use of a range of definitions and an absence of measures of pre-stroke function. Together, these methodological considerations mean that accurate assessment of interventions is difficult (Hoffmann et al., 2010b). However, where more specific activities have been addressed and the sample controlled for locus of stroke, there is evidence that rehabilitation is effective (Walker et al., 2012).

1.2.7: Health Education Campaigns

With 150,000 people suffering stroke each year, the importance of health education campaigns aimed at early symptom recognition and immediate intervention is self-evident. The FAST campaign (an acronym for Face, Arms, Speech and Time) was launched in 2009, as part of the Department of Health's National Stroke Strategy and highlighted both the symptoms and the need for urgent action. Initial evaluation of the campaign's impact suggests that it has done little to improve knowledge (Bietzk et al., 2012). Maasland et al. (2011) in a review of the effectiveness of health education for stroke and TIA patients, found that the basic knowledge of their condition and related risk-factors was insufficient, with no beneficial effects on health behaviour, risk modification or overall stroke outcome. These findings were corroborated by figures from the National Sentinel Stroke Audit (RCP, 2011), which suggested that 56% of patients were admitted to hospital within three hours of the initial onset of stroke symptoms - fewer than in 2008. However, the Stroke Association claims there was a

significant increase in the number of calls made to ambulance services since the FAST campaign started, indicating that it had been successful in raising awareness; however, the improvements may only have been temporary, with knowledge levels reportedly falling since the campaign ended (Stroke Association, 2011). Certainly, the evidence demonstrates that information provided post-stroke has a positive impact on patients' and carers' knowledge and psychological well-being (Forster et al., 2012). It would seem that more research into health education is required, since although it is an important aspect of stroke care, it remains largely neglected and currently appears ineffective.

1.3: Transient Ischaemic Attack

While stroke has been extensively researched, TIA - although defined as a medical emergency (Siket & Edlow, 2012) - has received significantly less attention, possibly because it has previously been regarded as a short-lived, minor event (Daffertshofer et al., 2004). TIA is defined as 'a transient episode of neurological dysfunction caused by focal brain, spinal cord, or retinal ischaemia, without acute infarction' (Easton et al., 2009, p2276). Relevant to this definition is the transient nature of the episode, with NICE (2008) noting that symptoms last less than 24 hours, although Siket and Edlow (2012) suggest that symptoms rarely last longer than an hour so the 24-hour time-based definition is no longer clinically relevant or useful. TIAs are caused by a temporary disruption to the blood supply to the brain, resulting in a lack of oxygen in the affected area; an estimated 30-40% of cases result in permanent brain damage (Poisson & Johnston, 2011). Although the symptoms are similar to stroke, most notably dysarthria, numbness/weakness in the arms, unilateral drooping of the face, visual disturbances, dizziness, balance and swallowing problems and occasional loss of consciousness, their severity and duration are attenuated (Easton et al, 2009). The variability in symptoms together with diagnostic imprecision (Castle et al., 2004) inevitably means that precise

prevalence and incidence data may be unreliable. However, it is estimated that there may be around 0.66 TIAs per 1000 population (between 50,000 – 60,000) per annum (Giles & Rothwell, 2007); of these, approximately 20% will go on to have a full stroke within a month, with the greatest risk being within the first two - three days (Fisher, 2008; Siket & Edlow, 2012).

The strong positive association between TIA and subsequent full stroke means that TIAs may be considered warning signs for secondary stroke. Patients who experience a TIA are also at increased risk of myocardial infarction and vascular death (Molina & Selim, 2012). It is therefore imperative that effective preventative measures are adopted to reduce the risk of stroke and its sequelae. Quite apart from the human cost, early, effective post-TIA intervention has been demonstrated to be both clinically and cost effective, reducing the risk of subsequent stroke and consequent acute care costs (Luengo-Fernandez et al., 2009; NICE, 2008). Rather surprisingly, despite the evidence, fewer resources and little research have been devoted to proactive TIA management

1.3.1: Risk Factors

The risk factors outlined for stroke in Section 1.2.1 apply to TIA. Of particular relevance are: family history of stroke or TIA; being 55 years or older; atherosclerosis; diabetes; and being of Afro-Caribbean or South Asian origin (as these populations tend to have higher blood pressure and diabetes, compounding TIA-risk - National Stroke Association, 2011). Hypertension is thought to be the most significant risk factor associated with TIA, with around 56.4% of ischaemic stroke patients under the age of 50 having hypertension (Janssen et al., 2011). As with stroke, lifestyle factors can have an impact. A poor diet - especially one high in salt - being overweight, and medical conditions such as sleep apnoea all increase blood pressure, and the consequent risk of

developing atherosclerosis, while smoking can double the risk of having a TIA (Sacco et al., 2006).

1.3.2: Diagnosis

Diagnosis of TIA remains worryingly subjective, even among specialist clinicians (Castle et al., 2010). Consequently, many individuals may go on to suffer a preventable stroke or be inappropriately treated. Diagnostic confusion results in part from a lack of an agreed definition of TIA, and its similarity with presenting symptoms of other transient neurological conditions due to seizure, migraine, or syncope (Fonseca & Canhao, 2011; Rothwell, 2007). Most commonly used as an initial diagnostic test is Rothwell et al.'s (2005) ABCD (**A**ge, **B**lood pressure, **C**linical features and **D**uration of symptoms) screening measure which is intended to predict the risk of stroke in the first seven days following a TIA. It has been found to have good predictive validity for secondary stroke (Giles & Rothwell, 2008), though its limited inter-rater reliability, low correlation with imaging findings and an inability to identify patients who require appropriate hospital intervention mean that it is not recommended as a sole decision-making tool (Molina & Selim, 2012). Subsequent adaptation of the scale - ABCD2 (Johnston et al., 2007) - was designed to predict very acute risk within the first two days post-stroke and has better credentials; this measure not only has good predictive validity for stroke within 90 days of the TIA, but is also associated with correct diagnosis of a true TIA against expert opinion, enabling clinicians to differentiate true TIA patients[1] from those presenting with mimic symptoms (Josephson et al., (2008). Nonetheless, use

[1] *'TIA patients' and 'stroke patients' should more properly be referred to as 'patients with TIA' and 'patients with stroke; however, because of word limitations, the former terms will be used throughout.*

of MRI and transcranial Doppler ultrasound to verify TIA is also recommended (Merwick & Kelly, 2011).

1.3.3: Physical and Cognitive Consequences of TIA

The definition of TIA, which emphasizes its transitory nature, implicitly suggests that there are no mid-to-long-term consequences of the event. Perhaps for this reason, the research-base on post-TIA consequences is less than for stroke. Yet there is growing interest in the implications of TIA for the well-being of the patient. Emerging evidence suggests that the physical impact of TIA may be considerable, with ongoing physical/clinical problems, functional impairments, disability-risk and survival (Coutts et al., 2012). For example, persistent fatigue is well-documented (Kessler & Thomas, 2009; Winward et al., 2009) and has a significant adverse effect on quality of life (Kessler & Thomas, 2009; Vohra et al., 2008), as well as being associated with a range of physical and occupational problems (Vohra et al., 2008). Anderson et al. (2004), in a 6-year follow-up of TIA patients reported reduced vitality. Lempert (2012) noted the association between TIA and recurrent attacks of dizziness, while Verbraak et al. (2012) reported motor skills below the population norm 1-month post-TIA, and problems with daily activities in 50% of patients considered to be fully recovered.

With regard to cognitive impairment, MacKenzie et al. (2011) found that 55% of their sample showed some degree of cognitive impairment on the Montreal Cognitive Assessment tool, while Mao et al. (2006) found that compared with matched healthy controls, TIA patients showed significant cognitive decline. Pendlebury et al. (2011) found transient cognitive impairment was evident in almost 40% of TIA patients within the first seven days of the event; moreover, the affected patients had an increased risk of cognitive impairment and severe dementia at 5 years. The persistent nature of these

impairments has also been reported by Sachdev et al. (2004) who found that 3-6 months after the event, TIA patients had problems with memory, mental flexibility and speed of information–processing, while van Wijk et al. (2007) reported enduring cognitive dysfunctions 15 years post-TIA. Sachdev et al. (2007) corroborated the cognitive decline in TIA patients, which they attributed to a smaller amygdala, consequent upon hypertension. Such evidence emphasises the need for proactive interventions, both psychological and pharmacological, to manage stress and hypertension.

1.3.4: Psychological Consequences of TIA

Despite a paucity of research on the psychological consequences of TIA, that which exists points to a significant psychological impact of TIA (van Wijk et al., 2007; Gibson & Watkins, 2012). It has been found that TIA sufferers can experience mood disturbances, often manifested as depression and/or anxiety, and related to the fear of suffering another TIA or full stroke. For example, Luijendijk et al. (2011) found that TIA was significantly and independently associated with a 68% increased risk of incident depression and a 2.5-fold increase for DSM IV-defined depressive disorders. The authors suggest that TIA independently confers an increased risk for depressive syndromes and disorders to a degree that is comparable with post-stroke levels. El Husseini et al. (2012) also reported levels of depression among TIA patients 1 year afterwards, that were comparable to stroke, yet 70% of their sample were receiving no anti-depressant treatment. A fifteen-year follow up of 200 TIA patients by van Wijk et al. (2007) found that despite health-status indicators that were comparable to the healthy population, 20% of TIA survivors were depressed, 15% had cognitive dysfunctions and 5% suffered both, though overall quality of life was similar to population norms. Given that depression is an independent risk-factor for subsequent stroke (Salaycik et al., 2007; May et al., 2002), it would appear to be essential that depression is not only assessed, but actively treated in

TIA as part of secondary stroke prevention. Other psycho-social sequelae include reduced vitality and social functioning 6-years post TIA (Anderson et al., 2004), impaired quality of life (Kessler & Thomas, 2009), and increased fear (Gibson & Watkins, 2012).

It might be expected that TIA patients would experience some degree of anxiety given the possible repercussions of the event, yet little research attention has been directed towards post-TIA anxiety. Although it is conceivable that patients' lack of knowledge of TIA and its implications could limit their anxiety-responses (Lecouturier et al., 2010; Sprigg et al., 2009), it is also possible that the predominant assumption that TIA is inherently transitory has meant that research interest has been focused elsewhere. The limited available evidence suggests that around 27% of TIA patients experienced anxiety 1 month post-TIA (Verbraak et al. 2012). Given the established link between anxiety and subjective distress with subsequent fatal stroke (Fiedorowicz et al., 2011; Katan et al., 2011; May et al., 2002; Surtees et al., 2008), it would seem a priority for further research.

1.3.5: Treatment of TIA

Because around one third of TIA patients will go on to have a full stroke, early identification of those at risk is essential (Poisson & Johnston, 2011). Diagnostic confirmation of TIA is important, since its symptoms can mimic those of other neurological conditions (see section 1.3.2). Molina and Selim (2012) suggest urgent initiation of preventative treatments following TIA, such as antiplatelets, statins and anticoagulants, to reduce subsequent stroke-risk. Aspirin is typically used for secondary prevention in patients with a low risk of stroke (Weber et al., 2010), but is taken in conjunction with dipyridamole, another anti-platelet medicine, when the patient is at a higher risk (Giles, 2011; Diener et al., 1996). Anti-coagulants, such as warfarin, are also

commonly prescribed in cases of ischaemic TIA, although evidence of the effectiveness of warfarin for preventing secondary ischaemic stroke is conflicting. Weber et al. (2010) found compared to a placebo, oral anticoagulants reduced the risk of stroke by 60-70%, with van Walraven et al. (2002) also finding that TIA patients taking warfarin had 65% fewer strokes than patients randomised to no anti-thrombotic therapy, and 52% fewer strokes that patients randomised to aspirin. However, Birman-Deych et al.'s (2006) study yielded more disappointing results, with warfarin associated with only a 35% reduction compared with no anti-thrombotic therapy, and a 25% reduction compared with aspirin. The new generation anticoagulants, such as dabigatran, have been found to be as efficacious as warfarin when administered at a lower dose, and more efficacious when given at a higher dose (Weber et al., 2010).

Addressing controllable risk-factors has been effective. For example, treating hypertension with ACE inhibitors (NICE, 2011), and high cholesterol with statins or aspirin have had positive outcomes (NHS Choices, 2009; Paciaroni et al, 2007), while TIA clinics with their stated aim of managing lifestyle factors, have also had some success (NICE, 2008). Carotid endarterectomy may also be an option in cases of atherosclerosis, and moderate to severe blockage of the arteries. The National Audit Office (2005) suggested that providing patients with carotid artery surgery within two weeks of the TIA could prevent 250 strokes, with a net saving to the NHS of £4 million a year.

Early intervention when dealing with TIA is now the norm, but there remain significant differences in admissions, provision of specialist services, hospitalisation and urgent clinical evaluation (Giles, 2011; Poisson & Johnston, 2011). Although the official recommendation is for all suspected TIA patients to be seen with 7 days of the event

(RCP, 2005), in reality, only the minority (42%) of UK hospital trusts meet this target, with one-fifth having no specialist TIA centre at all (RCP, 2007). Where TIA patients are treated as a matter of urgency, the risk of secondary stroke significantly reduces (Lavallee et al., 2007; Rothwell et al., 2007). A number of research studies have confirmed that early intervention reduces the risk of secondary stroke by 80% (Rothwell et al., 2007), preventing almost 10,000 strokes a year in the UK alone, and in this regard, rapid-access clinics providing specialist services are not only clinically effective, but also reduce costs and bed-days (Merwick & Kelly, 2011). However, a review of TIA clinics suggested that almost one third of patients wait 24 hours before seeking help (Merwick & Kelly, 2011), a statistic confirmed by Chandratheva et al. (2010). This latter study also noted that 68% of patients did not realise they had experienced a TIA, and that only 47% of TIA patients sought medical attention within three hours of symptom onset. Sprigg et al. (2009), in a systematic review of the topic, found significant delays in seeking medical attention post-TIA, much of which was attributable to patients not recognising the symptoms. The important of awareness-raising is self-evident. Furthermore, the emergence of TIA rehabilitation which focuses on the centrality of the patient's experience of TIA has demonstrable effectiveness (Arts el al., 2008).

1.4: Stress

The experience of stress and its impact on physical health is important to this thesis. Defined as a combination of physical, psychological and behavioural changes occurring over a prolonged period, which provokes the release of hormones such as cortisol and adrenaline (Ogden, 2012), stress can result in a range of physiological changes. For example, increased heart rate, tightened muscles, elevated blood pressure and faster, shorter breaths may all be immediate responses to a stressor, while the prolonged elevated release of stress hormones can not only suppress the immune system,

leaving the body susceptible to autoimmune diseases, but also elevate both heart rate and blood pressure, thus increasing the risk of a number of cardiovascular conditions, such as heart attacks, aneurysms and strokes (Ogden, 2012; Selye, 1970). Additionally, chronic or severe stress can leave individuals vulnerable to anxiety, depression, insomnia and peptic ulcers, due to increased acid secretion in the stomach (Ogden, 2012; Selye, 1970). Finally, high levels of a stress hormone (copeptin) have been found in patients with confirmed TIA and was strongly associated with an increased risk of a subsequent TIA or full stroke within 90 days (Katan et al., 2011); Surtees et al. (2008) and Fiedorowicz et al. (2011) have also demonstrated a link between psychological distress and raised likelihood of subsequent stroke.

Subjective distress, then, can inflict considerable cardiovascular damage; it has been identified both as a predictor of fatal stroke (Jood et al., 2009; Hankey, 2006; May et al., 2002) and an established consequence of it (eg. Bour et al., 2010; 2011). Furthermore, there is a growing body of evidence that suggests raised levels of depression and anxiety among TIA patients. Given the established and well-documented link between TIA and secondary stroke, it is conceivable that a key risk-factor is stress-level.

1.5: Justification for the thesis

The foregoing brief review provides the rationale for the thesis. Firstly, there is an established inter-relationship between physical and psychological condition generally, and between psychological distress and the raised likelihood of secondary stroke specifically; together this creates an imperative for more research into the psychological consequences of TIA. Secondly, the limited body of research that has been conducted into this area has focused primarily on depression and cognitive state, using proprietary measures to collect the data. These studies prescribed the outcomes to be measured and

used standardised psychometric techniques to do so. Consequently, they suffer from the logical fallacy of circularity, in that they collected only the outcomes the researchers deemed to be relevant. They are therefore not a comprehensive account of the spectrum of factors that may be perceived to be pertinent by TIA patients themselves. It is conceivable that patient-driven data-bases might offer a broader insight into psychological reactions, which might be usefully included in the management and rehabilitation of TIA, particularly with the aim of offsetting secondary stroke. Thirdly, rehabilitation from illness or injury involves a *comprehensive* programme of treatment intended to facilitate the process of recovery, and should incorporate a range of both psychosocial and physical/clinical factors. Since NICE Guidelines (2008) recommend that secondary stroke prevention programmes should be informed by individual risk factors and issues, it would seem similarly important for a wide variety of patient illness-experiences to be considered in post-TIA management, for instance, in the development of adaptive coping strategies. Where this has been undertaken, outcomes are improved (Arts et al., 2008). Other evidence from the stroke literature has confirmed the centrality of the patient's subjective experience as essential for full and effective engagement in post-stroke rehabilitation and adaptation (Prigatano, 2011).

Together, these points suggest that a broad-spectrum approach, involving the physical/clinical and psychosocial sequelae of TIA, might be optimally effective both in its management and in secondary stroke prevention. For example, rapid-access TIA clinics might include psychological risk-assessment and management as part of the post-TIA rehabilitation programme. However, the lack of research that explores the TIA patient's subjective experience means that the evidence-base necessary for providing information about any potential psychological impact of the TIA, and who is most affected, is limited, and thus the potential for using this in post-TIA rehabilitation is

hampered. An easy-to-use risk assessment scale aimed at identifying psychological reactions to TIA might be a valuable additional tool in its management. Identifying patients who have dysfunctional levels of reaction and distress could lead to targeted psychological support and interventions as a routine part of post-TIA treatment and rehabilitation, with the intention of reducing subsequent morbidity and mortality. This thesis, therefore, is concerned with the development of a psychometrically robust preliminary risk-assessment scale aimed at identifying TIA patients whose reactions to TIA might adversely affect their prognosis and recovery.

1.6: Scope of the thesis

The ultimate aim of the thesis was the development of a psychometrically robust risk assessment scale, which could be used to assess TIA patients' experiences and thereafter, inform care packages. However, it is important to clarify the scope of this thesis, and in particular what it covers and what it does not:

Table 1.1: The scope of the thesis

Within the scope of the thesis	**Outside the scope of the thesis**
TIA patients	Stroke patients
Patients' subjective experiences of TIA	Clinical/medical consequences and correlates of TIA
Outcomes of TIA	Causes/aetiology of TIA
The thesis is developmental, using well-established psychometric procedures	No assessment of the value of the scale for treatment, rehabilitation or psychological therapy.
The focus is the development of a pilot risk-assessment scale using appropriate construct and content validity protocols; limited test-retest reliability is measured.	No assessment of either the specificity/sensitivity of the scale or of its predictive and concurrent validity (tested against other proprietary psychological assessment instruments). Likewise there is no extensive test-retest reliability measurement.
The research is, for reasons of time and practical constraints, exploratory and small-scale.	There is no confirmatory hypothesis-testing or wide-scale assessment of the generalisability/replicability of the findings.

Chapter 2

METHODOLOGICAL OVERVIEW

2.1: Preamble

The aim of this chapter is to provide an overview of the principal methodology used in the thesis. As the thesis is concerned with the development of a robust risk-assessment scale, the underlying principles of psychometrics are relevant. Any scale, to be of value, must measure what it claims to measure and must measure the same construct consistently. These principles are known as validity and reliability respectively and each will be discussed in turn. The last part of the chapter reviews mixed-methodology as the approach best suited to ensuring that the psychometric properties of the test are maximised. Finally, the philosophical basis of the thesis is outlined. The specific methodology used at each stage will be reviewed in the relevant chapter.

2.2: Validity

Validity is the extent to which a measurement device actually measures the characteristic it is intended to measure (Carter & Porter, 2000). While such a property might be considered to be self-evident, the vast majority of psychometric tests of all types lack validity which renders them meaningless (Kline, 2000). There is no simple or single method of establishing validity; instead, a number of approaches are required (Kline, 2000).

2.2.1: Construct validity

Construct validity is possibly the most critical type of validity in test development (Cronbach & Meehl, 1955), and is

> *'viewed as an over-arching concept which encompasses all of the other forms. It is clearly the most significant aspect of thinking about validity because it is the common focus of evaluation of test usefulness'.* (Coaley, 2010, pp135-136).

However, there is no single way of determining construct validity (Robson, 2011). While Robson (1993, p69) notes the necessity of a degree of common sense and "intuitive reasonableness", achieved by simply focusing on the topic of interest without attempting to assess a deeper theoretical construct, Kline (2000) is more specific. He suggests that construct validity involves defining the underlying concept (usually an abstract notion) that is to be measured, and ensuring that this definition can be operationalised, so that the construct has a number of distinct, identifiable and measurable components that generate testable hypotheses. If these hypotheses are supported, the test is considered to have construct validity (Coaley, 2010; Kline, 2000). In the present study, the underlying construct to be measured is 'subjective experience of TIA', which might include a number of affective, cognitive and behavioural components that would give rise to testable hypotheses. So, for example, if a patient's emotional, cognitive or physical reactions to the TIA (as measured by the risk-assessment scale) were extreme or dysfunctional in some way, then these could be confirmed by a range of other independent outcome data eg:

- severe post-TIA anxiety or depression that required pharmacological intervention
- correlation with scores on established proprietary tests of functioning, such as activities of daily living; for example, in the absence of physical explanations, a

patient's inability to get out of the house might be attributable to extreme loss of confidence or agoraphobia

- correlation with scores on other tests of psychological state (eg Hospital Anxiety and Depression Scale - HADS).

If no relationship between the TIA risk-assessment scale and other independent outcome measures was observed, this would suggest problems with the measure's construct validity (Robson, 2011). However, at the development stage, the construct's components have to be established from a variety of data-types and sources, using a combination of methods and measures (Coaley, 2010; Cronbach & Meehl, 1955). In practice this might mean that the literature base is extensively searched (Coaley, 2010), and combined with the data from a focus-group brainstorming exercise (Field, 2005) to determine the extent and range of the component constructs and provide a 'mosaic of results' (Kline, 2000, p38). In the present study, a thematic review of the literature was undertaken (Chapter 3), TIA patients' experiences were elicited qualitatively using repertory grid analysis (Chapter 4), qualitatively/quantitatively combined using Q-methodology (Chapter 3) and quantitatively using factor analysis (Chapter 5). Together this multi-method approach ensured that a wide range of subjective experiences was captured and therefore satisfied the basic requirements for test development.

2.2.2: Content validity

The operational definition of construct validity in concrete terms means that specific questions can be devised to measure each of the construct's components. These items constitute the content validity of a test. Content validity refers to the extent to which a measure represents every element of a construct i.e. whether it reflects the intended content of the construct (Kline, 1986) and the 'degree to which a test samples

the domain' (Coaley, 2010, p132). To establish content validity, the measurement tool should cover a wide range of observable and quantifiable outcomes that have been derived from a multi-method examination of the basic construct under investigation (Coaley, 2010). Cronbach and Meehl (1955) suggest that content validity is determined by defining a set of items and systematically sampling within this set to establish the measuring tool. Content validity can therefore be seen as a measurable manifestation of the construct.

In practice, determining the content of a test may be achieved by using a grid-approach to identify the overlapping themes that emerged from the multi-methodologies used to establish construct validity (Rust & Golombok, 1999) and then asking experts in the field whether the measure appears to cover all relevant aspects of the topic (Carter & Porter, 2000). The extent to which a researcher can ensure content validity depends in part on the topic under investigation; the degree of precision and specificity of the behaviours or attributes that are generated by the constructs; and their measurability (Kline, 2000). Furthermore, the way in which items are formulated is critical, with ambiguously worded, complex questions likely to compromise content validity (Oppenheim, 2000). Finally, it is important that the items are worded to avoid bias. Known as demand characteristics, some tests are sufficiently transparent that the respondent can guess was it is required and may distort their answers accordingly (Coaley, 2010; Kline, 2000).

In relation to the present study, the component studies of this thesis (very briefly outlined in section 2.2.1), not only provided thematic constructs, but also their specific observable attributes. By comparing the similarities of the issues raised in each study, common topics were identified and then used to inform the items in the risk assessment

questionnaire (Chapter 6). The item construction followed Thurstone's Paired Comparison method (Thurstone, 1927) which both forces choices and offers a degree of opacity, thus minimising response-bias (Chapter 6).

2.2.3: Face Validity

Face validity refers to whether the measurement scale *looks* as though it is measuring what it is intending to measure. It is often considered a weak measure of validity (Kline, 2000; 1986) but has a public relations function, in that participants are more likely to complete the test if it looks as though it has some *prima facie* credibility (Kline, 2000). Apart from ensuring that the items appear to be relevant to the topic, face validity can be enhanced by using interesting formats, items and presentational styles, as well as ensuring they are suitable for the target population (Coaley, 2010). Pilot-testing the instrument can provide a measure of usability, and hence face validity, and affords the researcher the opportunity to adjust the measure before final use (Coaley, 2010).

In the current study, face validity was established by using an interesting, non-standard format (the Thurstone Paired Comparison method – Chapter 6) , which was short and simplified for ease of use by a population that may be elderly or compromised by TIA. The measure was also piloted to establish its feasibility. Furthermore, instructions were kept simple and explicit.

2.2.4: Predictive Validity

Predictive validity refers to the ability of the test to predict behaviour. It is considered the hardest and most important psychometric property to attain (Coaley, 2010; Kline, 2000; Schmidt & Hunter, 1998). Apart from the inherent variability of human behaviour, there are other problems, notably identifying a suitable criterion

against which to assess a test's predictive validity; the inevitable time-delay between taking the test and the occurrence of the behaviour; sample attrition (Coaley, 2010) and the tendency for statistical assessment of predictive validity to indicate significant correlations when the actual functional relationship is low (Kline, 2000). One alternative to predictive validity is concurrent validity, where the problem of time-delay is eliminated. Here, the new test is assessed against scores from established, proprietary tests, though this obviously requires the existence of other similar measures.

In the current study, time and practical constraints prevented the assessment of concurrent and predictive validity of the risk assessment scale. However, a larger, more comprehensive study which compared the test's scores with a range of other outcomes, such as HADS, activities of daily living, help-seeking behaviours for a range of TIA-related problems, would all be possible and desirable (see Chapter 7).

2.2.5: Reliability

Test reliability is defined in two ways. Firstly, a test should have the capacity to produce similar results on repeated occasions with the same participants; this is known as test-retest reliability (Kline, 2000). The test is usually taken on two occasions, with the inter-test gap depending partly on the nature of the attribute being measured. For relatively stable characteristics, such as IQ, a 3-month gap is recommended (Kline, 2000); for more transient attributes, like attitudes, Pedhazur and Schmelkin (1991) propose 1-2 weeks, on the basis that beyond this, real changes could have occurred which would confound any conclusion about the test's reliability. This is known as function fluctuation and is distinct from (though not necessarily distinguishable from) test-error (Cattell, 1957). However, short inter-test intervals may distort reliability because of memory effects, since recent experience of a measure can create artificially high levels of

agreement between the sets of test scores through reliance on past response patterns (Pedhazur & Schmelkin, 1991; Kline, 1986). For a test to be considered reliable, the correlation between the two sets of test scores should be >0.7 (Kline, 2000), although Carter and Porter (2000) note that if clinical decisions are being made on the basis of results from a measure, the coefficient should be slightly higher.

The second form of reliability is internal consistency reliability which refers to the ability of similar items within a test to measure the same attribute (Coaley, 2010; Kline, 2000). For example, test items that assess anxiety should each receive similar scores from respondents. Again, the cut-off correlation coefficient for acceptable internal reliability is 0.7, though many well-established tests achieve values well below this (Kline, 2000). Test-length is a determinant of reliability, in that the longer the test, the more likely it is to be reliable; however, there is a risk that in the search for reliability the test becomes overlong and boring, thus distorting responses (Kline, 2000). Kline recommends a minimum test-length of 10 items. There are a number of ways of assessing a test's internal reliability (eg: split-half) but the statistical measure that is widely accepted is the alpha (α) coefficient (Coaley, 2010; Kline, 2000). There are debates about internal reliability. Cattell (1957) notes that it is possible for a test to be too internally reliable, which would indicate it is over-specific and very narrow in focus. For this reason, short tests which have significant internal reliability are unlikely to be valid and are described by Cattell (1957) as bloated specifics.

In the current study, time constraints prevented any extensive measurement of test-retest reliability, but it was possible to check test-retest reliability over a ≤2-week period on the small sample who participated in the pilot study. Moreover, the nature of the test items, which were intentionally distinct and unrelated, would make internal reliability

assessment impossible. However, there are 21 items in the final risk assessment scale, which exceeds the minimum of 10 recommended by Kline (2000), while in the factor analysis section of the thesis (Chapter 5), the internal reliability of each of the emerging factors (used to inform test-content) was assessed using conventional Cronbach's α.

2.3: Mixed Methodology

The preceding discussion of construct and content validity demonstrated the importance of gathering information form a wide variety of sources and using a range of methods, in order to ensure the psychometric robustness of the instrument. This confirmed the decision to use mixed methodologies in the present thesis.

Mixed methodology involves the use and combination of both qualitative and quantitative approaches in the investigation of the same research topic, for example, combining semi-structured interviews conducted on a small sample with a large-scale numerically-scored questionnaire (Spratt et al., 2004). Defined as the use of different methodologies to study the same phenomenon (Denzin, 1978), its purpose is to provide a better-balanced perspective of the topic (Altrichter et al., 2008). Mixed-methodology enables the researcher to reduce or eliminate the shortcomings that are inherent to any single method (Mitchell, 1986, p19) and allows for cross-validation of different research techniques in order to determine whether the methods are congruent and elicit similar results (Jick, 2006; Thurmond, 2001). Combining qualitative and quantitative methods allows researchers to collect rich, subjective narrative as well as employing the objective, numerical advantages of quantitative data. Many authors have discussed in detail the strengths and weaknesses of qualitative and quantitative approaches (eg: Tashakkori & Teddlie, 2012; Kumar, 2010; Brown et al., 2003; Barbour, 1999) and it is beyond the scope of this thesis to provide a thorough review. Briefly, however, qualitative research

can be too context-specific, lacks generalisability due to unrepresentative samples, and cannot substantiate claims made about findings due to the absence of statistical rigour. Quantitative methods, on the other hand, overlook the importance of context, are overly simplistic, tend towards reductionism, and crucially, ignore the subjective meanings and experiences of the participants involved in the research (Brannen, 2005; Brown et al., 2003). Nevertheless, taken together, a mixed methodological approach goes some way towards ensuring that the disadvantages of each approach are offset to some degree by the advantages of the other.

In conclusion, while mixed methodology is more labour-intensive than studies employing a single technique, thus increasing the study's duration and required funding (Borkan, 2004), its advantages are numerous: it enables investigators to capitalise on the advantages of each approach; it is more acceptable to a range of epistemological perspectives; it allows for a multi-angle approach to be taken, providing the most comprehensive insight into the research question; it allows for additional perspectives and insights; and it is uniquely flexible (Borkan, 2004; Schillicai et al., 2004). More importantly here, the use of individual, subjective, narrative experiences together with the objective generalisbility of statistical findings drawn from large populations makes it especially applicable to primary care research (Ullrich et al., 2011; Borkan, 2004), while its salience for maximising the 'mosaic of results' essential for test-validity means that its is a pre-requisite in test construction (Kline, 2000, p38).

Therefore, to fulfil the demands of a mixed-methodology approach to test design, the current research used a number of paradigms to establish TIA patients' subjective experiences of TIA preparatory to developing the risk-assessment scale. In particular, it employed:

- a thematic analysis of the relevant literature which was a sub-element of the main methodology used in this chapter (Chapter 3)
- semi-structured interviews, which again were essential sub-elements of the main methodology (Chapter 3)
- Q-methodology (Chapter 3)
- repertory grids (Chapter 4)
- factor analysis of a large data-base of responses to two proprietary mental health and function scales (Chapter 5)

It was essential to use method-triangulation in this study to ensure the preliminary screening tool was based on the most comprehensive, rigorous and thorough data possible to increase the likelihood of it being both reliable and valid. This level of breadth and depth is essential for health research, and particularly, for the development of a screening tool (Wilson & Hutchinson, 1991).

2.4: The philosophical basis of the thesis

The foregoing review and justification for the study and the approaches used are not only based on the recommended guidelines provided by specialist psychometricians but are underpinned by the research philosophy considered here to be important to the management of patients. Within the context of evidence-based medicine, the Randomised Controlled Trial (RCT) is regarded as the gold-standard for health research (Sackett et al., 1996). RCTs developed out of an era when intervention decisions were largely founded on clinician hunch and assumption, and offered rigour, objectivity and the ability to identify best treatments. While the RCT has formed the basis of clinical research for over three decades, it has nonetheless been criticised for its reductionism

and over-reliance on outcomes that can be reliably and easily measured (Brown et al., 2003). Many of the intangible aspects of care, such as the patient-carer relationship, the therapeutic dialogue and experienced clinical judgement, cannot easily be investigated by an RCT; consequently, these aspects of the care-process have either been largely overlooked or are considered by many practitioners and policy-makers to be either lower-level 'soft' evidence or inconsequential (Dixon & Sweeney, 2000). The benefits of RCTs are not disputed, yet one consequence of the evidence-based care culture has been a disempowering of some healthcare professionals who believe their own professional expertise has been eroded by the requirement to adopt nationally agreed protocols (Brown et al., 2003). Furthermore, the use of RCT-evidence to inform clinical decision-making via NICE guidelines typically reflects government policies and priorities, rather than issues of concern to patients (Rogers, 2002). While various initiatives have been introduced at both the national and local levels to ensure that patients have a voice in health care (DfHSS, 2006), these have largely focused on service delivery and patient satisfaction with care, rather than on the illness-experience itself.

Furthermore, the principal philosophy in delivering care has been the biomedical model, which reduces the patient's condition to a set of symptoms which are interpreted, diagnosed and treated within a positivist framework (Neighbour, 1987). However, the patient's culture and context, psychosocial attributes and experience of illness are also essential to understanding the meaning of the illness for the individual and for making effective treatment decisions. Translating these constructs (in particular the patient experience) into treatment may be problematic since there is no agreed definition of 'patient-centred care' (Mead & Bower, 2000). Stewart et al. (1995) consider patient-centred care to consist of six inter-related features: exploring the disease and illness experience; understanding the whole person; agreeing the treatment options;

incorporating health promotion and illness prevention; enhancing the doctor/patient relationship; and 'being realistic' about resource availability. It is the first stage that has relevance to this thesis.

The importance of the patient's experience of illness has been acknowledged by many researchers. For example, using the concept of 'narrative' to reveal the patient's subjective illness experience, Greenhalgh and Hurwitz (1999) note that:

> *'The processes of getting ill, getting better (or worse), and coping (or failing to cope) with illness, can all be thought of as enacted narratives within the wider narratives (stories) of people's lives… The narrative provides meaning, context, and perspective for the patient's predicament. It defines how, why, and in what way he or she is ill…. Understanding the narrative context of illness provides a framework for approaching a patient's problems holistically, as well as revealing diagnostic and therapeutic options. ' (p48.)*

Similarly, Bury's seminal (1982) conceptualisation of illness as a biographical disruption suggests that the patient may view the onset of illness as a significant interruption to normal life; this may have potentially damaging social consequences, serving as a reminder of mortality. While the illness experience may depend on age, social background and co-morbidities (Pound et al., 1998), the key message here is that illness is a personal experience that is unique to the patient, and which has consequences for coping and recovery (Kaufman, 2011; Yasuhara et al., 2010; Sakalys, 2003). This aspect of patient-care is now acknowledged and patient experiences are being systematically collated in the form of resources like the Database of Individual Patient's Experiences of illness or DIPEx (Herxheimer et al., 2000). In addition, provision of information and involving the patient in treatment decisions have been routinely used as attempts to

address this need for individualised care, though these may not necessarily incorporate the subjective, individual experience of the illness and the significance it has for the patient.

These perspectives reflect an epistemological difficulty. The health-care culture focuses on RCT-based clinical guidelines; consequently, the patient-experience as a unique and individual phenomenon has little relevance for general treatment protocols. Moreover, the measurement of outcomes within the RCT is unbiased, objective and based on general principles, while the patient experience, by definition, is subjective, unique and individualised. Research into subjective patient experience has frequently used proprietary psychometric measures, such as Quality of Life, which have been developed and standardised on large populations. Thus, the patient experience is assessed in terms of the general characteristics that define the wider population, and which are prescribed by the researchers themselves; the patient experience, then, is no longer unique but is referenced against normative data. Such studies, therefore, cannot (and do not) claim to cover the whole spectrum of what is pertinent to any individual patient; instead, they place the patient on a scale that may or may not have relevance, assessing the individual only against those attributes that are considered useful to the investigators. Consequently, the value of such measures to recovery and coping may be limited (Carr & Higginson, 2001; Bernheim, 1999).

This section should not be regarded as a criticism of the questionnaire as a means of collecting patient information. The questionnaire is an essential tool for measuring a range of outcomes, for comparisons of patient groups and types, and for giving direction to care; by comparison with alternative approaches, it is also a cost-effective means of obtaining data. However, a questionnaire is only as good as its scope and psychometric

foundations. Undoubtedly, using disease-specific, rather than general, questionnaires may go some way towards highlighting more valuable patient experiences, while the structure of the questionnaire may also impact on the quality of the data (Bernheim, 1999). Weighting responses for their significance to the individual, phrasing items to focus on the impact of an event rather than on the event itself, and assessing the importance of the event, may all increase the individuality of a patient's response to a generic questionnaire and thus improve its value (Bernheim, 1999). In other words, the target is to develop a general self-assessment scale that meets the conflicting epistemological requirements of standardised measurement and subjective experience.

Therefore, this thesis has some key theoretical underpinnings. The first is that the patient experience is a core factor in post-illness recovery and coping, and as such, must be incorporated into treatment decisions. Secondly, within a culture of RCTs, evidence-based medicine and resource limitations, individualised assessments may be neither feasible nor desirable. And thirdly, as TIA can be a forewarning of stroke, effective early intervention and individualised management is imperative. Taken together, these propositions suggest that some mechanism by which the subjective experience of TIA can be routinely and efficiently captured and used to inform treatment is imperative, in a way that also meet the requirements of a standardised general assessment tool. Satisfying these principles reinforces the need for mixed methodology, and is further justification for its use here.

The next three chapters describe each stage in the development of the risk-assessment scale; Chapter 6 presents the resulting questionnaire.

Chapter 3

PATIENTS' EXPERIENCES OF TIA: A Q-METHODOLOGY STUDY*

3.1: Preamble

The aim of this chapter was to capture the patient perspective as a source of construct validity, as outlined in the previous chapter. Because subjective experience may be difficult for some patients to articulate, interview techniques may not yield the depth or range of information that is needed for psychometric development. Therefore, an alternative approach – Q-methodology – was adopted. Employing a blend of qualitative and quantitative approaches, the Q-methodology study formed the combined mixed-method approach in the thesis.

3.2: Q-methodology: an overview

Standard Q-methodology protocol was adopted (Webler et al., 2009; Corr, 2001; Donner, 2001; Stephenson, 1953). This technique is highly applicable to healthcare research, although it has not been used with TIA or stroke. Its use of rigorous and established quantitative analysis of rich subjective data makes the technique epistemologically acceptable to a range of healthcare professionals. Q-methodology captures subjective experiences and then organises these into common perspectives or

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stories, which can then be used in a variety of ways eg: to inform treatment-planning, information-provision and as the basis of risk-assessment tools (eg: Merrick & Farrell, 2012). Q-methodology does not require large or representative samples, since the aim is to select participants who will potentially reflect a range of views and experiences. Because the task involves sorting prepared statements, the technique offsets many of the methodological problems faced by patients when attempting to introspect and report their own personal experiences (Prigatano, 2011).

Essentially, the method requires participants to sort a set of statements (known as the concourse) that are relevant to the research topic, according to the degree to which each statement reflects the participant's own experience or viewpoint. The concourse statements are usually derived from a thematic review of information derived from variety of sources, such as a literature review, focus groups and interviews (Webler et al., 2009; Donner, 2001). The success of a Q-methodology study depends on the quality of the concourse of statements, which must not only reflect the whole range of issues relating to the topic, but must also follow the standard principles of questionnaire design regarding the clarity of wording and content (Webler et al., 2009; Donner, 2001). The concourse typically consists of c35-45 statements (van Exel & de Graaf, 2005). The statements are sorted into a grid arranged as a normal distribution curve (see Figure 3.2), with one pole of the grid representing statements that are 'totally unlike own experience/view', through 'neither like nor unlike own experience/view', to 'very like own experience/view', at the opposing pole. Because the grid uses a normal distribution format, a prescribed number of statements must be allocated to each part of it. The sorted statement sets are then factor-analysed case-wise (as opposed to the standard item-wise factoring, which is described in more detail in Chapter 5), to generate clusters (or factors) of similar Q-sorts (Webler et al., 2009; Donner, 2001). These clusters are

then interpreted by examining the responses of individuals whose perspectives define the cluster (represented statistically as a product of the factor analysis) and by the researcher's knowledge of the topic area (Webler et al., 2009). These resulting clusters represent groups of common experiences, beliefs or social narratives (Webler et al., 2009; Stephenson, 1953).

There are many advantages of Q-methodology. Prasad (2001) notes that Q-methodology can be used in numerous settings, on the same individual(s), repeatedly, and with short inter-test intervals. Zraick and Boone (1991) comment that Q-methodology is more focused and specific than a general attitude questionnaire, and is suitable for research questions that are concerned with 'hearing' many perspectives, and allowing individual expression of those voices (Stainton-Rogers, 1995). The sample does not need to be large or representative, with between 8 and 30 participants considered sufficient (Webler et al., 2009). Consequently, Q-methodology is particularly appropriate when the sample of interest is vulnerable or hard-to-reach, or when there are practical and/or financial constraints (Webler et al., 2009). Furthermore, the more typical methods of capturing patient experience such as interviews (Tong et al., 2011), telephone surveys (Sutherland et al., 2009) or questionnaires (Moore et al., 2004) may offer neither the rigour nor transparency that is important in health-care research. The card-sorting task may also be valuable for use with patients who have communication problems (such as stroke/TIA). However, the approach inevitably has limitations. When Q-methodology is repeated on the same person, it does not necessarily produce the same results; while this is not always issue, it may raise questions about the reliability of the method (Stainton-Rogers, 1995). The use of a fixed concourse of statements automatically imposes limits on how the participant can respond, while the clusters of perspectives are not necessarily generalisable. However, for the purpose of the current study, Q-methodology offered a

combined qualitative/quantitative approach which enabled themes of subjective clinical experiences to be obtained and was therefore directly relevant to the purpose of the development of the risk-assessment scale.

3.3: The Q-study

The Q-method protocol involves four stages:

1. development of a set of statements ('the concourse')
2. sorting the concourse statements into a normal distribution grid
3. analysis of the sorted grids using case-wise factor analysis
4. interpretation of the results

3.3.1: Ethics

None of the participants used at any stage of the Q-methodology study was at that point a National Health Service patient, so approval was obtained through the University of Birmingham School of Psychology ethics process (reference Psy 09/10).

3.3.2: Concourse development

As the concourse must capture the range of participants' experiences, (in this case, of a TIA), a variety of sources was used to develop the concourse statements. Here, a thematic review of a) the relevant literature; b) interview narratives from five TIA patients regarding their experiences of TIA; and c) internet TIA self-help chat-rooms was conducted using Thematic Network Analysis (TNA - Attride-Stirling, 2001). These stages are briefly outlined below.

3.3.3: The literature review

The literature pertaining to the outcomes and impact of TIA (briefly outlined in Chapter 1) was thematically analysed using Attride-Stirling's TNA (see section 3.3.6).

3.3.4: Interviews

Interviews are used to gather qualitative data by allowing the respondent freedom to talk openly, and without time restriction, about their feelings, opinions and experiences of a particular topic. The focus of the interview is determined by the researcher, and uses open-ended questions which allow scope for exploring ideas (Green & Thoroughgood, 2009; Pope & Mays, 2006). This technique allows for a greater depth of exploration of the topic. There are, however, a number of draw-backs with interviews. The quality and relevance of the data obtained depend on the skill of the interviewer and the ability of the participants to articulate their views (Green & Thoroughgood, 2009; Pope & Mays, 2006). Analysis of the narrative data may also be problematic, because the volume and scope of the data obtained may make decisions about what is relevant highly subjective (Green & Thoroughgood, 2009; Pope & Mays, 2006).

Here, a purposive sample of 5 people with confirmed TIA was used[1]. Of these three were male and 2 female; their ages ranged from 53 – 80. The time post-TIA varied from 6.5 months to <2 years. A single question was asked:

What did you feel or experience when you had your TIA?

The interviewer (LS) used probes where the participant was unable to articulate an idea, for example, asking the patient to develop an idea already expressed, or asking about the range of situations affected. The responses were recorded in note-form throughout and the narratives were analysed using Attride-Stirling's TNA.

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[1]While 5 participants at the interview stage may appear to be a small number, the use of an open-ended interview format, without time constraints, had the capacity to generate a considerable amount of data. Furthermore, the use of small samples (<20) is recommended by Crouch and McKenzie (2006) for interview-based research, because this will 'facilitate the researcher's close association with the respondents and enhance the validity of fine-grained, in-depth inquiry in naturalistic settings'. (p483)

3.3.5: Internet Self-Help Chat-rooms

The third source of narrative data used to inform the concourse statements came from all the publicly-available, but anonymous, internet chat-rooms that focused on self-help following TIA, and which were available at the time of the research. Because of the anonymous and on-going dialogue of chat-rooms, they were considered to be a valuable source of information about the day-to-day impact of TIA. The sources are listed in Table 3.1.

Table 3.1: Internet sources of patient experiences used to inform the concourse

- http://www.stroke.org.uk/talkstroke
- http://www.experienceproject.com/groups/Have-Crescendo-Transient-Ischemic-Attacks/97551/forum;
- http://neurotalk.psychcentral.com/thread34502.html
- http://forums.healthcentral.com/discussion/migraine/forums/a/tpc/f/2091082/m/620105431
- http://symptoms.rightdiagnosis.com/cosymptoms/transient-ischemic-attack/head-symptoms-sall.htm

3.3.6: Thematic Network Analysis of the Narrative Data derived from the Literature Review, Interviews and Chat-Rooms

Thematic analysis is a technique for distilling data and finding themes within it (Clarke & Braun, 2013). It is suitable for a range of research issues, can be used with narrative data that has been derived from a variety of sources and may involve large or

small data-bases (Clarke & Braun, 2013). It entails 6 stages – familiarisation with the data; coding the data; searching for themes; reviewing themes; naming the themes; and writing the findings up (Clarke & Braun, 2013). Many techniques are available, but the method selected here was Attride-Stirling's (2001) TNA. This generates three hierarchical levels of information – basic themes (the information that is derived from the narrative/text data); organising themes, (clusters of similar basic themes); and global themes (overarching categories that include all the basic and organising themes). Applied to the current study, TNA was used to distil these three levels of data derived from the literature review, the interviews and the internet chat rooms; four global themes were derived – cognitive, physical, psychosocial and practical problems. As the technique generates a vast corpus of narrative information and the process of data-reduction is lengthy, a highly simplified step-wise example of the process is provided as follows, using the global Psychosocial Impact theme by way of illustration.

Step 1: Coding the narrative material.

The first stage in reducing the narrative data is to break it down into manageable segments using a coding framework. There are numerous ways of doing this, but here, key words in statements were first identified and grouped semantically using Roget's Thesaurus. With reference to Table 3.2 (page 44), a small selection of narrative statements can be found in column 1, with the relevant semantic code in Column 2. These narrative statements constitute the Basic Themes.

Step 2: Identifying themes.

The aim of this stage is to represent the coded narrative text succinctly. From the semantic codes, common themes were initially abstracted by identifying the salient, common issues represented in the coded text. These were later refined to achieve

maximum specificity (to avoid repetition) and maximum breadth (to ensure that similar ideas were contained within a theme). These themes are presented in column 3 in Table 3.2, and provide the Organising Themes.

Step 3: Constructing the networks

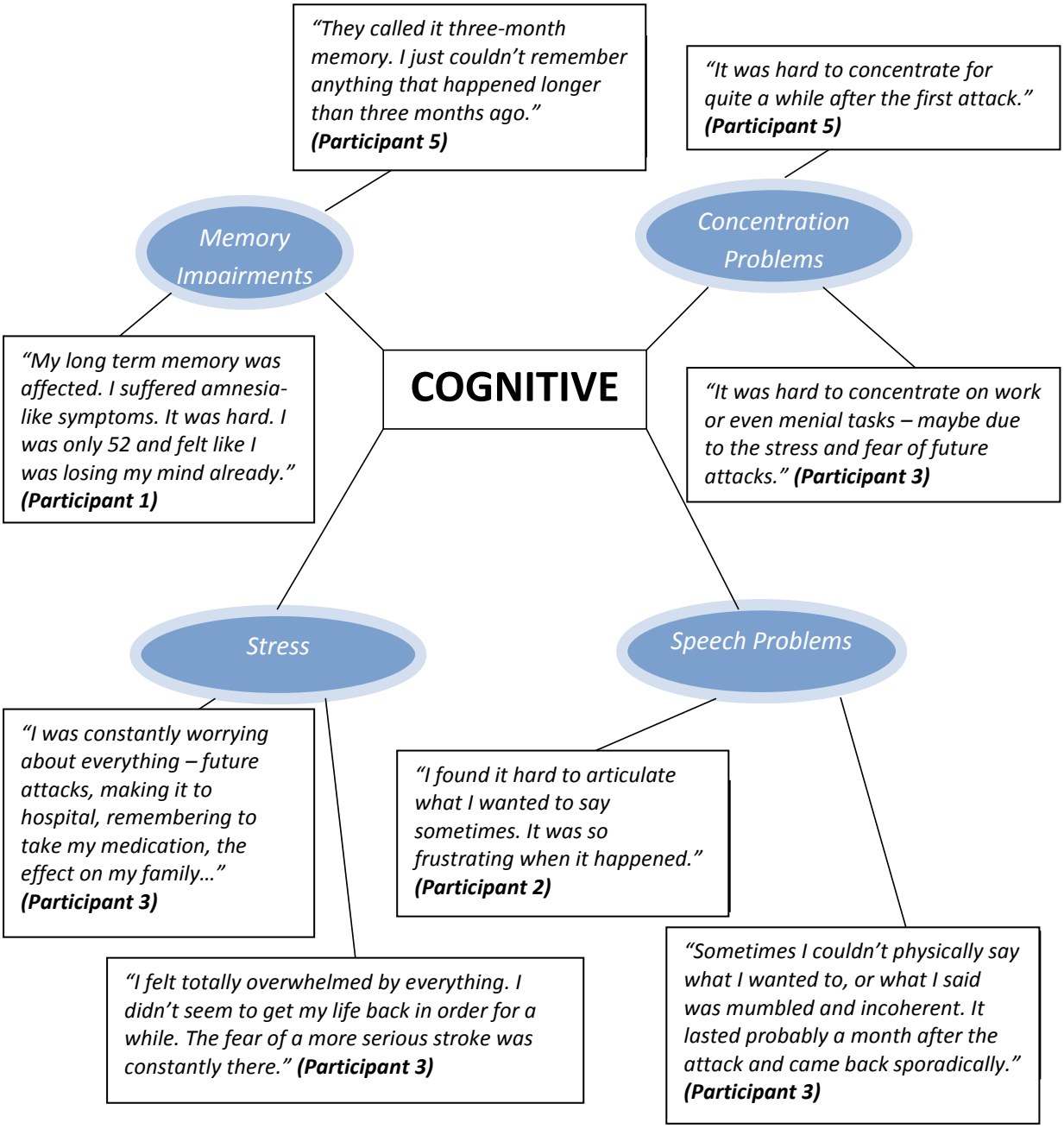
Firstly, the themes must be arranged into similar groupings to provide the thematic networks (ie themes about anxiety, themes about depression etc). From the Organising Themes, overarching Global Themes that encapsulate the essence of the Organising Themes can be deduced; these are presented in column 4, Table 3.2 (page 44).

Table 3.2: A Simplified Illustration of the Preliminary Development Stages of Attride-Stirling's Thematic Analysis

Narrative statements	**Semantic code**	**Themes identified (Organising themes)**	**Global theme**
I was permanently scared about the future	Fear	Fear for the future	Psychosocial impact
I suffered quite severe depression for months	Depression	Depression	Psychosocial impact
I was consumed with fear	Fear	Reactive anxiety	Psychosocial impact
I was very down and withdrawn	Depression	Depression	Psychosocial impact
I didn't really go out	Isolation	Social isolation	Psychosocial impact
I just couldn't see the light at the end of the tunnel	Depression	Depression	Psychosocial impact
I seemed constantly pre-occupied with anxiety	Fear	Reactive anxiety	Psychosocial impact
I just sort of went into myself	Isolation	Social isolation	Psychosocial impact
I didn't want to see anyone	Isolation	Social isolation	Psychosocial impact
My anxiety levels were sky-high	Fear	Reactive anxiety	Psychosocial impact
I remember spending a lot of time crying	Depression	Depression	Psychosocial impact
I was very, very worried about my health, my future, everything	Fear	Fear for the future	Psychosocial impact
I felt a sort of bereavement for what I had lost	Depression	Depression	Psychosocial impact
I felt very alone	Isolation	Social isolation	Psychosocial impact
I was frightened by what it might mean	Fear	Fear for the future	Psychosocial impact
I worried a lot about my family	Fear	Fear for the future	Psychosocial impact
I felt hopeless and helpless	Depression	Depression	Psychosocial impact
I was in a bad state	Depression	Depression	Psychosocial impact
I didn't socialise with friends	Isolation	Social isolation	Psychosocial impact

The Network Analysis, showing the three thematic levels (Basic, Organising and Global) is then constructed to provide a visual representation of the distilled data. A simplified example illustrating the three-tier hierarchical thematic analysis is presented in Figure 3.1, using the Cognitive Global Theme as an example:

Figure 3.1: Simplified thematic analysis of cognitive problems post-TIA (selected basic themes in outer boxes, organising themes in blue, global theme in bold black capitals)



3.3.7: The Concourse Statements

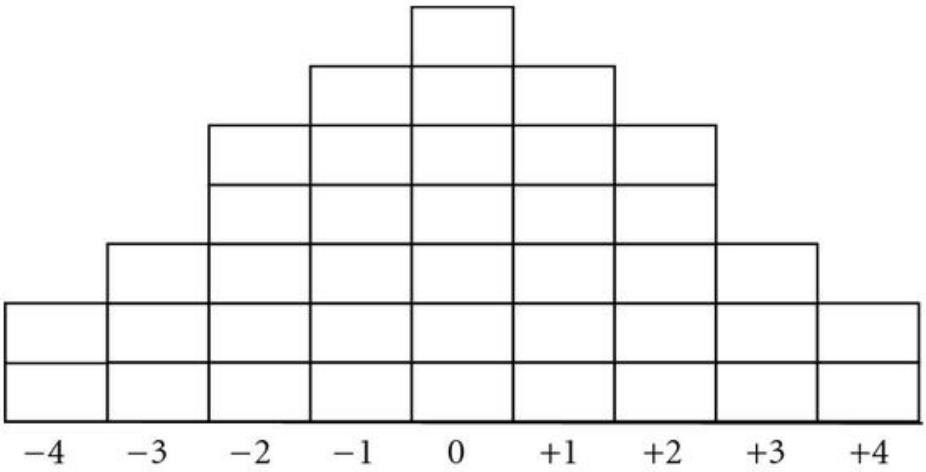
From these distilled themes, 39 statements were developed independently by three researchers; each statement was: individually distinct to avoid replication of concepts; unambiguous; non-contentious; and a comprehensive reflection of the issues affecting TIA patients (Donner, 2001). They are presented in Table 3.3:

Table 3.3: The concourse statements

Statement number	Statement	Statement Number	Statement
1	I was thankful I had been given this warning sign	21	I didn't realise how much I'd been affected by what happened
2	Not being able to speak or communicate for a while afterwards was particularly upsetting	22	I became very depressed after it happened
3	Since what happened, my head feels fuzzy and I can't think clearly	23	My memory was affected afterwards
4	People thought I was making a fuss about nothing	24	Every part of my life was affected by what happened
5	The healthcare staff didn't know much about my condition so didn't take it seriously	25	I let what happened take over my life and control what I did
6	I kept thinking how lucky I had been not to have had a full stroke	26	The impact of what happened went on for some time
7	Afterwards I was nervous about going out socially because I felt awkward and embarrassed	27	I didn't feel any different afterwards
8	I was back doing normal things shortly afterwards	28	I was scared about the long-term effects of what happened
9	My friends seemed to avoid me afterwards	29	I felt overwhelmed by anxiety afterwards
10	The numbness in my face afterwards really worried me	30	I felt my family was a bit irritated with me afterwards
11	The health care staff really knew what to do to help me	31	What happened made me re-think what's important to me
12	I felt really angry and resentful afterwards	32	I found the weakness in my arm afterwards very distressing
13	I felt that I was somehow to blame for what happened	33	I lost all confidence in my body afterwards
14	When it happened I didn't really know what it was	34	Afterwards, I felt really frustrated about what I could and couldn't do
15	After it happened, I kept thinking I would have a stroke	35	I felt I was a bit of a burden on my family afterwards
16	Afterwards I felt OK, but others noticed a change in me	36	When it happened, I felt reminded of my age
17	I really appreciated my family a lot more afterwards	37	I improved my lifestyle as a result of what happened
18	I felt I was wasting the doctor's time when it happened	38	Afterwards, I was tired all the time
19	I have no idea what to do in order to prevent it happening again	39	I couldn't sleep for worry afterwards.
20	I was very withdrawn afterwards		

Each statement was printed on a separate card; the cards were then randomly arranged and each was numbered on the reverse. A 39-cell normal-distribution grid was constructed to accommodate the statements and ranged from -4 (totally unlike my own experience), through to +4 (very like my own experience) (see Figure 3.2). The statements and procedure were piloted with three TIA patients to check for clarity and viability, prior to starting the main study.

Figure 3.2: Blank Q-sort grid



3.3.8: Sample

Twenty-three participants, who had experienced TIA within the previous two years, but without subsequent stroke, were selected; they excluded the participants who had been interviewed or who had taken part in the pilot trial. All were competent at English, sufficiently fit to participate and able to provide informed consent. The participants were identified via the Stroke Network and from a panel of volunteers attached to the University of Birmingham. As neither large nor random samples are required by Q-methodology, this small purposive sample of 23 TIA patients was consistent with the recommended protocol (Donner, 2001). Participant details were as follows:

Table 3.4: Participant Details (n=23)

Participant Number	Gender	Age	Marital Status	Occupational Status	Time since TIA
1	M	66-70	Married	Managerial/ Administrative	6-12 months
2	M	61-65	Married	Professional	6-12 months
3	M	>75	Married	Professional	6-12 months
4	F	71-75	Single	Managerial/ Administrative	6-12 months
5	F	61-65	Married	Professional	12-18 months
6	F	51-55	Married	Professional	6-12 months
7	F	>75	Married	Unskilled	6-12 months
8	M	>75	Married	Managerial/ Administrative	12-18 months
9	M	71-75	Married	Managerial/ Administrative	12-18 months
10	F	>75	Married	Managerial/ Administrative	6-12 months
11	F	61-65	Married	Professional	<6 months
12	M	66-70	Married	Professional	12-18 months
13	M	61-65	Single	Managerial/ Administrative	6-12 months
14	F	56-60	Single	Skilled/ Semi-skilled	<6 months
15	M	66-70	Married	Managerial/ Administrative	12-18 months
16	M	51-55	Single	Skilled/ Semi-skilled	<6 months
17	M	66-70	Married	Managerial/ Administrative	6-12 months
18	F	56-60	Married	Managerial/ Administrative	6-12 months
19	F	61-65	Single	Skilled/ Semi-skilled	6-12 months
20	M	56-60	Married	Managerial/ Administrative	6-12 months
21	M	56-60	Married	Managerial/ Administrative	6-12 months
22	M	61-65	Married	Managerial/ Administrative	6-12 months
23	M	61-65	Married	Skilled/ Semi-skilled	6-12 months

3.3.9: Procedure

The 39 cards, the Q-sort grid and an instruction sheet were given to individual participants. Each participant read every individual statement and then sorted these into three preliminary piles, without constraint at this stage on the number of cards in each pile; the three piles were nominally labelled: 'totally unlike my own experience of TIA', 'neither like nor unlike my own experience of TIA' and 'very like my own experience of TIA'. From these initial sorts, the participant was then asked to review the statements and then to refine their arrangement by allocating them to the ordinal categories in the 39-cell grid according to the extent to which each reflected his/her own experience. When the participant was satisfied with the allocation, the number on the reverse of each statement was recorded in the appropriate cell in the grid; Figure 3.3 provides an example.

Figure 3.3: Completed Q-sort Grid

				39				
			18	27	29			
		22	5	20	11	35		
		4	3	23	37	38		
	24	26	28	7	10	21	1	
30	16	33	9	34	19	32	31	14
12	8	25	13	2	36	15	17	6
−4	−3	−2	−1	0	+1	+2	+3	+4

The sorts were anonymous and confidential, though biographical details were collected. In addition, each participant was asked to record the reasons for selecting those statements which a) best reflected his/her own experience; and b) least reflected it. These narrative accounts were then used to elaborate and interpret the stories that emerged.

3.3.10: Data analysis

Proprietary software (PQMethod) was used to analyse the grids. Each participant's Q-sort was entered into the data-base, by recording the card numbers allocated to each of the 39 cells. Thus, 23 Q-sets of data were entered and analysed. The basis of Q-sort statistics is factor analysis, an established mathematical data-reduction technique designed to expose underlying groupings or patterns in the data, known as factors. Conventional factor analysis reduces a data-set by clustering variables into factors, according to the degree of association between the variables (see Chapter 5); with Q-sort, the data are instead factor-analysed case-wise, in order to group the participants according to the similarity of their perspectives. Standard Q-sort factoring uses eigenvalues>1[1], an orthogonal factor rotation[2] and z scores[3] to analyse and interpret the

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[1] *Eigenvalues are the relative contribution each factor makes in explaining the total variance in the data-set. The standard procedure for determining this are eigenvalues, which are automatically produced by the software programme for each factor. It is recommended that only those factors with eigenvalues >1 are used in the final interpretation of the data, since these will explain more of the total variance than those factors with eigenvalues <1 (Donner, 2001).*

[2] *Factor Rotation - to achieve the best solution to a data-set, factor analysis software automatically rotates the factors according to the purpose of the analysis; with Q-methodology, it is recommended that this rotation ensures that participants tend to be associated with only one factor or perspective, by maximising the variance between each factor; this is known as an orthogonal or Varimax rotation.*

[3] *Z-scores here are used as a measure of the salience of each statement to the factor on which it is loaded or associated; each statement that loads onto a factor will therefore have a z-score. As the z-score is a measure of standard deviation, a statement with a z-score of +3.0, for example, would suggest that this statement is 3 standard deviations above the mid-point of the data distribution and would therefore represent a high level of agreement with the statement (towards the right-hand pole of the Q-grid).*

statements that distinguish between the factors (Webler et al., 2009; Donner, 2001). Individuals' narrative explanations for their choices are also used to aid factor interpretation.

Summary details are presented in Table 3.5.

Table 3.5: Factor Structure of Q-sorts

Factor number and name	**Number of respondents loading on factor (% variance accounted for)**	**Significantly-loaded concourse statements**	**Z score**
1. Lack of knowledge and awareness of TIA	5 (21)	When it happened, I didn't really know what was happening to me	2.170
		I didn't feel any different afterwards	1.733
		I have no idea how to avoid it happening again	1.28
		I was scared about the long-term effects	-0.93
		The impact of what happened went on for some time	-1.46
2: Life impact of TIA	3 (15)	Every part of my life was affected by what happened	2.07
		Afterwards, I felt frustrated by what I couldn't do	1.815
		The impact of what happened went on for some time	1.756
		My memory was affected afterwards	1.44
3: Anxiety	3 (9)	I was overwhelmed with anxiety afterwards	2.35
		I was scared about the long-term effects	2.08
		I couldn't sleep for worry afterwards	2.03
		I lost all confidence in my body afterwards	1.17
4: Interpersonal impact	3 (8)	I felt my family was a bit irritated with me afterwards	2.11
		I felt I was a bit of a burden on my family afterwards	1.68
		Being unable to communicate afterwards was upsetting	1.564
		My friends seemed to avoid me afterwards	0.74
5: Depression	2 (7)	I was very withdrawn afterwards	2.30
		I became very depressed after it happened	2.065
		I thought how lucky I'd been not to have a full stroke	-1.41
6: Impact of physical symptoms of TIA	3 (6)	The numbness in my face afterwards really worried me	2.08
		Being unable to communicate afterwards was upsetting	2.08
		I found the weakness in my arm afterwards distressing	0.92
		I felt I was a bit of a burden on my family afterwards	0.86
7: Cognitive avoidance/denial	2 (3)	What happened made me re-think what's important to me	-0.90
		I was scared about the long-term effects	-1.45
		I was thankful I had been given this warning sign	-1.48
		Every part of my life was affected by what happened	-1.85
8: Constructive optimism	2(2)	I thought how lucky I'd been not to have a full stroke	2.26
		I improved my lifestyle as a result of what happened	1.79

Table 3.5 displays the 8 factors produced by PQMethod. In this table, each factor has been given a label that reflects the general nature of the perspective it represents (Column 1). Column 2 provides information about the number of participants loading on each factor and the % variance of the whole data-set accounted for. As a Varimax rotation was used, no participant loaded onto more than one factor and therefore, the perspectives can be considered to be discrete at this level. Column 3 represents those statements that loaded onto each factor. A statement can contribute to more than one perspective, so it is possible that any given concourse statement could appear on more than one factor; here, for example, the statement 'I thought how lucky I'd been not to have a full stroke' loads *negatively* onto Factor 5 (Depression) because these respondents did *not* consider this statement applied to their own experience, while it also load *positively* onto Factor 8 (Constructive Optimism), because these respondents reported that they *had* been lucky. In this way, the simultaneous loadings onto more than one factor can be explained in the context of that factor's theme. It would not be anticipated that the statements themselves would be discrete. Column 4 records the z-scores associated with each statement, and hence its salience to the factor.

Eight factors or perspectives were produced; each will be considered separately.

- *Factor 1: 'Lack of knowledge and understanding of TIA'*

Five participants and five statements loaded on Factor 1, which was labelled 'Lack of knowledge and understanding of TIA'. These statements together with the participants' narrative explanations indicated that these five respondents were either unaware that anything was happening to them, because they felt no symptoms, or that they did not realise the symptoms' significance or know what to do about them. Illustrative comments included:

'I didn't notice anything had happened; it was my partner who noticed that my mouth had started to droop'. (Participant 23)

'I knew something bad was happening, but I had no idea what I should do about it'. (Participant 9)

This factor highlights a lack of awareness of either the immediate or long-term significance of TIA.

- *Factor 2: 'Life impact of TIA'.*

The scope and enduring impact of TIA characterises Factor 2. Loading on this factor were three respondents and four defining statements, including specific issues of memory loss, general duration of the symptoms and the TIA's impact on all aspects of the respondents' lives. For the participants clustering on this factor, the scope and long-term impact of TIA were adverse and significant eg:

'My memory did suffer quite a bit, especially my short-term memory. It's better now, but still hasn't returned to how it was before. It's very infuriating'. (Participant 13)

'The fuzziness in my head is still there after more than 6 months; I wonder whether I will ever be able to function normally again'. (Participant 1)

This factor suggests that contrary to some research, the impact, if not the physical symptoms of TIA persist for a considerable period after the event.

- *Factor 3: 'Anxiety'*

Factor three, labelled 'Anxiety', comprised three respondents and 4 statements, for example:

'It was very frightening. I was really scared not just at the time, but for a long time afterwards'. (Participant 10)

'I couldn't stop thinking about it for ages; the worry stopped me sleeping and functioning properly'. (Participant 7)

These statements, coupled with the additional narratives provided, highlight an under-reported reaction to TIA. In contrast to the well-documented post-TIA depression (Luijendijk et al., 2011; Winward et al., 2009; Vohra et al., 2008; van Wijk et al., 2007), anxiety has not been widely recognised. Yet the anxiety experienced by these respondents was evidently considerable.

- *Factor 4: ' Interpersonal Impact'*

Factor four, comprising 3 respondents and 4 statements, highlights the social and familial impact of TIA, especially when speech is impaired. Illustrative comments loading on this factor included:

'Because my main symptoms went away quite quickly, my family thought I was making a fuss about nothing, so I didn't feel I could talk to them about it'. (Participant 11)

'My speech was a bit slurry afterwards and my family got irritated when they couldn't understand what I was saying'. (Participant 12)

'I felt really isolated afterwards. I was so embarrassed about my face and speech, that I couldn't go out with friends, even though everyone said they didn't notice any problems'. (Participant 6)

These experiences corroborate other research linking TIA to impaired social functioning (Anderson et al., 2011).

- *Factor 5: 'Depression'*

Factor five confirms depression as an enduring, significant consequence of TIA (Vohra et al., 2008; van Wijk et al., 2007). The two positively and one negatively-loaded defining statements together reflect a possibly morbid reaction to the TIA, bordering on clinical depression eg:

'I just sort of went inside myself afterwards; I didn't want to speak or be with anyone'. (Participant 20)

'I felt so very low for ages; I couldn't pull myself out of it. I really think I should have gone to my doctor and asked for something to help me stop being so depressed'. (Participant 5)

- *Factor 6: 'Impact of physical symptoms'*

Factor six confirms the physical consequences of TIA which have been noted in other research (Winward et al., 2009; Daffertshoffer et al., 2004). Illustrative comments included:

'I couldn't speak properly for about an hour after the TIA. It was probably the worst aspect of the whole experience'. (Participant 2)

'Because I was quite weak as a result, I needed quite a bit of care. I definitely felt I was a burden on my family'. (Participant 4)

Contrary to some other research that suggests TIA symptoms typically last no longer than an hour (Albers et al., 2002), these participants reported some persistent effects, such as weakness.

- *Factor 7: 'Cognitive avoidance'*

Factor seven is characterised by negativity and denial. Four defining statements negatively loaded on this factor, suggesting that the two respondents for whom this was central experience were apparently dismissive of the TIA. While it is conceivable that the TIAs in these cases actually were minor, these participants were still experiencing some physical and cognitive problems 6 months post-TIA, thus suggesting that they were in denial about the reality of the situation:

'There's no point worrying about the future; what will be, will be. I can't do anything to change it'. (Participant 2)

'I can't do anything to change what has happened or what will happen. I feel fine now, so what's to worry about?' (Participant 12)

- *Factor 8: 'Constructive Optimism'*

The final factor was characterised by two defining statements, both of which revealed a positive approach to the event, especially with regard to improving lifestyle. The two respondents loading on this factor reported feelings of relief and good fortune:

'I definitely considered myself to be lucky not to have had a stroke; it could have been a lot worse'. (Participant 23)

'I took the advice about improving my lifestyle very seriously; I improved my diet, took more exercise and went for regular check-ups at the doctor's'. (Participant 19)

Constructive optimism is a well-documented problem-solving coping strategy (Moos & Schaefer, 1984).

3.4: Discussion

The factor analysis revealed eight distinct perspectives, none of which was associated with a clear clustering of participants by demographic factors. Five factors (1,2,4,5,6) confirmed existing research, but three (Factors 3,7,8) yielded new information about participants' anxiety and coping strategies. Each will be discussed in turn.

Factor 1 (*'Lack of knowledge and understanding of TIA')* highlighted these respondents' lack of awareness either of what was happening to them at the time, or of the implications of the event. Despite intensive health education campaigns intended to increase public knowledge of stroke, it appears that their impact on these participants has been limited. This could be attributable to the focus of the campaigns (on stroke rather

than TIA), though a considerable body of research has also reported the ineffectiveness of recent stroke-focused health-education campaigns generally (Maasland et al., 2011; RCP, 2011). The sub-optimal level of knowledge of stroke and TIA in the population (Maasland et al., 2011; Ferris et al., 2005) would suggest that these health education activities are not having the desired effect at any level and may need to be re-considered. As an estimated 20% of TIA patients will go on to have a full stroke within a month, early secondary intervention measures are imperative (Fisher, 2008). However, lack of awareness/knowledge makes the possibility of secondary prevention difficult, since the chances of presenting for treatment are reduced (Sprigg et al., 2009). These points, together with the theme of Factor 1, indicate the need for a revised TIA-targeted health education programme to increase the population's baseline knowledge, to alert them to its potential implications and to sensitise people in high-risk categories to the likely symptoms.

Factor 2 (*'Life impact of TIA')* reveals the persistent adverse impact of TIA for these participants. While the long-term physical, cognitive and psycho-social consequences for stroke patients are well-documented (NICE, 2008), rather less is known about the sequelae of TIA. However, the TIA research which has been conducted has reported outcomes which, while less severe, are similar to those that result from full stroke. For example, fatigue (Kessler & Thomas, 2009; Winward et al., 2009), cognitive dysfunction (van Wijk et al., 2007), dysarthria (Brady et al., 2011) and quality of life (Vohra et al., 2008) have all been reported for TIA patients and mirror the experiences reported by stroke patients. The core theme of Factor 2, while corroborating these research findings, also challenges the notion that TIA is transitory. Instead, it would seem that the impact, if not the physical symptoms of TIA, may persist for a considerable period after the event and confirms the need for early individualised

management. It should, however, be noted that none of these respondents had significant physical impairments; their commentary while completing the task suggested that their confidence had been affected, which in turn had impacted on their functioning.

Factor 3, labelled 'Anxiety', highlights a reaction to TIA that has received sparse attention. Depression in post-TIA patients has been extensively reported (Luijendijk et al., 2011; Winward et al., 2009; Vohra et al., 2008; Wijk et al., 2007), though there is little reference to anxiety in the TIA research literature; however, a recent study by Gibson and Watkins (2012) reported fear, especially of secondary stroke, in their sample of TIA patients. Around 20% of stroke patients suffer high levels of anxiety, although no clear guidelines exist for its management (Campbell Burton et al., 2011). Since high levels of psychological distress in general, and anxiety in particular, have been noted as significant predictors of full stroke, especially in men (Fiedorowicz et al., 2011; Katan et al., 2011; Surtees et al., 2008; May et al., 2002), acknowledging anxiety as a consequence of TIA would be a first stage in its proactive and targeted management.

Factor 4 (*'Interpersonal Impact')* suggests that a range of interpersonal relationship are adversely affected by the TIA, particularly if speech is impaired, and confirms other research linking TIA to impaired social functioning (Anderson et al., 2004). The sense of being an irritant or burden will inevitably contribute to the patient's personal stress/distress and increase the chances of subsequent stroke (Fiedorowicz et al., 2011; Katan et al., 2011; Surtees et al., 2008). While the focus here was the TIA *patient's* perspective, it is well established within the stroke literature that between 25% and 54% of caregivers experience a considerable burden that may remain elevated for an indeterminate period (Ribgy et al., 2009). Therefore, if these findings have any application to TIA, it would seem that both the patient and their social networks may be

at risk of stress. Identifying patients and their carers who fall into this category would inform post-TIA management.

Factor 5 *('Depression')* confirms other TIA research which reported persistent and significant levels of depression (Vohra et al., 2008; van Wijk et al., 2007). Evidence suggests that the probability of developing ischaemic stroke increases 3-fold in the presence of depressive symptoms (Bos et al., 2008; May et al., 2002); moreover, depression is a significant consequence of stroke that is typically neither well-recognised nor effectively managed (Hackett et al., 2008). Therefore, early identification and proactive management of patients with post-TIA depression is therefore essential.

Factor 6 (*'Impact of physical symptoms')* corroborates other research findings that have reported the longer-term physical consequences of TIA (Winward et al., 2009; Daffertshofer et al., 2004). Of interest here is the implied persistence of the symptoms, which challenges the notion that TIA symptoms typically last less than an hour (Albers et al., 2002). It is, however, impossible to determine whether these symptoms were somatisations caused by event-induced anxiety or direct consequences of the TIA. Either way, the subjective experience merits attention for post-TIA care. The comments from participants loading on this factor, recorded while they were completing the Q-sort, revealed that it was primarily their confidence to undertake normal tasks (especially those outside the home) that had been affected.

Factor 7, labelled *'Cognitive avoidance'* has as its underlying theme, negativity and denial. The two respondents who loaded on this factor appeared to attach little salience to the TIA, which could reflect their lack of awareness of its possible implications; alternatively, it is possible that the TIAs in these cases were slight and transient. However, since the respondents appeared to be experiencing some physical and

cognitive impairment 6 months post-TIA, it is more likely that they were denying the potential gravity of the event. Denial is a well-documented defence against stress, and is central to appraisal-focused coping strategies, in which cognitive avoidance of the illness leads to minimising its seriousness (Moos & Schaefer, 1984). Its association with TIA had not been reported at the time of publication of this study, although since then, Gibson and Watkins (2012) have noted denial among their sample of TIA patients. However, denial following stroke is well-established (Aybeck et al., 2005) and is associated with poor outcomes (Santos et al., 2006), partly because it leads to late or no presentation for treatment (Kitko & Hupcey, 2008). If these findings apply to TIA, then it might be expected that patients in denial would also postpone help-seeking activities, preventing early secondary intervention.

Factor 8 ('Constructive Optimism') indicated that the participants coped with the TIA by re-construing it as a positive event that allowed them to consider a number of lifestyle changes that might improve their health status, and is consistent with Moos and Schaefer's (1984) classification of illness behaviours. Insofar as coping strategies determine illness outcomes, constructive optimism offers the patient some measure of control, which in turn may reduce stress and offset the chances of full stroke. This response to TIA had not been previously documented, though subsequent to the current study, Gibson and Watkins (2012) confirmed that some TIA patients regard TIA as a wake-up call. Similarly, Soundy et al (2011) noted the relevance of hope in the rehabilitation of neurological patients. This offers new possibilities for management. Within stroke research, a link has been established between low levels of pessimism and reduced incidence of stroke (Nabi et al., 2010). If a similar link between constructive optimism and positive post-TIA outcomes could be demonstrated, proactive cognitive reappraisal to encourage this coping strategy might be indicated.

There are limitations to the study. While the purposive sample of 23 participants accords with the recommendations of Q-methodology (Webler et al., 2009; Donner, 2001) these findings cannot be deemed definitive and therefore, need replication. However, the sample recruited here is similar in terms of age and gender to those in other studies of population demographics of TIA patients (Dennis et al., 1989) and therefore, it might be reasonable to suppose that the experiences reported here might apply to other TIA patients. Furthermore, the resulting Q-sort stories are only as valid as the concourse statements supplied. While every effort was made to capture a broad and comprehensive range of comments which were then distilled by independent researchers, it is nonetheless conceivable that the spectrum of experiences was incomplete. On a more positive side, the methodology has shown itself to be a valuable aid to investigating subjective experiences in a group where communication and introspection may be difficult. It also has the added advantage of using both qualitative and quantitative methods, making the approach potentially more acceptable to a range of epistemological perspectives.

These factors tell eight coherent stories about patients' subjective experiences of TIA; of these, lack of knowledge of TIA, its impact on physical, cognitive and social functioning, subsequent depression and impaired social functioning confirm existing research. However, new themes have also emerged - deep-seated, enduring anxiety, cognitive avoidance/denial and constructive optimism – which offer insights into the impact of TIA and emphasise the importance of targeted health education campaigns and active management. Moreover, the experiences of TIA were similar to those associated with full stroke, albeit at an attenuated level. The perspectives obtained here could be used to inform the construct and content validity of the planned risk-assessment scale.

This chapter has provided the combined qualitative/quantitative stage in the development of the risk-assessment scale; the next chapter presents the qualitative component.

Chapter 4

PATIENTS' EXPERIENCES OF TIA: A REPERTORY GRID INVESTIGATION*

4.1: Preamble

The aim of the second study was to develop the construct validity of the screening tool by exploring patients' experiences of TIA using a wholly qualitative approach, namely repertory grid analysis. This technique is well-established as a mechanism by which implicit subjective experiences can be made explicit and constitutes the qualitative aspect of the mixed methodologies used in the thesis. Consistent with recommended practice, the participants taking part here were selected from those in the Q-methodology study, with a time-difference of >6months (Spratt et al., 2004; Meetoo & Temple, 2003; Thurmond, 2001).

4.2: Repertory Grid Analysis

The research technique adopted here derives from the Theory of Personal Constructs (Kelly, 1955), which is complex and has many applications and interpretations which extend beyond the scope of this thesis (see Bannister & Fransella, 1986; Fransella & Bannister, 1977; Kelly, 1955). Essentially the theory is based on the proposition that there are multiple ways of construing people, events, objects or aspects of the world,

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known as 'constructive alternativism'; consequently, an individual's understanding of, and reactions to, the world are unique and a product of their life experiences and values. Because there are an infinite number of ways an individual can understand and interpret, standardised norm-referenced measures are considered neither appropriate nor relevant in Personal Construct Theory when capturing individual subjective experience (Walker & Winter, 2007; Leach et al., 2001). Therefore, an alternative, idiographic method is used, called Repertory Grid Analysis (RGA). The technique aims to capture the individual's own experience of events or aspects of the world (known as elements) by eliciting their reactions or interpretations of those events (known as constructs); however, the technique also allows for between-subject and within-subject comparisons. Analysis of the resulting constructs enables the researcher to gather a wide range of participant-driven data, which provide insight into the individual's understanding of their own life experiences, especially as they relate to the specific context of the research. The basis of the theory as a wholly individualised, ever-changing world-view means that conventional psychometric concepts such as reliability and validity do not apply to RGA.

RGA has been used successfully in a range of health-related studies, for example, counselling for severe aphasia (Cunningham, 1998), nurses' perceptions of caring for older people (Ellis, 1999), caregivers' experiences (Roland et al., 2010), patients' perspectives of treatment and intervention options (Schaffalitzky et al., 2009; Rowe et al., 2005; Frewer et al., 2001) and patients' experiences of illness (Compan et al., 2011; Kuchenhoff, 2002). RGA is an intensive and highly flexible data-gathering approach, generating a considerable amount of data, which can be analysed in a variety of ways; it does not require large or representative samples, may be conducted with single-case studies (Cunningham, 1998), and can be adapted for use for a range research topics (Walker & Winter, 2007). Consequently, concepts such as random sampling and power

calculations do not apply here, and while data saturation is not explicitly required, it is typically achieved as an inherent part of the construct-elicitation process. The technique allows access to experiences that cannot always be easily articulated, thereby generating potentially useful insights into the participant's tacit knowledge (Bjorklund, 2008). The novelty and flexibility of the technique and the depth and uniqueness of the data it generates made it particularly appropriate here.

4.2.1: Participants

A purposive sample initially of fourteen patients, with confirmed TIA within the preceding two years, was invited to participate. None had gone on to have secondary stroke. Of the sample, two reported that the TIA had not impacted on them and so they were eliminated from the study. The remaining sample included 5 females and 7 males, age range 47–86 (mean=71.5 years); 6 were retired professionals and 6 were retired managerial/skilled/unskilled workers. The sample size was determined by participant availability and is consistent with the principles of RGA.

4.2.2: Materials

For each participant, a 5x6 grid was created with the columns representing events (or elements) relevant to their experience of TIA, and the rows reflecting their perspectives or constructs relating to those elements. Using Kelly's (1955) recommended approach, circles were placed in three cells on each line. The location of these circles was randomly pre-determined and was different for each line, but the same for each participant (see Table 4.1); the purpose of the circles and the numbers 1 and 7 at either end of each row will be explained in Section 4.2.4 (Procedure).

Table 4.1: Blank grid illustrating the types of elements required and the bi-polar ranking of the constructs

ELEMENT →	**MOST AFFECTED ACTIVITY:**	**LEAST AFFECTED ACTIVITY:**	**MOST AFFECTED ACTIVITY:**	**LEAST AFFECTED ACTIVITY:**	**OTHER SALIENT ACTIVITY:**	**ELEMENT** ←
CONSTRUCT ↓						**CONSTRUCT CONTRAST** ↓
1	O	O	O			7
1	O		O		O	7
1			O	O	O	7
1		O		O	O	7
1	O	O		O		7
1	O		O	O		7

4.2.3: Ethics

None of the participants recruited was undergoing current treatment for TIA by the National Health Service (NHS) and nor were they recruited via the NHS; therefore, NHS ethical approval was not required. Instead, the study was conducted under the auspices of the University of Birmingham, following ethical approval from the Science,

Technology, Engineering and Mathematical Ethical Review Committee (reference ERN_12-0475).

4.2.4: Procedure

Participants were shown a list of 18 everyday life activities/events, covering social activities, cognitive functions, practical concerns, daily routines and hobbies all derived/adapted from the literature provided by the Stroke Association (2011; see Table 4.2) and asked to select two that were most affected by the TIA and two that were the least affected (Ellis, 1999).

Table 4.2. List of possible activities for use as elements in repertory grid procedure.

Category	Example activities
Social	Speaking on the phone Seeing friends Having a meal or drink out Attending a family gathering
Cognitive	Planning tasks Reading, writing letters, completing crosswords, puzzles, completing forms, etc. Work-related tasks
Concerns	Health Money Family Practical
Activities of daily living	Driving Cleaning Cooking Shopping Gardening
Other	Physical/sporting activities, e.g. playing golf, walking the dog Hobbies, e.g. sewing, music

The participant was then asked to select another activity/event that was significant in some way to their TIA. If the participant wished to substitute an activity/event that did not appear on the list, this was permitted. These five events were entered at the top of each column and represented the elements for the purposes of the Repertory Grid Analysis.

The process of eliciting the constructs, or the participant's perspective, required the participant to consider the elements indicated by the three circles on the first line (in the example in Table 4.1, these were in cells 1, 2 and 3) and describe how the impact of the TIA on any two of these three elements was similar, but different from the third. For example, using the participant data presented in Table 4.3 and the first line of the grid, two of her chosen activities made her feel frustrated, while the third did not. The construct 'frustrating' was then placed on the right hand end of the row, while 'not frustrating' was placed on the left hand side. The participant was then asked to think about the bi-polar construct 'frustrating/ not frustrating' in terms of a 7-point scale, with 'frustrating' = 7 and 'not frustrating' = 1. Using this measure, the participant rated each element according to how frustrated/not frustrated it made her feel. This process was continued for each of the 6 rows, with the participant generating 6 bi-polar constructs. The resulting 5x6 matrix contained numbers ranging from 1-7 in each row. The researcher recorded the participant's comments made throughout the procedure; these were used in the interpretation of the results. This participant's completed grid is presented in Table 4.3, by way of illustration.

Table 4.3: Sample of Completed Repertory Grid

ELEMENTS ⇨	**Activity most affected** Difficulty speaking on phone	**Activity least affected** Reading	**Activity most affected** Health	**Activity least affected** Cooking	**Other salient activity** Caring for children	**ELEMENTS** ⇦
CONSTRUCT ⇩						**CONSTRUCT CONTRAST** ⇩
Not frustrating 1	6	3	6	4	6	Frustrating 7
Not anxious 1	4	2	7	2	6	Anxious 7
No deep-seated concern for future 1	4	4	7	2	7	Deep-seated concern for future 7
Not angry 1	5	4	6	2	5	Angry 7
Not embarrassing 1	6	3	5	2	2	Embarrassing 7
No loss of confidence 1	5	4	6	3	5	Loss of confidence 7

4.2.5: Data Analysis and Results

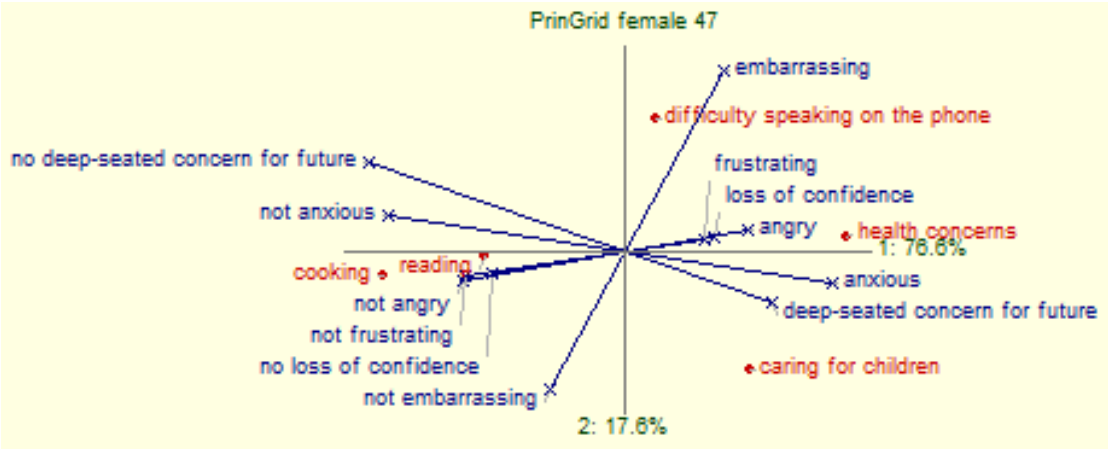
Free proprietary software (RepGrid IV) was used to analyse each grid separately (Gains & Shaw, 2005). Of interest to the current study are the constructs, or participant perspectives, rather than the elements selected, and so the description of the technique, the analysis and interpretation will concentrate on the constructs alone. The aim of the analysis is to uncover underlying patterns of constructs that are related within the participant's viewpoint; in so doing, the core dimensions by which the individual perceives his/her experiences can be captured. Two outputs from RepGridIV were used to interpret the grids –Principal Component Analysis (PCA) and the Focus Display Dendogram (Bjorklund, 2008). It should be noted that while these outputs were generated for each individual participant, for reasons of space, only one of each analysis type will be presented here by way of illustration[1].

The PCA (PrinGrid) presents the relationships between constructs and elements along two dimensions or principal components, with the first (horizontal) component accounting for most of the variation in the data, and the second (vertical) component accounting for the next largest degree of data variation. The total variance accounted for by these two components reflects the ability of the analytical process to fit the data. Typically, if the total variance accounted for by the two components ≥80%, the analysis is considered to be a good explanatory representation of the core constructs (Bjorklund, 2008). The constructs are represented in this graph as lines of varying lengths and proximities to the two principal components. Similarity, or patterning, between the constructs is indicated by a smaller angular distance, while the length of the construct line

[1] *The remaining 11 Principal Component Analyses and Focus Display Dendograms can be found in Appendix 3.*

reflects the amount of variance accounted for by that construct (the longer the line, the greater the variance). These concepts can be demonstrated by the PCA of the data from one of the participants and are presented in Figure 4.1 (constructs presented in blue, elements in red):

Figure 4.1: Sample Principal Components Analysis (PrinGrid) of a Completed Repertory Grid.

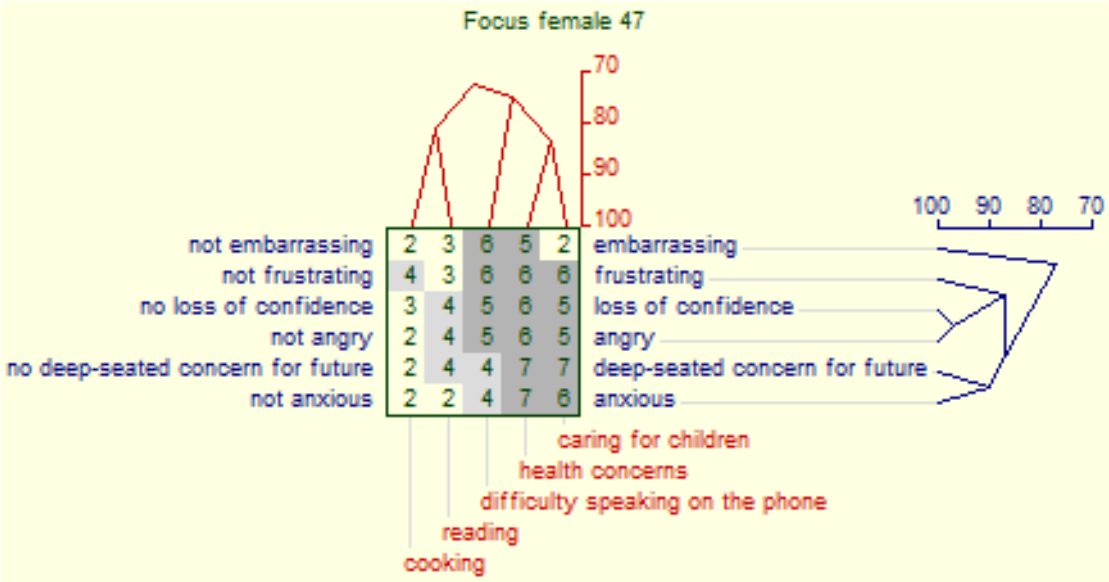


Here it can be seen that 'frustration', 'loss of confidence' and 'anger' have a very small angular distance between them, suggesting that these constructs form a group or pattern in the participant's experience of TIA. 'Anxiety' and 'deep-seated concern for the future' are also closely linked, while 'embarrassing/not embarrassing' has a greater angle of distance and is therefore perceived as a separate, unrelated construction of the TIA experience. The overall variance accounted for by the two principal components is 94.2%, indicating that the analysis provides a good explanation of the participant's ratings.

The second output – the Focus Display - provides a hierarchical clustering of the elements and constructs, which confirms the patterns between them in the form of a

dendogram. The similarity between constructs is represented along a scale; using the same 80% cut-off point, constructs showing ≥80% association may be considered to be conceptually similar in the participant's mind. This can be illustrated by the same participant's Focus Display (Figure 4.2; constructs presented in blue, elements in red).

Figure 4.2: Sample Focus Display of Completed Repertory Grid



Here, the most closely linked constructs are 'loss of confidence' and 'anger' (97%), with a slightly weaker link between these two constructs and 'frustration'(88%); 'anxiety and 'deep-seated concern for the future' are also linked at 90%, with a weaker connection between these two constructs and the previous three (87%). 'Embarrassment' is relatively independent and may be considered to be a separate perspective, only linking with the other constructs at <80% cut-off. The labelling of the construct patterns may be informed by the participant's commentary recorded during the administration of the repertory grid. Therefore, for this participant, four basic patterns of constructs emerge, which may be labelled 'frustration at personal restriction' ('loss of confidence' + 'anger' + 'frustration'); 'fear for the future' ('deep-seated concern for the future' + 'anxiety'), 'anxiety about role changes'; and 'embarrassment'.

Using the above protocol for the individual analyses from each participant, the following constructs were obtained and are summarised in Table 4.4.

Table 4.4: Summary of Construct Patterns by Participant

PARTICIPANT	LINKED CONSTRUCTS (≥80% association)	CONSTRUCT LABEL
1. Male, 75 years	1. Fear of being unable to cope/fear of loss of independence/anxiety	1. Fear for future role changes
	2. Uncomfortable in social settings/lack of confidence and control/desire to overcome the situation	2. loss of confidence
2. Female, 47 years	1. loss of confidence/anger/frustration	1. frustration and personal restriction
	2. deep-seated concern for the future/anxiety	2. fear for the future
	3. Embarrassment	3. embarrassment
3. Female, 67 years	1. sense of restricted world/embarrassment/ inhibition	1. personal restriction
	2. loss of independence and control	2. anxiety about loss of normality
4. Female, 69 years	1. fear for the future/resolved to change situation	1. wake-up call
5. Female, 73 years	1.sense of loss/mentally taxing	1. sense of loss and its management
6. Female, 76 years	1. frustration/loss of confidence/resentment	1. frustration at personal restriction
	2.having to slow down/anxiety about speed of response	2. anxiety about loss of normality
7. Male, 65 years	1. anxiety/sense of restriction	1. fear of personal restriction
	2. raised awareness of health issues/caution	2. wake-up call
8. Male, 71 years	1. need to achieve short-term goals/communication concerns/sense of disappointment	1. anxiety and disappointment
	2. concern about maintaining normality/fear of loss of independence	2. anxiety about loss of normality
9. Male, 75 years	1. anxiety/loss of independence	1. anxiety about loss of normality
10. Male, 75 years	1. fear for the future/anxiety	1. fear for the future
11. Male, 80 years	1. loss of confidence/increased caution/anxiety	1. loss of confidence
	2. sense of being lucky/concern for the future	2. wake-up call
12. Male, 86 years	1. problems planning for the future/loss of control/loss of self-identity	1. fear for the future
	2. loss of confidence/emotionally challenging	2. loss of confidence
	3. physical limitations	3. concern for future physical limitations

4.3: Discussion

The RGA yielded 22 constructs across the twelve participants, and revealed both distinct personal experiences, as well as similarities across the sample. Anxiety in some form was represented by five of the participants, ranging from a generalised anxiety about the future (Participants 1, 2, 10, 12), to a specific anxiety and sense of disappointment about the loss of normality (Participant 8), and identity (Participant 12). Anxiety about the implications of an illness both for current status and the future is well-documented and forms part of the Crisis Theory of physical illness (Moos & Schaefer, 1984), which suggests that following an illness-crisis, individuals attempt to try to re-establish normality and equilibrium via a range of coping strategies. Anxiety as a response to stroke has been widely reported (Kneebone et al., 2012; Campbell Burton et al., 2011); however, very few studies have noted anxiety among TIA patients (Verbraak et al., 2012; Gibson & Watkins, 2012), although this did emerge from the Q-methodology study (Chapter 3). Anxiety has an established causal link with stroke, significantly increasing its likelihood especially among men (Fiedorowicz et al., 2011; Katan et al., 2011). This finding confirms the Q-methodology results and strengthens the case both for early recognition of post-TIA anxiety and its proactive management, in order to offset the likelihood of secondary stroke. This construct of anxiety also incorporated concerns about the future, which is consistent with models of illness behaviour that suggest some preparation for an uncertain future is a necessary illness-management task (Moos & Schaefer, 1984). Again, while uncertainty about the future is known to be associated with stroke (Ch'ng et al., 2008), no comparable finding had previously been observed with TIA patients, though a link between mild stroke and uncertainty a year after the event has been noted (Carlsson et al., 2009). The loss of identity, reported by Participant 12, was linked with a perception of reduced capabilities and function and has been reported elsewhere in stroke patients (Becker, 1993).

Allied to anxiety was the construct 'loss of confidence', reported by participants 1, 11 and 12. Interpreting this in the context of the these participants' discussions during the administration of the repertory grid, loss of confidence emerged from a sense of insecurity about carrying out normal functions, preserving social functioning, maintaining activity levels, and a general sense that the participants could no longer rely on their own bodies. Changes to role, identity and social support, whether real or perceived, are central to the conceptualisation of illness as a life-crisis (Moos & Schaefer, 1984). While none of the sample had been severely incapacitated by the TIA, their concerns about its possible impact on normal role functioning were notable. Comments revealed that some participants felt let down by their bodies, that they had less confidence in their ability to pursue normal activities, such as taking foreign holidays, driving or attending social events, and that their sense of personal independence was threatened. Loss of confidence and its implications for other routine activities have not previously been reported for TIA patients, though research with stroke patients has suggested that it may constitute a significant psychological barrier to undertaking a range of activities, especially those that involve leaving the home, including travelling and driving (Barnsley et al., 2012; White et al., 2012; Logan et al., 2004a and b). While the significance of the TIA to these participants may not have been a reflection of its actual clinical consequences, it is clear that their health beliefs and concerns might both form an emotional barrier to normal functioning, and contribute to a sense of acknowledged or underlying anxiety. Moreover, this finding is corroborated to a degree by Factor 2 from the Q-methodology, which also suggested that the TIA's effect on life-functioning was partly to do with loss of confidence, rather than its actual impact. Where confidence-building has been introduced into post-stroke rehabilitation programmes, outcomes have improved (Jones et al., 2011); it might be expected that these findings would apply similarly in the rehabilitation of TIA patients.

The feeling that the TIA had limited the worlds of the participants, frustrating and restricting their scope of activity and outlook, was revealed by five participants (2,3,6,7,12). In the context of their commentary, together with the elements selected, the TIA was considered to have imposed limitations on everyday activities such as driving and holidays; as such, it is intricately related to the previous construct. Once again, frustration is a well-documented correlate of stroke, especially during rehabilitation (Zimmerli et al., 2012; Wood et al., 2009; White et al., 2008; Wallenbert & Jonsson, 2005), but has not before been reported for TIA. However, research with stroke patients has largely focused on patients with pronounced incapacity; for the TIA patients in the current study the frustration was a product more of a *belief* that activities could not be achieved or undertaken. Bound up with anxiety and loss of confidence, it adds corroboration both to the findings from the Q-sort, as well as to the understanding of illness-as-crisis (Moos & Schaefer, 1984), and further reinforces the proposition that any underlying stress and distress experienced by these participants would fuel their general anxiety levels, with potentially adverse effects.

For three participants (4,7,11), the TIA served as a wake-up call, allowing them to redefine their priorities, change their lifestyle and take some control over the crisis. This construct pattern is consistent with appraisal-focused and problem-focused coping, in which the illness is redefined in a positive, constructive way, such that the individual can regain some control (Affleck & Tennen, 1996; Roth & Cohen, 1986; Moos & Schaefer, 1984). Central to these participants' perspectives was the concern to prevent further TIAs or stroke, and reflects a search for mastery and progress towards adaptation (Ogden, 2012). Similar reactions were found in the Q-study, where constructive optimism was indicated in two of the 23 participants. Since low levels of pessimism have been found to be related to reduced likelihood of stroke (Nabi et al., 2010), encouraging

a positive cognitive appraisal strategy might be similarly advantageous to TIA patients, and thus could be incorporated in post-TIA rehabilitation. Certainly, the management of lifestyle is a stated aim of TIA clinics (NICE, 2008), and therefore, capitalising on the wake-up call as a route to reviewing life-habits is likely to be valuable. Furthermore, stroke patients who develop a positive, active coping strategy have been shown to respond better to rehabilitation (Ch'ng et al., 2008; Herrmann et al., 2000; Elmstahl et al., 1996). If these findings apply to TIA patients, then cognitive reappraisal programmes in the immediate post-TIA rehabilitation period might lead to beneficial lifestyle changes and a more positive outlook.

The fifth construct pattern represents a sense of loss of normality and associated sadness (participant 5, 8, 9). Once again, loss (of normality, of a sense of self, of functional capacity and independence) has been reported in stroke patients (Ch'ng et al., 2008; Becker, 1993), and is linked with sadness and depression (Kneebone et al., 2012; Ch'ng et al., 2008). Depression is a well-documented reaction to TIA (Vohra et al., 2008; van Wijk et al., 2007), emerging as Factor 5 in the Q-sort study, and may have implications for coping, especially with activities of daily living (Verbraak et al., 2012). As it is linked with poor psychological adaptation and stress, management of depression should be an essential focus of post-TIA rehabilitation.

The final construct of 'embarrassment', provided by Participant 2, was linked to the cumulative negative impact of the TIA on a wide variety of social functions. This participant had experienced cognitive confusion, unclear speech, and problems with eating and drinking in the immediate post-TIA period, which together generated a level of discomfort that led to her (self-imposed) temporary social isolation. Embarrassment in relation to specific problems such as falling and incontinence has been reported in stroke

patients (Pilcher et al., 2012; Logan et al., 2004a), though to date, no research has highlighted this as a post-TIA reaction. Given that physical symptoms of TIA may include unilateral facial droop, slurred speech, swallowing difficulties and balance problems, it might be expected that, for their duration, these issues could cause embarrassment, social restriction, enhanced anxiety and distress for some individuals.

These findings offer some confirmation of the perspectives found in the Q-methodology study. The RGA revealed a range of psychological sequelae of TIA, which, although analysed at the individual level, demonstrate commonalities across the sample. Some of these reactions (anxiety, sadness/depression) have been well-documented before in relation to TIA, while the constructive optimism implied by the construct 'wake-up call' has received less attention. Those constructs that relate to loss of confidence, embarrassment and the perception of a restricted world are novel and while they are inter-related with the other viewpoints, were sufficiently distinctive to be classified as separate constructs by the analysis. The emergence of these experiences has some appeal, in that they mirror the reactions to stroke documented in the literature. Since TIA may be considered to be a non-disabling stroke (Verbraak et al., 2012) or mini-stroke (Giles et al., 2006), it is possible that responses to TIA are an attenuated form of those experienced post-stroke. This suggestion gains support from research that has compared psychological coping strategies and reactions following a range of illnesses, finding no essential differences between them (Herrmann et al., 2000); in other words, reactions to illness may be broadly generic, with any differences being attributable to pre-morbid personality and demographic factors, rather than to the nature of the illness itself (Herrmann et al., 1997). Therefore, coping strategies and reactions to TIA may be sufficiently similar to stroke that its management and rehabilitation in the acute post-TIA phase could follow the same principles and objectives.

Illness of any sort may disrupt normal functioning, alter the individual's sense of identity and social activity, and require that psychological stability is regained (Moos & Schaefer, 1984). To achieve this, a range of coping strategies is required, which may be appraisal-focused, problem-focused and/or emotion-focused (Affleck & Tennen, 1996; Roth & Cohen, 1986; Moos & Schaefer, 1984). Where patients have been supported in developing an adaptive coping response following stroke, improved rehabilitation outcomes and psychosocial adjustment have been reported (Jones & Riazi, 2011; Ch'ng et al., 2008; Donnellan et al., 2006; Herrmann et al., 1997). No such work has yet been conducted on TIA, possibly because, despite its potential warning of secondary stroke, it is often considered to be minor and transitory (Daffertshofer et al., 2004). Yet many consequences of TIA persist long after the event (Verbraak et al., 2012; Vohra et al., 2008; van Wijk et al., 2007; Anderson et al., 2004) and may have a significant and adverse impact on quality of life (Kessler & Thomas, 2009; Vohra et al., 2008). Together, it would seem imperative that TIA patients' subjective experiences are considered as central to rehabilitation and management generally, and the development of adaptive coping strategies specifically. Certainly, promoting a positive affective response to illness contributes to resilience in terms of both psychological and physical well-being (Moskowitz, 2010). Therefore, the way in which a TIA patient makes sense of his/her experience may well be critical to psychological and physical survival. It should be noted that two participants were unable to complete the task because they reported no effects of the TIA. It is conceivable that these participants were in denial about the event, since in discussion, each revealed that there had been consequences; in particular, one did not travel abroad any more, while the other still had speech difficulties when tired. This would support the findings from the Q-sort.

The study is limited by a number of factors. Firstly, while RGA does not require large, representative samples, and may be undertaken with n=1 (Cunningham, 1998), the small-scale nature and sample-heterogeneity of the current study mean that the findings may not have general application. Secondly, the participants had experienced their TIA between 6 and 24 months prior to the study; while there is no evidence to suggest a link between length of time post-TIA and subjective distress (Winward et al., 2009; Daffertshofer et al., 2004; Gillespie, 1997), the participants were nevertheless relying on memory to respond to the task and this may have influenced their responses. The methodology also depends upon the ability of participants to articulate experiences and perspectives in order to make tacit knowledge explicit; this was initially problematic for some participants. Furthermore, while the technique generated a wealth of subjective data, it is also highly intensive and demanding for both researcher and participant. Consequently, it could not be considered to be a viable measure for use with large groups of TIA patients. However, the findings do suggest that there are sufficient potentially adverse psychological consequences of TIA to merit further attention, both in terms of research and clinical rehabilitation. The similarity between these responses and those to stroke, the link between subjective distress and secondary stroke and the importance of adaptive coping strategies to post-illness psychological and physical well-being together make a cogent case for the use of subjective experiences and perspectives in individualised post-TIA management and rehabilitation.

This study provided the qualitative stage in the development of the risk-assessment scale; the next chapter presents the quantitative element.

Chapter 5

FACTOR ANALYSIS OF THE HADS AND NEADL DATA SET*

5.1: Preamble

The aim of this section is to add to the findings described in Chapters 3 and 4, in order to strengthen the construct and content validity required for sound test development. In particular, this stage is concerned with the statistical analysis of two proprietary psychometric measures that are commonly used with clinical groups, and thus constitutes the quantitative element of the mixed methods approach used here. The introduction to the chapter will provide a brief outline of the analytical procedure used and a review of the psychometric measures involved.

5.2: Factor analysis

Factor analysis is a global term for a range of data-reduction techniques that enable a data-set to be distilled into sub-groups, based on the inter-correlations between the data-points (Child, 2006). It is a conventional preliminary stage in the development of psychometric tests because the technique produces coherent sub-scales which allow the identification of underlying theoretical constructs within the data-set; these, in turn, can be used to inform both the

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construct and content validity of a psychometric measure, thereby ensuring the measure addresses all the explicit and implicit issues that relate to the topic under investigation (Coaley, 2010; Furr & Bacharach, 2007; Pett et al., 2003; Streiner & Norman, 2003; de Vaus, 2002; Kline, 1993; 1986). The procedure is used extensively in the re-validation of existing scales using specific or new populations (eg. Wouters et al., 2012; Rocha et al., 2011), or in the development of new tests and measures (eg. Fountoulakis et al., 2012; von Steinbuechel et al., 2012; Dittrich et al., 2011).

Factor analysis is a complex statistical process which depends on proprietary software (in this case, SPSS). It neither tests hypotheses nor does it look at inter- and intra-group differences. Instead, it is used in a more investigative way to reduce an extensive data-base to the core themes that underpin that data-base (Child, 2006; Pett et al., 2003; Kline, 1993). It differs from other data-reduction techniques, such as Principal Components Analysis (PCA) in a number of ways; for example, in PCA all the variance within the data-set is accounted for when the data-base is reduced, while in factor analysis the sub-groups are determined using only the shared variance (Tabachnick & Fidell, 2007). However, PCA may also be used as a data-reduction technique in its own right or as a stage in factor analysis (as is the case here). Factor analysis techniques may be exploratory or confirmatory; the former technique is typically used in the early stages of questionnaire development to ascertain the underlying sub-groups in the data-base, while confirmatory factor analysis is used to test theories about those sub-groups (Pett et al., 2003; Kline, 1993). As the purpose of the current study is to develop a psychometrically robust preliminary risk-assessment scale, exploratory factor analysis was used.

Before factor analysis can be conducted, three conditions must be satisfied:

- *The data-set must be suitable for factor analysis*

Four principal issues are involved in this stage. Firstly, the sample must be a suitable size, though there is little agreement about what this means. Generally, factors derived from small samples tend not to generalise well, because the correlation coefficients are likely to be unreliable (Pallant, 2007). While Tabachnick and Fidell (2007) recommend using at least 300 cases, other researchers suggest that it is the ratio of cases-to-variables that is critical. For example, Nunnally (1978) suggests a ratio of 10 cases to every item. Usually, however, the larger the sample, the better.

The second issue of concern when assessing the data-set for factorability is the strength of correlations between the items. Correlation matrices are automatically produced as part of the factor analysis output; if there are few correlation coefficients >0.3, then the data-set may not be suitable (Tabachnick & Fidell, 2007).

The third and fourth conditions involve two statistics that are also automatically generated from SPSS factor analysis: Bartlett's Test of Sphericity and the Kaiser-Meyer-Olkin measure of sampling adequacy, which both assess the suitability of the data-base for factor analysis. The Bartlett Test of Sphericity should be significant at $p<0.05$ while the Kaiser-Meyer-Olkin measure provides a range of scores between 0 and 1, with a score of ≥ 0.6 considered adequate for undertaking factor analysis (Tabachnick & Fidell, 2007).

- *Factor extraction*

Factors can be extracted by a number of methods, though the most commonly-used approach is PCA. The number of factors extracted is determined by the researcher according to conventional guidelines and is based on the simultaneous requirements of factor analysis to a) explain as much of the variance as possible in the data-set and b) represent the inter-correlations between the items using the fewest number of factors possible. The methods most commonly used to decide on the number of factors are:

- Kaiser's criterion: this restricts the number of factors that are retained for use to those with eigenvalues ≥1.0. Eigenvalues represent the amount of variance accounted for by each factor and are automatically generated by the factor analysis programme. This technique has been criticised for generating too many factors (Pallant, 2007).
- Cattell's scree test (Cattell, 1966): this involves plotting the eigenvalues for each factor on a graph. Cattell recommends that all factors above the point at which the curve becomes horizontal are retained. However, the lack of precision of this method, and its tendency to produce too many factors, have been raised as concerns by some researchers (eg: Hubbard & Allen, 1987).
- Horn's Parallel Analysis (Horn, 1965): this technique is favoured by many psychometricians and statisticians as it is thought to produce the most accurate number of factors for consideration. The procedure involves comparing the eigenvalues generated by the conventional factor analysis software programme (points 1 and 2 above) with those obtained from a random data-base of the same size. Only those factors with eigenvalues greater than those generated from the random data-base are retained[1].

[1] *The decision about the number of factors retained in conventional item-wise factor analysis differs from that in the case-wise factor analysis used in Q-methodology, because the underlying aims and theoretical assumptions of the two approaches are different. In Q-sort, all the participants' voices are considered of primary importance, while statistical significance is the priority in conventional factor analysis. (Webler et al., 2009).*

- *Factor rotation and interpretation*

The resulting factors must be interpreted. This is a two-part process; firstly the software package rotates the factors to achieve the simplest factor structure, which aids their interpretation. Secondly, the researcher has to make sense of the items that cluster together in each factor, based on knowledge of those items and their likely meaning in the research context (Child, 2006; Pett et al., 2003; Kline, 1993). SPSS offers two broad types of rotation, each of which is founded on slightly different assumptions; it is the researcher's responsibility to decide which type of rotation best fits the needs of the research. The first main type of rotation, known as orthogonal ('Varimax') rotation, produces sets of factors that are uncorrelated with each other (as in Q-methodology). Because the factors are uncorrelated they tend to be clearer, more distinct and easier to interpret, but to justify the use of this method the researcher must make a case in advance of the analysis that the underlying factors are independent of each other (Tabachnick & Fidell, 2007). The second type of rotation is called oblique ('Oblimin') and is based on the assumption that the factors correlate with each other to some degree. The resulting factors may be less clear and hence more difficult to interpret (Tabachnick & Fidell, 2007). As the objective of factor analysis is the production of a set of factors that have clear meaning, it can be tempting to use an orthogonal rotation. However, because it may be difficult to make a convincing case that the factors will be uncorrelated, an oblique rotation is usually used in the first instance (Pallant, 2007); in practice, though, orthogonal and oblique rotations of the same data-base tend to generate similar outputs (Pallant, 2007).

Following factor analysis, the internal consistency of each factor should be calculated using Cronbach's α (Pallant, 2007). This measures the extent to which the variables that load onto the factor all measure the same construct; Cronbach's α should be >0.7 for a factor to be considered reliable (De Vellis, 2003). However , the coefficient may be distorted by the number of items

loading on the factor; where factors are composed of fewer than 10 items, low α scores may result (De Vellis, 2003).

The application of all the above criteria and conditions to the current study will be outlined at each of the relevant stages below.

5.3: The HADS and NEADL tests (Appendices 4 and 5)

The Hospital Anxiety and Depression Scale (HADS - Zigmond & Snaith, 1983) is used as a screening tool to identify mood disorders in clinical populations. It was designed with the specific intention of detecting aspects of anxiety and depression outside the scope of common, somatic symptoms of general illness, such as fatigue and insomnia/hypersomnia (Snaith, 2003). It comprises 14 questions, seven relating to anxiety and seven to depression; while the overall score assesses mood disorders, the two sub-scales have been classed as independent measures. Although its name suggests it is a screening tool used only in hospitals, it has validity in both community and primary care settings (Snaith, 2003). Participants are asked to answer the scale based on how they have felt in the last week. Scoring uses a 4-point Likert scale (from 0-3) with a total possible score of 21 for anxiety and 21 for depression. Scores between 0-7 are considered to be within normal range; between 8-10 is suggestive of the presence of anxiety or depression; and scores of ≥11 indicate a mood disorder (Zigmond & Snaith, 1983). Bjellend et al (2002) conducted a systematic review and concluded that the cut-off point for both anxiety and depression was a score of 8 out of 21, resulting in a specificity of 0.78 and sensitivity of 0.9 for anxiety, and a specificity of 0.79 and a sensitivity of 0.83 for depression.

HADS has been used in a range of clinical studies, for instance, back pain (Trudeau et al., 2012), cancer (Mitchell et al., 2010) and multiple sclerosis (Atkins et al., 2012). While Turner et al. (2012) found high internal reliability, a systematic review of 50 articles using the HADS conducted by Cosco et al. (2011), suggested that the underlying structure of HADS remains unclear. The authors suggest that although it is an effective measure of emotional distress it is unable to consistently distinguish between anxiety and depression, and therefore may be better employed as a measure of general distress. As yet, few studies have validated the use of HADS with stroke populations despite post-stroke depression being a well-documented problem, although Kang et al. (2012) confirmed the discriminating abilities of the HADS are good with mild-to-moderate stroke patients.

The Nottingham Extended Activities of Daily Living Scale (NEADL) was designed to assess the functional independence of patients once discharged from hospital, with answers reflecting what the individual has actually done in the weeks prior to completion of the assessment; it is therefore a record of activity rather than a test of capability (Nouri & Lincoln, 1987). The scale consists of 22 activity items divided into four categories: mobility; kitchen; domestic; and leisure (see Appendix 5). A maximum score of 22 can be obtained, with higher scores indicating greater levels of functionality and independence. The NEADL has frequently been used to assess functionality in stroke patients (Harwood & Ebrahim, 2002), and independence post-stroke (Crosby et al., 2012). The scale has been shown to be both reliable (Nouri & Lincoln, 1987) and valid (Lincoln & Gladman, 1992). Its value for follow-up studies of functional independence has been demonstrated (Rouillard et al., 2012; Nouri & Lincoln, 1987).

5.4: Data collection

Data from the HADS and NEADL tests were collected as part of a larger on-going national study on TIA (FACE-TIA), the aims of which were to assess the impact of TIA on physical, cognitive and affective state, the relationship between them and their duration (Sackley et al., 2010). The questionnaires were administered by post at baseline (within 4 weeks of the patient consenting to the study), and at regular intervals thereafter, using stamped addressed return envelopes. Because the subsequent measurement points would extend beyond the time-frame for this thesis and there was a possibility of sample attrition, the factor analysis conducted here used only baseline data.

5.4.1: Ethics

Ethics approval was obtained via the National Research Ethics Service (Birmingham, East, North and Solihull) prior to the start of the FACE-TIA study (Ethics Reference Number 10/H1206/36).

5.4.2: Participants

Participants were recruited from 12 TIA clinics and 4 GP practices in the West Midlands. While the FACE study collected data from confirmed TIA patients, TIA mimics and matched controls, the current study was only concerned with the confirmed cases. Clinical diagnosis was made within 2 weeks of the event, within the TIA clinic by a neurologist or Stroke Physician; for all participants, this was a first occurrence. Using these inclusion criteria, together with the ability to self-complete questionnaires, 642 patients were recruited. Of these, 301 were female and 341 were male; mean age was 68.65 years (range 96-42). With this sample size, the fourteen items of the HADS and the 22 from the NEADL, the ratio of participants to items was >17:1 and therefore exceeds the 10:1 requirement recommended by Nunnally (1978).

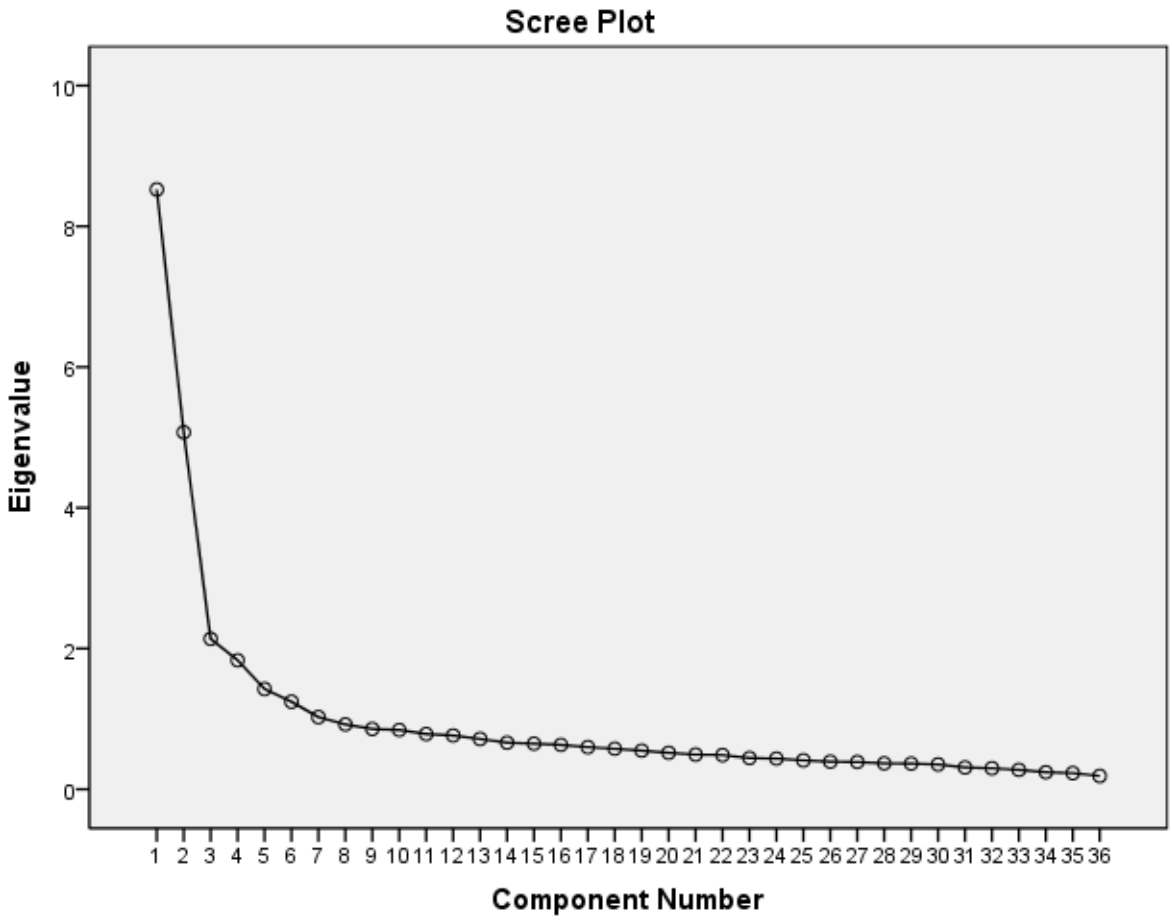
5.4.3: Procedure

Individual item scores from the HADS and NEADL were entered onto an SPSS data-base and factor-analysed. As the intention of the thesis was the development of a questionnaire with robust construct validity, exploratory factor analysis was considered appropriate here (Pett et al., 2003; Kline, 1993). An oblique (Oblimin) rotation was used as no *a priori* case could be made for independent factors. Cronbach's α coefficients were then calculated for each factor, to check their internal consistency.

5.4.4: Results

The factorability of the data-base may be confirmed firstly by the results of Bartlett's Test of Sphericity, which produced a p value of<.0.000 (required cut-off value <0.05 or less), and secondly by Kaiser-Meyer-Olkin Measure of Sampling Adequacy; this value was 0.9, which exceeded the cut-off point of ≥0.6 (Tabachnik & Fidell, 2007). The correlation matrix demonstrated a number of values ≥0.3, thus confirming the factorability of the data-set. The number of factors extracted using the conventional Kaiser's criterion of eigenvalues ≥1.0 and Cattell's scree plot was 7 in each case (see Figure 5.1).

Figure 5.1: Cattell's scree plot to determine the number of factor extracted



However, this number was checked using Horn's (1965) Parallel Analysis, which requires a comparison of the eigenvalues obtained from the actual factor analysis with those obtained from a similar-sized random data-set. Only those factors from the factor analysis with eigenvalues that are larger than those from derived the parallel analysis are retained. The findings are as follows:

Table 5.1: Parallel Analysis to determine the number of factors extracted

Component Number	Actual eigenvalue from factor analysis	Criterion value from parallel analysis	Decision
1	8.524	1.4755	Accept
2	5.073	1.4185	Accept
3	2.137	1.3750	Accept
4	1.834	1.3389	Accept
5	1.425	1.3051	Accept
6	1.244	1.2757	Reject
7	1.025	1.2468	Reject

This comparison indicated that only the first five factors should be retained for interpretation and therefore, the relevant information from these factors is presented in Table 5.3. It should be noted that variables marked with * are NEADL items, while those marked with ** are HADS items.

Table 5.2: Structure Matrix for Oblimin Rotation of HADS and NEADL scores

Factor	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**	**Factor 5**
Factor name	**Impact on external mobility**	**Emotional Distress**	**Nutritional self-sufficiency**	**Functional impact**	**Life impact – leisure**
% variance explained	23.679	14.091	5.936	5.094	3.959
Cronbach's α	0.776	0.891	0.787	0.840	0.571
Cross roads *	.764				
Walk on even ground*	.758				
Climb stairs*	.715				
Walk around outside*	.689				
Get in and out of car*	.625				
Manage own garden*	.543				
Go out socially*	.526				
Feel scared/frightened**	-.476	.414			
Drive car*	.461				
Do own shopping*	.454			-.422	
Travel on public transport*					
Feel as if slowed down**		.788			
Feel miserable or sad**		.770			
Lost interest in things**		.763			
Wake early/sleep badly**		.741			
Feel life is not worth living**		.733			
Have a good appetite**		- .732			
Feel anxious out of house on own**		.650			
Palpitation/butterflies in stomach/chest**		.633			
More irritable than usual**		.617			
Restless/can't keep still**		.544			
Very frightened/panic for no reason**		.527			
Still enjoy things I used to**		-.506			
Worrying thoughts constantly in mind**		.506			
Manage to make hot drink*	.317		-.721		
Take hot drinks from one room to another*			-.633		
Manage to feed self*			-.553		.387
Wash small items of clothing*				-.884	
Do full clothes wash*				-.867	
Do own housework*				-.736	
Do washing up*			-.418	-.590	
Make hot snack*			-.418	-.545	
Read papers/books*					.784
Use telephone*					.772
Write letters*					.540
Manage money if out*					.499

6.5: Discussion

The factor analysis generated 5 factors which together accounted for 52.759% of the total variance. Factor 1 (23.679% of the variance) primarily comprised tasks from the NEADL that involved the ability to move around outside the home. This has been labelled 'Impact of TIA on External Mobility' and accords with the NEADL's mobility category. Cronbach's α of 0.776 suggests this factor is internally consistent and that all the variables are measuring the same construct. The variables loading positively on this factor include: crossing roads, walking over uneven ground, climbing stairs, walking outside, getting in and out of a car, managing the garden, going out socially, driving the car, doing the shopping, and taking hot drinks from one room to another. The single variable that loaded negatively came from the HADS 'I feel as if I am slowed down'. The negative loading of this factor is logical, since respondents who did not feel slowed down would be able to undertake the NEADL activities loading on this factor. The restrictions on movement outside the home indicate the physical impact of TIA on daily functioning, and in this regard are allied to Factor 6 from the Q-methodology ('Impact of Physical Symptoms'). Factor 1 also links with the constructs relating to loss of confidence, loss of normality and life restriction generated by the Repertory Grid Analysis (RGA) study (Chapter 4). These constructs incorporated issues such as a perceived need to slow down, a loss of independence and an inability to take foreign holidays, drive or go to social events The impact on mobility, whether it is real or perceived, will inevitably impact on quality of life, personal independence and routine functioning of TIA patients and confirms that its consequences are neither minimal nor transient. Moreover, research with stroke patients has shown that activities outside the home, such as driving and travelling are particularly problematic, often through loss of confidence (Barnsley et al., 2012; White et al., 2012; Logan et al., 2004a). The conceptualisation of TIA as a mini-stroke would suggest that TIA patients might experience similar reactions, though to a lesser degree.

Factor 2 (14.091% of the total variance) comprised all 14 items from the HADS scale, which loaded positively on the factor[1]. It has consequently been labelled 'Emotional Distress'. Its Cronbach's α coefficient was 0.891 indicating a very high degree of internal consistency, and confirms Turner at al.'s (2012) findings. The combination of both the anxiety and depression items within this single scale is interesting in itself, since the HADS is intended to measure these affective states as separate, distinguishable sub-scales (Zigmond & Snaith, 1983). The current factor structure challenges this claim, though it does add support to Cosco et al.'s (2011) conclusions that the underlying structure of HADS is not clear, since it is unable to consistently differentiate between depression and anxiety, and instead measures more general emotional distress. While the current study corroborates this, Factor 2 nevertheless confirms that TIA patients experience significant emotional reactions consequent upon the TIA and is consistent with the findings from the previous two studies. The Q-sort, with its factors of anxiety (Factor 3) and depression (Factor 5), and the RGA with constructs of anxiety, sense of loss and sadness, fear for the future, and disappointment, all suggest that TIA patients experience some profound emotional reactions to the TIA. Both anxiety and fear for the future are causally associated with full stroke (Fiedorowicz et al., 2011; Katan et al., 2011; Ch'ng et al., 2008). Similarly, depression is an established correlate of TIA (Vohra et al., 2008; van Wijk et al., 2007) as well as being a significant risk factor for secondary stroke (Bos et al., 2008; May et al., 2002). Therefore, it would seem essential that TIA patients with high levels of subjective distress are identified for targeted emotional support.

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[1]*It should be noted that while two HADS items are constructed positively ('I have a good appetite' and 'I still enjoy the things I used to'), the scoring for these is reversed, such that high scores indicate the respondent does not agree with the statement. Hence a high score on these would be consistent with high scores on all the remaining negatively worded items and is indicative of an adverse affective state.*

Factor 3 (5.936% of the variance) comprised 5 items, all from the NEADL, and had a Cronbach's α score of 0.787. The five variables were all negatively loaded and included making a hot drink, taking hot drinks from one room to another, managing to feed oneself, do the washing up and make a hot snack. Their focus on eating and drinking provided the label 'Nutritional Self-Sufficiency' and confirms the NEADL category of 'Kitchen'. Two points are of importance here. Firstly, the scale has very high internal consistency, despite only containing 5 items; factors with fewer than 10 items are susceptible to very low α coefficients (De Vellis, 2003). This means all the items were measuring the same underlying construct of nutrition. Secondly, all the items negatively loaded on the factor, which because of the NEADL's scoring system, suggests that undertaking these tasks were not an issue for these TIA patients[1]. There is no research literature that has specifically highlighted food management and its associated activities, as problems post-TIA; moreover, the Q-methodology and RGA did not reveal this as an issue. Therefore, this factor may not be a relevant concern for TIA patients.

Factor 4 (accounting for 5.094% of the variance) had a Cronbach's α coefficient of 0.840 and comprised 6 negatively loaded items, all from the NEADL. The items included shopping, washing small items of clothing, doing a full wash, doing housework, doing the washing up and making a hot snack. Because of their focus on everyday activities, this factor has been labelled 'Functional Impact' and mirrors the NEADL scale of 'Domestic'. As with Factor 3, the degree of internal consistency was very high, despite the fact that the number of variables loading on the

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[1] *Again, this differs from the interpretation that was given to the negative variable loadings in the Q-sort. The differences here are attributable to the way in which each item was measured. In the Q-sort, a negative loading meant 'strongly disagree' and therefore had experiential meaning for the participants who used this score. Here, because of the way in which the NEADL is scored, the negative loadings meant that the tasks posed no problem ie: were not relevant to participants' experience of TIA and as such would equate to the mid-range 'neither agree nor disagree' scores of the Q-sort.*

factor was fewer than 10; this indicates that these items were all measuring the underpinning construct of ability to manage routine daily tasks. However, like Factor 3, the variable loadings were all negative, indicating that undertaking these tasks were not problematic for this sample of TIA patients. The Q-methodology and RGA studies did not reveal any evidence that specific daily chores were problematic post-TIA and nor is there any other research literature which suggests this is the case. Consequently, this factor may not have particular relevance for these patients.

Factor 5 (accounting for 3.959% of the total variance) had a Cronbach's α coefficient of 0.571. Five NEADL items loaded positively on this factor and included managing to feed oneself, read newspapers or books, use the telephone, write letters and manage money. It has been labelled 'Impact on leisure and social functioning' and is similar to the NEADL category of 'Leisure'. However, the α coefficient is below the statutory cut-off point needed for internal consistency, which may be a consequence of the low number of items loading on the factor. It does suggest that the items are not measuring the same construct and inspection of these confirms their range and lack of coherence. However, examination of the individual items indicates some link with the findings from the Q-methodology and the RGA; in the former, Factors 4 and 6 included statements that related to communication difficulties, while two participants in the RGA identified communication difficulties. These could underpin problems in using the telephone (item 18, NEADL), while the cognitive fuzziness noted in both studies could impact on the ability to write, read and manage money (items 19, 17 and 12, NEADL). Van Wijk et al. (2007) also noted cognitive problems post-TIA.

This factor analysis confirms the physical and affective impact of TIA for patients (Factors 1 and 2), though Factors 3 and 4, relating to selected activities of daily living, had little relevance for the sample. The final factor may be explained by some further consideration of what might underlie the item clustering and in this sense, could be seen to confirm some of the findings from the previous two studies. Of interest is the fact that the factor analysis suggests that for the most part, the NEADL comprises coherent and highly internally reliable sub-scales, even when they contain fewer than 10 items. In contrast, the HADS did not produce distinguishable sub-scales for anxiety and depression, but instead suggested a more general reaction of emotional distress. Also worth noting is that despite using an oblique rotation, there was very little overlap between the variable loadings, with only Question 8 from the HADS appearing on more than two factors (Factors 1 and 2); this suggests the factors are discrete and unrelated to each other. Secondly, all questionnaire items loaded significantly on a factor, with the exception of question 6 from the NEADL – travelling on public transport. This item may be considered an orphan item, with little relevance to this sample. The factor analysis has therefore yielded some useful factors, of which the first two, with their significant internal consistency and positive variable loadings, have clear relevance for the risk-assessment questionnaire. Factors 3 and 4, with negative loadings (and hence irrelevance), and Factor 5, with non-significant internal reliability, were not considered useful.

The next chapter incorporates these findings and those from Chapter 3 and 4, into the development and description of the risk-assessment scale.

Chapter 6

THE PRELIMINARY RISK-ASSESSMENT TOOL

6.1: Preamble

The aim of this chapter is to bring together the findings of the previous three studies, to form the screening tool, and to pilot it for its usability. To justify the way in which this was done, an overview of the principles of questionnaire design is presented. With regard to the selected format of the questionnaire, the manner of its intended use was relevant to the decisions taken. As the primary purpose of the risk-assessment scale is to capture post-TIA reactions when patients present either to GP practices or TIA clinics, the questionnaire will usually be completed at this point. Therefore, as it will typically not be administered by post or email, patients will have the opportunity to discuss any points of concern or confusion with available Health Care Professionals (HCPs). These points informed, in part, the construction and style of the questionnaire.

6.2: Questionnaires – some basic principles of design

Questionnaires have been described as a 'quick fix for research methodology. No single method has been so abused' (Gillham, 2000, p1). Yet provided the questionnaire is developed along proper principles, it has an important role in collecting a large amount of information relatively easily and cheaply. A considerable amount has been written about questionnaire design (eg: Robson, 2011; Bowling, 2009; Dawson, 2007; Boynton & Greenhalgh, 2004; Gillham, 2000; Oppenheim, 2000); this section will therefore provide a brief summary of the main points.

Depending on the purpose, questionnaires can follow a structured (closed-response) or unstructured (open-response) format, the former providing some measure of objectivity and comparability within and between respondents, and the latter offering a richer subjective response range. While structured questionnaires may narrow and control the focus of the research, they are easier to administer and analyse and consequently, are the typical format of choice (Robson, 2011; Dawson, 2007; Gillham, 2000). The advantages of questionnaires are numerous. They are relatively cheap, quick and easy to administer because they can be posted or emailed, enabling the researcher to access large samples; because there is usually no demand for the questionnaire to be completed immediately, it can be answered at the respondent's leisure; the questions are standardised and objective, making them less vulnerable to researcher bias and facilitating within/between comparisons; the answers can be anonymised and are usually easy to analyse because of numerical scoring keys (Robson, 2011; Boynton & Greenhalgh, 2004; Gillham, 2000). However, there are disadvantages too. Unless the instructions are clear and the questions totally unambiguous, there is the possibility that respondents will either omit questions or misinterpret them, thereby compromising the data-set; many target populations (in particular, patients) are saturated with questionnaires, which may reduce the return rate (Gillham, 2000); the quality of the data obtained is only as good as the questionnaire used, with large numbers of complex, poorly-worded questions compromising the data-set; there is no guarantee that the answers are honest or have been answered with sufficient care or thought; and they cannot be self-administered by anyone who has literacy problems or physical impairments (Robson, 2011; Boynton & Greenhalgh, 2004; Gillham, 2000). Consequently, a short, clear, interesting questionnaire that has some meaning for the respondent is more likely to generate an adequate response-rate and honest, accurate replies (Bowling, 2009; Dawson, 2007; Gillham, 2000).

The quality of the questionnaire is therefore of paramount importance if the data-set is to have any value. The foregoing drawbacks of questionnaires inform the principles of design

that need to be considered when constructing self-completion questionnaires. Firstly, the information to be collected must be defined clearly and must cover the range of topics that are relevant; these topics should be objectively justified, so that the resulting questionnaire does not simply cover the issues the researcher considers relevant (Robson, 2011; Gillham, 2000; Oppenheim, 2000). In practice, this means that the themes should emerge from focus-groups, interviews, and the available research literature, in order to provide some validity (Boynton & Greenhalgh, 2004; Oppenheim, 2000). The questionnaire must be also reliable (see Chapter 2) and the nature of the questions (closed or open-ended) must reflect the purpose of the questionnaire (Oppenheim, 2000).

Whichever type of question-format is used it must be fit for purpose, the questions must phrased clearly, succinctly, simply, unambiguously, should avoid double negatives (Oppenheim, 2000), and be specific rather than general (Robson, 2011). The way in which the responses are measured must reflect the purpose of the research. Simple YES/NO tick box answers provide basic nominal data and while they are easy for the respondent to complete and the researcher to analyse, provide only limited information. Scaled responses, such as ordinal Likert scales (usually between 4 and 7-points) or visual analogue scales (an unmarked 10-cm line which can be treated as interval/ratio data), provide more information and extend the possible range of analytical processes (Robson, 2011). However, if the response-type chosen uses a mid-point in the scale to measure a neutral perspective (eg: 'don't know'/'no opinion'/'neither agree nor disagree'), there is evidence that around 20% of respondents will select this option if it is available (Robson, 2011); therefore, where a non-committal answer which obscures a real viewpoint might compromise the study, it may be preferable to eliminate this option and force the choice instead (Robson, 2011). Likewise, where the answers involve some measure of agreement or disagreement with a statement, acquiescence response-sets may occur, with some participants simply agreeing with everything, irrespective of the wording. Using forced-choice items mitigate

this (Robson, 2011; Gillham, 2000). Biographical details may be requested, though the detail of these will depend on the purpose of the study (Robson, 2011; Dawson, 2007). Questionnaire layout should be simple, as should the covering instructions and letter (Robson, 2011; Dawson, 2007). These principles are outlined in Table 6.2 as a checklist adapted from Dawson (2007), illustrating their application to the current study.

6.3: Thurstone's Paired Comparison Method

Of particular relevance to the current study is the Thurstone Paired Comparison (TPC) method (Thurstone, 1927). This long-established technique has been used in a variety of settings, including health-care (eg: Brown et al., 2009; Jerome et al., 2009; McKenna et al., 1981; Hendel, 1975). The technique provides a way of eliciting priorities, attitudes and preferences through forced-choice comparisons and therefore facilitates weighted answers which allow a measure of how significant that topic is to the respondent (Bernheim, 1999; Allen & Locker, 1997). In essence, the method involves identifying core themes that are relevant to the research topic and then pairing each theme with every other, along a scaled dimension; this allows the respondent to be located along a psychological or subjective continuum in relation to the research topic. For each set of paired themes, the respondent has to identify which applies more to his/her own perspective. Thus it can be construed as a binary-choice method (Brown & Peterson, 2009). The scores given to each theme are added up to give a total score for that theme, allowing the themes to be rank-ordered for subjective importance. While it is possible for respondents simply to look at a set of themes and rank-order them, this approach to rank-ordering may be made difficult if there are a lot of themes, with the participant becoming increasingly unable to differentiate between them (McKenna et al., 1981). Nunnally suggests that people are simply "not accustomed to making absolute judgments in daily life, since most judgments are inherently comparative" (Nunnally, 1976, p40) and this may lead to inaccuracy and unreliability in absolute rankings or judgements. The TPC method offsets this problem. By

repeatedly comparing each topic with every other, the respondent's focus is restricted to just two topics at a time; this makes each comparison unique and demands a new and meaningful judgement (McKenna et al., 1981). Consequently, the participant's potential for differentiation is enhanced and the possibility of meaningless answers is reduced. Furthermore, if a respondent only has to respond to, or assess, an item or question once (as is the case with most questionnaires), there is the possibility that random factors will influence the answer; by repeatedly pairing a single concept with every other, the respondent has to respond to that item several times. This means that chance fluctuations will be normally distributed across the responses, providing a reduction in random error and a more stable data-set (McKenna et al., 1981).

It is important to note that the TPC method forces the participant to choose the relative importance of one theme over the other and so an even number of points on the scale is used (usually 8). This avoids selection of the mid-point value and therefore prevents neutral responses. This method increases the potential for obtaining maximum information about the participant's subjective views, and is supported by the Theory of Stochastic Preference, which proposes that the probability of actual indifference experienced by an individual at any one time is minimal (Brown & Peterson, 2009). Whilst forcing participants into a decision is useful for eliciting meaningful responses, it does not permit individuals *not* to have an opinion or to demonstrate neutrality towards the items presented. Consequently, this may lead to response-distortion, though this would apply to any scale using equal interval-points.

In practice, the TPC method is relatively simple to design and administer. A set of items is identified following the principles of validity outlined in Chapter 2, and each item is then randomly paired with every other. It is essential that all possible pairing combinations are provided. Two items are positioned at opposite ends of the 8-point scale; the points are

equidistant and unlabelled apart from the poles. Respondents are then forced to make a choice between one item over another in each pairing, according to the degree to which the items reflect subjective experience. Each item-pairing elicits two scores, one for each of the paired items. Scores are calculated by counting the number of marks on the scale, from either the far left or far right, to the respondent's answer. For example, a respondent might be given the following paired-comparison item:

When there is a thunderstorm, which reaction is more like yours?

|_____|_____|_____|_____|_____|_____|_____|

Storms make feel frightened

Storms give me a headache

The respondent is asked to make a mark on one of the vertical lines to indicate the salience of one of these concepts relative to his/her own feelings. Here the hypothetical respondent has made a mark at the third point from the left, which indicates that feeling frightened is more relevant than developing a storm-induced headache to this person. To score this response, the number of marks from the left would be counted and attributed to the left-hand concept ('Storms make me feel frightened'); here the mark is the third one from the left, so this theme would get a score of three. Then the number of marks from the right-hand pole would be counted and attributed to the concept at that side of the dimension; here, the mark is 6 points away from 'Storms give me a headache' and so this theme scores 6. This method of scoring is repeated for all the paired items. To achieve the final scoring, the scores for each theme are added up and then the total scores are rank-ordered. The lower the total the more important that theme is to the respondent. When determining priorities for intervention, it would be possible to use either the rankings alone (for instance, the top 1 or 2 ranked themes) or

in the event of skewed scores, a combination of rankings and actual scores. These decisions would have to be decided on the basis of the distribution of scores in conjunction with rankings and clinical judgement; it is anticipated that with further development, the scoring protocol would become easier and clearer to interpret. The scoring is relatively quick and easy to complete and the weightings attached to each theme can provide the clinical team with information about the focus of post-TIA management.

6.4: Designing the Risk-Assessment Scale

The general principles of questionnaire design (Section 6.2), together with the specific principles that apply to the TPC method (section 6.3), were used to develop the risk-assessment scale. Themes relevant to samples of TIA patients were identified from the Q-sort, RGA and factor analysis; to justify inclusion as themes in the paired-comparison questionnaire, the degree of overlap had to be assessed (Coaley, 2010; Rust & Golombok, 1999). It was essential that the number of themes was comprehensive, but not too numerous, since each had to be paired with every other. For example, 5 themes would give rise to $4+3+2+1 = \Sigma 11$ pairings or questions, while 10 themes would give rise to $9+8+7+6+5+4+3+2+1 = \Sigma 44$. Clearly, to meet the dual requirements of brevity and coverage, the themes obtained from the previous studies had to be distilled to a reasonable number, so that the resulting questionnaire would be neither onerous nor too limited. Rust and Golombok (1999) recommend a grid approach for this purpose and this is presented in Table 6.1.

Table 6.1: Themes obtained from the Q-sort, RGA and factor analysis

	Theme	Q-sort	RGA	Factor analysis	Number agreeing (accept/reject for inclusion)
1	Lack of knowledge/awareness of TIA	√			Reject
2	Life impact	√	√	√	3 (accept)
3	Anxiety	√	√	√	3 (accept)
4	Interpersonal impact	√	√	√	3 (accept)
5	Depression	√	√	√	3 (accept)
6	Physical consequences	√	√	√	Reject – focus of the questionnaire is *psychological* consequences
7	Cognitive avoidance/denial	√	?*		See 6.4.1
8	Constructive optimism	√	√		2 (accept)
9	Loss of confidence	?*	√		See 6.4.1
10	Frustration	?*	√		See 6.4.1
11	Embarrassment	?*	√		See 6.4.1

** ? denotes this theme may have been subsumed under a more generic issue emerging from this study*

6.4.1: Rationale for theme selection

For the purpose of assessing the overlap between results from the three studies, Factors 3 and 4 ('Nutritional Self-Sufficiency' and 'Functional Impact') from the factor analysis were excluded; since all the variables loaded negatively, this indicated limited salience for the participants. Furthermore, the actual meaning of the themes obtained from the previous three studies needed to be considered when assessing their degree of accord. For example, participants reported loss of confidence that prevented them from undertaking other activities, while embarrassment about indistinct speech or a temporarily drooping face, for instance, made social activities difficult for others. By referring back to the participant narratives, the component statements and commentary, it could be seen that some of the themes outlined in Table 6.1 were offshoots of over-arching, global themes. It was also hypothesised that if a TIA patient was in

denial about any consequences of the event, then it would self-evidently be the case that he/she would reject any statement directly addressing this. Moreover, it might be expected that such patients might also respond to all the paired-comparisons by using the middle-range scores, thus indicating that none of themes had particular relevance for them. Where this occurs, it would seem preferable to attempt to determine cognitive avoidance by looking the paired-comparison data in combination with other evidence – for example, whether the patient had been prescribed anti-depressants, was notably fatigued or whether he/she reported any change in behaviour that could be attributable to the TIA (eg cancelling an overseas trip); alternatively (or additionally), a partner or carer might be asked to complete the questionnaire on the patient's behalf. Finally, it should also be emphasised that the focus of the risk-assessment scale was the *psychological* impact of TIA on the patient, rather than its physical or clinical impact, which could be recorded by other means; therefore, issues relating to clinical/physical sequelae were omitted. The choice of wording of the themes had to be simple and suitable for a predominantly elderly population, comprising both men and women. Therefore, using emotional words such as 'distress', for example, might have been automatically rejected by the males because of their tendency to reject extremes of health-related emotion (Ogden, 2012). Therefore, the selection of themes for inclusion in the final questionnaire focused on the subjective, psychological reactions alone.

Taking these points together, the following decisions were made. With regard to theme 1, lack of knowledge and awareness is an issue that needs to be addressed in advance of a TIA occurring via a Health Education Campaign, rather than retrospectively. Furthermore, while there is evidence of the general lack of public awareness of stroke and TIA (Maasland et al., 2011), it was only recorded by the Q-sort study. This theme was therefore eliminated. Theme 2 – Life Impact – was confirmed by all three studies, albeit in slightly different ways; closer examination of the components that comprised this factor suggested that once the physical issues relating to this were eliminated, a sense of a restricted world was the key theme.

Therefore, these sub-components informed the final choice of 'life limitation'. Anxiety and depression were common to all three sets of findings and were included in the final selection of themes. Interpersonal issues were also recorded by all three studies and informed the theme relating to meeting people. Constructive optimism was recorded by two studies (the Q-sort and RGA) and provided the theme 'wake-up call'. Loss of confidence was a component of themes that emerged from both the Q-sort and the RGA, and reflected the respondents' sense that their bodies had let them down and that they were unable to continue as normal. This gave rise to the theme 'loss of confidence'. The final theme reflected the frustration implicit in the physical limitations, restricted world and social problems and explicit in the components of factors emerging from the Q-sort and RGA and was labeled 'frustration'. Therefore, using the stem of:

'After the TIA, I felt…',

the themes outlined in Table 6.2 were constructed:

Table 6.2: Final theme selection

Theme 1: 'my life had become more limited' ***(Life Impact)***
Theme 2: 'worried' ***(Anxiety)***
Theme 3: 'upset' ***(Depression)***
Theme 4: 'I didn't want to meet people' ***(Interpersonal issues)***
Theme 5: 'I had been given a wake-up call' ***(Wake-up call)***
Theme 6: 'I lost confidence to do the things I usually do' ***(Loss of confidence)***
Theme 7: 'Frustrated with what I could do' ***(Frustration).***

These seven themes gave a total of 21 paired items, each item appearing six times in total, three on the left-hand pole and three on the right. The items were randomly organised. In constructing the questionnaire, Dawson's (2007) checklist was used as guidance. This can be seen in Table 6.3.

Table 6.3: Checklist of questionnaire design principles adapted from Dawson (2007)

Dawson's checklist	**Action taken in development of the Risk-Assessment Scale**
Make questionnaire as short as possible	Seven themes identified, leading to 21 items
Ensure respondents will be able to answer the questions	The scale was piloted
Do not assume specialist knowledge	The focus was subjective experience
Start with easy questions, leaving the complex ones till the end	The questions were uniformly easy to answer throughout
Ask for personal information at the end to avoid creating demand characteristics	The biographical data section at the beginning, because the potential for demand characteristics was minimal.
Use a mix of question formats	The question format had to remain constant because of the nature of the method selected
Don't cause offence, frustration, sadness or anger	The themes used in the items were worded in a non-extreme way
Avoid double-barrelled questions	Not applicable
Avoid words with emotional connotations	The emotion-related themes were kept non-provocative
Avoid negative questions	Not applicable
Avoid jargon and technical words	No jargon or technical language was included
Avoid words with multiple meanings	No ambiguous language was used
Avoid leading questions	Not applicable
Avoid vague words such as 'sometimes' and 'often'	No vague words or terms were used
Provide all possible answers to closed-response questions	Not applicable
Consider as many alternatives as possible	Each theme was paired with every other
Use specific time frames when asking about behaviour	The time-frame was specified in the instructions
Use specific place frames	Not applicable

6.5: The Pilot Risk-Assessment Scale

Using the principles outlined above, the themes were randomly paired, each one with every other, using an 8-point scale to avoid a tendency to choose the non-committal mid-point score. The maximum possible score a theme could obtain would be a score of 8 x 6 occurrences (∑48) and the minimum would be a score of 1 x 6 occurrences (∑6). The final questionnaire pack comprised the components outlined in Table 6.4:

Table 6.4: Final Components of the Risk-Assessment Scale

- a covering information letter to explain the purpose of the study, the right to withdraw and how the data. This covering letter would only be used in the further stages of psychometric development; once the scale's properties have been established and it is in clinical use, no letter would be required. Note further that the address, date and signature are only indicative here (Figure 6.1 below).
- a set of instructions for completion was provided, together with an example; note that the text in blue was added following the pilot trial (Figure 6.2 below).
- a bio-data section was included. While it is anticipated that the risk-assessment scale would typically be completed in the GP's surgery or the TIA clinic where full medical and biographical records would be available, it was also conceivable that these questionnaires might occasionally be posted to patients for self-completion and therefore an easily-available record would be desirable. Names were not requested, but a numerical patient-identifier was used to cross-check the questionnaire scores with clinical information and also in the event of a re-test (Figure 6.2 below).
- The full 21-item questionnaire (Figure 6.2 below).
- A score-chart was provided, so that the scores attributed to each item could be recorded by the researcher or health care professional, totaled and then rank-ordered to establish which theme(s) were considered most important to the respondent; guidance for interpreting the scores is included in this section (Figure 6.3 below)

Figure 6.1: Indicative covering letter for the next stages of psychometric development

UNIVERSITY OF BIRMINGHAM

REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – QUESTIONNAIRE

Dear Patient,

There is some evidence to suggest that a patient's experience of Transient Ischaemic Attack (or TIA) can affect how well he or she recovers. You have been given this letter because you have been diagnosed with a TIA. The letter is inviting you to complete a short questionnaire about your own experiences of having a TIA. The questionnaire takes about 10 minutes to complete. There are no right or wrong answers; we are just interested to know about how you felt, especially just after your TIA. Your answers will be kept completely confidential, but they could help us provide the most suitable aftercare for you. You do not have to complete the questionnaire, but if you decide to complete it you can still withdraw at any point. Your care will not be affected if this is what you decide.

If you choose to complete the questionnaire, you can ask any questions you might have or you can discuss your answers with anyone in the health care team; they will be happy to help.

We hope that you will decide to complete the questionnaire, because your answers will help us provide you with the best possible care and support.

Thank you for your help.

[Appropriate signature]

Figure 6.2: Risk Assessment Scale

2013

REACTIONS TO TRANSIENT ISCHAEMIC ATTACK

AN ASSESSMENT INSTRUMENT

This questionnaire focuses on reactions to TIA in order to inform treatment

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Department of Primary Care Clinical Sciences

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REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – QUESTIONNAIRE

Patient Number	

INFORMATION ABOUT YOU

1. Are you:

Male ☐
Female ☐

2. Date of birth: ……..

3. When did you have your Transient Ischaemic Attack?

Within the last two weeks ☐
Within the last month? ☐
Within the last month? ☐
Between 3 and 6 months ago? ☐

Longer ago? ☐

4. Do you live:
On your own? ☐
With someone else? ☐

UNIVERSITY OF BIRMINGHAM

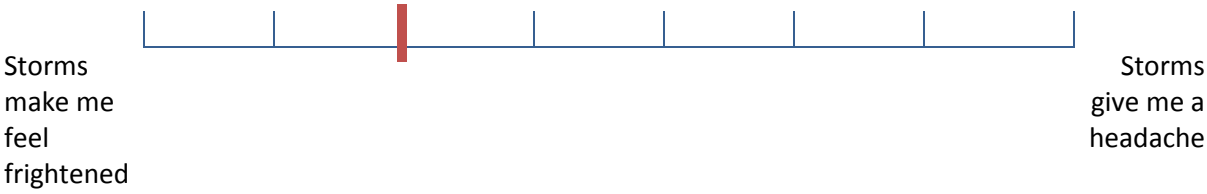
REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – QUESTIONNAIRE

INSTRUCTIONS

We are interested to find out how people react when they have a Transient Ischaemic Attack or TIA. We would like you to think back to when you had your TIA. We are particularly interested in its effect on you and how you felt at the time and shortly after. Below are 21 questions (and two examples). Each question has two reactions which *some* TIA patients may experience. We would like you to look at each question and think about the two reactions presented. Consider which of these two reactions applied more to you when you had the TIA and shortly afterwards, and then indicate with a mark on the line which reflects the strength of your feeling. You will see that on each line there are eight markers. Please put your response on one of these eight markers and *not* the spaces in between. This can be done with a circle, cross, arrow or just making the line thicker. There are no right or wrong answers; we are just interested in your own personal experiences. Do not take too long over each question, as it is your immediate response that we would like. The questionnaire should only take about 10 minutes to complete, but if you have any questions about it, please ask any member of the health care team. The same items will reoccur throughout the questionnaire, but this is intentional. The items are explained in more details on the next page. Please ensure you answer all the questions

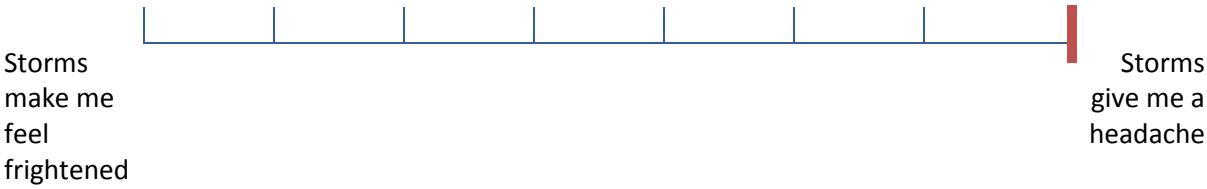
Here are two examples of how to answer the questions:

Example 1



Here the person answering the question feels that storms are more likely to make them feel frightened, and so has placed a red mark towards the 'Storms 'make me feel frightened' end.

Example 2



For this person, storms always given them a headache, and so they have placed their mark on the extreme right-hand mark.

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REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – QUESTIONNAIRE

The questionnaire on the next pages contains 21 questions; each question contains two reactions that some TIA patients may feel. Each reaction appears 6 times in the questionnaire. The reactions are listed below in bold type, with some examples of what they might mean for a TIA patient. These reactions might only have lasted a short time after the TIA or they may have lasted for a while afterwards. The examples provided are not the only things a TIA patient might feel - they are simply illustrations. Before you complete the questionnaire, please read the reactions and the examples below and think how they might apply to you.

1. **'After the TIA I felt worried'** – for example, you might have felt concerned about your health, or the future, or how you would cope, or anxious that you might have another TIA.

2. **'After the TIA I felt upset'** –for example, you might have felt low, or down, or sad, or fed up, or depressed.

3. **'After the TIA I felt that I had been given a wake-up call'** – for example, you might have felt lucky not to have had a full stroke, or that you now had a chance to change your diet, or your lifestyle.

4. **'After the TIA I felt frustrated with what I could do'** – for example, you might have felt that you couldn't think as clearly, or move as quickly, or speak clearly, or felt more tired than usual.

5. **'After the TIA I felt that my life had become more limited'** – for example, you might have felt that you couldn't go out on your own, or drive, or go on holiday, or do the things that you used to.

6. **'After the TIA I lost confidence to do the things I usually** do' – for example, you might have felt unable to go to your usual places, or go shopping, or drive the car, or do the things you normally do.

7. **'After the TIA I didn't want to meet people'** – for example, you might have felt that you didn't feel like meeting with friends, or speaking with friends or family on the phone, or go to work.

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REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – QUESTIONNAIRE

Below are 21 questions. In each question there are two reactions commonly felt by TIA patients. Each reaction is separated by a line with 8 marks on it. Look at each question and think about which of the two reactions was more like your own experience when you had the TIA, or after the TIA. Please put your answer, using a cross or a circle, on one of the marks on the line; do not use the spaces in between. If you are not clear about what to do, have a look back at the examples on page 1, or ask any of the health care professionals. We would like your first response, so please do not think too long about each question.

Question 1

After the TIA I felt:

Worried | | | | | | | | Upset

Question 2

After the TIA I felt:

Frustrated with what I could do | | | | | | | | That my life had become more limited

Question 3

After the TIA I felt:

I lost the confidence to do the things I usually do | | | | | | | | I didn't want to meet people

Question 4

After the TIA I felt:

Upset | | | | | | | | I had been given a wake-up call

Question 5
After the TIA I felt:

That my life had become more limited								Worried

Question 6
After the TIA I felt:

I had been given a wake-up call								Frustrated with what I could do

Question 7
After the TIA I felt:

That my life had become more limited								I lost the confidence to do the things I usually do

Question 8
After the TIA I felt:

Worried								I had been given a wake-up call

Question 9
After the TIA I felt:

Frustrated with what I could do							Upset

Question 10
After the TIA I felt:

I had been given a wake-up call							That my life had become more limited

Question 11
After the TIA I felt:

I didn't want to meet people							Frustrated with what I could do

Question 12
After the TIA I felt:

I lost the confidence to do the things I usually do							Worried

Question 13
After the TIA I felt:

Upset							That my life had become more limited

Question 14
After the TIA I felt:

I didn't want to meet people							I had been given a wake-up call

Question 15
After the TIA I felt:

Worried							Frustrated with what I could do

Question 16
After the TIA I felt:

Upset							I didn't want to meet people

Question 17
After the TIA I felt:

I had been given a wake-up call							I lost the confidence to do the things I usually do

Question 18
After the TIA I felt:

That my life had become more limited							I didn't want to meet people

Question 19
After the TIA I felt:

I lost the confidence to do the things I usually do							Upset

Question 20
After the TIA I felt:

I didn't want to meet people							Worried

Question 21

After the TIA I felt:

Frustrated with what I could do								I lost the confidence to do the things I usually do

Figure 6.3: Instructions for scoring and interpretation

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REACTIONS TO TRANSIENT ISCHAEMIC ATTACK – SCORE SHEET

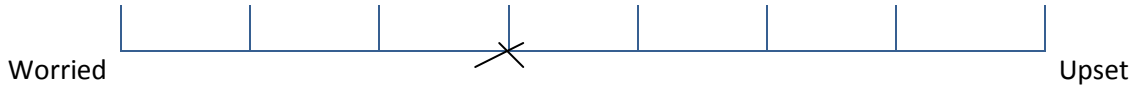
PATIENT NUMBER	

INSTRUCTIONS FOR SCORING AND INTERPRETING THE RESPONSES

The easiest way of explaining the marking system is by an example. Imagine the patient had responded to questions 1 and 2 in the following way:

Question 1

After the TIA I felt:



Question 2

After the TIA I felt:

- Taking the first question, look at where the patient has placed his/her response and add up the number of marks from 'Worried' on the left hand side to that mark. Here the number is 4, so that means 'Worried' gets a score of 4. Enter this number in the cell under 'Worried' and 'Appearance 1' because this is the first time 'Worried' has occurred (see table below). Staying with question 1, count up the number of marks from 'Upset' on the right hand side to the patient's response. Here it is 5, so enter 5 in the cell under 'Upset' and 'Appearance 1' because this is the first time 'Upset' has occurred.
- Moving to question 2, repeat the process. Here the score for 'Frustrated with what I could do' is 7, while for 'My life had become more limited', the score is 2. Enter these scores in the appropriate cells in the grid.
- When all the questions have been scored in this way, add up the total score for each column, to give the total score for the themes; the maximum possible score a theme could have would be 48, while the minimum would be 6.

Appearance	Worried	Upset	Frustrated	Didn't want to meet people	Wake-up call	Lost confidence	Life had become more limited
1	4	5	7				2
2							
Total							
Rank							

- Rank order the total scores, giving a rank of 1 to the smallest score, a rank of 2 to the next smallest and so on. The lowest ranked themes represent the most important issues for the patient, and are the ones that may need to be prioritised for intervention. The highest ranked themes are the ones that are least important to the patient and may need no management. However, you will need to use your clinical judgement and your knowledge of the patient and what he/she has said to you to confirm this. Some examples are:

1. A patient who has rated 'Wake-up call' as the least important issue may already have a healthy lifestyle that requires little modification; on the other hand, it may be that he/she has a very unhealthy lifestyle that they don't want to change. If it's the latter, then there is a need for appropriate intervention.
2. The actual scores rather than just the ranks alone may indicate a problem. If the lowest ranked theme also has a very low score then this may be an area of great concern to the patient; on the other hand, if the score is only just smaller than the others, then it may be that the patient doesn't really have any adverse reactions, or they may be denying the seriousness of the problem. Again, you would need to look at the patient's condition to assess whether there are any other obvious symptoms that are being ignored, or whether the patient is really unaffected.
3. Another example might be when a patient reports that their life has become more limited following the TIA; this might be the result of a real physical limitation or it may be a *perceived* limitation. Checking the patient's actual physical or cognitive problems against their reported problems would clarify this response.

You can clarify the responses by talking to the patient, the family or by looking at the medical notes to confirm whether or not any of the questionnaire responses require intervention.

6.6: Piloting the Risk-Assessment Scale

The preliminary Risk-Assessment scale was piloted for its ease of use and to highlight any areas of confusion in its completion. A purposive sample of 6 people who had experienced a TIA within the previous two years was asked to complete the questionnaire and to feed back any comments about its structure, content and appearance. The sample comprised 4 males and 2 females, between the ages of 57 and 84; two had been educated to degree level. Sample characteristics are shown in Table 6.5:

Table 6.5: Sample characteristics

Participant Number	**Gender**	**Age**	**Marital Status**	**Occupational Status**	**Time since TIA**
1	M	66-70	Married	Managerial/ Administrative	6-12 months
2	M	61-65	Married	Professional	6-12 months
3	F	>75	Married	Managerial/ Administrative	6-12 months
4	F	56-60	Single	Skilled/ semi-skilled	<6 months
5	M	61-65	Single	Managerial/ Administrative	6-12 months
6	M	66-70	Married	Professional	6-12 months

6.6.1: Ethics

Because none of the 6 participants was currently an NHS patient, University of Birmingham ethical approval was sought and given (#Psy 09/10).

6.6.2: Results

All participants were able to complete the scale, usually within 10 minutes. None had any problems with it, although Participants 2 and 5 suggested that for each theme, some examples of

reactions to TIA could be provided. These were incorporated and are highlighted in blue font in Figure 6.2 (page 116). The scoring was done by the researcher (LS). All participants re-completed the questionnaire after ≤2 weeks, to provide an initial assessment of test-re-test reliability (Pedhazur & Schmelkin, 1991). It should be noted this should more properly be conducted with a large sample (Kline, 2000).

6.6.3: Assessing the reliability of the scale

Test-retest reliability was calculated for each participant separately using intra-class correlation coefficients (ICCs) using a fixed-effect anova model[1], and the Bland-Altman Test of Agreement[2] (James & Doe, 2010; Rankin & Stokes, 1998; Bland & Altman, 1986; Shrout & Fleiss, 1979). Test-retest reliability for each item (inter-rater ICC) was calculated separately using a random-effect anova model[3] and Bland-Altman Tests of Agreement (Rankin & Stokes, 1998; Bland & Altman, 1986; Shrout &Fleiss, 1979)[4]. The ICC results are presented in Tables 6.6 and 6.7, together with a sample Bland-Altman graph; the remaining graphs (Figures 6.5 – 6.16) can be found in Appendix 6.

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[1] *A fixed effect anova was used to assess each individual participant's test-retest agreement, because at this stage these were the only raters of interest (Shrout & Fleiss, 1979).*

[2] *The Bland-Altman Test of Agreement involves calculating the differences between each pair of scores; the average of each pair of scores is then plotted against the difference between them. If 95% of the points fall between ± 2 standard deviations of the mean difference score, the measure can be assumed to be reliable. These tests of agreement have to be calculated for each set of paired scores, since there is no method of plotting more than two sets on the same graph (Rankin & Stokes, 1998).*

[3] *A random effects anova was used to assess each item's test-retest reliability, since its proposed use with a large sample means that it must be reliable for <u>any</u> set of raters (Shrout & Fleiss, 1979).*

[4] *Levels of agreement are classified as 'excellent' when they are >0.75, and as 'adequate' when they are between 0.4 – 0.74 (Rehabilitation Measures Database, 2010).*

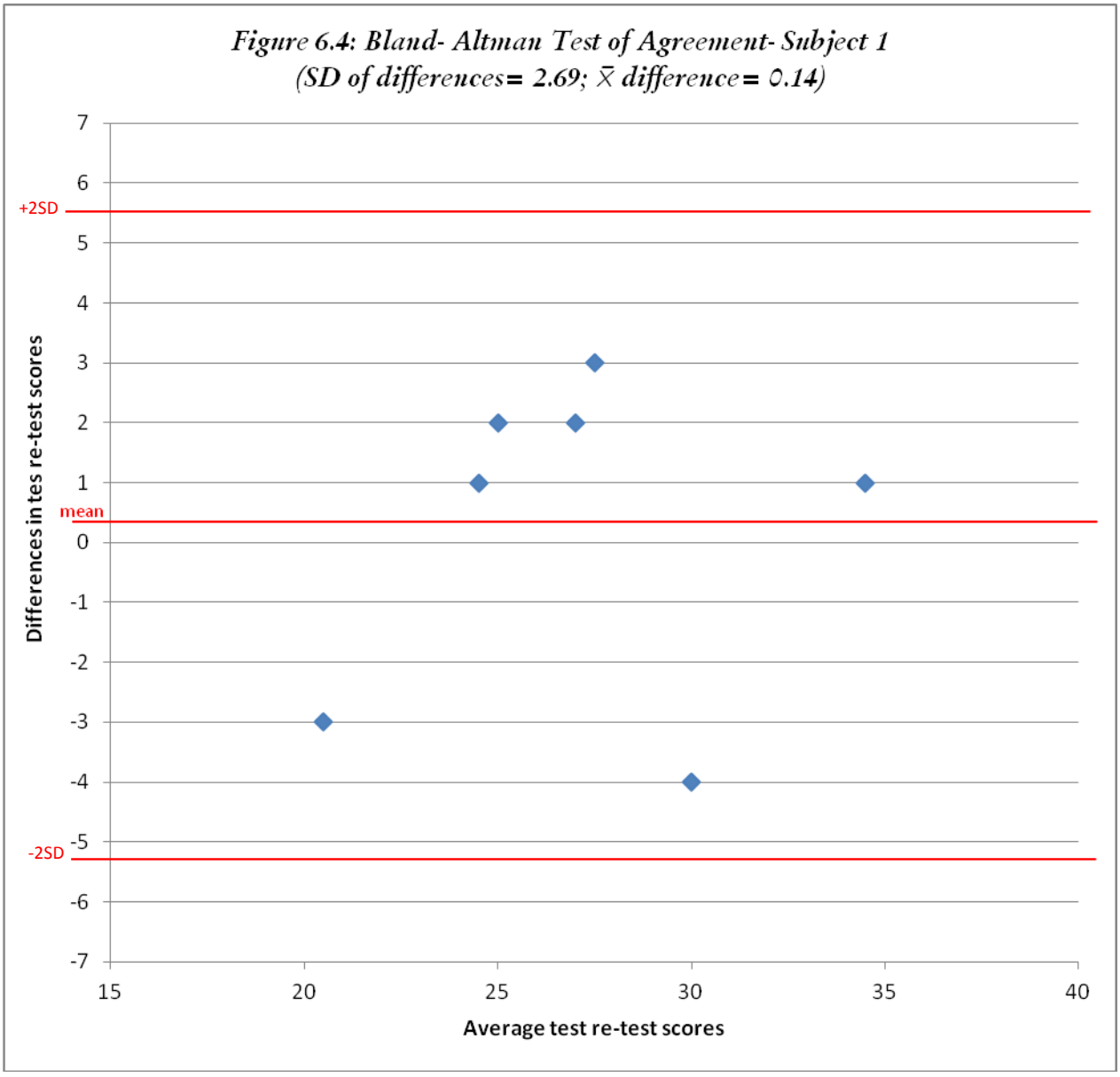
Table 6.6: ICC results for test-retest reliability (intra-rater)

Result ⇩	Subject 1	Subject 2	Subject 3	Subject 4	Subject 5	Subject 6
ICC coefficient	0.850	0.973	0.929	0.973	0.858	0.955
Significance	0.005	0.000	0.001	0.000	0.005	0.000
Level of agreement[1]	Excellent	Excellent	Excellent	Excellent	Excellent	Excellent

Table 6.7: ICC results for test-retest reliability (inter-rater reliability)

Result ⇩	Item 1 (Worried)	Item 2 (Upset)	Item 3 (Frustrated)	Item 4 (More limited life)	Item 5 (Lost confidence)	Item 6 (Meeting people)	Item 7 (Wake-up call)
ICC coefficient	0.950	0.882	0.845	0.950	0.960	0.662	0.808
Significance	0.000	0.005	0.003	0.001	0.000	0.053	0.019
Level of agreement[1]	Excellent	Excellent	Excellent	Excellent	Excellent	Adequate	Excellent

[1]*Levels of agreement are classified as 'excellent' when they are >0.75, and as 'adequate' when they are between 0.4 – 0.74 (Rehabilitation Measures Database, 2010).*



6.7: Discussion

This stage of the study has taken the evidence derived from the three preceding studies to construct a preliminary screening tool which, because of its development along established psychometric principles, has a good level of construct and content validity. The early trials of the tool, albeit with a very small number of participants, indicate that it is easy and acceptable to patients to use and therefore also has some measure of face validity. Initial tests of reliability demonstrate high levels of accord between testings, with all scores falling between the ± 2 standard deviations limit of agreement (Bland & Altman, 1986; Appendix 6); as 95% of data-

points are required to fall within these boundaries for a measure to be considered reliable, the current findings satisfy this criterion. The weakest item was Item 6 (loss of confidence), although this still produced an adequate level of agreement (Rehabilitation Measures Database, 2010). However, these rather elevated test- retest reliability scores may be an artificial product of the short test-retest interval, which could have allowed memory to enhance the results. Clearly, more extensive test-retest reliability assessment is required with longer (perhaps variable) intervals between testings.

Despite the promising initial results, the numbers involved in the preliminary reliability testing were small. It should be noted that some researchers suggest the number of raters x the number of measurements should ≥25 (Bruton et al., 2000). Likewise,. Walter et al.'s (1998) approximating formula for deriving an acceptable sample size also suggests that the numbers used here are not sufficient to draw definitive conclusions about the tool's reliability. This point notwithstanding, Walter et al nevertheless note that where intra-rater reliability is required to be ≥0.5, then between 2 and 5 observations per participant are required. Given this point and the pilot nature of the study, the number of data-points and their derivation could be considered adequate for the current purpose (Bland & Altman, 1986).

6.8: Conclusion

By following the principles of sound test construction, it has been possible to devise a risk-assessment scale that could be used more widely to identify TIA patients with psychological reactions that merit further intervention. Early testing suggests that the instrument has potential value for wider use in both research and clinical contexts. Clearly before it can be rolled out formally, the tool needs further extensive testing to provide full psychometric information about concurrent and predictive validity, and to confirm test-retest reliability. While the novelty of the paired-comparison method used here provides a more unusual format and hence might offset

questionnaire fatigue among participants, its unfamiliar format may make the scoring protocol initially complex for staff. User-friendliness for both respondents and scorers should also be a priority for future evaluation.

Chapter 7

DISCUSSION AND CONCLUSION

7.1: Preamble

The aim of this thesis was to develop a psychometrically robust screening tool to assess the psychological consequences of TIA. While the large-scale testing of the instrument to determine its capacity to identify and predict adverse subjective reactions was not possible within the scope of the thesis, a preliminary risk-scale has been constructed along established psychometric foundations. This chapter reviews the findings of the earlier studies and outlines the way in which the scale could be further developed and used.

7.2: An overview of the study's findings

The results of the three studies indicate quite clearly that for the samples involved, a range of psychological sequelae were experienced post-TIA. With the exception of constructive optimism/TIA as a wake-up call, these reactions can be classified as general subjective distress, comprising anxiety (Q-sort and Repertory Grid analysis - RGA), frustration (RGA), loss of confidence and normality (Q-sort and RGA), personal and social constraints (Q-sort, RGA and factor analysis), denial (Q-sort and RGA) and overarching emotional discomfort (Q-sort, RGA and factor analysis). The studies, although distinct in their aims and approaches, accorded in their findings and challenge the previously accepted notion of TIA as a trivial event (Daffertshofer et al.,

2004). Many of these responses, such as deep-seated anxiety, perceived loss, constructive optimism and denial, had not previously been reported for TIA patients, though a subsequent study by Gibson and Watkins (2012) has provided confirmation of these reactions. Moreover, they mirror the experiences of stroke patients. The range of responses obtained confirms the value of using research methodologies that are patient-driven, rather than researcher-led, since the degree of additional insight they provide into subjective experiences of TIA has revealed a number of possible follow-up studies and interventions. However, some of the results reported here do corroborate existing research on TIA; for example, depression, reported directly, or more indirectly as a sense of loss or generalised emotional distress, accords with evidence from van Wijk et al. (2007) and Vohra et al. (2008). Overall, it appears that TIA patients suffer a range of emotional responses that may impede their recovery and which may be similar to those experienced by stroke patients, albeit at a reduced level (eg Campbell Burton et al., 2011).

In particular, the distilled themes that form the basis of the risk-assessment tool enjoy some support from the existing TIA and stroke research literature. 'Life impact' subsumes a range of physical and functional problems, as well as overall quality of life, and accords with findings from Coutts et al. (2012), Kessler & Thomas (2009), MacKenzie et al (2011) among others. 'Anxiety' is corroborated by a significant corpus of stroke research (eg. Kneebone et al., 2012; Campbell Burton et al, 2011), as well as a limited amount of TIA research (Gibson & Watkins, (2012). 'Depression' has previously been well-documented for both stroke and TIA (eg. Robinson & Spalletta, 2010; Luijendijk et al, 2011 respectively), while 'Interpersonal Issues' have previously been suggested for stroke patients by Pilcher et al. (2012) and Logan et al. (2004a). 'Wake-up call', as an index of constructive optimism and positive thinking, has been reported for stroke patients by Nabi et al. (2010) and for TIA patients by Gibson & Watkins (2012),

while 'Loss of confidence' has been noted to be a common reaction post-stroke (eg. Barnsley et al., 2012; Logan et al., 2004a and b), though no link has previously been demonstrated with TIA. Likewise, 'Frustration' has been shown to be an established correlate of stroke (eg. Zimmerli et al., 2012; Wood et al., 2009), but has not before been associated with TIA. Together, this suggests that there is some logical and empirical appeal to the themes that comprise the risk-assessment tool.

Moreover, these findings highlight the salience of TIA and its psychological consequences for future health status. Both TIA and subjective distress are well-documented precursors to full stroke (Fiedorowicz et al., 2011; Katan et al., 2011; Fisher, 2008; Surtees et al., 2008), although their combined effect has not been investigated. Together these findings make an unassailable case for the proactive management of high levels of subjective distress following TIA as one means by which patients' chances of secondary stroke can be reduced. These suggestions mirror those of NICE guidelines (NICE, 2008) which recommend that secondary stroke prevention strategies should incorporate a wide spectrum of individual issues and risk factors, and corroborate the general principles of rehabilitation that recommend the inclusion of physical, clinical and psychosocial factors in intervention programmes (Prigatano, 2011). Furthermore, where this approach has been adopted for post-TIA patients, clinical and functional outcomes are improved (Arts et al., 2008). It would seem imperative, therefore, to take account of a wide range of patient variables in post-TIA management programmes.

7.2.1: A theoretical explanation for the psychological sequelae

The range of psychological sequelae obtained in the current study is consistent with the theoretical explanations of illness-reactions. A number of seminal theories about illness representations, illness behaviour and health beliefs exist, such as, *inter alia,*

Heider's (1944) Attribution Theory, Becker's (1974) Health Belief Model, Ajzen's (1985) Theory of Planned Behaviour and Schwarzer's (1992) Health Action Process Approach. While these theories, and their variants, have been supported to a greater or lesser extent by empirical evidence, the findings from the studies in the current thesis resonate particularly with the conceptualisation of illness as a crisis, perhaps because of the typically sudden and unexpected nature of TIA. For this reason, the psychological sequelae of TIA may be best interpreted within Moos and Schaefer's (1984) Crisis Theory of illness, which conceptualises illness as a disruption to normal functioning and a challenge to established psycho-social identity. These perspectives were highlighted in the Q-sort and RGA especially, where participants' experiences of TIA as a personal, social and normal-life constraint would seem to provide support for Crisis Theory. Many respondents' views were not corroborated by the reality of their situation; for example, there were typically no physical impairments that would be sufficient to prevent normal functioning, but instead there was a *perception* of limitation, perhaps as a product of loss of confidence. However, this would still fit with Crisis Theory which focuses on subjective interpretation of the meaning of illness for the individual. The way in which the individual copes with the illness may be further affected by other factors, such as prior experience and knowledge of the illness, its implications, and its unpredictability (Moos & Schaefer, 1984). The lack of knowledge reported by TIA patients in the Q-study, coupled with the evidence from elsewhere about the low levels of public awareness of stroke and TIA (Maasland et al., 2011), suggest that the potential for coping with TIA and regaining some degree of psychological equilibrium, may be compromised by lack of knowledge and understanding of the condition. This would confirm the need for more effective, targeted health care campaigns. The issue of unpredictability of TIA, both in terms of its occurrence, as well as the course of the event, will inevitably add to anxiety-levels, since individual psychological preparation for TIA and its impact would be

logistically very difficult. The findings reported here, which focus particularly on the disruption to normal cognitive and affective functioning, are also consistent with Leventhal et al.'s (1980) construction of illness as a threat to normality, to identity, to well-being and to the future. This model suggests that illness triggers both an affective response (fear, anxiety, optimism) as well as a more cognitive-focused appraisal of the condition, with which the patient has to cope and manage if some effective adaptive outcome is to be achieved. Alterations to identity, future plans, and normal functioning were all reported in the current study; the evidence and theoretical models can therefore seen to be mutually reinforcing, and further emphasise the need for early recognition of dysfunctional post-TIA reactions and effective intervention.

7.3: The Risk-Assessment Tool

The case for the proactive early intervention of adverse subjective reactions following TIA has been made. The information gathered via multiple methodologies has been used to develop a preliminary screening test with supportable construct and content validity, and early results suggest that in addition, it has face validity, is easy-to-use and has initial test-retest reliability. The questionnaire has the advantage of being disease-specific, making it more relevant to the target population, as well as focusing on the *impact* of the TIA, rather than on the TIA itself. Furthermore, the use of the Thurstone Paired-Comparison Method provides a mechanism by which experiences can be weighted for salience. This not only means that at an individual level reactions can be prioritised for intervention, but along with its other properties, suggests it has the potential for ensuring that a generic questionnaire can have individual application and relevance. Together, these features satisfy the requirements of a valuable questionnaire outlined by Bernheim (1999 – Section 2.4).

7.3.1: Clinical implications

At a specific practical level, the questionnaire is intended for use within the GP surgery or TIA clinic, following the TIA, although with minor modification to the instructions and covering letter, there would be no reason to suppose that it could not have use as a postal or email questionnaire. However, the initial purpose would be for the patient to complete the questionnaire, perhaps with help or support from the HCP, who would be well-positioned to add further meaning to the responses from knowledge of the patient's clinical condition and narrative. The questionnaire takes around 10 minutes for the patient to complete; the Health Care Professional (HCP) would score the responses and interpret the salience attributed to each theme using additional information provided by the distribution of actual scores (as opposed to the ranks alone), the medical data and the patient's commentary (see '*Guide to Interpreting the Scores*', Figure 6.3). The most salient themes would then be targeted for additional intervention, if considered necessary (see next section). Clearly, as with most scales, ranks associated with extremes of scores (eg: a top rank might be associated with an actual score of around 6-10, while a bottom-ranked theme might have obtained an associated score of around 40-48) are easy to interpret – in the former case, appropriate intervention would be required, while in the latter example, the theme has little importance for the patient and so can be classified as a low priority. However, the themes in the mid-range rankings and scores are more difficult to judge and may indicate denial or a genuinely non-salient issue. Such results would need to be interpreted in conjunction with other patient data. To further complicate the situation, it should be noted that a patient recording 'wake-up call' as a bottom-rank, low-priority issue, may be at risk from not adjusting lifestyle and therefore, in this case would be deemed to be at risk. Further work needs to be conducted to ascertain the ease with which the HCP could score and interpret the results, as well as more extensive test-retest evaluation.

7.3.2: Determining concurrent and predictive validity

The foregoing comments highlight the fact that the tool is in its very early stages and a further large-scale reliability/validity study would be needed before the tool could be recommended for wide-scale use. This would provide an extensive data-base which would add psychometric robustness, as well as informing a more systematic use of the data gathered, reducing the time taken to interpret the responses, and offering clearer guidance about where to target intervention. For example, a larger-scale study could clarify whether ranks associated with scores above a specified cut-off point are those that require proactive management. Construct validity also needs to be assessed by testing emerging hypotheses (Kline, 2000), while the concurrent and predictive validity of the scale require evaluation. With regard to concurrent validity, other data, either from proprietary questionnaires, medical information and/or family members, could be used to assess concurrent validity. For example, a patient recording anxiety and depression as top-ranking sequelae might be expected to have high scores on the HADS, possibly be in receipt of anti-depressants and/or have changed their normal behaviour patterns. Similarly, loss of confidence might be cross-checked with changes to daily activities in the absence of any physical/clinical cause, a tendency to agoraphobia, or a reduction in activities outside the home. Predictive validity, whilst known to be the most elusive psychometric property, could be assessed against a number of behaviours known to be associated with specific psychological and clinical reactions. Therefore, it might be expected that high levels of emotional distress, as indicated by anxiety, frustration and depression, might lead to more GP visits for either somatised complaints or for explicit problems with sleeping and affective disorders. Likewise, those patients recording constructive optimism/TIA as a wake-up call as a top-ranked response might be more likely to change various life-style behaviours, such as diet, exercise, cigarette and alcohol consumption compared with patients for whom this response was less relevant. Such

evaluation is beyond the scope of this thesis, but with a large-and more comprehensive data-base (such as that from the FACE-TIA study – Sackley et al., 2010), some of these elements could be addressed, and together, would add psychometric weight to the scale. In particular, the use of logistic or multiple regression to establish which themes in the risk-assessment scale are the best predictors of specified outcomes would be possible in large-scale longitudinal research, such as the FACE-TIA study.

7.3.3: Determining cut-off points for referral

The current scale is intended to screen for dysfunctional psychological reactions to TIA; while the preliminary development did not extend to establishing cut-off points in the scores for determining whether a patient is susceptible to adverse outcomes, it would be expected that future development might pursue this, as a means by which clearer guidance can be offered to HCPs when making decisions about who to refer for further targeted intervention. The standard procedure for establishing a test's capacity to assess risk is based on Receiver Operating Characteristics (ROC). Derived from signal detection theory, this is used both diagnostically and in health screening, especially where decisions to refer or treat may be complex (Berwick et al., 2007; Greenhalgh, 1997; Anthony, 1996; Altman & Bland, 1994a and b). Where resources are limited and the consequences of making an incorrect decision are potentially serious, it is imperative that the information on which decisions are based is as trustworthy as possible. Therefore, the current screening test, in common with others, should be able to correctly identify those patients at risk (true positives), which provides a measure of test-sensitivity. The test should also be able to identify those not at risk, or true negatives, which is a measure of test-specificity. A test should not generate a high number of false negatives (people at risk but not identified) or false positives (people identified to be at risk, but who are not). To illustrate how this would be established in practice, and taking the theme of

constructive optimism/TIA as wake-up call as an example, the first stage might be to select a group of post-TIA patients who had made significant changes to their lifestyle following the event, and a group who did not. The scale would be administered in the normal way but it would be anticipated that for the group who had modified their lifestyle, constructive optimism would be top-ranked, while for the group for whom this had no salience it would be bottom-ranked. If the scale has any ability to discriminate between patient reactions, significant differences between the groups' scores should be observed. Given that the range of possible scores for any one theme is 6-48, some decision would need to be made about the point at which a score would be deemed to indicate a risk. Using the standard procedure (Berwick et al., 2007; Anthony, 1996; Altman & Bland, 1994a and b), the constructive optimism scores from the two groups ('modified their lifestyle' and 'did not modify their lifestyle') would be tested statistically for significance (here using the unrelated t-test, because the intervals between the scores may be considered equivalent – Kerlinger, 1973). If the statistical results were significant, the scores would be plotted graphically; non-significant results would suggest that there would be no value in continuing with the ROC analysis. By systematically adjusting the cut-off threshold and using the established ROC formula, the best specificity and sensitivity levels can be determined. The related threshold then becomes the clinical cut-off point for referring post-TIA patients whose lifestyle may require modification through targeted support. The same procedure would be adopted for each theme to provide indicative cut-off points that would aid the decision to refer for appropriate intervention.

It should be noted that even with these proposed follow-up studies of the psychometric properties of the screening scale, the instrument cannot be precise and absolute. Decisions about referrals would still have to involve some measure of clinical

judgement and be based on a range of other clinical features and patient narratives. However, what the scale should do is raise awareness among HCPs that dysfunctional reactions to TIA are possible, take various forms and may have serious implications for future health and well-being, and that the use of the screening tool may offer useful information about how subsequent interventions should be targeted. Furthermore, if the scale could reliably identify individuals who are at risk of adopting maladaptive reactions to cope with TIA, then specialist support programmes, tailored to the nature of the individual problem(s), could be devised and provided by specialist HCPs (eg clinical psychologists); their effectiveness would then be evaluated. While this seems, at first glance, to be a highly resource-intensive process, stroke costs the NHS and general economy £7billion pa; given that 20% of TIA patients go on to have secondary stroke, provision of post-TIA support could potentially make significant financial savings, as well as reducing the human costs.

7.4: Shortcomings of the current study and recommendations for future research

In addition to the specific limitations outlined in Chapters 3-5, the foregoing discussion raises issues about the current study and by implication, makes recommendations for future research:

- The psychometric properties of the scale need to be confirmed and extended; construct validity needs to be assessed via specific hypothesis-testing, full test-retest reliability, predictive and concurrent validity and sensitivity/specificity data are all lacking and need to be investigated.
- The ease-of-use of the scoring system and interpretation by HCPs must be reviewed.

- The persistence of any psychological sequelae, their responsiveness to intervention and their impact on future health all require further research.
- The effectiveness of psychological support and intervention programmes need thorough investigation.
- The small-scale nature of two of these studies, using purposive and non-representative samples, means that replication of results is necessary.

7.5: Conclusions

The current study, through the use of a mixed methodology approach, has yielded a range of findings that suggest TIA patients experience an array of psychological, social, cognitive and physical problems, which, rather than being transitory and trivial as often previously assumed, may persist and cause significant subjective distress. The qualitative and quantitative methods used here to elicit these findings provide a cogent basis for the seven themes that comprise the risk-assessment scale, conferring both construct and content validity. Preliminary testing also suggests that the use of a forced-choice paired comparison protocol permits both easy use and weighted responses, which allow individual reactions to TIA to be prioritised for consideration and action. While large-scale testing of the instrument for both research and clinical purposes is necessary before the tool can be recommended for routine use, the early indications suggest that it may have value in identifying dysfunctional reactions to TIA. Effective management of these may go some way to ameliorating patient distress and offsetting secondary stroke with all the human and fiscal consequences.

REFERENCES

Affleck, G. & Tennen, H. (1996). Construing benefits from adversity: adaptational significance and dispositional underpinnings. *Journal of Personality,* 64, pp899-922.

Ajzen, I. (1985). From intentions to actions: A theory of planned behaviour. In Kuhl, J. and Beckman, J. (Editors). *Action control: from cognition to behaviour*. Berlin, Springer-Verlag; pp 11 – 39.

Albers, G.W., Caplan, L.R., Easton, J.D., Fayad, P.B., Mohr, J.P. & Saver, J.L. (2002). Transient Ischaemic Attack – proposal for a new definition. *New England Journal of Medicine,* 347, pp1713–1716.

Ali, M., Ashburn, A., Bowen, A., Brodie, E., Corr, S., Drummond, A., Edmans, J., Gladman, J., Kalra, L., Langhorne, P., Lees, K.R., Lincoln, N., Logan, P., Mead, G., Patchick, E., Pollock, A., Pomeroy, V., Sackley, C., Sunnerhagen, K.S., van Vliet, P., Walker, M. & Brady, M. (2010). VISTA-Rehab Investigators. VISTA-Rehab: a resource for stroke rehabilitation trials. *International Journal of Stroke,* 5(6), pp447-52.

Allen, P.F. & Locker, D. (1997). Do item weights matter? An assessment using the oral health impact profile. *Community Dental Health,* 14(3), pp133-8.

Altman, D.G. & Bland, J.M. (1994a). Diagnostic tests 1: sensitivity and specificity. *British Medical Journal,* 308, p1552.

Altman, D.G. & Bland, J.M. (1994b). Diagnostic tests 3: receiver operating characteristics plots. *British Medical Journal,* 309, p118.

Altrichter, H., Feldman, A., Posch, P. & Somekh, B. (2008). *Teachers investigate their work: an introduction to action research across the professions* (2nd Edition). London, Routledge.

Anderson, C.S., Carter, K.N., Brownlee, W.J., Hackett, M.L., Broad, J.B. & Bonita, R. (2004). Very long-term outcome after stroke in Auckland, New Zealand. *Stroke,* 35, pp1920-1924.

Anthony, D. (1996). Receiver operating characteristics analysis: an overview. *Nurse Researcher,* 4(2), pp75-88.

Arts, M.L., Kwa, V.I. & Dahmen, R. (2008). High satisfaction with an individualised stroke care programme after hospitalisation of patients with a TIA or minor stroke: a pilot study. *Cerebrovascular Diseases,* 25(6), pp566-71.

Åström, M. (1996). Generalized Anxiety Disorder in Stroke Patients: A 3-Year Longitudinal Study. *Stroke,* 27, pp270-275.

Atkins, L., Newby, G. & Pimm, J. (2012). Normative data for the Hospital Anxiety and Depression Scales (HADS) in multiple sclerosis. *Social Care & Neurodisability*, 3(4), pp172-178.

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research,* 1, pp385-405.

Aybeck. S., Carota, A., Ghika-Schmi, F., Berne, A., van Mell, G. & Gue, P. (2005). Emotional behaviour in acute stroke. *Cognitive & Behavioural Neurololgy,* 18, pp37-44.

Bannister, D. & Fransella, F. (1986*). Inquiring Man: the Psychology of Personal Constructs.* London, Routledge and Kegan Paul.

Barbour, R.S. (1999). The case for combining qualitative and quantitative approaches in health services research. *Journal of Health Services Research & Policy*, 4(1), pp39-43.

Barker-Collo, S.L. (2007). Depression and anxiety 3 months post stroke: prevalence and correlates. *Archives of Clinical Neuropsychology,* 22(4), pp519-531.

Barnsley. L., McCluskey, A. & Middleton, S. (2012). What people say about travelling outdoors after their stroke: a qualitative study. *Australian Occupational Therapy Journal ,* 59, pp71-78.

Becker, M.H. (1974). The health belief model and personal health behaviour. *Health Education Monographs*, 2, pp324 – 508.

Becker, G. (1993). Continuity after stroke: implications of life-course disruption in old age. *The Gerontologist*, 33, pp148-158.

Bergersen, H., Frøslie, K. F., Stibrant Sunnerhagen, K. & Schanke, A. K. (2010). Anxiety, depression, and psychological well-being 2 to 5 years poststroke. *Journal of Stroke & Cerebrovascular Diseases*, 19(5), pp364-369.

Bernheim, J.L. (1999). How to get serious answers to the serious question: 'How have you been?': subjective quality of life (QOL) as an individual emergent construct. *Bioethics,* 13(3/4), pp272 – 287.

Berwick, V., Cheek, L. & Ball, J. (2007). Statistics review 13: receiver operating characteristics curves. *Critical Care,* 8, pp502 – 512.

Bietzk, E., Davies, R., Floyd, A., Lindsay, A., Greenstone, H., Symonds, A. & Greenfield, S. (2012). FAST enough? The UK general public's understanding of stroke. *Clinical Medicine,* 12(5), pp410-415.

Birman-Deych, E., Radford, M. J., Nilasena, D. S. & Gage, B. F. (2006). Use and effectiveness of warfarin in Medicare beneficiaries with atrial fibrillation. *Stroke*, 37(4), pp1070-1074.

Bjelland, I., Dahl, A. A., Haug, T. T. & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale-An updated literature review. *Journal of Psychosomatic Research*, 52(2), pp69-78.

Bjorklund, L. (2008). The repertory grid technique. Making tacit knowledge explicit: assessing creative work and problem solving skills. In: Middleton H (Ed.). *Researching Technology Education: Methods and Techniques*. Rotterdam, Sense Publishers, pp46-69.

Bland, J.M. & Altman, D.G. (1986). Statistical methods for assessing agreement between two methods of clinical assessment. *The Lancet,* Feb 8, pp 307-310.

Borkan, J.M. (2004). Mixed methods studies: a foundation for primary care research *Annals of Family Medicine*, 2(1), pp4-6.

Bos, M.J., Lindén, T., Koudstaa, P.J., Hofman, A., Skoog, I., Breteler, M.M. & Tiemeier, H. (2008). Depressive symptoms and risk of stroke: the Rotterdam Study. *Journal of Neurology, Neurosurgery & Psychiatry,* 79(9), p977-1001.

Bour, A., Rasquin, S., Aben, I., Boreas, A., Limburg, M., & Verhey, F. (2010). A one-year follow-up study into the course of depression after stroke. *The Journal of Nutrition, Health & Aging*, 14(6), pp488-493.

Bour, A., Rasquin, S., Limburg, M. & Verhey, F. (2011). Depressive symptoms and executive functioning in stroke patients: a follow-up study. *International Journal of Geriatric Psychiatry*, *26*(7), pp679-686.

Bowling, A. (2009). *Research Methods in Health* (3rd Edition). Buckingham, Open University Press.

Boynton, P. & Greenhalgh, T. (2004). Selecting, designing and developing your questionnaire. *British Medical Journal,* 328, pp1312-1315.

Brady, M.C., Clark, A.M., Dickson, S., Paton, G. & Barbour, R.S. (2011). Dysarthria following stroke: the patient's perspective on management and rehabilitation. *Clinical Rehabilitation,* 25, pp935-952.

Brannen, J. (2005). Mixing methods: The entry of qualitative and quantitative approaches into the research process. *International Journal of Social Research Methodology, Special Issue,* 8(3), pp173-185.

Broomfield, N.M., Laidlaw, K., Hickabottom, E., Murray, M.F., Pendrey, R., Whittick, J.E. & Gillespie, D.C. (2011). Post-stroke depression: the case for augmented, individually-tailored Cognitive Behavioural therapy. *Clinical Psychology & Psychotherapy*, 18(3), pp202 – 217.

Brown, B., Crawford, P. & Hicks, C. (2003). *Evidence-Based Research: Dilemmas and Debates in Health Care*. Maidenhead, Berks, Open University Press.

Brown, T.C. & Peterson, G.L. (2009). An enquiry into the method of paired comparison: reliability, scaling, and Thurstone's Law of Comparative Judgment. Gen Tech. Rep. RMRS-GTR-216WWW. Fort Collins, CO: U.S. Department of Agriculture, Forest Service, Rocky Mountain Research Station. [online]. Available at http://www.fs.fed.us/rm/pubs/rmrs_gtr216.pdf (Accessed 28 October, 2012).

Bueno, V. F., Brunoni, A. R., Boggio, P. S., Bensenor, I. M. & Fregni, F. (2011). Mood and cognitive effects of transcranial direct current stimulation in post-stroke depression. *Neurocase*, 17(4), pp318-322.

Burvill, P.W., Johnson, G.A., Jamrozik, K.D., Anderson, C.S., Stewart-Wynne, E.G. & Chakera, T.M. (1995). Anxiety disorders after stroke: results from the Perth Community Stroke Study. *British Journal of Psychiatry,* 166, pp328-332.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness,* 4(2), pp167-182.

Campbell Burton, C.A., Holmes, J., Murray, J., Gillespie, D., Lightbody, C.E. & Watkins, C.L. (2011). Interventions for treating anxiety after stroke. *Cochrane Database of Systematic Reviews,* 12:CD008860.

Carey, L., Macdonell, R. & Matyas, T. A. (2011). SENSe: Study of the Effectiveness of Neurorehabilitation on Sensation: A Randomized Controlled Trial. *Neurorehabilitation & Neural Repair*, *25*(4), pp304-313.

Carlsson, G.E., Moller, A. & Blomstrand, C. (2009). Managing an everyday life of uncertainty--a qualitative study of coping in persons with mild stroke. *Disability & Rehabilitation*, 31(10), pp773-829.

Carod-Artal, F. J. & Egido, J. A. (2009). Quality of life after stroke: the importance of a good recovery. *Cerebrovascular Diseases*, 27(1), pp204-214.

Carr, A.J. & Higginson, I.J. (2001). Are quality of life measures patient centred? *British Medical Journal,* 322, pp1357-1360.

Carter, D.E. & Porter, S. (2000). Validity and reliability. In Cormack, D. (Ed) *The Research Process in Nursing.* (4th Edition). Oxford, Blackwell Science, pp29-42.

Castle. J., Mlynash, M., Lee, K., Caulfield, A.F., Wolford, C. & Kemp, S.(2010). Agreement regarding diagnosis of transient ischemic attack fairly low among stroke-trained neurologists. *Stroke,* 41, pp1367-70.

Cattell, R.B. (1957). *Personality and Motivation Structure and Measurement*. Yonkers, World Book Co.

Cattell, R.B. (1966). The scree test for number of factors. *Multivariate Behavioural Research*, 1, pp245-276.

Chandratheva, A., Lasserson, D. S., Geraghty, O. C. & Rothwell, P. M. (2010). Population-Based Study of Behaviour Immediately After Transient Ischemic Attack and Minor Stroke in 1000 Consecutive Patients Lessons for Public Education. *Stroke*, 41(6), pp1108-1114.

Child, D. (2006). *Essentials of Factor Analysis* (3rd Edition). London, Continuum International Publishing Group Ltd.

Ch'ng, A.M., French, D. & Mclean, N. (2008). Coping with the challenges of recovery from stroke: long-term perspectives of stroke support group members. *Journal of Health Psychology,* 13: 1136 [online]. Available at http://hpq.sage.pub.com/content/13/8/1136. (Accessed 3 September 2012).

Cinamon, J. S., Finch, L., Miller, S., Higgins, J. & Mayo, N. (2010). Preliminary evidence for the development of a stroke specific geriatric depression scale. *International Journal of Geriatric Psychiatry*, *26*(2), pp188-198.

Clarke, V. & Braun, V. (2013). Teaching Thematic Analysis. *The Psychologist*, 26(2), pp120-123.

Coaley, K. (2010). *An Introduction to Psychological Assessment and Psychometrics*. London, Sage Publishing Ltd.

Compan, V., Feixas, G., Varlotta-Dominguez, N., Torres-Vinals, M., Aguilar-Alonso, A., Dada, G. & Saul, L.A. (2011). Cognitive factors in fibromyalgia: the role of self-concept and identity related conflicts. *Journal of Constructivist Psychology,* 4(1), pp56-77.

Corr, S. (2001) An introduction to Q-methodology, a research technique. *British Journal of Occupational Therapy,* 64, pp293–297.

Cosco, T. D., Doyle, F., Ward, M. & McGee, H. (2012). Latent structure of the Hospital Anxiety and Depression Scale: a 10-year systematic review. *Journal of Psychosomatic Research*, 72(3), pp180-184.

Coutts, S. B., Modi, J., Patel, S. K., Aram, H., Demchuk, A. M., Goyal, M. & Hill, M. D. (2012). What causes disability after Transient Ischemic Attack and minor stroke? Results from the CT And MRI in the triage of TIA and minor cerebrovascular events to identify high risk patients (CATCH) Study. *Stroke*, [online]. Available at http://stroke.ahajournals.org/content/early/2012/09/13/STROKEAHA.112.665141.short (Accessed 15 December 2012).

Cronbach,L.J. & Meehl, P.E. (1955). Construct validity in psychological tests. *Psychological Bulletin,* 52, pp281–302.

Crosby, G. A., Munshi, S., Karat, A. S., Worthington, E. & Lincoln, N. B. (2012). Fatigue after stroke: frequency and effect on daily life. *Disability & Rehabilitation*, 34(8), pp633-637.

Crouch, M. & McKenzie, H . (2006). The logic of small samples in interview-based qualitative research. *Social Science Information,* 45(4), pp483-499.

Cumming, T.B. & Brodtmann, A. (2011). Can stroke cause neurodegenerative dementia? *International Journal of Stroke,* 6(5), pp416-24.

Cunningham, R. (1998). Counselling someone with severe aphasia: and explorative case study. *Disability & Rehabilitation,* 20(9), pp346-54.

Daffertshofer, M., Mielke, O., Pullwitt, A., Felsenstein, M. & Hennerici, M. (2004). Ischaemic attacks are more than 'ministrokes'. *Stroke,* 35, pp2453-2458.

Dawson, C. (2007). *Introduction to Research Methods* (4th Edition). Oxford, How To Books.

de Man-van Ginkel, J.M., Gooskens, F., Schuurmans, M.J., Lindeman, E. & Hafsteinsdottir, T.B. (2010). A systematic review of therapeutic interventions for post-stroke depression and the role of nurses. *Journal of Clinical Nursing,* 19(23-24), pp3274-3290.

Dennis, M.S., Bamford, J.M., Sandercock, P.A. & Warlow, C.P. (1989). Incidence of Transient Ishaemic Attacks in Oxfordshire, England. *Stroke,* 20, pp333-339.

Denzin, N.K (1978). *The Research Act: A Theoretical Introduction to Sociological Methods.* (2nd Edition). New York, McGraw Hill.

de Vaus, D.A. (2002). *Surveys in Social Research* (5th Edition). Crow's Nest, Allen and Unwin.

de Vellis, R.E. (2003). *Scale Development: Theory and Applications* (2nd Edition). London, Sage.

DfHSS (2006). A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services. [online] Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137040. (Accessed 6 March 2012).

Diener, H.C., Cunha, L., Forbes, C., Sivenius, J., Smets, P. & Lowenthal, A. (1996). European Stroke Prevention Study. 2. Dipyridamole and acetylsalicylic acid in the secondary prevention of stroke. *Journal of Neurological Sciences,* 143(1-2), pp1-13.

Dittrich, W.H., Johansen, T. & Fineberg, N.A. (2011). Cognitive Assessment Instrument of Obsessions and Compulsions (CAIOV-13)-A new 13-item scale for evaluating functional impairment associated with OCD. *Psychiatry Research,* 187(1-2), pp283-290.

Dixon, M. & Sweeny, K. (2000). *The Human Effect in Medicine: Theory, Research and Practice.* Abingdon, Oxford, Radcliffe Medical Press.

Donnan, G.A., Fisher, M., Macleod, M & Davis, S.M. (2008). Stroke. *The Lancet,* 371, 1612–1623.

Donnellan, C., Hevey, D., Hickey, A. & O'Neill, D. (2006). Defining and quantifying coping strategies after a stroke: a review. *Journal of Neurology, Neurosurgery & Psychiatry,* 77, pp1208–1218.

Donnellan, C., Hickey, A., Hevey, D. & O'Neill, D. (2010). Effect of mood symptoms on recovery one year after stroke. *International Journal of Geriatric Psychiatry*, 25(12), pp1288-1295.

Donner, J.C. (2001). Participatory processes; an introduction to the methodology. Chapter 3. In Krueger, R.A., Casey, M.A., Donner, J.C., Kirsch, S. & Maack, J.N. (Editors). *Social Analysis: Selected Tools and Techniques.* Washington, DC, World Bank, Social Development Papers; 24-49.

Easton, J.D., Saver, J.L., Albers, G.W., Albert, M.J., Chaturbedi, S. & Feldmann, E. (2009). Definition and evaluation of Transient Ischemic Attack. *Stroke*; 40, pp2276-2293.

El Husseini, N., Goldstein, L.B., Peterson, E.D., Zhao, X., Pan, W., Olson, D.M., Zimmer, L.O., Williams, J.W. Jr., Bushnell, C. & Laskowitz, D.T. (2012). Depression and antidepressant use after stroke and transient ischemic attack. *Stroke,* 43(6), pp1609-16.

Ellis, C., Zhao, Y. & Egede, L. E. (2010). Depression and increased risk of death in adults with stroke. *Journal of Psychosomatic Research*, 68(6), pp545-551.

Ellis, J.M. (1999). Nursing care of older people: a personal construct theory perspective. *Journal of Advanced Nursing,* 29(1), pp160-168.

Elmstahl, S., Sommer, M. & Hagberg, B. (1996). A 3-year follow-up of stroke patients: relationships between activities of daily living and personality characteristics. *Archives of Gerontology & Geriatrics,* 22, pp233-244.

Engstad, T., Viitanen, M. & Almkvist, O. (2007). Cognitive impairment after stroke--diagnosis and management. *Journal of the Norwegian Medical Association*, 127(10), p1390.

Ferris, A., Robertson, R-M., Fabunmi, R. & Mosca, L . (2005). American Heart Association and American Stroke Association national survey of stroke risk awareness among women. *Circulation,* 111, pp1321–1326.

Fiedorowic, J.G., He, J. & Merikangas, K.R. (2011). The association between mood and anxiety disorders with vascular diseases and risk factors in a nationally representative sample. *Journal of Psychosomatic Research,* 70, pp145-54.

Field, A. (2005). *Discovering statistics using SPSS* (2nd Edition). London, Sage.

Fisher, M. (2008). Stroke and TIA: epidemiology, risk factors and the need for early intervention. *American Journal of Managed Care,* 14, pp204-211.

Flinn, N. A. & Stube, J. E. (2009). Post-stroke fatigue: qualitative study of three focus groups. *Occupational Therapy International*, 17(2), pp81-91.

Fonseca, A.C.& Canhao, P. (2011). Diagnostic difficulties in the classification of transient neurological attacks. *European Journal of Neurology,* 8(4), pp644-8.

Forsberg-Wärleby, G., Möller, A. & Blomstrand, C. (2001). Spouses of first-ever stroke patients psychological well-being in the first phase after stroke. *Stroke*, *32*(7), pp1646-1651.

Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J.J. & Young, J. (2012). Information provision for stroke patients and their caregivers. Update of Cochrane Database Systematic Review. 2008;(2):CD001919; PMID: 18425877. *Cochrane Database of Systematic Reviews.* 11:CD001919, 2012.

Fountoulakis, K. N., Pantoula, E., Siamouli, M., Moutou, K., Gonda, X., Rihmer, Z., Iacovides, A. & Akiskal, H. (2012). Development of the Risk Assessment Suicidality Scale (RASS): A population-based study. *Journal of Affective Disorders*, 138(3), pp449-457.

Fransella, F. & Bannister, D. (1977). *A Manual for Repertory Grid Technique*. London, Academic Press.

Frewer, L.J., Salter, B. & Lambert, N. (2001). Understanding patients' preferences for treatment: the need for innovative methodologies. *Quality in Health Care*; 10(1) pp50-54.

Furr, R.M. & Bacharach, V.R. (2007). *Psychometrics: an Introduction*. London, Sage Publishing Ltd.

Gains, B.R. & Shaw, M.L.G. (2005). *RepGridIV Manual for Personal Version 1.10*. Centre for Person-Computer Studies, Calgary, Canada. [online].Available at http://www.repgrid.com (Accessed 15 August 2012).

Gibson, J. & Watkins, C. (2012). People's experience of the impact of transient ischaemic attack and its consequences: qualitative study. *Journal of Advanced Nursing*; 68(8) pp1707–1715.

Giles, M.F., Flossman, E. & Rothwell, P.M. (2006). Patient behavior immediately after Transient Ischemic Attack according to clinical characteristics, perception of the event, and predicted risk of Stroke. *Stroke,* 37, pp1254-1260.

Giles, M. F. & Rothwell, P. M. (2007). Substantial underestimation of the need for outpatient services for TIA and minor stroke. *Age & Ageing*, 36(6), pp676-680.

Giles, M. F. & Rothwell, P. M. (2008). Risk prediction after TIA: the ABCD system and other methods. *Geriatrics*, 63(10), pp10-16.

Giles, M. F. (2011). TIA management–speed and expertise are key. *European Journal of Neurology*, 18(11), pp1283-1284.

Gillespie, D.C. (1997). Poststroke anxiety and its relationship to coping and stage of recovery. *Psychological Reports*, 80(3, Pt 2), pp1059-1064.

Gillham, B. (2000). *Developing a Questionnaire (real world research)*. London, Continuum.

Glader, E. L., Stegmayr, B. & Asplund, K. (2002). Post-stroke Fatigue A 2-Year Follow-Up Study of Stroke Patients in Sweden. *Stroke*, 33(5), pp1327-1333.

Godefroy, O. & Bogousslavsky,J. (2007). *The Behavioural and Cognitive Neurology of Stroke.* Cambridge, CUP.

Gottesman, R.F. & Hillis, A.E. (2010). Predictors and assessment of cognitive dysfunction resulting from ischaemic stroke. *Lancet Neurology*, 9(9), pp895-905.

Green, J. & Thoroughgood, N. (2009). *Qualitative Methods for Health Research*. London, Sage.

Greenhalgh, T. (1997). How to read a paper: papers that report diagnostic or screening tests. *British Medical Journal,* 315, pp540-543.

Greenhalgh, T. & Hurwitz, B. (1999). Why study narrative? *British Medical Journal,* 318, pp48–50.

Hackett, M.L., Anderson, C.S., House, A. & Halteh, C. (2008). Interventions for preventing depression after stroke. *Cochrane Database of Systematic Reviews 2008*, Issue 3. Art. No.: CD003689. DOI: 10.1002/14651858.CD003689.pub3.

Hadidi, N., Treat-Jacobson, D.J. & Lindquist, R. (2009). Poststroke depression and functional outcome: a critical review of literature. *Heart & Lung*, 38(2), pp151-62.

Hankey, G. J. (2006). Potential new risk factors for Ischemic Stroke: what is their potential? *Stroke*, 37(8), pp2181-2188.

Harris, J. E., Eng, J. J., Miller, W. C. & Dawson, A. S. (2010). The role of caregiver involvement in upper-limb treatment in individuals with subacute stroke. *Physical Therapy*, 90(9), pp1302-1310.

Harwood, R.H. & Ebrahim, S. (2002). The validity, reliability and responsiveness of the Nottingham Extended Activities of Daily Living scale in patients undergoing total hip replacement. *Disability & Rehabilitation***,** 10, pp371-77.

Heider, F. (1944). Social perception and phenomenal causality. *Psychological Review,* 51, pp358 – 374.

Heinemann, A. W., Roth, E. J., Cichowski, K. & Betts, H. B. (1987). Multivariate analysis of improvement and outcome following stroke rehabilitation. *Archives of Neurology*, 44(11), pp1167- 1172.

Hendel, D.D. (1975.) Paired comparisons intransitivity: trends across domains of content and across groups of subjects. *Educational & Psychological Measurement,* 35(4), pp865-868.

Herrmann, M., Freyholdt, U., Fuchs, G. & Wallesch, C-W. (1997). Coping with chronic neurological impairment: A contrastive analysis of Parkinson's disease and stroke. *Disability & Rehabilitation,* 19(1), pp6-12.

Herrmann, M., Curio, N., Petz, T., Synowitz, H., Wagner, S., Bartels, C. & Wallesch, C.W. (2000). Coping with illness after brain diseases--a comparison between patients with malignant brain tumours, stroke, Parkinson's disease and traumatic brain injury. *Disability & Rehabilitation,* 22(12), pp539-46.

Herxheimer, A., McPherson, A., Miller, R., Sheppard, S., Yaphe, J. & Ziebland, S. (2000). Database of patients' experiences (DIPEx): a multimedia approach to sharing experiences and information. *The Lancet,* 355(9214), pp1540-1543.

Hoffmann, T., Bennett, S., Koh, C.L., McKenna, K.T. & Kriss, T. (2010a). Occupational therapy for cognitive impairment in stroke patients. *European Journal of Physical & Rehabilitation Medicine,* 47(3), pp513-519; [PMID: 21494221] *Cochrane Database of Systematic Reviews.* (9):CD006430, 2010.

Hoffmann, T., Worrall. L., Eames, S. & Ryan, A. (2010b). Measuring outcomes in people who have had a stroke and their carers: can the telephone be used? *Topics in Stroke Rehabilitation,* 17(2), pp119-127.

Hofgren, C., Björkdahl, A., Esbjörnsson, E. & Stibrant-Sunnerhagen, K. (2006). Recovery after stroke: cognition, ADL function and return to work. *Acta Neurologica Scandinavica*, 115(2), pp73-80.

Horn, J.L. (1965). A rationale and test for the number of factors in factor analysis. *Psychometrika*. 30, pp179 - 185.

Hubbard, R. & Allen, S.J. (1987). An empirical comparison of alternative methods for principal component extraction. *Journal of Business Research*, 15, pp173-190.

Jacobson, A.McC. (2011). Stroke recovery and rehabilitation. *Journal of Neurologic Physical Therapy,* 35(1), pp47–48.

James, G.A. & Doe, T. (2010). Craniocervical flexion test: intra-rater reliability in asymptomatic subjects. *Physiotherapy Research International,* 15(3), pp144-149.

Janssen, A. W., de Leeuw, F. E. & Janssen, M. C. (2011). Risk factors for ischemic stroke and transient ischemic attack in patients under age 50. *Journal of Thrombosis & Thrombolysis*, 31(1), pp85-91.

Jerome, S., Hicks, C. & Herron-Marx, S. (2009). Designing sexual health services for young people: a methodology for capturing the user voice. *Health & Social Care in the Community,* 17(4), pp350-7.

Jick, T.D. (1979). Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly*, 24, pp602-611.

Johnston, S.C., Rothwell, P.M., Nguyen-Huynh, M.N., Giles, M.F., Elkins. J.S., Bernstein, A.L. & Sidney, S. (2007). Validation and refinement of scores to predict very early stroke risk after transient ischaemic attack. *Lancet,* 369(9558), pp283-92.

Jones, F. & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disability & Rehabilitation*, 33(10), pp797-810.

Jood, K., Redfors, P., Rosengren, A., Blomstrand, C. & Jern, C. (2009). Self-perceived psychological stress and ischemic stroke: a case-control study. *BMC Medicine*, 7(1), 53. [online]. Available at http://www.biomedcentral.com/1741-7015/7/53/ (Accessed 3 September 2011).

Jørgensen, H. S., Nakayama, H., Raaschou, H. O. & Olsen, T. S. (1995). Recovery of walking function in stroke patients: the Copenhagen Stroke Study. *Archives of Physical Medicine & Rehabilitation*, *76*(1), pp27-32.

Josephson, S. A., Sidney, S., Pham, T. N., Bernstein, A. L. & Johnston, S. C. (2008). Higher ABCD2 score predicts patients most likely to have true transient ischemic attack. *Stroke*, 39(11), pp3096-3098.

Kang, H. J., Stewart, R., Kim, J. M., Jang, J. E., Kim, S. Y., Bae, K. Y. & Yoon, J. S. (2012). Comparative validity of depression assessment scales for screening post-stroke depression. *Journal of Affective Disorders.* [online]. Available at http://www.sciencedirect.com/science/article/pii/S016503271200732X (Accessed 15 November 2012).

Katan, M., Nigro, N., Fluri, F., Schuetz, P., Morgenthaler, N.G. & Jax, F. (2011). Stress hormones predict cerebrovascular re-events after transient ischaemic attacks. *Neurology,* 76, pp563-566.

Kaufman, S.R. (2011). Toward a phenomenology of boundaries in medicine: chronic illness experience in the case of stroke. *Topics in Stroke Rehabilitation,* 18(1), pp6-17.

Kelly, G. A. (1955) *Theory of Personal Constructs*. New York, Routledge.

Kerlinger, F.N. (1973) *Foundations of Behavioural Research*. New York, Holt, Rinehart and Winston.

Kessler, C. & Thomas, K.E. (2009). An examination of economic outcomes associated with misdiagnosis or under-treatment of TIA. *American Journal of Managed Care.* 15(6 Suppl), S170-6. [online]. Available at http://europepmc.org/abstract/MED/19601692/reload=0;jsessionid=bIsAZS0SNQvYw2EDetiK.4. (Accessed 30 September 2011).

Kitko, L. & Hupcey, J.E. (2008). Factors that influence health-seeking behaviours of patients experiencing acute stroke. *Journal of Neuroscience Nursing*, 40, pp333-40.

Kline, P. (1986). *A Handbook of Test Construction.* New York, Methuen.

Kline, P. (1993). *An Easy Guide to Factor Analysis*. London, Routledge.

Kline, P. (2000). *A Psychometric Primer.* London, Free Association Books.

Kneebone, I.I., Neffgen, L.M. & Pettyfer, S.L. (2012). Screening for depression and anxiety after stroke: developing protocols for use in the community. *Disability & Rehabilitation,* 34(13), pp1114-20.

Kootker, J., Fasotti, L., Rasquin, S.M.C., van Heugten, C.M. & Guerts, A.C.H. (2012). The effectiveness of an augmented cognitive behavioural intervention for post-stroke depression with or without anxiety (PSDA): the Restore4Stroke-PSDA trial. *BMC Neurology,* 12(51). [online]. Available at http://www.biomedcentral.com/1471-2377/12/51. (Accessed 3 Jan 2013).

Kouwenhoven, S. E., Kirkevold, M., Engedal, K. & Kim, H. S. (2011). Depression in acute stroke: prevalence, dominant symptoms and associated factors. A systematic literature review. *Disability & Rehabilitation*, 33(7), pp539-556.

Kuchenhoff, J. (2002). The personal constructs of the body: a comparative analysis of patients with chronic psychogenic pain and controls using the Rep Grid Technique. *Psychologische Beitrage,* 44(3), pp334- 348.

Kumar, R. (2010) *Research Methodology: a Step-by-Step Guide for Beginners*. London, Sage.

Langhorne, P., Stott, D.J., Robertson, L., MacDonald, .J, Jones, L., McAlpine, C., Dick, F., Taylor, G.S. & Murray, G. (2000). Medical complications after Stroke: A multicenter study. *Stroke,* 31, pp1223-1229.

Langhorne, P., Bernhardt, J. & Kwakkel, G. (2011). Stroke rehabilitation. *Lancet,* 377(9778), pp1693-702.

Lavallée, P. C., Meseguer, E., Abboud, H., Cabrejo, L., Olivot, J. M., Simon, O. & Amarenco, P. (2007). A transient ischaemic attack clinic with round-the-clock access (SOS-TIA): feasibility and effects. *The Lancet Neurology*, 6(11), pp953-960.

Leach, C., Freshwater, K., Aldridge, J. & Sunderland, J. (2001). Analysis of repertory grids in clinical practice. *British Journal of Clinical Psychology,* 40, pp225–248.

Lecouturier, J., Murtagh, M.J., Thomson, R.G., Ford, G.A., White, M., Eccles, M. & Rodgers, H. (2010). Response to symptoms of stroke in the UK: a systematic review. *BMC Health Services Research*, 10,157; doi: 10.1186/1472-6963-10-157. [online]. Available at http://www.ncbi.nlm.nih.gov/pubmed/20529351 (Accessed 19 June 2012).

Lee, S., Shafe, A.C.E. & Cowie, M. (2011). UK stroke incidence, mortality and cardiovascular risk management 1999-2008: time trend analysis from General Practice research Database. *British Medical Journal Open* 1:e000269 doi:10.1136/bmjopen-2011-000269. [online]. Available at http://bmjopen.bmj.com/content/1/2/e000269.long (Accessed 15 March 2012).

Legg, L., Drummond, A., Leonardi-Bee, J., Gladman, J.R., Corr, S., Donkervoort, M., Edmans, J., Gilbertson, L., Jongbloed, L., Logan, P., Sackley, C. & Walker, M. (2007). Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials. *British Medical Journal,* 335(7626), 922. [online]. Epub 2007 Sep 27. Available at http://www.ncbi.nlm.nih.gov/pubmed/17901469. Accessed 12 February 2013).

Lempert, T. (2012). Recurrent spontaneous attacks of dizziness. *CONTINUUM: Lifelong Learning in Neurology.* 18(5) pp1086-101.

Leventhal, H., Meyer, D. & Nerenz, D. (1980). The commonsense representation of illness danger. In Rachman, S. (Ed). *Medical Psychology Volume 2*. New York, Pergamon Press, pp7-30.

Lincoln, N. & Gladman, J. (1992). The extended activities of daily living scale: a further validation. *Disability & Rehabilitation*, 14, pp41–43.

Logan, P.A., Dyas, J. & Gladman, J.R. (2004a). Using an interview study of transport use by people who have had a stroke to inform rehabilitation. *Clinical Rehabilitation,* 18(6), pp703-8.

Logan, P.A., Gladman, J.R., Avery, A., Walker, M.F., Dyas, J. & Groom, L. (2004b). Randomised controlled trial of an occupational therapy intervention to increase outdoor mobility after stroke. *British Medical Journal*, 329(7479), pp1372-5.

Luengo-Fernandez, R., Gray, A. & Rothwell, P. (2009). Effect of urgent treatment for transient ischaemic attack and minor stroke on disability and hospital costs (EXPRESS study): a prospective population-based sequential comparison. *The Lancet Neurology,* 8, pp235 – 243.

Luijendijk, H.J., Stricker, B.H.C., Wieberdink, R.G., Koudstaal, P.J., Hofman, A., Breteler, M.M. & Tiemeier, H. (2011). Transient Ischemic Attack and incident depression. *Stroke,* 42, pp1857-1861.

Maasland, L., Brouwer-Goossensen, D., den Hertog, H.M., Koudstaal, P.J. & Dippe, D.W.I. (2011). Health education in patients with a recent stroke or transient ischaemic attack: a comprehensive review. *International Journal of Stroke,* 6, pp67-74.

MacKenzie, G., Gould, L., Ireland, S., LeBlanc, K.& Sahlas, D. (2011). Detecting cognitive impairment in clients with mild stroke or transient ischemic attack attending a stroke prevention clinic. *Canadian Journal of Neuroscience Nursing,* 33(1), pp47-50.

Mant, J., Wade, D.T. & Winner, S. (2004). Health care needs assessment: stroke. In Stevens, A., Raftery, J. & Mant, J. (Editors). *Health Care Needs Assessment: the Epidemiologically-Based Assessment Reviews.* First series. (2nd Edition). Oxford, Radcliffe Medical Press, pp141-244.

Mao, W., Yang, J., Wang, M., Wang, Y., Wang, D., Zhu, L. & Jia, J. (2006). Event-related potential N270 in detecting cognitive impairment in patients with transient ischemic attack. *Journal of Clinical Neurophysiology,* 23(6), pp559-64.

Martin, C., Dellatolas, G., Viguier, D., Willadino-Braga, L. & Deloche, G. (2002). Subjective experience after stroke. *Applied Neuropsychology,* 9, pp148-158.

May, M., McCarron, P., Stansfeld, S., Ben-Shlomo, Y., Gallacher, J, Yarnell, J., Davey Smith, G., Elwood, P. & Ebrahim, S. (2002). Does psychological distress predict the risk of ischemic stroke and transient ischemic attack? The Caerphilly Study. *Stroke,* 33(1), pp7-12.

McKenna, S.P., Hunt, S.M. & McEwen, J. (1981). Weighting the seriousness of perceived health problems using Thurstone's Method of Paired Comparisons. *International Journal of Epidemiology* , 10(10), pp93-97.

Mead, N. & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine,* 51, pp1087–1110.

Meetoo, D. & Temple, B. (2003). Issues in multi-method research: constructing self-care. *International Journal of Qualitative Methods,* 2(3), pp1-21.

Merrick, S. & Farrell, D. (2012). Head and neck cancer patients' experiences of percutaneous endoscopic gastrostomy (PEG) feeding: A Q methodology study. *European Journal of Cancer Care*, 21, pp 493 -504.

Merwick, A. & Kelly, P.J. (2011). Transient ischaemic attack clinics and management of transient ischaemic attacks. *Current Opinion in Neurology,* 24(1), pp50-58.

Mitchell, A. J., Meader, N. & Symonds, P. (2010). Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: a meta-analysis. *Journal of Affective Disorders*, 126(3), pp335-348.

Mitchell, E.S. (1986). Multiple triangulation: A methodology for nursing science. *Advances in Nursing Science*, 8(3), 18-26.

Molina, C. A. & Selim, M. M. (2012). Hospital admission after Transient Ischemic Attack: unmasking wolves in sheep's clothing. *Stroke*, *43*(5), pp1450-1451.

Moore, R.J., Chamberlain, R.M. & Khuri, F.R. (2004). Communicating suffering in primary stage head and neck cancer. *European Journal of Cancer Care,* 13(1), pp53–64.

Moos, R.H. & Schaefer, J.A. (1984). The crisis of physical illness: an overview and conceptual approach. In Moos, R.H. (Ed). *Coping with Physical Illness: New Perspectives. Vol 2*. New York, Plenum Press, pp3-25.

Morrison, V., Pollard, B., Johnston., M. & MacWalter, R. (2005). Anxiety and depression 3 years following stroke: demographic, clinical and psychological predictors. *Journal of Psychosomatic Research,* 59(4), pp209-213.

Moskowitz, J.T. (2010). Positive affect at the onset of chronic illness: planting the seeds of resilience. In Reich, J.W., Zautra, A. J. & Hall, J.S. (Editors). *Handbook of Adult Resilience*. New York, Guilford Press, pp465-483.

Nabi, H., Koskenvuo, M. Singh-Manoux, A., Korkeila, J., Suominen, S. & Korkeila, K. (2010). Low pessimism protects against stroke: the Health and Social Support (HeSSup) prospective cohort study. *Stroke,* 41, pp187-90.

Naess, H., Lunde, L., Brogger, J. & Waje-Andreassen, U. (2012). Fatigue among stroke patients on long-term follow-up. The Bergen Stroke Study. *Journal of the Neurological Sciences*, 312(1), pp138-141.

National Audit Office (2005). *Reducing Brain Damage: Faster Access to Better Stroke Care. HC452, session 2005 -2006*. London: The Stationery Office.

National Audit Office (2010). *Progress in Improving Stroke Care.* London: The Stationery Office. [online]. Available at http://www.nao.org.uk/wp-content/uploads/2010/02/0910291.pdf (Accessed 9 April 2013).

National Institute of Health and Clinical Excellence - NICE. (2008). *Stroke: National Clinical Guidelines for Diagnosis and Initial Management of Acute Stroke and Transient Ischaemic Attack (TIA).* London, Royal College of Physicians. [online]. Available at http://www.nice.org.uk/nicemedia/live/12018/41331/41331.pdf (Accessed 24 September 2011).

National Institute for Health and Clinical Excellence - NICE (2009). *Depression.* London, National Institute for Health and Clinical Excellence. [online]. Available at http://www.nice.org.uk/nicemedia/live/12329/45890/45890.pdf. (Accessed 25 October 2011).

National Institute of Health and Clinical Excellence - NICE (2010). *Stroke Rehabilitation Final Scope.* London, NICE. [online]. Available at http://www.nice.org.uk/nicemedia/live/11950/48694/48694.pdf (Accessed 4 October 2012).

National Institute of Health and Clinical Excellence - NICE (2011) *Stroke Rehabilitation: Full Guidelines.* London, National Institute of Health and Clinical Excellence. [online]. Available at http://guidance.nice.org.uk/CG/Wave21/4/Consultation/Latest. (Accessed 12 December 2011).

National Institute of Health and Clinical Excellence - NICE (2013). Stroke rehabilitation: long-term rehabilitation after stroke. London, National Institute of Health and Clinical Excellence. [online]. Available at http://publications.nice.org.uk/stroke-rehabilitation-cg162

National Institute of Neurological Disorders and Stroke (NINDS) (2011). *NINDS Stroke Information Page.* [online]. Available at www.ninds.nih.gov/disorders/stroke/stroke.htm (Accessed 11 December 2011).

National Stroke Association (2011). *Stroke: Risk Factors.* [online]. Available at http://www.stroke.org/site/PageServer?pagename=RISK. (Accessed 3 January 2013).

Neighbour, R. (1987). *The Inner Consultation.* Lancaster, MTP Press.

NHS Choices (2011). *National stroke strategy*. [online]. Available at http://www.nhs.uk/nhsengland/nsf/pages/nationalstrokestrategy.aspx. (Accessed 19 December 2011).

Nouri, F.M. & Lincoln, N.B. (1987). An extended ADL scale for use with stroke patients. *Clinical Rehabilitation,* 1, pp301-305.

Nunnally, J.C. (1976). *Psychometric Theory.* (2nd Edition). New York, McGraw-Hill.

Nunnally, J.C. (1978). *Psychometric Theory.* (3rd Edition). New York, McGraw-Hill.

Ogden, J. (2012). *Health Psychology: a Textbook.* (5th Edition). Buckingham, Open University Press.

Oppenheim, A. (2000). *Questionnaire Design and Attitude Measurement.* London, Continuum Academic Publishers.

Paciaroni, M., Hennerici, M., Agnelli, G. & Bogousslavsky, J. (2007). Statins and stroke prevention. *Cerebrovascular Diseases*, 24(2-3), pp170-182.

Pallant, J. (2007). *SPSS Survival Manual.* (3rd Edition). Maidenhead, Berkshire, Open University Press.

Pan, A., Sun, Q., Okereke, O. I., Rexrode, K. M. & Hu, F. B. (2011). Depression and risk of stroke morbidity and mortality. *Journal of the American Medical Association*, 306(11), pp1241-1249.

Pedhazur, E.J. & Schmelkin, L.P. (1991). *Measurement, Design and Analysis: an Integrated Approach.* Hillsdale, New Jersey, Lawrence Erlbaum Associates.

Pendlebury, S.T., Wadling, S., Silver, L.E., Mehta, Z. & Rothwell, P.M. (2011). Transient cognitive impairment in TIA and minor stroke. *Stroke,* 42(11), pp3116 – 3121.

Pett, M., Lackey, N.R. & Sullivan, J.J. (2003). *Making Sense of Factor Analysis: the Use of Factor Analysis for Instrument Development in Health Care Research.* London, Sage Publishing Ltd.

Pilcher, M. & MacArthur, J. (2012). Patient experiences of bladder problems following stroke. *Nursing Standard*, 26(36), 39-46.

Poisson, S. & Johnston, S. C. (2011). Prevention of stroke following transient ischemic attack. *Current Atherosclerosis Reports*, 13(4), pp330-337. [online]. Available at http://link.springer.com/article/10.1007/s11883-011-0181-4#page-1 (Accessed 3 January 2013).

Pope, C. & Mays, N. (2006). *Qualitative Research in Health Care.* (3rd Edition). London, Wiley-Blackwell.

Pound, P., Gompertz, P. & Ebrahim, S. (1998). Illness in the context of older age: the case of stroke. *Sociology of Health & Illness*, 20(4), pp489 – 506.

Prasad, R.S. (2001). Development of the HIV/AIDS Q-sort instrument to measure physician attitudes. *Family Medicine,* 33(10), pp772-778.

Prigatano, G.P. (2011). The importance of the patient's subjective experience in stroke rehabilitation. *Topics in Stroke Rehabilitation,* 18, pp30-34.

Rankin, G. & Stokes, M. (1998). Reliability of assessment tools in rehabilitation: an illustration of appropriate statistical analyses. *Clinical Rehabilitation,* 12, pp187 – 199.

Rehabilitation Measures Database (2010). Rehabilitation Institute of Chicago. [online]. Available at http://www.rehabmeasures.org/rehabweb/rhstats.aspx (Accessed 5 April 2013).

Rigby, H., Gubitz, G., Eskes, G., Reidy, Y., Christian, C., Grover, V. & Phillips, S. (2009). Caring for stroke survivors: baseline and 1-year determinants of caregiver burden. *International Journal of Stroke,* 4(3), pp152-8.

Robinson, R.G. & Spalletta, G. (2010). Poststroke depression: a review. *Canadian Journal of Psychiatry,* 55(6), pp341-9.

Robson, C. (1993). *Real World Research.* Oxford, Blackwell.

Robson, C. (2011). *Real World Research.* (3rd Edition). Oxford, Blackwell.

Rocha, K. B., Perez, K., Rodriguez-Sanz, M., Borrell, C. & Obiols, J. (2011). Psychometric properties and normative values of General Health Questionnaire (GHQ-12) in the Spanish population. *International Journal of Clinical & Health Psychology*, 11(1), pp125-139.

Rogers, W.A. (2002). Evidence-based medicine in practice: limiting or facilitating patient choice? *Health Expectations*, 5, pp95-103.

Roland, K.P., Jenkins, M.E. & Johnson, A.M. (2010). An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's Disease. *Movement Disorders,* 25(2), pp189 – 193.

Roth, S. & Cohen, L.J. (1986). Approach, avoidance and coping with stress. *American Psychologist,* 41, pp813-819.

Rothwell, P. M. (2007). Transient ischaemic attacks: time to wake up. *Heart*, 93(8), pp893- 894.

Rothwell, P. M., Giles, M. F., Flossmann, E., Lovelock, C. E., Redgrave, J. N. E., Warlow, C. P., & Mehta, Z. (2005). A simple score (ABCD) to identify individuals at high early risk of stroke after transient ischaemic attack. *The Lancet*, 366(9479), 29-36.

Rowe, G., Lambert, N., Bowling, A., Ebrahim, S., Wakeling, I. & Thomson, R. (2005). Assessing patients' preferences for treatments for angina using a modified repertory grid method. *Social Science & Medicine,* 60(11), pp2585-2595.

Royal College of Physicians of England and Wales - RCP. (2005). *Stroke: National Clinical Guideline for Diagnosis and Initial management of Acute Stroke and Transient Ischaemic Attack (TIA).* London, Royal College of Physicians.

Royal College of Physicians of England and Wales - RCP. (2007). *National Sentinel Stroke Audit 2006*. London: Royal College of Physicians. [online]. Available at http://news.bbc.co.uk/1/shared/bsp/hi/pdfs/09_05_07_stroke_report.pdf. (Accessed 14 October 2011).

Royal College of Physicians of England and Wales - RCP. (2011). *National Sentinel Stroke Audit 2010: Round 7*. London: Royal College of Physicians.[online]. Available at http://www.rcplondon.ac.uk/sites/default/files/national-sentinel-stroke-audit-2010-public-report-and-appendices_0.pdf. (Accessed 30 November 2011).

Rust, J. & Golombok, S. (1999). *Modern Psychometrics: the Science of Psychological Assessment.* (2nd Edition). London, Routledge.

Sacco, R.L., Adams, R., Albers, G., Alberts, M.J., Benavente, O., Furie, K., Goldstein, L., Gorelick, P., Halperin, J., Harbaugh, R., Claiborne Johnston, S., Katzan, I., Kelly-Hayes, M., Kenton, E.J., Marks, M., Schwamm, L.H. & Tomsick, T. (2006). Guidelines for prevention of Stroke in patients with Ischemic Stroke or Transient Ischemic Attack: a statement for healthcare professionals. *Circulation,* 113, pp409-449.

Sachdev, P.S., Brodaty, H., Valenzuela, M.J., Lorentz, L., Looi, J.C., Wen, W. & Zagami, A.S. (2004).The neuropsychological profile of vascular cognitive impairment in stroke and TIA patients. *Neurology*, 62(6), pp912-919.

Sachdev, P.S., Chen, X., Joscelyne, A., Wen, W. & Brodaty, H. (2007). Amygdala in stroke/transient ischemic attack patients and its relationship to cognitive impairment and psychopathology: the Sydney Stroke Study. *American Journal of Geriatric Psychiatry,* 15(6), pp487-496 .

Sackett, D.L., Rosenberg, W.M., Gray, J.A., Haynes, R.B. & Richardson, W.S. (1996). Evidence-based medicine: what it is and what it isn't. *British Medical Journal*, 312, pp71-72.

Sackley, C., Wade, D.T., Mant, D., Atkinson, J.C., Yudkin, P., Cardoso, K., Levin, S., Lee, V.B. & Reel, K. (2006). Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes. *Stroke,* 37(9), pp2336-41.

Sackley, C., Brittle, N., Patel, S., Ellins. J., Scott, M., Wright, C. & Dewey, M.E. (2008). The prevalence of joint contractures, pressure sores, painful shoulder, other pain, falls, and depression in the year after a severely disabling stroke. *Stroke,* 39(12), pp3329-3334.

Sackley, C., Mant, J., Brittle, N., Holder, R. & McManus, R. (2010). *Functional, cognitive and emotional outcomes after Transient Ischaemic Attack: a prospective, controlled cohort study to inform future rehabilitative interventions.* Unpublished proposal for ongoing cohort study, reference 10/H1206/36; protocol number RG_10-055.

Sakalys, J.A. (2003). Restoring the patient's voice. The therapeutics of illness narratives. *Journal of Holistic Nursing,* 21(3), pp228-41.

Salaycik, K.J., Kelly-Hayes, M., Beiser, A., Nguyen, A.H., Brady, S.M., Kase, C.S.& Wolf, P.A. (2007). Depressive symptoms and risk of stroke: the Framingham Study. *Stroke,* 38(1), pp16-21.

Santos, C.O., Caeiro, L., Ferro, J.M., Albuquerque, R. & Figueira, M.L. (2006). Denial in the first days of acute stroke. *Journal of Neurology,* 253, pp1016-1023.

Schaffalitzky, E., NiMhurchadha, S., Gallagher, P., Hofkamp, S., MacLachlan, M. & Wegener, S.T. (2009). Identifying the values and preferences of prosthetic users: a case series study using the repertory grid technique. *Prosthetics & Orthotics International,* 33(2), pp157 -166.

Schillaci, M. A., Waitzkin, H., Carson, E. A., López, C. M., Boehm, D. A., López, L. A. & Mahoney, S. F. (2004). Immunization Coverage and Medicaid Managed Care in New Mexico: A Multimethod Assessment. *Annals of Family Medicine*, 2, pp13-21.

Schmidt, F.L. & Hunter, J.E. (1998). The validity and utility of selection methods in personnel psychology: practical and theoretical implications of 85 years of research findings. *Psychological Bulletin,* 124(2), pp262–274.

Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviours. In Schwarzer, R (Editor), *Self-efficacy: Thought Control of Action.* Washington D.C., Hemisphere; pp217 – 243.

Scottish Intercollegiate Guidelines Network - SIGN (2008). Management of patients with stroke or TIA: Assessment, investigation, immediate management and secondary prevention. [online]. Available at http://www.sign.ac.uk/guidelines/fulltext/108/index.html (Accessed 15 November 2011).

Selye, H. (1970). The evolution of the stress concept: stress and cardiovascular disease. *The American Journal of Cardiology*, 26(3), pp289-299.

Shrout, P.E & Fleiss, J.L (1979). Intraclass correlations: uses in assessing rater reliability. *Psychological Bulletin;* 86(2), pp420–428.

Siket, M.S. & Edlow, J.A. (2012). Transient ischemic attack: reviewing the evolution of the definition, diagnosis, risk stratification, and management for the emergency physician. *Emergency Medicine Clinics of North America,* 30(3), pp745-70.

Snaith, R.P. (2003). The hospital anxiety and depression scale. *Health and Quality of Life Outcomes,* 1(29). [online]. Available at http://www.biomedcentral.com/content/pdf/1477-7525-1-29.pdf. (Accessed 29 November 2012).

Snaphaan, L., van der Werf, S. & de Leeuw, F.E. (2011). Time course and risk of post-stroke fatigue: a prospective cohort study. *European Journal of Neurology*, 18(4), pp611-617.

Sohier, R. (1988). Multiple triangulation and contemporary nursing research. *Western Journal of Nursing Research,* 10(6), pp732-742.

Soundy, A., Smith, B., Dawes, H., Pall, H., Gimbrere, K. & Ramsay, J. (2011). Patients' expression of hope and illness narratives in three neurological conditions: a meta-Ethnography. *Health Psychology Review*. [online]. Avaliable at http://www.tandfonline.com/doi/full/10.1080/17437199.2011.568856#tabModule (Accessed 23 March 2013).

Spratt, C., Walker, R. & Bernadette, R.R. (2004). Mixed Methods Research. *Commonwealth of Learning* , 352, 1– 55.

Sprigg, N., Machili, C., Otter, M.E., Wilson, A. & Robinson, T.G. (2009). A systematic review of delays in seeking medical attention after transient ischaemic attack. *Journal of Neurology, Neurosurgery & Psychiatry,* 80(8), pp871-5.

Stainton-Rogers, R. (1995). Q-methodology. In: Smith, J.A., Harris, R. & Longenhove, I. (Editors). *Rethinking Methods in Psychology*. London, Sage, pp178 -193.

Stewart, M., Brown, J., Weston, W., McWhinney. I., Mc William, C. & Freeman, T. (1995). *Patient-Centred Medicine: Transforming the Clinical Method*. London, Sage.

Stephenson, W. (1953). *The Study of Behaviour: Q-technique and its Methodology*. Chicago, University of Chicago Press.

Streiner, D.L. & Norman, G.R. (2003). *Health Measurement Scales: a Practical Guide to their Development and Use* (3rd Edition). Oxford, Oxford University Press.

Stroke Association (2009). Emotional changes after stroke. F36. [online]. Available at http://www.stroke.org.uk/about-stroke (Accessed 11 December 2011).

Stroke Association (2011). About Stroke. [online]. Available at http://www.stroke.org.uk/about-stroke (Accessed 11 December 2011).

Surtees, P.G., Wainwright, N.W.J., Luben, R.N., Wareham, N.J., Bingham, S.A. & Khaw, K.T. (2008). Psychological distress, major depressive disorder and risk of stroke. *Neurology,* 70, pp788-794.

Sutherland, G., Hill, D., Morand, M., Pruden, M. & McLachlan, S-A. (2009). Assessing the unmet supportive care needs of newly diagnosed patients with cancer. *European Journal of Cancer Care,* 18(6), pp577 – 584.

Tabachnik, B.G. & Fidell, L.S. (2007). *Using Multivariate Statistics.* (5th Edition). Boston, Pearson, Allyn & Bacon.

Tang, W. K., Lu, J. Y., Chen, Y. K., Mok, V. C., Ungvari, G. S. & Wong, K. S. (2010). Is fatigue associated with short-term health-related quality of life in stroke? *Archives of Physical Medicine & Rehabilitation*, 91(10), pp1511-1515.

Tashakkori, A, & Teddlie, C. (2012). *Handbook of Mixed Methods in Social and Behavioural Research*. London, Sage Publications.

Teasell, R., Foley, N., Salter, K., Bhogal, S., Jutai, J. & Speechley, M. (2009). Evidence-based review of stroke rehabilitation: executive summary. *Topics in Stroke Rehabilitation*, 16(6), pp463-488.

Thurmond, V. A. (2001). The point of triangulation. *Journal of Nursing Scholarship*, 33, pp253-258.

Thurstone, L.L. (1927). A law of comparative judgement. *Psychological Review,* 34, pp273-286.

Tong, M.C.F., Lee, K.Y.S., Yuen, M.T.Y. & Lo, P.S.Y. (2011). Perceptions and experiences of post-irradiation swallowing difficulties in nasopharyngeal cancer survivors. *European Journal of Cancer Care*, 20(2), pp170 -178.

Trialists' Collaboration, S. U. (2007). Organised inpatient (stroke unit) care for stroke. *Cochrane Database of Systematic Reviews*, 4(4). CD000197. [online]. Available at http://www.ncbi.nlm.nih.gov/pubmed/17943737. (Accessed 12 February 2013).

Trudeau, J., Turk, D., Dworkin, R., Benson, C., Biondi, D., Kim, M. & Katz, N. (2012). Validation of the Hospital Anxiety and Depression Scale (HADS) in patients with acute low back pain. *The Journal of Pain*, *13*(4), S24. DOI: 10.1016/j.jpain.2012.01.105 [online]. Available at http://journals.ohiolink.edu/ejc/article.cgi?issn=15265900&issue=v13i0004_s&article=s24_vothaapwalbp. (Accessed 22 December 2012).

Turner, A., Hambridge, J., White, J., Carter, G., Clover, K., Nelson, L & Hackett M. (2012). Depression screening in stroke: a comparison of alternative measures with the structured diagnostic interview for the diagnostic and statistical manual of mental disorders, fourth edition (major depressive episode) as criterion standard. *Stroke,* 43(4), pp1000-1005.

Ullrich, S., McCutcheon, H. & Parker, B. (2011). Reclaiming time for nursing practice in nutritional care: outcomes of implementing Protected Mealtimes in a residential aged care setting. *Journal of Clinical Nursing*, 20(9-10), pp1339-48.

van Exel, N.J.A.& de Graaf, G. (2005) Q-methodology: A sneak preview. [Online]. Available at www.qmethodology.net. [Accessed 5 May 2011].

van Walraven, C., Hart, R. G., Singer, D. E., Laupacis, A., Connolly, S., Petersen, P. & Hellemons, B. (2002). Oral anticoagulants vs aspirin in nonvalvular atrial fibrillation. *Journal of the American Medical Association*, 288(19), pp2441-2448.

van Wijk, I., Gorter, J.W., Lindeman, E., Kappelle, L.J., van Gijn, J. & Koudstaal, P.J. (2007). Mental status and health-related quality of life in an elderly population 15 years after limited cerebral ischaemia. *Journal of Neurology*, 254, pp1018–1025.

Verbraak, M.E., Hoeksma, A.F., Lindeboom, R. & Kwa, V.I. (2012). Subtle problems in activities of daily living after a transient ischemic attack or an apparently fully recovered non-disabling stroke. *Journal of Stroke & Cerebrovascular Diseases*. 21(2), pp124-130.

Vohra, R.S., Coughlin, P.A., McShane, P., Bains, M., Laughlan, K.A. & Gough, M.J. (2008). Predictors of return to work following carotid endarterectomy. *British Journal of Surgery,* 95, pp1111-1114.

von Steinbuechel, N., Wilson, L., Gibbons, H., Muehlan, H., Schmidt, H., Schmidt, S., Sasse, N., Koskinen, S., Sarajuuri, J., Hofer, S., Bullinger, M., Maas, A., Neugebauer, E., Powell, J., Wild, K., Zitnay, G., Bakx, W., Christensen, A-L., Formisano, R., Hawthorne, G. & Truelle, J-L. (2012). QOLIBRI Overall Scale: A brief index of health-related quality of life after traumatic brain injury. *Journal of Neurology, Neurosurgery & Psychiatry*, 83(11), pp1041-1047.

Walker ,B.M. & Winter, D.A. (2007). The elaboration of Personal Construct theory. *Annual Review Psychology*, 58, pp453 – 477.

Walker, M.F., Leonardi-Bee, J., Bath, P., Langhorne, P., Dewey, M., Corr, S., Drummond, A., Gilbertson, L., Gladman, J.R., Jongbloed, L., Logan, P. & Parker, C. (2004). Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. *Stroke,* 35(9), pp2226-2232.

Walker, M.F., Sunderland, A., Fletcher-Smith, J., Drummond, A., Logan, P., Edmans, J.A., Garvey, K., Dineen, R.A., Ince, P., Horne, J., Fisher, R.J. & Taylor, J.L. (2012). The DRESS trial: a feasibility randomized controlled trial of a neuropsychological approach to dressing therapy for stroke inpatients. *Clinical Rehabilitation*, 26(8), pp675-85.

Wallenbert, I. & Jonsson, H. (2005). Waiting to get better: a dilemma regarding habits in daily occupations after stroke. *American Journal of Occupational Therapy,* 59(2), pp218-24.

Walter, S.D., Eliasziw, M., & Donner, A. (1998). Sample size and optimal designs for reliability studies. *Statistics in Medicine,* 17, pp101 – 110.

Weber, R., Frank, B. & Diener, H. C. (2010). Antithrombotic and anticoagulation therapy after stroke and transient ischemic attacks. *Der Nervenarzt*, 81(12), 1509- 5017.

Webler, T., Danielson, S. & Tuler, S. (2009*). Using Q- Methodology to Reveal Social Perspectives in Environmental Research.* Greenfield MA: Social and Environmental Research Institute, USA. [online]. Available at http://www.seri-us.org/sites/default/files/Qprimer.pdf. (Accessed 25 October 2011).

White, J.H., Magin, P., Attia, J., Pollack, M.R., Sturm, J. & Levi, C.R. (2008). Exploring post-stroke mood changes in community-dwelling stroke survivors: a qualitative study. *Archives of Physical Medicine & Rehabilitation* , 89(9), pp1701-1707.

White, J.H., Miller, B., Magin. P., Attia, J., Sturm, J. & Pollack, M. (2012). Access and participation in the community: a prospective qualitative study of driving post-stroke. *Disability & Rehabilitation*, 34(10), pp831-8.

WHO (2013). Stroke: cerebrovascular accident. [online]. Available at http://www.who.int/topics/cerebrovascular_accident/en/. (Accessed 23 August 2013).

Wilson, H.S. & Hutchinson, S.A. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research*, 1(2), pp263-276.

Winward, C., Sackley, C., Metha, Z. & Rothwell, P.M. (2009). A population-based study of the prevalence of fatigue after transient ischemic attack and minor stroke. *Stroke*, 40, pp757-761.

Wolf, S. L., Winstein, C. J., Miller, J. P., Taub, E., Uswatte, G., Morris, D. & Nichols-Larsen, D. (2006). Effect of constraint-induced movement therapy on upper extremity function 3 to 9 months after stroke. *Journal of the American Medical Association*, 296(17), pp 2095-2104.

Wood, J.P., Connelly, D.M. & Maly, M.R. (2009). "Holding me back": living with arthritis while recovering from stroke. *Archives of Physical Medicine & Rehabilitation*, 90(3), pp494-500.

Wouters, E., Booysen Fle, R., Ponnet, K., Baron Van Loon, F. (2012). Wording effects and the factor structure of the Hospital Anxiety & Depression Scale in HIV/AIDS patients on antiretroviral treatment in South Africa. *PLoS ONE*.. 7(4):e34881. doi: 10.1371/journal.pone.0034881. Epub [online]. Available at. http://www.ncbi.nlm.nih.gov/pubmed/22536338. (Accessed 15 January 2013).

Yasuhara, Y., Takada, S., Tanioka, T., Kawanishi, C.& Locsin, R.C. (2010). Illness experiences of patients with ischemic heart disease during their transitional phase from hospitalization to discharge in Japan. *Journal of Medical Investigation*, 57(3-4), pp293-304.

Zigmond, A. S. & Snaith, R.P. (1983). The hospital Anxiety and depression scale. *Acta Psychiatrica Scandinavia,* 67(6), pp361 – 370.

Zimmerli, L., Krewer, C., Gassert, R., Muller, F., Riener, R. & Lunenburger, L. (2012). Validation of a mechanism to balance exercise difficulty in robot-assisted upper-extremity rehabilitation after stroke. *Journal of Neuroengineering & Rehabilitation,* 9, 6. doi:10.1186/1743-0003-9-6 [online]. Available at http://www.jneuroengrehab.com/content/9/1/6 (Accessed 15 December 2012).

Zraick, R.I. & Boone, D. (1991). Spouse attitudes towards the person with aphasia. *Journal of Speech & Hearing Research*, 34, pp*123*–128.

APPENDIX 1:

THE PUBLISHED Q-METHODOLOGY STUDY

Spurgeon, L., Humphreys, G., James, G. & Sackley, C. (2012). A Q-methodology study of patients' subjective experiences of TIA. *Stroke Research and Treatment* Volume 12; Article ID: 4886261; http://www.hindawi.com/journals/srt/2012/486261/abs/.

APPENDIX 2:

THE PUBLISHED REPERTORY GRID STUDY

Spurgeon, L., James, G.& Sackley, C. (2013). Subjective experiences of Transient Ischaemic Attack: a repertory grid approach. *Disability and Rehabilitation.* Available early online at: http://informahealthcare.com/doi/abs/10.3109/09638288.2013.774062

APPENDIX 4:

THE HOSPITAL ANXIETY AND DEPRESSION SCALE

APPENDIX 5:

NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING SCALE

APPENDIX 6:

BLAND-ALTMAN TESTS OF AGREEMENT BY SUBJECT (FIGURES 6.5 – 6.9) AND THEME (FIGURES 6.10 – 6.16)

AGREEMENT BY SUBECT

Figure 6.5: Bland-Altman Test of Agreement by Subject - Subject 2

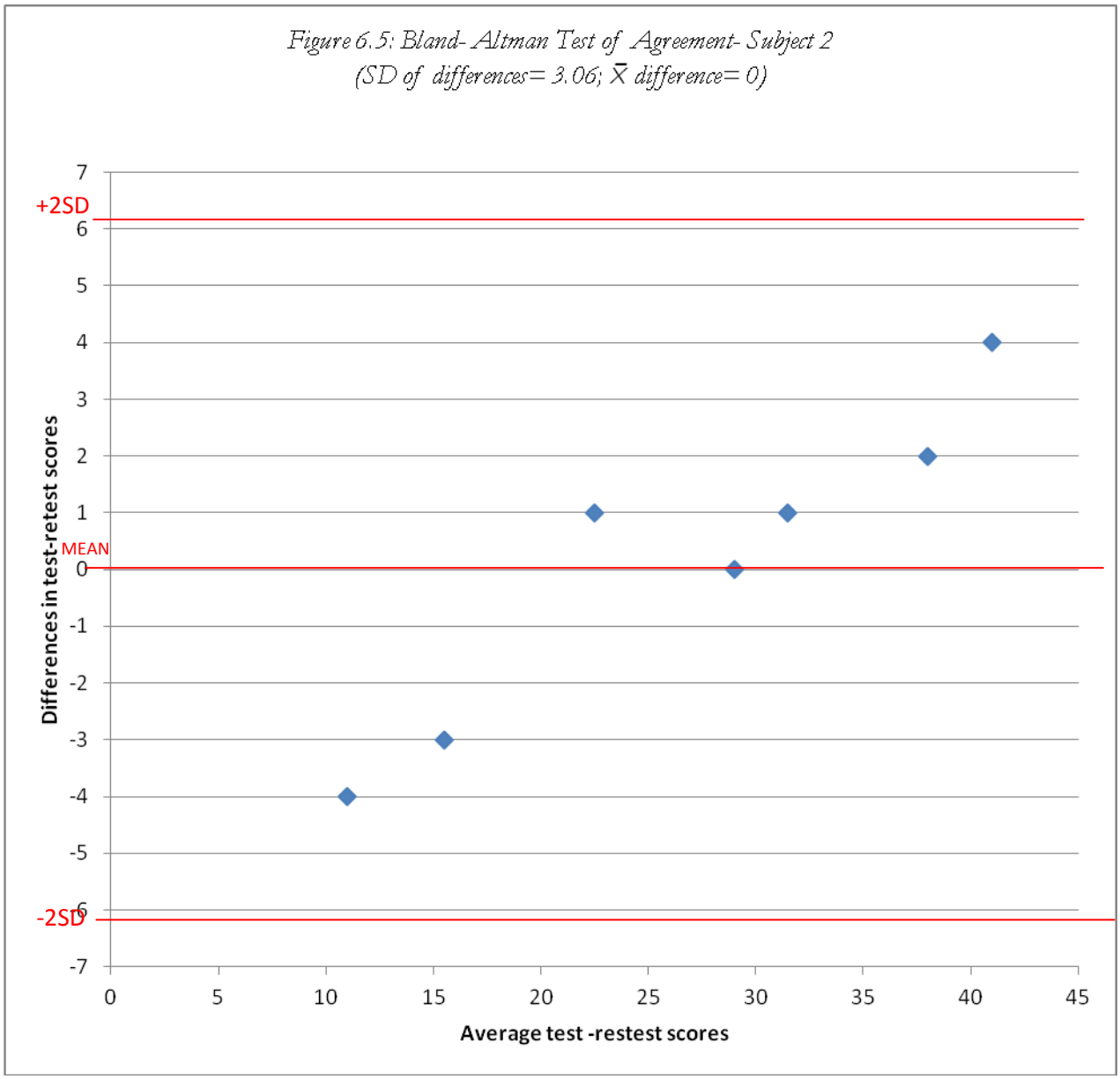


Figure 6.6: Bland-Altman Test of Agreement by Subject - Subject 3

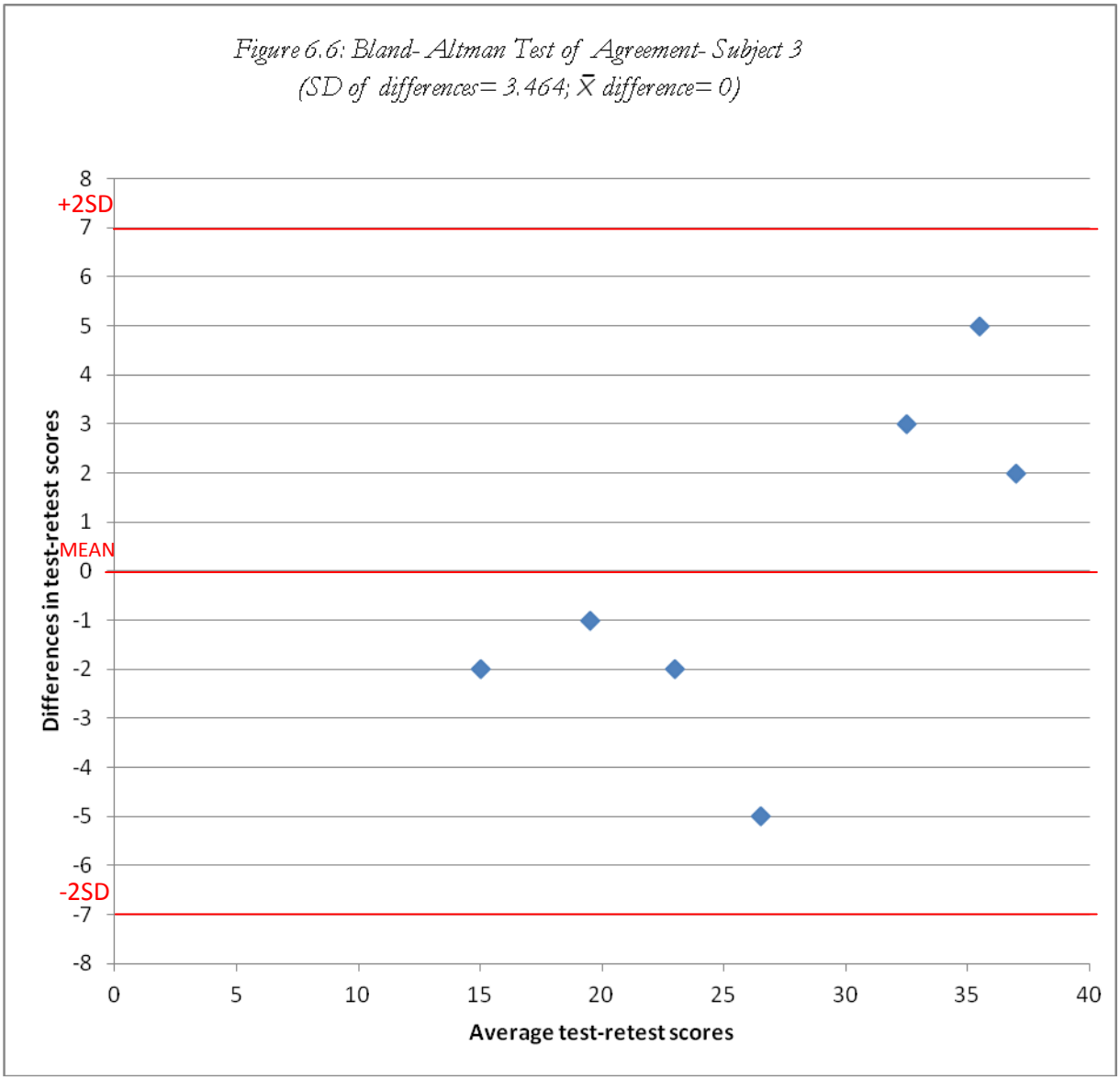


Figure 6.7: Bland-Altman Test of Agreement by Subject - Subject 4

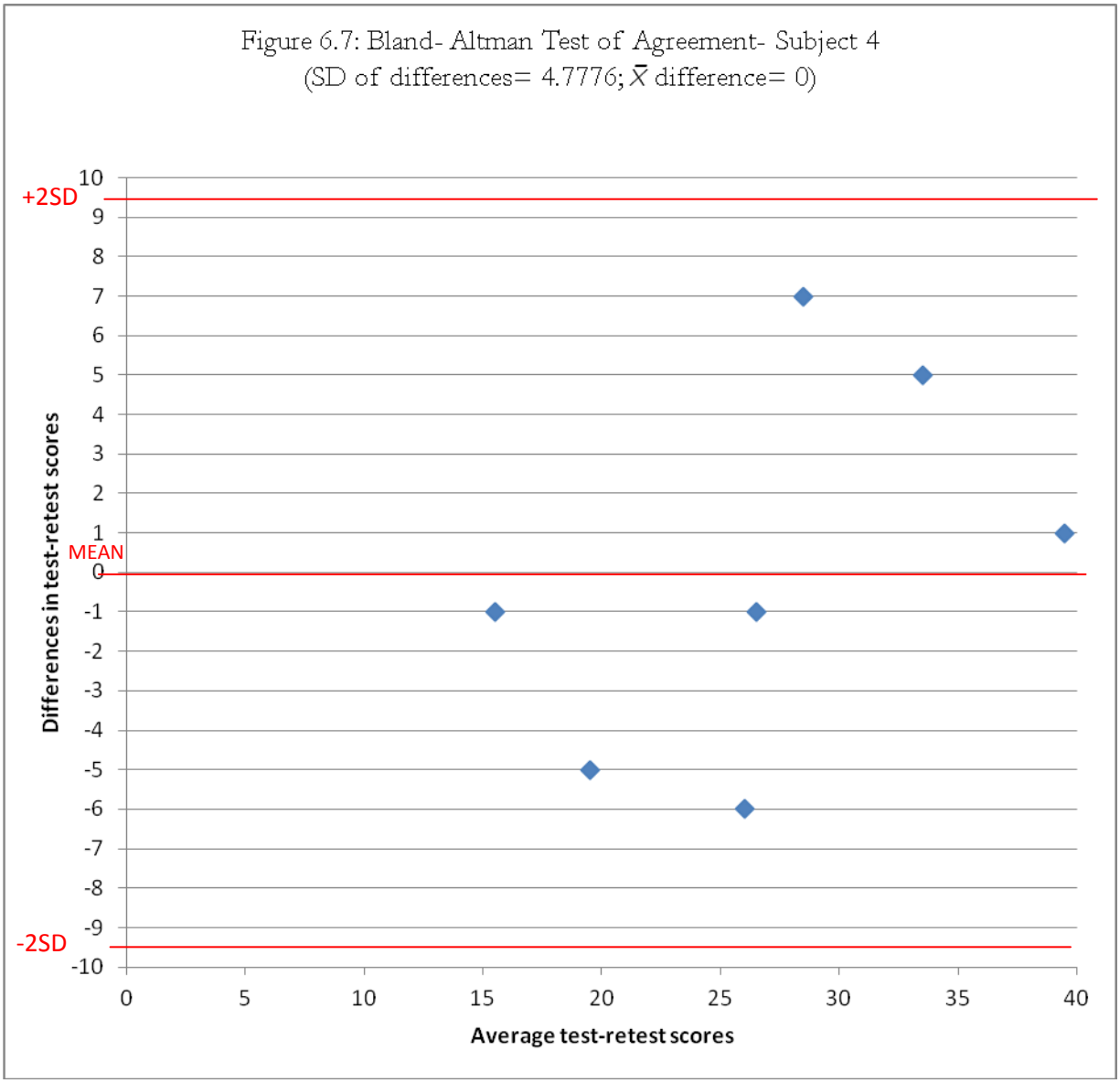


Figure 6.8: Bland-Altman Test of Agreement by Subject - Subject 5

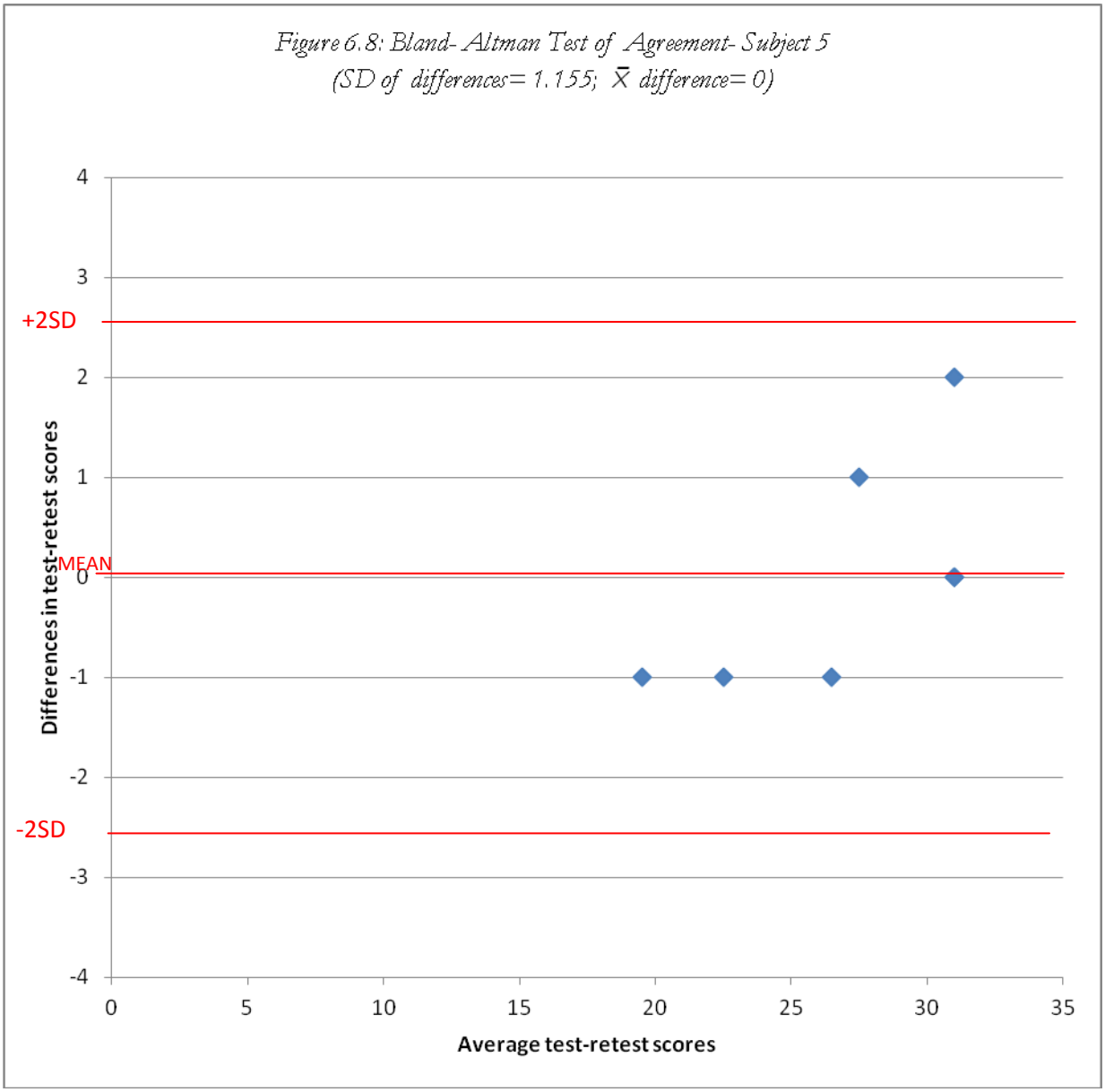
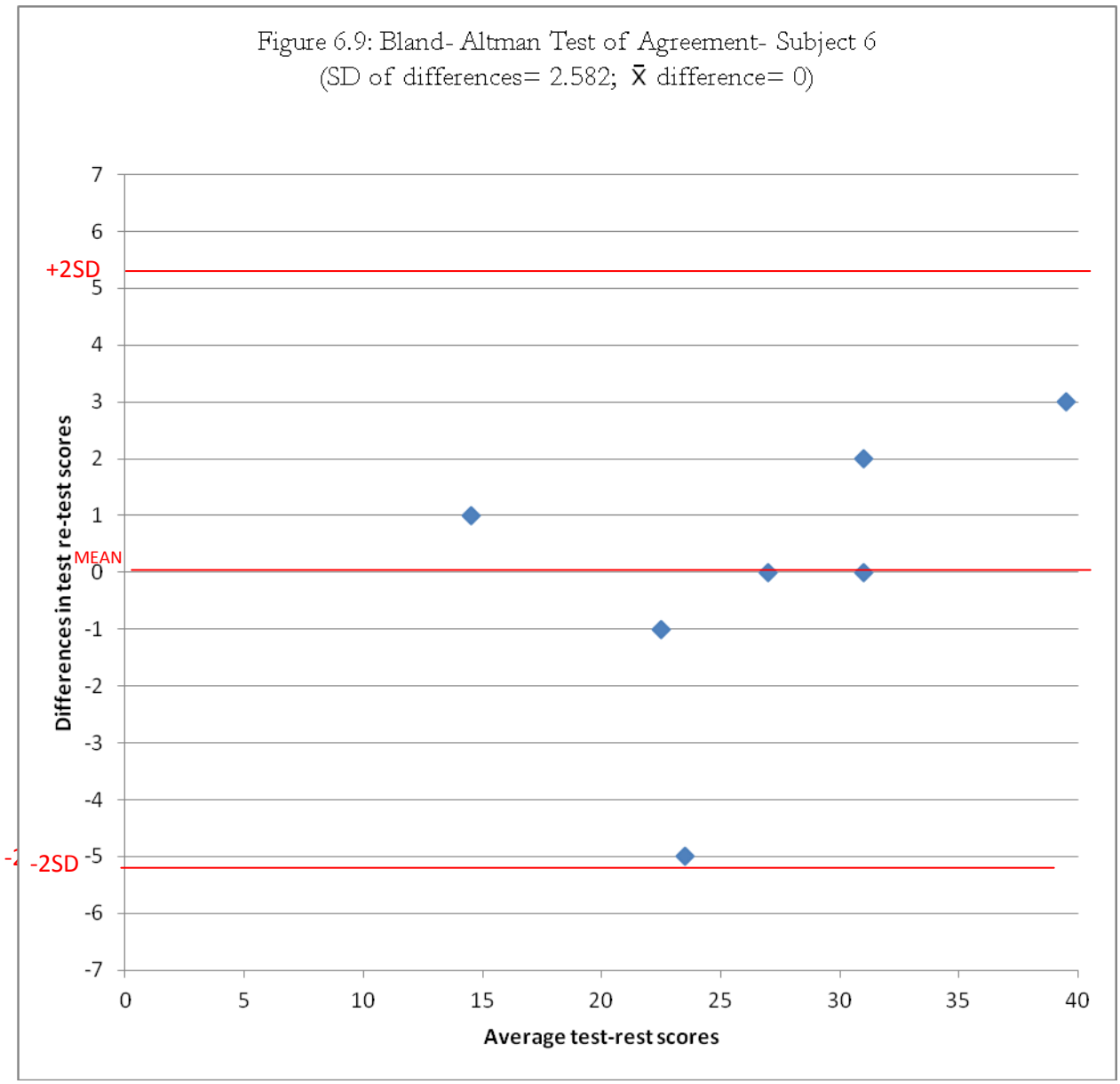


Figure 6.9: Bland-Altman Test of Agreement by Subject - Subject 6



AGREEMENT BY THEME

Figure 6.10: Bland-Altman Test of Agreement by Theme - 'Worried'

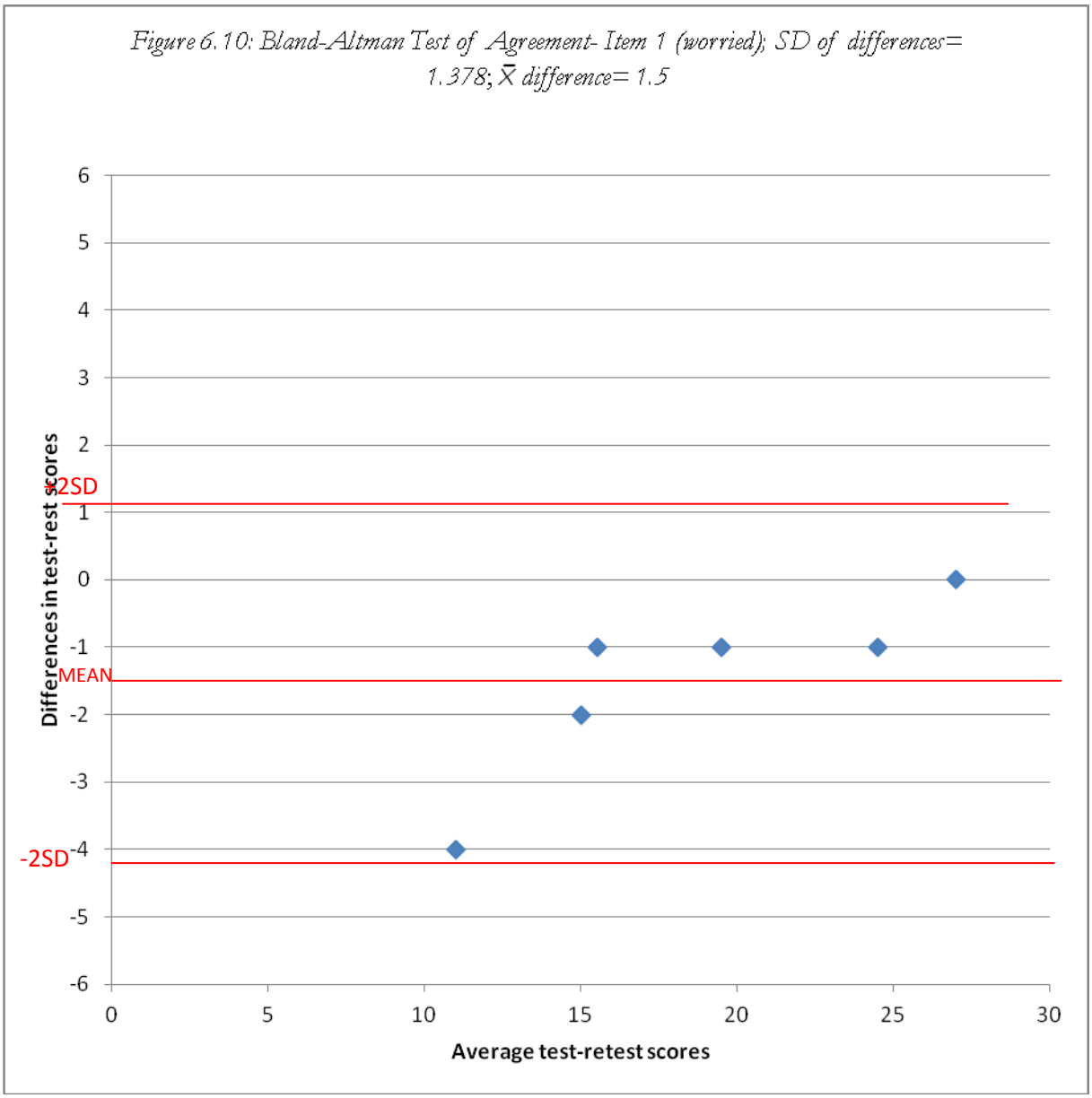


Figure 6.11: Bland-Altman Test of Agreement by Theme - 'Upset'

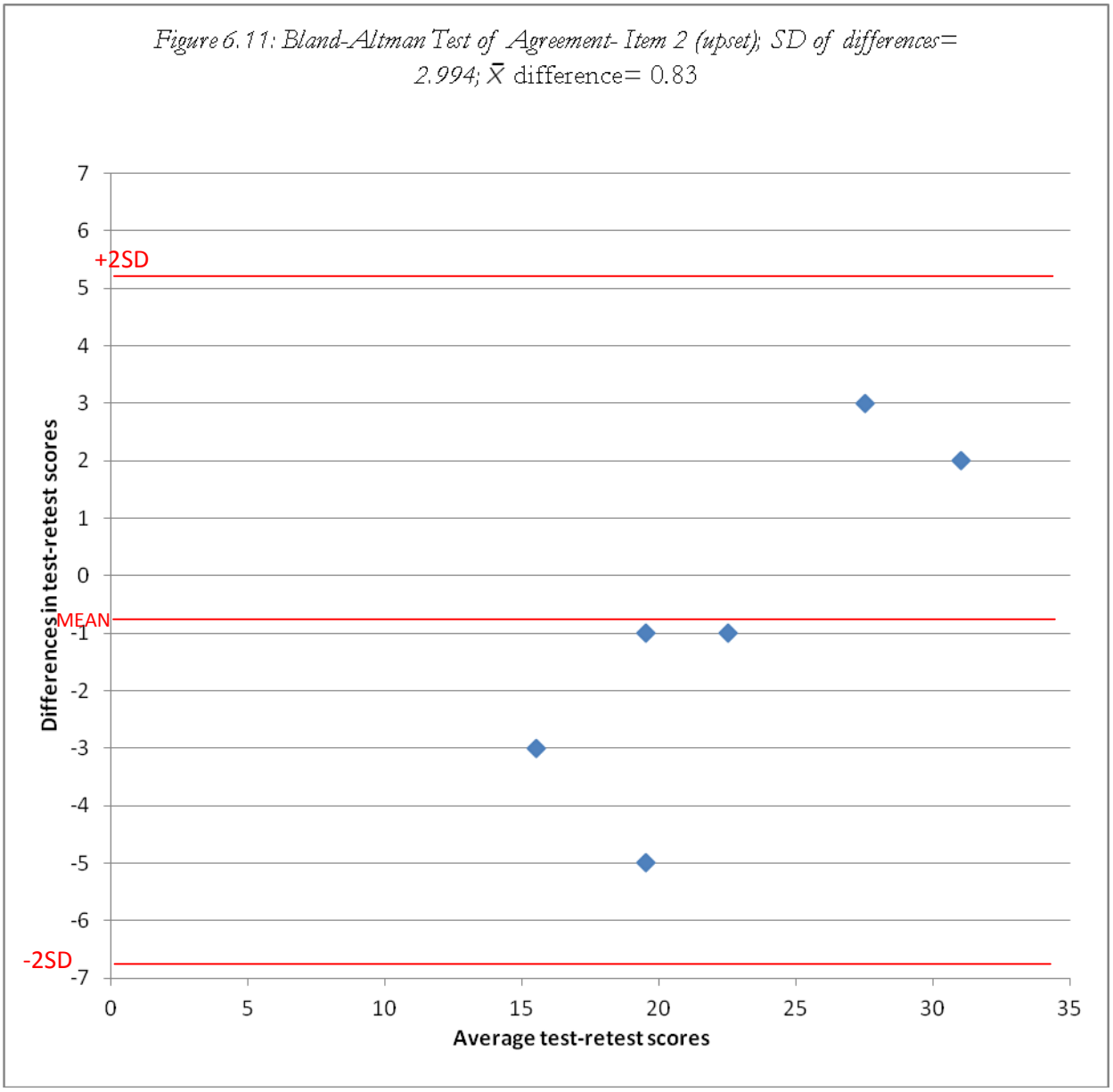


Figure 6.12: Bland-Altman Test of Agreement by Theme - 'Frustrated'

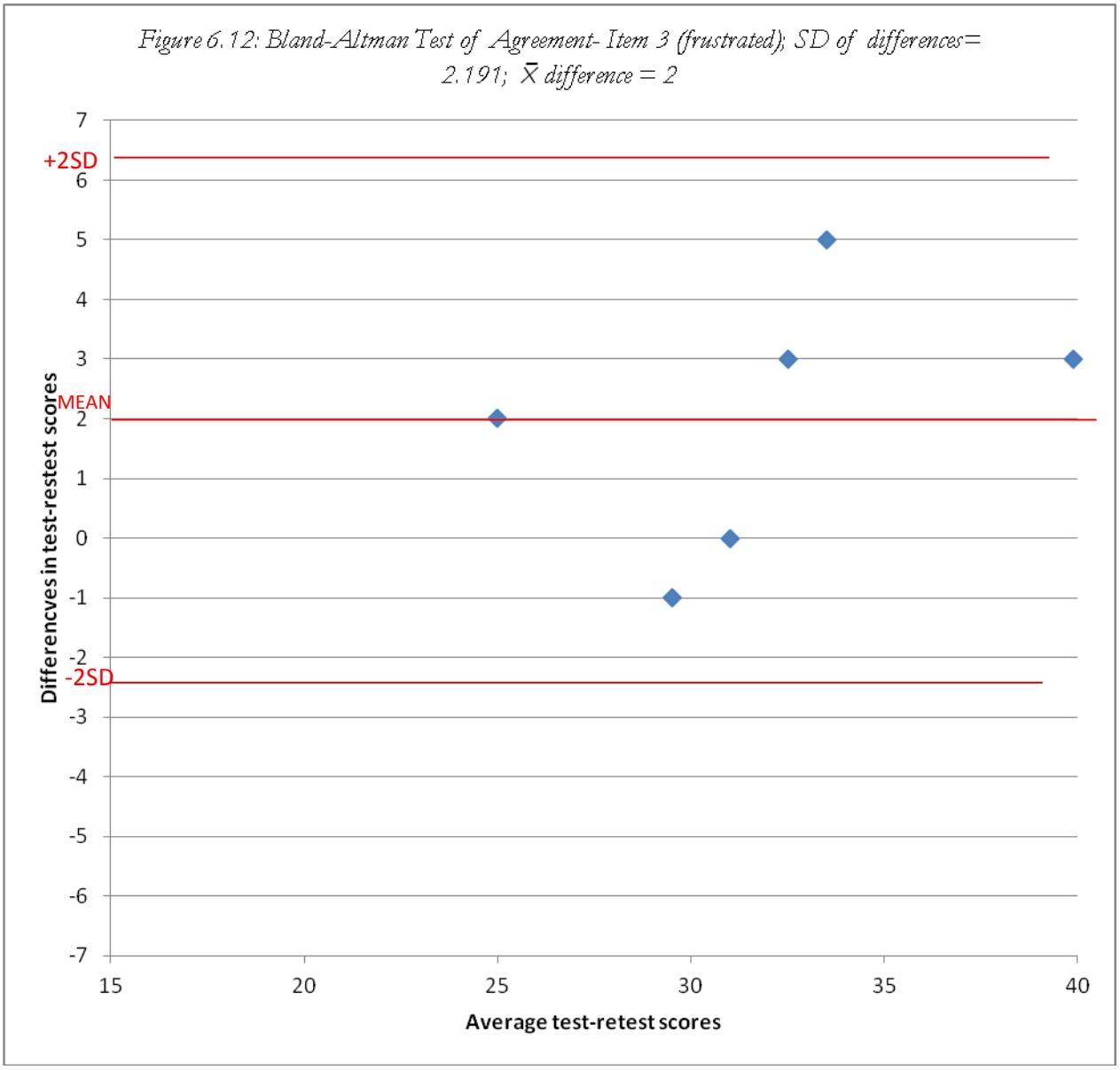


Figure 6.13: Bland-Altman Test of Agreement by Theme - 'Meeting people'

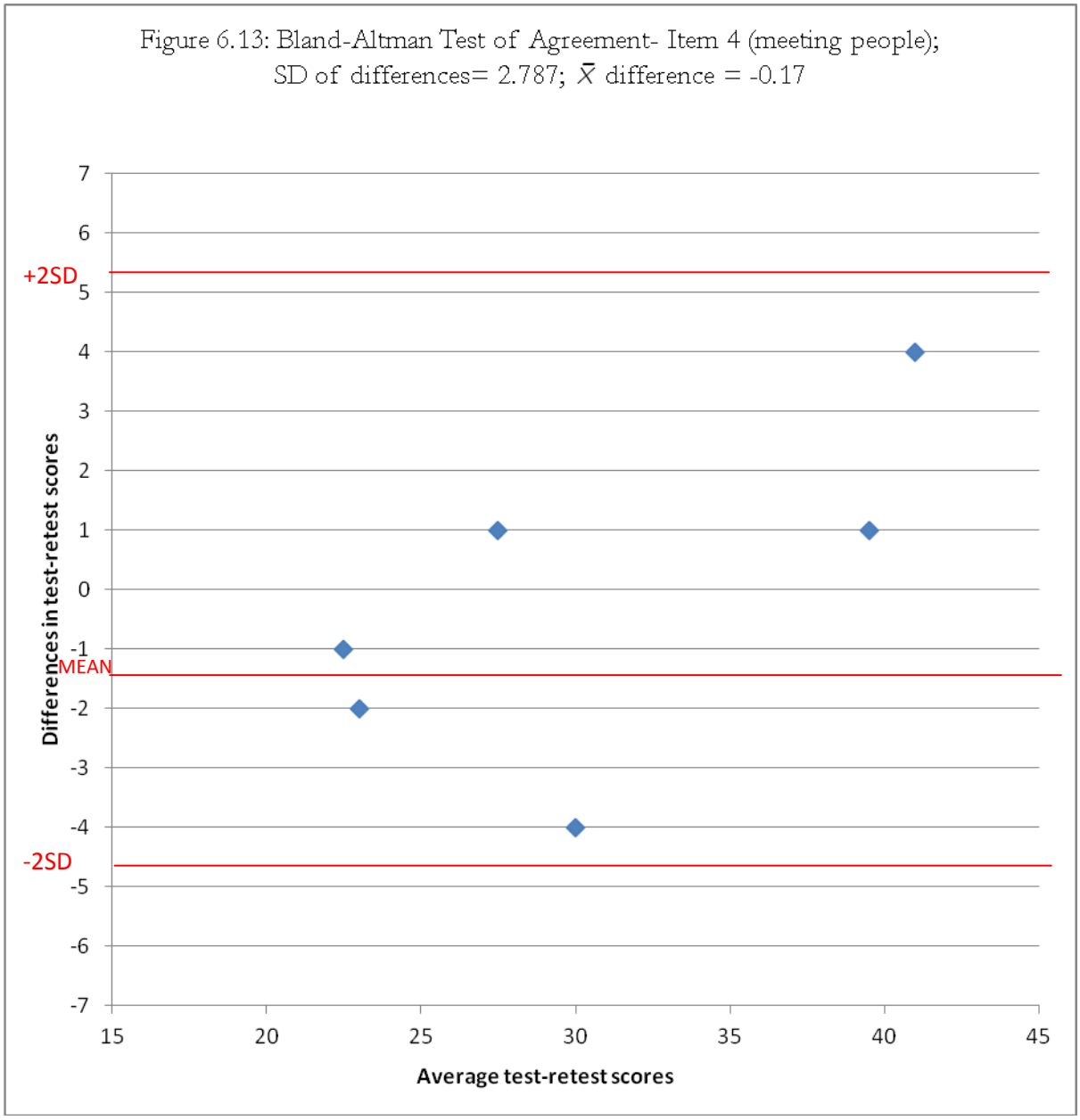


Figure 6.14: Bland-Altman Test of Agreement by Theme - 'Wake-up Call'

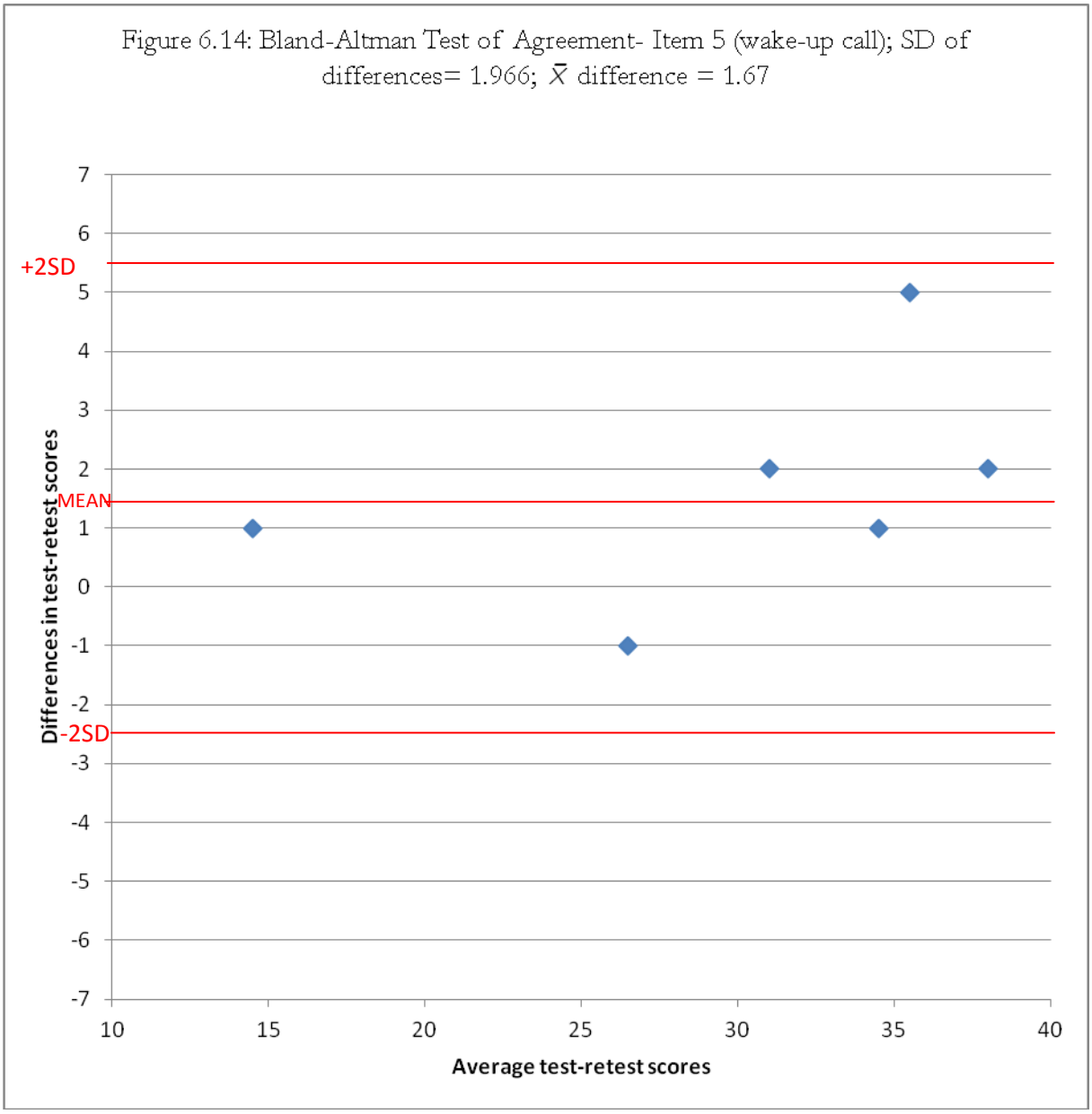


Figure 6.15: Bland-Altman Test of Agreement by Theme - 'Loss of Confidence'

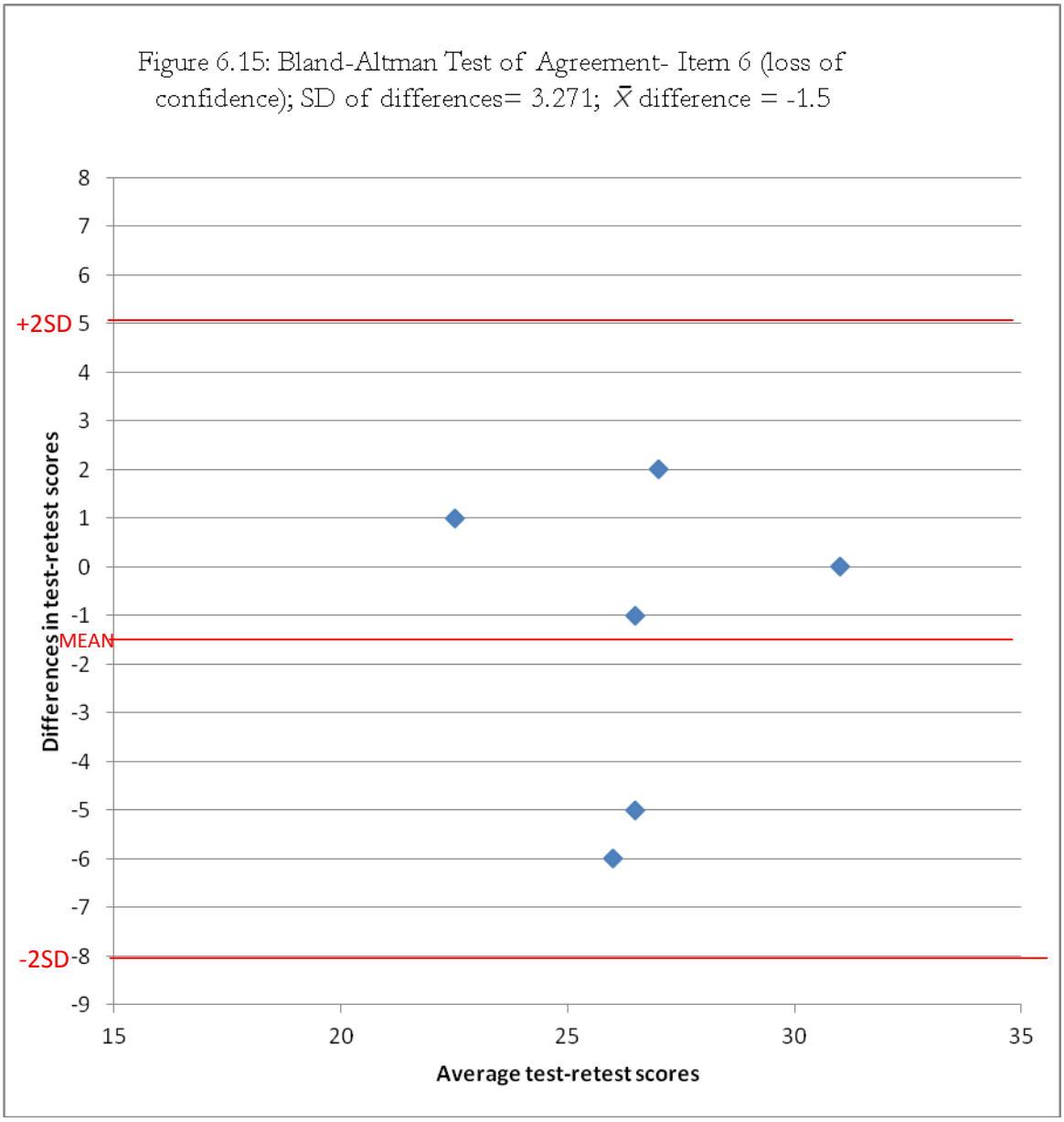
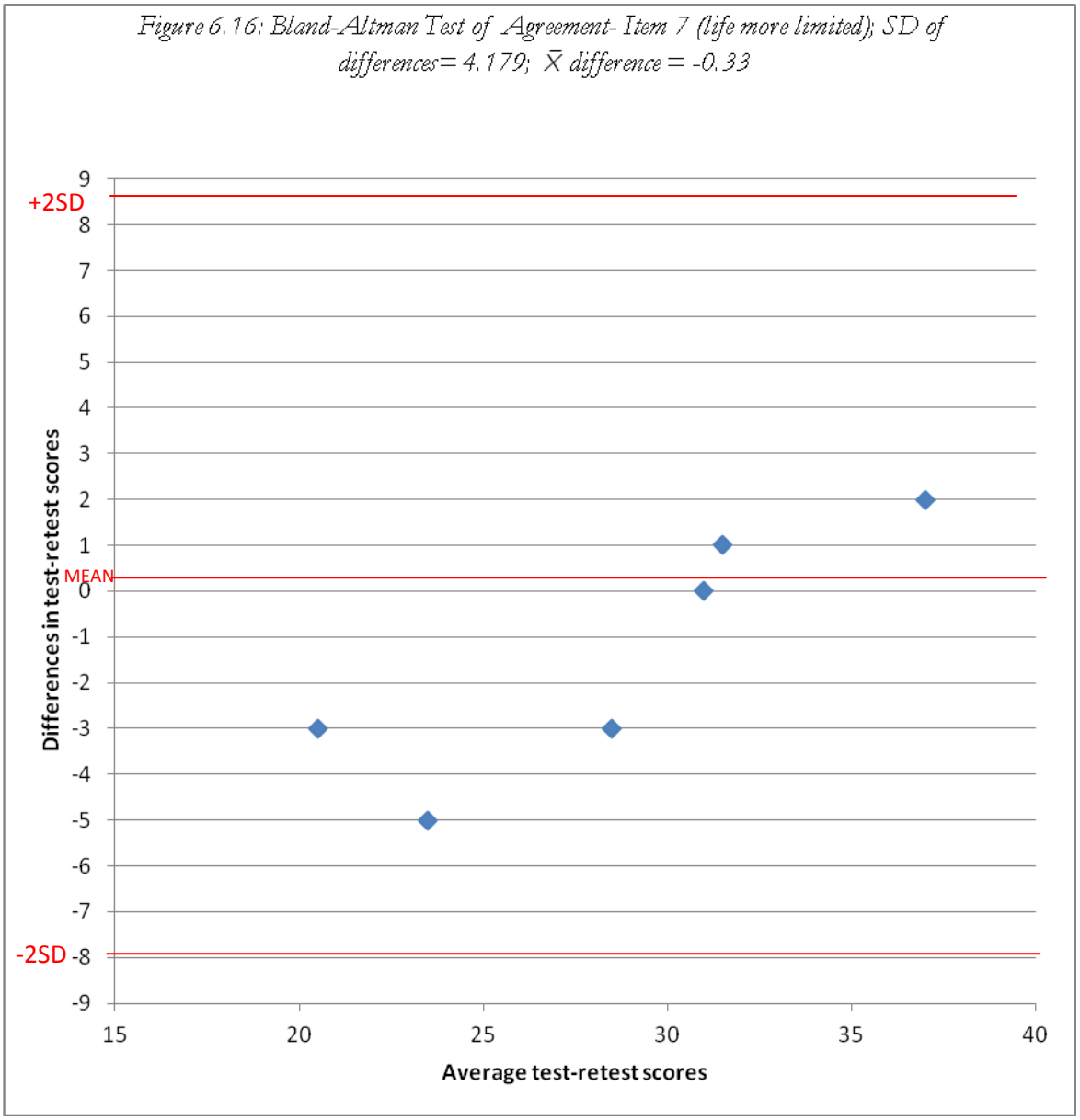



Figure 6.16: Bland-Altman Test of Agreement by Theme - 'Life More Limited'