

ACTion after Stroke: Exploring the Effects of an Acceptance and Commitment Therapy Group for Adult Stroke Survivors and Carers

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Abstract

The individual, familial, societal and economic impact of psychological distress following stroke is well established. Nevertheless, validated treatments to reduce psychological distress and enhance well-being in community-living stroke survivors is limited. Recently, Acceptance and Commitment Therapy (ACT) has demonstrated promising results for improving psychological wellbeing in a variety of presentations. However, there is a lack of research exploring ACT with adults who have survived a stroke.

The current thesis examines the efficacy of a four-session ACT intervention that was delivered to both stroke survivors and their carers via a third-sector charity organisation. A quasi-experimental design was used with 69 participants assigned to either the ACT intervention or waiting list control group. Outcome variables captured levels of psychological distress, post-traumatic growth and quality of life at three time points (pre-intervention, post-intervention and two month follow-up) and were analysed using linear regression whilst controlling for baseline levels. A mediational analysis examining specific ACT processes – psychological flexibility and goal directed thinking - were also examined. Additionally, a one-hour focus group including seven individuals who completed the group was analysed by inductive thematic analysis to gain greater insight in to the personal experiences of the group.

Group assignment predicted lower psychological distress in favour of the ACT group at post-intervention and at follow-up. There were no significant differences found for post-traumatic growth or quality of life. The mediational analyses suggest that the ACT intervention did not significantly alter levels of psychological flexibility, or goal directed thinking compared to the waiting list control group, and these measures did not appear to mediate the changes in psychological distress. The qualitative analysis supported the positive gains of the ACT group. The results are discussed in terms of developing ACT intervention for stroke survivors and carers.

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Chapter 1 Introduction

1.1 Introduction to the Thesis

An increasing number of stroke survivors are returning to reside in the community every day and there is currently a shift within stroke management to discharge survivors home from hospital earlier (National Clinical Guidelines for Stroke, 2012). Consequently, there is a strong and growing need for community support. However, it has been widely recognised that there are gaps in community services with emotional and psychological support being the biggest shortfall (National Audit Office, 2010). This is alarming given the large amount of psychological distress seen in stroke survivors and their carers (White et al., 2012). These shortfalls may have an unprecedented negative impact not only on personal wellbeing (as discussed in more depth below), but also on service usage and costs (Gillham, Carpenter, & Leathley, 2012). Despite these facts, and plans for the development of psychological services for those affected by stroke (Gillham, et al., 2012), no additional government funding has been allocated for this purpose. Hence, the goal for the researchers was to develop a psychological intervention that could be realistically delivered to a wide number of community-living stroke survivors and carers, utilising existing resources.

Recently, Acceptance and Commitment Therapy (ACT) (Hayes, 1999) has been identified as a promising approach for reducing psychological distress in a wide range of psychological (Ruiz, 2010, 2012) and physical health conditions (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007b). The benefit of ACT is that it is trans-diagnostic (Lang et al., 2012), therefore is readily applicable to a wide range of psychological presentations. It can also be delivered effectively and economically in group formats (Luciano et al., 2014). To date, there is a gap in assessing the efficacy of this psychological approach for stroke survivors and carers. Hence, the following thesis aims to evaluate the effectiveness of an ACT group intervention for improving psychological distress in adult stroke survivors and carers over a longitudinal period, compared to a waiting list control group. Building on this, the study aims to explore the mechanisms of therapeutic change by measuring the key mediating variables described

within ACT. In addition, a one hour focus group is conducted to gain deeper insights into the stroke survivors and carers experiences of the ACT intervention.

This introductory chapter is concerned with providing an overview of what a stroke is and how may it impact on an individual, focusing primarily on psychological factors. This is followed by an introduction to the stroke services currently available in community, before some of the treatments for psychological distress are described. An outline of ACT is then given, before its applicability to stroke survivors and carers is deliberated. A systematic literature review of the empirical evidence for ACT groups with adults who have a neurological condition is then reported. The section concludes with the rationale for the current study.

1.2 What is a Stroke?

According the World Health Organization (WHO), stroke is defined as “a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function” (WHO, 1988). Around 85 per cent of strokes are caused by a blockage in one of the blood vessels that supplies blood to the brain, denoting a lack of oxygen to the cells which may then become damaged or destroyed (Go et al., 2013). Stroke hits suddenly, and very often without any prior warning, and hence is often a disorientating and shocking life-threatening event (Lawrence, 2010).

1.2.1 Surviving stroke

In recent years advances made in the recognition and treatment of stroke have been substantial and the number of adults surviving a stroke is now higher than any other point in time, with around two-thirds surviving (Stroke Association, 2015). Sitting alongside the medical advances, much attention has been paid to improving public, governmental and healthcare initiatives for the recognition, treatment, and support of individuals who sustain a stroke (e.g., Department of Health, 2007; Gillham, Carpenter, & Leathley, 2012;

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Intercollegiate Stroke Working Party, 2012; Scottish Intercollegiate Guidelines Network, 2010; The Welsh Government, 2012).

Despite these initiatives, stroke remains one of the main causes of acquired adult disability in the UK (Murray et al., 2013), and the level and rate of recovery is highly variable. A report published on the 24th November, 2014, by the Welsh Government documented that there are around 6,000 new strokes every year in Wales alone (The Welsh Government, 2014), and that there are more than 65,000 people living with the effects of stroke in Wales at the present time. When looking at the statistics for the rest of the UK, the epidemiological data becomes even more significant. Reports document that approximately 152,000 strokes occur in the UK each year (Stroke Association, 2015), and Townsend et al (2012) suggests that there are currently around 1.1 million stroke survivors living in the UK. More than half of these individuals may be left dependent on others for everyday activities (Royal College of Physicians, 2012). Given that more people are surviving strokes, the majority of strokes occur in the elderly, and the fact that we are an increasingly aging population (Christensen, Doblhammer, Rau, & Vaupel, 2009), these numbers may only increase with time.

1.2.2 Consequences of stroke

Some of the most common and recognisable impairments resulting from stroke are those relating to physical abilities and communication difficulties. However, the course of illness can also involve less visible impairments, for example; post-stroke fatigue (Lerdal, Lee, Bakken, Kim, & Finset, 2012); cognitive impairment (Sun, 2014); pain (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2006); emotional difficulties (Kneebone & Lincoln, 2012) and behavioural problems (West, Hill, Hewison, House, & Knapp, 2010). All of which can have a significant impact on a stroke survivors life and may result in difficulties participating in social activities (Dijkerman, Wood, & Hower, 1996), returning to employment (Wolfenden & Grace, 2009), maintaining social relationships (O'Connell et al., 2001) and being able to care for oneself (Guidetti & Ytterberg, 2011), to just name a few.

1.2.3 Psychological distress following stroke

1.2.3.1 Depression

Stroke also has a substantial impact on psychological well-being (Lincoln et al., 2013). Post-stroke depression is the most studied of post-stroke psychological sequel and is viewed as one of the most pervasive symptoms of psychological distress (Gurr & Muelenz, 2011). It holds significant associations with poorer rehabilitation outcomes (Gillen, Tennen, McKee, Gernert-Dott, & Affleck 2001), lower functional status (Burvill, Johnson, Jamrozik, Anderson, & Stewart-Wynne, 1997), increased mortality (Williams, Ghose, & Swindle, 2004), and reduced quality of life (Rastenyte & Kranciukaite, 2007).

The prevalence rates for post-stroke depression vary dramatically in different areas of research, which may in part be a reflection of how the depression is categorised i.e. by diagnostic criteria such as the DSM-V or the ICD-10, or on the basis of self-rating mood scales. However, a conservative estimate is that depressive symptoms are present in around one third of stroke survivors during follow-up (Hackett, Yapa, Parag, & Anderson, 2005). Longitudinal studies have suggested that it can be seen both at the very acute stages, but also several years later. For example, a study by Ayerbe, Ayis, Crichton, Wolfe, & Rudd (2013) found significant rates of depression up to fifteen years after stroke onset.

1.2.3.2 Anxiety

The impact of other emotional disorders, particularly anxiety, is also significant. It is suggested that one in four individuals may experience clinically significant levels of anxiety (Campbell Burton et al., 2013) and recent longitudinal studies suggest that the level of anxiety may actually grow as people reach the more chronic stages (Campbell Burton, et al., 2013). This highlights the need for continued monitoring and interventions after acute symptoms have abridged.

1.2.3.3 *Psychological difficulties*

It is well recognised that large numbers of stroke survivors may also experience a wide range of additional emotional reactions that are not necessarily captured by these diagnostic classifications. Instead, they are often encapsulated under the umbrella terms of “psychological distress” or “psychological morbidity” (House, Anderson, & Hackett, 2001). At this level, studies have suggested the frequency is far greater. For example, in a study by Bogousslavsky (2003), 72% of the 300 stroke survivors interviewed, exhibited some signs of psychological distress, and over half of carers and survivors manifested some psychological problems in a survey conducted by the Stroke Association (2012). However, these difficulties tend to be overlooked by research, as the emphasis is often placed on the treatment of DSM diagnosable disorders. Consequently, there appears to be a dominance of mainstream measures that are built around the DSM criteria. None the less, under this umbrella, individuals have described a range of feelings such as frustration, anger, impatience, stress, low mood, uncertainty, fear of recurrent stroke, feelings of alienation, helplessness, apathy, low self-esteem, a loss of confidence and sense of self-reliance, lacking a sense of purpose or role, feeling socially isolated, experiencing a sense of mourning for losses endured, and losing a sense of “who they are” (Carota, Staub, & Bogousslavsky, 2002; Gillespie, Joice, Lawrence, & Whittick, 2011; Go, et al., 2013; Reed, Harrington, Duggan, & Wood, 2010; Taylor, Todman, & Broomfield, 2011; White, et al., 2012). These emotional reactions, whilst not meeting diagnostic classification criterias, are highly significant and have been recognised as playing a crucial role in post-stroke adjustment (Taylor, et al., 2011). Additionally, the ability to cope with these changes may be complicated by the cognitive changes brought about by the stroke.

Qualitative studies have begun to explore how psychological reactions may change with time, which may lead to improved understanding about the most appropriate time to provide psychological interventions. Whilst there appears to be some commonality in some of the “stages” that stroke survivors appear to move through (Eilertsen, Kirkevold, & Bjork, 2010; Kouwenhoven, Kim, Kirkevold, & Engedal, 2012; Kvigne & Kirkevold, 2003), each of these stages are complex and ever-changing, and hence capturing them in research studies which take snap shots of experiences at certain points in time is difficult. This can be

problematic for service providers in ensuring that psychological needs are met (Townsend et al., 2007).

A small number of psychological studies have hence focused their energies on exploring some of the trajectories involved in the development of distress. Such studies attempt to provide an improved understanding of the lived experience of stroke, but they may also serve to highlight those at greater risk. Such studies have identified increased social issues and higher levels of dependency; avoidance of pre-stroke activities; delays in setting meaningful goals for one's self; and holding an external locus of control as being associated with elevated levels of distress (Taylor, et al., 2011; White, et al., 2012). Lots of these factors may be addressed with the right support. Family, have also consistently been highlighted as playing an important role in both positive and negative experiences (Palmer & Glass, 2003).

1.2.3.4 Family carers

Increased recognition of the role that family members play in the welfare of stroke survivors, is now reflected in UK strategy documents which highlight the need for “carers” to be actively involved and informed about care planning, services available, and accessing training and interventions themselves (e.g. Department of Health, Social Services and Public Safety, 2006). In the community, it is the family carers who take on much of the responsibility of looking after the stroke survivors (Greenwood & Mackenzie 2010; Weir & Cadilhac, 2007) and hence it is relevant and indeed just that they are also given adequate attention. Without such, the strain experienced in providing this role can have a drastic impact on psychological wellbeing, and may eventually result in the breakdown of care. For example, qualitative data reports that often carers have to give up work to fulfil their caring role; they may lose friends and aspects of their social lives; they may have to curtail outings in line with the stroke survivors new abilities; they may experience altered relationships with their loved ones; they may feel undervalued; whilst at the same time holding lots of practical demands, such as having to sort and co-ordinate health and social care, deliver medication etc. (Backstrom & Sundin, 2009; Cecil, Thompson, Parahoo, & McCaughan, 2013; Draper & Brocklehurst, 2007; Simon, Kendrick, & Kumar, 2009). If stroke survivors are then

forced to reside in institutions, there are also significant cost implications for society (Bakas, Li, Habermann, McLennon, & Weaver, 2011). Thus it appears assisting carers to provide quality care, whilst at the same time providing them skills to maintain their personal strengths and resources, is imperative moving forward.

1.2.4 Current approaches to stroke research

It appears important when reflecting on the literature currently available on post-stroke experiences, that the vast majority of research studies are motivated by the aim of improving services, and hence tend to focus on negative experiences (Greenwood, Mackenzie, Cloud, & Wilson Alaszewski, Alaszewski, Potter, Penhale, & Billings, 2003; 2010; Ski & O'Connell, 2007). The survey methodologies employed are hence aimed at identifying need (see for example Wilkinson et al. (1997) for commentary), which may potentially bias the research by, perhaps unintentionally, placing an emphasis on deficits, difficulties and the burden of post-stroke experiences. Yet there is currently a growing field within the literature that emphasises the potential of psychological growth following a life-threatening event/s (Tedeschi & Calhoun, 1996), including stroke (Gangstad, Norman, & Barton, 2009; Gillen, 2005).

The concept of psychological growth appears to reflect a shift from a “disease-focused” approach, towards an approach that emphasises resilience and personal growth (Lincoln, Kneebone, Macniven, & Morris, 2012). For example, within the stroke literature, Mahrer-Imhof, Hoffmann, & Froelicher (2007) have found that a stroke may cause individuals to reflect on the value and meaning they place on life. This reflection may allow individuals to consider new goals and ambitions in line with their values. There is also a reported tendency to live life one day at a time and develop a new appreciation of the “gift of life” (Lawrence, 2010).

The work on post-traumatic growth after stroke has also been studied in carers (Hallam & Morris, 2014), and has shown that growth is reported in at least one area of experience.

Similarly, other studies have found that stroke carers reported a greater appreciation of life, and many valued feeling needed and appreciated (Bacon, Milne, Sheikh, & Freeston, 2009; Haley et al., 2009). This emerging literature base allows new interventions to build on the gains discovered by this research, and to understand the processes that may facilitate psychological growth.

1.2.5 Impact of the research discussed on services

In summary then, there is now increased recognition that psychological distress is highly prevalent following stroke and that good medical care alone is not sufficient for an effective recovery. The management of psychological distress for stroke survivors and their carers appears pivotal given that poor psychological adjustment appears to not only impact on quality of life, increased mortality and poorer functional outcomes, but also it has significant socio-economic consequences due to reduced social, community and occupational functioning. More recent literature also highlights the potential for psychological growth given the right circumstances.

Yet, despite this, the impact this knowledge is having on health practices and service delivery is slow (Cheeran et al., 2009). For instance, it is regularly documented that limited psychosocial services are freely available in public health settings, and at the present time there is less than one Clinical Psychologist for every 100 stroke unit beds (Intercollegiate Stroke Working Party, 2011). In Wales, whilst there is strong focus from the Welsh Government on emotional wellbeing, over half of stroke units still have no access to psychology services (National Sentinel Stroke National Audit Programme, 2012). There is to date, no comparable figures for community services but Lincoln et al. (2012, pg 43) suggest that the lack of psychology is likely to be as marked, or even greater.

It is therefore not surprising that reviews on stroke survivors' experiences of psychological care often report unmet needs. For example, a review by Low, Kersten, Ashburn, George, & McLellan (2003) of members of the Stroke Association's young adult group emphasised

unsatisfactory levels of provision for a range of rehabilitation therapies, and highlighted in particular a lack of longer-term therapy provision outside of the acute stages. Additionally, in 2010, around half of all patients and carers questioned in the National Audit Office's review of stroke services, rated psychological care as "poor" or "very poor" and suggested that current capacity is simply not sufficient to meet demand (National Audit Office, 2010). This was supported further by the Care Quality Commission's review of post-hospital stroke care, which found that the provision of even generic services for individuals experiencing mood disruption was inadequate in terms of availability (Care Quality Commission, 2010).

Hence, at the present time there appears to be a great need for interventions that are not only effective, but also reproducible in the community without complex healthcare infrastructures.

1.3 Psychological interventions

Testing the relationship between receiving a psychosocial intervention in the community and the impact on psychological difficulties is now becoming a priority for stroke research (Knapp, VandeCreek, Handelsman, & Gottlieb, 2013). A review of the available studies portrays that attention is most often directed towards specific psychological problems such as depression, anxiety, a lack of information, social isolation, etc. rather than towards ways of coping with the full range of experiences detailed above. It is not possible to include a review of all the psychological treatments available, instead a brief summary of the literature regarding psychological treatments for post-stroke mood disorders is given.

1.3.1 Psychological interventions for mood disorders following stroke

Most often psychological interventions for mood disorders or psychological distress appear to integrate both evidence-based psychotherapeutic models for managing distress, and educational components about the nature of stroke. One of the most popular evidence-based psychotherapies is conventional cognitive-behavioural therapies (Lincoln & Flannaghan, 2003). However, the outcomes have often shown mixed results (Hackett,

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Anderson, House, & Xia, 2008; Rasquin, Van De Sande, Praamstra, & Van Heugten, 2009). Consistent with CBT assumptions, in many of these studies researchers have aimed to equip stroke survivors with skills to monitor and control thoughts and feelings in an attempt to reduce distress. However, this may not be a realistic strategy. Each time a stroke survivor is faced with an activity that previously they were able to complete independently, or they are unable to rely on their cognitive abilities, they are faced with the psychological consequences of their stroke. Self-management techniques may therefore be of limited value and could even exacerbate distress if a stroke survivor believes that distress, fear, or worry must be stopped or reduced.

Alternative evidence-based approaches have therefore been explored. For example, a large scale (n= 411) and methodologically robust study conducted by Watkins *et al.* (2007) aimed to test whether four weekly sessions of motivational interviewing could benefit mood, and found a significant benefit on levels of depression. Other forms of psychotherapy with some support for reducing psychological difficulties after stroke include peer support groups (Coniglio, Hancock, & Ellis, 2012; Morris & Morris, 2012); relaxation classes (Carin-Levy, Young, Mead, & Kendall, 2009; Kneebone, Walker-Samuel, Swanston, & Otto, 2014); goal setting interventions (Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013); behaviour therapy (Thomas, Walker, Macniven, Haworth, & Lincoln, 2013) and information provision (Smith *et al.* 2008).

To date, there is minimal empirical evidence to support the choice of one treatment over another. In many large scale reviews, a great many of the studies have been criticised for having only weak to moderate methodological strength (Kirkevold, Bronken, Martinsen, & Kvigne, 2012; Levack *et al.*, 2006; Sugavanam, *et al.*, 2013), and the outcome data from individual clinical trials are often highly variable (Smith *et al.*, 2012). A review by Redfern *et al.* (2006), where 67 psychosocial studies were examined, concluded that “few complex interventions have been adequately evaluated, making it difficult to draw any firm conclusions about the benefit they may offer”, and very few studies have provided

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adequate theoretical accounts of the mechanisms assumed to contribute to positive outcomes.

Two Cochrane reviews completed in 2008, concerning both the prevention and treatment of depression after stroke, also concluded that the efficacy of psychological interventions is unclear (Hackett, Anderson, House, & Halteh, 2008; Hackett, Anderson, House, & Xia, 2008). However, they endorsed the use of structured approaches to providing education, advice, and problem solving for emotional recovery and adjustment. This is supported by many other authors who indicate that information combined with motivational and/or emotional support is important for the improvement of symptoms of distress (Ellis, Mant, Langhorne, Dennis, & Winner, 2010; Forster et al., 2012).

For carers, stress coping theory, cognitive behavioural therapy and teaching effective problem-solving skills appear to be the most common theoretical underpinnings for interventions (Forster & Young, 1996; Grant, 1999; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; van den Heuvel et al., 2002). Again the majority of studies appear to target specific areas such as caregiver burden (Bakas et al., 2009), depression (Wilz & Barskova, 2007), anxiety (King et al., 2007), or aim to improve general quality of life (Marsden et al., 2010). Comparable with the literature concerning stroke survivors, recent meta-analyses and systematic reviews reveal little consensus about the most effective therapeutic model for carers of stroke survivors (Eldred & Sykes, 2008; Legg et al., 2011; Smith, et al., 2008), but indicated that greater enhancements are achieved through interventions that are psychotherapeutic, psycho-educational, or multi-component in nature (Sorensen, Pinquart, & Duberstein, 2002). However, there are a lack of studies that explore the potential mediational variables, meaning that currently there is little information about the mechanisms through which these interventions exert their effects (Gholamzadeh, Hamid, Basri, Ibranhim, & Sharif, 2013). Hence, further research is required in order to ascertain which therapeutic model is most appropriate for this group of carers and what the mediation variables may be.

1.3.2 Group interventions

The number of stroke studies examining therapeutic interventions via group modalities is now substantial (Townsend, 2003; Vohora & Ogi, 2008). Within this field, psychoeducational groups are most commonplace. They are aimed at reinforcing information, augmenting knowledge and improving wellness.

To date, there is no consensual recognition about whether individual or group treatments are most effective for reducing or preventing the negative post-stroke psychological sequel mentioned. Yet, comparisons of individual vs. group psychotherapy of psychological difficulties in the general population have taken place over many years. Historically they have reported mixed results (Brown & Lewinsohn, 1984; Wierzbicki & Bartlett, 1987). However, one of the most recent reviews of 107 studies and 14 meta-analyses, concluded that there was now sufficient evidence to suggest that group therapy is equally as effective as individual therapy, both when being used as the primary form of intervention or part of a wider intervention (Burlingame, MacKenzie & Strauss, 2004).

Due to the great number of individuals presenting with unmet needs following stroke, group programs may therefore be appealing, and traditionally have been described as the most efficient means of treatment when there is not sufficient resources to meet demand (Scheidlinger, 2004). Two of the very many reasons offered is that group therapy is less costly, and it is often offered as a brief treatment (Yalom & Leszcz, 2005). Both of these reasons are important for under-resourced health care systems.

Furthermore, it has been proposed that group therapy produces additional therapeutic gains that individual therapy does not always see, such as: the instillation of hope through seeing others in the group improve; creating a sense of universality for example realising “I am not alone”; imparting knowledge widely; the development of altruistic tendencies and socialisation techniques; and interpersonal learning, including greater levels of insights and self-understanding (see Yalom & Leszcz, 2005, for a full review).

1.4 The ACT Model of Psychological Distress and Wellbeing

ACT has gained increasing interest amongst many clinicians and researchers in the past decade. It is an evidence-based, trans-diagnostic therapy, which is positioned within the larger CBT model, yet is arguably a distinct “third wave” behaviour therapy in its own right (Twohig, Hayes, & Masuda, 2006). It is designed to be applicable to a broad range of psychological problems. Whilst it was most widely used to treat anxiety and depression previously (Ossman, Wilson, Storaasli, & McNeill, 2006), it is now recognised as a promising and effective approach for improving functionality and well-being for other forms of mental health difficulties including “psychosis” (Bach, Hayes, & Gallop, 2012), eating disorders (Clark, 2014), anger (Eifert, McKay, & Forsyth, 2006), substance abuse (Lanza, Garcia, Lamelas, & Gonzalez-Menendez, 2014), “borderline personality disorder” (Morton & Shaw, 2012), post-traumatic stress disorder (Blevins, Roca, & Spencer, 2011), and work stress (Schwetschenau, 2009), to just name a few.

More recently, it has been successfully utilised with a wide range of psychological difficulties secondary to medical / health conditions, and indeed has proven its ability to exert influence over behaviours that are deemed problematic for the longer term management of these conditions. Such populations include individuals with diabetes (Hadlandsmyth, White, Nesin, & Greco, 2013), chronic pain (Alonso, Lopez, Losada, & Gonzalez, 2013), epilepsy (Lundgren, Dahl, Yardi, & Melin, 2008), cancer (Feros, Lane, Ciarrochi, & Blackledge, 2013), irritable bowel syndrome (Ferreira, Eugenicos, Morris, & Gillanders, 2013), trichotillomania (Flessner, Busch, Heideman, & Woods, 2008), obesity (Weineland, Arvidsson, Kakoulidis, & Dahl, 2012), and HIV (Silver, 2012).

Not only is the efficacy of this approach promising for a broad range of presentations, but the magnitude of the effect is highly promising in meta analyses of both high intensity (Hayes & Duckworth, 2006) and low intensity methods of delivering this model (Cavanagh, Strauss, Forder, & Jones, 2014).

1.4.1 Brief overview of ACT

Unlike many mainstream psychological and psychiatric approaches, ACT does not seek to reduce, change, or eradicate unwanted internal responses (e.g. thoughts, feelings, emotions or sensations). Instead, ACT views suffering as a normal part of human experience (Hayes, Levin, Plumb-Villardaga, Villatte, & Pistorello, 2013) and supports people to notice their experiences, but does not seek to change them. In fact, ACT takes the view that trying to change aversive internal responses as a means of coping can actually be counterproductive. As an alternative, ACT places its focus on supporting individuals to expand their lives in a direction that supports a connection with - and action towards - personally held values, despite aversive experiences (Luoma, Kohlenberg, Hayes, & Fletcher, 2012).

Because of its bottom up, inductive manner, ACT does not use any specific techniques, nor does it attempt to treat any one particular presentation (Hayes, et al., 2013). Instead, ACT relies heavily on metaphors and stories, experiential exercises and role plays to achieve “psychological flexibility”.

1.4.2 Theoretical position

ACT is built on traditional behaviour theory constructs such as operant and respondent conditioning (Hayes, 1999) but supplements this with recent knowledge about human thinking derived from relational frame theory (Hayes, Brownstein, Devany, Kohlenberg, & Shelby, 1987). This theory provides an understanding of the power that cognition and language has in promoting an emotional or behavioural response and emphasises the important role that experiential avoidance plays in psychological distress. Additionally, it is built on the philosophical approach of functional contextualism (Hayes, 1993).

1.4.2.1 Relational frame theory (RFT)

In more depth, relational frame theory explains that humans have an ability to respond to stimulus contextually and relationally (Hayes, Barnes-Holmes, & Roche, 2001). It therefore argues that environmental interactions or contexts have a large influence on human

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thought and behaviour (Hayes, et al., 2001). For example, hearing the word “stroke”, seeing a person with physical weakness, and associating the sound “stroke” with physical weakness.

Ascribing to this theory, ACT views many internal responses as the direct result of ongoing engagements of cognition, emotion, and physical reactions, that are interacting with both historical and situationally defined contexts (Hayes & Duckworth, 2006). For example, staying with the association of stroke already used (stroke -> physical weakness), this model would argue this association may be contextually related to loss of employment by someone who has previously read a newspaper article of someone with physical weakness losing their job (hence stroke -> physical weakness -> loss of employment). Loss of employment may be associated with not being able to provide for a family, which in earlier experiences resulted in the breakdown of marriage. This example is used to portray how a network of arbitrary relational combinations may be formed. The model would argue that soon this relational frame set may trigger many spontaneous aversive internal reactions felt when actually being alone, simply by hearing the word “stroke” (Hayes, 1999).

A positive implication of these networks is that we may hold an understanding of the way environmental contingencies function, allowing us to make effective behaviour plans without having direct experience of that exact contingency (Hayes, et al., 2001). Unfortunately, it can also form rules and behavioural reactions that do not accurately represent the environmental contingencies in place (Hayes & Lillis, 2012). We can carry forward aversive events, create similarities between events, form relationships between the past and present, experience past events as though they are present, and predict things that haven't even happened yet, all because of the power of our verbal and cognitive capabilities. We can also judge ourselves, imagine ideals, and hence ponder on our self-adequacy.

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Hayes et al. (2013) explain that distress is therefore influenced by the propensity to become entangled in these internal responses, taking them literally, and paying little attention to the environmental contingencies around us. It is argued further that aversive internal reactions often promote experiential avoidance and decreased contact with external environmental events (Hayes & Strosahl, 2004).

1.4.2.1.1 Experiential avoidance

There is much support available from both clinical and nonclinical populations that experiential avoidance is strongly correlated with various forms of distress (Goldstone, Farhall, & Ong, 2011; Kashdan & McKnight, 2013). Experiential avoidance is often achieved by averting circumstances that trigger these experiences (e.g. not going to the pub with friends in fear of appearing awkward and clumsy), and/or controlling or distracting oneself from internal experiences when they do occur (e.g. drinking alcohol to numb feelings). However, this avoidance-based way of coping is not only associated with psychological distress, but it also places limits on valued behaviours by putting life on hold (Luoma, Hayes, & Walser, 2007). This is described as “psychological inflexibility” (Rector, 2013).

It is suggested that psychological inflexibility often leads to the avoided event resurfacing more powerfully (Wegner & Zanakos, 1994) because more flexible ways of responding are either stopped, or never developed. For example, a stroke survivor who reports staying in bed all day “because my body is weak” is using direct avoidance, but is also employing a verbal rule - specifying the need to feel better before acting differently. The decision to stay in bed until feeling stronger, also prevents contact with other contingencies which might lead to the strengthening of muscles. ACT posits that this sort of verbal control over behaviour dominates nonverbal environmental control (Dougher & Hackbert, 2000).

Likewise, attempts to alter internal responses (e.g. thoughts, feelings, emotions or sensations), are often ineffective. In an attempt to avoid internal responses, humans often engage in reasoning (e.g. “Perhaps I shouldn’t worry so much about him going out, because

I know really that he won't have another stroke today"), comparing (e.g. "It could be worse. I could be unable to speak, walk, have nobody around me..."), categorising (e.g. "I am a disabled person now"), evaluating (e.g. "I'm not coping as well as I thought I would"), planning (e.g. "I am going to stop smoking to prevent another stroke"), etc. (Hayes & Lillis, 2012). However, such efforts are often ineffective and conversely may increase the quantity of the cognitions (Wegner & Zanakos, 1994). On the other hand, it has been evidenced that by allowing internal responses to occur without the intent to remedy, individuals are able to do what they value, instead of being drawn into a psychological struggle (Masuda et al., 2007).

In ACT it is therefore important to ensure individuals become more aware of their cognitive minds and ensure that they hold flexibility in following cognitive rules. Hence, skills are taught to assist individuals to make contact with actual environmental contingencies so that they are enabled to respond to them in the most effective ways.

1.4.2.2 *Functional contextualism*

All of what has been discussed this far is underpinned by the philosophical approach of functional contextualism (Hayes, 1993). Hence in ACT, the *functional* (I have a physical weakness -> I may fall -> I must keep myself safe) and *contextual* (I will avoid situations) features of an event are viewed as exceptionally important. ACT argues that similar actions may have completely different functions depending on the context. Hence, contextualism takes on a holistic approach to events, and the whole of an act is defined by its intended consequences, rather than its individual forms. As a result, something is defined as successful if the intended consequences are met. This also applies to internal responses, none of which are viewed as inherently problematic or positive on their own – it all has to do with how they *function* for the person (Blackledge & Hayes, 2001).

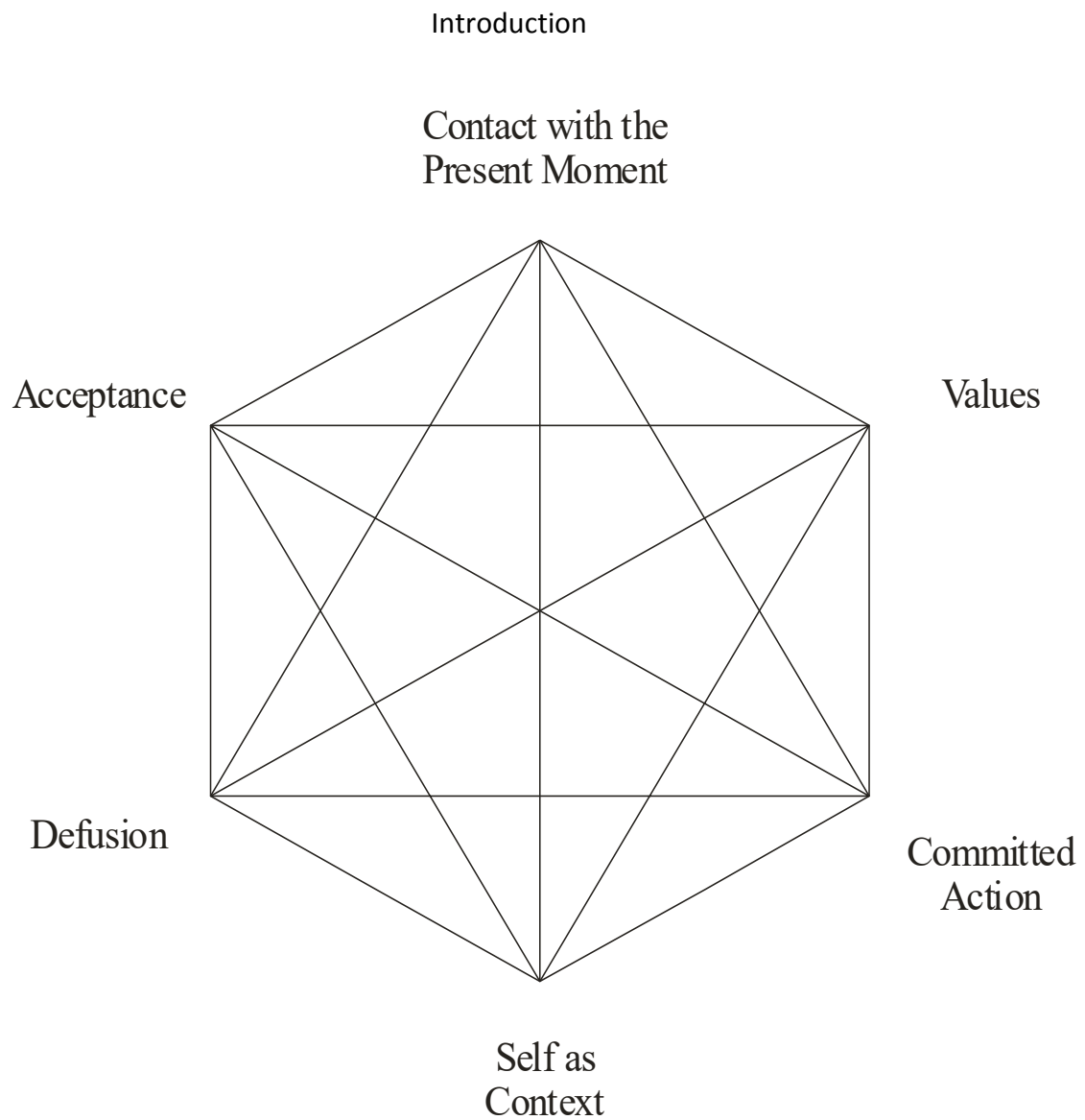
Clinically, functional contextualism leads to certain theoretical viewpoints that are central to ACT. Firstly, because of the emphasis on *function*, ACT takes a behavioural viewpoint of

inner experience. For example, if a stroke survivor believed that “Stress will cause me to be unwell again” then an assumption can be made that when feeling stressed, the person may feel distressed, anxious, and out of control. From a functional contextual framework, it may be considered helpful to change the context of this experiences, *if* this internal reaction led to distress. However, from this framework, this would not be necessary all of the time, as sometimes cognitions may have positive functions. For example, using the same example again, if the stroke survivor thought “Stress will cause me to be unwell”, but the person felt able to reduce his level of stress, for example by engaging in a relaxation exercise, then this thought would not be problematic. The person may simply take some time out to relax.

Secondly, it is important to have clarity about what someone is trying to achieve, as a contextualistic approach would argue, that for success to be achieved, an event is evaluated based on its intended outcome. For example, if someone’s goal was to “Be less worried about having another stroke”, it would be possible to evaluate whether or not a given intervention was effective, by measuring whether the person is less worried about having another stroke. However, in ACT it would also be important to access the value of the goal, so for example by asking the stroke survivor what would happen if they could reduce the fear, they may respond “I would be able to play golf again”, and looking for the value in this they may add “I would be able to be with my friends” etc.

1.4.3 The key processes of ACT

As a result of the above findings and principles, ACT uses acceptance and mindfulness strategies to increase contact with experiences (both good and bad) nonjudgmentally. Overall, the goal of ACT is to promote increased “psychological flexibility” (Hayes & Duckworth, 2006), through the following six key processes (also represented in the ACT Hexaflex model). Each has considerable support outside of larger treatment packages (Ruiz, 2010, 2012), and will now be discussed in turn.



*Figure 1 Diagram showing the proposed processes underlying psychological flexibility.
Source. Hayes et al. (2006).*

1.4.3.1 Acceptance

Above, it was argued that human beings have a tendency to attempt to control, regulate or fight against aversive inner experiences (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). However, ACT proposed there is another option, to choose to behave acceptingly by embracing experiences without trying to change them. Accepting does not imply giving in or resigning, but instead offers a way of recognising inner experiences as they are. It is argued that acceptance may counteract excessive entanglement with cognitions, and instead result in more flexible ways of responding (Hayes, 1999). This understanding is also applied to

events and circumstances that appear in the external world that one has no control over, for example, having a stroke.

1.4.3.2 Defusion

Cognitive defusion involves altering the context in which inner experiences occur. It is similar to the concept of “decentering” described in CBT (Beck, 1989). As described above, the ACT model relates distress to several key cognitive and language processes which can have a huge impact over an individual’s chosen action. Defusion aims to lessen this, by cultivating a more objective and open-ended view of inner experiences (e.g. thoughts are just thoughts, feelings are just feelings etc. that come and go), without disputing the content. Hence, by learning experientially to let aversive internal responses come and go, it decreases the automatic impact they can powerfully exert. Defusion hence promotes behavioural flexibility by curtailing avoidance reactions.

1.4.3.3 Contact with the present moment

Contacting the present moment fully and experientially is a process that is used to help people start from where they are, to get their attention to focus openly on what is happening around them in the here and now. This is often done through the utilisation of several proven mindfulness techniques. This is done without evaluation or judgment, and allows individuals to detach from inner experiences, such as worrying about the future or dwelling on the past.

1.4.3.4 Self-as context

As described above, we can become fused to the evaluations and categorisations that we hold (Hayes, et al., 2013). The same is stated to apply for the descriptions we hold about ourselves. In some instances, holding an inflexible idea of who we are can be unhelpful (Batten & Santanello, 2009). For example, believing “I am a disabled person since my stroke” might limit the nature and quality of interactions with the world. In ACT it is important to promote flexibility, so there is choice to adhere to a sense of self in one

situation, but not every situation. By making experiential contact with the world (i.e. environmental contingencies), and learning that different experiences and sense-of-self encompasses more than just being a “stroke survivor”, can produce a more valued life.

1.4.3.5 Values

Values are defined within ACT as “verbally construed global desired life consequences” (Hayes, 1999). In other words, they are the elements of life that are cared about most and a basis for all behavioural actions. Hence, it is seen as fundamentally important to gain clarity on values in order to develop open and flexible patterns of behaviour, which leads to living life in accordance to what matters most. In ACT, this is of greater importance than reducing psychological distress. In this sense, the hypothesised path of improved quality of life would be from a change in psychological flexibility. This is yet to be tested empirically.

1.4.3.6 Committed action

Although committed action is presented lastly, this process is vital to the theory and practice of ACT. All of the processes discussed thus far aim to help an individual to live in accordance with their values. Hence, committed action is the final step that follows through with goals and future quality life priorities (Beilby, Byrnes, & Yaruss, 2012).

1.4.4 Applicability to Stroke

In summary then, ACT offers a counterintuitive method of accepting, as opposed to changing or eliminating troublesome thoughts and feelings. The focus throughout the treatment is facilitating movement towards a valued and personally fulfilling life, in a context where previously obstructive unpleasant thoughts or emotions no longer serve as obstructions. This psychotherapeutic stance may have particular utility for helping stroke survivors and carers to carry out valued behaviours, and to reengage in a life that is meaningful, despite neurological and physical deficits (Hayes & Duckworth, 2006).

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A stroke may also call into question an individual's purpose or sense of identity. However, ACT aims to decrease the negative evaluations or fused associations that an individual may hold about themselves (Hayes, 1999). Hence, through the utilisation of acceptance and mindfulness strategies, a stroke survivor's experience may be recognised, but not necessarily used to define one's whole self. In this sense, the ACT model may assist a stroke survivor to re-construct their identity, by placing an emphasis on holding a flexible viewpoint of the here and now, whilst acknowledging that "now" is always changing.

Likewise, the fact that a stroke can be extremely life-disrupting, unpredictable and sudden, often means that family members are not given sufficient time to prepare for the complex responsibilities of caregiving. Acceptance in the ACT approach entails learning to accept both positive and negative internal responses, as well those experiences pertaining to circumstances in the environment that one cannot change. In particular, acceptance-based strategies may be particularly suitable for helping people to come to terms with their changed life circumstances. This may be highly supportive for both stroke survivors and carers who are both faced with the very real results of stroke on a regular basis. Indeed, it has been evidenced that individuals who employ acceptance skills when faced with poor physical health, may benefit from a renewed and potentially more positive sense of self (Cousins et al., 2013), as opposed to avoidance-based coping, which is related to a greater connection between "self and illness" (Meyer, 2010), higher levels of depression (Shahar & Lerman, 2013), lower quality of life (Coelho, Amorim, & Prata, 2003), lower adherence to medical regimes (Weijman et al., 2005) and generally lower levels of management of conditions (Richardson et al., 2010).

Furthermore, ACT is a "bottom up" inductive model, meaning that it has the potential to be successfully utilised for a great many of the experiences a stroke survivor and / or carer may face. For instance, the mindfulness component as an example, may be beneficial to the continued difficulties resulting directly from the stroke (e.g. emotional liability) and equally for reducing carers' stress etc. Indeed, if we explore the evidence above, the outcome

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literature is positive for a great many conditions, populations, and specific symptoms, yet the processes of change do not vary to meet each need.

Moreover, ACT has also proven its effectiveness when being delivered in group modalities (Alonso, et al., 2013; Blevins, et al., 2011; Butryn, Forman, Hoffman, Shaw, & Juarascio, 2011; Kocovski, Fleming, Hawley, Huta, & Antony, 2013). As stated above, there is a need to disseminate psychological interventions for stroke survivors widely and without additional resources (Townsend, 2003).

Additionally, the model does not require the cognitive capacity (which may be reduced due to the nature of stroke) to learn an extensive set of symptom-specific techniques, which circumvents the logistical and feasibility problems described in many techniques when applied to an individual with cognitive difficulties. ACT instead uses mindfulness-based approaches, and experiential role-plays and visual metaphors. These strategies do not require high levels of reasoning or evaluation, nor do they require high levels of verbal memory. Likewise, although the ACT model itself is built upon an extensive amount of complex theory, it is user friendly, as it does not require that the stroke survivor or carer understands the underlying processes in order to make applied use of them. These points have been supported in two recent reviews and a study protocol that explored the utility of ACT with individuals who have experienced brain injuries (Kangas & McDonald, 2011; Soo, Tate, & Lane-Brown, 2011; Whiting, Simpson, McLeod, Deane, & Ciarrochi, 2013). Further evidence documents the benefits of ACT among people with cognitive impairment (Cook, 2009; Pahnke, Lundgren, Hursti, & Hirvikoski, 2014).

Finally, whilst ACT has developed from the general clinical literature, specific components seem to be already working for stroke survivors when inductively tested. Looking at the hexagon model above, large scale reviews have already supported the use of mindfulness (Lawrence, Booth, Mercer, & Crawford, 2013), and goal setting (Sugavanam, et al., 2013). More widely than this, many of the ACT principles are generally well-matched to the aims of

many holistic neuropsychological rehabilitation programmes (e.g., Wilson et al., 2000; Wilson, 2008, 2010). For example, acceptance, self-as-context, valued goals, and committed action, are incorporated in many multidisciplinary programmes conducted in holistic rehabilitation settings. However, as outlined previously, the six core processes of ACT also include present-moment awareness and cognitive defusion. Additionally, a very recent study by Losada et al. (In Press) who analysed the differential efficacy of ACT and CBT for dementia family caregivers with high depressive symptomatology, found positive results for both ACT and CBT in reducing symptoms of depression and anxiety for these individuals who are caring for someone with cognitive impairments.

1.5 Systematic Literature Review

1.5.1 Methodology

To identify the literature relevant to the focus of this thesis, a systematic literature review has been carried out on seven electronic databases (*Pub Med, Medline, PsycINFO, CINAHL, the Cochrane Library, PsycARTICLES, Science Direct*) one Acceptance and Commitment Therapy (ACT) resource website (www.contextualpsychology.org), and the Stroke Association website (www.stroke.org.uk).

An initial review of the literature was carried out on the 25th November, 2014, to determine whether any existing studies had investigated Acceptance and Commitment Therapy with stroke survivors (see Appendix A for search terms). Of the 182 studies that were initially retrieved, only one study (Graham, Gillanders, Stuart, & Gouick, 2014) was partially relevant. However, this study did not meet the inclusion criteria (described below), as it employed a single case design.

A second systematic search was carried out to answer the question: “What is the efficacy for acceptance and commitment therapy in adults with cardiovascular conditions?” However,

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the results obtained only one extra relevant study that met the inclusion criteria (Goodwin, Forman, Herbert, Butryn, & Ledley, 2012; Losada et al., 2014). As such, a systematic literature search was conducted in order to answer the following the question: **“What is the efficacy of acceptance and commitment therapy in adults with an acquired neurological condition?”**

A list of keywords and MeSH terms was generated to identify studies, falling within two key search strategies:

(i) Terms relating to Acceptance and Commitment Therapy: *“Acceptance and Commitment Therapy”*

AND

(ii) Terms relating to Neurological Conditions: *“neurologic*impair*”* OR *“Acquired brain injury”* OR *“Traumatic brain injury”* OR *“brain damage”* OR *“head injury”* OR *“Neuropsych*”* OR *“Cerebr*”* OR *“Cog* impairment*”* OR *“Stroke”* OR *“CVA”* OR *“Cerebral vascular accident”* OR *“Mulitple Sclerosis”* OR *“Seizure disorder”* OR *“epilepsy”* OR *“Parkinson* disease”* OR *“Tourette* syndrome”* OR *“Huntington* disease”* OR *“dementia”* OR *“Alzheimer* disease”* OR *“Fibromyalgia”* OR *“meningitis”* OR *“encephalitis”*.

This initial search identified 390 citations (after de-duplication). The researcher was aware that in articles where the search terms employed were not mentioned in the title, keywords or abstracts, relevant studies may be missed. In an attempt to counteract this limitation, the references of retrieved articles were additionally reviewed. Furthermore, in an attempt to identify any studies in press or newly published, authors who had published feasibility studies or had presented oral presentations were contacted via email. The authors contacted included: Diane Whiting (currently collecting data on adults who have experienced a traumatic brain injury, and who are undergoing a group ACT intervention, in Sydney Australia), and Andrés Losada-Baltar (who has already completed a study on ACT with dementia care givers in Spain, but the article is currently under its second review and is yet to be published).

1.5.2 The Inclusion and Exclusion Criteria

The title and abstract of each study retrieved was then examined against the following pre-specified inclusion and exclusion criteria illustrated in table one.

Table 1 Inclusion / Exclusion Criteria

| |
|--|
| <p>1. The ACT interventions targeted:</p> <ul style="list-style-type: none">a. psychological difficulties in adults (aged 18 years or over) with an acquired neurological condition ORb. psychological difficulties in care givers of adults with an acquired neurological condition (again the person who was cared for was an adult). <p><i>Interventions that targeted psychological problems, without the presence of a neurological disorder, were excluded.</i></p> <p><i>Additionally, congenital neurological conditions such as learning disabilities, Autism Spectrum Conditions etc. were excluded.</i></p> |
| <p>2. The studies targeted group interventions, and explicitly tested the relationship between receiving an ACT group intervention on primary outcome measures.</p> |
| <p>3. The study used at least one psychological outcome measure.</p> |
| <p>4. Interventions from a variety of settings including, community, hospital, chronic care institution, or outpatient settings were included.</p> <p><i>No time frame criterion was employed.</i></p> |
| <p>5. The study was a randomised controlled trial (RCT), a quasi-randomised trial or due to the lack of studies, case-series trial.</p> <p><i>Reviews, feasibility studies, and discussion papers were excluded.</i></p> |
| <p>6. The article was published in English.</p> |

At the end of this process, 32 studies initially appeared to meet the inclusion criteria. Full-texts of these studies were obtained, and reference lists were then examined. All potentially

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eligible studies, plus identified texts from the references (n=2), were examined to confirm eligibility. A flow chart of this process is shown below (Figure 2).

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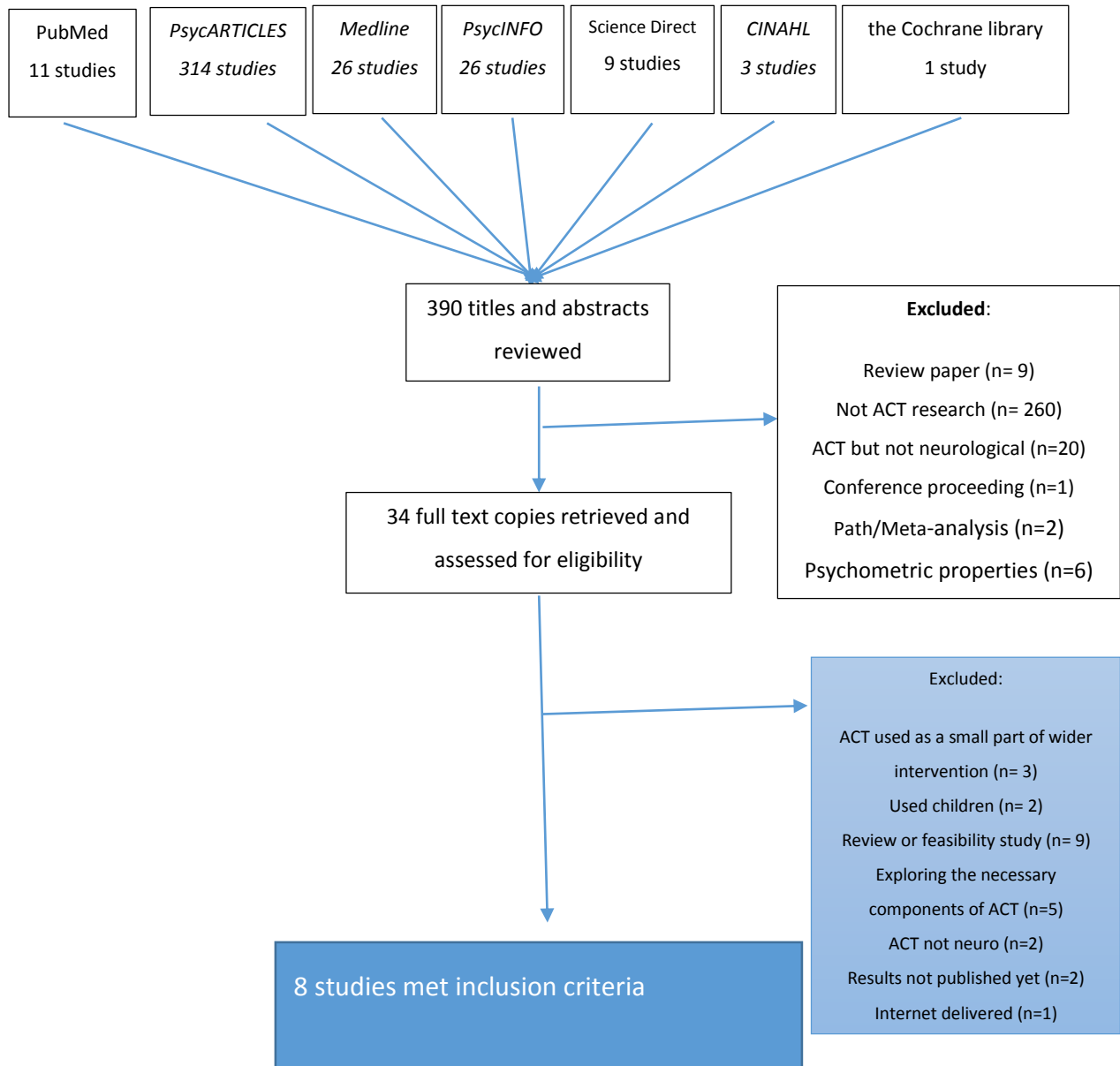


Figure 2 Flowchart of studies included in systematic literature review

As can be seen, 22 studies were subsequently excluded during full-text analysis, because the results were not yet published; they were exploring the psychological trajectories and hence were not group based studies; they looked at ACT with children; were review papers; or used ACT but not with a neurological condition. Therefore, 8 articles were included in the systematic review.

The 8 articles include three neurological conditions. The definitions, primary symptoms and proposed causes are described in table two.

Table 2 Neurological conditions included in systematic literature review

| | |
|---------------------------|--|
| Fibromyalgia | <p>Previously fibromyalgia was considered a rheumatic disease, due to the pain experienced by sufferers. However, it is now recognised as a neurological condition caused by changes in the way the brain and spinal cord process and transmit pain signals. Recent neuroimaging studies support this, reporting an observation of altered brain functions (Lannersten & Kosek, 2010), decreased grey matter density (Kuchinad et al., 2007) and altered levels of neurotransmitter substances (Sarchiello et al., 2007).</p> <p>Additional to pain, sufferers also experience high levels of fatigue, cognitive difficulties and a wide range of psychological and social difficulties (Smith & Barkin, 2011).</p> <p>Its onset is often acute, with most sufferers frequently reporting that symptoms started following a motor vehicle accident, surgery, or other trauma (Wolfe, Ross, Anderson, Russell, & Hebert, 1995).</p> |
| Epilepsy | <p>Epilepsy is the fourth most common neurological disorder (England, Liverman, Schultz, & Strawbridge, 2012). It is a brain disorder which is often associated with recurrent seizures caused by a “temporary alteration in brain functioning due to excessive and/or hypersynchronous neuronal activity” (Milligan, 2006).</p> <p>As well as seizures, individuals with epilepsy also often present with a wide range of psychological difficulties, cognitive impairment and social difficulties (Garcia, 2012).</p> <p>Epilepsy is a disorder that disturbs the normal pattern of neuron activity - from illness (e.g. encephalitis or meningitis) to brain damage (e.g. traumatic brain injury or stroke) to abnormal brain development.</p> |
| Multiple sclerosis | <p>Multiple sclerosis (MS), is a chronic inflammatory demyelinating disease that affects the central nervous system. Symptoms vary widely and can affect visual, motor, sensory, coordination, balance, bowel, bladder and sexual functioning.</p> <p>As well as the physical motor symptoms, individuals with MS often</p> |

| | |
|---|---|
| | <p>present with cognitive difficulties (Deloire et al., 2005) and “neuropsychiatric” symptoms (Politte, Huffman, & Stern, 2008). MS is characterised by lesions in the brain and spinal cord.</p> |
| <p><i>It is important to highlight that there isn't a unidirectional relationship between the above conditions and psychological distress, i.e. it is not the fibromyalgia, epilepsy, or muscular sclerosis, that is the cause of the psychiatric distress necessarily, but rather it appears that there is a strong relationship between the above conditions, and the development of psychological distress (potentially due to a diverse range of reasons, including biological, social and psychological aspects of the conditions).</i></p> | |

1.5.3 Methodological Characteristics of the Included Studies: A Review and Critique

1.5.3.1 Overview of studies.

Table three summarises the characteristics of the 8 studies included within this review. The studies were predominantly conducted within Sweden (n=3), followed by Spain (n=2), America (n=2), South Africa, and Australia. The potential impact of differences between health-care systems, the amount of social stigma associated with the conditions in each of the countries, and how frequently psychological interventions are offered and how well they are received, are therefore just some of the contextual factors that may affect the generalisation of these results to UK populations.

It is interesting to note that all studies were published within the past eight years, despite there being no date limit placed when retrieving articles. This potentially reflects the relative recency of ACT in general, and even more the recency of this approach with adults with neurological impairments.

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Table 3 Description of studies included

| <u>Study</u> | <u>Chronic Health Condition</u> | <u>Sample</u> | | | <u>Method</u> | <u>Interventio n</u> | <u>Psychologica l Outcome Measures</u> | <u>Additional Measures</u> | <u>Key Findings</u> |
|--|---------------------------------|---------------|----------------------------------|------------------------------|--|---|--|---|---|
| | | N | Gender (% female) | Mean Age (yrs) | | | | | |
| (Carbonel I-Baeza et al., 2011) | Fibromyalgia | 75 | ACT - 100% UC (education) – 100% | ACT 51.4 UC – 50 | Recruitment Referred by primary care physicians. Design: Randomised, controlled trial Analysis Pre, post and 3 month follow-up | ACT (n=41) UC (n=34) ACT + pool + exercise for 12 weeks (90 minutes of ACT each wk) | HADS SF-36 | FIQ VPMI Rosenberg self-esteem scale. | Sig interaction (group*time) for FIQ, the subscales fatigue, stiffness, anxiety and depression, and subscales of SF-36 physical role, bodily pain, vitality and social functioning. Post-hoc analysis revealed sig. improvements in total score on FIQ, fatigue, stiffness, anxiety, depression, physical role, bodily pain, vitality and social functioning. |
| (Jensen et al., 2012b) | Fibromyalgia | 43 | ACT – 100% WLCT – 100% | ACT 44.5 WCT 46.9 yrs | Recruitment Referred by primary care physicians. Design: Randomised, waiting list controlled trial Analysis Pre, post and 3 month follow-up | ACT (n=25) WCT (n=18) 12 weekly (90 minutes each). | -BDI -STAI-S | -PGIC -VAS -PPT - P50 -fMRI assessments | ACT group Sig. higher improvement on PGIC, BDI, STAI-S, compared to WCT. VAS dropped sig. over time. No group interaction. No sig difference in P50 or PPT. -fMRI pre-post change in cluster of increased brain activity in brain regions implicated in executive control in ACT group, but not in control. |
| (Luciano, | Fibromyalgia | 156 | ACT – | ACT | Recruitment: From | ACT (n= 45) | MINI v5.0 | FIQ | ACT sig. superior to RPT and WL in short and long |

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| | | | | | | | | | |
|---|-----------------|----|-----------------------------|------------------------------|---|---|-----------------------|---|---|
| et al., 2014) | | | 96.1% RPT – 98.1% | 48.8 RPT 47.7 | primary health centre. Design 6 month randomised control trial (3 conditions). Analysis pre, post, 2 month and six month follow-up. | RPT (n= 44) WL (n= 47) 8 sessions (2.5 hrs each). RPT – pregablin and duloxetine. | HADS EQ-5D | PCS CPAQ PVAS AEs | term follow-up on HADS-D, HADS-A, functional outcomes, pain catastrophising, subjective pain, HRQoL. ACT vs RPT or WL, large effect on global functioning, medium pain catastrophising and subjective pain, small anxiety ad HADS. No AEs for ACT. AE’s reorted for RPT. Sig. increase in pain acceptance for ACT and RPT. |
| (Lundgren , Dahl, Melin, & Kies, 2006) | Epilepsy | 27 | ACT - 50% ST - 53.8% | ACT - 38.85 ST - 42.5 | Recruitment: Participants were institutionalised or day workers in a centre for epilepsy. Design: randomised controlled study. Data analysis: pre, post, 6 months and 1 year following the end of treatment. | ACT (n=14) or ST (n=13) 4 sessions: 1 individual (1.5 hours) 2 group (3 hours) 1 individual (1.5 hours). | WHOQOL SWLS | Seizure frequency (via daily medical charts) Seizure index | Sig. difference between groups’ effect at every post-treatment point for SWLS. (higher ratings in the ACT group). Sig. interaction (group*time) on the WHOQOL-BREF at 1-year but not at post or at the 6-month follow-up. Sig. interaction (group*time) on the seizure index Sig. between group effects in favour of the ACT group at every post-treatment comparison between p < 0.048 and p < 0.011. |
| (Lundgren , et al., 2008) | Epilepsy | 18 | ACT 30% Yoga 37.5% | ACT 21.9 Yoga 25.8 | Recruitment: Participants recruited from an outpatient clinic. Design: randomised, controlled study Data analysis: pre, post, 6 months and 1 | ACT (n = 10) yoga (n = 8) 4 sessions: 1 individual (1.5 hours) 2 group (3 hours) 1 individual (1.5 hours) | WHOQOL- BREF SWLS, | Seizure frequency (via daily medical charts) Seizure index | ACT and yoga significantly reduce seizure index ACT reduced seizure index significantly more as compared with yoga. ACT and yoga groups significantly improved quality of life |

Introduction

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| | | | | | year following the end of treatment. | | | | |
| (Nordin & Rorsman, 2012) | Multiple sclerosis (MS) | 20 | ACT 80% R-T session 80% | ACT 43 R-T sessio n 48.5 | Recruitment: recruited from the Department of Neurology Design: Randomised, controlled study Data analysis: pre, post, 12 weeks following end of treatment. | ACT (n=11) Or R-T (n=10) 4 sessions weekly then gap of 11 weeks before 5 th session. | HADS BDI (AAQ-II) | Frequency of daily practice. | Within-subject analyses in the ACT group - significant decline in BDI scores from pre- to post- and sig. increase (improvement) in AAQ-II scores from pre- to post-treatment and from pre-treatment to follow-up Between-group analyses – sig. outcome on HADS-D, with the RT group showing a larger decline than ACT Patients in the RT group reported a higher frequency of daily practice than the ACT group. |
| (Sheppard et al. 2010) | Multiple Sclerosis (MS). | 15 | 80% | 53.1 yrs | Recruitment: advertisement at neurology clinic Design: Open trial. Case series (no control) Analysis: Pre, and 12 week follow-up. ANOVAs. | Half day (5-hour) ACT workshop | BDI-II QOLI | MFIS PES SF-36 WBSI MAAS | MS-related incidences' of impairment and Depression scores sig. decreased over time. Scores on SF-36 showed a nonsig. trend towards improvement. Impact of fatigue on behaviour did not improve sig. Reduction in tendency to suppress thoughts. No improvement on mindfulness. Sig. improvements in overall QoL. |
| (Wicksell et al., 2013) | Fibromyalgia | 40 | ACT (100%) (WLCT) (100%) | 45.1 yrs | Recruitment: Referrals via primary care physicians in Sweden. Design: randomised controlled trial Analysis: pre, post, 3 | ACT(n=19) WLC (n= 14) 12 weekly group sessions (90 min each) | SF-36 BDI STAI | PDI FIQ SES Pain intensity PIPS | Significant differences in favour of ACT were seen in pain-related functioning, FM impact, mental health-related QoL, self-efficacy, depression, anxiety and psychological inflexibility compared to control. No sig. changes in physical QoL or pain intensity. |

Introduction

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| | | | | | month follow-up. | | | | Changes in psychological inflexibility during the course of treatment were found to mediate pre- to follow-up improvements in outcome variables. |
|--|--|--|--|--|------------------|--|--|--|--|

Notes: Acceptance and Action Questionnaire - II (AAQ-II); Adverse effect (AEs); Beck Depression Inventory (BDI); Chronic Pain Acceptance Questionnaire (CPAQ); Chronic Pain Values Inventory (CPVI); European Quality of Life- dimensions(EQ-5D); Functional magnetic resonance imaging assessments (fMRI assessments); Fatigue Severity Scale (FSS); Fibromyalgia Impact Questionnaire (FIQ); Hospital Anxiety and Depression Scale (HADS); Mindful Attention Awareness Scale (MAAS); Modified Fatigue Impact Scale (MFIS); Mini-International Neuropsychiatric Interview (MINI v5.0); Stimulus Response Assessments (P50); Pain Catastrophizing Scale (PCS); Pain Disability Index (PDI); Pain Effect Scale (PES); Patients' Global Impression of Change (PGIC); Psychological Inflexibility in Pain Scale (PIPS); Pressure Pain Thresholds (PPT); Pain Visual Analogue Scale (PVAS); Quality of Life Inventory (QOLI); Relaxation Therapy (R-T); Recommended Pharmacological Therapy (RPT); Rosenberg self-esteem scale (RSES); *Satisfaction with Life Scale* (SWLS); Self-efficacy Scale (SES); Short Form (36) Health Survey (SF-36); State-Trait Anxiety Inventory (STAI); supportive therapy (ST); Trimbos and Institute of Medical Technology Assessment Cost Questionnaire for Psychiatry (TIC-P); Usual Care (UC); visual analogue scale (VAS); Vanderbilt Pain Management Inventory (VPMI); White Bear Suppression Inventory (WBSI); Waiting List Control Treatment (WLCT); World Health Organization Quality of Life (WHOQOL- BREF).

1.5.3.2 Study Populations

The studies included populations with a range of neurological conditions. Four focused on fibromyalgia, two focused on epilepsy, and two focused on multiple sclerosis. The majority of the studies screened participants to exclude specific comorbidities including: suicidality, psychotic symptoms and severe depression (Carbonell-Baeza et al., 2011; Jensen et al., 2012; Luciano et al., 2014; Nordin & Rorsman, 2012; Wicksell et al., 2013) alcohol or substance misuse (Luciano et al., 2014; Nordin & Rorsman, 2012) or progressive disorders such as dementia (Luciano et al., 2014; Lundgren et al., 2006). One article excluded stroke survivors (Carbonell-Baeza et al., 2011). The main purpose of these exclusions ensure the subjects have the attributes to accomplish the purpose of the research, i.e. to show that ACT is effective with a particular client group, without any interfering symptoms or behaviours. In other words, employing strict exclusion criteria may increase the internal validity, and likelihood of producing reliable and reproducible results. However, it simultaneously reduces the external validity and generalisability to clinical practice, as community and non-research individuals may often fall into one or more of these exclusion categories.

Likewise, many of the studies excluded those who used pharmacological interventions such as antidepressants, pain medication, anticonvulsants (Jensen et al., 2012b; Luciano et al., 2014; Wicksell et al., 2013), or at least stipulated that the prescriptions must remain constant throughout the study (Lundgren et al., 2008). This may have acted as a major barrier to recruitment, as pharmacological management is most often the first port of call for all of these neurological conditions. Interestingly, only three studies included active or recent psychological interventions as exclusion criteria (Carbonell-Baeza et al., 2011; Luciano et al., 2014; Wicksell et al., 2013).

Many studies employed additional inclusion criteria such as major depressive disorder or at least heightened scores on measures of: depression (Luciano et al., 2014; Nordin & Rorsman, 2012), pain (Carbonell-Baeza et al., 2011; Wicksell et al., 2013), or seizure activity

(Lundgren et al., 2006; Lundgren et al., 2008). This was to ensure that the population could potentially benefit from the conditions.

Additionally, all studies employed age ranges as an inclusion/exclusion criteria. All studies focused on adults (i.e. 18 years +), with the mean age of participants ranging from 21 years of age (Lundgren et al., 2008) to 53 years of age (Sheppard et al., 2010). All but one study employed an upper age limit (Carbonell-Baeza et al., 2011), with only one of the studies allowing adults over the age of 55 (Luciano et al., 2014), and even this excluded anyone over the age of 65.

Gender appears to be an important factor, with the majority of studies using female populations. Indeed three of the studies (Carbonell-Baeza et al., 2011; Jensen et al., 2012b; Wicksell et al., 2013) used females only. However, the studies involving adults with epilepsy (Lundgren et al., 2006; Lundgren et al., 2008), were more equally distributed with regard to gender. The amount of time passed since the onset of the conditions was published for the majority of studies (n=7), and ranged from 2 (Nordin & Rorsman, 2012) to 12.8 years (Luciano et al., 2014). No studies document any hypotheses about why the population was seeking psychological input now.

1.5.3.3 Design and Recruitment.

The quality of the research design was initially assessed using the five criteria for empirically supported psychotherapies outlined by Chambless and Hollon (1998).

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Table 4 Quality of included studies

| Study | Comparison condition | Sample size > 25 per group | Sufficient power for moderate effect | Inclusion criteria specified | Reliable/valid outcome measures |
|-------------------------------|-----------------------------|--------------------------------------|---|-------------------------------------|--|
| (Carbonell-Baeza et al. 2011) | + | + | - | + | + |
| (Jensen et al. 2012a) | + | - | - | + | + |
| (Luciano et al. 2014) | + | + | + | + | + |
| (Lundgren et al. 2006) | + | - | - | + | + |
| (Lundgren et al. 2008) | + | - | - | + | + |
| (Nordin & Rorsman, 2012) | + | - | - | + | + |
| (Sheppard et al. 2010). | - | - | - | + | + |
| (Wicksell et al. 2013) | + | - | - | + | + |

As can be seen from research design quality table above, only one study (Luciano et al., 2014) met the full criteria, with limited sample size being the main weakness across the majority of studies.

Exploring each section separately, most studies (n=6) used a randomised control design. The two studies which did not, employed an open trial case series design (Carbonell-Baeza et al., 2011; Sheppard et al., 2010). Studies appeared to match participants on the presence or absence of comorbid depression and anxiety scores, or blindly using a computerised table. It is interesting that none of the studies used neuropsychological tests to control for effects of cognition, despite the acknowledgment of comorbid cognitive difficulties across these conditions.

The control groups were most often an alternative treatment condition, such as yoga, relaxation class, education, supportive therapy (Carbonell-Baeza et al., 2011; Lundgren et

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al., 2006; Lundgren et al., 2008; Nordin & Rorsman, 2012), or a waiting list control (Jensen et al., 2012; Wicksell et al., 2013). Only Luciano et al. (2014) used both an active control (pharmacological intervention) and a waiting list control. Use of comparison conditions are considered to enhance methodological rigour as they attempt to control for nonspecific factors such as therapist contact, therapeutic alliance, elements of expectation, time and attention, spontaneous recovery, and regression to the mean effects etc. (Frank & Frank, 1991). However, it has been argued that all participants in clinical trials, whether receiving an active intervention or not, are provided substantially more contact with a treatment team than is observed in routine clinical practice; thus even patients assigned to a waiting list condition may experience substantial benefit (Freedland, Mohr, Davidson, & Schwartz, 2011). Hence, we may not be getting a true representation of the difficulties seen in these populations.

Nevertheless, waiting list controls are often advantageous to no control group. They demonstrate on some level that the intervention being tested is more effective than not receiving anything, and may assist to control for secondary effects (e.g. time). Additionally, employing a waiting list control is considered to have several ethical advantages, for example, allowing the provision of the intervention to all those seeking help. However, this widely held belief has recently come under scrutiny. Miller and Rollnick (2002) point out, assigning an individual to a “waiting list” implies that they are expected to “wait” to change and compliantly do so, biasing the results.

Most studies recruited from primary care settings (Jensen et al., 2012; Luciano et al., 2014; Nordin & Rorsman, 2012; Wicksell et al., 2013) or specialist clinics (Carbonell-baeza et al., 2011; Lundgren et al., 2008; Sheppard et al., 2010). It is interesting that more were not recruited from outpatient clinics, as this sample will differ from those managed in primary care, and are often considered more complex. Likewise those attending specialist clinics may have already received input above the level that is offered in routine clinical practice, and also having gained access to such services, suggests that individuals were motivated

enough to attend. Thus, even before any consideration of eligibility or exclusion criteria, potential recruits may already be unrepresentative of individuals in the local community.

1.5.3.4 Sample Size and Attrition.

Alongside the importance of recruitment biases, it is important to consider the sample size and statistical power in these studies. Low numbers such as those used in the majority of studies may not reliably reflect the population mean, and may not be able to detect statistically significant differences between groups. The sample sizes across the studies varied from just 8 per group (Lundgren, et al., 2008), to 47 per group (Luciano, et al. 2014). Few studies mentioned the statistical power of their tests, of those reporting this only one met the criteria set by Chambless and Hollon (1998). Hence, the conclusions that can be drawn from the studies are further limited by the small sample sizes.

All studies included within this review used a longitudinal design. One major methodological problem in this type of design is attrition, which often leaves incomplete outcome data. This means that information is only available from those who decided to stay in the study, and access is not granted to those who potentially did not find the intervention helpful (Gustavson, Von Soest, Karevold, & Roysamb, 2012). Within the studies included here however, the attrition rates were quite low. In both Lundgren (2006; 2008) studies not one person withdrew from the study but the number of participants recruited was low to begin with. The researcher found the highest attrition rate was in Sheppard et al. (2010) study with a 26% attrition rate. All the other studies had an attrition rate of 20% or lower. Although the number is far greater when looking at those who were initially referred and those who actually initiated the study. For example, this is most marked in Jensen et al. (2012), where 82 individuals were originally referred, yet only 43 actually enrolled in the study, hence 48% were not recruited due to not meeting the inclusion criteria or were unable to participate due to the practical aspect of the study protocol.

1.5.3.5 Intervention Delivery and Follow-up.

As described in the inclusion criteria, all studies delivered the ACT intervention via group modalities, or at least used group methods as a significant part of the intervention. The average amount of time spent in the ACT intervention ranged from just five hours (Sheppard et al., 2010; Nordin & Rorsman, 2012) to 20 hours (Luciano et al., 2014). All treatments were delivered by psychologists, and the majority had experience and had received training in ACT. Whilst it is important to ensure that the studies are testing the outcomes of ACT, hence requiring a thorough knowledge of the approach by facilitators, it has been argued that competence of treatment delivery may be greater in clinical trials than the level of clinical competence provided in community settings.

1.5.3.5.1 Content of sessions

Several of the studies delivered interventions that were based on previously published ACT treatment manuals or clearly written and established ACT protocols (Carbonell-Baeza et al., 2011; Jensen et al. 2012; Luciano et al. 2014; Nordin & Rorsman, 2012; Wicksell et al., 2013). Additionally, Luciano et al. (2014), Lundgren et al. (2006), Lundgren et al. (2008), and Wicksell et al. (2013) video recorded all sessions to ensure treatment integrity.

Some studies (Nordin & Rorsman, 2012; Wicksell et al., 2013) appeared to have relatively distinct treatment objectives for set sessions. Whilst others appeared to teach the core principles simultaneously. This second option may be more in keeping with ACT's underlying model, as ACT would stipulate that each underlying principle is simultaneously present and dependent on one another (as seen in the hexaflex above).

1.5.3.6 Outcomes and Efficacy Data

In all of the studies, apart from Sheppard et al. (2010), assessments were taken at three time points - pre-intervention, post-intervention and follow-up (most commonly completed at three months post-intervention). In four of the studies, independent researchers with no insight or involvement in the treatment intervention performed the assessments (Jensen et

al., 2012; Luciano et al., 2014; Nordin & Rorsman, 2012; Wicksell et al., 2013). Blinding of outcome assessors may reduce the risk of detection bias (e.g. change being recorded because of expectations based upon knowledge of which intervention was received by each participant biasing the results). Blinding of outcome assessors can be especially important for subjective measurements. However, the majority of studies used self-report questionnaires, which are relatively free from experimenter bias as they are completed by the participants. Self-report measures also carry additional benefits. They represent a cost effective and time efficient means of obtaining data, can be easily implemented to large samples; and can be used to measure subjective personal experiences (i.e. degree of psychological flexibility). However, there are difficulties associated with this measurement, not least because participants may lack the introspective ability to provide accurate responses as an example (Razavi, 2001).

1.5.3.6.1 Baseline characteristics

In all of the studies a description of baseline clinical and/or demographic characteristics is used to assess external validity by systematically comparing the differences between the groups on baseline characteristics. No significant pre-treatment comparisons were found on any of the variables tested, apart from Lundgren et al. (2008) who found a significant difference on the seizure index between the groups at baseline.

1.5.3.6.2 Psychological outcome measures

As discussed, all studies had at least one psychological outcome measure. Most (n=6) included a measure of depression (measured by the HADS or BDI-II) and / or anxiety (n=5) (measured by the HADS or STAI). However, focusing only on depression or anxiety rating scales as a measurement of psychological outcome can overlook other important clinical outcomes, for example quality of life and functioning. This is crucial within ACT, as it is often not the distress which is specifically tackled, but rather the ability to lead a meaningful life despite negative experiences. Hence most (n=6) of the studies measured some aspect of quality of life (measured by EQ-5D, WHOQOL, SWLS, or QOLI). Additionally, one study included a measure of self-esteem (Carbonell-Baeza et al., 2011), and one study (Luciano et

al., 2014) measured psychiatric disorders using the Mini-international neuropsychiatric interview (MINI v5.0).

1.5.3.6.2.1 Depression

There was a significant time * group interaction in favour of ACT for depression in Jensen et al. (2012), and Wicksell et al. (2013). However group * time interaction effects were not statistically significant for Luciano *et al* (2014) or Carbonell-Baeza et al. (2011). Nordin and Rorsman (2012) found a significant group*time interaction. However, in this study, the change was seen in favour of the relaxation group. It is important to bear in mind that this was a pilot trial including only ten participants in each group by the end of the study. Additionally, there were differences noted with regards to the emphasis placed on homework practice. In turn, the control group reported daily practice, whereas the majority of ACT participants only practised a few times a week. In addition, the control group also received individual support, which was not available in the ACT group. Hence, even though the researchers shortened the control group to match the ACT therapy, there are still considerable differences between the treatment designs.

Between subjects outcome measures, as reported here, are insensitive to individual change. Therefore, within subjects contrasts were also performed in all of the studies. There was a significant main effect of time on measures of depression for the ACT group separately in Carbonell-Baeza et al. (2011), Jensen et al. (2012), Luciano et al. (2014), Nordin & Rorsman (2012) and Wicksell et al. (2013). Likewise, with respect to MS-related indices of impairment, Sheppard et al. (2010), found that depression scores significantly decreased over time ($p < 0.05$).

1.5.3.6.2.2 Anxiety

Both Jensen et al. (2012) and Wicksell et al. (2013) demonstrated a significant interaction for group * time on measures of anxiety, with a significantly higher improvement in the ACT group. Similarly to the measures of depression, no group * time interaction effects were

found by Luciano *et al* (2014), or Carbonell-Baeza *et al.* (2011). However, both studies found that ACT was more effective than the comparison groups in reducing levels of anxiety, but this did not meet levels of significance. In comparison, no significant effects were found by Nordin & Rorsman (2012) between or within groups on measures of anxiety.

1.5.3.6.2.3 Quality of life

Additionally, Lundgren *et al.* (2006) found a significant difference between the groups in the satisfaction with life scale at post ($p < 0.05$) and follow-up ($p < 0.005$), and by one year post-intervention found a significant difference between the groups on the quality of life measure ($p < 0.05$). Likewise Carbonell-Baeza *et al.* (2011) found a significant interaction effect between the groups over time, as did Wicksell *et al.* (2013) for mental health quality of life ($p = 0.030$) and here the between group effect was large (0.84) at post- and follow-up (1.06). Additionally, ACT was more effective than control groups in increasing health related quality of life in the study by Luciano *et al.* (2014), but no group * time significant interaction was found. Sheppard *et al.* (2010) found that measures of quality of life showed a nonsignificant trend towards improvement ($p > 0.05$). However, Lungdren *et al.* (2008) did not find a significant interaction effect of time on measures of quality of life. However, they did find that the participants in the ACT group exhibited a strong effect from pre-test to post-test, but the changes in the groups over time were not significant.

1.5.3.6.3 Behavioural outcome measures

Several studies also examined discrete behavioural measures such as fibromyalgia symptoms (measured by the FIQ), seizures activity (measured by the seizure index which is seizure frequency x duration), pain severity (measured by weekly ratings on a visual analogue scale, pressure pain thresholds), pain disability (measured by the PDI and PES), pain catastrophising symptoms (measured by the PCS), and fatigue (measured by the FSS and MFIS).

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Carbonella-Baeza et al. (2011) found a significant interaction effect (group*time) for the FIQ total score and post hoc analysis revealed greater improvements in the ACT group. Additionally, Luciano et al. (2014) and Wicksell et al. (2013) found statistically significant group * time interactions on the FIQ.

Ljotsson et al. (2014) and Wicksell et al. (2013) also found significant decreases on measurements of pain disability and fatigue in their ACT groups, with medium to large effects. Likewise, Sheppard et al. (2010), found that the effect of pain on behaviour and mood significantly decreased over time after attending the ACT course. Luciano et al. (2014) used linear mixed effect models to demonstrate that ACT was more effective than other conditions in the short and long term in reducing functional impairment and pain catastrophising.

Lundgren et al. (2006) found a significant interaction between groups and time for the seizure index, with ACT group showing greater reductions. Likewise, Lundgren et al. (2008) found a significant reduction on the seizure index in both groups over time, and found the ACT group changed significantly more.

Jensen et al. (2012) found that weekly measures of pain ratings dropped significantly, but no significant interaction for group*time was found. Additionally, no interaction effect was found for pain pressure thresholds. Wicksell et al. (2013) additionally found no significant change in level of pain reported, and Sheppard et al. (2010) found no significant change in fatigue. This may be in keeping with ACT theory. ACT promotes acceptance of symptoms that cannot be addressed or improved, and instead attempts to modify the context in which these symptoms occur rather than addressing the symptoms themselves. All of these studies found positive changes in quality of life despite these unchanged symptoms.

1.5.3.7 Measuring core processes of ACT

The importance of assessing core ACT processes has been highlighted previously (Hayes et al., 2004), and there are several structured and unstructured approaches to assess the six core ACT processes. The approach used by the studies here was to use self-report measures. However, no measures exist to explore all six processes, hence the authors prioritised certain measures to explore specific processes. For example, Wicksell et al. (2013) used the Psychological Inflexibility in Pain Scale (PIPS) questionnaire to assess psychological flexibility in relation to chronic pain. The study found that the ACT group improved significantly more than the control condition ($p=0.008$) and the between-group effect size was large (1.05) at post-treatment and medium to large (0.71) at follow-up. Nordin & Rorsman (2012) used the Acceptance and Action Questionnaire (AAQ-II) to measure an individual's ability to accept undesirable thoughts and feelings. Within-group comparisons found a statistically significant increase in AAQ-II scores from pre to post and pre to follow-up data. Sheppard et al. (2010) used two process measures: the Mindful Attention Awareness Scale (MAAS) as a measure of attentional facets of mindfulness, and the tendency to suppress unwanted thoughts using the White Bear Suppression Inventory (WBSI). The results showed a significant reduction in the tendency to actively suppress their thoughts following the ACT workshop. Interestingly, mindfulness did not improve, the sample size was very low ($n=11$).

1.5.3.8 Mechanisms of change

Many researchers have emphasised the need to pay more attention to mediation analyses which explore the variables involved in the relationship between the independent variables and the dependent variables (Lee & Koo, 2015). This is a distinct strength of the ACT literature, with studies often exploring the extent to which one or more of the six core processes of ACT mediate the outcomes. Consistent with this, Luciano et al. (2014) examined whether the effect of treatment on outcomes at follow-up is mediated through changes in pain acceptance. Bivariate Pearson correlations were performed, and surprisingly the path analyses did not support pain acceptance change as a mediator of functional status, pain catastrophising, subjective pain, anxiety or depression. Rather the study conditions and clinical outcomes offered a direct path. However, it is rare that a single mediator might be able to completely explain the relationship between an independent and

a dependent variable, particularly in a therapy as complex as ACT (Luciano, et al., 2014). Wicksell et al. (2012) additionally explored the functional importance of changes in psychological flexibility as a mediator of improvement for the effects of treatment on the outcome variables. This study found that decreases in psychological inflexibility from pre to post-treatment significantly mediated the improvements in pain disability, fibromyalgia impact, depression and anxiety, which supports the ACT theory of psychological distress. Additionally, both of the epilepsy studies (Lundgren et al., 2006; Lundgren et al., 2008) demonstrated that improvements in the frequency of seizures and psychological well-being, were partially mediated through epilepsy-related acceptance, values attainment, and persistence despite obstacles.

1.5.4 Summary of systematic review

It appears that the use of ACT with neurological conditions is in its infancy. A systematic review obtained only eight studies that met the criteria set in this review, and even then, the quality of the research designs were limited, with most studies being low in numbers and statistical power. However, the results obtained across the studies appear to support the use of ACT with this population overall. Indeed the ACT groups significantly reduced levels of depression across all studies, and levels of anxiety in all studies except one. Whether ACT led to greater improvements compared to other active control conditions cannot be definitively determined. However, all studies saw an improvement in quality of life measures, with the change reaching levels of significance across all studies. All studies exploring the impact of the condition, the number of seizures endured, the level of pain related disability, and secondary fatigue, found significant improvements in all of the ACT groups. However, subjective measures of the problems themselves (i.e. pain ratings), did not significantly change across any of the studies, suggesting that the decrease is due to the ways in which participants related to their difficulties, as opposed to the difficulties themselves reducing. Likewise, all studies which explored the core processes of ACT (e.g. psychological flexibility, acceptance etc.) found significant improvements in the ACT group.

1.6 Summary of Chapter

Stroke hits suddenly, and very often without any prior warning. Hence, it is often a disorientating and shocking life-threatening event that has a substantial impact on psychological well-being (Lincoln, et al., 2012). Psychological wellbeing has significant associations with rehabilitation outcomes (Gillen et al., 2001), functional status (Burvill, et al. 1997), mortality (Williams, et al., 2004), and quality of life (RastenYTE & Kranciukaite, 2007). Increased recognition of the role that carers (frequently in the form of family members) play in the welfare of stroke survivors, and the negative impact that this role can have on their own personal wellbeing, is now also well recognised. The management of psychological distress for stroke survivors and their carers therefore appears crucial, yet psychological care within the community is often highlighted as being sparse. Therefore, there appears to be a great need for interventions that are not only effective, but also reproducible in the community without complex healthcare infrastructures.

There is a growing evidence base for psychological interventions for mood disorders or psychological distress following stroke, with the most popular therapy being CBT (Lincoln & Flannaghan, 2003). However, the outcomes have often shown mixed results. Other forms of psychotherapy with some support for efficacy include motivational interviewing (Watkins *et al.*, 2007) peer support groups (Coniglio, et al., 2012; Morris & Morris, 2012); relaxation classes (Carin-Levy, et al., 2009; Kneebone, et al., 2014); goal setting interventions (Sugavanam et al., 2013); behaviour therapy (Thomas, et al., 2013) and information provision (Smith, et al., 2008). However, the outcomes are often mixed, and many of the studies have been criticised for weak to moderate methodological strengths (Kirkevold, et al., 2012; Levack, et al., 2006; Sugavanam, et al., 2013).

ACT has become increasingly popular amongst many clinicians and researchers alike in the past decade. Overall, the goal of ACT is to promote increased “psychological flexibility”, through several key processes that have been discussed above (Hayes et al., 2006). Essentially, ACT takes the view that trying to change aversive internal responses as a means of coping can actually be counterproductive. Instead ACT places its focus on supporting

individuals to expand their lives in a direction that supports a connection with - and action towards - personally held values, despite aversive experiences (Luoma et al., 2007; Forsyth & Eifert, 2007).

A systematic literature review to determine whether any existing studies had investigated ACT with stroke survivors demonstrated that no studies are yet available, except one single case design (Graham et al., 2014). As a result, eight articles involving the use of ACT with three neurological conditions have been discussed. The studies have demonstrated that ACT groups can have a significant interaction effect on measures of depression, anxiety and quality of life, as well as a range of behavioural outcomes including fibromyalgia symptoms, seizure activity, pain severity, pain disability and pain catastrophising symptoms. Several core ACT processes were measured. Nonetheless only four used these within mediation analyses, which showed mixed results.

1.7 The Present Thesis

The systematic review has in general produced promising results for the use of group ACT with adults who have a neurological condition. However, differences exist between these conditions and stroke populations, and so it does not automatically follow that the same intervention would be equally valid. To take an example, cognitive and communication problems, which might impact on individuals' ability to understand and take on board some of the ACT messages, are more common following stroke than epilepsy, fibromyalgia or multiple sclerosis for example. Also, the types of problems and main sources of distress may differ considerably across the different conditions.

This will be the first controlled study to examine the effectiveness of ACT in adult stroke survivors or their carers. Thus the present thesis will aim to test the effectiveness of a community group based ACT intervention to improve levels of psychological distress in stroke survivors and their carers.

Introduction

The researcher hypothesised that:

1. Participants assigned to the four sessions ACTion after Stroke group would experience (a) improvements in levels of psychological distress (b) improved quality of life and (c) higher levels of post-traumatic growth, at both immediate post-treatment assessment and two month follow-up, compared with participants who were assigned to a waiting list.
2. A further aim of the study was to investigate the role of possible mediators. If distress is a manifestation of experiential avoidance, then psychological flexibility and the promotion of goal directed behaviours would be expected to mediate the outcome in a successful ACT treatment.
3. If the above hypotheses are met, then the qualitative focus group should support these findings, with the participants reporting positive experiences resulting from the group.

Chapter 2 Methodology

2.1 Chapter Overview

The previous chapter provided the conceptual and theoretical framework for the thesis, while this chapter presents the empirical research process. The chapter begins with a description of the research paradigm and approach, before the research design is introduced. A description of the ACT group intervention is then provided. Following these sections, a step by step guide of the procedures undertaken including recruitment, allocation to the groups, data collection methods and data analysis is shared.

2.2 Research paradigm and approach

As stated in Chapter one, the researcher began this study with certain key questions in mind. Broadly speaking, the researcher was interested in exploring whether the ACT group intervention (ACTion after Stroke) would lead to improved psychological outcomes for those attending the group, compared to those assigned to a waiting list. Quantitative methodology was considered a helpful approach in answering this question, as it provided a controlled identification of change. For example, many of the targeted psychological outcomes, such as psychological distress, quality of life, post-traumatic growth etc. are fairly ambiguous terms, with the meaning potentially varying from person to person. However, to explore whether an intervention is helpful in increasing or decreasing any of these variables, ambiguity must be minimised. Hence, by using standardised measures, which have pre-specified criteria, a more objective, precise and reliable look at change can occur.

The second question addressed the mechanisms by which the ACT intervention worked. More precisely, whether increased psychological flexibility and goal directed thinking could mediate psychological distress. Again quantitative methodologies appeared beneficial, as not only is the concept of psychological flexibility difficult to measure objectively, but also

they lend themselves more readily to sophisticated analyses, and therefore are able to capture the degree of mediation.

Another influencing factor was that many of the questions and hypotheses were based on previous studies exploring the utility of ACT with other neurological conditions. The researcher wanted to be able to systematically compare the results of the current study with those reported in chapter one. Hence, it was useful to employ a consistent methodological stance. Adding to this, this is the first study to test the research questions within a stroke sample. Hence, the results needed to be easily analysed, reliably interpreted, and straightforwardly replicable in future research.

However, the researcher acknowledged this type of information would not answer what the stroke survivors' and carers' personal experiences of the group were. This information was considered significant not only by the researcher but also by the stroke charity at which the intervention was taking place. Qualitative methodology was hence added. Therefore, the researcher invited participants to a small focus group, in order to gain a deeper insight and understanding into their personal experiences (Willig & Stainton Rogers, 2008).

The use of both quantitative and qualitative methodologies each provided valuable triangulation information to address the research question of "what is the efficacy of ACT with stroke survivors or carers?"

2.3 Design

The current study used a quasi-experimental approach, more specifically a Non-Equivalent Groups Design (NEGD) with repeated measures, to explore the effectiveness of the ACT group-based intervention to a waiting list control group. With respect to internal validity, this approach is considered inferior to randomised controlled experiments, as there was no

attempt to control the assignment to groups. Ideally, the researcher would have matched members of each group in pairs on relevant characteristics and, thereby, isolated the effects of the intervention. However, the researcher deemed that it was not ethically acceptable to withhold an intervention from individuals who had self-referred early to the group, as very often this was the only source of active psychological support available. It was deemed more ethically acceptable to make use of the naturally forming waiting list. Hence, the first 30 participants received the ACT intervention. Whilst, the following participants were placed on the waiting list.

Standardised psychometric measures were used as the dependent variables to compare both groups. All participants were asked to complete five self-report questionnaires: the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); the EuroQOL 5-D (Williams, 1990); the Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996); the Adult State Hope Scale (Snyder et al., 1996) and the Acceptance and Action Questionnaire-II (Bond et al., 2011). The outcomes were assessed at three time intervals: pre-intervention, post-intervention and at two month follow-up. Linear regression analyses were employed to explore relationships between the independent variables (i.e. the group allocation) and dependent variables (i.e. the outcome measures). Mediation analyses were employed to explore the roles of the process measures. An inductive thematic analysis (Braun & Clarke, 2006) was additionally employed to analyse the data obtained from the semi structured focus group.

2.4 Procedures

2.4.1 Service context

The ACT treatment programme was developed initially for use by an independent, local, charity organisation, whose mission was to support people to adjust to life after stroke. The service was funded from a variety of sources to offer information, guidance and education about stroke and its effects, and has since evolved to provide individual counselling sessions and group based activities for those who access its services. The service had not yet been

able to provide any group based interventions or courses that aimed to meet the psychological needs of its service users. Hence, this course appealed to both the service providers, and its service users.

2.4.2 Ethical approval

Ethical approval to formally research the effectiveness of the course was granted on the 28th November, 2013, from Cardiff University, School of Psychology Research Ethics Committee (confirmation of approvals is provided in Appendix K). However, the original ethical proforma only considered the quantitative analysis. Hence, to additionally analyse the focus group, an amendment was sought and granted on the 20th March, 2014.

2.4.2.1 Ethical considerations

The welfare of participants was paramount during all stages of the research and the British Psychological Society's Code of Ethics and Conduct (2009) was adhered to throughout. One ethical concern initially considered was the ability of participants to provide informed consent to participate in the research, due to potential cognitive impairment secondary to stroke. In line with the Mental Capacity Act for England and Wales (2005), an informal assessment of capacity was hence undertaken by the researcher. No such concerns were identified.

From the offset, it was made clear to all the individuals that their participation in the research was entirely voluntary, that it would not stop them from participating in the course or affect their involvement with the wider stroke charity in any way. Participants were also informed that they could choose to not complete the questionnaires, and / or could stop attending the group at any stage if they wished.

All participants were assured of complete confidentiality and anonymity of responses. To help ensure this, participants were asked to put two meaningful initials on all questionnaires

so that their names and identity would be protected. Access to any information provided by participants was restricted to the principal researchers only.

2.4.3 Service user involvement

Having gained ethical approval, the researcher and her supervisor met with staff and three volunteer stroke survivors from the charity to share a brief description of the group. From this meeting the structure of the group was amended (more information on this below) and the stroke survivors expressed a wish to be involved in the creation of session hand-outs and homework exercises. A sub-committee was created where the researcher began meeting with the stroke survivors on a regular basis to design aphasic friendly resources, which would highlight the main concepts discussed within each session. The service users had limited involvement in adapting or designing the PowerPoint slides at this stage, at their own choice. Instead they chose to attend the first group as participants, and wanted to then provide feedback following completion of the course.

2.4.4 Power analysis

At this stage the number of participants required to answer the questions meaningfully were considered. In general, the larger the sample size, the larger the power. However, increasing the sample size would involve tangible costs, both in the time that the stroke survivors and carers would have to wait before receiving the intervention, and in the time that the researcher could feasibly give due to the deadline of submission. Consequently, it was important to make the sample size large enough, but not wastefully so. Thus, in order to ascertain how big the sample needed to be, power analyses were conducted. Based on the study by Luciano et al. (2014) introduced above, who also used the HADS to investigate the psychological impact of a brief ACT group intervention on adults with a neurological condition, the study found a between groups effect size of $d = 0.86$, when comparing ACT to a waiting list control. Based on this effect size, and using standard parameters of $\alpha = 0.05$ and a power of 0.80 an estimated 56 participants ($N = 28$ intervention vs. $N = 28$ control group) were needed (Cohen, 1988).

2.4.5 Recruitment

Leaflets advertising the “ACTion after Stroke” course were then distributed by the stroke charity (see Appendix E for the leaflet), to individuals at any stage of the care pathway after discharge from hospital. The leaflets were hence sent to individuals who were currently known to the charity, to the local stroke early supported discharge teams, to local GP surgeries, to local inpatient stroke units, and to other independent community stroke teams. Additionally, leaflets were also sent to local carer organisations, and were publicised at local Stroke Cafés. An attempt was also made to advertise the group in the Evening Post. However, this story was not published.

2.4.5.1 Inclusion and exclusion criteria

The course was available to all individuals with a diagnosis of stroke, who were aged 18 or over (no upper age limit was set), and who were able to understand the English language. Additionally, the course was open to all individuals who considered themselves carers of someone who had experienced a stroke. The exclusion criteria set for taking part in the research was that the individuals had an alternative acquired brain injury, such as traumatic brain injury, encephalitis, brain tumour, etc. or were diagnosed with a degenerative condition (e.g. dementia). A further exclusion criteria was a severe level of cognitive / language impairment, which due to both the modality of the intervention, and the nature of the evaluation (i.e. questionnaires), would prevent them from engaging with the materials presented. Additionally, those who were receiving other therapies at the same time as part of a multi-component intervention (with the exception of drugs for depression and anxiety), were also excluded, as it is possible that this would prevent any changes specific to group psychotherapy to be estimated. Any participants who did not meet the inclusion criteria for the research study, were still invited to attend the group, but were excluded from the research.

2.4.6 Introduction to the course

At the point of interest, the participants were invited to contact a member of staff from the stroke foundation charity via telephone, letter or email. An initial consultation took place and the participants were screened for suitability for the research. Those who continued to show an interest were added to a database at the stroke foundation charity - in date order (whether or not they met the inclusion criteria for the research component). Those participants who met the inclusion criteria for the research were told that as this was the first time that this group had been delivered to stroke survivors and carers, there was interest in exploring its effectiveness. The participants were informed that they had the opportunity to take part in this evaluation *if* they chose that they wanted to. The participants were then informed that they would be contacted in due course with more information about the group and the research.

2.4.6.1 Allocation to the treatment group or waiting list

Allocation to the treatment or waiting list condition was based purely upon the order in which the participant self-referred. In order to not withhold the intervention from participants for lengthy periods, the group commenced when there was an excess of 30 participants recruited. Any persons who signed up after this, underwent the same initial consultation, and were assigned to the waiting list.

2.4.6.2 Welcome Packs

Batches of welcome packs were sent out in the post three weeks prior to the group starting. The welcome packs included further written information about the course (see Appendix G), and for those adults who expressed an interest and met the inclusion criteria for the research, an information sheet (Appendix H), and consent form (Appendix I). Participants were asked to bring their consent forms to the first group session. Baseline questionnaires were not sent out in the post at this time, due to the wealth of information already being provided. Additionally, due to the quick turnaround between receiving the information and the start date, the questionnaires were not sent out before the first group session. Instead participants were informed that an additional thirty minutes had been added to the first

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session so that they could complete the outcome measures before the group commenced if they wished to. Of the 30 participants invited, 25 (83%) consented to participate in the research study.

For those on the waiting list, the same procedures applied. If consent forms were returned, baseline questionnaires were disseminated. Participants were given the researcher's work number and email address to contact should they have experienced any difficulty completing the forms, or if they required any other additional support. They were also informed that they could meet with the researcher in person to complete the forms. Both groups were also told that they could miss out any questions that they found difficult to answer.

Following the intervention, the participants assigned to the treatment condition completed the same set of questionnaires following the last session, and then once again at two months post-intervention. Those assigned to the waiting list condition completed questionnaires at the same time intervals.

Following this final stage, participants were provided with a debriefing form (Appendix J), which outlined the value of their participation, who they could contact if there were any concerns or questions, the research ethics committee's contact details, and information about how to gain a summary of the findings.

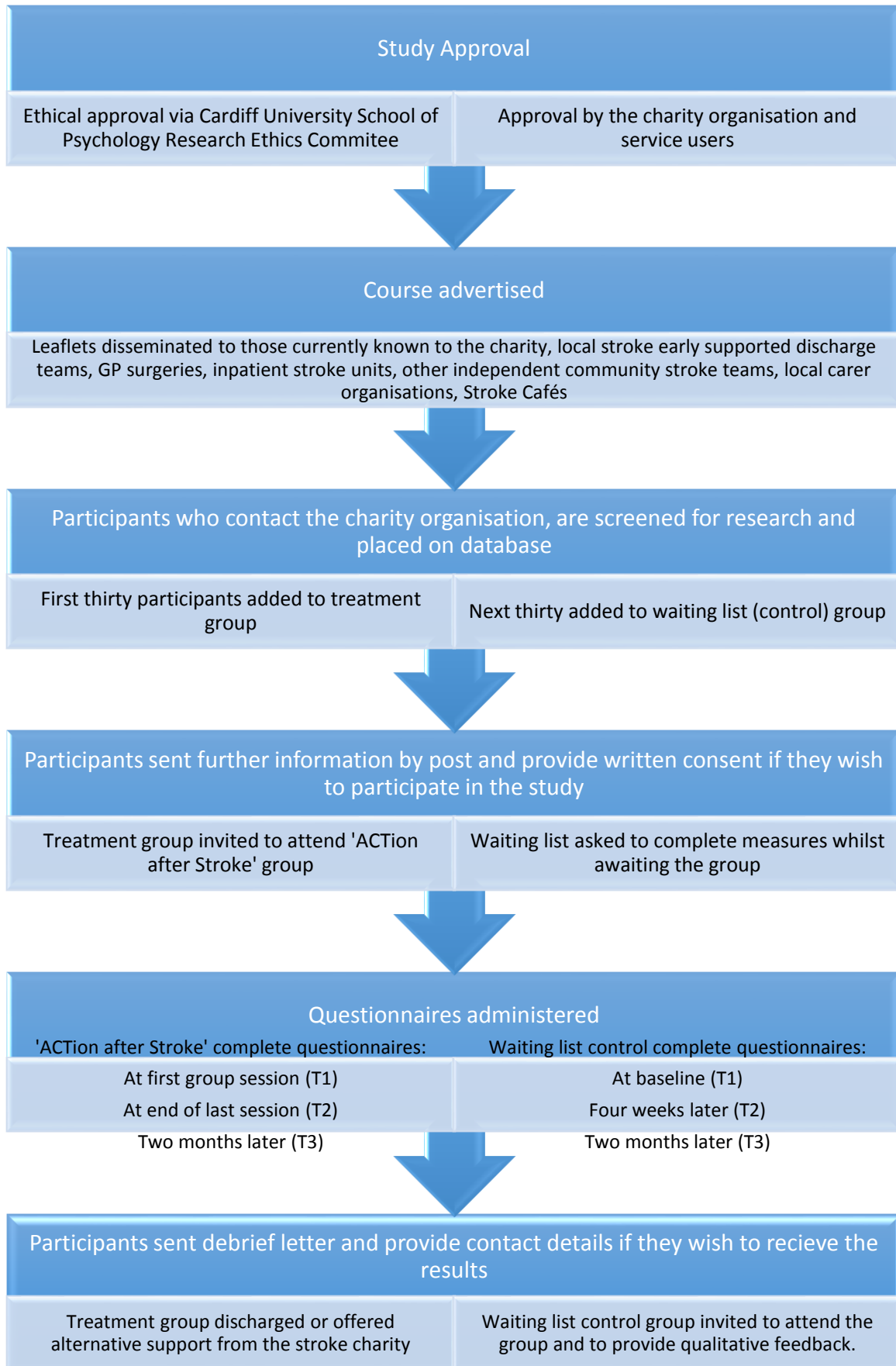
The second group commenced when 20 or more participants completed all three sets of questionnaires. This lowered number aimed to limit the time the stroke survivors and carers had to wait to receive the intervention. Participants referred after this time were then put on the next waiting list. During the third session of the second group, participants were verbally invited to attend an additional session to provide verbal feedback on how they experienced the group. Participants were informed that this was entirely optional. They

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were given another information sheet and consent form. The researchers ideally aimed to have between six to ten participants, holding in mind that having fewer than six might be difficult to sustain a discussion, whilst having more than ten may be difficult to control. Hence, participants were informed that the group facilitators would be at the same location the following week for those who wished to participate. A flowchart of this process is included in Figure 3 below.

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Figure 3 Flow chart of process



2.5 ACTION after Stroke

2.5.1 Structure of the intervention

Originally, the course was designed to be delivered over eight, one hour, weekly sessions. The researchers conjectured that a short duration would limit the amount of time that participants had to maintain their attention and concentration, and lower the impact of potential fatigue. However, following a consultation with stroke survivors, it was deemed preferable to hold the course over fewer weeks. The reasons discussed were that a significant number of participants would find it difficult to (1) get access to suitable travel arrangements for this many weeks (as most were considered to be reliant on others for travelling to and from groups currently run by the charity) (2) get time off work (3) get child care to attend all eight sessions, and (4) attend a course that traversed national holiday periods. As a result the integrated ACT intervention programme was adapted, and finally consisted of two hour sessions, which were conducted on a weekly basis over four consecutive weeks.

2.5.1.1 Facilitation of the intervention

The group was facilitated by three group leaders (one Consultant Clinical Neuropsychologist, one Trainee Clinical Psychologist and a Senior Counsellor), with three additional members of staff from the charity in attendance. All group leaders had extensive experience of delivering both individual and group interventions to stroke survivors and their carers. Additionally, two of the facilitators had received training, attended workshops, and attended CPD events in ACT.

2.5.2 Modality and components of the intervention

The course was delivered didactically using a standardised PowerPoint presentation which addressed all six core processes of ACT described in section one. Hence, the course was primarily educational. It focused on assisting the stroke survivors and carers to learn a set of simple and teachable techniques which were operationalised to accommodate for potential cognitive impairment. For instance, all information provided was shared in more than one

modality, and used experiential exercises, visual metaphors, as well as concrete stroke specific examples to enhance the learning opportunities. Additionally, the PowerPoint slides had been designed to be simple to follow, used frequent pictorial representations, and provided numerous repetitions and recapping of topics discussed. In addition, the group utilised session-by-session hand-outs (see appendix C) and weekly homework exercises (appendix D). As discussed both of these materials were developed in collaboration with stroke survivors who had not only lived experience of the effects of stroke, but additionally through their involvement with the charity, had received training in making materials accessible for those suffering with dysphasia. All materials handed out additionally adhered to the Royal National Institute for the Blind (RNIB) guidelines. The aim of these were to provide participants with a summary of the main topics discussed to enhance learning potential, and to personalise the generic skills taught within the sessions, thereby emphasising the potential of generalisation of skills (see Appendix F for the programme outline).

2.6 Measures

The choice of measures were guided by the following principles: the assessment of psychological problems after stroke should be broadly based; the assessment of post stroke experiences should not be focused solely on capturing the negative sequelae; and any measures administered should be valid and reliable for use with stroke survivors. Additionally, as ACT is underpinned by the philosophical approach of functional contextualism, and ACT's underlying theory of psychological distress is that distress is caused by psychological inflexibility (Hayes et al. 2006), attempts should be made to capture this. Finally, the researcher had to select measures that could be collectively completed in no longer than 30 minutes.

2.6.1 Psychological outcome measures

- **Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith (1983))**

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The HADS is a commonly used 14 item self-administered questionnaire, which generates interval data to determine the levels of anxiety and depression that an individual may be experiencing. Each item is scored on a 4 point scale, from 0-3, meaning that a person could score between 0 and 21 for either anxiety or depression. The HADS was chosen as the primary measure of psychological distress in this study, in part because it tends to be less confounded by somatic symptoms (which can be common in stroke survivors) in comparison to other anxiety and depression scales (Sagen et al., 2009), and it is also the only anxiety scale validated with stroke survivors with reported sensitivity and specificity data (Lincoln, et al., 2012). In a recent validation study Linley-Adams, Morris, & Kneebone (2014) reviewed published data on the sensitivity and specificity of the HADS with stroke survivors, and found its sensitivity ranged from 0.8 to 0.92 and specificity from 0.46 to 0.79, and Sagen et al. (2009) found these parameters generally exceeded the recommended minimum of 0.8 and 0.6 (Bennett & Lincoln, 2006). The measure also has good test-retest reliability data in the general population ($r = 0.84$: Herrmann, 1996).

- **EuroQOL 5-D (EQ-5D:(Williams, 1990)**

The EQ-5D is a relatively short self-report instrument that assesses a person's health related quality of life. The EQ- 5D covers five dimensions of health: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item is scored on one of three levels of disability, corresponding to: no, some/moderate, or extreme difficulties. The scores on this descriptive system can then be converted into a single index score. Basically, health states are converted into a weighted health state index by applying scores from the EQ-5D preference weights elicited from general population samples. These weights lie on a scale in which full health has a value of 1 and dead a value of 0. The U.K. population weights were used, and calculated on an excel database, which is downloadable from: [www.economicsnetwork.ac.uk/health /EQ 5D index calculator.xls](http://www.economicsnetwork.ac.uk/health/EQ_5D_index_calculator.xls). This assessment has been used in several studies as the preferred measure to evaluate quality of life (QoL) in stroke survivors (Haacke et al., 2006; Xie et al., 2006) and has also shown itself to be a valid, and reproducible instrument with stroke survivors (Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997).

Additionally, the assessment also collects information on health state values using a visual analogue rating scale, with end points of “best imaginable health state” to “worst imaginable health state”. The scale has numeric values of 100 and 0 respectively.

- **Post Traumatic Growth Inventory (PTGI: (Tedeschi & Calhoun, 1996).**

The PTGI is a 21 item self-report questionnaire, that comprises three domains (Changed Perception of Self, Changed Interpersonal Relationships, and Changed Philosophy of Life), and five factors (Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life). The items are scored on a five point Likert scale from zero to five. The scores can be collated in to a unitary dimension, which fits with literature suggesting that that PTG can be assessed as a unitary entity (Joseph, et al. 2012; Tedeschi & Calhoun, 1996). In the present study total scores were used and could range between zero and 105. The measure has shown high internal consistency (Chronbach’s $\alpha = .92$; Gangstad, et al., 2009) with a sample of stroke survivors, and adequate test–retest reliability in the general population ($r = 0.71$; Tedeschi & Calhoun, 1996).

2.6.2 Process Measures

These measures were used to explore the psychological variables that are targeted by ACT and are the hypothesised mediators of change. In the ACT literature, the wanted outcome is increased participation in valued behaviours and an increase in psychological flexibility. As ACT is yet to be effectively used with stroke survivors, no validated measures currently exist for this population. As a result the researcher chose measures which have been used in previous ACT studies, that attempt to capture psychological flexibility (i.e. the AAQ-II) and one's thinking about goal-directed activities (i.e. the ASHS). Both of these measures were validated on student populations.

- **The Acceptance and Action Questionnaire–II (AAQ-II: (Bond, et al., 2011)**

The AAQ-II is a 10-item self-report questionnaire that measures psychological flexibility or acceptance. Each item is scored on a 7-point Likert scale ranging from “never true” to

“always true”. The items are then summed leaving scores which range from 0 to 70. Each item provides a statement concerning experiential avoidance and psychological inflexibility. The reliability and validity of this assessment have been demonstrated across a number of samples (Chronbach’s α ranging from 0.78 to 0.88; Bond *et al.*, 2011) as well as good test-retest reliability data ($r = 0.81$ at three months; Bond *et al.* 2011).

- **Adult State Hope Scale (Snyder, et al., 1996)**

The ASHS is a six item self-report questionnaire which measures goal-directed thinking. All items are scored from one to eight, from definitely false to definitely true, respectively. All items relate to one of two measures of components: agency - which taps in to the participants’ capacity for initiating and maintaining the actions necessary to reach a goal, and pathways - which taps in to the participants’ perceived ability to generate routes to one's goals. The two components are summed to create a total score ranging from zero to 48. The questionnaire is internally consistent (Chronbach’s α ranging from 0.82 to a high 0.95; (Snyder, et al., 1996), and shows good validity, and good test-retest reliability ($r = 0.80$ range over a ten week period).

2.6.3 A post-treatment focus group

A one-hour, audiotaped, post treatment focus group was additionally developed. The focus group used a framework of open-ended semi-structured questions to loosely guide some of the discussions. It was decided that these questions were going to be used flexibly, with certain questions being replaced or adapted as the focus group took place. Willig (2008) describes that this approach allows participants to expand on ideas that are pertinent to them, allowing them to guide and shape the direction of the discussions. The wording of the questions were reviewed by two volunteer stroke survivors and adapted as necessary.

All three group facilitators attended the focus group and their roles were to assist the participants to feel at ease, to share experiences, and ensure that everyone had the opportunity to speak. Whilst, the facilitators deliberately avoided giving interpretations,

they did sometimes reflect back what the participants were saying to explore key themes further.

The focus group took place in the same location as where the ACTION after Stroke group was held. A total of eight participants attended the third and also final session. Of these, seven attended the focus group. The room was organised in a circle, so people could see each other. The conversations were recorded using an electronic Dictaphone and transcribed.

2.7 Data Analysis

The analyses presented in the following chapter are based on all of the participants who provided data at the three time points (pre-intervention (T1), post-intervention (T2), and follow-up (T3)). A flow chart of the participants through the study is provided in figure six. Participants who did not receive the intervention, or complete post or follow-up data were omitted from the statistical analyses. All data analysis was completed using SPSS version 20 (IBM Corporation 2011).

2.7.1 Quantitative

2.7.1.1 *Screening the data*

Prior to conducting the analysis, the data was screened in a sequence that is recommended by Tabachnick and Fidell (1989). The aim of the screening was to detect data peculiarities, to assess the appropriateness of each data set, and to ensure that the data met the assumptions relevant to the subsequent analyses. Minimum and maximum values for each variable were computed, thereby identifying any errors created when inputting the data. Next the missing data was addressed. Fortunately, this was quite sparse and as the responses were all in the form of interval data (i.e. Likert-scale responses), it was possible to impute the missing data points by replacing them with the mean for the individual for that particular variable.

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2.7.1.1.1 Normality

The assumption of normality prescribes that the distribution of the data fits the pattern of a normal curve (Field, 2013). The total score for each variable, at each time point, was screened for normality and linearity. The skewness and kurtosis values were calculated, and histograms were plotted and screened. Shapiro-wilk stats were additionally used to reject null hypothesis that the data is normally distributed.

2.7.1.1.2 Outliers

An outlier is considered to be a data point that is far outside the norm for a variable (Jarrell, 1994). Outliers increase error variance, can pull the mean away from the median, and can decrease normality. Hence, in order to detect any outliers, boxplots were created for the total scores on each of the individual variables. Outliers that appeared at the extremes were transformed by replacing them with the next highest/lowest non-outlier (Osborne, 2002).

2.7.1.1.3 Homoscedasticity

Homoscedasticity refers to the assumption that the dependent variables exhibit similar amounts of variance across the range of values for the independent variables (Field, 2013). Levene's test for homogeneity of variance was used to assess whether this assumption had been met. A scatter plot with the variable on the x-axis and the variable's residual on the y-axis was also drawn.

2.7.1.1.4 Assessing the bivariate relationships

Bivariate relationships between demographic characteristics and the main study variables were assessed to identify possible confounders that would need to be controlled for in subsequent analyses. Pearson's r correlation coefficients were used to investigate the relationship between age, the age of leaving school, the time passed since the stroke occurred, how many strokes they had, and each of the main study variables at each time point.

2.7.1.2 *Analysing the screened data*

2.7.1.2.1 Initial analyses.

Chi square (χ^2) tests, or independent samples t-tests were used to compare the demographic and clinical characteristics of the stroke survivors and carers in the ACT group, compared to those in the waiting list control group.

In addition, using the recode command in SPSS, the data was transformed so that the HADS scores were recoded into “normal” (scores up to 7), “mild” (scores 8-11), “moderate” (12-14) and “severe” (scores 15+). Such re-coding produced four groups rather than the original groupings (one for each separate score). This was later analysed separately. The index scores for the EQ-5D were also calculated and used as the principal value for quality of life.

2.7.1.2.2 Treatment evaluation

Initially a 3 (the three scores at each time point) x 2 (the two groups) factorial repeated-measures ANOVA design was going to be completed. In this model, the within-subject dependent (criterion) variables were the scores on the outcome measures at each time point (pre-intervention -T1, post-intervention, T2, and at follow-up – T3), and the group variable (e.g., ACT intervention vs. waiting list control) was the between-subjects factor. However, it was discovered that there were significant differences on clinical characteristics between the groups at baseline. This non-equivalence could affect the statistical analyses and hamper interpretation of this analysis. As a result the researcher considered two alternative analyses that could control for this pre-intervention difference.

The first and chosen analysis which is presented in the following chapter (Chapter 3 – Results) describes the results that have been observed from linear regression analyses. This approach analyses the effect of continuous and categorical variables on a continuous outcome and has been used in other controlled trials of complex interventions (Lincoln et

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al., 2011), including a recent randomised controlled trial of behavioural therapy for stroke survivors (Thomas, et al., 2013). For each regression model, the group allocation (ACT or waiting list control group) was entered as the independent variable, and the post and then follow-up outcome variables (separately) were entered in the first block, and then adding in the baseline values of the outcome variables in the second block (to control for the pre-existing differences at baseline). An independent statistician in the local NHS clinical trials unit was then contacted and reviewed this alternative analysis and concurred that this was an appropriate analysis.

Following on from the regression analyses, the ACT intervention group and the waiting list control group were also compared using area under the curve to analyse the differences over time (Matthews, Altman, Campbell, & Royston, 1990). The area under the curve was computed using the following formula: $AUC = ((\text{time2} - \text{time1}) \times (\text{measure2} + \text{measure 1}) / 2) + ((\text{time3} - \text{time2}) \times (\text{measure3} + \text{measure 2}) / 2)$. The area under the curve therefore uses all of the repeated measurements of the outcome variables to produce a single measure, which were then compared between groups. A univariate analysis of covariance (ANCOVA) was used to test for this between group effects whilst controlling for pre-intervention level by entering it as a covariate. A significance level of 0.05 was used for all analyses. In addition, the effect size was calculated by calculating a Cohen's d effect size (Sullivan & Feinn, 2012).

The alternative approach considered, was to use the *change* scores between T1 and T2, and T1 and T3 for each outcome variable, and then using a multivariate analysis (MANOVA) to compare the group differences at T2 and T3 (the results of this analysis can be found in Appendix L for further interest – the same pattern of significant and non-significant outcomes were found).

Whilst the statistical comparison of between group differences is useful for summarising how the group means differ, this method is less clinically useful, as it does not assess

whether the ACT group assisted individuals to change from clinically significant levels of anxiety and depression (caseness) to normal levels (non-caseness). As a result, exploratory analyses were run to look at the net positive gain change on the primary outcome measure (the HADS), for each stroke survivor and carer separately.

2.7.1.3 Mediation analyses

As described in Chapter one, mediation analyses are often conducted when it is hypothesised that a significant amount of the variance in the relationship between the independent variables and dependent variables are explained by another variable. These intervening variables are the mediators (M), in this case psychological flexibility (assessed by the AAQ-II) and goal directed thinking (assessed by the ASHS). These variables are seen to potentially mediate the relationships between the groups allocation (the predictor, or X), and the scores on the HADS, PTGI, and EQ-5D (the outcome variables, or Y).

In a mediation model the effect of variable X on Y can be partitioned into two parts. Firstly, the direct effect of the group (X) on the outcome variables (Y) – path ‘c’ described in figure four.

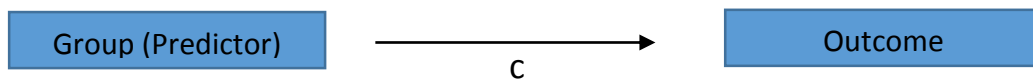


Figure 4 Direct effect of Group on Outcome

Secondly, the indirect effect of the group on the outcome variables, via the mediators (M). This is illustrated pictorially in figure five below. In this figure line ‘a’ illustrates that the predictor’s (group) effect on the process measures (i.e. presumed mediators - psychological flexibility and goal directed thinking), and path ‘b’ illustrates the mediators effect on the outcome (psychological distress, quality of life and post-traumatic growth). Line ‘c’ illustrates the relationship between the predictor and the outcomes. However, this time the relationship between the predictor and the outcome will be different as the mediator is

included in the model (Baron & Kenny, 1986). In other words, 'a' is predicting 'M' from 'X', and 'b' is predicting 'Y' from 'M'. The product of 'a' and 'b' quantifies the indirect effect of 'X' on 'Y' through 'M'. Whilst 'c' represents the direct effect, whilst controlling for 'a' and 'b'. The total mediation effects represents the difference between the total and direct effect of X (e.g. $ab = c - c'$).

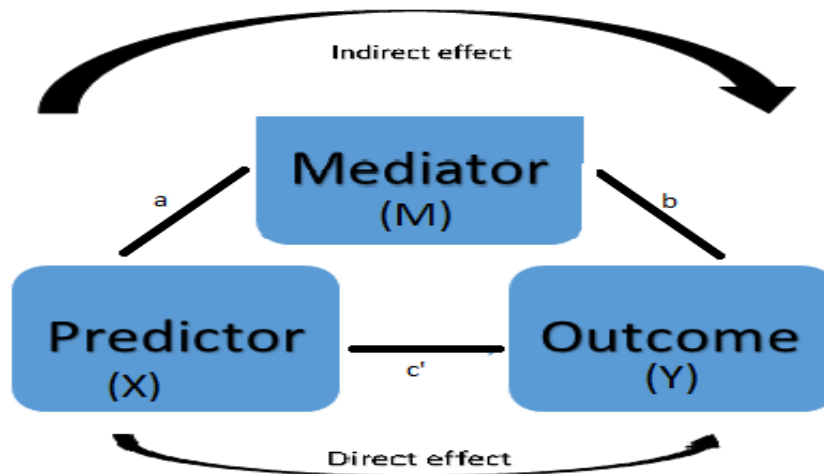


Figure 5 Mediation analysis - depicting direct and indirect effect

Traditionally, mediation has been assessed using the “causal steps approach” (Baron & Kenny, 1986). This involves completing a two-step hierarchical regression; first, testing the relationship between the independent and dependent variable; and then adding the proposed mediator to the model. Using this approach a mediation effect is indicated if both 'a' and 'b' paths are statistically significant and the relationship between X and Y becomes statistically less significant when 'M' is added to the model (Baron & Kenny, 1986). However, this approach has been criticised for lacking power (Fritz & Mackinnon, 2007; Mackinnon et al., 2002) and failing to directly test for mediation (Hayes, 2009). A non-parametric bootstrap approach which tests the significance of the 'a' and 'b' paths through the cross-product of the coefficients has been developed, and this approach is increasingly recognised as the best available test of mediation (MacKinnon et al. 2002; Preacher & Hayes, 2004, 2008). The non-parametric bootstrapping approach directly assesses the significance of the indirect (mediating) effect, and is stated to be particularly suited to

smaller data sets (Preacher & Hayes, 2004). It generates a bias-corrected 95% bootstrap confidence interval for the indirect effect using 10,000 bootstrap samples. This PROCESS tool is available from: <http://www.afhayes.com/spssas-and-mplus-macros-and-code.html>.

Empirical representations of the sampling distribution of the indirect effect are obtained through bootstrapping, where k “mimic” samples are obtained by repeatedly resampling the original sample with replacement. Once a sample size equivalent to the original n is sampled, ‘a’ and ‘b’ are estimated in the resampled dataset. The process is repeated ‘k’ times, with ‘a’ and ‘b’ coefficients recorded in each sample. In this study, 10,000 bootstrap samples (k) were generated.

2.7.2 Qualitative

Qualitative analytic methods are incredibly diverse and nuanced in their approaches (Holloway & Todres, 2003). Braun and Clarke (2006) argue that this means that researchers must be clear in describing how they went about analysing their data, and what assumptions informed their analyses. Hence, this section is aimed at providing clarity around the processes and practices undertaken for analysing the focus group material.

2.7.2.1 Choice of qualitative analysis

Braun and Clarke (2006) argue that in general qualitative approaches can be roughly divided into two camps. Firstly, there are those associated with specific theoretical or epistemological positions (e.g., interpretative phenomenological analysis (IPA), grounded theory, narrative analysis etc.). Secondly, there are those that can be applied *across* a range of theoretical and epistemological approaches.

The choice of analysis used within the present thesis was guided by the researcher wanting to adopt an approach which could analyse and report the stroke survivors and carers experiences of the ACTion after Stroke group as they were offered within the focus group. It

was intended to provide a rich description of the discussions shared, so that a deeper understanding of the group could be developed.

2.7.2.2 *Thematic analysis*

Thematic analysis is concerned with identifying, examining, and recording implicit and explicit ideas within data (Guest, 2012). It is hence considered a useful method that offers rich descriptions and meanings of data (Guest, 2012). Braun and Clarke (2006) argue that it is hence a research tool that strongly reflects the reality of the data provided (given that it is conducted in an appropriate way), and it holds the flexibility to adopt many epistemology paradigms.

The aim of the focus group led the researcher to an essentialist / realist method, where a unidirectional relationship is assumed between meaning, experience and language (i.e language reflects meaning and experience; Potter & Wetherell, 1987, cited in Braun & Clarke, 2006), as opposed to constructionist method, which would instead assume that experiences and meanings are an effect of a range of discourses operating within society. The realist method is more in keeping with the methodology adopted in the quantitative analysis. However, Braun and Clarke (2006) eloquently highlight that researchers cannot free themselves of their theoretical and epistemological commitments, and hence argue that data is not coded in an epistemological vacuum.

2.7.2.2.1 *Identifying themes*

Themes or patterns within data can be identified in one of two primary ways in thematic analysis: in an inductive or “bottom up” way, where the assumptions are data driven (Goddard & Melville, 2004), or in a theoretical or deductive or “top down” way, where the data is theory driven and hence more focused on aspects of the data that were determined prior to data analysis (Goddard & Melville, 2004). There are also different levels at which themes can be identified: 1) semantically, where important themes from the entire data set are represented, and hence data is analysed from the explicit and surface meaning, and 2)

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latently, where themes identify underlying ideas, patterns and assumptions based on specific areas of interest across the data (Boyatzis, 1998).

As can be gathered from the above descriptions, the researcher adopted an inductive approach, so that the themes created were strongly linked to the data itself, and the themes were generated using a latent approach that considered the material through the lens of ACT (i.e. only the themes relevant to the processes and principles of ACT were embodied and reported). Whilst there may be many other themes of general interest (e.g. regarding psychological reactions following stroke), these were not the focus of this research and were not elaborated within this analysis.

Some researchers (e.g. Boyatzis, 1998) argue that because of its flexible approach, thematic analysis it is not an approach in its own right, but rather can be considered a “tool” that is used across many qualitative analyses. Braun and Clarke (2006) in response argue, that it is very much an approach in its own right and have created a set of guidelines in the hope that thematic analyses can be applied in theoretically and methodologically robust ways. The following table describes these guidelines in the form of a checklist. The researcher has included a column to show how the current thesis meets these criteria.

Table 5 A 15-Point Checklist of Criteria for Good Thematic Analysis Provided by Braun and Clarke (2006).

| Process | No. | Criteria | How Criteria is met in the Current Study |
|---------------|-----|--|---|
| Transcription | 1 | The data has been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for “accuracy”. | The researcher listened to the recording soon after the focus group took place. This process was particularly helpful in getting a feel for the data. The data was then transcribed the day after the focus |

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| | | | group took place. All comments made throughout the two hour focus group were transcribed. The transcriptions were very detailed capturing features of timing, pauses, laughter, stutters etc. The tape was re-listened to on two separate occasions to ensure that all the details had been captured correctly. |
| Coding | 2 | Each data item has been given equal attention in the coding process. | Several copies of the transcripts were made. Different coloured pens were used to highlight data that was informative throughout the entire data set; this included single words such as <i>“isolated”</i> , sentences <i>“that I was just desperately trying to get back to how I was before”</i> and phrases <i>“Yes you don’t feel quite so swamped with all your emotions and nobody cares, nobody understands, all that sort of road you tend to go down from time to time, it can sort of draw you back into almost feeling that you’ve suddenly done something a bit more constructive as opposed to destructive”</i> . |
| | 3 | Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process | The researcher then began looking in detail at all of the highlighted data. Comments in the margins of each transcript were made to attempt to note what the participants were |

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| | | has been thorough, inclusive and comprehensive. | referring to for each sentence. Attempts were made to understand what the text is an example of. |
| | 4 | All relevant extracts for each theme have been collated. | The information was then cut up and sorted in to categories. Codes were developed ("codes" serving as labels for sections of data). This meant that some of the individual extracts of data were coded in several themes, depending on the categories. All the initial codes were then collated and sorted into broader potential themes. Some of the initial codes appeared to form a main theme (e.g. Feeling underprepared after hospital discharge), whereas others appeared to be sub-themes (e.g. "Longing for things to go back as they were", "Why me?" etc.) |
| | 5 | Themes have been checked against each other and back to the original data set. | The themes originally identified were revisited and each category was considered in light of the themes. |
| | 6 | Themes are internally coherent, consistent, and distinctive. | Broad themes were developed last as a result of the above steps. Descriptions for each themes were developed and amended. Data extracts which gave good illustrations were written up (and are provided below). |
| Analysis | 7 | Data have been analysed – | Broader levels of themes, involved |

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| | | interpreted, made sense of - rather than just paraphrased or described. | sorting the different codes into potential themes, which are described descriptively before presenting extracts. Additionally, a summary of the themes is presented. |
| | 8 | Analysis and data match each other – the extracts illustrate the analytic claims. | Extracts of data that have been coded in the analysis are provided in the write-up in Chapter three to allow for assessment. |
| | 9 | Analysis tells a convincing and well-organised story about the data and topic. | The way in which the themes, and sub-themes were developed are described in chronological manner starting with a description of early post stroke experiences, followed by subsequent social implications and ongoing psychological reactions. The positive impacts of the group follow, before future hopes are shared. |
| | 10 | A good balance between analytic narrative and illustrative extracts is provided. | A narrative of the overall theme is described in Chapter three, followed by relevant extracts so that the extracts can be scrutinised by the markers. At least two extracts are used so that the data can be accessed more. |
| Overall | 11 | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly. | The transcription took place early. This has allowed several weeks for the data to be carefully analysed. Following completion of the final analysis, the researcher has re-looked at the data on a further two occasions, and once more following her writing the |

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| | | | discussion. No amendments were made at this stage. |
| Written report | 12 | The assumptions about, and specific approach to, thematic analysis are clearly explicated. | This is provided above in section 2.1.2.2. Additionally, a description at the start of each theme in Chapter three gives further information. |
| | 13 | There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent. | All versions of the transcriptions from the scribbling down of initial ideas, to highlighted sheets, to final codes and matched quotations are available on request. |
| | 14 | The language and concepts used in the report are consistent with the epistemological position of the analysis. | The language and concept follows that seen in a “realist” epistemological stance. As often as possible the stroke survivors and carers words are used to describe each theme and subtheme. |
| | 15 | The researcher is positioned as <i>active</i> in the research process; themes do not just “emerge”. | In order to situate herself, the researcher described her own position in the section following this table (section 2.7.2.2.2). This is in-keeping with the guidelines produced by Elliot, Fischer & Rennie (1999) to improve the reliability and validity, and ensuring the methodological quality within qualitative research. |

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2.7.2.2.2 Owning ones perspective

It has been highlighted in the above table and additionally by Elliot et al. (1999) how it is important that as well as applying a method to data analysis, researchers need to make their epistemological and other assumptions explicit. It is noted that researchers cannot free themselves of their values (Porter, 1993), and so whilst it is expected that researchers make efforts to put aside their own values to describe the data as objectively as possible, it is hoped that their value base is also made apparent. The researcher used the “Ten Tips for Reflexive Bracketing” created by Ahern (1999), to provide an honest account of her own values and interests, which might impinge upon the research. This will hopefully assist the examiners to assess the validity of the material presented.

The researcher is a 27 year old, white, welsh female. The researcher has a working class background, and she grew up in the South Wales valleys, with her biological parents, and younger sister. The researcher moved away from her home town whilst studying her undergraduate degree, and has since moved across the UK for her assistant psychology posts. The researcher has now bought a house with her husband back in the Welsh valleys.

The researcher has worked in the NHS since 2009, and has delivered psychological therapy in all of her posts. The majority of her pre-training experience was working with adults with neurological impairment. Of particular relevance, she spent two years working in a community brain injury service. Many of the service users that she worked with had experienced a stroke. She was deeply moved by some of the very powerful ways that the lives of the service users and their families had changed following a stroke. She was struck by the resilience that many of these individuals conveyed, but also the way in which so many people became “stuck”.

The researcher moved back to south Wales to begin her training in Clinical Psychology. She was saddened by the lack of psychological support available for many of the people who had sustained a stroke. Many of the service users were referred in to third sector organisations for ongoing therapy, yet many of these organisations did not have access to

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Clinical Psychology, nor did they feel they had the expertise to engage the service users in any psychological intervention.

To contextualise the researchers position further, the researcher is currently working in a trauma informed mental health service. The majority of her work is working with adults who have experienced severe forms of trauma during childhood. In this line of work, the researcher often uses compassion focused therapy, of which mindfulness is large component (Gilbert, 2010). The researcher is always keen to explore with the service users “why” interventions are helpful.

Undoubtedly, it is these experiences that guided the researcher in to this area of interest for her doctoral thesis. The researcher wanted to explore whether this form of intervention may plug the gap between receiving no psychological support to some. It was important for the researcher to hold this in mind when analysing the data. The researcher attempted to keep an open, objective, and critical approach to the research.

Chapter 3 Results

3.1 Chapter Overview

This chapter presents the results of both the quantitative and qualitative analyses. The chapter begins with a portrayal of the flow of participants through the study, and provides a description of the demographic information obtained. Comparisons of the variables at baseline (i.e. pre-intervention, T1) between the ACT intervention group vs. the waiting list control group are then provided. The differences in both the outcome and process measures between the groups over time are then analysed before the mediation analyses are conducted. Following this, the global themes and overall thematic maps obtained via a thematic analysis from the focus group is outlined.

3.2 Participant information

3.2.1 Flow of participants through the study

Sixty-nine participants were invited to attend the ACTion after Stroke group. Thirty-one of these were assigned to the intervention group, and the other 38 were added to a waiting list. As described in Chapter two, assignment was based purely on the order in which the participants self-referred. Two stroke survivors assigned to the ACT group did not meet the inclusion criteria for the study due to their level of dysphasia, and three chose not to take part. Of the 38 assigned to the waiting list, two stroke survivors did not meet the inclusion criteria, and a further four declined the invitation to take part. From the total remaining, 57 stroke survivors and carers completed the pre-intervention questionnaires (T1). Twenty-five of these attended the ACTion after Stroke group, and the remaining 32 made up the waiting list control group.

3.2.2 Attrition

As can be seen from Figure 6 below, 100% of the participants assigned to the ACT group completed the group. One participant decided to not complete the post-intervention questionnaires, and a further three did not return the follow-up questionnaires. They were

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subsequently removed from any further analyses. Additionally, two participants assigned to the waiting list did not return their T2 questionnaires, one gentleman sadly passed away, and a further two did not return their T3 questionnaires. These participants are also excluded from subsequent analyses.

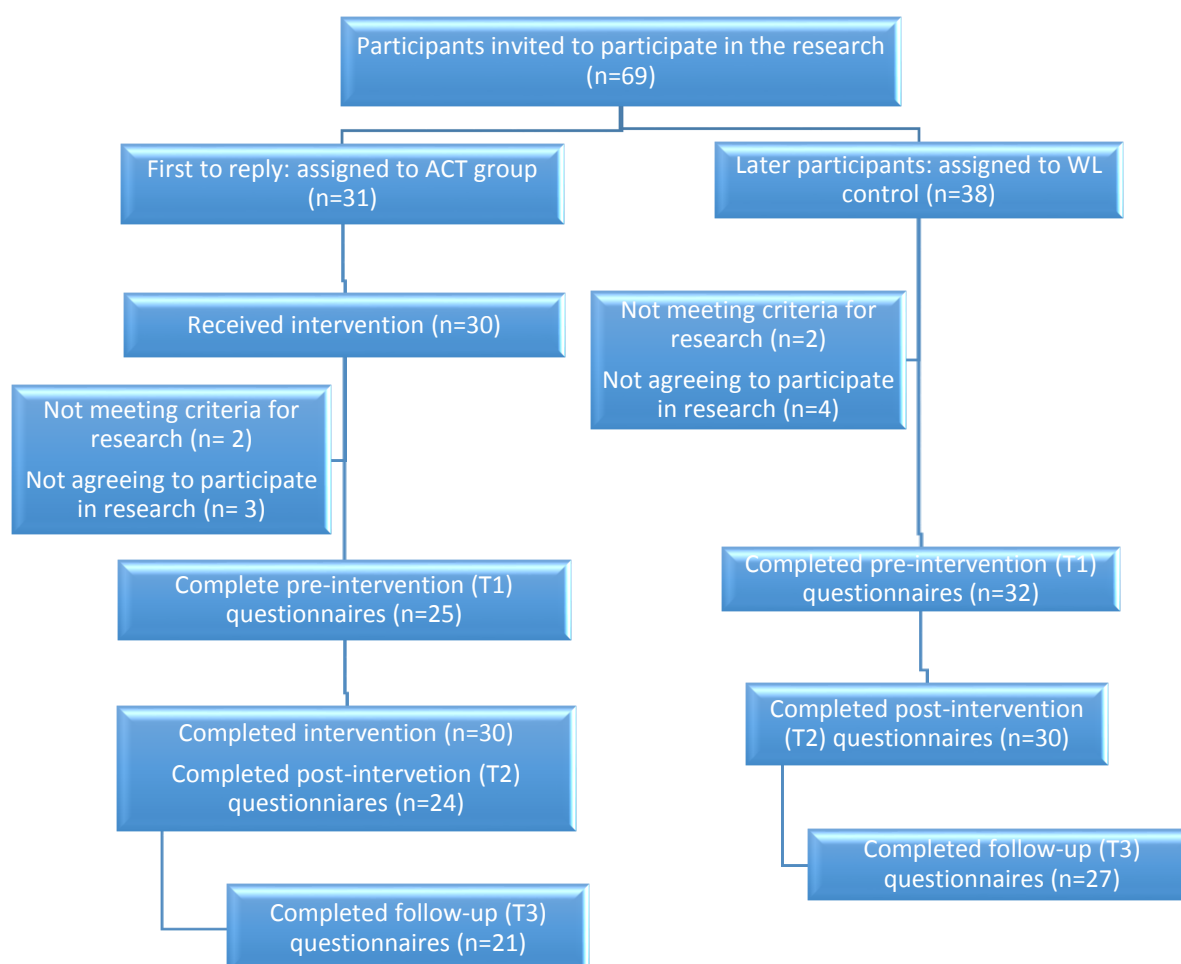


Figure 6 Flow of participants through the study

3.2.3 Participant Characteristics

Forty-eight adults ranging between 28 and 88 years old, living in Bristol, United Kingdom, hence completed the research. Seventy-five per cent of the sample consisted of stroke survivors, the majority of whom sustained their strokes between one and two years before taking part in the study. Of the 15 carers who took part, all of them were spouses to the stroke survivors. The sample as a whole were of mixed gender (54% were female) and most

were retired or unemployed. Despite efforts to capture the location and type of stroke endured by the survivors, over 70% did not know where their stroke had occurred, and even less knew the type of stroke they had experienced. Table 6 summarises the demographic data for the stroke survivors and carers.

3.2.3.1 Group comparability on demographic variables

Given the non-randomised assignment of participants to either the waiting list or the intervention group, it was important to examine the comparability of the groups at baseline. No significant differences were found between the groups with regard to age, gender, time since stroke, or the amount of strokes sustained per individual ($p > 0.05$). For ease of reading the time since stroke, and how many strokes each individual had experienced, are provided in the form of ordinal data. However, this information was collected as continuous variables, and were analysed as such. Other factors assessed were years in full-time education, qualifications obtained, and current employment status. Again there were no significant differences found ($p > 0.05$). However, a significant difference was found for current living circumstances, $\chi^2 (N = 48) = 5.83, p = 0.02$, where significantly more of the ACT group participants were living with a carer, as opposed to alone.

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Table 6 Participant Demographics

| | ACT (N=21) | Waiting List (N=27) | P-value (two-tailed) |
|------------------------------------|---------------|------------------------|---|
| Stroke survivor (%) | 13 (61.9%) | 23 (85.2%) | $\chi^2 (1) = 3.41,$ $p = 0.07$ |
| Mean Age (SD) | 61.43 (13.16) | 59.85 (12.61) | $t (46) = 0.42,$ $p = 0.68$ |
| Number of female (%) | 14 (66.6%) | 12 (44.4%) | $\chi^2 (1) = 2.35,$ $p = 0.13$ |
| Mean Age of Leaving Education (SD) | 18.14 (3.19) | 17.48 (2.53) | $t (46) = 0.80,$ $p = 0.43$ |
| Highest Qualification Obtained (%) | | | |
| <i>O level / GCSE</i> | 11 (52.4) | 14 (51.9) | $\chi^2 (1) = 2.79,$ $p = 0.73$ |
| <i>A level</i> | 1 (4.8) | 4 (14.8) | |
| <i>Degree</i> | 7 (33.3) | 6 (22.2) | |
| <i>Apprenticeship</i> | 1 (4.8) | 2 (7.4) | |
| <i>Post Grad</i> | 1 (4.8) | 1 (3.7) | |
| Employment Status | | | |
| <i>Employed</i> | 5 (23.8) | 8 (29.6) | $\chi^2 (1) = 0.20$ $p=0.65$ |
| <i>Retired / Unemployed</i> | 16 (76.2) | 19 (70.4) | |
| Living Circumstances | | | |
| <i>Living alone</i> | 2 (9.5) | 11 (40.7) | $\chi^2 (1) = 5.83,$ $p= 0.02$ |
| <i>Living with family</i> | 19 (90.5) | 16 (59.3) | |
| <u>Stroke (N = 42)</u> | | | |
| Time since most recent stroke (%) | | | |
| <3 months | 1 (3.7) | 0 | $t (34) = 0.06,$ $p = 0.96$ (calculated on the interval data) |
| <6 months | 0 | 4 (14.8) | |
| <1 year | 0 | 2 (7.4) | |
| <2 years | 5 (18.5) | 5 (18.5) | |
| <3 years | 2 (7.4) | 1 (3.7) | |
| >3 years | 3 (11.1) | 10 (37) | |
| Mean time (SD) | 4.60 (6.32) | 4.48 (4.72) | |
| How many Strokes (SD) | | | |
| 1 | 11 (40.7) | 18 (66.7) | $t (34) = -0.15, p =$ 0.43 (calculated on the interval data) |
| 2 | 1 (3.7) | 4 (14.8) | |
| 3 | 1 (3.7) | 1 (3.7) | |
| >3 | 0 | 0 | |

3.3 Assumptions for parametric statistics

As described in Chapter two, all of the data was assessed to ensure that all variables met the assumptions for subsequent parametric testing. The following variables were assessed: Hospital Anxiety and Depression Scale (HADS) total scores at each time frame (pre-intervention - T1, post-intervention – T2, and at follow-up – T3); Post Traumatic Growth Inventory (PTGI) total scores at each time frame; the Euro Quality of Life – 5D (EQ-5D) index scores at each time frame; the Adult State Hope Scale (ASHS) total scores at each time frame; and the Acceptance and Action Questionnaire – second edition (AAQ-II) total scores at each time frame. Following the computation of the area under the curve measurements, these new variables were also assessed.

3.3.1 Missing data

Of the all the questionnaires received, missing data accounted for only 1.2% of the total data set for both groups. Separately, the missing data accounted for 1.7% of the data in the intervention group compared to only 0.8% in the comparison group. Not one person had more than 8 missing data points across all time frames (from a possible 171). All missing data points were replaced by the mean for the individual, for that particular variable. There was no pattern to the missing data.

3.3.2 Outliers

An inspection of the boxplots created for the total scores identified nine outliers across both groups and across the three time intervals. Utilisation of an outlier labelling technique (Hoaglin & Iglewicz, 1987), a formula that operates on the upper and lower quartiles of each variable at each time frame, multiplied by the factor ‘g’, was calculated in an excel database, and used to consider whether the outlier represented a genuine score at the extreme end of a normal distribution, or if it was a genuine outlier that required replacing. When using this technique, only one data point was transformed using the next nearest data point within the normal distribution.

3.3.3 Normality

The total scores for each variable, for both groups, had standardised skewness and kurtosis statistics within the range of -1.96 and 1.96 (Doane & Seward, 2011). Hence, it was possible to conclude that the data was a little skewed and kurtotic, but it did not differ significantly from normality. Shapiro-Wilk tests showed all of the variables had p-values above 0.05, so it was possible to reject the null hypothesis for this test of normality, which is that the data *are* normally distributed. A visual inspection of the histograms, normal Q-Q plots and box plots also indicated that the variables were approximately normally distributed for both groups.

3.3.4 Homogeneity of variance

Levene's test for equal variance (homogeneity of variance) verified the assumption of homogeneity of variance had been met for the all of the outcome variables involved in group comparisons at each time frame ($p > 0.05$).

3.3.5 Group Comparability on test variables

The means, standard deviations, and ranges for all of the test variables at baseline (T1) for both groups are summarised in table 7 below. Independent sample t-tests were conducted to compare the group scores. A significant difference was found on the HADS total score (HADS-T: ACT $M = 11.95$ vs. waiting list $M = 16.91$, $t(48) = -2.19$, $p = 0.03$). Exploratory analyses found that the groups were significantly different on levels of depression (HADS-D: ACT $M = 4.8$ vs. waiting list $M = 7.62$, $t(48) = -2.53$, $p = 0.01$), but not anxiety. Significant differences were also found on the measure of psychological flexibility (AAQ-II: ACT $M = 49.50$ vs. waiting list $M = 43.19$, $t(48) = -2.14$, $p = 0.04$). This pre-existing difference in key outcome variables are discussed in Chapter four (Discussion) and are likely to be due to the non-random assignment of participants to the groups.

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Table 7 Comparison of baseline scores

| | ACT (N=21) | | Waiting List (N=27) | | P-value (two-tailed) |
|------------------|---------------|-------|------------------------|-------|---------------------------|
| | Mean | SD | Mean | SD | |
| HADS total score | 11.95 | 8.04 | 16.91 | 7.61 | t (46) = -2.19, p = 0.03 |
| HADS – A | 7.0 | 4.61 | 9.17 | 4.60 | t (46) = -1.63, p = 0.11 |
| HADS - D | 4.80 | 4.19 | 7.62 | 3.40 | t (46) = -2.53, p = 0.02 |
| PTGI | 57.86 | 16.56 | 58.18 | 15.26 | t (46) = -0.70, p = 0.945 |
| EQ-5D | | | | | |
| EQ Index | 0.79 | | 0.76 | | t (46) = 1.09, p = 0.28 |
| EQ Scale | 70.71 | 25.21 | 58.52 | 17.96 | t (46) = 1.96, p = 0.07 |
| AAQ-II | 49.50 | 9.80 | 43.19 | 10.36 | t (46) = -2.14, p = 0.04 |
| ASHS | 29.61 | 13.57 | 26.70 | 10.97 | t (46) = 0.07, p = 0.42 |

The severity of anxiety and depression provided by the standardised cut-offs on the HADS were also compared (see table 8). Similarly to the raw scores, between group differences were found on the classifications of depression, $\chi^2 = 6.73$, $p = 0.04$, where significantly more of the comparison group fell in the category outside of the normal range compared to those in the ACT intervention group. However, no statistical difference was found for anxiety, $\chi^2 = 2.72$, $p = 0.44$.

Table 8 Number of participants meeting the standardised cut offs provided by the HADS at baseline

| | ACT (N=21) | | Waiting List (N= 27) | |
|------------------|------------|-----------|----------------------|-----------|
| | HADS-A | HADS-D | HADS-A | HADS-D |
| Severe (15+) | 0 | 0 | 3 | 0 |
| Moderate (12-14) | 5 | 2 | 7 | 3 |
| Mild (8-11) | 5 | 3 | 6 | 13 |
| Normal (0-7) | 11 | 16 | 11 | 11 |

3.3.5.1.1 Bivariate Correlations

Pearson r correlations between the main study variables and demographic variables (age, gender, years in education, time since stroke, how many strokes and employment status) were investigated to identify potential confounding variables. The demographic variables did not correlate with any of the outcome or process variables, with the exception of the PTGI, which significantly correlated with time since stroke at each time point (at pre-intervention, $p = 0.00$, post-intervention, $p = 0.01$, and follow-up, $p = 0.01$, two-tailed). Since these variables did not show correlations with any of the pairs of variables involved in the hypotheses, it is implausible that they could act as confounding variables in determining relationships.

Pearson r correlations were then performed on each of the outcome and process variables at each time point. As expected each of the outcome variables correlated significantly with the same variable across each time point. However, there were additional significant correlations. For example, both the HADS and the EQ-5D correlated with the process variables, across each of the three time frames (see table 9 below). This is discussed in following chapter.

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Table 9 Bivariate correlations between measures at the three separate time frames

| | T1 PTGI | T1 HADS | T1 AAQ | T1 ASHS | T1 EQ | T2 PTGI | T2 HADS | T2 AAQ | T2 ASHS | T2 EQ | T3 PTGI | T3 HADS | T3 AAQ | T3 ASHS | T3 EQ |
|------------|----------------|-----------------|-----------------|-----------------|-----------------|---------------|-----------------|----------------|------------|-------|------------|------------|-----------|------------|----------|
| T1 PTGI | | | | | | | | | | | | | | | |
| T1 HADS | .178 .226 | | | | | | | | | | | | | | |
| T1 AAQ | -.158 .283 | -.758** .000 | | | | | | | | | | | | | |
| T1 ASHS | .007 .962 | -.583** .000 | .628** .000 | | | | | | | | | | | | |
| T1 EQ | .236 .106 | -.475* .001 | .404** .004 | -.421** .003 | | | | | | | | | | | |
| T2 PTGI | .746** .000 | .085 .564 | -.042 .776 | .232 .113 | -.018 .903 | | | | | | | | | | |
| T2 HADS | .114 .440 | .877** .000 | -.604** .000 | -.467** .001 | -.474** .001 | -.021 .888 | | | | | | | | | |
| T2 AAQ | -.232 .112 | -.712** .000 | .697** .000 | .516** .000 | .394** .006 | -.086 .562 | -.697** .000 | | | | | | | | |
| T2 ASHS | -.67 .652 | -.594** .000 | .582** .000 | .855** .000 | -.401* .006 | .214 .143 | -.593** .000 | .568** .000 | | | | | | | |

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|------------|----------------|-----------------|-----------------|-----------------|-----------------|----------------|-----------------|-----------------|-----------------|----------------|---------------|-----------------|----------------|----------------|--|
| T2 EQ | -.366 .051 | -.399** .005 | -.331* .023 | -.354* .015 | .867** .000 | .105 .482 | -.433** .002 | -.379** .009 | -.445** .002 | | | | | | |
| T3 PTGI | .689** .000 | .117 .427 | -.128 .386 | .202 .170 | -.022 .880 | .753** .000 | .019 .899 | -.056 .703 | .184 .211 | .098 .507 | | | | | |
| T3 HADS | .199 .176 | .849** .000 | -.670** .000 | -.508** .000 | -.509** .000 | .014 .926 | .922** .000 | -.609 .000 | -.655** .000 | .416** .003 | .039 .793 | | | | |
| T3 AAQ | -.260 .074 | -.687** .000 | .708** .000 | .500** .000 | .388** .006 | -.193 .190 | .644** .000 | .846** .000 | .593** .000 | -.352* .014 | -.094 .524 | .686** .000 | | | |
| T3 ASHS | -.079 .594 | -.593** .000 | .545** .000 | .799** .000 | -.423** .003 | .170 .247 | -.608** .000 | .641** .000 | .912** .000 | -.318* .028 | .259 .076 | -.633** .000 | .644** .000 | | |
| T3 EQ | -.183 .213 | -.464** .001 | .342* .018 | -.388** .006 | .881** .000 | .022 .880 | -.475** .001 | .412** .004 | .385** .007 | .793** .000 | .078 .599 | -.438** .002 | .338* .019 | .465** .001 | |

3.4 Comparison with previously reported data

In order to contextualise the data, the mean scores on each outcome and process variable at baseline were compared with the data available from previous stroke studies, or samples with neurological conditions if stroke specific data was unattainable.

Mean HADS scores in the current study were compared with data from 104 stroke survivors in a screening study by Sagen (2009). The mean baseline total HADS score in the current population ($M = 14.75$, $SD = 8.11$), was significantly higher than that in the comparison study ($M = 7.9$, $SD = 2.9$; $t(150) = 7.64$, $p < 0.00$, two sided), as was the mean baseline anxiety score ($M = 8.23$, $SD = 4.69$ vs. $M = 4.4$, $SD = 5.2$; $t(150) = 4.35$, $p < 0.00$, two sided) and mean baseline depression score ($M = 6.42$, $SD = 3.98$ vs. $M = 3.6$, $SD = 4.3$; $t(150) = 3.85$, $p < 0.00$, two sided). The HADS-A was also completed by 88 survivors in a more recent study by Linley-Adams et al. (2014), and found a mean score of 5.64 ($SD = 4.68$), which again is significantly lower than the current sample ($t(134) = 3.08$, $p = 0.00$).

Likewise, when the EQ-5D index score, was compared to a group of 210 stroke survivors before they underwent a rehabilitation programme ($M = 0.53$, $SD = 0.37$), the current population differed significantly from the group on the main index score, but this time in a positive direction, showing significantly greater levels of health related quality of life ($M = 0.76$, $SD = 0.29$; $t(256) = 2.15$, $p = 0.03$).

The total baseline PTGI score was compared to data obtained from 60 stroke survivors in a study by Gangstad et al. (2009). In this study associations between post-traumatic growth, cognitive processing and psychological distress were assessed ($M = 50.93$, $SD = 19.92$). The current sample was not statistically different on levels of post-traumatic growth at baseline ($M = 57.52$, $SD = 16.83$; $t(106) = 1.83$, $p = 0.07$).

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Currently, there are no studies available to provide statistics for the AAQ-II with a stroke population. As a result, the current AAQ-II scores were compared with Nordin and Rorsman's (2012) muscular sclerosis population (N= 22, M= 44.5). As no standard deviation was provided, a simple comparison of means was computed on SPSS, and found the current sample (M = 45.95, SD = 10.52) was not significantly different from Nordin & Rorsman's sample ($t(1) = 18.80, p = 0.08$). Due to the small number of participants in this study, the current sample was also compared to those assessed in a study by Kortte, Veiel, Batten, & Wegener (2009). This study used the AAQ-II with 139 participants (M=27.65, SD=7.67) in a physical rehabilitation setting. Eighty-two of the participants had spinal cord dysfunction secondary to spinal cord injury, Guillian-Barré, or multiple sclerosis; 23 had experienced a stroke; 16 had amputations; and 18 had orthopaedic replacements. The current study had significantly higher levels of post-traumatic growth ($t(186) = 12.88, p < 0.001$).

The researcher could not find any studies that had used the ASHS with stroke survivors, and couldn't find any published data to compare the current group with adults with neurological conditions. As a result, the group was compared with 444 students in the original validation study by Snyder et al. (1996) (M= 37.15, SD= 6.33). The current sample (M= 27.98, SD=12.13) was statistically different ($t(490) = 8.51, p < 0.00$) showing lower scores on goal directed thinking. This may be expected given the differences in the samples.

3.5 Quantitative

To recapitulate, the primary hypotheses predicted that the stroke survivors and carers assigned to the ACT group would experience (a) greater improvements in psychological distress (b) greater improvements in quality of life and (c) higher levels of post-traumatic growth, at both immediate post-treatment assessment and two month follow-up, compared to those assigned to a waiting list. A further aim of the study was to investigate the role of possible mediators. Descriptive statistics for the outcome measures are shown in Table 10.

Results

Table 10 Descriptive statistics for the outcome variables at each time frame.

| | ACT (N=21) | | | Waiting List (N= 27) | | |
|-------------|------------|-----------|----------------|----------------------|-----------|----------------|
| | Pre (T1) | Post (T2) | Follow-up (T3) | Pre (T1) | Post (T2) | Follow-up (T3) |
| | Mean | Mean | Mean | Mean | Mean | Mean |
| | SD | SD | SD | SD | SD | SD |
| HADS-T | 11.95 | 10.05 | 9.43 | 16.92 | 16.41 | 16.39 |
| | 8.04 | 7.51 | 6.53 | 7.62 | 6.03 | 5.93 |
| PTGI | 56.67 | 59.79 | 59.52 | 68.16 | 63.22 | 61.56 |
| | 19.01 | 19.46 | 17.67 | 15.26 | 12.09 | 13.26 |
| EQ-5D index | 0.79 | 0.82 | 0.77 | 0.74 | 0.73 | 0.74 |
| | 0.15 | 0.16 | 0.15 | 0.13 | 0.12 | 0.13 |

3.5.1 Regression analyses

In order to test for the effect of the group condition (ACT intervention vs. waiting list control) on the outcome variables, regression analyses were completed with baseline values added as covariates. The results of the regression analyses are shown in Table 11. At post-intervention (T2), group allocation alone was a significant predictor of psychological distress and quality of life, but not for post-traumatic growth. When baseline values were controlled for, the effect of the group was again significant for psychological distress ($p = 0.01$), but no longer for quality of life ($p = 0.06$), and again was not significant for post-traumatic growth.

At two month follow-up (T3), group alone was again a significant predictor of psychological distress ($p = 0.00$), which again remained highly significant when controlling for baseline values ($p = 0.001$). However, there were no significant effects of group for post-traumatic growth or quality of life. As described, the same pattern of significant and non-significant outcomes were found in the difference score analysis, which can be found in appendix L.

Results

Table 11 Regression analysis of the outcome variables for the stroke survivors and carers across groups.

| | Post-intervention (T2) | | | | Follow-up (T3) | | | |
|--|------------------------|-------|----------------|------|----------------|-------|----------------|------|
| | B | Beta | 95% CI | P | B | Beta | 95% CI | P |
| HADS-Total score | | | | | | | | |
| Unadjusted difference | 6.37 | 0.43 | 2.55 to 10.19 | 0.00 | 6.96 | 0.49 | 3.43 to 10.49 | 0.00 |
| Difference adjusted for baseline HADS score | 2.66 | 0.18 | 0.64 to 4.68 | 0.01 | 3.64 | 0.26 | 1.62 to 5.66 | 0.00 |
| PTGI-Total score | | | | | | | | |
| Unadjusted difference | 3.43 | 0.11 | -5.53 to 12.39 | 0.45 | 2.03 | 0.07 | -6.71 to 10.77 | 0.65 |
| Difference adjusted for baseline PTGI score | 2.39 | 0.08 | -3.65 to 8.43 | 0.44 | 1.09 | 0.04 | -5.33 to 7.51 | 0.74 |
| EQ-5D Total Score | | | | | | | | |
| Unadjusted difference | -0.086 | -0.29 | -0.17 to 0.03 | 0.04 | -0.032 | -0.12 | -0.11 to -0.04 | 0.44 |
| Difference adjusted for baseline EQ-5D score | -0.041 | -0.14 | 0.08 to 0.00 | 0.06 | 0.007 | 0.03 | -0.03 to 0.04 | 0.71 |

As described earlier, the sample consisted of a heterogeneous population of both stroke survivors and carers. In order to assess whether the changes were consistent across both groups, exploratory analyses were conducted. As noted, there were no statistically significant differences in the numbers of carers in both groups. Independent sample t-tests were therefore used to compare the *change* scores from baseline (T1) to post-intervention (T2) and then from baseline (T1) to follow-up (T3) between the stroke survivors and carers. At pre-post, there were no statistically significant differences found on any of the outcome measures (HADS, EQ-5D, PTGI) in either group, or as an entire sample, suggesting that they changed the same. Likewise no significant differences on any of the outcome measures at pre- to follow-up.

3.5.2 Area under the curve

As described in the previous chapter, repeated measure analyses were not appropriate due to the significant differences at baseline. As a result, an area under the curve measurement was used for all of the repeated outcome variables to produce a single measurement (i.e. so that there are no longer repeated measures, but just one). This was calculated for each outcome variable separately, to give an overall measure of psychological distress, quality of life and post-traumatic growth over time. These measures could then be compared between groups.

A univariate analysis of variance, with baseline HADS total values added as covariates, indicated a significant main effect on the HADS, $F(1, 45) = 10.51, p = 0.00$. The stroke survivors and carers who had attended the ACT group had lower scores on the HADS ($M = 121.90$) than those who were placed on the waiting list ($M = 197.88$). However, the intervention did not significantly affect the area under the curve measurement for post-traumatic growth or quality of life, when controlling for baseline differences.

Sullivan and Feinn (2012), argue that whilst a p value is informative for demonstrating whether an effect exists, the p value does not reveal the size of the effect. Thus, in order for thorough interpretation to be possible, both the statistical significance (p value), and the substantive significance (effect size) is calculated, and allows the analysis to move beyond “Does it work or not?” to the “How well does it work?” (Coe, 2002). For two independent groups, Sullivan and Feinn (2012) illustrate that the effect size can be measured by the standardised difference between two means ($M1 - M2 / SD$). However, in the present study an adjusted effect size was calculated, by subtracting the pre-effect size from the post-effect size (with the pre-effect size calculated in the same manner as the post; Wilson, Gottfredson & Najaka, 2001; Wilson & Lipsey, 2007). This was important as the group comparisons were confounded by the lack of pre-test equivalence. Using this method, there was a medium effect size ($d = 0.57$) found between the groups over time (Cohen's term d effect sizes; small $d = 0.2$, medium $d = 0.5$, and large $d \geq 0.8$). At follow-up, on average the ACT group reduced their scores by 2.72, in comparison to only 0.43 on the waiting list.

Results

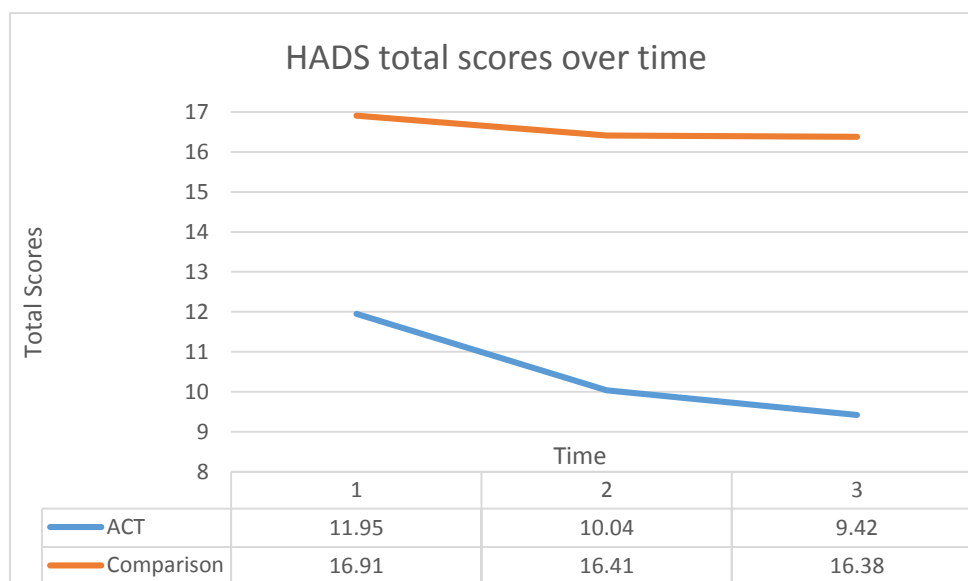


Figure 7 Graph to illustrate changes in HADS total score over time

3.5.3 Clinical classification on HADS

Effect sizes are subject to change based on the whole group and hence are focused on the group effect, rather than individual changes. As a result, they are not able to distinguish whether the medium effect size of change on the HADS, has moved the stroke survivors and carers from clinically meaningful levels of depression and anxiety, to levels that fall within the “normal” range. As a result, exploratory analyses were run to look at the net positive gain change between the groups on the standardised classification criteria for anxiety and depression, for each stroke survivor and carer separately. The choice of analysing the subscales of the HADS, as opposed to the total score, was because of the way that the HADS is most often utilised in clinical practice, and how the measure is actually standardised.

At pre-intervention, 47.62% of the stroke survivors and carers in the ACT group (10/21), and 59.26% (16/27) of participants in the waiting list group, demonstrated clinical levels of anxiety, with scores outside of the normal range. At two months post-intervention, 59.26% (16/27) of the comparison group remained outside of the normal range (i.e. there was no change). In contrast, only 14.28% (3/21) of the stroke survivors and carers in the ACT group were scoring outside of the normal range on the subscale of anxiety, meaning that seven of the participant moved from caseness to non-caseness. Written in another way, only three of

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the ten stroke survivors and carers who were scoring outside of the normal range on levels of anxiety at pre-intervention remained to fall in these classification criteria's after attending the ACT group. However, looking for statistical difference between caseness and non-caseness would be invalid due to the baseline differences. As a result, the total positive and negative movement across the classification categories for both groups separately, from baseline to follow-up was analysed. Within the anxiety subscale, nine stroke survivors and carers in the ACT group moved in a positive categorical direction (42%), compared to only one who moved in a negative direction (4%). Whereas, for the comparison group whilst four moved in a positive direction (14%), six also moved in a negative direction (22%). A Mann-Whitney U test was used to compare these differences after the data had been transformed in to ordinal data (1 = negative change, 2 = no change, 3 = positive change). From this data, it can be concluded that the ACT intervention group promoted statistically significant positive movements across the classification criteria's compared to the waiting list control ($U = 179, p = 0.02$) for levels of anxiety.

For the depression subscale there is a substantial floor effect which may mask any changes observed. Only 23.81% of the stroke survivors and carers (5/21), scored outside the normal range at baseline, in comparison to 57.14% (16/28) of the participants in the waiting list group. At two month follow-up, only one participant moved to within the normal range after attending the ACT group, the other four fell in the mild classification, of which two were previously classified in the moderate range. In the comparison group 50% (14/28), remained to fall outside of the normal levels of depression. Overall, within this subscale, four stroke survivors and carers moved in a positive direction and one moved in a negative direction in the ACT group, and two participants moved in a positive direction in the comparison group and one moved in a negative. This time there was no statistical differences ($U = 264, p = 0.56$).

3.5.4 The EQ VAS

In addition, exploratory analyses were completed on the visual analogue scale of the EQ-5D. As described in Chapter two the EQ-5D embodies two components, a health state index,

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and also a health state evaluation. This evaluation requires participants to translate their descriptions of personal well-being (represented by the extent of health problems across five dimensions), into a uni-dimensional value of health which is recorded on a vertical visual analogue scale (VAS). This information can be used as an additional quantitative measure of health related quality of life as judged by the individual respondents (The EuroQol Group, 1990). In order to present all aspects of the EQ-VAS data, both a measure of the central tendency and a measure of dispersion is provided in table 12 below.

Table 12 EQ VAS values across time for each group

| <u>Time</u> | | | | | | |
|-------------|-------|------------|-------|------------|-----------|------------|
| | Pre | | Post | | Follow-up | |
| EQ VAS | ACT | Comparison | ACT | Comparison | ACT | Comparison |
| Mean | 70.71 | 58.52 | 72.14 | 58.53 | 78.39 | 57.22 |
| Std Dev | 25.21 | 17.96 | 20.22 | 16.80 | 21.01 | 17.61 |

A graphical representation of the mean EQ VAS scores reported by the stroke survivors and carers across the time frames is provided in Figure 8. Mean EQ-VAS scores are seen to increase following attending the ACT group.

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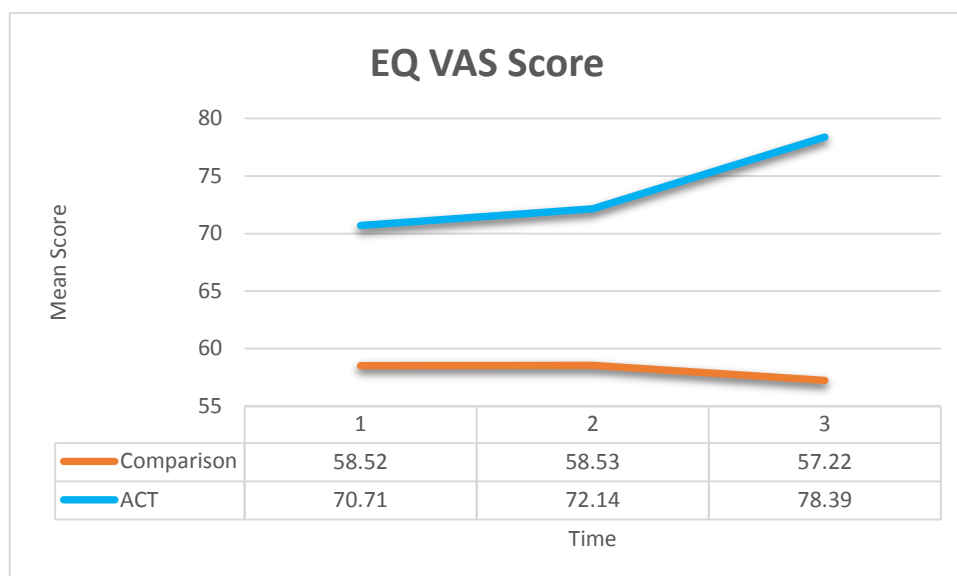


Figure 8 Graph to illustrate EQ VAS scores over time

An area under the curve measurement was computed for the EQ-Scale scores across the three time measurements (ACT: $M = 858.09$, $SD = 232.46$; Comparison: $M = 697.04$, $SD = 198.08$), which was then analysed using a univariate analysis of variance, with baseline EQ-VAS scores entered as covariates. The results did not find a main effect of group on this measure, $F(1, 45) = 2.61$, $p = 0.11$.

3.5.5 Mechanisms of therapeutic action

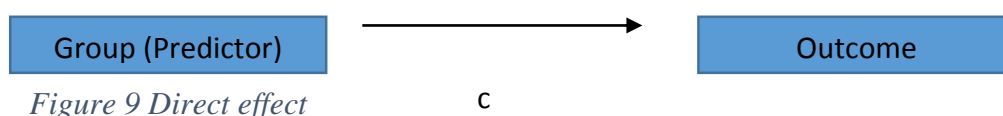
As described in Chapter one, the underlying theory of ACT led the researcher to hypothesise that the ACT intervention would increase psychological flexibility (represented by higher scores on the AAQ-II) and goal directed behaviours (represented by increased scores on the ASHS) and additionally that these processes would mediate the relationship between group allocation and changes on the outcome measures. Descriptive statistics for the process measures at pre, post, and follow-up intervention are presented in Table 13.

Results

Table 13 Descriptive scores on the process measures at each time frame (T1, T2, T3).

| | ACT Mean (SD) (N=21) | Waiting List Mean (SD) (N=28) |
|----------------------------------|-------------------------|----------------------------------|
| Psychological Flexibility | | |
| Pre | 49.50 (9.80) | 43.18 (2.0) |
| Post | 51.99 (10.11) | 44.67 (9.36) |
| Follow-up | 52.78 (10.74) | 45.15 (7.52) |
| Goal Directed Behaviour | | |
| Pre | 29.62 (13.57) | 26.70 (10.97) |
| Post | 33.24 (11.15) | 27.19 (9.08) |
| Follow-up | 33.33 (11.46) | 29.04 (8.69) |

Firstly, the total effect of the group allocation (X) on the outcome variables (Y) were analysed – path ‘c’. The area under the curve measurements were used as the outcome variables throughout. The results suggest that the group allocation significantly predicted levels of psychological distress, $b = 30.51$, $t = 3.24$, $p = 0.00$, 95% CI (11.55, 49.47) with baseline scores controlled for. But the total effect of the group allocation did not predict levels of post-traumatic growth, $b = 18.71$, $t = 0.68$, $p = 0.49$, 95% CI (-35.92, 73.33), nor quality of life, $b = -0.44$, $t = -1.41$, $p = 0.17$, 95% CI (-1.06, 0.19).



As described in Chapter two, the indirect effect of the group on the outcome variables, via the mediators (M) was then explored. Firstly, simple regression analyses of the putative mediators (AAQ-II and the ASHS) predicted from the group allocation (i.e. path ‘a’) were conducted. The findings illustrated that the group allocation did not predict levels of psychological flexibility, $b = -24.81$, $t = -1.13$, $p = 0.27$, or the goal directed thinking, $b = -8.41$, $t = -0.28$, $p = 0.78$, when the baseline scores were controlled for.

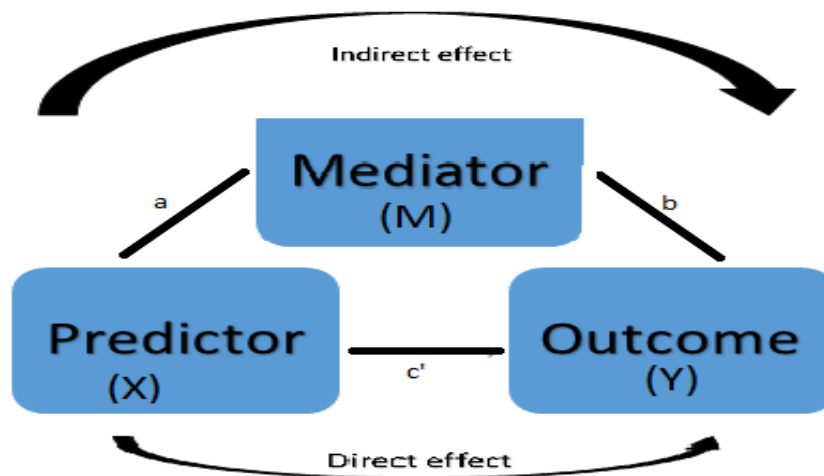


Figure 10 Indirect effect

Likewise for path 'b' (which is predicting the outcome from the mediators), the AAQ-II did not significantly predict the HADS score, $b = -0.03$, $t = -0.54$, $p = 0.59$, 95% CI (-0.16, 0.09), nor did the ASHS, $b = -0.073$, $t = -1.56$, $p = 0.120$, 95% CI (-0.17, 0.02). Likewise, the AAQ-II and ASHS did not predict the EQ-5D or PTGI.

For path 'c' the relationship between the predictor and the outcomes, whilst controlling for 'a' and 'b' were calculated, again with pre-scores entered as covariates. For the HADS, the group allocation significantly predicted the HADS score even with the AAQ-II in the model, $b = 29.66$, $t = 3.08$, $p = 0.004$, 95% CI (10.26, 49.04). When the ASHS replaced the AAQ-II, the group allocation again significantly predicted the HADS score, $b = 29.89$, $t = 3.23$, $p = 0.00$, 95% CI (11.22, 48.56). As expected based on the above results, the results of the regression on the PTGI and EQ-5D predicted from both group allocation (i.e. path c') with the AAQ-II or the ASHS in the model, did not significantly predict the PTGI or EQ-5D scores, when baseline scores were entered as a covariates.

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Finally, the total mediating effect of the group allocation on each of the outcome measures separately was analysed via the non-parametric bootstrap approach which tested the significance of the indirect (mediating) effects through the cross-product of the coefficients. As can be seen from table 14, given the 95% confidence interval, it can be concluded that the range for b – values pass through zero, for each of the potential mediators. The findings therefore suggest that there is no indirect effect of the AAQ-II or the ASHS as a mediator of the relationship between group allocations on any of the outcome measures. No further analyses are therefore provided.

Table 14 Indirect effects of group allocation on the outcome measures

| BCa ^(a) 95% CI | | | |
|--|-----------------------|----------|--------|
| | Point estimate (b) | Lower | Upper |
| Simple indirect effects on HADS | | | |
| Psychological flexibility | 0.8604 | -1.7902 | 8.7216 |
| Goal directed behaviours | 0.6183 | -0.0835 | 0.2995 |
| Simple indirect effects on the PTGI | | | |
| Psychological flexibility | -10.7926 | -39.9737 | 2.5857 |
| Goal directed behaviours | -19.2857 | -56.6930 | 2.0154 |
| Simple indirect effects on the PTGI | | | |
| Psychological flexibility | 0.0364 | -2.3523 | 1.8411 |
| Goal directed behaviours | 0.258 | -0.7265 | 2.1426 |

^aBCa = bias corrected and accelerated bootstrapping confidence intervals that include corrections for both bias and skewness. $N = 10,000$ bootstrap resample. Confidence intervals containing zero are interpreted as not significant.

3.6 Qualitative

The results of the thematic analysis will now be presented. Twenty participants were invited to attend the second ACTION after Stroke group. Sixteen participants attended the first session. Six participants dropped out after the first session, but another two joined the course in session two. However, they did not return to the third session. Another stroke survivor stopped attending after the second session. The reasons for this drop-out is unknown. Nine remaining participants were invited to come to a focus group to give qualitative feedback. Seven of the nine participants attended. These seven attended all four sessions. In order to aid and contextualise the reader's understanding and interpretation of the results, a brief description of the participants are presented.

3.6.1 Participant characteristics

The seven participants who were interviewed were not significantly different from the overall waiting list sample on any of the demographic measures on the demographic questionnaire. Six females and one male attended. Two of the participants were in a marital relationship, two of the women who attended were friends - having previously attended several courses run by the charity, and the three other ladies had become friendly whilst attending the group. All of the participants were stroke survivors with the exception of the couple where one was a carer. The participants were aged between 48 and 67 years. The time since stroke varied from six months to three years.

Participants in this group completed four pre and post-intervention questionnaires as part of the routine evaluation, the HADS, ASHS, AAQ-II, and EQ-5D (the scores of which can be found in table 15 below). A one-way within subjects (repeated measures) ANOVA was conducted to compare the outcome and process measure scores from pre to post-intervention, to further contextualise their responses. The ANOVA showed an effect at trend level, Wilks' Lambda, = 0.004, $F(2, 1) = 135.28$, $p = 0.06$, on the measures after attending the ACT group. In other words, the stroke survivors and carer who offer their experiences of the course, demonstrated change on the outcome and process measures after attending the ACTION after Stroke group. Looking at each variable separately, the mean scores demonstrate change in a positive direction on all variables.

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Table 15 Descriptive scores on the outcome and process measures pre- and post-intervention

| | Pre-scores | | Post-scores | |
|--------|------------|------|-------------|-------|
| | Mean | SD | Mean | SD |
| HADS | 20.0 | 3.94 | 18.25 | 8.09 |
| EQ-5D | 6.0 | 2.39 | 7.8 | 1.92 |
| AAQ-II | 39.0 | 6.36 | 41.75 | 13.33 |
| ASHS | 22.6 | 7.92 | 28.40 | 8.26 |

3.6.2 Thematic analysis

The first step in the thematic analysis was to become familiar with the data, this was done by repeated listening to the audio recordings, and then repeated reading of the transcripts (initial notes made can be found in Appendix M). The second step was to reduce the raw data into codes, and then into sub-themes. This was done on the basis of any leading issues that arose in the discussions. Hence, the themes created were strongly linked to the data itself. However, as discussed in section two, the themes were formed using a latent approach that considered the material through the lens of ACT so that the themes were relevant to the processes and principles of ACT.

The process of abstracting themes involved reading and re-reading the text segments within the context of the codes, which enabled the researcher to identify underlying patterns. The themes were refined so that they were specific enough to be separate and non-repetitive, yet broad enough to encapsulate a set of ideas contained in text segments.

It became readily apparent as the participants began describing their experiences of the group that all seven participants valued attending the course and all reported positive gains. The five overarching themes, and 10 subthemes, emerging from the data are now provided.

Results

Direct quotes are also provided to illustrate the themes and subthemes. Table 16 summarises the themes and subthemes.

Results

Table 16 Overarching Themes and Sub-Themes

| Theme | Sub-theme |
|--------------------------------|---|
| Initial context | Longing for things to be back to normal Resistance On our own |
| Psychological reactions | Continued fear Altered sense of self |
| Thank you ACT | Letting go of the struggle Reconnecting with what's important Stepping back from thoughts Noticing Exercises that stood out |
| Gains outside of ACT | |
| Wanting more | |

3.6.2.1 Initial context

“Initial context” was chosen as the title for the first initial theme as it has both descriptive and analytic power. Firstly, this theme represents the “initial” journey and experiences post-stroke, and secondly, it provided the “context” for their psychological distress, and reasons for attending the ACT group. Overall, it is interesting to observe that the stroke survivors all spent time reflecting on a host of behavioural, cognitive, emotional, and physical problems that they had experienced. Through examining the material via the lens of ACT, it became apparent that many of the individuals had spent time attempting to block out, reduce, or change these experiences (i.e. experiential avoidance). Indeed it became clear throughout the discussions that most of them had tried many things, such as “pushing” against symptoms, disputing thoughts, praying for things to “go back to how they were”, and avoiding demanding activities to manage their personal internal reactions. Yet, despite their best efforts, they reported frequently finding themselves “trapped” in a life that felt out of their personal control.

Results

It was interesting to note, how the participants shared – what can only be described as – a sense of obligation to share these experiences. It appeared that this mutual and shared history allowed the participants to connect with one another and validate each other's psychological pain. It also appeared to be an invitation to the researchers to understand what journeys the participants had been through before attending the ACTion after Stroke group. It additionally appeared to give them the “permission” they needed to go on to state how the group had facilitated positive changes in their lives.

3.6.2.1.1 Longing for things to be back to normal

Three-quarters of the stroke survivors described that initially there was very little present-moment focus, but rather a constant comparison of what life was like, to where life is now. These comparisons appeared to result in high levels of psychological pain, such as feeling sad, resentful, and also angry for the life they felt they had lost. The stroke survivors reflected on how they would often “long for things to go back to how they were”. The pre-stroke life was described as almost “perfect” in comparison to current circumstance and abilities. It appeared that by over-identifying with a conceptualisation of what life “should” be like, it invalidated life as a whole. In other words, their verbal and cognitive abilities were constantly forming relationships and connections between the past and present, allowing judgments to be made, and hence resulting in feelings often of inadequacy.

P1: “Yeah the things that made you the person you are have been taken away from you so you see you become more reliant, which I hate. I have always been fiercely independent. Before people were working, they were in a job, they were whatever, a secretary or whatever, well that's gone now.”

P3: “There's a sort of a period when you're very, very angry and you want things to go back the way they were so you're constantly trying to – what if? What if? its like grief in a way...”

P3: “Yes and also not being able to do the things you did before, like this is what I was saying to X, it's like everything you like to do, everything you loved, it's ticked off, it's gone. Boom. Just like that. You're just not prepared for it.”

Results

In addition, it seemed that the stroke survivors and carers were for a long time unable to let go of making desperate attempts to discover and understand “why” the stroke had happened. It felt like a very natural question that they all understood. However, it appeared that this created a type of living where the individuals were so consumed by finding the answer that they were unable to invest energy in behaviours that could make things feel enjoyable in the present. When there was no medical reason (as it appeared for many of the stroke survivors in this group), they shared that they were unable to let go of the mind’s need for an explanation, and instead appeared to spend lots of time and energy trying to reason with the mind of “why they shouldn’t” have had a stroke. This attentional pattern is known to exacerbate problems such as rumination, and appeared to prevent the participants in being able to re-engage in meaningful and valued behaviours.

P2: “...but that was the hardest bit, because for a long, long time I was just thinking this is just not fair, what did I do to deserve this...”

P5: “I’m a nurse by profession and all the GPs and the doctors would say, ‘Well we have no idea why this happened, there’s no reason, you have no risk factors, it’s just pure bad luck.’ But that’s not enough ((laughs)) that’s not an answer and I think that’s what you do is you look for...you do look for answers and sometimes they’re just not there. But that’s intolerable so you keep looking.”

3.6.2.1.2 Resistance

The stroke survivors and carer described the “struggles” and “battles” that they found themselves in post-stroke, and expressed the ways in which they would try and “push through” painful experiences, because to stay in contact with the feelings that having to “give in” produced was just “too much”.

P5: “...because if you’re normally fit and healthy and you just keep going, keep going, keep going and then you’re suddenly in a place when you can’t, that in itself is a huge factor and you try, and then you say to yourself, ‘Why can’t I do it, why can’t I push myself and do that bit more?’ So you do, but it ends worse.”

Results

P3: "I think that applies to carers as well, you're doing everything and you think you're doing it right but it's not working, what you're doing is not working, so you try a bit harder next time and still that doesn't work, and then it's exasperating so sometimes it's like ARGH it's like pushing a massive boulder up a hill, but constantly rolling back down."

P4: "Yeah, yeah it's kind of what it said about the fighting, you think I can makes this better, if I just try a little harder."

3.6.2.1.3 On our own

There appeared to be an entanglement (fusion) with thoughts and feelings about the actions or lack of actions that they "should" have experienced from their family and friends. These fixed rules resulted in five of the stroke survivors feeling hurt or invalidated by members of their family or friends, which eventually led to emotional distancing. Whilst emotional distancing appeared to be aimed at protecting themselves from further distress, it was discussed that it often ended with the individuals feeling extremely alone and unsupported, as the smaller and narrower their lives become. The reduced contact over time appeared to stymies valued and meaningful living.

P3: "Other people...say, 'Oh you looked really well, it's okay,' sort of thing and you feel like screaming and saying, 'No it's not, you haven't seen him every day.' They just see this person going along, you know."

P1: "sometimes I knew what the reaction would be so I just didn't even bother anymore."

P6: "I think with X it's his speech, he can't get out what he wants to say and that kind of leads to family and friends not speaking to him, and ignore him because they're embarrassed because they don't quite know what to do, so we had to stop meeting with them, you know."

3.6.2.2 Psychological reactions

“Psychological reactions” was chosen as the title for the second theme, whilst it seems linked to the first theme of “initial context” it appeared a distinct theme in its own right. The data reflects the ongoing psychological processes that the stroke survivors and carer continue to experience, as opposed to the reactions felt at the early stages of life after stroke. The stroke survivors and carer spoke about how they would find it difficult to decrease the believability of internal thoughts and how this subsequently had a powerful negative influence on their moods. For instance, the first subtheme speaks to the continued sense of threat and fear, which concerns being unable to effectively handle the pain and worry that stroke inevitably brings. The second appears to relate to the “Altered sense of self” and reflected the participants’ feelings on how “different” and “less capable” they feel since their strokes.

3.6.2.2.1 Continued fear

This subtheme reflects the participants’ discussions about how the future now felt uncertain both for themselves and their loved ones. The stroke appeared to shatter their beliefs that the world was a “safe place” and that their health was somewhat in their control. In the examples used most commonly, it appears that there was an excessive literal quality to the verbal thought that another stroke was imminent, as opposed to recognising this as simply a thought. Instead, this thought appeared to generate a constant state of fear, which often resulted in what appears to be behavioural action.

P6: “because you think I was in a safe spot, now I'm not safe anymore it'll happen again to somebody I know and all your world crumbles around you instead of feeling in this safe place, so you try to keep yourself safe.”

P5: “That’s what I find noticeable for carers as well because I know, I've noticed with my husband he's been a bit sort of anxious and as I said yesterday that I had a wobbly day, and it was the first time I came home from work early because I just couldn't cope with work yesterday and he was immediately, ‘Are you okay? Have you got a headache?’ you know, and I said to him I just really need to go to bed and he was...I could see he was like a cat on hot bricks, checking on me all the time.”

Results

P3: "If X goes out for a little walk and doesn't come back I'm thinking he's dropped down dead in the road or something and it's all out of proportion, but I ring him, and I keep checking he is OK."

3.6.2.2.2 Altered sense of self

Suffering a stroke and subsequently having changed abilities appeared to have threatened the conceptualisations that people held about themselves. This appeared to evoke strong emotions and the one which the stroke survivors and carer commented was the "hardest of all" to cope with. Their current self-evaluations or conceptualisations were always portrayed negatively, and appeared to be built largely upon being a "stroke survivor" or being a "carer", as opposed to being a male or a female, or a parent, or any other factor that made up who they were. Indeed, when three quarters of the group talked about themselves, they tended to describe the conceptualised self as being "less able" or "capable".

P5: "I think when you're angry like that, you're angry with yourself really, and you've got kind of self-hatred going on because you feel inadequate or a failure because you've had this thing."

P1: "That's the problem it's not just one thing, with a heart attack it's one thing isn't it, the heart, but with a stroke it affects every single part of your mind, the brain. You're just not you anymore."

P3: "But really to be carer you've got to be a saint, you know but no one is, so you fail every day ...because you think I'm just not good enough."

3.6.2.3 Thank you ACT

"Thank you ACT" was chosen as the title for the discussions surrounding the ACT specific dialogues, for several reasons. Firstly, two of the participants used the words "appreciate" and "grateful" about receiving the ACT group. Secondly, the participants were able to consider some of the "positive changes" that they had incorporated in to their lives since attending the ACTion after Stroke group and were thankful of this. Many of the participants

Results

grounded their responses with direct quotes used in the group, and reflected on particular exercises or metaphors to illustrate the change acquired. The subthemes provided, whilst distinguishable as distinct processes, may be understood more fully when considered relationally and in context of the other subthemes. Rather than focusing on changing the results of the stroke itself, as was described in the past, it appeared that the group allowed the stroke survivors and carers to begin to accept what was out of their personal control.

3.6.2.3.1 Letting go of the struggle

This subtheme reflects the sense of acceptance that the stroke survivors appeared to come to through attending the course. It reflected the stroke survivors' abilities to assent to the reality of their situation, without attempting to change it. Some participants appeared to develop almost a sense of compassion towards themselves.

P4: "I found the second week particularly helped...I think I was feeling that I was just desperately trying to get back to how I was before and the second week when we had to hold our breaths and things ((coughs)) it just made me think that actually I could cope with how things are now."

P3: "I used to think why can't it go back how it was because you're in a sense of mourning, it's like grief in a way, so this (referring to course) starts to give you the option to accept. It's not the end of the world...there is definitely light at the end of the tunnel."

P5: "It feels like I'm learning to let go of the struggle sometimes."

3.6.2.3.2 Re-connecting with what's important

The stroke survivors and carers spoke about the actions they were going to take to re-connect with their values, having gained some clarity through the group about what they prioritise most in life:

P5: "But I think that last session we had about working out our values and things was useful because it does make you you've got to evaluate what your life was like before"

Results

the stroke, what was important and it makes you think how you've come through, and how you can move forward."

P2: "For me, I've been thinking how I have always loved being with my family. That's where I get a lot of my enjoyment. That hasn't changed. In fact maybe I have more time for that now."

3.6.2.3.3 Stepping back from thoughts

The participants reflected on their perceived "new" ability to remain in the present and to "step back" and gain some distance from unhelpful thoughts and beliefs. They spoke of a strengthened ability to "observe" their minds at work, instead of getting "caught up" or being "pushed around" by them. In essence, there was an acknowledgement that the ongoing process of thinking was much more evident after attending the group.

P5: "And I think what the course has done is allowed that recognition between your mind and reality. That's been really important, although it's sometimes difficult to put into practice."

P4: "So getting that back like you say challenging what your mind is saying to you and driving that bus, being in control and driving that bus yourself it just builds your confidence again."

P1: "...And thinking about what this anger means to me, certainly just by the act of looking at it, defused it, rather than seeing it as an overall part of me, you're here at the end of the day."

3.6.2.3.4 Noticing

There are many facets that made up this subtheme including descriptions of being able to live in the present moment, being able to engage in what is happening right now, and allowing feelings to be present as they are. In this sense the participants described increased levels of emotional intelligence.

Results

P4: "I can recognise when I'm getting angry now, and so it has less influence over me - so it is hugely useful."

P3: "Yes you don't feel quite so swamped with all your emotions and nobody cares, nobody understands, all that sort of road you tend to go down from time to time, it can sort of draw you back into almost feeling that you've suddenly done something a bit more constructive as opposed to destructive."

P5: "Yeah, yeah it's kind of what it said about the fighting, you think I can make this better, thinking back to how I was, but if you just stay in that moment and think this is what I've got right now and I can still have a good life..."

3.6.2.3.5 Exercises that stood out

The stroke survivors and carers reflected on exercises that were particularly useful despite none of the questions addressing this. All of the stroke survivors recalled specific terms used by the facilitators, or specific images, as opposed to general principles or ideas. It appears that generally the experiential exercises were spoken about most explicitly.

P4: "I think about the driving the bus and getting what it meant that's it for me. I know where I am going again now."

P1: "I thought it was the quick sand... Because the temptation is to start clashing but if you can just let go, which is a very, very difficult thing to do."

P5: "I did get a lot out of like my former assumptions, I get like my mind is constantly going and it doesn't matter how much you try to explain it, it keeps going or so just do the mindfulness exercises and it's really helpful."

3.6.2.4 Gains outside of ACT

"Gains outside of ACT" was chosen as the title theme as it represents some of the discussions that were held about the benefits participants shared that were not specific to ACT (i.e. they might have been reported even if no specific ACT model was taught). Instead

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this theme was focused on the therapeutic gains of attending the group. The stroke survivors first reflected that the stroke appeared to leave a long-term emotional legacy for all of them, for which they felt that they were significantly underprepared for. However, they shared how through the group and meeting others in similar situations, they had begun to appreciate they were not alone, that their experiences were not abnormal. In this sense, the group appeared to offer a sense of belonging.

P4: "But again like in a hospital situation they don't prepare you...and they don't sort of say, 'Well you're going to get better physically but you will also suffer emotional...' They don't prepare you for that I don't think."

P5: "Because I found for me I come home from hospital I had everybody round me like physios and all that, they just all went then all the emotional turmoil kicked in following that and I wasn't prepared for it, but this group has helped with that."

P6: "I think that's what is important about this course, it was meeting people struggling with life and learning that it's a very normal and typical part of stroke that we all struggle with, and we're holistic beings aren't we and what happens to us can be very powerful things."

P3: "You don't feel quite so alone... So when you come to a group like this you feel you're not alone anymore. So things kind of go back into proportion again."

3.6.2.5 *Wanting more*

Despite the gains obtained described from attending, the participants all shared comments about how the group could have potentially offered more. Participants were able to identify some of the ways in which the facilitators might have been able to provide this, such as providing refresher courses, further reading, or more sessions. It appeared that the stroke survivors and carers felt under-confident in being able to apply the techniques taught into practice and to continue to do so over time.

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P3: "There's such a lot you could still do if you know what I mean if you go back with some things to practise because it's a long process isn't it?"

P5: "I think something fairly short and straightforward would be nice to dip into as opposed to...because initially I felt, oh I'll go and get a book on mindfulness and just read a bit more about it but I don't think I'm ready for that yet, but something light that you could dip in and out of just to give yourself that like a reminder, something like for five minutes yesterday when I was having a wobbly day just to have had a little small five minute break, let's just have a little look at what we've done on this course, what's going to help at this moment in time and almost something not to hold on to."

P2: "Because I think it would also be reaffirming as well to almost keep that alive because whilst we will all go on coping in our own ways it would be nice to sort of keep the ACT message alive in the way we are coping because it's quite constructive."

Chapter 4 Discussion

4.1 Chapter overview

Previous chapters have been concerned with the conceptual and theoretical frameworks employed, describing the empirical research process, and defining the results. The purpose of this final chapter is to interpret and describe the significance of the findings in light of what was already known and to explain new understandings. The discussion will begin with a recap of the research question addressed, followed by a systematic explanation of the findings and how they relate to the hypotheses described in Chapter one. The researcher then goes on to think critically about the methodological processes used and through this process possible improvements are explored. Implications for further research are then highlighted. The researcher concludes the thesis by highlighting the importance of the current study and how it has contributed to existing gaps in research and clinical practice.

4.2 Review of the research question and hypotheses set out in earlier chapters

There is a clear need for community-based interventions to improve the psychological wellbeing of stroke survivors and carers (Lincoln et al., 2013; Greenwood, et al., 2010). However, at the present time there are noted gaps in the amount of psychological support available (National Audit Office, 2010; Intercollegiate Stroke Working Party, 2011). Without support, psychological distress may have not only negative consequences for the stroke survivors and carers themselves, but also for service usage and cost (Gillham, et al., 2012). Nevertheless, there is currently a shortage of psychologists working within stroke (National Sentinel Stroke National Audit Programme, 2012). This has implications for community services, meaning that psychological interventions must be accessible for delivery by other staff groups and within resources already available. In addition, the interventions need to have the ability to reach a wide number of individuals requiring support. Consequently, the aim of the current thesis was to explore the efficacy of a group based therapeutic

intervention that could be easily utilised within existing infrastructures available in the community.

Acceptance and commitment therapy (ACT) was reviewed in Chapter one and demonstrated promising outcomes for improving psychological wellbeing in a wide range of conditions (Hayes, 2009; Gregg et al., 2007). However, to date, there is a lack of research exploring the use of this theoretical model in adults who have survived a stroke, and very few in adults with a neurological condition as a whole. Based on a systematic literature review, the researcher hypothesised that participants assigned to the ACTion after Stroke group would experience improved levels of psychological distress, quality of life and levels of post-traumatic growth, compared to those assigned to a waiting-list. The researcher also hypothesised that in line with ACT's theoretical underpinning, psychological flexibility and goal directed behaviours would mediate the relationship between the ACT intervention and the outcomes. Statistical analyses were conducted on the outcome and process measures completed at three time points (pre-intervention (T1), post-intervention (T2) and two month follow-up (T3)). A one-hour focus group including people who had completed the ACT sessions was also analysed via an inductive thematic analysis to gain greater insight in to the stroke survivors and carers experiences of the group.

4.3 Research findings

4.3.1 Summary

The results of the quantitative analyses suggest that the ACTion after Stroke group intervention was a useful intervention for reducing psychological distress in adult stroke survivors and carers. Relative to the waiting list control group, participants assigned to the ACT group evidenced significantly greater reductions on the HADS over time, compared to the waiting list controls. The magnitude of between group differences met the criteria for a medium effect size (Cohen, 1988). However, no statistically significant differences were found on levels of post-traumatic growth or quality of life, as measured by the PTGI and EQ-5D.

The mechanisms of therapeutic action were examined, surprisingly the ACT intervention did not appear to significantly alter levels of psychological flexibility as measured by the AAQ-II, or goal directed thinking as measured by the ASHS, and these measures did not appear to mediate the changes in psychological distress. The results will now be reviewed in greater detail and will be considered in light of previous research.

The qualitative data added important information at the level of psychological experience, which supported many of the underlying beliefs about psychological distress within ACT. It additionally added information about the specific benefits experienced through attending the group, including both ACT specific gains, and the gains experienced through meeting others in similar situations. These are discussed in more depth below.

4.3.2. Baseline assessments

4.3.2.1. Sample characteristics

At pre-intervention assessment, the stroke survivors and carers as an entire sample exhibited significantly higher levels of psychological distress relative to previous studies utilising the HADS with stroke survivors (Linley-Adams, et al., 2014; Sagen, et al., 2009). In the current study 54% of the total sample (26/48) scored outside of the “normal” range on the subtest of anxiety, which is substantially higher than the prevalence rates commonly recorded in the literature (25% - Campbell-Burton et al., 2013). Whilst 43% (21/48) scored outside of the “normal” range for depression, which again is higher than the 33% most widely recorded (33% - Hackett, et al., 2005). However, the participants were not randomly allocated to groups, which led to statistical differences on this primary outcome measure at baseline. This difference had to be controlled for throughout.

Statistical differences between the groups were also found on the AAQ-II at baseline, with the ACT group demonstrating higher levels of psychological flexibility. These findings may go

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some way to support the link between psychological flexibility and psychological distress, which supports the underlying theory of ACT (Hayes, 1999). Bivariate correlations across the whole sample support this through the significant negative correlations on the AAQ-II and the HADS within each of the three time frames. This suggests that higher levels of psychological flexibility are related to lower levels of psychological distress, and vice versa. This was also true for quality of life within each time period, which is again consistent with the ACT literature (Rastenyte & Kranciukaite, 2007).

The correlations additionally demonstrated that the ASHS was also negatively correlated with both the HADS, and EQ-5D index score. The ASHS assesses an individual's perceived ability to produce pathways of reaching their goals, and then utilising these pathways to actually achieve the goals. The bivariate correlations suggest that as these abilities increase, levels of psychological distress decrease and quality of life increases. This again lends support to the underlying principles of ACT, which suggest that living life in accordance to one's goals is beneficial to psychological wellbeing (Hayes & Strosahl, 2004).

However, these findings could be seen to contrast with the results that revealed an absence of mediation through these process measures (the AAQ and ASHS). One potential explanation for this is that mediation is a particular type of relationship. It implies a process that connects the independent variable (group allocation) and outcome variables by modelling how the mediators (i.e. psychological flexibility and goal directed thinking) transmits the influence of the group onto the outcomes (e.g. decreased psychological distress). It is therefore independent of the direct effect of the main variables. Whereas correlations on the other hand, provide a measurement of the strengths of the association between two variables (i.e. the total relationship). Hence, a significant correlation relationship does not imply a significant mediational relationship.

Moreover, the correlations between the AAQ and ASHS and the HADS reflected associations found within the sample at baseline and could represent relatively stable relationships in

the general population between the traits of flexibility and goal directed thinking and psychological distress. However, a mediational relationship between the intervention and outcome measures would require that these variables are susceptible to *change* as a result of the intervention. If our brief intervention was not effective in changing psychological flexibility and goal directed thinking then they could not have mediated the relationship between the intervention and distress. However, this lack of mediation is not inconsistent with the fact that, as relatively stable traits in the general population, they exhibit a correlation with distress.

Furthermore, it is perilous to make comparisons between statistics (such as the correlational and mediational analyses conducted here) when the estimates are based on different statistical procedures with different power (Hayes, 2013; Kenny & Judd, 2014). The lack of significance in one, and significance in the other, could reflect differing Type II error rates rather than real population differences.

The baseline assessments further demonstrated that of all the demographic characteristics assessed, there was only one significant correlation. There was a strong association between time since stroke and post-traumatic growth, suggesting that as the time since stroke increased, so did post-traumatic growth. This fits with the post-traumatic growth theory, as time since stroke is seen to moderate some of the known factors related to PTG, such as positive cognitive restructuring, downward comparison, resolution, and denial (Gangstad, et al., 2009).

4.3.3. Psychological distress

The results support the study hypothesis - that ACT significantly improves psychological distress. This finding is consistent with the outcomes of former brief group ACT interventions in populations with neurological conditions (Jensen, et al., 2012b; Luciano, et al., 2014; Wicksell, et al., 2013). It becomes evident that the current study demonstrated

comparable (e.g. Wicksell et al., 2013) or larger effect sizes (e.g. Luciano et al., 2014) in the level of difference between the groups.

Whilst statistically significant between group differences are informative for testing the efficacy of the ACT intervention, the comparison of group means is less clinically useful than the individual changes observed for the participants (Gavin, 2008). Therefore, exploratory analyses were run to look at the net positive changes across the standardised classification criteria for anxiety and depression, for each stroke survivor and carer separately. The results found significantly different changes in a positive direction for categorisations of anxiety between the groups in favour of ACT, but not for depression. However, only 23.81% of the stroke survivors and carers (5/21) scored outside the normal limits at baseline in the ACT intervention. This is in contrast to many of the studies included in the systematic review, as many screened for levels of depression, and only included participants who displayed clinically significant symptoms. The differences highlight that the current intervention was conducted within a routine charity based service, as opposed to being delivered for the purposes of a research trial. Thus, it could be argued that the present study has greater ecological validity than some of the comparable research trials and the results could potentially be more generalisable to real life clinical settings. Nevertheless, the low level of baseline scores is significant, not only because of the substantial floor effects as already mentioned, but also because differences in moderation have been found in ACT studies (i.e. that differences at baseline moderate outcomes at follow-up). For instance, Forman, Herbert, Moitra, Yeomans & Gellar (2007) compared the impact of a brief ACT intervention for food cravings to a CBT intervention, and no treatment. They found that the outcomes differed depending on an individual's level of sensitivity to food in the environment at baseline. Individuals who reported fewer baseline difficulties did worse with ACT, but individuals who reported high levels of difficulty did significantly better than either CBT or no treatment when exposed to ACT. This has also been demonstrated elsewhere (Zettle, 2003).

This finding was not true for levels of anxiety, as 47.62% of the stroke survivors and carers in the ACT group (10/21), demonstrated clinical levels of anxiety. This finding is interesting alone, as anxiety has received substantially less attention than depression in stroke research.

4.3.4. Quality of life

Utilising the index score of the EQ-5D, there was an effect at trend level ($p = 0.06$) between the groups at post-intervention when controlling for baseline levels, but this was not sustained at follow-up. Hence, the initial hypothesis had to be rejected. This is in contrast to the majority of studies in the systematic literature review (Lundgren, et al., 2006; Carbonell-Baeza, et al., 2011; Wicksell, et al., 2013) where they all found significant interaction effects between the groups over time. There are a number of potential reasons for this. Firstly, it may be that, as discussed in the qualitative review, the group was not as “intensive” as one would have hoped, potentially adding further sessions may have assisted the individuals to gain further support to incorporate the group in to their everyday lives further. Secondly, the measure itself (EQ-5D) may not be the most appropriate measure of quality of life for the current population. Whilst the EQ-5D is a widely used measure of health related quality of life, it has been critiqued for being less responsive or sensitive than “disease” specific outcome measures. Indeed recommendations from the EuroQol group are that a condition specific measure should be administered alongside EQ-5D. In addition, the measure has been criticised for strong ceiling effects across each domain for the index values. As the ACT group demonstrated relatively high levels at baseline (0.79), this may have influenced the results. Furthermore, some of the studies in the systematic review, used measures such as the Satisfaction With Life Scale (SWLS) or explored mental health quality of life, despite the neurological nature of the samples. By using a health related quality of life scale, this study may have missed opportunities to capture gains outside of the health related field. Indeed, when reviewing the purpose of the group, ACT was not formally targeting health related quality of life at all, but very broadly speaking, hoped to assist the individuals to gain skills to live in the present, to become more aware of their internal dialogues, and live life in accordance to their goals, whatever they may be. Perhaps a measure such as the SWLS would have been more fruitful in capturing these changes.

4.3.5. Post-traumatic growth

Whilst the current intervention was not specifically designed to promote post-traumatic growth as a primary outcome, it was hypothesised that the ACT group may help the stroke survivors and carers to make the most of adversity, and cultivate personal growth and wellbeing. Hence, this measure was included as a wider exploratory interest. Indeed, it was known before commencing the study, that it is unclear how common it is for people to experience post-traumatic growth after engaging in a psychological therapy (Roepke, 2014). Likewise, it was known that empirical work does not clearly indicate whether growth helps people recover from psychological distress, or whether psychological distress makes room for post-traumatic growth, or if neither is true (Ickovics et al., 2006). However, it is important for research to contribute to areas where there are currently gaps. The current study did not find any significant changes in post-traumatic growth after attending the ACT group in comparison to the waiting list control, despite there being changes in psychological distress.

4.3.6. Psychological flexibility and goal directed thinking

In addition, the mechanisms of therapeutic action were examined. Exploring the potential mediating relationship of psychological flexibility and goal directed thinking on the outcome variables would have ideally allowed the analysis to move beyond an evaluation of the *impact* of the ACT group, to examining the relationship between ACT theory, practice, and outcomes. This is a major benefit within this model, as significant advances have been made in the development of measures that capture the key processes targeted within ACT. As discussed in Chapter one, accumulating evidence has supported the importance of psychological flexibility in determining psychological distress (Gloster, Klotsche, Chaker, Hummel, & Hoyer, 2011). But surprisingly, this study found no evidence that the ACT group improved psychological flexibility as measured by the AAQ-II, nor was any direct or indirect effect found for a mediating role.

It is unclear at the present time to what extent this finding is due to the way in which ACT was taught within the group, or the complex psychological, cognitive or generational

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influences of this population. It could also be queried whether the AAQ-II was the most appropriate measure of psychological flexibility. It has been noted that effective measurement of psychological flexibility involves developing questionnaires to suit that particular population (Whiting, et al., 2013). Indeed, this measure has been subjected to several alterations to make it appropriate for use with a variety of conditions and presentations, for instance diabetes - AADQ (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007a), epilepsy - AAEPQ; (Tobias Lundgren, Dahl, & Hayes, 2008), substance abuse - AAQ-SA (Luoma, Drake, Kohlenberg, & Hayes, 2011), auditory hallucinations - VAAS (Shawyer et al., 2007) etc. There is also now a measure for psychological flexibility relating to acquired brain injury - AAQ-ABI (Whiting, Deane, Ciarrochi, McLeod, & Simpson, 2014). One of the challenges in trialling a new therapeutic model with a particular population is the limited availability of appropriate and validated outcome measures. As a result, a generic measure of psychological flexibility was used. The adapted AAQ-ABI measure was not available at the time of administering the first questionnaires at pre-intervention (T1), but may be used in future stroke studies as an interim measure.

Another possibility considered was that the ACT group demonstrated significantly higher levels of psychological flexibility at baseline (total score = 49.50) compared to both the waiting list control group and a large comparison study (Kortte *et al.*, 2009). This may have an impact on the validity of the results, i.e. the ACT group was designed to increase psychological flexibility, but the initially high levels of psychological flexibility may have engendered a ceiling effect.

Given, the importance of process within ACT (Hayes, Levin, Plumb-Villardaga, Villatte, & Pistorello, 2011), another measure was included in the assessment – goal directed thinking. It was known to the researcher that the ASHS is not a widely used measure of process within ACT studies. However, it is a well-recognised measurement of goal-directed thought processes. As discussed, when confronted with a stroke many previous goals and ambitions are halted or no longer are perceived as attainable (Reed, et al., 2010). Hope (as measured by the ASHS) is seen to facilitate an individual's ability to find alternative paths to still

achieve goals, as well as the motivation to use those paths (Snyder et al., 2005). In this sense it could be argued that in order for change to occur, there is a need for some level of psychological flexibility to continue with, or change behaviour, in order to create new paths to meet one's goals. In many ways this reflects the core purpose of ACT – to increase the ability to persist or change behaviour in the service of one's chosen values (Hayes, 1993).

Whilst there were positive changes in this measure, these changes did not reach levels of statistical significance. This suggests that whilst the stroke survivors and carers attending the ACTion after Stroke group tended to perceive themselves to be generally more able to produce pathways of reaching their goals, and more capable of utilising their pathways to achieve their goals, but this was not statistically significant.

4.3.6.1. Other process measures

Given that ACT is a process-focused model (Hayes, et al., 2011), it is important to consider that the changes may have been due to factors that were not systematically measured. For instance, when considering some of the themes discussed in the qualitative analysis, participants frequently spoke of being more able to “notice” different emotions and thought processes, as opposed to being consumed by them. Although the definition of mindfulness varies across investigations, it could be argued that this is what is being reported, i.e. an enhanced attention to, and non-judgmental awareness of, present moment experiences (Brown & Ryan, 2003). In addition, the stroke survivors and carers described patterns of behaviour that were suggestive of defusion techniques. For example, participants reported that following an enhanced awareness to cognitive processes, they became able to “challenge the way the mind thinks” and “regain control” over what the mind was telling them. These concepts were not formally measured, but are likely to have impacted on the improvements in psychological distress.

Participants also spoke about the positive impact of peer support and feeling like “you're not alone”, “this is understandable” etc. This has been found in previous stroke studies

(Morris & Morris, 2012). It is therefore likely that some of the positive gains, may be attributable to experiential knowledge derived from personal experience rather than the theoretical ACT training.

4.3.7. Qualitative data

Given the paucity of the use of ACT with stroke survivors and carers, and the relative novelty of ACT in neurological conditions as a whole, it was felt important to explore how participants had experienced the group. It was hoped that this might generate new understandings that may not have been captured by quantitative methodologies alone. The data from a one hour focus group, has added important information about why participants had sought psychological support (despite none of the questions exploring this), and some of the reasons for their psychological suffering. Participants described feelings of “inadequacy”, and an altered sense of self, which parallels much of the literature regarding adaptation to changed circumstance (e.g. Lawrence, 2010; Schkade & Schultz, 2003). It emerged that the individual’s desire for mastery remained the same as pre-stroke, but their response post-stroke was judged to be inadequate. The resultant press for unattainable mastery therefore provoked an emotional response. It appears that the distress experienced, in part came from the fused evaluations and categorisations that they held (Hayes, et al., 2013), such as the excessive reliance on rules about what is possible for one’s life, by comparing previous abilities to current. The participants appeared to find it incredibly difficult to stay in contact with a more transcendent sense of self.

In addition, the stroke survivors and carers described a variety of ways in which they resisted giving in to their changed abilities. These findings appeared to fit with many of the underlying beliefs about psychological distress within ACT, for instance many participants described “pushing” against symptoms, disputing thoughts, ruminating, praying for things to go back to how they were, and engaging in experiential avoidance, which appeared to keep them feeling “trapped” in a life that felt out of their personal control, and were actually counterproductive in the longer term. The participants also spoke about how traumatic and frightening the stroke initially felt, two participants’ spoke about it as a significant trauma

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which they described resulted in “PTSD like symptoms”, which has been described by other authors such as Noble et al. (2011).

They also spoke about fearing future health, which resonates with previous reviews of stroke survivors experiences (McCormick, 2001), where a profound fear of a future stroke is often perceived with greater devastating consequences. In the descriptions provided, there was a literal quality to the thought, which often resulted in behavioural reactions such as seeking reassurance, and high levels of anxiety and distress. The alternative of being able to recognise the process as thoughts and feelings, and then let them go, was very difficult.

As time passed, participants described difficulties in interacting with people both within and outside the family. The struggle to maintain relationships is also evident in previous stroke studies (Murray & Harrison, 2004). In particular the stroke survivors and carers spoke about the sense of isolation they felt due to their diminished social interactions, which appeared to stymie valued and meaningful living. They spoke of how “invalidated” they often felt when people would pass judgments on how “well” they looked. This fits with lots of the literature which suggests that attention is often directed to the observable physical aspects of stroke (Judd, 1999) but the invisible emotional changes are often experienced as more disabling (Murray & Harrison, 2004). It appeared that many participants held fixed rules about what they wanted from their friends and family but felt unable to share this, instead they would often feel let down and hurt as their expectations were not met. This resulted in the participants withdrawing from these interactions in an attempt to avoid the aversive feelings experienced when feeling invalidated. From the ACT perspective, an alternative would be to accept that friends were unable to acknowledge the emotional consequences without being informed of them, and then working to find ways to still have meaningful and valued interactions with them.

As introduced above, the qualitative data also added rich insights with regards to the benefits experienced specifically as a result of attending the group. This was split in two

separate themes, the first related to ACT specific gains. Within this theme, participants described a range of positive gains, which appeared to map on to many core processes of ACT, such as a greater sense of separation between “me and my mind”, an ability to “notice” internal experiences such as both thoughts and emotional reactions, an ability to “accept”, and reconnecting with “values”. In addition, the participants shared specific parts of the course which they found particularly helpful. Of note, many of the participants commented on metaphors e.g. the quick sand effect, passengers on the bus etc., which until recently, were misconstrued as too difficult for persons who may be concrete in their thinking. What this study found was that metaphors were effective in exploring quite challenging concepts, and they appeared to form the memories which were most easily recalled during the focus group.

The stroke survivors and carers also reflected on the positive gains that they experienced in meeting others in similar situations through the group format of the ACT intervention. Morris and Morris (2012) like the study here, reported there is a positive value of meeting with peers. Participants also shared how the group had validated their emotional responses, which they had previously felt “underprepared” for. This emphasises the need for continued support, and suggests strongly that recovery does not stop when someone is discharged from hospital or the early supported discharge teams. This is shared in a recent survey completed by the Stroke Association, where four in ten individuals felt abandoned after leaving hospital (Stroke Association, Feeling Overwhelmed Campaign, 2012). This lends strong support for the need for input in the later stages of rehabilitation.

4.4. Study limitations - Difficulties encountered in the methodology

4.4.1. Design

Firstly, the quasi-experimental design needs to be thought about. The lack of a double-blind randomisation procedure to allocate the participants to the ACT intervention or waiting-list control group, is not in line with best practice guidelines (Higgins et al., 2011). As described

in the systematic review, randomised controlled trials are considered the gold standard for establishing effectiveness. However, using a randomised procedure would have led to ethical concerns, such as withholding the ACT group for some time from people who requested a place soon after the group was advertised. This was especially difficult as there was no other active psychological intervention available. Although this limits the current study's internal validity, it enhances its external validity, since RCT's often have "ideal conditions" which are not always available in routine clinical practice.

Nevertheless, the quasi-experimental design led to some difficulties - namely, the waiting list control group appeared to exhibit higher levels of psychological distress, and lower levels of psychological flexibility at baseline. The participants assigned to the control group were largely unknown to the charity. This is in contrast to the first group where later analyses showed that approximately 75.8% were recruited from persons already known to the charity. Whilst the charity did not provide any active psychological therapy, they did run several supportive groups, such as social groups, bowls, gardening projects etc. Hence, many of the participants recruited had already received low-level input. It could therefore be argued that the intervention group in the present study may have been more likely to respond well to treatment (i.e. a term described in research as "enrichment"), as the individuals had already been socialised in to this type of intervention. Internal validity is therefore potentially undermined here.

4.4.2. Sample

The sample also consisted of a heterogeneous population of both stroke survivors and carers. Whilst this type of intervention may be considered most favourable in meeting a larger populations' needs, the conclusions that can be drawn (by using the outcomes from both) may be limited. In order to counteract this limitation, exploratory analyses were conducted to assess whether or not the group produced different outcomes for the stroke survivors compared to the carers. As noted in Chapter three, there were no statistically significant differences found on any of the outcome measures. These findings suggest that

the stroke survivors experienced greater improvements in goal directed thinking compared to the carers. This did not appear to reflect a difference on the outcome measures.

More widely, the size of sample needs to be noted. It could be argued that such a modestly sized sample will not necessarily produce effects that meaningful estimate what a larger better controlled study would obtain. The participants predominantly also described themselves as “White British”, as such, it is unclear how these results would generalise to other socioeconomic groups.

4.4.3. Control condition

A further area that requires comment, is that individuals who made up the control group were placed on a waiting list. This issue has been canvassed in some detail elsewhere (see Hart, Fann, & Novack, 2008). Ideally, an active control condition would have been used to control for the non-specific effects of therapy. This research compared a group of individuals who had contact with clinical psychologists, a counsellor, and other stroke survivors and carers, with those who may have been totally isolated. Consequently, it is possible that the observed decreases in psychological distress are attributable to factors related to the group process, the therapist contact, or the participants’ own individual characteristics (e.g. motivation to change) as opposed to the ACT therapy per say. However, in order to provide an active control condition, the researcher would have to ensure an equivalent level of standardisation across treatments. The only comparison group that was available at that time was a peer support group. However, it was deemed unethical to invite people to attend the peer support for just four weeks, and then ask them to go back on a waiting list for a further two months, and the researcher did not have the time to establish another therapeutic group that was equivalent to the ACT group.

4.4.4. Uncontrolled and unmeasured variables

The researcher did not record the amount of medication taken by the stroke survivors or carers during the study period. This may potentially confound the reported results. Had the

researcher measured this, multilevel modelling could have potentially allowed a sensitivity analysis to be completed (with participants in both groups subdivided between those receiving and not receiving medication). However, this type of analysis would be complex for a pilot study.

4.4.5. Capturing the data

4.4.5.1. Choice of primary outcome measure

When thinking about the theoretical underpinning of ACT, it is questionable whether the HADS was the most appropriate primary outcome measure. The reason for utilising this measure was because it is the most widely used mainstream measure of psychological distress in stroke survivors. When reflecting back on the original aim of the thesis - to assess whether ACT could assist to lower levels of psychological distress in stroke survivors and their carers – the HADS met this need. However, some authors may argue that this could show a lack of understanding regarding the fundamental approach that ACT adopts. In ACT, reducing levels of anxiety and depression would be a secondary concern, compared to valued actions and life functioning. Instead then, the primary measures of importance may have instead targeted behavioural outcomes. The researchers did not include measures of targeted behavioural outcomes in the current study as the individual targets were largely unknown prior to the intervention, and are likely to have varied dramatically between each person. The purpose of employing the ACT model was for this exact reason, that it can be used without any significant tweaks, for a variety of presenting problems. However, by not capturing the reasons for engaging in the intervention, the authors were unable to capture whether the group was effective in meeting the goals the individual stroke survivors and carers came with. This is key, due to the philosophical approach of the model (i.e. functional contextualism). An alternative would have been to use the Psychological Outcomes Profiles (Psychlops) outcome measure, which generates a person-centred definition of outcome, through the creation of individual goals which are then used as outcomes. However, this would also be difficult, as goals are developed as part of the ACT treatment.

4.4.5.3. Self-report measures

The reason for utilising standardised self-report measures were discussed in Chapter two, i.e. they appeared to offer a reliable and objective measurement of fairly ambiguous psychological concepts. Nonetheless, the reliance on self-report measures can also be problematic. For example, these questionnaires do not detect subtle differences that may be seen before and after the groups. In addition, all the questionnaires relied on the use of self-rating scales. The response bias reported by many authors (e.g. Austin, Deary, Gibson, McGregor, & Dent, 1998) may lead to analyses of the questionnaires being more reflective of the respondent's style of answering than a genuine relationship between variables. Furthermore, these types of responses require a high level of self-analysis. Undoubtedly, we are all, to some extent unable to introspectively assess ourselves completely accurately and this could be exacerbated further after stroke.

4.4.5.4. Qualitative feedback

When reviewing the literature on ACT, very few studies have actually explored the participant's perspectives and experiences of attending an ACT group. However, much is to be learnt from listening to these experiences (Silverstein & Auerbach, 2009). Yet there are some limitations regarding the data obtained. Firstly, as with any qualitative study, the findings reported are highly subjective and may not be representative of a wider stroke population. This is intensified in the present study, when understanding that the focus group consisted of those participants who stayed in the second group and wished to give qualitative feedback. Had the feedback been gained from a randomised sample of all those who had participated in the ACTion after stroke group, this would have been less of an issue. Additionally, the sample consisted of only one carer. Whilst sample size is not a critical factor in qualitative research, as emphasis is not placed on power calculations, the study may have been strengthened by further inclusion of participants representing carers.

Secondly, the means of gathering the qualitative data needs comment. One of the major advantages of using a focus group for the researcher, was that it offered a means for the stroke survivors and carers to come together and reflect on their shared experienced as a

group. It was hoped that this would provide them with an arena to build on one another's responses, and to reflect on similarities but also differences, hence improving the richness of data gathered. However, the participants appeared to generate only themes that they shared. It would be interesting to see whether more themes would have been generated had the interviews been conducted on a 1:1 basis.

Thirdly, it may be questioned whether the conversations would have been quite different had the focus group not been conducted by the facilitators of the ACT group. Whilst this pre-existing knowledge and familiarity appeared to place participants at ease, it may have simultaneously led the participants to be inhibited in their responses. This limitation was addressed within the focus group, as the researcher encouraged the participants to be as honest as possible in their responses, and that their comments would never be taken as a personal criticism etc.

4.4.6. Data Analysis

As the study did not use the original pre-specified statistical analysis, due to sample not meeting the assumptions required for a MANOVA and the baseline differences in the outcome measures, selecting methods of analysis that favour the outcomes of the researchers hypotheses could become a serious cause for concern. However, to limit this risk, the researcher explored analyses used in previous stroke intervention studies, and then contacted a statistician in the local NHS clinical trials unit to ensure that this method was robust before completing the analysis. Additionally, the alternative analysis considered is also reported in the appendix (appendix L).

4.5 Further Research

Although this study offers important insights about the utility of a brief group based ACT intervention for stroke survivors and carers in the community, there are questions that

remain unanswered, and methodological limitations that could be ironed out in future research.

4.5.1. Design

Following on from the methodological limitations of this research, future studies would benefit from utilising a randomised controlled trial design that meets the criteria set forth by the Cochrane Collaboration (Higgins, et al., 2011). The methodological quality of research studies is especially important for stroke populations as they are critical for establishing evidence-based guidelines (Perdices et al., 2006), which to date are sparse for psychological interventions following stroke. Bearing this in mind, whilst the waiting list control was ethically acceptable to demonstrate the usefulness of ACT with stroke survivors and carers, future studies may benefit from testing the efficacy of ACT against other active treatments which would enable a control for the non-specific effects of therapy, and also help to answer whether ACT approaches are more accessible to this population in terms of their delivery and principles.

4.5.2. Sample

Given the low level of depression exhibited by the majority of stroke survivors and carers in the ACT intervention, and the findings that ACT may not work quite as well for minor problems and less entangled / avoidant presentations (Forman, Herbert, Moitra, Yeomans, & Geller, 2007; Zettle, 2003), it would be useful to repeat this study with a population that exhibited higher scores on measures of depression at baseline. Likewise, at the present time it is unclear if ACT would be equally as suitable for individuals who may present with increased levels of cognitive and language impairments.

4.5.3. ACTion after Stroke Course

In the designing of the intervention, the group content was based on ACT principles, but modifications were made such as using stroke specific examples, metaphors, repetition, pictorial representations etc. All of which aimed to compensate for potential cognitive

impairments, which may be common following stroke. In addition, easy-to-read written hand-outs at the end of each therapy session were provided to summarise the key components covered in each session. Mindfulness exercises were also given on CD's so that the stroke survivors and carers could practice the skills at home. This appeared to work well. However, based on the qualitative feedback, it appears that the group would have benefitted from additional sessions to reinforce and consolidate some of the skills discussed. Therefore, future research could include refresher courses, or potentially even expert patient led groups, where participants who had completed the course could facilitate ACT based discussions and exercises.

4.5.4. Measures

As has been discussed throughout this chapter, the purpose of utilising mediation analyses was to explore the mechanisms by which the ACT group worked. Since there were no statistically significant changes on the AAQ-II or the ASHS, further analyses are required to address whether this was due to the measure employed, components of the group, or due to some other factor. It would be interesting to measure the six core processes which are proposed to increase psychological flexibility, such as cognitive defusion, self as observer etc. Such an approach may allow future researchers to more readily identify the minimum boundary conditions of the model (i.e. which parts are required to be taught explicitly to derive positive gains), and hence suggest areas for further development. The researcher was conscious of asking people with potential cognitive impairment to complete too many forms in the present study.

Similarly, future studies could include measures of the non-specific effects of therapy, particularly those that capture constructs such as the individual's motivation to change, their willingness to practice the ACT techniques after the intervention has ended, or measures of group process or engagement.

4.5.5. Wider considerations

Other factors relevant to the broader aim of the work i.e. *to explore the efficacy of a group based therapeutic intervention that could be easily utilised in the community*, should also be established and disseminated, such as exploring the feasibility and acceptability of the treatment by clinicians as well as service users. Additionally, the economic and financial implications of the group could be measured to ascertain whether the ACTion after Stroke group reduced some of the wider financial ramifications of stroke such as the breakdown of care, increased rehabilitation outcomes etc.

4.6 Strengths of the current study

This is the first study to test the efficacy of an ACT intervention with stroke survivors and carers. It has provided preliminary evidence that this group could be recommended for individuals who are experiencing psychological distress in response to their own or their loved ones' stroke. Due to the nature of ACT, it can be used as a model that addresses the diversity of the psychological issues after stroke without significant adaptation, which appears to be a much needed resource.

There are also other non-scientific positive gains that are clinically useful. Firstly, the excellent retention rates in the first group needs to be considered, along with the long-term plans of the charity. The researcher and her supervisor were actively involved in the dissemination of the first two groups along with one of the counsellors from the charity. However, it is encouraging to note that the third group which commenced on the 17th March, 2015, was run by the charity alone. It has hence left a legacy and has been adopted as a rolling programme. The charity struggled to deliver psychological therapies on demand within its limited resources prior to this. The group has hence met the aim of providing an intervention that can be used and run in the community with infrastructures and resources already in place. In addition, the charity have recruited another 30 participants to attend this group. The demand for the ACT intervention has hence increased the numbers of individuals accessing the charity, which strongly supported the case for continued funding to be made available in order for the promising work to continue.

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The mechanisms of delivering the therapy also means that it can be fairly easily replicated where and when needed in the community. As already discussed through the qualitative analysis, the absence of psychological distress at the point of discharge, did not predict later psychological distress when initial support was taken away. This is also supported elsewhere (Townsend, 2007). Additionally, the way in which the intervention is delivered, means that it may be supplied by a range of staff, and does not require extensive knowledge or expertise in the model.

An additional strength of this research is that it focused on a range of measures, and primarily on psychological constructs rather than psychiatric diagnoses, which may be more helpful in capturing the full range of psychological difficulties potentially apparent following stroke. The implementation of both qualitative and quantitative methodologies is another major strength, and the themes generated from the qualitative analysis regarding the importance of key processes that were described as helpful have been reported.

Given the recruitment procedures of the current research (i.e. self-referral from wide ranging advertisement of the group), it could be argued that the findings provide an innovative supplement to the evidence obtained from more formal RCT's. Additionally, the multiple assessment time frames are a strength of the current design, and have allowed an exploration of both the immediate, and longer-term effects of the group, which in turn, has allowed an assessment of retention effects.

There is also increasing emphasis placed on the need to clarify the mechanisms by which psychological therapies produce change in the general population. Yet there is a paucity of studies that tests the moderator and mediation effects of psychological treatments within the existing stroke literature. The use of advanced statistical techniques (i.e. bootstrapping), offered a contemporary means of testing the hypotheses regarding the mechanisms of

therapeutic action within the current study and further research questions have been proposed as a result.

Finally, this service was implemented within an English charity, at the Welsh level it has been demonstrated that several government initiatives exist to improve the lives of those affected by stroke (Welsh Assembly Government, 2010, 2012). The results of the current thesis may potentially now be used as part of a wider bid to enable this course to be rolled out across Wales. One potential avenue would be through primary care services, i.e. Part one of the mental health measure. Another avenue is via the well-established Stroke Association. Indeed, in the current economic climate, where services are under-resourced, providing support to third sector organisations may be an effective use of a psychologist's time. Additionally, due to the modality of the intervention (i.e. the fact that a PowerPoint presentation is used) therapists' adherence to the therapy programme is likely to be high, without a huge amount of prior training.

4.7 Summary

It seems clear that the field of stroke rehabilitation is changing, with psychological and emotional wellbeing becoming more widely recognised. Likewise, in the psychological literature, mindfulness and acceptance-based approaches are becoming more and more popular, and the emphasis appears to be moving away from changing the *content* of thoughts; to changing *awareness of* and *relationship to* thoughts. This fits with the needs of a stroke population, as this model does not require any major alterations to meet a variety of presenting difficulties. In the current thesis, an ACT based therapeutic model has been piloted with stroke survivors and their carers. The results are promising and demonstrated an ability to reduce levels of psychological distress, both at immediate measurement and longer term follow-up. Further research and clinical recommendations and goals have been considered.

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Appendix A Search terms and databases used in the first literature review:

Stroke related search terms:

Stroke* OR cerebr* OR CVA OR intracran* haemorrhage OR ICH OR brain infarction OR
isch?emi* OR *Cerebral haem**

AND

Acceptance and Commitment Therapy search terms:

ACT OR Acceptance and Commitment*

Appendix B – Sample Homework exercise

ACTION after STROKE - Practice exercises

ACT1

Exercise 1. The experiences that are causing me grief

- List the **feelings** and **experiences** that are distressing you and spoiling your life.
- Focus **psychologically** - on your **experiences** rather than **situations**.


Example - "I am worried about money" rather than 'debt problems'.

- Identify the issues that are **distressing** you these days.

| | | |
|----------|-------------------|----------|
| thoughts | memories | emotions |
| urges | physical feelings | anxiety |

Only you will see this. **Be honest.**

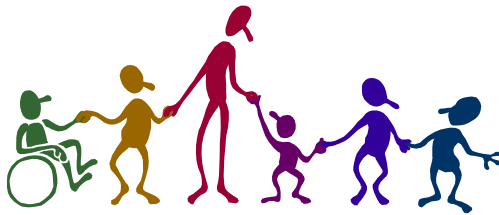
- Below, write down how long each of them has been affecting you - it could be weeks, months or years.

|  current painful experiences | How long this has been with me |
|---|--------------------------------|
| 1. | |
| 2. | |
| 3. | |
| 4. | |

Try looking at your list more closely. For example you could look at:

Which is the **biggest negative impact** on your life? Order your list from '**strongest**' → '**weakest**'.

- Which **issue** has been with you for the '**longest**' → '**shortest**'.
- Think about the **similarities** and **differences** between your issues.



- How are some of the **issues related** to each other?

Example - 'having fights with my partner' might be **related** to 'feeling depressed'.

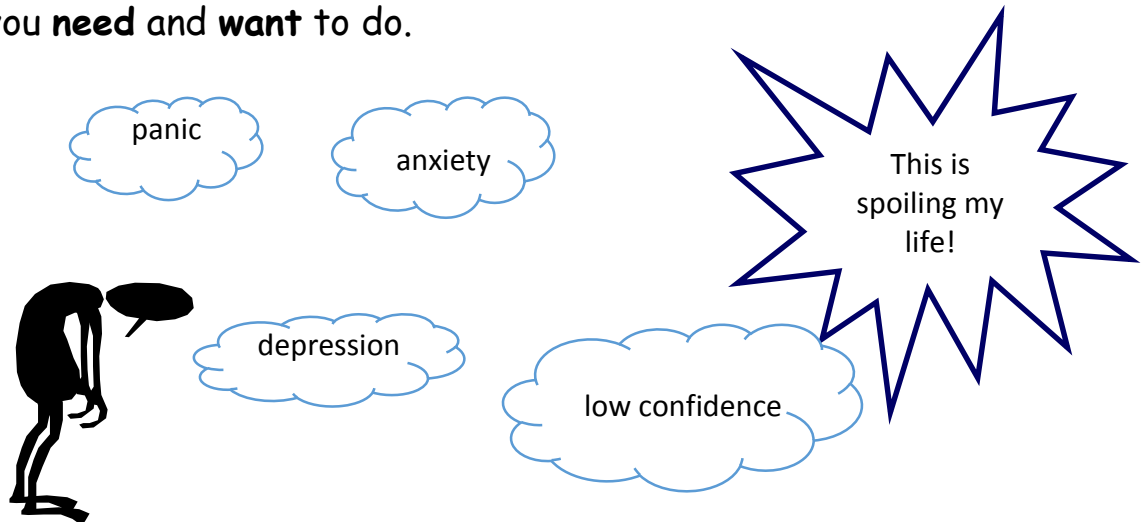
Can you make sense of such overlaps or which might lead to the other?

Each of these **ideas** suggests way for you to **explore** your own **problem issues**.

This will **help** you to **apply** the 'ACTION after Stroke' course material to **your own** situation

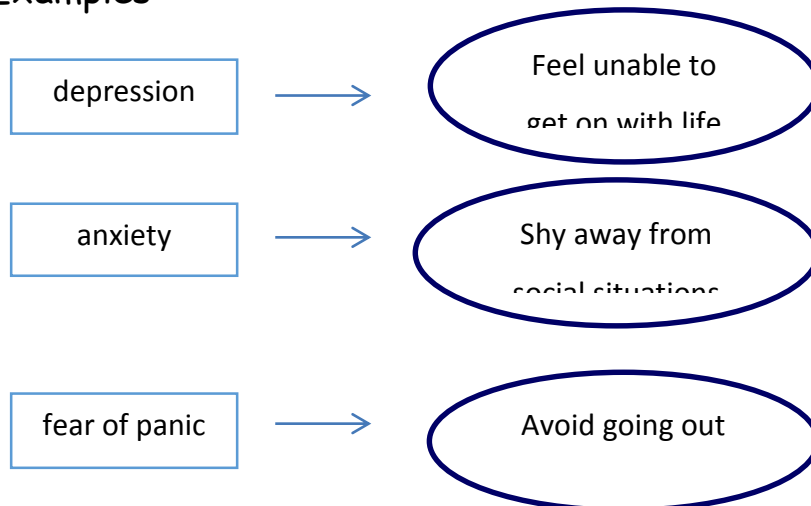
Exercise 2. The added cost of living in pain

Psychological pain not only **hurts you** but **holds you back** from doing things you **need** and **want** to do.



The **pain** and the limiting effects of the pain can act as a '**double whammy**', so what you can **comfortably do** in your **life** becomes **smaller and smaller**.

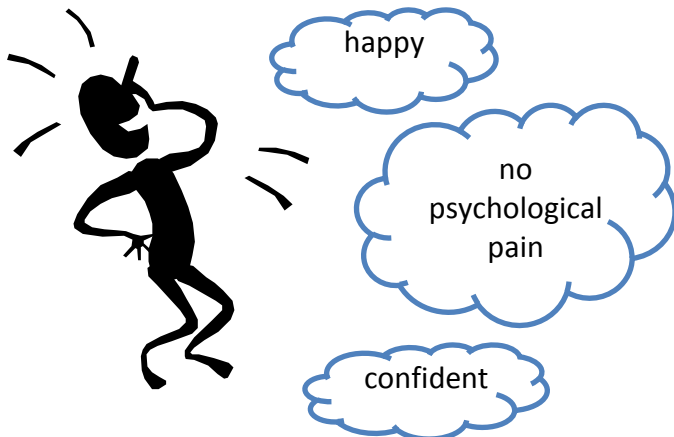
Examples -



Your **life** may have **shrunk** as a result. This **exercise** will show you just how your **distress** is **interfering** with your life.

The Magic Wand - how my life would be if ...

You can recognise the **added negative effects** of your suffering by **imagining** how your life would be different if your **pain** just **disappeared**.



What could you **do now**?

What would the **benefits** to your life be?

What would you then look **forward to**?

If all your major psychological pains had **disappeared** and you didn't have to struggle to cope with them, how would it **change your life**?

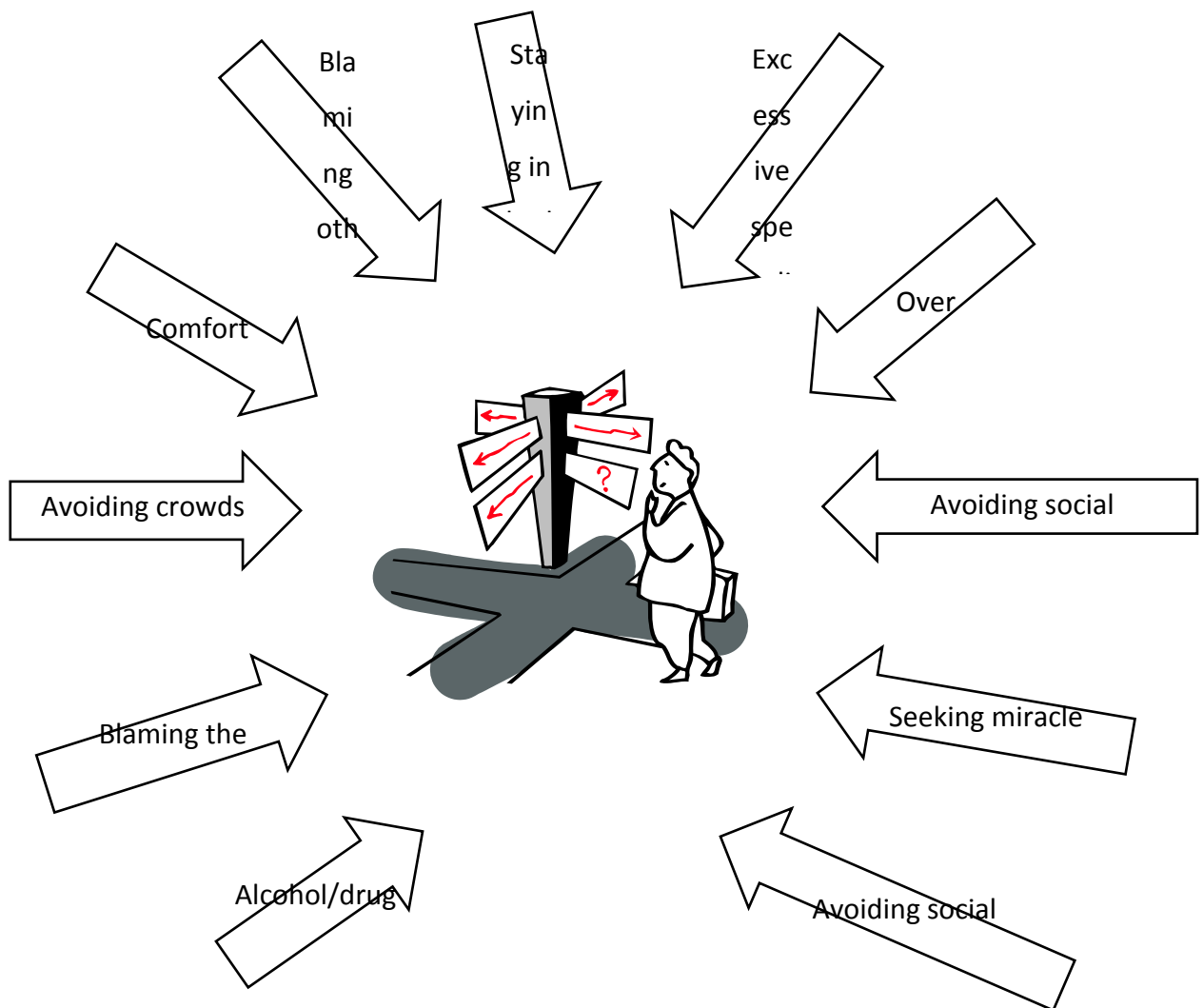


| |
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| |
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| |

- Consider the **benefits** that have come from losing your psychological pain. These are the **added costs** that are currently **associated with your suffering**.

Exercise 3. 'My quick fixes'

- Feeling **distressed** is unpleasant. It's natural for us to try to **avoid** it. People use various '**quick fix**' strategies to do this.
- Here are some of the everyday '**quick fix**' coping techniques that people use to try to **cover up, control/reduce painful thoughts, emotional feelings and physical sensations**.



- Can you think of any other '**quick fixes**' (especially ones you use yourself)?




Task A - consider each of the "quick fixes" above. Think about which ones you have **ever** used yourself. **Tick** this/these

Task B - which of these are your current favourites? **Circle** them.

These are the "quick fixes" that you have used at one time or another.

- Now, referring back to exercise 1, choose **three** of the **major thoughts** or **feelings** that currently **distress** you and **list** them in column 1 below.

| 1: Feelings | 2: Quick Fixes | 3: Short term effect | 4: Longer term effect |
|---|----------------|----------------------|-----------------------|
|  | | | |
| | | | |
| | | | |

- Now think about any '**quick fixes**' that you use when this feeling arises.

e.g. having a stiff drink or going up to bed. **Write** these in column 2.

- Then **think** what using this '**quick fix**' does for you in the **short term**. **Write** this in column 3.
- Finally **note** the longer term effects in column 4.



Example

| | | | |
|-------------------|-----------------------|------------------------------|------------------------------|
| <i>1: feeling</i> | <i>2: quick fix</i> | <i>3: short term effects</i> | <i>4: longer term effect</i> |
| <i>Anxious</i> | <i>Bottle of wine</i> | <i>relief</i> | <i>hangover</i> |

Appendix C - ACTION after Stroke



Summary of presentation

This course is based on an effective type of therapy called 'Acceptance and Commitment Therapy' (ACT). It challenges many 'common sense' ideas about the best way to overcome suffering.

Act 1 – Towards Less Suffering

Pain and Suffering

If we can't get rid of **pain**, it is possible to reduce the **suffering** caused by the **pain**.

If you had a **physical pain**, you would probably use **painkillers** or other **medical treatments**. But what if there was no effective relief and you had to live with the pain?

Pain is inevitable BUT suffering is optional

The "**fix it**" approach is fine for a problem with the plumbing or the car. But distressing **thoughts** and **feelings** **cannot** be "fixed" in the same way.

A lot of our suffering **doesn't** come directly from our painful emotions, thoughts or memories - it comes from our **reactions** to these things, and especially from our **struggles to control and eliminate** our psychological pain.



Think of "**THE QUICKSAND EFFECT**" - The best way to get out of a quicksand safely is not to struggle but to quietly lie flat and log-roll to safety

DON'T PUT LIFE ON HOLD! Another challenging ACT idea is that when you have a problem that can't be readily fixed, it's better to accept this and carry on with your life rather than putting it on hold.

Act – Key Components

1. Acceptance:

This DOESN'T mean "*just tolerating the emotional pain*" or "*admitting defeat*". It DOES mean being willing to live with the emotional pain.

2. Mindfulness:

A powerful way of focusing your attention. It helps you to focus sharply on the 'now'.

3. Commitment:

ACT helps you live your life in a way that fits in with the things that are really important to you.

How The Mind Works

The process of **linking images** and **words** is a **natural mental process** for human beings who have learned language. There is a **FUSION** between the **word** and **image** so that it's difficult to have one in your mind without the other being there also.



It is mainly through language that we are able to **create situations** that are **not real** at the time and to generate strong **emotional feelings** as a result.



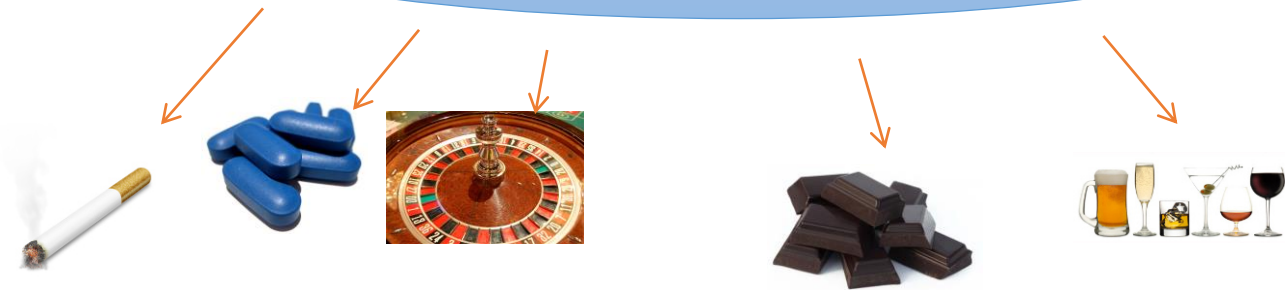
There is a lot to be said for *living in the real world*, not in the past or in the imagined future, but firmly in the here and now.

Avoidance

When you look into the **future**, and imagine a **negative emotional consequence** of doing something (e.g. going to the supermarket) - the natural tendency is “**not to go there**” – **avoidance**.

Avoidance is **natural**. It brings **short-term** relief from anxiety.

Quick fix strategies don't work for **very long** and they often have **serious negative effects** on the person's health, relationships and finances.



The Mind Train

It may feel as if the only choice you have is to go **along** the tracks in one direction or the other. But there's also a third option – **to get off the train!**

Once you get off the train, you will be able to walk in any direction you choose.



So it's **not** even **worth thinking** about whether **judgements** (e.g. **I'm** are **not popular, stupid, clever, ugly**, etc) are **right** or **wrong, true** or **false**.

Just don't go there; you don't have to!

So, how do you get off the train?

That's what this course is all about.....**Keep coming!**

Appendix E: Programme Outline

| | |
|---|---|
| <p>Session One – Towards Less Suffering.</p> | <ul style="list-style-type: none"> • Session one began with a general introduction to the course where individuals were taught about the group rules, concepts of confidentiality, the structure of the sessions etc. The general treatment rationale, consistent with the ACT model, was then shared. • Distinctions were first made between ‘pain’ and ‘suffering’, introducing the concept that even when if it is not possible to get rid of pain, it is possible to reduce suffering. • Next the therapists introduced the distinction between ‘fighting’ and ‘acceptance’, to emphasise that often our attempts to control or eliminate pain (both physical and psychological) can often be counterproductive. • Next the participants were introduced to different ways of coping with difficulties, highlighting strategies that were predominantly focused on avoiding or struggling. • Finally, the participants were orientated towards the need to live life in accordance to values. <p>Throughout the session, metaphors and exercises were used by the therapists, such as: ‘the late train’, ‘struggling in quick sand’, ‘the Chinese finger trap’, and ‘the Pink Elephant’ to help the participants observe the counterproductive effects of attempting to escape from, or fight against, aversive experiences.</p> |
| <p>Homework</p> | <p>EXERCISE 1 : The Experiences that are causing me grief</p> <p>EXERCISE 2 : The Added Costs of Living with Pain</p> <p><i>These exercises aimed to help participants to appreciate how much they are suffering, and how much their life is being affected by psychological pain</i></p> <p>EXERCISE 3 : “My Quick Fixes”</p> <p><i>This exercise focused on helping participants to recognise the things that they do to try to avoid psychological pain and distress and to monitor their use of such strategies.</i></p> |
| <p>Session Two – The Trouble with</p> | <ul style="list-style-type: none"> • In session two, the therapists began to more formally introduce the components of ‘psychological acceptance’, and framed it as a helpful alternative to experiential avoidance. • The therapists then aimed to increase their participants’ ability to |

Appendices

| | |
|--|---|
| <p>Thinking.</p> | <p>observe the minds activities, without becoming entangled in them</p> <ul style="list-style-type: none"> • The therapists then shared the need to adopt a healthy and objective scepticism of what the mind sometimes tells us. • Finally defusion skills were taught. <p>Several key experiential exercises were used throughout this session. For example, ‘the lost keys’ exercise was employed to allow participants to view their minds at work; the ‘breath holding exercise’ was used to encourage individuals to experientially notice their thoughts and feelings whilst feeling physical discomfort, and then to complete the same exercise but this time with ‘acceptance’ of this discomfort. Similarly, participants were encouraged to view how their minds get things wrong, through several visual illusions. Additionally, metaphors such as ‘the scary tomato’ were also used where a neutral tomato can become ‘threatening’ through the process of relating them to aversive events.</p> <p>Defusion skill exercises were also practiced such as: word repetitions and making sentences sound differently.</p> |
| <p>Homework</p> | <p>EXERCISE 4: Capturing Your Thinking Processes through Writing.</p> <p><i>This exercise simply encouraged participants to spend some time paying careful attention to their own thinking</i></p> <p>Exercise 5: “Poisonous Word Defusion”</p> <p><i>In this exercise participants were asked to identify a word that was personally distressing, and to subject this word to constant repetition in order to reduce the ‘sting’ that this word has</i></p> <p>Exercise 6: “Sentence Completion”</p> <p><i>This activity demonstrated some of the strong verbal patterns in their minds.</i></p> |
| <p>Session Three – Being Here and Now (Mindfulness)</p> | <ul style="list-style-type: none"> • This third session focused further on cognitive defusion, and began by making distinctions between ‘descriptions’ and ‘evaluations’, and employed techniques aimed to build a sense of ‘self as context’. • Participants were then encouraged to ‘contact the present moment’ and observe their internal experiences. • Finally the concept of ‘psychological flexibility’ was introduced with several exercises introduced to be practiced at home. |

Appendices

| | |
|---|---|
| | <p>Several key mindfulness exercises were practised within this session such as: ‘floating leaves on moving stream’, ‘the brief body focus’ and the ‘three minute breathing space’ to help people become present.</p> |
| Homework | <p>EXERCISE 8: Descriptions and Evaluations <i>This exercise was a quiz in which participants were asked to make distinctions between descriptions and evaluations</i></p> <p>EXERCISE 9: It’s the Way that You Say It <i>This offered de-fusion practice – participants were asked to speak about things in their lives – but using one voice that ‘fit’ and one that didn’t</i></p> <p>EXERCISE 10: Watching the Mind at Work <i>This exercise provided a demonstration of the mind making things up</i></p> <p>Exercise 11: Mindfulness Exercises <i>Four mindfulness exercises recorded on to CD.</i></p> |
| Session Four – Getting on with your life | <ul style="list-style-type: none"> • Throughout this session, the therapists encouraged patients to increase their willingness to experience unwanted thoughts and feelings in the service of valued based living. • Participants were encouraged to identify psychological barriers that prevented them from following a valued directed path in life. • Acceptance and mindfulness exercises were framed as techniques which could facilitate valued directed living. <p>Examples of ACT metaphors used during this phase include: ‘Passengers on the Bus’.</p> |
| Homework | <p>Exercise 12 – Your 100th Birthday Party <i>This exercise was used to identify values</i></p> <p>Exercise 13 – Increasing Flexibility <i>This exercise asked participants to deliberately change some of their rehearsed actions in an attempt to increase psychological flexibility</i></p> <p>Exercise 14 – Three Commitments <i>This final exercise asked participants to think about putting their goals in to practice.</i></p> |

Appendix F: Confirmation Letter

3 March 2014

Dear

ACTion after Stroke course

I would like to confirm that you have a place on the ACTion after Stroke course which starts on XX. The course takes place on four consecutive Wednesdays for four weeks. It is important that you attend every week to make the most of the course.

The dates and times are below:

19 March 10.00 - 12.30

26 March 10.00 - 12.00

2 April 10.00 - 12.00

9 April 10.00 - 12.30

Please note that the first and last week is 30 minutes longer than the other weeks finishing at 12.30pm.

The course is being held at:

XX

Parking and public transport

XX is opposite the large Sainsbury's and retail park at XX beside the ring road.

There is a small car park at the Hall and some limited on-road parking. There is ample parking in the retail park a short walk away. To minimise your walk from the Sainsbury's car park, park close to the walkway that goes to Costa Coffee. This leads you down directly opposite Sainsbury's. There is a ramp to avoid the steps. Please be aware of the time restriction on parking at Sainsbury's.

Buses: the 48 and 49 go from Bristol City Centre to the Retail Park

As ACTION after Stroke has been newly designed for people affected by stroke and this is the first course of its kind, we want to evaluate how effective it is at helping you. To do this, a Trainee Clinical Psychologist, X X, will ask people at the first course if you want to take part in the study to see how helpful ACTION after Stroke is to you. You don't have to take part in the research to go on the course. You can choose at the first meeting. I enclose an information sheet about the research so that you can understand more about it. X will explain more about it at the first meeting and ask you if you are willing to take part in the evaluation. Obviously it helps us if as many people as possible take part in the evaluation, but you choose.

If you are unable to come or have any queries, please call the office on 0117 964 7657.

We look forward to seeing you at the course on XX. I hope you find it very helpful.

Kind regards

XX

Operations Manager

X

Appendix G: Participant Information Sheet

ACTion after Stroke

Participant information sheet

You are invited to attend a four week therapeutic course called '*ACTion after Stroke*'. The sessions will all last two hours. The group will be run by staff of the XXXX, X X (Trainee Clinical Psychologist), and X X (Consultant Clinical Psychologist). The group will take place at X on the following dates:

Wednesday, 19th March, 2014

Wednesday, 26th March, 2014

Wednesday, 2nd April, 2014

Wednesday 9th April 2014

What is Acceptance and Commitment Therapy?

Acceptance and Commitment Therapy (also known as ACT) is different from many therapies, such as Cognitive Behavioural Therapy – which is more widely known. It is a therapy which teaches people to accept what is out of our personal control. It is **based on the idea that, generally, trying to rid ourselves of pain and distress only serves to increase it. The alternative then, is to accept it - but that doesn't mean being defeated or tolerating suffering. ACT is about learning skills and ways of managing to make room for painful feelings, thoughts, and sensations - allowing them to be there, without having to struggle against them. But it is more than just this, it is also about** committing to action that improves and enriches our lives.

How may it benefit me?

There is a lot of research available, which has shown that this therapy is successful in reducing levels of distress in people who have both physical health conditions and psychological distress. One person who has received this therapy stated **“You can learn to free yourself from the traps and barriers of life, and see what you really want your life to be”**.

What will I need to do?

You will need to commit to attend four sessions of this group. Each session will last two hours, and there will be a break included at the middle of each session. The layout of each session will be the same. There will be a presentation given by X staff, myself and X (Consultant Clinical Psychologist). You do not have to contribute or speak at all if you do not wish to do so. We just ask that you listen to the session content with an open mind.

As part of your attendance we would be really grateful if you would be willing to spend some time to fill out some questionnaires that asks you questions about how you have been feeling recently. We will ask you to complete these questionnaires before attending the group, after the group has finished and then finally three months later. This is to help us to evaluate how effective the group is.

If you wish to be part of the research could you please read the accompanying consent form, and return them to us at the first ACTION after Stroke session.

How will my information be used?

The results of the research will be written up as a thesis and as an article and submitted as part of my Doctorate in Clinical Psychology. It is important that you know that no participants will be identified in any way as part of this process.

Before you decide whether you would like to take part, please read this information sheet carefully, so that you know exactly what is involved, and how you can help. Please feel free to discuss this with others, and feel free to contact myself, or X (details below) to ask any questions if there is anything you are not sure about, or if you would like more information.

Do I have to take part?

There is absolutely no requirement to participate in the research, and if you wish to join the group but not take part in the research you will still be welcomed as a valuable member.

What is the purpose of the study?

We understand that sustaining a stroke can be a really difficult experience for some survivors, and indeed for their carers. There is lots of evidence that suggests that there is a higher amount of anxiety and depression in people who have sustained a stroke than in the general population. This is also true of carers. We want to explore ways in which we may be able to reduce this. We think that this model of therapy could be really useful to stroke survivors and carers. However, to date, there is no research available to explore how useful it is.

The aim of this project is therefore to look at how effective or not this group is in reducing levels of anxiety or depression, and assisting with positive adjustment.

Do both the stroke survivor and his/her carer/spouse need to take part?

Either one, or both, can participate, but we ask that all participants come to all four sessions.

What exactly is involved if I do agree to take part?

If you decide to take part in the research there will be five questionnaires for the stroke survivors to complete, and five for the carers. These should take no longer than 30 minutes to complete. As described above, both carers and survivors will then complete the same questionnaires after completing the group, and with your permission, we would like you to complete these again three months after you finished attending. We may contact you via telephone, letter or email to complete these forms for the final time if you are willing for this.

Will my participation in the study be confidential?

Your participation in the research will be kept strictly confidential. The questionnaires will be seen only by myself and my research supervisor (X) and will be kept in a locked filing cabinet and identifiable information will be destroyed after 2 years.

I have a duty of care to protect people from harm, so there are some legal and ethical rules I must obey which could require me to over-ride confidentiality if there is a risk of harm.

Who has reviewed the study?

All research is looked at by a Research Ethics Committee in order to protect your safety, rights, dignity and wellbeing. This study has been reviewed and approved by the Cardiff University School of Psychology Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or need further information please do not hesitate to contact the Researcher.

Appendices

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated.

If you would like more information about the project, please feel free to contact us:

X X

Trainee Clinical Psychologist, Postgraduate student.

South Wales Doctoral Programme in Clinical Psychology

11th Floor, School of Psychology, Tower Building,

70 Park Place,

Cardiff,

CF10 3AT

Email: Jenna.L.Ivey@wales.nhs.uk

Tel: 029 20870582

Clinical and Academic supervisor:

Prof. X X

Consultant Clinical Psychologist

South Wales Doctoral Programme in Clinical Psychology

Cardiff & Vale UHB

Email: Reg.Morris@wales.nhs.uk

Tel: 02920 206464

Information Sheet for Control group.

As you are aware we are about to run an Acceptance and Commitment Therapy Group for stroke survivors and their carers, at the X X X X (X). As you have shown some interest in attending this group, this sheet gives you a little more information about what this group is about, and how it is being evaluated. It also asks for your assistance in this evaluation.

What is Acceptance and Commitment Therapy?

Acceptance and Commitment Therapy (also known as ACT) is different from many therapies, such as Cognitive Behavioural Therapy – which is more widely known. It is a therapy which teaches people to accept what is out of our personal control. It is **based on the idea that, generally, trying to rid ourselves of pain and distress only serves to increase it. The alternative then, is to accept it - but that doesn't mean being defeated or tolerating suffering. ACT is about learning skills and ways of managing to make room for painful feelings, thoughts, and sensations - allowing them to be there, without having to struggle against them. But it is more than just this, it is also about committing to action that improves and enriches our lives.**

How may it benefit me?

There is a lot of research that is available, that has shown that this therapy is successful in reducing levels of distress in people who have both physical health conditions and psychological distress. One person who has received this therapy stated **“You can learn to free yourself from the traps and barriers of life, and see what you really want your life to be”**.

Evaluation

This is the very first use of ACT with stroke survivors and their carers, and we are interested in to seeing how effective it is. So we are asking that the people who are currently about to attend the group fill out five questionnaires that explore how they are currently feeling. We are asking them to complete these questionnaires before attending the group, after the group has finished and then finally three months later, so that we can see if there are benefits. We would really value your help in this process by completing questionnaires at similar time intervals while you are waiting to be included in an ACT programme. This will enable us to determine if ACT is better than no treatment.

Why are you doing this?

We understand that sustaining a stroke can be a really difficult experience for some survivors, and indeed for their carers. There is lots of evidence that shows there is a higher amount of anxiety and depression in people who have sustained a stroke than in the general population. This is also true of carers. We want to explore ways in which we may be able to reduce this. We think that this model of therapy could be really useful to stroke survivors and carers. However, to date, there is no research available to explore how useful it is.

The aim of this project is therefore to look at how effective this group is in reducing levels of anxiety or depression, and assisting with positive adjustment. In order to do this we need the help of those who are currently receiving ACT therapy, and those who are waiting to receive it.

What will I need to do?

At the moment you are on the waiting list to attend the next group, which we hope you will attend. What we would like you to do, if you chose to, is to complete the same questionnaires, at the same time points as the people attending the group.

Why do you need me to complete the forms when I am not attending the group now?

When conducting research, there are lots of factors that may lead to change in how a person feels, for example, time may be a factor in why somebody's scores may improve on questionnaires which assesses mood, etc. One of the ways in which we try to "control" for these other factors, is to also include a "control" group in the study. What this basically means is, the researcher can use two groups, so that one group receives an intervention and the other one doesn't. The two groups are assessed in the same ways. Now, any difference between the two groups can be ascribed to the intervention itself, with much greater confidence.

Will this mean that I will be stopped from attending the group?

Not at all! We are just asking you to complete these questionnaires now whilst you are not receiving an intervention. You will be invited to attend the next group that is run.

How will my information be used?

The results of the research will be written up as a thesis and submitted as part of my Doctorate in Clinical Psychology. It is important that you know that no participants will be identified in any way as part of this process.

Before you decide whether you would like to take part, please read this information sheet carefully, so that you know exactly what is involved, and how you can help. Please feel free to discuss this with others, and feel free to contact myself, or Professor X X (details below) to ask any questions if there is anything you are not sure about, or if you would like more information.

Do I have to take part?

There is absolutely no requirement to participate in the research, and if you wish to join the group but not take part in the research you will still be welcomed as a valuable member.

Do both the stroke survivor and his/her carer/spouse need to take part?

No, either party can take part.

What exactly is involved if I do agree to take part?

If you decide to take part in the research there will be five questionnaires for the stroke survivors to complete, and five for the carers. These should take no longer than 30 minutes to complete. As described above, you will then be asked to complete the same questionnaires in eight weeks time, and then again three months after this. We may contact you via telephone to complete the final questionnaires, if you are willing for this.

Will my participation in the study be confidential?

Your participation in the research will be kept strictly confidential. The questionnaires will be seen only by myself and my research supervisor (X X) and will be kept in a locked filing cabinet and identifiable information will be destroyed after 2 years.

I have a duty of care to protect people from harm, so there are some legal and ethical rules I must obey which could require me to over-ride confidentiality if there is a risk of harm.

Who has reviewed the study?

All research is looked at by a Research Ethics Committee in order to protect your safety, rights, dignity and wellbeing. This study has been reviewed and approved by the Cardiff University School of Psychology Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or need further information please do not hesitate to contact the Researcher

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated.

Jenna Ivey

If you would like more information about the project, please feel free to contact us:

X X

Trainee Clinical Psychologist, Postgraduate student.

South Wales Doctoral Programme in Clinical Psychology

11th Floor, School of Psychology, Tower Building,

70 Park Place,

Cardiff,

CF10 3AT

Email: Jenna.L.Ivey@wales.nhs.uk

Tel: 029 20870582

Clinical and Academic supervisor:

X X

Consultant Clinical Psychologist

Appendices

South Wales Doctoral Programme in Clinical Psychology

Cardiff & Vale UHB

Email: Reg.Morris@wales.nhs.uk

Tel: 02920 206464

Appendix H: Consent Form

Please read each statement below, and circle the appropriate Yes or NO response

I understand that my participation in this study will involve completing five questionnaires, which should take no longer than forty minutes to complete.

YES / NO

I understand that I will be asked to complete these questionnaires on three separate occasions (At the beginning of the group, at the end of the group and three months after completion of the group)

YES /NO

I understand that my participation in this study is entirely voluntary and that I can choose to stop attending the sessions, or complete the questionnaires at any time, without giving a reason.

YES / NO

I understand that I am free to ask questions at any time. I am free to discuss my concerns with Professor Reg Morris, consultant Clinical Psychologist and Programme Director on the South Wales Doctoral Programme in Clinical Psychology.

YES / NO

I understand that the information provided by me will be held confidentially, such that only the Researcher can trace this information back to me individually. The information will be retained for up to 2 years then it will be destroyed. I understand that I can ask for information I provide to be destroyed at any time, and I can have access to the information at any time.

YES / NO

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I give permission for the information to be used in reports with the understanding that it will maintain anonymous.

YES / NO

I understand that if the researcher is concerned that I may harm myself or another person, that she will share this information with somebody else in her team who may request to speak with me to assess this risk. Action may then be taken to help keep me or others safe.

YES / NO

I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study

YES / NO

I, _____ (please enter your NAME) consent to participate in the study conducted by X X, who is working under the supervision of Professor X X.

I am / am not (please circle your response) willing for X to contact me via telephone to complete the final questionnaires.

Signed (participant): _____

Date: _____

Appendix I Participant Debrief Sheet

I would like to really thank-you for taking part in this study! Your time and input is very much appreciated indeed.

The aim of this study was to evaluate how effective Acceptance and Commitment Therapy (as delivered in this group) is in alleviating distress in stroke survivors and carers. We have used the questionnaire data that you have kindly completed, to see whether there were any changes in the questionnaires completed before the group, after the group, and also at a three month follow-up. We also have compared your scores to a group of stroke survivors and carers who have not yet taken part in the group, so that we can conclude with more certainty that it was the intervention that caused the changes rather than some other factor, such as time for example. We are hoping that these comparisons will lead to some conclusions to be drawn about how helpful this group is, and whether it is a field to explore further. We are also hoping that this information can be used for stroke survivors in the future.

The information that you have provided will be coded (so that no names are ever written down) and then analysed. As stated at the beginning, your data will be held confidentially and you have the right to withdraw your data without explanation and retrospectively if you so choose, up until the point that the data is fully anonymised.

If you wish to have information about the results of the study please let X X know and she will send you a summary of the results as soon as they are available.

Additionally, if you would like to make any comments then please feel free to contact either myself or Professor X X.

Appendices

Many thanks,

X X

Trainee Clinical Psychologist

Supervised by,

X X

Consultant Neuropsychologist

If you would like more information about the project, please feel free to contact us:

X X

Trainee Clinical Psychologist, Postgraduate student.

South Wales Doctoral Programme in Clinical Psychology

11th Floor, School of Psychology, Tower Building,

70 Park Place,

Cardiff,

CF10 3AT

Email: Jenna.L.Ivey@wales.nhs.uk

Tel: 029 20870582

Clinical and Academic supervisor:

Prof. X X

Consultant Clinical Psychologist

South Wales Doctoral Programme in Clinical Psychology

Cardiff & Vale UHB

Email: Reg.Morris@wales.nhs.uk

Tel: 02920 206464

If you have any concerns or complaints about the research you can contact the **School of Psychology Research Ethics Committee** in writing at:

Appendices

Secretary to the Research Ethics Committee

School of Psychology, Tower Building

70 Park Place, Cardiff, CF10 3AT

Email: psychethics@cardiff.ac.uk

Appendix J Measures

POST TRAUMATIC GROWTH INVENTORY

Author: Tedeschi & Calhoun (1996)

Listed below are 21 areas that are sometimes reported to have changed after traumatic events. Please mark the appropriate box underneath each description indicating how much you feel you have experienced change since your stroke. The 0 to 5 scale is as follows:

- 0 = I did not experience this change as a result of my crisis.
- 1 = I experienced this change to a very small degree as a result of my crisis.
- 2 = I experienced this change to a small degree as a result of my crisis.
- 3 = I experienced this change to a moderate degree as a result of my crisis.
- 4 = I experienced this change to a great degree as a result of my crisis.
- 5 = I experienced this change to a very great degree as a result of my crisis.

1. I changed my priorities about what is important in life. (V)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

2. I have a greater appreciation for the value of my own life. (V)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

3. I developed new interests. (II)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

4. I have a greater feeling of self-reliance. (III)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

5. I have a better understanding of spiritual matters. (IV)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

6. I more clearly see that I can count on people in times of trouble. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

7. I established a new path for my life. (II)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

8. I have a greater sense of closeness with others. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

9. I am more willing to express my emotions. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

10. I know better that I can handle difficulties. (III)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

11. I am able to do better things with my life. (II)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

12. I am better able to accept the way things work out. (III)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

13. I can better appreciate each day. (V)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

14. New opportunities are available which wouldn't have been otherwise. (II)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

15. I have more compassion for others. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

16. I put more effort into my relationships. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

17. I am more likely to try to change things which need changing. (II)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

18. I have a stronger religious faith. (IV)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

19. I discovered that I'm stronger than I thought I was. (III)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

20. I learned a great deal about how wonderful people are. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

21. I better accept needing others. (I)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

Hospital Anxiety and Depression Scale

Author: Zigmond & Snaith (1983)

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or 'wound up'

Most of the time
A lot of the time
From time to time, occasionally
Not at all

I feel as if I am slowed down

Nearly all the time
Very often
Sometimes
Not at all

I still enjoy the things I used to enjoy

Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I have lost interest in my appearance

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I can laugh and see the funny side of things

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

Worrying thoughts go through my mind

A great deal of the time
A lot of the time
Not too often
Very little

I look forward with enjoyment to things

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I feel cheerful

Never
Not often
Sometimes
Most of the time

I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

I can sit at ease and feel relaxed

Definitely
Usually
Not at all
Occasionally

I can enjoy a good book or radio or television programme

Often
Sometimes
Not often
Very Seldom

Appendices

The Acceptance and Action Questionnaire (AAQ-2)

Author: Bond et al. (2011).

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|
| never true | very seldom true | seldom true | sometimes true | frequently true | almost always true | always true |

| | | | | | | | |
|--|---|---|---|---|---|---|---|
| 1. Its OK if I remember something unpleasant. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. My painful experiences and memories make it difficult for me to live a life that I would value. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I'm afraid of my feelings. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. I worry about not being able to control my worries and feelings. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. My painful memories prevent me from having a fulfilling life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I am in control of my life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. Emotions cause problems in my life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. It seems like most people are handling their lives better than I am. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. Worries get in the way of my success. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. My thoughts and feelings do not get in the way of how I want to live my life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Adult State Hope Scale

Author: Snyder et al. (1996)

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes *how you think about yourself right now* and put that number in the blank before each sentence. Please take a few moments to focus on yourself and what is going on in *your life at this moment*. Once you have this “here and now” set, go ahead and answer each item according to the following scale:

- 1 = Definitely False
- 2 = Mostly False
- 3 = Somewhat False
- 4 = Slightly False
- 5 = Slightly True
- 6 = Somewhat True
- 7 = Mostly True
- 8 = Definitely True

- _____ 1. If I should find myself in a jam, I could think of many ways to get out of it.
- _____ 2. At the present time, I am energetically pursuing my goals.
- _____ 3. There are lots of ways around any problem that I am facing now.
- _____ 4. Right now, I see myself as being pretty successful.
- _____ 5. I can think of many ways to reach my current goals.
- _____ 6. At this time, I am meeting the goals that I have set for myself.

EUROQOL 5D (For Stroke Survivors only)

Author: The EuroQol Group (1987)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

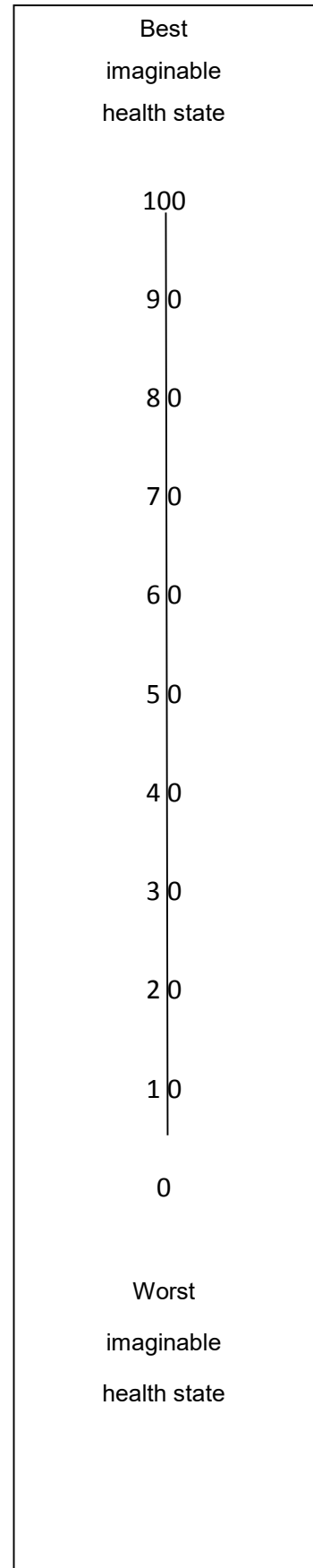
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

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To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own
health state**



Appendix K Confirmation of Ethical Approval

CARDIFF UNIVERSITY

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE

Committee Decision and Feedback Form

This project has been scrutinised by the School of Psychology Research Ethics Committee. The Committee's general remit is to ensure that adequate measures have been taken to avoid any ethical problems that could reasonably be anticipated on the basis of generally agreed ethical guidelines like those set out by the BPS. Approval of a research proposal means that in the Committee's opinion this proposal meets this criterion; responsibility for any breach of ethical conduct rests with the individual researcher. Should any unforeseen problems arise during the conduct of this research, the Chairman of the Ethics Committee (Dr Michael Lewis) should be informed.

Project Proposal: Jenna Ivey (PG) - Acceptance and Commitment Therapy Group for Stroke Survivors and Carers (EC.13.11.12.3592), supervised by Reg Morris.

The Ethics Committee considered the above proposal and noted that it was very clear and comprehensive. The following comments were made:

- .1** The Committee sought clarification on when the exclusion/exclusion criteria would be applied and by whom. Will this be self-referral? Does the section under capacity related to this?
- .2** The Committee noted that 2 information sheets will be given out - one for the control and one for the treatment group. At what stage will they be put into groups? How will they be assigned? It is good to have two separate information sheets but it means that assignment must have taken place before participants have agreed to take part.
- .3** The Committee queried whether there should also be 2 different consent forms.
- .4** The Committee noted that participants will be placed on a waiting list. Will they be told how long they need to wait?
- .5** On the Consent form the 7th statement should provide more of an explanation about what would happen in the event of a disclosure.

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.6 The Committee noted that there are strong links with the organisation but requested a copy of a gatekeeper letter/agreement confirming that they are happy for the research to take place.

.7 The Committee queried whether the researchers would agree to this proposal being placed on the web as a good example, after all identifying information is removed.

DECISION: Revise and resubmit proposal (to be dealt with prior to the next meeting of the Ethics Committee).

Please submit the following to Psychethics as soon as possible:

- Written response to each of the above points with details (incl. Page numbers) of any changes made to the proposal. (Please insert your response after each of the points above.)
- A copy of the amended proposal with any changes **highlighted**

NB: You may not proceed with this study until the requested revisions have been made and approved by the Ethics Committee.

Please note that it is in the researcher's interests to submit revisions to the Secretary of the Ethics Committee as soon as possible. Upon receipt, revisions will be passed immediately to the Chair of the Committee. If satisfactory, the proposal will be approved via Chair's action PRIOR to the next meeting of the Ethics Committee. The Secretary will notify the researcher and supervisor of the Chair's decision.

Appendices

From: Natalie Moran (MoranN@cardiff.ac.uk)

28/11/2013

To: j.livey@hotmail.co.uk

Cc: reg.morris@wales.nhs.uk

Dear Jenna,

The Chair of the Ethics Committee has considered your revised postgraduate project proposal: Acceptance and Commitment Therapy Group for Stroke Survivors and Carers (EC.13.11.12.3592R).

The project has now been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Natalie Moran

School of Psychology Research Ethics Committee

Tower Building

Park Place

CARDIFF

CF10 3AT

Ffôn /Telephone: +44 (0) 29 2087 0360

Ffacs/Fax: +44 (0) 29 2087 4858

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Appendix L Results of MANOVA

A multivariate analysis (MANOVA) was carried out to assess the impact of the intervention on the three outcome measures (HADS, PTGI and EQ-5D) at post-intervention and follow-up. It made good theoretic sense to include only the outcome measures in the initial MANOVA, as it is these measures which would answer the question as to whether this ACT group therapy would increase psychological wellbeing and quality of life, and facilitate post traumatic growth in adult stroke survivors and their carers. However, separate analyses were run to assess the group differences in the process measures over the separate time frames, as exploratory analyses. In this sense the first analysis was of heuristic interest and the second was of theoretical interest (i.e. the process measures that explore some of the key underpinnings within ACT).

The differences at baseline (T1) needed to be controlled for. As a result *change* scores were calculated based on the differences at post (T2) from pre intervention (T1). These change scores were entered in the MANOVA, rather than the raw total scores. The box's test of the assumption of equality of covariance matrices, was non-significant ($p = 0.276$); hence the covariance matrices are roughly equal as assumed. Using Pillai's trace, there was a significant multivariate effect of group, on the psychological outcome measures, $V = 0.22$, $F(3, 44) = 4.090$, $p = 0.012$. Separate univariate ANOVAs on the outcome variables separately revealed significant effects on the HADS, $F(1, 46) = 3.54$, $p = 0.022$, but not the EQ-5D, $F(1, 46) = 0.707$, $p = 0.218$, or the PTGI, $F(1, 46) = 0.317$, $p = 0.576$. Inspection of the group means revealed significantly lower scores on the HADS ($M = -2.96$, $SD = 4.31$) in the ACT group compared to the control group ($M = -0.51$, $SD = 3.52$). These findings indicate that ACT group significantly influenced positive changes in psychological wellbeing.

At follow up, again the change scores were used to control for the pre-group differences by calculating the differences at follow up (T3) compared to baseline (T1). Again, box's test of the assumption of equality of covariance matrices, again is non-significant ($p = 0.151$). Using

Pillai's trace, the level of significance was lost at follow up. There was no longer a significant multivariate effect of group on the psychological outcome measures, $V = 0.60$, $F(3, 44) = 0.941$, $p = 0.429$. Separate univariate ANOVAs on the outcome variables revealed a significant effect on the HADS at follow up, $F(1, 46) = 3.631$, $p = 0.012$. However, no significant effect was found for EQ-5D, $F(1, 46) = 0.387$, $p = 0.537$, or the PTGI, $F(1, 46) = 2.63$, $p = 0.890$.

As described in Chapter one, the underlying theory of ACT led the researcher to hypothesise that the ACT intervention would increase psychological flexibility (represented by higher scores on the AAQ-II) and goal directed behaviours (represented by an increase of scores on the ASHS). Exploratory MANOVAs were conducted on the process measures to assess any differences between the groups at T2 and T3. As described above, whilst there were no statistical differences on the scores of goal directed thinking at baseline (ASHS: ACT $M = 29.61$ vs. waiting list $M = 26.70$, $t(47) = 0.074$, $p = 0.415$), the groups were significantly different on the measure of psychological flexibility at baseline (AAQ: ACT $M = 49.50$ vs. waiting list $M = 43.19$, $t(47) = -2.14$, $p = 0.038$). As a result the change scores were used again to assess these variables over time. Using Pillai's trace, there was no significant effect of group, on the psychological process measures at post intervention, $F(2, 45) = .969$, $p = 0.387$. Likewise, no statistical differences were found on the univariate analyses for either process measure (ASHS: $F(1, 46) = 1.36$, $p = 0.247$; AAQ: $F(1, 46) = 0.179$, $p = 0.674$). Using Pillai's trace, on the same measures at follow up, there again no significant effect of group, $V = 0.010$, $F(2, 45) = 0.236$, $p = 0.791$. Separate univariate ANOVAs on the process variables again revealed no significant effects on AAQ, $F(1, 46) = 0.278$, $p = 0.601$, and no statistical effect on the ASHS, $F(1, 46) = 0.417$, $p = 0.522$.

Appendix M Extract from Transcription

- P3: You don't feel quite so alone. After a stroke you feel isolated even amongst friends and family that you have. So when you come to a group like this you feel you're not alone anymore. So things kind of go back in to proportion again. Whereas normally things go right up and out of proportion. It's terrible when its just he two of you sometimes.
- P2: I felt that it was useful for me because I had no contact with the stroke association before this course and not really any contact with anybody since my stroke, because initially I contacted Headway, although it's just a few emails they never got back to me and at that point I felt well I can't be bad enough to warrant their input. So it rather put me off going to approach anybody else. So it felt very much as though my husband and I have been sort of alone with it almost. And I think what the course has done is allowed that recognition between your mind and reality. That's been really important for although it's sometimes difficult to put into practice and you still find yourself arguing with your mind...
- All ((laughs))
- P3: Well it's a bit of both really because you've got the stroke club which is good but with this you get to talk to other people and their experiences, with some who are still recovering, others are still struggling and I found it useful to talk to you and you're partner, you know you're not alone because it can be very isolating after a stroke, and everything can become out of propotion can't it and takes a lot to go out and socialise especially when you've got a speech impediment it's easier just to stay in and not bother, this gives you a bit of hope that if I do these exercises there is a way out I'm sort of saying.
- P4: I found the second week particularly helped...I think I was feeling that I was just desperately trying to get back to how I was before and the second week well we had to hold our breaths and things ((coughs)) it just made me think that actually I could cope with how things are now.

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- P2: ...I'm sure with a bit of practice and a bit more time having got that knowledge now will take us forward and we'll be able to build on that I think as a direct result of the course.
- F2: And did you do the homework exercises?
- P2: Yes and I think we'll probably repeat them over time just to revisit because it's easy to forget isn't it when you've done the course it's easy to forget some of parts of it so I think it will be useful for us to revisit from time to time which in fact is what we did yesterday, where I had a bit of a wobbly day yesterday and it was almost scrabbling back through the folder and saying, "Look what can I draw from this that will help me cope a bit better yesterday?"
- P3: Yes you don't feel quite so swamped with all your emotions and nobody cares, nobody understands, all that sort of road you tend to go down from time to time, it can sort of draw you back into almost feeling that you've suddenly done something a bit more constructive as opposed to destructive.
- P3: There's a sort of a period when you're very, very angry and you want things to go back the way they were so you're constantly trying to – what if? What if? Why can't it go back how it was because you're in a sense of mourning, its like grief in a way, so this starts to give you the option to accept this is the way it is but it's not the end of the world of the world there is light at the end of the tunnel.
- P5: It feels like letting go of the struggle sometimes.
- P2: Yeah, yeah it's kind of what it said about the fighting, you think I can makes this better, thinking back how I was and if you just stay in that moment and think this is what I've got now and I can still have a good life, but that was the hardest bit, because for a long, long time I was just thinking this is not fair...
- All ((laughs))
- P2: ...like I want it back like it was before like X says sometimes you forget that you've had the stroke, like you wake up and think and you forget for a split second that you've got this problem and you've got to go through the whole lot over again, and I would've never been able to understand what that was like,

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but having lived it the last three years, the frustration, anger all kind of emotions going on.

P1: But everyone's experience is entirely different I suppose

P4: Because I've found as well it's like your whole... your confidence goes as well with the stroke, all your emotions and I don't think they teach you about how to cope with that and then with like coming here to the group like with your mind, your mind tends to control you, like when you're low and your confidence is gone you do let your mind control and then your mind overtakes and all your emotions and everything overtake, so getting that back like you say challenging what your mind is saying and driving that bus, being in control and driving that bus yourself it just builds your confidence again.

P3: I think there must be a lot of post-traumatic stress as well because like it's like being knocked down, if you think someone's been knocked down by a lorry it's a similar thing isn't it, the amount of suffering and extreme shock, it is like being knocked down,

P5: I was only saying to my husband the other day about the tiredness, when will I get my, you know, the energy back it's just such a long road.

P3: Yes and also not being able to do the things you did before, like this is what I was saying to X, like everything you like to do it's ticked off, it's gone! Boom. Just like that. You're just not prepared for it. So things he could do are less and less and less and made him never want to bother with any of them cos he can't do some of the things he used to do so he doesn't bother.

P1: Well I'm saying that I mean I feel sometimes when I'm tired I need to sit down but then with the sitting down comes the sleeping, I try to push myself beyond that and keep myself active or do something, but do it in little small bits now rather than trying to push myself past it.

F3: I guess that's also probably part of it trying and error, learning your sort of limits.

P1: Exactly.

F3: So you're not over doing it to the point of exhaustion,

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- P3: Yeah it is hard.
- P4: It's also being kind to yourself
- P3: Yes that's exactly what I was going to say
- P2: Its true its not about being to hard on yourself
- P5: And it's recognising when you've hit that, or we were talking just now, because people say 'I've hit the wall' and use it quite casually but we were talking and said that actually that's such a reality with that overwhelming tiredness is literally like getting to a brick wall and you can't even lift the bricks out never mind climb over it. You're just sort of...and that is very alien I'm sure to everybody who's experienced because if you're normally fit and healthy and you just keep going, keep going, keep going and then you're suddenly in a place when you can't, that in itself is a huge factor and you try and say to yourself, "Why can't I do it, why can't I push myself and do that bit more?" So you do, but it ends worse because you physically can't because you've got there and it's almost like admitting defeat and you don't want to because you've got there and you say well I should be able to do another two seconds but you actually physically can't and that's really difficult to deal with sometimes when you've always been fit and healthy beforehand. You're dealing with something you don't quite know how to deal with.
- P3: Well no because you've never experienced it before.
- P2: No not unless you've had flu or something really...
- P3: Other people haven't got a clue, well I didn't I knew nothing about strokes whatever and I find people who say, "Oh you looked really well, it's okay," sort of thing and you feel like screaming and saying, "No it's not, you haven't seen him every day." They just see this person going along, you know.
- P2: Mm people used to come to my house and say, "Oh you don't look...you know, how I was expecting you to look".
- P3: Yeah they're almost frightened to come and see you because they expect to see this person dribbling person and then when they do come round they say "you

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look the same as you did before” more or less and people have said to me, “You look really well now,” you know, in other words “what’s all the fuss about... everything...it’s fine”.