

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/121564/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Large, Rebecca, Samuel, Victoria and Morris, Reg 2020. A changed reality: Experience of an acceptance and commitment therapy (ACT) group after stroke. *Neuropsychological Rehabilitation* 30 (8) , pp. 1477-1496.  
10.1080/09602011.2019.1589531

Publishers page: <http://dx.doi.org/10.1080/09602011.2019.1589531>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



**Title Page:**

**A Changed Reality: Experience of an Acceptance and Commitment Therapy (ACT) group after stroke.**

Dr. Rebecca Large<sup>1</sup>, Dr. Victoria Samuel<sup>1</sup>, and Professor Reg Morris\*<sup>1</sup>

*1 Cardiff University, Psychology Department, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT, United Kingdom*

\*Corresponding author information: Professor Reg Morris, Cardiff University, Psychology Department, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT, United Kingdom, [Reg.morris@wales.nhs.uk](mailto:Reg.morris@wales.nhs.uk)

**Word Count:** 5,668, including quotations

**A changed reality: Experience of an Acceptance and Commitment Therapy (ACT) group after stroke.**

**Objective:** Copious research on the utility of Acceptance and Commitment Therapy (ACT) in long-term conditions has demonstrated promising results. However, little research has been conducted on ACT within stroke, particularly studies that are qualitative in nature. The aim of this paper was to gain insight into stroke survivors' experiences of ACT and to explore what processes help facilitate adjustment in living with residual disability.

**Method:** Interviews with thirteen stroke survivors following their attendance at a stroke adapted ACT group were analysed using a grounded theory approach. Stroke survivors varied in age, severity of stroke limitations and duration since stroke.

**Results:** Interviews revealed a main difficulty of 'accepting a changed reality' following stroke. Survivors' narratives regarding their experiences of ACT revealed insight into which processes helped facilitate movement towards accepting symptoms and a changed reality and into helpful and less helpful aspects of the intervention.

**Conclusion:** Stroke survivors find ACT helpful in adjusting to stroke limitations. ACT appears to have potential as a psychological intervention for stroke survivors experiencing psychological distress. Amendments to the format of the intervention to enhance its impact are identified.

**Keywords:**

Acceptance Commitment Therapy • Group Intervention • Stroke • Acceptance • Adjustment

## INTRODUCTION

In the UK 152,000 adults are hospitalised each year following stroke (Townsend *et al.*, 2012). Stroke often causes huge upheaval, destabilisation and life-long consequences for stroke survivors and their families (Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk & Leeuw, 2014; Newton *et al.*, 2015; Rutten-Jacobs, Arntz, Maaijwee, Schoonderwaldt & Dorresteijn, 2013). Stroke may produce deficits in motor, perceptual, emotional and/or cognitive functioning (Lezak, Howieson, Loring, Hannay & Fischer, 2004; Toole, Bhadelia, Williamson & Veltkamp, 2004), alongside secondary consequences of social isolation, reduced psychological wellbeing and a generalised sense of loss (Ayerbe, Ayis, Wolfe & Rudd, 2013; Campbell-Burton *et al.* 2013; The Stroke Association [TSA], 2015). The heterogeneous effects of stroke pose adjustment difficulties and can impair quality of life (QoL)(TSA, 2015).

It is important to understand how individuals appraise and make meaning of their stroke and the strategies they employ to support successful adjustment (Gillies & Neimeyer, 2006; White, 2004). Adjustment to living with stroke is complex and multi-faceted, influenced by the severity and visibility of functional impairment (Stone, 2005); degree of emotional disturbance (Taylor, Todman & Broomfield, 2011); the meaning attached to stroke, disability and rehabilitation (Hjelmblick, Bernsten, Uvhagen, Kunkel & Holstrom, 2007); level of disruption to sense of self (Lawrence, 2010) and perceived amount of social/peer support (Kessler, Egan & Kubina, 2014; Venna, Xu, Doran, Patrizz & McCullough, 2014).

### *Current treatments for psychological issues following stroke*

The focus on the medical management of acute stroke means that longer-term psychological, cognitive or social needs may be overlooked (O'Neill, Horan, Hickey & McGee, 2008). National health strategies (Department of Health, 2007; Welsh Government, 2012) and clinical guidelines (National Institute for Health and Clinical Excellence [NICE], 2013) have therefore emphasised the need to extend support beyond physical care and rehabilitation, to facilitate healthy psychological adjustment. There is emerging evidence supporting the use of psychotherapeutic interventions in stroke (NICE, 2013); with the potential to deliver a fivefold improvement in QoL (Gillham, Carpenter & Leathley, 2012).

Acceptance and Commitment Therapy (ACT) is an effective psychotherapeutic intervention for improving well-being and function for patients experiencing a range of chronic conditions including cancer (Feros, Lane, Ciarrochi & Blackledge, 2013), pain (Hann & McCracken, 2014), and neurological conditions such as multiple sclerosis (Carrigan & Dysch, 2015) or acquired brain injury (Kangas & McDonald, 2011). Recent quantitative research (on which this current qualitative study is based) suggests this approach may be efficacious in reducing low mood and increasing hopefulness for patients with stroke (Majumdar & Morris, 2018).

A key aim of ACT is to shift an individual's focus away from counterproductive experiential control strategies centred on trying not to have undesirable (yet inevitable) unpleasant thoughts, feelings and physical sensations, towards a more mindful, observational orientation about such experiences (Hayes, Luoma, Bond, Masuda & Lillis, 2006). A therapeutic process central to ACT is 'psychological flexibility'; the ability to connect consciously to the present moment and to adapt or persist with behaviours according to personal values, even in the presence of unpleasant internal events (Hayes & Smith, 2005).

Majumdar & Morris (2018) note a number of features of ACT that make it suitable for stroke survivors: it adopts a well-being stance and is not focused on only symptom reduction; its emphasis on acceptance is applicable to those with enduring effects of stroke; it seeks to change the person's relationship to thoughts and feelings to reduce distressing cognitions - this may be more acceptable to those with lasting disabilities; the inclusion of mindfulness focuses attention on the present and away from distressing ruminations; the differentiation of the '*observing self*' from distressing thoughts and feelings facilitates the development of a stable self-identity; the discovery of 'core values' and development of goals based on them provides a personally meaningful way to approach goal setting after stroke.

The current intervention was delivered using a time-limited low-intensity group format since this is a cost-effective medium in the context of funding limitations (Scheidlinger, 2004) and group delivery of therapy has demonstrated efficacy following stroke (Visser et al. 2016). The intervention was adapted in collaboration with stroke survivors to make it more 'stroke-friendly', allowing for cognitive and perceptual limitations. It was didactic, using a standardised format, since this permitted delivery by non-specialist staff (with appropriate training and support) and enhanced fidelity. Traditionally, ACT interventions include high levels of experiential activities and exercises

after which the client is encouraged to reflect on their observations and discuss learning regarding different ways of relating to thoughts and feelings. However, this low-intensity adapted ACT intervention, whilst including some brief experiential exercises, was didactic in format as this had the potential to reach large numbers of stroke survivors and enabled the intervention to be shorter in duration.

#### *Study Aims*

This study sought to understand survivors' experiences of an adapted ACT group and explore what processes helped survivors' in living with residual stroke symptoms. This adds depth and nuance to a relatively new area of stroke inquiry, and extends the growing ACT research base to a new condition.

## METHODOLOGY

Ethical approval was by a National Research Ethics Committee (NREC) in the UK.

The analysis used constructivist Grounded Theory (GT) analysis (Charmaz, 2014) of in-depth semi-structured interviews conducted with stroke survivors. The participants were all recruited from a group-based ACT programme for stroke survivors and carers reported in Majumdar & Morris (2018).

### *Sample*

Stroke survivors (and carers) reporting difficulty adjusting to residual stroke symptoms were recruited from NHS services and third sector organisations. Twenty-six participants in the ACT intervention arm of the study were invited to participate in this qualitative research following completion of the intervention. Further details of the study can be found in Morris and Majumdar (2018). Thirteen stroke survivors were interviewed for the present study; two additional survivors expressed interest in participating but withdrew. Eleven did not consent to enter the qualitative study.

### *Intervention*

The 'ACTivate Your Life after Stroke' intervention comprised two-hour weekly didactic group sessions, for four consecutive weeks. The intervention was based on a mental health version of ACT described in more detail in Cartwright & Hooper (2017), adapted for stroke in collaboration with stroke survivors and carers. The ACT material was manualised and psychoeducational in nature, delivered by Microsoft PowerPoint with several ACT-based individual activities throughout, such as guided mindfulness practices. Changes included: reducing contrasting colours, simplifying language and number of words on the slides, and inclusion of stroke specific examples. The modified version was used in all groups. The session-by-session outline is in Table 1. A handout was provided for each session which included a session summary and suggested home activities.

[INSERT TABLE 1 HERE]

Courses were run in community venues across four sites (three NHS in south Wales and one third sector organisation in south west England). Sessions had at least two facilitators; one was always a clinical psychologist supported by assistant psychologists or stroke care co-ordinators. No relationships were established between the researcher and survivors prior to the study; the

researcher was not involved in delivery of the intervention. To ensure fidelity, all of the course facilitators received the same intensive two day training and supervision. The didactic nature of the intervention further ensured fidelity.

#### *Data Collection and Analysis*

Data collection and analysis occurred simultaneously, as part of the GT framework (Charmaz, 2014). Theoretical sampling ensured interviews were driven by emerging theory and helped identify participants that would either challenge or elaborate on tentative categories. This continued until data saturation was achieved (Charmaz, 2014).

Interviews were conducted in participants' own home lasting 30 – 70 minutes. An interview schedule comprising of seven stem questions was used as a guide (Box 1); this was revised regularly to progressively focus on new lines of enquiry and emerging theory.

Interviews were audio-recorded and transcribed verbatim by the researcher (a trainee clinical psychologist at time of study, with robust research skills and transcription experience). Transcripts were read/re-read alongside audio playback to keep the researcher immersed in the data, thus maintaining fidelity to GT (Charmaz, 2014). The final analytic stage involved generating a framework to explain the main concern or dilemma reported by survivors. Memo-writing, reflective journals, and cycling between interpretation and collection of the data helped to ensure the fit and sufficiency of the data. This facilitated the development of more abstract concepts, identified areas requiring greater elaboration and aided conceptualisation/refinement of emerging codes/categories and the overarching framework. Triangulation via theoretical sampling and gathering different perspectives on the data from other researchers helped to increase confidence in the findings.

To ensure the methodological rigour of this study, validity (Glaser, 1998) and reliability (Elliott et al., 1999) of the data were considered to minimise bias and to address the credibility and trustworthiness of the findings. This included reviewing the 'fit, workability, relevance and modifiability' of the data (Glaser, 1998, p18), as well as adhering to Elliott et al.'s (1999) guidelines e.g. owning one's perspective, situating the sample and grounding in examples etc.

[INSERT BOX 1 HERE]



## RESULTS

### *Participants*

Demographic data are presented in Table 2. Survivors reported wide-ranging, comorbid residual disabilities.

[INSERT TABLE 2 HERE]

### *Grounded Theory Findings*

All reported difficulty learning to adjust and manage the sequelae of stroke; there was a pervasive issue of needing to accept a changed reality. The analysis generated a conceptual framework explaining how stroke survivors work towards accepting change after attending an ACT group.

GT analysis yielded six core categories. Quotations, in ***bold italics*** and inverted commas, are used to represent verbatim statements to illustrate these categories; pseudonyms are used for participants. Information in square brackets [ ] has been added by the researcher, whilst three dots (...) indicate quotes have been shortened.

#### CORE CATEGORY 1: NEGOTIATING THE CHALLENGES OF STROKE

Survivors needed to first situate their experiences by describing the initial impact of stroke. Potential threat to self-identity, functional capabilities, aspired futures and psychological wellbeing meant all faced negotiating the challenges of stroke and a changed reality.

All survivors acknowledged feelings of guilt and self-worthlessness associated with diminished functional abilities and increased dependency on others, some also described intense fears of re-stroking. Negative self-appraisals of being ***“a failure”***, ***“useless”*** or ***“inadequate”*** and concerns of being evaluated unfavourably exacerbated negative affect. To alleviate distress, survivors described avoiding situations, battling with thoughts or ploughing on regardless; however this was found to have a paradoxical effect and imposed further restrictions in addition to existing stroke impairments.

***“I was suffering a lot of anxiety... the pain I was causing myself... It was like I had lost everything. I hadn't, but it had blown out of proportion...it just kept coming back that I was useless” (Connor).***

Reports of feeling far removed from previous life and disruptions to planned futures punctuated narratives. Survivors described experiencing loss; acknowledging a profound shift in roles, responsibilities, identity, sense of self and changes to their known reality. For two wheelchair users, distress and difficulty accepting a changed reality were compounded by denying the severity of their disabilities and continued efforts to return to full mobility.

***“I woke up [from my stroke] and found my situation totally removed from where I had been before. When I’m asleep I think about myself walking about, doing things and having the mobility that I used to have. When I open my eyes and become conscious, all those things peel away.” (Ron)***

#### CORE CATEGORY 2: THE HOW, WHO AND WHERE OF THE GROUP MATTERS

The ACT group was described as a highly positive experience that helped to make meaning of the stroke experience. Contextual factors were central to feeling able to assimilate course information; including group practicalities, teaching methods and the translatability of material.

##### *Practicalities*

Venue appropriateness and consideration of survivors’ disability needs facilitated learning and enjoyment of the ACT group, helping to create an environment that minimised distraction or discomfort. A good learning environment was viewed as essential to assimilation of material.

***“The venue is very important when you are running groups, if you’re just being lectured at your mind tends to wander because the chairs are uncomfortable.... You lose your concentration and might start thinking about the discomfort you’re in” (Paul).***

Transparency around group agendas and scheduled breaks further aided learning by structuring the course. The didactic format of the group also offered security for some participants; five individuals mentioned disclosing personal information to a group would have deterred them from attending.

***“The biggest thing I was worried about was whether we’d be sat in a circle and be talking about our feelings. I didn’t want to talk to anybody about my feelings. If that would have happened, I would have just walked straight out the door. It was really good in that as soon***

***as we got there [the facilitator] said...you just have to sit and listen... that actually put me at ease really quickly” (Connor)***

Despite some preferences for a non-discursive group, others desired increased interaction. They felt the didactic approach minimised the value of shared learning, and suggested the material could have been taught via self-practice: ***“we were just being talked at...I felt I could have just been given a handout to read” (Josh)***. Several survivors indicated discussion might have aided their understanding, and provided a chance to learn vicariously from others: ***“There wasn’t much opportunity to interact with others, it would have been nice to have heard other people’s experiences as well because until I had this stroke unfortunately I hadn’t realised what a stroke was or what effect it can have on your life” (George)***.

#### *Teaching Methods and Translatability*

Educating survivors via multiple teaching modalities (e.g. psychoeducation; metaphors; and experiential exercises) supported different learning styles and needs. Survivors had choice in how they took on information; this was particularly useful given the spectrum of stroke disability. ***“I think some of the descriptions and analogies relating to how your brain is working, how you feel, memories coming in and drifting out...I found those really helpful. They were quite intuitive to me and they were things I could remember” (Mark)***. Learning was strengthened when material was personally salient, with some describing an ‘epiphany moment’ from gaining insight into causes of their distress; helping them make more meaning out of their stroke experience: ***“you know when someone says something and you think ‘that’s what I’ve been missing’, it was like that hurrah moment” (Mark)***.

Application of material depended on the authenticity of group facilitators and was best when facilitators clearly understood ACT and were able to elaborate with examples: ***“breaking things down with personal examples was easier to understand and get ideas across because I struggled with abstract concepts” (Charles)***. This not only normalised survivors’ experiences (i.e. unwanted events are universal), but helped individuals witness real-life applications of the model. Facilitators with superficial knowledge of ACT were criticised and it was reported to be a barrier to taking on ideas: ***“...they didn’t have that inner thing to get across the points” (Paul)***.

### CORE CATEGORY 3: TRANSLATING KNOWLEDGE INTO PRACTICE

Survivors' narratives indicated how knowledge was translated into practice. Variations in accounts suggest some survivors felt ACT offered new insight ("***I learnt that the mind is an absolute b\*\*\*\*r, it has so much sway over you... it was very powerful***" (Mark)), whilst others believed it reinforced pre-existing knowledge ("***It gave me reassurance that I was going down the right path***" (Josh)). Knowledge afforded participants more choice and control over how to proceed with their recovery. "***I wouldn't have faced them [my fears] if I hadn't gone to the course...the information I took from the group gave me courage to do that***" (Abigail).

Application of knowledge benefitted from a number of factors, including group tasks, homework sheets and repetition of experiential exercises (especially for individuals with cognitive deficits to aid recall).

***"I'd do the homework and try to use the tips they were giving...it meant you had a bit of reference material if I perhaps forgot something"*** (Mark)

***"The paperwork - that was really useful, because you know [the group] is only once a week and you need to go through it a couple of times to remind you of what you've heard. .... you can highlight what you've taken on, the messages that you've taken on and you can keep going back and looking at it"*** (Connor)

Difficulty understanding abstract concepts meant some participants struggled to generalise ideas outside of the group, deterring independent practice: "***I could see what they were saying when they were doing it, but after the session I got a bit confused***" (Phil).

In addition, filtering information based on its personal relevance helped with memory and translating knowledge into practice: "***If it wasn't helpful I would tend to blank it from my mind...I took what was relevant for me***" (George). Extracting salient information managed demands on survivors' cognitive reserves. Likewise, discussing and sharing knowledge with wider social networks (e.g. partners) supported skill acquisition: "***I had [my wife] with me...we'd talk about it after the group, what we got from it***" (Chris). This strengthened connection to the material, aided recall and provided a forum for rehearsal, which in turn opened up more opportunities to implement strategies.

#### CORE CATEGORY 4: REALISING THERE'S A CHOICE

Participants reported broadening their psychological repertoires to manage painful experiences. Applying knowledge to internal events helped improve capacity for self-awareness, to feel more

confident in confronting fears, and provided greater choice over actions: ***“Your mind sort of bullies you into a certain direction and you can decide to take a different direction if you want to”*** (Josh). ACT provided a basis to experiment in changing habitual patterns of behaviour that previously governed recovery and facilitated movement towards acceptance of a changed reality. ***“I started to do things differently...put myself into situations I might not normally have done...I couldn’t use my hands the way I used to, so I’ve had to think of ways to adapt and change”*** (Paul).

In contrast, two participants acknowledged the value of ACT but were unwilling to nurture these skills, instead showing continued inflexibility, and pursuit of unattainable goals regardless of the struggles and distress that ensued.

***“I go to bed every night thinking I’m going to wake up and it’s all going to disappear. I’m going to be the person I was before... but it hasn’t happened yet. Since the stroke I’m a different person....I’m still stuck with it and I still want answers”*** (John).

Becoming more attuned to subjective experiences and learning to accept their presence (despite negative or critical content) was conducive to recovery: ***“rather than listening to those things [critical thoughts]...you need to not struggle with them, let them go over you”*** (Charles).

Altering relationships with difficult internal events cultivated distance (supporting participants in letting go, stepping back and living in the moment), and helped disentangle from the content of these events (reappraising the power of thoughts). ***“This thing of ‘you are not your mind’, that had never connected with me, I always thought even before I had the stroke this thing constantly pushing me, criticising me, I thought you just had to put up with it, it was part of life...so you’re disconnecting yourself from your mind and thinking about what is it that I am actually doing now, what’s important now, that was really helpful”*** (Connor). Through reducing internal struggles, more than half of stroke survivors’ narratives highlighted a shift in perspective; descriptions of richer, more fulfilling lives despite residual disability. ***“Before the group, I would have thought well I won’t go [out with the family]...it does give you a different perspective...it makes you realise there is life after stroke”*** (Abigail).

Participants further reflected on feeling more empowered and in control of their reactions towards stroke limitations: ***“I take things a bit at a time now... or look at things in a different way... so I’m feeling more relaxed and in control of myself”*** (Phil).

Although a few participants reported fighting against their limitations (e.g. not being able to complete tasks as before), they recognised making even small adaptations could allow continued participation in activities. ***“I’ve done my best to apply myself...I can’t do the shopping in the same sort of way, but I go shopping on a Sunday with my wife, I go in this [wheel]chair...I like to think I’m taking an active role... I find it really important. I like the interface with doing something I used to do”.*** (Ron)

#### CORE CATEGORY 5: VALUING OTHER STROKE SURVIVORS

All participants emphasised being amongst other stroke survivors was unique, highly valuable and helpful in facilitating adjustment to stroke limitations; ***“[it’s] a little community where everyone understands what it’s like”*** (Paul). Although interaction was not encouraged during the group, participants nonetheless enjoyed sharing experiences during the break which helped to develop a sense of belongingness and a platform where participants felt valued and equal. This unity allowed emotions and stroke experiences to be normalised and validated, whilst simultaneously assisting in reducing feelings of isolation. This engendered acceptance of the current situation, which facilitated acceptance of a changed reality. ***“To be able to go [to the group] and understand that you are not alone, that there are other people out there who have gone through the same thing, their feelings of despair are exactly like yours, and just to have those other people to relate to is a benefit”*** (Abigail)

Participants also made comparisons against other survivors, leading many to situate themselves along a continuum in terms of their health, stroke experiences, and stage of recovery. In most instances, this was deemed a helpful strategy instilling hope and optimism, enabling participants to positively re-define their sense of self in light of stroke disability. ***“I was expecting to be the youngest person there and I wasn’t. Some people had far worse experiences than what I had...it made me quite thankful, dare I say it, that my experience for having had to have an experience of that type, was quite positive”*** (Josh)

#### CORE CATEGORY 6: ACCEPTING A CHANGED REALITY

From strong narratives about the challenges of living with stroke limitations (both physical and psychological), the main dilemma confronting stroke survivors was accepting a changed reality. Moving towards acceptance was considered to be a process dictated by time which fluctuated depending on participants’ willingness or readiness to change. Eleven survivors recognised the value of attending the ACT group in developing new coping skills and insights: ***“I could have walked round with blinkers on if I wanted but I had to accept that I’d had a stroke and I***

**needed to learn to deal with the aftermath of it” (Mark).** Some individuals who were able to connect to ACT ideas and implement skills reported regaining a sense of control and working more towards things they valued regardless of the impact of stroke. Re-engaging with a life that survivors thought was previously lost or unattainable engendered a more optimistic outlook on the future: **“I’m not glad I’ve had the stroke by a long shot, but positives have come out of it. (Liam).** One highlighted her move towards accepting a changed reality by stating: **“People don’t like change but change is good...if you can embrace that and accept that, then you can get over your stroke a lot better..... You can give yourself a life that you didn’t think you could have in the beginning. You’ve got to come to accept the fact that you aren’t the same person you were before, doesn’t mean to say you are a lesser person, but just understand where your limits are....” (Abigail)**

#### CONCEPTUAL FRAMEWORK LINKING THE CORE CATEGORIES

A sense of safety and belonging appear to be necessary prerequisites for any movement towards acceptance. These components are achieved through the authenticity of the facilitators, the group context itself, and the interaction of others with similar backgrounds. Collectively, these factors increase confidence in ability to attend to and apply ACT ideas. As survivors become confident with ACT they show greater willingness to experiment with strategies that enable greater flexibility and choice in how to respond to internal events (e.g. painful thoughts/feelings); supporting translation of knowledge into practice.

Some survivors oscillated between acquiring and practicing skills before progressing forward (illustrated by the arrows in Figure 1); perhaps due to initial difficulty transferring knowledge into practice or in practicing certain techniques. **“I could see what they were saying when they were doing it, but after the course I got a bit confused...I needed to keep going back to the material” (Phil).** Others were unwilling or resistant to incorporate new ideas due to an inflexibility around recovery goals or difficulty understanding ACT principles: **“If I accept that I am in a wheelchair, this situation, then there is no point in me making any effort to walk” (Ron).** These individuals reported slight improvements in accepting some of the private experiences associated with their residual stroke symptoms, but acceptance levels then continued to fluctuate without progressing any further towards accepting a different reality.

This pathway varied considerably between survivors and even within individuals the process was fluctuating and non-linear. **“I get ‘up’ times where I think this is going well, then you slip back into it...you drift back to where you were before” (Connor).** The degree of acceptance fluctuated for survivors as they worked towards accepting a changed reality. With movement

between the phases of acquiring knowledge and practicing ACT skills came a shift in responses in living with stroke limitations; subsequently moving towards acceptance of changed reality. ***“I couldn’t justify it [the stroke], it didn’t seem real...as the course went on it became quite apparent that it was very real and I needed to deal with it” (Mark)***

[INSERT FIGURE 1 HERE]



## DISCUSSION

GT analysis revealed a pathway towards 'accepting a changed reality' as the principal challenge experienced. This was understandable given the wide-ranging implications of stroke, its unpredictable nature and the vast disruption it can cause to lives (Falvo, 1999; Newton *et al.*, 2015).

### *Negotiating Challenges of Stroke*

Participants' initial need to situate themselves (core category 1) captured the challenges faced when living with the effects of stroke; highlighting issues pertaining to increased distress, disrupted self-identities and loss of meaningful activities. This feedback substantiates past literature on mood disturbance post-stroke (Donnellan, Hickey, Hevey & O'Neill, 2011; TSA, 2013), grief associated with identity change (Ellis-Hill & Horn, 2000; Levack *et al.*, 2014), and reduced life satisfaction (Cloute, Mitchell & Yates, 2008). Identity specifically was raised as a main challenge by survivors, with large discrepancies between pre- and post-stroke self linked to negative affect and increased resistance or nonacceptance of symptoms. This echoes Lapadatu and Morris (2017) where identity change after stroke was associated with anxiety, depression, impaired self-esteem and poor quality of life.

### *Conceptual Framework*

The pathway towards improved acceptance was reported as a non-linear process, with oscillation between acquiring knowledge, implementing skills and greater psychological flexibility. Oscillation in adjusting to physical illness is evidenced in past literature; with adjustment described as a dynamic path that is neither linear nor lockstep (Stanton, Revenson & Tennen, 2007). Our framework postulates oscillation is important for improved acceptance of stroke, and supports past research by highlighting variability and heterogeneity in the pathway towards acceptance of a changed reality. This emphasis corroborates other theoretical frameworks on adjustment, including posttraumatic growth (PTG; Calhoun & Tedeshi, 1999, 2013; Cann *et al.*, 2011; Gangstad, Norman & Barton, 2009; Hallam & Morris, 2014; Kelly, Morris & Shetty, 2017) and grief (Strobe & Schut, 2010) models.

Safety and belonging were identified as necessary prerequisites to applying ACT skills; these factors have been reported as strong determinants of improved wellbeing and successful adjustment to chronic illness (Ambrosio, Navarta & Portillo, 2014; Repper & Carter, 2011).

Establishing a sense of belonging through meeting peers has been linked to increased feelings of personal empowerment, hope, reduced isolation (Tomaka & Palacios, 2006), and opportunities to re-build a sense of self and identity (Amarshi & Reid, 2006). As interaction was not actively encouraged within the group, it may suggest mere proximity to others in a shared experience can induce beneficial outcomes. Social comparisons within the group may similarly have contributed to acceptance as most survivors reported positive comparisons enhanced their self-perceptions, self-esteem (Collins, 2000; Wills, 1981), and elicited optimism (Chambers & Whindschitl, 2004).

Reports of practice of ACT strategies was linked with reports of greater capacity to tolerate distress and greater choice over responding to the challenges of stroke (i.e. improved flexibility); this is consistent with research on adjustment post-stroke (Alaszewski, Alaszewski & Poter, 2006; Kessler *et al.*, 2009) and outcomes of ACT in other physical health domains (Hayes *et al.*, 2011). Similar to PTG (Calhoun & Tedeshi, 1999, 2004) where transformative changes are experienced as a result of struggling with a traumatic event, acceptance emerged through attempts at reappraising personal goals and painful internal experiences in light of their stroke. Taylor's (1983) cognitive adaptation model similarly stresses the flexibility of cognitions in allowing positive views in the face of traumatic experiences, and in encouraging personal growth and development. Whilst Folkman (2001) further emphasises the importance of finding positives from challenging experiences; suggesting cognitive re-framing supports successful coping and increases positive affect.

However, not all group participants followed this trajectory; some seemed less ready to consider changing their behaviour. According to the Transtheoretical Stages of Change Model (Prochaska & DiClemente, 1982) these survivors seemed to be 'pre-contemplative' or 'contemplative' of taking new action; ruminating on their pre-stroke self, reporting greater resistance in using ACT concepts and demonstrating greater fluctuations in acceptance. Within PTG literature, rumination can be perceived as either a destructive or constructive strategy depending on whether it perpetuates distress or aids understanding of the trauma (Calhoun *et al.*, 2010). This appears to be closely associated with 'denial' coping within health, grief models and psychodynamic frameworks (Christensen, Cook & Martin, 1997; Telford, Kralik & Koch, 2006).

### *Strengths and Limitations*

The present study possessed several strengths, including an adequate sample suitable for achieving data saturation (Evans, 2013), triangulation of the data to reduce interpretation bias, and inclusion of a broad range of stroke survivors. However, there are important limitations. The

sample was a self-selected group (58%) of those who completed the ACT intervention. Lack of sample diversity may limit generality of the data to wider stroke contexts; the sample was unrepresentative of 'oldest old' adults, females, ethnic minorities and survivors with severe disability or in long-term care facilities. External credibility checks were completed to support the methodological quality of the study but ideally credibility checks with participants via use of a focus group would also be completed to reflect on emerging data categories. Third, the group was delivered didactically; this design is therefore somewhat inconsistent with traditional formats of ACT groups that are interactive, discursive and more experiential. Comparisons between didactic and interactive ACT groups and their respective outcomes would be worth exploring in future. Finally, interviews were conducted at least one month after completion of the course to allow for practice and consolidation of the material. Unfortunately, memory decay affected recall abilities. Future extensions of this research should account for memory difficulties to ensure the overall framework is inclusive for all stroke survivors.

It should be emphasised that these findings exhibit only perspectives on attending ACT sessions of stroke survivors interviewed in this study. These findings require replication to imbue confidence in generalisation beyond this sample and in the value of the emergent conceptual framework as a guide for other stroke samples or settings.

#### *Clinical and Service Implications*

To the best of the researcher's knowledge this is the first qualitative study exploring survivors' experiences of ACT. Narratives suggest ACT is a valuable and effective resource for stroke; however certain adaptations are recommended to support the physiological-neurocognitive needs of survivors (e.g. pain; cognitive deficits etc.). This includes adaptations to the environment and presentation of the ACT material (Box 2).

The framework acknowledges a fluctuating trajectory towards accepting a changed reality; suggesting facilitators consider the element of time, readiness-to-change and ability to acquire/implement ACT skills. Modifications to the environment and the importance of meeting others are reported to help facilitate a sense of safety and belonging. The latter suggests that group interventions should feature as a standard component of post-stroke rehabilitation. In instances where survivors decline group work or services are unable to facilitate groups, ACT could be offered individually. Additional considerations should be made to normalise experiences

and create a sense of belonging/safety in this context in the absence of others with lived experiences.

The implementation of ACT in stroke could broaden the prospective benefits of rehabilitation, extending support beyond physical care to wider and long-term needs of survivors. Implementation of ACT in community setting, as here, could address concerns of survivors who describe “*being set adrift*” upon discharge from hospital. It may also have economic benefit in reducing long-term dependency on stroke and mental health services in future (O’Neill *et al.*, 2008).

[INSERT BOX 2 HERE]

## CONCLUSION

Improved understandings of how stroke survivors come to accept a changed reality through attending an ACT group have been highlighted. This research moreover offers an account of how ACT groups can be adapted to meet the needs of this population, as well as the trajectory that individuals may follow in developing greater personal awareness and psychological flexibility.

## REFERENCES

- Alaszewski, A., Alaszewski, H. & Potter, J. (2006). Risk, uncertainty and life threatening trauma: Analysing stroke survivors' accounts of life after stroke. *Forum: Qualitative Social Research*, 7(1), Art. 18. Retrieved from: <http://www.qualitative-research.net/fqs-texte/1-06/06-1-18-e.htm>
- Ambrosio, L., Navarta, M.V. & Portillo, M.C. (2014). Promoting a positive living with Parkinson's disease in the community: adequacy of assessment and interventions. *Primary Health Care*, 24(10), 26 -29.
- Amarshi, F. & Reid, D. (2006). Exploring social and leisure participation among stroke survivors: Part two. *International Journal of Therapy and Rehabilitation*, 13(5), 199-208.
- Ayerbe, L., Ayis, S., Wolfe, C. & Rudd, A. (2013). Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *British Journal of Psychiatry*, 202(1), 14-21.
- Calhoun, L. G. & Tedeschi, R. G. (1999). *Facilitating posttraumatic growth: A clinician's guide*. New York: Routledge.
- Calhoun, L. G. & Tedeschi, R. G. (2013). *Posttraumatic growth in clinical practice*. New York: Brunner Routledge
- Calhoun, L. G., Tedeschi, R. G., Cann, A., & Hanks, E. A. (2010). Positive outcomes following bereavement: Paths to posttraumatic growth. *Psychologica Belgica*, 50(1-2), 125-143.
- Campbell Burton, C. A., Murray, J., Holmes, J., Astin, F., Greenwood, D. & Knapp, P. (2013). Frequency of anxiety after stroke: A systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 8(7), 545-559.
- Cann, A., Calhoun, L. G., Tedeschi, R. G., Triplett, K. N., Vishnevsky, T. & Lindstrom, C. M. (2011). Assessing posttraumatic cognitive processes: The Event Related Rumination Inventory. *Anxiety, Stress, & Coping*, 24 (2), 137-156.
- Carrigan, N. & Dysch, L. (2015). Acceptance and Commitment Therapy for the Management of Chronic Neuropathic Pain in Multiple Sclerosis: a case study. *Neuro-disability and Psychotherapy*, 3(2), 69-92.
- Cartwright, J., & Hooper, N. (2017). Evaluating a transdiagnostic Acceptance and Commitment Therapy psychoeducation intervention. *The Cognitive Behaviour Therapist*, 10 (e9), 1-6. doi: 10.1017/S1754470X17000125.
- Chambers, J. R. & Windschitl, P. D. (2004). Biases in social comparative judgments: The role of non-motivated factors in above-average and comparative-optimism effects. *Psychological Bulletin*, 130(5), 813-838.
- Charmaz, K. (2014) *Constructing Grounded Theory: a practical guide through qualitative analysis (2nd ed.)*. London: Sage.
- Christensen, J. M., Cook, E. A., & Martin, B. C. (1997). Identifying denial in stroke patients. *Clinical Nursing Research*, 6(1), 105 -118.
- Cloute, K., Mitchell, A. & Yates, P. (2008). Traumatic brain injury and the construction of identity: a discursive approach. *Neuropsychological Rehabilitation*, 18(5-6), 651-670.
- Collins, R.L. (2000) Among the better ones: Upward assimilation in social comparison. In J. Suls & L. Wheeler (Eds.) *Handbook of social comparison* (pp159-172). New York: Kluwer Academic/Plenum.
- Department of Health (2007). *National stroke strategy*. London: Department of Health.

- Donnellan, C., Hickey, A., Hevey, D. & O'Neill, D. (2011) Effect of mood symptoms on recovery one year after stroke. *International Journal of Geriatric Psychiatry*, 25(12), 1288-1295.
- Dowswell G., Lawler J., Dowswell T., Young J., Forster A. & Hearn J. (2000). Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*, 9(4), 507-515.
- Elliot, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(2), 215-222.
- Ellis-Hill, C.S. & Horn, S. (2000). Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clinical Rehabilitation*, 14(3), 279-287.
- Evans, G. (2013). A novice researcher's first walk through the maze of grounded theory: Rationalization for classical grounded theory. *The Grounded Theory Review*, 12(1), 37-55.
- Falvo, D. (1999). *Medical and psychosocial aspects of chronic illness and disability* (2<sup>nd</sup> ed.). Gaithersburg, MD: Aspen.
- Feros, D., Lane, L., Ciarrochi, J. & Blackledge, J. (2013). Acceptance and Commitment Therapy (ACT) for improving the lives of cancer patients: a preliminary study. *PsychoOncology*, 22(2), 459-464.
- Folkman, S. F. (2001). Revised coping theory and the process of bereavement. In H. Schut (Ed.), *Handbook of bereavement research: Consequences, coping, and care*. Washington, DC: American Psychological Association.
- Gangstad, B., Norman, P. & Barton, J. (2009) Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology*, 54(1), 69-75.
- Gillham, S., Carpenter, M. & Leathley, M. (2012). *Psychological care after stroke: economic modelling of a clinical psychology led team approach*. Leicester: NHS Improvement.
- Gillies, J. & Neimeyer, R.A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*, 19(1), 31-65.
- Hallam, W., & Morris, R. (2014). Post-traumatic growth in stroke carers: A comparison of theories. *British Journal of Health Psychology*, 19(3), 619-635.
- Hann, K. & McCracken, L. (2014). A systematic review of randomised controlled trials of acceptance and commitment therapy for adults with chronic pain: outcome domains, design quality and efficacy. *Journal of Contextual Behavioural Science*, 3(4), 217-227.
- Hayes, S.C., Luoma, J.B., Bond, F.W., Masuda, A., & Lillis, J. (2006) Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.
- Hayes, S., & Smith, S. (2005) *Get out of your mind and into your life: the new acceptance and commitment therapy*. Oakland: New Harbinger.
- Hayes, S., Villatte, M., Levin, M., & Hildebrandt, M. (2011). Open, aware, and active: Contextual approaches as an emerging trend in the behavioral and cognitive therapies. *Annual Review of Clinical Psychology*, 7, 141-168.
- Hjelmblick, F., Bernsten, C.B., Uvhagen, H., Kunkel, S. & Holmstrom, I. (2007). Understanding the meaning of rehabilitation to an aphasic patient through phenomenological analysis - a case study. *International Journal of Qualitative Studies on Health and Well-being*, 2(2), 93-100.

- Kangas, M. & McDonald, S. (2011). Is it time to act? The potential of Acceptance and Commitment Therapy for psychological problems following acquired brain injury. *Neuropsychological Rehabilitation*, 21(2), 250-276.
- Kelly, G., Morris, R. & Shetty, H. (2017). Predictors of posttraumatic growth in stroke survivors. *Disability and Rehabilitation*, 10, 1-9. (EPub).
- Kessler, D., Dubouloz, C.J., Urbanowski, R. & Egan, M. (2009). Meaning perspective transformation following stroke: the process of change. *Disability Rehabilitation*, 31(13), 1056-1065.
- Kessler, D., Egan, M. & Kubina, L.A. (2014). Peer support for stroke survivors: a case study. *BMC Health Services Research*, 14(1), 256. doi/10.1186/1472-6963-14-256
- Lapadatu, I. & Morris, R. (2017). The relationship between stroke survivors' perceived identity and mood, self-esteem and quality of life. *Neuropsychological Rehabilitation*, 11, 1-15.
- Lawrence, M. (2010). Young adults' experience of stroke: a qualitative review of the literature. *British Journal of Nursing*, 19(4), 241-248.
- Levak, W.M.M., Boland, P., Taylor, W.J., Siegert, R.J., Kayes, N.M., Fadyl, K...McPherson, K.M. (2014). Establishing a person-centred framework of self-identity after traumatic brain injury: a grounded theory study to inform measure development. *BMJ Open*, 4(5), e004630.
- Lezak, M., Howieson, D., Loring, D., Hannay, H. & Fischer, J. (2004). *Neuropsychological Assessment*. 4<sup>th</sup> ed. New York: Oxford University Press.
- Maaijwee, N., Rutten-Jacobs, L., Schaapsmeeders, P., van Dijk, E. & Leeuw, F.E. (2014). Ischaemic stroke in young adults: risk factors and long-term consequences. *Nature Reviews Neurology*, 10(11), 315-325.
- Majumdar, S. & Morris R. (2018). The efficacy of an ACT-based group for stroke survivors. *British Journal of Clinical Psychology*. Jul 12. doi: 10.1111/bjc.1219
- Moore, D. A. & Small, D. A. (2007). Error and bias in comparative judgment: On being both better and worse than we think we are. *Journal of Personality and Social Psychology*, 92(6), 972-989.
- Mukherjee, D., Levin, R.L. & Heller, W. (2006). The cognitive, emotional and social sequelae of stroke: psychological and ethical concerns in post-stroke adaptation. *Topics in Stroke Rehabilitation*, 13(4), 26-35.
- National Institute for Health & Clinical Excellence (2013). *Stroke rehabilitation in adults; Clinical Guideline 162*, London: NICE. [www.nice.org.uk/guidance/cg162](http://www.nice.org.uk/guidance/cg162)
- Newton, J., Briggs, A. & Murray, C., et al. (2015). Changes in health in England, with analysis by English regions and areas of deprivation, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet*, 386(10010), 2257-2274.
- O'Neill, D., Horgan, F., Hickey, A. & McGee, H. (2008). Long term outcomes of Stroke: stroke is a chronic disease with acute events. *British Medical Journal*, 336(7642), 461.
- Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice*, 19(3), 276-288.
- Repper, J. & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, 20(4), 392-411.
- Rutten-Jacobs, L., Arntz, R., Maaijwee, N., Schoonderwaldt, H. & Dorresteijn, L., (2013). Long-term mortality after stroke among adults aged 18 to 50 years. *JAMA*, 309(11), 1136-1144.

Scheidlinger S. (2004). Group psychotherapy and related helping groups today: An overview. *American Journal of Psychotherapy*, 58(3), 265-280.

Stanton, A., Revenson, T., & Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annual Review of Psychology*, 58, 565-592.

Formatted: Spanish (Spain)

Stone, S. (2005). Reactions to invisible disability: the experiences of young women survivors of haemorrhagic stroke. *Disability Rehabilitation*, 27(6), 293-304.

Strobe, M., & Schut, H. (2010). The dual process model of coping with bereavement: a decade on. *Journal of Death and Dying*, 61(4), 273-289.

Taylor, G.H., Todman, J. & Broomfield, N. (2011). Post-stroke emotional adjustment: a modified Social Cognitive Transition model. *Neuropsychology Rehabilitation*, 21(6), 808-824.

Telford, K., Kralik, D. & Koch, T. (2006). Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing*, 55(4), 457-464.

The Stroke Association (2013). *Feeling overwhelmed: the emotional impact of stroke*. London: Stroke Association. Retrieved from: [https://www.stroke.org.uk/sites/default/files/feeling\\_overwhelmed\\_final\\_web\\_0.pdf](https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0.pdf)

The Stroke Association (2015) *State of the nation: stroke statistics*. London: Stroke Association. Retrieved from: <https://www.stroke.org.uk/resources/state-nation-strokestatistics>

Tomaka, J., Thompson, S. & Palacios, R. (2006). The relation of social isolation, loneliness, and social support to disease outcomes among the elderly. *Journal of Aging and Health*, 18(3), 359-384.

Toole, J., Bhadelia, R., Williamson, J. & Veltkamp, R. (2004). Progressive cognitive impairment after stroke. *Journal of Stroke and Cerebrovascular Diseases*, 13(3), 99-103.

Townsend, N., Wickramasinghe, K., Bhatnagar, P., Smolina, K. & Nichols, M. *et al.* (2012). *Coronary heart disease statistics 2012 edition*. London: British Heart Foundation.

Venna, V.R. , Xu, Y., Doran, S. J., Patrizz, A. & McCullough, L. D. (2014) Social interaction plays a critical role in neurogenesis and recovery after stroke. *Translational Psychiatry*, 4, e351.

Visser, M.M., Heijenbrok-Kal, H.H., van't Spijker, A., Lannoo, E., Busschbach, J.J.V., Ribbers, G.M. (2016). Problem-solving therapy during outpatient stroke rehabilitation improves coping and health-related quality of life: Randomized controlled trial. *Stroke*, 47, 135-142.

Welsh Government (2012). *Together for health – stroke delivery plan: A delivery plan for NHS Wales and its partners*. Cardiff: Welsh Government.

Wills, T.A. (1981) Downward comparison principles in social psychology. *Psychological Bulletin*, 90(2), 245-271.

White, C. A. (2004). Meaning and its measurement in psychosocial oncology. *Psycho-Oncology*, 13(7), 468-481.

Wortman, C.B. & Silver, R. (2001) The myths of coping with loss revisited. *In handbook of bereavement research: consequences, coping and care* ed. MS Stroebe, RO Hansson, W Stroebe, H Schut, pp. 405 – 429. Washington, DC: American Psychological Association.



## List of Figures

**Figure 1:** A conceptual framework for stroke survivors in working towards acceptance of a changed reality.

**Box 1:** Draft Interview Schedule

**Box 2:** Recommendations for adapting ACT groups for stroke

## Tables

**Table 1:** Session-to-Session Outline of ACT Group

**Table 2:** Demographic Data