

The Application of Third-Wave Therapies to  
Psychological Wellbeing following Stroke

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## Contents

Thesis abstract.....	9
<b>CHAPTER ONE: LITERATURE REVIEW</b>	
<b>1.0 Abstract.....</b>	<b>11</b>
<b>2.0 Background.....</b>	<b>12</b>
2.1 Stroke.....	12
2.2 Psychological Impact of Stroke.....	12
2.3 Impact of Psychological Wellbeing on Physical Health.....	13
2.4 Guidance Around Interventions.....	14
2.5 Psychological Interventions Following Stroke.....	14
2.6 Third-Wave Therapies.....	14
2.7 The Use of Third-Wave Therapies in Promoting Psychological Wellbeing.....	19
2.8 Relevance of Third-Wave Therapies to Stroke.....	19
2.9 Summary.....	22
<b>3.0 Review of the Evidence for Third-Wave Interventions in Stroke.....</b>	<b>22</b>
3.1 Methods.....	22
3.1.1 Information Sources.....	22
3.1.2 Study Selection.....	24
3.1.3 Summary of Studies.....	26
3.2 Evaluation of Papers.....	30
3.2.1 Evaluation of Single Case Experimental Design Papers.....	30
3.2.1.1 Establishment of Baseline.....	30
3.2.1.2 Appropriateness of Outcome Measures.....	31
3.2.1.3 Analysis of Data.....	32
3.2.1.4 Summary of Single Case Experimental Designs.....	32
3.2.2 Evaluation of Group Design Papers.....	32
3.2.2.1 Participants.....	33

3.2.2.2 Intervention.....	35
3.2.2.3 Comparisons.....	35
3.2.2.4 Outcomes.....	36
3.2.2.5 Study Design.....	37
3.2.2.6 Summary of Group Design Papers.....	37
3.3 Bias.....	38
3.4 Critical Appraisal Summary.....	38
<b>4.0 Synthesis of Findings.....</b>	<b>38</b>
4.1 Anxiety and Depression.....	39
4.2 Compassion.....	40
4.3 Psychological Flexibility.....	40
4.4 Mindfulness.....	41
4.5 Acceptance.....	42
4.6 Valued Living.....	42
4.7 Quality of Life.....	43
4.8 Cognitive Appraisal.....	44
4.9 Physiology and Physical Health.....	44
4.10 Cognitive Symptoms.....	45
4.11 Other Findings.....	46
4.12 Summary.....	48
<b>5.0 Discussion and Recommendations for Future Research.....</b>	<b>49</b>
5.1 Measuring Outcomes.....	49
5.2 Generalisability of Results.....	51
5.3 Research Design and Setting.....	52
5.4 Components of Third-Wave Interventions.....	53
<b>6.0 Conclusion.....</b>	<b>53</b>
<b>7.0 Funding.....</b>	<b>54</b>
<b>8.0 References.....</b>	<b>55</b>

<b>9.0 Appendices</b> .....	<b>64</b>
Appendix A Critical appraisal table for single case design papers.....	64
Appendix B Critical appraisal table for group design papers.....	65
<b>CHAPTER TWO: EMPIRICAL PAPER</b>	
<b>1.0 Abstract</b> .....	<b>67</b>
<b>2.0 Background</b> .....	<b>68</b>
2.1 Research Question.....	69
<b>3.0 Method</b> .....	<b>70</b>
3.1 Reflexivity.....	70
3.2 Epistemological Position.....	70
3.3 Methodology.....	71
3.4 Rationale for using Q Methodology.....	71
3.5 Materials.....	72
3.5.1 Creation of the Concourse.....	72
3.5.2 Selection of Statements (The Q set) .....	73
3.6 Ethical Approval.....	75
3.7 Participants.....	75
3.7.1 Inclusion and Exclusion Criteria.....	75
3.7.2 Recruitment.....	75
3.7.3 Sample Size.....	75
3.7.4 Ethical Considerations.....	76
3.8 Procedure.....	76
<b>4.0 Results</b> .....	<b>77</b>
4.1 Participants.....	77
4.2 Q sorts.....	79
4.3 Factors.....	80
4.3.1 Factor One.....	81
4.3.2 Factor Two.....	83

4.3.3 Viewpoint Three.....	85
4.4 Distinguishing Statements.....	87
4.5 Consensus Statements.....	88
4.6 Adequacy of Concourse.....	88
<b>5.0 Discussion.....</b>	<b>89</b>
5.1 Clinical Implications.....	91
5.2 Strengths.....	91
5.3 Limitations.....	92
5.4 Future Research.....	92
<b>6.0 Conclusion.....</b>	<b>92</b>
<b>7.0 Funding.....</b>	<b>93</b>
<b>8.0 References.....</b>	<b>94</b>
<b>9.0 Appendices.....</b>	<b>98</b>
Appendix A: List of statements and the constructs they represent.....	98
Appendix B: Statements and their visual representation given to participants...100	100
Appendix C: Independent Peer Review Letter.....	105
Appendix D: Favourable ethical opinion from the REC (Research Ethics Committee) .....	106
Appendix E: Approval from the HRA (Health Research Authority) .....	111
Appendix F: Confirmation of capability and capacity from the R&D (Research and Development) department of each Trust.....	114
Appendix G: Participant Information Sheet (standard version) .....	115
Appendix H: Participant Information Sheet (Aphasia-Friendly Version) .....	119
Appendix I: Consent to Contact Form.....	127
Appendix J: Informed Consent Form.....	128
Appendix K: Instructions for Participants doing the Q-sort.....	129
Appendix L: Representation of Q-grid distribution.....	130
Appendix M: Questions asked of participants following the Q-sort.....	131

Appendix N: Colour-coded factor arrays used for analysis.....	132
Appendix O: Journal of Contextual Behavioural Science Guidelines for Publication.....	133
<b>CHAPTER THREE: REFLECTIONS</b>	
<b>1.0 Reflections on the Research Process.....</b>	<b>147</b>
<b>2.0 References.....</b>	<b>155</b>



## Abstract

Stroke has a major impact on the health and wellbeing of the world's population. As well as physical health difficulties, many people experience psychological distress, which can also impact on recovery. There is, however, little known about which psychological interventions may be beneficial to psychological wellbeing following stroke.

There is growing interest in the application of third-wave therapies in this area. A literature review found eight studies where this type of intervention has been used with stroke survivors, five group studies and three case studies. The methodological quality of these was generally low; however, they provided data regarding the potential benefits of third-wave therapies. These benefits included reducing symptoms of anxiety and depression, improving physical health, and helping people to live valued lives. This is a good starting point for further work; however, it was unclear which aspects of third-wave therapies were important.

To address this, a Q methodology study was designed which aimed to explore the components of third-wave therapies and their relevance to people's psychological wellbeing following a stroke.

Ten participants were recruited from inpatient stroke wards. They sorted 40 statements which represented different components related to third-wave therapies. A two-factor solution was uncovered, with a third unique viewpoint also retained. Factor one revealed the importance of values and committed action, which was related to psychological wellbeing following stroke. Factor two was characterised as creative hopelessness, with people accepting that they need help, being focused on the past and future. Viewpoint three was defined as a disconnection from humanity with a lack of compassion for self and others. Three statements were identified which could be used to identify an individual's viewpoint. This could provide a helpful way to think about the most appropriate intervention for an individual following stroke.

The final paper provides reflections on the research process.

## CHAPTER ONE

The Application of Third-Wave Therapies  
to Psychological Wellbeing Following  
Stroke: A literature review.

## **1.0 Abstract**

**Background:** Stroke is one of the leading causes of death and disability in the world. An estimated 30-60% of people experience difficulties with their mental health as they adjust to life after stroke. Higher levels of psychological wellbeing following stroke predict better mental and physical health outcomes, however, there is little guidance regarding which psychological interventions may promote wellbeing.

**Aim:** To examine what is known about the application of third-wave therapies to psychological wellbeing following stroke.

**Search strategy:** A literature search was conducted to identify relevant papers. Eligibility criteria were; participants over the age of 18 who had experienced a stroke; the intervention used was a third-wave psychological therapy; the outcomes were related to participants' psychological wellbeing. The search covered papers in English since 2005.

**Results:** Eight papers were found, five group interventions and three case studies. The results were synthesised thematically and critically appraised with a combination of evaluation tools. Improvements were seen in depression and anxiety symptoms, functioning, social engagement and physical health. The number and quality of the papers, including small sample sizes and no randomised control groups, limited the review.

**Conclusion:** Results indicated that third-wave therapies have potential in supporting people's psychological wellbeing following a stroke, and provide a foundation for further research.

**Recommendations:** Further research should include control groups, focusing on psychological wellbeing rather than symptom reduction. Attention should be given to which aspects of therapy are relevant to this population.

## 2.0 Background

### 2.1 Stroke

Stroke has been defined by the World Health Organisation (WHO) as “rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (Aho et al. 1980, p. 114). Put more simply, a stroke occurs when the blood supply to part of the brain is cut off (Stroke Association, 2016).

Stroke has a significant impact on the health of the world’s population. The second leading cause of death (Lozano et al. 2013), it is also the third greatest cause of disability-adjusted life-years (DALYs) worldwide (Murray et al., 2013). Stroke is one of the leading causes of morbidity in the UK, with over 110,000 people experiencing a stroke each year in England alone (National Institute for Health and Care Excellence; NICE, 2013). In the UK, survival rates are steadily increasing, and most people will now survive a first stroke (NICE, 2013). However, those who do survive often have significant difficulties, and can face a complex journey through recovery (Eilertsen, Kirkevold, & Bjørk, 2010). In addition to the physical effects of stroke, many people will also experience an impact on their psychological wellbeing.

### 2.2 Psychological Impact of Stroke

Psychological distress is common following stroke, with an estimated one-third of people experiencing clinical levels of depression (British Psychological Society, 2010). This has long-term consequences for health outcomes, such as quality of life (Ayerbe, Ayis, Crichton, Wolfe & Rudd, 2014). One-quarter of people are also estimated to experience clinical levels of anxiety (Campbell Burton et al., 2011), with many more predicted to

experience distress at a sub-clinical level (Intercollegiate Stroke Working Party (ISWP), 2016).

### 2.3 Impact of Psychological Wellbeing on Physical Health

Psychological wellbeing is also important for an individual's physical health. Using data from the Chicago Health and Aging project, which looked at 6158 adults over the age of 65, Henderson et al. (2013) found an increased incidence of both fatal and non-fatal strokes in those with higher levels of psychosocial stress. Ayerbe et al. (2014) followed 3240 people on the South London Stroke Register, from stroke onset over 10 years, and found that depression, as measured by the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), was independently associated with poorer health outcomes such as increased disability (measured using the Barthel Index) and mortality. A meta-analysis of prospective and case-control studies also indicated that perceived psychosocial stress is independently associated with an increased risk of stroke (Booth et al., 2015).

Conversely, emotional vitality, defined as "a sense of positive energy, the ability to effectively regulate emotions and behaviour, and positive wellbeing" (Kubzansky & Thurston, 2007, p. 1393), has been found to be associated with lower stroke risk in a sample of 6019 people in the first National Health and Nutrition Examination Survey in America (Lambiase, Kubzansky & Thurston, 2015). An interest in promoting psychological wellbeing following stroke is, therefore, relevant to an individual's mental and physical wellbeing, as well as having economic implications in terms of health and social care costs and lost productivity. This has been estimated to cost the UK £8.9 billion a year (Saka, McGuire & Wolfe, 2009).

## 2.4 Guidance on Interventions

The importance and value of psychological care following stroke is increasingly recognised in policy and guidance. The NICE Quality Standard (QS2) on Adults with Stroke, updated in 2016, states that people should have access to a clinical psychologist with expertise in stroke rehabilitation (NICE, 2016). The new guidelines issued by the ISWP (2016) recommend that a specialist clinical psychologist or neuropsychologist should have input into a multi-disciplinary team, and that psychological support is offered to all patients, regardless of whether or not they are exhibiting specific mental health or cognitive difficulties.

## 2.5 Psychological Interventions Following Stroke

Despite this focus on wellbeing, the new stroke guidelines (ISWP, 2016) are not prescriptive about what type of psychological intervention may help. The ISWP cite studies on brief psychological interventions, including motivational interviewing, problem solving and behavioural therapy. They do not, however, advocate the use of any particular therapy, and conclude that more research is needed into interventions. This reflects a lack of published research and guidance in the area, which is still in its infancy (Kootker et al. 2015). There has been a growth of research in stroke interventions in recent years, which has coincided with a dramatic increase in interest in third-wave psychological therapies.

## 2.6 Third-Wave Therapies

The term 'third-wave' refers to a group of psychological interventions that have grown out of behavioural, or first-wave, and then cognitive behavioural, or second-wave, therapies. This new wave of interventions has the common thread of being based on mindfulness. Mindfulness is a concept founded on Eastern philosophical practices, which has been

adopted and popularised in the West, most notably in the field of health by Jon Kabat-Zinn (Kabat-Zinn, 1982). According to Kabat-Zinn, mindfulness concerns three essential aspects of attention; paying attention on purpose, paying attention to the present moment, and paying attention without judgement (Kabat-Zinn, 1994).

Kabat-Zinn first introduced this in the 1970s with Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1982), and further therapies have since emerged. These include Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999), Mindfulness-Based Cognitive Therapy (MBCT; Segal, Williams & Teasdale, 2002) and Compassion Focused Therapy (CFT; Gilbert, 2009). These each have their own focus and nuances, but at heart they maintain a common thread of present moment awareness, which is approached without judgement. This is done with curiosity and kindness, and while some therapies focus more explicitly on one aspect or another, acceptance and compassion are woven into each approach, inherently linked to a non-judgemental stance.

This non-judgemental stance highlights the key practical difference between the groups of therapy. Second-wave CBT interventions approach difficult thoughts and feelings as 'negative', and they aim to eliminate these through processes such as cognitive restructuring. Third-wave therapies, on the other hand, hold that these experiences are part of being human and it is our struggle with them, rather than the experiences *per se*, that creates difficulties. By not judging experiences as good or bad, a different relationship with them emerges which allows the living of a meaningful life alongside them. While this often results in a reduction in symptoms associated with the diagnostic categories of anxiety and depression, third-wave therapies are process focused and trans-diagnostic, and it is not a goal

to reduce symptomatology (Harris, 2007).

The main characteristics of the most prevalent third-wave therapies are as follows:

#### Mindfulness-Based Stress Reduction (MBSR)

MBSR (Kabat-Zinn, 1982) was the first structured mindfulness based programme to be popularised in healthcare. Developed as an 8-week programme, it aims to help people become more aware of the body, how they feel, and their mental state, through mindful practice. It aims to help participants recognise the unhelpful patterns they can get into when responding to internal and external stressors (Shapiro, Astin, Bishop, & Cordova, 2005).

Mindful practice includes the body scan; a systematic mental examination of the body to cultivate an awareness of whatever sensations are present, hatha yoga; gentle physical exercises which encourage an awareness of the body, and sitting meditation; focusing on an awareness of the breath and then widening this to the physical and mental environment. Through these practices, it is thought that individuals gain a greater moment-to-moment awareness, and are better able to observe their beliefs, thoughts and emotions without becoming attached to them, leading to a better sense of wellbeing (Ludwig & Kabat-Zinn, 2008).

#### Mindfulness-Based Cognitive Therapy (MBCT)

MBCT (Segal et al., 2002) also uses the techniques in MBSR in an 8-week group based programme, which is done alongside more traditional cognitive techniques such as thought monitoring.



## Acceptance and Commitment Therapy (ACT)

ACT (Hayes et al., 1999) focuses on developing the areas of psychological flexibility shown in Figure 1. These are mindfulness and present moment awareness, acceptance of difficult thoughts and feelings as just one aspect of the self, and taking committed action to behave in accordance with one's values.

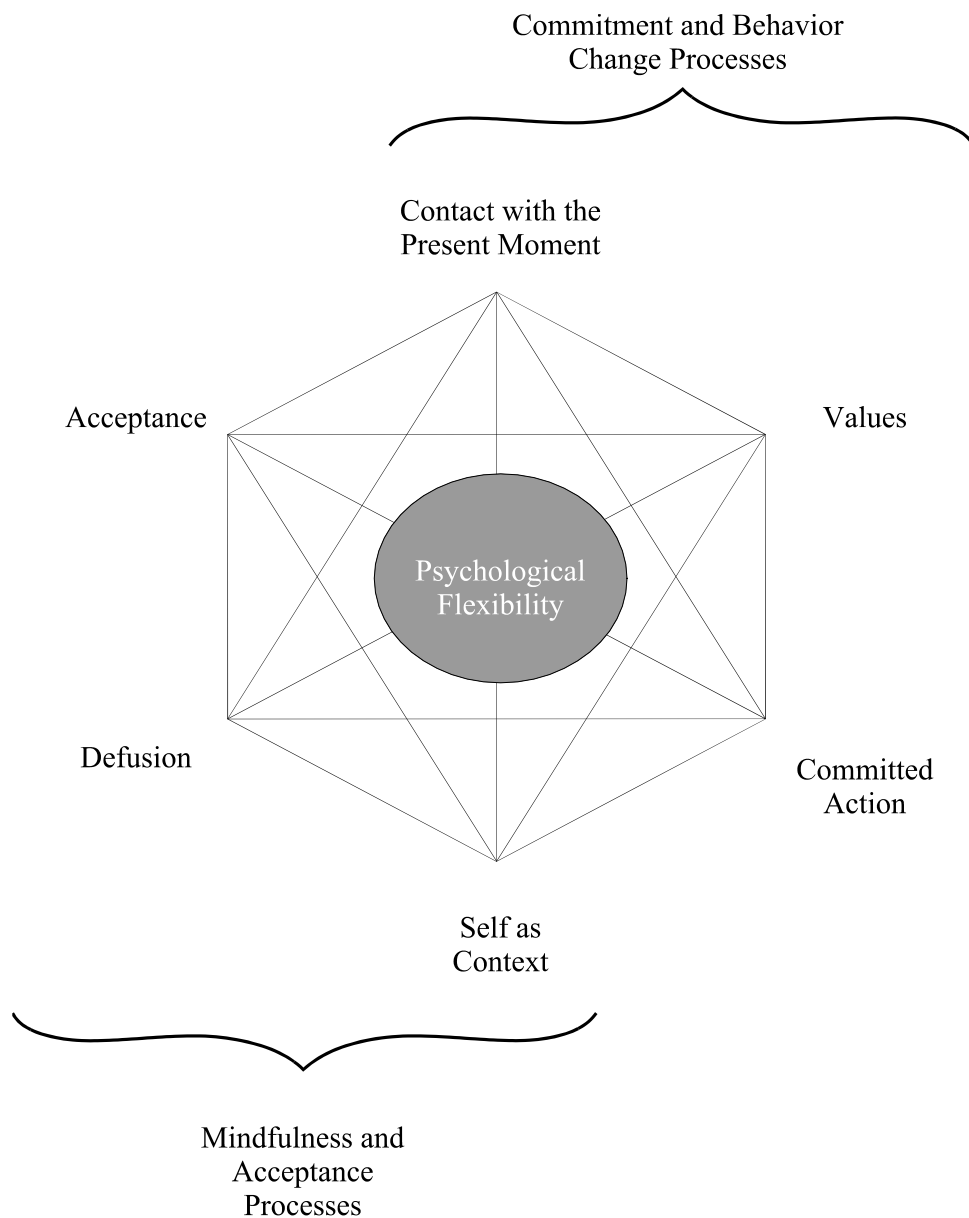


Figure 1. A model of psychological processes ACT seeks to strengthen (Hayes, Luoma, Bond, Masuda & Lillis, 2006; reproduced with the kind permission of Professor Steven Hayes).

## Compassion Focused Therapy (CFT)

CFT (Gilbert, 2009) centres around the idea that humans have ‘tricky brains’ which have evolved to focus on threat as a survival mechanism. The threat system, which is associated with anger, anxiety and disgust, tends to override feelings of excitement and vitality, or safe connectedness, if there is any indication of danger. These three types of affect regulation can be seen in Figure 2. As human brains have evolved to be able to *imagine* threat, this can occur even when no physical danger is present. CFT uses compassion and mindfulness to rebalance the self-soothing and threat based systems. Compassion is commonly defined in this context as “sensitivity to suffering in self and others, with a deep commitment to try to alleviate and prevent it” (Gilbert & Choden, 2013, xxv).

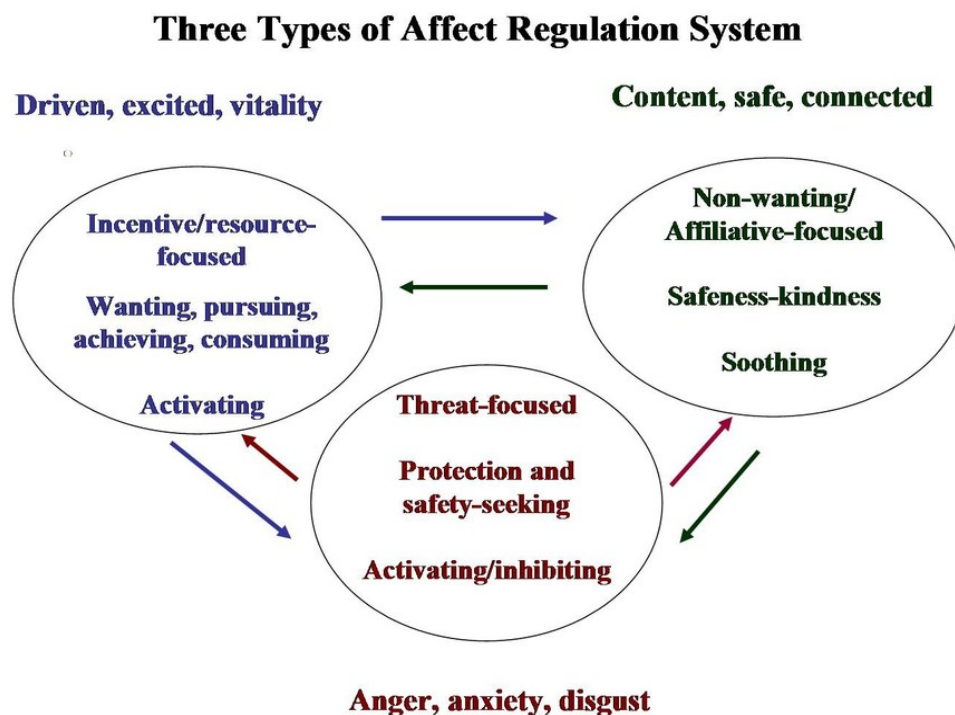


Figure 2. Three types of affect based regulation system (Gilbert, 2009; reproduced with kind permission from Professor Paul Gilbert).

## 2.7 The Use of Third-Wave Therapies in Promoting Psychological Wellbeing

Mindfulness has been approved for use in recurrent depression by NICE (2009; updated 2016), and its potential as an intervention for depression and anxiety is well documented in several systematic reviews (for example, Fjorback, Arendt, Ørnbøl, Fink & Walach, 2011; Leaviss & Uttley, 2015; Öst, 2014; Piet & Hougaard, 2011; Swain, Hancock, Hainsworth & Bowman, 2013). Qualitative research has also demonstrated that third-wave therapies generally have a high level of acceptability amongst service users (Williams, McManus, Muse & Williams, 2011; Shonin, Van Gordon, & Griffiths, 2014).

## 2.8 Relevance of Third-Wave Therapies to Stroke

The processes and difficulties targeted by third-wave therapies may have relevance to the difficulties experienced following stroke, therefore it is important to also review the literature in this area. These processes include acceptance and compassion, values based living, emotional regulation, fatigue and sense of self.

An Interpretative Phenomenological Analysis (IPA) study conducted by Crowe et al. (2015) noted that processes involving a lack of acceptance and compassion underlined themes around fear of stroke, loss of self and isolation. Other studies have shown that acceptance is a greater predictor of psychological wellbeing following stroke than level of disability (Townend, Tinson, Kwan & Sharpe, 2010), and people who are unable to accept post-stroke changes tend to have higher rates of anxiety (Lander, 2009). Higher levels of compassion, such as a sense of common humanity and connectedness (Neff, 2003), have been identified as important in promoting subjective wellbeing following stroke (Brunborg & Ytrehus, 2014), and as a mediator between physical health diagnoses and wellbeing (Register & Herman, 2010).

Focusing on valued activities rather than goals, which is especially important in ACT, may also be relevant to stroke survivors. Achieving tangible goals can be unrealistic for people with an acquired brain injury (Brands, Stapert, Köhler, Wade & van Heugten, 2015). Goals that tend to be set by professionals are also not experienced as meaningful to patients (Brown et al., 2014), and patients tend to view progress to adapting to life post-stroke in terms of reengagement with personally valued activities (Davis, Egan, Dubouloz, Kubina & Kessler, 2013).

Many stroke survivors also experience difficulties with emotional regulation (Morris, Robinson, & Raphael, 1993). This is not necessarily due to negative appraisals (Huang et al., 2015), but can be affected by damage to brain structures that regulate emotional processes (Philippi, Mehta, Grabowski, Adolphs, & Rudrauf, 2009). Mindfulness has been found to help with emotional regulation in students (Hill & Updegraff, 2012), and evidence from brain scans indicates that mindful meditation may be connected with changes in areas of the brain indicated in emotional processing (Lazar et al., 2005). While it is not yet clear if this can be generalised to stroke survivors, there is evidence that the brain can retain plasticity even following brain injury (Wieloch & Nikolich, 2006), and mindfulness-based interventions can promote structural brain changes in people with neurological conditions (Pickut et al., 2013).

Fatigue is also reported as one of the most difficult problems to manage following a stroke (Ingles, Eskes & Phillips, 1999). This can impact upon psychological wellbeing and an individual's ability to engage with valued activities and roles. Mindfulness-based approaches may be relevant in helping people who have had a stroke to manage fatigue by enhancing their awareness of symptoms and management of its triggers (Hofer et al.,

2014).

Another common reaction to brain injury is people reporting that they have lost a sense of who they are (Meili & Kabat-Zinn, 2004). Myles (2004) suggests that this is related to a strong sense of conceptualised self, which is a “network of verbal self-relations that develops as a person repeatedly applies categorical concepts to her behaviours” (Myles, 2004, p.493). For example, a person’s sense of self may be strongly connected to being a ‘wife’ which is strongly associated (for this hypothetical individual) with behaviours such as ‘cooking’ and ‘shopping’. To no longer be able to cook or shop following a stroke can threaten this identity.

This ‘conceptualised self’ is one of three senses of self which is proposed in Relational Frame Theory (RFT), the model which underpins ACT. RFT proposes that we learn things, including this sense of self, through symbolic interactions and associating different constructs with one another. This conceptualised sense of self often dominates, causing emotional distress when a person becomes aware of this challenge to their identity (Myles, 2004). Mindfulness has potential to help with this by shifting focus to observing these processes. This can “provide the survivor with a safe place from which to know and accept the changes in her functioning and self-concept that she experiences post-injury, thus facilitating adjustment” (Myles, 2004, p.500).

A loss of identity can also be complicated by additional problems associated with aphasia and language loss. Sense of identity can be compromised by difficulties in communicating with others and positioning oneself as a relational being (Shadden, 2005). Aphasia can also hinder therapeutic learning following stroke. Whilst there is evidence to indicate that people with aphasia can learn mindfulness and derive positive benefits

from it (Orenstein, Basilakos & Marshall, 2012), aspects of this intervention, which have a strong focus on the use of language and the learning of new associations, may not be as accessible to everyone.

It seems, therefore, that third-wave therapies have potential relevance to the difficulties experienced by people following stroke, but it is important to be aware that there may also be some important limitations regarding language in this population.

## 2.9 Summary

There is promising evidence which points towards the relevance of third-wave therapies following stroke. There is a small body of literature where third-wave therapies have been tested in this area that has not yet been critically appraised. The following review evaluates and synthesises the current state of this knowledge.

## **3.0 Review of the Evidence for Third-Wave Interventions Following Stroke**

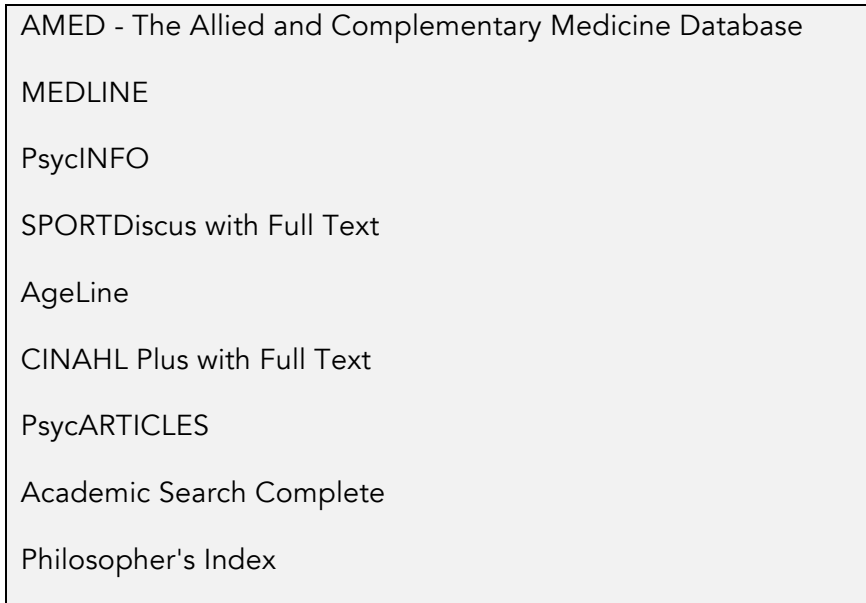
A review protocol has not been registered for this review because it does not fall within the scope of a full systematic review.

### 3.1 Methods

#### 3.1.1 Information Sources

A search was completed using EBSCO Host including All Health Databases and Academic Search Complete; this covered the databases shown in Figure 3.

Additional searches were also carried out using WebofScience, Google Scholar and Research Gate, and lead authors in the area were also contacted (for example, Professor Steven Hayes).



AMED - The Allied and Complementary Medicine Database
MEDLINE
PsycINFO
SPORTDiscus with Full Text
AgeLine
CINAHL Plus with Full Text
PsycARTICLES
Academic Search Complete
Philosopher's Index

*Figure 3. Databases included in search*

The final search was carried out on 21<sup>st</sup> October 2016, and the search terms used are shown in Table 1.

Limiters were applied to restrict the search to papers from 2005 in the English language. No further limiters such as age were applied as this was seen to exclude relevant papers.

Table 1. *Terms used in EBSCO Host search*

PICO <sup>1</sup> category	Search terms used	Field searched
Participant	stroke or brain or cerebral* or abi or tbi or vascular* or hemorrhag* or haemorrhag* or ischaem* or ischem*	Title
	AND	
Intervention	compass* or cft or accept* or mindful* or third wave or mbsr or mbct or act or mbi or dbt or dialectical	Title
	AND	
Outcome	well* or psych* or cop* or recover* or quality or mood or depression or anxiety or emotion* or feel*	Abstract

<sup>1</sup>PICO Participant, Intervention, Comparison, Outcome (Sayers, 2008)

### 3.1.2 Study Selection

Eligibility criteria for the inclusion of papers, including working definitions of the terms used, are shown in Table 2.

Most studies were screened by reviewing the title, however where titles were more ambiguous, the abstract or full paper was reviewed. To check for consistency, when the records were screened, a sample of studies was given to two peers who had access to the inclusion and exclusion criteria. This showed that there was 100% consistency across reviewers. A flow chart for the papers retained can be seen in Figure 4.



Table 2. *Eligibility criteria and limiters for the inclusion of papers in the literature review, including the PICO (participants, intervention, comparisons, outcomes; Sayers, 2008) framework.*

Inclusion criteria	Definition and rationale
Related to humans over the age of 18 (Participants)	The experience of stroke in children is likely to be different, and therapies will need to be adapted for use with this client group.
Focused on the person who has experienced a stroke (Participants)	Papers focused on the person who has experienced a stroke were included, rather than the parents or carers of someone who has had a stroke.
Related to third-wave or mindfulness based therapies (Intervention)	Psychological therapies that have emerged from cognitive behavioural therapies, with their basis in mindfulness.
The effectiveness of the therapy was evaluated (Comparison)	Participants were either compared with their own pre-intervention measures or with a waiting list control group.
Focused on wellbeing or psychological outcomes (Outcome)	Papers were excluded if they focused on medical or physical outcome exclusively as this was not the topic of interest.
All types of literature including grey literature	Research in this area is still in its early stages; therefore all types of literature were included.
English Language	Foreign language papers were not included due to restrictions on the time and funding necessary to translate these.
Published between 2005 to 2016	The first paper relating to mindfulness-based therapy for stroke was in 2007. Papers were included from 2005 to account for publication lag.

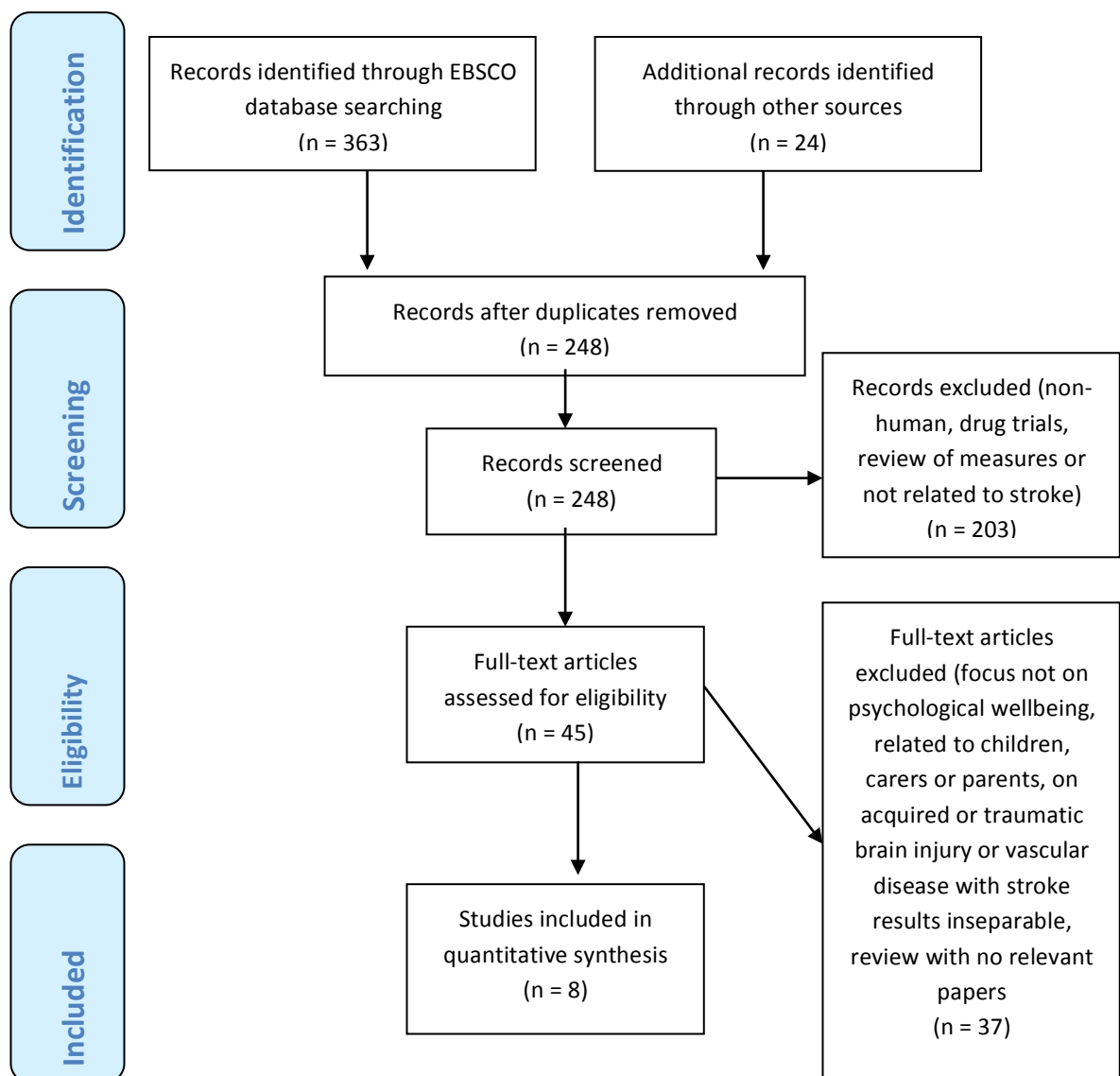


Figure 4. PRISMA flow diagram of papers selected for review

### 3.1.3 Summary of Studies

Eight papers remained following adherence to the exclusion criteria, these are summarised in Table 3. Five were conducted in the UK, with one study conducted in the United States, one in Korea and one in Sweden. There were two different methodologies amongst the eight papers reviewed. Three papers were single case experimental designs (SCED), and five looked at group interventions. One of the group intervention studies used a waiting list control group.

Table 3. *Summary of Papers Included in the Literature Review*

Design	Authors, date and title (Country)	Participant characteristics	Intervention	Key Findings/ Outcomes	Key strengths/ limitations (Critical appraisal score)
Comparison of intervention group v. waiting list control group	Johansson, Bjuhr & Rönnbäck (2012). Mindfulness-based stress reduction (MBSR) improves long term mental fatigue after stroke or traumatic brain injury (Sweden)	22 (Stroke; 12, TBI; 10) Mixed group however outcome data was obtained for stroke population only. Mean age of group 1 53.7, group 2 59.1 12 Female, 10 Male.	8 weeks; group MBSR.	Significantly decreased scores for depression and anxiety in intervention group. Significant correlation for improvement in mental fatigue and information processing speed. No significant changes were found in the control group.	+ Used a control group. - Unclear if the significant reduction in scores was clinically significant or what the experience of participants was like. (13/20)
Comparison of group pre- and post-intervention measures	Ashworth, Clarke, Jones, Jennings & Longworth (2014) An exploration of compassion focused therapy following acquired brain injury (UK)	12 (Stroke; 3, Traumatic Brain Injury; 7, Tumour; 1, Overdose; 1). Time since stroke unknown. Mean age (of all participants) 40.1, range 21.4-54.5. 5 Female, 7 Male.	Individual weekly CFT (mean=16 sessions) and 6 group sessions.	Emergent themes around the importance of the therapeutic relationship/group processes, gaining a new understanding of difficulties and psychological difficulties following stroke.	+ Qualitative data gives a rich account of the experience of CFT and where the important mediators of change might lie. - Only process data could be used due to mixed population, unable to obtain quantitative data for stroke only. Working age sample so generalisability restricted. No control group. (12/20)

Study Design	Author, date and title and country	Participant characteristics	Intervention	Key Findings/ Outcomes	Key strengths/ limitations (Critical appraisal score)
Comparison of group pre- and post-intervention measures	Joo, Lee, Chung & Shin (2011). Effects of MBSR programme on depression, anxiety and stress in patients with aneurysmal subarachnoid haemorrhage (Korea)	11 (Subarachnoid haemorrhage) Mean age 52.6 Female 6, Male 5.	8 weeks; group MBSR.	Statistically significant reduction in Beck Depression Inventory value and depression levels. Reduction in anxiety levels.	+ Used objective physiological measures to monitor outcomes - No indication of clinical significance. Small sample size. No control group. Acceptability not considered. (10/20)
Comparison of group pre- and post-intervention measures	Merriman, Walker-Bircham, Easton & Maddicks (2015). The development of a mindfulness group for stroke patients: A pilot study (UK)	4 (Ischaemic stroke) 1-4 years post-stroke Age range 47-62.	Number of sessions unknown; group MBCT.	Three participants improved on the HADS for anxiety and depression as well as the psychological domain of the WHO QoL-Bref.	+ Qualitative data regarding group adaptations to therapy. - Clinical and personal significance of improvements in depression anxiety and QoL are unclear. (9/18)
Comparison of group pre- and post-intervention measures	Moustgaard, Bedard & Felteau (2007). Mindfulness Based Cognitive Therapy (MBCT) for individuals who had a stroke: Results from a pilot study (UK)	23 (Stroke) Mean age 63.3 6 Female, 17 Male	9 weeks, 1 3/4 hours a week; group MBCT.	Statistically and clinically significant overall improvements in QoL, anxiety and depression. Indicates that the effectiveness of MBCT is not limited to those who are clinically depressed. Suggestion that empowerment & self-direction are prerequisites for psychological change.	+ First study to present data on effectiveness of MBCT following stroke. - Potential volunteer bias, no control group, difficult to know what aspect of the programme mediated change. (15/20)

Study Design	Author, date and title and country	Participant characteristics	Intervention	Key Findings/ Outcomes	Key strengths/ limitations (Critical appraisal score)
Single Case Experimental Design	Graham, Gillanders, Stuart & Gouick (2014). An acceptance and commitment therapy (ACT) based intervention for an adult experiencing post-stroke anxiety and medically unexplained symptoms (UK)	1 (Stroke & medically unexplained symptoms. Stroke described as main problem). Several months post-stroke. Early 40s. Male.	9 individual sessions of ACT.	Increased psychological flexibility, decrease in anxiety symptoms and improved illness cognitions. Medically unexplained pain eliminated, client returned to work.	+ In-depth data. - Case study with previous CBT experience limits generalisability. (6/15)
Single Case Experimental Design	Marino, DePasquale & Sirey (2015). Cognitive Behaviour Therapy with mindfulness and acceptance skills for the treatment of older adults (USA)	1 (Stroke) Age 84 Male.	12 weeks of individual CBT with mindfulness and acceptance skills.	Indicates that CBT with mindfulness can reduce symptoms of depression and improve the quality of life in a socially isolated 84 year old man with comorbid health problems.	+ Comorbid factors make it more generalisable. Rich qualitative data, detailed description of intervention and what may have mediated change. (6/15)
Single Case Experimental Design	Shields & Onsworth (2013). An integration of third wave cognitive behavioural interventions following stroke: A case study (UK)	1 (Stroke) 18 months post-stroke Age 48 Female.	10 individual sessions; An integrated CBT/CFT approach.	Clinically significant reduction in emotional distress, fewer avoidance behaviours, and an increase in self-compassion. Three-month follow-up; improvements in emotional status was maintained, avoidance behaviours returned to almost pre-treatment levels.	+ Detailed session content and outcome measures for replicability and examination of relationship between session and outcome scores. - Limited generalisability due to age and level of education of patient. (9/15)

## 3.2 Evaluation of Papers

As the papers fell into two methodological categories, single case experimental design and group intervention designs, it was necessary to devise two evaluation tools, one for each category of paper. The two groups of papers were then evaluated separately according to these checklists.

### 3.2.1 Evaluation of Single Case Experimental Design Papers

An evaluation tool for the single case design papers was created by combining Morley's gold standard of single case design (Morley, 1996), the recommendations included in Chambless and Hollon (1998) on defining empirically supported therapies, and the Centre for Evidence Based Medicine Checklist (C-EBM, 2016).

The evaluation checklist for these papers can be seen in Appendix A. None of the papers met all the evaluation criteria, with two fulfilling only six criteria (Marino et al. 2015, Graham et al. 2015) and the remaining paper (Shields & Onsworth, 2013) fulfilling nine out of the fifteen criteria. The number of criteria fulfilled is not a straightforward comparative measure of quality, and should be viewed alongside the more detailed evaluation below. Case study research is also generally considered to be the lowest ranked quality data in terms of the hierarchy of evidence, ranked as 'poor' by Evans (2003).

#### 3.2.1.1 Establishment of Baseline

None of the studies achieved a stable baseline prior to commencing the intervention; therefore it cannot be said with any confidence that the participants' scores changed due to the introduction of the intervention.

### 3.2.1.2 Appropriateness of Outcome Measures

Morley (1996) recommends the use of three different measures to monitor the efficacy of a single case intervention; global/standard measures, individual target measures and process measures. All three case studies used global/standard measures at the beginning and end of the intervention. These have normative data within the wider population and have reliability and validity statistics.

While two studies recorded session-by-session data (Graham et al., 2015 and Shields & Onsworth, 2013), they used global measures rather than an individual target measure designed to monitor an individual's progress on a specified event. Using target measures would have enabled the accurate and reliable measurement of an individual's progress tailored to their specific difficulties (for example, time spent out of the house). In single case design research, this would be the main outcome measure of interest (Morley, 1996). In effect, this means that people were measured against the wider population rather than against their own progress towards their own goals, which may not have been meaningful for the participants.

Process measures, which monitor the treatment sessions, were not reported in any of the case studies. All the studies did, however, provide some qualitative data regarding the participants' experience of the intervention and behavioural changes. While this was not done methodically or systematically as an outcome measure, this data does, nonetheless, provide information regarding the efficacy of the intervention and its mediators of change.

Only one of the studies (Shields & Onsworth, 2013) reported follow-up data.

### 3.2.1.3 Analysis of Data

Morley (1996) recommends the presentation of data in a clear graph as the best way to interpret and understand the data. A graph of the outcome measures was provided in two of the studies (Graham, Gillanders, Stuart & Gouick, 2014, and Shields & Onsworth, 2013). Without a stable baseline, however, this has less meaning as the trajectory of data might have been following this trend regardless of the intervention.

In addition to graphing the data, non-parametric analysis alongside an interpretation of its clinical significance is also advocated. This was only completed in one study (Shields & Onsworth, 2013).

None of the studies reported that they employed another researcher-clinician to independently review the data to see if they corroborate their interpretation or findings. This is considered especially important in single case clinical studies due to the risk of bias from the clinician also performing the researcher role.

### 3.2.1.4 Summary of Single Case Experimental Designs

None of the studies established a stable baseline of data, and they failed to use target or process measures to monitor the impact of the intervention. Nevertheless there was a large amount of qualitative process data reported.

### 3.2.2 Evaluation of Group Design Papers

An evaluation tool for the five papers using group designs was created by combining the criteria set out by Downs and Black (1998) and the Critical Appraisal Skills Programme checklist (CASP, 2013).

As none of the papers used a Randomised Controlled Trial (RCT) design, the criteria relating to this type of study were not used. A summary



of the evaluation is presented here, organised in terms of the Participants, Interventions, Controls, Outcomes and Study Design (PICOS) criteria. A summary can be seen in Appendix B. The overall critical appraisal score can be found in Table 3. It should be noted, however, that a higher score does not necessarily equate to a higher quality paper, as the criteria do not have equal weighting with regard to quality. The scores should be considered in light of the more detailed appraisal below.

### 3.2.2.1 Participants

#### Recruitment of participants

Recruitment was through existing service users in three papers (Ashworth, Clarke, Jones, Jennings, & Longworth, 2015; Joo et al., 2011; Merriman, Walker-Bircham, Easton & Maddicks, 2015). Two papers recruited participants from the wider community (Johansson et al., 2012 & Moustgaard et al., 2007). Of these, one study demonstrated a comprehensive effort to recruit widely through different community and clinical channels (Moustgaard et al. 2007), while the other recruited only through an advertisement in a local newspaper (Johansson et al., 2012), which may not have reached a representative sample of the target population.

Three papers reported that informed consent was gained (Johansson et al., 2012, Ashworth et al., 2015 and Moustgaard et al., 2007), and one paper made it explicit that treatment would have been provided regardless of participation in the study (Ashworth et al., 2015).

#### Sample size

Sample sizes were small, with a mean of 10.6 stroke survivors per study (ranging from 4 to 23). A power calculation was not completed in any of the

studies, and it is unclear whether any of the papers had sufficient power to detect effects if they were present.

#### Generalisability of the results to the local population

Due to a lack of reported data, it was not possible to calculate the mean age of participants across all the papers. The reported ages do indicate, however, that the ages of participants were much lower than the mean age of first stroke in the population (77 in women and 71 in men, Lee, Shafe & Cowie, 2011). Only one paper (Moustgaard et al., 2007) had a sample whose age was reflective of this. This is in part due to the studies being carried out by services that only cater for people under 65 (Ashworth et al., 2015, personal correspondence). Another study excluded anybody over the age of 65 without providing a rationale for this (Johansson et al., 2012).

All studies specified exclusion criteria of severe cognitive impairment or similar, and only one paper noted the inclusion of participants with aphasia (Moustgaard et al. 2007), therefore the results cannot be generalised to the wider stroke population.

Only one paper reported the cultural or ethnic background of participants, who were all white British (Ashworth et al., 2015). Three of the studies were conducted in the UK, one in Sweden (Johansson et al., 2012) and one in Korea (Joo et al., 2011). As Sweden and Korea have different healthcare systems and cultures, it is difficult to know the generalisability of these studies to a UK stroke population and health service. It is, however, useful to have cross-cultural data to consider wider generalisability.

All studies reported dropout rates, but did not account for all of them. Some reasons given for non-completion were cognitive difficulties (Johansson et al, 2012), transport problems (Moustgaard et al., 2007) and

bereavement (Ashworth et al., 2015). The characteristics of any people lost to follow up were not reported in any papers.

### 3.2.2.2 Intervention

#### Replication

All studies reviewed gave a detailed description of the intervention they used and replication would be possible.

#### Concordance with intervention

Engagement with the intervention, in terms of attendance or home practice, was not consistently reported, therefore reliability of compliance with the intervention is largely undetermined. One study noted that participants struggled with the home practice and with longer practices (Merriman et al. 2015).

### 3.2.2.3 Comparisons

A limitation of all the group studies was the absence of a randomised control group, with only one study employing a waiting list control (Johansson et al., 2012). The quality of evidence from the evaluation of standard clinical practice is generally considered to be of a much lower standard than that of a controlled trial or an RCT. They are open to bias from the conducting clinicians as their objectivity is often compromised. There are also potential confounding variables, including that of the therapeutic relationship between client and therapist. There is also the possibility of demand characteristics from client. 'Before and after' studies such as these are ranked as 'fair' in terms of effectiveness and feasibility in the hierarchy of evidence, on a scale of 'poor', 'fair', 'good' and 'excellent' (Evans, 2003).

### 3.2.2.4 Outcomes

#### Characteristics of measures

The outcomes used in all the studies were adequately described and information was provided regarding validity and reliability data.

#### Appropriateness of measures

All papers used some measure of anxiety and depression symptoms, and it is arguable whether these are congruent with trans-diagnostic third-wave based approaches.

Two studies used measures more reflective of the interventions, measuring mindfulness and elements related to self-compassion (Five Facet Mindfulness Questionnaire (FFMQ), Baer, Smith, Hopkins, Krietemeier & Toney, 2006, in Merriman et al., 2015, and the Forms of Self-Criticism/Self-Attacking and Self-Reassuring Scale (FSCRS), Gilbert, Clark, Hempel, Miles & Irons, 2004, in Ashworth et al., 2015). Two papers used a Quality of Life measure (Merriman et al., 2015 and Moustgaard et al., 2007).

#### Analysis and reporting of results

Statistical analysis was appropriately conducted, and all papers reported the statistical significance of their results, with all but one giving the probability statistics in full (Ashworth et al., 2015). The clinical significance of changes in outcome measures was, however, only reported in one paper (Moustgaard et al. 2007). It is unclear, therefore, if overall changes were meaningful, especially where no qualitative data was provided to complement this.

Follow up data

Only two of the five studies completed three-month follow-ups with their participants (Ashworth et al., 2015 & Moustgaard et al., 2007), making the long-term outcomes unclear.

### 3.2.2.5 Study Design

Aims

All studies used a mindfulness-based therapeutic approach with individuals following stroke, with the presumed aim of evaluating its effectiveness. It was intimated in all papers that there was a lack of evidence in this area that they were looking to address.

Appropriateness of method to the question

All studies looked at pre- and post-intervention measures, or used a control group as a comparison to evaluate the intervention. Therefore the methods used to evaluate the therapeutic use of third-wave therapies with stroke survivors were appropriate. The methods are, however, of a low quality in terms of the accepted gold standard of the RCT (Evans, 2003).

### 3.2.2.6 Summary of Group Design Papers

The samples used in the group design papers were small in number and, overall, not representative of the general population of people who have had a stroke. The absence of randomised control groups also limits the certainty that the results can be attributed to the intervention.

### 3.3 Bias

Both the single case design studies and the group studies included in this review were open to bias from a number of different sources. It is recognised that there will be publication bias regarding the likelihood of papers being written and published only where positive outcomes were found in practice (Fanelli, 2012). Publication bias will be problematic in any systematic review, however, when there is a paucity of research and there is a reliance on evaluation of clinical data, this is perhaps even more pertinent. Questions must be asked about how, and why, one client or group is chosen for review and publication. It is also notable that no authors declared their position or interest in relation to the research.

### 3.4 Critical Appraisal Summary

The eight studies reviewed are generally of low quality in terms of the hierarchy of evidence (being ranked 'poor' to 'fair', Evans, 2003). They are based on single cases or have small sample sizes with no power calculations. This brings into question the generalisability of the findings and the ability of the studies to detect effects if they are present. They also have poor quality statistical data in terms of clinical significance, and they often lack measurement in the most meaningful data for people who have had a stroke. They may, nonetheless, provide some useful information regarding the use of third-wave interventions in stroke. The findings of the papers are synthesised below.

## **4.0 Synthesis of Findings**

The studies used a variety of interventions and methods for data analysis, and as effect sizes were not calculated, comparison of the quantitative outcomes across studies was not possible; instead the outcomes of the papers were synthesised thematically. This allowed the qualitative and

process related data to also be included. The papers were reviewed and the findings extracted, then synthesised by looking at common themes across all papers.

#### 4.1 Anxiety and Depression

All of the studies looked at measures related to the diagnostic categories of anxiety and/or depression to evaluate outcomes, despite this not being congruent with the philosophy of mindfulness. The measures chosen varied and included the Beck Depression Inventory Revised (BDI-II; Beck, Steer & Brown, 1996), the HADS (Zigmond & Snaith 1983), and the Depression Anxiety Stress Scales (DASS-21: Lovibond & Lovibond, 1995), this challenges the validity of the measure used to assess effectiveness.

Across all of the studies, anxiety decreased or was reported as better managed, and depression scores decreased. Statistically significant differences were found where analysis was done, and an increased ability to manage symptoms or a decrease in scores was noted where statistical analysis was not appropriate. A clinically significant improvement was found in two papers (Moustgaard et al., 2007; Shields & Onsworth, 2008). No other papers reported on this, although Marino et al. (2015) described the clinical change in their participant's score on the HAMD (Hamilton Depression Rating Scale, Hamilton, 1960). This moved from 'moderate severity' (20) to 'absent' (5) at the end of the intervention, to consistent with 'Major Depression, in remission' (10) at follow up. Merriman et al. (2015) detailed the raw scores of their four participants, which showed that anxiety and depression scores on the HADS for one participant had increased marginally (from 6 to 7 and 7 to 8 respectively).

Overall, anxiety and depression symptoms were found to decrease using validated self-report measures and appropriate statistical analysis.

While these findings were consistent across studies, the quality of the studies and number of participants was limited.

#### 4.2 Compassion

Two papers noted changes related to self-compassion. Shields and Onsworth (2008) reported that their participant had an increase in self-compassion, measured by self-report on the SCS-SF (Self-Compassion Scale-Short Form; Raes, Pommier, Neff, & Van Gucht, 2011). This was not, however, determined to be clinically significant and did not reach the cut-off for reliable change. The authors note this participant appeared to have a fear of self-compassion, and she expressed concern that taking time out to care for herself ultimately meant that she had become selfish.

Ashworth et al. (2015) noted that in qualitative interviews, conducted after a compassion focused intervention, that participants reported an increased ability to show care towards themselves, and a decrease in self-criticism and self-blame.

Compassion was, therefore, found to increase, with a suggestion that it may be important to also consider the role of a fear of compassion. This was, however, only considered in two studies, one of which was a single case study.

#### 4.3 Psychological Flexibility

Psychological flexibility was shown to increase in the case study by Graham et al. (2014). While this was only explicitly measured in one study, aspects of psychological flexibility were noted in other studies. These showed an increase in mindfulness and acceptance (Merriman et al., 2015; Marino et al., 2015), and in valued living in terms of increased social or occupational functioning (Shields & Onsworth, 2013; Marino et al., 2015). The hexaflex in



ACT (Figure 1) illustrates the overlap and interrelations between these different areas of psychological flexibility, with changes in one area impacting on other dimensions (Baer, 2010; Hayes et al., 2006).

Psychological flexibility increased in the one study where it was explicitly measured, this was, however, only considered in a single case study.

#### 4.4 Mindfulness

Mindfulness was only measured explicitly in one paper (Merriman et al., 2015) by the FFMQ (Bohlmeijer, ten Klooster, Fledderus, Veehof & Baer, 2011). This score increased in 3 out of 4 participants, although there was no analysis of this data in terms of its significance. Mindfulness was seen to decrease in the fourth participant.

While not specifically measured, mindfulness was identified in two further papers as being important. Shields and Onsworth's (2013) client described it as being the most beneficial aspect of therapy, using it as a grounding technique when feeling overwhelmed. Similarly, mindfulness was identified by Marino et al. (2015) as an important aspect of the intervention. Their client reported that these skills helped him to "remain in the present and identify and implement 'what I can do' versus 'what I used to do'." (p. 270).

Mindfulness was directly measured in one study with very low participant numbers, and an increase was found in most but not all participants. Two case studies also provided qualitative evidence that mindfulness skills were important tools for participants. Overall, however, these findings are based on five participants across the studies.

#### 4.5 Acceptance

Marino et al. (2015) identified their client's increased ability to accept and work with his physical limitations since his stroke, which enabled him to focus on the things that he could do. Acceptance was, however, noted as a controversial topic in Merriman et al. (2015). They report that strong feelings were raised for people as they felt a conflict with the concept of acceptance and the way they had to push themselves through rehabilitation exercises to make improvements in their physical health.

Evidence for a role of acceptance came from one case study. Acceptance was not explicitly measured in any studies, therefore there is limited evidence from these studies regarding its role in psychological wellbeing following stroke.

#### 4.6 Valued Living

Marino et al. (2015) noted that their client had started cooking again (a previously enjoyed hobby), socialising with neighbours, and had started to tackle his debt problems. Similarly, Shields and Onsworth (2013) reported that their client had increased their social activity and had started cooking again. At the 3-month follow up they noted that their client's 'avoidance' behaviours had returned to almost pre-intervention levels, however this was no longer associated with distress, and may have been more of a personal choice linked with the client redirecting their energy to more valued activities.

This suggests that valued living increased, however this was based on only two case studies that reported this information qualitatively.

#### 4.7 Quality of Life

Quality of life is defined by the World Health Organisation (WHO) as an “individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHO, 1997; p1), and was measured in three of the studies (Merriman et al. 2015, Moustgaard et al. 2007, & Marino et al., 2015).

Marino et al. (2015) found that the Quality of Life score improved for their participant, increasing from 60 to 80 on a 100-point scale. Merriman et al. (2015) found that three out of four of their participants showed improvement on the psychological domain of World Health Organisation-Quality of Life-Brief version (WHO QoL-Bref; The WHOQOL Group, 1998), although they do not report the data for this subscale. On the overall Quality of Life score, however, they found that only 1 person improved (their score increasing from 101 to 106). 1 person’s score remained the same (at 78) and 2 people’s scores worsened (one from 81 to 77, and one from 91 to 87). Moustgaard et al. (2007) found statistically significant improvements on 10 of the 13 subscales of the Stroke Specific Quality of Life Scale (SS-QOL; Williams, Weinberger, Harris, Clark, & Biller 1999), including personality, social roles, mobility and thinking (at the level  $p=0.001$ ). A post-hoc analysis on this data did not, however, show that there was any significant change over time on the mood subscale. The mean score for this increased from 29.91 to 33.62. The subscales for Vision and Language also showed improvements but failed to reach significance. It would, perhaps, not be expected that the intervention would show an improvement in more medically dominated domains such as vision and language, and it is possible that these areas are skewing some of the results in this area. There may also

be a greater awareness of difficulties raised by these questionnaires that can make these results difficult to interpret.

The overall evidence for Quality of Life measured quantitatively was mixed and inconclusive. The quality of this evidence was mixed, with the case study using a 100-point scale, and the group interventions using more standardised and validated measures. The number of participants was also limited across studies.

#### 4.8 Cognitive Appraisal

Three papers commented on the relationship people had with their thoughts about stroke and its impact on them. Marino et al. (2015) reported that "Mr R gained insights into the development and reinforcement of his beliefs, as well as the current role these beliefs and behaviours played in his mood symptoms and functioning" (p. 268). Ashworth et al. (2015) found that their clients reported developing a new understanding of their difficulties in the framework of the compassion-focused formulation used. Graham et al. (2014) found that illness cognitions changed such that their client had accepted that his stroke was permanent but had fewer consequences that gave him less cause for concern. However, he also felt he understood his stroke less than he did prior to the therapeutic intervention.

Overall, the participants' views and understanding of their stroke changed, which was generally reported as being beneficial to psychological wellbeing. This was, however, based on qualitative comments from two case studies and one group intervention study with limited participant numbers.

#### 4.9 Physiology and Physical Health

Three papers measured physiology or physical health as an additional outcome to the psychological outcomes. Graham et al. (2014) found that

their client was free of his Medically Unexplained Symptoms (MUS) following therapy. Moustgaard et al. (2007) found a change on the overall physical component score of the SF-36 (Medical Outcome Study short-form health survey; Ware & Sherbourne 1992). This was reported as surprising as it was not an intended outcome, and given that the average length of time following stroke was three and a half years, the intervention was not within the window of opportunity for the most significant physical recovery following stroke. They suggest that a reduction in anxiety and depression symptoms may have enabled greater engagement in physical activities, or enabled more attainable goal setting. Scores on the SSQoL mobility and upper extremity functioning scales (Stroke Specific Quality of Life Scale; Williams et al., 1999) also improved following intervention, which again they suggest was due to improved mood and anxiety.

Joo et al. (2011) measured Heart Rate Variability and used the Physical Stress Index to measure changes in physiology. They found statistically significant improvements in both these areas, indicating that the autonomic nerve system had an improved homeostatic control mechanism, equating to an increased ability to adapt physiologically to the environment. They also found significant improvements in blood pressure, which is associated with a decreased risk of further stroke.

Overall, physical health was found to improve following the intervention. The quality of the evidence was mixed, with two of the studies relying on self-report of symptoms only, and one study using more objective physiological measures.

#### 4.10 Cognitive Symptoms

An improvement in cognitive symptoms was noted in four papers. There was an improvement in mental fatigue and information processing speed

(Johansson et al. 2012), an improvement in attention (Moustgaard et al., 2007; Merriman et al., 2015) and an increased ability to develop cognitive strategies (Shields & Onsworth, 2013). Cognitive symptoms are related to psychological wellbeing (Kauhanen et al., 1999), and an increased ability to attend to things, process information and manage tasks may facilitate psychological or cognitive flexibility.

Four studies, therefore, found improvements in aspects of cognitive symptoms, with three of these utilising standardised measures. This evidence is, again, limited by the quality of the studies and the low participant numbers.

#### 4.11 Other Findings

Papers also noted important factors in mediating change, such as relationships with others, or had recommendations for delivering therapy to this client group.

##### Relationships with others

The value of the therapeutic relationship with the therapist was mentioned in two papers. Shields and Onsworth (2013) noted that their client had some resistance to self-compassion. Through developing a good therapeutic relationship, the therapist was able to model compassion, and demonstrate empathy and distress tolerance. The creation of a safe environment was considered to be central to the client being able to develop these skills herself. Ashworth et al. (2015) found that many participants saw their therapist as “their primary source of care and comfort” (p.12), which helped them to feel understood.

There is, therefore, some evidence that the therapeutic relationship is important in the intervention, however, this is based on qualitative evidence from a limited sample of one case study and a small group study.

#### Group processes

Three papers noted group processes as important, giving people the opportunity to share their experiences in a safe place with other stroke survivors. Having experienced the world and self as unsafe following stroke, participants reported finding safety in the group setting which facilitated learning (Ashworth et al. 2015). Using mindful movement in another group evoked feelings of loss and a greater awareness of changes in functioning. It was reported that experiencing this in a group setting allowed people to share and explore this in order to process it (Merriman et al., 2015). It was also suggested that attending a group after a period of acute care can give people a sense of routine and purpose, as well as the opportunity to meet other people and share experiences (Moustgaard et al., 2007).

The importance of group processes was noted qualitatively in three of the five group interventions, however the number of people in each group expressing this view was not documented and the quality of this evidence is low.

#### Adaptations for practice

Several papers noted that adaptations would be required to ensure that the therapeutic interventions were accessible for stroke survivors. It was reported that extensive cognitive difficulties were a barrier to some people being able to participate, and others were unable to follow the instructions and left the group (Johansson et al., 2012). Audio and visual hand-outs were described as useful (Merriman et al., 2015). People with attentional

difficulties or fatigue found the longer meditations difficult, and there was difficulty with written tasks such as keeping a diary. The body scan exercise was also reported as challenging for people with hemiplegia due to the differing sensations on different sides of the body (Merriman et al., 2015).

Moustgaard et al. (2007) noted that the yoga positions required modification, and they also included some psycho-education regarding stroke. In addition, they included some discussion around aspects of emotional and physical coping. This included adapting to changed abilities and roles, barriers to functioning, and changes in personality.

#### Timing of clinical intervention

Two papers noted indications that the timing of the intervention may be important. Merriman et al. (2015) commented on the reluctance of some people to engage with the idea of acceptance or non-striving when trying to maintain motivation and impetus for physical therapy, while Moustgaard et al. (2007) highlighted the potential relevance of third wave therapies in helping people to engage more in physical therapy. None of the eight papers reviewed specifically investigated the timing of the intervention.

Recommendations for adaptation were based on the researchers' observations of interventions and informal participant feedback in four studies and is, therefore, of low quality.

#### 4.12 Summary of Findings

Overall, the data provided in the studies to date indicate that when third-wave therapies are used with people following stroke, improvements are made on the measures described, notably depression and anxiety symptoms, attention, physical health, acceptance and mindfulness skills.



There is mixed evidence regarding quality of life measures, although qualitative data suggests that third-wave therapies can support people to live more valued lives. There were also findings regarding the intervention being acceptable to participants, feasible to deliver in clinical settings, and in need of adaptation for use with stroke survivors. These findings should, however, be considered in light of the low quality and limited number of studies.

## **5.0 Discussion and Recommendations for Future Research**

The quality of the research included in this review is generally considered to be of low quality and has several limitations. It has, however, gone some way in demonstrating the potential utility of third-wave therapies to improve stroke survivors' psychological wellbeing. This provides a good starting point for further research, and a discussion of the main limitations provides a good basis to consider future directions.

### **5.1 Measuring Outcomes**

One of the main limitations in the papers reviewed concerns the choice of outcome measures. All the papers reviewed measured symptoms of anxiety and depression, and generally found a reduction in these symptoms. It is important to consider, however, if these measures are useful and meaningful in work with people who have had a stroke, or if something else is more important to people in mediating this change.

Davis et al. (2013) found that while practitioners tend to focus on the acceptance of disability or global indicators of wellbeing and symptomatology, people with stroke are much more focused on their reengagement with personally valued activities. They suggest that post-

stroke assessments of general well-being, anxiety, or depression may not be an effective way of assessing post-stroke adaptation. Brown et al. (2014) found that “participants spoke mostly about common-sense physical or social goals that any patient would naturally want to aim for after stroke: “...‘just normal everyday things’ ... or ‘the simple little things in life I used to enjoy’.” (p.1024). A dichotomy of views can, therefore, exist on what recovery or ‘success’ looks like between service users and professionals (Lamb, Buchanan, Godfrey, Harrison & Oakley, 2008).

A similar difference exists with third-wave therapies and services. Mindfulness-based therapies are strongly influenced by Eastern philosophy, they acknowledge suffering as part of our common human experience (Hayes, 2005), and look to make room for this, while allowing us to live a rich and meaningful life (Harris, 2007). For this reason, mindfulness-based therapies may not yet sit well within outcome driven systems, as is currently the case in the NHS (National Health Service) in the United Kingdom (Gilbert, 2009). A reduction in depression and anxiety is not an explicit aim of mindfulness-based therapies (Harris, 2007), but appears to be an aim of services, as illustrated by the papers in this review. This creates a tension where the therapeutic approach is concerned with acceptance and non-judgement of basic human emotions, while the measurements used to monitor the ‘success’ of these therapies continue to suggest the opposite. Studies have also failed to find conclusive links between diagnostic symptoms, quality of life and wellbeing following stroke (D’Aniello et al., 2014), therefore focusing on symptoms might miss important outcomes for people. While some studies did measure aspects such as psychological flexibility, mindfulness and acceptance, these were done alongside measures of anxiety and depression. It is recommended that future research

employs outcome measures that are more consistent with third-wave therapies and more meaningful for stroke survivors.

Reducing symptoms rather than increasing quality of life or valued activities may not be a priority for stroke survivors. The most relevant data in the studies reviewed, in terms of relevance to third-wave therapies and meaning to participants, concerned quality of life and changes in functioning. These aspects were more readily available in the three case studies, where richer information of individual outcomes is documented. Findings regarding restarting a previous hobby or re-establishing social contacts, perhaps demonstrates more meaningful change in people's lives than a statistically significant decrease in a depression score. More work needs to be done, therefore, concerning the best way to meaningfully measure outcomes following stroke in collaboration with service users.

## 5.2 Generalisability of Results

A further limitation of the studies reviewed concerned generalisability. This review highlighted a bias of research towards working-age stroke survivors. This may reflect those who might be more in need of psychological support, for example, Brunborg and Ytrehus (2014) considers people who are of working age with dependents to be a particularly vulnerable group. More research is needed, however, using more representative samples to establish who the interventions are suitable for more widely. The ability to generalise the results to people with cognitive difficulties and aphasia was also limited, and further research should look at adaptations to include more people in research.

### 5.3 Research Design and Setting

This review has evaluated mostly service evaluation level research, with only two out of the eight papers recruiting people specifically for the research rather than using an existing sample. From one perspective, this indicates that the quality of research in this area is currently low (Evans, 2003), however, the value of these studies should also be acknowledged. In addition to providing good ecological validity, they also illustrate the importance of clinicians sharing information and outcomes from practice. Without these papers, there would be only two studies available providing information on the efficacy of third-wave therapies in stroke. Some recognition should be given, therefore, to clinicians contributing to the evidence base, despite the pressures placed on the NHS.

This body of literature is small and generally of low quality, however it goes some way to providing the foundation for an evidence base for third-wave therapies in stroke. Studies have looked in detail at a smaller number of cases which can help refine therapy and gain a better understanding of its meaning for individuals, before investment is made into larger scale research studies. Without this basis, it could be considered unethical to conduct a large scale RCT.

Without better quality evidence and properly controlled trials, however, there is a risk of confounding variables and the uncontrolled influence of other factors. In the absence of tighter controls it is somewhat unclear if the outcomes in any study are due to the intervention, or if placebo effects, demand characteristics, or other variables and factors are influencing the outcome. Ideally, large-scale RCT trials need to be conducted to provide robust clinical data. This should be done, however,

with careful consideration for the most appropriate outcomes that are relevant to stroke survivors and the therapies used.

#### 5.4 Components of Third-Wave Interventions

As the therapies under review are the combination of multiple techniques, it is difficult to determine the critical components of the intervention. This makes it unclear if there are particular aspects of third-wave therapies that are more relevant for some stroke survivors. If specific aspects of therapy are more effective in bringing about change, resources could be best focused on these elements. Therefore in addition to widening out the focus to larger scale research, it would also be useful to consider using other methods, such as Q methodology, which can enable the examination of the elements of third-wave therapies in more detail.

### 6.0 Conclusion

The studies reviewed are of low quality but have provided a good foundation for an evidence base. They have indicated that third-wave therapies have utility in improving stroke survivors' psychological wellbeing, reducing symptoms of anxiety and depression, and helping people to live more valued lives. The studies have also provided useful information about third-wave interventions being feasible to deliver in services and acceptable to people who have had a stroke, in addition to recommending adaptations which may need to be made for this population.

Further research is now needed which will strengthen this preliminary research, especially using control groups and session-by-session outcome measures. Particular attention should be given to considering what outcomes are most relevant to stroke survivors in the context of third-wave therapies.

Research is also needed to look in greater detail at the different aspects of third-wave therapies and their relative importance to stroke survivors. This will hopefully help to more clearly identify what the mediators and mechanisms of change might be in third-wave therapies, and improve understanding of what aspects it may be helpful to focus on for different difficulties.

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## 9.0 Appendices

### Appendix A: Critical Appraisal Checklist for Single Case Experimental Design Studies

	Graham et al. (2014)	Marino et al. (2015)	Shields & Onsworth (2013)
Clear aim	✓	✓	✓
Appropriate research method	✓	✓	✓
Baseline established	x	x	x
Measures described	✓	✓	✓
Data collection method described	x	x	x
Use of standard/global measures	✓	✓	✓
Sessional individual target measures	x	x	✓
Follow up data	x	✓	x
Process measures reported	x	x	x
Graph of data	✓	x	✓
Non-parametric analyses	x	x	✓
Inter-observer agreement	x	x	x
Clinical significance described	x	x	✓
Researcher's perspective accounted for	x	x	x
Setting representative of standard treatment	✓	✓	✓
Number of criteria achieved	6/15	6/15	9/15



## Appendix B. Critical Appraisal Checklist for Group Intervention Studies

	Johansson et al. (2012)	Ashworth et al. (2014)	Joo et al. (2011)	Merriman et al. (2015)	Moustgaard et al. (2007)
Clear question, aim or objective?	✓	✓	✓	✓	✓
Appropriate method to answer question?	✓	✓	✓	✓	✓
Were the participants recruited ethically?	✓	✓	?	?	✓
Were participant characteristics adequately described?	X	✓	X	X	X
Were outcome variables accurately described and measured to reduce bias?	✓	✓	✓	✓	✓
Was a control group used?	✓	X	X	X	X
Was the intervention clearly described?	✓	✓	✓	✓	✓
Was the sample size appropriate? Power calculation?	X	X	X	X	X
Were findings appropriately analysed?	✓	✓	✓	✓	✓
Were findings interpreted with clinical significance?	X	X	X	X	X
Is there a clear statement of findings?	✓	✓	✓	✓	✓
Were participants' details lost to follow up noted?	X	X	X	N/A	X
Were any probability statistics given in full?	✓	X	✓	N/A	✓
Can the results be applied to the local population?	X	X	X	X	✓
Were participants asked representative?	X	X	X	X	✓
Were participants who took part representative?	X	X	X	X	✓
Was the setting representative of standard treatment?	✓	✓	✓	✓	✓
Was compliance with the intervention reliable?	✓	✓	X	X	✓
Were the outcome measures valid?	✓	✓	✓	✓	✓
Is the research valuable?	✓	✓	✓	✓	✓
Number of criteria achieved	13/20	12/20	10/20	9/18	15/20

## CHAPTER TWO

An exploration of third-wave therapies and psychological wellbeing following stroke:  
A Q methodology study.

## 1.0 Abstract

**Background:** Following a stroke many people experience psychological distress, and there is a growing evidence base that third-wave psychological interventions can support people during this time. A Q methodology design was used to explore the relevance of different aspects of third-wave therapies to the psychological wellbeing of stroke survivors.

**Method:** 10 stroke survivors were given 40 statements concerning aspects of third-wave therapies to rank, in accordance with their experience following a stroke.

**Principal Results:** Two factors were found and one individual viewpoint retained. Five participants loaded onto the positive pole of Factor one, and one participant loaded onto the negative pole. This factor was characterised by valued living and committed action, and those loading onto it positively had good psychological wellbeing. Three participants loaded onto Factor two which was concerned with creative hopelessness and was past and future focused. The third viewpoint was characterised by disconnection, with a lack of compassion for self and others.

**Major Conclusions:** High levels of psychological wellbeing in this sample were associated with a strong connection to values and committed action. People who are disconnected from their values may therefore struggle with wellbeing. A position of creative hopelessness might be functional for people during the early stages of recovery to accept help, with a focus on then moving towards hope and a focus on the present. For people who struggle with a detachment from themselves and others, a focus on compassion might be a more appropriate starting point for therapeutic intervention.

**Keywords:** Stroke, Q-methodology, acceptance, compassion, mindfulness.

## 2.0 Background

Stroke occurs when there is disruption to the blood supply of part of the brain, causing damage that lasts longer than 24 hours (Aho et al. 1980; Stroke Association, 2016). Worldwide, stroke is the second leading cause of death (Lozano et al. 2013), and while survival rates are increasing (National Institute for Health and Care Excellence (NICE), 2013), people who do survive often have significant difficulties. Stroke is the third biggest burden on the world's health in terms of people losing years of life unaffected by disability (Murray et al., 2013). Psychological distress is also common following stroke (British Psychological Society, 2010), and it is recommended that people have access to a clinical psychologist following stroke (Intercollegiate Stroke Working Party, 2016; NICE, 2016). The evidence base for psychological interventions following stroke is not yet well developed (Kootker et al. 2015).

There is emerging evidence that third-wave therapies may have some value for stroke survivors. Third-wave therapies have their roots in Cognitive Behavioural Therapy (CBT), but are based on mindfulness; a way of paying attention to the present moment, on purpose and without judgement (Kabat-Zinn, 1994).

Mindfulness has been found to help with several difficulties experienced following a stroke, such as fatigue (Hofer et al., 2014), emotional regulation (Hill & Updegraff, 2012) and loss of a sense of self (Kangas & McDonald, 2011). In addition, it has been found to promote processes linked with psychological wellbeing following stroke, such as acceptance (Townend, Tinson, Kwan & Sharpe, 2010), compassion (Brunborg and Ytrehus, 2014) and values based living (Davis, Egan, Dubouloz, Kubina & Kessler, 2013).

The current evidence base for mindfulness-based therapies for psychological wellbeing following stroke is limited but growing. A systematic literature review found eight papers, five were group interventions and three were case studies. The studies were limited by a lack of randomised control groups and low sample sizes, and there were limitations in terms of clinical significance and the use of outcomes measures incompatible with third-wave therapies. The studies found that mindfulness-based interventions show promise in improving attention, physical health, acceptance, skills in mindfulness and symptoms of anxiety and depression. There was no overall indication that these interventions can help improve quality of life on the measures used, however qualitative data suggested that people were living more valued lives.

While these papers found indications that third-wave therapies might be helpful for people following stroke, they do not provide much insight into the aspects of therapy most relevant to stroke survivors.

This paper aims to explore perspectives on the importance and relevance of different aspects of third-wave therapies to the psychological wellbeing of stroke survivors. It is hoped that this can be used to further the understanding of which aspects of third-wave therapies may be relevant and of importance in mediating change. This can help professionals have a better understanding and awareness of the psychological impact of stroke and which processes to target.

## 2.1 Research Question

The current study aims to explore the underlying components of third-wave psychological therapies and examine their personal relevance to stroke survivors, with particular consideration for their psychological wellbeing.

## **3.0 Method**

### **3.1 Reflexivity**

The research was carried out by a trainee Clinical Psychologist, whose interest in the area came from a first-year specialist placement in stroke. There was no prior personal experience of stroke or any related chronic health conditions. The development of the research idea came from finding a lack of guidance for the use of any particular psychological interventions with this population, and having an existing interest in mindfulness-based approaches.

Having a particular interest in the area introduces the potential for bias in the research. Q methodology was chosen because it allows the exploration of different perspectives. Having an awareness of this viewpoint also ensured that steps were taken to safeguard against this affecting the scientific quality of the research, and the research was peer reviewed at several stages of the process.

### **3.2 Epistemological Position**

The epistemological stance taken in this paper was one of pragmatism. This enables the use of the method which best answers the question being asked, rather than engaging in the debate about whether the answer sought is objectively knowable (positivism), or composed of multiple constructed truths (interpretivism or constructionism).

It was considered that taking a pragmatic approach would give flexibility and the best chance of discovering knowledge that will be useful in addressing the question. The principal concern was whether or not the knowledge gained would serve the purpose for which it was sought, i.e. if it is useful and it can be used to practically meet a need.

### 3.3 Methodology

Q methodology was considered to be the most appropriate method for gaining access to individual viewpoints in this population. It involves a sample of participants from the population of interest sorting a number of statements (Q set) on a topic of interest (concourse) into a normal distribution curve according to a specific question (the condition of instruction).

These individual viewpoints are then factor analysed to investigate which are highly correlated to reduce them into factors. Each factor then represents a group of people with a similar perspective (Watts & Stenner, 2012).

The resulting factors are then interpreted alongside the characteristics of the individuals within the factor and any further information gained from a post-sort interview.

### 3.4 Rationale for using Q Methodology

The current study aims to explore the different constructs in third-wave psychological therapies and their relation to psychological wellbeing following stroke. Q methodology is considered appropriate to do this as it allows people to rank the constructs according to their personal importance. The diversity and quality of people's experiences can then be collated in a quantitative analysis to organise common perspectives. Patterns of experience of different people can then be mapped together, generating clusters of similar experiences.

Q methodology allows a wider diversity of viewpoints to be heard, especially from people whose communication difficulties might be a barrier to them taking part in other types of research. Aphasia is common following

a stroke and people with aphasia are often excluded from stroke research (Brady, Fredrick & Williams, 2013). Q allows these voices to be heard (Ford, 2014).

### 3.5 Materials

#### 3.5.1 Creation of the Concourse

The concourse is the field of information from which a representative sample of statements is taken for the Q set. It should contain all relevant aspects of discourses within the field (van Exel & De Graaf, 2005).

The following questionnaires were used to identify the statement concourse:

Five Facets of Mindfulness Questionnaire, short form (FFMQ-SF; Bohlmeijer, ten Klooster, Fledderus, Veehof & Baer, 2011). This measures different identified aspects of mindfulness. Due to word finding difficulties following stroke (Berthier, 2005), statements regarding linguistic description were removed from this scale.

Forms of Self-Criticism and Self-Reassurance Scale (Gilbert, Clarke, Hempel, Miles and Irons, 2004). This measures aspects of shame, self-criticism and the ability to self-soothe.

Self-Compassion Scale – Short Form (SCS-SF; Raes, Pommier, Neff & Gucht, 2011). This is a measure of self-compassion with items measuring self-kindness/self-judgement, common humanity/isolation and mindfulness/over-identification.

Compassion Towards Others Scale (Pommier, 2011). This measures compassion for others and has statements measuring kindness/indifference, common humanity/separation, and mindfulness/disengagement.



Illness Cognitions Questionnaire (ICQ; Evers et al. 2001). This represents different cognitions associated with illness, with subscales of acceptance, positive benefits and helplessness.

Acceptance and Action Questionnaire-Acquired Brain Injury (AAQ-ABI; Whiting, Deane, Ciarrochi, McLeod, Simpson, 2014). This looks at aspects of avoidance and acceptance following an acquired brain injury.

### 3.5.2 Selection of Statements (The Q set)

Four trainee clinical psychologists with training in third-wave therapies were asked to rate the statements according to if, and how strongly, they thought they represented each component derived from the subscales in the questionnaires.

A table was created with the statements alphabetically down one side and the constructs across the top. The trainee Psychologists were requested to indicate any constructs that they thought the statement represented, and to rank their choices.

Statements with an agreement of 60% were retained. Where there was 80% agreement or above that two different components were represented by the same statements, they were considered to represent a single paradigm. This left 95 statements across 24 components. The statement with the most agreement for each component was retained. Each of these 24 statements represented only the component they were chosen to represent. As 24 statements were considered too few to gain meaningful data, a further statement was then chosen for each component using the same criteria. The second statement was permitted to overlap with another construct. This was not considered problematic as it is widely accepted that there is interconnection between the different components (for example in

ACT, Harris, 2007). This resulted in 36 statements being identified which represented the key components relating to third-wave therapies.

Psychological wellbeing and willingness to accept support was also included after further consultation with experts in the field. Ryff's scale of psychological wellbeing was used (Ryff, 1989) which has good validity (Van Dierendonck, 2004) and is compatible with the third-wave philosophy of psychological wellbeing. Its subscales include autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. Existing statements already covered most of these, therefore it was only necessary to include three further statements. One additional statement was included to cover acceptance of support. These statements were again checked with peers. There were 40 statements in the final Q set (Appendix A).

To assist understanding, pictures were used to supplement the statements (Sclera, 2016a, Sclera, 2016b). To better represent the statements, some images were changed, and others added, especially to signify stroke. The accuracy of representation and simplicity was checked with five peers experienced in working with people with cognitive difficulties. The statements were amended accordingly, for example the word 'woe' was changed to 'sadness'.

The final statements and pictures can be found in Appendix B. Each statement was laminated and the cards measured 6.8cm x 10cm.

The Q grid was constructed on stiff card with Velcro on the grid and the back of each statement. This meant that the statements were held in place securely, but could easily be moved and allowed participants to take part in bed or at their bedside.

### 3.6 Ethical Approval

Approval for the study was gained from Staffordshire University, followed by a Research Ethics Committee, the Health Research Authority, and the Research and Development departments of three NHS Trusts (see Appendices C, D, E & F respectively). Ethical guidelines from The British Psychological Society (BPS, 2010) were also followed.

### 3.7 Participants

#### 3.7.1 Inclusion and exclusion criteria

Participants were invited to take part in the research if they had had a stroke, were able to understand what was involved and were able to communicate their opinions. Participants were only recruited from adult services with patients over 18 years of age. People were excluded if they had a TIA only (a transient ischemic attack).

#### 3.7.2 Recruitment

Participants were invited from three different NHS Trusts in the Midlands region of the UK. Participant Information Sheets (Appendices G & H) and consent to contact forms (Appendix I) were distributed to clinicians working with people following a stroke. The services included a rehabilitation ward, a team supporting stroke survivors in the community, an acute stroke ward and a psychology service for people following stroke.

#### 3.7.3 Sample size

There are no definitive guidelines for sample size in Q methodology, with a rule of thumb being to not recruit more participants than the number of statements in the Q set. More important than size *per se* is the selection of

participants with “interesting, informative and relevant viewpoints” relative to the research question (Watts & Stenner, 2012 p.71).

#### 3.7.4 Ethical Considerations

Particular attention was given to ensuring that participants were able to give their informed consent due to the potential of cognitive difficulties impacting on this. Clinicians were only asked to identify potential participants who they were confident could give informed consent, and the recruiting researcher had received training in this area.

#### 3.8 Procedure

Potential participants were first identified by clinicians, the researcher then approached them and informed consent was gained (Appendix J). No participants withdrew from the study after agreeing to participate.

Details were taken of the participants’ stroke and demographics, and they were given the instructions for completing the card sort (Appendix K). This requested that they sort the cards into order of ‘most like me’ to ‘least like me’, particularly in relation to their stroke.

Participants were invited to sort the cards into three piles of ‘most like me’, ‘neutral’ and ‘least like me’. They then refined their card sort further onto the Q grid (Appendix L). Assistance was provided where necessary with reading out the text on the cards and placing the cards.

Following the placement of all the cards, participants were asked to review the statements and make any adjustments they required. They were then asked some follow-up questions regarding the statements (Appendix M).

## **4.0 Results**

### **4.1 Participants**

10 participants were recruited, five from a rehabilitation ward and five from an acute stroke ward. No participants responded from the psychology service or the community team. The demographic characteristics of the participants are shown in Table 1.

The participants ranged in age from their 20s to their 80s, with a mean age of 64 and a median age of 71. Four participants were of working age. The majority were male (80%), and all were white British which reflected the ethnic composition of the wards at the time of recruitment. Time since stroke ranged from one day to four months, with seven out of the 10 participants having had a right-sided stroke.

Table 1. *Participant Characteristics*

Participant	Age	Gender	Time since stroke	Stroke location	Mobility	Other difficulties	Employment status	Living situation	Ethnicity
1	61-70	M	3 months	Right	Difficulty walking	Reduced vision	Employed	With housemate	White British
2	41-50	M	4 months	Right	Unable to walk	Left arm/leg weakness	Unemployed	No fixed address	White British
3	21-30	M	6 weeks	Right	Unable to walk	Left arm/leg weakness	Employed	With friends	White British
4	81-90	F	11 weeks	Right	Unable to walk	Nil by mouth, dysarthria	Retired	With spouse	White British
5	81-90	F	2 weeks	Left	Able to walk unaided	Right sided weakness	Retired	With spouse	White British
6	51-60	M	5 weeks	Right	Unable to walk	Left side weakness	Disability benefits	With spouse	White British
7	61-70	M	1 day	Right	Able to walk unaided	Numbness in left arm, headaches	Retired	With spouse	White British
8	71-80	M	4 weeks	Right	Unable to walk	Expressive aphasia	Retired	Alone	White British
9	71-80	M	2 days	Left	Able to walk unaided	Difficulty swallowing	Retired	Alone	White British
10	81-90	M	2 weeks	Left	Difficulty walking	Reduced vision, headaches	Retired	With spouse	White British

## 4.2 Q sorts

The data from the Q sorts were analysed using the computer programme PQMethod (Schmolk, 2014). A correlation matrix revealed that nine of the participants' sorts significantly correlated with at least one other sort, indicating a similar viewpoint. These are shown in bold in Table 2. Q sort 2 did not correlate significantly with any other Q sort.

Table 2. *Inter-Correlation Matrix.*

		Q sort number									
		1	2	3	4	5	6	7	8	9	10
Q sort number	1	100	0.04	-0.08	<b>-0.38</b>	-0.27	0.22	-0.20	0.10	<b>-0.38</b>	0.08
	2		100	-0.06	0.20	-0.25	0.12	0.11	0.08	0.01	0.10
	3			100	<b>0.46</b>	<b>0.44</b>	-0.18	<b>0.53</b>	-0.02	<b>0.39</b>	-0.02
	4				100	<b>0.55</b>	0.08	<b>0.34</b>	0.03	<b>0.46</b>	<b>0.35</b>
	5					100	0.02	0.28	0.03	<b>0.35</b>	<b>0.37</b>
	6						100	0.25	<b>0.38</b>	-0.11	0.29
	7							100	0.04	0.12	-0.04
	8								100	-0.04	<b>0.39</b>
	9									100	0.08
	10										100

Note: Numbers in bold indicate a significant correlation at the level of  $p < 0.05$ , using Brown's (1980) formula of  $1.96(1/\sqrt{n})$ , where  $n$  = the number of statements in the Q set. Using this formula the value required was 0.31.

The data was analysed using Centroid Factor Analysis (CFA) that allows for more exploration and examination of the data. This was chosen over Principal Components Analysis (PCA) that would have provided a purely mathematical solution (Watts & Stenner, 2012). Following the guidance of Watts and Stenner (2012), a one-factor and two-factor solution were explored based on the sample size of ten Q sorts. Examination of these solutions revealed that a two-factor solution accounted for 35% of the variance, and all but one of the sorts loaded significantly onto at least one of the two factors. The two factors were, therefore, retained.

A varimax rotation was then completed by hand in order to optimise the fit of the data according to knowledge of viewpoints represented by the sorts. The rotated factor matrix can be seen in Table 3. This shows that Q-sorts 3, 4, 5, 7 and 9 load significantly onto factor one, with Q-sort 1 also loading significantly onto this factor, occupying the opposite position. Q-sorts 6, 8 and 10 load significantly onto Factor two. Q-sort 2 does not load significantly onto either factor, this is consistent with it not being significantly correlated with any other sort. This was retained as a unique viewpoint.

Table 3. *Rotated Factor Matrix*

Q-sort	Factor	
	One	Two
1	<b>-0.41</b>	0.30
2	-0.01	0.18
3	<b>0.62</b>	-0.23
4	<b>0.85</b>	0.36
5	<b>0.64</b>	0.08
6	-0.08	<b>0.52</b>
7	<b>0.49</b>	0.19
8	-0.06	<b>0.57</b>
9	<b>0.55</b>	-0.06
10	0.16	<b>0.57</b>

Note: Sorts loading significantly onto each factor are highlighted in bold.

The rotated factor matrix accounts for 36% of the variance. This is adequate following Watts & Stenner's (2012) guidelines of the variance being explained exceeding 35%.

#### 4.3 Factors

Each factor and viewpoint was examined and the distinguishing statements highlighted for each. These can be seen in Tables 4, 5 and 6. The statements in bold represent the statistically different statements for each



factor, these statements were ranked at least three points away from their ranking in the other viewpoints. Three statements were significantly different for all three viewpoints and are highlighted in italics. These are detailed in Table 7.

#### 4.3.1 Factor one - *Psychological wellbeing, values and committed action*

Factor one accounted for 22% of the variance in the data. Five Q sorts loaded positively onto this factor (3, 4, 5, 7 and 9), and one sort loaded negatively (1). The highest and lowest ranking statements can be seen in Table 4.

Table 4. *Highest and Lowest Ranked Statements for Factor One*

Statement	Rank
<b>I think I can cope effectively with my stroke</b>	<b>+4</b>
<i>I can handle any problems related to my stroke</i>	+4
<b>I stop doing things when I feel scared about my stroke</b>	<b>-4</b>
My stroke controls my life	-4
<b>I do things I care about even when I'm upset</b>	<b>+3</b>
I encourage myself for the future	+3
My stroke has helped me realise what is important in life	+3
My stroke defines me as a person	-3
<i>There is part of me that feels like I am not good enough</i>	-3

Note: Statements highlighted in bold indicate distinguishing statements specific to this factor, statements in italics were distinguishing statements for all factors.

#### Positive Pole

This consisted of five participants, one male (aged in his 20s) and two females (both in their 80s) from the rehabilitation ward, and two males from

the acute ward (one in his 60s, the other his 70s). Time since stroke was between 1 day and 11 weeks.

All the statements representing good psychological wellbeing were ranked towards 'most like me'. This suggested that people on the positive pole for this factor had high levels of psychological wellbeing. The factor array can be seen in Appendix N.

The statements ranked most highly by these participants were around values and committed living, such as "I can handle any problems related to my stroke" (+4), and "My stroke has helped me realise what is important in life" (+3). The reverse of these statements were also ranked lowest in this factor, such as "I stop doing things when I feel scared about my stroke" (-4).

Overall, items regarding compassion were ranked around the middle 'neutral' area, lower than those on values and action. Statements regarding compassion for others tended to be ranked higher than compassion for self. There were some seemingly conflicting statements such as "My heart goes out to people who are unhappy" (0) and "I don't concern myself with other people's problems" (0) ranked closely to each other. This ambivalence was captured well by Participant 4 - 'I do care about people, but there's only so much you can listen to'.

Participants in this factor disagreed with items which were self-critical, such as "I feel a sense of disgust with myself" (-3) and "There is a part of me that feels I am not good enough" (-3).

Overall these participants expressed a positive attitude towards their lives, which was long held. Participants reported that "Feeling sorry for yourself doesn't help" (Participant 4) and they had a determination that

“This isn’t going to get me down” (Participant 7). They also recognised that the stroke had helped them appreciate things more.

Overall, this factor represented people who had good psychological wellbeing and felt they could cope with their stroke. They were connected with what was important to them.

#### Negative Pole

Participant 1 loaded negatively onto this factor, indicating an opposite position from those on the positive pole. This was a male in his 60s, who had his stroke three months previously. This participant described not feeling in control of his life. He had been in employment prior to his stroke, and as he was no longer able to drive, he would be unable to return to work. He commented that “Not being able to drive will break my heart”. Work had been very important to him throughout his life, it was linked with his identity and independence, without which he felt that he had nothing. He also described how having a stroke “can make you less of a person”. This participant’s feelings of a lack of autonomy, mastery, purpose and self-acceptance was reflected in his positioning of these statements towards the ‘least like me’ end of the sort.

#### 4.3.2 Factor two - Being ok with needing to be looked after: past and future focused

Factor two represents three participants (6, 8 and 10) and accounts for an additional 14% of variance in the data. These were all male and on the acute stroke ward. One was in his 50s, one his 70s and one his 80s, and it had been between 2 and 5 weeks since their stroke. The highest and lowest ranked statements can be seen in Table 5.

Table 5. *Highest and Lowest Ranked Statements for Factor Two*

Statement	Rank
I miss the things I like to do most	+4
<i>It's ok to accept help from others</i>	+4
<b>I'm a stronger person</b>	<b>-4</b>
I tend to worry what other people think of me	-4
I feel detached from others' sadness	+3
I tell myself I shouldn't be feeling the way I am	+3
I do jobs or tasks automatically without awareness	+3
<i>I can handle any problems related to my stroke</i>	-3
I pay attention to physical experiences	-3
<b>I can notice distressing thoughts without reacting</b>	<b>-3</b>
<b>I often pretend I didn't have a stroke</b>	<b>+2</b>

Note: Statements highlighted in bold indicate distinguishing statements specific to this factor, statements in italics were distinguishing statements for all factors.

A key aspect of this factor relates to needing to be looked after. There was an acknowledgement from people that they needed support (“I’m a stronger person since having a stroke”, -4; “I can handle any problems related to my stroke”, -3). People were willing to accept support from others, and to a lesser extent give themselves this support (“It’s ok to accept help from others”, +4; When I’m going through a very hard time, I give myself the caring and tenderness I need”, +2).

Compassion appears to be present and important in this factor, but is potentially mediated by some experiential avoidance. There is evidence of compassion for self and others (“I encourage myself for the future”, +2, “When I’m going through a very hard time, I give myself the caring and tenderness I need”, +2, “My heart goes out to unhappy people”, +2), however, there is also a detachment from this (“I feel detached from other’s

sadness", +3; "I shouldn't be feeling the way I'm feeling" +3), and some detachment from the present moment (I do tasks automatically without awareness, +3; I often pretend that I didn't have a stroke, +2; "I pay attention to physical experiences", -3).

Items related to values and committed action do not come out as particularly important in this factor, rated between -1 and +1.

Overall, people on this factor tended to miss their old lives and could still encourage themselves for the future. They weren't able to find much value in the present. They had positive relationships with others, accepted that they could not cope and were willing to accept help and be cared for.

#### 4.3.3 Viewpoint three - Disconnected with a lack of compassion for self and others

Viewpoint three came from a male in his 40s who was seen on the rehabilitation ward. He had difficulties prior to having a stroke, and had no fixed address at the time of his stroke. It had been four months since his stroke. The highest and lowest ranked statements can be seen in Table 6. This viewpoint was characterised by a lack of compassion, a disconnection from humanity, and self-criticism. This viewpoint did not appear to be defined by the impact of the stroke.

One of the most strongly rated items was "I miss the things I liked to do most" (+4). In the Q sort feedback, it was apparent that the sort had not been completed relative to the stroke, but to on-going difficulties. This viewpoint was present prior to the stroke, and appeared to be a different sense of loss than in Factor two. It was not just that he missed things from before the stroke, but there was a sense of grief for a life that he had not lived.

Table 6. Highest and Lowest Ranked Statements for Viewpoint Three

Statement	Rank
<i>There is part of me that feels I am not good enough</i>	+4
I do jobs or tasks automatically without awareness	+4
<b>I am caring towards myself when going through a hard time</b>	<b>-4</b>
My stroke defines me as a person	-4
I'm not afraid to voice my opinions	+3
<b>I don't concern myself with other people's problems</b>	<b>+3</b>
<b>When I fail at something important to me I feel alone in my failure</b>	<b>+3</b>
I hate how my stroke makes me feel about myself	-3
<i>It's ok to accept help from others</i>	-3
<b>My heart goes out to people who are unhappy</b>	<b>-3</b>

Note: Statements highlighted in bold indicate distinguishing statements specific to this factor, statements in italics were distinguishing statements for all factors.

Some of the most important statements for this individual related to aspects of compassion. He showed criticism towards himself ("There's a part of me that feels I'm not good enough"; +4, "I tend to be caring towards myself; -4), a lack of compassion for others (I don't concern myself with other people's problems; +3, My heart goes out to people who are unhappy; -3), and a sense of disconnection from humanity (When I fail at something, I tend to feel alone in my failure; +3).

Items regarding the impact of the stroke specifically tended to be ranked as 'least like me' ("My stroke defines me as a person"; -4, "I hate how my stroke makes me feel about myself"; -3, "My stroke controls my life"; -2). This indicates that the stroke hadn't had a perceived significant impact on this individual, despite its physical effects.

The only wellbeing item ranked highly was “I’m not afraid to voice my opinions” (+3). This represents autonomy and may relate to having to speak up for himself given his circumstances. This person also stated that he didn’t care what people thought of him, which may be connected with the reduced sense of common humanity as already detailed.

Items around values and committed action were not ranked strongly at either end of the sort, occupying positions around -1, 0 and +1.

#### 4.4 Distinguishing statements

Three statements had significantly different rankings across all three viewpoints, defined by a difference in three ranked places. These can be seen in Table 7.

Table 7. *Significantly Distinguishing Statements for each Factor/Viewpoint*

No.	Statement	Statement Rank		
		Factor One	Factor Two	Viewpoint Three
8	I can handle any problems relating to my stroke	+4	-3	+1
32	There is part of me that feels I am not good enough	-3	0	+4
39	It's ok to accept help from others	+1	+4	-3

Note: Score indicates where the statement was ranked, with +4 being ‘most like me’, 0 being neutral and -4 being ‘least like me’.

Factor one is distinguished by a confidence in being able to handle problems relating to stroke, feeling that they are good enough and feeling neutral about accepting help. Factor two is distinguished by feeling strongly that it is ok to accept help, not being able to handle problems relating to stroke and feeling neutral with regards to being good enough. Viewpoint

three is characterised by feeling strongly about not being good enough, it not being ok to accept help and being more neutral regarding being able to handle any problems. As these statements significantly distinguish between the three perspectives, they have the potential to give the greatest knowledge of an individual's viewpoint and what might help support them.

#### 4.5 Consensus statements

Consensus statements are those ranked in a similar position by all participants. The exception to this being the participant who loaded negatively onto Factor one.

There was consensus across participants on disagreeing with 'I have a sense of disgust with myself' (-3,-2,-2) and 'I hate how my stroke makes me feel about myself' (-2,-2,-3), indicating a lack of shame in this sample. Participants were also generally more neutral on believing their emotions were inappropriate (-1,-1,0), and being understanding towards bits of their personality they don't like (0,-1,0). The people in this sample also slightly disagreed that they needed to get rid of anxiety about the stroke (-1,-2,-1), and were generally in agreement that they had at least partly accepted the limitations imposed by their stroke (+2,+1,+2).

#### 4.6 Adequacy of Concourse

One participant said that he would have liked statements regarding the impact of stroke on people close to him. Another participant commented that they would have preferred a statement regarding hating the stroke rather than how it made him feel about himself. The remaining participants reported that the existing statements adequately covered their experience.



## 5.0 Discussion

The three viewpoints identified offer very different perspectives and needs following stroke that can be met by using different aspects of third-wave therapies. Three statements were identified which distinguish the viewpoints and can serve to more quickly identify which position an individual might align with.

In this sample, Factor one demonstrates that values and committed action appear to be the strongest factor associated with psychological wellbeing following a stroke. This supports previous findings that reengaging with valued activities is important following a stroke (Davis, Egan, Dubouloz, Kubina & Kessler, 2013), and supporting people to do this should be prioritised. This may involve helping people to reconnect with their values and helping them to find ways to live by these values in different ways following limitations imposed by their stroke.

Loading negatively onto Factor one indicates that the individual is not living by their values, and could be connected with a strong sense of a conceptualised self. This is linked to one's roles and behaviours, rather than an enduring sense of self that endures regardless of circumstances (Hayes, 1995). The individual loading negatively onto Factor one identified strongly with 'being a driver', and being unable to drive challenged this identity. People who indicate being in-line with the negative pole of Factor one might, therefore, benefit from connecting with their values underlying this, and connecting with a wider view of their identity.

This research adds further weight to existing findings that outcomes for stroke survivors should be focused around meaningful and valued activities. Some people may not be ready for this however, and may need to

build their present moment awareness or compassion to be able to focus on this.

In contrast with Factor one, values and committed action were not ranked highly in Factor two, and this may be related to people's lack of investment in the present moment and uncertainty regarding what they can do.

People in this factor may be in the stage of creative hopelessness, where they have accepted that they need help, and are accepting it from others, but they have not yet found the way that they can help themselves. In the initial stages of recovery this may be helpful to enable people to take some time to be cared for and recover. These individuals were still in a very important recovery phase, the length of time that had elapsed since their stroke was not long (2 to 5 weeks), and they had significant physical difficulties related to their stroke. They were in a place of uncertainty and opportunity, and people can be helped to find these opportunities when they are ready. This is the place in which hope can be found, they are not in despair as they are still able to encourage themselves for the future.

It may be important to identify people whose viewpoint is congruent with Factor two because they may benefit from being supported to move through the stage of creative hopelessness to find hope and move towards more of a present focus and self-determination.

Viewpoint three was distinctive from the rest of the sample, possibly connected with this individual's homelessness. There are wider issues regarding homelessness that may be impacting on this individual's viewpoint. As Seager (2011) points out, homelessness is not just houselessness, it goes much deeper than that. He argues that people who are homeless long-term do not struggle to come off the streets just for

practical reasons, but due to past experiences they are “alienated from themselves, distrustful of others, and unable to relate to wider society” (p.185). While this may seem only relevant to homeless people, emotional disconnection is not just the preserve of those with no fixed address. Seager (2011) sees entrenched homelessness as the extreme end of mental alienation that can also affect those from more wealthy backgrounds, which he terms “psychological homelessness” (p.185). This viewpoint may, therefore, also be applicable to anyone who feels a sense of estrangement from themselves and humanity. It would be important to identify people who are aligned with Viewpoint three and work to build their compassion for themselves and help them to reconnect with a sense of common humanity.

### 5.1 Clinical Implications

This research provides a way to identify where people might be psychologically following a stroke to help formulate their difficulties and identify an appropriate intervention. It demonstrates that even in the early stages following a stroke when people are still in hospital, there is important work that can be done psychologically to help people reconnect with what is important to them and improve their psychological wellbeing. This is valuable information for clinicians working with people following a stroke, and for their families and carers who can be supported to help stroke survivors to do this. Improving psychological wellbeing has important implications for physical recovery and longer-term health outcomes, and this paper indicates that there is opportunity to start this work early on.

### 5.2 Strengths

This paper’s originality lies in the methodology and area of intervention. No previous studies have explored the relative importance of different aspects of third-wave therapies to stroke survivors and looked at their relevance to

psychological wellbeing. This paper has also moved away from using the more traditional symptomatic measures of anxiety and depression to include a measure of psychological wellbeing that is more consistent with a third-wave philosophy, and utilised a method that is able to include those with communication difficulties.

### 5.3 Limitations

It was not possible to gain qualitative data from all participants. As data was collected on inpatient wards, there was some competition for patients' time with medical, nursing and domestic staff, and with visitors. Some participants completed the Q sort but then did not have the time to discuss this further. Others had communication difficulties or fatigue from completing the task. This made the interpretation of the results more challenging and some important information may have been lost from the analysis.

### 5.4 Future research

In this study, participants were only recruited from inpatient settings in the months following stroke. Future research could include people discharged from hospital and living in the community. It would be interesting to follow people through their recovery journey to see if, and how, their viewpoint changes over time.

## 6.0 Conclusion

Q methodology has been conducive to exploring different viewpoints of stroke survivors. Three distinct viewpoints were found in this sample, with each identifying different aspects of third-wave therapies as more relevant. Identifying if an individual is aligned with one of these viewpoints early in the recovery journey can help to target the most appropriate intervention.

## **7.0 Funding**

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### Publication

Papers one and two have been written for submission to the Journal of Contextual Behavioral Science (JCBS), the guidelines for which can be found in Appendix O. This specifies the use of APA (American Psychiatric Association) style, which has been used throughout.

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## 9.0 Appendices

### Appendix A. List of statements used and the constructs they represent

Statement	Constructs represented
1 I think some of my emotions are inappropriate and I shouldn't feel them	Self-judgement, acceptance of internal states (-), self-acceptance (-)
2 I do jobs or tasks automatically, without being aware of what I'm doing	Mindfulness (-), acting with awareness (-)
3 Because of my stroke, I miss the things I like to do most	Helplessness
4 Dealing with my stroke has made me a stronger person	Perceived benefits, personal growth
5 Everyone feels down sometimes, it is part of being human	Common humanity
6 Generally, I pay attention to sounds, such as clocks ticking, birds chirping, or cars passing	Present moment awareness, mindfulness, observing
7 I can cope effectively with my stroke	Committed action
8 I can handle any problems related to my stroke	Committed action
9 I do things I care about even when I feel upset about my stroke	Living according to values, acceptance of internal states, purpose in life
10 I don't concern myself with other people's problems	Indifference to others, positive relations with others (-)
11 I encourage myself for the future	Reassuring self, purpose in life
12 I feel detached from others when they tell me their tales of sadness	Indifference to others, disengagement from others, positive relations with others (-)
13 I find myself doing things without paying attention	Acting with awareness (-)
14 I hate how my stroke makes me feel about myself	Hated self, self-acceptance (-)
15 I have a sense of disgust with myself	Hated self, self-acceptance (-)
16 I have learnt to accept the limitations imposed by my stroke	Acceptance of stroke
17 I need to get rid of my anxiety about my stroke	Reactive avoidance of emotions
18 I often pretend I didn't have a stroke	Denial
19 I often tune out when people tell me about their troubles	Disengagement from others
20 I pay attention to physical experiences such as the wind in my hair or the sun on my face	Present moment awareness, mindfulness, observing

Statement	Constructs represented
21 I stop doing things when I feel scared about my stroke	Reactive avoidance of emotions, living according to values (-)
22 I tell myself I shouldn't be feeling the way I'm feeling	Self-judgement, self-acceptance (-)
23 I try not to think about having had a stroke	Denial, reactive avoidance of emotions
24 I try to be understanding and patient towards those aspects of my personality I don't like	Self-kindness
25 I watch my feelings without getting carried away by them	Self-as-context
26 If I see someone going through a difficult time, I try to be caring toward that person	Kindness to others, positive relations with others
27 My heart goes out to people who are unhappy	Kindness to others, positive relations with others
28 My stroke controls my life	Helplessness, environmental mastery
29 My stroke defines me as a person	Self-as-context (-)
30 My stroke has helped me realise what's important in life	Living according to values, perceived benefits, personal growth, purpose in life
31 Suffering just a part of the common human experience	Common humanity
32 There is part of me that feels I am not good enough	Inadequate self, self-acceptance (-)
33 Usually, when I have distressing thoughts or images, I can just notice them without reacting	Cognitive defusion
34 When I fail at something that's important to me, I tend to feel alone in my failure	Isolating self, positive relations with others (-)
35 When I going through a very hard time, I give myself the caring and tenderness I need	Self-kindness, reassuring self
36 I tell myself I shouldn't be thinking the way I'm thinking.	Self-judgement
37 I tend to worry about what other people think of me	Autonomy (-)
38 I am not afraid to voice my opinions, even when they differ from others	Autonomy
39 It's ok for me to accept help from others	Acceptance of support
40 I often feel overwhelmed by my responsibilities	Environmental mastery (-)

Note: (-) represents a reverse scored statement.

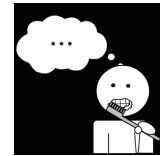
Appendix B. Statements and their visual representation given to participants

I think some of **my emotions** are **inappropriate** and I shouldn't feel them



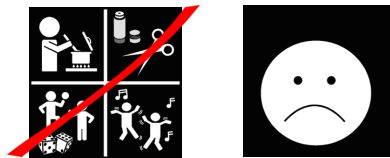
1

I do **jobs** or tasks automatically, **without being aware** of what I'm doing



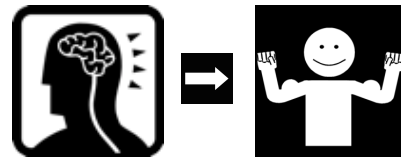
2

I **miss** the things I **like** to do most



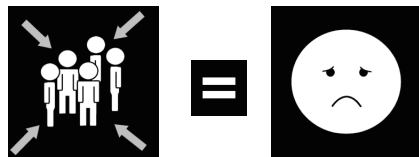
3

I'm a **stronger** person



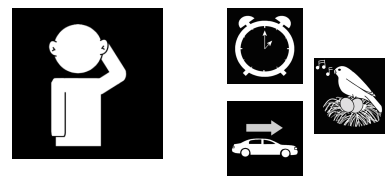
4

I think **everyone feels down** sometimes, it is part of being **human**



5

I pay **attention** to **sounds**, such as clocks ticking, birds chirping, or cars passing



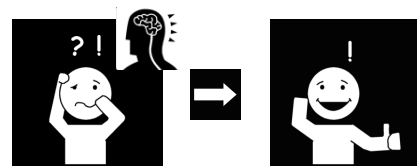
6

I think I can **cope** effectively with my **stroke**



7

I can **handle** any **problems** related to my stroke



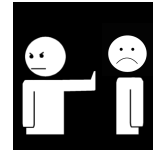
8

I **do** things I **care about** even when I feel **upset** about my stroke



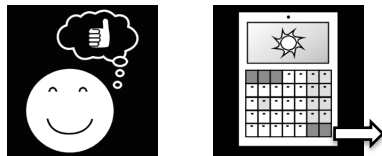
9

I **don't concern** myself with other people's **problems**



10

I **encourage** myself for the **future**



11

I feel **detached** from others when they tell me their tales of **sadness**



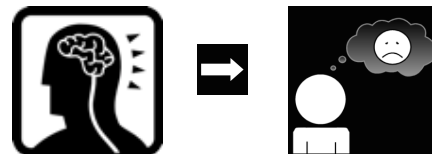
12

I find myself doing things **without** paying **attention**



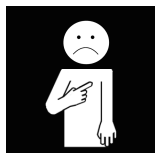
13

I **hate** how my **stroke** makes me **feel** about myself



14

I have a sense of **disgust** with myself



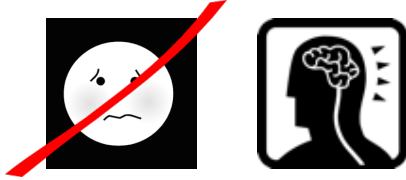
15

I have learned to **accept** the **limitations** caused by my **stroke**



16

I need to get **rid** of my **anxiety** about my **stroke**



17

I often **pretend** that I **didn't have** a **stroke**



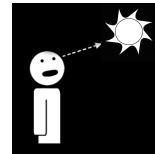
18

I often **tune out** when people **tell** me about their **troubles**



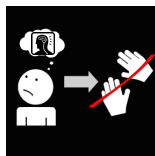
19

I pay **attention** to **physical experiences** such as the wind in my hair or sun on my face



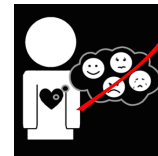
20

I **stop** doing things when I feel **scared** about my **stroke**



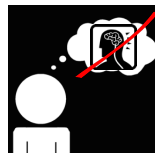
21

I tell myself that I **shouldn't** be **feeling** the way I'm feeling



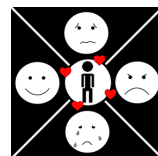
22

I try **not** to **think** about having had a **stroke**



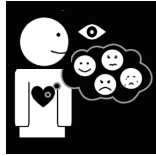
23

I try to be **understanding** and **patient** towards those aspects of my **personality** I **don't like**



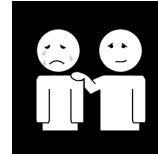
24

I watch my **feelings** without getting **carried away** by them



25

If I see someone going through a **difficult** time, I try to be **caring** toward that person



26

My **heart** goes out to people who are **unhappy**



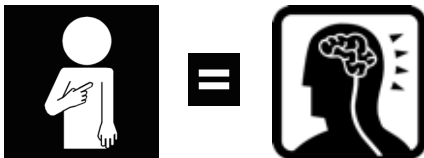
27

My stroke **controls** my life



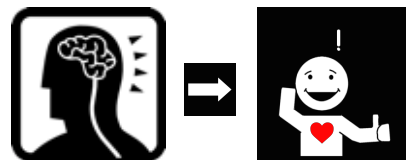
28

My **stroke** defines me as a person



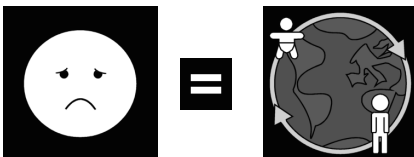
29

My **stroke** has **helped** me realize what's **important** in life



30

I think that **suffering** is just a part of the **common** human experience



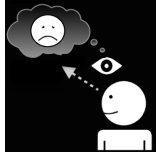
31

There is a **part** of me that feels I am **not good** enough



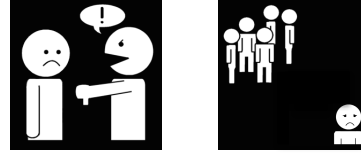
32

When I have **distressing thoughts** or **images**, I can just **notice** them without reacting



33

When I **fail** at something that's important to me, I tend to feel **alone** in my failure



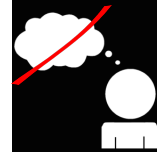
34

When I'm going through a very **hard time**, I give myself the **caring** and tenderness I need



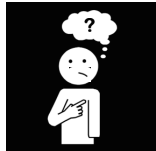
35

I tell myself I **shouldn't** be **thinking** the way I'm thinking



36

I tend to **worry** about what other people **think** of me



37

I am not afraid to **voice** my **opinions**, even when they differ from others



38

It's ok for me to **accept help** from others



39

I often feel **overwhelmed** by my **responsibilities**



40





**Faculty of Health Sciences**

**INDEPENDENT PEER REVIEW APPROVAL FEEDBACK**

**Researcher Name** Rachel Smith  
**Title of Study** An exploration of acceptance and compassion for self and others following stroke: A Q methodology  
**Award Pathway** Prof Doc Clin Psych  
**Status of approval:** **Approved**

Thank you for addressing the amendments requested by the Independent Peer Review Panel (IPR)

**Action now needed:**

You must now apply to the Local NHS Research Ethics Committee (LREC) for approval to conduct your study. You must not commence the study without this second approval.

Please forward a copy of the letter you receive from the LREC to Deb Edwards as soon as possible after you have received NHS ethics approval.

Once you have received LREC approval you can commence your study. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the Faculty ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

A handwritten signature in black ink, appearing to read 'E Boath'.

**Signed:** PP Dr E Boath  
Chair of the Faculty of Health Sciences IPR Panel

**Date:** 12<sup>th</sup> January 2016

Appendix D. Favourable ethical opinion from the REC (Research Ethics Committee)



**Health Research Authority**

**South East Coast - Surrey Research Ethics Committee**

Bristol Research Ethics Committee Centre  
Whitefriars  
Level 3, Block B  
Lewins Mead  
Bristol  
BS1 2NT

Telephone: (020) 71048053

23 May 2016

Miss Rachelle Smith  
Trainee Clinical Psychologist

[Redacted contact information]

Dear Miss Smith

**Study title:** An exploration of acceptance and compassion for self and others following stroke: A Q-methodology study.  
**REC reference:** 16/LO/0561  
**IRAS project ID:** 199781

Thank you for the revised documents submitted on 19 May, responding to the Committee's request for further information on the above research.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mr Raj Khullar, nrescommittee.secoast-surrey@nhs.net.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Management permission must be obtained from each host organisation prior to the start of the

A Research Ethics Committee established by the Health Research Authority

study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

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### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employer's Liability Certificate]	1	17 February 2016
GP/consultant information sheets or letters [GP letter]	1.0	17 February 2016
Interview schedules or topic guides for participants [Interview schedule]	1.0	12 March 2016
IRAS Checklist XML [Checklist_18052016]		18 May 2016
Letter from sponsor [IPR Approval letter]	1	12 January 2016
Other [Potential statements for the Q sort ]	1	17 February 2016
Other [Email clarifications]		15 March 2016
Other [Consent to contact form]	1.0	12 March 2016
Other [Table of amendments made in response to the points raised by the committee]	1.0	05 May 2016
Other [Example pictures to support communication ]	1.0	05 May 2016
Participant consent form [Consent Form V3.0]	3.0	29 April 2016
Participant information sheet (PIS) [Participant Information Sheet V2.0]	2.0	29 April 2016
Participant information sheet (PIS) [Aphasia Friendly Participant Information Sheet V2.0]	2.0	29 April 2016
REC Application Form [REC_Form_18052016]		18 May 2016
Research protocol or project proposal [Protocol]	1.0	05 February 2016
Research protocol or project proposal [Protocol]	2.0	29 April 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	17 February 2016
Summary CV for supervisor (student research) [Academic supervisor CV]	1	04 February 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol for participants]	1	20 February 2016
Validated questionnaire [Hospital Anxiety and Depression Scale]	1	17 February 2016

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

**A Research Ethics Committee established by the Health Research Authority**

- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

**16/LO/0561**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



**PP Dr Mark Atkins  
Chair**

Email: [nrescommittee.secoast-surrey@nhs.net](mailto:nrescommittee.secoast-surrey@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments  
"After ethical review – guidance for researchers"*

*Copy to: Dr Helen Combes*

**A Research Ethics Committee established by the Health Research Authority**

**South East Coast - Surrey Research Ethics Committee**  
**Attendance at Sub-Committee of the REC meeting in correspondence**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Mark Atkins	Consultant Virologist	Yes	
Mrs Chrissie Lawson	Nurse Specialist	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Wai Yeung	REC Assistant

A Research Ethics Committee established by the Health Research Authority

Appendix E. Approval from the HRA (Health Research Authority)



**Health Research Authority**

Miss Rachelle Smith  
Trainee Clinical Psychologist

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

29 July 2016

Dear Miss Smith

**Letter of HRA Approval for a study processed through pre-HRA Approval systems**

**Study title:** An exploration of acceptance and compassion for self and others following stroke: A Q-methodology study.  
**IRAS project ID:** 199781  
**Sponsor** Staffordshire University

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **HRA Approval**

This has been issued on the basis that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA

Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).

#### **Participation of NHS Organisations in England**

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with [HRA Approval Processes](#). It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate [Statement of Activities and HRA Schedule of Events](#). The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study. If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA..

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

#### **After HRA Approval**

In addition to the document, "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).



- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the [HRA website](#).

Your IRAS project ID is 199781. Please quote this on all correspondence.

Yours sincerely

Steph Macpherson  
Senior Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Helen Combes, University of Staffordshire [Sponsor contact]*

Appendix F. Confirmation of capability and capacity from the R&D (Research and Development) department of each Trust.

**From:**  
**Subject:** IRAS 199781: An exploration of acceptance and compassion for self and others following stroke  
**Date:** 28 September 2016 18:50:39 BST  
**To:** "s026517e@student.staffs.ac.uk" <s026517e@student.staffs.ac.uk>  
**Cc:**

Dear Rachelle

**RE: IRAS 199781. Confirmation of Capacity and Capability at**  
**Full Study Title:** An exploration of acceptance and compassion for self and others following stroke

On behalf of Dr Associate Medical Director Medical Director, this email confirms that has the capacity and capability to deliver the above referenced study.

We agree for you to start this study on **03 October 2016**.

If you wish to discuss further, please do not hesitate to contact me.

Best wishes

Research Delivery Unit Manager

**From:**  
**Subject:** IRAS [199781] Compassion and Acceptance Following Stroke - Confirmation of Capacity and Capability at NHS Trust  
**Date:** 23 September 2016 15:30:35 BST  
**To:** "SMITH Rachelle"  
**Cc:**

Dear Rachelle

**RE: IRAS [199781] [Compassion and Acceptance Following Stroke] – Confirmation of Capacity and Capability at NHS Trust**

**Full Study Title:** An exploration of acceptance and compassion for self and others following stroke – A Q-methodology study

This email confirms that NHS Trust has the capacity and capability to deliver the above referenced study.

We agree for you to start your study from this date forwards as agreed.

For further information regarding how to notify us of any amendments to the study please refer to the [Amendments Guidance for Researchers](#) .

If you wish to discuss this further, please do not hesitate to contact me.  
Kind regards

**From:**  
**To:** "SMITH Rachelle"  
**Cc:**

**Subject: IRAS 199781 Confirmation of Capacity and Capability at NHS Trust**

Dear Rachelle,

RE: IRAS 199781 Confirmation of Capacity and Capability at NHS Trust

Full Study Title: An exploration of acceptance and compassion for self and others following stroke: A Q-methodology study.

This email confirms that NHS Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.  
We agree to start this study on 1st November 2016 as previously discussed.  
If you wish to discuss further, please do not hesitate to contact me.

Kind regards

Research Governance Facilitator

# Appendix G. Participant Information Sheet (standard version)

Version 3.0  
01/10/2016

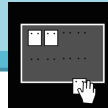


## Participant Information Sheet

### Acceptance and compassion following stroke:

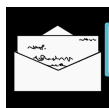
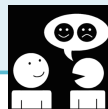
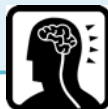


### A Q-methodology study



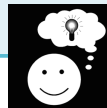
### What is the study about?

After a stroke, people may need different kinds of care. This might be physiotherapy, occupational therapy or psychological support. This study aims to add what we know about people's psychological wellbeing after a stroke. We are interested in how people feel, and how they act towards themselves and others. We are also interested in how people view their stroke and its impact on them.



### Invitation

You are invited to take part in this study if you have had a stroke. This might have been a hemorrhagic or ischemic stroke. These are the two main types. If you have had a transient ischemic stroke (a TIA or mini-stroke) you would not be eligible. We are interested in the experiences and opinions of lots of different people who have had a stroke. This research is open to anybody who has experienced a stroke. You just need to understand what is involved and be able to communicate your opinions.



This research is separate to any care or services you are receiving. Taking part in this research, or choosing not to, will not affect your care in any way.



### What would taking part involve?

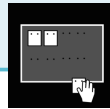
If you agree to take part, you will be asked to meet with a member of the research team. This may be somewhere you go as part of your care, or at Staffordshire University. It may be possible to see you in your home. We should only need to meet once, and the meeting is likely to take about an hour. Some people may find that it takes a little more or less time.



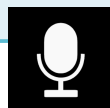
You will be asked some questions about yourself and your stroke. For example you will be asked your age and when you had a stroke.



After this you will be asked to sort some cards with different statements on them. These statements are about things you may have experienced, thought or felt since having a stroke. You will be asked put them into order of how much you agree or disagree with them. There are no right or wrong answers; we are just interested in your experience.



After you have sorted the cards you will have the chance to talk about the statements. You can say how you found sorting them and if there was anything that you felt was missing. If you agree, the meeting will be audio taped so that notes can then be of made your opinions. This recording will be destroyed within 4 weeks.





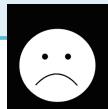
### What are the possible benefits of taking part?

It is hoped that this work can help people to better understand the experience of having a stroke. Some people value taking part in things that can help others with a similar condition. We do not expect that taking part will benefit you, and cannot give any payment for taking part.



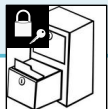
### What are the possible risks of taking part?

Taking part in this research can cause people to think about things that have been difficult for them. Some people can find this upsetting. If this is the case you may wish to talk to friends or family about how you're feeling. Alternatively you can seek further support through your GP. We will inform your GP that you are taking part. The Samaritans are also available on email ([jo@samaritans.org](mailto:jo@samaritans.org)) or you can call them 24 hours a day on 08457 90 90 90.



### How will my information be kept confidential?

Your personal information will be securely held at Staffordshire University in a locked filing cabinet or on an encrypted NHS memory stick. It will be treated confidentially in line with the Data Protection Act (1998) for the purposes of this research. Your name and any identifiable information will be removed and destroyed after 4 weeks. This will make it anonymous so when the research is written there is no way to identify you. Your research data will be kept for 10 years and then be securely disposed of.



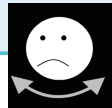
Confidentiality may be broken if the researcher knows that you or someone else may be at risk of harm. Then we might have a duty of care to share this information. This would usually mean talking to the people you are already working with. In some circumstances it may mean contacting other services for support.





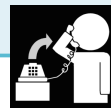
### What will happen if I don't want to carry on with the study?

Even if you agree to take part, you can change your mind. You can leave the study at any time before taking part, or within four weeks of meeting with the researcher if you do take part. Saying you do not want to take part will not change your care at all. If you wish to withdraw, please contact Rachelle Smith by telephone (07729 794861) or email (s026517e@student.staffs.ac.uk) within four weeks of taking part.



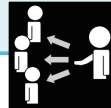
### What if I'm concerned about something?

If you have any concerns, please talk to Rachelle Smith who will try to help (s026517e@student.staffs.ac.uk/ 07729 794861). If you are still unhappy you can contact the research supervisor Dr Helen Combes on h.a.combes@staffs.ac.uk. You can also contact the Patient Advice Liaison Service (PALS) who support service users and their carers. You can phone them on 0800 030 4563 (freephone) or email feedback@staffordshireccs.nhs.uk



### What will happen to the results of this study?

The research will be written up as a doctoral thesis. It may be also published in an academic journal or presented to health or social care professionals. You can have a copy of the results if you would like to.



### What happens now?

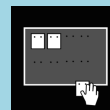
If you would like to take part in the study or find out more, you can contact Rachelle Smith. Please email s026517e@student.staffs.ac.uk or call 07729 794861. Someone you work with may have given you this form. If so, you can fill in the contact form and return it to them. The research team will then contact you.

01/10/2016 Version 3

**Acceptance and compassion following stroke:**



A **research** study using a **card sort**



What is the study about?

This is about **wellbeing** after a **stroke**.



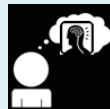
We want to know how people **act** towards **themselves**.

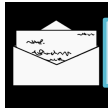


We want to know how people **act** towards **others**.



We want to know how people **think** about their **stroke**.





## Invitation

Anyone who has had a **stroke** can take part.



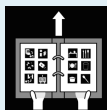
You need to **understand** what is involved.



You need to be able to **tell us** what you think.



This might be through **pictures**.



This is **separate** to your care. You do not have to take part.

Your **care** will **continue**.







## What would I have to do?

You will **meet** with a researcher.



This may at be the **hospital**, Staffordshire **University** or your **home**.



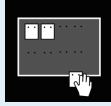
We will probably meet once for about **1 hour**.



You will be asked some **questions** your stroke.



You will be asked to **sort** some **cards**. These have statements on about how you might think or feel.



You will be asked put them into **order** of how much you **agree or disagree** with them.



You can **tell us** what you thought about doing this.



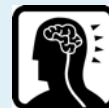
If you agree we will **audio tape** the meeting. We don't have to do this.





## What are the possible **benefits**?

We hope it will help us **understand** what it is like to have a **stroke**.

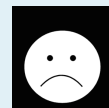


We **cannot pay you** for taking part.



## What are the possible **risks**?

It might cause you to think about **difficult** things. This can be **upsetting**.



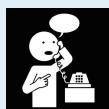
You can **talk to friends or family** about how you're feeling.



We will tell your **GP** that you are taking part. You can talk to them.



You can **call** (08457 90 90 90) or **email** (jo@samaritans.org) the Samaritans.





## How will my information be kept safe?

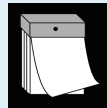
Your information will be kept in a **locked filing cabinet** or **memory stick**.



Your **name** will not be shown to anybody. It will be **deleted** after **4 weeks**.



Your research data will be kept for **10 years**. It will then be **destroyed**.



Any **audio** recordings will be **deleted** after **4 weeks**.



If you or someone else are at **risk of harm**, we have to **tell** somebody.



This might be someone you are working with. It might mean contacting other services for **support**.



## What if I want to stop?

You can **stop at any time** before or during taking part.

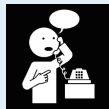


You **can withdraw** your information within **four weeks** of taking part.



If you want to withdraw, please contact Rachelle Smith:

by telephone (07729 794 861) or email ([s026517e@student.staffs.ac.uk](mailto:s026517e@student.staffs.ac.uk))



## What if I'm concerned about something?

Please **talk** to Rachelle Smith ([s026517e@student.staffs.ac.uk](mailto:s026517e@student.staffs.ac.uk) / 07729 794 861).



Or you can email Dr Helen Combes on [h.a.combes@staffs.ac.uk](mailto:h.a.combes@staffs.ac.uk).

You can also contact the NHS Patient Advice Liaison Service (PALS) on 0800 030 4563 or email [feedback@staffordshireccs.nhs.uk](mailto:feedback@staffordshireccs.nhs.uk)



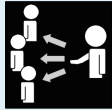


## What will happen to the results?

The research will be **written** up as a doctoral thesis. It may be **published** in an academic journal.



It may be **shared** with health or care professionals. You can have a **copy**.



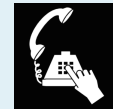
## What happens now?

If you want to **take part** or **find out more**, please fill in the **contact form**.

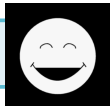


You can give it to whoever gave you this sheet. We can then **contact you**.

Or you can contact Rachelle Smith.




Please **call** 07729 794 861 or **email** [s026517e@student.staffs.ac.uk](mailto:s026517e@student.staffs.ac.uk)




Thank you for reading this.


Appendix I. Consent to Contact Form

  
STAFFORDSHIRE  
UNIVERSITY

Consent to contact form




Name:




Telephone number:


OR



Email:

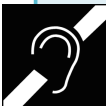
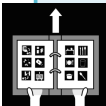



I give permission for the research team to contact me by **email or phone** to talk about taking part in the study.



Signed:

Date:

Please let us know if you have any special needs. For example if you have any **communication** requirements or **mobility** difficulties:

12/03/2016 Version 1.0

# Appendix J: Informed Consent Form

Version 3.0  
29/04/2016



Centre Number:  
Study Number:  
Participant Identification Number for this trial:

## CONSENT FORM

Title of Project: Acceptance and compassion following stroke  
Name of Principal Researcher: Rachelle Smith

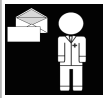
Please initial each box



1. I confirm that I **have read the information sheet** (Version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.



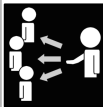
2. I understand that my **participation is voluntary** and that I am free to withdraw at any time up to **four weeks** after participating without giving any reason, without my medical care or legal rights being affected.



3. I agree to my **General Practitioner (GP) being informed** of my participation in the study.



4. I understand that the information gathered will be **securely stored** by the University of Staffordshire for up to **ten years and then destroyed**, in accordance with the Data Protection Act (1998).



5. I understand the information collected about me might be used to support other research in the future, and may be **shared anonymously** with other researchers.



6. I **agree to take part** in the above study



7. **Optional** - I consent to my meeting with the researcher being **audio recorded**. Notes will be made from the recording which will then be **destroyed within 4 weeks**. I understand that if I am recorded, **quotes may be used** in the research. My name will not be used and any identifying information will be removed.

\_\_\_\_\_  
Name of participant                                  Date                                  Signature of participant/  
witness

If signed by a witness: I \_\_\_\_\_(witness) have provided the information to the best of my ability on behalf of \_\_\_\_\_(participant).

\_\_\_\_\_  
Name of person taking consent                  Date                                  Signature



Appendix K. Instructions for Participants doing the Q-sort



**Instructions for participants:** I am interested in what things are like for you since having had a stroke.



I would like you to **sort the statements** below.



Please think about how much they describe **your experience now**,



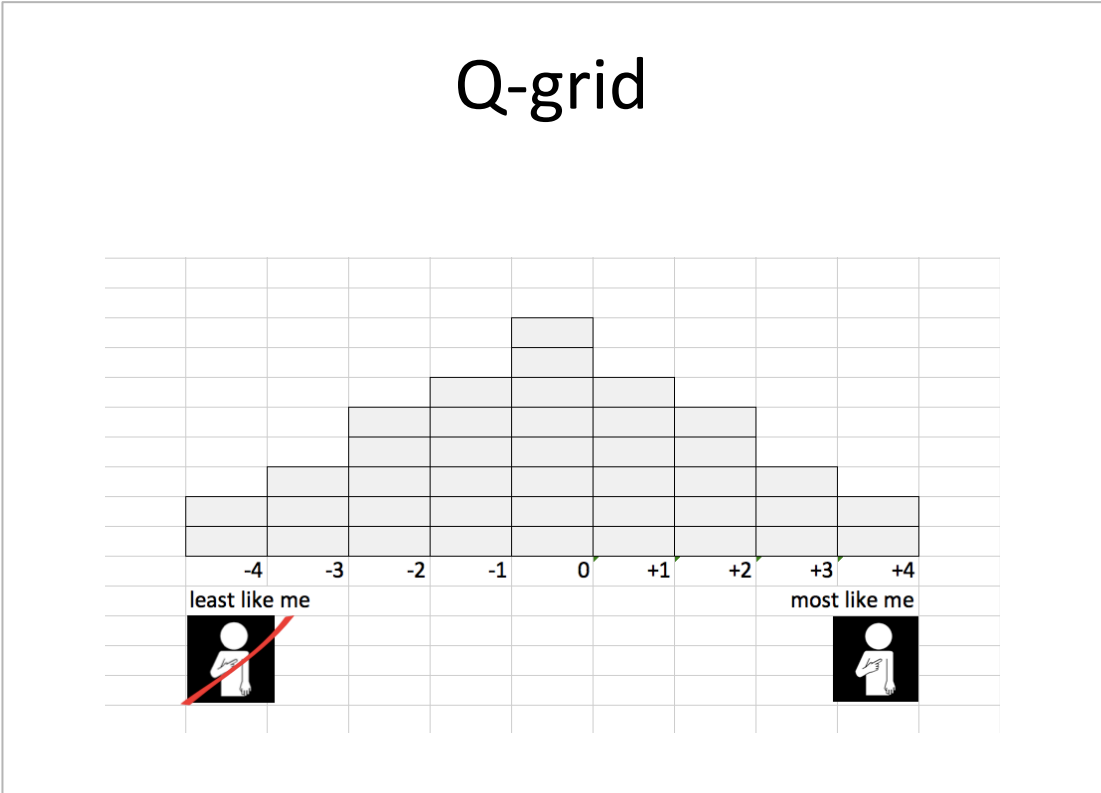
particularly in relation to having had a **stroke**.

Please rate the statements based on how much they describe your experience, from:

'**least like me**' (-4) through neutral (0) to '**most like me**' (+4).



Appendix L. Representation of Q-grid distribution



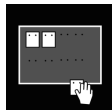
Appendix M. Questions asked of participants following the Q-sort

12/03/2016 Version 1.0

Proposed interview schedule



**How was it sorting the statements?**



Are there any **statements** that you would like to **comment on**?



How well did they describe **your experience**?



Was there anything important you thought was **missing**?



Is there anything else you'd like to **say**?



Appendix N. Colour-coded factor arrays used for analysis.

	Factor 1					Factor 2					Viewpoint 3				
	Rank	Construct	Wellbeing	Stmnt	Brief summary	Rank	Construct	Wellbe	Stmnt	Brief summary	Rank	Construct	Wellbein	Stmnt	Brief summary
Most like me ↑	+4	1		7	Cope effectively	+4	1		3	Miss things	+4	1		3	Miss things
	+4	2		8	Handle problems	+4	2		39	Ok to accept help	+4	1		32	Part of me is not good enough
	+3	3		11	Encourage self for future	+3	3		2	I do tasks automatically without awareness	+3	2		10	Not concerned with others problems
	+3	4		30	Helped me realise what's important	+3	4		22	Shouldn't be feeling this way	+3	2		34	Alone in failure
	+3	5		9	Do things when upset	+3	5		12	Detached from others sadness	+3	2		38	Not afraid to voice opinions
Neutral	+2	6		16	Accept limitations	+2	6		11	Encourage self for future	+2	3		12	Detached from others sadness
	+2	7		25	Watch feelings ok	+2	7		35	Caring toward self	+2	3		13	Autopilot things
	+2	8		23	Don't think about stroke	+2	8		27	Heart goes out to unhappy people	+2	3		16	Accept limitations
	+2	9		31	Suffering is human	+2	9		31	Suffering is human	+2	3		22	Shouldn't be feeling this way
	+2	10		38	Not afraid to voice opinions	+2	11		18	Deny stroke	+2	3		33	Notice distressing thoughts
	+1	11		26	Caring to others in difficulty	+1	11		25	Watch feelings ok	+1	4		2	I do tasks automatically without awareness
	+1	12		39	Ok to accept help	+1	12		16	Accept limitations	+1	4		4	Stronger person
	+1	13		6	Attention to sounds	+1	13		5	Everyone feels down	+1	4		8	Handle problems
	+1	14		5	Everyone feels down	+1	14		21	Stop doing things when scared	+1	4		11	Encourage self for future
	+1	15		4	Stronger person	+1	15		7	Cope effectively	+1	4		19	Tune out from others' problems
	+1	16		20	Attend to physical experineces	+1	16		38	Not afraid to voice opinions	+1	4		30	Helped me realise what's important
	0	17		3	Miss things	0	17		10	Not concerned with others problems	0	5		1	Emotions inappropriate
	0	18		27	Heart goes out to unhappy people	0	18		36	Shouldn't be thinking	0	5		5	Everyone feels down
	0	19		22	Shouldn't be feeling this way	0	20		13	Autopilot things	0	5		6	Attention to sounds
	0	20		35	Caring toward self	0	20		34	Alone in failure	0	5		21	Stop doing things when scared
	0	21		36	Shouldn't be thinking	0	21		40	Feel overwhelmed by responsibilit	0	5		24	Understanding towards bits I don't like
0	22		24	Understanding towards bits I don't like	0	22		32	Part of me is not good enough	0	5		25	Watch feelings ok	
0	23		33	Notice distressing thoughts	0	23		26	Caring to others in difficulty	0	5		31	Suffering is human	
0	24		10	Not concerned with others problems	0	24		6	Attention to sounds	0	5		40	Feel overwhelmed by responsibilit	
Least like me ↓	-1	25		19	Tune out from others' problems	-1	25		19	Tune out from others' problems	-1	6		7	Cope effectively
	-1	26		40	Feel overwhelmed by responsibilit	-1	26		1	Emotions inappropriate	-1	6		9	Do things when upset
	-1	27		2	I do tasks automatically without awareness	-1	27		9	Do things when upset	-1	6		17	Get rid of stroke anxiety
	-1	28		1	Emotions inappropriate	-1	28		30	Helped me realise what's important	-1	6		20	Attend to physical experineces
	-1	29		17	Get rid of stroke anxiety	-1	29		28	Stroke controls my life	-1	6		23	Don't think about stroke
	-1	30		12	Detached from others sadness	-1	30		24	Understanding towards bits I don't like	-1	6		37	Worry about what others think
	-2	31		37	Worry about what others think	-2	31		14	Hate how stroke makes me feel about myself	-2	7		15	Disgusted with self
	-2	32		14	Hate how stroke makes me feel about myself	-2	32		23	Don't think about stroke	-2	7		18	Deny stroke
	-2	33		18	Deny stroke	-2	33		15	Disgusted with self	-2	7		26	Caring to others in difficulty
	-2	34		13	Autopilot things	-2	34		17	Get rid of stroke anxiety	-2	7		28	Stroke controls my life
	-2	35		34	Alone in failure	-2	35		29	Stroke defines me	-2	7		36	Shouldn't be thinking
	-3	36		32	Part of me is not good enough	-3	36		20	Attend to physical experineces	-3	8		14	Hate how stroke makes me feel about myself
	-3	37		29	Stroke defines me	-3	37		8	Handle problems	-3	8		27	Heart goes out to unhappy people
	-3	38		15	Disgusted with self	-3	38		33	Notice distressing thoughts	-3	8		39	Ok to accept help
	-4	39		21	Stop doing things when scared	-4	39		37	Worry about what others think	-4	9		29	Stroke defines me
	-4	40		28	Stroke controls my life	-4	40		4	Stronger person	-4	9		35	Caring toward self

Key:	
	Statements that indicate good psychological wellbeing
	Statements that indicate poor psychological wellbeing
	Compassion to self
	Compassion to others
	Mindfulness
	Valued behaviours
	Acceptance
	Perceived benefits
	Cognitive defusion
	Indicates a negatively scored item



## JOURNAL OF CONTEXTUAL BEHAVIORAL SCIENCE

### AUTHOR INFORMATION PACK

#### TABLE OF CONTENTS

● <b>Description</b>	<b>p.1</b>
● <b>Abstracting and Indexing</b>	<b>p.2</b>
● <b>Editorial Board</b>	<b>p.2</b>
● <b>Guide for Authors</b>	<b>p.4</b>



ISSN: 2212-1447

#### DESCRIPTION

The *Journal of Contextual Behavioral Science* is the official journal of the [Association for Contextual Behavioral Science \(ACBS\)](#).

Contextual Behavioral Science is a **systematic and pragmatic approach** to the understanding of behavior, the solution of human problems, and the promotion of human growth and development. Contextual Behavioral Science uses **functional principles and theories** to analyze and modify action embedded in its historical and situational context. The goal is to **predict and influence behavior**, with precision, scope, and depth, across all behavioral domains and all levels of analysis, so as to help create a behavioral science that is more adequate to the challenge of the human condition.

Contextual behavioral science is a strategic approach to the analysis of human behavior that proposes the need for a **multi-level** (e.g. social factors, neurological factors, behavioral factors) and **multi-method** (e.g., time series analyses, cross-sectional, experimental) exploration of **contextual and manipulable** variables relevant to the prediction and influence of human behavior.

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## CHAPTER THREE

### Reflective paper

## 1.0 Reflections on the research journey

This reflective account looks back over a research journey exploring mindfulness-based therapies and their application to stroke. This has included a systematic literature review, and the design, planning, implementation, analysis and interpretation of a piece of empirical research. It will focus on my own personal journey with mindfulness during this time, which is intricately linked with the research, and reflect on how the two have influenced each other.

I have decided to write this reflective account in the first person as it concerns my experience of the research process. This is in line with my chosen methodology, Q, which appreciates individual viewpoints and perspectives, and with the experiential nature of mindfulness.

When I started this research project, I had an interest in mindfulness and this, combined with a placement in stroke, led me to want to investigate its potential in this area. I thought I had a fairly good understanding of mindfulness. I had attended several day workshops, read books, and incorporated it into individual therapy sessions with clients whenever it seemed appropriate. I felt that I also had a well-established mindful outlook woven into my everyday life, despite not having a solid daily formal practice.

During the course of the research, however, I had the opportunity to co-facilitate an eight-week mindfulness based cognitive therapy group for people who had been through treatment for cancer (MBCT-Ca). This eight-week course was a revelation to me. I practiced everyday along with the recommendations for participants. I prepared hand-outs week by week as we went through the course, which required me take the time to process and really consider what new teaching and wisdom each new session brought. I witnessed the participants' journey through the programme

alongside my own, and this was a true privilege. It gave me a deeper felt sense of the power of mindfulness to have a profound impact on people's lives.

On taking a break from writing up my research one day and doing a mindful yoga exercise, it struck me that I hadn't yet fully connected these experiences. On the one hand I was writing academically about the potential uses of mindfulness, and on the other hand experiencing its transformative power, as if they were two separate things. And, in a way, perhaps they are. Mindfulness can be studied from a distance, it can be measured and investigated under a CT scanner, it can be asked about and written about and discussed and debated. But at its centre, and its very heart, is the felt sense of it. Maybe it can be put into words, but those words will never be able to equate with an appreciation of its experiential qualities.

I realised then that there was something missing from this thesis that cannot be put into words. I found writing an academic definition of mindfulness particularly hard. A little empty. It was frustrating not being able to get across a felt sense of mindfulness. My experience of it. While I have no desire to disparage the attempts of experts in the field to define it with words, there remains for me a feeling that something is missing from this work that cannot be put into written text.

Having deliberated over how to try and express this, I decided to include within this account something, which, to me, represents more of this felt sense of mindfulness. Something which better captures my journey through this research. Something that characterises more of what mindfulness can bring, the compassion that can unfold, the connection and presence it can promote, the revelations and wisdom that can emerge. But also the difficulty, the struggle with judgements, the messiness and the

uncertainty. While, in a way, an object can do this no more than words can, for me it provides a more tangible way of expressing this.

The item I have chosen to submit comes from a parallel journey. In the third year of the course, I started attending a pottery class, in part to have something of a distraction from the pressures of training. This also represents a connection with my cultural heritage and the history of the area of Staffordshire where the course is based.

I find working with clay can be a very mindful experience. It is easy to become completely absorbed in. There are also important lessons to learn about not becoming too attached to anything. Pieces can be so fragile, and the process so unpredictable. Things are always left in the hands of the 'kiln gods', where a piece can be transformed or destroyed when it goes in to be fired. I have learnt to be more in the moment with the creation of each piece, and to appreciate this process, without such an attachment for the end product. As I write this, the piece I hope to submit has not yet been fired or glazed. There is a good chance it will not survive the process. Judgements and frustrations frequently creep in about how 'good' something is. It has its highs and it has its lows. I think this is also reflective of the research journey.

The object I chose to make is also a traditional symbol of spiritual growth and enlightenment in Buddhism, the lotus flower. It grows out of the mud and remains rooted there, but emerges into the light above the water, unblemished by the journey it has taken through the muddy waters. There are different ways to interpret this, but I am drawn to the unfolding and openness of the flower, its emergence from the dark into the light, and its continued connection with its roots. One cannot exist without the other. As Thich Nhat Hanh puts it in the title of his book, "No Mud, No Lotus". This is

an acknowledgment and acceptance of suffering as a part of human experience. This lotus has also been crafted from the earth (Figure 1). "Clay takes us back to where we started; it grounds and earths us" (British Ceramics Biennial (BCB), 2016, p.1).



Figure 1. Lotus flower sculpted from clay.

The last five words of the poem 'The Summer Day' by Mary Oliver (1992) are imprinted onto the middle of the lotus. They cannot be reprinted here for copyright reasons, however I would encourage the reader to seek out this poem. I read it as part of the MBCT-Ca group, and I think encapsulates mindfulness beautifully. Its final line resonates with me and with my journey through mindfulness and this research. It asks of the reader what it is that they intend to do with their life, one that the author describes as wild and precious. This feels especially relevant to me working in physical health settings, and bearing witness to the experience of people who have come closer to their own mortality than I have ever dared to go. It has made me more aware of how fragile and precious life is, and these words especially remind me of the group of participants in my research, who, despite having experienced a stroke and being in hospital, were able to maintain a focus on their values and live a life that was meaningful to them.

This reminds me to maintain a sense of what is important about this work when getting caught up in the struggle of it, and the frustrations of things that are outside of my control. I speak here especially of the difficulties I encountered with the procedures for gaining ethical approval and recruitment. It reminds me in the face of this to ground myself in staying true to my values, to not lose sight of why I was doing this research and what I hoped it would achieve.

The participants in the study were Experts by Experience as they were in the process of recovering from a stroke. They were able to comment on their experience of this in order to give some insight into what aspects of third-wave approaches might be relevant to them. They had not, however, experienced this therapeutically and were not in a position to comment on how helpful this may have been.

One gentleman who took part in the study had a stroke the previous day, and while he demonstrated enthusiasm in taking part in the research, I did recognise the potential vulnerability of this individual in having just undergone a potentially life-threatening and life-changing event and he would possibly still be processing this.

It was unusual to be working with someone so soon after a stroke. This would not usually be a time when people would receive direct input from a Clinical Psychologist. This made me think more about the wider role of the Psychologist in promoting an individual's psychological wellbeing at this time in providing information and training to the multi-disciplinary team.

Part of what was really important to me in doing this was being able to make the research as accessible as possible to people, and I committed myself to adapting the materials for this purpose and considering what methodology would particularly lend itself to this. I was grateful that the methodology I chose enabled me to bring the research to more people, and capture their voices, more than other methods would have allowed me to do.

Q methodology enabled people to express their viewpoint where this wouldn't have been possible through other means of communication such as verbal speech or writing. One gentleman could only nod or shake his head to communicate, and I do not believe that the rich information gained from his Q sort could have been communicated in any other way in such a short space of time. This method also enabled the research to be done in locations that were more convenient for participants, such as in a hospital bed or at a bedside, without compromising confidentiality. When collecting data on a busy hospital ward it is virtually impossible to find a free



confidential space, however, with Q people were able to express their opinions without anybody else nearby knowing what that opinion was. In addition, information was imparted that I do not believe would have been disclosed if a more traditional approach had been taken such as an interview or a questionnaire.

Throughout the research I was acutely aware of my own interest and views on mindfulness and the impact it has had on my life. I recognise that this introduces bias, and I'm also conscious of maintaining an awareness of this. It was this interest that, in part, led to choosing it as a topic of study. Being aware of this, I carefully considered my rationale, discussed it with my supervisor and ensured that I stayed grounded in the evidence. In my literature review, it was important to consider the potential to overstate the current evidence due to my own commitment to the approach. I also considered the potential impact of my position in my empirical paper, and I recognised, for example, that this had the potential to influence the range of statements available to the participants, and included statements around general illness cognitions and wellbeing in addition to those more explicitly concerned with third-wave therapies. I also took this into account in my interpretation of the data. When looking at one factor from my data, the first thing I noticed about it was that the members of that group appeared to be somewhat avoidant of the present. My initial instinct was to think about what might be helpful to this group in terms of utilising mindfulness as a tool for present moment awareness. I then realised that I was judging their experiential avoidance, forgetting that sometimes this is a helpful and functional mechanism for people to employ in itself. Mindfulness-based approaches are not about forcing people to be more mindful, but I recognise that sometimes my enthusiasm can lead me a little in that direction. Fortunately, being mindful can also lead me back again.

This has made me consider the role of clinicians and researchers' own mindfulness practice and its importance in mindfulness research. Because mindfulness is such an experiential process, I wonder how effectively it can be taught or delivered as an intervention by someone who does not have a solid personal foundation in it themselves, and how this can impact on the results of a study. There were no declarations made by the authors of any of the papers I reviewed of a personal interest in mindfulness, or a commitment to personal practice.

My personal journey through this research has given me a different perspective on mindfulness. This has also shaped my experience and helped me to connect more strongly with my values concerning research and my role as a psychologist more widely.

## 2.0 References

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