



School of Psychology

Ysgol Seicoleg

**A systematic review of the effectiveness of group-based
Acceptance and Commitment Therapy for Neurological
Conditions and an Empirical Study of Staff perceptions of a
Stroke specific self-management book**

Thesis submitted in partial fulfilment of the requirement for the
degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

Hannah Lewis-Dunford

Supervised by: Professor Reg Morris

26th May 2020

Table of Contents

Acknowledgements.....	4
Preface.....	5
Paper 1.....	8
Title Page.....	8
Abstract.....	9
Introduction.....	10
Systematic Review Method.....	16
Results.....	19
Discussion.....	40
References.....	47
Paper 2.....	55
Title Page.....	55
Abstract.....	56
Introduction.....	57
Method.....	61
Results.....	65
Discussion.....	79
References.....	88
Appendices.....	97
Appendix 1. Author Guidance for Journal Submission.....	97
Appendix 2: Psychotherapy Outcome Study Methodology Rating Form	98

Appendix 3: Table of Quality Ratings using the POMRF.....	102
Appendix 4: Participant Information Sheet.....	103
Appendix 5: Participant Consent Form.....	108
Appendix 6. Demographic Questionnaire for Staff.....	110
Appendix 7. Staff Interview Schedule.....	113
Appendix 8. Participant Debrief Letter	115
Appendix 9. Participant Panel Invitation.....	116
Appendix 10. Confirmation of Ethical Approval	117
Appendix 11. Letter of Access for Research	119
Appendix 12. Example Transcript Excerpt and Coding.....	121
Appendix 13. Code Transformation.....	134
Appendix 14. 15-point checklist of criteria for Good Thematic Analysis.....	136
Appendix 15. Thematic Maps.....	141

Acknowledgements

I wish to thank all the staff members working within stroke services who graciously gave up their time to take part in this research. The passion you have for supporting stroke survivors and their families was clearly evident and your knowledge was invaluable to the success of the study. I would also like to thank my supervisor, Professor Reg Morris, for his knowledge and guidance throughout the project.

I would also like to extend a huge thank you to all my family and friends who have been such a pillar of strength to me throughout my DClIn journey– it takes a village!

To my Mammy and Daddy – Thank you for your constant love, support and patience in everything I have chosen to do. You are both my heroes and I could never have done this without you. You always give me sunshine on a cloudy day.

To Ashley and Tom – You continue to inspire me with your work hard, play hard attitude to life and I am so proud of everything you have both achieved. Thank you for your humour and for always keeping my feet on the ground in your very special way.

To my Dunford family – You are the kindest and most thoughtful people I could hope to have in my life. Thank you for always cheering me on and keeping me going with tea, biscuits and delicious roast dinners.

Finally, and most importantly, to my wonderful Mark and Ruby - Without you none of this would have been possible. The drive to make you proud has kept me going when things got tough and you will always be my most special achievement. Thank you for always believing in me and being by my side every step of the way. Words could never express how much you both mean to me, ‘you give me this feeling, this everglow.’

Preface

This thesis comprises of two papers; a systematic review and an empirical study. The systematic review explored the effectiveness of group-based Acceptance and Commitment Therapy interventions for those with a diagnosed neurological condition. Individuals with a neurological condition have the lowest health related quality of life of any long-term health condition with around one quarter being diagnosed with a co-morbid mental health condition. Acceptance and commitment therapy (ACT) is effective for those with long-term health conditions with a growing evidence base. However, reviews of effectiveness in those with neurological conditions are lacking. The systematic review aimed to evaluate effectiveness and quality of studies of group-based ACT for adults with neurological conditions. Searches for peer-reviewed articles were carried out using Psych Info, Ovid MEDLINE and EMBASE. Two reviewers independently screened and rated all relevant studies. Twelve studies were included: eight were randomised controlled trials, one used a randomised design with repeated measures, one used a quasi-experimental design with pre-post measures and two used pre-post designs with no control group. The neurological conditions which were covered by the included studies were Multiple Sclerosis, Epilepsy, Fibromyalgia, Stroke and Chronic Headache. Interventions were targeted at a number of outcomes including Quality of Life, distress and the processes of ACT. The results of the review generally supported the finding that group-based ACT seems to be as effective as other active treatments and more effective than Treatment as Usual or Waiting list controls. Improvements as a result of ACT were found in all studies which examined the level of pain related disability, the impact of the neurological condition, frequency of seizures, secondary fatigue, and the core processes of ACT.

The empirical paper was a qualitative study of a stroke specific self-management book. The study was thought to be beneficial to the evidence base for stroke as despite pressure to deliver psychological interventions to those who have experienced a stroke, there continues to be a lack of psychological resources available for this patient group. Depressive symptoms have also been found to be reduced in stroke survivors when they are provided with information post-stroke, thus emphasising the potential role for self-help resources in this area. The aim of the paper was therefore to gain insight into staff working within stroke services experiences of using a stroke specific self-management book in their practice. Interviews with fifteen staff members working within stroke services who had used the 'Rebuilding your life after stroke' (Morris et al., 2017) self-management book were conducted and analysed using a thematic analysis approach. Staff members varied in their role, training, age and length of service working with a stroke population. All participants appeared to believe that the book was a welcome addition to the resources available within stroke services. The book appeared to be considered as a form of peer support and was felt to be accessible from a practical point of view. Professional role and level of training appeared to influence the views of interviewees, how they used the book in practice and how user-friendly they felt certain ACT concepts were for themselves and the stroke survivors they work with. The main conclusion of the current study was that in general 'Rebuilding your life after stroke' (Morris et al, 2017) had been positively received and welcomed by those staff interviewed. All participants agreed that the book had in some way supplemented their practice with most remarking on the benefits of having such a resource available both for themselves and the stroke survivors they work with. The study did however find that staff without knowledge of psychological concepts such as ACT may find training around the book useful in order to gain the most benefit from it within their practice. This therefore

outlines a potential role for psychologists within the area of staff training and upskilling of the workforce working within stroke services.

Paper 1 has been prepared for submission to the British Journal of Psychology in accordance with the guidelines for authors (Appendix 1).

Paper 1: A systematic review to consider the evidence base for group ACT for individuals with neurological conditions with regards to its quality and effectiveness.

Hannah Lewis-Dunford^a and Reg Morris^a

a South Wales Doctoral Programme in Clinical Psychology, Cardiff University, Cardiff, CF10 3AT

Corresponding author:

**Hannah Lewis-Dunford Cardiff University, 70 Park Place, Tower building 11th floor
Cardiff CF10 3AT lewish29@cardiff.ac.uk**

Word count (exc. figures/tables): 7608

Abstract

Individuals with a neurological condition have the lowest health-related quality of life of any long-term health condition. Around one quarter are diagnosed with a co-morbid mental health condition. Acceptance and commitment therapy (ACT) is effective for those with long-term health conditions with a growing evidence base. This systematic review aimed to evaluate effectiveness and quality of studies of group-based ACT for adults with neurological conditions. Searches for peer-reviewed articles were carried out using Psych Info, Ovid MEDLINE and EMBASE. Two reviewers independently screened and rated all relevant studies. Twelve studies were included: eight randomised controlled trials, one used a randomised design with repeated measures, one used a quasi-experimental design with pre-post measures and two used pre-post designs with no control group. Studies covered; Multiple Sclerosis, Epilepsy, Fibromyalgia, Stroke and Chronic Headache. Interventions targeted outcomes including Quality of Life, distress and processes of ACT. Results suggest group-based ACT is as effective as other active treatments and more effective than Treatment as Usual or Waiting list controls. Improvements as a result of ACT were found in all studies which examined the level of pain related disability, the impact of the neurological condition, frequency of seizures, secondary fatigue and the core processes of ACT.

Introduction

It has been reported that there are around 14.7 million people in the UK living with a neurological condition. This equates to around 1 in 6 adults in the UK being diagnosed with one of these long-term health conditions (Neurological Alliance, 2019). Neurological conditions can cause physical, cognitive, communication or behavioural impairments (Connell and Tyson, 2012). They can arise from damage to the spinal cord, brain or nerves as a consequence of an injury or illness (Neurological Alliance, 2012). There are many health conditions which come under the category of neurological conditions. These include, multiple sclerosis (MS), Parkinson's disease and fibromyalgia. Increased age may also increase the risk of developing neurological conditions such as stroke (Asplund et al., 2009) and dementia (Lobo et al., 2000).

On a global scale, the growing and ageing population has resulted in the prevalence and burden of neurological conditions continuing to increase. This in turn has meant that demand for treatment, rehabilitation and support services for neurological conditions has also been on the rise (GBD, 2019). Services treating those with neurological conditions made up 3.5% of NHS spending in 2012 – 2013 with 14% of the social care budget being spent on those living with neurological conditions (NHS England, 2019).

Around a quarter of those with a long-term health condition such as a neurological disorder have also been found to experience comorbid mental health conditions (Department of Health, 2009). For example, depression rates in those with conditions such as stroke, MS, epilepsy, Parkinson's disease and dementia range from around 20-50% (Kanner, 2005). Those with neurological conditions have also been found to have the lowest health related quality of life of any long-term health condition (NHS England, 2019). Furthermore, poor

quality of life can also be predicted by the presence of depression in these groups and can impact on successful treatment and recovery (Kanner, 2005).

Traditionally, evidenced-based psychological approaches used in other mental health settings have been used to support individuals with neurological conditions who display psychological difficulties. Cognitive Behavioural Therapy has been the most evidence based (Fernie, Kollman and Brown, 2015) with effectiveness being shown for treating depression in those with epilepsy (Fiest et al., 2013), MS (Hind et al., 2014) and TBI (Fann, Hart, and Schomer., 2009). A recent meta-analysis also found positive results for the impact of CBT on depressive symptoms in stroke populations, however the evidence was considered inconclusive with regards to effectiveness due to the limitations of included studies (Wang et al., 2018).

Many long-term neurological conditions share a number of features such as executive dysfunction and functional limitations (Fernie et al., 2015). They also share psychological difficulties such as changes in self-concept (Roger et al., 2014). Those with neurological conditions may also display emotional distress in a number of similar ways (Shields, Ownsworth, O'Donovan and Fleming, 2016). Such reactions may not meet the criteria for specific psychological diagnoses but may instead present as co-morbidity of the health condition itself (Gracey, Longworth and Psaila., 2015). It has been argued that such similar aetiologies within neurological conditions may encourage a transdiagnostic approach to treatment (Gracey et al., 2015), whereby the principles on which the treatment is based are believed to apply to a number of diagnostic categories and are therefore not specific (Craske, 2012). Such a move encourages a switch from therapies such as CBT which seek to alter thoughts, cognitive schemas and beliefs and instead change the relationship an individual has

with their psychological experiences (Hayes, 2004). Such transdiagnostic therapies have been referred to as ‘third wave therapies’ and are an extension of CBT principles (Hayes, 2004).

One particular third wave therapy that is gaining popularity within health settings when working within individuals with long-term health conditions is ‘Acceptance and Commitment Therapy (ACT)’ (Angiola & Bowen, 2013; Graham et al., 2015; Hadlandsmyth, White, Nesin, & Greco, 2013; Low et al., 2012). ACT has been considered to be potentially helpful for those with long-term conditions due to its focus on enabling emotional acceptance and integration of health-related difficulties as a new sense of self (Graham, Gouick, Krahe & Gillanders, 2016).

Acceptance and Commitment Therapy

ACT is based upon six principles which aim to enhance ‘psychological flexibility’ in order to provide individuals with the skills to handle difficult thoughts, feelings, and sensations (Harris, 2013). The reduction of distress is not a primary aim of ACT as it instead suggests that psychological distress is a normal part of the human experience. ACT aims to enable individuals to live a meaningful life in spite of difficult situations they may experience (Harris, 2013). The purpose of ACT is different to many other psychological approaches in that it does not aim to reduce or change unwanted thoughts, feelings, emotions, or sensations. ACT argues that attempting to cope with aversive internal responses by changing them may actually be counterproductive and instead it aims to enable individuals to learn to notice difficult experiences and change their relationship with them without seeking to eliminate them (Hayes, Levin, Plumb-Villardaga, Villatte, and Pistorello, 2013). Many with a long-term health condition may experience distress and negative beliefs which could be considered realistic at particular times. The focus of ACT on enabling individuals to accept such feelings

and thoughts rather than challenge them that suggests its potential efficacy for those with health difficulties (Graham et al., 2015).

A substantial review of ACT randomised control trials concluded that ACT is probably efficacious for a variety of health conditions and difficulties. It called for better quality studies to increase the efficacy of ACT and the interventions developed from its principles (Ost., 2014). Recent evidence has suggested that ACT when applied in physical health settings can demonstrate positive effects with regards to quality of life, reduction of psychological distress and self-management of disease (Graham et al., 2016). There is also a growing evidence base to indicate that ACT techniques are being used in clinical practice by those working within health settings. (Thewes et al., 2014). ACT has also been shown to be as effective as other psychological interventions such as CBT for anxiety (Swain, Hancock, Hainsworth and Bowman, 2013). A meta-analysis found ACT had superior outcomes when compared to CBT for depression, OCD and psychological sequelae of cancer such as distress and worry (Ruiz, 2012). ACT was also found to be more effective when compared to waiting list controls (Ruiz, 2012). Research has also indicated that ACT may be successfully utilised when working with the management of problematic behaviours in populations where psychological difficulties may arise as a result of a specific health condition. These health conditions have included epilepsy (Lundgren, Dahl, Yardi, & Melin, 2008) and diabetes (Hadlandsmyth, White, Nesin, & Greco, 2013). ACT also improved well-being and function for patients diagnosed with neurological conditions such as multiple sclerosis (Carrigan and Dysch, 2015) and acquired brain injury (Kangas and McDonald, 2011). Research with individuals who have suffered a traumatic brain injury found a reduction in psychological distress and increased psychological flexibility following an ACT intervention. This highlights its potential benefits of promoting psychological adjustment in those with

neurological conditions (Whiting, Deane, McLeod, Ciarrochi and Simpson, 2019). Pain acceptance in relation to chronic pain secondary to neurological disorders has also been investigated. A need for further research to determine the extent to which treatments that increase acceptance result in positive outcomes was identified (Kratz, Hirsh, Ehde and Jensen, 2013).

Group-based therapy

There are calls on health care providers to reduce the costs of interventions provided to individuals with long term health conditions, such as neurological conditions, whilst still delivering high standards of care (Department of Health, 2012). Therefore, the development of interventions which are considered effective, innovative and efficient are essential to reducing the economic burden of long-term health conditions (Department of Health, 2012). In order to increase the accessibility of psychological therapies, group-based interventions may be seen as an appropriate way to manage the effects of neurological conditions and their long-term consequences (Kuipers Cavaco & Quoidbach, 2014).

Group-based interventions have been shown to increase a feeling of group identity, acceptance of chronic illness and to engender peer support (Chambers, Foley, Galt, Ferguson, & Clutton, 2012) through a shared experience of a particular health condition (Stafford et al., 2013). They have also been shown to enhance feelings of hope, and personal empowerment whilst offering the opportunity to decrease isolation (Tomaka, Thompson & Palacios, 2006). Group-based psychological interventions may be both cost and time-effective for health care providers when compared to 1-1 interventions and may therefore be seen as the prudent choice (Nicholas, 2016).

Rationale for Review

The research outlined above provides evidence that interventions based on ACT and interventions delivered through group therapy are potentially effective for patients and also cost effective for services working with individuals with neurological conditions. This review was undertaken to consider the evidence base for group ACT for individuals with neurological conditions with regards to its quality and effect. Through exploration and critical appraisal, it was hoped that this would provide a comprehensive outline of the outcomes of existing research and also an up-to-date knowledge base for the effectiveness of such interventions in this population.

Systematic Review Method

Search Strategy

PsycINFO, MEDLINE and EMBASE databases were searched for published articles until the 25th February 2020. Records were searched from 1999 to the present day. This was due to the fact that Acceptance and Commitment Therapy was considered to emerge at this time. The search was restricted to English Language papers or those with an English language abstract. Due to the complex nature of neurological conditions a broad search strategy was applied. Thus, the search only used one term; ‘Acceptance and Commitment Therapy*’.

Inclusion and Exclusion Criteria

Only studies which evaluated the delivery of face to face, group based, ACT were included in the review. Interventions were only included if they aimed to target psychological difficulties in those with an acquired neurological condition. Studies which were not targeted at those effected directly by the neurological condition such as care givers were excluded. Only quantitative studies were included with qualitative studies excluded. Furthermore, studies which evaluated already reported data were also excluded. Participants from the included studies were required to be aged 18 or over.

Screening

Titles and abstracts were examined initially with the aim of removing any erroneous articles. Two reviewers then independently screened the titles, abstracts, and full text of the remaining papers. Any discrepancy was discussed until a consensus was reached between reviewers.

The full process for selecting studies is outlined in the Preferred Reporting Items for Systematic Reviews and Meta Analyses flow diagram (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009) (See figure 1).

Data Extraction

A standardised data extraction table was developed to record information relating to participants, study location, study quality, neurological condition, interventions, treatment effects, methodological details, and key findings. One reviewer extracted the data from the articles which had been considered to meet the inclusion criteria. This was reviewed independently by another researcher. Data extraction information can be found in Table 1.

Quality Assessment

In order to assess the methodological rigour of the included studies, a quality assessment tool was utilised. As the designs of the included studies were quantitative and the studies focused on outcomes of psychotherapy interventions the Psychotherapy Outcome Study Methodology Rating Form (POMRF) was chosen. It was considered essential in order to ensure a fair comparison of quality across the board. The POMRF was chosen as evidence has demonstrated it has good validity and reliability (intra-class correlation =.92) and also good internal consistency (Cronbach's α =.86) (Ost, 2008) when assessing studies with relevant methodological designs. The POMRF consists of 22 items. Quality of studies is assessed using a three-point rating scale: 0, 'poor'; 1, 'fair'; 2, 'good.' The maximum total score was 40 after removal of items 2 and 4 that relate to psychiatric diagnoses (Graham et al., 2016). A higher score on the POMRF is considered suggestive of increased methodological quality. The articles were assessed by two reviewers independently. If inconsistencies were found

between ratings, the reviewers discussed any disagreements with the aim of reaching a consensus.

Results

The results of the search are shown in Figure 1. Of the 40 papers where full-text articles were reviewed, a total of 28 articles were excluded as they did not meet the inclusion criteria.

Twelve studies were therefore considered to meet the inclusion criteria for this review.

Figure 1 PRISMA Flow Diagram of Systematic Search

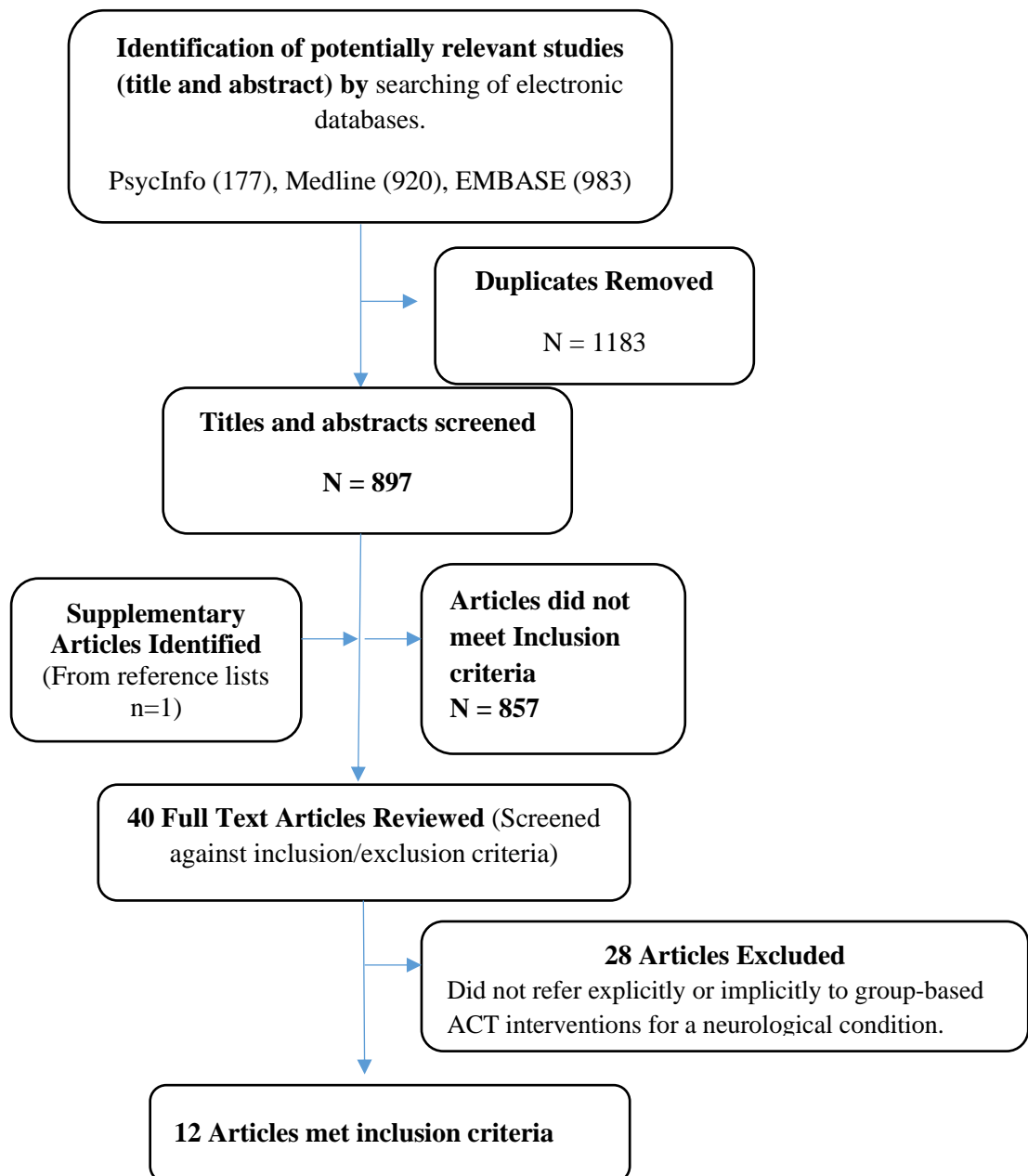


Table 1: Data Extraction table

Study, location, POMFR rating (Q)	Neurological Condition	Sample Size (Finished)	Primary target of Intervention	Group Sizes	Mean age (% Female)	Control Condition	ACT Sessions (Total hours)	Analysis Time points	Outcome Measures
Bayati et al (2017) Iran Q=7	Multiple Sclerosis	15 ACT 15 WL (unknown)	Psychological Wellbeing	15	Unknown (100%)	WL	8 sessions 2 hours (16)	Pre-Post	Psychological Wellbeing (PWB)
Carbonell – Baeza et al (2011) Spain Q=15	Fibromyalgia	41 ACT 34 TAU (33 ACT 32 TAU)	Symptomatology and Quality of Life	10-12	50 (100%)	TAU	12 sessions of Unknown duration (Unknown)	Pre-Post	Fibromyalgia Impact (FIQ), QoL (SF-36), Anxiety and depression (HADS), pain management (VPMI), self-esteem (RSES).
Luciano et al (2014) Spain Q=24	Fibromyalgia	ACT:51, RPT: 52, WL: 53 (ACT:45 RPT:44 WL: 47)	Functional Status	10-15	48.31 (96.2)	Recommended Pharmacological Treatment (RPT) or waiting list (WL)	8 sessions, 2.5hrs (20)	Pre, post, 3 & 6 month follow-up	Fibromyalgia impact (FIQ), pain catastrophizing (PCS), anxiety and depression (HADS), pain acceptance (CPAQ), pain experience

Lundgren et al, (2006) South Africa Q = 22	Drug-refractory epilepsy	ACT: 14 ST: 13 (ACT:14 ST: 13)	Improve Seizure Control and Quality of Life	13-14	40.68 (51.85)	Supportive Therapy 12 hours (ST)	2 sessions, 3 hours + 4 1:1 sessions, 1.5 hours (12)	Pre, post, 6 and 12 month follow up.	(PVAS), QoL (ED-5Q visual analog scale) Seizure frequency, seizure index, QoL (WHOQOL-BREF), life satisfaction (SWLS)
Lundgren et al, (2008) India Q = 22	Drug-refractory epilepsy	ACT:10 Yoga:8 (ACT:10 Yoga:8)	Improve Seizure Control and Quality of Life	8-10	23.85 (33.33)	Yoga 12 hours	2 sessions, 3 hours + 4 1:1 sessions, 1.5 hours (12)	Pre, post, 6 and 12 month follow up	Seizure frequency, seizure index, QoL (WHOQOL-BREF), life satisfaction (SWLS)
Majumdar et al (2019) UK Q = 23	Stroke	ACT:26 TAU:27 (ACT: 22 TAU:25)	Distress and Quality of Life	7-9	63 (40)	TAU	4 sessions, 2 hours (8)	Pre, post, 2 month follow up	Depression (PHQ-9), Anxiety (GAD-7), QoL (EQ-5D-5L), Hope (Adult hope scale), Mental well-being (Warwick and Edinburgh Mental Well-being Scale)
Nordin et al (2012) Sweden Q = 15	Multiple Sclerosis	ACT: 11, RT: 10 (ACT: 10 RT: 10)	Distress	10-11	45.75 (76.19)	Relaxation Training (RT)	5 sessions (unknown)	Pre, post, 3 month follow up	Anxiety (HADS), Depression (BDI), psychological acceptance (AAQ-II)

Pakenham et al (2017) New Zealand Q = 16	Multiple Sclerosis	ACT:38 (ACT:20)	Resilience, Quality of Life and Distress	7-12	49.3 (72.97)	No Control Condition	8 sessions, 2.5 hours (20)	Pre, post, 3 month follow up	Resilience (RS-15), Quality of Life (MSQoL-54), Distress (DASS-21), Mindfulness (MAAS), Values (Valued Living Questionnaire), Acceptance (MSAQ), Defusion (DDS)
Wicksell et al (2013) Sweden Q = 22	Fibromyalgia	ACT:23 WL:17 (ACT:19 WL:14)	Role of psychological inflexibility	6	45.1 (100)	Waiting list (WL)	12 sessions, 1.5 hours (18)	Pre, post, 3 month follow up	Disability (PDI), fibromyalgia impact (FIQ), QoL (SF-36), depression (BDI), anxiety (STAI-T), pain scale 0-10, psychological inflexibility (PIPS)
Jensen et al (2012) Sweden Q = 22	Fibromyalgia	ACT:25 WL:18 (ACT:19 WL:15)	Clinical Improvement	6	44.5 (ACT) 46.9 (Control) (100)	Waiting list (WL)	12 sessions 1.5 hours (18)	Pre, post, 3 month follow up	Patient impression of improvement (PGIC), Depression (BDI), State anxiety (STAI-S)

Mo'tamedi et al, (2012)	Chronic Headache	ACT:15 MTAU:15 (ACT:11 MTAU:15)	Pain, disability and distress	15	37.87 (MTAU) 34.18 (ACT)	Medical Treatment as Usual (MTAU)	8 sessions 1.5 hours (12)	Pre, post	Pain intensity (SF-MPQ), disability (MIDAS) anxiety (STAI-T)
Iran									
Q = 22									
Sheppard et al, (2010)	Multiple Sclerosis	ACT:15 (ACT:15)	Quality of Life and Distress	15	53.13 (80%)	No Control Condition	1 session, 5 hours	Pre, post, 3 month follow up	Depression (BDI-II), Fatigue (MFIS), Impact of Pain (PES), Health status (SF-36), Thought Suppression (WBSI), Mindfulness (MAAS), Quality of Life (QOLI)
USA									
Q = 13									

Notes: Acceptance and Action Questionnaire - II (AAQ-II); Beck Depression Inventory (BDI); Chronic Pain Acceptance Questionnaire (CPAQ); Depression, anxiety and stress scales (DASS-21) European Quality of Life- dimensions(EQ-5D); Fibromyalgia Impact Questionnaire (FIQ); Hospital Anxiety and Depression Scale (HADS); Mindful Attention Awareness Scale (MAAS); Modified Fatigue Impact Scale (MFIS); Pain Catastrophizing Scale (PCS); Pain Disability Index (PDI); Pain Effect Scale (PES); Patients' Global Impression of Change (PGIC); Psychological Inflexibility in Pain Scale (PIPS); Pain Visual Analogue Scale (PVAS); Quality of Life Inventory (QOLI); Relaxation Therapy (R-T); Recommended Pharmacological Therapy (RPT); Rosenberg self-esteem scale (RSES); Satisfaction with Life Scale (SWLS); Self-efficacy Scale (SES); Short Form (36) Health Survey (SF-36); State-Trait Anxiety Inventory (STAI); supportive therapy (ST); Vanderbilt Pain Management Inventory (VPMI); White Bear Suppression Inventory (WBSI); Waiting List (WL); World Health Organization Quality of Life (WHOQOL- BREF); EuroQol-5D (ED-5Q); Patient Health Questionnaire-9 (PHQ-9), General Anxiety Disorder – 7 (GAD-7); Shortened Resilience Scale (RS-15); Multiple Sclerosis Quality of Life - 54 (MSQOL-54); MS Acceptance Questionnaire (MSAQ); Drexel Defusion Scale (DDS); Short Form McGill Pain Questionnaire (SF-MPQ); Migraine Disability Assessment Test (MIDAS)

Table 2: Study Outcome Table

Study	Control-Condition	Outcome (Measures)	Improvement post-intervention	Improvement at follow-up
Lundgren et al (2006)	Supportive therapy	QoL (WHOQOL-BREF)	Non-Significant (d=0.62)	Non-Significant (d=0.37)
		Life Satisfaction (SWLS)	Significant (d=0.73)	Significant (d=1.72)
		Seizure Intensity (SI)	Significant (d = 1.21)	Significant (d = 1.45)
Lundgren et al (2008)	Yoga	QoL (WHOQOL-BREF)	Significant (d=0.81)	Improvement in favour of yoga (d=-0.38)
		Life Satisfaction (SWLS)	Non-Significant (d = 0.55)	Non-significant (d = 0.12)
		Seizure Intensity (SI)	Significant (d = 1.3)	Significant (d = 1.14)
Nordin & Rorsman (2012)	Relaxation Training	Distress (HADS-D)	Significant in favour of RT	Non- significant
		Distress (HADS-A)	Non-significant	Non-significant
		Distress (BDI) Psychological Flexibility (AAQ)	Non-significant Significant	Non-significant Non-significant
Sheppard et al (2010)	-	Distress (BDI – II)	Significant	-
		QoL (SF-36 PCS)	Non-significant	-
		QoL (SF-36 MCS)	Non-significant	-
		QoL (QOLI)	Significant	-
		Pain (PES)	Significant	-
		Thought Suppression (WBSI)	Significant	-
		Mindfulness (MAAS)	Significant	-
Fatigue (MFIS)	Non-significant	-		
Luciano et al (2014)	RPT WL	Fibromyalgia impact (FIQ)	RPT: Significant in favour of ACT (d=1.43)	RPT: Significant in favour of ACT (d=1.43)
			WL: Significant in favour of ACT (d=2.35)	WL: Significant in favour of ACT (d=2.11)

		Pain catastrophizing (PCS)	RPT: Significant (d=0.76) WL: Significant (d=0.89)	RPT: Significant WL: Significant
		Anxiety (HADS-A)	RPT: Significant (d=0.36) WL: Significant (d=0.77)	RPT: Significant WL: Significant
		pain acceptance (CPAQ)	RPT: Significant (d=1.05) WL: Significant (d=1.01)	RPT: Significant (d=1.21) WL: Significant (1.14)
		pain experience (PVAS)	RPT: Significant (d=0.62) WL: Significant (d=0.47)	RPT: Significant (d=0.93) WL: Significant (0.80)
		QoL (ED-5Q visual analog scale)	RPT: Significant (d=0.85) WL: Significant (d=0.66)	RPT: Significant (d=1.06) WL: Significant (0.84)
Carbonell – Baeza et al (2011)	TAU	Fibromyalgia Impact (FIQ)	Significant	-
		QoL (SF-36)	Significant (domains of physical role, bodily pain, vitality, social functioning) Non-Significant (domains of physical function, general health, emotional role, mental health)	-
		Anxiety and depression (HADS)	Non-Significant	-
		Pain management (VPMI)	Non-Significant	-
		Self-esteem (RSES)	Non-Significant	-
Mo'tamedi et al, (2012)	MTAU	Pain intensity (SF-MPQ),	Non-Significant	Not reported
		Disability (MIDAS)	Significant	Not reported
		Anxiety (STAI-T)	Significant	Not reported

Jensen et al (2012)	WL	Patient Impression of Improvement (PGIC)	Significant	Not reported
		Depression (BDI)	Significant	Not reported
		State Anxiety (STAI-S)	Significant	Not reported
Wicksell et al (2013)	WL	Disability (PDI)	Significant (d=0.75)	Significant (d=0.73)
		Fibromyalgia Impact (FIQ)	Significant (d=0.41)	Significant (d=0.66)
		QoL (SF-36)	Mental Health QoL: Significant	Mental Health QoL: Significant
			Physical Health QoL: Non-significant	Physical Health QoL: Non-significant
		Depression (BDI)	Significant	Significant
		Anxiety (STAI-T)	Significant	Significant
Majumdar et al (2019)	TAU	Psychological inflexibility (PIPS)	Significant	Significant
		Depression (PHQ-9)	Significant	Significant
		Anxiety (GAD-7)	Non-significant	Non-significant
		QoL (EQ-5D-5L)	Non-significant	Non-significant
		Hope (Adult hope scale)	Significant	Significant
		Mental well-being (Warwick and Edinburgh Mental Well-being Scale)	Non-Significant	Non-significant
Bayati et al (2017)	WL	Psychological Wellbeing (PWB)	Significant	Significant
Pakenham et al (2017)	-	Resilience (RS-15)	Non-Significant	Significant
		QoL (MSQoL-54)	Significant	Significant
		Distress (DASS-21)	Depression: Significant	Depression: Significant
			Anxiety: Non-Significant	Anxiety: Non-Significant
		Stress: Non-Significant	Stress: Significant	

Mindfulness (MAAS)	Non-Significant	Non-Significant
Values (Valued Living Questionnaire)	Significant	Significant
Acceptance (MSAQ)	Significant	Significant
Defusion (DDS)	Significant	Significant

Notes: Acceptance and Action Questionnaire - II (AAQ-II); Beck Depression Inventory (BDI); Chronic Pain Acceptance Questionnaire (CPAQ); Depression, anxiety and stress scales (DASS-21) European Quality of Life- dimensions(EQ-5D); Functional magnetic resonance imaging assessments (fMRI assessments); Fibromyalgia Impact Questionnaire (FIQ); Hospital Anxiety and Depression Scale (HADS); Mindful Attention Awareness Scale (MAAS); Modified Fatigue Impact Scale (MFIS); Pain Catastrophizing Scale (PCS); Pain Disability Index (PDI); Pain Effect Scale (PES); Patients' Global Impression of Change (PGIC); Psychological Inflexibility in Pain Scale (PIPS); Pain Visual Analogue Scale (PVAS); Quality of Life Inventory (QOLI); Relaxation Therapy (R-T); Recommended Pharmacological Therapy (RPT); Rosenberg self-esteem scale (RSES); Satisfaction with Life Scale (SWLS); Self-efficacy Scale (SES); Short Form (36) Health Survey (SF-36); State-Trait Anxiety Inventory (STAI); supportive therapy (ST); Vanderbilt Pain Management Inventory (VPMI); White Bear Suppression Inventory (WBSI); Waiting List (WL); World Health Organization Quality of Life (WHOQOL-BREF); EuroQol-5D (ED-5Q); Patient Health Questionnaire-9 (PHQ-9), General Anxiety Disorder – 7 (GAD-7); Shortened Resilience Scale (RS-15); Multiple Sclerosis Quality of Life - 54 (MSQOL-54); MS Acceptance Questionnaire (MSAQ); Drexel Defusion Scale (DDS); Short Form McGill Pain Questionnaire (SF-MPQ); Migraine Disability Assessment Test (MIDAS)

Description of the included studies

Of the 12 included studies, 8 were randomised controlled trials (RCT) (Wicksell et al., 2013; Luciano et al., 2014; Carbonell-Baeza et al., 2011; Mo'tamedi et al., 2012; Lundgren et al., 2006; Lundgren et al., 2008; Jensen et al., 2012; Nordin and Rorsman., 2012); one used a randomised design with repeated measures (Majumdar et al., 2019); one used a quasi-experimental design with pre-post measures (Bayati et al., 2017) and two used pre-post designs with no control group (Sheppard, Forsyth, Hickling, and Bianchi, 2010; Pakenham, Mawdlsey, Brown and Burton, 2017.) Six neurological conditions were represented: MS, Epilepsy, Fibromyalgia, Stroke and Chronic Headache. Sample sizes ranged from 18 to 156 (mean = 34.1) with 546 participants in total. They were recruited from a range of settings including condition specific support networks, primary care clinics, general medical clinics, and condition specific clinics. The average age of participant was 45 years with the majority of participants being female. Studies were undertaken in a number of countries: Spain (N=2), Sweden (N=3), Iran (N=2), USA (N=1), India (N=1), South Africa (N=1), UK (N=1) and New Zealand (N=1).

The included studies compared ACT to a waitlist (WL) control group (Wicksell et al, 2013; Jensen et al, 2012; Bayati et al., 2017), treatment as usual (TAU) (Carbonella-Baeza et al, 2011; Majumdar et al; Mo'tamedi et al, 2012), and other active treatments (including, yoga, relaxation training, supportive therapy) (Lundgren et al., 2006; Lundgren et al., 2008; Nordin & Rorsman, 2012). One study had two control groups (WL and recommended pharmacological treatment (RPT)) (Luciano et al, 2014). Two studies had no control group and used pre-post designs (Pakenham et al, 2017; Sheppard et al, 2010). Low drop-out rates

were reported for the majority of studies with 86% of participants (n=471) on average completing the intervention.

Study Quality

Seven of the twelve included studies achieved more than half of the total number of points available on the POMRF. Scores ranged from 7- 24 with a mean score of 18.08 (5.24).

Luciano et al (2014) was the highest rated paper (N=24) with the lowest rated study being Bayati et al (2017) (N=7). A number of strengths were shown to be consistent across the majority of studies. All twelve studies were considered to provide a 'fair' description of the included sample, with two studies (Majumdar et al., 2019; Jensen et al., 2012) providing a 'good' description of the included sample. These descriptions included inclusion/exclusion criteria, demographics, and the prevalence of comorbid disorders. All studies were considered to be 'fair' in the representativeness of the included sample as exclusions were made for those with other major disorders.

Seven studies were considered as having used outcome measures with good psychometric properties (Lundgren et al., 2006; Lundgren et al., 2008; Nordin et al., 2012; Wicksell et al., 2013; Majumdar et al., 2019; Mo'tamedi et al., 2012; Sheppard et al., 2010). Specificity of outcome measures for symptom clusters was also rated as good in six studies (Luciano et al., 2014; Wicksell et al., 2013; Majumdar et al., 2019; Jensen et al., 2012; Mo'tamedi et al., 2012; Sheppard et al., 2010). The use of blind assessors, independent researchers with no insight or involvement in the treatment intervention, to carry out assessments was only used in three studies (Nordin et al., 2012; Luciano et al., 2014; Jensen et al., 2012). Furthermore, no studies reported assessor training.

Nine studies were assessed as having at least 'fair' methods of assigning participants to treatment conditions. Three studies were classed as having 'biased assignment' due to the method of allocation (Pakenham et al., 2017; Carbonell-Baeza., 2011) or due to only having one group (Sheppard et al., 2010). Eight of the twelve included studies were RCT's indicating a score of 'fair' or above for quality of design. However, power analysis made prior to the initiation of the study to inform sample size was used in just two papers (Luciano et al., 2014; Majumdar et al., 2019).

The majority of studies (N=7) carried out follow up analysis at three- or six-month time points. Of the remaining studies, two carried out follow-up analysis at six and twelve months (Lundgren et al., 2006; Lundgren et al., 2008), two studies carried out pre-post analysis (Mo'tamedi et al., 2012; Carbonell-Baeza et al., 2011) whilst one study used pre assessment measures and 3-month follow-up with no immediate post-treatment measure (Sheppard et al., 2010). The majority (n=9) of studies were assessed as providing at least a 'fair' description of the intervention with five studies (Lundgren et al., 2006; Lundgren et al., 2008; Wicksell et al., 2013; Majumdar et al., 2019; Mo'Tamedi et al., 2012) being rated as 'good'. These studies outlined treatments designed for the specific disorder with a detailed treatment manual and/or a description sufficient to make the intervention replicable.

Furthermore, the majority of studies (N=9) reported having at least one therapist, with all but one study (Bayati et al., 2017) reporting therapists with at least some clinical experience of the treatment.

Interestingly, treatment adherence and therapist competence, items 16 and 17 on the POMRF respectively, were found to be rated identically for all studies. Two studies were rated as

‘good’ (Pakenham et al., 2017; Mo’tamedi et al., 2012) and five as ‘fair’ (Lundgren et al., 2006; Lundgren et al., 2006; Wicksell et al., 2013; Luciano et al., 2014; Jensen et al., 2012). The remaining papers were rated as ‘poor.’ No studies were shown to completely control for con-comitant treatments with six studies being rated as ‘fair’ on this domain and six as ‘poor.’

With regards to statistical methods and results the majority of studies were deemed to at least provide a ‘fair’ description. One study was the exception, Nordin and Rorsman, 2012, being rated as inadequate in this area. Consideration of clinical significance was apparent in all but one study (Bayati et al., 2017). However, Jacobsen’s criteria for clinical significance was only outlined in one (Luciano et al., 2014). Six studies discussed attrition rates with intent to treat or dropout analysis performed (Majumdar et al., 2018; Pakenham et al., 2017; Luciano et al., 2014; Carbonell-Baeza et al., 2011; Mo’tamedi et al., 2012; Sheppard et al., 2010). Control interventions in RCT’s were also found to be differ somewhat (N=6) or markedly (N=5) to the duration of the ACT intervention.

ACT Intervention

Of the twelve included studies, the majority (N=11) delivered ACT based group interventions consisting of between 2 – 12 sessions, with the average number of sessions being seven. Sessions lasted between 1.5 – 3 hours per session, totalling on average 15 hours. Two studies (Nordin et al, 2012, Carbonella-Baeza et al, 2011) did not report session length. The remaining study used a one-off ACT based workshop lasting five hours (Sheppard et al, 2010). The number of people included per group ranged between six to fifteen. Two studies (Lundgren et al., 2006; Lundgren et al., 2008) included 1:1 as well as group sessions as part

of the ACT intervention. The way in which ACT was delivered also varied with regards to session content. For example, some studies discussed delivering education around the core principles of ACT concurrently whereas others set out treatment objectives for each session (Nordin and Rorsman., 2012; Wicksell et al., 2013). The use of established ACT protocols or treatment manuals for ACT were used to guide intervention in some studies (Carbonell-Baeza et al., 2011; Luciano et al., 2014; Nordin and Rorsman., 2012;Wicksell et al., 2013; Jensen et al., 2012).

Applications and their emerging effect

The ACT interventions described within the included studies outlined a number of outcomes as their primary and secondary targets. The effectiveness of the interventions in relation to the main outcomes are analysed below. Results in terms of significance are shown in Table 2.

Quality of Life

Quality of life was assessed in eight studies (Luciano et al., 2014; Lundgren et al., 2006; Lundgren et al., 2008; Sheppard et al., 2010; Wicksell et al., 2013; Pakenham et al., 2017; Majumdar et al., 2018; Carbonell-Baeza et al., 2011), using a number of different measurement tools (QOLI, SF-36, ED-5Q, WH0-QOL, MSQoL-54). Group ACT was shown to be more effective in increasing health related QoL for fibromyalgia patients ($p > 0.1$) than RPT and WL post treatment and at follow up ($d = 0.66 - 1.06$) in a study rated as high-quality (Luciano et al., 2014). Another high-quality study (Wicksell et al., 2013) found significant improvements in mental health QoL in an ACT group compared to WL post-intervention ($d = 0.84$) and at follow up ($d = 1.06$). A significant increase in physical health QoL and mental

health QoL from pre-to post intervention and maintained at follow up ($p > .001$; $p = 0.006$) was found in a group ACT intervention (Pakenham et al, 2017). A significant interaction between groups over time was also found in Carbonell-Baeza et al (2011) on the QoL measure. A modest impact on QoL ($d = 0.24$) was also found in a brief (one session) intervention (Sheppard et al., 2010).

When compared with supportive therapy, ACT was found to produce a significant change on the Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen and Griffin, 1985) in patients with drug-refractory epilepsy pre, post and at follow-up (Lundgren et al, 2006). However, in the same study, significant group differences in favour of ACT were only found on the WHOQOL-BREF (Amir et al., 2003) at one-year follow-up ($d = 1.78$). In contrast, QoL was shown to be improved by ACT in comparison to Yoga on the WHOQOL-BREF in Lundgren et al (2008) but yoga was found to be superior to ACT on the SWLS. QoL was not found to be improved in Majumdar et al., (2018) on the EQ-5D-5L. There does not appear to be a clear explanation as to why QoL was not improved in all studies however those with longer interventions appeared more likely to find significant changes in QoL between groups (Luciano et al., 2014; Wicksell et al., 2013; Pakenham et al., 2017; Carbonell-Baeza et al., 2011).

Direct symptom control

Two studies which used the same ACT intervention (Lundgren et al., 2006; Lundgren et al., 2008) in patients with epilepsy assessed the impact of ACT for controlling its symptoms. The intervention included sessions on improving seizure control which was found to be significantly improved in the ACT group in comparison to supported therapy ($d = 1.4$)

(Lundgren et al., 2006) and yoga ($d=1.45$) (Lundgren et al., 2008). However, these findings should be considered cautiously as both studies were carried out by the same research group and may also be deemed to be underpowered due to small sample size ($n= 27$ and 28 , respectively).

Fibromyalgia Impact

Three studies used the FIQ to assess the effect of ACT on symptoms of Fibromyalgia (Luciano et al, 2014; Wicksell et al, 2013; Carbonell-Baeza, 2011). In a high-quality study, group ACT was found to be more effective ($p<0.1$) than RPT and WL in the short term (post-treatment) and the long-term (follow-up) in reducing functional impairment (Luciano et al, 2014). Another high-quality study found a significant interaction for functional impairment in favour of ACT (Wicksell et al, 2013) with medium effect sizes post treatment ($d=0.41$) and at follow-up ($d=0.66$).

Distress

A number of studies outlined ‘distress’ as the primary target of intervention. For the purpose of this review distress has been defined as reported psychological distress on standardised psychological outcome measures that assess symptoms of emotional/psychological difficulties.’ All studies used at least one psychological outcome measure. The majority ($N=8$) included a measure of anxiety (HADS, GAD-7, STAI-T) separate to or alongside a measure of depression ($N=8$) (HADS or BDI-II). Of the twelve studies included in this review, six assessed the impact ACT interventions had on reducing distress in those with Neurological conditions as a primary target of intervention (Sheppard et al, 2010;

Mo'Tamedi et al, 2012; Pakenham et al, 2017; Nordin et al, 2012; Majumdar et al.,;Bayati et al, 2017). These findings will be discussed more specifically in relation to the individual outcomes of depression and anxiety.

Anxiety

In the majority of studies comparing ACT to WL or TAU, anxiety was found to be reduced by ACT intervention (Luciano et al., 2014; Mo'tamedi et al., 2012; Wicksell et al., 2013; Carbonella-Baeza, 2011; Jensen et al, 2012). In those studies which reported effect sizes, they ranged from medium ($d = 0.51 - 0.77$) (Luciano et al., 2014; Wicksell et al., 2013) to large ($d = 2.54$) (Mo'tamedi et al., 2012). Those studies which carried out follow up studies found improvements were sustained at three-months ($d = 0.55$ and 0.74) (Wicksell et al., 2013) and six-months ($d = 0.85$) (Luciano et al., 2014). Majumdar et al (2019) however, found no significant effect of an ACT intervention when compared with TAU in a stroke population.

Studies which compared ACT to active treatment (Luciano et al., 2014; Nordin and Rorsman, 2012) found mixed results for the effect of ACT. A significant effect ($d = 0.36$) was found for the reduction of anxiety symptoms produced by ACT in comparison to RPT. This was maintained at six-month follow-up ($d = 0.39$) (Luciano et al., 2014). However, Nordin and Rorsman (2012) in a study rated as low quality, found relaxation was more effective in reducing the symptoms of anxiety when compared to ACT. This was maintained at three-month follow up.

Depression

Eight studies reported on the impact of ACT interventions on depression (Majumdar et al., 2019; Luciano et al., 2014; Wicksell et al., 2013; Carbonella-Baeza 2011; Jensen et al, 2012; Nordin and Rorsman, 2012; Pakenham et al, 2017; Sheppard et al, 2010). Significant improvements in reported depressive symptoms were found post-intervention in studies with TAU or WL controls as a result of ACT interventions (Majumdar et al., 2019; Luciano et al., 2014; Wicksell et al., 2013; Carbonella-Baeza, 2011; Jensen et al, 2012). In those studies which reported effect size, they ranged from small to large ($d=0.46 - 1.01$) (Wicksell et al., 2013, Majumdar et al, 2019; Luciano et al., 2014) and were found to be maintained at follow up, two, three or six-months later ($d = 0.15 - 0.88$) (Majumdar et al, 2019; Luciano et al., 2014; Wicksell et al., 2013).

In contrast, those studies that compared ACT to active treatment reported mixed outcomes (Luciano et al., 2014; Nordin and Rorsman., 2012). Luciano et al (2014) reported that ACT was significantly more effective in reducing depressive symptoms than RPT both post-treatment ($d = 0.43$) and at six-month follow up ($d=0.37$). However, relaxation training was found to be more successful in improving depression in a sample of MS patients when compared to ACT at post-treatment. (Nordin and Rorsman, 2012). But this effect was not maintained at three-month follow up.

Two studies (Pakenham et al, 2017; Sheppard et al, 2010) without a control condition reported significant improvements in depression with these improvements maintained at three-month follow up.

In summary, with regards to measurements of distress, with one exception (Nordin & Rorsman, 2012), improvements were found to be related to ACT interventions. It is of note that there is ambiguity around whether ACT is significantly more effective than other active

treatments or TAU or whether improvements are the result of placebo effects or other factors since none of the studies that found effects included attention control or placebo control conditions.

Measuring core processes of ACT

There are a number of approaches to assessing the core processes of ACT. Assessing these six processes has been seen as important (Hayes et al, 2004). Within the included studies a number of self-report measures were used (PIPS, AAQ-II, MAAS, WBSI) as there is no one measure that is able to assess all six core processes. Using the AAQ-II, group ACT was found to increase acceptance of unwanted feelings and thoughts at pre, post and follow-up time points in a sample of multiple-sclerosis patients (Nordin and Rorsman, 2012). This lower-quality study did find however, that relaxation training also produced a significant improvement post-intervention so this finding should be taken with caution. A higher quality study found pain acceptance was found to be significantly improved post-treatment ($d=1.01$) and at six-month follow up ($d=1.21$) when compared to RPT and WL groups (Luciano et al., 2014). Psychological flexibility in relation to chronic pain was also found to be increased in an ACT group compared to control with a large effect size ($d=1.05$) post-treatment and a medium effect ($d=0.71$) at follow-up (Wicksell et al, 2013). Wicksell et al (2013) also found that reductions in psychological inflexibility mediated improvements in fibromyalgia impact, distress, and pain disability in comparison to WL controls. A reduction in thought suppression was found in a study with no control group on the White Bear Suppression Inventory (WBSI) (Sheppard et al, 2010). In another study with no control condition, significant improvements in the core ACT processes of defusion and acceptance were found in a high-quality study of MS patients (Pakenham et al, 2017). However, no improvement on

the Mindful Attention Awareness Scale (MAAS) was found following the ACT intervention. Two studies examining the impact of ACT interventions in Epilepsy found that reductions in seizure frequency and increases in psychological well-being were somewhat mediated by acceptance of health condition, persistence and values (Lundgren et al., 2006; Lundgren et al., 2008). This evidence appears to suggest that psychological flexibility may be more improved through ACT intervention when compared to TAU. However, other active treatments such as relaxation training also appear to be effective. Also, as two of the included studies had no control condition this must also be considered when drawing comparisons on the effectiveness of ACT interventions.

Disability

Three studies assessed disability (Luciano et al., 2014; Mo'tamedi et al., 2012; Wicksell et al., 2013). Within fibromyalgia (Wicksell et al, 2013) and chronic headache (Mo'tamedi., 2012) samples, ACT showed significant improvement in disability compared to TAU and WL controls with medium to large effect size ($d = 0.75 - 0.93$). This was maintained at 6-month follow-up within the fibromyalgia sample ($d=0.73$) (Wicksell et al, 2013). Small to large effect sizes on measures of disability post intervention were also found in two high quality studies comparing ACT to RPT and WL controls ($d=0.41 - 2.35$) (Luciano et al., 2014; Wicksell et al., 2013).

Pain

A number of studies also used behavioural outcome measures to assess the impact of pain on those receiving the intervention (Luciano et al., 2014; Wicksell et al., 2013; Sheppard et al.,

2010; Jensen et al., 2012; Mo'tamedi, 2012). The impact of pain on mood was found to significantly decrease post ACT intervention in one study (Sheppard et al., 2010) with pain disability found to be reduced with medium to large effect in two studies (Luciano et al., 2014; Wicksell et al., 2013). ACT was also found to reduce levels of pain catastrophizing over time (Luciano et al., 2014) and pain rating (Jensen et al., 2012). A significant increase in pain acceptance was also found in one study (Luciano et al., 2014). However, this was found in both ACT and RPT groups. No significant change in pain intensity was found in one high quality study (Wicksell et al., 2013). The sensory aspect of pain was also found not to be reduced by ACT in another study (Mo'tamedi et al., 2012). These findings appear to be in line with ACT theory which suggests that symptoms such as pain cannot be changed and therefore it is the acceptance of pain and reduction of self-defeating reactions that is the aim of ACT based interventions. This is also further supported by the fact that QoL was found to be improved in the majority of studies.

Discussion

Summary of the use of group-based ACT in Neurological Conditions

This paper has outlined that ACT has been applied in group settings with a variety of neurological conditions; Stroke (Majumdar et al., 2019), Fibromyalgia (Carbonella-Baeza et al., 2011; Luciano et al., 2014; Wicksell et al., 2013; Jensen et al., 2012), Multiple Sclerosis (Bayati et al., 2017; Nordin and Rorsman., 2012; Sheppard et al., 2010; Pakenham., 2017), Epilepsy (Lundgren et al., 2006; Lundgren et al., 2008) and chronic headache (Mo'Tamedi., 2012). Group ACT has been shown to produce change in a number of areas such as improving Quality of Life (Lundgren et al., 2006; Lundgren et al., 2008), reducing symptoms of distress such as depression (Majumdar et al., 2019; Luciano et al., 2014; Wicksell et al., 2013; Carbonella-Baeza, 2011; Jensen et al, 2012; Pakenham et al, 2017; Sheppard et al, 2010) and anxiety (Luciano et al., 2014; Mo'tamedi et al., 2012; Wicksell et al., 2013; Carbonella-Baeza, 2011; Jensen et al, 2012) and management of symptom control (Lundgren et al., 2006; Lundgren et al., 2008). ACT intervention was also found to reduce the impact of pain on mood (Sheppard et al., 2010), ratings of pain disability (Luciano et al., 2014; Wicksell et al., 2013), pain catastrophising (Luciano et al., 2014), pain rating (Jensen et al., 2012) and pain acceptance (Luciano et al., 2014). However, pain intensity (Wicksell et al., 2013) and the sensory aspect of pain (Mo'tamedi et al., 2012) were not found to be significantly impacted by ACT intervention (Wicksell et al., 2013).

Findings in relation to the existing evidence base

The evidence outlined in this review indicates that ACT interventions delivered in a group format appear to be more effective than TAU/WL controls in reducing the impact of distress and disability, improving QoL and direct symptom control.

The findings of this review indicate that group-based ACT interventions can be effective at reducing anxiety (Luciano et al., 2014; Mo'tamedi et al., 2012; Wicksell et al., 2013; Carbonella-Baeza 2011; Jensen et al., 2012) and depression (Majumdar et al., 2019; Luciano et al., 2014; Wicksell et al., 2013; Carbonella-Baeza 2011; Jensen et al, 2012; Nordin and Rorsman, 2012; Pakenham et al, 2017; Sheppard et al, 2010) in those with a variety of neurological conditions. Improvements were largely maintained at follow-up which offers encouragement to the impact that ACT interventions can make in the long term. It is, however, of note that there were varied results for ACT in comparison to active treatments. ACT was found to significantly reduce symptoms of anxiety and depression when compared to RPT (Luciano et al., 2014). However, when compared to relaxation, ACT was found to be less effective at reducing the symptoms of anxiety and depression (Nordin et al., 2012). This therefore indicates a need more directly to assess the impact of ACT interventions relative to other active treatments in order to understand the reasons for the improvements and why it is more effective than some and not others. There remains an ambiguity around whether ACT is significantly more effective than other active treatments or TAU, or if such improvements are the result of placebo effects, non-specific therapy factors or regression to the mean in groups selected for high symptom levels. Graham et al (2016) made similar conclusions in a review of ACT in long-term health conditions. It would also be beneficial to explore if such effects are found for all health conditions, or if particular client groups respond better to the principles of ACT. As ACT is a transdiagnostic approach it is believed that it's principles should encompass various health conditions. However, it is worth considering if interventions need to be more specific to the neurological condition that the intervention is targeting (e.g. by providing condition-specific examples and exercises). Nonetheless, the results of the current review generally support previous evidence that ACT was as effective as other psychological interventions such as CBT for anxiety (Swain, Hancock, Hainsworth and

Bowman, 2013) and more effective when compared to waiting list controls in those with depression, OCD and psychological sequelae of cancer such as distress and worry (Ruiz, 2012). It also supports previous research which suggested that ACT when applied in physical health settings can demonstrate positive effects with regards to quality of life, reduction of psychological distress and self-management of disease (Graham, et al 2016).

There were, however, no differences found between ACT and TAU in subjective measures of pain intensity and the sensory aspect of pain which indicates that there was a change in the way people experienced their difficulties rather than the difficulty itself decreasing. Such findings appear to be in line with the aims of ACT whereby individuals are encouraged to learn to notice and accept difficult experiences without seeking to change them (Hayes, Levin, Plumb-Villardaga, Villatte, and Pistorello, 2013). The lack of difference in subjective pain ratings between ACT and TAU groups indicates more research is needed to discover which elements of the intervention in particular caused the improvement in other areas such as measurements of distress and QoL. Other reviews have found similar outcomes for pain intensity and the impact of ACT interventions. Veehof et al., (2016) put forward that, as the primary aims of ACT are not the reduction of pain or pain control, then large effects on experience of pain would not be expected. This is in line with the findings of the current review.

The majority of studies included in this review cited the existence of a co-morbid mental health condition as an exclusion-criteria for participation. For example, dementia (Luciano et al., 2014; Lundgren et al., 2006; Lundgren et al., 2008), substance misuse (Luciano et al., 2014; Nordin and Rorsman., 2012), severe depression and psychotic symptoms (Jensen et al.,

2012; Carbonell-Baeza et al., 2011; Luciano et al., 2014; Wicksell et al., 2013; Nordin and Rorsman., 2012) were all excluded. This is interesting given that around a quarter of those with a long-term health condition such as a neurological disorder have also been found to experience comorbid mental health conditions (Department of Health, 2009). Evidence has also indicated that depression rates in those with conditions such as stroke, multiple sclerosis and epilepsy range from around 20-50% (Kanner, 2005). The aim of such exclusions is to ensure the internal validity of the study so the results may be considered reliable. However, in doing so the results may then be considered to not be externally valid and generalisable as they exclude much of the clinical population with the particular condition. Thus, highlighting a weakness of research of this kind.

A QoL of life measure was also used in the majority of studies to assess the impact of ACT interventions on this domain. Health-related QoL was found to be increased by an ACT intervention in patients with fibromyalgia (Luciano et al., 2014) with mental health QoL also found to be improved by ACT in another study (Wicksell et al., 2013). This is encouraging as those with neurological conditions have been found to have the lowest health related quality of life of any long-term health condition (NHS England, 2019). Furthermore, poor quality of life can also be predicted by the presence of depression in these groups and can impact on successful treatment and recovery (Kanner, 2005). The evidence highlighted in the current review demonstrated that, despite there being post-treatment improvement in QoL in a number of studies, it is not clear if ACT is superior to TAU or other active treatments. Thus, there is an inconsistent evidence base for the effectiveness of group-based ACT interventions in improving QoL for those with neurological conditions. Future research is needed to further investigate such interventions and the factors which may impact QoL.

Many researchers (Graham et al., 2015; Hadlandsmyth et al., 2013) and practitioners (Thewes et al., 2014) have highlighted the benefits of ACT for those with long-term health conditions such as the neurological conditions included in this study. The fact that a range of conditions was included appears to support the flexibility and utility of the ACT model. However, the number of neurological conditions that exist is a far greater number than those included in this study thus highlighting a difficulty in generalising its results.

Specific Implications for Theory and Clinical Practice

In comparison to other more established therapies, such as CBT, ACT may still be considered as a relatively new therapeutic approach. Further research is needed in order to broaden its evidence base for use within clinical populations. Despite this, the current systematic review has highlighted that group-based ACT is effective for those with a number of neurological conditions with encouraging findings outlining the potential of group-based ACT as a low-intensity intervention in healthcare settings. Such interventions have the potential for wide-spread use as their cost-effective and time limited nature fit with government priorities of increasing access to evidence-based psychological therapies in line with national and international recommendations (Kuipers Cavaco and Quoidbach, 2014; National Collaborating Centre for Mental Health, 2010). Group-based interventions based on other theories such as CBT and Dialectical Behavioural Therapy (DBT) are already widely used within health care settings. Such interventions generally have diagnosis-based content specifically focusing on topics such as 'anxiety management' or 'coping skills.' Skills and strategies are taught based on the presenting problem or diagnosis, meaning services require staff to be trained in multiple approaches. Furthermore, multiple groups need to be run which impacts on staff time and expense. In contrast, due to the transdiagnostic nature of ACT, similar information and strategies for all presenting problems can be incorporated into one group, meaning fewer groups would need to be run. This would benefit services in terms of cost and time and is also in line with prudent healthcare. It is hoped that the outcomes of this review have provided evidence to indicate that group-based ACT can

be a cost-effective, low-intensity and accessible psychological intervention. It is also hoped that the review will both increase current knowledge and encourage further research in the area of ACT and its utility in a clinical health population.

Implications of Quality Assessment for interpretation of results

The current systematic review used the POMRF to assess the quality of included studies. Studies' quality was rated as 'good', 'fair' or 'poor'. This tool was chosen as it fits with the methodology of the review. Studies were assessed for quality by a second independent rater. While historically it has been suggested that quality should be assessed under blind conditions to reduce selection bias (Chalmers et al., 1981), there is a lack of empirical evidence to support this practice (Irwig et al., 1994; Fisher et al., 1994). Due to this reason and in addition to blinding being a time-consuming process which is considered to be unlikely to alter the results of the review (Berlin, 1997) quality assessment in the current review was not conducted under blind conditions. It is also worth considering that the use of a quality assessment tool such as the POMRF has been called in to question previously due to the fact that outcomes are largely subjective dependent on the individual using the tool. As such no one bias domain is more important than another, nor are the number of domains met proportional to the overall quality rating. Instead the qualitative interpretation of the bias in the study influenced the overall interpretation.

A number of studies included within this review were considered to be low quality. This was defined as a score less than 20 in line with a similar review paper using the same quality appraisal tool (Graham et al., 2016). Scores on sections of the tool which addressed adherence to the ACT model were particularly low. The majority of the studies scored poorly on their use of replicable treatment programs, treatment adherence checks and therapist

competence checks. It is therefore difficult to ascertain whether comparable treatments were offered to participants within the studies. However, as stated by Swain et al (2013) in a similar review of ACT for anxiety, the quality appraisal of methodological rigour of such studies using the POMRF is based on the published detail. Given that many publications have strict word counts it may be that the study was carried out with the highest methodological rigour. However, this level of detail may not be contained within the write up, thus attracting a low-quality score.

Strengths and Limitations

The focus of the current paper was to consider the existing evidence around study quality and effect of ACT when delivered in a group format to those with a neurological condition. To the author's knowledge, this is the first systematic review of group-based ACT for adults which is specifically focused on neurological conditions. As all interventions were delivered through the same modality it allowed for easier comparison between studies. However, despite encouraging results for the impact of group-based ACT in this population, as the review covered five different neurological conditions (Stroke; MS; Epilepsy; Chronic Headache; Fibromyalgia) it is impossible to make generalised statements regarding its applicability to other neurological conditions. Furthermore, many of the studies utilised different outcome measures for key outcomes such as depression and anxiety thus it was not possible to carry out a meta-analysis. A meta-analysis would be useful as the evidence base increases in order to further explore the specific components of interventions which are of most benefit to those who use them. The limitation of a lack of the ability to meta-analyse

findings also extends to the fact that the review's search strategy may have introduced a systematic bias as unpublished studies were not searched.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to guide and structure the current literature search. This was to ensure it was conducted in a systematic and transparent manner (Moher, Liberati, Tetzlaff and Altman 2009). The search strategy used was broad due to the high number of neurological conditions in existence. It was hoped such a strategy would enable a thorough search of all potential studies. Each study was assessed for quality using the POMRF. Quality was assessed by two researchers and data extraction was also cross-checked by a second researcher to ensure consistency. All of the included studies involved Group Act interventions in neurological conditions indicating that the inclusion criteria appeared to be fit for purpose. Articles published in a language other than English were however excluded from this study. There may be other relevant research that was not included which is a limitation of the current review. It is also of note that self-selection with regards to sampling may occur in this type of research as it has been argued that certain participants prefer to attend group-based interventions thus potentially impacting on outcomes of research (Wylde et al., 2014.)

The studies included within this review use a wide range of procedures and conditions meaning it is difficult to draw firm conclusions regarding the effectiveness of group-based ACT for neurological conditions. However, early stage systematic reviews, such as this, are

important to identify gaps in the knowledge base which can in turn promote further research. Many long-term neurological conditions share a number of features such as executive dysfunction and functional limitations. They also share psychological difficulties such as changes in self-concept and may also display emotional distress in a number of similar ways. The fact that a range of conditions was included appears to support the flexibility and utility of the ACT model and its transdiagnostic nature. However, the number of neurological conditions that exist is a far greater number than those included in this study thus highlighting a difficulty in generalising its results. Systematic reviews such as this can therefore play an interesting role in shaping our knowledge about group-based ACT for neurological conditions and the requirements necessary for future research.

Conclusion

This review was undertaken to consider the evidence base of group ACT for individuals with neurological conditions with regards to its quality and effect for this patient group. The findings indicate that there have been applications of group ACT in a number of neurological conditions with promising results. The majority of the included studies were RCT's, however, there were a number of studies which were of low quality. Despite this, improvements as a result of ACT were found in all studies which examined the level of pain related disability, the impact of the neurological condition, frequency of seizures, secondary fatigue and the core processes of ACT. There were however no differences found between ACT and TAU in subjective measures of factors such as pain ratings. This indicates that there was a change in the way people experienced their difficulties rather than the difficulty itself decreasing.

References

- Angiola, J. E., & Bowen, A. M. (2013). Quality of life in advanced cancer: An acceptance and commitment therapy view. *Counseling Psychologist, 41*(2), 313-335.
<https://doi.org/10.1177/0011000012461955>
- Asplund, K., Jonsson, F., Eriksson, M., Stegmayr, B., Appelros, P., Norrving, B., Terent, A., & Asberg, K.H. (2009) Patient dissatisfaction with acute stroke care. *Stroke* 40 (12): 3851–6 doi: 10.1161/STROKEAHA.109.561985
- Bayati, A., Abbasi, P., Bashiri, H., Dehghan, F., & Yazdanbakhsh, K. (2017). The Effectiveness of Acceptance and Commitment Therapy on Psychological Well-Being in Women with MS. *IIOAB JOURNAL, 8*(1), 82-86.
- Berlin, J. A. (1997). Does blinding of readers affect the results of meta-analyses?. *The Lancet, 350*(9072), 185-186.
- Carbonell-Baeza, A., Aparicio, V., Chillón, P., Femia, P., Delgado-Fernández, M., & Ruiz, J. (2011). Effectiveness of multidisciplinary therapy on symptomatology and quality of life in women with fibromyalgia. *Clinical and experimental rheumatology, 29*. S97-103.
- Carrigan, N. and Dysch, L. (2015). Acceptance and Commitment Therapy for the Management of Chronic Neuropathic Pain in Multiple Sclerosis: a Case Study. *Neuro-Disability and Psychotherapy, 3*(2), 69-92.
- Chalmers, T. C., Smith, H., Blackburn, B., Silverman, B., Schroeder, B., Reitman, D., & Ambroz, A. (1981). A method for assessing the quality of a randomized control trial. *Controlled clinical trials, 2*(1), 31-49.

- Chambers, S. K., Foley, E., Galt, E., Ferguson, M., & Clutton, S. (2012). Mindfulness groups for men with advanced prostate cancer: a pilot study to assess feasibility and effectiveness and the role of peer support. *Support Care Cancer*, 20(6), 1183-1192. doi:10.1007/s00520-011-1195-8
- Connell, L. & Tyson, S. (2012). Measures of sensation in neurological conditions: A systematic review. *Clinical rehabilitation*. 26. 68-80. 10.1177/0269215511412982.
- Craske, M. G. (2012). Transdiagnostic treatment for anxiety and depression. *Depression and Anxiety*, 29(9), 749–753. <https://doi.org/10.1002/da.21992>
- Department of Health. (2009). *Psychological assessment and treatment for medically unexplained symptoms and long-term conditions*. UK: Author
- Department of Health. (2010). *Improving the health and well-being of people with long term conditions*. UK: Author.
- Department of Health. (2012). *Long-term conditions compendium of Information: 3rd edition*. UK: Author.
- Fernie, B.A., Kollman, J., & Brown, R.G. (2015). Cognitive behavioural interventions for depression in chronic neurological conditions: A systematic review. *Journal of Psychosomatic Research*, 78, 411-419. <https://doi.org/10.1016/j.jpsychores.2015.02.012>
- Fiest, K. M., Dykeman, J., Patten, S. B., Wiebe, S., Kaplan, G. G., Maxwell, C. J., Bulloch, A. G., & Jette, N. (2013). Depression in epilepsy: a systematic review and meta-analysis. *Neurology*, 80(6), 590–599. <https://doi.org/10.1212/WNL.0b013e31827b1ae0>
- Fisher, M., Friedman, S. B., & Strauss, B. (1994). The effects of blinding on acceptance of research papers by peer review. *Jama*, 272(2), 143-146.

Flessner, C., Busch, A., Heideman, P., & Woods, D. (2008). Acceptance-Enhanced Behavior Therapy (AEBT) for Trichotillomania and Chronic Skin Picking. *Behavior modification*, 32, 579-94. DOI: 10.1177/0145445507313800.

GBD 2016 Neurology Collaborators. (2019) Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019; **18**: 439-458. DOI: 10.1016/s1474-4422(18)30499-X

Gracey, F., Ford, C., & Psaila, K. (2015). A provisional transdiagnostic cognitive behavioural model of post brain injury emotional adjustment. . *Neuro-Disability and Psychotherapy*, 3(3), 154–185. Obtained from https://ueaeprints.uea.ac.uk/id/eprint/59044/1/CBT_Model_Gracey_Longworth_Psaila_NDP_FINAL.pdf

Graham, C. D., Gouick, J., Krahe, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, 46, 46-58.
doi:dx.doi.org/10.1016/j.cpr.2016.04.009

Hadlandsmyth, K., White, K. S., Nesin, A. E., & Greco, L. A. (2013). Proposing an Acceptance and Commitment Therapy intervention to promote improved diabetes management in adolescents: A treatment conceptualization. *International Journal of Behavioral Consultation and Therapy*, 7(4), 12-15. <http://dx.doi.org/10.1037/h0100960>

Harris, R. (2013). *Getting unstuck in ACT: A clinician's guide to overcoming common obstacles in acceptance and commitment therapy*. Oakland, CA: New Harbinger Publications; US.

Hayes, S. C., Levin, M. E., Plumb-Villardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and Commitment Therapy and Contextual Behavioral Science: Examining

- the Progress of a Distinctive Model of Behavioral and Cognitive Therapy. *Behavior therapy*, 44(2), 180-198. doi:10.1016/j.beth.2009.08.002
- Hayes, S. C. (2004). Acceptance and Commitment Therapy, Relational Frame Theory, and the third wave of behavioral and cognitive therapies. *Behavior Therapy*, 35, 639-665. doi: 10.1016/S0005-7894(04)80013-3.
- Hind, D., Cotter, J., Thake, A., Bradburn, M., Cooper, C., Issac, C., & House, A. (2014). Cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: a systematic review and meta-analysis. *BMC Psychiatry* **14**, 5. <https://doi.org/10.1186/1471-244X-14-5>
- Irwig, L., Tosteson, A. N., Gatsonis, C., Lau, J., Colditz, G., Chalmers, T. C., & Mosteller, F. (1994). Guidelines for meta-analyses evaluating diagnostic tests. *Annals of internal medicine*, 120(8), 667-676.
- Jensen, K., Loiotile, R., Kosek, E., Petzke, F., Carville, S., Fransson, P.,... Jian, K. (2012). Patients with fibromyalgia display less functional connectivity in the brain's pain inhibitory network. *Molecular pain*. 8. 32. 10.1186/1744-8069-8-32.
- Kangas, M. & McDonald, S. (2011) Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychol Rehabil*. 21(2):250–276. doi: 10.1080/09602011.2010.540920.
- Kanner, A.M. (2005). Should neurologists be trained to recognize and treat comorbid depression of neurological disorders? Yes. *Epilepsy Behav*. 6(3): 303–311. <https://doi.org/10.1016/j.yebeh.2005.02.008>
- Kemani, M. K., Olsson, G. L., Lekander, M., Hesser, H., Andersson, E., & Wicksell, R. K. (2015). Efficacy and Cost-effectiveness of Acceptance and Commitment Therapy and

- Applied Relaxation for Longstanding Pain: A Randomized Controlled Trial. *The Clinical journal of pain*. 31(11), 1004-1016. doi: 10.1097/AJP.0000000000000203
- Kratz, A. L., Hirsh, A. T., Ehde, D. M., & Jensen, M. P. (2013). Acceptance of pain in neurological disorders: Associations with functioning and psychosocial well-being. *Rehabilitation Psychology*, 58(1), 1–9. <https://doi.org/10.1037/a0031727>
- Kuipers Cavaco, Y., & Quoidbach, V. (2014). *Public Health in the EU: State-of-play and key policy challenges*.
- Lincoln, N., & Flannaghan, T. (2003). Cognitive Behavioral Psychotherapy for Depression Following Stroke: A Randomized Controlled Trial. *Stroke; a journal of cerebral circulation*. 34. 111-5. 10.1161/01.STR.0000044167.44670.5
- Lobo, A., & Launer, L., Fratiglioni, L., Andersen, K., Carlo, A., Breteler, M., Copeland, John., Dartigues, J., Jagger, C., Martinez-Lage, J., Soininen, H., & Hofman, A. (2000). Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. *Neurology*. 54. S4-9.
- Low, N.C., Dugas, E., O’Loughlin, E., Rodriquez, D., Contreras, G., Chaiton, M., & O’Loughlin, J. (2012). Common stressful life events and difficulties are associated with mental health symptoms and substance use in young adolescents. *BMC Psychiatry* **12**, 116. <https://doi.org/10.1186/1471-244X-12-116>
- Luciano, J. V., Guallar, J. A., Aguado, J., Lopez-Del-Hoyo, Y., Olivan, B., Magallon, R., . . . Garcia-Campayo, J. (2014). Effectiveness of group acceptance and commitment therapy for fibromyalgia: a 6-month randomized controlled trial (EFFIGACT study). *Pain*, 155(4), 693-702. doi: 10.1016/j.pain.2013.12.029.

- Lundgren, T., Dahl, J., Melin, L., & Kies, B. (2006). Evaluation of acceptance and commitment therapy for drug refractory epilepsy: a randomized controlled trial in South Africa--a pilot study. *Epilepsia*, 47(12), 2173-2179. DOI:[10.1111/j.1528-1167.2006.00892.x](https://doi.org/10.1111/j.1528-1167.2006.00892.x)
- Lundgren, T., Dahl, J., Yardi, N., & Melin, L. (2008). Acceptance and Commitment Therapy and yoga for drug-refractory epilepsy: a randomized controlled trial. *Epilepsy & behavior : E&B*, 13(1), 102-108. doi: 10.1016/j.yebeh.2008.02.009.
- Majumdar, S., & Morris, R. (2019) Brief group-based acceptance and commitment therapy for stroke survivors. *Br J Clin Psychol*. 58(1):70–90. doi: 10.1111/bjc.12198
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The, P. G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, 6(7), e1000097. doi:10.1371/journal.pmed.1000097
- Mo'tamedi, H., Rezaieamaram, P., & Tavallaie, A. (2012). The effectiveness of a group-based acceptance and commitment additive therapy on rehabilitation of female outpatients with chronic headache: preliminary findings reducing 3 dimensions of headache impact. *Headache*, 52(7), 1106-1119. doi: 10.1111/j.1526-4610.2012.02192.x
- Neurological Alliance (2019). Neuro Numbers.
- Neurological Alliance (2012) Neuro Numbers.
- NHS England (2019). *Transforming Community Neurology: What commissioners need to know*.
- Nicholas, D., R. (2016). *Psychological care of the adult cancer patient: Evidence-based practice in psycho-oncology*: Oxford University Press.

- Nordin, L., & Rorsman, I. (2012). Cognitive behavioural therapy in multiple sclerosis: a randomized controlled pilot study of acceptance and commitment therapy. *Journal of rehabilitation medicine*, 44(1), 87-90. doi: 10.2340/16501977-0898
- Ost, L. G. (2008). Efficacy of the third wave of behavioral therapies: a systematic review and meta-analysis. *Behaviour Research and Therapy*, 46(3), 296-321.
doi:10.1016/j.brat.2007.12.005
- Ost, L. G. (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy*, 61, 105-121.
doi:10.1016/j.brat.2014.07.018.
- Pakenham, K. I., & Fleming, M. (2011). Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychology & Health*, 26(10), 1292-
doi:10.1080/08870446.2010.517838
- Roger, K., Wetzel, M., Hutchinson, S., Packer, T., Versnel, J. (2014) "How can I still be me?": Strategies to maintain a sense of self in the context of a neurological condition, *International Journal of Qualitative Studies on Health and Well-being*, 9:1, DOI: [10.3402/qhw.v9.23534](https://doi.org/10.3402/qhw.v9.23534)
- Ruiz, F. J. (2012). Acceptance and commitment therapy versus traditional cognitive behavioral therapy: A systematic review and meta-analysis of current empirical evidence. *International Journal of Psychology & Psychological Therapy*, 12(3), 333-357. Corpus ID: 27998613
- Sheppard, S. C., Forsyth, J. P., Hickling, E. J., & Bianchi, J. (2010). A Novel Application of

Acceptance and Commitment Therapy for Psychosocial Problems Associated with Multiple Sclerosis. *International Journal of MS Care*, 12(4), 200-206. doi: doi:10.7224/1537-207312.4.200

Shields, C., Ownsworth, T., O'Donovan, A., & Fleming, J. (2016) A transdiagnostic investigation of emotional distress after traumatic brain injury. *Neuropsychological Rehabilitation*. 26(3), 410 – 445. Doi:10.1080/09602011.2015.1037772

Stafford, L., Foley, E., Judd, F., Gibson, P., Kiropoulos, L., & Couper, J. (2013). Mindfulness based cognitive group therapy for women with breast and gynecologic cancer: a pilot study to determine effectiveness and feasibility. *Support Care Cancer*, 21(11), 30093019. doi:10.1007/s00520-013-1880-x

Swain, J., Hancock, K., Hainsworth, C., & Bowman, J. (2013). Acceptance and commitment therapy in the treatment of anxiety: a systematic review. *Clinical psychology review*, 33(8), 965-978. doi: 10.1016/j.cpr.2013.07.002.

Thewes, B., Brebach, R., Dzidowska, M., Rhodes, P., Sharpe, L., & Butow, P. (2014). Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals. *Psycho-Oncology*, 23(4), 390-396. doi: 10.1002/pon.3423

Tomaka, J., Thompson, S. and Palacios, R. (2006) The Relation of Social Isolation, Loneliness, and Social Support to Disease Outcomes among the Elderly. *Journal of Aging and Health*, 18, 359-384.
<http://dx.doi.org/10.1177/0898264305280993>

Whiting, D., Deane, F., McLeod, H., Ciarrochi, J., & Simpson, G. (2019) Can acceptance and commitment therapy facilitate psychological adjustment after a severe traumatic brain

injury? A pilot randomized controlled trial, *Neuropsychological Rehabilitation*, DOI:
10.1080/09602011.2019.1583582

Wicksell, R. K., Kemani, M., Jensen, K., Kosek, E., Kadetoff, D., Sorjonen, K., Ingvar, M. &
Olsson, G. L. (2013). Acceptance and commitment therapy for fibromyalgia: a
randomized controlled trial. *European journal of pain (London, England)*, 17(4), 599-
611. doi: 10.1002/j.1532-2149.2012.00224.x.

Wylde, V., Marques, E., Artz, N. Blom, A., & Gooberman-Hill, R. (2014) Effectiveness and
cost-effectiveness of a group-based pain self-management intervention for patients
undergoing total hip replacement: feasibility study for a randomized controlled trial.
Trials **15**, 176. <https://doi.org/10.1186/1745-6215-15-176>

Paper 2 has been prepared for submission to the British Journal of Psychology in accordance with the guidelines for authors (Appendix 1).

Paper 2: Rebuilding Life After Stroke: A qualitative study of staff perceptions and experiences of using a stroke specific self-management book.

Hannah Lewis-Dunford^a and Reg Morris^a

a South Wales Doctoral Programme in Clinical Psychology, Cardiff University, Cardiff, CF10 3AT

Corresponding author:

**Hannah Lewis-Dunford Cardiff University, 70 Park Place, Tower building 11th floor
Cardiff CF10 3AT lewish29@cardiff.ac.uk**

Word count (exc. figures/tables): 8000

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abstract

The experiences and perceptions of stroke service staff using a stroke-specific self-management book were explored. Semi-structured interviews were conducted with fifteen staff members who had used the 'Rebuilding your life after stroke' self-management book. Staff varied in role, training, age and length of experience in stroke. Interviews were analysed using Inductive Thematic Analysis. All participants welcomed the book as a resource for stroke services. The book was considered a form of peer support for stroke survivors and was experienced as accessible and practically helpful. Professional role and level of training were implicated in the experience of the book, its use in practice and views on accessibility of ACT concepts for practitioners and stroke survivors. 'Rebuilding your life after stroke' was positively received. Participants agreed the book supplemented their practice, benefitting practitioners and survivors. Staff without knowledge of psychological concepts such as ACT may find training about the book enhances its benefit to their practice.

Introduction

Stroke

There are over 1.2 million people in the UK living with lasting medical problems as a result of experiencing a stroke (Department of Health, 2016). Difficulties include physical problems such as visual impairment, limb weakness and incontinence (Stroke Association, 2018).

There can also be a lasting psychological impact of experiencing a stroke with over half of survivors reporting anxiety symptoms (Ayerbe, Ayis, Crichton, Wolfe and Rudd, 2014) and a third suffering from depression (Hackett and Pickles, 2014). Such difficulties may lead to individuals becoming dependent on others for their care (National Audit Office, 2010).

Current Provision for Stroke

Research has indicated that 45% of stroke survivors feel abandoned once they have left hospital (Stroke Association, 2016), with one third of individuals living alone post stroke (SSNAP, 2017) and half of stroke survivors in a community study reporting one or more unmet long-term needs in the first five years following stroke (McKevitt et al., 2011). The use of psychological interventions to support stroke survivors has been outlined in National Institute for Health and Clinical Excellence (NICE) (2013) guidance. However, recent reviews identify limited evidence for interventions for anxiety (Campbell-Burton et al, 2013), depression (Hackett and Pickles, 2014) and post-traumatic stress disorder (Edmondson et al, 2013) experienced post stroke. This is significant because NICE (2009a) guidance states that treating co-morbid mental health difficulties in those with long-term health conditions can have a positive impact on health-related quality of life, it's course and outcome.

Self Help

Despite pressure to deliver psychological interventions to those who have experienced a stroke, there continues to be a lack of psychological resources available (SSNAP, 2017). In this context, self-help interventions provide the opportunity to offer standardised psychological interventions to large numbers of people with minimal input from the therapist (Watkins & Clum, 2007). Evidence has indicated that self-help is beneficial for conditions such as depression (Williams et al, 2013) and anxiety (Lewis, Pearce and Bisson, 2012). Furthermore, depressive symptoms have been found to reduce in stroke survivors when they are provided with information post-stroke, emphasising the potential role for self-help resources in this area (Lambert and Loiselle, 2007).

With regards to implementation, self-help delivered with no input or support from a health professional has been considered to be the most far reaching, cost effective and easy access for stroke survivors. However, those who have experienced depression and anxiety as a consequence of their stroke may lack motivation to engage in such self-help (Gellatly et al, 2007). These difficulties may be overcome through the use of 'guided self-help' whereby there is some input and guidance from a health professional which can increase engagement (Williams et al, 2013). NICE (2009) guidance outlines that such interventions should be delivered by staff who have sufficient skills, training and knowledge to explain and adapt interventions to meet the needs of the individuals they work with. Furthermore, implementation of self-help has been shown to be more successful if staff have the knowledge and motivation to work within a particular setting (Benzer et al, 2012). This is pertinent when considered in line with Department of Health (DOH) (2009) guidance outlining that 'many good initiatives flounder because insufficient attention is paid to the

staff themselves and the actions needed to create the climate in which the desired attributes can ensure success.’

One particular form of self-help that has been considered useful for those with long-term conditions are Self-management approaches. Self-management approaches have been described as useful for those with long-term health conditions as they aim to empower patients to work effectively with health care professionals. They also include a focus on patient needs, goals, skills practice and emotional and role management (Expert Patients Programme, 2014). This approach has been evidenced to improve health outcomes in those with long-term conditions such as diabetes, arthritis and heart disease (Taylor et al, 2014). Self-management interventions have also been shown to improve self-efficacy (Jones, Mandy and Partridge, 2009) and recovery from disability (Morrison, Johnston, MacWalter and Pollard, 1998) in a stroke population. Furthermore, interventions containing elements of self-management have been successfully implemented within rehabilitation services for stroke survivors (Parke et al, 2015).

‘Rebuilding your life after Stroke

'Rebuilding Your Life after Stroke' (Morris, Falck, Miles, Wilcox and Fisher-Hicks, 2017) is a self-management book written by clinicians working within stroke services in collaboration with stroke survivors and their carers. It was developed as a therapeutic self-help tool with the aim of improving the wellbeing of this patient group. The book uses cognitive behavioural therapy (CBT) combined with neuropsychology as an initial approach to psychological problems. For more intractable problems the Acceptance and Commitment Therapy (ACT) approach is utilised. It covers the psychological impact of stroke using the views of stroke survivors and their carers to illustrate the issues. It also contains exercises and

links to further audio-visual resources. The aim of the book is to provide accessible and clear information, support and therapy to stroke survivors and carers and to be a resource for staff working within stroke services.

The Current Study

Experiencing a stroke is a life changing event and can lead to range of psychological difficulties, including anxiety, fatigue and low mood. The aim of this study is to explore how staff working within stroke services experience using the ‘Rebuilding your life after stroke’ (Morris et al, 2017) self-management book. It is important to understand professionals’ opinions about the book in order to determine whether the content and format was perceived as appropriate for this patient group. It was also of interest to understand the reasons why staff may or may not use or recommend the book to patients.

Semi-structured interviews will seek to explore the following questions:

- Was this book experienced as an effective tool for use by staff who work within stroke services?
- What did staff experience as being the key elements of the book which produced any beneficial change as a result of reading or using it?
- What could be changed to improve its utility and impact?

Method

Research Site

The interviews took place either at an NHS site or via Skype.

Ethical Approval

Health and Care Research Wales awarded ethical approval for this study (REC Reference 18/WA/0323) (see appendix 10).

Target Population

The target population were staff working with stroke survivors within the NHS and charitable sector in the UK who had experience of using the book.

Participants

Convenience sampling was used to recruit participants willing to engage in the study.

Participants were recruited from two Health Boards in Wales and third sector organisations in Wales and Bristol. The sample consisted of three clinical psychologists, three assistant psychologists, four stroke co-ordinators, two counsellors, two physiotherapists and a specialist nurse in stroke. Eleven female and four male participants were interviewed. All participants had used the book with stroke survivors.

Procedure

Interviews took place between the 28th June and the 9th September 2019. Interviews were either conducted face to face in an NHS location or via Skype. Participants were provided with an information sheet (appendix 4) prior to taking part and written informed consent was

obtained (appendix 5). The purpose of the study, confidentiality and its limitations were outlined. Participants were given the opportunity to ask any questions and reminded they could terminate the interview at any point. All interviews were audio-recorded to ensure integrity of the data. Interviews were semi-structured and took place on a single occasion, each lasting up to 40 minutes in duration. On completion of the interview, participants received a verbal and written debrief (appendix 8) including information on how they could access any emotional support or exercise their right to withdraw from the study. To standardise the interview procedure, the first author (HD) interviewed each participant. Each interview was transcribed verbatim prior to the next interview taking place. This allowed for the researcher to review the transcripts to identify emerging patterns, potential codes and areas of interest for future interviews.

Design and theoretical background

This research employed a thematic analysis (TA) of in-depth semi-structured interviews conducted with staff working within stroke services with the aim of elucidating how they experienced the book. Interviews explored staffs' own experiences of using the 'Rebuilding your life after stroke' (Morris et al, 2017) book as well as their perceptions of how stroke survivors experience the book.

Critics have argued that TA is merely a flexible 'tool' that can be used across qualitative approaches to analyse data (Boyatzis, 1998). However, Braun and Clarke (2006) countered that TA should be considered an approach to analysis and as such developed a framework for its use in theoretically and methodologically robust ways. They consider that qualitative approaches to analysing data can be placed into two different perspectives (Braun and Clark,

2013). Qualitative approaches such as interpretative phenomenological analysis or grounded theory are associated with particular theoretical or epistemological stand points. Whereas others, such as TA, are broader so can in turn be used with a variety of theoretical and epistemological approaches. TA is used to identify, examine and record implicit and explicit ideas within a data set (Guest, 2012). As a result, it has been deemed a useful method of analysis to obtain rich descriptions and meanings from data (Guest, 2012).

In view of the manifold strengths of inductive TA it was chosen to analyse the data in this study so that a deeper understanding of the information gained through interview could be taken and rich data obtained as a result. Since the themes developed in this study were created using an inductive approach, they can be considered to be strongly linked to the data itself.

Analysis

In order to guide the coding process, Braun and Clarke's (2013) six stages of TA were used. During the data collection phase, a number of preliminary codes were created. Transcribed data transcripts were read a number of times with codes being assigned to relevant text. New codes were thus developed if subsequent text did not fit within existing preliminary codes. On completion of coding there were found to be 37 tentative codes which were then refined to 22 codes (appendix 13). Codes were then placed into groups dependent on their conceptual similarities. This resulted in three overarching themes and a total of six sub-themes (Table 1).

Trustworthiness of the data and findings

In order to verify the trustworthiness of the data and to ensure the themes generated appeared to fit with it, 'member checking' was completed. This involved a small sample of five participants who agreed to sit on a participant panel by completing the 'Participant Panel Invitation' (appendix 9) when initially consenting to participate in the study. The participant panel was invited to verify the themes and offer feedback and suggestions for amendments, if required.

Subjective Positioning

Kacem & Chaitin (2006) argue that the findings and conclusions of any study are formed under the influence of the researcher's own world view. Taking this into account the researcher was aware of the need to hold in mind their own world view and values when interpreting language, asking questions and filtering information gained through the interview process to take meaning from it.

The research was carried out by a trainee clinical psychologist under the supervision of a clinical psychologist who was also one of the authors of the book being studied. Both the trainee clinical psychologist and clinical psychologist had previously worked within Stroke Services.

A research diary was kept by the researcher with the aim of enhancing reflexivity. External supervision was also sought from a clinical psychologist not working with the project or within stroke services as a way of discussing the researcher's position with regards to the data. However, as the external supervisor was also a clinical psychologist it is worth noting

that positioning is likely to be similar by nature of training and professional experience.

Results

Themes were identified that best represented the variety of codes generated, quotations were then selected to describe the themes in conversational terms. In order to verify the trustworthiness of the data, the themes and quotations were presented to a participant panel in a written format by email. Participants were then asked to respond outlining whether they agreed or disagreed with the findings, giving reasons for their decision if they wished. Participants were made aware that their responses would be confidential, and they could withdraw from being a member of the panel at any time. This member checking exercise revealed that the participants agreed the themes generated accurately reflected the perspectives of the participants. However, the name of the sub-theme 'I'm not alone' was changed from 'peer support' to encompass the power the participant panel felt it had. Each theme and sub-theme are outlined in bold in the text below along with a selection of narrative excerpts that have been edited (e.g., speech errors removed) to improve clarity.

Table 1: Themes and Sub-themes

Theme	Sub-theme
1) Perceived impact of the book for Stroke Survivors	1) 'I'm not alone' - Normalisation 2) Perceived scope of the book
2) Perceived impact of the book on staff	1) Professional Role 2) Use in Practice
3) Features of the book	1) Accessibility 2) Exercises

Table 2: Participant Characteristics

Participant Number	Profession	Gender	Age	Years of Service in Stroke
1	Clinical Psychologist	Female	42	15
2	Clinical Psychologist	Female	30	3
3	Stroke Coordinator	Female	35	4
4	Research Assistant	Male	28	2
5	Stroke Coordinator	Male	47	10
6	Lead Counsellor	Female	52	20
7	Counsellor	Male	50	2
8	Stroke Coordinator	Male	45	12
9	Physiotherapist	Female	34	8
10	Assistant Psychologist	Female	25	2
11	Assistant Psychologist	Female	30	2
12	Physiotherapy Assistant	Male	42	4
13	Clinical Nurse Specialist	Female	52	30

14	Assistant Psychologist	Female	27	2
15	Clinical Psychologist	Female	38	5

Theme 1: Perceived Impact of the book for stroke survivors

‘I’m not alone’ – Normalisation

The majority of staff interviewed perceived that the main benefit stroke survivors had gained from the book was a sense of ‘I’m not alone.’ Interviewees spoke of the power of the service user contributions throughout the text and how for many stroke survivors this was an opportunity to normalise the difficulties they have experienced post stroke and to learn there are many others out there who have a shared experience.

“He...said, ‘oh my god this book is me it’s like reading about my life, its brilliant.”(Clinical Psychologist, Participant 1)

“The first quote is ‘it was like being hit by a ten-tonne truck’ and everyone always says that’s exactly how I felt.” (Stroke Coordinator, Participant 3)

“...give survivors the feeling of I’m not alone because it is an isolating condition...they can read other people have felt this it’s not just me.”(Clinical Nurse Specialist, Participant 13)

Interviewees talked at length about the perceived impact of the book for stroke survivors. All viewed the book on the whole as a positive addition to someone’s toolkit when recovering from a stroke and a welcome addition to the field as it was felt that there is a lack of resources available.

“I think this book has helped some people get an understanding of what’s going on and it’s ok, it’s not abnormal, they’re not going mad.” (Clinical Psychologist, Participant 15)

“I would say it has helped generally by providing a resource.” (Clinical Nurse Specialist, Participant 13)

Perceived scope of the book

Many interviewees seemed keen to emphasize that they felt the way the book was received by stroke survivors was largely dependent on the individual, their cognitive functioning, personality, and their recovery. Staff members talked of recognising that not everyone requires the same input, and this determines how the book can be used.

“...it depends really on the person because I’ve mentioned it to people...high functioning...and they’ve gone ‘oh this is brilliant’ and they’ve...used it themselves...for some people with...cognitive difficulty I think doing it on a 1-1 basis would be more helpful to clarify and explain...” (Clinical Psychologist, Participant 1)

Staff appeared to believe how applicable the book was to stroke survivors also largely depended on their level of motivation.

“I think people still have to be motivated....” (Clinical Psychologist, Participant 1)

“I give out a lot of information...unless they have the capacity and motivation to actually pick it up... it’s not going to have any benefit on them.” (Stroke Coordinator, Participant 5)

Another aspect relating to the scope and applicability of the book for stroke survivors was the varying degrees of impairment experienced post stroke. These impairments range from physical to psychological with staff outlining aphasia, visual and cognitive impairment as those they considered potential barriers to its effective use.

“I didn’t feel it was very aphasia friendly. I know the audio exercises exist, but I felt that it was a bit intense for people with aphasia.” (Research Assistant, Participant 4)

“...the way the font is it isn’t too hard to read but then my vision’s fine so maybe people with visual difficulties would struggle.” (Clinical Psychologist, Participant 1)

“There was one man I was working with who cognitively really struggled to engage with some of it even with me supporting him.” (Assistant psychologist, participant 12)

Interviewees largely felt that the applicability of the book would be related to the stage of post-stroke recovery. It was felt that it may be too much information to be given at the start of the pathway but more useful after discharge from hospital or a few months post stroke.

“Some people we would see a few hours after their stroke and anything about acceptance is too soon...whereas people who are on the wards for several months it felt like a much better place to have those...conversations.” (Clinical psychologist, participant 2)

“...careful around the timing of someone reading particular chapters as it might not be the right time for certain messages...” (Physiotherapist, participant 9)

Staff also felt that the book was a useful resource for individuals to return to once they are further along in their recovery. It was thought that those who were more aware and accepting of the fact their recovery would not follow a linear pathway would be more likely to revisit the book.

“The people that benefitted most were those that realised their recovery would not be linear...revisited certain parts at a later stage in their recovery.” (Stroke coordinator, participant 8)

Theme 2: Staff perspectives about using the book

There were a number of different staff groups interviewed as part of this study. This theme reflects that the way various staff groups perceived, experienced and utilised the book seemed to be linked to their profession, their perception of their role and also the training they received around concepts contained within the book.

Use in Practice

Interviewees highlighted a number of different ways the book can be used in practice with stroke survivors, carers, and staff. Staff reflected that individual difference; job role and service constraints may influence this. There seemed to be a consensus that initial guidance and support from a staff member may be beneficial to ensure that the concept of the book and its potential utility is recognised. Those interviewed appeared to feel that without such guidance the book may appear daunting.

“I think it would work best if the therapist would introduce the book...help individuals understand the role of it and how to use it. This would hopefully empower them to take it on...this could follow on with family and other stroke survivors. More of a self-management tool...invest time in getting stroke survivors on board to get the best out of it.” (Clinical psychologist, participant 15)

Staff discussed using the book on a 1:1 basis with stroke survivors. However, the opportunity and inclination to do this varied dependent on the particular staff group interviewed and how they viewed their role.

“I’m working with an individual whereby I am choosing a couple of the exercises, going through them and explaining them and getting them to go away and do it for homework...try the strategies and then come back and we’ll discuss how they got on with them.” (Clinical psychologist, participant 1)

“Directly using the exercises 1-1 and getting them to think in more of a values-based way and bringing in family and staff on board with that when we needed.” (Clinical psychologist, participant 2)

A number of interviewees talked about using elements of the book in a group setting. The benefits of this seemed to be related to fostering a sense of peer support amongst group members and also picking topics for discussion. The exercises also seemed to be particularly useful in this.

“The peer support group they were going through the book to see what parts they enjoyed the most, what parts they found most relevant to them...it starts them off on their stories and their own recovery journeys...they even tried the exercises as well together.” (Stroke coordinator, participant 3)

The value of using the book with families and caregivers to increase their knowledge and understanding was also discussed. There is much evidence to indicate that stroke survivors may feel isolated from those around them, so this may be a particularly helpful use of the book as a tool to bring families together.

“My recommendations are; let your family read it as well, encourage them to have a look at it and maybe look at it together...insight into what their loved one might be experiencing.” (Clinical psychologist, participant 1)

“A lot of family members will say to me ‘they don’t listen to me anymore’ and ‘they just forget’ ...that lack of understanding that it’s cognitive impairment due to the brain injury itself.” (Assistant psychologist, participant 10)

Other staff discussed using concepts from the book to deliver training to those working with stroke survivors. It appears the book may be a useful tool to cascade information through services by providing education and tools to work with stroke survivors in a psychologically minded way.

“...incorporate it into training for staff. So, the magic wand exercise and the 90th birthday party one I used to use as part of a stroke package for staff.” (Clinical psychologist, participant 2)

All interviewees agreed that the book had in some way enhanced or supplemented their practice mainly with regards to having a resource to support their work with patients.

“It’s changed or supplemented in terms of you may have been floundering thinking where do I go with this problem the patient has got.” (Clinical nurse specialist, participant 14)

“I think it can add value to my practice because I find myself talking about lots of these concepts in my treatments and actually the book can be a nice back-up maybe in terms of what I’m talking about and that there’s evidence for it.” (Physiotherapist, participant 9)

A number of the staff interviewed who felt unable to use the book in a hands-on way as part of their role with individuals did express a wish to do so if the time constraints of their role allowed for it.

“I could go through the book individually with someone...it may even encourage people to open...about how they are struggling...to do the exercises together they might find it a bit more reassuring but it’s the time.” (Stroke coordinator, participant 3)

Professional role

How participants used the book appeared to be related to what they perceived their professional role to be and the level of training they had received as part of it. For example, those working in a stroke coordinator role appeared to be more likely to give the book to individuals as part of a pre-set information giving exercise. They seemed to encourage individuals to read and use the book in their own time.

“I haven’t tended to use the exercises with people as I don’t really have the time. It’s a case of providing the book and saying look through it and use it.” (Stroke coordinator, participant 5)

In contrast, those working in more therapies-based roles communicated that they used the book in a more hands-on way with stroke survivors. They talked about being familiar with much of the content and concepts included such as ACT and Mindfulness.

“As a psychological therapist I use a lot of ACT and as soon as I saw the content I thought ‘this is amazing’ ...stuff I tend to use anyway with the patients I work with.” (Clinical psychologist, participant 1)

This was in contrast to those not trained in psychological therapies who felt that they did not have the knowledge and confidence to recommend either the whole book or to use some of the exercises. Staff expressed there needed to be training around the book given to those distributing it as part of their roles within stroke services to increase their confidence in doing so.

“It can be hard to recognise when people have cognitive problems...it may take a more qualified person to pick these things up. If there was a re-publication it should come with face to face training for staff...it would take you through some of the things that you might not necessarily be sure or certain of in terms of delivering.” (Stroke coordinator, participant 8)

“Training would provide reassurance... I’m an experienced therapist so I’m happy to have difficult conversations with people as I can fall back on my experience, but this would be difficult for new therapists to this field.” (Physiotherapist, participant 9)

Theme 3: Features of the book

This theme refers to how interviewees experienced the book with regards to its usability. The interviews gave insight into how staff experienced the four different parts of the book however there were a number of key features which staff consistently highlighted as particularly useful or not.

Accessibility

Interviewees highlighted the accessibility of the book as a strength. Particular reference was made to language, design and layout, and sequencing of the content. This is particularly pertinent given the impact stroke can have on many aspects of an individual's functioning, both physically and cognitively.

"It was relatively large print, a few pictures in there. A picture is a thousand words...I found it very well laid out, easy to follow." (Counsellor, participant 7)

"...it's easy for them to read because of the way it's all laid out. The ring binder on it...it opens with one hand you can pop it on the table open and there's spaces for people to make notes in." (Stroke coordinator, participant 5)

A number of the interviewees also highlighted that the fact the book was split into distinct parts was helpful as it allowed themselves as practitioners to dip in and out and also enabled individuals to work through the book in stages.

"For someone who's got fatigue or memory problems or concentration problems I think it keeps them interested. I don't think people can read it all in one I think they do have to read it in stages but if they think part 1 is most relevant...they can go back to just that bit." (Stroke coordinator, participant 3)

"I think it's really well laid out and it's hard to get a good balance between stuff that's useful for clinician and that's helpful enough for people without a clinical background but I think it does a really nice job." (Clinical psychologist, participant 2)

Interviewees also talked of the accessibility of various sources of information and therapy in one place due to the content covered by the book. There appeared to be a strong belief that the psychological impact of stroke is the area which stroke survivors are usually not aware of. This part of the book seemed to stand out as being what staff perceived as significantly helpful both as practitioners and for stroke survivors.

“I think the parts explaining about what stroke is and how it can affect you. I think as much as they get informed of these things when they are an inpatient whether it’s too much for them at that point to take in or they just don’t take it in...I think this book has helped some people get an understanding of what’s going on...” (Clinical psychologist, participant 1)

“It’s the psychological and emotional support that’s in it because that’s often overlooked, and it’s not understood...the hidden side of stroke that it covers really well.” (Stroke coordinator, participant 5)

However, interviewees did report feeling that the size of the book be potentially daunting to stroke survivors. Those who felt this way did reason that it may be unavoidable as the benefits of having features such as the ring binder and the larger font to make the book accessible are one of its strengths for this population. Some interviewees discussed the potential of having an index page to enable readers to easily navigate to certain terms .

“...if there was an index with page numbers or a divider it would be useful for people to be able to flick to the page straight away. Without the index you end up reading about all the symptoms you could have which may be depressing.” (Physiotherapist, participant 9)

Exercises

The book features a section containing exercises designed for the use of stroke survivors, many of which are based on the principles of ACT. The exercises appeared to be found useful by those interviewees who felt confident in using them. However, some felt there needed to be a guided element to their delivery as individuals may not be used to using them and may therefore be put-off using them. Some interviewees expressed concern that if stroke survivors did not have a thorough understanding of the purpose of the exercise this could have a detrimental effect on the person using the book.

“There’s an exercise in there where you have to write your worries and stresses on a leaf and then you imagine the leaf going down the stream...one lady said she wanted to kick the leaf because it just stressed her out even more...I was then a bit more mindful of encouraging people to use the exercises as I didn’t want it to be a negative I wanted it to a positive.”

(Stroke coordinator, participant 3)

There was a feeling from some interviewees that the ACT concepts covered in the exercises may be considered abstract as they are not generally things people would be familiar with. It was thought they could be most helpful if they were guided by a practitioner to allow for explanation of the purpose and the intended outcome. It also appears that some parts of the ACT approach are seen by those interviewed as better fitting for this population than others.

“They aren’t something that people would normally do. It helps to have someone to explain the reasons why the exercises may be helpful and also for the individual to have the space to reflect after completing the exercises.” (Assistant psychologist, participant 14)

“Feedback we’ve had on some of the thought defusion exercises are ‘that’s all very well but that’s easier said than done when you’ve got persistent thoughts’ ... The mindfulness approaches have been more helpful...the acceptance exercises I think you need to be sat there and do it alongside someone...if there’s cognitive impairment or if they are someone who has never really been good at introspecting their thoughts.” (Assistant psychologist, participant 10)

With regards to using the exercises in practice, interviewees who had experience in using concepts such as ACT appeared to have more confidence in recommending appropriate exercises.

“I’ve used the breathing exercises and the body scan which is something I’d learnt as a counsellor anyway so I’d had no problem in talking or actually using those exercises and teaching people about them where I thought it might be of some help.” (Counsellor, participant 7)

A number of interviewees talked about the usefulness of the audio-visual exercises that are a supplementary part of the book. They talked of their utility not just for stroke survivors and their carers but also for the staff themselves.

“I use the audio visuals in the carers group as the themes match with what we are doing...They can draw a lot of comparisons on what they are experiencing with their loved ones and they can then reflect on this.” (Assistant psychologist, participant 11)

“I have myself used the breathing ones...it was a new book and I fancied doing something from it while I was getting all excited about it.” (Stroke coordinator, participant 5)

Discussion

The main conclusion of the current study was that in general ‘Rebuilding your life after stroke’ (Morris et al, 2017) had been positively received and welcomed by those staff interviewed. All participants agreed the book had in some way supplemented their practice, with most remarking on the benefits of having such a resource available both for themselves and the stroke survivors they work with. This is encouraging given that there is a reported dearth of self-help books in this area (SSNAP, 2015) which was reflected in respondents’ views. Existing literature, clinical and service implications will be discussed in relation to the themes that arose out of the findings.

Findings in relation to existing literature

Theme 1: Perceived impact of the book on Stroke Survivors

When considering the theme of ‘Perceived impact of the book on stroke survivors’ and more specifically the subtheme of ‘I’m not alone’ it appears that staff may have felt the book acted as a form of peer support through normalising stroke survivor experiences. Staff noted that the book allowed stroke survivors and their carers the opportunity to compare themselves to others who have shared a similar experience. They gave examples of survivors making comments such as ‘this is me’ when reading quotes cited within the text. Others expressed that they felt it allowed stroke survivors to not feel alone in what can be an isolating situation, whilst providing families with an opportunity to gain a better understanding of their loved one’s experience. All staff members interviewed believed the input of stroke survivors and carers to the development of the book was a strength. They talked particularly of the emotive power of the stroke survivors’ quotes which are used throughout the text. Staff highlighted that there was a strong sense that survivors were able to connect with the content of the books

through the quotes. This is in line with previous research which highlighted that self-help for health conditions is most powerful when perspectives of others with the same condition are included (Moss-Morris et al, 2012). Evidence indicates that individuals often look to those with the same health condition to gauge how their own illness and symptoms compare (Bogart and Helgeson, 2000), developing adaptive coping strategies based on such comparisons (Proudfoot et al, 2012). Increased self-esteem, self-efficacy and wellbeing through comparison to others in similar situations have also been proposed (Kessler et al, 2014). Social Comparison Theory (SCT) offers a framework for understanding this phenomenon. SCT proposes that in order to reduce feelings of uncertainty individuals appraise themselves by comparing to similar people (Festinger, 1954). Thus, due to the uncertainty and anxiety around the impact that health conditions such as stroke may have on an individual's future, it has been argued that social comparisons may be particularly important in this group (Dibb and Yardley, 2006).

Staff also discussed a need to recognise that how stroke survivors experience the book is dependent on the individual and its applicability for them at their stage of recovery. For this reason, designing interventions for stroke survivors can prove difficult as what is useful for some may not be for others. This is emphasised by the dearth of literature to support stroke survivors (SNNAP, 2015). It is also unclear which factors of complex interventions, such as this, contribute to positive outcomes with regards to the different stages of stroke recovery and subgroups of stroke survivors (Forster et al, 2012). With regards to the present study, 'Rebuilding your life after stroke' is a self-management book which encompasses a number of different approaches. Staff interviewed talked positively about this, with the sections on stroke education, the psychological impact of stroke and the ACT based approaches considered particularly helpful. The majority of staff felt this view was shared by the stroke

survivors they had worked with. It seemed they felt that most found some part applicable, dependent on their individual stroke recovery trajectory. This is in line with implementation guidance for self-management, whereby the individual nature of each stroke survivor with regards to their stroke, personal challenges and previous abilities should be considered when planning interventions (Jones and Bailey, 2013).

Theme 2: Staff perceptions of using the book

The core psychological model of ‘Rebuilding your life after stroke’ (Morris et al, 2017) is ACT (Harris, 2013). How participants in the current study used the ‘Rebuilding your life after stroke’ book appeared to be related to their pre-existing knowledge and experience of the ACT model. The premise of ACT is that psychological distress is a normal element of the human experience. It aims to enable individuals to accept, rather than extinguish distress through increasing ‘psychological flexibility.’ Individuals are encouraged to live a meaningful life regardless of difficult emotions or physical limitations (Harris, 2013). ACT uses three broad categories of techniques; mindfulness and defusion techniques; acceptance; and commitment to values-based living. Participants in the current study talked of the usefulness of the ACT model, believing that values appeared particularly applicable to the stroke survivors they work with. This supports recent literature where ACT has been shown to be effective or perceived as useful in stroke survivors (Graham, Gillanders, Stuart & Gouick, 2015; Majumdar & Morris, 2018; Large, Samuel & Morris, 2019).

There were, however, differences described by staff in how they experienced using the ACT model in practice. These were conceptualised under the subthemes of ‘professional role’ and ‘use in practice’. Those who reported being clinically trained with knowledge of ACT and prior experience of using similar self-help and self-management materials expressed a more

positive attitude towards ACT and its utility. They seemed more confident and comfortable in guiding individual's through the book, discussing ease of use and relevance for the client group. They also demonstrated ways in which they have used the book successfully with stroke survivors. For example, 1-1 and in group settings and as a tool when delivering staff training. In contrast, participants who reported having no training or knowledge of the ACT model were more likely to express that they gave the book to stroke survivors to read in their own time, citing reasons such as lack of knowledge and the remit of their professional role. Such reluctance of some interviewees to guide individuals through the book seems to be validated by the findings of a similar study of a group-based ACT intervention for stroke-survivors. Large et al (2019) highlighted that group facilitators with a clear understanding and knowledge of ACT were found to improve stroke-survivor experiences of the intervention. This may be explained by self-efficacy which has been considered fundamental to understanding whether staff have the capacity and confidence to implement interventions: Those with confidence in their ability to implement evidence-based interventions were far more likely to do so, with positive outcomes reinforcing their continued use (Turner and Sanders, 2006). This is supported by evidence indicating that self-management has been shown to be more successful when there was a focus on specialised skills, training, and ongoing support for both professional and non-professional staff (Kennedy, Reeves and Bower, 2007). This may be difficult to achieve given the pressure on stroke teams, however, a UK Kings Fund report has outlined that self-management is a priority within health and social care (Naylor et al, 2013). This supports the importance of training teams in approaches such as ACT to increase confidence, limit differences and ensure effective implementation (Reeves, Perrier, Goldman, Freeth & Zwarensten, 2013). Providing training to those staff groups who use the book as part of their role would therefore potentially increase levels of

self-efficacy and may improve the way in which the book and other similar self-management resources are used with most effect.

Theme 3: Features of the book

With regards to the theme 'Features of the book', staff discussed the accessibility of the book as a key strength, highlighting the design, layout and sequencing as particularly beneficial for use with the stroke population. Staff also talked positively about the exercises and the option to use audio-visual materials. However, there was concern expressed by some around the potential utility of the book for stroke survivors with impairments. They appeared to feel that the content may be too intense for those with aphasia despite the existence of the audio-visual exercises. There was also a query around the level of support needed for those with cognitive impairment to benefit from using the book. The inclusion of aphasia and dementia-adapted tools such as visual aids and online exercises were felt to have potential to overcome this (Rose, Worrall, Hickson and Hoffman, 2011). This is particularly important when considered in line with evidence that outlines a link between aphasia (Shehata, Misitikawi, Risha and Hassan, 2015) and cognitive impairment (Pratiwi, Tamtomo and Murti, 2019) in the development of post-stroke depression.

It is also pertinent to note that a number of interviewees were concerned that some ACT-based techniques contained within the book may be too abstract for stroke survivors with no prior knowledge of ACT to grasp without guidance. They felt this may prevent stroke survivors from using and benefitting from the book due to a lack of understanding. In support of this, Large et al (2019) in a study of group ACT for stroke survivors found that some participants struggled to generalise ACT ideas outside of the group setting due to difficulties understanding the abstract concepts. However, this contrasts to work which has indicated that

ACT has utility for those with cognitive impairment due to its emphasis on experiential learning (Pahnke, Lundgren, Hursti, and Hirvikoski, 2014; Brown and Hooper, 2009). In order to address these concerns a further study to explore the experiences of those stroke survivors impacted by impairments such as aphasia and cognitive impairment would be beneficial. This may provide a more thorough understanding of the impact of such difficulties on the usability of the book.

Strengths and Limitations

The current study had several notable strengths. Data saturation was felt to have been achieved. Data saturation “entails bringing new participants continually into the study until the data set is complete, as indicated by data replication or redundancy” (Bowen, 2008). Data saturation was judged to have been reached after the fourteenth interview as no new themes were seen to emerge after interview fifteen. Triangulation through the use of ‘member checking’ was also used to limit biased interpretations. However, the findings reported are only relevant to those staff interviewed as part of this study. Efforts were made to recruit a variety of staff from different professions working within stroke services, but due to the nature of opportunistic sampling not all of those professions involved in stroke care were represented.

Despite the fact that the results may not be typical of staff working in stroke services as a whole, a range of staff groups were interviewed, therefore the findings may be used cautiously to guide further self-help resources being developed in this area. There is a dearth

of similar studies to allow for comparison of these results. However, this does constitute a strength of this research as it was designed to be seminal.

The themes which emerged from the data in the present study may be considered ‘concrete’ in nature which may be perceived as a potential limitation as psychological processes were not identified as core themes. There was discussion from participants around the usefulness of psychological concepts such as ACT contained within the book. However, concepts such as mindfulness, values and the abstract nature of ACT were discussed in ‘concrete’ terms in relation to the practicality and usability of the book for survivors, carers’ and services with no mention of underlying psychological processes. This is in contrast to the findings of a study of group-based ACT for stroke-survivors which revealed themes in relation to the processes of change engendered by ACT, such as acceptance and values-based living. For example, Large et al (2019) discussed stroke survivors ‘accepting a changed reality’ in relation to moving towards acceptance. In the current study there was mention of ‘accepting the nature of stroke recovery’ but this was not explicitly related to the ACT process of acceptance. As noted previously, a number of the staff interviewed were in non-clinical roles so may not have been in a position to form a view on such processes. They may also have been focussed on the practical aspects of improving care provided to stroke-survivors. However, those in therapies-based roles may have held views towards the psychological processes and their underpinning theory, but these were not drawn out within the interviews. This may explain why psychologically informed themes were not developed in the same way in this study as others of its kind and should be considered when appraising its results.

There may also have been a ‘Hawthorne Effect’ whereby interviewees may have changed their behaviour and responses due to the fact they were participating in a study. However, this

is an issue with all research of this kind (McCambridge, Kypri and Elbourne, 2014) and it is impossible to fully guard against this. As highlighted in the analysis, feedback on the content of the book was generally positive but some participants did feel able to comment on negative aspects and areas for improvement. For example, staff talked of their caution over using the book with aphasic patients and those with cognitive impairment. It is worth noting that the positive flavour of responses may have been accounted for by the fact they saw the researcher as being closely linked to the authors, or a wish to remain professional during the interviews so as not to offend fellow clinicians. Despite this, the feedback does, however, present opportunities for the authors to consider ways in which the book could be improved to further support and help stroke survivors, their carers and the staff groups that work with them.

Implications for clinical practice and research

In the UK, NHS improvement guidelines for stroke services recommend a stepped-care approach to psychological care post-stroke (NHS Improvement, 2011). Evidence outlined previously has, however, indicated the lack of resources for psychological input in stroke services which may impact on the level of care for the psychological consequences of stroke (Royal College of Physicians, 2016). Responses from those interviewed in this study appeared to support this. They indicated that some staff who are expected to deliver interventions do not feel they have sufficient training in psychological skills and therefore do not feel equipped to do so. A number of participants in the current study who were not clinically trained expressed concern about whether they were the right staff member to be introducing the book to stroke survivors. This appeared to be due to what they perceived as their lack of knowledge around its content. They talked of the difficulty in recognising issues

such as cognitive impairment and felt that a qualified member of staff with sufficient training would be better placed to decide if the book would be appropriate. This highlights a gap in service provision for those needing psychological care (SNNAP, 2017). It is also not in line with NICE (2013) guidance that recommends interventions should be delivered by staff who have sufficient skills, training and knowledge to outline, explain and adapt interventions to meet patients need.

With regards to clinical practice, this perceived skills shortage offers an opportunity for psychology staff to deliver training to other professions on ACT. This may provide them with new skills and knowledge of concepts such as mindfulness and working with values. The Stroke Specific Education Framework (Stroke Specific Education Framework, n.d.) 'Courses' section, which contains information on available training courses and resources, could also be used as a potential resource for non-psychology staff to gain information to develop their skills. These initiatives could help to increase the provision of basic psychological support within stroke services and allow psychology staff to work with those needing more complex care.

The current system for stroke survivors in the NHS involves a six-week early supported discharge programme with limited clinical psychology input and a lack of opportunity to offer further psychological support beyond this. This is particularly pertinent in the Welsh context as the services cover vast geographical regions across Wales. The National Clinical Guidelines for Stroke suggest services should offer brief psychological interventions to all stroke survivors with, or at risk of, depression or anxiety and to plan for the long-term management of psychological distress. Across the UK, 40% of stroke survivors reported feeling abandoned post hospital discharge; 50% did not receive any information or support

for anxiety or depression; and two thirds said their emotional needs were not met as well as their physical needs following their stroke (Stroke Association, 2013). Therefore, the 'Rebuilding your life after stroke' book has the potential to offer psychological input in the community beyond this usual six-week discharge programme. Whilst it is acknowledged that self-help interventions are not for everybody and outcomes will not always be optimal, this empirical study highlighted that it is well needed and well thought of amongst those working with the stroke population. With the addition of training around the material in the book to those staff who are not clinically trained, the book has potential to both increase the reach and the cost-effectiveness of psychological interventions for this client group.

Conclusions

This study has identified that a self-help book is a valued self-management tool within stroke services. However, staff considered that in order for it to be implemented effectively they need to feel confident that they understand the information and models it uses. A number of staff felt that in order for the book to be used with effect there needs to be education for staff around the concepts contained within it. There also appears to be a perceived need for more aphasia and dementia-friendly material to be included within the book, as those staff interviewed felt this was an area that was lacking in the current format.

References

- Ayerbe, L., Ayis, S. A., Crichton, S., Wolfe, C. D. and Rudd, A. G. (2014). Natural history, predictors and associated outcomes of anxiety up to 10 years after stroke: the South London Stroke Register. *Age Ageing*, 43, 542–547. doi: 10.1136/jnnp-2013-306448
- Ayerbe, L., Ayis, S., Wolfe, C. D. A., & Rudd, A. G. (2013). Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *Br J Psychiatry*, 202(1), 14-21. doi:10.1192/bjp.bp.111.107664
- Benzer, J. K., Beehler, S., Miller, C., Burgess, J. F., Sullivan, J. L., Mohr, D. C., ... Cramer, I. E. (2012). Grounded Theory of Barriers and Facilitators to Mandated Implementation of Mental Health Care in the Primary Care Setting. *Depression Research and Treatment*, 2012(597157). doi:10.1155/2012/597157
- Bogart, L., & Helgeson, V.S. (2000). Social comparisons among women with breast cancer: A longitudinal investigation. *Journal of Applied Social Psychology*, 30(3), 547-575. Doi:10.1111/j.1559-1816.2000.tb02496.x
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*, 8 (1), 137-152. doi:10.1177/146879410708530
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN 1478-0887
- Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. SAGE Publication, London.

- Brown, F.J., & Hooper, S. (2009). Acceptance and commitment therapy (ACT) with learning disabled young person experiencing anxious and obsessive thoughts. *Journal of Intellectual Disabilities*, 13, 195-201. doi: 10.1177/1744629509346173
- Campbell Burton, C. A., Murray, J., Holmes, J., Astin, F., Greenwood, D. & Knapp, P. (2013). Frequency of anxiety after stroke: A systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 8, 545–559. doi:10.1111/j.1747-4949.2012.00906.x
- Cutler, M., Nelson, M. L. A., Nikoloski, M., & Kuluski, K. (2016). Mindful Connections: The Role of a Peer Support Group on the Psychosocial Adjustment for Adults Recovering From Brain Injury. *Journal of social work in disability & rehabilitation*, 1-25. DOI:[10.1080/1536710X.2016.1220879](https://doi.org/10.1080/1536710X.2016.1220879)
- Department Of Health (2016) Reducing Brain Damage: Faster Access To Better Stroke Care. National Audit Office.
- Dibb, B., & Yardley, L. (2006). How does social comparison within a self-help group influence adjustment to chronic illness? A longitudinal study. *Social Science & Medicine*, 63(6), 1602–1613. <https://doi.org/10.1016/j.socscimed.2006.03.031>
- Edmondson, D., Richardson, S., Fausett, J.K., Falzon, L., Howard, V.J., & Kronish, I.M. (2013) Prevalence of PTSD in Survivors of Stroke and Transient Ischemic Attack: A Meta-Analytic Review. *PLoS One*. 8(6):e66435. doi: 10.1371/journal.pone.0066435
- Evans, G. (2013). A novice researcher’s first walk through the maze of grounded theory: Rationalization for classical grounded theory. *The Grounded Theory Review*, 12(1), 37-55.
- Expert Patients Programme. Control your condition, don’t let it control you. Available: <http://www.expertpatients.co.uk> (Accessed January 2020).

- Fann, J., Hart, T., & Schomer, K. (2009) Treatment of depression after traumatic brain injury: a systematic review. *Journal of Neurotrauma*. 26:2383-2402.
doi:10.1089/neu.2009.1091.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117–140.
<https://doi.org/10.1177/001872675400700202>
- Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J. J., & Young, J. (2012). Information provision for stroke patients and their caregivers. *The Cochrane database of systematic reviews*, 11(11), CD001919. doi.org/10.1002/14651858.CD001919.pub3
- Gellatly, J., Bower, P., Hennessy, S., Richards, D., Gilbody, S., & Lovell, K. (2007). What makes self-help interventions effective in the management of depressive symptoms? Meta-analysis and meta-regression. *Psychological Medicine* 37, 1217–1228. DOI: 10.1017/S0033291707000062
- Graham, C.D., Gillanders, D., Stuart, S., & Gouick, J. (2015) An acceptance and commitment therapy (ACT)–based intervention for an adult experiencing post-stroke anxiety and medically unexplained symptoms. *Clin Case Stud*. 14(2):83–97.
doi.org/10.1177/1534650114539386
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. Thousand Oaks, CA: Sage.10.4135/9781483384436
- Gurr, B., Plummer-D'Amato, P., Carod-Artal, F. J., & Gustafsson, L. (2009). Emotional support for stroke survivors: share your story group...including commentary by Plummer-D'Amato P, Carod-Artal FJ, and Gustafsson L. *International Journal of Therapy & Rehabilitation*, 16(10), 564-572.
<https://doi.org/10.12968/ijtr.2009.16.10.44566>

- Hackett, M. L., & Pickles. K. (2014) Part I: Frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *Int J Stroke* 2014; 9:1017–1025 doi: 10.1111/ijvs.12357
- Harris, R. (2013). *Getting unstuck in ACT: A clinician's guide to overcoming common obstacles in acceptance and commitment therapy*. Oakland, CA: New Harbinger Publications; US.
- Royal College of Physicians (2016) *Intercollegiate Stroke Working Party National clinical guideline for stroke*. London.
- Johnston, M., Bonetti, D., Joice S., Pollard, B., Morrison, V., Francis, J, J.(2007) Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disability and Rehabilitation*. 2007 Jul 30;29(14):1117-27 DOI:[10.1080/03323310600950411](https://doi.org/10.1080/03323310600950411)
- Jones F, Mandy A, Partridge C (2009) Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522–533. DOI: 10.1177/0269215508101749
- Jones, F., & Bailey, N. (2013). How can we train stroke healthcare professionals about self-management? Description and evaluation of a pathway wide training programme. *European Journal of Person Centered Healthcare*, 1(1), 246-254. DOI:[10.5750/ejpch.v1i1.660](https://doi.org/10.5750/ejpch.v1i1.660)
- Kacen, L., & Chaitin, J. (2006). “The Times They are a Changing” 1 : Undertaking Qualitative Research in Ambiguous, Conflictual, and Changing Contexts . *The Qualitative Report*, 11(2), 209-228. Retrieved from <https://nsuworks.nova.edu/tqr/vol11/iss2/1>

- Kanner, A.M. (2005). Should neurologists be trained to recognize and treat comorbid depression of neurological disorders? Yes. *Epilepsy Behav.* 6(3): 303–311.
<https://doi.org/10.1016/j.yebeh.2005.02.008>
- Kennedy A., Reeves D., Bower P. (2007) The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J. Epidemiol. Community Health.* 61:254–261.
DOI:[10.1136/jech.2006.053538](https://doi.org/10.1136/jech.2006.053538)
- Kessler, D., Egan, M. & Kubina, L-A. (2014). Peer support for stroke survivors: a case study. *BMC Health Services Research*, 14:256 <https://doi.org/10.1186/1472-6963-14-256>
- Lambert, S. D., & Loiselle, C.G. (2007) Health information-seeking behaviour. *Qual Health Res.* 2007;17(8):1006–1019. DOI:[10.1177/1049732307305199](https://doi.org/10.1177/1049732307305199)
- Large, R., Samuel, V., & Morris., R. (2019). A changed reality: Experience of an acceptance and commitment therapy (ACT) group after stroke. *Neuropsychological Rehabilitation* [10.1080/09602011.2019.1589531](https://doi.org/10.1080/09602011.2019.1589531)
- Lewis, C., Pearce, J., & Bisson, J.I. (2012) Efficacy, cost-effectiveness and acceptability of self-help interventions for anxiety disorders: systematic review. *British Journal of Psychiatry* 2012; 200(1): 15-21. doi: [10.1192/bjp.bp.110.084756](https://doi.org/10.1192/bjp.bp.110.084756)
- Majumdar, S., & Morris, R. (2019). Brief group-based acceptance and commitment therapy for stroke survivors. *British Journal of Clinical Psychology*, 58, 70-90.
DOI: [10.1111/bjc.12198](https://doi.org/10.1111/bjc.12198)
- McCambridge, J., Kyprilou, K., & Elbourne, D. (2014) Research participation effects: a skeleton in the methodological cupboard. *J Clin Epidemiol.* 2014;67(8):845–849. doi: [10.1016/j.jclinepi.2014.03.002](https://doi.org/10.1016/j.jclinepi.2014.03.002)

- McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A. R., . . . Wolfe, C. D. (2011). Self-reported long-term needs after stroke. *Stroke*, 42(5), 1398-1403.
doi:10.1161/strokeaha.110.598839
- Morris, R., Falck, M., Miles, T., Wilcox, J., & Fisher-Hicks, S. (2017) *Rebuilding your life after: Positive steps to wellbeing*. Jessica Kingsley.
- Morrison, V., Johnston, M., MacWalter, R. and Pollard, B. (1998) Improving emotional outcomes following acute stroke: A preliminary evaluation of a workbook based intervention. *Scottish Medical Journal*, 43,52-54.
<https://doi.org/10.1177/003693309804300208>
- Moss-Morris, R., McCrone, P., Yardley, L., van Kessel, K., Wills, G., Dennison, L. (2012) A pilot randomized controlled trial of an Internet-based cognitive behavioural therapy self-management programme (MS Invigor8) for multiple sclerosis fatigue. *Behaviour Research and Therapy* 50(2012) 415-421. DOI.org/10.1177/0296215515584800
- Mudge, S., Kayes, N., & McPherson, K. (2015) Who is in control? Clinicians' view on their role in self-management approaches: A qualitative metasynthesis. *BMJ Open*, 5.
<http://dx.doi.org/10.1136/bmjopen-2014-007413>
- National Collaborating Centre for Mental Health. (2010). Depression in adults with a chronic physical health problem: The NICE guideline on treatment and management. The British Psychological Society: Leicester.
- National Institute for Health & Clinical Excellence (2013). Stroke rehabilitation in adults; Clinical Guideline 162, London: NICE. www.nice.org.uk/guidance/cg162
- Naylor, C., Mundle, C., Weaks, L., & Buck, D. (2013) *Volunteering in health and care. Securing a sustainable future*. London: The King's Fund

- Naylor, C., Curry, N., Holder, H., Ross, S., Marshall, L., & Tait, E.. (2013) Clinical commissioning groups. Supporting improvement in general practice? London: The King's Fund and Nuffield Trust;
- NHS Improvement Psychological care after stroke. (2011). Available at http://www.nice.org.uk/media/default/sharedlearning/531_strokepsychologicalsupportfinal.pdf Accessed January 2020.
- Ost, L. G. (2008). Efficacy of the third wave of behavioral therapies: a systematic review and meta-analysis. *Behav Res Ther*, 46(3), 296-321. doi:10.1016/j.brat.2007.12.005
- Ost., L. G. (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy*, 61, 105-121.
- Pahnke, J, Lundgren, T, Hursti, T. (2013) Outcomes of an acceptance and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: a quasi-experimental pilot study. *Autism*. Epub ahead of print 18 October. DOI: [10.1177/1362361313501091](https://doi.org/10.1177/1362361313501091).
- Parke, H. L., Epiphaniou, E., Pearce, G., Taylor, S.J.C, Sheikh, A., Griffiths, C.J., Greenhalgh, Tet al. (2015) Self-management support interventions for stroke survivors: a systematic Meta-Review. *PLoS One* 2015;10:e0131448 10.1371/journal.pone.0131448
- Pratiwi, Dinda & Tamtomo, Didik & Murti, Bhisma. (2019). Is Cognitive Impairment a Risk Factor for Post-Stroke Depression? A Meta-Analysis Study. *Journal of Epidemiology and Public Health*. 4. 81-87. 10.26911/jepublichealth.2019.04.02.03.
- Proudfoot, J. G., Jayawant, A., Whitton, A. E., Parker, G., Manicavasagar, V., Smith, M., & Nicholas, J. (2012). Mechanisms underpinning effective peer support: A qualitative analysis of interactions between expert peers and patients newly-diagnosed with bipolar disorder. *BMC Psychiatry*, 12(1), 196. doi:10.1186/1471-244X-12-196

- Reeves, S., Perrier, L., Goldman, J., Freeth, D., & Zwarenstein, M. (2013). Interprofessional education: Effects on professional practice and healthcare outcomes (update). *Cochrane Database of Systematic Reviews*, 2013(3), 1-49. doi:10.1002/14651858.CD002213.pub3.
- Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffman, T. C. (2011) Aphasia friendly written health information: Content and design characteristics, *International Journal of Speech-Language Pathology*, 13:4, 335-347, DOI: 10.3109/17549507.2011.560396
- Royal College of Physicians Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke. 4th ed. London: Royal College of Physicians; 2012.
- Royal College of Physicians. (2012). Sentinel Stroke National Audit Programme (SSNAP): Acute organisational audit report. London:
- Royal College of Physicians. (2015). Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party. Sentinel Stroke National Audit Programme (SSNAP): Clinical audit April—June 2015 public report. London
- Satink, T., Cup, E. H., Ilott, I., Prins, J., De Swart, B. J., & Nijhuis-Van Der Sanden, M. W. (2013). Patients' views on the impact of stroke on their roles and self: A thematic synthesis of qualitative studies. *Archives of Physical Medicine & Rehabilitation*, **94**, 1171– 1183. doi: 10.1016/j.apmr.2013.01.011
- Shehata, G.A., Mistikawi, T.E., Risha, A.S.K., Hassan, H.S. (2015). The effect of aphasia upon personality traits, depression and anxiety among stroke patients. *Journal of affective disorders*. 172, 1. 312-314. <https://doi-org.abc.cardiff.ac.uk/10.1016/j.jad.2014.10.027>
- Stroke Association. (2016). State of the Nation: Stroke statistics January 2016. London: UK.
- Stroke Specific Education Framework. (n.d.) *Courses*. Retrieved from: <https://stroke-education.org.uk/courses/>
- Taylor, S.J.C., Pinnock. H., Epiphaniou. E., Pearce. G., Parke. H.L., & Schwappach. A., et al.

- (2014) A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions. *Health Serv Deliv Res* 2014;2(53).
DOI: 10.3310/hsdr02530
- Tregea, S., & Brown, K. (2013). What makes a successful peer-led aphasia support group? *Aphasiology*, 27(5), 581-598. <https://doi.org/10.1080/02687038.2013.796506>
- Turner, K. M. T., & Sanders, M.R. (2006a). Help when it's needed first: A controlled evaluation of brief, preventive behavioral family intervention in a primary care setting. *Behavior Therapy*, 37(2), 131–142. DOI:[10.1016/j.beth.2005.05.004](https://doi.org/10.1016/j.beth.2005.05.004)
- Turner, K. M. T., & Sanders, M. R. (2006b). Dissemination of an evidence-based, population-level parenting and family support strategy: Our experience with the Triple P-Positive Parenting Program. *Aggression and Violent Behavior*, 11(2), 176–193. <https://doi.org/10.1016/j.avb.2005.07.005>
- Veehof, M.M., Trompetter, H.R., Bohlmeijer, E.T., & Schreurs, K.M.G. (2016) Acceptance- and mindfulness-based interventions for the treatment of chronic pain: a metaanalytic review, *Cognitive Behaviour Therapy*, 45:1, 5-31, DOI: 10.1080/16506073.2015.1098724
- Wang, S. B., Wang, Y. Y., Zhang, Q. E., Wu, S. L., Ng, C. H., Ungvari, G. S., ... Xiang, Y. T. (2018). Cognitive behavioral therapy for post-stroke depression: A meta-analysis. *Journal of Affective Disorders*, 235, 589-596. <https://doi.org/10.1016/j.jad.2018.04.011>
- Watkins & G. A. Clum (Eds.), *Handbook of self-help therapies* (p. 1–24). Routledge/Taylor & Francis Group; Lawrence Erlbaum Associates Publishers
- Williams, C., Wilson, P., Morrison, J., McMahon, A., Andrew, W., et al. (2013) Guided Self-Help Cognitive Behavioural Therapy for Depression in Primary Care: A Randomised Controlled Trial. *PLoS ONE* 8(1): e52735. doi:[10.1371/journal.pone.0052735](https://doi.org/10.1371/journal.pone.0052735)

Appendices

Appendix 1- Journal Submission Criteria

Proposed target journal for publication of both papers: British journal of Psychology.

The main criteria are as following:

- 8000 word-limit (excluding abstract, diagrams, figures, tables and references)
- Double-spacing
- Numbered pages
- Abstract of up to 200 words
- APA style referencing

Appendix 2: Psychotherapy Outcome Study Methodology Rating Form (POMRF; Ost, 2008)

Note: If not enough information is given regarding a specific item a rating of 0 is given.

1. Clarity of sample description

0 Poor. Vague description of sample (e.g. only mentioned whether patients were diagnosed with the disorder).

1 Fair. Fair description of sample (e.g. mentioned inclusion/exclusion criteria, demographics, etc.).

2 Good. Good description of sample (e.g. mentioned inclusion/exclusion criteria, demographics, and the prevalence of comorbid disorders).

2. Severity/chronicity of the disorder

0 Poor. Severity/chronicity was not reported and/or subsyndromal patients were included in the sample.

1 Fair. All patients met the criteria for the disorder. Sample includes acute (01 yr) and/or low severity.

2 Good. Sample consisted entirely of chronic (41 yr) patients of at least moderate severity.

3. Representativeness of the sample

0 Poor. Sample is very different from patients seeking treatment for the disorder (e.g. there are strict exclusion criteria).

1 Fair. Sample is somewhat representative of patients seeking treatment for the disorder (e.g. patients were only excluded if they met criteria for other major disorders).

2 Good. Sample is very representative of patients seeking treatment for the disorder (e.g. authors made efforts to ensure representativeness of sample).

4. Reliability of the diagnosis in question

0 Poor. The diagnostic process was not reported, or not assessed with structured interviews by a trained interviewer.

1 Fair. The diagnosis was assessed with structured interview by a trained interviewer.

2 Good. The diagnosis was assessed with structured interview by a trained interviewer and adequate inter-rater reliability was demonstrated (e.g. kappa coefficient).

5. Specificity of outcome measures

0 Poor. Very broad outcome measures, not specific to the disorder (e.g. SCL-90R total score).

1 Fair. Moderately specific outcome measures.

2 Good. Specific outcome measures, such as a measure for each symptom cluster.

6. Reliability and validity of outcome measures

0 Poor. Measures have unknown psychometric properties, or properties that fail to meet current standards of acceptability.

1 Fair. Some, but not all measures have known or adequate psychometric properties.

2 Good. All measures have good psychometric properties. The outcome measures are the best available for the authors' purpose.

7. Use of blind evaluators

0 Poor. Blind assessor was not used (e.g. assessor was the therapist, assessor was not blind to treatment condition, or the authors do not specify).

1 Fair. Blind assessor was used, but no checks were used to assess the blind.

2 Good. Blind assessor was used in correct fashion. Checks were used to assess whether the assessor was aware of treatment condition.

8. Assessor training

0 Poor. Assessor training and accuracy are not specified, or are unacceptable.

1 Fair. Minimum criterion for assessor training is specified (e.g. assessor has had specific training in the use of the outcome measure), but accuracy is not monitored or reported.

2 Good. Minimum criterion of assessor training is specified. Inter-rater reliability was checked, and/or assessment procedures were calibrated during the study to prevent evaluator drift.

9. Assignment to treatment

0 Poor. Biased assignment, e.g. patients selected their own therapy or were assigned in another non-random fashion, or there is only one group.

1 Fair. Random or stratified assignment. There may be some systematic bias but not enough to pose a serious threat to internal validity. There may be therapist by treatment confounds. N may be too small to protect against bias.

2 Good. Random or stratified assignment, and patients are randomly assigned to therapists within condition. When theoretically different treatments are used, each treatment is provided by a large enough number of different therapists. N is large enough to protect against bias.

10. Design

0 Poor. Active treatment vs. WLC, or briefly described TAU.

1 Fair. Active treatment vs. TAU with good description, or placebo condition.

2 Good. Active treatment vs. another previously empirically documented active treatment.

11. Power analysis

0 Poor. No power analysis was made prior to the initiation of the study.

1 Fair. A power analysis based on an estimated effect size was used.

2 Good. A data-informed power analysis was made and the sample size was decided accordingly.

12. Assessment points

0 Poor. Only pre- and post-treatment, or pre- and follow-up.

1 Fair. Pre-, post-, and follow-up 01 year.

2 Good. Pre-, post-, and follow-up X1 year.

13. Manualized, replicable, specific treatment programs

0 Poor. Description of treatment procedure is unclear, and treatment is not based on a publicly available, detailed treatment manual. Patients may be receiving multiple forms of treatment at once in an uncontrolled manner.

1 Fair. Treatment is not designed for the disorder, or description of the treatment is generally clear and based on a publicly available, detailed treatment manual, but there are some ambiguities about the procedure. Patients may have received additional forms of treatment, but this is balanced between groups or otherwise controlled.

2 Good. Treatment is designed for the disorder. A detailed treatment manual is available, and/or treatment is explained in sufficient detail for replication. No ambiguities about the treatment procedure. Patients receive only the treatment in question.

14. Number of therapists

0 Poor. Only one therapist, i.e. complete confounding between therapy and therapist.

1 Fair. At least two therapists, but the effect of therapist on outcome is not analyzed.

2 Good. Three, or more therapists, and the effect of therapist on outcome is analyzed.

15. Therapist training/experience

0 Poor. Very limited clinical experience of the treatment and/or disorder (e.g. students).

1 Fair. Some clinical experience of the treatment and/or disorder.

2 Good. Long clinical experience of the treatment and the disorder (e.g. practicing therapists).

16. Checks for treatment adherence

0 Poor. No checks were made to assure that the intervention was consistent with protocol.

1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).

2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

17. Checks for therapist competence

0 Poor. No checks were made to assure that the intervention was delivered competently.

1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).

2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

18. Control of concomitant treatments (e.g. medications)

0 Poor. No attempt to control for concomitant treatments, or no information about concomitant treatments provided. Patients may have been receiving other forms of treatment in addition to the study treatment.

1 Fair. Asked patients to keep medications stable and/or to discontinue other psychological therapies during the treatment.

2 Good. Ensured that patients did not receive any other treatments (medical or psychological) during the study.

19. Handling of attrition

0 Poor. Proportions of attrition are not described, or described but no dropout analysis is performed.

1 Fair. Proportions of attrition are described, and dropout analysis or intent-to-treat analysis is performed.

2 Good. No attrition, or proportions of attrition are described, dropout analysis is performed, and results are presented as intent-to-treat analysis.

20. Statistical analyses and presentation of results

0 Poor. Inadequate statistical methods are used and/or data are not fully presented.

1 Fair. Adequate statistical methods are used but data are not fully presented.

2 Good. Adequate statistical methods are used and data are presented with M and SD.

21. Clinical significance

0 Poor. No presentation of clinical significance was done.

1 Fair. An arbitrary criterion for clinical significance was used and the conditions were compared regarding percent clinically improved.

2 Good. Jacobson's criteria for clinical significance were used and presented for a selection (or all) of the outcome measures, and conditions were compared regarding percent clinically improved.

22. Equality of therapy hours (for non-WLC designs only)

0 Poor. Conditions differ markedly (>20% difference in therapy hours).

1 Fair. Conditions differ somewhat (10–19% difference in therapy hours).

2 Good. Conditions do not differ (<10% difference in therapy hours).

Appendix 3: Table of Quality Ratings using the POMRF

POMRF ITEM	Lundgren et al (2006)	Nordin et al (2012)	Lundgren et al (2008)	Bayati et al (2017)	Wicksell et al (2013)	Pakenham et al (2017)	Luciano et al (2014)	Majumdar et al (2018)	Carbonell- Baeza et al (2011)	Jensen et al (2012)	Mo'tamedi et al (2012)	Sheppard et al (2010)
1	1	1	1	1	1	1	1	2	1	2	1	1
2	0	0	0	0	0	0	0	0	0	0	0	0
3	1	1	1	1	1	1	1	1	1	1	1	1
4	0	0	0	0	0	0	0	0	0	0	0	0
5	1	1	1	0	2	1	2	2	1	2	2	2
6	2	2	1	1	2	1	2	2	1	1	2	2
7	0	1	0	0	0	0	1	0	0	1	0	0
8	0	0	0	0	0	0	0	0	0	0	0	0
9	1	1	2	1	2	0	2	1	0	1	1	0
10	1	2	2	0	0	0	2	1	1	1	1	0
11	0	0	0	0	0	0	2	2	0	0	0	0
12	2	1	2	1	1	1	1	1	0	1	0	0
13	2	1	2	0	2	1	0	2	1	1	2	0
14	1	1	1	0	2	1	0	2	1	1	0	1
15	2	2	2	0	2	1	2	1	1	2	2	2
16	1	0	1	0	1	2	1	0	0	1	2	0
17	1	0	1	0	1	2	1	0	0	1	2	0
18	1	0	1	0	1	0	0	0	1	1	1	0
19	0	0	0	0	0	1	2	0	1	0	2	1
20	2	1	2	0	2	2	2	2	2	1	2	2
21	1	1	1	0	1	1	2	1	1	1	1	1
22	2	2	2	0	0	0	0	0	0	0	0	0
Total	22	18	25	5	21	16	24	20	13	19	22	13

Appendix 4: Participant Information Sheet

Participant Information Sheet

We would like to invite you to take part in a research study. Before you decide whether or not to take part, we want to tell you more about the study.

Please read this Participant Information Sheet carefully as it is important that you fully understand why we are running the study and what it would involve if you decide to take part. You do not have to decide now whether you would like to take part. Please take your time to think about this information sheet and talk about it to your friends and family if you wish.

If you would like to take part in the study, please complete the enclosed Participant Contact Information Form and return it in the envelope provided. The researcher will then contact you to arrange an interview and to provide further information about the study.

Title of the study

Rebuilding Your Life after Stroke: A Qualitative Exploration of Stroke Survivor and Staff Experiences

Why have I been asked to take part?

You have used the 'Rebuilding Your Life After Stroke' self-help book with stroke survivors and carers you have worked with in a professional capacity. This book has been developed by Stroke survivors, carers and staff working in Stroke Services. This study is being carried out throughout South Wales and Bristol and professionals in your area are part of the research team. They have identified you as a potential participant and have given you information about this study.

What is the purpose of the study?

As the book is new, we would like to know your views about the book and your experiences of using it. In the doing this, we want to find out what the most helpful parts of the book were and the parts that could be improved to help other Stroke survivors and their carers in the future.

Do I have to take part?

Your involvement in the study is completely voluntary and you will only be involved in the research after reading this information sheet, agreeing to be contacted by the researcher and signing a consent form to confirm your participation in the study. If you decide to take part, but later change your mind, you can withdraw from the study at any time, without giving any reason.

Choosing not to take part in the study will not affect your employment.

What will taking part in the study involve?

You will be asked to commit to an interview session with the researcher, which should last about an hour. You will be asked to complete a consent form before participating in the interview session. The interview can be at an NHS location near you, your home, or over the telephone/Skype. The interview will be audio-recorded to support the researcher in understanding and analysing what you have said.

To ensure that the researcher has accurately captured everyone's responses, the researcher will be inviting participants to be part of a participant panel. Being part of this panel will mean that the researcher will send you the initial findings of the research and you will be invited to comment/ suggest changes if you wish. If you want to be part of this panel, please tick the box on the Participant Panel Invitation. When the research findings have been finalised, the final results of the study will be sent to all participants who have opted to see them. This is for your own personal reference at can be read at your leisure, you will not be asked to provide any feedback on the finalised results.

How will the information obtained during the study be used?

The information gathered might be used in a number of ways:

- The results of the research will be written up as a thesis and submitted as part of a Doctorate in Clinical Psychology at Cardiff University.
- It is also hoped that the results will be published in a scientific journal and presented at Stroke Conferences.
- All research participants will be offered the opportunity to receive a summary of the research findings when they are finalised.

Whilst it is possible that the researcher may use direct quotes obtained from the interview sessions, please be assured that names of participants and/or other identifiable information will not be included in any reports so you will not be identified in any report/publication related to this research.

What are the benefits of taking part?

We hope that by taking part in the research it will give you an opportunity to think about your experience of using the book with stroke survivors and their carers and encourage you to share the things that you found helpful about the book with other professionals.

We also hope that participation may benefit those you work with and others like them, as well as other professionals who may use the book in the future. As this is a new stroke book, we hope that your direct feedback and views can help contribute to the development of new psychological and support services for stroke survivors and their carers.

Are there any disadvantages of taking part?

Talking about stroke and the events after it can be distressing and you may feel upset. The researcher will minimize this risk by having focused questions about the book. If you do become distressed, the researcher will stop the interview, discuss any issues that arise and provide you with information of local support groups, if appropriate.

Will my taking part in the study be confidential?

All information collected from you during the study will be kept strictly confidential and any personal data you provide will be held in accordance with data protection law (please see 'What will happen to my Personal Data' below for further information).

The audio-recordings will only be heard by the named researcher, members of the research team and transcribers (from an external agency who will be subject to appropriate confidentiality provisions) whilst transcribing the material, and all data within the transcript will be anonymised to protect your identity. The audio-recordings will be stored at Cardiff University as a locked and encrypted file and destroyed within 1 year of completion of the study. The anonymised research data, and all other paper records (including your consent form) will be retained securely at Cardiff University for a period of 15 years, in accordance with Cardiff University's Records Management Policy.

As an exception, if the researcher or a member of the research team has concerns about your safety, or the safety of others, they may be legally required to override confidentiality and report this to appropriate persons. The researcher would try and discuss this with you in the first instance if appropriate to do so.

What will happen to my Personal Data?

Cardiff University is the sponsor for this study based in the United Kingdom. Cardiff University will be using information from you in order to undertake this study and will act as the data controller for this study. This means that the University is responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished (namely your consent form).

As noted above, transcripts from the audio-recorded interviews will be anonymised to remove identifiable information and the audio-recordings destroyed within 1 year of study completion.

Under data protection law, the University has to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards, and is in the public interest. The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. The charter can be found on the Cardiff University website.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Cardiff University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain about how your personal data has been handled, can be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>.

Who has reviewed this study?

This research has been reviewed by an NHS Research Ethics Committee [insert reference number] who have given it a favourable ethical opinion for conduct.

Contact for further information

If you wish to obtain further information about this study, or if you have any queries, please contact the named researcher, using the contact details below. Alternatively, you are invited to contact the Academic Supervisor using the contact details below.

Raising a concern and complaints

If you wish to raise a concern, or complain about the study, please contact the named researcher or the Academic Supervisor of the study, using the contact details below.

Alternatively, if you would like to raise a concern or complaint with someone who is independent of this study, please contact Dr Dougal Hare, Research Director on 02920 206464.

Thank you for taking the time to read this information sheet.

The Research Team

The Research Team

<u>Researcher:</u>	<u>Academic Supervisor</u>
<p>Hannah Dunford Trainee Clinical Psychologist South Wales Doctoral Programme in Clinical Psychology School of Psychology Cardiff University 70 Pack Place CF 10 3AT</p> <p>Email: lewish29@cardiff.ac.uk Tel: 02920 206464</p>	<p>Professor Reg Morris Consultant Clinical Psychologist South Wales Doctoral Programme in Clinical Psychology School of Psychology Cardiff University 70 Pack Place CF 10 3AT</p> <p>Email: Reg.morris@wales.nhs.uk Tel: 02920 206464</p>

Appendix 5: Participant Consent Form

Consent Form

Title of the study

Rebuilding Your Life after stroke: A Qualitative Exploration of Stroke Survivor and Staff Experiences

Name of Researcher: Hannah Dunford

Please initial the boxes if you agree with the following statements and sign and date at the bottom of the form:

1. I confirm that I have read and understood the Participant Information Sheet dated [5/6/18], version [0.3], for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without it affecting my care or rights in any way.

3. I understand that all of the information I provide during the study will be held securely and in confidence by the research team, unless they are legally required to disclose information as a result of concerns about my safety, or the safety of others.

4. I agree to the interview being audio-recorded and for this to be transcribed in full by an external party subject to a strict duty of confidence.

5. I understand that the audio recording will be stored securely at Cardiff University in locked and protected files and destroyed within 1 year of study completion. I understand that the transcripts of the audio-recordings will be anonymised by the researcher and retained securely at Cardiff University for 15 years.

6. I am aware that excerpts from my interview, or descriptions of them, may be used by the researcher within their thesis or other papers published in scientific journals or presented at conferences, for the purpose of research. I give permission for the information to be used with the understanding that I will remain anonymous.

7. I understand that the anonymised research data, and all other paper records (including this consent form), will be retained securely at Cardiff University for a period of 15 years.

8. I agree to take part in the study.

9. I have been informed about the opportunity to become a member of the Participant Panel and am aware that there is no obligation to be part of this panel. I understand that if I would like to be part of this panel then I will need to complete the invitation and return it to the researcher.

10. I **would** like to receive a summary of the findings of this study once finalised by the research team. I agree that the summary may be sent to my email or postal address below.

Email Address:

Postal Address (including postcode):

Participant Signature

Date.....

Name (please print)

Researcher Signature

Date.....

Appendix 6: Demographic Questionnaire

Demographic Questionnaire for staff

The following information will be used anonymously in the study. Please answer as many questions as possible. However, you do not have to answer anything that you don't want to. Thank you.

Today's Date: _____

Participant #: [office use]_____

Gender (please tick):

<input type="checkbox"/>	Male
<input type="checkbox"/>	Female

What is your age?

What is your profession/?

What organisation do you work for?

What service do you work in?

How long have you worked there?

How long have you worked in stroke services?

How long have you worked in healthcare?

What is your usual role in working with stroke survivors and carers?

Do use any particular psychological therapies or therapeutic approaches?

About 'Rebuilding Your Life After Stroke' book

How many stroke survivors have you used the book with? _____

How many carers have you used the book with? _____

How long has the book been part of your practice? _____

How did you find about the book? _____

	Please tell us about what you used in each part
In Part 1 <ul style="list-style-type: none"> • About this book^{[L][SEP]} • What you will find in the book • Psychological effects of stroke 	
In Part 2 <ul style="list-style-type: none"> • Chapter 1: Difficult feelings • Chapter 2: Feeling different • Chapter 3: Changing relationships • Chapter 4: Thinking differently 	
In Part 3 <ul style="list-style-type: none"> • Chapter 5: Becoming mindful^{[L][SEP]} • Chapter 6: Watching your thoughts^{[L][SEP]} • Chapter 7: Building acceptance^{[L][SEP]} • Chapter 8: Making the most of life after stroke 	
In Part 4 <ul style="list-style-type: none"> • Resources – More information Websites • Helplines^{[L][SEP]} • Books^{[L][SEP]} • List of videos and audio exercises available via web links 	

Which parts of the book have you used?

Did you use any of the written exercises with the survivor/carer?

	Please tick	
YES		Which ones?
NO		

Did you use any of the audio visual exercises with the survivor/carer?

	Please tick	
YES		Which ones?
NO		

Thank you for completing this questionnaire

Appendix 7: Interview Schedule

Staff Interview Schedule

Accessibility

1. How did you find out about the book?
2. Was it easy to obtain? YES/NO
 - a. If no, say why

Content

1. Were there any parts of the book that applied to your practice the most?
Prompts: *i. Which ones? Why?*
ii. Were there any parts of the book that weren't relevant to your practice?
2. Did you encourage the survivor to use any of the exercises in the book?
Prompts: *i. If yes, which ones were the most useful?*
ii. If no, why not?
3. In what ways (if any) has the book changed/supplemented your practice?

Experience

4. When working with the survivor, how did you use the book?
Prompts: *i. How did you support them?*
ii. Did you work through it in parts on a 1:1 basis or in a group?
iii. Did you give them the book to use independently or use it with them?
iv. What would have been the best way to use the book?
5. How was the book received by survivors?
Prompt: *i. Did you have any positive/negative feedback*
6. Do you think the book easy or difficult to use?
Prompts: *i. Which parts are easy?*
ii. Which parts are difficult?
7. What was the most helpful part of the book?
Prompts: *i. For you*
ii. For the survivor?
8. What was the most unhelpful part of the book?
Prompts: *i. For you*
ii. For the survivor?
9. Do you think that the book may have helped survivors?
Prompts: *i. in what way?*
ii. If not, why?
10. If you had a magic wand, what would you change about the book?

Usability

11. Was the book easy to use?
Prompt: *i. Was the book easy to navigate?*
ii. Was the text easy to read?
iii. Were the written exercises easy to complete?
iv. Were the Audio-visual exercises easy to do?
v. What changes would make the book easier to use.
12. Was the language understandable?

- 13.** How do you think the book could be used to be most helpful?
- a. Reading by yourself (stroke survivor alone)
 - b. Reading with a friend/partner/carer
 - c. Reading with another stroke survivor
 - d. Reading with a group of stroke survivors
 - e. Reading with a member of staff

Appendix 8: Participant Debrief Letter

Participant Debrief Letter

Study Title: Rebuilding Your Life After Stroke: A Qualitative Exploration of Stroke survivors, carers and staff views.

Dear Participant,

Thank you for participating in the research study. From your interview your anonymised responses have been recorded and will be combined with other participants' responses.

As the book is new, we wanted to know what you found helpful about the book, as well as the parts that were less useful. Your feedback will guide us in the future, to make sure that the best possible book is printed, so that it is helpful for those who need to use it. After all the interviews have been completed, we will send the draft findings to participants who have opted to be part of the Participant Panel. The Participant Panel Invitation should have been given to you at the time you consented to participate in the study. The panel will review the draft findings and suggest amendments to the research team. If you would like to be part of the Participant Panel but have not completed the invitation, you can still become a member of the panel, please ask the researcher for another copy.

We also want others to know about, and learn from this research. Therefore, we are hoping to present these findings at conferences and publish it in scientific journals.

As well as this, your anonymised responses have been used as part of a project that will contribute to the researcher gaining a Doctorate in Clinical Psychology. We will learn from your experience and apply it to our practice when we qualify as Clinical Psychologists in the future.

We hope that you have found the experience positive and we will send you the findings of the research when it is completed.

Thank you once again.

Yours sincerely,

Trainee Clinical Psychologist

Appendix 9: Participant Panel Invitation

Participant Panel Invitation

Thank you for agreeing to take part in our study. After we have completed the interview, your responses will be collated with other participants' answers and written up as a piece of research. It is important to us that the research accurately captures what participants have said. To ensure this, we need a small panel of participants to read a draft of the research and suggest any modifications if required. This can be done via email or post and further information about this activity is outlined in the Participant Information Sheet.

We would like to invite you to be part of this panel. This is completely voluntary and you do not have to be part of this panel. Deciding not to be part of this panel will not affect your responses or opportunity to participate in any future research.

You do not have to decide now whether you would like to be part of the panel, you can think about it, take this information sheet away with you and talk about it to friends and family before you make up your mind. If you would like to know more, or like to be part of this panel, please write your details below and return it in the envelope provided. The researcher will then call you to establish the best way to do this.

Please tick one of the boxes below, complete your contact details and return the reply slip to the research team in the enclosed envelope.

No, I would not like to be part of the panel

Yes, I agree to being part of the panel and agree for the researcher to contact me about it.

Name: _____

Telephone Number: _____

The best time to contact me is:

Appendix 10: Confirmation of ethical approval



Professor Reg Morris
South Wales Doctoral Programme in Clinical
Psychology, Cardiff University
11th Floor, Tower Building, 70 Park Place
Cardiff
CF10 3AT

Email: hra.approval@nhs.net
Research.permissions@wales.nhs.uk

26 April 2019

Dear Professor Morris

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Rebuilding life after stroke: A Qualitative Exploration of Stroke Survivor and Staff Experiences
IRAS project ID:	227883
Protocol number:	SPON1676-18
REC reference:	18/WA/0323
Sponsor	Cardiff University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

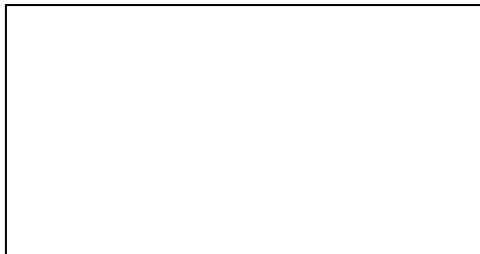
The document *'After Ethical Review – guidance for sponsors and investigators'*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

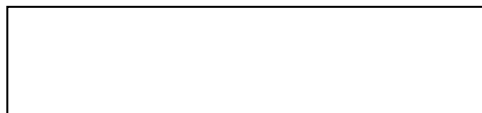
Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.



Please quote this on all correspondence.

Email: **INSERT for nation of sender** hra.approval@nhs.net Research-permissions@wales.nhs.uk



Appendix 11: Letter of Access for Research

	ur Ref/ eich cyf: ur ref/ ein cyf: ite/ dyddiad: / ffôn: Fax/ ffacs: Email/ ebost: Dept/ adran:	
--	-------------------------------------------------------------------------------------------------------------------	--

Hannah Dunford
Trainee Clinical Psychologist
South Wales Clinical Psychology Doctorate Programme
School of Psychology
Tower Building
Park Place
Cardiff
CF10 3AT

Dear Ms Dunford

Re: LETTER OF ACCESS FOR RESEARCH

CT/1067/227883	Rebuilding life after stroke: survivor and staff experiences
----------------	--------------------------------------------------------------

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this

--

 management check are in place in accordance with the

--

 is letter confirms your right of access to conduct rese

--

 Health Board for the purpose and on the terms and

--

 commences on 11/06/19 and ends on 01/10/19 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the | Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a

--

 y Health Board premises. You are not entitled to any

--

 ovided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research the

--

 board, you will remain accountable to your employer

--

 follow the reasonable instructions of your nominated

--

 sion or those given on his/ her behalf in relation to the terms of this right of access.

[Redacted]

whether or not legal proceedings are issued, arising out of or in connection with this claim, you are required to co-operate fully with any investigation by this NHS organisation in relation to such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Y
P
Y
d
to
M

[Redacted]

ork.
ing its
n and
ust

observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Cwm Taf Morgannwg University Health Board will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where applicable, your substantive employer will initiate your Independent Safeguarding Authority (ISA) registration in-line with the phasing strategy adopted within the NHS and the applicable legislation. Once you are ISA-registered, your employer will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your substantive employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or ISA registration, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

[Redacted]

Appendix 12: Example Transcript Excerpt and Coding

Example 1

<p>Interviewer: Brilliant. In what ways, if any, has the book changed or supplemented your practice?</p>	
<p>Participant: Um, I think it's been quite helpful um actually kind of using it with um patients but also kind of signposting them to have something I think that they can refer back to.</p>	Signposting
<p>Interviewer: Yeah.</p> <p>Participant: And, but also the feedback I've got as well from patients they quite enjoy the first couple of chapters as well because it helps them understand what's happened to them.</p>	Understanding what's happened to them
<p>Interviewer: Aw brilliant. You said you've used it with people. When working with them how did you use the book?</p>	
<p>Participant: Actually choosing a couple of the exercises, going through them and explaining them and getting them to go away and do it for homework. I don't like that word homework but in essence go</p>	Guided Bibliotherapy

<p>away, try the strategies and then come back and we will discuss how they got on with them, any problems or what not.</p> <p>Interviewer: How did you particularly support them? Did you have to do it hand's on or?</p> <p>Participant: Yeah you know the experiential practice with some it depends on what exercise we are doing. Or kind of do it in the session and get them to go away and build on what we've done particularly around like values stuff and kind of thinking about goals and coming back and we'll reflect ad go over what work they've done.</p>	<p>Guided Bibliotherapy</p>
<p>Interviewer: Ah brilliant. And did you work through it in parts on a 1-1 basis or in a group?</p> <p>Participant: 1 – 1 yeah.</p>	<p>Guided Bibliotherapy</p> <p>1-1</p>
<p>Interviewer: And have you given them the book to use independently or use it with them?</p> <p>Participant: Both, yeah both. To be honest I recommend it to pretty much all of my patients because I just think it's such a good book but I've also recommended um to kind</p>	<p>Signposting</p>

book is me it's like reading about my life, its brilliant. So he found it really helpful.

Um yeah pretty much everyone I've recommended it to have really found it yeah just helpful and particularly I think the first kind of couple of parts explaining about what stroke is and how it can effect you I think as much as they get informed of these things when they are an inpatient whether it's too much for them at that point to take in or they just don't take it in. When they get home they are like what's happening to me I don't understand so I think this book has helped some people get an understanding of what's going on and it's ok, its not abnormal, their not going mad or yeah.

Interviewer: OK that's great. Have you had any negative feedback on the book at all?

Participant: No, No. Not that anyone's said anything to me.

Interviewer: Do you think the book is easy or difficult to use?

Participant: I think it's quite easy and I think that's what I liked about it when I first

Understanding what's happened to them

Stroke Journey

Understanding what's happened to them

Nothing unhelpful

<p>used it. There's not too much information on each page. The kind of Diagrams and no jargon so it's quite easy to read and I think relatable from what patients have fed back to me.</p>	<p>Clearly set out</p> <p>Clearly set out</p>
<p>Interviewer: Are there any particular parts that you've found easy?</p>	
<p>Participant: I think all of it really because I think even the third part with some of the exercises because I think ACT based stuff can sometimes feel a little bit abstract but even some of those exercises I feel are really well written.</p>	<p>ACT</p> <p>Well written exercises</p>
<p>Interviewer: Are they any parts which you've found difficult?</p>	
<p>Participant: Um, no, not really, not difficult. The third part as I said because it is the therapy part of it, making improvements I think people still have to be motivated to try those things and I think that's why sometimes working with someone alongside with the book you know Is quite a helpful approach but again it just depends on the person.</p>	<p>Third part – motivation to change</p> <p>Guided Bibliotherapy</p> <p>Depends on the person</p>

Example 2

<p>I: Has the book supplemented your practice or changed it in any way?</p>	
<p>P: Yeah I think it's definitely in my awareness when I'm running groups or courses or suppose my reticence to mentioning it to 1-1 clients is they are often in such financial hardship for a lot of reasons, the cost sounds like quite a lot.</p>	Group Work
<p>However, it's certainly lodged well in my mind, the first port of call for someone who's stroke affected. It certainly has been key when taking on board students and volunteer counsellors as part of mentioning it as part of their induction as a really good read and resource because again it contextualises how stroke can affect somebody in all those various ways.</p>	Signposting
<p>I: So am I right in surmising that you've used the book maybe to supplement the training of other staff?</p>	
<p>P: Yes that's nicely summarised that's what I'm getting at. I haven't thought about it that way until you asked the question as I've</p>	Understanding what's happened to them.

<p>always just thought you'd be asking about my 1-1 work but actually my whole role encompasses training and certainly in terms of taking on board volunteers and making sure that they have a very thorough grounding on how stroke impacts.</p>	<p>Used to train staff</p>
<p>I: If someone was working directly with a stroke survivor and the book how do you think it could be best used?</p>	
<p>P: Interesting question. I think its got potential for 1-1 and group work. What I find at the end of the Action After Stroke course where he have a session where there's no specific input but an opportunity for people to reflect on what people have got out of it those sorts of environments are really useful for peer support so I can imagine that perhaps given that if time was no object it is feasible that there could be a group or short course we could run around the book potentially. That's not what we are doing at the moment because of how we use time etc. And in terms of 1-1 I do think that perhaps because we are so resource limited that our counselling sessions are limited to 6</p>	<p>1-1/Group work</p>
	<p>Role Related</p>

<p>but it would be really interesting to know.</p> <p>There could be some mileage to the book but it probably needs quite a skilled person to work with somebody with it. It flitted across my mind for a moment that it might be more useful for someone who is further along in their recovery and has found the book useful to have conversations with somebody maybe like a buddying thing. But to really get the mileage out of the book there needs to be a skills facilitator.</p> <p>I: Have you had any feedback at all from people you've recommended the book to or people who have used it?</p> <p>P: Only in terms of the volunteer counselling team and they said it was useful. I know that they have then gone on to recommend it to some of their counselling clients so it's a good resource in that respect.</p> <p>I: Do you think the book would be easy or difficult to use?</p> <p>P: Personally, I'm not stroke affected but I think it's one of the best presented books</p>	<p>Role Related</p> <p>Useful later</p> <p>Role Related</p> <p>Signposting</p> <p>Easy to use</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------

<p>potentially for that audience that I have seen.</p> <p>Because of the colour coding, because of the spiral bounding, the tabs, the pictures for the aphasic clients. I thought it was incredible, there's a lot of thought around the design gone into it and it's been one of the best aids or books I could imagine recommending to the stroke affected community.</p>	<p>Clearly set out</p>
<p>Interviewer: Do you think the book has the potential to help survivors?</p> <p>P: Yes I think it does. Those exercises are very thought provoking and very useful and they are really in line with some of the ACT principles.</p>	<p>Well written exercises</p>
<p>I: In terms of usability did you think the book was easy to navigate and the text was easy to read etc</p> <p>P: Yes like I say in terms of the colour coding and the tabs and things really really helped.</p>	<p>Easy to use</p>

Example 3

<p>Interviewer: In what ways if any has the book changed or supplemented your practice?</p>	
<p>Participant: It's definitely added because I think sometimes when you go to visit people um you can be there for quite a while talking about the psychological impact it</p>	<p>Psychological impact</p>
<p>has on them especially if they've got anxiety or depression um but it's nice to know that you've left something with them</p>	<p>Signposting</p>
<p>that they can go back to when you're not there. And I think because it has the stories from other stroke survivors and I think the</p>	<p>Stroke Survivor Stories</p>
<p>hardest bit is not everybody, because we do have groups in Cardiff that we encourage people to go to, to speak to people in the same situation but not everybody likes</p>	<p>Depends on the person</p>
<p>group so it's very difficult. That's why I find this book is their own little group their</p>	
<p>getting peer support and stories and</p>	<p>Stroke Survivor Stories</p>

information from this book, so I do find it adds a lot to my service.

Interviewer: That's really good. And when working with stroke survivors how did you use the book?

Participant: Depending on what they were going through and if their visually impacted so not everyone can use but then I found that I didn't just give it to the person who had the stroke I gave it to their relatives or carers because I found they could gain some information from it. I definitely said to look at it in parts. I'd go through it with them anyway to briefly go through it all just to explain the parts and remind them that there the exercises in there if they wanted to do them and I'd leave it with them then to read it in their own time.

Interviewer: So, you gave it for them to use independently then?

Participant: Yeah.

Involve family/carers

Guided bibliotherapy

1-1/Own time

Interviewer: Have you ever used it in a group?

Participant: The peer support group they were going through the book to see what parts they enjoyed the most, what parts they found most relevant to them and it actually gave them a great topic to talk about. And it starts them off on their stories and their own recovery journeys and things like that. So, they've gone through it bit by bit and I think they even tried the exercises as well together. So, it was good to see who it worked on and who it didn't.

Interviewer: In an ideal world what do you think would be the best way to use the book?

Participant: I could go through the book individually with someone if that's what they needed. I haven't actually trialled that, so I don't know but maybe it's something to think about going forward. But maybe to go

Group Work

Stroke Survivor Stories

Depends on the person

Role Related –

Confidence/time/training/resource

through it more, in more depth and it may even encourage people to open up a bit more about how they are struggling and obviously to do the exercises together they might find it a bit more reassuring but it's the time.

Appendix 13: Code Transformation

37 tentative codes were developed in accordance with stage 2 of Thematic Analysis (Braun & Clarke, 2006). 12 codes were then established following further refinement as per stage 3 of Thematic Analysis. 6 sub themes were then developed within 3 overarching themes from the 23 codes (Stage 5 of Thematic Analysis).

Tentative Codes (37)	Code (22)	Sub Themes (6)	Themes (3)
Signposting	Confidence	“I’m not alone” – Normalisation	Perceived impact of the book for stroke survivors
Understanding what has happened to them	Resource	Perceived scope of the book	Perceived impact of the book on staff
1-1	Knowledge	Professional role	Features of the book
Depends on the person	Modes of Use	Use in practice	
Role Related	Support	Accessibility	
Third part – motivation to change	Level of Training	Exercises	
Nothing unhelpful	Involving Family and Carers		
Helped Survivors	Motivation to change		
Clearly set out	Stroke Journey		
Recommendations for Change	Psychological impact		
Involve family/carers	Impairment		
Guided bibliotherapy	Usability		
Well written exercises	Profession		
Feels relevant	Service User Contribution		
Staff training	Language		
Changed way of working	Format		
Easy to use	Sequencing		
Didn’t know about audio-visual exercises	Exercises		
Psychological impact	Audio-Visual		
Useful later	Staff Training		
Stroke Survivor Stories	Guided Practice		
Visual Impairment	Nature of ACT		
Aphasia			

Peer Support			
Group work			
Confidence			
Resource			
Knowledge – survivors			
Knowledge - staff			
Usability			
Involving the system			
Stroke Journey			
Visual Impairment			
ACT			
Psychological Impact			
Cognitive Impairment			
Aphasia			

Appendix 14: A 15-Point Checklist of Criteria for Good Thematic Analysis (Braun and Clarke, 2006)

Process	No.	Criteria	How criteria is met in the current study
Transcription	1	The data has been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for “accuracy”.	Recordings were listened to by the first author as soon as possible after the interview took place. The data was then transcribed by the first author the same day or as soon as practicable. All of the comments made by the interviewee were transcribed. The transcriptions captured any pauses, laughter, or other features of conversation. The recording was re-listened to post transcription to ensure the conversation had been transcribed correctly.
Coding	2	Each data item has been given equal attention in the coding process.	The researcher highlighted data that they felt gave important information throughout the transcript. Such information included single words such as ‘normalising’; sentences such as ‘they are not alone’ and ‘it provided opportunities for peer support.’
	3	Themes have not been generated from a few	The highlighted data was then re-read by the researcher. Attempts were made to try and understand what each participant was referring to in the highlighted excerpt.

		vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.	
	4	All relevant extracts for each theme have been collated.	The information was then placed into categories. This gave rise to the developments of a number of codes. Initial codes were then placed into broader themes which appeared to fit the data. Main themes and sub-themes were then developed based on these themes.
	5	Themes have been checked against each other and back to the original data set.	The researcher then re-looked at the themes and considered how they felt in relation to each of the other themes and in relation to the data set as a whole.
	6	Themes are internally coherent,	Following the above steps, overarching themes then developed from the sub-themes and initial codes. Excerpts from the transcripts

		consistent and distinctive.	were used to illustrate descriptions of each theme.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.	Different codes were sorted into sub themes and overarching themes. These are then described descriptively within the text with example excerpts being provided.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.	Excerpts are provided within the text and example excerpts from transcripts are provided within the appendices.
	9	Analysis tells a convincing and well-organised story about the data and topic.	The way in which themes and sub-themes were developed are discussed in the methodology. The themes themselves are outlined and discussed within the results section starting with perceived impact for stroke survivors, perceived impact for staff and following with features of the book. The themes are then discussed in relation to psychological theory and clinical implications within the discussion section.
	10	A good balance between analytic narrative and	Overall themes are outlined within the main body of the texts with extracts of the transcripts used to support the themes.

		illustrative extracts is provided.	
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once over lightly.	Transcription took place as soon as practicable following the interview. Sufficient time was then allowed for the transcripts to be analysed. The data has been re-looked at several times following analysis. Member checking also took place via the participant panel. This allowed for triangulation of the data. The data was then written up for the final project.
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.	This is provided within the method section.
	13	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported	All raw data is available on request.

		analysis are consistent.	
	14	The language and concepts used in report are consistent with the epistemological position of the analysis.	The language used within the analysis follows a 'realist' epistemological stance whereby themes and subthemes are described using the words of the participants wherever possible.
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'.	The researcher outlined their own stance in relation to the data within the method section. The second authors position was also outlined.

Appendix 15: Thematic Maps

