

The process of adjustment from the place of loss and disconnection into rediscovery of
sense of wellness following Acquired Brain Injury

Alice Victoria Rose

Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology
University of East Anglia

Faculty of Medicine and Health Sciences

Submission Date: 04th April 2018

Thesis portfolio word count: 30,125

© This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived there from must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.

Thesis Portfolio Abstract

Context: Acquired brain injury (ABI) can have a profound impact on virtually any aspect of an individual's functioning and recent figures suggest ABI affects approximately 700,000 people in the UK each year. However, treatment and rehabilitation guidelines state there is currently insufficient evidence to recommend any specific form of therapy to support the process of emotional adjustment following ABI.

Aim: This research portfolio aimed to increase the understanding of the experience of well-being following ABI and the resources, which may contribute to this.

Design: The project is presented in a thesis portfolio format combining two main research papers: a systematic review and a qualitative, Interpretative Phenomenological Analysis (IPA), research study. The systematic review explored the existing evidence for the effectiveness of creative activity groups on psychological well-being including mood and quality of life. The IPA study examined eleven participant's accounts of their experience of well-being post-ABI and explored the resources that helped them to achieve this.

Results: The systematic review identified some tentative, preliminary evidence for the usefulness of creative activity groups as a potential resource towards improving psychological outcomes well-being post-stroke. The IPA research identified six main themes, which illuminated the experience of wellbeing in relation to internal and external resources. The resources identified broadly related to either; personality traits or states of mind, engaging in activities or support from others. Well-being tended to be described as feelings of "inner-peace", warmth or happiness.

Conclusion: Findings are presented tentatively, and further research is required. However, there is some evidence to suggest that supporting individuals to engage meaningfully in their environments may be beneficial to post-ABI adjustment and well-being.

Table of Contents

Acknowledgements	5
Chapter 1.	6
Systematic Review Prepared for Submission to: Disability and Rehabilitation	6
Abstract	8
Introduction	9
Aims	15
Research Questions	15
Method.....	15
Table 1. Keywords used in the literature search.....	19
Results	21
Figure 1. PRISMA Flow diagram	23
Table 2. Study Demographics	25
Table 3. Treatment information.....	29
Table 4. Summary of Results	41
Discussion	47
References	53
Chapter 2. Systematic review: Extended methodology	62
References	65
Chapter 3. Bridging Chapter	67
References	69
Chapter 4.	70
Qualitative Research Paper Prepared for Submission to: Disability and Rehabilitation	70
Abstract	72
Introduction	73
Research Questions	78
Method.....	79
Results	84
Discussion	103
References	110

Chapter 5. Extended methodology	115
References	122
Chapter 6. Overall Discussion and Critical Appraisal	123
Summary of Findings	123
Critical Evaluation of qualitative review	124
Critical Evaluation of systematic review	126
Conclusion	128
References	129
Appendices	131
Appendix A: Global self-system (Ownsworth, 2014)	131
Appendix B: “Y-shaped” model of rehabilitation following ABI (Gracey, Evans, and Malley, 2009)	132
Appendix C: The Enduring Experience of TBI Model (Levack et al., 2010)	133
Appendix D: Definition of Well-being (Dodge, Daly, Huyton and Sanders, 2012)	134
Appendix E: “Dwelling-Mobility” lattice (Galvin & Todres, 2011)	135
Appendix F: Research and Ethics Approval	136
Appendix G: Health and Research Authority Approval	141
Appendix H: Interview Topic Guide	149
Appendix I: Study advertising poster	151
Appendix J: Participant information Sheet	153
Appendix K: Consent to Contact Form	161
Appendix L: Demographic Screening Questions	162
Appendix M: Consent to Participate Form	163
Appendix N: Email confirmation of confidentiality agreement with transcription service	165
Appendix O: Signed confidentiality agreement with transcription service	166
Appendix P: Guidelines for Authors	167
Appendix Q: Samples of analysis	174

Acknowledgements

Firstly, I would like to thank my Supervisor Fergus Gracey for always being supportive, encouraging, enthusiastic and available at short notice. I would also like to my secondary Supervisor, Paul Fisher, for his valuable insights into qualitative research and my Advisor, Kiki Mastroyannopoulou for her support and guidance.

I would especially like to acknowledge the individuals that participated in this research. A truly heartfelt thank you to each of you for sharing such personal experiences with me. Thank you also to the kind staff at the services that helped with recruitment, I'm extremely grateful for your input. This research would not have been possible without the interest and support from yourselves.

Finally, I would like to thank all the family and friends that have supported me to do this. Special thanks go to Harry and my Mum and Dad for their unconditional support. You have all supported me through this journey and I simply would not have made it this far without your love, faith and generosity.

Chapter 1.

Systematic Review Prepared for Submission to: Disability and Rehabilitation

What is the evidence for the effectiveness of “creative activity groups” for improving psychological outcomes for people who have had a brain injury?

Alice Rose^a, Fergus Gracey^{b*}, and Paul Fisher^c

^{abc}Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom

*Correspondence concerning this article should be addressed to Fergus Gracey,
Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom.

Email: f.gracey@uea.ac.uk, 01603 456161 (ext.2898)

Abstract

What is the evidence for the effectiveness of “creative activity groups” for improving psychological outcomes for people who have had a brain injury?

Aims: The primary objective was to review the evidence for the effectiveness of creative activity groups on psychological well-being including mood and quality of life (QOL). The review examined the types of creative activity groups offered and the outcome measures used to assess their effectiveness.

Methods: A systematic review of the literature was conducted using the CINAHL, PsycINFO, PubMed and Cochrane databases alongside relevant manual searches. Eleven studies fitted the inclusion criteria and the data from each study was collated. Study quality was evaluated using the Cochrane risk of bias tool.

Results: Eight of creative activity groups identified were music-based interventions, and three studies provided art-therapy based interventions. Ten different mood outcome measures were utilised across the studies reviewed. Just five studies reported statistically significant improvements in mood, and only one reported significant improvements in QOL scores following intervention. Only one study reporting statistically significant improvements in mood and QOL had a low risk of bias. Therefore, the findings in the current literature should be viewed with caution.

Conclusion: There are some promising findings within the literature regarding the possible potential benefits creative activity groups may have on psychological outcomes following an ABI. However, the findings are diverse and inconclusive. Therefore, definitive conclusions about effectiveness of creative activity groups on improving psychological sequelae following an ABI cannot be made.

Keywords: acquired brain injury; arts in health; mood; quality of life; creative interventions; activity groups; rehabilitation

Introduction

Brain Injury prevalence and impact

A recent meta-analysis suggests that approximately 12% of the general adult population has a history of Traumatic Brain Injury (TBI) [1]. In the UK, 348,934 people were admitted to hospital as a result of head injuries in 2013-14, an increase of 10% since 2005-6 [2].

The consequences of brain injury for individuals can be varied and devastating, and there is a wealth of research documenting the impact of Acquired Brain Injury (ABI). It can affect almost any aspect of physical and cognitive functioning and, at the deepest level, can alter one's sense of self or self-identity [3]. It is unsurprising therefore, that ABI has been shown to increase vulnerability to developing a range of DSM-IV Axis-I and Axis-II disorders, including depression, anxiety, PTSD and personality disturbances, in both the short- and long-term after brain injury [4,5].

Levack, Kayes and Fadyl [6] completed a meta-synthesis of qualitative research into the lived experience of recovery following brain injury. They concluded that the most significant effects of brain injury were the subsequent mind/body, pre-injury identity and social 'disconnect' which impact upon individuals emotional sequelae. They posit that successful recovery requires 'reconstruction' of self-identity, place in the world and personhood. In their 'enduring experience of TBI' model Levack, Kayes and Fadyl [6] indicate internal and external resources are central to the reconstruction process. The 'internal' resources they refer to include the personal strengths that people retain following their injury such as, capacity for hope, optimism, strength of will, appreciating successes and good things in life. External resources include the support and opportunities provided by clinicians, professional rehabilitation services, communities, friends and family members. This includes opportunities to try activities that are achievable, meaningful and a

means of learning or coming to terms with the effects of brain injury. It is these external resources and sources of support that are of particular interest in this review, specifically, the impact of participating in creative activity groups.

Treatment

For long-term rehabilitation treatment following ABI, the NICE Head Injury Quality Standard (QS74) [7] directs clinicians to the SIGN guidelines for brain injury rehabilitation in adults [8]. These guidelines recommend implementing a goal-focussed, comprehensive/holistic neuropsychological rehabilitation programme involving a multidisciplinary team to address cognitive, emotional and behavioural difficulties; the aim is to improve functioning in meaningful everyday activities. However, the guidelines state there is insufficient evidence to recommend any specific form of therapy, including Cognitive Behavioural Therapy (CBT), for many of the behavioural and emotional difficulties patients may experience after brain injury, such as challenging behaviour or depression. This suggests further research is required to discover the most effective treatments for people with a brain injury and further develop treatment guidelines.

There is “a paucity” of adequately powered and controlled studies, including randomized controlled trials” into the effectiveness of CBT following ABI [9–11]. Within the research that has been conducted, is a lack of consistent evidence for the efficacy of CBT as a treatment for depression and mood disorders following ABI (See: Fann, Hart & Schomer, 2009 [9]; Kangas and McDonald, 2011 [12]; Khan-Bourne and Brown, 2003 [10]; Soo and Tate, 2007 [11]; Waldron, Casserly, O’Sullivan, 2013 [13] for review). Waldron, Casserly and O’Sullivan [13] found that, although there is some support for the use of CBT in treating depression and anxiety post-ABI, “CBT is not a panacea” as its beneficial effects were rarely generalised and often only created a partial reduction in symptoms. Additionally, there were “frequently cases that do not improve” following

CBT treatment [13]. One of the key arguments to explain why CBT is inconsistently effective as a treatment with the ABI population is that people experiencing cognitive deficits may struggle to apply the cognitive restructuring (CR) techniques that form the basis of treatment. This raises the question whether traditional CBT is the best choice of treatment for this population [12]. Khan-Bourne and Brown [10] have published recommendations on how to adapt CBT for the ABI population to address this criticism. However, some authors have suggested alternative interventions altogether, such as Acceptance and Commitment Therapy (ACT) [12]. Kangas and McDonald [12] propose ACT may be beneficial for patients with ABI as this treatment modality focuses on enabling individuals to try to live a valued life whilst taking into account the limitations imposed by any physical or neurological deficits caused by ABI. Notably, four of the six core ACT principles already tend to be incorporated in holistic, multidisciplinary rehabilitation programmes [12].

The SIGN guideline [8] recommends that holistic rehabilitation programmes for patients with brain injury should improve functioning in meaningful everyday activities. Quality of life outcomes in people with ABI have been linked to satisfaction with leisure activities [14]. Mitchell, Craig and Passey [14] found that group therapy is an effective method for improving leisure satisfaction, quality of life and self-esteem in patients with an ABI. However, Iwasaki, Coyle and Shank [15] identified that leisure is often a “neglected life activity in the rehabilitation process” and developed a heuristic ecological frame work to demonstrate the central influence of engaging with enjoyable and meaningful leisure activities on quality of life and recovery from mental illness due, in part, to the positive influence leisure can have on emotion, identity and social connection. They state that meaningful leisure activities “can and should be considered when designing interventions” to promote recovery, health and quality of life [15]. Given the potential impact of ABI on mental health [4,5], this ethos can be readily applied to ABI rehabilitation. Reistetter and

Abreu [16] conducted a review of community integration after ABI concluding it should be a premiere goal of rehabilitation. They indicated treatment groups and protocols that facilitate naturalistic social situations could be employed as useful facilitators of community integration following ABI [16]. There is growing evidence in the ABI literature to suggest social group membership and participation might be helpful in supporting people to adjust to ABI and improve their subsequent quality of life. Gracey et al. [17] found that following ABI both subjective experience and activity, “meaning and doing”, are important to how individuals make sense of themselves. They identified that “feeling part of things” related to a sense of “belonging” and combining this with “relating”, “assertiveness”, “independence” and “active self” formed the construct “experience of self on the world” [17]. Findings such as these suggest rehabilitation should feature ways to support individuals find activities that are meaningful to them and offer opportunities to form connections with others.

Arts as treatment in health settings

One potential domain that is gaining interest and evidence to facilitate this is group-based arts and creative activities. Art, dance and music therapies have penetrated all areas of the healthcare system [18]. Creative activities have been shown to have a positive effect on health and well-being. Bungay and Vella-Burrows [19] conducted a review of the literature to explore the effect of participating in creative activities including music, dance, singing, drama and visual arts on the health and well-being of children and young people aged between 11 and 18 years. Although the research evidence they reviewed was generally weak, they found that participating in creative activities can have a positive effect on behavioural changes, self-confidence, self-esteem, levels of knowledge and physical activity. Leckey [20] conducted a systematic review into the effectiveness of creative activities on mental well-being of people aged 16 to 65. Similar to Bungay and Vella Burrows [19], weak evidence and assumptions in the literature that lack reliability and

validity were an issue [20]. However, they concluded evidence for including creative activities in healthcare is promising as it suggests the therapeutic effects can include: relaxation, a means of self-expression, improved immune-system and reduced blood-pressure and stress [20]. Additionally, Leckey [20] notes engaging individuals in creative activities may promote developing social networks as well as improve psychological and physical well-being.

Within the ABI literature there have been a number of studies investigating the effects of art therapy after ABI. Most published reports offer single case examples, meaning generalisation of the findings needs to be done with caution, however, the available evidence suggests art therapy “may address many of the diverse cognitive, emotional and functional needs” of people affected by ABI [21]. Music therapies have been shown to impact on cognition, speech, physical abilities, behaviour, mood and the phenomenon of unilateral neglect within the ABI literature [22]. Magee, Clark, Tamplin and Bradt [23] completed a Cochrane review of music interventions for ABI. They found that “music interventions may be beneficial for gait, the timing of upper extremity function, communication outcomes, and quality of life after stroke” [23]. However, many of the studies included in the review were at a high risk of bias, therefore they concluded more high-quality randomised controlled trials are needed on all outcomes before recommendations can be made for clinical practice [23].

Engagement with the Arts

Governmental cultural policy within the UK is based on an emerging therapeutic ethos that culture can help deliver improved quality of life and well-being [24]. The National Alliance for Arts, Health and Well-being was launched in 2012 because “creative activity has long been known to have tangible effects on health and quality of life” [25]. Supported by the Arts Council England it has been growing in momentum since its launch with an

ever-growing evidence base to support it. The Alliance seeks to promote the role creativity can play in health and well-being and promote diverse and dynamic disciplines in a variety of healthcare and community settings to prevent illness, enhance recovery and improve quality of life in long-term conditions [25]. Due to the long-term, life changing impact of brain-injury, Arts in Health interventions are well-suited to this population. The All Party Parliamentary Group for Arts, Health and Well-being Inquiry reported the strength of the evidence base renders arts initiatives for stroke particularly worthy of consideration by all CCGs [26]. There is some evidence to suggest that policies to support and promote arts in health are effective in increasing engagement. In 2016/17, 77.4% of adults had engaged with the arts at least once [27]. The Department for Culture, Media and Sport “Taking Part Survey” [27] shows there has been a significant increase in engagement levels the arts amongst adults who have a long-standing illness or disability, rising from 69.8% in 2005/06 to 73.7% in 2016/17. Although engagement remained 5.3% higher for adults with no long-standing illness or disability, this increase has reduced the engagement gap from 9.2 percentage points in 2005/06.

Group treatment in ABI

Group work is central to treatment in many different health and social services establishments [28] and ABI is no different, with group interventions primarily focussed on addressing impairments, such as cognition [29]. In an RCT comparing the effectiveness of group, individual and combined interventions, Ownsworth et al. [30] found that gains in behavioural competency and psychological well-being were most likely to occur in group settings, whereas individual interventions contributed particularly to gains in performance in goal-specific areas. This provides support for delivering therapeutic creative activities in a group setting to increase psychological well-being. Art therapy often takes place in groups; using art-making as a group activity, a form of self-

expression and a means of sharing art and experiences within a supportive group environment [31].

Aims

The main objective was to review the evidence of the effectiveness of creative activity groups in improving psychological outcomes for people with an ABI.

Research Questions

The primary research question was identified as:

- What is the evidence for the effectiveness of “creative activity groups” for improving psychological outcomes for people who have had a brain injury?

Three secondary questions were developed to enable this to be answered:

- (1) What creative activity group interventions have been evaluated using randomised controlled trials incorporating a quantitative measure for psychological outcomes?
- (2) What quantitative measures are used to evaluate psychological outcomes following a creative activity group intervention?
- (3) What effect do creative activity groups have on psychological sequelae, such as mood, well-being and/or quality of life, following brain injury?

Finally:

- What recommendations can be drawn from the literature reviewed?

Method

This review followed the Cochrane guidelines [32] and the five-step framework set out by Khan, Kunz, Kleijnen and Antes [33]:

- Step 1: Framing questions for a review
- Step 2: Identifying relevant work

- Step 3: Assessing the quality of studies
- Step 4: Summarising the evidence
- Step 5: Interpreting the findings

The primary review question was developed using the PICO (Participant, Intervention, Control, Outcome) structure outlined by both Khan et al. [33] and the Cochrane guideline [34]. This structure was also used to develop the search terms.

Identifying search terms

The five word groups were selected based on the PICO structure: Word group 1 identifies the participants included in the review; word group 2 reflects the interventions of interest; as there was no specific comparison group or treatment identified word group 3 reflects the study design that meets the inclusion criteria; word group 4 represents the outcomes of interest; and finally, word group 5 was added to reflect that the review is specifically interested in group interventions. Search terms were chosen based on the eligibility criteria and definition of “creative activity groups” outlined below. The final identified search terms are presented in Table 1.

Eligibility criteria

The review examined quantitative and mixed methodology studies that evaluated creative interventions that were facilitated in a group context for participants post-ABI. Eligibility criteria incorporated studies that included a control comparison group and were available in English. Further inclusion criteria were: (1) participants in the study intervention group have a diagnosis of non-progressive ABI such as stroke, tumour or traumatic brain injury (TBI) (i.e. a combination of participants with ABI and other diagnoses or purely ABI within the intervention group). Participants in the control group could have a combination of ABI and other diagnosis, purely ABI or no ABI; (2) Adult participants (mean age over 18 years); (3) The group intervention must comprise of more than two participants; (4) The

intervention group must have a rehabilitation focus (i.e. aimed to restore function, and to promote activity and participation, or adjustment to disability) and incorporate a creative element; (5) The creative element of the intervention group must involve participants actively participating in a creative activity, as defined by the Department for Culture Media and Sport [27], to produce novel creative output (i.e. playing music or singing, not simply listening to music or painting rather than visiting art galleries or viewing art); (6) The outcome evaluations reported must include a quantitative measure of mood, well-being or quality of life. This could include measures which incorporate these elements such as the Stroke Impact Scale.

Studies were excluded if they used qualitative methodology only or mixed methodology that did not report quantitative measures of mood or quality of life outcomes. Studies were also excluded from this review if they were case studies or intervention protocols which did not report outcome data, conference abstracts, critique or commentary articles. Studies were also excluded if participants were caregivers only (i.e. no participants in the intervention groups had a TBI).

Defining “Creative Activity Group” Interventions

The intervention(s) selected for this review were “creative activity groups”. This was defined by the review authors as participation in an art based activity which included an element of generation or production of artistic output. Therefore, the search terms were selected to reflect the definitions of art therapy and arts participation as outlined by the All Parliamentary Group for Arts, Health and Well-being [26,35] and the Department for Culture, Media and Sport [27]. Arts Therapies refers to drama, music and visual arts activities offered to individuals in a clinical setting by practitioners accredited by the Health and Care Professionals council [26,35]. The Department for Culture, Media and Sport Taking Part Survey (2017) [27] outlines several eligible activities and events which

may be defined as “arts participation” including: dance, music or singing, art and creative writing.

Table 1. Keywords used in the literature search

Word group 1	Word group 2	Word group 3	Word group 4	Word group 5
Brain Injur*	activit*	Randomi#ed	wellbeing or	Group
Stroke	art or artist* or draw* or paint*	Control*	well-being or	
Cerebrovascular accident or CVA	craft* or creative	Trial	well being	
brain tum#r	drama or theat* or danc*	case control*	quality of life or QOL	
	creative writing or poetry or poem	Comparison	Identity	
	music* or singing or choir	evaluat*	mental health	
	sew* or knit* or needlework		Mood	
	Photography		outcome*	
	pottery or ceramics		Impact	
	woodwork*		effect*	
	garden*		Rehabilitation	
			Treatment	
			psychological	
Notes:	*truncation 'phrase searching' #wildcard Words within groups combined with OR Groups combined with AND			
Limits:	English Language Adults			

Identifying relevant studies

The first author conducted searches of the CINAHL, PsycINFO, PubMed and Cochrane Database of Clinical Trials in November 2017 using the MeSH search terms presented in Table 1. These terms were selected to identify papers relevant to the study question based on the inclusion and exclusion criteria. The search was limited to studies of adult populations, published in English. Search terms within each of the first four word groups (Table 1) were combined with OR in the first instance. These were then combined with AND before adding AND “group” as a search limiter to complete the search. Manual searches of the reference lists of the articles included from the database search were also carried out.

Study selection

The first author conducted initial screening of titles of all articles identified to determine eligibility. Duplicate studies and studies that were clearly not eligible (i.e. studies of a medical nature such as drug intervention studies) were excluded from the review. Titles and abstracts of the retained articles were then screened for eligibility. If eligibility was not clear from review of the title and abstract the articles proceeded to a full text review. If it was still unclear if a study should be included in the review e.g. due to a lack of information about whether the intervention was delivered as a group programme (n = 1 studies) corresponding authors were contacted to clarify eligibility.

Data extraction and Quality assessment

Data was extracted from each included study following the Cochrane guidelines for data extraction [36]. This included details on number of participants and their demographics, interventions including the type of intervention, the setting and the duration of the intervention, the outcome measures used and a summary of the findings relating to well-being or quality of life and information relating to methodology relevant for the risk of bias

evaluation. Data were charted in table format that enabled extraction of key characteristics such as comparisons of participant groups, settings and interventions across the different studies (Table 2.).

As the papers included in the review were required to be controlled trials or RCT's the Cochrane Risk of Bias tool was used to assess the methodological quality of the studies [37]. This tool identifies six items across five different types of bias on which to rate studies: selection bias (random sequence generation and allocation concealment), performance bias (blinding of participants and personnel), detection bias (blinding of outcome assessment), attrition bias (incomplete outcome data) and reporting bias (selective reporting) along with a section for "other sources of bias". Items are rated as being "low risk", "high risk" or "unclear risk" of bias and judgements should be based on "material bias" which is defined as "bias of sufficient magnitude to have a notable impact on the results or conclusions of the study"[37]. After rating the studies for risk of bias on each of the seven domains, conclusions about the overall risk of bias for each study was made. All the articles were rated by the first author (AR). Three of the included papers were also rated by a second independent reviewer (final year trainee clinical psychologist). Where differences in the scores arose, the reviewers discussed these to reach a consensus.

Results

Study identification

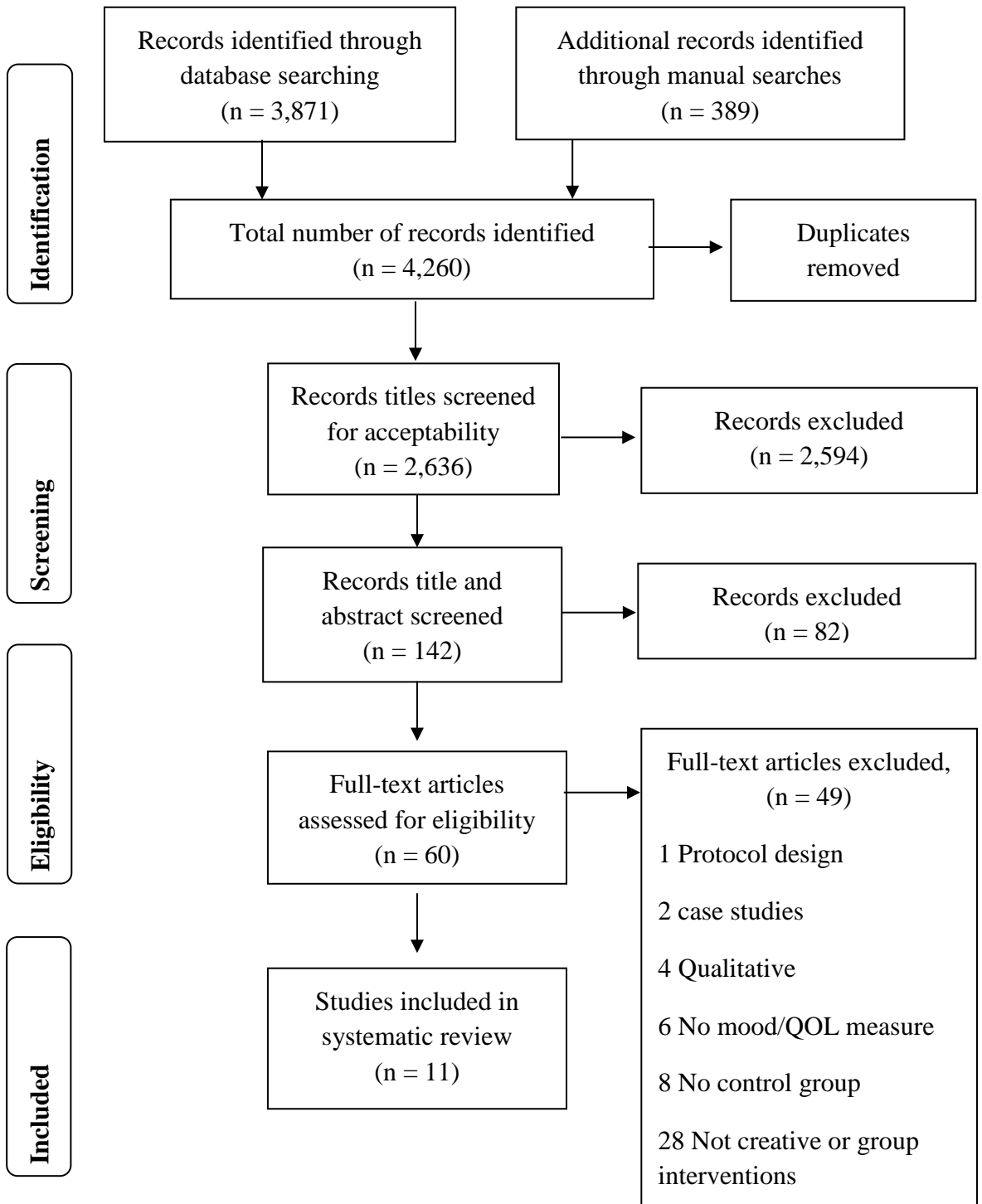
The initial search of the databases identified 3,871 papers, which combined with the 389 records identified through the manual search strategy meant 4,260 studies were reviewed for eligibility for inclusion. Duplicates were removed and the titles of these records were screened for eligibility. At this stage records were removed if they clearly did not meet the inclusion criteria, e.g. medical intervention studies, non-ABI population, participants were all carers or under the age of 18, interventions were not creative or delivered in groups.

After screening 142 studies remained to be screened by abstract. Studies removed at this phase included case studies, published study protocols with no outcome data, qualitative designs and interventions that were not creative activity group interventions. A total of sixty papers needed to be screened by accessing the full-text, reasons for exclusion at this stage are included in the PRISMA diagram presented in Figure 1. A total 11 studies were included in the review. A summary of the results of searches and stages are summarised in Figure 1.

Figure 1. PRISMA Flow diagram

Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009).

Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement [38].



Study characteristics

Participants

The 11 studies included in the review had a cumulative total of 637 participants. Of these participants, 435 had stroke and 44 had TBI. Two participants were diagnosed with each of the following: brain tumour, toxic exposure, and seizure disorder and one had a cerebral aneurysm. Two studies (n=152) did not report how many participants had each diagnosis of brain injury included in their studies inclusion criteria; one study stated participants (n=134) had “non-progressive neurotraumas” which included either TBI, Stroke or cerebral aneurysm [39], the other recruited 18 participants with “TBI or stroke” [40] (Table 2.).

Study designs

Five of the studies were Controlled Trials [39–43], and five were Randomised Controlled Trials (RCT’s) [44–48]. One study used an uncontrolled convenience sample for the comparison group [49]. Five of the included studies were conducted as feasibility or pilot studies[39,44,47–49]. All of the studies reported outcomes relating to mood or quality of life collected at baseline (pre-) and post- intervention. Two studies included additional data collection time points; both collected data at three-months post-intervention [46,47] and one also included an additional six-month follow-up [46] (Table 2.).

Table 2. Study Demographics

Study Authors [reference]	Country	Study design	N Total (T) Intervention (N) Control (C)	Setting	Diagnosis: Stroke (Haemorrhage /Infarct) TBI Other	Outcome measure(s) relating to psychological outcomes	Outcome assessment time points	Overall Risk of Bias Rating
Kim, et al., (2011) [41]	Korea	Controlled Trial	T = 18 N = 9 C = 9	in-patient	Stroke = 18 (8/10)	BDI BAI	pre-and post- intervention	High
Jeong & Kim, (2007) [44]	South Korea	RCT	T = 36 N = 18 C = 18	community	Stroke = 33 (13/20)	PMS RCS Stroke Specific QOL scale	pre-and post- intervention	High
Kongkasuwan, et al., (2006) [45]	Thailand	RCT	T = 118 N = 54 C = 59	in-patient	Stroke = 118 (25/93)	HADS Pictorial Thai QOL questionnaire	pre-and post- intervention	Low
Jun, Roh & Kim, (2012) [42]	Korea	Quasi- experimental Controlled Trial	T = 30 N = 15 C = 15	in-patient	Stroke = 30 (5/25)	PMS (Korean version) CES-D	pre-and post- intervention	Unclear

Bunketorp-Käll, et al., (2017) [46]	Sweden	3-armed, RCT	T = 123 N = 40 C = 82 (41 active control)	community	Stroke = 123 (36/87)	Stroke Impact Scale	pre- and post-intervention 3- and 6-month follow-up	Low
Nayak, Wheeler, Shiflett & Agostinelli, (2000) [40]	USA	Controlled Trial	T = 18 N = 10 C = 8	in-patient	Stroke and TBI Figures not reported	faces scale	pre- and post-intervention	High
Ali, Gammidge & Waller, (2014) [49]	UK	Feasibility Study	T = 6 N = 6 C = 21	in-patient	Stroke = 6 (not reported)	HADS (intervention group only) TOM (intervention and control group)	pre- and post-intervention	High
Morris, et al., (2017) [47]	UK	RCT	T = 81 N = 41 C = 40	in-patient	Stroke = 81 (10/71)	Stroke Impact Scale PANAS Visual Analogue Self-Esteem scale	pre- and post-intervention 3 month follow-up	Low

Thaut, et al., (2009) [43]	USA	Quasi-experimental design (controlled trial)	T = 54 N = 31 C = 23	Unclear	Stroke = 5 (not reported) TBI = 44 Other = 5 (2 Toxic exposure, 1 brain tumour, 2 seizure disorder)	BSI-18 MAACL	pre- and post-intervention	Unclear
Berrol, Ooi & Katz, (1999) [39]	USA	Quasi-RCT. Mixed methods	T = 134 N = 70 C = 64	community	Stroke, TBI and cerebral aneurysm Figures not reported	MOSES Geriatric Depression Scale Minimal Data Set	pre- and post-intervention	Unclear
Zumbansen, et al., (2017) [48]	Canada	3 armed-RCT pilot	T = 22 N = 8 C = 14 (7 active control)	in-patient	Stroke = 21 (not reported) Other =1 (brain tumour)	Visual Analogue Mood Scales Sickness Impact Profile	pre- and post-intervention	Low

Notes:
Study Designs; RCT (Randomised Controlled Trial).
Outcome Measures; BDI (Beck Depression Questionnaire), BAI (Beck Anxiety Questionnaire, PMS (Profile of Mood States), RCS (The Relationship Change Scale), HADS (Hospital Anxiety and Depression Scale), CES-D (Centre for Epidemiological Studies Depression Scale), TOM (Therapy Outcome Measure), PANAS (The Positive and Negative Affect Scale) BSI-18 (Brief Symptom Inventory-18), MAACL (Multiple Affect Adjective Check List), MOSES (the Multi-dimensional Observation Scale for Elderly Subjects)

Interventions

Of the eleven studies included in this review, six investigated the effectiveness of group music therapy interventions [40–44,46], three examined group art therapy interventions [45,47,49], one involved a group Dance/Movement Therapy (DMT) intervention [39] and one investigated a Choir group singing intervention [48]. Seven of the studies reported that the interventions had been delivered by the relevant qualified and experienced arts therapist specialising the type of intervention being offered [39,40,43,45,47–49]. One study reported the intervention was delivered by the researchers with input from a qualified music therapist [42]. In the other three studies it was not reported who delivered the interventions [41,44,46] (Table 3.).

All participants in the intervention groups continued to receive treatment as usual (TAU) in addition to the experimental creative activity, however participants who received DMT had one of their regular rehabilitation activities substituted for the intervention [39]. In addition to the group intervention sessions, one study provided a session of individual art therapy in addition to the group art therapy each week [47], and two studies ensured that participants received weekly counselling with a licenced psychotherapist [40,41]. Additionally, one study provided intervention group participants with brief, weekly telephone counselling to remind participants of the next group session and encourage them to practice exercises at home [44].

There were five different types of group Music Therapy interventions examined by the six music therapy studies; two investigated the effectiveness of group Music Therapy (MT) [40,41], the other four studies investigated group Neurologic Music Therapy (NMT) [43], Rhythmic Auditory Stimulation (RAS) [44], Rhythm-and-Music Therapy (R-MT) [46], or Music and Movement Therapy (MMT) [42].

Table 3. Treatment information

Study Authors [reference]	Intervention	Number of participants allocated to intervention	Intervention group size	Intervention duration (weeks)	Number of sessions per week	Session duration (minutes)	Total possible sessions (minutes) treatment	Session facilitator	Additional counselling received?
Kim, et al., (2011) [41]	Music therapy	9	Not reported	4	2	40	8 (320)	Not reported	Yes. Licenced psychotherapist
Jeong & Kim, (2007) [44]	Rhythmic auditory stimulation (RAS)	18	Not reported	8	1	120	8 (960)	Not reported	Yes. Weekly telephone counselling to remind participants of the next session and encourage home practice
Kongkasuwan, et al., (2006) [45]	Creative art therapy	54	5-10 participants per group	4	2	90-120	8 (960)	Creative Art Therapist	No

Jun, Roh & Kim, (2012) [42]	Music and movement therapy (MMT)	20	Not reported	8	3	60	24 (1,440)	Researcher with input from a Music Therapist to select music	No
Bunketorp-Käll, et al., (2017) [46]	Intervention: rhythm-and-music therapy (R-MT) Active control: horse riding therapy (H-RT)	40	Not reported	12	2	Not reported	24 (unknown)	Not reported	No
Nayak, Wheeler, Shiflett & Agostinelli, (2000) [40]	Music therapy	10	2-3 participants per group	up to 5	2 or 3	Not reported	10 (unknown)	Music Therapist	Yes
Ali, Gammidge & Waller, (2014) [49]	Interactive art therapy group	6	Not reported	6	2	50	12 (600)	Art Psychotherapist and Speech and	No

								Language Therapist	
Morris, et al., (2017) [47]	Modelled visual arts participation programme	41	Not reported	4	2	90 (group session) 60 (individual session)	8 (1,200)	Two qualified Visual Artists (with 5 and 7 years experience)	No. N.B. participants received one group and one individual art therapy session per week.
Thaut, et al., (2009) [43]	Neurologic music therapy (NMT)	31	Not reported	2	2	30	4 (120)	Board-certificated music-therapist with additional certification in NMT	No
Berrol, Ooi & Katz, (1999) [39]	Dance/ Movement therapy (DMT)	70	Ten treatment groups; 6-8 participants per group	22 (5 months)	2	45	44 (1,980)	Eight registered Dance/ Movement Therapists with comparable training plus experience	No

working with
geriatric
populations

Zumbansen, et al., (2017) [48]	Intervention: Choir group	7	Not reported	26 (6 months)	1	120	26 (3,120)	Experienced Choir leader and two experienced Drama Teachers	No
	Active control: Drama group								

Control groups

All the control participants received TAU and two studies had an additional control group which received an alternative group intervention such as horse-riding therapy [46] or drama therapy [48]. Three studies enabled the TAU control group to receive the creative group intervention after the study was complete [42,46,48]. Treatment was most commonly delivered twice per week ($n = 7$, 63.64%) with session length ranging from 30 minutes to 2 hours. The treatment delivery period ranged from two-weeks to six-months (26 weeks) in duration. The size of the intervention groups was only explicitly reported in three (27.27%) of the studies; the reported group sizes were 2-3 [40], 6-8 [39], and 5-10 [45] participants per group. Two studies reported that treatment sessions were sometimes unintentionally delivered to individuals rather than as a group because not all participants were able to consistently attend [40] or because “frequently only one participant per unit was randomised to receive art at any time making it difficult to organise group sessions” [47]. Morris et al. [47] stated participants therefore actually received fewer group sessions than one-to-one sessions during their art therapy intervention.

Risk of Bias

Risk of bias (Table 2.) was assessed using the Cochrane risk of bias tool [37]. Using this assessment tool [37], four studies [45–48] were rated low risk of bias, three posed an unclear risk of bias [39,42,43] and four were rated as being at a high risk of bias [40,41,44,49].

Low risk of bias

The four studies with the lowest risk of bias [45–48], had clear random sequence generation procedures with adequate allocation concealment. In all four studies the outcome assessors were blinded to treatment allocation however there was an unclear risk of bias in three of the studies from participants being aware of treatment allocation as this

could influence or bias participant reporting. Only one study [46] reported a process for ensuring double-blinding of participants and assessors and this was only possible because the study had two control conditions; an active and wait-list control and participants were not informed about the aims of the experimental versus control conditions. Three studies clearly reported the outcomes of the assessments as outlined in the methods section and were therefore judged to be low risk of bias on the “selective reporting” domain [45,47,48]. One study added an outcome measure after it had commenced, meaning this was not completed by all of the participants [46] so there was an unclear risk of bias on selective reporting for this study.

Despite being deemed low risk of bias overall, the studies still had some potential unclear or high risk of bias in certain areas. For example, the studies did not provide power calculations for the sample size and there was an unclear risk of bias due to variability in the dose of treatment (number of sessions attended) than was originally planned. Only two of the low risk studies reported the creative activity group sizes [45,48], and one study reported that participants actually received more one-to-one than group sessions because the randomisation procedure made it difficult to organise group sessions [47].

Although all the participants in the experimental conditions of all 11 studies received the creative activity group intervention in addition to treatment as usual, only two studies had an alternative active control group [46,48]. The general lack of active control group across the other nine studies included in this review means there is no control for the additional attention and therapy time patients were offered in all except these two studies.

Unclear risk of bias

Of the studies with unclear risk of bias [39,42,43], randomisation [42] or quasi-randomisation [39,43] and concealment procedures were not fully described. Participants

were not blind to the treatment condition in all three studies. Performance and detection bias were judged to be high risk in one study because assessors were involved in treatment delivery [42]. This was rated as unclear in the other two studies because blinding procedures for assessors were not described [43] or quantitative data collectors were blinded but qualitative data collectors delivered the creative intervention [39]. Severity of injury of the experimental and control groups was reported by one study that concluded this varied too greatly to “provide a strong direct comparison” [43]. Only one study with an unclear risk of bias reported a power calculation, and they reported recruiting two participants short of this figure [42]. The reporting of attrition in these studies was mixed; two studies reported the amount of attrition over the course of the study [39,42], however only one provides reasons for this [42]. In the third study, treatment and control group sizes fluctuate for each outcome and the reasons for this are not addressed [43]. The size of the creative intervention group was only reported by one study in this category [39]. All of the studies report the outcomes of the assessments in the methods section and were judged to have a probable low risk of reporting bias.

Whilst all study participants received the creative activity group intervention in addition to TAU, the participants of the dance-movement therapy had their TAU schedules adjusted to substitute DMT for one of their regular rehabilitation activities [39]. This poses an unclear risk of bias to the study outcomes because no further details are provided about which activities the intervention was substituted for, or whether this was the same for all participants. It appears this substitution has been made for scheduling and practicality reasons rather than as an intentional study comparison or control.

High risk of bias

Of the four studies deemed to be at a high risk of bias [40,41,44,49], only one described randomisation procedures [44]. Nayak et al. [40] described that their goal for

randomisation was not achieved due to ensuring that two or more patients were assigned to each scheduled treatment group. Two studies intervention groups consisted of patients who had volunteered to receive the therapy [41,49]. Additionally, there was no evidence of allocation concealment or blinding in any of these four studies. Therefore, the studies have a high risk of selection, performance and detection bias. Only one study reported conducting a power calculation [49]. This indicated the study would require 60 participants to be sufficiently powered, however they were only able to recruit six participants into the intervention group. Only one study had no attrition to report [41] and Jeong and Kim [44] reported attrition rates but did not state the reasons for non-completion. Two studies did not report any missing data [40,49] but did report high variability in the number of sessions participants attended and this is not addressed in the data before analysis. All of the high risk studies were judged to be at low risk of reporting bias as outcomes from all the assessments outlined in the method section were reported.

Study measures and outcomes

Mood

Ten studies (90.91%) included a mood specific outcome measure [39–45,47–49]. Half of the studies which assessed mood measured depression using a depression specific outcome measure including the Beck Depression Inventory (BDI) [41,50], Geriatric Depression Scale (GDS) [39,51] and the Centre for Epidemiological Studies Depression Scale (CES-D) [42,52]. Two of the outcome measures had scales specifically for depression alongside other mood ratings the Multiple Affect Adjective Check List (MAACL) [43,53] and the Hospital Anxiety and Depression Scale HADS [45,49,54]. All six of these studies observed an improvement in depression scores in participants receiving the creative activity group intervention [39,41–43,45,49]. However, only three found the change in depression scores to be significant [41,43,45] and two assessed the

change to be not significant [39,42] (Table 4). Of these studies, both those which found insignificant effects for depression were rated to have an unclear risk of bias [39,42], while those with significant results were found to have high [41], unclear [43] and low [45] risk of bias (Table 2). Ali, Gammidge and Waller [49] were unable to collect HADS data for the control group and did not conduct a statistical analysis on the scores they obtained from their participants and the study was judged to be a high risk from bias. However, the HADS scores demonstrated a clinically meaningful improvement in the depression scores of the intervention group as participants scores dropped from the “borderline range” into the “normal range”. Due to the variability in both the results found and the risk of bias ratings, it is not possible to confidently conclude that creative activity groups have a positive effect on depression ratings.

In addition to the depression specific outcome measures listed above, five other mood measures were used to evaluate possible psychological outcomes by the studies included in this review. These included: the Korean version of the Profile of Mood States-Brief instrument [42,44,55]; the seven-point Faces Likert-scale [40,56]; the Visual Analogue Mood Scales [48,57]; The Positive and Negative Affect Scale [47,58]; and the Global Severity Index from the Brief Symptom Inventory-18 (BSI-18) [43,59]. Therefore, in total, ten different mood outcome measures were used across the ten studies which assessed mood as a potential outcome of the creative activity groups. Only two of these measures, the Hospital Anxiety and Depression Scale [45,49], and the Profile of Mood States [42,44], were used by more than one study.

All ten studies that included a measure of mood, reported improvements in mood outcome measure scores as a result of creative activity group interventions (Table 4). However, only three studies (excluding depression specific outcome scores) reported these effects to be significant in the intervention group compared to controls [42–44]. The

significant effects were found using three different measures: the PMS [42,44], BSI-18 [43], and the anxiety scale of the MAACL [43] (Table 4). One of these studies was judged to have high risk of bias [44]. The risk of bias in the other two studies reporting significant effects of the creative activity intervention on mood was unclear [42,43] (Table 2). Five studies reported the improved mood scores in the creative activity intervention group to be non-significant [39–41,45,48] (Table 4) and two studies did not run the necessary statistical analyses to report p scores [47,49]. However, Morris et al. [47] do report small effect sizes using Cohen's d for changes to the intervention group PANAS scores (Table 4); the intervention group showed greater improvement in positive affect and lower increase in negative affect than the control group. Ali et al. [49] observed the participants in their intervention group experienced clinically meaningful change in their HADS anxiety scores, which transitioned from the “borderline” to “normal” range. Although this result is encouraging, there is no control group data to compare this result to and the study is deemed to be at high risk of bias.

Of the four studies which measured anxiety [41,43,45,49] using the Beck Anxiety Inventory (BAI) [41], HADS [45,49], or MAACL-Anxiety [43]. Only Thaut et al. [43] showed significant positive effects of the creative activity group intervention on anxiety scores ($p = .04$) however one additional study showed clinically meaningful change on the HADS anxiety scores following participation in the intervention group [49].

Quality of Life

Three studies [44,45,48] included a quality of life (QOL) outcome measure e.g. Stroke Specific QOL Scale (Korean Version) [44], The pictorial Thai Quality of Life questionnaire [45], and the Sickness Impact Profile [48]. QOL improved following the creative activity group interventions in two of these research studies [44,45], however this change was only found to be significant in one study by Kongkaswan et al. [45] ($p < .001$).

Zumbansen et al. [48] found no significant effect of creative activity groups on QOL scores ($p = .211$) the active control (drama) group's QOL scores improved slightly however, there was no improvement in reported QOL in the intervention (choir) group. Kongkaswan et al. [45] and Zumbansen et al. [48] were both assessed to have low risk of bias, however they report conflicting results. Jeong and Kim [44] was rated as being at high risk of bias and the improvement in QOL scores they reported was insignificant ($p = .831$).

Two studies [46,47] assessed perceived recovery and QOL outcomes using the Stroke Impact Scale [60,61]. Bunketorp-Käll et al. [46] showed significantly greater perceived recovery from stroke in the intervention and active control groups compared to the wait list control group ($p = .048$). This effect was maintained at 3-month follow up ($p = .002$), however the perceived recovery dipped below significance at 6-month follow up ($p = .054$). Morris et al. [47] reported participants in the intervention group had higher positive change scores than controls on the social participation, emotion and hand function subscales. However, the differences in scores were small and variability was high.

Social Interaction and Communication

Five of the studies included measures of communication or social interaction [39,40,44,47,48]. Zumbansen et al. [48] found no significant difference between groups on any measure, including their primary outcome: functional communication ($p = .501$). However, they did find a positive correlation between functional communication changes and attendance to social activities, suggesting that it may be social interaction of creative activity groups that has the beneficial effect on well-being. Morris et al. [47] drew similar conclusions as the changes in social participation (Stroke Impact Scale), although small, were greater in the intervention group than the control group. However, they also found that the Stroke Impact Scale communication scores declined in both the control and

intervention group, with the greatest decline reported in the intervention group. Both these studies were judged to have a relatively low risk of bias and therefore these insignificant results are deemed to be trustworthy. Similarly, Berrol et al. [39] found no significant effect using the Multi-dimensional Observation Scale for Elderly Subjects (MOSES, $p = .474$) [62]. However, they did find statistically significant between-group differences favouring the intervention group on the social interaction index of the MDS ($p = .0027$) [39]. This study has an unclear risk of bias, meaning these results may be somewhat less reliable than those reported by Zumbansen et al. [48] and Morris et al. [47]. The two studies which reported significant changes in social interaction [40] and social relationships [44] were both found to have a high risk of bias and therefore these results may be less reliable than the other studies'. Nayak et al [40] found family members of participants in the intervention group (music therapy) rated a significant improvement ($p < .02$) in social interaction among participants who were more impaired at the outset using the social interaction subscale of the Sickness Impact Profile [63]. Jeong and Kim [44] reported significant improvements on the Relationship Change Scale for the intervention group ($p = .003$).

Table 4. Summary of Results

Study Authors [reference]	Outcome measure(s) relating to psychological outcomes	Baseline outcome measure scores (Control) Experimental group (Mean, ±SD)	Post-intervention outcome measure scores (Control) Experimental group (Mean, ±SD)	Mean Change scores (control) Experimental group (Mean, ±SD)	<i>F</i> score <i>t</i> score Cohen's <i>d</i> ^b	<i>p</i> value
Kim, et al., (2011) [41]	BDI	(10.9, ±2.5) 14.8, ±6.4	(11.1, ±2.5) 12.4, ±4.6	(0.2a) 2.3	None reported	.048*
	BAI	(9.2, ±4.0) 9.2, ±4.0	(9.2, ±2.6) 9.0, ±4.3	(No change) 0.2	None reported	not reported
Jeong & Kim, (2007) [44]	PMS	(2.81, ±0.90) 2.11, ±1.02	(2.29, ±0.77) 1.56, ±0.82	Not reported	<i>F</i> = 0.013	.017*
	RCS	(3.03, ±0.67) 2.96, ±0.63	(2.83, ±0.68) 3.39, ±0.74	Not reported	<i>F</i> = 10.087	.003*
	Stroke Specific QOL Scale	(2.54, ±0.80) 3.25, ±1.08	(2.92, ±0.90) 3.58, ±0.87	Not reported	<i>F</i> = 0.046	.831
Kongkasuwan, et al., (2006) [45]	HADS: anxiety (0–21)	(6.5, ±3.7) 6.4, ±4.6 <i>p</i> = .877	(4.5, ±3.5) 3.3, ±3.1	(2.0, ±2.9) -3.1, ±4.6	None reported	.123
	HADS: depression (0–21)	(9.8, ±5.0) 10.7, ±5.8 <i>p</i> = .361	(7.9, ±4.9) 4.4, ±4.0	(-1.8, ±3.9) -6.3, ±6.5	None reported	<.001*
	Pictorial Thai QoL scale (0–72)	(33.3, ±12.6) 31.7, ±14.4 <i>p</i> = .519	(42.0, ±15.1) 49.6, ±12.7	(8.6, ±11.5) 17.5, ±14.9	None reported	<.001*
	PMS	(51.32, ±10.41) 46.31, ±14.77	(53.42, ±7.34) 36.85, ±14.55	(-2.08, ±15.59) 9.46, ±16.08	<i>t</i> = 1.818	.040*

Jun, Roh & Kim, (2012) [42] Bunketorp-Käll, et al., (2017) [46]	CES-D	(40.40, ±13.05) 32.06, ±11.34	(30.86, ±6.25) 25.60, ±11.82	(9.67, ±15.27) 6.46, ±11.82	$t = -0.589$.280
	Stroke Impact Scale (perceived recovery %)	Not reported	Post-intervention (W-L 17%; H-RT 56%) R-MT 38%	(W-L: -0.5, H-RT: 9.8 $p < .0001$) R-MT 5.2	None reported	(.001*) .048*
		3-month follow-up (W-L 22%; H-RT 49%) R-MT 55%	3-month follow-up (W-L 22%; H-RT 49%) R-MT 55%	$p = .032$		(.012*) .002*
		6-month follow-up (W-L 22%; H-RT 56%) R-MT 43%	6-month follow-up (W-L 22%; H-RT 56%) R-MT 43%	effect sizes % improvement (W-L: 0.7%, H-RT: 23.8%) R-MT 12.4%		(.001*) .054
Nayak, Wheeler, Shiflett & Agostinelli, (2000) [40]	Faces scale (self-report)	(5.00, ±1.41) 4.60, ±1.71	(3.88, ±1.36) 2.80, ±1.32	Not reported	$F = 3.27$	$p < .10$
	Social Interaction (family rating)	(44.50, ±7.19) 37.60, ±7.55	(42.88, ±8.34) 29.60, ±4.50	Not reported	F Not reported due to heterogeneity of covariance	$p < .02^*$
Ali, Gammidge & Waller, (2014) [49]	HADS: anxiety (0–21)	(Not assessed) 8 [borderline range]	(Not assessed) 6 [normal range]	Not reported	None reported	Not calculated
	HADS: depression (0–21)	(Not assessed) 10 [borderline range]	(Not assessed) 4 [normal range]	Not reported	None reported	Not calculated
	Therapy Outcome Measure	(10) 9	(12) 10.5	Not reported	None reported	Not calculated

Morris, et al., (2017) [47]	Stroke Impact Scale Emotion:	(72.4, ±20.4) 69.6, ±19.5		Post-intervention (5.3, ±18.5) 5.8, ±23.9 Follow-up (3.5, ±20.8) 3.9, ±19.1	post- intervention <i>d</i> = -0.35 Follow-up <i>d</i> = -0.18	
	Communication:	(69.5, ±24.9) 75.5, ±21.6		Post-intervention (-1.4, ±17.2a) -10.1, ±24.9a Follow-up (9.3, ±21.8) 1.1, ±21.8	post- intervention <i>d</i> = -0.54 Follow-up <i>d</i> = -0.11	
	Hand function:	(17.1, ±26.8) 16.1, ±27.3	Not reported	Post-intervention (25.7, ±35.2) 26.7, ±31.9 Follow-up (34.5, ±41.3) 29.8, ±31.3	post- intervention <i>d</i> = -0.05 Follow-up <i>d</i> = -0.12	Not calculated
	Social participation:	(39.5, ±26.3) 37.0, ±26.5		Post-intervention (-2.7, ±34.0) 3.4, ±27.7 Follow-up (19.5, ±33.9) 18.3, ±30.3	post- intervention <i>d</i> = 0.01 Follow-up <i>d</i> = -0.17	
	PANAS Positive affect (higher score better)	(24.3, ±7.8) 23.5, ±8.2	Not reported	Post-intervention (1.7, ±9.9) 5.4, ±9.2 Follow-up (2.8, ±10.1) 4.3, ±7.5	post- intervention <i>d</i> = 0.24 Follow-up <i>d</i> = 0.07	Not reported

	PANAS			Post-intervention	post-intervention	
	Negative affect	(20, ±8.1)		(4.5, ±9.4)		
	(lower score better)	20.2, ±7.8	Not reported	3.2, ±10.8	$d = 0.42$	Not reported
				Follow-up	Follow-up	
				(5.2, ±9.8)	$d = 0.18$	
				3.3, ±11.0		
	Visual analogue self-esteem scale (0-50)	(37.4 ±8.5)	Not reported	Post-intervention	post-intervention	Not reported
		37.6 ±7.6		(2.1, ±8.4)		
				-0.4, ±6.7	$d = -0.51$	
				Follow-up	Follow-up	
				(-0.2, ±7.5)	$d = -0.06$	
				-0.3 ±6.6		
Thaut, et al., (2009) [43]	BSI-18	(14.73, ±10.20)	(12.27, ±9.40)	Not reported	$t = (2.64) 3.60$	(.01*)
		18.87, ±16.40	14.57, ±13.51		$d = (0.25) 0.29$	<.01*
	MAACL					
	positive affect	(6.06, ±5.69)	(4.75, ±4.58)		$t = (1.91) -0.28$	(.04a*)
		10.35, ±7.20	15.57, ±8.02		$d = (-0.26) 0.03$.39
	Sensation Seeking	(1.31, ±1.58)	(0.88, ±1.36)		$t = (2.15) -2.91$	(.02a*)
		2.35, ±2.31	3.04, ±2.75		$d = (-0.29) 0.27$	<.01*
	Anxiety	(2.50, ±2.68)	(2.25, ±2.44)	Not reported	$t = (0.55) 1.86$	(.29)
		1.61, ±2.27	1.09, ±1.44		$d = (0.10) 0.28$.04*
	Depression	(1.31, ±1.96)	(1.31, ±1.99)		$t = (0.00) 2.14$	(.50)
		1.61, ±2.57	0.65, ±1.15		$d = (0.00) 0.52$.02*
	Hostility	(0.88, ±1.26)	(0.63, ±1.09)		$t = (2.24) 1.59$	(.02*)
		0.70, ±1.46	0.22, ±0.52		$d = (0.21) 0.48$.06
	MOSES	Not reported	Not reported	(4.43) 4.66	None reported	.474
	GDS	Not reported	Not reported	(3.91) 4.29	None reported	.435

Berrol, Ooi & Katz, (1999) [39]	MDS					
	Cognitive Performance Scale			(1.51) 0.84	None reported	.006*
	Social interaction	Not reported	Not reported	(4.73) 5.21		.0027*
	Mood Symptoms			(3.48) 3.02		.447
Zumbansen, et al., (2017) [48]	Test Lillois Communication Functional Communication (Global score)	W-L: 77.9, ±6.1; Drama: 78.1, ±13.6 Choir: 71.9, ±8.8 <i>p</i> = .393	Not reported	W-L: 0.6, ±3.2; Drama: 1.8, ±3.4 Choir: 6.6, ±11.4	None reported	.501
	Visual Analogue Mood Scales (Positive mood score)	(W-L: 980.2, ±3.7; Drama: 977.0, ±6.7) Choir: 970.9, ±6.9 <i>p</i> = .032	Not reported	(W-L: -0.5, ±4.1; Drama: -2.5, ±6.1) Choir: -6.7, ±0.4	None reported	.190
	Sickness Impact Profile (Positive quality of life score)	(W-L: 63.8, ±9.5; Drama: 68.3, ±14.3) Choir: 49.4, ±7.5 <i>p</i> = .016	Not reported	(W-L: -0.4, ±5.9; Drama: 3.5, ±4.9) Choir: -1.1, ±5.3	None reported	.211

Notes:

Outcome Measures; BDI (Beck Depression Questionnaire), BAI (Beck Anxiety Questionnaire), PMS (Profile of Mood States), RCS (The Relationship Change Scale), HADS (Hospital Anxiety and Depression Scale), CES-D (Centre for Epidemiological Studies Depression Scale), PANAS (The Positive and Negative Affect Scale) BSI-18 (Brief Symptom Inventory-18), MAACL (Multiple Affect Adjective Check List), MOSES (the Multi-dimensional Observation Scale for Elderly Subjects), GDS (Geriatric Depression Scale), MDS (Minimal Data Set).

W-L (wait list control), H-RT (horse riding therapy), R-MT (rhythm-and-music therapy).

a Represents a decline in functioning.

* $p < .05$.

^b Based on Cohen's *d* for effect size, where 0.2 is considered a small effect size, 0.5 a medium effect, and 0.8 or greater a large effect.

Additional outcomes

Physiological outcomes. Four studies included measures of physiological outcomes using the Range of Movement (ROM) [39,42,44], Timed Up and Go [46] or Functional Assessment of Movement and Perception (FAMP) [39] tests. All four studies employing measures of physical function [39,42,44,46] found some significant positive effects of the creative intervention on physical outcomes compared to TAU controls.

Activities of Daily Living. Two studies [42,45] measured activities of daily living (ADL's) using the modified-Barthel Index [64], however only Kongkasuwan et al. [45] found ADL's significantly improved following the creative activity groups.

Cognitive outcomes. Four studies measured potential cognitive changes using the Abbreviated Mental Test [45], Cognitive Performance Scale (CPS) [39], or elements of the Wechsler scales such as Digit Span and Letter-Number Sequencing [43,46]. Three studies found that cognitive changes significantly favoured the experimental group over the controls [39,43,46] and one found no significant change in cognitive scores [45]. The findings from Thaut et al. [43] revealed no significant improvement in memory or attention, but mental flexibility improved significantly after one 30 minute session of NMT.

Qualitative outcomes. Nayak et al. [40] reported that clinician's ratings showed participants of the music group were significantly involved in therapy and tended to be more motivated to participate than the control group. Berrol et al. [39] found that 84.4% of participants reported the treatment was enjoyable, 87% reported they enjoyed interacting with others in the group and 60% reported they had made new friends as a result of being in the group. It is also notable that 85.5% said being in a group made them feel happier and no one reported it making them sadder.

Synthesis of Results

Of the four studies that were deemed to have the lowest risk of bias [45–48], and therefore most trustworthy results; Kongkasuwan et al [45] found a significant effect for the intervention group on depression ($p < .001$) and quality of life ($p < .001$) however, anxiety scores did not significantly improve ($p = .123$). Similarly, Bunketorp-Käll et al. [46] reported participants perceived recovery on the stroke impact scale significantly improved after receiving the intervention ($p = .048$). However, Morris et al. [47] only reported small, variable, improvements to emotion, hand function and social interaction on the stroke impact scale, but declines in participants communication scores and Zumbansen et al. [48] reported participants did not significantly improve on either the measures of functional communication, mood or quality of life which they employed in their study.

The studies with higher risk of bias [40,41,44,49] reported clinically meaningful [49] or significant effects on depression and mood scores [41,44] and significant improvements in relationship or social interaction [40,44] outcome measure scores. This means that although creative intervention groups may have beneficial effects on well-being following ABI, the findings in the current literature cannot be asserted with confidence.

Discussion

This systematic review was conducted to investigate what quantitative research has been conducted into the effect of creative activity groups on psychological outcomes for people who have an ABI. It sought to answer three main questions to achieve this. The first question was, “what creative activity group interventions have been evaluated using randomised controlled trials incorporating a quantitative measure for psychological outcomes?” The review found that almost half (45.5%) of the studies identified provided interventions based on music therapy interventions [41–44,46] and a further two interventions also loosely fell within this domain as they have music at their core;

dance/movement therapy [39] and choral singing [48]. The other three studies all involved Art Therapy interventions delivered in group settings [45,47,49]. Considering the potential range and scope of creative activity group interventions defined as eligible for this review, the variety that have been evaluated by the identified research studies is limited. However, this finding is perhaps unsurprising given that art and music therapy are both established psychotherapeutic interventions with dedicated, qualified therapists who are registered with the Health Care Professions Council (HCPC) and employed within healthcare settings.

The second question examined by this review was, “what quantitative measures are used to evaluate psychological outcomes following a creative activity group intervention?” A broad range of qualitative measures were used to evaluate the outcomes of the studies included in this review. Ten different mood outcome measures were used in as many studies and only two of these mood measures were used by more than one study: the Hospital Anxiety and Depression Scale (HADS) [45,49,54] and the Korean version of the Profile of Mood States-Brief instrument [42,44,55]. Although many of the outcome measures were similar in nature, e.g. visual analogue and Likert rating scales, the number of different tools used makes a comprehensive synthesis of the results challenging as the results are not directly comparable. The outcome measures selected by the studies measure a variety of different variables which may contribute to overall well-being: mood, depression, anxiety, QOL, ADL’s, cognition and physical ability. This highlights the importance of researchers, healthcare professionals and patients having a shared understanding of target outcomes for rehabilitative interventions following ABI so that these can be assessed accordingly and measured consistently.

One noticeable omission from the studies included in this review, is an evaluation or investigation of the potential effects of the group processes involved in the interventions

and their impact on the groups outcomes. Six of the studies sought feedback from participants about their satisfaction of the creative activity group they attended [39,41–43,45,49] however, only two reported specifically the opinions of participants about the group aspect of the treatment [39,49]. Both these studies found that participants had rated the group element of the intervention favourably. There are several potential therapeutic benefits of group interventions including peer interaction, support and guidance [29], which may be especially pertinent to creative activity groups as both art and music therapies emphasise the importance of the relationship with the therapist [65,66]. Therefore, it is disappointing that not more attention has been given to this aspect of the intervention in this cohort of studies. Researchers could achieve this by directly comparing the effectiveness of creative activities in group, individual and combined settings. However, Patterson, Fleming and Doig [29] concluded this type of comparison may not be beneficial due to the different potential benefits of individual and group treatments.

The third question was “what effect do creative activity groups have on psychological sequelae, such as mood, well-being and/or quality of life, following brain injury?” Five of the ten studies which assessed depression and mood outcomes, reported significant improvements in depression or mood scores for the experimental group [41–45]. A further two documented non-significant improvements in mood [39,49], one of which represented a clinically meaningful change in anxiety and depression scores [49]. Of the three studies that measured QOL [44,45,48] only two found scores of the intervention group improved [44,45] and only one of these results was a significant change compared to controls [45].

There are some promising findings within the current literature noting positive outcomes for creative activity group interventions. However, only two of the studies judged to have a low risk of bias reported significant effects of the treatment on mood and

quality of life or perceived recovery for the intervention group over the controls [45,46]. The other studies reporting significant change were assessed to have unclear or high risk of bias. Consequently, little confidence can be placed in the findings for the effectiveness of creative activity group interventions in improving well-being following an ABI. In summary, the published findings for the effectiveness of creative activity group interventions are diverse and inconclusive. Therefore, definitive conclusions about effectiveness of creative activity groups on improving psychological sequelae following an ABI cannot be made.

Further research into the effectiveness of creative activity group interventions for improving well-being outcomes post-ABI is required. Currently, there is a wide variety of clinical measures being used to assess outcomes within the literature in this area and mood and quality of life outcomes often appear secondary to physical health outcomes. This is somewhat surprising given the potential benefits this type of intervention may have on domains important to post-ABI recovery such as social interaction with others, finding enjoyment, meaning and purpose and rediscovering a sense of self and place in the world. Therefore, well-being and quality of life outcomes appear to be somewhat overlooked within the current literature.

To effectively assess the impact of creative activity groups on well-being, greater consistency is required in the outcome measures used. To achieve this, researchers will need to take a theoretically coherent approach to how they view (a) the potential benefits of such groups, (b) what post-ABI recovery and well-being is and (c) how can it be measured. There are several published models of post-ABI recovery, however the Levack, Kayes and Fadyl [6] “enduring experience of TBI model” (Appendix C) provides a clear account of the recovery process and a theoretically grounded rationale for this type of intervention. The model posits that people with an ABI use both internal and external

resources to transition from a place of loss and disconnection to a state of reconstruction of self-identity, personhood and place in the world. Creative activity groups have the potential to be an “external resource” which can create a place of belonging for individuals who attend and help people transition from a place of loss to reconstruction of one’s self-identity and place in the world. How to effectively measure this change using an outcome measure is a challenge. Some of the studies reviewed have included measures of mood and quality of life that go somewhat towards toward this aim. The Basic Psychological Need Satisfaction Scale [67–69] is a questionnaire that assesses the degree to which people feel satisfaction with the three universal psychological needs posited by self-determination theory: competence, autonomy and relatedness [69], and appears to be a good fit with the potential gains participants may experience from creative activity groups which may contribute towards, and equate to, a general sense of well-being.

Limitations

Papers were selected for the review based on the inclusion criteria, however the definitions of the interventions included in the review was intentionally broad and a wide range of outcome measures were also considered acceptable for inclusion. This meant there is considerable variability within the range of interventions and outcomes identified and the search terms were intentionally far-reaching, which presented challenges in identifying relevant studies. However, the amount of eligible literature was limited and the methodological quality varied. Therefore, making direct comparisons between the interventions and their respective outcomes is challenging and the results of this review need to be viewed with caution.

As this review was conducted as part of a doctoral thesis, it was not possible in the time scale to have a second independent reviewer of study eligibility however, a second reviewer did rate the quality of three of the papers using the risk of bias tool [37]. The

methodological validity of this review would have been enhanced had there been a second reviewer for all papers on both of these key elements of the review.

Clinical Implications and Recommendations

Due to the inconsistent methodological quality and the variability in the interventions delivered, outcome measures used and the findings of the studies identified for this systematic review, it is not possible to make any firm recommendations regarding implications for clinical practice as a result of this review.

Conclusion

Although the results need to be interpreted with caution, there are some promising findings within the literature regarding the possible potential benefits creative activity groups may have on psychological outcomes following an ABI. However, the results of the review need to be viewed with caution as there is, as yet, insufficient research of adequate quality to draw firm conclusions and provide clear guidance about the provision of creative activity groups to improve psychological outcomes in ABI rehabilitation and further research is required.

Acknowledgements

The study authors would like to acknowledge Katherine Jackson for their helpful contributions as second reviewer evaluating the risk of bias in papers included in this review.

Disclosure of interest

The author reports no conflict of interest. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology.

References

- [1] Frost RB, Farrer TJ, Primosch M, et al. Prevalence of traumatic brain injury in the general adult population: A meta-analysis. *Neuroepidemiology*. 2013;40:154–159.
- [2] Headway. Acquired Brain Injury: The numbers behind the hidden disability. 2015;12. Available from: <https://www.headway.org.uk/media/2883/acquired-brain-injury-the-numbers-behind-the-hidden-disability.pdf>.
- [3] Ownsworth T. *Self-identity after brain injury*. Hove: Psychology Press; 2014.
- [4] Hibbard MR, Uysal S, Kepler K, et al. Axis I psychopathology in individuals with traumatic brain injury. *J. Head Trauma Rehabil*. 1998;13:24–39.
- [5] Koponen S, Taiminen T, Portin R, et al. Axis I and II psychiatric disorders after traumatic brain injury: A 30-year follow-up study. *Am. J. Psychiatry*. 2002;159:1315–1321.
- [6] Levack WMM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disabil. Rehabil*. 2010;32:986–999.
- [7] National Institute for Health and Care Excellence. *Head Injury: Quality Standard 74*. 2014; Available from: <https://www.nice.org.uk/guidance/qs74/resources/head-injury-pdf-2098848108229>.
- [8] Scottish Intercollegiate Guidelines Network (SIGN). *Brain injury rehabilitation in adults: a national clinical guideline*. SIGN Guidel. [Internet]. 2013; Available from: <http://www.sign.ac.uk>.
- [9] Fann JR, Hart T, Schomer KG. Treatment for Depression after Traumatic Brain Injury: A Systematic Review. *J. Neurotrauma* [Internet]. 2009;26:2383–2402.

Available from: <http://www.liebertonline.com/doi/abs/10.1089/neu.2009.1091>.

- [10] Khan-Bourne N, Brown RG. Cognitive behaviour therapy for the treatment of depression in individuals with brain injury. *Neuropsychol. Rehabil.* 2003;13:89–107.
- [11] Soo C, Tate R. Psychological treatment for anxiety in people with traumatic brain injury (Review). *Cochrane Database Syst. Rev.* 2007;
- [12] Kangas M, McDonald S. Is it time to act? the potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychol. Rehabil.* 2011;21:250–276.
- [13] Waldron B, Casserly LM, O’Sullivan C. Cognitive behavioural therapy for depression and anxiety in adults with acquired brain injury. What works for whom? *Neuropsychol. Rehabil.* 2013;23:64–101.
- [14] Mitchell EJ, Veitch C, Passey M. Efficacy of leisure intervention groups in rehabilitation of people with an acquired brain injury. *Disabil. Rehabil.* 2014;36:1474–1482.
- [15] Iwasaki Y, Coyle CP, Shank JW. Leisure as a context for active living, recovery, health and life quality for persons with mental illness in a global context. *Health Promot. Int.* 2010;25:483–494.
- [16] Reistetter TA, Abreu BC. Appraising evidence on community integration following brain injury: A systematic review. *Occup. Ther. Int.* 2005;12:196–217.
- [17] Gracey F, Palmer S, Rous B, et al. “Feeling part of things”: Personal construction of self after brain injury. *Neuropsychol. Rehabil.* 2008;18:627–650.

- [18] Pratt RR. Art, dance, and music therapy. *Phys. Med. Rehabil. Clin. N. Am.* 2004;15:827–841.
- [19] Bungay H, Vella-Burrows T. The effects of participating in creative activities on the health and well-being of children and young people: A rapid review of the literature. *Perspect. Public Health.* 2013;133:44–52.
- [20] Leckey J. The therapeutic effectiveness of creative activities on mental well-being: A systematic review of the literature. *J. Psychiatr. Ment. Health Nurs.* 2011;18:501–509.
- [21] Reynolds F. Art therapy after stroke: Evidence and a need for further research. *Arts Psychother.* [Internet]. 2012;39:239–244. Available from: <http://dx.doi.org/10.1016/j.aip.2012.03.006>.
- [22] Ard J, Wheeler B. Music Therapy and Stroke: An Integrative Review. *Music Med.* [Internet]. 2016;8:146–161. Available from: <http://mmd.iammonline.com/index.php/musmed/article/view/496>.
- [23] Magee W, Clark I, Tamplin J, et al. Music interventions for acquired brain injury (Review). *Cochrane Database Syst. Rev.* 2017;1–132.
- [24] Galloway S. Cultural participation and individual quality of life: a review of research findings. *Appl. Res. Qual. Life* [Internet]. 2006;1:323–342. Available from: <http://dx.doi.org/10.1007/s11482-007-9024-4>.
- [25] Jackson R. A charter for Arts, Health and Wellbeing [Internet]. The National Alliance for Arts, Health and Wellbeing; 2012. Available from: www.artshealthandwellbeing.org.uk.
- [26] All-Party Parliamentary Group on Arts Health and Wellbeing. *Creative Health: The*

Arts for Health and Wellbeing [Internet]. 2017. Available from:
www.artshealthandwellbeing.org.uk.

- [27] Department for Culture Media & Sport. Taking Part Survey: England Adult Report, 2016/17. 2017;1–35.
- [28] Waller D. Group Art Therapy: An Interactive Approach. In: Malchiodi CA, editor. *Handb. Art Ther.* New York: Guildford Press; 2003. p. 313–324.
- [29] Patterson F, Fleming J, Doig E. Group-based delivery of interventions in traumatic brain injury rehabilitation: a scoping review. *Disabil. Rehabil.* 2016;38:1961–1986.
- [30] Ownsworth T, Fleming J, Shum D, et al. Comparison of Individual, Group and Combined Intervention Formats in a Randomized Controlled Trial for Facilitating Goal Attainment And Improving Psychosocial Function Following Acquired Brain Injury. *J. Rehabil. Med.* 2008;40:81–88.
- [31] Malchiodi CA. *Handbook of Art Therapy.* Psychiatr. Serv. New York: Guildford Press; 2003.
- [32] Chandler J, Higgins JP, Deeks JJ, et al. Chapter 1: Introduction. In: Higgins J, Churchill R, Chandler J, et al., editors. *Cochrane Handb. Syst. Rev. Interv.* [Internet]. 5.2.0. Cochrane; 2017. p. 1–10. Available from:
<https://training.cochrane.org/handbook/chapter-01>.
- [33] Khan KS, Kunz R, Kleijnen J, et al. Five steps to conducting a systematic review. *J. R. Soc. Med.* 2003;96:118–121.
- [34] Connor DO, Green S, Higgins JPT. Chapter 5 : Defining the review question and developing criteria for including studies. In: Higgins J, Green S, editors. *Cochrane Handb. Syst. Rev. Interv.* 5.1.0. Chichester, UK: John Wiley & Sons Ltd.; 2011. p.

1–11.

- [35] All-Party Parliamentary Group on Arts, Health and Wellbeing. Creative Health: The Arts for Health and Wellbeing: The short report. All-Party Parliam. Gr. Arts, Heal. Wellbeing. 2017.
- [36] Higgins JP, Deeks JJ. Chapter 7: Selecting studies and collecting data. In: Higgins JPT, Green S, editors. *Cochrane Handb. Syst. Rev. Interv.* 5.1.0. Chichester, UK: John Wiley & Sons Ltd.; 2011. p. 1–28.
- [37] Higgins JP, Altman DG, Sterne J. Chapter 8: Assessing risk of bias in included studies. In: Higgins JPT, Churchill R, Chandler J, et al., editors. *Cochrane Handb. Syst. Rev. Interv.* [Internet]. 5.2.0. Chichester, UK: Cochrane; 2017. p. 8:1-8:73. Available from: www.training.cochrane.org/handbook.
- [38] Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med.* 2009;6.
- [39] Berrol CF, Ooi WL, Katz SS. Dance/movement therapy with older adults who have sustained neurological insult: A demonstration project. *Am. J. Danc. Ther.* 1997;19:135–160.
- [40] Nayak S, Wheeler BL, Shiflett SC, et al. Effect of music therapy on mood and social interaction among individuals with acute traumatic brain injury and stroke. *Rehabil. Psychol.* 2000;45:274–283.
- [41] Kim DS, Park YG, Choi JH, et al. Effects of Music Therapy on Mood in Stroke Patients. *Yonsei Med. J.* [Internet]. 2011;52:977. Available from: <https://synapse.koreamed.org/DOIX.php?id=10.3349/ymj.2011.52.6.977>.
- [42] Jun EM, Roh YH, Kim MJ. The effect of music-movement therapy on physical and

- psychological states of stroke patients. *J. Clin. Nurs.* 2013;22:22–31.
- [43] Thaut MH, Gardiner JC, Holmberg D, et al. Neurologic music therapy improves executive function and emotional adjustment in traumatic brain injury rehabilitation. *Ann. N. Y. Acad. Sci.* 2009;1169:406–416.
- [44] Jeong S, Kim MT. Effects of a theory-driven music and movement program for stroke survivors in a community setting. *Appl. Nurs. Res.* 2007;20:125–131.
- [45] Kongkasuwan R, Voraakhom K, Pisolayabutra P, et al. Creative art therapy to enhance rehabilitation for stroke patients: A randomized controlled trial. *Clin. Rehabil.* 2016;30:1016–1023.
- [46] Bunketorp-Käll L, Lundgren-Nilsson Å, Samuelsson H, et al. Long-Term Improvements after Multimodal Rehabilitation in Late Phase after Stroke. *Stroke.* 2017;48:1916–1924.
- [47] Morris JH, Kelly C, Joice S, et al. Art participation for psychosocial wellbeing during stroke rehabilitation: a feasibility randomised controlled trial. *Disabil. Rehabil.* [Internet]. 2017;0:1–10. Available from: <https://doi.org/10.1080/09638288.2017.1370499>.
- [48] Zumbansen A, Peretz I, Anglade C, et al. Effect of choir activity in the rehabilitation of aphasia: a blind, randomised, controlled pilot study. *Aphasiology* [Internet]. 2017;31:879–900. Available from: <https://doi.org/10.1080/02687038.2016.1227424>.
- [49] Ali K, Gammidge T, Waller D. Fight like a ferret: A novel approach of using art therapy to reduce anxiety in stroke patients undergoing hospital rehabilitation. *Med. Humanit.* 2014;40:56–60.
- [50] Beck AT, Ward CH, Mendelson M, et al. An Inventory for Measuring Depression.

Arch. Gen. Psychiatry. 1961;4:561–571.

- [51] Yesavage J, Brink T, Rose T, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *J. Psychiatr. Res.* [Internet]. 1983;17:37–49. Available from: <http://linkinghub.elsevier.com/retrieve/pii/0022395682900334><http://www.sciencedirect.com/science/article/pii/0022395682900334>.
- [52] Cho M, Kim K. Diagnostic validity of the CES-D(Korean version) in the assessment of DSM-III-R major depression. *J. Korean Neuropsychiatr. Assoc.* 1993;32:381–399.
- [53] Zuckerman M, Lubin B. *Manual for the Multiple Affect Adjective Check List*. San Diego, CA: Educational and Industrial Testing Service; 1965.
- [54] Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr. Scand.* [Internet]. 1983;67. Available from: <https://doi.org/10.1111/j.1600-0447.1983.tb09716.x>.
- [55] Shin YH. A Study on Verification of the Profile of Mood States(POMS) for Korean Elders. *J. Korean Acad. Nurs.* 1996;26:743–758.
- [56] McDowell I. *Physical Disability and Handicap. Meas. Heal. A Guid. to Rat. Scales Quest.* [Internet]. 2nd ed. New York: Oxford University Press; 2006. p. 55–149. Available from: <http://books.google.com/books?id=06t-63RaYk0C&pgis=1>.
- [57] Stern RA. *Visual analog mood scales (VAMS)*. Odessa, FL: Psychological Assessment Resources; 1997.
- [58] Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: The PANAS scales. *J. Pers. Soc. Psychol.* US:

American Psychological Association; 1988. p. 1063–1070.

- [59] Franke GH. Brief Symptom Inventory. Minneapolis, MN: Pearson Assessments; 2000.
- [60] Duncan PW, Bode RK, Lai SM, et al. Rasch analysis of a new stroke-specific outcome scale: The stroke impact scale. *Arch. Phys. Med. Rehabil.* 2003;84:950–963.
- [61] Richardson M, Campbell N, Allen L, et al. The stroke impact scale: Performance as a quality of life measure in a community-based stroke rehabilitation setting. *Disabil. Rehabil.* 2016;38:1425–1430.
- [62] Helmes E. Multidimensional Observation Scale for Elderly Subjects (MOSES). *Psychopharmacol. Bull.* 1988;24:733–745.
- [63] Bergner M, Bobbitt R, Carter W, et al. The Sickness Impact Profile: development and final revision of a health status measure. *Med. Care.* 1981;19:787–805.
- [64] Granger C, Dewis L, Peters N, et al. Stroke rehabilitation: analysis of repeated Barthel index measures. *Arch. Phys. Med. Rehabil.* 1979;60:14–17.
- [65] American Art Therapy Association. Definition of Art Therapy [Internet]. *Defin. Art Ther.* 2017. Available from: https://www.arttherapy.org/upload/2017_DefinitionofProfession.pdf.
- [66] British Association for Music Therapy. Music therapy - using the power of music. British Association for Music Therapy; 2017.
- [67] Deci, Edward L.; Ryan RM. Basic Psychological Need Satisfaction Scale: General. 2011;

- [68] Gagne M. The role of autonomy support and autonomy orientation in the internalization of autonomous regulation for prosocial behavior. *Motiv. Emot.* [Internet]. 2003;27:199–223. Available from:
http://ezproxy.msu.edu/login?url=http://search.proquest.com/docview/619710938?accountid=12598%5Chttp://za2uf4ps7f.search.serialssolutions.com/?ctx_ver=Z39.8-2004&ctx_enc=info:ofi/enc:UTF-8&rft_id=info:sid/PsycINFO&rft_val_fmt=info:ofi/fmt:kev:mtx:dissertation.
- [69] Deci EL, Ryan RM. The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior. *Psychol. Inq.* 2000;11:227–268.

Chapter 2. Systematic review: Extended methodology

This chapter provides additional information on defining “creative activity groups” and the identification of search terms for use in the systematic review along with further information about how the search terms were combined to carry out the database searches.

Identifying search terms

To identify the appropriate search terms it was necessary to be clear about the research question and the terms to include within each separate PICO (Participant, Intervention, Control, Outcome) heading. The search terms that should be included within the ‘Intervention’ word group necessitated careful consideration. They were subsequently selected based on the authors agreed definition of “Creative Activity Groups”, which is outlined below.

Defining “Creative Activity Group” Interventions. There are two specific forms of well-established creative therapies that were considered for inclusion by this review: art therapy and music therapy. Both require therapists to be accredited by their respective professional bodies and registered with the Health Care Professionals Council (HCPC). A brief definition of each therapy is provided below:

Art therapy. Art therapy is based on the idea that the experience of the creative process of active art-making, within the context of a therapeutic relationship, can enrich the lives of individuals and groups (American Art Therapy Association, 2017). It is a form of psychotherapy which uses art media as its primary mode of expression and although sessions can be enjoyable, art therapy is not intended to be a recreational activity or an art lesson (The British Association of Art Therapists, 2017). A key strength of art therapy is that it can be used with a variety of populations and problems and enables non-verbal expression of feelings, thoughts, and views; providing an opportunity to explore problems, strengths, and possibilities for change (Malchiodi, 2003).

Music therapy. The British Association for Music Therapy (BAMT) states that “music plays a fundamental role in our identity, culture, heritage and spiritual beliefs” (British Association for Music Therapy, 2017). Music therapy is an established intervention, which uses music to “to facilitate positive changes in emotional wellbeing and communication through the engagement in live musical interaction between client and therapist” (British Association for Music Therapy, 2017). The BAMT claim that music therapy is “uniquely placed” to help people with neuro-disabilities such as ABI because music is processed across many parts of the brain, thus making music increases brain activity and promotes neuroplasticity (The British Association for Music Therapy, 2017).

“Creative Activity Groups”. The authors of this review considered studies conducted using both these forms of therapy as relevant for inclusion within the review. However, the scope of “creative activity groups” was not limited specifically to established creative therapy interventions because the review authors were interested in discovering whether the potential therapeutic effects of a range of creative activities had been investigated. Therefore, “creative activities” was defined in the broadest sense as being: any activity with a rehabilitative focus, which involves the production of novel creative output. The Department for Culture, Media and Sport (Department for Culture Media & Sport, 2017) provide a comprehensive definition of activities that are considered to be participatory arts-based activities, as follows:

- Dance – ballet or other dance (not for fitness)
- Singing – live performance or rehearsal/practice (not karaoke), singing as part of a group or taking singing lesson
- Musical instrument – live performance, rehearsal/practice or playing for own pleasure
- Written music

- Theatre – live performance or rehearsal/practice (e.g. play or drama)
- Opera/musical theatre – live performance or rehearsal/practice
- Carnival (e.g. as a musician, dancer or costume maker)
- Street arts (art in everyday surroundings like parks, streets, shopping centre)
- Circus skills (not animals) – learnt or practised
- Visual art – (e.g. painting, drawing, printmaking or sculpture)
- Photography (as an artistic activity, not family or holiday “snaps”)
- Film or video making (as an artistic activity, not family or holiday videos)
- Digital art – producing original digital artwork or animation with a computer
- Craft – any craft activity (e.g. textiles, wood, metal work, pottery, calligraphy)
- Creative writing – original literature (e.g. stories, poems or plays)
- Book club – being a member of one (Department for Culture Media & Sport, 2017)

The search terms to define “creative activity groups” were based on The Department for Culture, Media and Sport definition of artistic participation (Department for Culture Media & Sport, 2017). However, some of the activities were not considered eligible to be included in this review and therefore were excluded from the search terms. For example, reading or being a member of a book club was not specifically included in the search terms as this activity does not fit the review criteria of generating artistic output. Carnival and Circus skills were also not included as these were deemed to be cultural (rather than specifically artistic) activities and it was considered that there is a complex distinction between functional circus skills and creative circus artistry. Street art and digital art were also not specifically included in the search terms, as the author believed other terms already selected would retrieve any studies conducted into these specific areas of arts participation.

Identifying relevant studies

The search terms identified within each of the word groups were combined with OR to form groups of terms which reflected the Cochrane (2017) (Higgins, Churchill, Chandler, & Cumpston, 2017) and PRISMA (2015) (Moher et al., 2015) PICO guidelines i.e. patient group (group 1), intervention (group 2), comparison group (group 3), and outcome (group 4). These four word groups were then combined with AND before the search term “group” was added to the search, applied as a limiter, using AND. The rationale for including AND “group” as a search limiter, rather than including it in the intervention search terms, is described below.

The initial search of titles, abstracts and key words included the term “group” in the intervention subset, however, this returned an unwieldy large number of irrelevant articles because the term “group” returned papers that referred to participants in terms of the “control group” or “intervention group”, rather than studies that specifically studied treatments delivered in a group setting. Therefore “group” was separated from the intervention terms and used a search term in its own right. This term was applied to the search using AND after the other four word groups had been combined to ensure the studies returned by the search contained all other necessary features of the inclusion criteria before attempting to limit to group treatment. This still yielded a large number of irrelevant results based on “group” being used as a descriptor to separate and refer to the intervention and control groups of a study, however it produced a more manageable data set than other attempts to effectively include and combine this search criteria with other terms.

References

American Art Therapy Association. (2017). *Definition of Art Therapy. Definition of Art Therapy*. Retrieved from

https://www.arttherapy.org/upload/2017_DefinitionofProfession.pdf

British Association for Music Therapy. (2017). *Music therapy - using the power of music*.

British Association for Music Therapy.

Department for Culture Media & Sport. (2017). Taking Part Survey: England Adult Report, 2016/17, 1–35.

Higgins, J. P. T., Churchill, R., Chandler, J., & Cumpston, M. (2017). *Cochrane Handbook for Systematic Reviews of Interventions* (5.2.0). Cochrane. Retrieved from www.training.cochrane.org/handbook.%0ACopyright

Malchiodi, C. A. (2003). *Handbook of Art Therapy. Psychiatric Services*. New York: Guildford Press. <https://doi.org/10.1176/appi.ps.54.9.1294-a>

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ...

PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1), 1–9. <https://doi.org/10.1186/2046-4053-4-1>

The British Association for Music Therapy. (2017). *Music therapy and neuro-disability – A brain changer*. The British Association for Music Therapy.

The British Association of Art Therapists. (2017). What is art therapy? Retrieved from <http://www.baat.org/About-Art-Therapy>

Chapter 3. Bridging Chapter

The overarching aim of this research portfolio is to ascertain greater insight into how people rediscover a sense of well-being after having an acquired brain injury (ABI).

The intention is to explore this in relation to the resources people draw on following ABI which influence the natural process of identity and social role change following ABI. The ‘resources’ that people draw on may include both ‘external resources’, such as social group membership and support services and ‘internal resources’ or mechanisms that come from within the self, such as personality characteristics or traits. The purpose of this is to develop a better understanding of how these resources may (a) influence identity and social role change and (b) contribute to a felt sense of well-being following ABI. It is hoped that this will increase our understanding of how people adjust and adapt to the consequences of ABI and subsequently inform the development of treatment models and rehabilitation services for survivors of ABI.

The systematic review addressed the aim of reviewing the evidence of the effectiveness of creative activity groups, a potential ‘external resource’ that could be facilitated to improve psychological outcomes for people with an ABI. It examined the current quantitative evidence regarding the effectiveness of these groups by examining (1) the types of creative activity groups being delivered, (2) the measures used to evaluate them and (3) the effects they may have on psychological sequelae such as mood, well-being and quality of life. Findings from the review suggest that there is some support for creative activity groups improving mood and quality of life. However, the risk of bias was low in just four of the eleven studies identified and results were varied. Thus, further high-quality research is required into the potential benefits of creative activity groups as an intervention for improving mood and overall well-being in ABI before any

firm conclusions are drawn or recommendations made to influence rehabilitation policy and delivery.

Overall, the research presented in this portfolio is approached from a critical realist stance with a phenomenologist perspective. Critical realists assume that data can tell us about reality, but do not assume data directly mirrors reality (Harper, 2012).

Phenomenologists believe the ‘body-self-world are intertwined’ (Finlay, 2011) and as such, we can only experience reality through our personal embodied experience and is neither directly realist or relativist in its approach (Harper, 2012). Critical Realism, a useful philosophical framework for social science, posits that human knowledge and experience “only captures a small part of a deeper and vaster reality” and that there are three levels of reality; (1) the empirical level, which is “the realm of events as we experience them”; (2) the actual level, where there “is no filter of human experience” and events occur whether we experience them or not; and (3) the real level in which “causal structures or ‘causal mechanisms’ exist” (Fletcher, 2017). Critical Realism’s epistemological and ontological perspective uses components of both positivist and constructionist approaches (Fletcher, 2017). Therefore, it recognises the value and contributions of research from different perspectives without having to reconcile competing epistemological assumptions.

The following qualitative research study presented in Chapter 4 aims to explore the individual experience of achieving a sense of wellbeing after ABI. Its purpose is to provide insight into the idiosyncratic resources individuals draw on to support their ‘re-discovery’ of well-being and identity and subsequently identify any pertinent holistic commonalities across the accounts, which may serve to help others along their journey to well-being post-ABI.

References

Finlay, L. (2011). *Phenomenology for Therapists: Researching the Lived World*.

Chichester, UK: John Wiley & Sons Ltd.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181–194.

<https://doi.org/10.1080/13645579.2016.1144401>

Harper, D. (2012). Choosing a Qualitative Research Method. In D. Harper & A. R.

Thompson (Eds.), *Qualitative Research Methods in Mental Health and*

Psychotherapy: A Guide for Students and Practitioners (pp. 83–97). Chichester, UK:

John Wiley & Sons Ltd.

Chapter 4.

Qualitative Research Paper Prepared for Submission to: Disability and Rehabilitation

The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury: A qualitative Study

Alice Rose^a, Fergus Gracey^{b*}, and Paul Fisher^c

^{abc}Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom

*Correspondence concerning this article should be addressed to Fergus Gracey, Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom.

Email: f.gracey@uea.ac.uk, 01603 456161 (ext.2898)

Abstract

Aims: To gain insight into the experience of well-being post-ABI and explore the resources people draw on to help them achieve this.

Methods: Eleven individuals were interviewed individually, using semi-structured interviews, about their experiences of well-being following-ABI. Interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Six main themes were identified which illuminated the experience of wellbeing in relation to internal and external resources. The themes were: (1) Having the right information and knowledge can empower you; (2) Being able to help others gives you a sense of pride and social-role; (3) Being valued and supported by others / freedom to find your own way; (4) Love the life you live but keep trying to make it better; (5) Live in the moment: experience the world to its fullest; (6) Doing the thing(s) you love makes you feel alive. It means the world.

Conclusions: This study offers valuable insight into the felt experience of well-being following ABI and the resources that contribute to these experiences. The findings are idiographic and at the same time resonate with broader theoretical models of well-being, with implications for practice. Being in the moment, and embodied experiencing of the world were the most powerful accounts of well-being described by the participants. The findings suggest a rationale for including approaches that foster in-the-moment or embodied knowing such as cultivation of mindfulness, or use of creativity or arts-based approaches within the care pathway.

Keywords: acquired brain injury, ABI, adjustment, well-being, identity, rehabilitation

Introduction

Incidence of ABI

Acquired Brain Injury (ABI) refers to damage or disease that disrupts brain functioning and produces persisting physical, cognitive, and behavioural impairments [1]. ABI can be caused by (a) Traumatic Brain Injuries (TBI) such as open or closed head injuries or (b) non-traumatic brain injuries such as those caused by strokes, tumours, infectious diseases, hypoxia, metabolic disorders or toxins [2]. The term ABI does not include injuries that are congenital or induced by birth trauma [2].

Approximately 700,000 people in the UK attend Accident and Emergency departments for a head injury each year [3]. Headway [4] reported there were 348,934 subsequent admissions to hospital in 2013-14, an increase of 10% from 2005-6. This figure equates to one admission every 90 seconds [4].

Impact of ABI

The impact of ABI can be profound, and recovery is often a lengthy process. It has been well established that ABI can adversely affect virtually any aspect of an individual's functioning including: physical, cognitive, emotional, behavioural and interpersonal facets [5], which can result in perceived personality change [6]. ABI increases the risk of developing a range of emotional disorders including depression, anxiety and PTSD [7]. Perhaps most significantly, ABI has been shown to impact and alter an individual's sense of self and social identity [8–13] and subsequent well-being [14–17]. Haslam et al. [14] suggest it is the cognitive deficits people experience following brain injury which make it harder to maintain valued group memberships, and therefore social identity [14]. However, Jones et al. [15] discovered “more severe head injuries were associated with higher levels of life satisfaction” as individuals adopt a “survivor identity” and experience improved social relationships and support. Research evidence has shown people view

themselves more negatively post-injury in terms of their activity, capability, independence and value following a stroke [13] and experience significant changes in their happiness, interest in life, hopefulness, feelings of capability and independence [17]. These changes in perceived pre- and post-injury identity are associated with depression and grief [17]. However, Ellis-Hill and Horn [13] also found that individuals rate themselves as being 'just as friendly, calm, caring and hopeful' as their pre-injury self. This supports evidence indicating that the maintenance of social identities following ABI positively influences well-being [14,15,18]. Walsh, Muldoon, Gallagher and Fortune [18] found that engagement with meaningful activities, maintaining group membership and receiving social support all interact in reciprocal ways to influence well-being following ABI.

Identity

The concept of identity represents the very core of who we perceive ourselves to be. There are differing theories about how identity is constructed (See Ownsworth, 2014 [1], for a detailed overview) however, it is argued that there are two key interrelated aspects: self-identity and social-identity [1]. Self-identity is broadly considered to be the construct by which we recognise ourselves as being unique and distinguishable from others, whereas social-identity relates to how we perceive ourselves to be similar and connected to others. Stets and Burke [19] state social-identity can be best understood through the merger of two fundamentally linked perspectives on identity: Identity Theory and Social Identity Theory. Despite being "remarkably similar" there are underlying differences to these two theories [20]. Social Identity Theory [e.g. 19] states that identity is developed through identifying the similarities we share with others and feeling like we fit in and belong to a particular social group or category. Identity theory [e.g. 21] claims it is the various, specific roles we have within society that are central to identity formation because these influence the way in which our group membership is understood, evaluated, and maintained as an individual

[21,22]. Stets and Burke [19] conclude the key difference is that Social Identity Theory emphasises “being part of a group” whereas Identity Theory emphasises “having a role” as the basis of identity formation [23]. Haslam, Jetten, Postmes, and Haslam [24] conclude social groups and roles provide individual’s ‘with a sense of meaning, purpose and belonging’, which positively influences their well-being. Narrative theories of identity development claim identity is created and maintained over time in a narrative sequence connecting past, present and ideal selves [25–27]. Ellis-Hill, Payne and Ward [27] assert “continuity is essential for psychological well-being and personal integration and for an individual to experience him or herself as one person, despite change and disruption, throughout the life cycle” [28]. Hence, as “being and doing” are both central features of one's identity, a complete theory of the self would consider the importance of both group membership and role, as well as the narrative identities based within in the person that provide stability across different groups, roles, and situations [23]. Ownsworth [1] developed a schematic representation of self-identity, the “global self-system” (Appendix A). The global self-system is based on a diverse range of theories and visually constructs a connection between social identity and narrative theories.

Reconstruction of identity following ABI

There are several theories and models relating to the reconstruction of identity following ABI. The life-thread model [27] was developed to include psychological, social and physical aspects of rehabilitation. It uses the metaphor of “life threads” to represent the stories, or strands, of ourselves which create a sense of our identity, situation and future possibilities. The life stories we create and re-create throughout life contribute to well-being by providing a sense of continuity between past and present selves [27,29]. This is particularly relevant within the context of ABI because life threads can become “broken

and frayed” thus disrupting the continuity of past (pre-injury) and future (post-injury) selves [13,27].

Gracey, Evans, and Malley [30] present a biopsychosocial “Y-shaped” model of rehabilitation following ABI (Appendix B). This model conceptualises that the process of adjustment to an “updated, adaptive, realistic” self-representation involves developing an awareness of, understanding and reducing the social and psychological discrepancies that occur when the self is under threat. Consolidation of the “developing post-injury sense of self” occurs when individuals (1) discover and develop “aspects of continuity”, (2) identify “new, adaptive and personally salient meanings” resulting from the injury, and (3) consolidate these meanings “through activity in meaningful contexts” [30]. This model goes beyond the concept of rehabilitation being about compensation for deficits and towards an ideal for optimal level of functioning in task performance and society by focussing on the personal meaning of experience.

Levack, Kayes and Fadyl [9] conducted a meta-synthesis of qualitative research and developed “the enduring experience of TBI” model (Appendix C) using eight identified themes. They represented the “central experiences” of loss, and the emotional sequelae associated with it, in three themes: (1) disconnect with pre-injury self, (2) mind/body disconnect and (3) social disconnect. These themes of loss were identified to relate to three complimentary themes of “reconstruction”: (1) reconstruction of self-identity; (2) reconstruction of their place in the world; and (3) reconstruction of personhood. The internal (personal strengths) and external (supports and opportunities provided by others or society) resources that people with ABI draw on during their recovery, were also represented in a central theme. Levack, Kayes and Fadyl [9] identified the personal strengths that enabled participants to continue to strive against adversity or discomfort included: capacity for hope and optimism, strength of will, spirituality, and the ability to

appreciate successes and the good things in life. External resources included opportunities to try activities and support provided by others including: clinicians, professional rehabilitation services, community advocacy groups as well as friends, family and community members [9].

Well-being

Dodge, Daly, Huyton and Sanders [31] completed an extensive review of the well-being literature and subsequently defined well-being as “the balance point between an individual’s resource pool and the challenges faced” (Appendix D). In a phenomenological model of well-being, Galvin and Todres [32], claimed that “a felt experience of well-being is particularly important to people as an inner resource when they are facing health-related challenges”. They refer to well-being as something “much deeper and more complex than just the absence of illness”; it is a nuanced experiential phenomenon hard to quantifiably define, but undeniably recognised when it is present or absent.

The deepest experience of well-being was conceptualised by Todres and Galvin [33], in their “dwelling-mobility” theory. This claims well-being is experienced through the unity of dwelling and mobility when “dwelling” relates to a peaceful sense of “at homeness” with what is given, and “mobility” encapsulates the ways which one can access feelings of possibility or a “sense of adventure”. Galvin and Todres [32] applied six phenomenological constructs (spatial, temporal, inter-personal, bodily, in mood, and identity) to their “dwelling-mobility” theory [33] and created a lattice (Appendix E) denoting 18 levels of well-being [32].

Rationale for Proposed Study

The models outlined above explain the process of identity reconstruction following ABI and make valid recommendations for supporting people with ABI to achieve this.

However, they do not fully explain the underlying mechanisms involved in the reconstruction process. The Levack, Kayes and Fadyl [9] model indicates that both “internal” and “external” resources are central to this process but what these resources are more specifically has not been further explored. Therefore, further insights are required into how individuals adapt and adjust following an ABI. This study aims to examine this concept more deeply and explore the resources that people draw on to reconstruct their sense of self and their lives following ABI. Additionally, no research to date has explored Galvin and Todres [32] 18-levels of well-being in relation to individuals’ experiences of well-being following ABI. Therefore, this theory of well-being currently sits disconnected from the ABI literature. This gap forms the premise for this study which, aims to develop the ABI literature by obtaining insights into the resources individuals draw on during the reconstruction process and how these relate to the experience of well-being. It is anticipated, that by exploring these domains further, links may be drawn to identify the interaction between the deeper underlying processes contributing to well-being and the current conceptualisations of the process of identity change outlined by current models. The aim is to provide relevant information to improve our understanding of recovery following ABI and identify potential developments for both therapeutic interventions and service delivery to better facilitate adjustment to the lasting effects of ABI.

Research Questions

This study aims to explore how people experience the use of “resources” following ABI and how this contributes to the experience of well-being post-ABI. For the purposes of this study, “resources” refers to “external” sources of support and “internal” attributes or traits.

As this study is exploratory in nature, the research questions are broad and open-ended:

- What resources do people draw on to achieve a sense of well-being following ABI?

- How do people experience the use of these resources in relation to the reconstruction of identity and sense of well-being following ABI?

Method

Design

This study is dedicated to exploring the experience of well-being following ABI. It employed a phenomenological approach, which suggests we can only access objective knowledge through lived experience [34–37]. This research considers the experiences that might contribute to sense of well-being as a “person in context” [36]. As such, the current study, employed an Interpretative Phenomenological Analysis (IPA) approach. This involved direct individual interviews with participants to focus on “how individuals experience and deal with specific situations or events in their lives” [36].

Participants

Eleven participants were recruited via three recruitment sites. All participants were recruited from a voluntary service providing ABI rehabilitation day services in three locations across the East of England.

Recruitment Procedure

A poster (Appendix I) was provided for recruiting services to display so participants could self-refer into the study if they identified with having a sense of well-being. Each service also allocated a study ‘gatekeeper’ who informed their clients about the study and provided participant information leaflets (Appendix J) to those who were interested to know more. The study gatekeepers were also able to take consent to contact and facilitate introductions between the researcher and potential participants to discuss the research further and ensure the inclusion criteria were met prior to recruitment.

Inclusion Criteria

The inclusion criteria were: participants must have a non-progressive ABI, acquired after the age of 18 and at least 12 months ago, subjectively report having had (at least a temporary) positive experience of well-being since their ABI and have insight into that experience, fluent in the English language and able to communicate sufficiently (with aids if required) to provide signed informed consent and participate in in-depth interviews.

Potential participants were excluded if: they reported any current severe and enduring mental health difficulties or substance misuse disorders which would prevent participation in the study interviews, did not subjectively report having achieved a sense of well-being post-ABI or lacked the necessary insight and awareness into their difficulties and well-being following ABI, or had any other impairment of functioning of sufficient severity to preclude engagement in study requirements.

The subjective experience of well-being was the primary inclusion criteria because participants needed to be able to identify with this to be able to discuss their experiences in detail during the semi-structured interviews. It was not necessary for this to be a permanent feeling or state, but participants needed to have an awareness of at least temporary or fleeting moments of well-being to be able to reflect on. As well-being is experienced differently by all individuals, participants were not required to meet an arbitrary standard of well-being on any rating scale or mood-state questionnaire, rather they self-identified that they had experienced a qualitative sense of well-being that they felt able, and willing, to discuss with the researcher. Therefore, the term “well-being” was personally meaningful to the participants who expressed an interest in taking part in this study.

Demographic information

Information about the participants' characteristics is an important aspect of understanding the context within which the research has been conducted. Therefore, demographic information has been provided in Table 1 to enhance the understanding of the experiences described. As this studies cohort is drawn from a small community of individuals the participant's demographic data has not been identified with the allocated pseudonyms to further protect participant's identities.

Table 1. Participant information

Gender	Age	Nature of Acquired Brain Injury	Time Since Injury (years)
Female	44	Tumour/ Stroke	24
Female	49	TBI as result of accidental fall	14
Male	52	Tumour/ Stroke	5
Female	54	TBI as result of road traffic accident	15
Male	42	TBI as result of accidental fall	22
Female	51	Tumour/ Stroke	11
Male	73	TBI as result of road traffic accident	54
Male	51	Tumour/ Stroke	2
Male	45	TBI as result of road traffic accident	4
Male	27	Tumour/ Stroke	8
Male	34	TBI as result of road traffic accident	6

Procedure

Ethical approval was granted by an NHS Research Ethics Committee (Appendix F), the Health Research Authority (Appendix G) and relevant research and development departments.

Potential participants self-identified with the experience of well-being. Participants were able to self-refer to the study from recruitment posters (Appendix I) or were informed of the study by staff and clinicians within the recruiting services and expressed an interest in taking part. Consent was gained from potential participants by the study gatekeepers for the researcher to contact them and initial introductions were subsequently facilitated by them. Potential participants were then screened for eligibility and recruited in to the study by the researcher as appropriate. Participants had a minimum of 72 hours to read the participant information leaflet (Appendix J) and the opportunity to ask the researcher questions before giving informed consent to take part in the study.

The semi-structured research interviews (SSIs) took place at the recruiting sites and lasted between 25 and 60 minutes. An interview topic guide (Appendix H) was used to structure the interviews; however, these were ultimately guided by the participants experiences of well-being and subsequent exploration of emerging themes relating to these experiences. Interviews were recorded using a digital Dictaphone and then transcribed by a professional transcription service. Transcripts were checked for accuracy and anonymised by the primary author.

Data Analyses

An IPA methodology was used to analyse the interview transcripts. There is considerable flexibility and variation in the guidance about how to complete the process of undertaking the highly intensive and detailed analysis of participant accounts in order to identify meaningful patterns and results [36]. This study adopted the process of analysis as

outlined by Smith, Flowers and Larkin [35]. This process involved actively engaging with the research data by simultaneously reading and listening to the interviews and re-reading the transcripts [35]. Initial noting and exploratory comments were then made, predominantly at the descriptive and conceptual levels, as the researcher attempted to ‘stay close’ to participants explicit meaning whilst making sense of the patterns of meaning within the accounts [35]. Where appropriate, linguistic comments were also made, although this intentionally did not form a significant part of analysis due to the apparent, but mild, speech difficulties experienced by the majority of participants. Emerging themes were identified following the initial noting process and transcripts were re-organised as connections across themes were identified and superordinate themes developed. This interpretative process was conducted on a case-by-case basis before identifying resonant patterns of themes across cases and making holistic interpretations of the data set [35].

Results

The analysis revealed six main themes which are described below and supported by relevant excerpts from the participant’s interviews.

Having the right information and knowledge about your brain injury can empower you. This theme reflects that participants spoke about the importance of having access to the right information about their brain injury. This knowledge enabled them to discover and use the coping strategies that worked for them. It is based on the premise that the better you understand your brain injury, the better you can manage it and feel in control of your own life and this was something pivotal in the experience of well-being for many of the participants. Kate explained understanding and recognising the difficulties she experiences post-ABI has empowered her to know what tools and strategies to use to manage them. This keeps her feeling well and balanced:

Kate: “I would say, for my own well-being, it's knowing and recognising my difficulties, knowing what tools and things I can use to ease those difficulties and very much, for me, it's being able to have a steady routine. Having a bit of a plan...”

Kate and Rob both described how looking and searching for information and answers is part of the process of understanding how brain injury impacts them and what things help. They really highlight the importance of self-discovery to obtain this knowledge and understanding to develop personalised coping strategies through perseverance and trial and error:

Kate: “Some of the old clichés, time is a healer is helpful. Don't stop searching. Keep looking for help, and answers, and information. Having a good support team, friends, family, Brain injury groups, a counsellor, whatever it might be. I would say search for the right help. Try things, try things out. Things that I've tried haven't always worked for me. I thought, "No, that doesn't suit." But then don't stop there. Look for something else. Just find what's right for you.”

Kate: “I think just really myself, trial and error, that I found different methods and coping strategies and things to help me.”

Rob: “My advice would be to, well, look deep, deep, deep within yourself. Do as much research as you can about what parts of your brain have been affected. Is it memory? Concentration? is it planning? is it tiredness? is it noise filter? Anxiety, depression, frustration? And, you know, learn about that, accept it, have- take

as much help as you can out there, accept it and on a shitty day feel, "Okay. Today I've got low mood. Right, what can I do to change it?" I can come up with various things..."

Although gaining knowledge and awareness about your own injury and support needs requires some independent self-discovery, being able to access resources through brain injury charities, support groups and the internet was highly valued by participants. These services, and the increased availability of information, enables individuals to seek information or support on their own terms:

Kate: "Like I say, now, I'm more aware. Now, there's more information available. You can seek it out. You can look things up on the Internet. Find groups and things. That's helpful."

Paul: "Listen to people from [charity] and then you'll reap the benefits. But if you don't listen to people from [charity] and go along with them, you'd never know. And that's the truth."

Helping others can give you a sense of pride and social-role.

Several participants relayed how being able to help others was something they wanted to do:

Louise: "it's my positive thinking, and making myself- not making myself- I want to do things for others as well as myself."

Frank: "I want to get myself popular. I want to get myself famous because I want to help people."

For some participants it was also a way to repay a favour or show their gratitude for the help they received:

Daniel: “I like to cook for mum. Because she always cooks for me every other day of the week, so why not once a week?”

Daniel described how cooking for his mum made him feel:

Daniel: “A proud son...A sense of achievement that I’ve done something for my Mum.”

As we start to understand what participants get out of helping others the reason for this desire becomes apparent; helping others seems to give participants a sense of pride and was often something that was important to them before their brain injury:

Louise: “the Louise that was a caring and kind person, have a strong nature, it's what kept me buzzing and everyone that comes to my door, they first get welcomed in and say, “hey, how you feeling today mate?”.”

Being able to support others is also linked to social-role and having a place in the world:

Kate: “helping other people from the things I’ve learnt is, again, helping me. I’ve got a nice routine here, I’ve got a good role and it’s nice-”

Kate found that sharing her experiences of helpful strategies to manage the effects of ABI to help others was something that also helped her because it could lead to discovering new ideas:

Kate: “I think it puts things into perspective. It reminds me- for instance, if we talk about the memory group, I can get my memory kit out. We can go through it. I can offer solutions to other people if they're struggling with routines and so on, and I can suggest a lot of things that I use. But then again, someone in the group might come up with something else and say, "Well I do this," and then that's a new tool for my toolkit. It's a shared thing. Yeah, very much two way.”

Interpreting this, we come to understand that helping others does not only contribute to well-being by offering people a social role within a group of individuals, but in some instances, it also contributes to the continuity of self.

Being valued and supported by others, whilst having the freedom to find your own way, can keep you going and help you make progress with your goals.

The support received from others, or organisations, was mentioned by almost all of the participants. Paul emphasises how receiving support from people he knows are genuine, makes him feel valued and cared for, and he attributes this support to the recovery he has made so far:

Paul: “That’s the people. That’s the people who I know that genuinely care and want to get me better.”

The enormity of how vital support from others can be after ABI to enable you to live your life was summed up by Frank who also really touches on how unbelievable and astonishing receiving genuine care can be:

Frank: “Thing's my dad's done for me, unbelievable. And my sister, again, the same. Things that she's done for me, unbelievable.

Interviewer: It sounds like that support has been really vital?

Frank: Number one. *Interviewer:* Number one? *Frank:* Number one. I'd be dead and buried if I didn't have my Dad and my sister.”

Support was delivered in several different ways, including: practical support, teaching or guidance, encouragement, motivation or “tough love”. Participants appeared to value support from others most when the support offered was enabling them to act and achieve things independently. Jane explains this in the context of attending an art class:

Jane: “...I was going and I was learning different things as I went along and she got me to draw right. She got me to look at how these things were working, how to do it and you know, she didn't sit with me all the time and say do this, do this, do this but she came around to see how I was getting on make sure I was doing it the right way...”

Exploring Jane's comments further we can see that the instruction she received taught her new skills and was supportive whilst still giving her the space and freedom to do things her own way. Jane described how she feels when the right balance of being supported and being independent is struck:

Jane: “Brilliant. You see, I know- or I feel I could do a majority of the stuff on my own. There are bits I think “oh god, I couldn't do without my carer being here.” but there are times where, I'd like to- it's nice to be on your own.”

Frank explained what it was like to know he is supported by others whilst being able to retain control over his own life, and recognise it is his own hard work that is paying off:

Frank: “I just suppose it's me. It's me that's doing all the hard work now. Of course, I've got all of these wonderful people helping me and that, but I don't know. I'm in control and I know what is going on. I've got a smile on my face while I'm talking.”

Fiona spoke about how valuable she found the type of support she labelled “tough love”. She found this highly motivating because being challenged triggered her competitive nature into action and made her even more determined:

Fiona: “He said, "Well prove me wrong." and that was the consultant, and he said, "I like to be proved wrong, prove me wrong." I said, "Next time, I'd see you I'll walk through this." He said, "I hope you can.”

Fiona spoke about how it felt to prove the doctor wrong and walk again:

Fiona: “*Interviewer:* I'm wondering that day were you able to go in there and say, "Hey doctor, I'm walking now. Look at me." What was that moment like? *Fiona:* Like a championship, really.
Interviewer: Like winning the cup? *Fiona:* Yes, yes.”

Interpreting Fiona's “championship” metaphor more deeply, it suggests that the preparation and effort that precedes winning a championship cup makes success feel so much more gratifying. Fiona had said re-learning to walk had taken “a lot of effort” and had previously described the experience of winning a cup as something that “lifts you up.

Lightens your soul, so to speak.” Further to this, you can’t win a championship on your own. Therefore, this metaphor also reflects the central role others play in supporting you to succeed.

Love the life you live but keep trying to make it better.

This theme captures how participants value and appreciate the life they live, but balance this with a constant effort to improve their post-ABI lives and make it better, primarily through rehabilitation and recovery. The theme is made up of two related aspects: “confronting challenges” and “focusing on the positives” of life. These two ideas, like two sides of the same coin, frequently appeared to co-exist in the pursuit of well-being.

Confronting challenges

Challenges were spoken about in terms of goals that people had set for themselves as well as challenges related to the impact of ABI. The key message of this theme was that setting goals or confronting and overcoming challenges created a sense of well-being because it motivated participants, made them better, improved their lives or gave them a sense of achievement. Fiona states it is setting her own goals that has got her through the challenges she has faced since ABI:

Fiona: “*Interviewer:* I’m wondering then, thinking about that journey that you’ve been on, that real fight that you’ve had, what things helped you along the way? ... *Fiona:* Goals, really. ...

Interviewer: Who set those goals? *Fiona:* Me. Myself.”

Steve reflected that life after brain injury is hard. He notes the importance of challenging yourself to try things and facing those challenges because that is the only way you can succeed:

Steve: “It's hard. It's hard. But now I'm learning what I can and can't do quickly. See, the trouble is, you're either going to learn- you're either going to know- See, all these people will say, "You can't do this; you can't do that," but all they've done is read a book. How do they know if you can't do it if you didn't try? See, you don't know unless you try. Simple then. If you don't try them things, you're not even going to know if you can do it, mate. That's how I see it.”

David spoke about the experience of challenging himself to complete an open-water swim, he elucidates his motivation for facing challenges and the importance of action, mitigating risk and having confidence in your abilities:

David: “it was a challenge [laughs] so I thought I'd- I'd do it. ... I like to face a bit of music. [laughs]”

David: “I thought, "Well, it's now or never", and "If I go carefully because of the ships coming in and out, I'll make it all right." Because I knew I could swim that distance. [pause] I really enjoyed it.”

His enjoyment of facing this challenge was linked to both anticipation and success:

David: “I felt I'd achieved something. ... Because I'd [wanted to do it] for two years by then. I was very glad to have done it.”

Confronting the challenges ABI presents is not easy. Fiona reveals the fight she faced and her competitive, determined nature which, she has always had, and meant she channelled her anger into a positive drive to succeed:

Fiona: “I want to win. I think that's what got me through the brain injury. A bit of fight... With the brain injury, you can either roll up and die or you can go fire brimstone and snot everywhere you know to- ...Because when I came out of the hospital, I couldn't talk. I couldn't put a sentence together without blah-ing. I couldn't walk without falling over. And so I was angry, just angry. But I channelled it. ...I think with brain injury, you can either roll over and try to accept it or you can try and do your best to fight it.”

Focus on the positives

Focusing on the positives can be a challenge because of the emotional challenges ABI presents, as explained previously by Fiona and here by Louise whose focus on the positive things she has in her life is up-lifting and motivating:

Louise: “I was so anxious and angry because with what happened to me. Then I think “Louise, get yourself together here love, think about good things. You got a lot of living to do, you've got a lovely husband and daughters and a good life.” Think more positive, put things into- that people said you shouldn't be able to do- and say I am going to do it...”

Daniel also advocates positive thinking, and being optimistic that things will get better:

Daniel: “I've overcome a whole lot of different things. I just take it on the chin. *Interviewer:* You take it on the chin? How do you do that? *Daniel:* Stay positive. Because I've always said to myself, when [I was] in the hospital all [that time], I always thought to

myself "There's always a worse pain than what you're in now, worse can happen to you." That's what got me through it."

Positivity comes in many forms including: enjoying the things you do and feeling in control or sharing humour with others because it keeps your spirits up and you going:

Frank: "Enjoying the day, doing different stuff, staying positive, staying aware, staying in control. Yeah, stay positive."

Roger: "I've been positive about this. My dad helps me get going. He's funny. *Interviewer:* Your dad helps you get going? What sorts of things does your dad do to help you get going? *Roger:* Yes. He's funny, some of the things he does. Him and my mum are always larking about and laughing. *Interviewer:* What's that like for you? ...when they're larking about and laughing? *Roger:* I'm happy. I love it. [laughs]"

For Louise, it also comes from being resolute that the losses she experienced as a result of ABI will not prevent her from being independent and enjoying life; preferring instead to focus on how the amount of eyesight she still has enables, rather than disables her:

Louise: "I've got glasses at home that shows people my vision and somebody put them on once, she said "Oh my god!" I said, "what's the matter?" "You can't see!" I said, well I've got a little vision in one eye, darling. ... I can see. I have a little bit of vision." I've had to learn to be more methodical and learning as I go, instead of being a manic depressive and say I can't cope, I say: "Louise check it out the window, get the good vibes in, think more positive and act more positive not just for yourself but for others around you"."

The advice Roger would give to other people recovering from brain injury reflects the notion of determination, positivity and hope. The simplicity of his statement is what made it so poignant:

Roger: “Don’t give up.”

Live in the moment: experience the world to its fullest.

Living in the moment was described in different ways, from taking life one-step (or day) at a time to being fully present in a moment and experiencing it to its fullest. Living in the moment sometimes required conscious effort however, the unexpected moments when this happened seemed to contribute most to experiencing well-being:

Rob: “Just, just the- Seriously, the simple act of peas, from a freezer, running it, in a sieve, running it under a hot tap for 30 seconds, adding it in the curry, warm it up for four or five minutes, bizarre. You know, I’m thinking because that feeling of warmness was just massive.”

Understanding the effort Rob makes to complete day-to-day tasks in order to achieve well-being by; structuring his day, breaking down tasks, doing things he enjoys and practicing mindfulness (something he had enjoyed pre-injury) enables us to appreciate the significance of “inner peace” occurring unexpectedly:

Rob: “considering last week I was reading, [musical instrument], socialising, [playing sport] and my birthday. You know, on paper it was all prezzies, money, beer, birthday cake, duh-duh-duh-duh, gym. The biggest sense of feeling was having the peas in curry.”

Rob: “[I once did a course on] mindfulness. I really loved that, Then obviously since the injury that- it's kind of gone because my brain is constantly rushed and I need to, "Woah, stop". ... Things like, you know, stop and just breathe because of the damage there where “bang!” it’s all go and going. I'm learning just to stop and breathe and try and think before I speak sometimes.”

Rob: “I have to try and live in this moment and stop the brain from going into like Wednesday or Thursday afternoon and actually panicking about the future.”

In the moment with the peas Rob experiences a moment of inner-peace, a quiet mind, “just for a second”:

Rob: “I'm just for a second thinking curry, chicken curry, peas and chips. I've added peas. That’s such a simple thing which gave me so much pleasure and just the feeling of well-being and satisfaction.”

David experienced well-being through travel and art. These are both about exploration and discovery. His recollections of discovering something new were as captivating as the moments he described. Hearing him speak about these moments of seeing something for the first time gave me a felt sense of exhilaration which seemed to have been present for him in these moments:

David: “I got in there and looked round. It had some nice paintings in. Right at the end of my visit, I went along to the end of this gallery and turned the corner and there was a [Artist] painting. It

was superb. It was lovely. I was quite keen on [Artist] ... This [painting] was something I'd never seen before. It was superb."

It is moments of discovering something new, either through observing or creating art, that David says make his life interesting:

David: "It's the discovery of new colour combinations or new compositions. They just make my life interesting, I think."

To make these new discoveries, David fully immersed himself in places and was open to being captivated by the art and architecture he experienced on his travels, sometimes forgoing his original plans to live in the moment:

David: "I remember I missed out on the [Art Gallery] in [City] because it was- there was such beautiful architecture that I wandered around in the city just gazing at the architecture. And I missed out going to the [Art Gallery]."

Participants spoke about experiencing well-being most significantly when they were fully immersed in experiencing their environment in a way which connected to their embodied sensory experience of the world. These experiences happened whilst engaged with activities or hobbies and participants reported noticing and appreciating every aspect of these experiences as a complete whole. In these moments participants depicted feelings of connection with others, the world and themselves. David illustrates this when explaining what he loves about his favourite city and how he feels when he is there:

David: "It's the architecture. It's the ambiance. It's the light. It's- it's the smell of the -- it does stink, [laughs] but it's beautiful."

David: “I feel very alive when I'm in [place]. ... It's just the feeling of being there. It's wonderful.”

Fiona describes feeling “at one” with the world around her when she is outdoors riding her horse:

Fiona: “Just being at one with nature and when I'm with the horse, we have- deer walked past me. If I was with the dogs or with my husband, deer in wildlife would see us as a threat. When they see me on the horse, they don't see me. They see the horse. Deer and foxes just trot past. There's rabbits just sitting and just carry on their eating because they know horses aren't a threat. It's just lovely just to stop and just take five minutes out of the mad world.

Interviewer: The “country life” is the nature and that connection with nature? *Fiona:* Yes. This time of year, in the fall, you've got beautiful colours. I just stop -- I'll have a fag and just sit. I've said to the horse “let's just have five minutes here” and the horse just rest their leg and just look and have a look around. It's peaceful, there's no-one about, especially when I'm in the forest. A thousand-acre forest and there's nothing about bar animals and the odd aircraft to spoil it.

These moments of outer peace facilitate inner-peace:

Fiona: “There's nothing in my mind, which is good.”

Jane credited being absorbed in a moment of pleasure as being like “heaven on earth”. This related specifically to enjoying every aspect of her cinema-going experience, which would be incomplete without her choice of “treat” ice-cream:

Jane: “well, getting the ice cream, is amazing and going and sitting down and eating it is just gorgeous and you just disappear into the-- you're watching a film, you're eating your ice cream it's just heaven on earth. There you go heaven on earth. ... Heaven is somewhere you'd like to be in preference to anywhere else. ...the majority of films I go to see, that's where I want to be. Nowhere else. And I want to have my ice cream in my hand, obviously, and I have a nice drink next to me and heaven on earth, pig in S-H-I-T or whatever.”

Louise spoke about her experience of visiting a butterfly park and going to the coast. Being in the moment, and embracing the full sensory experience of those environments is what gave her the feeling of inner-peace:

Louise: “Oh, you've got to go there. It's lovely because you got all the greenery, see the butterflies, it's warm and they sometimes have music playing in the background. All different plants that come across all the countries and it's good meditation feeling to go there and to see pleasurable things. Lovely plants, flowers, butterflies. ... I get good vibe, a good feeling.”

She describes the “good feeling” she gets in this moment and how it positively affects her mood:

Louise: “I'd say it's quite a warm peaceful feeling, a happy glow in your body. If you have that feeling and you breathe all the goodness in, you think, "oh, wow this is really wonderful." It

makes me feel good physically and mentally and until I've had that feeling, I think I could be a grouchy old mare. [laughs]"

At the coast, this sensory experience of well-being also relates to a felt sense of open expanse; inner-peace and freedom:

Louise: "If you go to the coast, it's lovely. Doesn't matter it's cold or warm. I love to walk along the prom, and see the sea, and hear the waves come whoosh, whooshing in, and if you've got the cold sea air on your face or it's just the warmth. Of being in that expanse of being open. You've got the coast, you've got the sea and you've got that feeling of like," this is lovely, glow, feeling here love." the freedom-"

The sensory experiences described by the participants are often intense and exhilarating. These embodied experiences of feeling and sensation, of feeling present in a moment, can be conceptualised at a deeper interpretative level as feeling present or connected to the world or feeling alive. Additionally, these moments seem to encompass both a comfortable, "warm" feeling of "inner-peace", which some participants were able to name as indicative of well-being, and an element of creativity and looking outward, metaphorically or literally, to the "vast" horizon. This reveals a sense of possibility and a feeling of curiosity and movement.

Doing the thing(s) you love makes you feel alive. It means the world.

The theme "Doing the thing(s) you love makes you feel alive. It means the world" is closely connected to the theme "Live in the moment: take it all in and experience the world around you to its fullest". However, while "living in the moment" transcends engaging

with any one given activity or hobby, it seems that hobbies certainly help contribute to achieving the combined sense of inner-peace and possibility. This can be interpreted as being because engaging with hobbies connects people to a sense of who they are. Interpreting this further, this is linked to a continuity of self- and social-identity as participants often spoke about doing activities they had previously enjoyed before their ABI. Jane's primary hobby is art, and always has been. She describes how much she loves art and says this has always been an important part of her life:

Jane: "Well-being to me means I'm happy and satisfied with what I'm doing. I enjoy art, I love it to pieces. ...I just enjoy everything to do with it. It's something I've been interested in ever since-- before I started school, I just loved doing art so it's been something I've enjoyed."

For Roger this hobby was football. He and his Dad support the same team and this was something they enjoyed together before Roger's ABI and continue to share an interest in:

Roger: "He used to take me to all our teams matches when I was younger."

Roger: "We're talking about football because we both support the same team. I like it when he comes to see the football with me. He'd come Tuesday to see the match."

Roger also spoke about how music was something he enjoyed both before and after his injury:

Roger: "I like to have the music on. I have CDs. In the '80's I used to be a DJ. I liked my music."

In contrast to maintaining engagement in old hobbies that gave participants an experience of well-being from the enjoyment and continued sense of self-identity, participants also described discovering new hobbies and having the opportunities to try new things post-ABI. The enjoyment of these new hobbies was often linked to participants abilities and a sense of achievement. For example, Frank also enjoyed listening to music, but rather than connecting him to a former sense of himself, his enjoyment stemmed from discovering a new sense-of-self because music was something he could engage with without being reminded of the difficulties he experiences as a result of his ABI:

Frank: “[Music] means the world to me. I don't watch television anymore. I don't watch it. ... The way of using my hands and the remote control not so easy, but I don't- just listen to music. It's great!”

Steve has also found a new hobby since his brain injury. As Steve spoke, his sense of pride in having a constructive way to spend his time was apparent. He spoke about his need to find help and something he enjoyed doing:

Steve: “I just knew that I needed the help; I needed something, because I was just sitting around bored all day.”

He discovered woodwork. A hobby which was constructive for him in more ways than one. It was a more constructive use of his time, and was a hobby that involved making things with a material he had previously only used in a destructive way:

Steve: “the thing I did with wood, I just set fire to it. You know what I mean? But now I'm here, making things out of wood. That's completely different.”

Steve: “I’ve made some good things actually. I made a bird table. I made a bridge to go over my pond -- a wooden bridge”

David sums up the pertinence of taking action to engage with your hobbies. He speaks about taking a trip to visit a gallery to view some artwork. This statement highlights how much more rewarding it is to experience something directly than observing the world through a lens. David expresses that despite having seen the artwork in photographs he still did not know what to expect, this represents a clear level of disconnection from the world which is contrasted against how ‘glorious’ it is to experience the world directly. The interpretative meaning therefore is that connection to the world is dependent on taking action and “doing” the things that interest you.

David: “Well, I didn't know what to expect. I'd seen photos of it. But the actual thing was so much better. It was glorious...”

Discussion

The purpose of this study was to explore the phenomenon of well-being following ABI. It aimed to obtain an insight into the experience of well-being post-ABI and discover the resources people draw on to help them achieve a sense of well-being. The intended objective was to identify which ‘internal’ and ‘external’ resources, central to the enduring experience of TBI model [9], contributed to an experience of well-being and to ascertain whether these experiences reflected the kinds of well-being outlined in the “dwelling-mobility lattice” [32,33].

All participants were able to identify resources that had helped them in their adjustment to ABI and recall experiences of well-being within their post-ABI life. Participants attributed the resources they accessed to their experience of well-being. The

connections between resources and experiences of well-being were unique to each individual, however there were identifiable commonalities across the participant's accounts. The resources identified broadly related to either; personality traits or states of mind, engaging in activities or support from others. Well-being tended to be described as feelings of "inner-peace", warmth or happiness. It was evident that although participants could recall experiences of well-being they have had since their ABI, for many this was not an enduring experience. Well-being was described as being something temporary, momentary and, at times, fleeting. It was also something participants strived for and tried hard to achieve.

The research set out to establish how "internal" and "external" resources [9] contributed to experiences of well-being. The enduring experience of ABI model [9] identified that both internal and external resources are required for coping with and moving on from ABI and transitioning from a place of "disconnection" to "reconstruction" of the self. This study identified both internal and external resources that contributed to a sense of well-being. The internal resources (personal strengths) of participants in this study, included: determination, positivity and hopefulness, and an appreciation for life. These traits, and the external resources cited by participants map closely to the personal strengths and external resources identified by Levack, Kayes and Fadyl [9] in their meta-synthesis of the qualitative literature. This suggests that experiences of well-being post-ABI are closely linked to the process of reconstructing self-identity and one's place in the world.

Whilst a causal relationship between resource use, reconstruction of identity and well-being can be assumed, it is important to acknowledge this relationship is not yet fully understood. Participants were clear that their experiences of well-being were transient and not a permanent state which they had achieved. Additionally, well-being was not always present in the moments it was most expected, i.e. at times when participants were engaging

in activities (external resources) perceived to be significant to their sense of self or mood. As such, well-being is not guaranteed to follow resource use and supports Galvin and Todres [32] claim that “experiential well-being possibilities can happen unpredictably in spontaneous and unexpected ways”. Therefore, although Aristotle believed achieving well-being was “the overarching goal of all human activities” [31], the relationship between well-being, resources use and reconstruction of identity is not linear.

Galvin and Todres [32] conceptualised 18 different intertwined and inter-related levels of well-being based on the existential “dwelling-mobility” theory of well-being [33]. This model built on the idea of well-being being an intertwining of “peace” and “movement” at metaphorical, existential and literal levels [38]. The concept of “dwelling-mobility” seems to directly relate to the Stets and Burke [23] conceptualisation of identity combining a sense of both “being” and “doing”; a feature of every aspect of the lattice.

The lattice [32] features an experiential domain of “identity” which, unifies a sense of “I am” (dwelling) with “I can” (mobility) and suggests well-being is experienced as “layered continuity” of personal identity. The theme “confront challenges and focus on the positives” strongly reflects the essence of identity dwelling-mobility [32]. Within the accounts, was an inexplicable acknowledgement of “I am” and an essence of optimism and determination to overcome challenges (“I can”) [32]. The theme “do what you love” also maps onto this domain because it connected participants to their pre-ABI sense of self: “I (still) am” and “I (still) can”. Whereas “having the right knowledge and information” emphasises the action of finding out who you are and what you can do, resonating clearly with the “I can” optimism of identity mobility.

The themes “helping others” and “being valued and supported by others” relate to the inter-subjective dwelling domain, which emphasises a sense of kinship and belonging. These themes also relate loosely to the inter-subjective dwelling-mobility “mutual

complementarity” domain. Although, the mobility aspect of “mysterious inter-personal attraction” is less apparent, there is an underlying essence of feeling both “at home” with and sensing the “novelty that each brings to the other” [32]. This is a bold interpretive step as the “inter-personal mystery” is more attributable to the skills or ideas one could learn or teach, rather than seeing the person as inherently mysterious or desirable in a relational sense. Additionally, these themes also relate to developing a sense of “I can” (Identity mobility) and “future orientation” (temporal mobility) [32].

The theme that links most directly to the mobility-dwelling lattice [32] is “live in the moment and experience the world around you to its fullest”. This theme encapsulates several experiential dwelling-mobility paradoxical domains including “spatiality: abiding expanse”, “temporality: renewal”, “mood: mirror-like multi-dimensional fullness” and “embodiment: grounded vibrancy”. The descriptions capture feelings of present-centeredness, peacefulness and comfort combined with the sense of excitement about future possibilities and adventurous horizons. These experiences of well-being, felt by being in the moment are the epitome of dwelling-mobility as it was first conceived [32,33,38]: the “intertwining of peace and movement, at metaphorical, existential and literal levels” [33].

Ryff [39] operationalised six core dimensions of psychological well-being: self-acceptance, positive relations with others, autonomy, environmental-mastery, purpose in life and personal growth. These six dimensions are all recognisable in participant’s accounts of experiencing well-being: (1) “Self-acceptance” relates to acceptance of self and one’s past life [39]. This features in participant’s descriptions of “searching deep within yourself” to gain an understanding and knowledge of their current difficulties to enable them to apply optimal coping strategies. (2) “Positive relations with others” is characterised by warm, trusting relationships that achieve a balance of give and take [39].

The experience of this is discussed in relation to being valued and achieving the right balance of support. (3) “Autonomy” relates to qualities such as self-determination, something many participants had, and independence, which was highly valued by participant’s. This is demonstrated most clearly by the accounts of receiving support from others, because even within this context, participants spoke about the importance of having autonomy and control over their lives. Autonomy also relates to having an internal locus of evaluation [39] which, is evident in experiences of well-being relating to achieving a goal; many participants attributed these achievements to their own hard work and this was an apparent source of pride and satisfaction. (4) “Environmental mastery”, actively engaging with your environment, choosing or creating environments that suit your needs and values, and taking opportunities, also featured in the participant interviews.

Participant’s frequently described the benefits of ‘being present’ in a moment. The descriptions capture an experiential inter-play between the internal (cognitive) and external (physical) environment to reach a sensory experience of well-being. (5) “Purpose in life”, having goals and a sense of directedness, gives meaning to the present and past life [39]. Participants all had goals related to their adjustment to brain injury such as improving functioning and “getting better”. Arguably, these goals provide a sense of ‘directedness’ towards their ideal, future self. (6) “Personal Growth” is a feeling of continued development and improvement in self over time including improved self-knowledge and effectiveness [39]. Therefore, this dimension seems especially pertinent to rehabilitation and adjustment to ABI and encapsulates the other five dimensions of well-being outlined by Ryff [39] and the experiences of well-being relevant to these as outlined above.

Study Limitations

The main limitations of this study relate in part to the limitations of IPA research in general. Fitting with IPA research, the results presented offer an interpretation from one

researcher and no claims are made to any absolute truth about the experience of well-being related to resource use following ABI or the generalisability of the findings. According to hermeneutics findings of IPA research are two steps removed from the phenomenon of interest because individuals report their interpretations of an experience (the phenomenon) and researchers then interpret these accounts. Although steps were taken to maximise the quality and rigour, and increase the trustworthiness of the study, the analysis was ultimately conducted by one researcher and therefore this study only reflects a single perspective of the possible interpretations of participants' experience.

Clinical Implications

This study offers valuable insight into the felt experience of well-being following ABI and the resources that contribute to these experiences. This has direct implications for post-rehabilitation as it provides information about the types of support and experiences people need to achieve a felt-sense of well-being.

Firstly, it highlights patients need to retain a sense of control and ownership over their own adjustment and rehabilitation journey, especially whilst receiving valuable help and support from others. The importance of this has previously been posited by Ellis-Hill, et al. [27], who advocate increasing the centrality of the patient in health care settings. To achieve this, clinicians can ensure patients are provided with access to the right resources and sources of information so people can access these and be empowered to become their own expert. Additionally, facilitating support groups and opportunities for people with ABI to meet and share experiences of adjustment to life with an ABI may be beneficial to an individual's reconstruction of identity because it provides a unique opportunity for "being and doing".

Being in the moment, and embodied experiencing of the world were the most powerful accounts of well-being described by the participants. This suggests people with

an ABI may benefit from rehabilitative programmes that incorporate mindfulness skills, as previously proposed by Kangas and McDonald [40].

Acknowledgements

The study authors would like to acknowledge the individuals that participated in this research and the staff at the services that helped with recruitment. This research would not have been possible without your interest, participation and support.

Disclosure of interest

The author reports no conflict of interest. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology.

References

- [1] Ownsworth T. *Self-identity after brain injury*. Hove: Psychology Press; 2014.
- [2] West Midlands Quality Review Service. *Quality Standards: Care of Adults with Acquired Brain Injury*. 2014.
- [3] National Institute for Health and Care Excellence. *Head Injury: Clinical Knowledge Summary* [Internet]. 2009. Available from: <http://cks.nice.org.uk/head-injury>.
- [4] Headway. *Acquired Brain Injury: The numbers behind the hidden disability*. 2015;12. Available from: <https://www.headway.org.uk/media/2883/acquired-brain-injury-the-numbers-behind-the-hidden-disability.pdf>.
- [5] Gracey F, Ownsworth T. The experience of self in the world. In: Jetten J, Haslam C, Alexander SH, editors. *Soc. cure Identity, Heal. well-being*. Hove: Psychology Press; 2012. p. 273–295.
- [6] Yeates GN, Gracey F, McGrath JC. A biopsychosocial deconstruction of “personality change” following acquired brain injury. *Neuropsychol. Rehabil.* 2008;18:566–589.
- [7] Fleminger S, Oliver DL, Williams WH, et al. The neuropsychiatry of depression after brain injury. *Neuropsychol. Rehabil.* 2003;13:65–87.
- [8] Gracey F, Palmer S, Rous B, et al. “Feeling part of things”: Personal construction of self after brain injury. *Neuropsychol. Rehabil.* 2008;18:627–650.
- [9] Levack WMM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disabil. Rehabil.* 2010;32:986–999.

- [10] Nochi M. "Loss of self"; in the narratives of people with traumatic brain injuries: a qualitative analysis. *Soc. Sci. & Med.* 1998;46:869–878.
- [11] Satink T, Cup EH, Ilott I, et al. Patients' views on the impact of stroke on their roles and self: A thematic synthesis of qualitative studies. *Arch. Phys. Med. Rehabil.* 2013;94:1171–1183.
- [12] Tyerman A, Humphrey M. Changes in self-concept following severe head injury. *Int. J. Rehabil. Res.* 1984;7:11–24.
- [13] Ellis-Hill CS, Horn S. Change in Identity and Self Concept: a New Theoretical Approach To Recovery Following a Stroke. *Clin. Rehabil.* [Internet]. 2000;14:279–287. Available from: <http://cre.sagepub.com/content/14/3/279.full.pdf>.
- [14] Haslam C, Holme A, Haslam SA, et al. Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychol. Rehabil.* 2008;18:671–691.
- [15] Jones JM, Haslam SA, Jetten J, et al. That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychol. Heal.* 2011;26:353–369.
- [16] Douglas JM. Social linkage, self-concept, and well-being after severe traumatic brain injury. In: Jetten J, Haslam C, Alexander SH, editors. *Soc. cure Identity, Heal. well-being*. Hove: Psychology Press; 2012. p. 237–254.
- [17] Carroll E, Coetzer R. Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol. Rehabil.* 2011;21:289–305.
- [18] Stephen Walsh R, Muldoon OT, Gallagher S, et al. Affiliative and self-as-doer identities: Relationships between social identity, social support, and emotional status

- amongst survivors of acquired brain injury (ABI). *Neuropsychol. Rehabil.* 2015;25:555–573.
- [19] Tajfel H, Turner J. An Integrative Theory of Intergroup Conflict. In: Austin WG, Worchel S, editors. *Soc. Psychol. Intergr. relations*. Monterey, CA: Brookes-Cole; 1979. p. 33–40.
- [20] Hogg MA, Terry DJ, White KM. A Tale of Two Theories : A Critical Comparison of Identity Theory with Social Identity Theory. *Soc. Psychol. (Gott)*. [Internet]. 2010;58:255–269. Available from: <http://www.jstor.org/stabl>.
- [21] Stryker S. Identity Salience and Role Performance : The Relevance of Symbolic Interaction Theory for Family Research. *J. Marriage Fam.* 1968;30:558–564.
- [22] Stryker S, Burke P. The Past , Present , and Future of an Identity Theory. *Soc. Psychol. Q.* 2009;63:284–297.
- [23] Stets JE, Burke PJ. Identity Theory and Social Identity Theory. *Soc. Psychol. Q.* 2000;63:224–237.
- [24] Haslam SA, Jetten J, Postmes T, et al. Social identity, health and well-being: An emerging agenda for applied psychology. *Appl. Psychol.* 2009;58:1–23.
- [25] Freeman M. Self as narrative: The place of life history in studying the life span. In: Brinthaupt TM, Lipka RP, editors. *self Defin. Methodol. issues*. New York: State University of New York Press; 1992. p. 15–43.
- [26] Markus H, Nurius P. Possible Selves. *Am. Psychol.* 1986;41:954–969.
- [27] Ellis-Hill C, Payne S, Ward C. Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability.

- Disabil. Rehabil. 2008;30:150–159.
- [28] Myerhoff BG, Simić A. *Life's Career—Aging: Cultural Variations on Growing Old*. London: SAGE Publications Ltd; 1978.
- [29] Battista J, Almond R. The development of meaning in life. *Psychiatry J. Study Interpers. Process.* 1973;36:409–427.
- [30] Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychol. Rehabil.* 2009;19:867–890.
- [31] Dodge R, Daly A, Huyton J, et al. The challenge of defining wellbeing. *Int. J. Wellbeing [Internet]*. 2012;2:222–235. Available from: <http://www.internationaljournalofwellbeing.org/index.php/ijow/article/view/89/238>.
- [32] Galvin KT, Todres L. Kinds of well-being: A conceptual framework that provides direction for caring. *Int. J. Qual. Stud. Health Well-being.* 2011;6:1–13.
- [33] Todres L, Galvin K. “Dwelling-mobility”: An existential theory of well-being. *Int. J. Qual. Stud. Health Well-being.* 2010;5:1–6.
- [34] Reid K, Flowers P, Larkin M. Exploring lived experience. *Psychologist.* 2005;18:20–23.
- [35] Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications Ltd; 2009.
- [36] Larkin M, Watts S, Clifton E. Giving voice and making sense in interpretative phenomenological analysis. *Qual. Res. Psychol.* 2006;3:102–120.
- [37] Smith JA. Evaluating the contribution of interpretative phenomenological analysis.

Health Psychol. Rev. 2011;5:9–27.

- [38] Dahlberg K, Todres L, Galvin K. Lifeworld-led healthcare is more than patient-led care: An existential view of well-being. *Med. Heal. Care Philos.* 2009;12:265–271.
- [39] Ryff, Carol D. Happiness Is Everything, or Is It? Explorations on the Meaning of Psychological Well-Being. *J. Pers. Soc. Psychol.* 1989;57:1069–1081.
- [40] Kangas M, McDonald S. Is it time to act? the potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychol. Rehabil.* 2011;21:250–276.

Chapter 5. Extended methodology

Chapter overview

This chapter presents a discussion on the epistemological position of Interpretative Phenomenological Analysis (IPA) as well as the context and position of the first author. This is presented alongside information and reflections relating to the study design, interview process and analysis. Ethical considerations for the study are also relayed here.

Study Design

In selecting the study design, the first author considered the phenomena of interest and their epistemological position to determine the best research method to employ to answer the research questions.

Epistemology

Epistemology is the philosophy of knowledge relating specifically to what it is possible to know and how knowledge can be obtained (Harper, 2012). The epistemological view adopted for this study was phenomenology. Phenomenological philosophy is informed by the ideas of Husserl, Heidegger and Merleau-Ponty, theorising that we experience the world through embodiment as a 'person-in-context' (Larkin, Watts, & Clifton, 2006). Therefore objective knowledge can only be attained through experience and processes of consciousness and therefore individuals are "an inclusive part of reality" (Larkin et al., 2006). Interpretative Phenomenological Analysis (IPA) was subsequently chosen as the methodology for this research.

IPA methodology

Interpretative Phenomenological Analysis (IPA) is an idiographic research method "concerned with the detailed examination of personal lived experience" (Smith, 2011). It aims to examine how individuals experience and deal with specific situations or events in their lives" (Larkin et al., 2006). To achieve this, IPA requires a highly intensive and

detailed qualitative analysis of personal accounts derived from participants (Larkin et al., 2006; Smith, 2011). To obtain insight into individuals experiences of well-being this study utilised the most common method of data collection in IPA research (Reid, Flowers, & Larkin, 2005; Smith, 2011); one-to-one in-depth, semi-structured interviews (SSI's). The interviews were designed to maintain a structured baseline, whilst being flexible enough to enable participants to tell their own unique stories of experiencing well-being post-ABI.

IPA is an approach to qualitative research informed by three areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography (Smith, Flowers, & Larkin, 2009, p. 11). An overview of these areas is provided below.

Phenomenology, hermeneutics and idiography. Phenomenology is a philosophical approach to the study of the experience of our lived world, and is especially interested in things which matter to us (Smith et al., 2009, p. 11). Phenomenology “champions a holistic, non-dualistic approach to life” (Finlay, 2011, p. 21). The dualist approach views the mental and material world as separate entities, whereas phenomenology posits the “body-self-world are intertwined” (Finlay, 2011, p. 21).

In qualitative research, the researcher must recognise that they play a central role in the co-construction of data and therefore must explore these dynamics reflexively (Finlay, 2011, p. 9). In IPA research, the interpretation process is informed by hermeneutics which surmises that participants interpret their experience and the researcher then interprets this account through their own experience. This “making sense of sense-making” is referred to as a “double hermeneutic” (Smith et al., 2009, p. 35). Therefore, the challenge of analysis is to break free of the literal meaning of what participants have said is their experience and “intuit implicit meanings” by focussing on the phenomenon (Finlay, 2011, p. 16). As the researcher plays a ‘central role’ in IPA research, I have provided some contextual

information about myself, my relevant clinical experience with ABI and my epistemological position as a novice IPA researcher, below.

Context and Researcher position. I am a 30-year-old white-British female trainee clinical psychologist. Prior to conducting this research, the only experience I had working with people who have a brain injury was volunteering twice per week at a brain injury service for approximately nine months. However, it is this experience that fuelled my curiosity in this area and inspired my research questions. The most significant moment that stood out for me during this time was listening to a person speak candidly about their experience of loss following their brain injury. Reflecting on this experience, I wanted to discover more about the process of recovery and rediscovering a sense of self, place in the world and experience of well-being following brain injury. This is what motivated me to explore the existing research literature and develop research questions, as presented in this portfolio.

The first authors beliefs about epistemology are located approximately mid-way along the realism-relativism continuum. The realist position assumes that things exist independently of being perceived, i.e. “data collected mirror reality” (Harper, 2012, p. 87). The relativist stance however, assumes our knowledge about the world is mentally constructed in the context of culture or society i.e. “data are not seen as directly mirroring reality” (Harper, 2012, p. 87). The researcher believes that there is a reality that can become known and understood through experiencing the world. This view fits most closely to the phenomenological philosophy of knowledge.

Sample size

IPA is an idiographic research method which aims to examine a specified subjective phenomenon in depth. Therefore, smaller sample sizes are favoured, on the premise that ‘less is more’, because it is assumed this will enable researchers to (a) collect

richer information and (b) conduct the depth of analysis intended by the IPA research method (Hefferon & Gil-Rodriguez, 2011; Reid et al., 2005; Smith et al., 2009). Smith, Flowers and Larkin (2009) recommend that IPA research conducted within a professional doctorate should aim to achieve ‘four to ten’ interviews (Hefferon & Gil-Rodriguez, 2011; Smith et al., 2009, p. 52). They also state that ‘successful analysis requires time, reflection and dialogue’ and larger data sets ‘inhibit’ this: particularly when the researcher lacks experience using IPA (Smith et al., 2009, p. 52). Following this recommendation, this study aimed to recruit eight to twelve participants. This number was considered appropriately small for a first-time IPA researcher, yet adequately large to acquire a rich data-set if any participants withdrew from the study.

Recruitment and Procedure

Four brain injury services were approached as potential recruitment sites. Two were NHS organisations with specialist brain injury services specialising in rehabilitation and two were separate branches of a voluntary sector organisation which provides support to people and their carers affected by ABI, including rehabilitation day services. Participants were all recruited from one branches of the voluntary sector organisation and recruits came from three of their ABI rehabilitation day services sites across the East Anglian region of the UK.

Each recruiting organisation identified a study ‘gatekeeper’ to act as a contact link between the researcher and ABI service. Gatekeepers were informed of the study protocol and inclusion criteria and provided with posters promoting the study (Appendix I), participant information sheets (PIS, Appendix J), and consent to contact forms (Appendix K) to display in their service and approach suitable potential participants with. The gatekeepers approached participants with details about the study and gained written consent for the participants to be contacted by the first author (Appendix K) or introduced

the researcher to potential participants who expressed an interest in the study. The first author screened potential participants (Appendix L) to ensure they fitted the inclusion criteria and gained their written consent to participate (Appendix M) prior to collecting data for each participant via semi-structured interviews (SSI's).

Ethical considerations

All participants received the participant information leaflet (Appendix J) at least 72 hours before they gave their signed informed consent to take part in the research. Participants were given the opportunity to ask any questions they had about the research before giving consent and during the interview process.

In accordance with the code of human research ethics (The British Psychological Society, 2014) all participants were informed of their right to withdraw themselves and their data from the study. Due to the practical implications of transcription and analysis participants were given up to two-weeks following their interview to withdraw their data.

Interviews

As a novice IPA researcher, the interviews were perhaps more akin to the style of a clinical psychology therapeutic interview and not focussed enough on circling in on the phenomenon of interest. Conducting IPA interviews was a challenge and I was self-aware of attempting to ensure they were open and curious enough while noticing 'right' experiences to focus in on and pursue further during the interview. Aware of the impact of hermeneutics being not just something that may influence interpretation of the data, but the direction of interviews and therefore, the nature of the data obtained from the outset. Inevitably, it is impossible to entirely determine the extent of the researchers influence, however the researcher attempted to address this issue by: having supervisory discussions, using a reflective journal, and noticing assumptions or leading questions made during the

interviews, in an attempt to bracket their pre-conceptions of the phenomenon and hear participant's stories.

Transcription

Smith, Flowers and Larkin (2009) suggest the first phase of engaging with the data is achieved by completing the transcription process because it enables the researcher to immerse themselves in the data and become familiar with it. Unfortunately, due the time constraints of this research study, the interviews were sent to a professional transcription service for typing. All participants provided signed consent for their interview to be transcribed by a professional transcription service (see Appendix L). The transcription service provided (a) confirmation that all transcribers were based within the UK (Appendix N) and (b) a signed a non-disclosure agreement (Appendix O) to protect participant confidentiality. Upon receipt, the first author checked the typed transcripts for accuracy by proof-reading them whilst listening to the audio-recordings. Any inaccuracies were corrected and the author attempted to complete any sections of the interviews that the transcription service had deemed inaudible. The transcripts were then anonymised by removing any identifying details and ascribing pseudonyms.

IPA guidelines (Smith et al., 2009) recommend interviews are transcribed using 'strict verbatim' so that all noteworthy features of speech can be interpreted and commented on for meaning making. However, as a number of the participants had speech impediments and aphasic symptoms caused by their brain injury, the interviews were transcribed 'verbatim' because it was hard to distinguish which features of speech dysfluency, such as hesitations or repetitions, were meaningful and interpretable.

Analysis and write up

An IPA methodology was used to analyse the interview transcripts. There is considerable flexibility and variation in the guidance about how to complete the process of

undertaking the highly intensive and detailed analysis of participant accounts to identify meaningful patterns and results (Larkin et al., 2006). This study adopted the process of analysis as outlined by Smith, Flowers and Larkin (2009) (Smith et al., 2009). The first stage of analysis, is to actively engage with the research data (Smith et al., 2009, p. 82). This was achieved by reading the transcripts whilst listening to the interviews to ensure accuracy and then re-reading the transcripts. Initial noting and exploratory comments were made whilst reading the transcripts, this process was conducted by undertaking line-by-line analysis and, at times, chunking the text into units of meaning. The comments were both descriptive and conceptual as the researcher attempted to stay close to the text and the participants explicit meaning whilst also being reflexive and interpretative in order to ask questions of the data and make sense of the patterns of meaning within the accounts. Where appropriate linguistic comments were also made, however this intentionally did not form a significant part of the analysis and sense making because it was apparent that some of the participants had some degree of mild speech difficulties akin to anomic aphasia. The next phase of the analysis was to identify emerging themes and re-organise the data as connections between themes were identified and super-ordinate themes developed. Within qualitative research and IPA, it is essential to understand individual experience and therefore, the experience of each individual participant needs to be understood before trying to make sense of the experiences as a unified cohort. This process of analysis was conducted on a case-by-case basis before identifying patterns resonant across cases.

During the process of analysis, the researcher attempted to bracket their possible pre-conceptions of well-being based on their own experience or knowledge of theories, in an attempt to remain close to the participant's accounts of experiences of well-being and be open to discovery of new understandings of well-being experiences through the process of interpretation.

References

- Finlay, L. (2011). *Phenomenology for Therapists: Researching the Lived World*. Chichester, UK: John Wiley & Sons Ltd.
- Harper, D. (2012). Choosing a Qualitative Research Method. In D. Harper & A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 83–97). Chichester, UK: John Wiley & Sons Ltd.
- Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. *The Psychologist*, 24(10), 756–759. <https://doi.org/10.1002/9780470776278.ch10>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102–120. <https://doi.org/10.1191/1478088706qp062oa>
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20–23. <https://doi.org/Article>
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9–27. <https://doi.org/10.1080/17437199.2010.510659>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications Ltd.
- The British Psychological Society. (2014). *Code of Human Research Ethics*. *British Psychological Society* (Vol. 1). Leicester, UK. <https://doi.org/180/12.2014>

Chapter 6. Overall Discussion and Critical Appraisal

Overview of the Chapter

This chapter aims to summarise and critically evaluate the findings from the systematic review and the empirical paper. It will consider how these findings may relate to one another and how they may contribute to the research literature and clinical practice.

Summary of Findings

The aim of the research conducted for this thesis portfolio was to explore and provide insight into the internal and external resources people draw on to rediscover a sense of self and experience well-being following an acquired brain injury (ABI). The systematic review and Interpretative Phenomenological Analysis (IPA) research, which make up the portfolio, are grounded in different epistemological perspectives however, both explore related phenomenon: ‘resource’ use and well-being following ABI. The IPA research explores the experience of how people achieve a sense of well-being following an ABI using ‘internal’ and ‘external’ resources while the systematic review investigates the effectiveness of one specific type of ‘resource’ provided in a variety of health and rehabilitation settings (Pratt, 2004; Waller, 2003): creative activity groups.

The systematic review examined the influence of ‘creative activity groups’ on psychological outcomes after stroke. These types groups serve as an external ‘resource’ or source of support because they incorporate an enjoyable activity or hobby, and the support of others (including the group facilitator(s) and peer-support/interaction with other group members). However, for the purpose of this review, creative activities were defined as any activity involving active participation and which produces a novel creative output (i.e. playing music or painting rather than music listening or viewing art). Therefore, creative activity groups are not simply external resources people can access for rehabilitation and support, but also require people to draw on internal resources through engaging with the

creative process. As such, the two papers presented in this portfolio are intrinsically linked as both share an interest in the phenomenon of internal and external resources linked to improving psychological outcomes or well-being after ABI.

The IPA research presented in this portfolio provides rich and detailed accounts of people's experiences of using internal and external resources to achieve a sense of well-being after ABI. It contributes to this area of research by offering unique insights into the nature of the resources that people draw on to achieve experiences, or moments, of well-being and offers a novel perspective by relating these experiences to models of well-being (Galvin & Todres, 2011; Todres & Galvin, 2010) and recovery from ABI (Levack, Kayes, & Fadyl, 2010).

One of the key points of interest was that although the IPA research did not specifically ask about creative activities or involvement in the arts, this was raised as a significant contributor to well-being by several of the participants. This included art, music and woodwork. The enjoyment people got from these activities were related to discovery, creating something new and being engaged with the activity, which generated experiences of "being in the moment". As hobbies these were often activities people had engaged with before their brain injuries and so they also served to connect the person to their pre-injury sense of self, as suggested by the life-thread model this sense of continuity is an important part of self-identity (Ellis-Hill, Payne, & Ward, 2008).

Critical Evaluation of qualitative review

Smith, Flowers and Larkin (2009) recommend a sample size of four to ten interviews is sufficient for research conducted within the remit of a professional doctorate. This study interviewed 11 participants and therefore meets the recommended, accepted level for research of this scope and nature. Although this means there was plenty of data to interpret, having a larger sample has meant I have had less time available to dedicate to

analysing each individual interview. Ironically, in IPA research larger sample sizes can potentially ‘inhibit’ successful analysis, which requires time, reflection and dialogue’ particularly when the researcher lacks experience using IPA (Smith, Flowers, & Larkin, 2009, p. 52).

Unfortunately, due the time constraints of this research study, the participant interviews were sent to a professional transcription service for typing, which was not my initial intention as I had hoped to use the transcription process as the first stage of the analysis to help engage with the interviews (Smith et al., 2009). Using a transcription service brought a unique set of challenges to the process of data analysis. Firstly, not all the interviews were transcribed by the same individual. Therefore, there was slight variability in the quality and style of the transcriptions, for example the quantity and type of speech inflections that were included in each participant’s transcript varied, as did the amount of “inaudible” data. During the process of checking the transcripts for accuracy, the researcher attempted to resolve these issues by developing consistency across the transcriptions. This was achieved by listening to the interviews while reading the transcripts and adding any relevant features of speech that were missing, and appeared significant, completing ‘inaudible’ sections of the transcripts and amending any inaccuracies. This was a time-consuming process, and contrary to the claims by Smith et al. (2009), I did not feel like I was “engaging” with the data at this stage, although it did help to familiarise me with it. However, as a novice IPA researcher I attempted to ensure all the transcripts were complete and accurate before beginning the analysis phase of the research, forgetting that this careful listening and listening was in fact the first stage of the analysis of each individual account. This is a valuable learning point for any future qualitative research I conduct.

Due participant's speech dysfluencies resulting from their ABI, the decision was made to transcribe interviews 'verbatim' rather than 'strict verbatim'. Consequently, some of the potential richness in the data for meaning making using IPA analysis was lost as noteworthy features of language and speech can inform part of the meaning making (Smith et al., 2009) because this is how participants are able to express their experience and how researchers are able to access the experiences of others. It is possible that these speech dysfluencies impacted on the quality of the data that was obtained through the interviews. During the interviews and process of analysis and write up I certainly felt that some of the interviews provided a much richer and deeper insight into the phenomenon of interest than others. I had considered whether some of the interviews should be excluded from the research as a result and discussed these dilemmas with the research supervisor. However, I was also aware of wanting to give all of the participants 'a voice' (Larkin, Watts, & Clifton, 2006) and therefore none of the interviews were excluded from the analysis.

Despite this, there is so much richness in the data obtained. As the principle of hermeneutics implies, the data could be interpreted in different ways depending on the position and personal or contextual experience of the researcher. During analysis I recognised several moments of interpretative dilemmas during this process and attempted to document these in a reflective journal and stay true to the participant's accounts of their experience. This presented a unique challenge, as I often felt uncertain whether my 'sense-making' was a personal reflection to be bracketed or a valid interpretation of the data anchored to the accounts. I attempted to resolve these dilemmas by completing a reflective journal and discussing ideas in supervision.

Critical Evaluation of systematic review

The systematic review presented in this portfolio contributes to the existing literature on the provision of creative activity interventions after ABI. With a specific

focus on the effectiveness of creative activity groups on psychological outcomes it is a novel contribution to the current research literature.

The review was structured and conducted according to the PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009), Cochrane handbook (J. P. T. Higgins, Churchill, Chandler, & Cumpston, 2017) and the five-step framework set out by Khan et al. (Khan, Kunz, Kleijnen, & Antes, 2003). The initial search returned a large number of results, many of which were not relevant to the review, therefore if this review was conducted again further exploration and specification of the search terms would be carried out to conduct a more targeted search.

Papers were selected for the review according to the inclusion criteria. This was challenging due to the ambiguous nature of the broad definition for “creative activity” group interventions and the accepted outcome evaluations. The variety of creative interventions that the search returned was limited, with most having a grounding in art or music therapy which were applied in various ways. The interventions also varied in duration in terms of session length, number of sessions delivered and overall duration of the intervention. This makes the different creative interventions difficult to compare, although this was not a specific aim of the review. The outcome assessment had to include a quantitative measure of mood, well-being or quality of life and could include measures which incorporated these elements into a more general assessment tool such as the Stroke Impact Scale. This was necessary in order to obtain a sufficient number of articles that had included a quantitative measure of mood to conduct the review however, there is considerable variability in the constructs these different types of assessment measure, which makes a coherent synthesis challenging.

There was a limited amount of literature eligible for inclusion in the systematic review and the studies methodological varied according to the Cochrane risk of bias tool

(J. P. Higgins, Altman, & Sterne, 2017). Unclear reporting of the methodological procedures such as randomisation and blinding made rating the quality of studies accurately a challenge. Reporting of the intervention delivery, e.g. group size and content was also variable, so it was difficult to directly compare the interventions. If this research was conducted again, authors would have been contacted to clarify any outstanding queries arising during the risk of bias analysis. Of the eleven studies included in the review four were deemed to be low- and four high- risk of bias while three studies had an unclear risk of bias. This means the results of the review need to be viewed with caution as there is, as yet, insufficient research of adequate quality to draw firm conclusions and provide clear guidance about the provision of creative activity groups to improve psychological outcomes in ABI rehabilitation.

Conclusion

The results of this study are drawn from an idiographic research methodology and systematic review of a limited published research literature. As such, they should not be generalised to the wider brain injury community without extreme caution. However, the results of these two related studies provide novel insights into the phenomenon of well-being following ABI and how it relates to the internal and external resources and sources of support people draw on during their adjustment to living with an ABI. Further research is required to identify the prevalence of these contributors to well-being to establish how idiosyncratic or widely experienced they may be.

References

- Ellis-Hill, C., Payne, S., & Ward, C. (2008). Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation, 30*(2), 150–159.
<https://doi.org/10.1080/09638280701195462>
- Galvin, K. T., & Todres, L. (2011). Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies on Health and Well-Being, 6*(4), 1–13. <https://doi.org/10.3402/qhw.v6i4.10362>
- Higgins, J. P., Altman, D. G., & Sterne, J. (2017). Chapter 8: Assessing risk of bias in included studies. In J. P. T. Higgins, R. Churchill, J. Chandler, & M. Cumpston (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions* (5.2.0, p. 8:1-8:73). Chichester, UK: Cochrane. <https://doi.org/10.1001/jama.2013.109501.Conflict>
- Higgins, J. P. T., Churchill, R., Chandler, J., & Cumpston, M. (2017). *Cochrane Handbook for Systematic Reviews of Interventions* (5.2.0). Cochrane. Retrieved from www.training.cochrane.org/handbook.%0ACopyright
- Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *Journal of the Royal Society of Medicine, 96*(3), 118–121.
<https://doi.org/10.1258/jrsm.96.3.118>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102–120. <https://doi.org/10.1191/1478088706qp062oa>
- Levack, W. M. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disability and Rehabilitation, 32*(12), 986–999.

<https://doi.org/10.3109/09638281003775394>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009).

Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6(7). <https://doi.org/10.1371/journal.pmed.1000097>

Pratt, R. R. (2004). Art, dance, and music therapy. *Physical Medicine and Rehabilitation Clinics of North America*, 15(4), 827–841. <https://doi.org/10.1016/j.pmr.2004.03.004>

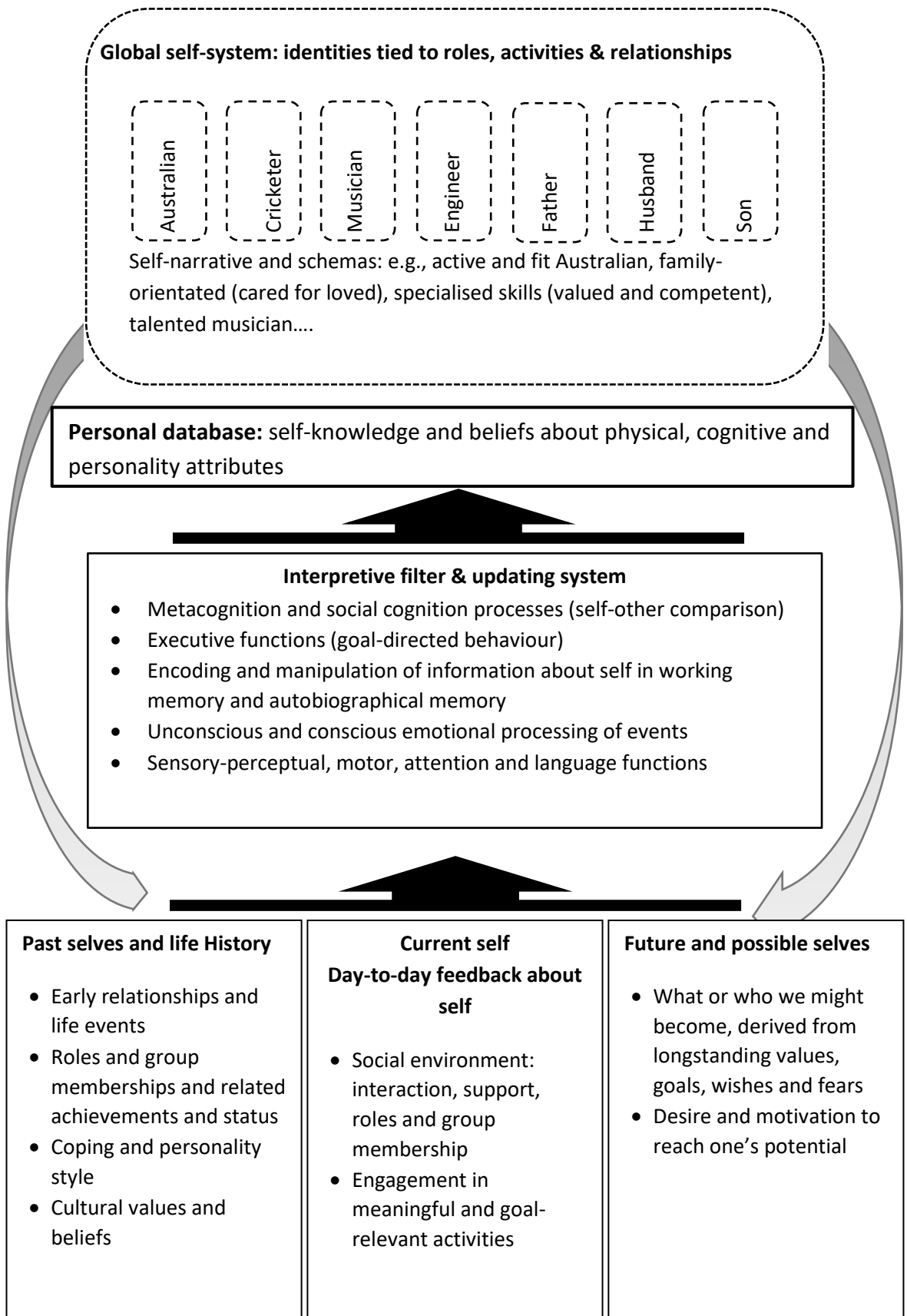
Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications Ltd.

Todres, L., & Galvin, K. (2010). “Dwelling-mobility”: An existential theory of well-being. *International Journal of Qualitative Studies on Health and Well-Being*, 5(3), 1–6. <https://doi.org/10.3402/qhw.v5i3.5444>

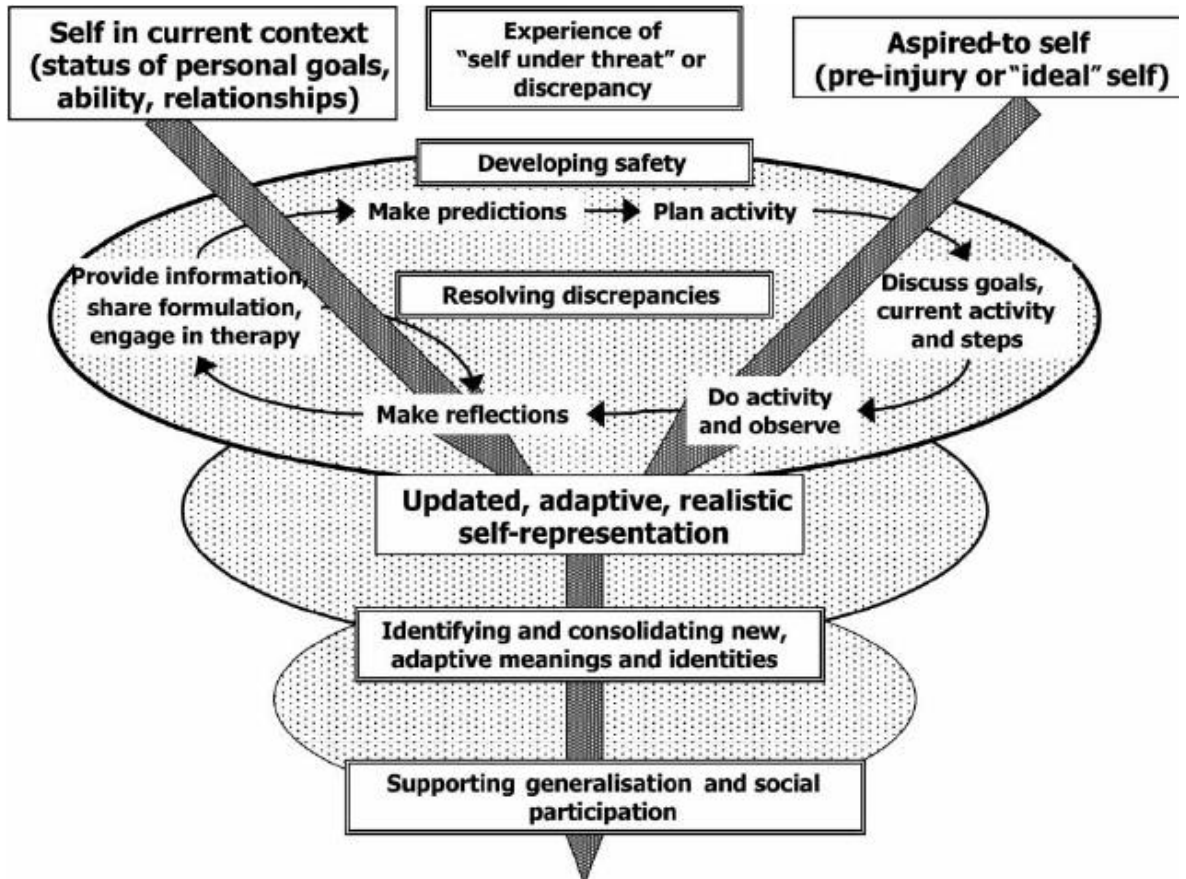
Waller, D. (2003). Group Art Therapy: An Interactive Approach. In C. A. Malchiodi (Ed.), *Handbook of Art Therapy* (pp. 313–324). New York: Guildford Press.

Appendices

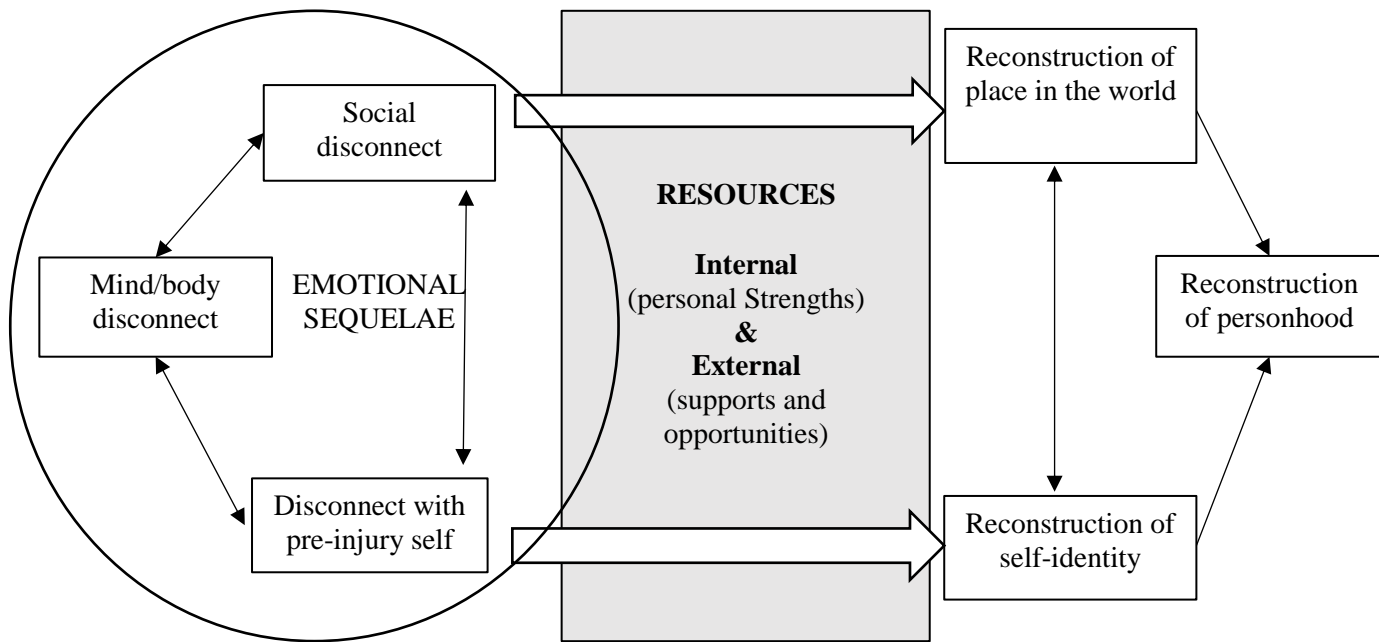
Appendix A: Global self-system (Owensworth, 2014)



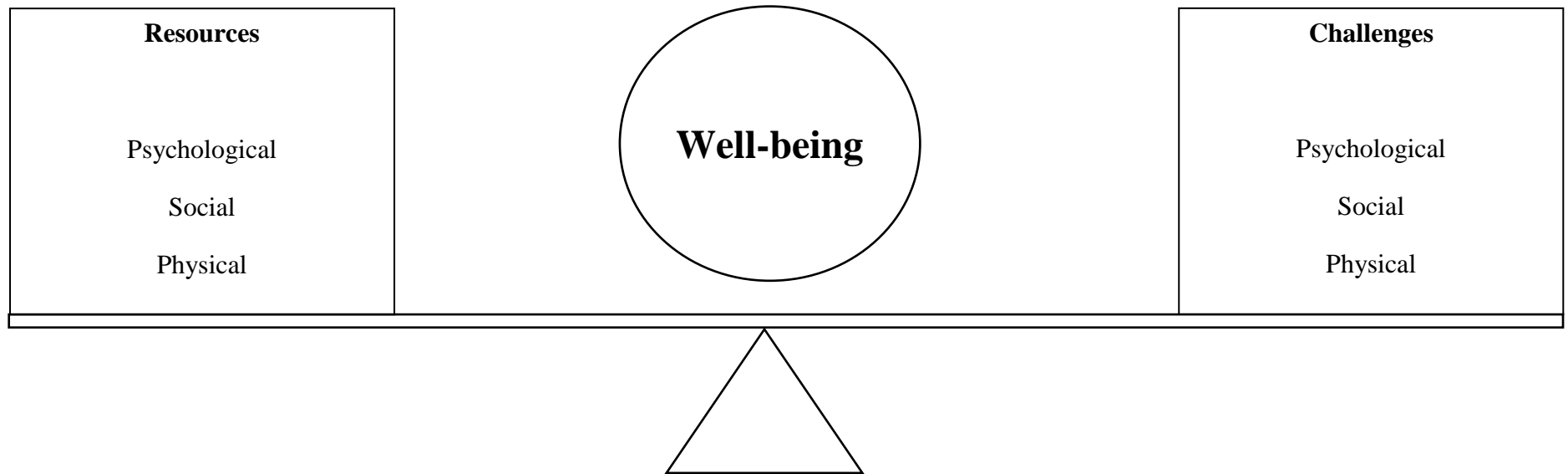
Appendix B: “Y-shaped” model of rehabilitation following ABI (Gracey, Evans, and Malley, 2009)



Appendix C: The Enduring Experience of TBI Model (Levack et al., 2010)



Appendix D: Definition of Well-being (Dodge, Daly, Huyton and Sanders, 2012)



Appendix E: “Dwelling-Mobility” lattice (Galvin & Todres, 2011)

	Mobility	Dwelling	Dwelling-Mobility
Spatiality	Adventurous horizons	At homeness	Abiding expanse
Temporality	Future orientation	Present-centeredness	Renewal
Inter-subjectivity	Mysterious Inter-personal attraction	Kinship and belonging	Mutual complementarity
Mood	Excitement or desire	Peacefulness	Mirror-like multi-dimensional fullness
Identity	I can	I am	Layered continuity
Embodiment	Vitality	Comfort	Grounded Vibrancy

Confirmation of ethical opinion

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

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

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

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

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

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

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

Registration of Clinical Trials

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

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

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

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

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

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	1.7	09 October 2017
Covering letter on headed paper [Letter of Introduction]	1.5	22 August 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity and Insurance document from Sponsor]	1	13 July 2017
Interview schedules or topic guides for participants [Interview topic guide]	1.3	01 May 2017
IRAS Application Form [IRAS_Form_11082017]		11 August 2017
Letter from sponsor [Letter from Sponsor]	1	13 July 2017
Other [215766 Alice Rose REC provisional opinion response letter]	1	10 October 2017
Participant consent form [Consent to be contacted]	1.4	26 April 2017
Participant consent form [Consent Form]	1.7	26 September 2017
Participant information sheet (PIS) [Participant Information Sheet]	1.6	09 October 2017
Research protocol or project proposal [Thesis Research Proposal]	1.6	09 October 2017
Summary CV for Chief Investigator (CI) [AR Research CV]	1.6	26 April 2017
Summary CV for student [AR Research CV]	1.1	21 July 2017

Summary CV for supervisor (student research) [FG Research CV]	1	09 June 2017
Summary CV for supervisor (student research) [PF Research CV]	1	24 July 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Summary]	1.1	22 August 2017

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

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

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

HRA Training

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

17/EE/0362

Please quote this number on all correspondence

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

Yours sincerely



pp

Dr Lydia Drumright Chair

Email: NRESCommittee.EastofEngland-CambridgeCentral@nhs.net

Enclosures: "After ethical review – guidance for
researchers" SL-AR2

Copy to: Ms Tracy Moulton

*Helen Sutherland, Norfolk & Suffolk Primary & Community Care
Research Office, Hosted by South Norfolk CCG*

Appendix G: Health and Research Authority Approval



Health Research Authority

Miss Alice Rose
Doctoral Programme in Clinical Psychology
Elizabeth Fry Building
Faculty of Medicine and Health Sciences
University of East Anglia
NR4 7TJ

Email:
hra.approval@nhs.net

23 October 2017

Dear Miss Rose

Letter of HRA Approval

Study title: The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury.

IRAS project ID: 215766

REC reference: 17/EE/0362

Sponsor University of East Anglia

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 8

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

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

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.

In addition to the guidance in the above, please note the following:

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

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

Scope

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

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

Your IRAS project ID is **215766**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe

Assessor

Email: hra.approval@nhs.net

Copy to: Tracy Moulton, University of East Anglia, Sponsor Representative
Helen Sutherland, Norfolk & Suffolk Primary & Community Care Research
Office, Lead NHS R&D contact

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	1.7	09 October 2017
Covering letter on headed paper [Letter of Introduction]	1.5	22 August 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity and Insurance document from Sponsor]	1	13 July 2017
GP/consultant information sheets or letters [GP Letter]	1.3	22 August 2017
HRA Schedule of Events [Validated SoE]	1.0	01 September 2017
HRA Statement of Activities [Validated SoA]	1.0	01 September 2017
Interview schedules or topic guides for participants [Interview topic guide]	1.3	01 May 2017
IRAS Application Form [IRAS_Form_11082017]		11 August 2017
Letter from sponsor [Letter from Sponsor]	1	13 July 2017
Other [215766 Alice Rose REC provisional opinion response letter]	1	10 October 2017
Participant consent form [Consent Form]	1.7	26 September 2017
Participant consent form [Consent to be contacted]	1.4	26 April 2017
Participant information sheet (PIS) [Participant Information Sheet]	1.6	09 October 2017
Research protocol or project proposal [Thesis Research Proposal]	1.6	09 October 2017
Summary CV for Chief Investigator (CI) [AR Research CV]	1.6	26 April 2017
Summary CV for student [AR Research CV]	1.1	21 July 2017
Summary CV for supervisor (student research) [FG Research CV]	1	09 June 2017
Summary CV for supervisor (student research) [PF Research CV]	1	24 July 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Summary]	1.1	22 August 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in

England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Tracy Moulton

Tel: 01603 597197

Email: researchsponsor@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments

4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities and schedule of events will act as agreement of an NHS organisation to participate. No further agreements expected.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this
Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The statement of activities confirms that no funding will be available to participating NHS sites from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC FO dated 20/10/2017

6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type in this study; participating NHS organisations will conduct all study activities. Participants will initially be identified by the clinical care team however consent and interviews will be conducted by the researcher (chief investigator) at the participating site.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator is expected at participating NHS organisations to arrange access and identify potential participants. A local collaborator has already been identified.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

A Letter of Access (or equivalent) would be expected for any external NHS/research staff undertaking study activities (consent and interviews) at the participating NHS sites where the research team will access areas where patient care is delivered. The pre-engagement checks should include DBS check and Occupational Health Clearance.

Where study activities will be carried out in non-clinical areas, away from where patient care is being delivered, a Letter of Access is not expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.



Semi-Structured Interview Topic Guide

The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury.

The interview schedule is a guide to questions which may help to access the phenomenon this study is interested in learning about.

These sample questions will be applied to the participant interviews sensitively and flexibly in a way that is responsive to the participants' personal experience and responses. The intention of the semi-structured interviews is that they will feel more conversational in style than interrogative. The aim is to create a relaxed and comfortable atmosphere where the participant feels at ease discussing their deep, personal experience in sufficient detail to uncover the phenomenon the study is aiming to explore. Therefore, questions may be presented in a different order to the schedule outlined below and may be re-worded to make them more meaningful to the individual being interviewed.

The interview schedule will be shared with participants during the interview process and used as a tool to keep the conversation on the right track and to check meaning and understanding with participants as the interview unfolds.

-
- ◇ Can you please tell me about your brain injury and the impact it has had on you and your life?
 - Many people describe feeling a great sense of loss and disconnection from themselves/others/their life before brain injury, does this resonate with you?

 - ◇ Can you tell more about your experience of the impact/changes you felt following your brain injury?
 - Can you describe your journey from how you were immediately following your brain injury to what your life is like today?

- ◇ People often talk about a sense of having changed and ‘rebuilt’ their lives or ‘rediscovering’ themselves and reconstructing their place in the world, has this happened for you?
 - Has this given you a sense of ‘well-being’? how would you describe it, in your own words?
 - What was this process like for you?
 - How did you manage this journey?
 - What was your experience of what you needed to do to get to where you are today from that place of ‘disconnection and loss’ (*use participants’ own words of descriptors for this place*)?

- ◇ What does well-being mean to you?

- ◇ Can you tell me about/describe your experience of a sense of well-being that you have had since your brain injury?
 - When did you first notice this?
 - What was happening for you at this time?
 - How would you describe this feeling/sense of well-being?
 - What contributed to/helped you achieve this sense of well-being?

- ◇ In the transition between that place of *loss and realisation of all that had changed (use participants’ own words of descriptors for this place)* to where you are now, what helped you/guided you/motivated you/kept you going in this process of ‘reconstruction’ *<using interviewees own words>* to a place of ‘well-being’?
 - Can you describe to me what that feeling was like?
 - How did you overcome any difficulties you experienced along the way? What did you do? How did you manage it? What motivated you or supported you to do this? Did you have support from: others? Groups? Organisations?
 -

- ◇ Were there times when you had to draw on something from within yourself to achieve a sense of well-being/maintain momentum/overcome the difficulties you were facing as a result of your brain injury?
 - Can you tell me more about this?
 - How did you experience this?
 - What was this like for you?
 - What impact did this have on you?

- ◇ What advice would you give to another person who has a brain injury to help them re-discover and/or achieve their sense of wellbeing?



Volunteers Needed!

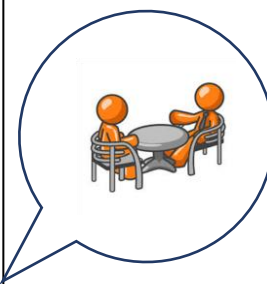
To take part in a research study exploring the experience of rediscovery of well-being following Acquired Brain Injury.

The research is exploring how people rediscover a sense of well-being after acquired brain injury (ABI). I am particularly interested in the external sources of support or internal strengths and traits that help people achieve a sense of well-being.



What will the study involve?

- ✓ You will be interviewed about your experience of well-being following your brain injury.
- ✓ The interview will last about one hour.
- ✓ The interview will be audio recorded.



Who can take part?

You must:

- ✓ have a non-progressive brain injury acquired after the age of 18 years, which is evidenced in your medical history.
- ✓ Have acquired your brain injury at least 12-months ago
- ✓ have experienced a positive sense of well-being since your ABI and be able to talk about your experience in an in-depth interview lasting around 1 hour.
- ✓ be fluent in English and able to provide signed informed consent
- ✗ Must not have any severe, enduring or current mental health difficulties, mood disorder or substance misuse disorder.

If this sounds like you, and you are interested in taking part, please speak to:



They will pass on your contact details to the researcher at the University of East Anglia who can give you more information about the study and what it involves.

Alternatively, please contact the researcher directly using the details below:

Well-being after ABI: Alice Rose, Alice.Rose@uea.ac.uk 07445 159198	Well-being after ABI: Alice Rose, Alice.Rose@uea.ac.uk 07445 159198	Well-being after ABI: Alice Rose, Alice.Rose@uea.ac.uk 07445 159198	Well-being after ABI: Alice Rose, Alice.Rose@uea.ac.uk 07445 159198
--	--	--	--



Participant Information Sheet

The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury.

Alice Rose, Trainee Clinical Psychologist.

email: alice.rose@uea.ac.uk Tel: 07445 159198

We would like to invite you to take part in our research study. We have put together some information about the study to help you decide if you would like to take part.

Please ask the researchers if there is anything that you don't understand or if you have any questions. You can contact the researchers using the contact details below.

Who are the Researchers?

This study is being carried out as part of a Doctorate in Clinical Psychology at the University of East Anglia.

Alice Rose (Trainee Clinical Psychologist) is the Chief Investigator. Alice can be contacted at alice.rose@uea.ac.uk or on 07445 159198.

Fergus Gracey (Senior Research Fellow, UEA) is the Primary Research Supervisor and can be contacted at F.Gracey@uea.ac.uk or 01603 592898.

Why are we carrying out this study?

Brain injury can have a significant impact on people's lives. It may result in changes to functioning, social relationships and activities.

People often report feeling like a different person after brain injury. There is often a period of adjustment to new ways of doing things and being. Many people also reconstruct their identity or sense of self after brain injury. This can be a long and difficult journey but there is increasing information showing that people find this has a positive effect on their well-being.

Unfortunately, there is currently little information telling us how people make their journey of identity change following brain injury.

This study aims to find out what resources and processes people believe are involved in this change and how this relates to well-being. Resources may include external sources of support or internal strengths and traits that have helped you experience a sense of well-being.



Who can take part?

Participants must:

- ✓ Be aged over 18 years
- ✓ have a non-progressive brain injury acquired after the age of 18 years. The brain injury may be caused by either trauma, stroke, illness, infection, tumour or surgery and must be evidenced in their medical history
- ✓ have acquired their brain injury at least 12-months ago
- ✓ have experienced at least a temporary positive sense of well-being since their ABI and have insight into that experience
- ✓ be fluent in English and able to provide signed informed consent and be able to participate in in-depth interviews lasting approximately 1 hour.
- ✗ Must not have any severe, enduring or current mental health difficulties, mood disorder or substance misuse disorder.

What will taking part involve?

If you feel you have moments where you have experienced positive sense of well-being since your brain injury, or feel you have adjusted well and would be happy to talk about what helped you achieve this with the researcher of this study:

- ❖ You will be interviewed about this experience individually for an hour.
- ❖ The interview will be audio recorded.
- ❖ The interview can take place at <insert name of service>.



The interview is semi-structured. This means there are some set questions but the interviewer wants to enable you to tell them about your experience of the process of change since your brain injury in your own way.

The researcher will ask you some information about yourself and will look at your medical record to obtain information about your brain injury.

Will my taking part in the study be kept confidential?

The person who normally manages your care at <insert name of service> will be informed if you choose to take part in the study and a copy of your consent form will be added to your clinical record.

Will what I say be kept confidential?

Your confidentiality will be taken very seriously. All confidential information will be transported in a lockable case and will be stored securely. It will only be accessed by the Chief Investigator, who interviews you, and the Research Supervisors.

All data will be treated as confidential. Confidentiality will only be broken if you tell the researcher something which makes them concerned for your safety or the safety of others. This information may need to be shared with your care team. In rare circumstances, other statutory services such as social services or the police may also need to be informed if the researcher is concerned for your or someone else's safety. Whenever possible this would be discussed openly with you and you would be told before this happened. Your confidentiality will not be

broken without telling you first unless it would put you or someone else at risk to do so.

Will what I say be anonymous?

To help maintain your confidentiality your data will be anonymised. One way of doing this will be with a pseudonym. This means a different name will be used to identify the data. Other ways will be to make any specific details about you more generic, for example 'football' may be changed to 'team sport'.

A lot of care will be taken not to include information that could identify you. However, in this type of research quotes are used to support the points made by the researcher.

There is a small chance that people who know you well may guess which quotes belong to you if they know you are participating in the study. Therefore, we cannot guarantee 100% anonymity.

How will you keep my information secure?

- ❖ After the interview the audio recording will be transported in a locked bag and transferred to an encrypted memory stick. It will be deleted from the recording device.
- ❖ Recordings may be sent securely to a transcription service for typing.
- ❖ Typed interview transcripts will be anonymised and stored on a password protected computer.



- ❖ All paper information, including consent forms will be stored in a locked filing cabinet.
- ❖ All data will be stored according to current data protection legislation and will be destroyed after 10 years.

What will happen to the information from the interview?

The interview will be listened to by the researcher and typed up. In some cases the recordings may be typed up by a transcriber. Typed data will be made anonymous to help protect your confidentiality.

The researcher will analyse the data to try to understand your experience of well-being following ABI. The researcher will then look for similarities or differences between all the participants' experiences.

What will you do with the research findings?

It is important to share research results because they might be interesting or useful to other people.

The research findings of this study will be shared with participants and the services they use including Headway and NHS brain injury services.

The findings will also be written up in a report which could be published in an academic journal. They may also be presented on a research poster or in presentations at research conferences.



Do I have to take part?

No. Taking part in this study is optional. It is up to you to decide if you want take part or not. Your decision will not affect the care or support you receive.

We encourage you to speak to your care team, family or friends to help you decide if you wish to take part in this research. You will have a minimum of 72 hours to decide if you would like to take part. If you do agree to take part, you will need to sign a consent form with the researcher next time you meet.

If you do decide to take part, you can withdraw from the study without giving any reason. This will not affect your clinical care in any way. It will only be possible to withdraw up to two weeks after your interview has taken place. This is because it is not possible to take out individual information once it has been anonymised and analysed by the researcher.

What are the possible benefits of taking part?



- ❖ Some people find it useful talk to someone in detail about their experience.
- ❖ It can sometimes feel helpful to put into words something you may not have spoken about before.
- ❖ It may be important for other people to understand the impact of brain injury
- ❖ It may be beneficial to other people who have also had a brain injury to hear about the experience of those who have adjusted well to the changes it brings. This could foster hope in others and aid their journey of adjustment.

What are the possible disadvantages of taking part?

- ❖ The interview will take up to an hour. It may be tiring or difficult to talk for long periods. You can choose to take breaks during the interview if this is the case.
- ❖ I will be asking about the resources you used in the process of your adjustment to the changes caused by your brain injury. This topic may bring up strong emotions and feelings. If this happens, it is important you let the researcher know. We can stop the interview to talk about what has upset you, or to take a break. If the interview is stopped you can choose whether you wish to withdraw from the study or would continue the interview the same day or at another time.
- ❖ Interviews will last approximately one hour and although we appreciate your time, unfortunately it is not possible to pay you for your time or reimburse any travel costs.



Who has reviewed the study and how is it funded?

The research study is being carried out as part of a doctorate in clinical psychology at the University of East Anglia and has been approved by an NHS research ethics committee and Headway.

The study has also been reviewed by service-user research panels and members of Headway services to inform the design of the study and this information sheet.

Will everyone who is interested be able to take part?

Unfortunately, it may not be possible to interview everyone who is interested. This is due to time constraints of the research study.

What if there is a problem?

If you have any concerns about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers can be contacted via email, telephone or post:

Alice Rose (Chief Investigator):

Alice.Rose@uea.ac.uk or 07445 159198

Fergus Gracey (Primary Research Supervisor):

F.Gracey@uea.ac.uk or 01603 592898

Or write to us at:

Department of Clinical Psychology
The Elizabeth Fry Building
Norwich Research Park
University of East Anglia
Norwich
Norfolk
NR4 7TJ



What if I have a Complaint?

If you wish to make a formal complaint about the researcher or any aspect of the conduct of this study, please contact:

Professor Ken Laidlaw (Head of Clinical Psychology Department, UEA):

K.Laidlaw@uea.ac.uk or 01603 593600

Department of Clinical Psychology
The Elizabeth Fry Building
Norwich Research Park
University of East Anglia
Norwich
Norfolk
NR4 7TJ



Consent to be Contacted Form

The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury.

Alice Rose, Trainee Clinical Psychologist.

email: alice.rose@uea.ac.uk

Tel: 07445 159198

Please initial
box if you agree:

I confirm I am interested in taking part in the above study and give consent for the researchers to contact me using the following contact details:

Name: _____

Preferred method of contact (please tick):

Tel. Number: _____

Email: _____

Signature

Date

Appendix L: Demographic Screening Questions

The process of adjustment from the place of disconnection into rediscovery of sense of wellness following Acquired Brain Injury

Participant Number:

Age / DOB:

Age when brain injury occurred:

Type of injury (progressive/non-progressive)

Date of / Time since ABI:

Have you at least a temporary positive sense of well-being since your brain injury occurred that you feel able to talk about?

Do you have any current mental health difficulty, mood or substance misuse disorder?

Is there anything that would be helpful for me to know to help with the interview?
(e.g. fatigue, communication support etc)

Appendix M: Consent to Participate Form

Participant Consent Form: Version: 1.7 Date: 26/09/2017



Participant Consent Form

The process of adjustment from the place of loss and disconnection into rediscovery of sense of wellness following Acquired Brain Injury.

Alice Rose, Trainee Clinical Psychologist.

email: alice.rose@uea.ac.uk

Tel: 07445 159198

Participant ID:

Please initial if
you agree with
the statement

1. I confirm that I have read and understood the information sheet (Version: 1.6, Date: 09/10/17), and I have had the opportunity to ask questions, and these have been answered to my satisfaction.
2. I confirm that I am signing this consent form at least 72 hours after having first had the study explained to me.
3. I understand that my participation is completely voluntary and that I am free to withdraw without giving any reason, without this affecting my current or future healthcare.
4. I understand that my care team will be informed I am participating in this study and consent to the researcher accessing my medical records.

5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from The University of East Anglia or from regulatory healthcare authorities for the purposes of audit and monitoring this research. I give permission for these individuals to have access to my records.
6. I understand that the interview will be audio-recorded and the digital audio stored securely.
7. I understand that the audio-recording may be sent via email to a transcription service for typing.
8. I understand that absolute anonymity cannot be guaranteed due to the use of direct quotes, but that the utmost care will be taken to anonymise and remove identifying information.
9. I understand that I can change my mind and withdraw my interview data, up to two weeks after my interview without giving any reason. It will be my responsibility to contact the researcher to let her know if I wish to withdraw my information.
10. I agree to take part in the above study.

Name of Participant

Signature

Date

Name of Researcher

Signature

Date

3 copies to be made:

One each for: researcher site file; participant; and participant's medical notes.

Appendix N: Email confirmation of confidentiality agreement with transcription service

Re: Welcome to GoTranscript.com

Peter Trebek / GoTranscript.com <info@gotranscript.com>

Thu 21/12/2017 17:44

To: Alice Rose (MED - Student) <Alice.Rose@uea.ac.uk>;

1 attachments (152 KB)

GoTranscript-agreement 1.pdf;

Hello,

I attach signed NDA for you. I also will set for your account that only from UK IP address transcribers/editors would work with your files.

On Thu, Dec 21, 2017 at 7:34 PM, Alice Rose (MED - Student) <Alice.Rose@uea.ac.uk> wrote:

Dear GoTranscript,

I would like to use your transcription services for my university doctoral thesis research interviews.

Before I can upload my audio, please could I have a signed copy of your non-disclosure agreement to satisfy my ethics committee. Please could I also ensure with you that my recording will be transcribed within the UK and not sent overseas.

Many thanks,


Alice

Appendix O: Signed confidentiality agreement with transcription service

21/12\2017

Confidentiality agreement between GoTranscript - Parker Corporation LP & the client Alice Rose

1. I hereby undertake not to provide consultancy services to the client during the term of my agreement or after its termination for any reason unless expressly authorised by the client, or required by law to disclose information to any unauthorised person, nor use any of the confidential information related to or received from the client.
2. Such information includes but is not limited to financial information, client personal files and research data. Information is also confidential information if it is clearly marked as such or by its very nature is evidently confidential.
3. I understand that the use and disclosure of all information about identifiable living individuals is governed by the Data Protection Act. I will not use any personal data I acquire during my work for any purpose that is or may be incompatible with the purposes specified in this agreement.
4. I understand that I am required to keep all confidential and personal data securely.
5. I hereby undertake, during the term of my agreement to provide consultancy services to the client, to store all the records and materials related to the client in a safe, secure location as long as they are in my possession.
6. I hereby undertake to ensure that all records provided for the purposes of this agreement, including any back-up records, are deleted as directed, once I have received confirmation that the contract has been satisfactorily completed and all the required information has been provided in accordance with the client's wishes. I also confirm that the client will be able to personally remove the completed transcriptions from our database, and that the records and all the information and data related to them will be completely removed from the translators ' computers once the contract is satisfactorily completed.
7. I understand that the client reserves the right to take legal action against any breach of confidence, and will proceed with upmost speed to protect its interests in the event of any such breach.

Signed 

Name: Peter Trebek

On behalf of GoTranscript

Appendix P: Guidelines for Authors

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).



This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Contents list

[About the journal](#)
[Peer review](#)
[Preparing your paper](#)

- [Structure](#)
- [Word count](#)
- [Style guidelines](#)
- [Formatting and templates](#)
- [References](#)
- [Checklist](#)

[Using third-party material in your paper](#)
[Declaration of interest statement](#)
[Clinical Trials Registry](#)
[Complying with ethics of experimentation](#)

- [Consent](#)
- [Health and safety](#)

[Submitting your paper](#)
[Publication charges](#)
[Copyright options](#)
[Complying with funding agencies](#)
[Open access](#)
[My Authored Works](#)
[Article reprints](#)

About the journal

Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of article: Reviews, Research Papers, Case Studies, Perspectives on Rehabilitation, Reports on Rehabilitation in Practice, Education and Training, and

Correspondence. Systematic Reviews should be submitted as “Review” and Narrative Reviews should be submitted as “Perspectives in Rehabilitation”.

Special Issues and specific sections on contemporary themes of interest to the Journal’s readership are published. Please contact the Editor for more information.

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. For submissions to *Disability and Rehabilitation* authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is ‘Anonymous’ or ‘Not Anonymous’ during submission, and should pay particular attention to the below:

- Authors who wish to remain **anonymous** should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main Document” and will be sent to the referees. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.
- Authors who wish to be **identified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

Once your paper has been assessed for suitability by the editor, it will be peer-reviewed by independent, anonymous expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the [Uniform Requirements for Manuscripts Submitted to Biomedical Journals](#), prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the [American Psychological Association's \(APA\) Ethical Principles of Psychologists and Code of Conduct](#).

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports - [CARE](#)
- Diagnostic accuracy - [STARD](#)
- Observational studies - [STROBE](#)
- Randomized controlled trial - [CONSORT](#)
- Systematic reviews, meta-analyses - [PRISMA](#)

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

Word count

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

Style guidelines

Please refer to these [style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Formatting and templates

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

A [LaTeX template](#) is available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact authortemplate@tandf.co.uk

References

Please use this [reference guide](#) when preparing your paper. An [EndNote output style](#) is also available to assist you.

Checklist: what to include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) [requirements for authorship](#) is included as an author of your paper. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include [ORCiDs](#) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).

2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on [writing your abstract](#).
3. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming](#).
4. 5-8 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:
Example 1: Leprosy
 - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
 - Reconstructive surgery is a technique available to this group.
 - In a relatively small sample this study shows participation and social functioning improved after surgery.

Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. [Read more on declaring conflicts of interest](#).

Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the [Declaration of Helsinki](#).

Consent

All authors are required to follow the [ICMJE requirements](#) on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this [Patient Consent Form](#), which should be completed, saved, and sent to the journal if requested.

Submitting your paper

This journal uses ScholarOne to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in the submission centre. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

If you are submitting in LaTeX, please convert the files to PDF beforehand (you will also need to upload your LaTeX source files with the PDF).

Please note that *Disability and Rehabilitation* uses [Crossref™](#) to screen papers for unoriginal material. By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about [sharing your work](#).

Open access

This journal gives authors the option to publish open access via our [Open Select publishing program](#), making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check [open access funder policies and mandates here](#).

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. Please contact openaccess@tandf.co.uk if you would like to find out more, or go to our [Author Services website](#).

For more information on license options, embargo periods and APCs for this journal please go [here](#).

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via [My Authored Works](#) on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your [free eprints link](#), so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to [promote your research](#).

Article reprints

For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk. To order a copy of the issue containing your article, please contact our Customer Services team at Adhoc@tandf.co.uk.

Queries

Should you have any queries, please visit our [Author Services website](#) or contact us at authorqueries@tandf.co.uk.

Updated May 2016

Taylor & Francis Standard Reference Style | NLM

National Library of Medicine (NLM) is a member of the National Information Standards Organization and its various published standards have been adopted for the Library's MEDLINE/PubMed database. See <https://www.nlm.nih.gov/citingmedicine/>

References are numbered consecutively in the order in which they are first mentioned in the text. Identify references in text, tables, and captions by bracketed numbers [1], and provide a list of references at the end of the article in numerical order with square brackets around the numbers. Reuse the original number assigned to the reference each time a reference is repeated in the text. Insert the citation numbers at the relevant place in the text, inside any adjacent punctuation mark. Examples: Myopathy typically occurs in fewer than one in 10,000 patients on standard doses [1]. This approach was successfully implemented by Benders et al. [30] and Zhao [31] for modular NN. For this purpose, the NNs were widely used in structural inverse problems [24], damage identification [14,25], or parameters estimation [26], among many applications.

When citing multiple references, use commas (without spaces) to separate them. Use an unspaced en dash to join inclusive first and last numbers, e.g. [2,3,4,5,7,10] would be abbreviated to [2–5,7,10]. Examples: Compared to the initial shape, the optimized surface shape can substantially improve the structural characteristics [12,13]. Most of the optimization methods proposed in previous studies are parametric methods [3–7]. See, for example, [1,3,10–13,15–20,22–25,27,28]. For some work along these lines, see [3,13,17,18,27]. The crack boundary was discretized using 10 discontinuous quadratic elements, where the crack-tip elements are discontinuous quarter-point [see 17,28].

Give a number even if the author is named in the text: Jones [10] has argued that ... Jones and Smith [12] have argued that ... If you want to name more than two authors in the text, use: Jones et al. [3] have argued that ...

Reference list

Numerical order based on first appearance in the text.

Surname and initials. Capitalize surnames and enter spaces within surnames as they appear in the document you are citing, e.g. Van Der Horn or van der Horn; De Wolf or de Wolf or DeWolf. Initials follow surname without punctuation, without spaces or full points between initials, e.g. Author AA. Place family designations of rank after the initials, without punctuation, e.g. Author AA Jr

Author AA. Title of article. Abbreviated Journal Title. Date;volume(number):pages. MacGregor RJ. A functional view of consciousness and its relations in brain. *J Integ Neurosci*. 2004;3(3):253–266.

Title page template:

Taylor & Francis Word Template for journal articles

Author Name^{a*} and A. N. Author^b

^aDepartment, University, City, Country; ^bDepartment, University, City, Country

Provide full correspondence details here including e-mail for the *corresponding author

Provide short biographical notes on all contributors here if the journal requires them.

Appendix Q: Samples of analysis

Sample of exploratory comments and theme development:

line number	Original transcript extract	Quote	exploratory comments	Emergent themes	what's the phenomenology? The experience?	superordinate theme	reflections for reflective journal.
1					wellbeing is the experience of inner-peace and a warm glow that comes from within. This can be experienced outwardly as moment of peace and quiet and cosy, comfortable environments.		
1-11	I: Participant Eight. I wonder if you can start off by telling me a little bit about what well-being means to you and what that, in your own words, what that word would mean to you. Participant eight: Well-being is- it's the ability to take care of yourself both physically, mentally. I get dressed, shower, take care of your food but also, also I think, well-being is your state of mind. Your mental well-being and that means trying to feel at peace with things and feel in control and a sense of purpose. You know- Anything to do with Maslow's needs putting into one. So it's- Well-being isn't just case of- Because in my case, I'm doing lots of positive things but I don't often feel good about myself and that's partly because of- it's obviously down to the effect on parts of the brain.	Well-being is- it's the ability to take care of yourself both physically, mentally. I get dressed, shower, take care of your food but also, also I think, well-being is your state of mind. Your mental well-being and that means trying to feel at peace with things and feel in control and a sense of purpose. You know- Anything to do with Maslow's needs putting into one. So it's- Well-being isn't just case of- Because in my case, I'm doing lots of positive things but I don't often feel good about myself and that's partly because of- it's obviously down to the effect on parts of the brain.	wellbeing is the ability to take care of yourself both physically and mentally, not just a case of doing activities you enjoy but a state of mind. It is feeling at peace with things, feeling in control and having a sense of purpose	wellbeing encompasses everything but especially incorporates mental wellbeing and feeling at peace, in control and having a sense of purpose.			
111-125	Participant eight: And the other one, I had a little bit of well-being, but no-where near as intense was, Saturday was my birthday. So, what we done was, we was in the gym, both of us. Work out there. Then we went for lunch. We had lunch in the gym there, home, showered, and [my partner] likes going to [market town] at this time of year. Because if you're [in this part of the county], then [market town], the Christmas lights and all the quirky shops there. I can't stand it so, but I thought "Right, let's play the game". So, the deal was, she can drive to [market town], [my partner] can drive to [market town]. She can bugger off around the shops. I'll find a pub, couple of beers and a book. So, we got there. There's a pub called [pub name], popped in there, pint of ale, had to move seats three times because the pub was busy. Eventually, I sit down in this- in the comfy room, log fire there, chair, book, by the window. I'm on my second pint and I'm like "This is good now..."	I'll find a pub, couple of beers and a book. So, we got there. There's a pub called [pub name], popped in there, pint of ale, had to move seats three times because the pub was busy. Eventually, I sit down in this- in the comfy room, log fire there, chair, book, by the window. I'm on my second pint and I'm like "This is good now..."	describes their day and "playing the game" going along with what your partner wants to do. Making plan for what you are going to do to enjoy the day and following it through. Finding peace and quiet, and the combination of elements comfy room, pint of ale, log fire, book, by the window. from later in the interview was just starting to feel 'peaceful' and 'feeling comfy'	feeling peaceful and comfy			they actually move the interview on from the peas experience without me getting to asking about it. At home-ness cosyness and being by the window being able to look out at the world - thinking of dwelling-mobility here also really connects to senses of well-being I have experienced in the past. to me this is classic imagery of being in a physical place that brings well-being, cosied up by a fire etc
139- 142	I: You was just having this-- It just started to bubble up, that feeling of- Participant eight: Of- peace- I: -of p- You said it was like peacefulness. Participant eight: Peace. Inner peace. Inner peace. Inner peace, yeah	Peace. Inner peace. Inner peace. Inner peace. Inner peace, yeah	how it was feeling in that moment.	well-being is experiencing inner peace			

Sample of case-by-case themes:

Pseudonym	Case-by-case superordinate themes	Emergent themes	Line	Section of transcript
Kate	experiment to find the coping strategies that work for you	discovering new ways of living/being through trial and error - experimenting	42-4	I think just really myself, trial and error, that I found different methods and coping strategies and things to help me with my memory problems, my moods, and those sort of things.
		seek out the things that support you	54-6	It's letting that person still be able to have their independence and freedom. Just taking those small steps and risks to be able to get back on the right path. It's just finding the right things.
		find the activities that suit you best	80-6	Interviewee: Swimming, yes. I think it's finding- particularly with my loss of field of vision, it's finding activities. I can't play like racket sports, things like that, because it's just knowing my own disabilities, if you like. I can't do racket sports because I'll just be forever losing the ball, or the shuttle cock, or whatever. But swimming I love because I can swim in a lane. I know I'm safe. I know I'm not going to bump into anybody. So swimming I do a lot. Just finding those -- Routine. Routine is a real important thing to me. I feel a bit unsafe out of my routine, if you like.
		identifying and putting helpful strategies into place for yourself	128-132	Kate: The things that help are- I devised what I'm calling my memory toolkit, and in my memory toolkit I have things like a calendar, a whiteboard, post-it notes, a mobile phone because I take pictures and keep diaries and keep notes and things in that, bit like a filofax I guess. So I've got a toolkit which I can dip into and those things will help put things back in place for me.

finding the
right coping
strategies for
yourself

- 135- Kate: No **[the toolkit is] something I discovered for myself, like I said, when I**
143 **went back to work and I felt I was losing my marbles a bit, I found that I was**
making notes during the day to help me remember what I needed to do for the
following day. So in came the whiteboard, in came the post-it notes, in came the
calendar and things like that. But then funnily enough now I found [charity] and
their website is amazing, it's got lots of self-help tips. On there is actually how to cope
with memory problems, and executive dysfunction of things, and actually I found a
lot of my memory kit tools are actually in there – [crosstalk] So little did I know –
- 260- Kate: Yes. I think as well- I think the old me, and the younger me would've done lots
275 of aerobics and quite high energy stuff. I think now with my brain injury, that sort of
exercise would just make my head pound.

I: Right.

accepting the
difficulties
you have after
brain injury
and seeking
out the
activities that
are beneficial
to you.

Kate: So I can't do that, and as I'm getting older, [laughs] I don't feel that I want to do
that sort of high impact stuff, but like I say, swimming is good exercise. It's good
mentally. It helps you switch off and relax. Yoga particularly, as well.

I: It sounds like you've always been quite an active, outgoing person, and that this is a
good way to --

Kate: Yes, it's finding- it's hard to accept that you can't do the activities that you once
did, and particularly again, my driving comes into it. To be able to drive to the gym
and get there and those sort of things now I can't do. So, if I wanted to go to the gym
I'd have to find a good bus route. I'd have to find one close enough that I can walk to.
So you have to plan all those things ahead. Again, lots of planning, so my driving has
been a huge impact, but then it's- finding the things that, "Okay, I can't do that. Let's
look at what I can do."

independence
to live a
'normal' life

experiment,
try things out
and keep
searching for
what does
help

overcoming
adversity to
regain
independence
and freedom
to do things
for yourself is
part of the
support
required from
others
living a
'normal' life;
having the
independence to

407- I: Yeah. Ok. I suppose- perhaps my final question would be what advice would you
420 give to another person who has a brain injury to help them to rediscover or to achieve,
that sense of wellness that you have?

Kate: Some of the old clichés, time is a healer is helpful. Don't stop searching. Keep
looking for help, and answers, and information. Having a good support team, friends,
family, [charity] groups, a counsellor, whatever it might be. I would say search for the
right help. Try things, try things out. Things that I've tried haven't always worked for
me. I thought, "No, that doesn't suit." But then don't stop there. Look for something
else. Just find what's right for you.

I: It sounds like there's a bit of persistence that's really important. Try something else.
Keep, keep going --

Kate: I suppose it's hard to accept, sometimes, the difficulties that the brain injury has
caused but, then, I very much now embrace the new me and just keep searching, keep
looking for ways that can be helpful and that suit.

44-6 Driving and my eyesight was the biggest hurdle to get over. Because that really -sort
of- clipped my independence, not being able to drive. So, yeah, just really, it's just
searching and finding my own sort of way through.

52-6 No. I think, well, living at home, as any- **now I'm a parent myself, any parent
would just want to wrap their children up and keep them well, whereas that
probably with brain injury is not always the right thing. It's letting that person
still be able to have their independence and freedom.** Just taking those small steps
and risks to be able to get back on the right path. It's just finding the right things.

64-8 Interviewee: Yes, probably. It's just still being able to have that positive thought that
you still going to achieve and live your life and do things. Like luckily, I've still been
able to do my career. I carried on with my career. I met my husband. I got married,

	do 'normal' things and make life choices		had children. And have lived a-, but I've been able to have those positive things to know that – kind of --
	being strong and independent means you can find ways to live life without relying on others	71-5	Interviewee: Yes. I think so. I'm quite a strong, independent person. So I've always searched for -- I've had acupuncture for my headaches and I swim a lot and do exercise. I've got my free bus pass because my eyesight, which meant that I could hop in the bus and get myself from A to B without relying on other people. It's just being able to find those --
	Routine makes me feel safe	80-6	Interviewee: Swimming, yes. I think it's finding- particularly with my loss of field of vision, it's finding activities. I can't play like racket sports, things like that, because it's just knowing my own disabilities, if you like. I can't do racket sports because I'll just be forever losing the ball, or the shuttle cock, or whatever. But swimming I love because I can swim in a lane. I know I'm safe. I know I'm not going to bump into anybody. So swimming I do a lot. Just finding those -- Routine. Routine is a real important thing to me. I feel a bit unsafe out of my routine, if you like.
routine and sense of safety	Routine makes me feel safe	218-222	Kate: Perhaps it was, and-but- I find that I can't be like that so much now. I don't like surprises, I like to know my routine, I like to know what I'm doing day in, day out. If someone springs something on me I find that quite challenging, someone is to ring and say, "We've got a party tonight, can you come?" I would find that really difficult. I would have to reorganize my --
	Routine keeps me motivated	231-241	Kate: I swim three times a week if I can, I do yoga, at the weekends I walk the dog, that's really important to have -- [crosstalk] I: I wonder what it is about those that really help to --

Kate: They do help, they pop my routine, I think it's good for the mind, body, and soul, all of that. It's an effort sometimes as well, because with fatigue, with brain injury, I have to push myself to do it sometimes.

I: Those times when you're quite fatigued and you really have to push yourself, how do you manage that? What helps in those moments where you're struggling?

Kate: I think because I always swim after work, I've always got my kit with me, so I sort of can't back down.

knowing
where your
difficulties lie
empowers
you

185-
190 I think still the sort of- essence for me and my personality is still there, and very much now I just know where my difficulties lie... I can sort of pinpoint those now, more easily.

having the
right
information
empowers
you to make
the right
changes to
your life

being able to
access
knowledge
and tips from
others

133-
143 I: How did you kind of come across this toolkit? Was it something that someone suggested to you at some point, or was it something that you discovered along the way?

Kate: No that's something I discovered for myself, like I said, when I went back to work and I felt I was losing my marbles a bit, I found that I was making notes during the day to help me remember what I needed to do for the following day. So in came the whiteboard, in came the post-it notes, in came the calendar and things like that. But then **funnily enough now I found [charity] and their website is amazing, it's got lots of self-help tips. On there is actually how to cope with memory problems, and executive dysfunction of things, and actually I found a lot of my memory kit tools are actually in there** – [crosstalk] So little did I know –

knowing and
recognising
own
difficulties

397-
406 I: Having that follow-up. Just thinking about what to ask next. I suppose if you had to describe what well-being is for you, in your own words, how would you describe it?

Kate: That's tough. **I would say, for my own well-being, it's knowing and**

	and how to overcome them	<p>recognising my difficulties, knowing what tools and things I can use to ease those difficulties and very much, for me, it's being able to have a steady routine.</p> <p>Having a bit of a plan, having a bit of a plan, getting your friends and family on-board with that. Like I say, just using all my tools from my toolkit, my calendar, my post-it notes, my diary, a journal that I write and keep track of things. It's just being able to use those tools and tricks that, just in your everyday life.</p>
having a role supporting others; finding your place in the world	being able to help others gives me a sense of purpose and achievement helping others, helps me. Sharing experiences and mutual support	<p>121-5 Kate: Everything was different. We were in a new house and got back in Norwich. I thought I needed to apply myself to something else now and just by pure chance found [charity]. And actually being a support worker here, and helping other people from the things I've learnt is again, helping me. I've got a nice routine here, I've got a good role and it's nice --</p> <p>304-8 Kate: I think finding [charity] this year has been fantastic. I wish I'd found it over 20 years ago maybe as a client, but there is something uplifting about [charity], despite all our difficulties and our disabilities and there's something and there's just something that unites us all. There's a theme running through, and me helping clients, little do they realise, is helping me.</p>

Cross case Theme development:

Having the right information and knowledge about your brain injury can empower you to discover and use the coping strategies that work for you: the better you understand your brain injury, the better you can manage it and feel in control of life.

Participant	Individual superordinate themes
Kate	experiment to find the coping strategies that work for you; understanding your brain injury make this more effective having the right information empowers you to make the right changes to your life routine and sense of safety
Louise	Using strategies to achieve a healthy body and mind
Frank	I'm lucky to be alive so I have to focus on myself and be in control of my life
Jane	be the best you can be; focus on what you want to improve and keep going
Rob	breaking down overwhelming tasks so you can achieve the everyday things is satisfying. adjusting to life with a brain injury is hard work, you have to look deep within yourself to understand your injury and discover the right tools and strategies to help you manage your ABI. But the better you manage it, the better you feel, the more in control you feel of your life.
Paul	Having a sense of belonging is comforting and makes you feel secure
Daniel	having a supportive environment to be in, where you have the freedom and respect to be yourself gives you

Being able to use personal experience to help others gives you a sense of pride and social-role.

Kate	having a role supporting others; finding your place in the world
Louise	Supporting others; maintaining your social-role and self-identity Mutual support and respect
Frank	want to have a voice to be heard so that I can use my experiences to help others
Daniel	supporting others gives you a sense of pride

Being valued and supported by others can keep you going and help you to make with your goals if it is teamed with the freedom to find your own way and be yourself.

Fiona	Uplifting to achieve goals: Being competitive and "tough love", being challenged by others to "prove me wrong", keeps you going.
Roger	connecting with others through shared humour keeps you going
Frank	support from others has been unbelievable - it helps me to help myself
Jane	support from others can teach you and help you progress if it is teamed with the freedom to find your own way
Rob	'play the game': find the right balance of give and take so you can be both supported and independent. having support from others to adjust to life after ABI give you hope for the future.
Paul	being valued by others gives you the confidence to be yourself and motivates you to better yourself Accepting genuine support and following trustworthy advice enables you to re-learn how to live independently.
Daniel	having a supportive environment to be in, where you have the freedom and respect to be yourself gives you

Challenge yourself and focus on the positives; love the life you live and keep trying to make it better.

Fiona	You can either roll-up and die or you can “go fire and brimstone”: Channelling your anger and fighting for your life
Roger	positive thinking and hope in achieving the goals you have set yourself: having the determination to keep going and not give up
Louise	Positive thinking gives you the strength to love the life you live
Frank	I'm lucky to be alive so I have to focus on myself and be in control of my life
Jane	face your fears to become the best you can be; focus on what you want to improve and keep going
David	challenge yourself and take risks set personal challenges to achieve
Daniel	Live your life one day at time and always look forward to the future, be optimistic that things will get better. being grateful for the life you have helps you to stay positive and resilient Challenging yourself and being successful makes you feel proud and 'over the moon'.
Steve	brain injury makes you stop and think more, it's made me calmer and take less risks; keep calm, and focus on the positives

Live in the moment: take it all in and experience the world around you to its fullest.

Fiona	<p>A slower pace of life gives you a richer life</p> <p>Commitment to good, clean hobbies: being "at one with nature" vs. enjoying the "glitzy" city life</p>
Louise	<p>Take joy from fully experiencing the world around you and the things you do</p>
Jane	<p>immerse yourself in the moment, experience it fully</p>
David	<p>be present in your surroundings. Take it all in and enjoy every aspect of it</p>
Rob	<p>stop and just breathe, try to live in this moment</p> <p>Well-being is the experience of inner-peace and a warm glow that comes from within. This can be experienced outwardly as moment of peace and quiet and cosy, comfortable environments.</p>

Doing the thing(s) you love makes you feel alive. It means the world.

Fiona	Commitment to good, clean hobbies: being "at one with nature" vs. enjoying the "glitzy" city life
Roger	having a routine doing the activities you enjoy
Louise	Take joy from fully experiencing the world around you and the things you do
Frank	music means the world to me ... [it makes me feel] brilliant. Number one.
Jane	"Art is my most important thing": know what's important to you and enjoy it
David	<p>be spontaneous and take opportunities that come up to try new things, travel and see the world – expanding your horizon</p> <p>art is like religion - it gives meaning to life and makes me feel alive because it's about new discovery</p>
Steve	<p>having a variety of things to do and being busy doing constructive activities gives you a sense of achievement</p> <p>being able to do the things you used to enjoy and maintain your independence is brilliant, especially if you can prove to others you are still capable.</p>