Understanding the benefits, barriers and correlates to social connectedness and participation for people following an acquired brain injury

Georgina Berger

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Thesis portfolio abstract

Context: Following Acquired Brain Injury (ABI) people often become socially isolated, which has been associated with poorer wellbeing and worse health outcomes.

Aim: This research portfolio aimed to improve our understanding of both social isolation and connection after ABI.

Method: In order to address the research aim, mixed methods were used. The systematic review searched the existing literature to identify predictors, correlates and effects of social isolation after brain injury. The empirical paper then investigated how people can become more socially connected after ABI. It explored how people come to access community groups following ABI, what barriers and facilitators they experience, and how accessing community groups can support wellbeing.

Results: The systematic review identified demographic, impairment, wellbeing and mental health related factors which were related to social isolation after brain injury. It indicated that there is also a paucity of studies identifying causal relationships. The empirical paper found that attending community groups can begin a virtuous cycle of increasing activity and connection which can support wellbeing. However, it found that people needed both practical and emotional supports and resources in order to access these groups.

Conclusion: The findings provide evidence for the benefits, barriers and correlates to social connectedness following ABI and suggest ways in which people can be better supported to maintain their connections and wellbeing following ABI. Further research is needed to establish causal relationships between variables and to see if this virtuous cycle of increasing activity and connection is replicated in other settings.

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Chapter 1. Introduction to the thesis portfolio

This thesis portfolio consists of two main papers: a systematic review (Chapter 2) and an empirical paper (Chapter 5). The systematic review specifically explores variables relating to social isolation after brain injury and the empirical paper then explores how people access community groups after brain injury in order to support wellbeing. A bridging chapter (Chapter 4) links the two papers together. Extended methodology chapters for the systematic review (Chapter 3) and empirical paper (Chapter 6) are included within the portfolio to provide additional information of the research process. The portfolio ends with an overall discussion and critical evaluation (Chapter 7). This integrates the findings of both papers with the wider literature and discusses the wider implications for clinical practice and research.

Definition of Acquired Brain Injury

Acquired brain injury (ABI) is the term given to an ‘injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma’ which results in an alteration to brain functioning (Brain Injury Association of America, 2020). Acquired brain injuries can be either traumatic or non-traumatic. Traumatic brain injuries (TBIs) are caused by external factors (e.g. falls or car accidents), whereas non-traumatic brain injuries are caused by internal factors (e.g. a stroke, aneurysm, tumour or infection) (Brain Injury Association of America, 2020)

Within the UK alone there were 348,453 recorded admissions to hospitals with ABI between 2016 and 2017, which was a 10% increase in the number of cases of ABI since 2005-2006 (Headway, 2020). Stroke and TBI are the most common types of brain injury (Feigin, Barker-Collo, Krishnamurthi, Theadom & Starkey, 2010). Worldwide it is estimated that 69 million individuals sustain a TBI each year (Dewan, Rattani, Gupta, Baticulon, Hung et al., 2018) and it is estimated that there are over 13.7 million new strokes each year, with over 80 million people living who have experienced a stroke (World Stroke Organisation, 2020).

Outcomes of Acquired Brain Injury

Brain injury can have physical, cognitive, social and psychological impacts on people (Hoofien, Gilboa, Vakil & Donovick, 2001) and outcomes are often poor for this population (Fleminger & Ponsford, 2005). Cognitive and communication difficulties are common following ABI (Eslinger, Downey-Lamb, Ward, Robertson & Glisky, 2002; Sarno, Buonaguro, & Levita, 1986). They can have a negative impact on quality of life (Sarno, Buonaguro, & Levita, 1986) and are associated with depression following stroke (Lee, Lee, Choi & Pyun, 2015). Survivors of brain injury have been found to be at greater risk of developing depressive disorders (Kreutzer, Seel & Gourley, 2009) and death by suicide compared to the general population (Teasdale & Engberg, 2001). People with ABI are also at greater risk of becoming socially isolated (Morton & Wehman, 1995) as the physical, cognitive, communication and behavioural changes associated with brain injury can impact on people's close relationships (Wood et al., 1997; Shorland & Douglas, 2010). This can result in survivors of brain injury becoming less socially active and losing friends (Rowlands, 2000). People with ABI often become disconnected from their communities and report being poorly integrated into the community in the long term (Doig et al., 2001; Sloan et al., 2007). This suggests that many people with ABI experience social isolation, which for the purpose of the thesis is defined using Cornwell and Waite's (2009) definition of social isolation. This definition encompasses both objective social isolation (disconnectedness which is indicated by people having a small social network, infrequent social interactions or a lack of participation in social activities or groups) and perceived social isolation (which describes people's subjective experiences of isolation, including whether they feel lonely or perceive that there is a shortfall in their social resources). Social isolation and loneliness have been linked to poor mental and physical well-being and increased mortality (Cacioppo & Cacioppo, 2014). This suggests that in being more socially isolated, those with ABI are also at increased risk of negative mental and physical health outcomes.

Wellbeing and brain injury

Due to the poor psychological and social outcomes associated with acquired brain injury, it is important to understand which factors can support well-being within this vulnerable population. The International Classification of Functioning (ICF) of Disability and Health (World Health Organization, 2001) provides a framework for understanding the consequences of ABI across biological, psychological and social domains. The framework recognises the importance of engaging in activities and participation for maintaining people's health and wellbeing and suggests that having interpersonal interactions and relationships is an important part of this. Therefore, social connectedness needs to be considered as a factor when supporting a person's health and wellbeing following brain injury, especially, as it has been shown that having social relationships can improve mental and physical health in the general population (Umberson & Karas Montez, 2010).

Psychological models of wellbeing also suggest that having meaningful interpersonal relationships and engaging in meaningful activities is important for wellbeing and can support people to flourish (Ryff, 1989; Seligman, 2011). Seligman's PERMA model (2011) takes a positive psychology approach to wellbeing and suggests that experiencing positive emotions, engaging in activities, having relationships, leading a meaningful life and having a sense of accomplishment are all important for positive wellbeing. Therefore, interventions focusing on increasing people's experience of any of these factors have the potential to enhance a person's wellbeing. This is supported by evidence from studies into the effects of participation and social connection for people with ABI, which found that arts groups

(Baumann, Peck, Collins & Eades, 2013; Kongkasuwan, Voraakhom, Pisolayabutra, Maneechai, Boonin, et al., 2016) and a song-writing programme (Roddy, Rickard, Tamplin, Lee, & Baker, 2018) that increase participation and social connection, can improve wellbeing, life satisfaction and reduce depression after brain injury.

Summary and aims of the thesis portfolio

This chapter identified that there is a trend of increasing cases of ABI in the UK (Headway, 2020), which suggests there will be an increasing need for rehabilitation and disability support. It also identified that there is an increased risk of social isolation after ABI, which can have negative impact on wellbeing. Therefore, it is important to improve our understanding of both social isolation and connection after ABI, so that we can better support people to maintain their connections and wellbeing following ABI.

The current thesis aims to increase our understanding of the benefits, barriers and correlates to social connectedness and social participation following ABI.

Overall research questions

1) What factors are associated with social isolation and connection following ABI?
2) What are the barriers to and facilitators of social connectedness following ABI?
3) What are the benefits of social connection and participation following ABI?
4) How can we best support people to maintain or increase social connectedness following ABI?

In order to answer these research questions, a systematic review and an empirical research study were completed. The systematic review specifically explores variables relating to social isolation after brain injury (the causes, predictors, correlates and effects). The main research paper will then explore how people can become more socially connected after brain injury. It will explore how they come to access community groups, what the barriers and facilitators are to accessing groups, and how accessing these groups can support wellbeing after brain injury. In doing so it is hoped that we can find ways to better support people to maintain their social connections after brain injury and thereby enhance their wellbeing

Chapter 2. Systematic review prepared for submission to: Disability and Rehabilitation

In this chapter, the systematic review that was conducted as part of this thesis will be discussed.

Understanding social isolation following acquired brain injury - What are the causes, effects and correlates: a systematic review and narrative synthesis

Georgina Berger[a], Fergus Gracey[a*], Ciara Shiggins[b], and Rebecca Bealey[a]

[a] *Department of Clinical Psychology and Psychological Therapies, University of East Anglia, Norwich, United Kingdom.*

[b] *Post-doctoral research fellow and Speech Pathologist, La Trobe University, Melbourne, Australia*

*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

Abstract

Purpose: Social isolation is a common long-term consequence of brain injury. This systematic review aims to synthesize the evidence relating to the predictors, correlates and consequences of social isolation following Acquired Brain Injury (ABI).

Method: Four databases were systematically searched up to January 2020: Medline, CINAHL, PsycINFO and Web of Science. Articles were reviewed according to the predefined eligibility criteria; a quality appraisal was conducted on all included articles; there was a narrative synthesis of results.

Results: 25 articles met the eligibility criteria. Demographic variables, injury-related factors, and size of social network at baseline were identified as predictors of social isolation following ABI. Poorer mental health, physical and perceived cognitive functioning were positively correlated with social isolation. There was a negative correlation with quality of life and life satisfaction. Social isolation at the time of ABI affected physical functioning at 3 and 6 months. However, study quality was variable.

Conclusions: Several correlates of social isolation after brain injury were identified by the review, however fewer predictors or effects were identified. Future research is needed to establish causal relationships between variables and to address the methodological limitations of the current body of research.

Introduction

Social isolation is one of the long-term consequences of brain injury [1]. Social isolation can be measured both objectively (e.g. by assessing amount of contact with others and size of social networks), and subjectively (e.g. by assessing the person's perceived feelings of social isolation or loneliness) [2]. Following Acquired Brain Injury (ABI) people often experience both types of social isolation, many report a significant decrease in their friendships and social support [3,4,5], they say their friendships go 'downhill' [6] and they can experience rejection or a sense of being forgotten by their friends [7]. Survivors of brain injury also report having fewer opportunities to make new friends or social connections [3] and so are at risk of becoming socially isolated [8]. The make-up of social networks can also change after ABI: social networks consist more of family and staff members at rehabilitation facilities, and people report having fewer non-relatives within their networks than those without ABI [9,10], with 30% of people with aphasia following stroke reporting they had no friendships at all [11].

People with ABI describe becoming socially isolated and struggling to maintain relationships for a number of reasons including: reduced ability to participate in and the loss of shared activities [12,7], the impairments they live with as a consequence of ABI (communication, physical and cognitive difficulties) [12,7,13,14], barriers within the environment [12], unhelpful responses from others [12], traumatic experiences [13] and changes in their social desires [12]. However, the causes of social isolation in this population are not fully understood.

Research suggests social isolation can have a negative effect on people's lives: loneliness can impair executive functioning, sleep, mental health and physical well-being, and has been linked to higher rates of mortality in older adults [15]. Within ABI populations, lack of social contact was reported to be one of the greatest subjective burdens for people with TBI [16], with loneliness and low satisfaction with one's social network contributing to the psychological distress experienced after stroke [17]. Social isolation and failure to resume social activities are both associated with depression following stroke [18,19]. Conversely, being socially connected after brain injury has been linked with positive outcomes: higher levels of perceived social support are associated with faster and more extensive recovery of functioning [20]; life satisfaction after brain injury is improved if people can maintain social connections [21]; and group memberships may be important in reducing the risk of developing post-traumatic stress symptoms after ABI [22]

People with ABI are therefore vulnerable to social isolation and disconnectedness and the resultant negative outcomes. However, the causes, effects and consequences of social isolation after ABI are still not fully understood and it remains unclear why some people are able to maintain social connections after brain injury when others struggle to. By better understanding factors which make people more likely to become socially isolated after brain injury and what the consequences of social isolation are, we can better identify and protect those at risk. Therefore, this review aims to explore the predictors, correlates and consequences of social isolation for people with ABI.

Methods

The systematic review followed Khan, Kunz, Kleijnen and Antes' [23] five steps to conducting a systematic review: 1) framing questions for a review; 2) identifying relevant work; 3) assessing the quality of studies; 4) summarising the evidence and 5) interpreting the findings.

Framing the question

Three research questions were developed and defined using a PICOS framework [24] (appendix 1) the Population, Intervention/exposures, Comparators, Outcomes and Study designs were all considered:

1. What factors predict or cause social isolation in adults who have had an ABI?
2. What factors are related to social isolation in adults who have had an ABI?
3. What are the impacts of social isolation on adults who have an ABI?

Predictors or causes of social isolation were defined as either variables linked to social isolation which occurred prior to the observed score on a measure of social isolation (e.g. demographic variables, injury-related variables or variables in longitudinal study designs which were observed to occur prior to the outcome variable of social isolation) or variables in randomised control trials or other experimental designs which had been manipulated and had effected scores on measures of social isolation. Factors relating to social isolation were defined as any correlates of social isolation (these were identified through cross-sectional or longitudinal study designs). Finally, the impacts of social isolation were defined as any variables which were observed to occur following social isolation or connection within longitudinal study designs, or any variables that changed following a manipulation to people’s social connectedness within experimental study designs.

Eligibility criteria

Studies were included if they reported quantitative data with corresponding statistical analysis, if they investigated either predictors, effects or correlates of social isolation after brain injury, and used a valid and reliable measure of social isolation or social connectedness. This could be a subscale of a broader outcome measure. Participants within the studies had to be adults over the age of 18 living in community settings who have had an ABI (defined as damage or injury to the brain occurring after birth which is not related to any congenital disorders, developmental disabilities or progressive processes which cause damage to the brain, [25]). Community settings included residential settings, supported living accommodation and independent living arrangements, but not inpatient hospitals. Only full text articles published in peer-reviewed academic journals that were published in English were included in the review. Randomised controlled trials, quasi-experimental studies (e.g. pre-post or time series designs) and observational studies (e.g. cohort studies, cross-sectional designs, case-control studies and case series) were all included in the review.

Articles were excluded from the review if they used a qualitative methodology, were systematic reviews, meta analyses, commentaries or case studies. Articles were also excluded if they included participants aged under 18 years (unless analysis was carried out separately for the different age groups), participants who are residing in inpatient hospital settings or participants without acquired brain injury (unless a sub-group analysis was carried out for people with ABI). Studies were not included if they did not assess for predictors, effects or correlates of social isolation, if they did not use valid and reliable measures of social isolation or connectedness, or if they measured relationship satisfaction, quality of life or social participation (without specifically measuring social interactions or loneliness). Studies not published in English or published in peer-reviewed academic journals were also excluded.

Identifying relevant studies

Search terms were developed in collaboration with a librarian based on the research question, PICOS framework and eligibility criteria in order to identify relevant articles from the databases. Search terms were kept broad in order to ensure no relevant papers were missed. Keyword searching was used for the keywords ‘brain injury’ and ‘social isolation’ and relevant MeSH terms (Appendix 2).

Searches of the CINAHL, PsycINFO, Medline and Web of Science databases were conducted up until January 2020 by the lead author (GB) using search terms to identify relevant papers. Once duplicates were removed the remaining articles were transferred to Rayyan QCRI (systematic review web application). Titles and abstracts were screened by the lead author (GB) using the predetermined eligibility criteria and the remaining papers progressed to a full text review.

Risk of bias (quality) assessment

Risk of bias/study quality was appraised for each included study. The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies from the National Heart Lung and Blood Institute (2020) was used to assess the quality of observational cohort and cross-sectional studies [27]; the Quality Assessment of Pre-Post Studies [28] from the National Heart Lung and Blood Institute (2020) for Pre-Post designs with no control group; and the Cochrane Risk of Bias tool 2 [29] for RCT’s .

Risk of bias and quality assessment tools were piloted on a sample of six articles by two independent reviewers (GB, RB), to ensure the consistent application of the criteria [30]. Where differences in the scores were found, reviewers discussed these to reach a consensus. The lead author (GB) reviewed the remaining articles independently using the quality assessment and risk of bias tools appropriate for the study design [27,28,29]. Decisions made about the quality of papers and risk of bias were transparent, and the reasoning behind quality ratings is provided (Supplementary tables 3-6).

Data extraction

Data were extracted following the York guidelines for undertaking systematic reviews [31] (Appendix 3). Quality rating and data extraction tables were checked and discussed in the wider research team (CS and FG).

Data synthesis and analysis

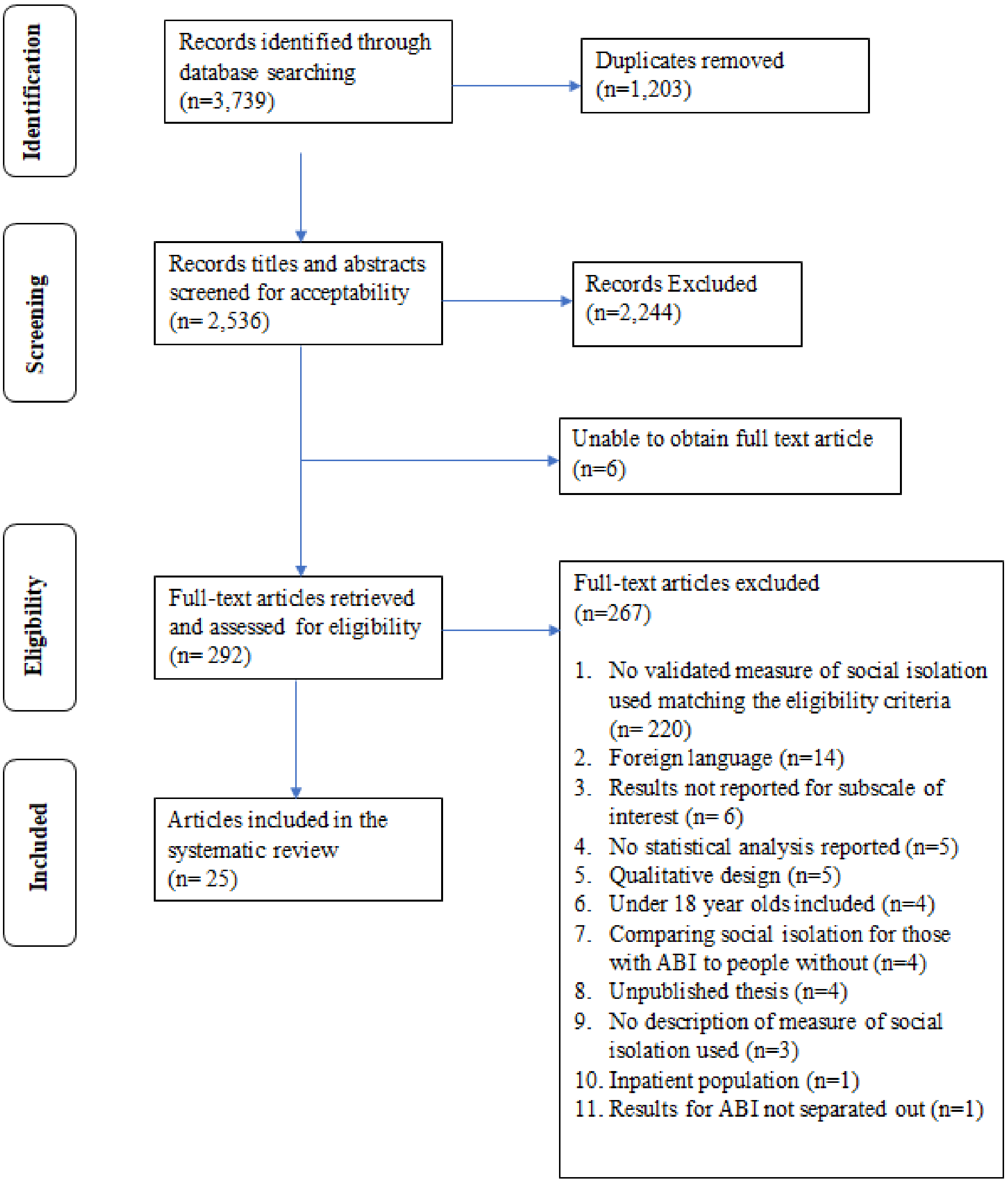
A narrative synthesis of results was completed due to the diversity of methods, variables, measures and analyses within articles. The narrative synthesis summarized research findings from the selected studies, looking at similarities and the differences between the findings of different studies as well as for patterns in the data [30].

Results

Search results

The search yield at each stage of the review is outlined in the PRISMA flow diagram (Figure 1). A total of 25 articles (consisting of 26 studies) met the inclusion criteria and were included in the review.

Figure 1: PRISMA Flow diagram.



Study characteristics

Table 1 provides details of included articles. A cumulative total of 4,108 participants with ABI were included across the 26 studies. Of these, 2,725 had experienced a stroke, 1,092 had experienced a TBI, 81 had a brain tumour and 210 had a non-traumatic brain injury which was not specified. Three studies were Randomised Controlled Trials [32,33,43], one was a quasi-experimental pre–post design [38], nine were observational cohort studies [14,34-36,44-47,53] and thirteen were observational cross-sectional studies [37,39-42,46,48-52,54,55].

A description of the different measures of social isolation used by the articles included in this review is provided in Supplementary table 2 (Appendix 4). Eight measures of objective social isolation, four measures of perceived social isolation/loneliness, and two measures assessing for both objective and subjective experiences of isolation were used.

Table 1. Data Extraction table

Study [Ref]	**Country**	**N (Total n; (n male and female))**	**Participants Mean age (SD)**	**Type of brain injury**	**Study design**	**Measure assessing social isolation**	**Type of measure of social isolation**	**Results**	**Quality appraisal tool (1,2,3)**	**Quality Score**
[32]	Norway	Total n= 62 (33 male, 29 female). Intervention group: n= 31 Control group: n=31	(Total and SDs not reported). Intervention group: 76.9 years; Control group: 76.3 years	Stroke	RCT	Nottingham Health profile: Social isolation scale	Subjective	No significant differences in social isolation between the extended and normal service groups at 6 or 52 week (p>.05). There was a significant difference in favour of the extended service group (p=0.046) at 26 weeks.	1	Some concerns
[33]	UK	Total n= 20 (11 men, 9 women) Immediate intervention group: n=10 Wait-list control: n=10	57.8 years (11.58).	Stroke	RCT	The friendship scale	Subjective	No significant effects of completing a virtual aphasia intervention on scores on the Friendship Scale (p > .05)	1	High risk of bias
[34]	Turkey	n = 60 (42 male, 18 female)	58.22 years (13.55)	Stroke	Observational: cohort	Nottingham Health profile: Social isolation scale	Subjective	The correlation between motor recovery and functional status as measured by FIM scores and social isolation was significant (r=-0.37, p<.05).	2	9/14

								Tendency to depression was the only demographic variable associated with social isolation (p<.001)		
[35]	Denmark	n = 46 (33 male, 13 female)	38 years (SD not reported)	TBI	Observational: Cohort	Nottingham Health profile: Social isolation scale	Subjective	Social isolation was significantly worsened in hypopituitary TBI patients relative to TBI patients with a preserved pituitary function (p= 0.04)	2	8/13
[36]	Norway	n = 195 (113 male, 82 female). Patients with aphasia: n = 20 Patients without aphasia: n = 175	Patients with aphasia: 42 years; Patients without aphasia: 42 years. (SD not reported)	Stroke	Observational: longitudinal prospective cohort	Nottingham Health profile: Social isolation scale	Subjective	There was no significant difference in social isolation scores between those with and without aphasia (p=0.054)	2	8/13
[37]	UK	n= 85 (49 male, 36 female)	67.5 years (11.4)	Stroke	Observational: cross-sectional	Nottingham Health profile: Social isolation scale	Subjective	Having an affected right side was associated with greater social isolation (p<0.05). Both anxiety and depression were significantly associated with social isolation (p < 0.001). Independence in activities of daily living was negatively associated with social Isolation (p < 0.05). When entered into a multiple linear regression model 23% of the variance in social isolation was predicted (adjusted R2 = 0.22; F5,75 = 5.64; p<.001) with Anxiety	2	8/13

								as the only significant predictor (β = 0.30; p = 0.02).		
[38]	USA	n=67 (59 male, 7 female)	Mean age not reported (91% age 22-40; 9% age 41-55)	TBI	Quasi experimental: pre–post study	UCLA Loneliness Scale	Subjective	There was a significant decrease in loneliness scores for people with TBI following completion of a veteran civic service programme (d = 0.4; p<.05).	3	7/11
[39]	USA	n=121 (70 male, 51 female)	67.18 years (13.77)	Stroke	Observational: cross sectional	The three-item short UCLA Loneliness Scale	Subjective	Increased loneliness was associated with reduced quality of life on all subscales of the Neuro-QoL: Ability to Participate in Social Roles (β=−1.98, p<.01); Anxiety (β=1.72, p<.01); Applied Cognition Executive Function (β=−1.75, p<.01); Applied Cognition General Concerns (β=−2.42, p<.01); Depression (β=2.10, p<.01); Emotional and Behavioural Dyscontrol (β=1.79, p<.01); Fatigue (β=1.75, p<.01); Positive Affect and Well-Being (β=−2.53, p<.01); Sleep Disturbance (β=1.67, p<.01) and Stigma (β=2.06, p<.01). Diagnosis of a current emotional, nervous, or psychiatric problem was correlated with loneliness (t = 5.2, p < .001). Participants who went to a nursing home or from a nursing home to an outpatient rehabilitation services reported higher loneliness scores than those who were able to go home and have either outpatient therapy, in-home therapy, or a combination of both (f=6.68, p=.002). No significant differences in loneliness	2	7/13

								between those living alone compared with those who lived with others, nor between those with haemorrhagic and ischemic stroke (p>.05).		
[40]	Canada	n=592,(137 Males, 427 Females, 28 people did not report their sex)	44.51 years (11.69)	TBI, N = 374; other type of ABI N = 210.	Observational : cross sectional	Social and emotional loneliness scale for adults – short form	Subjective	Increased romantic loneliness is associated with reduced satisfaction with life (β=-.157, p<.001) and Lower Leisure Satisfaction was associated with higher Social Loneliness (r = −0.422, p < .0001). Romantic loneliness was significantly higher for males than females (p =.002), and for those who had experienced their injury more than 2 years previously than for those who had experienced their injury less than 2 years ago (p = .007). Higher Social Loneliness was related to both Fear of Social Isolation (r = 0.15, p < .000) and Social Isolation (r = 0.39, p = .0001). Social, romantic and family loneliness were all associated with higher depression, reduced life satisfaction and social isolation (p<.001)	2	7/13
[41]	USA	n = 132 (132 male, 0 female)	63.29 years (2.85)	TBI	Observational : cross sectional	UCLA loneliness scale	Subjective	Loneliness scores were associated with the total satisfaction (r=−0.516, p<.001), pleasant emotions (r= −0.636, p<.001), happiness balance (r= −0.667, p<.001), psychological flourishing (r= −0.586, p<.001) and unpleasant emotions (r= 0.566, p<.001) subscales on the Well-Being Questionnaire.	2	7/13

								Loneliness was correlated with carer ratings on the apathy (r=0.287, p=0.003) and executive dysfunction subscales (r=0.217, p=0.024 of the Frontal Systems Behavioural Scale (FrSBe) and with patient ratings on the apathy (r=0.551, p<0.001), disinhibition (r=0.300, p=0.001), and executive dysfunction (r=0.360, p<0.001) subscales of the FrSBe. Loneliness scores were associated with friendship quality scores (ρ = −0.356,p< 0.001), but not with the size of their social circle (r= 0.127, p= 0.184). Individuals with selective lesions to the right anterior insula (AI) and right PFC were less likely to report loneliness compared to healthy controls (right AI: p = 0.016, d = 1.160; right PFC: p = 0.010, d = 0.828) but there were no significant differences between the posterior lesion subgroup and the healthy controls. A significant positive indirect effect was found of right AI and right PFC damage, mediated by UCLA Loneliness Scale scores, on the total satisfaction and psychological flourishing subscales		
[42]	UK	n = 65 (50 males, 15 females)	47 years (12)	TBI n= 41; Stroke n=13 Brain	Observational : cross sectional	UCLA Loneliness Scale	Subjective	Concealment of brain injury predicted loneliness (p=0.003), and this was partly mediated by distress and anxiety in social situations and social avoidance (p=0.038)	2	7/13

				tumour n= 11						
[43]	USA	n=46 (32 male, 14 female) Dyad: n=16 Large group: n= 15 Delay: n = 15	Total (Not reported). Dyad: 65.6 years (9.4); Large group: 61.4years (14.3); Delay: 65.8 years (11.9)	Stroke	RCT	Lubben social network scale	Objective	There were no significant differences in scores (pre, post, 6 weeks and 11 months post intervention) for people who participated in a group conversation intervention, those who participated in a dyad conversation intervention or wait list controls (p>.05)	1	High risk
[44]	USA	n= 172 (84 male, 88 female). Ps with network size <7: n=77 Ps with network size ≥7: n = 95	Total 61.6 years (15.6)	Stroke	Observational: multi-centre prospective, longitudinal cohort	General Social Survey	Objective	Social networks contracted over time, and the average change per individual was −1.25 people over 6 months (SD = 4.00, p < .001). Degree of contraction was related to baseline network size. There was an increase in density and constraint over time (p < .001). The networks also changed compositionally over time, with a 7.25% increase in kin (p < .001). There was no change in the range of ages or diversity of sex or race in the network. The networks became healthier, with a reduction in smokers (p< .01) and people who do not exercise (p < .01). Main effects influencing network size change were: time (Estimate = −0.17; SE = 0.05; p = .0006), years of education (Estimate = 0.38; SE = 0.12; p = .002), and PHQ-9 depression score (Estimate = −0.15; SE = 0.05; p = .006). No interactions between any factors and	2	12/14

								time. The main effects that influenced constraint were time (Estimate = 0.99; SE = 0.25; P = .0001), age (Estimate = −0.24; SE = 0.12; P = .04), years of education (Estimate = −1.36; SE = 0.57; P = .02), and PHQ-9 depression score (Estimate = 0.65; SE = 0.25; P = .01). No interactions between any of these factors and time. In a multivariable regression model where covariates were adjusted for, baseline network size continued to be strongly associated with physical function PROMIS score at 3 months (Estimate = 0.58; SE = 0.20; P = .005) and 6 months (Estimate = 0.66, SE = 0.22, P = .004)		
[45]	USA	n= 382 (male = 162, female = 220)	74 years (6)	Stroke	Observational : cohort	Lubben Social Network Scale	Objective	There was a decrease in social network over time compared with a baseline trajectory (−0.14 points per year, p=0.0364). Interactions between depression, stroke, and time (β −0.09; 95% confidence interval, −0.36–0.17, p=0.4945) and interactions between cognition, stroke, and time (β 0.03; 95% confidence interval, −0.17–0.23, p=0.7900) were not significant	2	11/14
[46]	UK	n=48 (28 male, 20 female)	67.63 years (12.92)	Stroke	Observational : cohort	The Lubben Social Network Scale	Objective	At 18 months, there were no significant emotion regulation predictors of social network size, 2-month emotion regulation variables did not significantly predict LSNS scores at 18 months and changes in DERS	2	9/14

								scores between timepoints were also not associated with LSNS scores (p>.05)		
[47]	Japan	n=1023 (676 male, 347 female) Right PFC (n = 11), Right AI (n = 26) Posterior lesions (n=28)	65 years (SD not reported)	Stroke	Observational: retrospective cohort	Lubben Social network scale - abbreviated validated six-item version of the original 10-item scale	Objective	There was a small positive association between patients' social networks and their Life Space Area scores in the adaptation period (R2=0.03, p<0.0001, β = 0.77), however once entered into a multivariate model Social Network Scale score had no significant effects on Life Space Area.	2	8/13
[48]	Tanzania	n=76 (43 male, 33 female)	54.1 years (14.1)	Stroke	Observational: cross sectional	Berkman-Syme social network index	Objective	A higher number of depressive symptoms was correlated with a lower social network index (r=-0.51, p<0.0001). More social isolation was reported by women than men (p<0.05). The correlation between higher social network index and lower motor disability approached but did not reach statistical significance, p=0.061	2	7/13
[49]	China	n = 189 Post stroke depression group: n = 27. No post-stroke depression	Total (NR) Post stroke depression group: 67.3 years (10.9). No post-stroke depression	Stroke	Observational: cross sectional	Lubben Social Network Scale	Objective	Post stroke depression was significantly associated with social network score (p< 0.05) and within a multivariate model LSNS score remained an independent risk factor for post-stroke depression, (p=.019)	2	7/13

		group: n = 158	group: 68.3 years (11.8)							
[46]	UK	n=75 (47 male; 28 female)	65.99 years (12.09)	Stroke	Observational: cross sectional	The Lubben Social Network Scale	Objective	Adding emotion regulation into the covariate model improved the fit, $F(5, 70) = 2.73$, $p < .05$; $\Delta R2 = .08$, $p < .01$. and Difficulties in Emotion Regulation Scale (DERS) Awareness scores significantly predicted social network score.	2	7/13
[50]	Japan	n=20 (14 male, 6 female)	36.0 years (12.8)	TBI	Observational: cross sectional	Japanese version of the Revised Craig Handicap Assessment and Reporting Technique (R-CHART)	Objective	No significant correlations were found between social cognition scores or neurocognitive assessments and the social integration subscale of the CHART. R-CHART ($p>.05$).	2	7/13
[51]	Australia	n=70 (28 male, 42 female)	51.29 years (12.08)	Brain tumour	Observational: cross sectional	Exeter Identity Transition Scale	Objective	Older age was related to greater maintenance of social group memberships (SGMs) ($r = .41$, $p < .001$) and fewer new SGMs ($r = −.28$, $p < .05$). No significant associations between time since diagnosis and SGMs ($p> .05$). Greater perceived physical impairment (PPI) was significantly associated with loss of SGMs ($r = −.54$, $p < .001$) and fewer new SGMs ($r = −.23$, $P < .05$). Objective global cognitive status was	2	7/13

								not significantly associated with SGMs (p > .05). Greater perceived cognitive impairment (PCI) was significantly associated with loss of SGMs (r = −.48, p < .001) but was not associated with new SGMs (r = −.03, p > .05). Loss of SGMs was significantly associated with higher levels of depression (r = −.51, p < .001) and anxiety (r = −.53, p < .001) and lower life satisfaction (r = .41, p < .001). New SGMs were not significantly associated with depression, anxiety, or life satisfaction (p > .05). Significant indirect effects of PPI on depression and anxiety through the mediator of maintenance of SGMs but not life satisfaction. Indirect effect of SGM maintenance on the relationship between PCI and life satisfaction, but the confidence interval for the effect size (95% CI, −0.023 to 0.168) indicated this finding was not robust.		
[52]	USA	n=242 (230 male, 12 female) TBI only: n= 210 TBI plus PTSD: n =32	Total (mean and SD not reported, median = 29).	TBI	Observational: cross sectional	Participation Assessment with Recombined Tools Objective, PART-O: Social relations subscale	Objective	Veterans with PTSD and TBI did not significantly differ in their number of social interactions to veterans with TBI only (p>.05). Unmarried veterans had significantly fewer social interactions than those who were married (p<0.001).	2	6/13

[14]	UK	n=87 (52 male, 35 female)	69.7 years (14.1)	Stroke	Observational: Cohort (prospective longitudinal)	Stroke Social Network Scale	Combined	Social network scores (SSNS) declined poststroke (p = .001). Children and Relatives factors remained stable, but the Friends factor significantly weakened (p < .001). There were 2 baseline predictors of social network: premorbid social network and aphasia (adjusted $R^2 = .60$). Baseline perceived social support was associated with 6 month SSNS, r = .36, p = .01, although this was no longer significant when entered into the multivariate model. Poststroke, people became less satisfied with their social networks, although this trend didn't reach significance. At 6 months social network scores (SSNS) were associated with perceived social support r = .46, p < .001; ADLs, r = .36,p = .01; extended ADLs, r = .33, p = .01; and aphasia, r = .37, p = .01. Women had higher social network scores on the SSNS than men (p = .05.) and there was a significant difference in the social network scores on the SSNS of participants from different ethnic backgrounds, (p = .05) with black participants scoring significantly higher than Asian participants.	2	13/14
[53]	UK	n = 71 (40 male, 31 female). Participants with aphasia: n=11	Total (Not reported): People with aphasia = 66.5 years (13.7); People without aphasia = 69.8 years (14.3)	Stroke	Observational study: retrospective cohort	Stroke Social Network Scale	Combined	There was a significant difference in overall social networks between those with aphasia following stroke, those without aphasia following stroke and healthy controls, F(2, 174) = 11.5, p < .001, $\eta p^2 = .89$.; pairwise comparisons showed people with aphasia had significantly lower scores than those without aphasia after stroke (p = .018). There was a significant difference between	2	8/13

		Participants without aphasia: n= 60						the 3 groups in the friends domain of the SSNS, F (2, 174) = 6.48, p = .002,ηp^2 = .07., and pairwise comparisons showed the scores of people without aphasia following stroke were higher than for those with aphasia (p = .032)		
[54]	USA	n = 24 (13 male, 11 female)	54.21 years (13.45)	TBI	Observational cross sectional	UCLA loneliness scale and National Social Life, Health, and Aging Project: Social Network Module	Both (one measure subjective, one objective)	Social network size was significantly associated with both loneliness (b= − 1.67; t= − 2.95; p=.004) and neuroticism (b= − .83; t= −2.05; p=.03) and neuroticism was a significant predictor of loneliness (b=.78; t=5.45; p<.001). The mediation model revealed a statistically significant indirect effect of social network score on loneliness through neuroticism (b= − .27; 95% CI[− .55, − .01]). There was no significant relationship between extraversion and loneliness (r= − .29; p=.08) or extraversion and social network size (r=.32; p=.06). Chronicity was not significantly associated with loneliness or network size (p>.05). Age was significantly and negatively associated with loneliness (r= − .51; p=.01) but not network size (p>.05)	2	7/13
[55]	Canada	n = 46 (31 male, 15 female)	44.17 years (10.87)	TBI	Observational: cross-sectional	UCLA Loneliness Scale and Adult Subjective Assessment of Participatio	Both (one measure subjective, one objective)	Increased loneliness was associated with reduced perceived social support (p < 0.001) and reduced community integration (p < 0.01) Doing more activities with others was significantly associated with increased	2	6/13

n - activities with others subscale	quality of life (p = 0.006) and increased happiness (p < 0.001). There was no significant relationship between loneliness and diversity of activities, frequency of activities, enjoyment of activities, satisfaction with performance on activities, the proportion of activities outside of home or the proportion of activities done with others (ASAP) (p>.05).

(N = number of participants and includes only participants with ABI, TBI = Traumatic Brain injury, ABI = Acquired brain injury);Quality assessment tools: 1 = A revised tool to assess risk of bias in randomized trials (RoB 2), 2= Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies, 3 = Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group

Methodological quality of studies / quality appraisal

The ratings for this body of evidence are collated into four tables (Supplementary tables 3–6, Appendix 5).

The RCTs included in this review were assessed as posing either an unclear risk of bias [32] or high risk of bias [33,43] on the Cochrane risk of bias tool [29]. One had a high risk of randomisation bias [33] and there were some concerns regarding risk of bias due to deviations from the intended intervention for two studies [32,43]. One study [43] had a high risk of bias due to missing outcome data, due to high participant attrition. Two studies [33,43] were assessed to have a high risk of bias in the measurement of outcomes and there were some concerns regarding the risk of bias due to the selection of the reported result for two studies [32,43] as the protocols for these studies were not available to ascertain whether the analysis plan was followed.

Lawrence et al. [38] was the only pre-post design study, the study was rated 6 out of 11 using the quality assessment tool [28]. As a pre-post design without a control group the study is intrinsically weak, and there is a concern that the study population may not adequately represent the target population, that the sample size may not be sufficiently large to provide confidence in the findings, that there may be bias in the reporting of outcomes and that outcome measures may be less accurate.

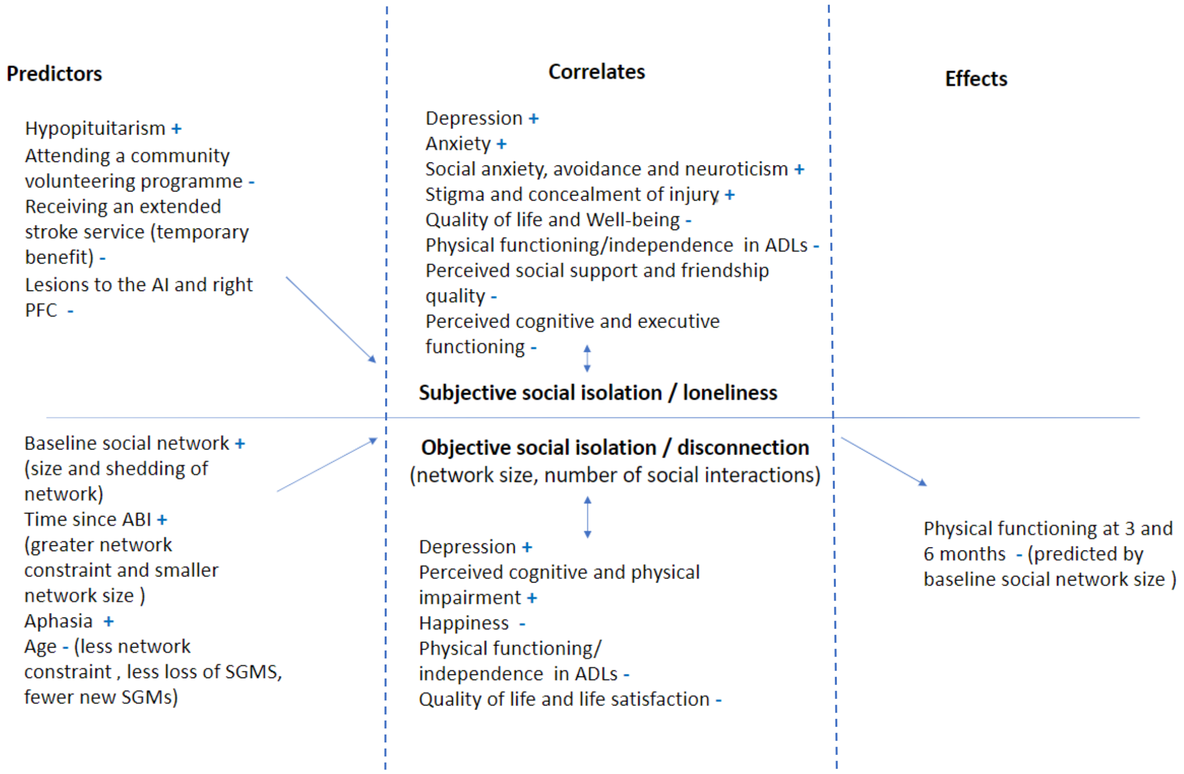
The cohort studies were all rated between eight and thirteen out of a possible 14 on the quality assessment tool [27]. There are concerns that four of the study populations do not adequately represent the target population reported [35,34,46,53]. It is also unclear for all cohort studies whether the sample sizes were sufficiently large to provide confidence in the findings. Six papers [34-36,44,45,53] measured the independent variable prior to the outcome variable which makes it more likely that a causal relationship can be established, however, longitudinal studies still do not provide a particularly strong basis for establishing cause and effect relationships [58], and other external factors may be impacting on or mediating the observed relationships between variables. There may also be bias in the results reported as none of the cohort studies reported whether outcome assessors were blinded to the independent variables participants' had been exposed to and key potentially confounding variables were not measured and adjusted statistically for three studies [34,36,53].

The cross-sectional studies were all rated between six and eight out of a possible thirteen on the quality assessment tool [27]. Cross-sectional study designs are intrinsically weak, as it is not possible to establish causal relationships between exposures and outcomes. Additionally for nine papers [39-42,46,50-52,55] there is a concern that the study population may not adequately represent the target population and for twelve studies [37,39-41,46,48-52,54,55] it was unclear whether the sample sizes were sufficiently large to provide confidence in the findings. For all studies there may be bias in the outcomes reported, as no studies reported whether outcome assessors were blinded to the participants' interventions and four studies [42,48,54,55] did not control for confounding variables.

Predictors, outcomes and associations of social isolation

A summary of the findings of this review in relation to predictors, correlates and effects of social isolation are illustrated in Figure 2. Where results were found to be inconsistent between studies, these were not included in the diagram.

Figure 2: Predictors, correlates and outcomes of perceived and objective social isolation *(+ indicates positive correlation, - indicates negative correlation)*



Twelve out of the 25 articles reported that they were primarily exploring either objective or subjective social isolation [14,33,39-41,43-45,48,51,53,54]. Four studies [42,46,52,55] looked at social participation, social engagement or social functioning, within which there were subscales specifically related to social isolation. Three studies were interested in health-related quality of life and used the Nottingham Health Profile which has a subscale measuring social isolation [34,35,37]. The remaining six studies [32,36,38,4749,50] used a measure or subscale relating to social isolation as part of a number of different outcome measures used.

A number of different facets of social isolation were assessed by the studies included in this review, as measures explored social network size, make-up, frequency of social interactions, number of social groups or loneliness. This may account for some of the variability in results.

Demographic variables

Demographic variables were never the primary outcome measured; these were only ever explored as covariates or potential confounding variables, when testing for the hypothesis of interest. Seven out of the 25 studies measured for an association between age and social isolation, three of these were better quality cohort studies [14,34,44] and the other five were cross-sectional [37,42,51,52,54]. Overall the results suggest that age may impact on some objective aspects of social isolation, but findings are mixed: older people experienced less constraint of their networks [44], were found to lose fewer social group memberships, but also joined fewer new groups [51], and participated less socially [52]. However, age was found to have no effect on social network score [14], overall social network size [54] or change in social network size over 6 months [44]. Results are similarly mixed for perceived social isolation: age was found to have no effect on loneliness or perceived social isolation in three studies [34,37,42], but older adults reported less loneliness in another [54].

Five studies looked at the association between gender and social isolation. The results are mixed: women were found to have a higher social network score then men by one cohort study [14] however, the gender differences reported in cross-sectional studies indicated that men reported more social isolation than women [48] and higher romantic loneliness [40]. No association was found between gender and perceived social isolation by the other cohort study [34] and cross-sectional study [37]. This suggests that gender may influence social isolation, but it is not possible to draw any firm conclusions.

Four studies explored marital status as a confounding variable. Only one study found an effect, that being unmarried was associated with reduced social participation [52]; the others found no association between marriage status and perceived social isolation [34], loneliness [42] or social network score [14].

Five studies included measures of education. The highest quality cohort study found years of education was positively associated with change in network size and negatively associated with network constraint [44], however these results were not reflected in the rest of the articles, as education was not found to be associated with perceived social isolation [34], loneliness [42] or social participation [52].

Two studies looked at employment; one found no association with loneliness [42] and the other found being employed was associated with greater social participation [52]. Ethnicity and race were also explored by two studies, the higher quality study found that being Black was associated with higher social network scores, and being Asian was associated with lower scores [14], however this was not reflected in the findings of Snow et al., [52] who found no association between social participation with ethnicity or race. Two studies explored living arrangements, however neither found an association with social isolation [14,39]. Only one study looked at comorbidities and smoking behaviour and found no associations with loneliness. For these demographic variables there is a paucity of studies exploring associations with social isolation and so these results have to be interpreted with caution and it difficult to draw any firm conclusions.

Injury related variables

Injury related variables were explored by seven studies [14,34,35,37,39,41,52], however only two studies [35,41] aimed specifically to look at injury variables. One study looked at pituitary function and found post-traumatic hypopituitarism was associated with greater perceived social isolation [35] and the other looked at the location of brain injury and found right anterior insula and right prefrontal cortex injuries were associated with reduced loneliness, whereas having a posterior brain injury was not [41]. However, as only one study provides evidence for these factors, the results must be interpreted with caution. The other five studies measured associations with injury related variables in order to control for these as confounding variables. Stroke type (ischemic or hemorrhagic) had no impact on social network score [14] or perceived social isolation and loneliness [34,37,39]. Evidence suggests that severity of ABI does not influence objective isolation, social network score [14] or social participation [52], however discharge to nursing home was associated with higher loneliness than being discharged home [39], which the authors suggested may be due to worse stroke severity. Side of stroke had no effect on social network score [14], but results were mixed for perceived social isolation with one study finding no effect [34] but the other finding that having a left sided stroke was associated with higher social isolation [37], which the authors suggested may be linked to difficulties communicating.

Time post-ABI

Three longitudinal cohort studies of high-quality explored changes in social network over time following stroke, and four cross-sectional studies included time as a covariate. Social networks declined and constricted post-stroke [14,33,44,45,53]. This was not affected by cognition or depression [45,18] and mostly affected friendships rather than familial relationships [53,44]. Social network scores at baseline were predictive of social network scores at 6 months [14], but those with larger baseline networks were found to experience greater shedding of network members [44]. Over time people's networks contained fewer smokers or people who do not exercise [44]. Exceptions to these findings come from weaker cross-sectional studies [51,54] which found no association between time since diagnosis and social network size or social group membership. Weaker cross-sectional evidence suggests loneliness generally does not increase over time [54, 42, 40] but that romantic loneliness may [40].

Mental health and psychological wellbeing

Fourteen studies included either a measure of mood or psychological wellbeing. Of these only three aimed to look specifically at the relationship between scores on measures of social isolation and depression [48, 49, 51]. For two, the primary outcome measure of quality of life included subscales measuring depression, anxiety or wellbeing [39, 55]. An association was found between mood and perceived social isolation after brain injury. However, all five of these were cross-sectional designs, which impacted on the quality of these studies. The other nine explored mood or wellbeing variables as covariates within a multivariate model or as potential confounding variables when answering their primary research question [14,34,37,40,41,44,46,52].

Loneliness and perceived social isolation scores were positively associated with depression [34,37,39,40], anxiety [37,39] and having a current diagnosis of an emotional, nervous, or psychiatric problem [39]. Loneliness was also found to be negatively associated with wellbeing [39,41], and life and leisure satisfaction [40] following ABI.

Associations between mood and objective measures of social isolation are more mixed. Depression was negatively associated with social network score [48,49], and positively associated with social network reduction [44], social network constraint [44] and loss of social group memberships [51]. Anxiety was also associated with increased loss of social group memberships [51] and doing activities with others and maintaining social group memberships was found to increase quality of life, happiness and life satisfaction [51,55]. However, five studies found that social network score, frequency of social contact and the number of new social groups were not associated with anxiety, depression, psychological distress, post-traumatic stress disorder or life satisfaction [14,46,52,51,52].

Physical disability

Seven studies explored associations between physical functioning/impairment and social isolation. Overall, there does appear to be an association between physical functioning and social isolation, as the better-quality studies found significant negative associations. Longitudinal studies found that social network size at the time of injury was found to be predictive of physical functioning at 3 and 6 months post-injury, but changes in network size did not predict functioning [44]; and that higher social network scores were associated with greater independence in extended activities of daily living (ADLs) at 6 months, but that baseline social network was not predictive of ADLs at 6 months [14]. Within weaker cross-sectional studies, higher social network scores were also associated with greater life space ability (ability to move around and function in the community) [47] and a positive trend was found with motor functioning [48]. Loss of social groups and having fewer new social groups were both associated with increased perceived physical impairment, with loss of social group memberships mediating the relationship between perceived physical impairment and both anxiety and depression [51]. Perceived social isolation was also found to be associated with lower functional status and less independence in ADLs [34,37].

Cognition and language

Seven studies explored associations between cognition or language and social isolation. The quality of studies was mixed with three cohort studies scoring 8-13 out of 14 and the four cross sectional studies scoring 7 out of 14 on the quality appraisal tool [27].

The best quality studies employing a longitudinal follow-up design found having aphasia was predictive of higher objective social isolation, particularly having fewer and less contact with friends [14, 53]. While perceived social isolation was found to be higher in those with aphasia than those without, this relationship was not significant [36].

Results for cognitive functioning are mixed; however overall, they suggest perceptions of cognitive functioning may impact on social isolation. A longitudinal study found that objective social isolation was associated with emotional awareness at 2 months but was not predicted by or associated with emotional awareness at 18 months [46], and cross-sectional studies similarly found no associations between cognition and memory with objective measures of social isolation [50, 51]. However, a positive association was found with greater perceived cognitive impairment [51], and higher loneliness was associated with poorer perceived cognitive and executive functioning [41,39].

Social factors

Eight studies measured for associations between social isolation with social variables. The best quality study employing a longitudinal follow-up design found that perceived social support was a concurrent predictor of social network score, but that baseline perceived social support did not predict social network at 6 months [14]. This association with perceived support was also found in a weaker cross-sectional study [55], and the link between perceptions of support and feelings of social isolation were echoed across other cross-sectional studies of weaker design, as higher social isolation was associated with greater concealment of brain injury from others [42], stigma [39] social anxiety and distress [42], social avoidance [42], fear of social isolation [40], friendship quality [41], participation in social roles [39] and community integration [55]. These results also support distinction between objective and subjective social isolation as separate constructs, as loneliness were not associated with the number of activities done with others [55] or the size of people's social circle [41]. One study did find that social network size was associated with loneliness, but found this relationship was mediated by neuroticism [54].

The impact of interventions or treatment on social isolation

Four studies explored the impact of treatment on social isolation, three of which were RCTS (however two of these were rated as having a high risk of bias and there were some concerns about bias for the third). The other study design was a pre-post design with no control group, which is intrinsically weaker as a design. For all studies, social isolation was only one of several outcome variables measured. This suggests assessing for loneliness may not have been the studies' primary aim. The results suggest that interventions may be effective for improving feelings of social connectedness, although more research is needed.

Two approaches seemed to have a positive impact on subjective social isolation. Experiencing an extended stroke unit service (consisting of stroke unit treatment, home-based follow-up care and early supported discharge while working in cooperation with primary healthcare systems) was associated with reduced perceived social isolation at 26 weeks post discharge (but not at 6 and 52 weeks), when compared with the normal stroke service treatment on the unit [32]. For veterans with a history of TBI, completing a 26-week programme of volunteering for 20 hours per week at a non-profit organisation of the veterans' choosing was also found to lead to a significant decreased loneliness [38].

The impact of interventions on objective measures of social isolation is less clear. Both RCTs assessing for changes in objective isolation were looking at the impacts of taking part in communication/conversation treatment for people with Aphasia (group or dyad conversation treatment [43], or EVA PARK virtual reality intervention [33]). Neither treatment was found to impact on social network score. However, both studies were rated as having a high risk of bias, and for both treatments reducing social isolation was only a secondary aim. Dede et al., [43] also found, that when asked directly many participants did report forming or strengthening friendships during treatment, they suggest the measures used were not sensitive to picking up changes in networks.

Discussion

This systematic review investigated the predictors, correlates and effects of social isolation after brain injury.

Overall, aphasia, age and time since ABI and size of social network at baseline were identified as predictors of social isolation following ABI, and social network at the time of injury may impact on physical recovery. There is also some evidence that interventions can reduce perceived isolation following ABI. Mental health, physical functioning, perceived cognitive functioning, social factors, quality of life and life satisfaction were all associated with measures of social isolation, however the correlational nature of results means that the direction of causality cannot be established and there was a lot of variability within the quality of studies.

Having aphasia and communication difficulties does seem to predict increased social isolation [14,53,34,37]. However, the results for other demographic and injury related variables are more mixed. There does appear to be some influence of age on social isolation; the evidence suggests older people's networks may remain more stable after brain injury [44,51], but there is not strong enough evidence to draw firm conclusions. Social networks were found to decrease in size over time for those with ABI and became more constrained [14,44,45]. This suggests that people may become increasingly socially isolated after brain injury. This observed reduction in social network after stroke is also concerning as social networks may be protective against some of the negative effects of brain injury, for example social resources at baseline were found to be associated with the physical functioning of patients at 3 and 6 months [44].

Social isolation was found to be associated with poorer mental health after brain injury, with increased symptoms of anxiety and depression [34,37,39,48,49]. Social network reduction was correlated with increased depression and anxiety and reduced life satisfaction [44,51], which suggests that the social losses people experience directly after brain injury can have a negative impact on their psychological wellbeing or that anxiety and depression causes a reduction in their social network. This aligns with research which suggests that social isolation and failure to resume social activities after ABI is associated with depression [18,19]. Positive outcomes such as better quality of life and improved wellbeing were found to be negatively associated with social isolation [39,40,41,51,55]. Although from these studies it is hard to determine cause and effect, they strongly suggest that there is a link between psychological wellbeing, quality of life and social isolation.

Social factors other than the size of a person's network may be associated with social isolation: increased social isolation was associated with less perceived social support, reduced community integration and poorer quality friendships [14,41,55]. This suggests that it may be beneficial for interventions to focus not only on increasing the size of people's social networks but also on reducing their perceived feelings of social isolation through increasing social support, improving integration into the community, and helping people to form meaningful friendships. Social anxiety and avoidance was found to mediate the relationship between concealment of injury and loneliness [42], neuroticism mediated the relationship between social network size and loneliness [54] and perceived cognitive and physical impairment (but not measures of actual cognition) were associated with social group memberships [41,39, 51], which suggests that the interpretations people have of their difficulties, social situations and their network can contribute to feelings of social isolation and loneliness.

While this review found limited evidence to support the effectiveness of interventions in reducing social isolation, only four intervention studies measuring changes in connectedness were identified, and for these measures of social isolation were not the primary outcome measure. Participating in community volunteering programmes [38], receiving an extended stroke service [32] and completing a group or dyad community conversation intervention [43] may help reduce social isolation, which suggests interventions connecting people within the community can be effective in reducing social isolation. This is supported by McLean et al. [55] who found that doing activities with others was associated with increased quality of life and happiness, and by research suggesting life satisfaction after brain injury is improved if people can maintain social connections [21] and that taking part in arts or creative therapy groups can improve wellbeing, reduce depression, and increase quality of life [56, 57]. However, in order to strengthen confidence in these findings it may be beneficial for more interventions to focus on and measure for changes in social connectedness and isolation. By systematically addressing the processes known to be associated with social isolation and connectedness, this may help to improve our understanding of the direction of causality between the relationships identified within the current review.

Limitations of the studies reviewed

Most articles explored correlates of social isolation rather than predictors or outcomes. This means that while associations with social isolation were able to be identified, the direction of cause and effect cannot be established. The quality of studies was variable and for several studies, measures of social isolation were not the primary outcome measure and the aims of the study were not directly linked to exploring social isolation after brain injury. There were also often only a limited number of studies exploring each variable of interest, with studies often assessing different facets of social isolation (i.e. loneliness, social interactions or size of social network) and measuring the variables in different ways (e.g. having dichotomous versus continuous measures). This made direct comparisons between studies difficult.

Strengths and limitations of the review

Within the inclusion criteria it was stated that the review would explore any associations with social isolation found within the literature; this meant the variables to be included were left intentionally broad to capture all associations. This was a strength of the study, as it allowed for all variables associated with social isolation to be identified and systematically reviewed together, within one comprehensive review. However, this also resulted in considerable variability within the range of associations identified, which made making direct comparisons and synthesizing results challenging.

It was not possible within the timescale to have a second independent reviewer of study eligibility or rate the quality of all articles included, which may have impacted on the validity of the methodology. However, a second reviewer (RB) rated the quality of a subset of six studies, which may have mitigated some of this bias.

Clinical and Research Implications and Recommendations

Due to inconsistent methodological quality and difficulties in establishing causal relationships due to the use of cross-sectional study designs it is difficult to identify where to intervene and to make firm recommendations regarding clinical practice. However, the review does highlight the need for more research into causes and effects of social isolation, in order to determine the direction of causation for some of the variables identified as correlates by this review. It also suggests that there is a need for more evidence into the effectiveness of interventions on reducing social isolation and for more interventions specifically targeting social isolation.

The findings of the review do suggest that identifying those with smaller or weaker social networks prior to their ABI may be helpful, as this was predictive of poorer social networks following ABI [14]. This suggests these people may need more support. Support to maintain social networks may also be needed at several timepoints because social networks were found to change over time after ABI, with increased time since injury leading to smaller and more constrained networks, consisting of kin relationships rather than friendships [14,45,44]. People, therefore, may need ongoing support to maintain existing relationships and friendships, as well as to establish new friendships to replace those lost.

Conclusions

The review identified demographic, impairment, social, wellbeing and mental health related factors which were related to social isolation after brain injury. However, there is a lack of studies identifying causal relationships and the quality of studies was variable. Future research is needed to establish causal relationships between variables, to evaluate the effectiveness of interventions on reducing social isolation and to address the methodological limitations of the current body of research.

References

1) Salas CE, Casassus M, Rowlands L, Pimm S, Flanagan DA. “Relating through sameness”: a qualitative study of friendship and social isolation in chronic traumatic brain injury. Neuropsychol Rehabil. 2018;28(7):1161-78.

2) Cornwell EY, Waite LJ. Measuring social isolation among older adults using multiple indicators from the NSHAP study. J Gerontol Series B: Psychological Sciences Soc Sciences. 2009;64(suppl1):38-46.

3) Morton MV, Wehman P. Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. Brain Inj. 1995;9(1):81-92.

4) Hoofien D, Gilboa A, Vakil E, Donovick PJ. Traumatic brain injury (TBI) 10? 20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. Brain Inj. 2001;15(3):189-209.

5) Rowlands A. Understanding social support and friendship: Implications for intervention after acquired brain injury. Brain Impair. 2000;1(2):151-64.

6) Douglas J. Loss of friendship following traumatic brain injury: A model grounded in the experience of adults with severe injury. Neuropsychol Rehabil. 2019:1-26.

7) Shorland J, Douglas JM. Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. Brain Inj. 2010;24(4):569-80.

8) Kozloff R. Networks of social support and the outcome from severe head injury. J Head Trauma Rehabil. 1987;2(3):14–23. https://doi.org/10.1097/00001199-198709000-00004

9) Zenicius MD, Wesolowski AH. Is the social network analysis necessary in the rehabilitation of individuals with head injury?. Brain Inj. 1999;13(9):723-7.

10) Tomberg T, Toomela A, Pulver A, Tikk A. Coping strategies, social support, life orientation and health-related quality of life following traumatic brain injury. Brain Inj. 2005;19(14):1181-90.

11) Hilari K, Northcott S. Social support in people with chronic aphasia. Aphasiology. 2006;20(1):17-36.

12) Northcott S, Hilari K. Why do people lose their friends after a stroke?. Int J Lang Commun Disord. 2011;46(5):524-34.

13) Callaway L, Sloan S, Winkler D. Enabling people to maintain and develop friendships following severe traumatic brain injury. Austral Occupat Ther J. 2005;52:292-5.

14) Northcott S, Marshall J, Hilari K. What factors predict who will have a strong social network following a stroke?. J Speech Lang Hear Res. 2016;59(4):772-83.

15) Cacioppo JT, Cacioppo S. Social relationships and health: The toxic effects of perceived social isolation. Soc Personality Psychol Compass. 2014;8(2):58-72.

16) Thomsen IV. Late outcome of very severe blunt head trauma: a 10-15 year second follow-up. J Neurol Neurosurg Psychiatry. 1984;47(3):260-8.

17) Hilari K, Northcott S, Roy P, Marshall J, Wiggins RD, Chataway J, Ames D. Psychological distress after stroke and aphasia: the first six months. Clin Rehabil. 2010;24(2):181-90.

18) Appelros P, Viitanen M. Prevalence and predictors of depression at one year in a Swedish population-based cohort with first-ever stroke. J Stroke Cerebrovasc Diseases. 2004;13(2):52-7.

19) Angeleri F, Angeleri VA, Foschi N, Giaquinto S, Nolfe G. The influence of depression, social activity, and family stress on functional outcome after stroke. Stroke. 1993; 24(10):1478-83.

20) Glass TA, Matchar DB, Belyea M, Feussner JR. Impact of social support on outcome in first stroke. Stroke. 1993;24(1):64-70.

21) Haslam C, Holme A, Haslam SA, Iyer A, Jetten J, Williams WH. Maintaining group memberships: Social identity continuity predicts well-being after stroke. Neuropsychol Rehabil. 2008;18(5-6):671-91.

22) Jones JM, Williams WH, Jetten J, Haslam SA, Harris A, Gleibs IH. The role of psychological symptoms and social group memberships in the development of post-traumatic stress after traumatic injury. Br J Health Psychol. 2012;17(4):798-811.

23) Khan KS, Kunz R, Kleijnen J, Antes G. Five steps to conducting a systematic review. J Royal Society Medicine. 2003;96(3):118-21.

24) Impellizzeri FM, Bizzini M. Systematic review and meta-analysis: A primer. Int J Sports Phys Ther. 2012;7(5):493.

25) Rees L, Marshall S, Hartridge C, Mackie D, Weiser M. Cognitive interventions post acquired brain injury. Brain Inj. 2007;21(2):161-200.

26) O'Rourke HM, Sidani S. Definition, determinants, and outcomes of social connectedness for older adults: A scoping review. J Gerontol Nursing. 2017;43(7):43-52.

27) National Heart, Lung and Blood Institute. The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies for observational cohort and cross-sectional studies. 2020. Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

28) National Heart, Lung and Blood Institute. The Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group. 2020. Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

29) Sterne JAC, Savović, J, Page, MJ. Elbers, RG. Blencowe, NS, Boutron, I, Cates CJ, Cheng H-Y, Corbett MS, Eldridge SM, Hernán MA, Hopewell S, Hróbjartsson A, Junqueira,

DR, Jüni P, Kirkham JJ, Lasserson T, Li T, McAleenan A, Reeves BC, Shepperd S, Shrier I, Stewart LA, Tilling K. White IR, Whiting PF & Higgins JPT RoB 2: a revised tool for assessing risk of bias in randomised trials. BMJ.2019; 366: l4898.

30) Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, & Welch VA (editors). Cochrane Handbook for Systematic Reviews of Interventions version 6.0. Cochrane, 2019. Available from www.training.cochrane.org/handbook.

31) Centre for Reviews and Dissemination University of York (2009). Systematic Reviews: CRD's guidance for undertaking reviews in health care York: York Publishing Services Ltd. Retrieved from: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf

32) Askim T, Rohweder G, Lydersen S, Indredavik B. Evaluation of an extended stroke unit service with early supported discharge for patients living in a rural community. A randomized controlled trial. Clin rehabil. 2004;18(3):238-48.

33) Marshall J, Booth T, Devane N, Galliers J, Greenwood H, Hilari K, Talbot R, Wilson S, Woolf C. Evaluating the benefits of aphasia intervention delivered in virtual reality: results of a quasi-randomised study. PloS one. 2016;11(8).

34) Gokkaya NK, Aras MD, Cakci A. Health-related quality of life of Turkish stroke survivors. Int J Rehabil Res. 2005;28(3):229-35.

35) Klose M, Watt T, Brennum J, Feldt-Rasmussen U. Posttraumatic hypopituitarism is associated with an unfavorable body composition and lipid profile, and decreased quality of life 12 months after injury. J Clin Endocrinology & Metabolism. 2007;92(10):3861-8.

36) Naess H, Hammersvik L, Skeie GO. Aphasia among young patients with ischemic stroke on long-term follow-up. J Stroke Cerebrovascular Diseases. 2009;18(4):247-50.

37) Morris JH, Van Wijck F, Joice S, Donaghy M. Predicting health related quality of life 6 months after stroke: the role of anxiety and upper limb dysfunction. Disabil Rehabil. 2013;35(4):291-9.

38) Lawrence KA, Matthieu MM, Robertson-Blackmore E. Completion of a veteran-focused civic service program improves health and psychosocial outcomes in Iraq and Afghanistan veterans with a history of traumatic brain injury. Military medicine. 2017;182(7):1763-70.

39) Theeke L, Horstman P, Mallow J, Lucke-Wold N, Culp S, Domico J, Barr T. Quality of life and loneliness in stroke survivors living in Appalachia. J Neurosci Nurs: J Am Assoc Neurosci Nurses. 2014;46(6):3.

40) Proctor CJ, Best LA. Social and psychological influences on satisfaction with life after brain injury. Disabil Health J. 2019;12(3):387-93.

41) Cristofori I, Pal S, Zhong W, Gordon B, Krueger F, Grafman J. The lonely brain: evidence from studying patients with penetrating brain injury. Soc Neuroscience. 2019;14(6):663-75.

42) Hagger BF, Riley GA. The social consequences of stigma-related self-concealment after acquired brain injury. Neuropsychol Rehabil. 2019;29(7):1129-48.

43) DeDe G, Hoover E, Maas E. Two to tango or the more the merrier? A randomized controlled trial of the effects of group size in aphasia conversation treatment on standardized tests. J Speech Lang Hearing Res. 2019;62(5):1437-51.

44) Dhand A, Lang CE, Luke DA, Kim A, Li K, McCafferty L, Mu Y, Rosner B, Feske SK, Lee JM. Social network mapping and functional recovery within 6 months of ischemic stroke. Neurorehabil Neural Repair. 2019;33(11):922-32.

45) Dhand A, Longstreth Jr WT, Chaves PH, Dhamoon MS. Social network trajectories in myocardial infarction versus ischemic stroke. J Am Heart Assoc. 2018;7(8):e008029.

46) Cooper CL, Phillips LH, Johnston M, Whyte M, MacLeod MJ. The role of emotion regulation on social participation following stroke. Br J Clin Psychology. 2015;54(2):181-99.

47) Nakao M, Izumi S, Yokoshima Y, Matsuba Y, Maeno Y. Prediction of life-space mobility in patients with stroke 2 months after discharge from rehabilitation: a retrospective cohort study. Disabil Rehabil. 2018:1-8.

48) Saadi A, Okeng'o K, Biseko MR, Shayo AF, Mmbando TN, Grundy SJ, Xu A, Parker RA, Wibecan L, Iyer G, Onesmo PM. Post-stroke social networks, depressive symptoms, and disability in Tanzania: A prospective study. Int J Stroke. 2018;13(8):840-8.

49) Tang WK, Chan SS, Chiu HF, Ungvari GS, Wong KS, Kwok TC, Mok V, Wong KT, Richards PS, Ahuja AT. Poststroke depression in Chinese patients: frequency, psychosocial, clinical, and radiological determinants. J Geriatric Psychiatry Neurology. 2005;18(1):45-51.

50) Ubukata S, Tanemura R, Yoshizumi M, Sugihara G, Murai T, Ueda K. Social cognition and its relationship to functional outcomes in patients with sustained acquired brain injury. Neuropsychiatric Disease Treatment. 2014;10:2061.

51) Cubis L, Ownsworth T, Pinkham MB, Foote M, Legg M, Chambers S. The importance of staying connected: Mediating and moderating effects of social group memberships on psychological well-being after brain tumor. Psycho-oncology. 2019;28(7):1537-43.

52) Snow JC, Tang X, Nakase-Richardson R, Adams RS, Wortman KM, Dillahunt-Aspillaga C, Miles SR. The relationship between posttraumatic stress disorder symptoms and social participation in veterans with traumatic brain injury: A veterans affairs traumatic brain injury model systems study. J Applied Rehabil Counseling. 2019;50(1):41-56.

53) Hilari K, Northcott S. “Struggling to stay connected”: comparing the social relationships of healthy older people and people with stroke and aphasia. Aphasiology. 2017;31(6):674-87.

54) Rigon A, Duff MC, Beadle J. Lonely but not alone: neuroticism mediates the relationship between social network size and loneliness in individuals with traumatic brain injury. J Int Neuropsychol Soc. 2019;25(3):285-92.

55) McLean AM, Jarus T, Hubley AM, Jongbloed L. Associations between social participation and subjective quality of life for adults with moderate to severe traumatic brain injury. Disabil Rehabil.2014;36(17):1409-18.

56) Baumann M, Peck S, Collins C, Eades G. The meaning and value of taking part in a person-centred arts programme to hospital-based stroke patients: findings from a qualitative study. Disabil Rehabil. 2013;35(3):244-56.

57) Kongkasuwan R, Voraakhom K, Pisolayabutra P, Maneechai P, Boonin J, Kuptniratsaikul V. Creative art therapy to enhance rehabilitation for stroke patients: a randomized controlled trial. Clin Rehabil. 2016;30(10):1016-23.

58) Taris TW, Kompier MA. Cause and effect: Optimizing the designs of longitudinal studies in occupational health psychology. 2014; 28(1): 1-8.

Chapter 3. Systematic Review: Extended Methodology

This chapter will outline the extended methods for the systematic review paper.

During the full text review process, it was identified that there were a number of different standardised outcome measures being used that looked at social isolation, social connectedness, social participation, difficulties socialising and relationships. Therefore, inclusion criteria for measures of social isolation were developed through discussion with supervisors and returning to the literature.

Inclusion criteria for measures of social isolation

As previously discussed in the introduction of this thesis, Cornwell and Waite's (2009) definition of social isolation includes both objective and perceived social isolation. They say objective social isolation or disconnectedness, is indicated by people having a small social network, infrequent social interactions or a lack of participation in social activities and groups. Perceived social isolation describes people's subjective experiences of social disconnection, for example if they perceive that there is a shortfall in their social resources or feel lonely. This suggests that measures of social network size, social participation and interaction can be used to identify those who are socially isolated. Therefore, we wanted to ensure that these components were being assessed by the outcome measures used in studies that would be included in the systematic review. However, some measures of social participation are ambiguous and focus on social interactions alongside other community or leisure activities (for example, The Utrecht Scale for Evaluation of Rehabilitation–Participation). In order to clarify the measures used that capture the components of the Cornwell and Waite's (2009) definition of social isolation, the lead author GB coded the outcome measures using the World Health Organisation's International Classification of

Functioning (ICF) (2001) description of activities and participation and the codes were checked by other members of the research team (FG and CS).

The Interpersonal Interactions and Relationships domain of functioning is part of the Activities and Participation component of the ICF model of functioning. This domain explores people's ability to participate in and maintain social relationships and interact with other people (including strangers, friends, relatives, family members and lovers). It looks at people's ability to participate in both basic and more complex interpersonal interactions. If people do not have interactions with others, they are not participating socially, and are therefore socially disconnected and isolated. This suggests that by measuring the number of social interactions people have, we can measure how socially connected or isolated a person is. Based on this and in order to be systematic in our approach to the review, measures of participation were only included if they looked specifically at the number or frequency of social interactions.

While the ICF does also look at people's ability to engage in community, social and civic life as well as their ability to participate in social interactions and relationships, measures of community, social and civic life were not included in the study. This was decided because the ICF's description of this construct is more closely linked to participation in the activities themselves (e.g. participation in spiritual or leisure activities) rather than looking at social connection or isolation, which may be linked to these activities. Measures which look more generally at participation within the community will therefore be excluded if they do not specifically measure the amount of social interaction or connections people have.

Studies which use measures of loneliness or perceived feelings of social connection and isolation were included in the review, as this aligns with Cornwell and Waite's (2009) definition of social isolation. Studies were, however, excluded if the measures or subscales used are not primarily focused on perceived feelings of social isolation or connection and instead focus on other aspects of social relationships, which may imply or be linked to social connection, but where it is not their primary focus. Therefore, measures of relationship satisfaction and quality were excluded.

A list of outcome measures assessing for social isolation or connection which met the inclusion criteria for this study was collated (Appendix 6). One of these outcome measures had to have been used within a study for it to be included in this systematic review.

Chapter 4. Bridging Chapter

This chapter aims to summarise the findings from the systematic review and outlines why the empirical paper was developed based on these findings.

In the previous chapter the systematic review explored variables which were either predictors, correlates or effects of social isolation after acquired brain injury. Associations were identified between both perceived and objective social isolation and reduced wellbeing after brain injury, and so the findings of the review suggest that social connectedness and wellbeing are linked. However, these associations are not fully understood, and a direction of causality cannot be established due to the cross-sectional nature of results. Furthermore, the review identified that there is limited research into the effectiveness of interventions on improving social connectedness after ABI. Therefore, the empirical study described in the next chapter was developed in order to better understand people's subjective experiences of becoming connected through participating in community groups which aim to promote social connectedness after brain injury. It explores how people come to access community groups, the barriers and facilitators to accessing them, and how accessing community groups can improve wellbeing after brain injury.

Chapter 5. Empirical paper prepared for submission to: Disability and Rehabilitation.

In this chapter, the empirical research that was conducted as part of this thesis will be discussed.

How do people make use of opportunities for engagement in communitygroups to enhance wellbeing post brain injury?

Georgina Berger[a], Fergus Gracey[a*] and Ciara Shiggins[b]

a Department of Clinical Psychology and Psychological Therapies, University of East Anglia, Norwich, United Kingdom.

b Post-doctoral research fellow and Speech Pathologist, La Trobe University, Melbourne, Australia

*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

Abstract

Purpose: Survivors of acquired brain injury (ABI) often have poor long-term outcomes, particularly in relation to social isolation. This study sought to understand how people come to access community groups after brain injury and how attending these groups can affect wellbeing.

Method: Semi-structured interviews and focus groups were conducted with 23 adults with ABI, recruited from third sector organisations and charities providing support to people following ABI. Grounded theory was used to explore the processes involved in accessing community groups to enhance wellbeing after brain injury and findings will be presented in a diagrammatic model.

Results: Attending community groups after brain injury can enhance people's wellbeing by providing opportunities for connection, acceptance and the experience of positive emotions, and can lead to a virtuous cycle of increased activity and connection. People may, however, need to draw on emotional and practical supports to overcome the internal, environmental and impairment-related barriers to accessing groups.

Conclusions: This study extends prior research into wellbeing and social connection following brain injury, by suggesting that opportunities for connection and participation can begin a virtuous cycle of wellbeing. It also suggests that those who are more socially isolated may need more support to attend community groups.

Introduction

The impact of brain injury

Survivors of acquired brain injury (ABI) are vulnerable to poor psychological outcomes [1,2] and are at greater risk of becoming socially isolated [3,4,5,6]. Loss of friendships is experienced by many after brain injury [7,8,9]. People with ABI report finding it difficult to maintain friendships and relationships due to the loss of shared activities [10,11] and as a result of the cognitive physical and communication difficulties they live with as a result of the injury [10,11,12,13]. They are often poorly integrated into their community in the long term and have fewer opportunities for meaningful occupation and role fulfilment [14,15]. Many people are unable to return to their previous job roles or leisure activities [16,17] and difficulties in resuming preinjury lifestyle and loss of pre-injury roles or social groups can impact on wellbeing and contribute to depressive symptoms after brain injury [18,19]. Brain injury survivors often report being dissatisfied with what they have accomplished in life after their brain injury [20], and the changes people experience following brain injury can alter their sense of self or identity and impact on wellbeing [21].

However, research suggests that not everyone experiences poor outcomes after acquired brain injury (ABI). Asikainen et al. [22] found that 57% of adults with a moderate to severe traumatic brain injury (TBI) were in independent employment in the long term and 60% of survivors of brain injury were found to be married or co-habiting [23]. Additionally, some survivors of brain injury do report positive changes after brain injury, experiencing long-term positive changes in outlook and post-traumatic growth [24,25]. This suggests that although many survivors of brain injury experience negative outcomes and struggle to maintain close relationships or resume employment after injury, some people do maintain social connections and experience positive outcomes. Therefore, it is important to understand what factors help some people to do this, while others struggle.

Improving wellbeing after brain injury

Positive psychology approaches suggest that improving people's wellbeing can act as a buffer against both mental and physical illness [26] and can be an important resource for people facing challenges to their health [27]. Due to the many negative outcomes that people with ABI can experience and the potential for resultant poor wellbeing [1,3,4], this may be particularly pertinent for those who have survived brain injury.

Salutogenic [28] and asset-based approaches to healthcare [29] suggests people can be supported to move towards health and wellness by identifying and mobilising the resources available to that person. In addition, Seligman's [30] positive psychology model of wellbeing suggests wellbeing can be increased through increasing experiences of positive emotions, engagement in activities, relationships, leading a meaningful life and having a sense of accomplishment. In line with both Seligman's [30] model of wellbeing and asset-based approaches to healthcare [29], research suggests that supporting people to maintain social connectedness, offering opportunities for participation, and helping people to identify and access resources can protect against poor mental health and improve psychosocial wellbeing in the general population [29,31]. Interventions focusing on improving wellbeing was also found to be beneficial for those with ABI. Asset-based approaches can help people maintain wellbeing and overcome barriers after stroke [32]; positive psychology interventions were acceptable and provided opportunities for post-traumatic growth for brain injury survivors experiencing psychological distress [33,34]; and participating in or mentoring for a positive psychotherapy group enhanced wellbeing in individuals living with ABI [35]. This evidence supports a move towards more asset-based and positive psychology approaches to rehabilitation, which focus on supporting wellbeing and health.

Attending community groups (for example sports, arts or peer support groups) may therefore be one way to support wellbeing after brain injury. They were found to provide opportunities to form positive relationships with people [36], engage in activities [37], find meaning or a purpose in life [36,38,39], experience positive emotions [37,40,41] and experience a sense of accomplishment [42], all of which Seligman [30] describes as important for improving wellbeing.

Models of brain injury rehabilitation also suggest social connections, participation and meaningful activity are important for recovery from brain injury. Gracey et al.'s [43] Y-shaped model of brain injury rehabilitation suggests that engaging in meaningful activity after brain injury can support the updating and consolidation of people's identity and improve their wellbeing. Similarly, Levack et al.'s [44] meta-synthesis of qualitative research on recovery following TBI proposes that survivors of injury move from a state of loss (of identity, social connectedness and a sense of control over one's body) and the emotional consequences of these loses, towards reconstructing their lives by drawing on internal and external resources. They suggest external support and opportunities provided by clinicians, professional rehabilitation services, community advocacy groups, friends, family and community members, can help people to find out what can be achieved and help them to come to terms with the limitations of their disability, as well as providing them with emotional support, normalising their experiences and reducing isolation. They suggest that this allows brain injury survivors to re-establish their sense of identity, their place in the world and their sense of personhood.

In line with these models of wellbeing and recovery from ABI, it has been found that life satisfaction post-ABI is improved if people can maintain their social connections [45], and that community integration after brain injury is positively related to life satisfaction and inversely related to psychological distress [46]. Furthermore, people with aphasia (a specific language disorder that affects approximately 38% of people post-stroke [47]) describe how connecting to others is important for helping them to live well with aphasia [32]. Participation in meaningful activities has also been identified as helpful for recovery after brain injury. Participation in a song-writing programme led to improvements in self-concept and subjective wellbeing [48] and taking part in arts or creative therapy groups was found to improve wellbeing, reduce depression, and increase quality of life following a stroke [49,50].

Drawing on resources within the community may help to support wellbeing following brain injury, for example by increasing social connectedness and providing opportunities to participate in meaningful activity. However, the benefits of social connection and participation are still not fully understood. Nor do we fully understand how to best support people to access opportunities for connection and participation within their communities, which could help to reduce social isolation and its negative consequences after brain injury.

Therefore, this research aims to explore how people can become more socially connected after brain injury. It will look at how people come to access groups within their community, what the barriers and facilitators are to accessing these groups, and how accessing community groups can support wellbeing. This may then help us to improve services and support more survivors of brain injury to access these groups to maintain their wellbeing.

Research Questions

1. What are the processes involved in people accessing and participating in community groups following brain injury?
2. What are the barriers and facilitators to people accessing community groups after brain injury?
3. How does participating in community groups affect people's wellbeing after brain injury?

Method

Design

The research was approached from a social constructionist epistemological stance [51] and was conducted following a constructivist grounded theory methodology [52]. This was chosen because the focus was on understanding processes in order to develop a theory grounded in the data about how people come to access community activities after brain injury, and how participation in these activities impacts on wellbeing.

Ethics

Ethical approval was sought and granted by the UEA Faculty of Medicine and Health ethics committee (Appendix 7). Written informed consent was gained from all participants. All reported information has been anonymised and pseudonyms are used.

Data collection

A choice of individual interviews or focus groups was given to potential participants when they were initially approached by the lead researcher (GB). This decision was made to facilitate participation [53], considering that different methods of data collection can be supportive for people depending on the nature of their brain injury and resultant cognitive and/or communication difficulties [54,55,56]. Supportive communication strategies were used to aid participants with cognitive or communication difficulties to participate in the research [57,58,59] and GB received training in these.

In line with a grounded theory approach, data collection and analysis were conducted iteratively [52]. An interview topic guide (Appendix 8) was developed to guide the interviews/focus groups based on the literature and through discussions with supervisory panel members (which included a carer whose husband has a brain injury, and a psychologist and occupational therapist, both working in brain injury services) and thesis supervisors (who both work within brain injury services). However, this was flexible and guided by participants' responses, and for later interviews, was also informed by interviews that had already been analysed in line with iterative Grounded Theory methods [52].

The research interviews and focus groups lasted between 40 and 70 minutes. They followed the participants' pace and breaks were given when needed. Interviews and focus groups were carried out by the lead author (GB), a trainee Clinical Psychologist, and were audio recorded using a Dictaphone. These were done either at recruitment sites or at participants' homes.

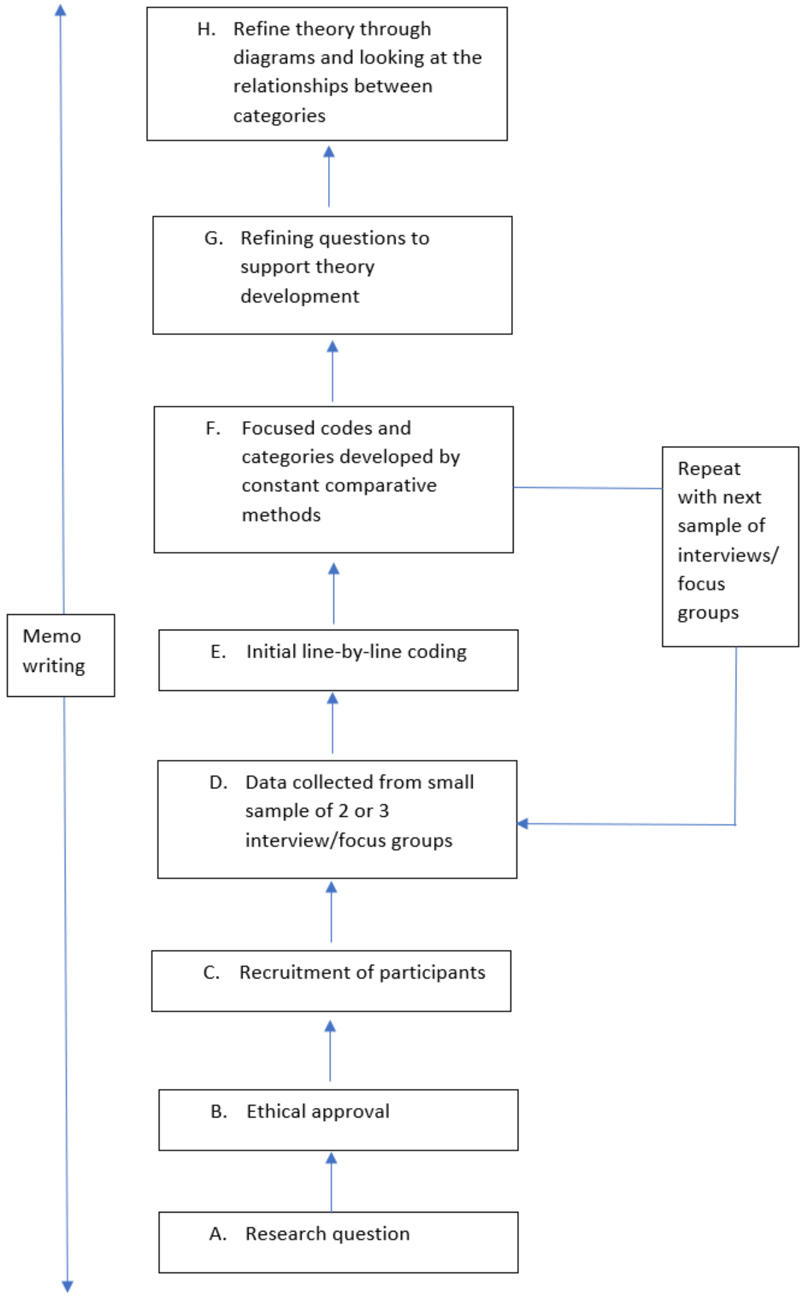
For two interviews a conversation partner or carer was present, and for three of the focus groups, group facilitators were present during the interview. This had been agreed in order to encourage participants to feel comfortable, but it was requested that they did not get involved in the interviews themselves.

Data analysis

It was decided to combine data from both focus groups and individual interviews, in order to add to the completeness of the data and to develop a more comprehensive and nuanced understanding of the phenomenon [60].

Interviews were transcribed by the lead author (GB). In keeping with standard practice in Grounded Theory analysis, there was a constant comparison and iteration between the data collection and analysis [62]. Initial coding was conducted by the lead author (GB) for 2-3 individual or group interviews and then analysed for commonality of processes to develop preliminary focused codes. Further iterations of analysis were conducted for further interviews and codes were refined into focused codes in order to develop categories to inform the theoretical codes [52] as shown in Figure 1. Codes were discussed with co-authors at each stage. Data collection continued until saturation of data was reached. Reflective notes and memos were written by GB throughout the data collection and analysis process in order to allow for transparency of the researcher’s thought processes and subjective viewpoint.

Figure 1. Flow chart of the recruitment, interviewing and analysis process following the grounded theory method.



Sampling

The researchers aimed to explore the perspectives of survivors of brain injury who have accessed community groups following their brain injury, and therefore consistent with guidance for the conduct of Grounded Theory research, purposive sampling was used to recruit a diverse sample of participants [52].

Eligible participants were required to (a) have capacity to consent, (b) be over 18 years old, (c) have sustained an ABI more than one year previously, which was significant and resulted in enduring needs which require intervention or support [63], (d) be participating in a community group or have done so within the past year. Adaptations were made to the research process, so as to be inclusive for those with cognitive, communication or neurological difficulties.

Recruitment procedure

Participants were recruited from third sector organisations and charities involved in brain injury rehabilitation and social and community support groups in the East of England and South Wales. Participants were taking part in a variety of different community groups. These included brain injury specific groups (e.g. surfing, cycling, art, woodwork, forestry/green woodworking, furniture restoration, and cognitive skills groups), a social group for people with post-stroke aphasia, a community art and woodwork group for people with disabilities, and non-disability specific community groups (e.g. a martial arts group and a sculpture class). They were recruited by word of mouth through group facilitators, and through posters (Appendix 9) and flyers (Appendix 10) distributed at the groups. The lead author (GB) initially approached group facilitators to explain the study and request support with recruitment. Group facilitators then screened participants in order to ensure the inclusion criteria were met prior to recruitment. They explained the research to potential participants and if they were interested in taking part, participants signed a consent to contact form (Appendix 11). Participants then had the opportunity to talk to GB about the study (the aims and process of taking part) prior to signing a consent form (Appendix 12) to take part in the study.

Participant demographics

Twenty-three participants were recruited via five recruitment sites across the East of England and South Wales. No participants refused to participate or dropped out of the study. Participant demographic information is provided in Table 1, participants have been allocated pseudonyms in order to protect anonymity.

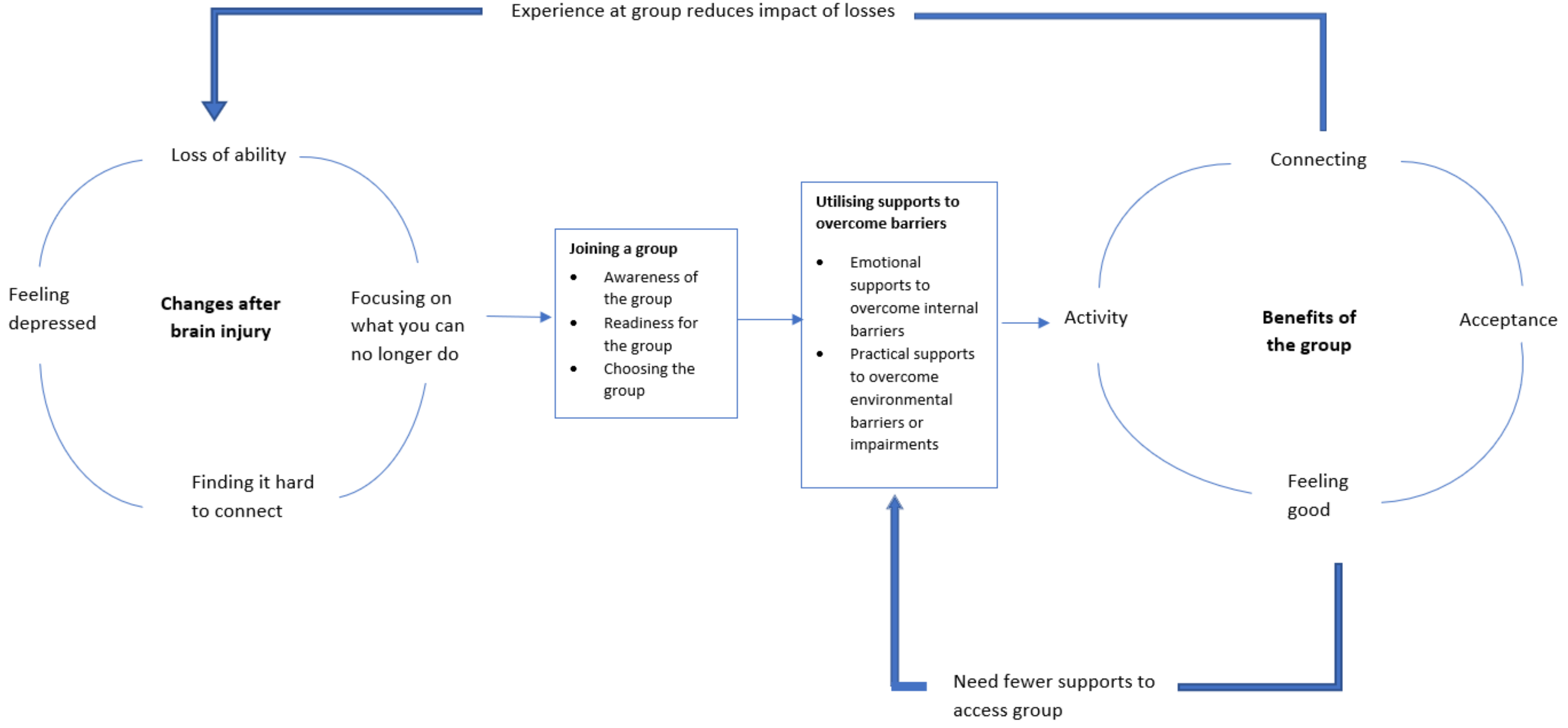
Table 1. Participant demographic information

Gender	Age	Nature of Acquired Brain injury	Time since injury (years)	Community project involved in	Focus group (FG) or individual interview (II)
Female	68	Brain Tumour	14	Furniture restoration group	FG
Male	57	TBI	38	Furniture restoration group	FG
Male	55	ABI (not specified)		Furniture restoration group	FG
Male	61	Brain Haemorrhage	8	Community social group for people with aphasia	II
Male	32	TBI	28	Community art/woodwork project for people with disabilities, Martial arts group	II
Male	74	Stroke	1	Community social group for people with aphasia	II
Male	58	TBI	1	Inclusive cycling group	II
Male	57	TBI	33	Inclusive cycling group	II
Male	54	TBI	4	Inclusive cycling group/ Inclusive surfing group	II
Female	62	Brain Haemorrhage	1	Inclusive cycling group	II
Female	53	Stroke	13	Art group	II
Male	75	TBI	56	Art group and Tai chi group	FG
Male	47	TBI	33	Memory group, Taiichi group, Art group, Woodwork group	FG
Male	64	Tumour	10	Woodwork group, Bocchia group	FG
Male	36	TBI	9	Woodwork group	FG
Male	23	TBI	5	Inclusive surfing group	FG
Male	50	TBI	3	Inclusive surfing group	FG
Male	53	Stroke	2	Inclusive surfing group	FG
Female	55	Stroke	1	Inclusive surfing group	FG
Male				Inclusive surfing group	FG
Male	30	Brain tumour and stroke	14	Green Woodworking group	FG
Male	61	ABI from diabetic coma	3	Green woodworking group	FG
Male	25	Brain tumour	24	Green woodworking group	FG
Male		Brain Haemorrhage		Green woodworking group	FG

Results

Participants described a number of changes after brain injury (loss of ability, focusing on what you can no longer do, feeling disconnected from themselves and others, and feeling depressed). They described the process of joining a group (becoming aware of the group, feeling ready for the group and choosing a group). In order to access these groups participants had to utilise supports. Emotional supports were needed to overcome participants' internal barriers, whereas practical supports were needed to overcome external barriers caused by the environment and impairments as a result of brain injury. By attending groups participants described benefitting through connecting (with others and themselves), by moving towards accepting themselves, their injury and challenges in life, and through experiencing more positive emotions as a result of the group. People were motivated by attending groups and this led to a snowballing of activity and connection. These findings are outlined in the model of how people access community groups in order to enhance their wellbeing (Figure 2).

Figure 2: Grounded theory model for how people access community groups in order to enhance their wellbeing.



Joining a group

The first overarching process identified was ‘joining a group’ for the first time. This consisted of three sub-processes: 1) ‘becoming aware of the group’, 2) ‘readiness for attending the group’ and 3) ‘choosing the group’.

Becoming aware of the group

Participants within this study had often heard about groups specific to brain injury through staff at brain injury or stroke rehabilitation services; others heard about brain injury-specific and mixed disability groups through social care and one person learnt about the service they attended through a mental health charity. However, for non-brain injury-specific groups, participants described having learnt about them through existing friendships and chance encounters. Once already attending a group, people found that staff at these groups and other group members were valuable sources of information about other available groups. Group members encouraged each other to try groups they themselves had enjoyed.

“Everybody I have talked to, who have previously done it, they have basically said the same - do it do it” (Adam).

Readiness for the group.

Feeling ready to join a group was very individual to each person and achieved by different participants in different ways and at different times. Some were eager to join groups as soon as they could. Others needed to go through several personal stages in preparation for attending a group. These stages could include: allowing time for changes to stabilise after having a brain injury, being encouraged by others, practising bus routes and first attending other groups (which they perceived as less challenging).

"I think they were incremental steps to get up there in so much that they were the small challenges prior to it so instead of one major challenge…that could have been a push too far" (Isaac).

Choosing a group

Participants described their reasons for choosing specific groups and the process of finding groups that matched their needs. Some chose groups that focused on physical activity because they wanted to lose weight, some wanted to improve their memory or cognition and others chose groups where they already had an interest in the activity, for example one participant with an interest in horticulture joined a forestry group. The types of groups or activities available in their area and how well these matched participants' needs and interests impacted on the groups people joined. Some described accessing several groups, as different groups met different needs (for example, one participant appreciated one group for its work-like environment, but also enjoyed another for its more relaxed and sociable atmosphere).

"the atmosphere here is more relaxed whereas at the other group it's a more work-driven so I get the best of both worlds" (James)

Utilising supports to overcome barriers

People described having needed emotional and practical support to access groups. When these supports were not available this could act as a barrier to participation.

Emotional supports to overcome internal barriers

Fear, anxiety, low mood, negative preconceptions about groups, difficulty accepting their disability, internalised stigma about identifying as having a disability, and previous negative group experiences were identified as barriers to group attendance and participation.

"I was embarrassed to be part of a I don't know...yeah special group yeah whatever and again that was one of the reasons I didn't want to go in the first place" (Michael)

Encouragement from healthcare staff, group facilitators, family and friends helped to persuade participants to try groups. When the person recommending a group offered suggestions about groups and described potential benefits, this was identified as beneficial by participants. Participants also described how it was important for them to feel they have a choice to do the activity and are not being pushed into it. This can be seen in this extract of a conversation between Belinda and Michael:

"Sometimes it works like that though a little bit drip feeding you information about what might be good for you" (Belinda)

"It's good isn't it rather then you're gonna do this I'd be like no" (Michael)

Participants were more likely to listen to the recommendations of, and were more willing to try, a new group when they trusted the person recommending the group or had previous positive experiences of groups with them.

Encouragement also helped participants feel brave enough to try new things and push themselves to attempt new challenges when at the group. Having an environment where it is okay for people to make mistakes, where people feel physically safe, where group members are allowed to go at their own pace and progress in manageable steps, and where people feel they were treated like equals, gave people the confidence to develop and practise skills within these groups. These skills extended to everyday life for some participants.

"I think really is just a really good place to not just maybe do things - where if I fail here it doesn't matter - whereas in the past I have rushed back to work thinking 'it is what I need to do to get where I need to be' and just fallen back further than where I started" (Matt)

Participants' own internal resources also helped them to overcome the emotional and cognitive barriers to attending groups. Participants often described having a willingness and openness to try new things which supported them to try new groups or activities:

"Well give it a go innit it's what have they got to lose but different people work in different ways didn't they…I was like no let's do this this my reasoning was to get better" (Ivan)

This was often part of people's pre-injury personality but being motivated to improve and move forward helped. Participants described how determination and not wanting to miss out on life kept them going when it was difficult to attend groups or do activities, and how seeing obstacles as a *'challenge we have to solve'* rather than *'a disaster'* was both fostered by the group environment and helped them to continue to attend groups.

"I went because if I didn't, I'd never do anything, I'd just be staying in the house" (Irene)

Practical support to overcome environmental barriers or impairments

Practical supports were vital for all participants. Physically getting to groups was often difficult, particularly for groups which were not located in towns or city centres. Many participants relied on friends and family for transport. Some had funding for taxis or transport, but others relied on public transport which was often unpredictable. Participants really valued when group facilitators or volunteers supported them by offering lifts. Being able to drive was very beneficial for accessing groups, however even then, people may have needed support initially, for example to learn the route. Fatigue affected people's ability to get to and participate in groups. Having local groups, practical support getting to groups and with juggling other commitments helped reduce the impact of fatigue for some participants.

Practical support was also needed while at groups, for example when putting on a wetsuit or balancing on sand at the surfing group. This support was often provided by family members.

"I personally physically needed support of somebody my daughters to come to come help me with dressing and undressing putting my wetsuit on" (Belinda).

Staff also helped people to overcome some of the environmental challenges, explaining tasks and providing practical support. The equipment and resources provided by the groups themselves were also important in enabling access, for example having adapted three-wheel bikes, art supplies and wetsuits available all helped participants to access the activities. Free groups or access to funding helped people to overcome financial barriers to participation, as some described how they may not have been able to access groups if they were required to pay for them themselves. However, for those with financial resources, there was a willingness to pay if groups were beneficial. The flexibility and structure of groups could also be a facilitator or a barrier to participation. For those with other commitments outside the group (e.g. family, work, hobbies) being able to change days, dip in and out of groups or attend short courses was helpful for juggling multiple commitments. Others, however, found that having regular groups on set days gave structure to their week.

"It proper gets me off my backside basically, because I'd probably sit in the house and watch TV all day" (Larry)

Benefits of groups

Participants described how brain injury and the resulting physical, cognitive and emotional changes led to them losing confidence in themselves and their abilities, becoming focused on what they can no longer do, feeling disconnected from others and themselves, and feeling depressed. These factors influenced each other and can result in the person becoming increasingly disconnected, doing less and feeling worse. Zack describes how changes following brain injury impacted on his connections with others and sense of identity:

"I still find it hard to speak to my old friends because they expect me from old and I am not me from old anymore I have changed totally" (Zack)

However, through attending community groups participants described a process of becoming more connected to others and themselves, accepting themselves and their injury, feeling good and being motivated to do more, as illustrated in the following themes and quotations:

Connecting

By attending groups, participants connected with other group members, became more connected with people outside of the group and reconnected with themselves and their sense of identity.

Outside of the group many participants described experiences of being misunderstood or persecuted:

"Not long ago some lad who was calling me a half brain and half brain stupid spastic retard" (Frank)

In contrast, at groups participants connected with other group members through their shared experience of brain injury and feeling understood. This gave people a sense of belonging and acceptance:

"It's being being somewhere where you can be yourself and where you are understood and um and and you I think one of the more unpleasant consequences of of brain injury is that you lose a sense of belonging and I think it is probably that it's that I think on a Monday morning when we are there and we all belong there in that group" (Dennis)

Doing the activity or learning a skill together, helped to instil a sense of camaraderie. Participants described feeling like they were on a '*level playing field'* and feeling like they were all *'in the same boat'* which helped foster connection. Laughter and providing support for each other helped these connections to develop, and some of these connections developed into lasting friendships.

"Coming here I meet all my friends here" (Dominic)

Participants also described becoming more connected with people outside the group. Attending groups helped participants become more aware of their and others' relationships and how they had changed. This awareness helped them to find ways to reconnect with loved ones:

"It just brought that home to me that I am not as connected as I could be because I isolate myself and I felt I have got better by being aware of it" (Belinda)

Attending groups also gave participants something to talk about with others, which helped them connect with people outside of the group. When loved ones also attended groups this strengthened connections by allowing them to share in participant's experiences. It also helped some family members to become less overprotective, as they were able to see what the person can achieve and access peer support themselves from other family members.

Some groups helped participants to connect with the wider community. Brain injury-specific groups provided a safe place to practice interactions with the public, helped connect group members to wider organisations (e.g. universities or hospitals) and could be a stepping-stone for some towards joining non-brain injury specific groups and being more integrated in the community. Feeling understood and accepted outside of brain injury groups, and having people make adjustments to include them was very meaningful for people:

"Someone we know locally who had a music group on on at their home and I thought well I'd really like to do this and talking to them they said well why don't we put a seat for you um at the side near the door so that and it's that sort of thoughtfulness that that that when you when you experience it means so much" (Dennis)

Some participants described reconnecting with themselves through attending groups. They were able to reconnect with aspects of their pre-injury identities through reconnecting with hobbies they thought they had lost through the injury (e.g. cycling), aspects of their identity (e.g. being an active, caring or creative person) and family roles,

"I like to help people out and I now because before I was ill I was a nurse … and I really do enjoy that being able to help here" (Laura)

Some also integrated the new things they had learned about themselves through attending groups (e.g. that they are more understanding of others) into their new post-brain injury identities.

Connecting, however, could sometimes be difficult for group members. Some described how cognitive changes in themselves or other group members sometimes made it difficult to form connections, however being supported to better understand each other's specific difficulties could help people to develop understanding of each other's difficulties and could make it easier for group members to empathise with each other.

"Quite often other people with brain injury aren't as accepting of other people with brain injury they become less tolerant of others and so being at forestry they flag up to you where other people might be falling down so you can become more empathetic to others as well" (Matt)

Some found it harder to connect with people at groups, if they struggled to find things in common with other group members, for example, if others did not have a brain injury or if they had a different level of ability. This could sometimes deter people from accessing or enjoying certain groups.

“I have been offered man-shed (community spaces where men can enjoy practical hobbies) …but it's not like this place what it is right I found old men sort of thing they sort of go and make woodwork and stuff but they are just normal people” (Ryan)

Acceptance

Participants described an ongoing process of moving towards accepting themselves, their brain injury and accepting challenges their injury and life may bring. At times participants struggled with this.

Through trying different activities and having to do things differently, some only then understood the full extent of their loss and disability. However, once they accepted this loss, they were then able to start with small steps in order to move forward.

“Well I hate the fact that anybody knows I am disabled, so to sit on a three-wheeler bike is ... to me ... is giving, well sort of giving everything up that I will never go on my own bike again. I have accepted it now that I am not going and I have quite enjoyed doing it” (Irene)

Participants described valuing the opportunities for learning that the groups provided, particularly learning from other group members and their ways of managing the impacts of brain injury:

“there is 1 2 3 4 5 more people’s experience to put onto my own to help me get over my glitch ….so I'm thinking that's pretty worth its weight in gold” (Sean)

For this learning from others to occur, participants needed to first accept that they might need support and might be able to learn from others.

Some participants found that accepting the difficulties they experience in other people at the group, helped them to accept the same difficulties in themselves. Seeing others who are worse off than them, also helped participants be more accepting of their own situation.

"meeting other people not in the same situation, but could be a better situation, worse situation - and its you know it is meeting those people I feel a lot better myself for that - but it is hard to accept it sometimes" (Larry)

Encountering people at different stages of rehabilitation helped people accept where they are in their own rehabilitation journey and the ongoing nature of recovery.

The focus for many groups was on what you can do, which helped participants to focus on their strengths. The achievements and progress made at groups also helped people to move towards accepting themselves, as they described feeling proud of themselves and what they were doing, particularly when they exceeded their own and others' expectations.

"I am happy here…I think it is pride in what I am doing" (Danielle)

Creating or making things and having something tangible as a result, acted as a reminder of people's achievements and helped people focus on what they can do. Social factors also influenced people's experience: Ppeople valued doing activities that: impressed others, were valued regardless of whether or not you had a brain injury or involved making things that others valued or wanted to buy.

"Just sense of achievement that that that I'm actually doing something that someone wants you know" (James).

These processes appeared to be important for increasing self-esteem and confidence after brain injury and increasing feelings of self-worth.

Only one participant described finding it hard to see any progress made due to external factors outside the group remaining stable (e.g. his housing) and finding it difficult to recall achievements due to memory difficulties

"I'm afraid once I walk out the door, I forget about it" (Arnold)

Helping others was identified as important, as participants described feeling better about themselves and finding meaning and purpose through helping others at the group. Both being able to help others and letting others benefit from helping them resulted in participants feeling that they themselves and what they were doing was worthwhile.

"Seeing the way Zack is trying to help me…I can see it is helping him in so much that he feels that it's something positive he is doing…then I think to myself well hang on now then listen that's not too bad because I am glad that he is up here so I am gaining secondary… you don't feel so negative about yourself because you are actually helping somebody"(Isaac)

Participants benefitted not only from seeing their own progress, but also experienced joy sharing in each other's successes.

The increase in self-acceptance can be seen in how participants reported being kinder towards and less critical of themselves and in how they described feeling pride in what they have achieved and what they are doing.

Participants also described becoming more accepting of challenges in life through attending the groups, both by learning strategies to overcome difficulties and through gaining confidence by successfully overcoming challenges within the group.

Feeling good

Participants described enjoying the activities and connecting with others in the group. Some described feeling excited again and experiencing an adrenaline rush, something they rarely experienced outside of the groups. This feeling was often recalled and remained, even if the details of the activity were more difficult to remember.

"Because of the memory again I don't remember things clearly, but I just remember the rush and I'd feel really good the next day" (Ben).

Groups gave people something to look forward to throughout the week, and participants described how being at the groups reduced their experience of negative emotions while they were at the group and between groups.

"People who do sort of gradually get down and down during the week and then they think oh its Monday you know they've got that to look forward to" (Steve)

One negative effect experienced by one group member, was that the positive emotions experienced at the group then highlighted the negative emotions and feelings of loneliness he experienced when not at the group.

"So to have that surfing where you are interacting with other members of the group where you are talking to the instructors and the helpers to then come away and have nothing of it's like a great big high and then it's a big…dip again" (Ben)

Becoming motivated: Snowballing activity and connection

The positive aspects of attending groups motivated people and begin a virtuous cycle of increased activity and connection. Participants described being motivated to continue activities beyond the group, to be more active generally, to take the ethos of groups into their daily lives, to return to groups as volunteers and to join new groups. Connecting with others, experiencing positive emotions, wanting to give back to groups, and wanting to build on the successes they experienced at groups were all drivers for increased activity.

"Now that I know that we, I, have been a big part of making something like this it's spurred me on to do what's the next project" (Sean)

The connections made at groups also helped people to increase their activity, as group members were able to support each other to continue the activity outside of the group. Doing activities together outside groups, then helped to strengthen connections between group members. Attending groups also increased activity by giving some the confidence to do activities outside the group with loved ones, which then also increased connectedness. Some found attending groups helped them to engage in their rehabilitation, as the activity gave people a more tangible reason for practising their exercises.

"The exercises that I should be doing to improve my core I found hard and not not motivated to do - but since doing the surfing I am doing it - because there's a reason for me" (Belinda).

The supports discussed previously continued to be needed to build on this momentum. However, for many, attending groups actually helped remove or reduce barriers to attending groups: people became less anxious the more they attended groups, negative preconceptions were disconfirmed, practical barriers were overcome (e.g. by sharing transport), and the positive effects of being at a group made the challenges to attending feel worthwhile:

"Now we have done it I would do it in rain I don't care about the weather anymore I think in rain and even thunderstorm harsh weather… I think it will give you more of a rush make you feel more alive" (Ben)

Discussion

The grounded theory analysis of in-depth interviews and focus groups provided an understanding of the processes involved in people accessing community groups after brain injury and how attending these groups helped improve people's wellbeing. The types of groups participants attended varied greatly: in how structured they were; in their length, in how active they were; and in whether they were ABI-specific or not. These differences between the groups meant that participants' experiences at the different groups will have varied greatly. However, having such a range of groups has allowed for a better understanding of the common processes which can occur across all these different types of community group, all of which can support wellbeing after brain injury. Participants described benefitting from the groups through becoming more connected, moving towards acceptance and feeling good. These processes overlap with prior research findings and theoretical models regarding specific factors that are important to wellbeing. They suggest wellbeing post-ABI was supported through attending community groups by participants becoming more connected with others (by forming new or improving existing relationships) [30,32,45,46,59,64] and through people reconnecting with their sense of identity and incorporating new aspects learned about themselves at the group into their post injury identity [43,44]. Wellbeing was also supported through participants experiencing positive emotions when doing group activities [30,35,37,40,41,48,49,50]. Moving towards self-acceptance was also important for wellbeing [36,64], and was done by participants focusing on their strengths [65,66] finding meaning and purpose in helping others and doing the activity [30,32,36,37,38,39,64] and experiencing a sense of achievement through their successes at the group [30,42,64]. This suggests that accessing community activity groups may be particularly beneficial for wellbeing if they provide opportunities to connect with, help and learn from others; if they provide experiences for success, excitement and positive emotions; and if they focus on people's strengths and what they can still do.

However, this specific grounded theory approach also highlights the importance of seeing group participation and the outcome of wellbeing as being dynamic and complex. While the benefits of attending community groups have been divided into three processes, these were found to interconnect and impact on each other and can lead to a virtuous cycle of increasing motivation, activity and connection, which is not described elsewhere in the literature. People can be helped to start this virtuous cycle by being supported to access community groups which promote connection, self-acceptance and activity.

The study also identified challenges that had to be overcome in order for people to access and benefit from these groups. Participants described how practical and emotional supports were important for overcoming barriers and facilitating access to groups. This echoes Levack et al.'s [44] model of recovery from brain injury, which suggests internal and external resources can support recovery, but goes further, and suggests that supports are necessary for people to be able to make use of the opportunities available to them within communities. However, not everyone will have equitable access to groups, as the opportunities and supports available may depend on the person's life situation, location and other contextual factors [52]; for example, self-funded groups may not be accessible for some with fewer financial resources. This suggests a need to identify and mobilise the resources which are available to people within both themselves and the community, in order to help them to access community groups after brain injury. This also aligns with asset-based approaches to healthcare [29]. The current research suggests several ways in which more people can be supported to access community groups after brain injury.

Supports and opportunities provided by clinicians, professional rehabilitation services, community advocacy groups, friends, family and community members can help facilitate recovery from brain injury [44] and the current study provides valuable information on ways in which they can do this within the context of supporting people to attend community groups. Brain injury and stroke services were particularly important for connecting people to brain injury specific groups, but this means those who are no longer in regular contact with brain injury/stroke services do not have the same opportunities to access groups. Making GP practices, social care and any other services more aware of brain injury specific groups, could help to connect this group of people to groups.

Levack et al. [44] suggest support from family and friends helps recovery from brain injury, and many participants within the current study found the practical and emotional supports provided by family or loved ones vital for facilitating attendance at groups. This suggests that for those who already have some connections, it may be easier to access groups and become more connected. However, for those without this additional support, it may therefore be more difficult for them to overcome barriers to accessing groups which may mean that those who are already socially isolated may become even more so. It is therefore important for those who are less socially connected to access this support from elsewhere, for example from healthcare professionals or social services.

Individual participants felt ready to attend groups at different stages of their rehabilitation, which suggests it may be helpful for people to have multiple opportunities to access groups after ABI; otherwise they might miss opportunities to enhance their wellbeing, if they are not offered groups at a time when they feel ready. Furthermore, pushing someone to do a group when they don't feel ready, might negatively impact on their experience of the group and services; and it may be that there are time points in recovery when groups do not suit or are unhelpful for the individual. This is supported by Lanyon, Worrall and Rose (2019) [71] who found that participants in their study didn't want to participate in community aphasia groups during the early phase of adjustment (which varied in length between participants), and that when people weren't motivated to attend groups, they were also more likely to drop out of them. This suggests there may be a need for longer-term contact with services after brain injury, in order to ensure that people can access groups when they feel ready, so that they can benefit from them. Similarly, Hawley et al [67] found that services with policies of long-term regular but infrequent contact with patients and carers following active rehabilitation improved outcomes following ABI, as they enabled patients and families to voice concerns or difficulties and access support when needed before problems escalated. Many participants needed encouragement from staff or family before joining a group, which also suggests simply being told about a group once may not be enough. Having a good relationship with the person recommending a group or with group facilitators helps people to trust their recommendation and encourages them to try a new group.

If people are interested in an activity or can see a reason for a group, it motivates them to access the group [68]. Similarly, participants within this study described how both suggestions about available groups and how those groups might be beneficial, as well as having an interest in or a reason to do the activity, supported participation. It is therefore important for people to have opportunities to access a range of different groups, so that there will be groups which appeal to different people and which can meet their varying needs, as was also described by Attard et al. [36]. Allowing people to access more than one type of group may also be important, as different groups can benefit people in different ways and different types of groups can all enhance wellbeing by facilitating social connectedness and identification [69].

Participants valued connecting with others who have had brain injuries and found it was often easier to form these connections at groups because they feel understood by those who have had similar experiences and difficulties; this is described also in Attard et al. [36]. Therefore, it is important for brain injury-specific groups to be offered, as these are places where it can be easier for survivors of brain injury to connect with each other and experience feeling understood and a sense of belonging [68]. The consequences of brain injury can sometimes make it difficult for group members to connect with each other; however, identifying things people have in common and making group members more aware of each other's specific difficulties, can help increase people’s understanding and compassion for one another and support the formation of connections at groups.

Strengths

Using a social constructionist grounded theory methodology [52] allowed for an in-depth exploration of the processes involved in becoming socially connected, and how this can enhance wellbeing, whilst also allowing for sensitivity to context. The virtuous cycle identified of increasing connection, participation and wellbeing would have been difficult to identify within a quantitative study where the researcher would have been unable to explore people's individual experiences in depth [70].

Limitations

Participants in this study were all attending groups; therefore, the views of those who are not attending any community groups have not been captured. This limits how fully we can understand the barriers to taking part in community groups. However, from participants' descriptions of barriers to attending groups and the reasons why they have chosen not to attend other groups, it has been possible to identify some ways of supporting people to access groups. The current model could benefit from further elaboration to better incorporate the times when people do not benefit from groups or when experiences of groups could be harmful. For example, Lanyon et al.'s (2019) [71] research found that not all attempts at reengaging with social activity were positive for people with post-stroke aphasia. However, as all participants in the study enjoyed the groups they were currently attending, it was more difficult within the model to capture these negative experiences. Nevertheless, some of these were captured within the model, for example, in how some participants described not enjoying groups where they had struggled to connect with other group members. Therefore, this suggests that if people are unable to connect, move towards acceptance or experience positive emotions while at groups, this could negatively impact on their wellbeing and prevent this virtuous cycle from occurring.

Due to time pressures no second interviews were conducted and results were not checked back with participants, which would have helped to ensure the results reflect participants' views. However, the researcher is planning to disseminate the results back to participants and services. Finally, approaching the research from a social constructionist perspective, means that the focus was on developing an understanding of people's experiences of becoming connected through community groups within specific contexts. Therefore, it is likely that different factors may be more or less influential in other settings.

Clinical implications

Community groups can support wellbeing after ABI by providing opportunities for people to connect with, help and learn from others; by providing opportunities for people to experience success and positive emotions; and by helping people to focus on their strengths and what they can still do.

Staff within brain injury rehabilitation, stroke, GP and social services should be aware of available community groups (both brain injury-specific and non-brain injury-specific groups) so they can connect clients with these groups. People may also need to have multiple opportunities to access groups after ABI, otherwise they may not have the opportunity to join a group when they feel ready. Offering a range of groups may facilitate engagement and meet people's differing needs and interests after ABI. Those who are socially isolated may need more practical and emotional support from services in order to access groups.

Research implications

It would be helpful to see if this virtuous cycle of increasing activity and connection is found in other contexts and to investigate how current ABI services can support this cycle. As all participants were socially connected in some way through their experiences at community projects, a negative case analysis of those who are not connected to community groups could help to broaden our understanding of the barriers to connection.

Conclusions

The current research paper suggests that attending community groups after brain injury can enhance people's wellbeing by providing opportunities for connection, acceptance and the experience of positive emotions, which can all extend beyond the group into people's everyday lives. The results also suggest that attending groups can be motivating and can lead to a positive cycle of increased activity and connection, which can reduce the impacts of the negative sequelae of brain injury.

In order to attend groups after ABI people may need to draw on emotional and practical supports to overcome the internal, environmental and impairment-related barriers to accessing groups. These supports can be internal or can come from people's existing connections, staff at groups or supportive environments. This means that it may be more difficult for those who are more socially isolated to access groups and suggests that more support may be needed from services to help these people connect with and attend groups.

References

1) Kreutzer JS, Seel RT, Gourley E. The prevalence and symptom rates of depression after traumatic brain injury: a comprehensive examination. Brain Inj. 2001;15(7):563-76.

2) Teasdale TW, Engberg AW. Suicide after traumatic brain injury: a population study. J Neurology Neurosurg Psychiatry. 2001;71(4):436-40..

3) Morton MV, Wehman P. Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. Brain Inj. 1995;9(1):81-92.

4) Hoofien D, Gilboa A, Vakil E, Donovick PJ. Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. Brain Inj. 2001;15(3):189-209.

5) Wood RL, Yurdakul LK. Change in relationship status following traumatic brain injury. Brain Inj. 1997;11(7):491-501.

6) Rowlands A. Understanding social support and friendship: Implications for intervention after acquired brain injury. Brain Impair. 2000;1(2):151-64.

7) Zenicius MD, Wesolowski AH. Is the social network analysis necessary in the rehabilitation of individuals with head injury? Brain Inj. 1999;13(9):723-7.

8) Tomberg T, Toomela A, Pulver A, Tikk A. Coping strategies, social support, life orientation and health-related quality of life following traumatic brain injury. Brain Inj. 2005;19(14):1181-90.

9) Hilari K, Northcott S. Social support in people with chronic aphasia. Aphasiology. 2006;20(1):17-36.

10) Northcott S, Hilari K. Why do people lose their friends after a stroke?. Int J Lang Commun Disord. 2011;46(5):524-34.

11) Shorland J, Douglas JM. Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. Brain Inj. 2010;24(4):569-80.

12) Callaway L, Sloan S, Winkler D. Enabling people to maintain and develop friendships following severe traumatic brain injury. Austral Occupat Ther J. 2005;52:292-5.

13) Northcott S, Marshall J, Hilari K. What factors predict who will have a strong social network following a stroke?. J Speech Lang Hear Res. 2016;59(4):772-83.

14) Doig E, Fleming J, Tooth L. Patterns of community integration 2-5 years post-discharge from brain injury rehabilitation. Brain Inj. 2001;15(9):747-62.

15) Sloan S, Winkler D, Anson K. Long-term outcome following traumatic brain injury. Brain Impair. 2007;8(3):251-61.

16) Ponsford JL, Downing MG, Olver J, Ponsford M, Acher R, Carty M, Spitz G. Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. J Neurotrauma. 2014;31(1):64-77.

17) Van Velzen JM, Van Bennekom CA, Edelaar MJ, Sluiter JK, Frings-Dresen MH. How many people return to work after acquired brain injury? A systematic review. Brain Inj. 2009;23(6):473-88.

18) Haslam C, Holme A, Haslam SA, Iyer A, Jetten J, Williams WH. Maintaining group memberships: Social identity continuity predicts well-being after stroke. Neuropsychol Rehabil. 2008;18(5-6):671-91.

19) Ownsworth T, Fleming J, Haines T, Cornwell P, Kendall M, Nalder E, Gordon C. Development of depressive symptoms during early community reintegration after traumatic brain injury. J Int Neuropsychol Soc. 2011;17(1):112-9.

20) Mailhan L, Azouvi P, Dazord A. Life satisfaction and disability after severe traumatic brain injury. Brain Inj. 2005;19(4):227-38.

21) Ownsworth T. Self-identity after brain injury. New York and London: Psychology Press; 2014.

22) Asikainen I, Kaste M, Sarna S. Predicting late outcome for patients with traumatic brain injury referred to a rehabilitation programme: a study of 508 Finnish patients 5 years or more after injury. Brain Inj. 1998;12(2):95-107.

23) Wood RL, Rutterford NA. Psychosocial adjustment 17 years after severe brain injury. J Neurology Neurosurg Psychiatry. 2006;77(1):71-3.

24) Hawley CA, Joseph S. Predictors of positive growth after traumatic brain injury: A longitudinal study. Brain Inj. 2008;22(5):427-35.

25) Collicutt McGrath J, Linley PA. Post-traumatic growth in acquired brain injury: A preliminary small scale study. Brain Inj. 2006;20(7):767-73.

26) Seligman ME. Positive health. Applied Psychol.2008;57:3-18.

27) Galvin K, Todres L. Kinds of well-being: A conceptual framework that provides direction for caring. Int J Qualitative Stud Health Well-being. 2011;6(4):10362.

28) Antonovsky A. Health, stress & coping. Michigan: Jossey-Bass.1979.

29) Hopkins T, Rippon S. Head, hands and heart: asset-based approaches in health care. London: Health Foundations. 2015.

30) Seligman M. Flourish. New York, NY: Free Press. 2011.

31) Marmot M. Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England post 2010 (The Marmot Review). Institute of Health Equity. 2010.

32) Shiggins C, Soskolne V, Olenik D, Pearl G, Haaland-Johansen L, Isaksen J, Jagoe C, McMenamin R, Horton S. Towards an asset-based approach to promoting and sustaining well-being for people with aphasia and their families: an international exploratory study. Aphasiology. 2020;34(1):70-101.

33) Cullen B, Pownall J, Cummings J, Baylan S, Broomfield N, Haig C, Kersel D, Murray H, Evans JJ. Positive PsychoTherapy in ABI Rehab (PoPsTAR): a pilot randomised controlled trial. Neuropsychol rehabil. 2018;28(1):17-33.

34) Karagiorgou O, Evans JJ, Cullen B. Post-traumatic growth in adult survivors of brain injury: A qualitative study of participants completing a pilot trial of brief positive psychotherapy. Disabil Rehabil. 2018;40(6):655-9.

35) Tulip C, Fisher Z, Bankhead H, Wilkie L, Pridmore J, Gracey F, Tree J, Kemp AH. Building wellbeing in people with chronic conditions: A qualitative evaluation of an 8-week positive psychotherapy intervention for people living with an acquired brain injury. Frontiers Psychology. 2020;11:66.

36) Attard MC, Lanyon L, Togher L, Rose ML. Consumer perspectives on community aphasia groups: a narrative literature review in the context of psychological well-being. Aphasiology. 2015;29(8):983-1019.

37) Phinney A, Moody EM, Small JA. The effect of a community-engaged arts program on older adults' well-being. Can J Aging/La Revue canadienne du vieillissement. 2014;33(3):336-45.

38) Crone D. Walking back to health: A qualitative investigation into service users' experiences of a walking project. Issues Ment Health Nurs. 2007;28(2), 167–183.

39) Ormsby J, Stanley M, Jaworski K. Older men’s participation in community-based men’s sheds programmes. Health Social Care Community. 2010;18(6):607-13.

40) Mowatt RA, Bennett J. Veteran stories, PTSD effects and therapeutic fly-fishing. Ther. Recreat. J. 2011;45:286-308.

41) Otter L, Currie J. A long time getting home: Vietnam Veterans' experiences in a community exercise rehabilitation programme. Disabil Rehabil. 2004;26(1):27-34.

42) Hyer L, Boyd S, Scurfield R, Smith D, Burke J. Effects of outward bound experience as an adjunct to inpatient PTSD treatment of war veterans. J Clin Psychology. 1996;52(3):263-78.

43) Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. Neuropsychol Rehabil. 2009;19(6):867-90.

44) Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. Disabil Rehabil. 2010; 32(12):986-99.

45) Jones J, Williams WH, Haslam SA, Jetten J, Morris R, Saroyan S. 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 Health, 2011 26(3):353-369

46) Williams MW, Rapport LJ, Millis SR, Hanks RA. Psychosocial outcomes after traumatic brain injury: Life satisfaction, community integration, and distress. Rehabil Psychology. 2014;59(3):298.

47) Berthier ML. Poststroke aphasia. Drugs Aging. 2005;22(2):163-82.

48) Roddy C, Rickard N, Tamplin J, Lee YE, Baker FA. Exploring self-concept, wellbeing and distress in therapeutic songwriting participants following acquired brain injury: A case series analysis. Neuropsychol Rehabil. 2020;30(2):166-86.

49) Baumann M, Peck S, Collins C, Eades G. The meaning and value of taking part in a person-centred arts programme to hospital-based stroke patients: findings from a qualitative study. Disabil Rehabil.2013;35(3):244-56.

50) Kongkasuwan R, Voraakhom K, Pisolayabutra P, Maneechai P, Boonin J, Kuptniratsaikul V. Creative art therapy to enhance rehabilitation for stroke patients: a randomized controlled trial. Clin Rehabil. 2016;30(10):1016-23.

51) Liebrucks A. The concept of social construction. Theory Psychology. 2001;11(3):363-91.

52) Charmaz K. Constructing Grounded Theory (2nd ed.). London: Sage. 2014.

53) Taylor B. The experiences of overseas nurses working in the NHS: results of a qualitative study. Diversity in Health and Social Care. 2005;2(1):17-27.

54) Sargeant R, Webster G, Salzman T, White S, McGrath J. Enriching the environment of patients undergoing long term rehabilitation through group discussion of the news. J Cog Rehabil. 2000;18(1):20-3.

55) Togher L, McDonald S, Code C, Grant S. Training communication partners of people with traumatic brain injury: A randomised controlled trial. Aphasiology. 2004;18(4):313-35.

56) Lynch RT, Kosciulek JF. Integrating individuals with traumatic brain injury into the group process. J Specialists Group Work. 1995;20(2):108-13.

57) Paterson B, Scott-Findlay S. Critical issues in interviewing people with traumatic brain injury. Qualitative Health Res. 2002;12(3):399-409.

58) Luck AM, Rose ML. Interviewing people with aphasia: Insights into method adjustments from a pilot study. Aphasiology. 2007;21(2):208-24.

59) Douglas JM. Conceptualizing self and maintaining social connection following severe traumatic brain injury. Brain Inj. 2013;27(1):60-74.

60) Lambert SD, Loiselle CG. Combining individual interviews and focus groups to enhance data richness. J Advanced Nurs. 2008;62(2):228-37.

62) Glaser BG, Strauss AL Discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine. 1967

63) Turner-Strokes L. (Ed.). Rehabilitation following acquired brain injury: national clinical guidelines. London: Royal College of Physicians.2003.

64) Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. J Pers Soc Psychol. 1989;57(6):1069–1081.

65) Shardlow S. Values, ethics and social work. In R. Adams L, Dominelli, Payne M. (Eds.). Social work: Themes, issues and critical debates (pp. 23–33). Basingstoke, United Kingdom: Macmillan. 1998

66) Rowlands A. Ability or disability? Strengths-based practice in the area of traumatic brain injury. Families in Society. 2001;82(3):273-86.

67) Hawley C, Davies C, Stilwell J, Stilwell P. Post-acute rehabilitation after traumatic brain injury. Br J Ther Rehabil. 2000;7(3):116-22.

68) Perna RB, Bubier J, Oken M, Snyder R, Rousselle A. Brain injury rehabilitation: activity based and thematic group treatment. J Cog Rehabil. 2004;22(3):20-4.

69) Jetten J, Haslam C, Haslam SA, Dingle G, Jones JM. How groups affect our health and well-being: The path from theory to policy. Soc Issues Policy Review. 2014;8(1):103-30.

70) Carr LT. The strengths and weaknesses of quantitative and qualitative research: what method for nursing? J Advanced Nurs. 1994;20(4):716-21.

71) Lanyon L, Worrall L, Rose M. “It’s not really worth my while”: understanding contextual factors contributing to decisions to participate in community aphasia groups. Disabil Rehabil. 2019;41(9):1024-36.

Chapter 6. Empirical Paper: Extended Methodology

In this chapter, methodological processes and issues relating to the empirical study will be considered and the data collection and analysis process will be described. The author will then provide reflections on her position and the process of completing the research project.

Ethical considerations

Consent procedure

Participants were given information about the study prior to participation (Appendix 13) and had the opportunity to ask questions about the research before, during and after taking part. This information was also reviewed at the interview or focus group to ensure participants were aware of the purpose of the research, the positives and negatives of taking part, what participation would involve and how their data would be stored. Written informed consent was then sought using a consent form (Appendix 12).

Data management

Audio recordings were taken using a Dictaphone. The seven principles of the General Data Protection Regulation (GDPR, 2018) were followed throughout the research process. In order to ensure any data obtained were used fairly and stored securely audio recordings were transferred to and stored on password protected servers as soon as possible after the interview or focus group. Once the data was transcribed it was then anonymised and the audio file was deleted.

Distress

Due the nature of the interview and discussing their and others' lived experiences there was a possibility that participants could become distressed during the interviews or focus groups.

Potential participants were informed of this prior to taking part through the information sheet (Appendix 13) and at the time of the interview or focus group. Any distress was managed in session by the interviewer who used her clinical skills as a trainee clinical psychologist and participants were also signposted to further support (Appendix 14). Although all data were kept confidential and anonymity maintained, participants were informed confidentiality would need to be broken was if it was believed there was a risk of harm to the participant or someone else.

Design

Social constructionist perspectives emphasize the influence of society, culture and context on knowledge and our understanding of the world (Kim, 2001). They suggest that the processes to be studied within this research project arise within socially created situations and structures (Charmaz, 2008). Each person's lived experience of Acquired Brain Injury (ABI) is influenced by the contexts within which they live, and communities can vary greatly in terms of wealth, diversity, resources and culture. Therefore it seemed particularly important to take a social constructionist stance which acknowledges the importance of these social contexts. Using a qualitative methodological approach facilitated a deeper understanding of people’s subjective experiences of accessing community groups after brain injury, allowing for the meanings and interpretations participants have ascribed to their experiences to be better understood by the researcher (Hennink, Hutter & Bailey, 2020). This can therefore improve our understanding of both common processes and individual differences in people’s experiences of accessing community groups after brain injury. The ways in which people come to access community activities will vary and is likely to be strongly influenced by contextual factors. Therefore, gaining access to participants’ subjective experiences alongside information about the contextual facilitators and barriers influencing access to groups, is invaluable for understanding how to better support people to access groups.

Adaptions to the research process to support inclusion

Fatigue after periods of sustained attention is common after ABI (Hibbard, Uysal, Sliwinski, and Gordon,1998) and participants report it takes considerable energy to focus on interview questions (Paterson & Scott-Findlay, 2002). Therefore, participants were offered breaks or to stop the interview or focus group at any point, and the interviewer also monitored for signs of fatigue (Paterson & Scott-Findlay, 2002).

Participants were also facilitated to participate through the use of supportive communication strategies (Paterson & Scott-Findlay, 2002) and adaptions to the interview process (Luck & Rose, 2007), including the use of scaffolding techniques (Douglas, 2013). These included allowing participants more time to respond, inviting expansion on answers, and refocusing participants if they got side-tracked in conversations. The lead researcher (GB) also received Conversation Partner Training prior to completing the interviews, and one supervisor (CS) is a qualified Speech and Language Therapist who provided guidance when needed. Participant information sheets (Appendix 13), consent forms (Appendix 12), posters (Appendix 9), flyers (Appendix 10) and the consent to contact forms (Appendix 11) were reviewed by people with ABI prior to their use, in order to ensure they were inclusive. The researcher also went to meet some participants in person prior to the interviews and focus groups, and conducted the interviews in person either at participants' homes or the services they attend, in order to better support participants to take part in the research.

Collecting data through both focus groups and individual interviews was also done in order to facilitate participation in the study. Offering a choice of either a focus group or an individual interview can be helpful due to the variety of difficulties experienced by people after brain injury. Some people with brain injury find it helpful to participate in focus groups rather than individual interviews, as they may struggle to recall events individually but will find that the responses of other participants can prompt their recollection (Sargeant, Webster, Salzman, White & McGrath, 2000). In contrast, for those with attention deficits, slower processing speeds or communication difficulties, it can be more difficult to keep track of topics in conversations and express themselves in group situations, and they may find that being in a group produces too much external stimuli for them to be able to attend effectively to interview questions (Togher, McDonald, Code, & Grant, 2004; Lynch & Kosciulek, 1995). Therefore, including both focus groups and individual interview methods should increase people's ability to participate in the research.

Data collection and analysis

In keeping with standard practice in Grounded Theory analysis, there was a constant comparison and iteration between the data collection and analysis (Glaser & Strauss, 1967). Interviews and focus groups were initially coded by the lead author (GB) line-by-line using words reflecting actions to help the researcher focus on processes (Charmaz, 2014). The initial codes were then studied, compared and refined to develop focused codes and categories were developed to link data together. Initially groups of between two and three interviews or focus groups were coded. The focused codes for these then directed further iterations of data collection and analysis, through both changes to the interview questions and by posing experiences of earlier participants to later participants to see whether they had experienced the same thing. For example, participants often talked about feeling understood at groups without any prompting, which highlighted to the researcher how important this shared experience and feeling understood was for helping people to connect. However, wary of being drawn towards only looking for confirmatory evidence, the researcher also asked questions about, and was sensitive to, examples of when people had found it more difficult to connect or didn’t feel understood at groups, and then explored the reasons why (Appendix 15).

Further groups of between two and three interviews or focus groups were then analysed, focused codes were refined and these then informed the next iteration of data collection and analysis, continuing the iterative process. Previous interviews were also returned to and recoded, as focused codes were refined based on new data collected. Finally, theoretical codes were developed (Appendix16) by exploring how focused codes related to each other (Charmaz, 2014). Diagrams were used to facilitate this process (Appendix 17). Quotes which helped to synthesise and form each of the theoretical codes presented in the paper can be found in Appendix 18. Memos and reflective notes were written throughout the data collection and analysis process in order to allow for transparency of the researcher’s thought processes and subjective viewpoint when developing the theory.

Researcher position and reflections on the process of conducting the research

I am a 29-year-old white-British female trainee clinical psychologist, who prior to beginning this thesis had only worked for a year as an assistant psychologist within a community brain injury service. Within this role I was able to see how people were affected in different ways by brain injury and see differences in the ways in which people coped, which drew my interest to the topic. As an assistant psychologist I gained a lot of experience assessing people’s cognitive functioning, and in doing so increased my understanding of the cognitive changes which can result from brain injury and how these can impact on people’s functioning. I remember, however, feeling somewhat uninspired by the rehabilitation pathway within the service I worked for, as the focus had been largely on the assessment of difficulties, and it felt like less was being done to support people to live well with these changes. Although I acknowledge now that this view may have been biased by the scope of my role at the time, I recall wondering if more could be done to support people's wellbeing after brain injury. I remember thinking that it felt like we were just telling people what their difficulties were, rather than supporting them to find a way to do the things which are important to them in spite of the changes they had experienced. Movements like 'living well with dementia', values based psychological approaches and seeing how some people refused to let their brain injury stop them from doing the things that were important to them, inspired me to learn more about strengths-based and positive psychology approaches to wellbeing after brain injury and drew me to this research project. I found it exciting that people were being supported to be active and connect with others at these groups, and I was impressed by how these groups did not let brain injury get in the way of participation and how there was an attitude of 'we will find a way'.

Before I started the project, I had not expected to be quite as moved as I was by people's descriptions of the losses they had experienced, and how this contrasted with the emotions they felt when experiencing a sense of belonging and feeling understood at groups. This was something that really stood out to me throughout the process - how important it was for survivors of brain injury to be able to connect with others who have had the same experiences. Hearing people's stories of disconnection and reconnection has also made me think differently about the connections I have in my own life and think more about connectedness in relation to my clinical work. I was also moved by people's stories of helping each other and benefitting from seeing one another progress. In particular, I recall interviewing two participants in a row, where they both described the same situation: one was helping and guiding the other participant who had visual difficulties when cycling. The first described how he had gained so much confidence from being able to help someone else, and the other participant who had received the help, described how seeing how the first participant had benefitted from helping him, had also made him feel better about himself. He described how it had made his own experience at the group feel worthwhile. This illustrated to me how human it is to want to be able to help others, and how giving and kind people can be, even when they are having to overcome challenges themselves. It also demonstrated to me how being able to help others can be so important for self-esteem, and how having opportunities to help others may be particularly important when people have experienced a loss of confidence and self-esteem as a result of brain injury.

Chapter 7. Critical Appraisal and discussion

In this chapter, the findings from the empirical study and systematic review will be integrated and contextualised within the current literature. The contribution this work brings to our knowledge of social connection and isolation after brain injury will also be outlined. The strengths and limitations of the research will be discussed, along with the implications for clinical practice and future research.

Summary

The current thesis aimed to increase our understanding of the benefits, barriers and correlates to social connectedness and participation following an Acquired Brain Injury (ABI). Furthermore, it aimed to improve our understanding of how to support people to maintain social connections in order to enhance their wellbeing after brain injury.

Both the systematic review and empirical study highlight how people can become socially disconnected after brain injury and the importance and value of maintaining social connectedness. The systematic review largely focuses on the risk factors for, and deficits associated with, social isolation after ABI, and thereby helps with defining the problem of social isolation after brain injury. The empirical paper then explores both barriers and facilitators to social connection, and how social connectedness can improve wellbeing. The two studies complement each other by using quantitative and qualitative methodologies to explore the phenomenon of social connection. They provide valuable insight into how, after brain injury, it is important to make sure people have access to both opportunities for connection within their communities and have the supports and resources they will need in order to make use of these opportunities, as this can support wellbeing.

Integration of findings with the existing literature

The systematic review and empirical study both suggest that connection is important for wellbeing after brain injury, which fits with existing models of wellbeing (e.g. the PERMA model (Seligman, 2011) and the six dimensions of wellbeing (Ryff, 1989). These models suggest that having positive and meaningful relationships can improve wellbeing and protect against poor mental and physical health. The systematic review supports this, as it identified that both objective and perceived social isolation were associated with low mood and poorer psychological wellbeing, and that social isolation was associated with poorer physical functioning after ABI. This also aligns with the wider literature which suggests social isolation and loneliness can impact on mental health and physical well-being (Cacioppo & Cacioppo, 2014) and can contribute to psychological distress (Hilari, Northcott, Roy et al., 2010) and depression following stroke (Appelros & Viitanen, 2004; Angeleri, Angeleri, Foschi, Giaquinto, & Nolfe, 1993). The current review could not however, establish the direction of causality due to the correlational nature of results.

However, by exploring individuals' experiences of accessing community groups, the empirical study provides some insight into the ways in which social connection can improve wellbeing and mood. Similar to Attard, Lanyon, Togher and Rose's (2015) findings, this study found that connecting with others at groups helped people to feel understood and experience a sense of belonging after brain injury. It also helped people to become more accepting of themselves as they experienced acceptance from others, learnt skills to help them cope with the impacts of brain injury and found meaning and purpose through helping others at groups. This echoes the findings of Shiggins et al (2020), who also found that helping others and being altruistic helped people to live well with aphasia. These findings also fit with both Ryff (1989) and Seligman's (2011) models of wellbeing, as they suggest that self-acceptance and finding meaning and purpose in life supports wellbeing. However, the current findings go beyond these two models which suggest that relationships, finding meaning and purpose, and self-acceptance are distinct factors which can contribute to wellbeing. Instead the grounded theory paper suggests these factors are interrelated, and that supporting improvements in one area (e.g. helping people become more connected) can begin a virtuous cycle of increased activity and connection, which can improve wellbeing in all areas.

The study shows a bi-directional relationship between activity and connection, which can be observed in how doing activities and learning together at groups helped people to connect with one another, and then in turn, how the connections people made at groups supported them to be more active. Forming new connections gave participants more opportunities to hear about different activities and enabled them to pool their resources and support each other to access these. Doing activities at groups also helped people with ABI to focus on their strengths and provided opportunities for them to experience success, which is important for wellbeing (Ryff, 1989; Seligman, 2011) and which helped people to be more accepting of themselves. Participants described how participating in group activities can help with re-establishing a sense of identity, as it allowed them to connect with past hobbies and aspects of their pre-injury selves, as well as allowing them to incorporate new things they learnt about themselves into this identity. This fits with existing models of psychological adjustment from brain injury which suggest that re-establishing a sense of identity is important and that participating in meaningful activity can help with this (Levack et al., 2010; Gracey et al., 2009).

Both the grounded theory and systematic review papers demonstrated how people have access to different resources and, therefore, have different barriers to and opportunities for social connection. These are influenced by the person’s individual impairments, context, personal circumstances and the setting they are in, which have been shown to differ greatly for people with ABI, who are a heterogenous population (Bruns & Hauser, 2003; Wong, Dashner, Baum et al., 2017). This can make it harder for some to connect than others; for example, the systematic review identified that those with Aphasia are more at higher risk of becoming socially isolated. This is consistent with the wider literature suggesting that aphasia and communication difficulties following ABI can make it more difficult for people to maintain relationships and connect with others (Shorland & Douglas, 2010; Northcott & Hilari, 2011; Callaway, Sloan, & Winkler, 2005). The empirical study also showed how the resources available to individuals (the emotional and practical supports provided by loved ones, services and environments) can enable people to make use of opportunities within their communities to improve wellbeing. This reflects Levack's model (2010) as he identified how internal and external resources can support recovery after brain injury. Without these resources being available, participants may not have been able to access these groups which increased people's social connectedness and improved wellbeing. As the supports available varied between individuals, this suggests that some people with brain injury may need access to more resources than others in order to utilise these opportunities for connection. For example, those without family, who are more socially isolated may need more emotional or practical support from healthcare professionals. This is is consistent with the findings of Graff, Christensen, Poulsen and Egerod (2018) who found that barriers to rehabilitation after TBI were often overcome with help from families rather than healthcare professionals. This means that those without families need to access this support from elsewhere in order to facilitate social participation and connection. Furthermore, some may need more financial support or support with transport than others depending on their financial resources, personal circumstances, location and the nature of their impairment.

The systematic review found that brain injury itself can affect the social resources available to people, as social networks decreased in size and become more constrained over time. It found that those with more social resources (who either objectively have more connections or subjectively feel less socially isolated, lonely or disconnected) experienced better psychological and physical wellbeing after ABI. While the direction of causality between wellbeing and connectedness could not be established due to the correlational nature of results, these findings do suggest that by increasing people's social resources and connections through community engagement, it may be possible to improve outcomes after brain injury. The grounded theory paper supports and builds on this, as it illustrates how interventions to foster connectedness within the community, can increase people's social resources after brain injury and can enhance wellbeing.

Overall, these findings suggest that in order to ensure that a person with ABI remains connected we need to look beyond the impairment or pathogenesis and towards a salutogenic model of what keeps people feeling well (Antonovsky, 1996). The empirical study identified that there were resources within the person, family and community that can help mobilise a person with ABI towards social connection and can improve their wellbeing, which aligns with both asset-based (Hopkins & Ripon, 2015) and positive psychology approaches (Seligman, 2011). While positive psychology models (Seligman, 2011) focus on what makes individuals 'well' and how to intervene to enhance wellbeing, asset-based approaches to healthcare look at this from a different angle and focus on how the resources available within communities and families, as well as individuals, can support wellbeing (Hopkins & Ripon, 2015). They suggest that it is important to understand the resources available to individuals and communities, so that these can then be mobilised in order to promote health and wellbeing. Mobilising community resources and increasing community engagement is thought to help with reducing health inequalities (NICE guidance NG44, 2016) which can be caused by people having different access to resources.

Overall, this suggests that it is important to make sure people not only have access to opportunities for connection within their communities, but that they also have access to the supports and resources they will need in order to access these opportunities. Asset-based approaches to healthcare would suggest that community organisations, health and social care are ideally placed to work together in order to support this (Marmot, 2010).

Strengths of the thesis

A key strength of the overall thesis is how the different methodologies used complement each other. Using both quantitative and qualitative methodologies to explore the complex problem of social connection after brain injury, has allowed the problem to be looked at from two angles, allowing for the researcher draw on the strengths of the different methodologies in order to get a more comprehensive understanding of the problem of social isolation and connection after brain injury (Duffy 1986). The benefit of looking at studies that employed a quantitative methodology within the systematic review, is that it allows for the strength of relationships between different variables to be objectively measured and quantified (Carr, 1994). Through synthesising and summarising the findings of relevant individual studies in a systematic review (York guidance for undertaking systematic reviews, 2009), the complex nature of social connectedness has been highlighted, as it found that many different variables may be linked to social isolation and connection after brain injury. The systematic review also provides evidence from a number of contexts across the ABI pathway and across ten countries into why social connectedness is important after brain injury and what the negative outcomes might be if people cannot maintain connections. However, because of the nature of quantitative research, participants within these studies are unable to explain how other factors not pre-selected for by researchers might be influencing their connectedness, nor describe their subjective experiences of social isolation or connection, and the meaning and influence this has on the individual (Carr, 1994).

Using a qualitative methodology within the empirical paper allowed for people's subjective experiences and the meanings and interpretations they ascribe to these to be better understood, which then allowed for a richer and more nuanced understanding of the phenomenon of social connectedness after brain injury (Ochieng, 2009, Hennink, Hutter & Bailey, 2020). Using a grounded theory methodology (Charmaz, 2014) allowed for the exploration of the processes involved in becoming socially connected through attending community groups, and how this can enhance wellbeing. The bi-directional and complex relationships identified between connection, participation and wellbeing would have been difficult to identify within a quantitative study and shows the value of being able to explore people's individual experiences in depth through the grounded theory (Carr, 1994). By taking a constructionist grounded theory perspective, this allowed for sensitivity to context (Charmaz, 2014), which is important for understanding the differing resources and opportunities for social connection available to people after brain injury.

A further strength of the empirical study were the efforts made to facilitate participation and to be inclusive of all people with ABI. By attending conversation partner training, traveling to people's homes across the East of England and South Wales to conduct interviews in person, and meeting with people prior to their interviews and offering a choice between focus groups or individual interviews, the author attempted to make it easier and less stressful for people with cognitive, communication and physical disabilities to be included in the study.

Limitations of the thesis

The findings within the empirical study arose within specific contexts at community groups in England and Wales, and while this provides insight into potential barriers to and benefits of social connection, these may not be the same in other contexts, where people have access to different resources and opportunities. There was also a lack of ethnic diversity within participants, which reflected the people using the services in these localities.

While coming at the grounded theory study from a social constructionist perspective allowed for contextual factors to be explored (Charmaz, 2014), it also meant that the researcher’s own position influenced the resulting theory. Quotes and themes which held more meaning to the researcher, may have been given greater significance. The author attempted to use reflection throughout the process of data collection and analysis through the use of notes, memos, diagrams and discussions in supervision, in order to record how decisions were made and how processes and categories were refined, in order to be transparent about the decisions made and her own influence and biases. By consistently going back and forth between participant quotes, during the analysis and write-up process the researcher has tried to ensure participants’ voices are reflected and that the theory remains grounded in the data. Using triangulation and checking the results back with participants for the empirical paper would have been helpful for ensuring the meanings interpreted by the researcher truly reflect those of participants (Doyle, 2007).

There were also challenges to defining social isolation and selecting measures of social isolation when completing the systematic review. These were overcome through consulting the World Health Organization’s (2001) International Classification of Functioning (ICF), and supervisors on the project. Inclusion and exclusion criteria for the measures used within studies were developed in order to ensure the construct of interest was being measured.

A further limitation of the systematic review was that it was not possible within the timescale to have a second independent reviewer of study eligibility or rate the quality of all articles included, which is ideal practice (Cochrane, 2019). This was particularly difficult as the intended second reviewer had to pull out at short notice, and this may have impacted on the validity of the methodology. However, the risk of bias and quality assessment tools were piloted on a sample of articles (six papers) by two independent reviewers, which is recommended if not all papers can be independently checked (Cochrane, 2019).

Clinical implications

The systematic review demonstrated that people become increasingly disconnected over time and the grounded theory paper suggests that people feel ‘ready’ to make use of opportunities for connection at different stages in their recovery. This suggests that the timing of interventions is important, and that people may need ongoing support and interventions to improve connectedness and wellbeing at different stages within the rehabilitation process. It suggests there may be a need for Healthcare professionals and services to follow up care with people with ABI for an extended period, and to assess for social isolation and connection at different points of time.

The grounded theory suggests participating in community groups can instigate a virtuous cycle of increasing activity and social connection and therefore using a behavioural activation approach in order to begin this cycle may support wellbeing. Behavioural activation has been used successfully to treat depression after stroke (Thomas et al., 2013), and these findings suggest there may be a wider role for behavioural activation in promoting positive outcome as well as reducing negative ones. However, the findings of the current thesis do suggest that there is something about doing activities in groups and the processes involved in being at a group (rather than doing activities individually) which can be particularly beneficial to wellbeing. This is supported by a scoping review which reported that the majority of group-based interventions in brain injury rehabilitation found positive changes from pre to post-group and that patients find groups helpful for reducing isolation, sharing experiences, receiving help and adjusting to life after TBI (Patterson, Fleming, & Doig, 2016). Therefore, having more groups where people have opportunities to learn from each other, feel understood, and help others, may be more supportive of wellbeing than an individualised behavioural activation approach.

The results suggest that having better links between services (acute, third sector, primary care, charities, health and social care) may help to create more opportunities for connection and may help organise the supports needed in order for people to be able to make use of, and benefit from these, when they are ready. This supports taking an asset-based approach to healthcare rather than following a pathogenic medical model, as supporting people to identify and utilise the resources within their communities may help them to move towards social connection and improved wellbeing after brain injury. It also aligns with the NHS Long Term Plan (2019) for Integrated Care Systems (ICSs), which aim to bring together local organisations including health and social care and move the focus towards population health. Having a 'seamless services' where there is good communication between different agencies, has been shown to improve outcomes after brain injury (Hawley, Stilwell, Davies & Stilwell, 2000). Furthermore, focusing on community rather than individual-centred practice, has been shown to improve mental and physical health outcomes (Friedl, 2009; Marmot, 2010) and may help to reduce health inequalities (NICE guidance NG44, 2016). This type of working may include social prescribing, which enables health and care professionals to prescribe activities within the community which are typically provided by voluntary and third sector organisations, e.g. arts activities, group learning, sports and befriending schemes (Public Health England, 2019).

Research implications and future directions

The thesis suggests that more quantitative research is needed into causes and effects of social isolation and connection after ABI in order to establish causality. The thesis suggests that social connectedness is important for wellbeing after brain injury and therefore it would be beneficial to have more intervention studies which look specifically at fostering connectedness, to explore the benefits to wellbeing. The virtuous cycle identified within the grounded theory paper (of increasing social connectedness, acceptance, activity and positive emotions), suggests a mechanism through which the association between social connection and wellbeing can be investigated. It would be helpful to see if this positive cycle is found in other contexts and to investigate how current ABI services can support this virtuous cycle and what adaptations need to be made to enhance this in current stroke and brain injury pathways and services. Within the current project all participants were socially connected in some ways through their experiences at community projects, and therefore a negative case analysis of those who are socially isolated and not connected to community groups could also help to further develop and enrich our understanding of the impacts of social isolation and the barriers to connection.

Conclusions

The current thesis suggests that over time after brain injury many people become more socially disconnected, which is associated with poorer mood, wellbeing and functioning. Factors were identified which can make people more vulnerable to social isolation (e.g. having communication difficulties), and there were a number of emotional, environmental and impairment related barriers to social connection. People may need both practical and emotional supports from services, family or friends to overcome these barriers so that they are able to access opportunities to become more socially connected. Connecting with others at community groups can begin a virtuous cycle of increasing activity and connection after brain injury. This improves people’s wellbeing and motivates them to seek out more opportunities for connection. It can also reduce the number and impact of barriers to further connection. Therefore, it is important to make sure people both have access to opportunities for connection within their communities, and that they have access to the supports and resources they will need in order to make use of these opportunities to support wellbeing.

Thesis References

Angeleri, F., Angeleri, V. A., Foschi, N., Giaquinto, S., & Nolfe, G. (1993). The influence of depression, social activity, and family stress on functional outcome after stroke. *Stroke*, *24*(10), 1478-1483.

Antonovsky, A. (1979). Health, stress & coping. Michigan: Jossey-Bass

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, *11*(1), 11-18.

Appelros, P., & Viitanen, M. (2004). Prevalence and predictors of depression at one year in a Swedish population-based cohort with first-ever stroke. *Journal of Stroke and Cerebrovascular Diseases*, *13*(2), 52-57.

Asikainen, I., Kaste, M. and Sarna, S. (1998) Predicting late outcome for patients with traumatic brain injury referred to a rehabilitation programme: a study of 508 Finnish patients 5 years or more after injury. *Brain Injury, 12:* 95-107

Askim, T., Rohweder, G., Lydersen, S., & Indredavik, B. (2004). Evaluation of an extended stroke unit service with early supported discharge for patients living in a rural community. A randomized controlled trial. *Clinical Rehabilitation*, *18*(3), 238-248.

Attard, M. C., Lanyon, L., Togher, L., & Rose, M. L. (2015). Consumer perspectives on community aphasia groups: a narrative literature review in the context of psychological well-being. *Aphasiology*, *29*(8), 983-1019.

Baumann, M., Peck, S., Collins, C. & Eades, G. (2013). The meaning and value of taking part in a person-centred arts programme to hospital-based stroke patients: findings from a qualitative study. *Disability Rehabilitation, 35,* 244–56.

Berthier, M. L. (2005). Poststroke aphasia: Epidemiology, pathophysiology and treatment. *Drugs and Aging, 22*(2), 163–182.

Brain Injury Association of America (2020). What is the difference between an acquired brain injury and a traumatic brain injury? Retrieved from: https://www.biausa.org/brain-injury/about-brain- injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury

Bruns Jr, J., & Hauser, W. A. (2003). The epidemiology of traumatic brain injury: a review. *Epilepsia*, *44*, 2-10.

Cacioppo, J. T., & Cacioppo, S. (2014). Social relationships and health: The toxic effects of perceived social isolation. *Social and Personality Psychology Compass*, *8*(2), 58-72.

Callaway, L., Sloan, S., & Winkler, D. (2005). Enabling people to maintain and develop friendships following severe traumatic brain injury. *Australian Occupational Therapy Journal*, *52*, 292-295.

Carr, L. T. (1994). The strengths and weaknesses of quantitative and qualitative research: what method for nursing?. *Journal of Advanced Nursing*, *20*(4), 716-721.

Centre for Reviews and Dissemination University of York (2009). *Systematic Reviews: CRD's guidance for undertaking reviews in health care* York: York Publishing Services Ltd. Retrieved from: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). London: Sage.

Collicutt McGrath, J., & Linley, P. A. (2006). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury*, *20*(7), 767-773.

Cooper, C. L., Phillips, L. H., Johnston, M., Whyte, M., & MacLeod, M. J. (2015). The role of emotion regulation on social participation following stroke. *British Journal of Clinical Psychology*, *54*(2), 181-199.

Cornwell, E. Y., & Waite, L. J. (2009). Measuring social isolation among older adults using multiple indicators from the NSHAP study. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *64* (1), 38-46.

Cristofori, I., Pal, S., Zhong, W., Gordon, B., Krueger, F., & Grafman, J. (2019). The lonely brain: evidence from studying patients with penetrating brain injury. *Social Neuroscience*, *14*(6), 663-675.

Crone, D. (2007). Walking back to health: A qualitative investigation into service users' experiences of a walking project. Issues in Mental Health Nursing, 28(2), 167–183.

Cubis, L., Ownsworth, T., Pinkham, M. B., Foote, M., Legg, M., & Chambers, S. (2019). The importance of staying connected: mediating and moderating effects of social group memberships on psychological well-being after brain tumor. *Psycho-oncology*, *28*(7), 1537-1543.

Cullen, B., Pownall, J., Cummings, J., Baylan, S., Broomfield, N., Haig, C., Kersel, D., Murray, H. & Evans, J.J. (2018). Positive psychotherapy in ABI rehab (PoPsTAR): a pilot randomised controlled trial. *Neuropsychological Rehabilitation*, *28*(1), 17-33.

DeDe, G., Hoover, E., & Maas, E. (2019). Two to tango or the more the merrier? A randomized controlled trial of the effects of group size in aphasia conversation treatment on standardized tests. *Journal of Speech, Language, and Hearing Research*, *62*(5), 1437-1451.

Dewan, M. C., Rattani, A., Gupta, S., Baticulon, R. E., Hung, Y. C., Punchak, M., Agrawal, A., Adeleye, A.O., Shrime, M.G., Rubiano, A.M. & Rosenfeld, J. V. (2018). Estimating the global incidence of traumatic brain injury. *Journal of Neurosurgery*, *130*(4), 1080-1097.

Dhand, A., Lang, C. E., Luke, D. A., Kim, A., Li, K., McCafferty, L., Mu, Y., Rosner, B., Feske, S.K. & Lee, J. M. (2019). Social network mapping and functional recovery within 6 months of ischemic stroke. *Neurorehabilitation and Neural Repair*, *33*(11), 922-932.

Dhand, A., Longstreth Jr, W. T., Chaves, P. H., & Dhamoon, M. S. (2018). Social network trajectories in myocardial infarction versus ischemic stroke. *Journal of the American Heart Association*, *7*(8), e008029.

Doig, E., Fleming, J., & Tooth, L. (2001). Patterns of community integration 2-5 years post-discharge from brain injury rehabilitation. *Brain Injury, 15*, 747–762.

Douglas, J.M. (2013) Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury, 27*, 60-74.

Douglas, J.M. (2019). Loss of friendship following traumatic brain injury: A model grounded in the experience of adults with severe injury. *Neuropsychological Rehabilitation*, 1-26.

Doyle, S. (2007). Member checking with older women: A framework for negotiating meaning. *Health Care for Women International, 8,* 888–908.

Duffy M E (1986) Quantitative and qualitative research antagonistic or complementary' *Nursing and Health Care 8*(6), 356-357

Eslinger, P., Downey-Lamb, M., Ward, S., Robertson, I. & Glisky, M. (2002) Neuropsychological interventions: Clinical research & practice. The Guilford Press, New York

Feigin, V. L., Barker-Collo, S., Krishnamurthi, R., Theadom, A., & Starkey, N. (2010). Epidemiology of ischaemic stroke and traumatic brain injury. *Best Practice & Research Clinical Anaesthesiology*, *24*(4), 485-494.

Fleminger, S., & Ponsford, J. (2005). Long term outcome after traumatic brain injury, *BMJ, 331*. doi: https://doi.org/10.1136/bmj.331.7530.1419

Friedli, L. (2009) Mental health, resilience and inequalities. Denmark: World Health Organization Europe.

Galvin, K., & 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), 10362.

Glaser, B.G., & Strauss, A.L (1967). *Discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Glass, T. A., Matchar, D. B., Belyea, M., & Feussner, J. R. (1993). Impact of social support on outcome in first stroke. *Stroke*, *24*(1), 64-70.

Gokkaya, N. K., Aras, M. D., & Cakci, A. (2005). Health-related quality of life of Turkish stroke survivors. *International Journal of Rehabilitation Research*, *28*(3), 229-235.

Gracey, F., Evans, J.J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A ‘Y-shaped’ model. *Neuropsychological Rehabilitation*, *19*, 1–24.

Graff, H. J., Christensen, U., Poulsen, I., & Egerod, I. (2018). Patient perspectives on navigating the field of traumatic brain injury rehabilitation: a qualitative thematic analysis. *Disability and Rehabilitation*, *40*(8), 926-934.

Hagger, B. F., & Riley, G. A. (2019). The social consequences of stigma-related self-concealment after acquired brain injury. *Neuropsychological Rrehabilitation*, *29*(7), 1129-1148.

Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation, 18*(5-6), 671-691.

Hawley, C., Davies, C., Stilwell, J., & Stilwell, P. (2000). Post-acute rehabilitation after traumatic brain injury. *British Journal of Therapy and Rehabilitaiton, 7*(3), 116-122.

Hawley, C. A., & Joseph, S. (2008). Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury*, *22*(5), 427-435.

Headway (2017), Acquired Brain Injury Statistics 2016-2017. Available from: https://www.headway.org.uk/about-brain-injury/further-information/statistics/

Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. SAGE Publications Limited.

Hibbard, M. R., Uysal, S., Sliwinski, M., & Gordon, W. A. (1998). Undiagnosed health issues in individuals with traumatic brain injury living in the community. *The Journal of Head Trauma Rehabilitation*, *13*(4), 47-57.

Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., & Welch, V.A. (editors). *Cochrane Handbook for Systematic Reviews of Interventions* version 6.0 (updated July 2019). Cochrane, 2019. Available from: www.training.cochrane.org/handbook

Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, *20*(1), 17-36

Hilari, K., & Northcott, S. (2017). "Struggling to stay connected": comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology*, *31*(6), 674-687.

Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R. D., Chataway, J., & Ames, D. (2010). Psychological distress after stroke and aphasia: the first six months. *Clinical Rehabilitation*, *24*(2), 181-190.

Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P. J. (2001). Traumatic brain injury (TBI) 10? 20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain injury*, *15*(3), 189-209.

Hopkins, T., & Rippon, S. (2015). Head, hands and heart: Asset-based approaches in health care. London: The Health Foundation

Hyer, L. Boyd, S. Scurfield, R. Smith, D. & Burke, J. (1996) Effects of outward bound experience as an adjunct to inpatient PTSD treatment of war veterans, *Journal of Clinical Psychology*, 52, 263-278

Impellizzeri, F. M., & Bizzini, M. (2012). Systematic review and meta-analysis: A primer. *International Journal of Sports Physical Therapy*, *7*(5), 493.

Jetten, J., Haslam, C., Haslam, S. A., Dingle, G., & Jones, J. M. (2014). How groups affect our health and well-being: The path from theory to policy. *Social Issues and Policy Review*, *8*(1), 103-130.

Jones, J., Williams, W. H., Haslam, S. A., Jetten, J., Morris, R. & Saroyan,S. (2011). 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, *Psychology and Health*, *26*(3):353-369

Jones, J. M., Williams, W. H., Jetten, J., Haslam, S. A., Harris, A., & Gleibs, I. H. (2012). The role of psychological symptoms and social group memberships in the development of post-traumatic stress after traumatic injury. *British Journal of Health Psychology*, *17*(4), 798-811.

Karagiorgou, O., Evans, J. J., & Cullen, B. (2018). Post-traumatic growth in adult survivors of brain injury: A qualitative study of participants completing a pilot trial of brief positive psychotherapy. *Disability and Rehabilitation*, *40*(6), 655-659.

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.

Kim, B. (2001). Social constructivism. *Emerging Perspectives on Learning, Teaching, and Technology*, *1*(1), 16.

Klose, M., Watt, T., Brennum, J., & Feldt-Rasmussen, U. (2007). Posttraumatic hypopituitarism is associated with an unfavorable body composition and lipid profile, and decreased quality of life 12 months after injury. *The Journal of Clinical Endocrinology & Metabolism*, *92*(10), 3861-3868.

Kongkasuwan, R., Voraakhom, K., Pisolayabutra, P., Maneechai, P., Boonin, J., & Kuptniratsaikul, V. (2016). Creative art therapy to enhance rehabilitation for stroke patients: a randomized controlled trial. *Clinical Rehabilitation*, *30*(10), 1016-1023.

Kozloff, R. (1987). Networks of social support and the outcome from severe head injury. *The Journal of Head Trauma Rehabilitation*, *2*(3), 14-23. https://doi.org/10.1097/00001199-198709000-00004

Kreutzer, J. S., Seel, R. T., & Gourley, E. (2001). The prevalence and symptom rates of depression after traumatic brain injury: a comprehensive examination. *Brain Injury*, *15*(7), 563-576.

Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, *62*(2), 228-237.

Lanyon, L., Worrall, L., & Rose, M. (2019) "It's not really worth my while": understanding contextual factors contributing to decisions to participate in community aphasia groups. *Disability and Rehabilitation*, *41*(9):1024-36.

Lawrence, K. A., Matthieu, M. M., & Robertson-Blackmore, E. (2017). Completion of a veteran-focused civic service program improves health and psychosocial outcomes in Iraq and Afghanistan veterans with a history of traumatic brain injury. *Military Medicine*, *182*(7), 1763-1770.

Lee, H., Lee, Y., Choi, H., & Pyun, S. B. (2015). Community integration and quality of life in aphasia after stroke. *Yonsei Medical Journal*, *56*(6), 1694-1702.

Levack, W., Kayes, M., & Fadyl, J. (2010). Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disability and Rehabilitation, 32*, 986–999.

Liebrucks, A. (2001). The concept of social construction. *Theory & Psychology*, *11*(3), 363- 391.

Luck, A. M., & Rose, M. L. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology, 21*(2), 208-224.

Lynch, R. T., & Kosciulek, J. F. (1995). Integrating individuals with traumatic brain injury into the group process. *Journal for Specialists in Group Work*, *20*, 108-113.

Mailhan, L., Azouvi, P. & Dazord, A. (2005) Life satisfaction and disability after severe traumatic brain injury. *Brain Injury*, 19, 227–238.

Marmot, M. (2010). *Fair society, healthy lives: Strategic review of health inequalities in England post 2010 (The Marmot Review).* Institute of Health Equity

Marshall, J., Booth, T., Devane, N., Galliers, J., Greenwood, H., Hilari, K., Talbot, R., Wilson, S. & Woolf, C. (2016). Evaluating the benefits of aphasia intervention delivered in virtual reality: results of a quasi-randomised study. *PloS one*, *11*(8).

McLean, A. M., Jarus, T., Hubley, A. M., & Jongbloed, L. (2014). Associations between social participation and subjective quality of life for adults with moderate to severe traumatic brain injury. *Disability and rehabilitation*, *36*(17), 1409-1418.

Morris, J. H., Van Wijck, F., Joice, S., & Donaghy, M. (2013). Predicting health related quality of life 6 months after stroke: the role of anxiety and upper limb dysfunction. *Disability and Rehabilitation*, *35*(4), 291-299.

Morton, M. V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*, *9*(1), 81-92.

Mowatt, R. & Bennett, J. (2011) War narratives: veteran stories, PTSD effects, and therapeutic fly-fishing, *Therapeutic Recreation Journal*, 45, 286-308

Naess, H., Hammersvik, L., & Skeie, G. O. (2009). Aphasia among young patients with ischemic stroke on long-term follow-up. *Journal of Stroke and Cerebrovascular Diseases*, *18*(4), 247-250.

Nakao, M., Izumi, S., Yokoshima, Y., Matsuba, Y., & Maeno, Y. (2018). Prediction of life-space mobility in patients with stroke 2 months after discharge from rehabilitation: a retrospective cohort study. *Disability and Rehabilitation*, 1-8.

National Heart, Lung and Blood Institute. The Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group. 2020. Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

National Heart, Lung and Blood Institute. The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies for observational cohort and cross-sectional studies. 2020. Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

National Health Service (2019). NHS Long Term Plan. Retrieved from: https://www.longtermplan.nhs.uk/

National Institute for Health and Care Excellence (2016). NICE guideline [NG44]: Community engagement: improving health and wellbeing and reducing health inequalities. Retrieved from: https://www.nice.org.uk/guidance/ng44

Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders*, *46*(5), 524-534.

Northcott, S., Marshall, J., & Hilari, K. (2016). What factors predict who will have a strong social network following a stroke?. *Journal of Speech, Language, and Hearing Research*, *59*(4), 772-783.

O'Rourke, H. M., & Sidani, S. (2017). Definition, determinants, and outcomes of social connectedness for older adults: A scoping review. *Journal of Gerontological Nursing*, *43*(7), 43-52.

Ochieng, P. A. (2009). An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century*, *13,* 13.

Ormsby J., Stanley M. & Jaworski K. (2010) Older men’s participation in community-based men’s sheds programmes. Health and Social Care in the Community 18 (6), 607–613.

Otter, L. & Currie, J. (2004). A long time getting home: Vietnam veterans' experiences in a community exercise rehabilitation programme, *Disability and Rehabilitation*, 26, 27-3440

Ownsworth, T. (2014). *Self-identity after brain injury*. New York and London:Psychology Press.

Ownsworth, T., Fleming, J., Haines, T., Cornwell, P., Kendall M., Nalder, E., & Gordon, G. (2011). Development of depressive symptoms during early community reintegration after traumatic brain injury. *Journal of the International Neuropsychological Society, 17,* 112–119.

Patterson, F., Fleming, J., & Doig, E. (2016). Group-based delivery of interventions in traumatic brain injury rehabilitation: a scoping review. *Disability and Rehabilitation, 38*(20), 1961-1986.

Paterson, B., & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research, 12*, 399-409

Perna, R. B., Bubier, J., Oken, M., Snyder, R., & Rousselle, A. (2004). Brain injury rehabilitation: activity based and thematic group treatment. *The Journal of Cognitive Rehabilitation, 22*(3), 20-24.

Phinney, A., Moody, E. M., & Small, J. A. (2014). The effect of a community-engaged arts program on older adults’ well-being. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement*, *33*(3), 336-345.

Ponsford, J.L., Downing, M.G., Olver, J., Ponsford, M., Acher, R., Carty, M., & Spitz, G. (2014). Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. *Journal of Neurotrauma, 31*, 64–77

Proctor, C. J., & Best, L. A. (2019). Social and psychological influences on satisfaction with life after brain injury. *Disability and Health Journal*, *12*(3), 387-393.

Public Health England (2019). Social Prescribing: Applying All Our Health. Retrieved from: https://www.gov.uk/government/publications/social-prescribing-applying-all-our-health/social-prescribing-applying-all-our-health

Rees, L., Marshall, S., Hartridge, C., Mackie, D., & Weiser, M. (2007). Cognitive interventions post acquired brain injury. *Brain Injury*, *21*(2), 161-200.

Rigon, A., Duff, M. C., & Beadle, J. (2019). Lonely but not alone: neuroticism mediates the relationship between social network size and loneliness in individuals with traumatic brain injury. *Journal of the International Neuropsychological Society*, *25*(3), 285-292.

Roddy, C., Rickard, N., Tamplin, J., Lee, Y. E. C., & Baker, F. A. (2018). Exploring self-concept, wellbeing and distress in therapeutic songwriting participants following acquired brain injury: A case series analysis. *Neuropsychological Rehabilitation*, 1-21.

Rowlands, A. (2000). Understanding social support and friendship: Implications for intervention after acquired brain injury. *Brain Impairment, 1(2)*, 151-164.

Rowlands, A. (2001). Ability or disability? Strengths-based practice in the area of traumatic brain injury. *Families in Society*, *82*(3), 273-286.

Ryff, Carol D. (1989) Happiness is everything, or is it? Explorations on the meaning of Psychological Well-Being. *Journal of Personality and Social Psychology*;57:1069–1081.

Saadi, A., Okeng'o, K., Biseko, M. R., Shayo, A. F., Mmbando, T. N., Grundy, S. J., Xu, A., Parker, R.A., Wibecan, L., Iyer, G., & Onesmo, P. M. (2018). Post-stroke social networks, depressive symptoms, and disability in Tanzania: A prospective study. *International Journal of Stroke*, *13*(8), 840-848.

Salas, C. E., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. A. [2018). "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological rehabilitation*, *28*(7), 1161-1178.

Sargeant, R., Webster, G., Salzman, T., White, S., & McGrath, J. (2000). Enriching the environment of patients undergoing long term rehabilitation through group discussion of the news. *Journal of Cognitive Rehabilitation*, *18*(1), 20-23.

Sarno, M. T., Buonaguro, A., & Levita, E. (1986). Characteristics of verbal impairment in closed head injured patients. *Archives of Physical Medicine and Rehabilitation*, *67*(6), 400-405.

Seligman, M. E. (2008). Positive health. *Applied Psychology*, *57*, 3-18.

Seligman, M. (2011). *Flourish*. New York, NY: Free Press.

Shardlow, S. (1998) Values, ethics and social work. In R. Adams, L. Dominelli & Payne, M. (Eds.). Social work: Themes, issues and critical debates (pp. 23–33). Basingstoke, United Kingdom: Macmillan.

Shiggins, C., Soskolne, V., Olenik, D., Pearl, G., Haaland-Johansen, L., Isaksen, J., ... & Horton, S. (2020). Towards an asset-based approach to promoting and sustaining well-being for people with aphasia and their families: an international exploratory study. *Aphasiology*, *34*(1), 70-101.

Shorland, J., & Douglas, J. M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain Injury*, *24*(4), 569-580.

Sloan, S., Winkler, D., & Anson, K. (2007). Long-term outcome following traumatic brain injury. *Brain Impairment*, *8*(3), 251–261.

Snow, J. C., Tang, X., Nakase-Richardson, R., Adams, R. S., Wortman, K. M., Dillahunt-Aspillaga, C., & Miles, S. R. (2019). The Relationship Between Posttraumatic Stress Disorder Symptoms and Social Participation in Veterans With Traumatic Brain Injury: A Veterans Affairs Traumatic Brain Injury Model Systems Study. *Journal of Applied Rehabilitation Counseling*, *50*(1), 41-56.

Sterne, J.A.C, Savović, J., Page, M.J., Elbers, R.G., Blencowe, N.S., Boutron, I., Cates, C.J., Cheng, H-Y., Corbett, M.S., Eldridge, S.M., Hernán, M.A., Hopewell, S., Hróbjartsson, A., Junqueira, D.R., Jüni, P., Kirkham, J.J., Lasserson, T., Li, T., McAleenan, A., Reeves, B.C., Shepperd, S., Shrier, I., Stewart, L.A., Tilling, K., White, I.R., Whiting, P.F. & Higgins, J.P.T. (2019). RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ*; *366*: l4898.

Tang, W. K., Chan, S. S., Chiu, H. F., Ungvari, G. S., Wong, K. S., Kwok, T. C., Mok, V., Wong, K.T., Richards, P.S. & Ahuja, A. T. (2005). Poststroke depression in Chinese patients: frequency, psychosocial, clinical, and radiological determinants. *Journal of Geriatric Psychiatry and Neurology*, *18*(1), 45-51.

Taris, T.W & Kompier, M.A. J. (2014) Cause and effect: Optimizing the designs of longitudinal studies in occupational health psychology, *Work & Stress*, *28*(1), 1-8.

Taylor, B. (2005). The experiences of overseas nurses working in the NHS: results of a qualitative study. *Diversity in Health & Social Care*, *2*(1).

Teasdale, T. W., & Engberg, A. W. (2001). Suicide after traumatic brain injury: a population study. *Journal of Neurology, Neurosurgery & Psychiatry, 71(*4), 436-440.

The General Data Protection Regulation (GDPR, 2018). Retrieved from: https://www.gov.uk/government/publications/guide-to-the-general-data-protection-regulation

Theeke, L., Horstman, P., Mallow, J., Lucke-Wold, N., Culp, S., Domico, J., & Barr, T. (2014). Quality of life and loneliness in stroke survivors living in Appalachia. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, *46*(6), E3.

Thomas, S. A., Walker, M. F., Macniven, J. A., Haworth, H., & Lincoln, N. B. (2013). Communication and Low Mood (CALM): a randomized controlled trial of behavioural therapy for stroke patients with aphasia. *Clinical Rehabilitation*, *27*(5), 398-408.

Thomsen, I.V. (1984). Late outcome of very severe blunt head trauma: a 10-15 year second follow-up. *Journal of Neurology, Neurosurgery & Psychiatry*, *47*(3), 260-268.

Togher, L., McDonald, S., Code, C., & Grant, S. (2004). Training communication partners of people with traumatic brain injury: A randomised controlled trial. *Aphasiology*, *18*(4), 313-335.

Tomberg, T., Toomela, A., Pulver, A., & Tikk, A. (2005). Coping strategies, social support, life orientation and health-related quality of life following traumatic brain injury. *Brain Injury*, *19*(14), 1181-1190.

Tulip, C., Fisher, Z., Bankhead, H., Wilkie, L., Pridmore, J., Gracey, F., Tree, J., & Kemp, A. H. (2020). Building wellbeing in people with chronic conditions: A qualitative evaluation of an 8-week positive psychotherapy intervention for people living with an acquired brain injury. *Frontiers in Psychology*, *11*, 66.

Turner-Strokes, L. (Ed.). (2003). Rehabilitation following acquired brain injury: national clinical guidelines. Royal College of Physicians.

Ubukata, S., Tanemura, R., Yoshizumi, M., Sugihara, G., Murai, T., & Ueda, K. (2014). Social cognition and its relationship to functional outcomes in patients with sustained acquired brain injury. *Neuropsychiatric Disease and Treatment*, *10*, 2061.

Umberson, D., & Karas Montez, J. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior, 51*(1), 54-66.

Van Velzen, J. M., Van Bennekom, C. A. M., Edelaar, M. J. A., Sluiter, J. K., & Frings-Dresen, M. H. W. (2009). How many people return to work after acquired brain injury?: a systematic review. *Brain Injury*, *23*(6), 473-488.

Williams, M.W., Rapport, L.J., Millis, S.R. & Hanks, R.A. (2014) Psychosocial outcomes after traumatic brain injury: life satisfaction, community integration, and distress, *Rehabilitation Psychology*, *59*, 298–305.

Wong, A.W., Ng, S., Dashner, J., Baum, M.C., Hammel, J., Magasi, S., Lai, J.S., Carlozzi, N.E., Tulsky, D.S., Miskovic, A. and Goldsmith, A. (2017). Relationships between environmental factors and participation in adults with traumatic brain injury, stroke, and spinal cord injury: a cross-sectional multi-center study. *Quality of Life Research*, *26*(10), 2633-2645.

Wood, R.L.l, & Rutterford, N.A. (2006) Psychosocial adjustment 17 years after severe brain injury. *Journal of Neurology, Neurosurgery and Psychiatry; 77*: 71–73.

Wood, R.L., & Yurdakul, L.K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury*, *11*(7), 491–502.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

World Stroke Organization (2016). Global Stroke Fact Sheet. Retrieved from: https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf

Zenicius, M.D., & Wesolowski, A. H. (1999). Is the social network analysis necessary in the rehabilitation of individuals with head injury?. *Brain Injury*, *13*(9), 723-727.

Appendix 1: PICOS Framework

PICOS Framework for Systematic Review

The research questions were defined using a PICOS framework (Impellizzeri & Bizzini, 2012); the Population, Intervention/exposures, Comparators, Outcomes and Study designs were all considered.

Population: Adults over the age of 18 living in community settings who have had an ABI. ABI was defined as damage or injury to the brain occurring after birth which is not related to any congenital disorders, developmental disabilities or progressive processes which cause damage to the brain (Rees, Marshall, Hartridge, Mackie & Weiser, 2007).

Community settings included residential settings, supported living accommodation and independent living arrangements, but not inpatient hospitals.

Intervention/exposures:

1. Social isolation or social connectedness - to explore any outcomes or effects of social isolation
2. Any predictor of social isolation after brain injury – to explore predictors and causes of social isolation
3. Any correlates of social isolation after brain injury – to explore correlates of social isolation

Comparison: Participants with ABI who have not experienced the intervention or been exposed to the same variables, and comparisons may be made between different cohorts of patients with ABI based on pre- or post-injury characteristics. For some study designs there may be no control group

*Outcome(s): T*o identify predictors, causes and correlates of social isolation after brain injury the following outcomes were explored:

1) Social isolation can be defined as either being socially disconnected (lacking social contact with others) or by perceived feelings of social isolation (e.g. the subjective experience of a shortfall in one's social resources or feelings of loneliness) [2].

2) Social connectedness, defined as the extent to which one has meaningful, close, and constructive relationships with others (individuals, groups, and society) [26].

In order to explore outcomes of social isolation after ABI the review also included as an outcome:

3) Any variable that is a consequence of social isolation. This outcome variable is left open, because the review explores all outcomes related to social isolation following ABI.

Study design: Studies reporting quantitative data with corresponding statistical analysis were eligible.

Appendix 2: Search terms for systematic review

Search terms for the systematic review:

Keyword searching (i.e. searching of titles and abstracts) was used for the following keywords:

"brain injur*" OR ABI OR TBI OR stroke* OR "brain h#morrhage*" OR "brain tum#r" OR "brain infect*" OR encephalitis OR "head injur*" OR "head trauma" OR "cerebrovascular accident*" OR CVA OR "brain aneurysm*" OR "carbon monoxide poisoning" OR hydrocephalus OR hypoxi* OR anoxi* OR meningitis

AND

"social network" or "social isolat*" or lonel* or "social connect*" or "friends*" or "social inclus*" or “social participat*”

*(Symbols key: *truncation, ‘phrase searching’, #wildcard, Words within groups combined with OR, Groups combined with AND)*

Appendix 3: Data extracted in the systematic review

The following data were extracted and tabulated: general information (authors, date, title, country); study characteristics (aims/objectives of the study, study design, study inclusion and exclusion criteria); participant characteristics (number, age, gender, type of brain injury); intervention, exposure or correlate; and outcome data/results.

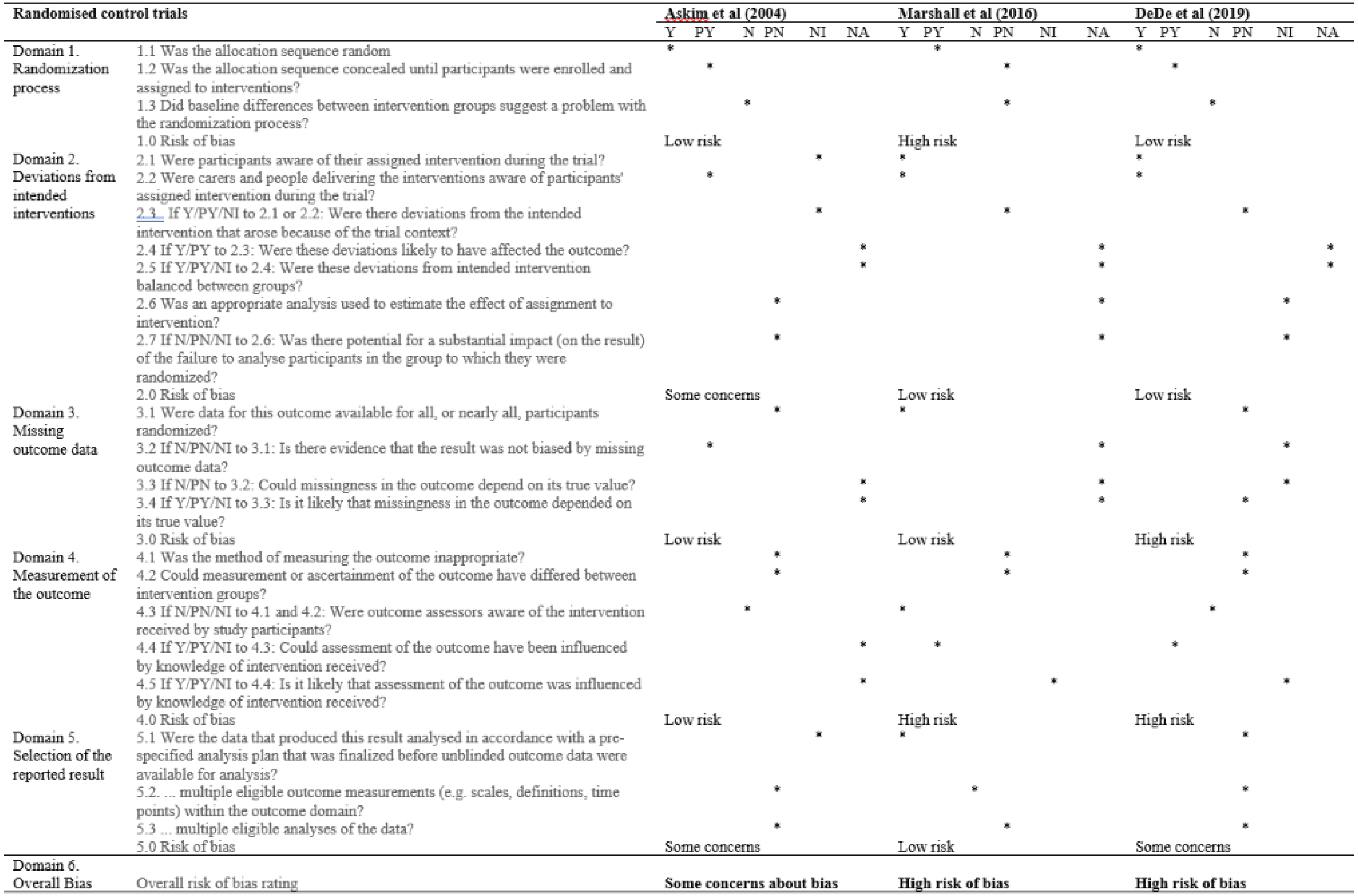
Appendix 4. Supplementary Table 2: Measures of Social Isolation used by each study

Name of measure	Type of social isolation measured	Description of the measure	Studies using the measure
Lubben social network scale (LSNS)	Objective	Looks at size of network, frequency of contact and how many people within their network they would go to for support.	43, 45, 46, 47, 49
General Social Survey	Objective	Explores the size, structure, density and constraint of people's social networks	44
National Social Life, Health, and Aging Project Social Network Module (NSHAP)	Objective	Measures social network size by the number of names people provide	54
Participation Assessment with Recombined Tools Objective (PART-O): Social relations subscale	Objective	Measures the frequency of social contacts and presence or absence of relationships (friends/partner/ spouse)	52
The Berkman-Syme Social Network index	Objective	Explores the size of the social network, the types of connections people have, the closeness of members within the network, and frequency of contact	48
Exeter Identity Transition scale	Objective	Explore the number of social groups people belong to	51
Adult Subjective Assessment of Participation: Activities with Others subscale	Objective	Explores the number of activities people do with others	55
Japanese version of the Revised Craig Handicap Assessment and Reporting Technique (R-CHART): Social integration subscale	Objective	Looks at social network and number of social contacts	50

Nottingham Health Profile (NHP): Social Isolation subscale	Subjective	Measures feelings of loneliness, feeling disconnected from others and experiences of finding it to have interactions with others	32, 34, 35, 36, 37
University of California, Los Angeles Loneliness scale (UCLA-LS)	Subjective	Explores subjective feelings of loneliness and how often people experience these feelings	38, 41, 42, 54, 55
University of California, Los Angeles Loneliness scale (UCLA-LS): 3 item short version	Subjective	Explores subjective feelings of loneliness and how often people experience these feelings	39
Social and Emotional Loneliness Scale for Adults – short form	Subjective	Explores feelings of loneliness within family, romantic and social relationships	40
Friendship scale	Combined	Explores whether people had someone to share feelings with, whether people felt like a burden to people, loneliness and how easy they find it to make contact with people	33
Stroke Social Network Scale	Combined	Measures objective social isolation (by looking at social network size) and perceived social isolation (by exploring feelings of loneliness and people's satisfaction with contact)	14,53

Appendix 5. Supplementary Tables 3-6: Quality appraisal ratings for included studies

Supplementary Table 3: Quality appraisal of randomised control trials



Randomised control trials		Askim et al (2004)						Marshall et al (2016)						DeDe et al (2019)					
		Y	PY	N	PN	NI	NA	Y	PY	N	PN	NI	NA	Y	PY	N	PN	NI	NA
Domain 1. Randomization process	1.1 Was the allocation sequence random	*							*					*					
	1.2 Was the allocation sequence concealed until participants were enrolled and assigned to interventions?		*								*				*				
	1.3 Did baseline differences between intervention groups suggest a problem with the randomization process?			*							*					*			
	1.0 Risk of bias	Low risk						High risk						Low risk					
Domain 2. Deviations from intended interventions	2.1 Were participants aware of their assigned intervention during the trial?					*		*						*					
	2.2 Were carers and people delivering the interventions aware of participants' assigned intervention during the trial?		*					*						*					
	2.3. If Y/PY/NI to 2.1 or 2.2: Were there deviations from the intended intervention that arose because of the trial context?					*					*						*		
	2.4 If Y/PY to 2.3: Were these deviations likely to have affected the outcome?						*						*						*
	2.5 If Y/PY/NI to 2.4: Were these deviations from intended intervention balanced between groups?						*						*						*
	2.6 Was an appropriate analysis used to estimate the effect of assignment to intervention?				*								*					*	
	2.7 If N/PN/NI to 2.6: Was there potential for a substantial impact (on the result) of the failure to analyse participants in the group to which they were randomized?				*								*					*	
	2.0 Risk of bias	Some concerns						Low risk						Low risk					
Domain 3. Missing outcome data	3.1 Were data for this outcome available for all, or nearly all, participants randomized?				*			*									*		
	3.2 If N/PN/NI to 3.1: Is there evidence that the result was not biased by missing outcome data?		*										*					*	
	3.3 If N/PN to 3.2: Could missingness in the outcome depend on its true value?						*						*					*	
	3.4 If Y/PY/NI to 3.3: Is it likely that missingness in the outcome depended on its true value?						*						*				*		
	3.0 Risk of bias	Low risk						Low risk						High risk					
Domain 4. Measurement of the outcome	4.1 Was the method of measuring the outcome inappropriate?				*						*						*		
	4.2 Could measurement or ascertainment of the outcome have differed between intervention groups?				*						*						*		
	4.3 If N/PN/NI to 4.1 and 4.2: Were outcome assessors aware of the intervention received by study participants?			*				*								*			
	4.4 If Y/PY/NI to 4.3: Could assessment of the outcome have been influenced by knowledge of intervention received?						*		*						*				
	4.5 If Y/PY/NI to 4.4: Is it likely that assessment of the outcome was influenced by knowledge of intervention received?						*					*						*	
	4.0 Risk of bias	Low risk						High risk						High risk					
Domain 5. Selection of the reported result	5.1 Were the data that produced this result analysed in accordance with a pre-specified analysis plan that was finalized before unblinded outcome data were available for analysis?					*		*									*		
	5.2. ... multiple eligible outcome measurements (e.g. scales, definitions, time points) within the outcome domain?				*					*							*		
	5.3 ... multiple eligible analyses of the data?				*						*						*		
	5.0 Risk of bias	Some concerns						Low risk						Some concerns					
Domain 6. Overall Bias	Overall risk of bias rating	**Some concerns about bias**						**High risk of bias**						**High risk of bias**					

Y = Yes, PY= Probably Yes, N = No, PN = Probably No, NI = No Information, NA = Not applicable

Supplementary table 4: Quality appraisal of pre-post designs with no control group

Pre-post designs	**Lawrence et al. (2017)**			
	Y	N	NR	NA
1. Was the study question or objective clearly stated?	*			
2. Were eligibility/selection criteria for the study population prespecified and clearly described?	*			
3. Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?	*			
4. Were all eligible participants that met the prespecified entry criteria enrolled?			*	
5. Was the sample size sufficiently large to provide confidence in the findings?			*	
6. Was the test/service/intervention clearly described and delivered consistently across the study population?	*			
7. Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants?	*			
8. Were the people assessing the outcomes blinded to the participants' exposures/interventions?			*	
9. Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?			*	
10. Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?	*			
11. Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e., did they use an interrupted time-series design)?		*		
12. If the intervention was conducted at a group level (e.g., a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group level?				*
Total score	**7**			

Y = Yes, N = No, NR = Not Reported, NA = Not applicable

Supplementary Table 5: Quality appraisal of cohort studies

Cohort studies	**Gokkaya et al (2005)**				**Hilari & Northcott (2017)**				**Dhand et al (2019)**				**Naess et al (2009)**				**Cooper et al (2015): Study 2**			
	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA
1. Was the research question or objective in this paper clearly stated?	*				*				*				*				*			
2. Was the study population clearly specified and defined?	*				*				*				*				*			
3. Was the participation rate of eligible persons at least 50%?			*				*		*				*					*		
4. Were all the subjects selected or recruited from the same or similar populations? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	*				*				*				*				*			
5. Was a sample size justification, power description, or variance and effect estimates provided?			*				*				*				*				*	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	*				*				*				*					*		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	*				*				*				*				*			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome?	*							*	*							*	*			
9. Were the exposure measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*					*			*			
10. Was the exposure(s) assessed more than once over time?	*				*				*					*			*			
11. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*				*				*			
12. Were the outcome assessors blinded to the exposure status of participants?			*				*				*				*				*	
13. Was loss to follow-up after baseline 20% or less?			*				*		*				*					*		
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?		*				*			*					*			*			
Total score	**9**				**8**				**12**				**8**				**9**			

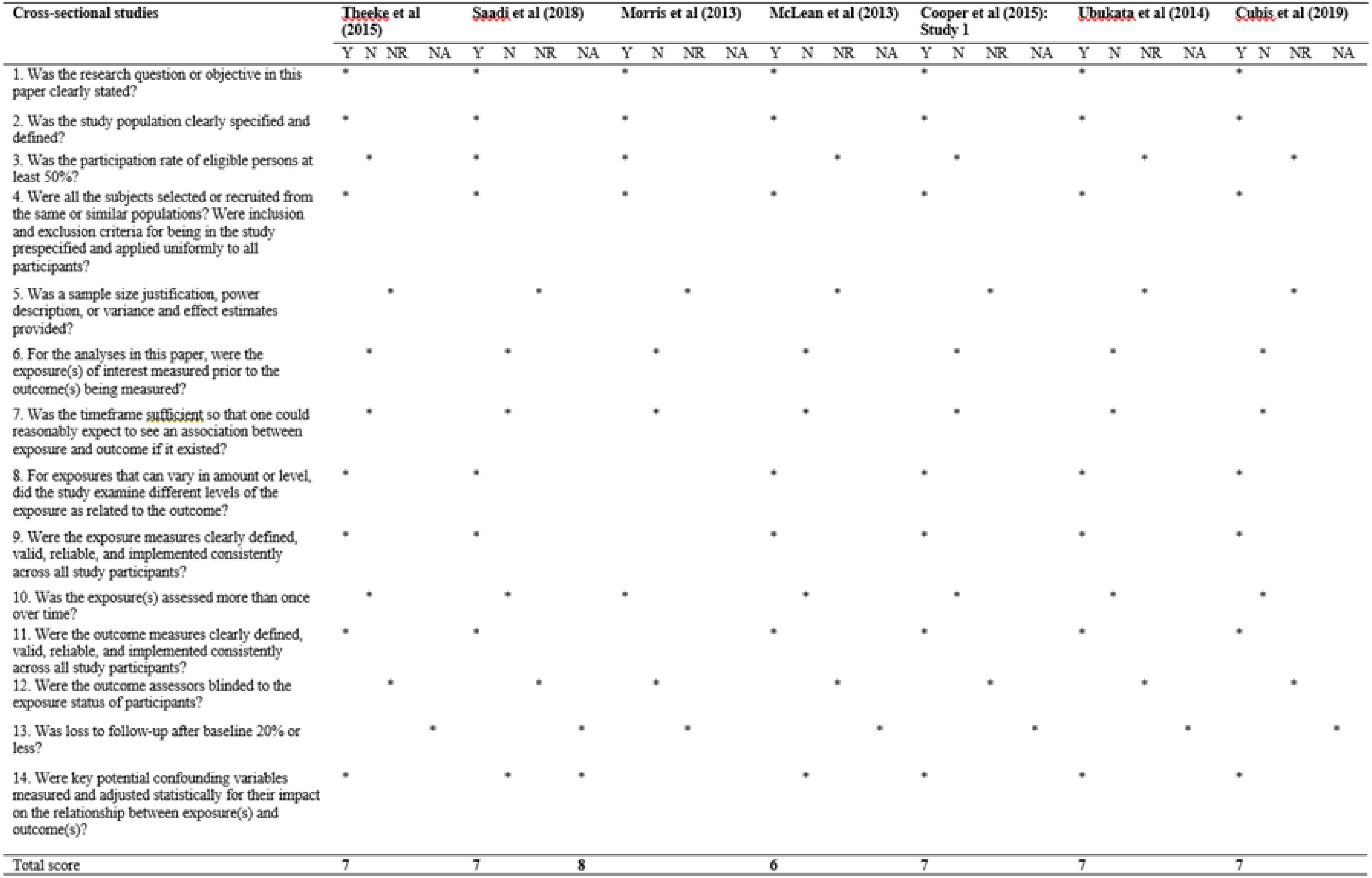
Y = Yes, N = No, NR = Not Reported, NA = Not applicable

Supplementary Table 5 continued: Quality appraisal of cohort studies

Cohort studies continued	**Northcott et al (2016)**				**Nakao et al (2019)**				**Dhand et al (2018)**				**Klose et al (2007)**			
	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA
1. Was the research question or objective in this paper clearly stated?	*				*				*				*			
2. Was the study population clearly specified and defined?	*				*				*				*			
3. Was the participation rate of eligible persons at least 50%?	*				*				*					*		
4. Were all the subjects selected or recruited from the same or similar populations? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	*				*				*						*	
5. Was a sample size justification, power description, or variance and effect estimates provided?	*						*				*				*	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	*					*			*				*			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	*					*			*				*			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome?	*				*				*							*
9. Were the exposure measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*				*			
10. Was the exposure(s) assessed more than once over time?	*					*			*				*			
11. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*				*			
12. Were the outcome assessors blinded to the exposure status of participants?			*				*				*				*	
13. Was loss to follow-up after baseline 20% or less?	*							*			*				*	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	*				*				*				*			
Total score	**13**				**8**				**11**				**8**			

Y = Yes, N = No, NR = Not Reported, NA = Not applicable

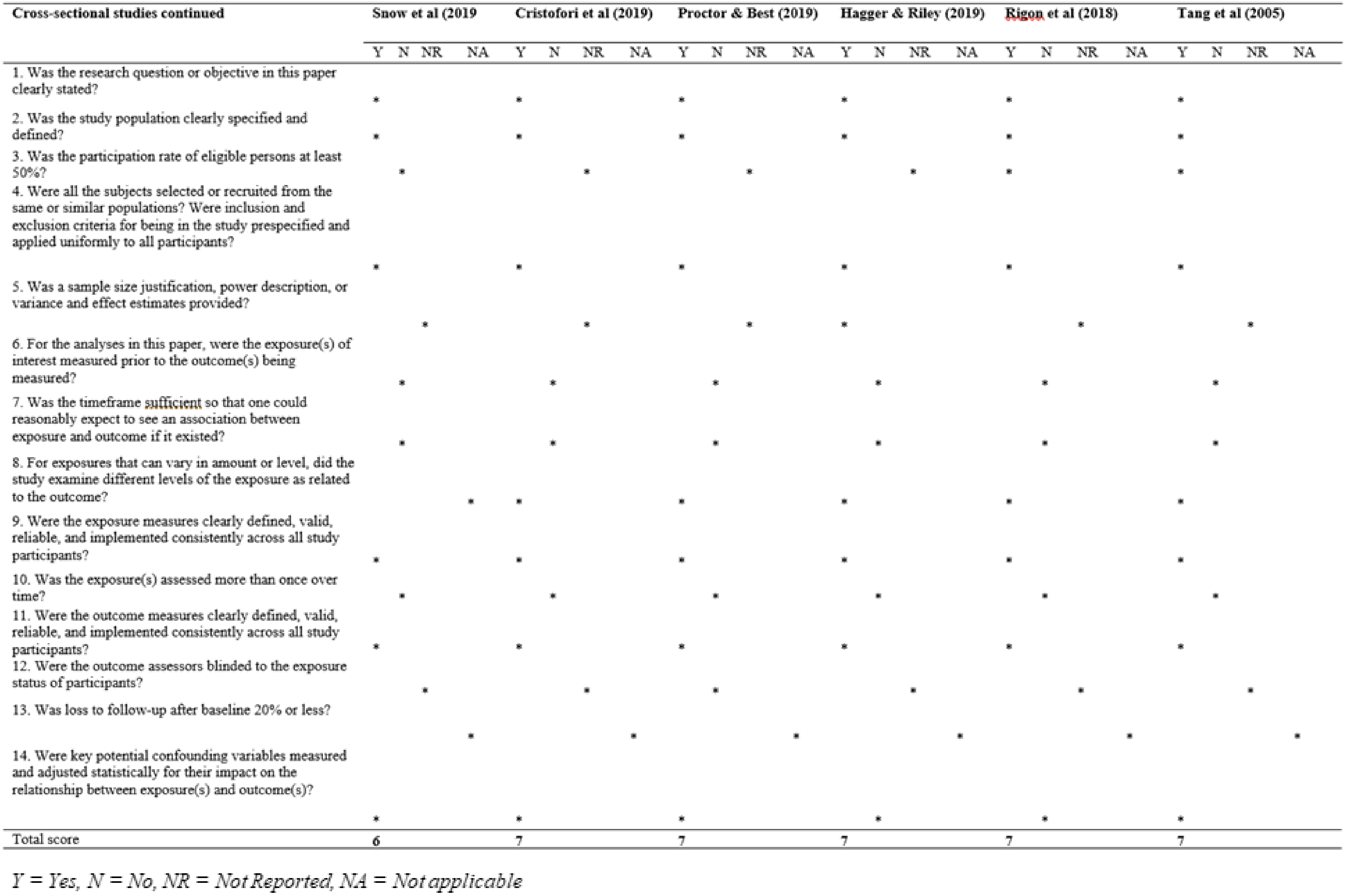
Supplementary Table 6: Quality appraisal of cross-sectional studies



Cross-sectional studies	Theeke et al (2015)				Saadi et al (2018)				Morris et al (2013)				McLean et al (2013)				Cooper et al (2015): Study 1				Ubukata et al (2014)				Cubis et al (2019)			
	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA
1. Was the research question or objective in this paper clearly stated?	*				*				*				*				*				*				*			
2. Was the study population clearly specified and defined?	*				*				*				*				*				*				*			
3. Was the participation rate of eligible persons at least 50%?		*			*				*						*			*					*				*	
4. Were all the subjects selected or recruited from the same or similar populations? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	*				*				*				*				*				*				*			
5. Was a sample size justification, power description, or variance and effect estimates provided?			*				*				*				*				*				*				*	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		*				*				*				*				*				*				*		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		*				*				*				*				*				*				*		
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome?	*				*								*				*				*				*			
9. Were the exposure measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*								*				*				*				*			
10. Was the exposure(s) assessed more than once over time?		*				*			*					*				*				*				*		
11. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*								*				*				*				*			
12. Were the outcome assessors blinded to the exposure status of participants?			*				*			*					*				*				*				*	
13. Was loss to follow-up after baseline 20% or less?				*				*			*					*				*				*				*
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	*					*		*						*			*				*				*			
Total score	7				7			8					6				7				7				7			

Y = Yes, N = No, NR = Not Reported, NA = Not applicable

Supplementary Table 6 continued: Quality appraisal of cross-sectional studies



Cross-sectional studies continued	**Snow et al (2019**				**Cristofori et al (2019)**				**Proctor & Best (2019)**				**Hagger & Riley (2019)**				**Rigon et al (2018)**				**Tang et al (2005)**			
	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA	Y	N	NR	NA
1. Was the research question or objective in this paper clearly stated?	*				*				*				*				*				*			
2. Was the study population clearly specified and defined?	*				*				*				*				*				*			
3. Was the participation rate of eligible persons at least 50%?		*					*				*				*		*				*			
4. Were all the subjects selected or recruited from the same or similar populations? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	*				*				*				*				*				*			
5. Was a sample size justification, power description, or variance and effect estimates provided?			*				*				*		*						*				*	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		*				*				*				*				*				*		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		*				*				*				*				*				*		
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome?				*	*				*				*				*				*			
9. Were the exposure measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*				*				*				*			
10. Was the exposure(s) assessed more than once over time?		*				*				*				*				*				*		
11. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	*				*				*				*				*				*			
12. Were the outcome assessors blinded to the exposure status of participants?			*				*			*					*				*				*	
13. Was loss to follow-up after baseline 20% or less?				*				*				*				*				*				*
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	*				*				*					*				*			*			
Total score	6				7				7				7				7				7			

Y = Yes, N = No, NR = Not Reported, NA = Not applicable

Appendix 6. Outcome Measures meeting eligibility criteria for the systematic review

Measure	Reason for Inclusion
UCLA loneliness scale	Looks specifically at subjective feelings of loneliness and how often people feel this way
Nottingham health profile: Social isolation subscale.	Looks specifically at feeling lonely, feeling disconnected from others and finding it to have interactions with others
Stroke Social Network Scale (SSNS)	Measures social network size and perceived isolation (satisfaction with contact and loneliness)
Berkman-Syme social network index	Included as looks at social networks and activities e.g. work or church are explored in relationship to networks there.
Lubben Social Network Scale	Looks at size of network, frequency of contact and perceived quality of support (e.g. go to the person for help)
The Friendship Scale	Looks at social connection: loneliness/ perceived support/social contact
The Craig Handicap Assessment and Reporting Technique (CHART): Social integration subscale	Social integration subscale looks specifically at social network and number of social contacts
Participation Assessment with Recombined Tools-Objective (PART-O): Social relations subscale	Social relations subscale asks about frequency of contacts and presence of relationships which fits with ICF interpersonal interactions and looks at size of network
The Exeter Identity Transition Scale (EXITS)	Looks at number of groups people are members of, therefore size of social network
The Brain Injury Community Rehabilitation Outcome Scales (BICRO-39 scales): family contact subscale	Looks at frequency of contact with family
Social and emotional loneliness scale for adults	Asks about presence of certain relationships, but also has some information about the quality
National Social Life, Health, and Aging Project Social Network Module (NSHAP)	Measures social network size by the number of names provided
General social Survey	Explores social network characteristics (size, structure, density and constraint)

Appendix 7. Ethical approval for research project and minor amendments

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Georgina Berger
MED

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

19 December 2018

Dear Georgina

Title: How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Reference: 201819 - 042

The submission of your research proposal was discussed at the Faculty Research Ethics Committee meeting on Thursday 13 December.

The Committee considered your proposal to be a nice hybrid approach. They were happy to approve your application in principle but have the following concerns which they would like you to address and amend accordingly:

- Application Form – inclusion/exclusion criteria is not sufficiently detailed. Should fluent English be an inclusion? The definition of mild vs moderate in the exclusion criteria needs clarification. How would this be assessed?
- Allowing participants to self-categorise during interviews might not be good enough, would being accompanied by next of kin to answer some of the questions or clarify, be helpful?
- What is your provision for participants who are unable to write their written consent?
- The interviews or group sessions seem quite lengthy and might be tiring for some participants.
- The possibility of recalling people for further interviews or group meetings needs clarification of the categories you propose to recall.
- Is your transcriber to be internally or externally appointed? If it is an external appointment, they will need to sign a confidentiality agreement.
- Lone worker policy – the sentence about calling the police and senior staff is confusing.
- Both Appendix A and B – confidentiality should be mentioned.
- PIS, posters and leaflets – would it be possible to individualise/personalise these for each site and project?
- PIS – Suggest replacing 'focus groups' with 'group chat'.
- PIS – you mention that the data collected on the dictaphone is to be destroyed at the end of the study but it reads as if **all** the data will be destroyed which is not the intention. It is also suggested that storage of data should be on UEA servers and password protected, not memory sticks.
- Appendix 11 – Where and how is the demographic data to be collected? Depending upon the degree of severity - will some of the detailed information need to be cross checked through gate keepers?
- Appendix 13 – This letter needs to be softened a little.
- Are you going to Wales to conduct all the interviews and group meetings in person?

Please write to me once you have resolved/clarified the above issues. I require documentation confirming that you have complied with the Committee's requirements. The Committee have requested that you detail the changes below the relevant point on the text in this letter and also include your amendments as a tracked change within your application/proposal. The revisions to your application can be considered by Chair's action rather than go to a committee meeting, which means that the above documentation can be resubmitted at any time. Please could you send your revisions to me as an attachment in an email as this will speed up the decision making process.

As your project does not have ethics approval until the above issues have been resolved, I want to remind you that you should not be undertaking your research project until you have ethical approval by the Faculty Research Ethics Committee. Planning on the project or literature based elements can still take place but not the research involving the above ethical issues. This is to ensure that you and your research are insured by the University and that your research is undertaken within the University's 'Guidelines on Good Practice in Research' approved by Senate in July 2015.

Yours sincerely

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Georgina Berger
MED

18 February 2019

Dear Georgina

Title: How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Reference: 201819 - 042

Thank you for your response to the recommendations from the FMH Ethics Committee to your proposal. I have considered your amendments and can now confirm that your proposal has been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely

Professor M J Wilkinson
Chair, FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Georgina Berger
MED

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

15 May 2019

Dear Georgina

Title: How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Reference: 201819 - 042

Thank you for your e-mail of 15 May notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely

Professor M J Wilkinson
Chair, FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Georgina Berger
MED

10 July 2019

Dear Georgina

Title: How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Reference: 201819 - 042

Thank you for your e-mail of 08 July notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely

Prof Alastair Forbes
Chair
FMH Ethics Committee

Appendix 8. Topic Guide

Intro – what project, how long involved, demographics etc…
Can you tell me about your stroke/brain injury
How did you feel then? Relationships etc.

Before attending
Practicalities – Awareness of the group
How did you become involved with the group?
How did you first hear about the group ?
Was there anything that influenced your decision to join the group?
What made you want to take part in the group?
Was there someone who influenced your decision to join the group?
    Family, friend, professional?
What other groups were you offered?
    Did you attend these?
    Why/why not?
    Who told you about X group?

Thoughts and Feelings:
What did you think about the group before coming?
How did you feel about the group before you joined it?
How did you feel about yourself before starting the group?
What were your relationships like before starting the group?
    With family/ friends

Getting to the group
Practicalities:
What makes it easier for you to come to this group?
    Transport availability, Location, brain injury specific?
Is there anything that makes it hard to come to this group?
Has any organisation helped you to get to the group?
    How did they help?
What advice would you give someone else about the group?

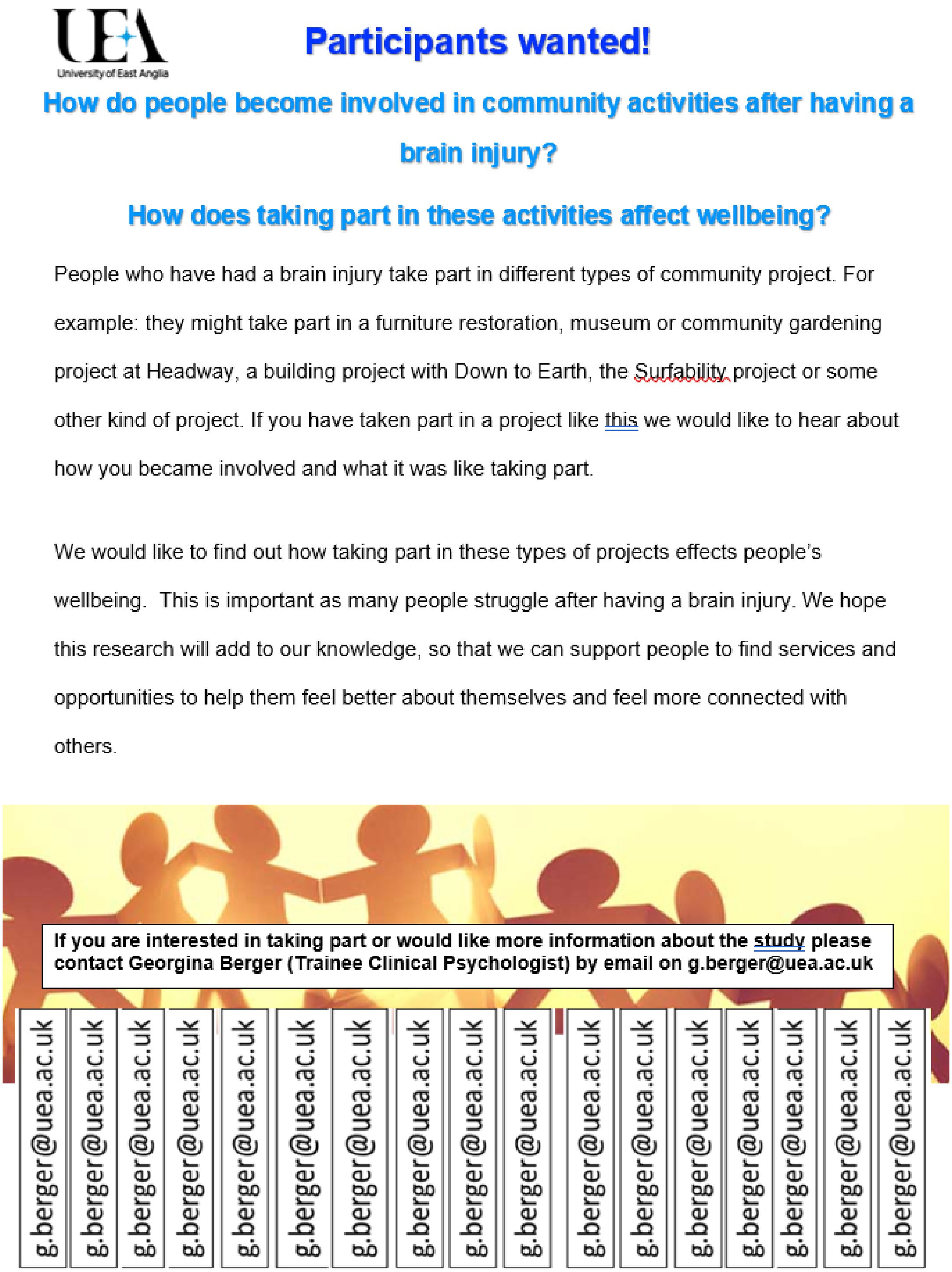
Emotions/Thoughts
How did you manage any difficult thoughts or feelings about coming to the group
You mentioned thinking /feeling ….. before attending the group, what helped you to attend in spite of this?

Part of the group – Now
What keeps you coming to the group?
Have you encountered any problems that make it difficult to keep attending the group?
    How have you managed these?
Have your thoughts about the group changed since attending the group?
    In what ways?
Have you noticed any changes in your life since attending the group?
    Good things?
    Bad things?

What do you think has led to these changes?
Were they slow/quick?
Do you think attending the group has affected your wellbeing (how happy or sad you feel)?
How has it done this?
(Making social connections, giving back to the community, identity, acceptance, active)
Have your thoughts or feelings about yourself changed since starting the group?
If so, in what way?
What do you think has led to these changes?
Were they slow/quick?
Have there been any changes in your relationships since starting the group?
Positive?
Negative?
What do you think has led to these changes?
Were they slow/quick?
Are there any events that stand out throughout your experience of the group?
What happened?
How did it affect you? - Thoughts, feelings, behaviour
Are there any lessons you feel you have learnt by attending the group?
Do you think other people could benefit from taking part in this group after having a brain injury?
In what ways?
What advice would you give them?

Ending questions
Is there something else you think I should know to better understand your experience of being part of the group?
Is there anything you would like to ask me?

Appendix 9. Recruitment poster advertising empirical study



UEA
University of East Anglia

Participants wanted!

How do people become involved in community activities after having a brain injury?

How does taking part in these activities affect wellbeing?

People who have had a brain injury take part in different types of community project. For example: they might take part in a furniture restoration, museum or community gardening project at Headway, a building project with Down to Earth, the Surfability project or some other kind of project. If you have taken part in a project like this we would like to hear about how you became involved and what it was like taking part.

We would like to find out how taking part in these types of projects effects people's wellbeing. This is important as many people struggle after having a brain injury. We hope this research will add to our knowledge, so that we can support people to find services and opportunities to help them feel better about themselves and feel more connected with others.

If you are interested in taking part or would like more information about the study please contact Georgina Berger (Trainee Clinical Psychologist) by email on g.berger@uea.ac.uk

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Appendix 10. Recruitment flyer advertising empirical study

University of East Anglia

Participants wanted!

How do people become involved in community activities after having a brain injury?

How does taking part in these activities affect wellbeing?

People who have had a brain injury take part in different types of community project. For example they might take part in a furniture restoration, museum or community gardening project at Headway, a building project with Down to Earth, the Surfability project or some other kind of project. If you have taken part in a project like this we would like to hear about how you became involved and what it was like taking part.

We would like to find out how taking part in these types of projects effects people's wellbeing. This is important as many people struggle after having a brain injury. We hope this research will add to our knowledge, so that we can support people to find services and opportunities to help them feel better about themselves and feel more connected with others.

If you are interested in taking part or would like more information about the study please contact Georgina Berger (Trainee Clinical Psychologist) by email on g.berger@uea.ac.uk

Appendix 11. Consent to Contact Form

University of East Anglia

CONSENT TO CONTACT FORM

Title of Project:

How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Name of Researcher:

Georgina Berger, Trainee Clinical Psychologist

1. I consent to you sharing my contact details with the researcher, so they can contact me to tell me more about the study

____

Name of ParticipantDateSignature

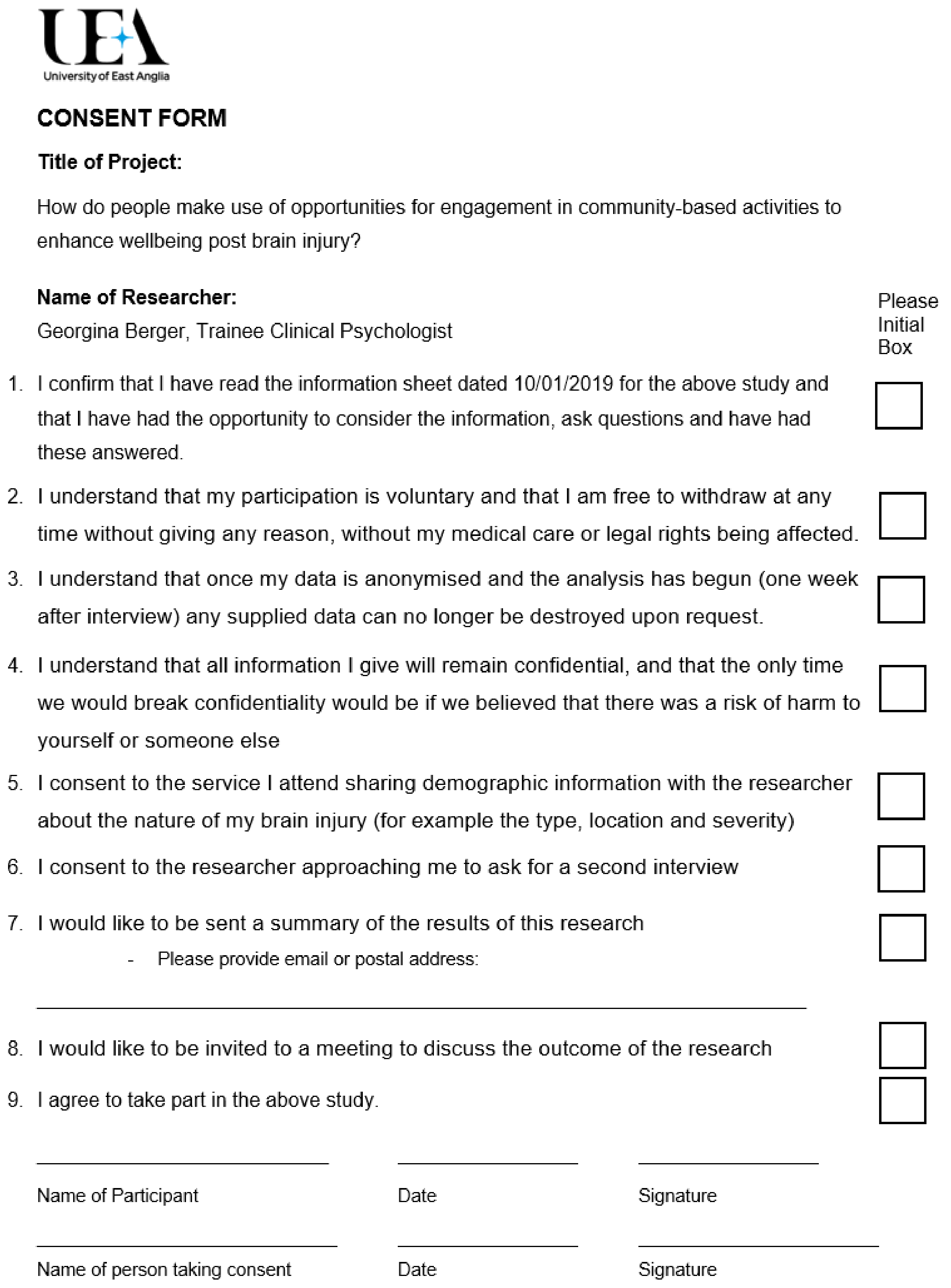
Please provide your telephone number or email address, and let us know whether you would prefer to be contacted by telephone or email

Telephone number: ____________________________

Email address: ______________________________

Circle your preferred method of communication: Telephone / email

Appendix 12. Consent forms for Individual Interviews and Focus Groups



University of East Anglia

CONSENT FORM

Title of Project:

How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Name of Researcher:
Georgina Berger, Trainee Clinical Psychologist

Please Initial Box

1. I confirm that I have read the information sheet dated 10/01/2019 for the above study and that I have had the opportunity to consider the information, ask questions and have had these answered. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that once my data is anonymised and the analysis has begun (one week after interview) any supplied data can no longer be destroyed upon request. ☐
4. I understand that all information I give will remain confidential, and that the only time we would break confidentiality would be if we believed that there was a risk of harm to yourself or someone else ☐
5. I consent to the service I attend sharing demographic information with the researcher about the nature of my brain injury (for example the type, location and severity) ☐
6. I consent to the researcher approaching me to ask for a second interview ☐
7. I would like to be sent a summary of the results of this research ☐
    - Please provide email or postal address:

    ____

8. I would like to be invited to a meeting to discuss the outcome of the research ☐
9. I agree to take part in the above study. ☐

______________________ ______________ ______________
Name of Participant Date Signature

______________________ ______________ ______________
Name of person taking consent Date Signature

CONSENT FORM

Title of Project:

How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Name of Researcher:

Georgina Berger, Trainee Clinical Psychologist

Please Initial Box

1. I confirm that I have read the information sheet dated 29/11/2018 for the above study and that I have had the opportunity to consider the information, ask questions and have had these answered. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that once I have completed the group chat my data can no longer be destroyed upon request. ☐
4. I understand that all information I give will remain confidential, and that the only time we would break confidentiality would be if we believed that there was a risk of harm to yourself or someone else ☐
5. I consent to the service I attend sharing demographic information with the researcher about the nature of my brain injury (for example the type, location and severity) ☐
6. I consent to the researcher approaching me to ask for a second interview ☐
7. I would like to be sent a summary of the results of this research ☐
    - Please provide email or postal address:

____

8. I would like to be invited to a meeting to discuss the outcome of the research ☐
9. I agree to take part in the above study ☐

______________________	__________	______________
Name of Participant	Date	Signature
______________________	__________	______________
Name of Person taking consent	Date	Signature

Appendix 13. Participant Information Sheet

Version 3 10/01/2019

University of East Anglia

Participant Information Sheet

Study title

How do people make use of opportunities for engagement in community-based activities to enhance wellbeing post brain injury?

Brief summary

We are looking for people to take part in a study about the activities people do after having a brain injury. The research will look at the different kinds of community projects people get involved in after a brain injury, for example community gardening projects at Headway, Surfability, the Aphasia café in Norwich or building projects at Down to Earth. We want to find out how people heard about and became involved with the projects. We also want to know if they have been helpful, and if so, in what ways.

What would taking part involve?

- Taking part will involve being interviewed about your experiences of being involved in a community-based project
- You will be offered the choice of being interviewed either on your own or taking part in a group chat. If you are willing, you can also be interviewed both alone and as part of a group.
- Taking part in a group chat will involve being asked questions in a group of between 4 and 10 people. Everyone in the group will have been involved in the same community-based project as you.

- You will be asked some questions about how you became involved in community activities, your experiences of taking part, and how taking part in the project affected you.
- Both individual interviews and group chats will last up to 60 minutes. People with a brain injury who have taken part in research before, say that this length of time is usually manageable.
- However it will be possible to have breaks at any point during individual interviews or focus groups if you are feeling tired.
- You can leave the group chat or we can shorten or end individual interviews at any time if you decide that you would no longer like to take part.
- We may ask you to return for another interview or group chat to get more information about your experience. You do not have to agree to this if you do not want to. We will ask you again at the time if you would still like to take part.
- Individual interviews can be conducted either at the service you are attending (e.g. Headway or Down to Earth) or at your own home, depending on which you would prefer. Group chats will be conducted at the service you attend.
- Both interviews and group chats will be audio-recorded. The interviewer may also make some notes during the interview.
- At the end of the interview or group chat there will be time to discuss any difficult thoughts or emotions that might have come up, and we can direct you to further support if you would like it.

What are the possible benefits of taking part?

- By taking part in the study you will have the opportunity to tell us about your personal experience of taking part in a community project

- Hearing your story should help to increase in our understanding of how people come to be involved in these projects after brain injury, and how these types of project can help to improve people's lives
- If we can understand this, it may help us to improve services so that more people can benefit from these types of project.

<u>What are the possible disadvantages or risks of taking part?</u>

- Taking part in interviews like this can be tiring and it can be difficult to concentrate for long periods of time. However, it is possible to have a break at any point during the interview, and we can break the interview up into several shorter sessions if this would be more manageable.
- Talking about your experiences or hearing about others' experiences may bring up some difficult memories, thoughts and feelings. You can talk about these with the researcher, who is a trainee clinical psychologist, and while we cannot provide psychological care beyond the study, we can tell you who you might go to for more help.

<u>What will happen if I don't want to carry on with the study?</u>

- You can withdraw yourself from the study at any time and we will stop contact and destroy any personal information we have of yours
- If you have been interviewed individually, your data will be anonymised one week after the interview. The analysis will then begin, and from this point forward your data can no longer be withdrawn. Before this point this any supplied data can be destroyed upon request.

- If you have taken part in a group chat, your data cannot be withdrawn once the group has finished, as this would impact on other group members' data.

How will my information be kept confidential?

- The audio recording will be stored on UEA servers and will be password protected.
- The recording will then be typed up, word-for-word and all information that could identify you will be removed or changed when the recording is typed up. The original audio recording will then be destroyed.
- Any personal information will be either securely stored in a locked cupboard at the University of East Anglia or on UEA servers where they will be password protected.
- The personal information you have given will be destroyed once you have completed the study and received a summary of the results (if you have chosen to receive one).
- The only time we would tell anyone else what you have told us, would be if we believed that there was a risk of harm to yourself or someone else. If so, we would talk to you first about our worries and then we would have to pass on our concerns to a relevant person.

What will happen to the results of this study?

- The aim is for this research to be published, so that it can add to the body of knowledge about brain injury rehabilitation.
- I will provide summaries of the research findings which will be sent to you, if you have opted for this at interview.

- You will also be invited to meet and discuss the results and your experiences of taking part in the research.

Who to contact for further information

Georgina Berger (Trainee Clinical Psychologist)	g.berger@uea.ac.uk	
Fergus Gracey (Clinical Senior Lecturer in Clinical Psychology)	f.gracey@uea.ac.uk	01603 456161 Extension 2898
Ciara Shiggins (Academic Fellow, HSC : School of Health Sciences)	c.shiggins@uea.ac.uk	01603 456161 Extension 1686

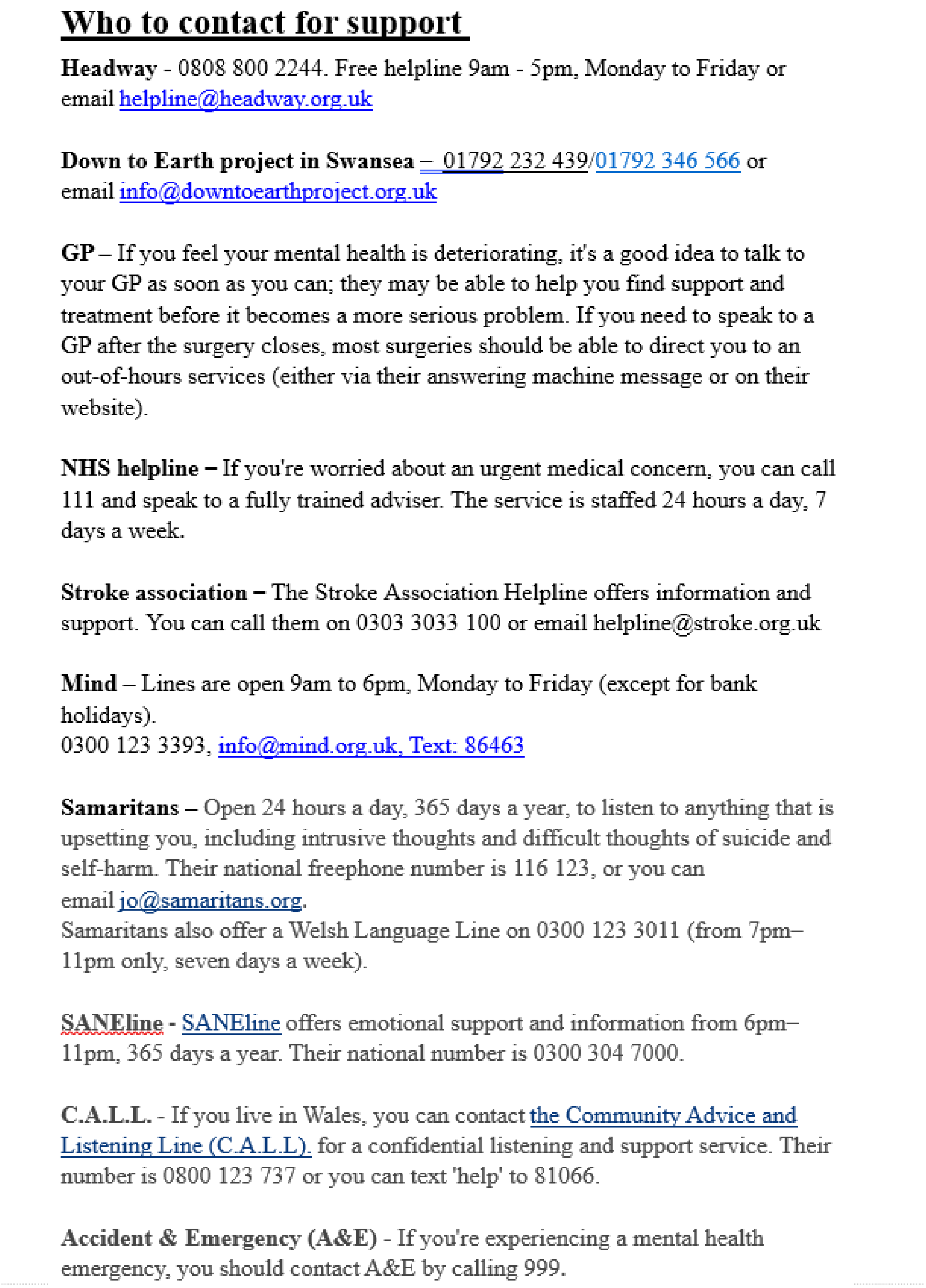
Concerns or Complaints

If you have any concerns or complaints please contact Professor Niall Broomfield, Head of department for the Clinical Psychology Doctorate Programme at the University of East Anglia.

Email address: n.broomfield@uea.ac.uk

Phone number: 01603 456161 Extension 1217

Appendix 14. Information about where to access further psychological support



Who to contact for support

Headway - 0808 800 2244. Free helpline 9am - 5pm, Monday to Friday or email helpline@headway.org.uk

Down to Earth project in Swansea – 01792 232 439/01792 346 566 or email info@downtoearthproject.org.uk

GP – If you feel your mental health is deteriorating, it's a good idea to talk to your GP as soon as you can; they may be able to help you find support and treatment before it becomes a more serious problem. If you need to speak to a GP after the surgery closes, most surgeries should be able to direct you to an out-of-hours services (either via their answering machine message or on their website).

NHS helpline – If you're worried about an urgent medical concern, you can call 111 and speak to a fully trained adviser. The service is staffed 24 hours a day, 7 days a week.

Stroke association – The Stroke Association Helpline offers information and support. You can call them on 0303 3033 100 or email helpline@stroke.org.uk

Mind – Lines are open 9am to 6pm, Monday to Friday (except for bank holidays).
0300 123 3393, info@mind.org.uk, Text: 86463

Samaritans – Open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and self-harm. Their national freephone number is 116 123, or you can email jo@samaritans.org.
Samaritans also offer a Welsh Language Line on 0300 123 3011 (from 7pm–11pm only, seven days a week).

SANEline - SANEline offers emotional support and information from 6pm–11pm, 365 days a year. Their national number is 0300 304 7000.

C.A.L.L. - If you live in Wales, you can contact the Community Advice and Listening Line (C.A.L.L). for a confidential listening and support service. Their number is 0800 123 737 or you can text 'help' to 81066.

Accident & Emergency (A&E) - If you're experiencing a mental health emergency, you should contact A&E by calling 999.

Appendix 15. Example of the iterative process of data collection and analysis

The theme of connection came out in my very first interview. Steve said “I don’t really know, I think it's just meeting people and and being on a level with them you know it’s it’s hard to say isn’t it”

I made a note to myself that ‘meeting people and feeling on the same level as them, is something which helps after brain injury’. I then elaborated on this during focused coding and refined this as an example of how groups provided opportunities for connecting with others through shared experiences and feeling understood.

This code was then also reflected in the second interview I conducted: Dennis says “ I suppose it’s it's being being somewhere where you can be yourself and where you are understood and um and and you, I think one of the more unpleasant consequences of of brain injury is that you lose a sense of belonging and I think it is probably that it’s that, I think on a Monday morning when we are there and we all belong there in that group”

This crystallised for me the idea that people can benefit from attending groups through connecting with other group members through their shared experience of brain injury which helps them to feel understood. I continued to ask about connections and feeling understood at groups in subsequent interviews in order to develop and refine this theme. For example, through more general questions e.g. ‘how was it being with the other group members?’ and ‘have you noticed any other changes in your relationships since starting (the group)’, and also more specific and focused questions like ‘does that help do you think having staff who have also had head injuries’ to help clarify the themes.

Often participants talked about feeling understood at groups without any prompting, which really highlighted to me how important this shared experience and feeling understood was for helping people to connect. I was, however, aware that I was being drawn towards only looking for confirmatory evidence, and so made sure to also ask questions about and be sensitive to examples of when people had found it more difficult to connect or didn't feel understood and then explored the reasons why.

Extract from memo demonstrating how the code of 'connecting through shared understanding' was developed (and included examples of people finding it easy and difficult to connect at groups:

Memo 12.02.20 Feeling understood – due to shared experiences of brain injury ('Being in the same boat')

CONNECTING – though understanding

Sense that people are able to connect with others at community group through shared experience of brain injury. Understanding each other's difficulties helps group members to feel accepted, so that they are able to be themselves and they describe feeling a sense of belonging and feeling less alone. People made less negative comparisons between themselves and other group members as they felt they were 'on the same level'. It appears that this sense of connection and belonging can promote wellbeing and makes these connections very meaningful for group members.

Irene) yeah I enjoyed you know some of them are how can I say worse off than me because I I don't see myself as disabled or whatever I know I am obviously because I lose my words and I mix them up and I forget things but I felt quite comfortable because we were all the same and it was just nice.

Isaac) you understand the situation so you don't have to say you don't have to say things like oh hang on or excuse me or that takes probably internal pressure off and so you don't feel so self-conscious and that ...

Adam and Ben) A: what I found was um meeting sort of like people like yourself and the rest of the surfies I call them surfies but ah but people under very similar situations where people understand what we are going through ourselves with the brain injury ...
B: (interrupts) Yeah sitting with you on the beach the other day when we got back from fighting the waves it was really nice to share the experience of...

Isaac) it's just that everyone is in the same boat and that builds a camaraderie a group feeling up you do it picks you up lifts you up you're not the bottom down there you know

Steve) well it it has it it is a positive thing you know um you tend to think there's all sorts and all types and things like that but you you get there and you you realise, I realise how how they're all intermingled with this with this um with this um aphasia you know its its that its its good

Dennis) I suppose it's it's being being somewhere where you can be yourself and where you are understood and um and and you I think one of the more unpleasant consequences of of brain injury is that you lose a sense of belonging and I think it is probably that it's that I think on a Monday morning when we are there and we all belong there in that group

Finding it hard to connect with people who aren't 'in the same boat'

However sometimes people found it hard to connect with group members, for example if they were at a different level of ability or had different difficulties (e.g. learning disability rather than brain injury).

Ivan) me and Bill would go there have some food have a beer have a laugh but didn't interact with other people a lot because we just didn't seem to have anything in common with them

James) yeah it is just that I thought that while I was at Involve don't get me I did enjoy it and I made some friends there which was good but I felt that that the mental capacity of the young people there was a lot lower than where I needed to be at sort of thing for for myself whereas you basically have to tell them how to just spell like what we would class as simple words

Green: indicates when the theme was seen within interactions in focus groups; red: indicates quotes that grabbed my attention or seemed to particularly reflect the theme; underlined: indicates the quote chosen to reflect this in the paper

Appendix 16. Example extract of how codes developed from the interview transcript into initial line-by-line codes, focused codes and finally theoretical codes

Extract from Focus group transcript:

[B= Belinda, M = Michael, L=Larry (all pseudonyms) G= Interviewer Georgina Berger]

B I don’t know it just brought that home to me that I am not as connected as I could be because I isolate myself and I felt I have got better by being aware of it because it was a question I haven't thought about

M it almost gives you a new question to ask yourself when you're in a situation

B yeah yeah

L you can give the relatives the same questions and perhaps they have a different idea to what you think you've got you think you're acceptable and perhaps they say no you're more moody or my wife and my relatives would have answered differently my questionnaire

B I just hadn't realised that I was definitely not connected

L but I don't feel anxious at all in surfing because I've never done it but I say the swimmers taught us well

G what do you think about it helped you to feel more connected with people

B I think it was the way they I can remember that one analogy of the sea but a few different things they talked about that I don't remember that just made me think of life as a whole and not the activity yes you were there for surfing but they kept it means so much more than that skills were transferring to my everyday connection with my family and things when I realised how awkward I was for them and that I didn't need to be like that I could do something about it

G did you guys find that as well they changed

L yes

G your relationships with other people

M yeah with regards to new people anyway yeah like I said

L because I've always been a talker they tell me I talk too much

G so you've not had problems connecting

L know I always tell people that I meet for the first time that if I talk too much tell me please because I do talk a lot I don't remember names very good never have done long before any injury whatsoever but faces I don't forget

M it is made me realise as well that with new groups especially you turn up for the first couple of times and yeah it is a bit awkward and you know there are gaps in conversation and things like that and you are trying to ask questions to keep it going but then after a couple of times it just becomes normal and I've just spoken to Jack about this it's like like with you guys now now I have met you 4×5 times I can just sit and have a conversation with you

L and we can appreciate what you've gone through as well

G so it becomes more effortless

L because it is nothing physical you can see

B yes I definitely see a difference in people's the way they connect with me or talk with me when I'm sitting down like this they think I'm normal and then when I go to move they think oh my god they are different than

L yes they're afraid that they can upset you yes I can believe that as well so

G you said the questionnaire also asked about how happy you feel and how anxious you feel did you guys notice a change in how happy or anxious you are feeling

B I definitely felt happier and less anxious

G what you think helped with that

B I don't know whether it was because I was actually getting out and doing an activity that I I was part of and being outside is beautiful anyway we were lucky the weather was lovely

L yes yes

B and the sea was lovely and the surroundings

L and there were never any 40 foot waves down the because even yesterday it was only later it got a bit choppy and the waves came up a little bit towards the end

M the last week was the biggest yeah yeah that's it good fun

G was there anything you noticed with anxiety or

M I think thinking about how I was filling out the forms that connected with people went up and the anxiety went down and the happiness sort of I wasn't sad really anyway so it was more just anxiety rather than versus happy or sad I think that stayed relatively high throughout I was happy that even though I felt bad that I was having time off work I was I was happy that I was on the beach in the sun rather than being at work

B we were so lucky with the weather

L we couldn't actually sunbathe though because we were covered up but the worst bit of it was getting the skinsuit on getting the wetsuit on and they were damp anyway because where they kept them perhaps they haven't used them for a week you don't know how often they use those suits for other people but they didn't dry completely

B there was a changing room a disabled changing room linked to surf ability that was probably open this week I don't know but they put it there during our course and on the last day was there and it was

G did that make things easier

B Oh so you’re like that would have been nice yeah so hopefully…

G so for the next group that comes along that would be nice

B that that would be massive

L because the new shower because the outside shower the water was 10 times colder than the sea was

B yeah

G so hot water would also be nice might be asking for a bit much though

B yeah I think you just realise that actually there's another thing I just thought about the fact that if you've had because I had had a stroke and hadn't been well you get very pampered and looked after I don't if you would register with that I don't know

M it was almost the opposite for me because no one expects you know why aren’t you normal what's wrong with you

B because it is not obvious

L because there's nothing you can see as such people tend to think there's nothing wrong with you

B yeah

L when they can see you've gotta like that gentleman down there with one leg missing

B he was amazing you've got to be inspired by people like that

L I didn't see him yesterday

G so it sounds like at Surfing you weren’t being pampered and looked after you were having to do it for yourself

B yes push push get that wetsuit on

L he was going down on one leg I wouldn't say hopping down by you know quite mobile so but there we are say have we stopped recording now

G no it's still going it is the last final bit of kept you here for a long time now

L the battery has a run out on it

G no the battery is still going the lights still on (laughter) I guess still what are your plans for the future has Surfing changed anything for you for the future

L I hope it has so not just that but other courses as well so I don't know what other courses they've got planned for me for the rest so

G so that is inspired you to go to more courses

L yes the boy said I've got to go with him to the bike on Saturday morning so

G keep everything going

L because it was nothing for me to do a 40 or 50 mile bike ride by myself

B bit by bit

L but so there we are

B can you tell me you said again

G so is there anything going forward now from Surfing any plans for the future or how to build on what you've done

B I personally it definitely inspired me to be more active and try be more physically do the exercises I'm supposed to and also I've downloaded a walking app so I do get out of my house in a safe space so either with my children at the moment I'll aim to go on my own I can't quite get down steps across the road so but it's inspired me to be more physical so now I've got a physical programme that I want to keep going that will benefit me generally because I found my dressing skills and my stamina has definitely improved because I've been physical so I want to keep that physicality going in the in my own way

Extract from excel sheet to show how codes were refined:

Participant	Extract	Initial coding	Focused code	Alternate focused code	Notes	Theoretical codes
B (Belinda)	121) I don't know it just brought that home to me that I am not as connected as I could be because I isolate myself and I felt I have got better by being aware of it because it was a question I haven't thought about	Becoming aware of her disconnection from family and tendency to isolate herself and as a result making changes and becoming more connected	being disconnected from family	Becoming more connected through increased awareness	before injury Through the group	Finding it hard to connect. Connecting with family (awareness)
M (Michael)	122) it almost gives you a new question to ask yourself when you're in a situation	being given a new question to ask yourself in situations (about how connected you feel).	changing perspective	becoming more aware of connectedness	growth	Connecting (awareness)
L (Larry)	123) you can give the relatives the same questions and perhaps they have a different idea to what you think you've got you think you're acceptable and perhaps they say no you're more moody or my wife and my relatives would have answered differently my questionnaire	Family having a different perspective. Might have noticed changes that you don't realise	family views differing	Family able to answer questions		

B (Belinda)	124) I just hadn't realised that I was definitely not connected	Not realising how disconnected she was before Surfing	Being unaware of disconnection	Becoming aware of disconnection	Through the group	Connecting (awareness)
L (Larry)	125) but I don't feel anxious at all in surfing because I've never done it but I say the swimmers taught us well	Not feeling anxious surfing due to the instructors	Feeling safe	due to instructors		Emotional supports (Staff/ volunteers)
B (Belinda)	126) a few different things they talked about that I don't remember that just made me think of life as a whole and not the activity yes you were there for surfing but they kept it means so much more than that skills were transferring to my everyday connection with my family and things when I realised how awkward I was for them and that I didn't need to be like that I could do something about it	Seeing life as a whole. Becoming more connected to family. Realising how awkward she was for her family, realising she didn't have to be and doing something about it.	connecting with family	making changes	Changes extending beyond the group	Connecting with family (awareness)
M (Michael)	127) yeah with regards to new people anyway yeah like I said	Relationships with new people changing	connecting with people at the group			Connecting (new people)

M (Michael)	128) it is made me realise as well that with new groups especially you turn up for the first couple of times and yeah it is a bit awkward and you know there are gaps in conversation and things like that and you are trying to ask questions to keep it going but then after a couple of times it just becomes normal and I've just spoken to (psychologist) about this it's like like with you guys now now I have met you 4×5 times I can just sit and have a conversation with you	Feeling awkward and noticing gaps in conversation when first meeting people. Over time feeling less awkward and now finding it normal and easy to sit and have a conversation	overcoming fears	connecting	Gets easier to attend groups the more you do it (barriers get less)	Attending groups reduces barriers to attending groups (barrier of anxiety)
L (Larry)	129) and we can appreciate what you've gone through as well...because it is nothing physical you can see	Appreciating each other's stories/experiences because there is nothing physical that others can see	understanding each others difficulties	shared experiences/ connecting with people	Connecting due to shared experience and understanding each other	Connecting with others at the group (Through shared experience and Understanding)
B (Belinda)	130) yes I definitely see a difference in people's the way they connect with me or talk with me when I'm sitting down like this they think I'm normal and then when I go to move they think oh my god they are different than	People connecting better with you when they don't realise you have a disability	finding it harder to connect with people since brain injury	being treated differently	Since brain injury (causes disconnection)	Finding it harder to connect (after brain injury)

L (Larry)	131) yes they're afraid that they can upset you yes I can believe that as well so	People worrying about upsetting you if they know you have a disability	being treated differently	people worrying about upsetting you	When people realise you have a disability – connections change	Finding it harder to connect (after brain injury)
B (Belinda)	132) I definitely felt happier and less anxious	feeling happier and less anxious	feeling happier and less anxious	improving mood	By attending the group	Feeling good
B (Belinda)	133) I don't know whether it was because I was actually getting out and doing an activity that I I was part of and being outside is beautiful anyway we were lucky the weather was lovely...and the sea was lovely and the surroundings	feeling happier and less anxious due to getting outside in a beautiful setting, having good weather and being part of an activity	being active/ exercising/beautiful setting	improving mood	Activity and setting impacts on mood	Feeling good (through activity/group)
L (Larry)	134) and there were never any 40 foot waves down the because even yesterday it was only later it got a bit choppy and the waves came up a little bit towards the end	The waves not being too big	feeling safe		not too big waves – environment helped to feel safe	Emotional supports (environment)
M (Michael)	135) the last week was the biggest yeah yeah that's it good fun	finding bigger waves more fun	enjoying the course	enjoying more of a challenge (bigger waves)	Enjoying a challenge as well as needing to feel safe	Feeling good (excitement and challenge)

M (Michael)	136) I think thinking about how I was filling out the forms that connected with people went up and the anxiety went down and the happiness sort of I wasn't sad really anyway so it was more just anxiety rather than versus happy or sad	Feeling more connected with people and less anxious.	feeling more connected	feeling less anxious	Groups help with connection, reduced anxiety	Connecting and feeling better (less anxious)
M (Michael)	137) I think that stayed relatively high throughout I was happy that even though I felt bad that I was having time off work I was I was happy that I was on the beach in the sun rather than being at work	Staying happy - balancing feeling bad about missing work against being happy that he was on the beach in the sunshine	feeling happy due to the activity and location	missing work	balancing out challenges – enjoyment of group reduces barrier of juggling work	Attending groups reduces barriers to attending groups (enjoyment reduces impact of having to juggle commitments)
B (Belinda)	138) we were so lucky with the weather	feeling lucky to have had good weather	challenges of the group	weather being good	Weather facilitating accessing group	Emotional support (environment and weather facilitated enjoyment of group)

L (Larry)	140) but the worst bit of it was getting the skinsuit on getting the wetsuit on and they were damp anyway because where they kept them perhaps they haven't used them for a week you don't know how often they use those suits for other people but they didn't dry completely	Having difficulty getting the wetsuit on and the wetsuit being damp	challenges of the group	struggling with wetsuits	Barriers to overcome	Physical barrier (Practical supports needed to overcome barrier of getting wetsuit on)
B (Belinda)	141) there was a changing room a disabled changing room linked to surf ability that was probably open this week I don't know but they put it there during our course and on the last day was there and it was ... so you're like that would have been nice yeah so hopefully… that that would be massive	building a disabled changing room which will make attending the group easier	challenges of the group	changing facilities, no disabled	Barriers to overcome – group facilitators doing something to help overcome these	Practical supports (needed to overcome physical barriers – facilitators providing this)
L (Larry)	142) the outside shower the water was 10 times colder than the sea was	having a cold shower	challenges of the group	cold shower	Barriers to overcome	Physical barrier
B (Belinda)	143) I just thought about the fact that if you've had because I had had a stroke and hadn't been well you get very pampered and looked after	feeling pampered and looked after because of the stroke	being treated differently because of brain injury	being looked after	Being treated differently	Disconnection (people not understanding, being treated differently)

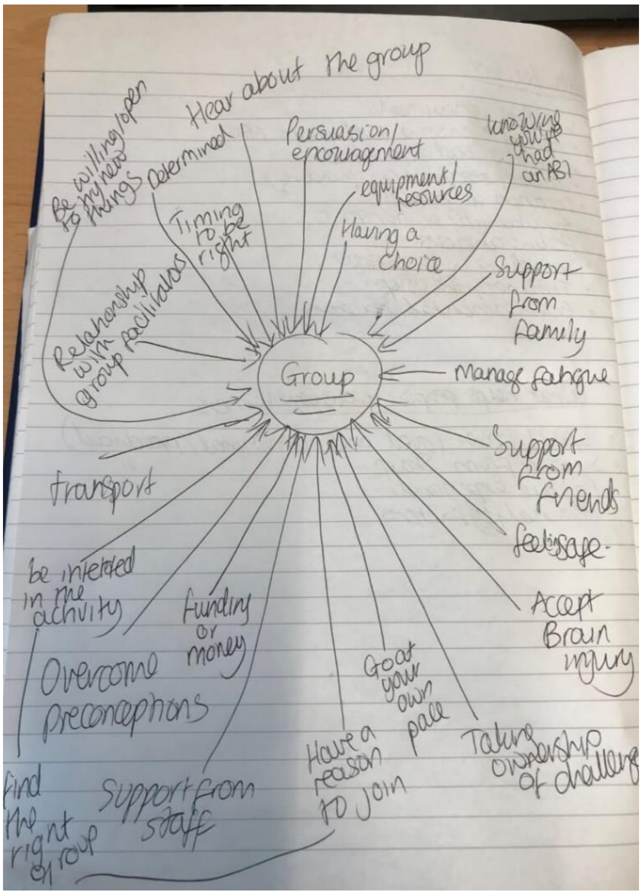
M (Michael)	144) it was almost the opposite for me because no one expects you know why aren't you normal what's wrong with you	People not changing how they treat you or not looking after you because they don't realise anything has changed	not being treated differently because people can't see brain injury	People not understanding outside of group		Disconnection (people not understanding)
B (Belinda)	145) because it is not obvious	brain injury not being an obvious disability	not being treated differently because people can't see brain injury	People not understanding outside of group		Disconnection (people not understanding)
L (Larry)	146) because there's nothing you can see as such people tend to think there's nothing wrong with you…when they can see you've gotta like that gentleman down there with one leg missing	People not knowing there is anything wrong with you if you don't have a physical disability	not being treated differently because people can't see brain injury	People not understanding outside of group		Disconnection (people not understanding)
B (Belinda)	147) he was amazing you've got to be inspired by people like that	Feeling inspired by seeing a man with a physical disability surfing	feeling inspired by people overcoming difficulties		Seeing others with difficulties overcoming them is motivating	Becoming motivated (inspired by people overcoming difficulties)

B (Belinda)	148) G so it sounds like at Surfing you weren't being pampered and looked after you were having to do it for yourself B yes push push get that wetsuit on	Not being pampered at Surfing group. Having to get on with things	having to do it for yourself	Being treated as an equal		Emotional supports (being treated as an equal)
L (Larry)	149) I hope it has so not just that but other courses as well so I don't know what other courses they've got planned for me for the rest so	relying on others to plan courses for him. Hoping to do more courses.	wanting to do more courses	being motivated	Motivated by the group to do more	Becoming motivated (to do more groups)
L (Larry)	150) yes the boy said I've got to go with him to the bike on Saturday morning so	Being active with family	connecting with family	being active	Motivated to do more with family	Becoming motivated (doing activities with family)
L (Larry)	150b) because it was nothing for me to do a 40 or 50 mile bike ride by myself	(Previously) cycling without difficulties	Loss of ability/hobbies	As a result of brain injury	Loss of ability	Changes after Brain injury (Loss of ability)
B (Belinda)	151) I personally it definitely inspired me to be more active and try be more physically do the exercises I'm supposed to	Feeling inspired to be more physically active	being more active	doing rehab	Motivated to do rehab exercises	Becoming motivated (to do rehab exercises)
B (Belinda)	152) and also I've downloaded a walking app so I do get out of my house in a safe space so either with my children at the moment	preparing to be more active. Exercising with family	being more active	feeling motivated	Motivated into becoming more active	Becoming motivated (to be more active)

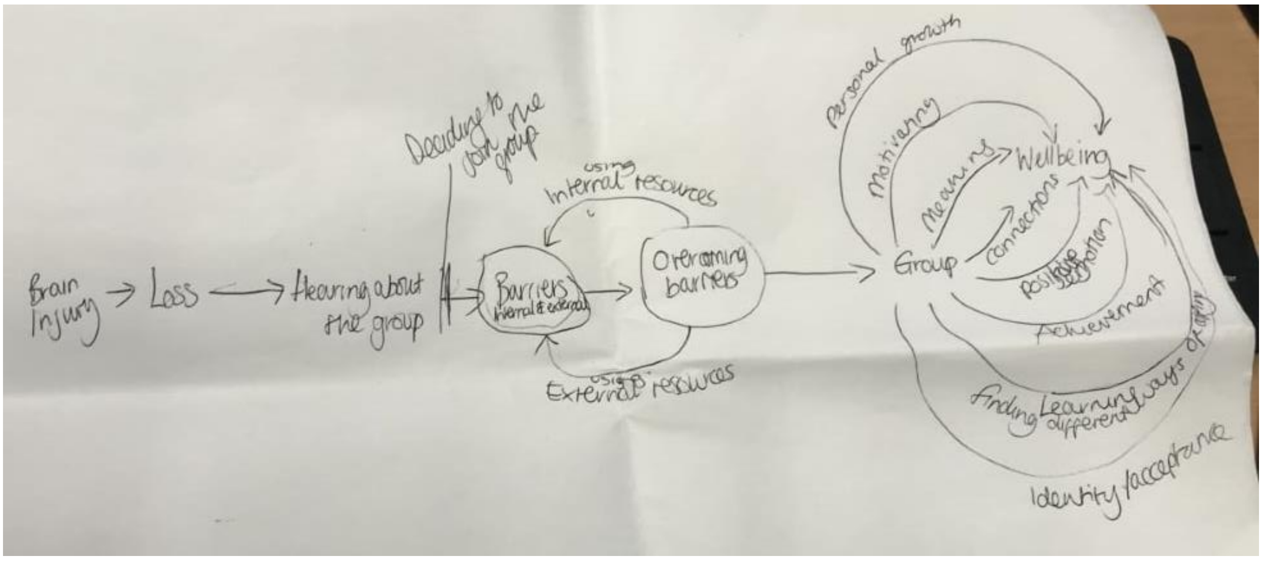
B (Belinda)	153) I'll aim to go on my own I can't quite get down steps across the road so but it's inspired me to be more physical	Setting goals for yourself	setting goals	feeling motivated		Becoming motivated (to be more active)
B (Belinda)	154) so now I've got a physical programme that I want to keep going that will benefit me generally	continuing to be more active	being more active	physically improving	Being motivated by the physical improvement seen	Becoming motivated (by seeing successes and improvements)
B (Belinda)	155) because I found my dressing skills and my stamina has definitely improved because I've been physical so I want to keep that physicality going in the in my own way	Noticing unexpected benefits to being more active and wanting to keep this going. Being active in your own way	being active	physically improving	Being motivated by the physical improvements you see	Becoming motivated (by seeing successes and improvements)

Appendix 17. Example of diagrams used to assist development of theoretical codes

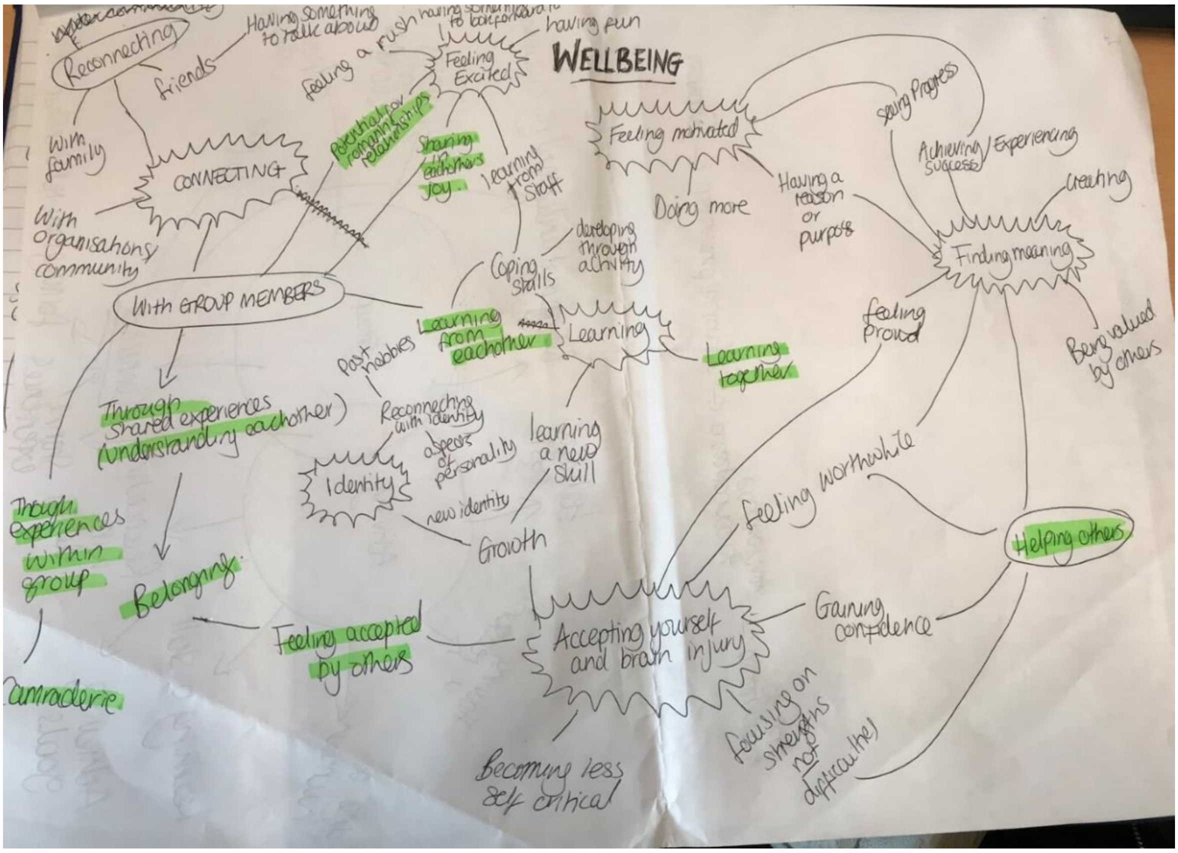
Example of diagram showing what supports people needed to get to group (later refined into practical and emotional supports):



Early diagram of the process of getting to the group, using supports to overcome barrier and the benefits of attending groups:



Early diagram showing connections between connecting, acceptance, feeling good and activity (green highlighters show where it’s particularly important to be in a group)



Appendix 18. Examples of quotes within each of the theoretical codes

Changes after brain injury

1. **Loss of ability**

"I can't do it anyway" Irene

"I could still work but I just stopped just because of if I take your car to parts today if I do your breaks today if I take them apart today but I can't get the part until tomorrow and I've been asleep imagine if I forget how to put your brakes together I don't know you could end up like I wouldn't want to put this on anyone" Ryan

"I could walk miles we used to do a lot of mountain walking and I have I can't do any of that now because of my foot and my leg because of knee damage not knee nerve sorry I get my words mixed up sorry" Irene

"its very very hard when you no longer have your the ability to think in the way you did" Dennis

"I have lost all that I can't just go up to anybody and talk like I used to" Irene

2. **Feeling depressed**

"I was in a bad, bad way. Lots of depression, not a lot of good at all" Ivan

"I certainly was quite suicidal at a stage which I suppose was the low point and you sort of climb climb your way out again umm slowly and very gently" Dennis

3. **Finding it hard to connect**

With others:

"when you've had a head injury your old friends are still your friends but everything is different" Zack

"it is and then the boys from school that I have known all years that I was in school they're on about going back out, getting together and do I want to go out with them so I say yes no problem the only problem is that 2 pints and I'm I'm 5 pints drunk before I start my head if I had to explain it imagine being on the walzers and then coming off and getting on to a kids bouncy castle so your head is going round like that and your legs are just back and forth so whenever you walk you are great for five steps next five you have not got a clue what you are doing" Isaac

"yes well I think my siblings have got a bit more what's the point of us being here because all this you look after Sean because he's Mr potato head now" Sean

"I think your relationship with everything changes umm and of course some relationships just vanish overnight really and I'm sure other people have that experience" Dennis

"I am usually I am generally quite passive you know can't sort of in a my friends in a group of people outside of the surfing group"

With self/loss of identity:

"It's when you know it's not you that really drives you crackers" Issac

4. **Focusing on what you can't do**

***"**I do criticise myself something terrible since my accident awful I hate it I hate the way I look I hate the things I can't do" Irene*

"you start to think that's the end of it now" Ben

"just no-confidence" Zack

Joining a group

1. **Becoming aware of the group**

Through brain injury/stroke services:

***"**I think I learnt about it through (traumatic brain injury service)" Isaac*

"Through the team with (name of nurse)" Steve
"Early, early stroke discharge team, that was called" Steve's wife

"I was invited by (psychologist at brain injury service)" Irene

"I think it's from here the hospital" Adam

Through social care:
"there was a community worker, or I can't remember what it was now but this woman got me in to the charity shop but after little while I got bored of going there and then she said to me about the group" James

Through a mental health charity:
"(mental health charity) said you haven't got an anger problem mate go to (group provider) you've got brain injury" Frank

Through chance encounters:
"we were meeting it was a Monday morning and we were all having coffee and and communicating and this guy came over and he said excuse me he says I I I've been watching the group and um its clear that you know everybody is enjoying themselves but I can't work out what you have in common …so so I I explained and and er I said something about brain injury and heads and um we had quite a chat actually and he was asking what what I was

thinking of doing um so er anyway at one point he said have you thought about sculpture I said well no I have never thought of sculpture er and he said because there is a course at (building name) which is sculpting heads and I thought that's amazing that" Dennis

"I met a friend in there (pub) one day and he had a friend with him called CK and I was talking to CK about martial arts because I was saying originally I wanted to do Aikido...and and then he said to me well there's a group down down the road from here and they do ju-jitsu which I think would be better for you so I went along" James

Through attending other groups:

"because he also did walking rugby as well" Larry

" the same as me I have been coming to other courses here and um I got invited along then which was um a bonus for me really to do something extra as well um" Ben

2. Becoming ready for the group

"*prior to going about (brain injury service) I went over with rehab (service) staff member took me over on a side by side tandem that was only a one off but I had tried them before that was to teach me what can be done with a visual impairment so I had been over there once before but I hadn't been on a solo bike which is what I did" Isaac*

"so it's been several stages to get to this point?" Interviewer
"many stages" Matt

"it was a big step that was prior to biking because I did a gardening course a gardening group which basically the same thing I think it's a ..sorry a confidence builder a psychology course thing so that was it was at that point that I learned to catch a bus to over there and this then was just an extension of that" Isaac

"when I first met (psychologist) as I said the first time I met (psychologist) I said yes yes yes (psychologist) said I think we should leave it a couple of months and I said fine so I turned up a couple of months later and I didn't even recognise (psychologist) and (psychologist) said I knew you weren't with us when she was speaking to me I knew you weren't with us you were still away... it would have it was too early (psychologist) recognised it straight away it was too early for me so the second time I came then she knew then she could tell he is ready to go on courses so we'll do that" Zack

3. Choosing a group

"*it's a group I'm proud to say it's a group without goals um a group without you know without documented structure and organisation and goals and it's just people who who want to go on who want to come together on a Monday and have a cup of coffee" Dennis*

"I heard about this (memory group) and I thought this would be a good idea because it does gives you something to think about" Laura

“what makes that group one you’re interested in?” Interviewer
“it’s putting on the weight” Steve

“I already had quite a keen interest in horticulture” Matt

“I think what's good about it is that it’s so specific you set your goals before you go you don't just turn up and do stuff” Belinda

Utilising supports to overcome barrier

1. **Emotional supports to overcome internal barriers**

Emotional support from staff:

“So that was yeah it was quite if you were feeling a little bit iffy about it they were quite boosting” Ivan

“what I needed was just encouragement” Zack

“they are absolutely brilliant they watch and they they oh what's the word when they help cheer me on yes” Irene

“I don't about you but I have sometimes I find that what I like about the group is it's gradual there's no kind of like you're not expected to jump on a horse and know how to do something you've got to take time which I think that's quite true in the real world as well so” Matt

Emotional support from loved ones:

“really as if it wasn't for my mum I don't think I would you know my mum's been the one that's always pushed” Sean

“did it help having him (husband) come along with you?” Interviewer
“oh yeah I wouldn’t have gone otherwise at all I would not have gone there even you would not have got me on a bike” Irene

Internal emotional supports:

“and so anything and everything I can try I do I try and I have to go on from there” Laura

“I am not going to sit on my arse and let life pass me by I am (age) I have gotta get on with it so” Isaac

Emotional support from the environment:

“by the nature of the fact you're down the beach and it is a beautiful setting it’s incredible” Belinda

“which is a beautiful place to have to go every day.” Ben

“Yeah yeah it's enjoyable because it felt safe, I didn't feel like a truck was going to run me over or anything (off road cycle paths)” Ivan

“there were never any 40 foot waves” Larry

2. Practical supports to overcome environmental and impairment-related barriers

Provided by staff/groups:

“they lend all the wetsuits to us didn’t they you know and if you had to go in there without the wetsuits that would have been too cold” Andrew
“I wouldn't have gone in” Ben

“that the people are great over there they they are quite… they are willing to spend time and explain to you what you’re doing and it's nice” Isaac

“It is great they’re great over there I get into (hospital) and I get a lift in and they drop me back” Ivan

“(previous group leader) was a proper carpenter by trade wasn't he so he was teaching us how to do it all” Frank

Provided by loved ones/existing connections:

“so she (mum) let me drive there and she would drive my car back... and then obviously she would come and pick me up at the end of the day, you know ... she just did that as a confidence thing … to make sure that I got that I was all right to get there on my own sort of thing you know “ James

“I personally physically needed support of somebody my daughters to come to come help me with dressing and undressing putting my wetsuit on is a bit of” Belinda

“because I am not allowed to drive anymore because they took my licence off me so if it weren't for my wife and my daughter I couldn't drive here so I’d have to rely on public transport” Larry

Benefits of the group

1. Connecting

With group members through shared understanding:

“here we all have a good laugh and a joke and we’ll take the mickey out of each other but it is fine here because we are all in the same situation” Frank

“So you do you do find it easy to talk in amongst those people. Because they know what you are going through. And the same yourself you have seen it all.” Isaac

“well it it has it it is a positive thing you know um you tend to think there’s all sorts and all types and things like that but you you get there and you you realise, I realise how how they’re all intermingled with this with this um with this um aphasia you know its its that its its good” Steve
“so though you’ve all come from very different places or different routes” Interviewer
“that’s right” Steve
“that shared experience” Interviewer
“ yeah” Steve
“ brings you all together” Interviewer
“that’s right yeah, good” Steve

“It's not you want anyone else to be in this state. But it is easier to think you are not the only one in this state” Isaac

“well in fact sometimes I don't really feel like I am like I'm further behind other's and that's a big problem for me as well I get very down about that” Matt

Forming friendships through the groups:

“I can see us or a couple of us from the group cycling doing something but I don't know what yet but I can see us developing that and moving forward” Isaac

“Oh god yeah I got a few friends from there (group)” Laura

“I would say we all we were jovial with each other to start with it's as the weeks go on you tend to spend more time talking to people and you do then over the consecutive weeks you sort of you become more friends as opposed to just straight acquaintances” Isaac

“Bill (friend made at a group) when I went to his funeral me and Clare (wife) both upset like we went to the wake and people were coming up shaking my hand saying hello telling me my name and I was alright thinking I don't know you and they said we feel like we know you Bill spoke about you so much we feel like we've known you…yeah it was upsetting enough as it was from losing him” Ivan

“I will adopt you as a friend” Adam (said to Ben within focus group)

Connecting with loved ones and people outside the group:

“but I have gained so much confidence from doing this course I have been out with my grandchildren which is important they are all learning on their bikes and we go out and we are one line and so we keep going” Zack

“before Surfability I couldn't sort of say oh I dressed myself today you know and pipe up into a conversation because it is not that appropriate nobody wants to know but then if I say in a group oh I have gone surfing they’re like oh my God and then I feel like I have done something other people think is wow tell us about it like rather than like I put my socks on today your my other conversations (laughs) are not that inspiring you know” Belinda

“yeah only thing I suffer with is obviously the memory I remember being happy doing it but my physical days of what actual day it happened on I can't quite remember that but I can

remember that being happy coming from it and the buzz then telling my family and friends about it and uh that's the buzz out of it then" Adam

"I value the relationship with the university and they're sort of combined really because it's even though (speech and language therapist at the university) doesn't come along every week um there is always the sort of presence of the university just as there is the presence for me at least of of the (brain injury rehab) hospital" Dennis

Connecting to self and identity:

Through reconnecting with hobby
"it's my older memories appear to be there again I don't know why I don't know obviously so the fact that I could actually ride it was a good was a positive in so much that I didn't have to have stabilisers on as soon as I started moving it just came back it came naturally" Isaaac

"it was good because I never consciously stopped surfing on purpose" Michael
"once my minds not on it I I I go back to almost riding a bike like before" Zack

"oh it's huge yeah I don't know what to say my life when I was living abroad I spent every moment in the ocean it's just so good to get back in" Ben

Reconnecting with aspects of your personality and forming a post-injury identity:

"but coming here I'm still hands on I am learning new things" Ryan

"well usually I am a really practical person and I quite thought you know doing things with furniture yes I could be in for that" Danielle

"it sort of brought back creativity and stuff like that it is definitely goals oh it was brilliant" Ben

"I didn't realise before how much I enjoy helping other people and I do" Zack

2. Acceptance

Becoming more accepting of brain injury and challenges in life:

"well it was um it was con-constant reminders that that there is a process at work here and um you can't skip it you have to accept it and then you have to work hard at it" Dennis

*"It has changed it I'm still conscious still very much self-*conscious *at the moment but I do that the fact that I have achieved the biking group has given me the incentive to move on and accept the fact there will be challenges" Isaac*

Through experiencing a sense of achievement and progress:

"yesterday I felt quite proud yesterday I walked over to someone and I spoke to them" Irene

"it's something I haven't been able to do well most people haven't cycled since they were children and yes I can still do it yeah it is not the same and I'm a bit nervous but yep I can do this" Zack

“definitely rather than just you know you're doing well you turn up you turn up and do it but specifically coming back and realising wow I wanted to do this and I've done it and more” Belinda

“I mean brain injury aside which is learning all these things you don't learn day-to-day like how to make something out of something you can just see around you it is nice to have that finished article to show for it is very rewarding… it feels somewhat foreign and to find out it actually works as well” Matt

“the general public I don't think are that judgmental they might look because they don't understand why you walk with a stick or why you look like you do but I had the feeling there that people were looking and thinking and one or two people did actually say that oh fair play just get on with it like you know” Belinda

“It really helped you to feel like you have accomplished something the sense of accomplishment from seeing people waving at you” Ben

“how did you feel when it was done?” Interviewer
“really pleased” Danielle

“I never thought I'd get back on the bike and that that took me over a major barrier so I'd say that’s the biggest thing that's been good for me” Isaac

“for me it is making a nice piece of art drawing painting” Laura

“for you Ken is it good when you take something home” Group facilitator
“yeah yeah” Ken

“well for me well you know it’s a fact that well when I first came out of hospital my attention I couldn't stand for literally like half a minute without walking off somewhere so to be able to wait at a bus stop or to catch a bus here every morning it’s a pretty damn good thing for me sorry because it is a sense that because I’ve done it once I can do it again” Sean

Finding meaning and gaining confidence by helping others:

“because it's given me a sense of purpose like because of because of like doing projects myself but also I have actually there have been times when I've had to help to do other people's projects um not in a great great deal but you know” James

“oh it was fantastic I benefited a lot more my confidence by helping people” Zack

“so the ability to help someone else then gives you the reward feeling that you are actually it's worth doing it's like a payback for a doing something good if you know what I… Well yeah you feel like it is not pointless because you have actually done something” Isaac

“I am there to help myself but I like to be able to do some of the stuff that we do I like to be able to help” Laura

Feeling more confident, focusing on what you can do and being less self-critical:

“I think I am less, what's the word, dismissive of myself” Isaac

“if I am not as good as I expected I am quite hard on myself this is helping me sort of step away from the habit” Michael

“I feel much more confident yes” Danielle

“I think one thing I would say is that so far we've got we can all be downbeat about things and so on one thing about forestry is that it does show what you can still do almost so even if that is build a shave-horse or navigate your way from the car park to where you need to be” Matt

3. Feeling Good (or better)

“it's so enjoyable you and you just feel so much better driving home rather than driving down like not not that I’m driving either way but going home” Belinda

“I think it will give you more of a rush make you feel more alive” Ben

“I definitely felt happier and less anxious…I don't know whether it was because I was actually getting out and doing an activity that I I was part of and being outside is beautiful anyway we were lucky the weather was lovely...and the sea was lovely and the surroundings” Belinda

“I still suffer with depression but the group still helps it just brings you out and groups like this it’s like I said I wouldn’t like to think where I'd be if it wasn't for a groups like this” Zack

“sometimes when I’m in one of those kind of moods I have just the feeling that I am not worthy or you know quite often quite often as well which is unfortunate but I then sort of I think about the things the good thing is that I'm doing and that sort of makes me pick myself up again” James

4. Becoming motivated

“it's not just how can I say it it is just when you succeed at something when you success that was a big thing to succeed at once I succeeded then you look for the next challenge” Isaac

“it's given me goals as in all right I can join that group so like I am into kayaking but I don't go because none of my mates do it so why don't I go join a kayaking group” Michael

“think that now that I know that we I have been a big part of making something like this is spurred me on to do what's the next project” Sean

“It’s progress I don't want to stop there I am going to ask the guys I have forgotten their names I'm terrible the instructors how I can get a surfing instructor qualification yes see if I can do that” Ben

"that's why I come out and do things it's a charity isn't it you know what I mean so I have to do things for them you know what I mean it's like I said earlier you scratch my back I'll scratch yours and this place is helping me I wouldn't be where I am now if it weren't for this place do you know what I mean" Ryan

"so that's why why don't I I try and volunteer to be a helper so I can carry on… I think it's a hopefully good way to make friends" Ben

5. Attending groups reduces barriers to increased activity

"the biggest worry of that is yeah the time again and the anxiety of the new group but then I think if I did that with this group I can do with another group as well" Michael

"Yeah and I spoke to the people that were there as well which is good for me because I have lost all that I can't just go on to anybody and talk like I used to… yeah I enjoyed you know some of them are how can I say worse off than me because I I don't see myself as disabled or whatever I know I am obviously because I lose my words and I mix them up and I forget things but I felt quite comfortable because we were all the same and it was just nice…." Irene "So that kind of reduced some of those worries about being in a group" Interviewer "yeah" Irene

"once I was in the water I forgot about it (being part of a disability group) apart from it rubbing my neck but I forgot about it" Matt

"but then again when you meet the people who were either taking the training or the people like yourself it doesn't take long before you feel comfortable in the group" Zack

"I hope so I wouldn't say it's all of us because we are all on different abilities one of the guys now Zack he has got my number and he is on about he's in a position and he can drive he is on about going for a ride somewhere well I don't mind but it will have to be a cycle path so yes I think they will develop you know" Isaac

Appendix 19. Instructions for Authors for paper submissions to Disability and Rehabilitation

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.

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From 2018, this journal will be online only, and will no longer provide print copies.

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.

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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).

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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.

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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.

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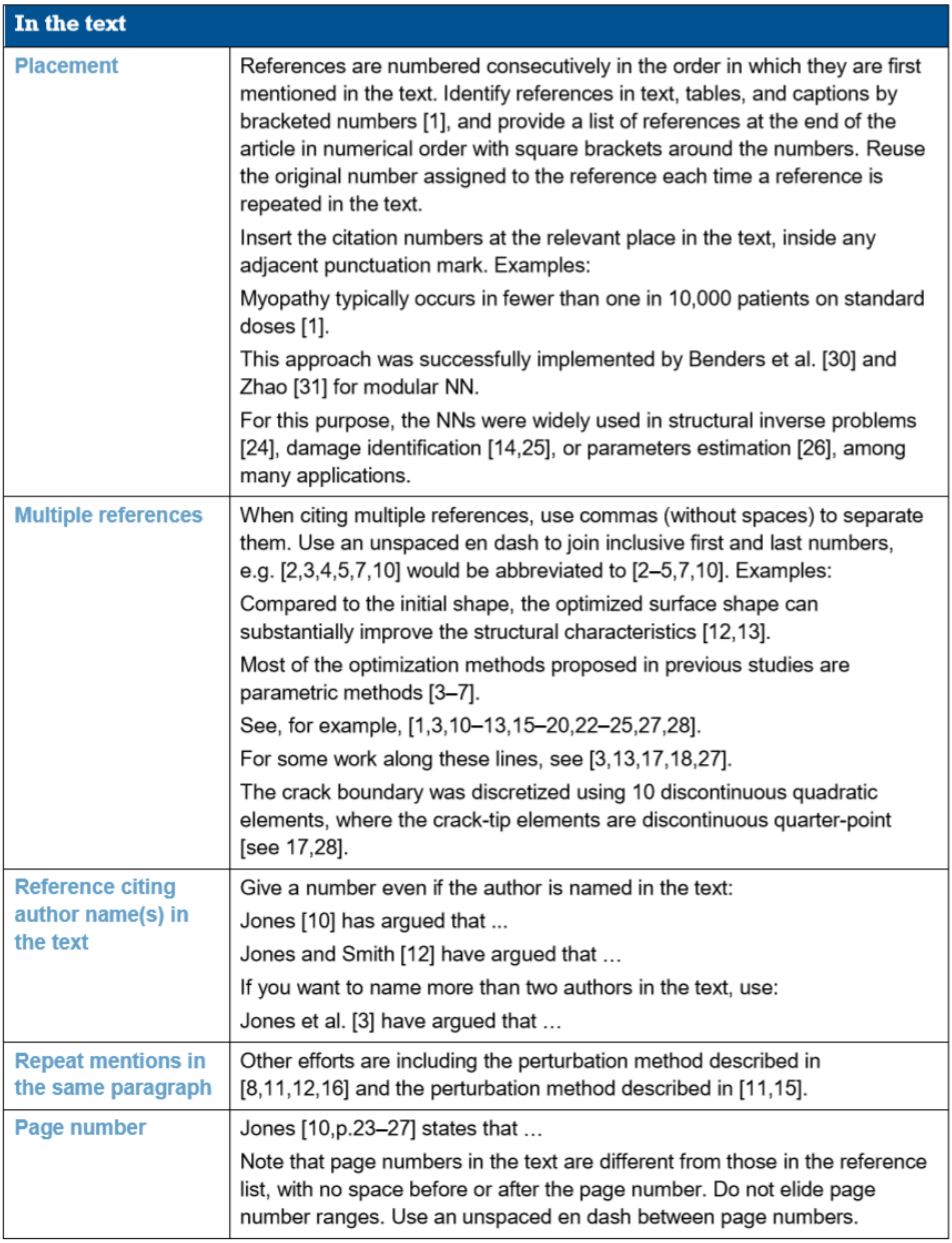
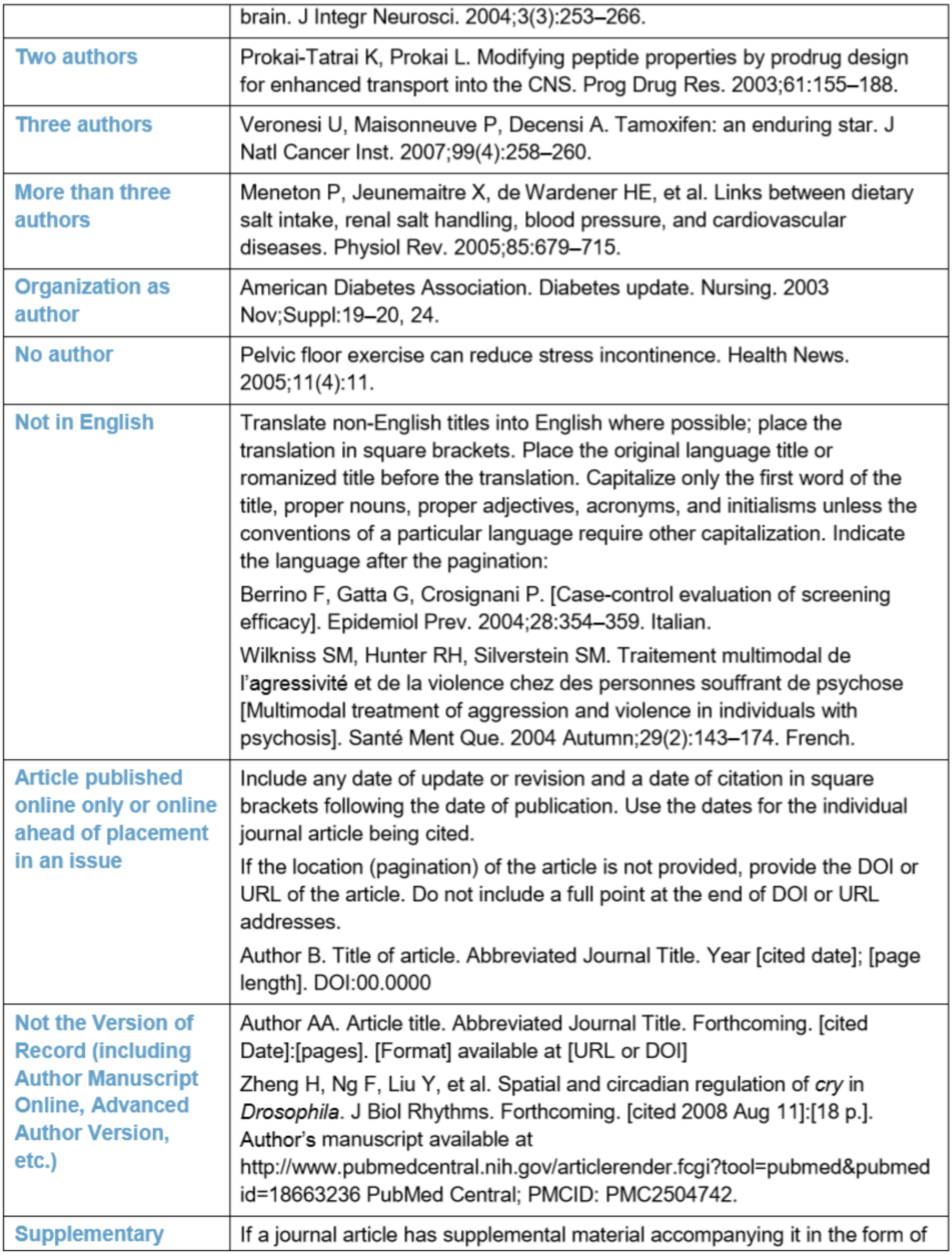


In the text	
Placement	References are numbered consecutively in the order in which they are first mentioned in the text. Identify references in text, tables, and captions by bracketed numbers [1], and provide a list of references at the end of the article in numerical order with square brackets around 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.
Multiple references	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].
Reference citing author name(s) in the text	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 …
Repeat mentions in the same paragraph	Other efforts are including the perturbation method described in [8,11,12,16] and the perturbation method described in [11,15].
Page number	Jones [10,p.23–27] states that … Note that page numbers in the text are different from those in the reference list, with no space before or after the page number. Do not elide page number ranges. Use an unspaced en dash between page numbers.

	In the text and in the reference list NLM uses p. rather than pp.
With a quotation	Author maintains that “This is author’s quoted text” [1,p.3].
Personal communication	References to personal communications are cited only in the text. … and most of these proved to be fatal (2003 letter from RS Grant to me; unreferenced, see “Notes”) …

Tables and figures	
Table and figure captions	References cited only in tables or figure captions should be numbered in accordance with the sequence established by the first identification in the text of the particular table or figure.

Reference list	
Order	Numerical order based on first appearance in the text.
Form of author name	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. See http://www.ncbi.nlm.nih.gov/books/NBK7282/ for further guidance.
Journal	
Journal titles	Journal titles are abbreviated according to ISO 4. See http://www.issn.org/services/online-services/access-to-the-ltwa/ Journal title abbreviations should not include full points, except at the end of the title; see examples below. Do not abbreviate journal titles consisting of a single word.
Issue numbers	The month is omitted if the journal is continuously paginated throughout the volume. The issue number can be omitted if the journal is paginated consecutively through the volume, but it is not incorrect to include it.
DOIs	There is no need to include the DOI numbers for published articles; they will be added as links in any online version of the article during the production process.
Basic format (with one author)	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 Integr Neurosci. 2004;3(3):253–266.
Two authors	Prokai-Tatrai K, Prokai L. Modifying peptide properties by prodrug design for enhanced transport into the CNS. Prog Drug Res. 2003;61:155–188.
Three authors	Veronesi U, Maisonneuve P, Decensi A. Tamoxifen: an enduring star. J Natl Cancer Inst. 2007;99(4):258–260.
More than three authors	Meneton P, Jeunemaitre X, de Wardener HE, et al. Links between dietary salt intake, renal salt handling, blood pressure, and cardiovascular diseases. Physiol Rev. 2005;85:679–715.
Organization as author	American Diabetes Association. Diabetes update. Nursing. 2003 Nov;Suppl:19–20, 24.
No author	Pelvic floor exercise can reduce stress incontinence. Health News. 2005;11(4):11.
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Supplementary	If a journal article has supplemental material accompanying it in the form of

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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.

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.

5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

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.

Example 2: Multiple Sclerosis

Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).

People with MS have complex reasons for choosing to exercise or not.

Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Acknowledgement. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .

Declaration of Interest. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a declaration of interest and how to disclose it.

Data availability statement. If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

Data deposition. If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.

Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

Units. Please use SI units (non-italicized).

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In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

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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.

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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.

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Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

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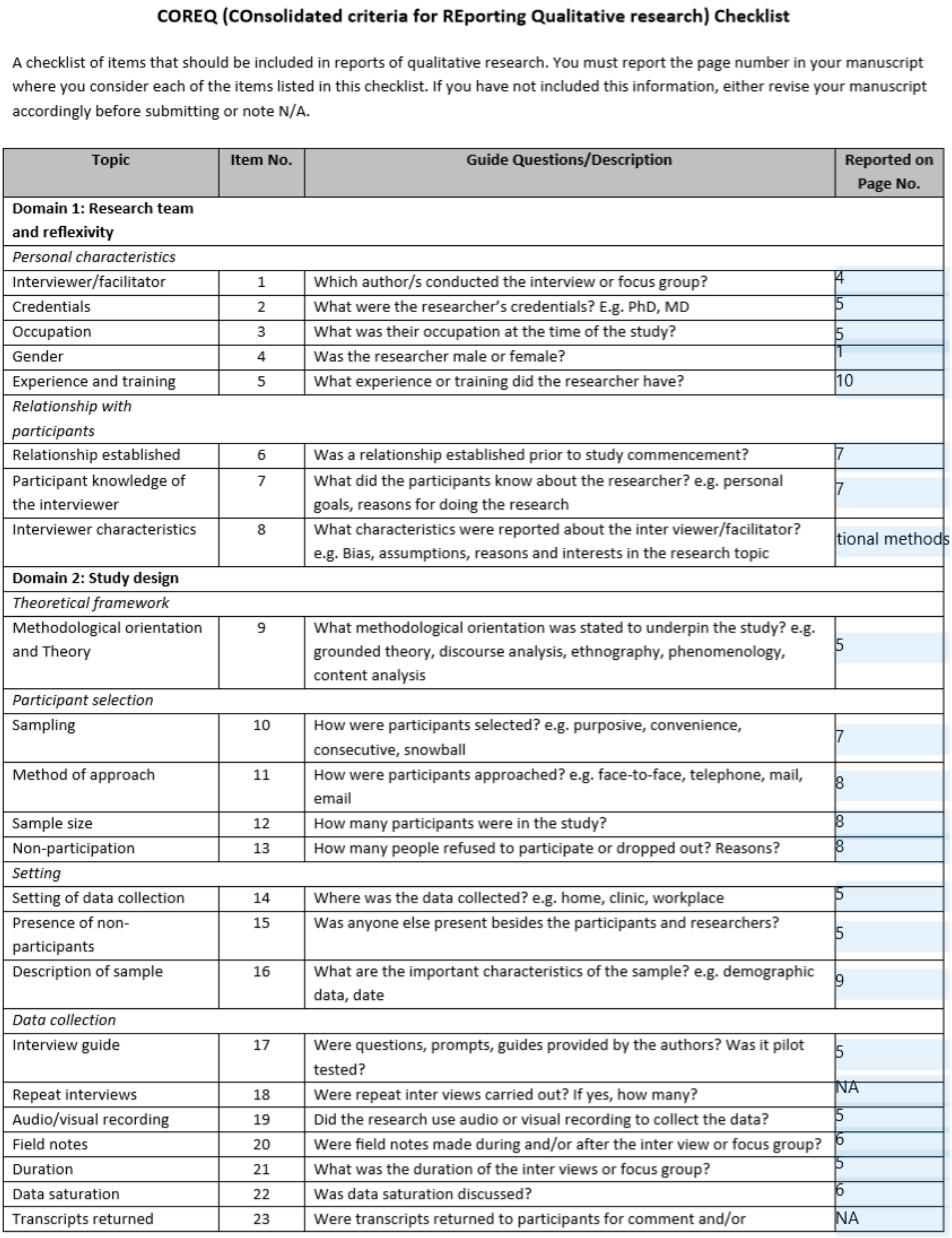
Appendix 20. COREQ checklist



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

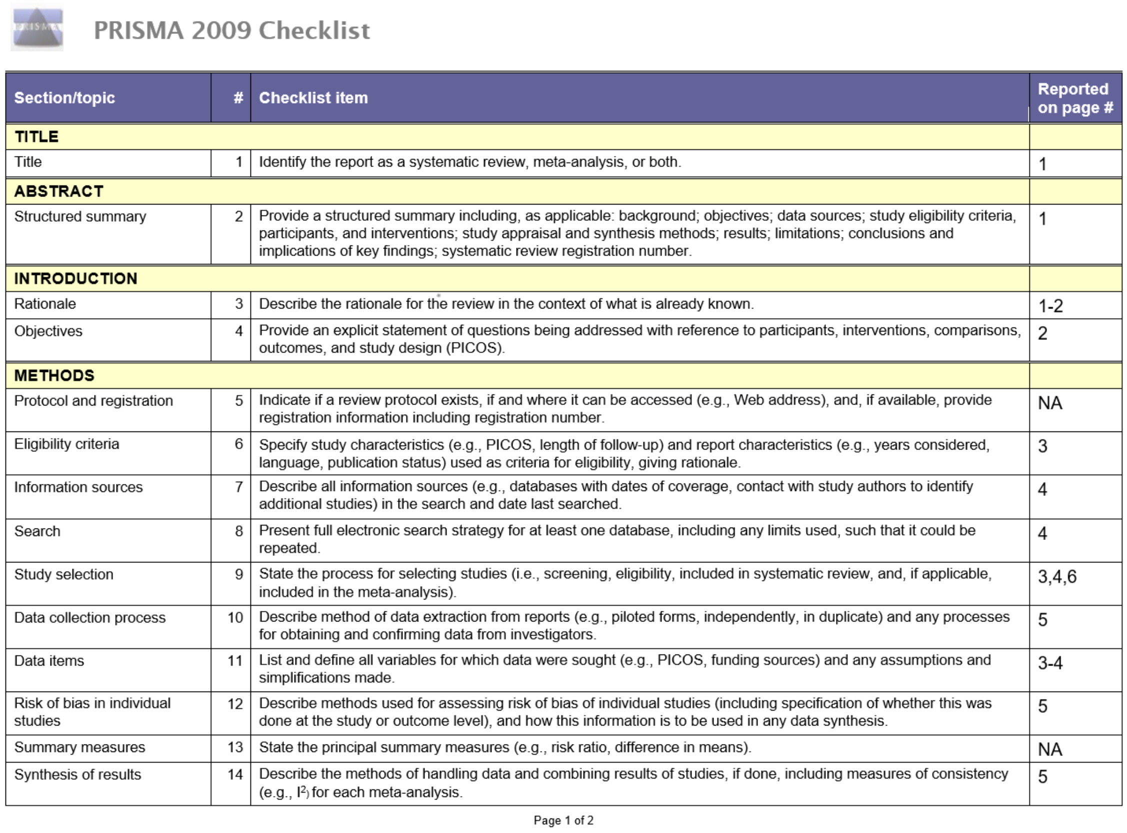
Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5
Occupation	3	What was their occupation at the time of the study?	5
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	10
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	tional methods
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	8
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NA
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	NA

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6-7
Description of the coding tree	25	Did authors provide a description of the coding tree?	11
Derivation of themes	26	Were themes identified in advance or derived from the data?	11
Software	27	What software, if applicable, was used to manage the data?	NA
Participant checking	28	Did participants provide feedback on the findings?	28
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	12-24
Data and findings consistent	30	Was there consistency between the data presented and the findings?	12-24
Clarity of major themes	31	Were major themes clearly presented in the findings?	12-24
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	12-24

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 21. PRISMA checklist



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	1-2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	3,4,6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	3-4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5

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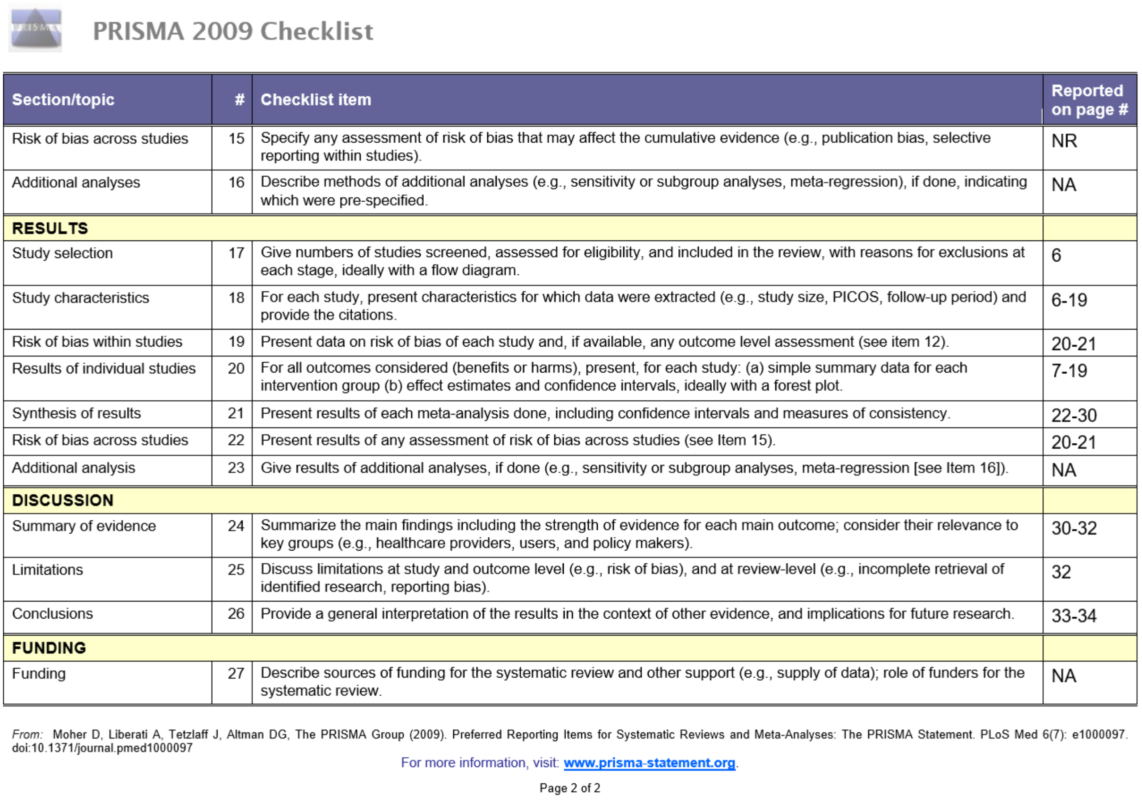

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NR
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	6-19
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	20-21
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7-19
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	22-30
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	20-21
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	30-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	32
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	33-34
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	NA

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. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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