Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

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Submitted May 2022

Thesis Portfolio Word Count (excluding appendices): 33,567

Thesis Portfolio Abstract

Context: Individuals living with Acquired Brain Injury (ABI) often face psychosocial difficulties, including social isolation which has been associated with poor physical and mental health outcomes.

Aim: The thesis portfolio aims to improve our understanding of processes and practices involved in maintaining and sustaining social connectedness following ABI.

Method: Mixed methods were used to address the research aim. The systematic review identified published interventions addressing social isolation and connection in adults with ABI and narratively synthesised their effectiveness. The empirical paper used a Grounded Theory approach to investigate the processes involved and practices used by individuals living with ABI, family members/carers and community ABI support people in maintaining and developing social connectedness.

Results: The systematic review identified eleven heterogenous interventions with variable study quality. Six of the eleven reviewed interventions showed some statistical difference or small effect size on measures assessing constructs related to social isolation or connectedness. The empirical study suggests four interlinked processes to be involved in developing and/or maintaining social connectedness: understanding of oneself and from others, acceptance of oneself and from others, rebuilding confidence and creating safe spaces. Practices used slightly differed both within and between participant groups.

Conclusion: The findings suggest how individuals can be best supported to maintain and sustain social connections following ABI by using strategies themselves and in their wider community, which proposes a framework to guide clinical practice. Further research is needed to develop and evaluate interventions addressing social connection and isolation.

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Acknowledgements

I would like to thank my supervisors, Dr Fergus Gracey and Dr Ciara Shiggins, for their continued support and encouragement throughout this research process. Your guidance, knowledge and enthusiasm for this project has been crucial for me completing this project. I would also like to thank my wider supervisory team, Julia Ajayi and Dr Zoe Fisher, for their support and ideas throughout this research process. I really appreciate all the time and support you gave me and enjoyed learning from you all.

I would like to thank all the participants for sharing their experiences with me, as well as everyone involved in the recruitment process. I truly value you taking the time to make this project happen.

Finally, I would like to thank my family, trainee colleagues and friends for your endless support and encouragement over the last three years. Thank you for keeping me going throughout this process.

Chapter 1. Introduction

The projects included in this thesis portfolio are part of a wider programme of research which focuses on wellbeing following Acquired Brain Injury (ABI). The research completed as part of the Doctorate in Clinical Psychology specifically focuses on social connectedness in individuals living with ABI and included a systematic review and empirical research project. This introductory chapter provides background definitions and information, which contextualise the research and information in the following chapters. Chapter two of the portfolio includes a systematic review of the literature investigating the elements and effectiveness of interventions addressing social isolation in individuals living with ABI. The empirical paper (chapter 3) reports the empirical research study, which is a qualitative exploration of the processes involved in maintaining and/or developing social connections following brain injury from the perspective of people living with ABI, family members/carers of people living with ABI, and community ABI support people. Both chapters are prepared for Disability and Rehabilitation. Chapter four provides an extended methodology for the empirical research study, which provides further information on the research design and process. The portfolio closes with an overall discussion and critical evaluation (chapter 5), which integrates the findings of both papers in the context of the wider literature. Wider implications for research and clinical practice are discussed.

Definition of Acquired Brain Injury

ABI is defined as an injury to the brain arising after a period of normal development, which is sustained through a variety of causes (Turner-Stokes et al., 2015), and leads to changes in the brain's functioning. There are two types of ABI: traumatic brain injury (TBI) and non-traumatic brain injury (Brain Injury Association of America, 2022). TBI is caused by external forces, such as road traffic accidents or falls, whereas non-traumatic brain injuries are caused by damage to the brain due to internal factors, such as a stroke, infection or tumour (Brain Injury Association of America, 2022).

In the United Kingdom, stroke is a leading cause of disability and death (Public Health England, 2018) and TBI is one of the most severe types of injury, in particular with regards to long-term impacts for individuals (Brazinova et al., 2021). In 2019, more than 1.3 million people were living with the effects of an ABI in the UK (UKABIF, 2019). More specifically, in 2016-17, there have been 132,199 UK hospital admissions for stroke and 155,919 admissions for head injury (Headway, 2022). ABI admissions have increased by 10% since 2005-6 (Headway, 2022) and it has been estimated that the number of strokes will increase by 60% between 2015 and 2035 (King et al., 2020).

Outcomes of Acquired Brain Injury

ABI can lead to a range of difficulties, depending on the nature and area of the injury (Turner-Stokes et al., 2015) and can result in temporary or permanent physical, cognitive, behavioural, communication and/or emotional changes, affecting all areas of the individual’s life (Abrahamson et al., 2017).

Cognitive and communication difficulties are common following ABI (Hilari et al., 2021; van Heugten et al., 2012). Aphasia is a specific language impairment that affects approximately one third of individuals with acute stroke and about 16-30% of the stroke population experience aphasia long-term (Hilari et al., 2021). Cognitive-communicative difficulties, as well as social communication problems, are commonly described following TBI (Dahlberg et al., 2006; Shorland & Douglas, 2010) and can lead to difficulties in activities of daily living and participation in the community (van Heugten et al., 2012).

Psychological and interpersonal changes have often been reported as long-lasting challenges that individuals with ABI face (Proctor & Best, 2019). Andelic and colleagues (2010) described that nearly half of the participants with ABI in their study experienced poor psychological wellbeing at one-year post-injury. In addition, a study by Proctor and Best (2019) found that nearly 48% of participants with ABI experienced moderate to severe depression. Psychological needs appear to be greater for individuals who experience communication difficulties following stroke with 62% of individuals with aphasia reporting depression one-year post-stroke (Kauhanen et al., 2000). While individuals with ABI are at greater risk of developing depressive disorders compared to the general population, they have also been found to be at greater risk of death by suicide (Kreutzer et al., 2001).

Physical, communication, cognitive and behavioural changes can impact individual's relationships (Shorland & Douglas, 2010) and lead to challenges in social interactions (Andelic et al., 2010). This can result in difficulties for individuals with ABI to maintain old and/or develop new social connections. In fact, seventy percent of people living with ABI experienced a decline in their social life after injury (Headway, 2022). In individuals who had a stroke, the loss of friendships and social groups has often been reported (Haslam et al., 2008). In stroke survivors with aphasia, social networks frequently become smaller with family members becoming their key contacts (Hilari & Northcott, 2017). This suggests that individuals living with ABI often experience social isolation.

In this thesis, Cornwell and Waite’s (2009) definition of social isolation will be used. It describes two components of social isolation: objective isolation, which describes small social networks, lack of participation in group activities, or infrequent social interactions; and perceived social isolation, which is a person's subjective experience of social disconnect (Cornwell & Waite, 2009). Social isolation has been linked to poorer physical and mental wellbeing in the general population, as well as in people with ABI (Dhand et al., 2019; Proctor & Best, 2019), suggesting an increased risk of poor physical and emotional health outcomes for people living with ABI who feel socially isolated. On the contrary, social connectedness has been linked to more positive life outcomes (Haslam et al., 2015).

Wellbeing Following Acquired Brain Injury

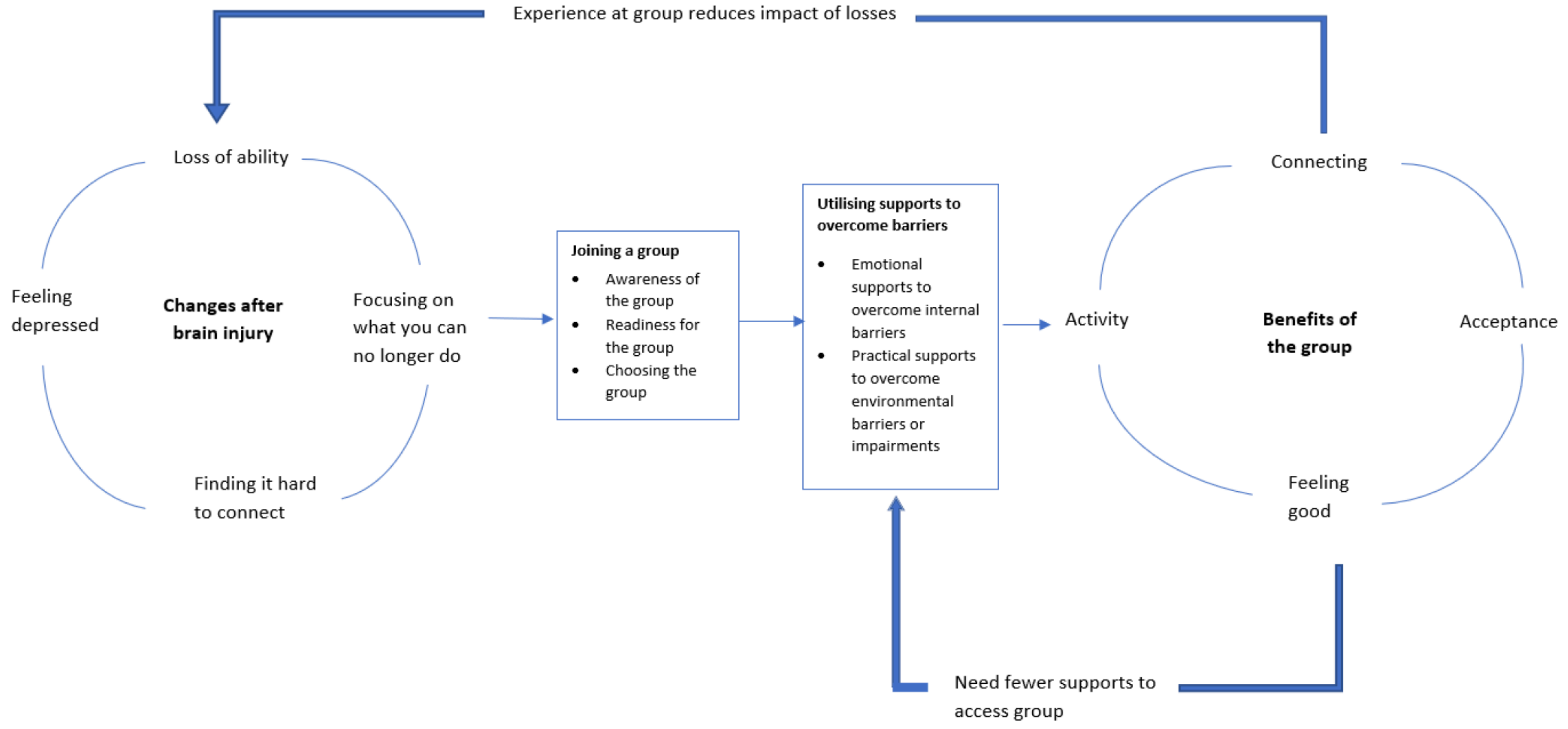
Due to poor social and psychological outcomes associated with ABI, it is important to understand how individuals living with ABI can be best supported. There are several models proposing factors important to wellbeing. Seligman’s (2011; 2018) psychological model of wellbeing, the PERMA model, suggests five pillars of wellbeing: Positive Emotions, Engagement, Relationships, Meaning and Accomplishment. Based on this model, positive psychology interventions have been developed to support individuals to flourish in life (Wilkie et al., 2021), which showed promising outcomes in the ABI population (Andrewes et al., 2014; Tulip et al., 2020).

A biopsychosocial model of wellbeing, the GENIAL model (Genomics, Environment, vagus Nerve, social Interaction, Allostatic regulation, Longevity; Fisher et al., 2019; Kemp et al., 2017), highlights the main domains of wellbeing across different levels, namely the individual domain (balanced mind and healthy body), the community domain (social connectedness) and the environmental domain (connection with nature; Gibbs et al., 2022). It emphasises that wellbeing is influenced by socio-contextual factors outside the individual's control and suggests that a psychophysiological underpinning, the vagal function, contributes to one's ability to connect to self, others and the natural environment (Gibbs et al., 2022). It is in line with recent developments from the field of positive psychology (Wong, 2019) and psychosocial interventions grounded in this understanding of wellbeing have been shown promising results for individuals living with ABI (Gibbs et al., 2022; Wilkie et al., 2021).

Previous research by the trainee's supervisory team investigated how individuals access community groups following brain injury and how attending these community groups can affect wellbeing (Berger, 2020) by interviewing individuals living with ABI. It found that attending these groups enhances wellbeing by providing opportunities for social connection, acceptance and experiencing positive emotions (Berger, 2020), which is in line with the PERMA model (Seligman, 2011; Seligman, 2018). In addition, the research suggests that attending these groups has a positive effect on wellbeing and social connection and can be motivating, leading to a virtuous cycle of increased activity and connection (Figure 1.1; Berger, 2020).

Figure 1.1

Grounded Theory Model of How People Access Community Groups In Order To Enhance Their Wellbeing (Berger, 2020)



Aims of the Thesis Portfolio

The current thesis portfolio is part of ongoing research focusing on how wellbeing is achieved after ABI. Relationships and social connectedness play an important role in wellbeing (e.g., PERMA model; Seligman, 2011) and we, therefore, aim to enhance our understanding of social connectedness with the objective of developing a resource that will facilitate social connections for those living with ABI. Intervention mapping (IM; Bartholomew-Eldredge et al., 2016) is used to structure the ongoing research within a coherent framework. IM is a recognised approach for the development of health and wellbeing interventions and is characterised by the involvement of relevant stakeholders. It involves six steps covering the identification of the problem, what and who needs to change, drawing on methods and theory to facilitate change, as well as designing, implementing and evaluating the intervention (Bartholomew-Eldredge et al., 2016).

In line with steps two, three and four of the IM framework, the thesis aims to increase our understanding of available interventions addressing social connection and isolation for adults living with ABI, as well as of the processes involved in, and practices used by, individuals living with ABI, family members/carers and community ABI support people to maintain and/or develop social connections following ABI. The specific research questions for the systematic review and the empirical research study are outlined in chapters 2 and 3 respectively.

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

Effectiveness of interventions addressing social connection and isolation for people with acquired brain injury: a systematic review

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Abstract

Purpose: Social isolation is a common consequence of acquired brain injury (ABI) and can have long-term negative effects on individuals' physical and mental health. This systematic review aims to identify interventions addressing social isolation and/or social connection for people living with ABI, detail the key elements of these interventions and synthesise their effectiveness.

Method: Four databases (PsycINFO, MEDLINE, CINAHL, EMBASE) were systematically searched. Articles were screened based on predefined eligibility criteria; quality/risk of bias assessment was carried out for all included articles; elements of interventions were identified based on the Template for Intervention Description and Replication checklist (TIDieR) [1] and the interventions' effectiveness was synthesised narratively.

Results: Eleven intervention studies were included. Not all interventions reported on all eleven elements of the TIDieR checklist. Six of the eleven reviewed interventions showed some statistical difference or small effect size on measures assessing constructs related to social isolation or connectedness. Interventions, study designs and quality of studies varied.

Conclusions: Variable study quality and intervention types made it difficult to draw firm conclusions about the effectiveness of the interventions. Results suggest that social support intervention could be effective in addressing social isolation/connection. More research is needed to develop interventions addressing social isolation and to evaluate their effectiveness.

Introduction

Acquired brain injury (ABI) describes several conditions that impact on individuals’ health and quality of life [2]. ABI can be caused by a variety of aetiologies including stroke and those living with ABI can present with a variety of resultant presentations, such as physical, cognitive or emotional difficulties [3], which can occur in a variety of combinations and severities. It can significantly affect survivors’ social connections, with social isolation being a long-term effect of ABI [4]. In fact, seventy percent of individuals experience a decline in their social life after injury [5]. Loss of friendships, social groups and social support [6, 7] as well as a decline in friendship quality [8] have been reported. In addition, the structure of social networks has also been reported to change with family members becoming key contacts [9] and in one study, 30 percent of participants described having no social contacts outside their family [10].

Cornwell and Waite [11] described two components of social isolation: objective and perceived social isolation. Objective social isolation is defined by small social networks, infrequent social interactions or lack of participation in group activities, whereas perceived social isolation is defined as a person's subjective experience of social disconnect [11]. Both types of social isolation have been described in the ABI population [6-8]. Conversely, social connectedness describes the sense of belonging and the subjective bond people feel towards other individuals and groups [12].

There are various factors contributing to social isolation following ABI. Some factors are directly linked to the impairments as a result of the individual’s injury. Post-injury difficulties, such as cognitive changes, or perceived changes in functioning have been found to contribute to an individual’s ability and confidence to engage in social roles and activities [9, 13]. Aphasia can lead to communication barriers, which can impact social relationships and lead to social isolation [14]. Other barriers are related to the individual's environment. For example, research has highlighted that lack of transport, or the inability to use transport independently, as well as financial strains due to changes in employment, can create barriers to engagement in social activities and remaining socially connected in the community [15]. Environments where individuals with ABI do not feel accepted or face negative attitudes from others can also contribute to feelings of social isolation [4, 16].

Social isolation and loneliness can have detrimental effects on an individual's sleep, executive function, mental health as well as physical health [17] and mortality [18]. It has been found to be one of the greatest subjective burdens for people with traumatic brain injury (TBI), leading to psychological distress post-stroke [19] and suggested to increase the risk of a second adverse event in stroke survivors [20]. On the other hand, a sense of belonging to social networks after ABI has been found to have a positive impact on adjustment and life satisfaction post-injury [6], as well as the individual's recovery [21].

Social isolation has been recognised in the general population as a public health problem, which led the UK government to consider social isolation as a public health and social care priority [22, 23]. Several literature reviews on strategies to reduce social isolation and/or loneliness have been carried out across different populations, including older adults, students, widows and individuals with severe mental health difficulties [24]. Based on these reviews, Masi and colleagues [25] identified four primary strategies to reduce social isolation that were appraised in the literature: improving social skills, including communication; enhancing social support; increasing opportunities for social interaction; and addressing maladaptive social cognition. Similar strategies have been used in interventions for individuals living with ABI [26, 27]. However, this work was not based on literature including those living with ABI and no systematic review on interventions addressing social isolation post ABI has previously been completed.

Given the high prevalence and negative impact of social isolation on people living with ABI's physical and mental wellbeing, there is a great need to support people to maintain and/or develop new relationships. Therefore, this systematic review aimed to identify and collate studies investigating interventions addressing social connection and isolation specifically for adults living with ABI. Three specific review questions were developed:

1. Which interventions, formally evaluated through peer reviewed research, address social connection and isolation for adults living with acquired brain injury?
2. What are the key elements of these interventions that address social connection and isolation for adults living with acquired brain injury?
3. What is the evidence of effectiveness of these interventions in reducing social isolation or enhancing social connection in adults living with acquired brain injury?

Methods

This systematic review was completed following the five steps proposed by Khan and colleagues [28]: 1) frame the questions for the review; 2) identify relevant work; 3) assess the quality of studies; 4) summarise the evidence; and 5) interpret the findings. The systematic review was registered on the International Prospective Register of Systematic Reviews (PROSPERO; CRD42021251167).

Eligibility Criteria

Studies were included if they investigated interventions with the primary or secondary aim of reducing social isolation or enhancing social connection, which might have been through improving social participation, for adults over the age of 18. Interventions were defined as any action taken to target social isolation (including, but not limited to, psychological therapy, befriending programmes, digital technology, support and/or community groups). Articles were included if outcomes were evaluated quantitively by using measures of social isolation as defined by Berger and colleagues [29] , using Cornwell and Waite's definition of social isolation and the World Health Organisation's International Classification of Functioning's [30] description of activities and participation. Cornwell and Waite's definition of objective and perceived social isolation [11] suggest that measures of social network size, social participation and interaction could be used to identify individuals who are socially isolated. However, as some measures of social isolation focus on social interactions alongside other community activities, Berger and colleagues [29] suggested using the World Health Organisations International Classification of Functioning's [30] description of activities and participation to determine eligibility of outcomes measures. The Interpersonal Interactions and Relationships domain investigates individual's ability to participate in interpersonal interactions and suggests that if people do not have interactions with others, they are not participating socially and, therefore, are socially isolated. Based on this, measures were included in this review if they specifically captured the number or frequency of social interactions. Measures of community, social and civic life were not included, as the ICF's description of this construct is more closely linked to participation in activities themselves rather than to social connection and/or isolation. Measures assessing loneliness or perceived feelings of social isolation were included, as they are in line with Cornwell and Waite's [11] definition of subjective social isolation. However, measures focussing on other aspects of relationships, such as relationship satisfaction or quality, were not included in the review. Overall, measures of participation that assess the number or frequency of social interactions, measures assessing loneliness, perceived feelings of isolation, social connection or belonging, or measures of social network sizes were included. Mixed-methods studies were included if the quantitative data was in line with eligibility criteria and could be analysed separately. Studies were included if the intervention was compared to an alternative intervention (i.e., treatment-as-usual, waitlist control, or alternative interventions) or if there was no comparison group (i.e., uncontrolled studies, pre-post design studies).

Studies were excluded if they used a qualitative methodology or were a meta-analysis or systematic review. Articles with participants under the age of 18 were not included unless the study included both children and adults and data relating to participants over the age of 18 were analysed and presented separately. If studies did not use measures of social isolation or connectedness, or if the measures assessed community or social life, generic community participation (unless a subscale measured social isolation) or social relationships where the primary focus was not on perceived feelings of isolation or social connection, they were not included in the review. Articles not published in peer-reviewed journals or not in English were also excluded. Conference abstracts about unpublished research were excluded.

Identifying Relevant Studies

To identify relevant studies, search terms were developed based on the research questions, eligibility criteria, and in collaboration with a librarian. Search terms were in line with the concepts ‘brain injury’ and ‘social isolation’ and relevant MeSH terms were used (Appendix A). The concept ‘intervention’ was not used as a search term to ensure no relevant papers were missed. A comprehensive, systematic search was conducted on the following databases for appropriate studies published in peer-reviewed journals using keyword searches and Boolean operators: PsycINFO (1859-present), MEDLINE (1949-present), CINAHL (1971-present) and EMBASE (1974-present). The search syntax was adapted for each database. Searches were limited to articles published in English, to human research and to adults (18+ years) and were carried out until August 2021. Once duplicates were removed, titles and abstracts were screened, based on the predefined eligibility criteria, by the lead author (LW) and ten percent of papers were screened by a second reviewer (LJW) at each step. Differences were discussed at each stage to reach consensus. The lead author’s supervisors (FG and CS) were consulted on the eligibility of two outcome measures (Social Functioning Scale [31] and Sense of Belonging Instrument [32]) used, both of which were included based on relevance due to network size and underlying construct. Studies were excluded if they had no detailed information about the intervention available from published work or by contacting the researchers. Reference lists of articles that were included after full-text screening were searched for further relevant journal articles.

Risk of Bias (Quality) Assessment

Risk of bias or study quality was assessed for each study using quality appraisal tools appropriate for the study design. The Cochrane Risk of Bias tool 2 (RoB 2.0)[33] was used for randomised controlled trials (RCT), the National Heart, Lung, and Blood Institute (NIH) Quality Assessment of Pre-Post Studies [34] was used for pre-post intervention studies, and the NIH Quality Assessment for Case Series Studies [35] was used for case series research studies. Two reviewers (LW, LJW) independently reviewed all articles using the risk of bias and quality assessment tools. Differences in the researchers' ratings were discussed to reach consensus.

Data Extraction

Relevant data were extracted with regards to general study information (i.e., authors, title, country of origin, study design, outcome measures, results) and participant characteristics (i.e., sample size, age, gender, type of brain injury). Key elements of interventions were extracted using the Template for Intervention Description and Replication (TIDieR) [1]. A data extraction table was developed for this review (Table 2.1), which was discussed with the wider research team (CS, FG). Effect sizes were extracted when reported and calculated, where possible, if not reported.

Data Synthesis and Analysis

A narrative synthesis was conducted to summarise available interventions addressing social isolation, their key elements as categorised by the TIDiR checklist [1] and their effectiveness. Narrative synthesis was used to aggregate intervention outcomes following Popay and colleagues' [36] procedures and was divided in terms of type of intervention and target population. A meta-analysis of intervention effectiveness was not deemed appropriate due to the heterogeneity of evidence [37].

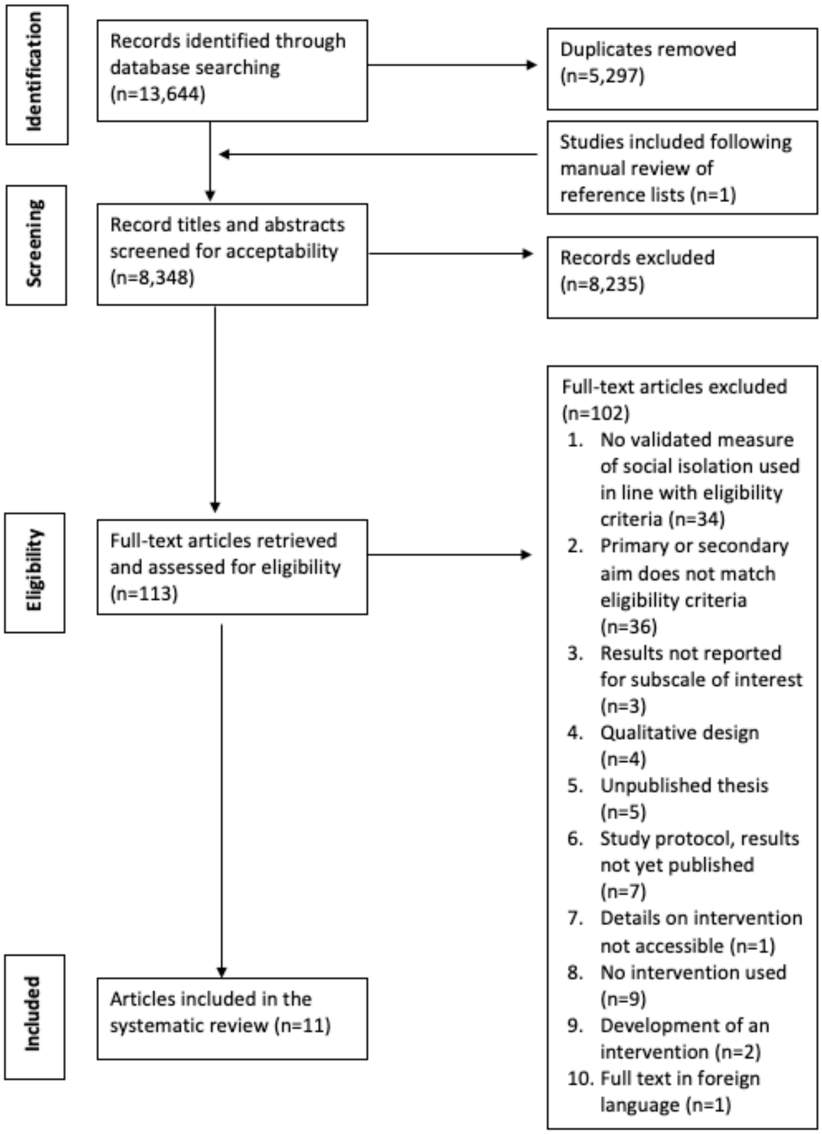
Results

Search Results

The search yielded 13,644 studies and 8348 studies were included after duplicates were removed. The PRISMA [38] flow diagram (Figure 2.1) shows the number of studies included at each stage of the systematic review and reasons for exclusion. A total of eleven studies met the eligibility criteria and were included in the review. Details of these studies can be found in Table 2.1.

Figure 2.1

PRISMA flow diagram



Study Characteristics

Across the eleven included studies, there were a total of 293 participants with ABI. Of all participants, 152 had experienced a TBI and 141 had post-stroke aphasia. Seven interventions were designed for participants with aphasia following stroke [27, 39-44] and four for participants with TBI [45-48], with sample sizes ranging from 1 to

67 . Six studies used a randomised controlled trial (RCT) design [27, 39-41, 45, 46], one of which was a feasibility RCT [27] and one a pilot RCT [45]. Four studies used a pre-post intervention design with no control group [42-44, 47], two of which were pilot pre-post studies [42, 43] and one study used a case series design [48]. Five studies were conducted in the United Kingdom [27, 40-42, 44], five were conducted in the United States of America [39, 45-48] and one study was conducted in Australia [43]. Three different types of interventions were used: social support interventions [27, 43, 45, 47, 48], communication interventions [39-41, 44, 46], and psychological interventions [42]. Nine different measures of social isolation were used across the included studies, four of which were measures of subjective social isolation, four were measures of objective social isolation and one measure assessed both subjective and objective social isolation. A detailed description of social isolation measures can be found in the supplementary table in Appendix B.

Risk of Bias

Six studies were assessed for risk of bias using the RoB 2.0 [27, 39-41, 45, 46], four studies using the NIH Quality Assessment of Pre-Post Studies [42-44, 47], and one study using the NIH Quality Assessment for Case Series Studies [48]. The ratings of all included studies are presented in three tables in Appendix C.

The RCTs included in this review were assessed to have a low risk of bias [27], some concerns [41] and a high risk of bias [39, 40, 45, 46]. Two studies had a high risk of randomisation bias [40, 46] and there were some concerns of risk of bias for two studies due to deviations from the intended protocol [45, 46]. One study posed a high risk of bias due to missing outcome data because of high participant attrition [39]. There was a high risk of bias in the measurement of outcomes for two studies [40, 45] and two studies were assessed to pose some concerns regarding the selection of the reported results [39, 45], as some information, including the analysis plan, were not reported.

Two pre-post design studies [41, 45] were rated as fair and two as poor [40, 42] on the assessment tool [34]. All four studies had a relatively small sample size, which led to difficulties of robust statistical analyses for one study [42]. One study had a high attrition at follow-up [43] and one study did not report any follow-up data [47].

Johnson and Davis [48] was the only case series design study and it was rated as poor. Due to a small sample size only descriptive, rather than inferential statistics, were used. There was some variation between participants and a count of contacts rather than a validated and reliable outcome measure was used.

Table 2.1

Study characteristics

Author, Country	Intervention used	N (Total n; n male and female)	Age Mean (SD)	Ethnicity	Type of ABI	Study design	Measure assessing social isolation (S)/O)	Results	Quality appraisal tool (1, 2, 3) and score
Hilari et al., 2021 UK	6 (or more) peer befriending sessions including skills practice (e.g., goal setting, problem solving) (Supporting wellbeing through peer-befriending; SUPERB)	People with aphasia total n=56 Intervention group: n=28 (15 male, 13 female) Control group: n=28 (14 male, 14 female) Significant others n=48 Peer befrienders n= 10	People with aphasia - Intervention group 70.5 (13.7) Control group 69.7 (13.4),	People with aphasia: Intervention group - Asian (n=1), Black (n=11), White (n=15), Mixed (n=1) Control group - Asian (n=1), Black (n=3), White (n=23), Mixed (n=1); Peer befrienders: white (n=6), other (n=4)	Stroke	single-blind parallel-group feasibility RCT	Friendship Scale [49] (S)	The Friendship Scale showed a small benefit of the intervention over the control group at 4 months (estimated difference -1.18, CI [-3.56, 1.20]) and 10 months (estimated difference -0.65, CI [−3.03, 1.73]) with a lower score suggesting clinical improvement. However, these comparisons should be interpreted cautiously as a difference of zero cannot be ruled out. Estimated differences represent the point differences on the scales between treatment and control groups after adjusting for the baseline scores.	1; low risk of bias

		(8 male, 2 female							
Marshall et al., 2016 UK	Daily, individual sessions for interaction and communication skills in a virtual reality (EVA park)	Total n=20 Immediate treatment group n=10 (6 male, 4 female) Waitlist control group n=10 (5 male, 5 female)	Immediate group: 59.0 (13.61) Waitlist control group: 56.6 (9.73)	not reported	Stroke	Quasi-RCT	Friendship Scale [49] (S); Social Network Analysis [50] (O; not used for analysis)	There were no significant effects found in the mixed or one factor ANOVA for scores on the Friendship Scale. The data from the Social Network Analysis was not analysed due to high levels of variability over testing occasions, which appeared to be due to participants' naming difficulties.	1; high risk of bias
Marshall et al., 2020 UK	14 communication group sessions in a virtual reality (EVA park)	Total n=34 Immediate group n=16 (12 male, 4 female) Delayed group n=18 (5	Immediate group median: 51 (IQR 46.5-57.5) Delayed group median: 65 (IQR: 51.5-71.25)	not reported	Stroke	Randomised, waitlist-controlled design	Social Connectedness Scale-Revised (SCS; S)) [51]	Mean (SD) of the SCS for the immediate group across 3 timepoints: T1: 83.87 (17.20), T2: 88.12 (17.04), T3: 89.43 (15.03); Mean (SD) of the SCS for the delayed group across 3 timepoints: T1: 81.22 (17.77), T2: 85.00 (17.16), T3: 86.65 (16.76); between group difference at T2: F(1, 31)=.09, p = .77, $\eta_p^2 = .003$ After adjusting for T1 scores, there was no significant different between immediate and delayed EVA recipients at T2.	1; some concerns

		male, 13 female)							
Northcott et al., 2015 UK	3 to 5 sessions of Solution focused brief therapy	n=5 (3 male, 2 female)	Age range: 40-75	Asian: 1; Black: 2; White: 2	Stroke	Proof-of-concept feasibility study using a mixed-methods pre-post design	Friendship Scale [49] (S); Stroke Social Network Scale [52] (S, O)	Friendship Scale: pre-therapy mean (SD): 16.6 (3.91), post-therapy mean (SD): 17.6 (4.5), (Cohen's d = 0.27 calculated by the review's author); Stroke Social Network Scale: pre-therapy mean (SD): 61.48 (10.74), post-therapy mean (SD): 61.45 (16.59), (Cohen's d = 0.0024 calculated by the review's author). No significance testing was carried out.	2; poor
Tamplin et al., 2013 Australia	Weekly choir rehearsal ("Strike a Cord")	n=13 (10 male, 3 female)	58.3 (13.8)	Not reported	Stroke	Pilot, pre-post study	Sense of Belonging Instrument - Psychological Experience subscale [32] (S)	No inferential statistics used due to small n. Means (SD) reported as follows: SOBI Psychological Experience at baseline: 36.4 (9.2), at 12 weeks: 37.6 (10.9), Cohen's d = 0.24; at 20 weeks: 35.9 (10.2), Cohen's d = 0.1	2; fair
Caute & Woolf, 2016 UK	16 sessions of using Voice recognition software to compensate for written communication difficulties	n=1 (male)	61	Not reported	Stroke	Repeated measures, single case design	Social Network Analysis [50] (O)	Increase in social network from 30 (pre-therapy) to 75 (post-therapy) to 77 (8-weeks post therapy) with the biggest increase in workmates due to starting a new voluntary role and reconnecting with previous workmates. Frequency of weekly (1 pre- to 33 8-weeks post-therapy) and fortnightly (5 pre- to 23-weeks post-therapy) contact increased the most. Biggest increase in type to contact for see/visit them (27 pre- to 59 8-weeks post-therapy) and emails (0 pre- to 43 8-weeks post-therapy).	2; poor

DeDe et al., 2019 USA	20 sessions of aphasia conversation treatment (in group or pair-setting)	Total n=46 Large group n=15 (11 male, 4 female) Dyad n=16 (12 male, 4 female) Delayed n=15 (9 male, 6 female)	Delayed treatment: 65.8 (11.9); Dyad: 65.6 (9.4); Large group: 61.4 (14.3)	Not reported	Stroke	Multi-centre, parallel-group RCT with delayed treatment control group and balanced randomisation	Lubben Social Network Scale-6 [53] (O)	No statistically significant changes on Lubben Social Network Scale. Delayed treatment group: Pre: 16.4 (8.1) Post: 14.7 (6.7) 6 weeks: 15.7 (6.5); Dyads: Pre: 18.3 (7.9) Post: 17.4 (7.0) 6 weeks: 16.6 (6.0) 11 months: 16.7 (7.5); large group: Pre 17.1 (6.5) Post: 16.0 (6.5) 6 weeks: 15.9 (6.5) 11 month: 15.8 (6.3)	1; high risk of bias
Dahlberg et al., 2007 USA	12 group social communication skills sessions	n=52 Treatment n=26 (19 male, 5 female) Delayed treatment n=26 (25 male, 1 female)	Treatment - 42.43 (11.86) Delayed treatment - 39.91 (11.40)	Treatment - 92.3% White, 3.8% African American, 3.8% Hispanic; Delayed treatment - 84.6% White, 7.7% African American, 7.7% Hispanic	TBI	RCT with deferred treatment	Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF) social integration (SI) [54] (O)	No significant difference found between baseline measures and 12-week post-treatment and no-treatment for CHART-SF SI self-reported ($p = .804$) and significant other reported ($p = .394$). No significant differences found between outcome ratings collected at baseline, post-treatment ($p = .922$), 3 months post-treatment ($p = .164$), and 6 months post-treatment ($p = .451$) for CHART-SF SI self-reported and between outcome ratings collected at baseline, post-treatment ($p = .374$), 3 months post-treatment ($p = .122$),	1; high risk of bias

								and 6 months post-treatment (*p* = .882) for significant other reported.	
Struchen et al., 2011 USA	6 (or more) social peer-mentoring sessions	Peer partners total n=30 (24 male, 6 female; (active peer mentoring n=12; wait-list n=18) Social peer mentors n=11 (7 male, 4 female)	peer partners: 31.7 (11.7); mentors: 36.3 (13.1)	Peer partners: 7 Black, 8 Hispanic/Latino, 1 other, 14 White Mentors: 1 Black, 1 Hispanic/Latino, 0 other, 9 White	TBI	Pilot RCT	UCLA Loneliness Scale-Version 3 [55] (S); Craig Handicap Evaluation and Reporting Technique-Short Form (CHART-SF) Social Integration subscale [54] (O)	There was no significant main or interaction effect for the CHART social integration scores F(1, 25) = 2.10, p = .16; however, changes in mean were in the predicted direction for the intervention group, though not statistically significant (baseline scores mean (SD) = 68.5 (24.3); post mentoring scores mean (SD) = 79.8 (29.3)). No significant main or interaction effects were observed for the UCLALS-3, F(1,25) = 3.0, p = .10 (baseline scores mean (SD) = 43.7 (12.0); post mentoring scores mean (SD) = 42.5 (13.2)).	1; high risk of bias
Johnson & Davis, 1998 USA	4 (or more) supported relationships sessions	Participants n=3 (1 male, 2 female) Community partners n=12	Participants 30.33 (5.69) Community partners: 28	Not reported	TBI	Multiple baseline design	Frequency of integrated social contacts (ISCs) Johnson and Davis [48] (O)	Means of weekly ISCs during baseline, intervention, follow-up 1 and follow-up 2 presented per participant: Participant 1: 1.75, 5, 5.25, 4.5; Participant 2: 2.2, 4.25, 4, 2.75; Participant 3: 0, 3, 1.3, drop-out. Reported the intervention to be “mildly effective in increasing the number of ISCs”.	3; poor

Lawrence et al., 2017 USA	26-week volunteering programme (The Mission Continues Fellowship Program)	Total n=67 (59 male, 7 female)	age 22-40: 61; age 41-55: 6	White/Caucasian: 44; Black/African American: 10; Asian/Pacific Islander: 1; Native American/Alaskan Native 2; Multiracial/ Biracial: 3; Other race: 7; Hispanic/Latino: 12	TBI	Pre-post study	UCLA Loneliness Scale-Version 3 [55] (S)	Results based on n=62, mean (SD) pre-intervention: 48.6 (11.9), post-intervention: 44.3 (12.5); Difference scores (post minus pre): -4.3, Z=-3.4 (significant at 0.05 alpha level), Cohen's d = 0.4	2; fair

(S = subjective; O = objective; Quality assessment tools: 1 = A revised tool to assess risk of bias in randomized trials (RoB 2), 2 = Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group, 3 = Quality Assessment Tool for Case Series)

Intervention Characteristics according to the TIDieR Checklist

A detailed summary of all intervention elements is presented in the supplementary table in Appendix D. Not all studies reported all elements and “tailoring” and “modifications” were the elements that were least reported.

Theory and rationale (why)

All studies highlighted the impact of ABI on wellbeing and social connectedness. Interventions drew on different strategies when addressing social isolation, including improving social communication skills [39, 44], social skills [47], participants’ social and emotional wellbeing [42] and/or increasing opportunities for social interactions and social support [27, 40, 41, 43, 45, 48]. Two studies [39, 41] described theories underpinning aspects of the interventions related to social isolation and connectedness, for example using activities in line with Positive Psychology [39] or asset-based interventions [39].

Most studies reported adapting the intervention to participants’ needs, including communication and cognitive abilities [27, 42, 43], goals [39, 40], and interests [45]. Adaptations for communication and cognition included providing materials to support communication [27], use of all communication modalities, allowing more time for a person to communicate and avoiding complex questions [42], as well as providing different options of participation (e.g., humming or singing lyrics) and modifying lyrics to repeat the verse rather than learning all verses [43].

Materials and procedure (what)

All studies reported basic intervention procedures which ranged from goal setting [27, 40, 41, 44, 47] to conversation practice [27, 39-41, 43, 44, 46] and social skills [46, 47]. Most studies described training and supervision provided to intervention providers [27, 39-41, 43, 45, 47, 48]. Materials required for the interventions included technical devices [40, 41, 44], intervention manuals [27, 39, 48], CDs and handouts [43], as well as materials to support communication [27, 39].

Intervention provider (who)

Healthcare professionals were involved in the delivery of the intervention in five studies (speech and language therapists and social workers) [40, 42, 44, 46] and to provide training and supervision [27, 39, 45]. Other interventions were provided by peers with ABI (n = 2) [27, 45], graduate students [39], volunteers from the community under supervision from the research team [48], or experienced community volunteers who have led aphasia groups previously [41]. One study was provided by local organisations and organised by a charity with no detailed information about providers [47].

Mechanism of delivery and location (how and where)

Six interventions were provided individually; two of which were delivered in person at the participant's home or in the community [27, 48], two were delivered in person, virtually or on the phone [42, 45], one was delivered in a virtual reality [40] and one study did not report the mode of delivery [44]. Three interventions were provided in a group setting; one of which was delivered in person in a community setting [46], one in a virtual reality [41], and one did not report the mode of delivery [43]. One intervention was delivered in person and in a group setting or in pairs, depending on intervention arm [39]. One study did not report detailed information on how the intervention was provided; however, it took place in an organisation in the individual's hometown [47].

Five studies reported the involvement of family members and/or friends [27, 43-46]; however, only two studies [27, 46] involved family and/or friends in a pre-planned way. In Dahlberg and colleagues' [46] study family and friends were involved for the assessment, goal setting, practising and generalising skills in the community and providing written feedback as part of homework tasks. In Hilari and colleagues' [27] study, psychological and social wellbeing outcomes of participants' significant others were explored. In a study aiming to improve social participation through improving written communication [44], the participant's family and friends were involved as the written communication recipients. In two other studies, family members supported through providing transport to outings with peer befrienders [45] or family and friends assisted at choir rehearsals in an unstructured way [43].

Intervention schedule and intensity (when and how much)

Some interventions described a minimum requirement of contact time with the option of more intervention time (ranging from three sessions for 45 minutes to at least two sessions per month for three months) [27, 40, 42, 43, 45, 48], whereas others described a pre-determined schedule (ranging from 14 group sessions (21 hours) over six months to 20 hours per week for 26 weeks) [39, 41, 44, 46, 47]. Intervention schedules ranged from daily sessions [40] to two sessions per month [27, 45]. The intervention intensity ranged from around at least three sessions for a minimum of 45 minutes [42] to 20 hours per week for 26 weeks (total of 520 hours) [47].

Individual adaptations (tailoring and modifications)

One study reported tailoring the intervention by offering participants choice of spacing and location of sessions [42]. Four studies reported modifications of the intervention. Two studies modified the intervention schedule due to the participants' availability [44, 48], one study reduced the training session of peer befrienders from six to five hours [27] and one study introduced another assisted communication software [44].

Adherence and attrition (how well)

Nine studies reported attrition rates ranging from no attrition [40, 42, 44] to 33 percent at follow-up; however, this equalled one participant in the study [48]. Only three studies reported adherence to the study, which ranged from 50 [40, 45] to 81 percent [27]. Fidelity has been evaluated in five studies by rating video recordings of a pre-determined number of intervention, training and/or supervision sessions against a fidelity checklist [27, 39, 41], as well as recording of attendance of all study components [27, 40, 45].

Intervention Effectiveness on Social Outcomes

Table 2.1 summarises the results of intervention effectiveness. The effectiveness is described based on intervention type and targeted population. Overall, six of the eleven included interventions showed some statistical difference or small effect size on outcomes related to social isolation or connectedness. Four of the interventions used social support approaches [27, 43, 47, 48] and, more specifically, peer befriending was used for two of these interventions [27, 48]. One intervention targeted communication [44] and one used a psychological approach [42]. Two studies explicitly referred to measures related to social isolation/connection as primary outcomes [27, 48], four as secondary outcome measures [39-41, 46] and five studies did not distinguish between primary and secondary measures [42-45, 47].

Social Support Interventions

This category of studies encompassed interventions that focused on opportunities for social support, two of which were designed for individuals living with aphasia following stroke [27, 43] and three were designed for individuals living with TBI [45, 47, 48]. Of the five studies, four studies showed an effect [27, 43, 47, 48]. Hilari and colleagues [27] had an adequate sample size in their feasibility RCT with low risk of bias and tested a peer befriending approach for people with aphasia with at least six one-hour peer-befriending sessions over a three months' period. It also supported the development of strategies for adjusting to life after ABI and the intervention was tailored to the participants and peer befrienders' needs [27]. The programme's befrienders received 5-6 hours training prior to meeting with participants and received monthly supervision [27]. At baseline, participants scored low on the Friendship Scale [47], indicating high social isolation. This study showed a small benefit of the intervention over the control group [27]. Lawrence and colleagues [47] had a powered sample size to assess a 26-week formal volunteering programme for veterans with TBI. The intervention showed a medium effect; however, no control group was used, and no follow-up data was reported [47]. At baseline, participants' mean score on the UCLA Loneliness Scale-Version 3 [54] indicated medium to high levels of social isolation. A weekly choir intervention for people with aphasia showed a small effect after 12 weeks, which reduced at 20 weeks [43]. Participants appeared to have an average sense of belonging at baseline. This pilot, pre-post study was assessed to be of fair quality but had a small sample size [43]. Participants' family and friends were able to join choir rehearsal and participants' involvement was adapted to their needs [43]. Another study for individuals with TBI used a supported relationship programme and showed a small effect of the intervention; however, only descriptive statistics were used due to a small sample size and the quality of the study was assessed to be of poor quality [48]. For this intervention, participants were matched with community partners rather than peers [48].

An RCT [45] testing a peer mentoring programme for individuals with TBI aimed to increase the participants' network size. Participants and mentors were matched based on their interests. Mentors received two hours of training and weekly support calls with the trial therapist [45]. The study did not explicitly involve skills practice. It used a smaller sample, was assessed to be of high risk of bias and no significant effect of the intervention was found [45]. At baseline, participants were assessed to be more socially isolated and lonelier than the social peer mentors.

Social support interventions appeared to be effective if they involved an element of developing strategies for adjusting to life after ABI, they were adapted to the participants' needs or involved friends or family in the activity.

Interventions targeting communication

This category included studies with interventions addressing individuals' communication needs following ABI. Four communication interventions were designed for individuals living with aphasia following stroke [39-41, 44] and one for individuals living with TBI [46].

Of the five studies, four used an RCT design [39-41, 46]. None of these interventions showed an effect based on the quantitative data; however, one study reported that "many participants did report forming or strengthening friendships during treatment" when asked directly [39]. This study described twice weekly aphasia conversation treatment groups, which were tailored to individuals' communication needs [39]. Three interventions were assessed to be of high risk of bias [39, 40, 46] and one was deemed to have some concerns [41].

The single case study described an intervention which used voice recognition software to support the individual's ability to communicate [44]. It involved twice weekly one-hour sessions over 16 weeks and showed an effect [44]; however, the quality of the study was assessed to be poor.

Communication interventions in this review appeared to be of poorer quality and most studies did not primarily aim to improve social connectedness; however, their primary aim was to improve communication skills. Participants in the studies in this category appeared to have medium to high levels of social connection and/or integration at baseline, which might account for a lack of statistically significant changes on rating scales despite qualitative reporting of strengthened relationships [39].

Psychological Interventions

One psychological intervention used a brief solution-focussed therapy approach and was designed for individuals living with aphasia following stroke [42]. The intervention showed a small effect on a subjective outcome measure (Friendship Scale [49]) and no effect on an objective measure (Stroke Social Network Scale [52]) post-intervention and no follow-up data was available [42]. In the study's qualitative analysis, one participant reported a positive relationship change as the main outcome of the intervention [42]. The feasibility mixed-methods pre-post design study was assessed to be of poor quality. At baseline, participants' scores indicated high levels of social isolation on the subjective measure and medium levels on the objective measure.

It is challenging to draw conclusions about the effectiveness of psychological interventions, as the only reviewed psychological intervention showed mixed effects and was of poor quality.

Discussion

This systematic review was the first to systematically collate and synthesise the types and effectiveness of interventions addressing social isolation and/or social connectedness for individuals living with ABI that have been evaluated through peer reviewed research. Overall, there is limited research into interventions addressing social isolation post-ABI available. Eleven intervention studies (6 RCTs, 4 pre-post studies, 1 case series study) were included; interventions either targeted individuals with TBI or aphasia following stroke. There were no interventions aimed at individuals with other types of ABI. There is some evidence that social support interventions, in particular peer befriending and volunteering, might be effective in reducing social isolation; however, it is not possible to draw firm conclusions about intervention effectiveness. Across the included studies, there was large variability in relation to study design, type of intervention, elements within interventions and outcome measures used.

The interventions identified in this review were grouped into three areas: increasing opportunities for social support, improving communication and psychological interventions; broadly in line with the strategies identified by Masi and colleagues [25] based on reviews of interventions aiming to reduce social isolation in other populations. More interventions with a social support approach, rather than skill-based or traditional therapeutic interventions, appeared to be effective to improve social connectedness following ABI, which suggests that connecting people within their community might be an effective intervention. However, it should be noted that more studies with this approach were conducted. This finding is in line with a systematic review conducted in the general population, which found that befriending interventions appear to reduce social isolation [24]. Contrary to most effective studies in this review having been carried out on an individual level, a systematic review of interventions targeting social isolation and loneliness in the elderly found that most effective programmes were group interventions [56]. It could be argued that the social nature of befriending and volunteering programmes might be considered different from more traditional individual approaches and could have similar underpinning mechanisms to group interventions, such as connecting with others within their community who would not be considered as someone providing care.

Cattan and colleagues' [56] review of interventions targeting social isolation and loneliness in the elderly also found that interventions with an educational component are most effective. This could be linked to the difference in effectiveness between the two included peer intervention studies [27, 45], as one [27] emphasised adjustment to living life following ABI as part of the intervention. Cattan and colleagues' [56] review further concluded that including a targeted activity contributes to intervention effectiveness. Shared activities took place in most effective interventions and most studies described adapting them to be meaningful to the individual. This is also associated with further positive outcomes, such as happiness and improved quality of life [57]. The review of interventions for elderly individuals also suggested that targeting a specific group and adapting the intervention to the participants' needs is beneficial [56], highlighting the need to develop ABI-specific interventions.

Various outcome measures were used, which were categorised to assess subjective or objective social isolation [29]. Only two studies administered and analysed both types of measures [42, 45]; one of which showed a slight difference in effect on the different measures [42]. A systematic review of social isolation interventions for people with mental health difficulties suggested that group-based interventions or interventions supporting socialisation appeared more effective when assessed on objective social isolation measures [58]. Studies investigating effective interventions used outcome measures more closely linked to the intervention aim, which suggests that careful consideration of outcome measure is needed. For example, the Friendship Scale [49] may be well placed to assess a peer befriending intervention [27] but less appropriate for a communication intervention [e.g., 40] due to the difference between primary intervention aim and construct of the outcome measure. In addition, despite most outcome measures used being reliable and valid, very few have been validated in the ABI population to the researchers' knowledge (e.g., Stroke Social Network Scale [52]).

Overall, the methodological quality of reviewed studies was inadequate. Only one RCT was assessed to be of low risk of bias, and, in addition, it was the only RCT which tested an intervention that appeared to be effective [27]. All other studies that showed interventions to be effective were of lower-level evidence, as classified by the National Health and Medical Research classifications [59]. In addition, these studies were assessed to be of fair or poor quality, mostly concerning small sample sizes, so caution must be taken when interpreting these findings.

Limitations of reviewed studies

The quality of available studies was variable, though some of the highlighted issues might possibly be unavoidable when conducting interventions in real-world settings, for example blinding of intervention arm. There were few interventions targeting social connectedness and/or isolation directly, rather than through improving communication, and it was noted that most interventions used were not underpinned by, or referred to, relevant theory related to social isolation and/or connectedness, as highlighted by guidelines form the Medical Research Council for the development and evaluation of complex interventions [60]. Sample sizes in all studies were small, leading to insufficient power for statistics used or only reporting descriptive statistics. Five studies did not include a control group [42-44, 47, 48] and three studies did not report any follow-up data [42, 45, 47]. The primary aim of some studies was linked to improving related concepts such as social participation or community integration rather than reducing social isolation directly and some studies did not measure social isolation as a primary outcome. At baseline, participants of some studies did not score as highly on measures of social isolation, especially in studies addressing communication, which might contribute to why the interventions did not show an effect. For individuals, for whom social isolation is not a significant difficulty, additional social interactions as part of the intervention or taught strategies might not lead to large differences in their perceived social connections. Most included studies used valid and reliable outcome measures; however, most have not been validated or routinely used in the ABI population. One study highlighted that the outcome measure used might have not been sensitive to changes in friendships, as participants qualitatively reported forming and tightening friendships because of the intervention [39]. It is unclear if participants of other studies noted changes in feeling socially connected that have not been picked up by measures used and which measures would be sensitive to this. There was high variability between intervention approaches and elements as well as outcome measures used, which made comparison and synthesis of intervention effectiveness challenging. All reviewed studies targeted individuals with TBI or post-stroke aphasia. A lot of brain injury research focusses on the most prevalent types of ABI, including TBI and stroke, due to funding processes; however, this can be problematic to identify the most effective clinical practice for other types of ABI. For example, issues of progressive onset, treatment complications and effects as well as uncertainty of prognosis with brain tumour may need a different treatment approach compared to TBI or stroke.

Strengths and Limitations of the Review

The review's protocol was reviewed and accepted by PROSPERO. Broad inclusion criteria allowed for the inclusion of various study designs, including both randomised and non-randomised controlled studies; however, heterogeneity in intervention type and outcome measure made comparison across included studies more difficult. Due to the timeline of this review, only interventions that have been evaluated through peer reviewed research have been reviewed. This might have provided a limited overview of available interventions, as clinical interventions or their adaptations are routinely used and not formally evaluated or published in the grey literature. Two independent reviewers were involved to review the quality and risk of bias of studies, using design specific frameworks, and to check eligibility of studies. The second reviewer (LJW) reviewed ten percent of articles at each stage of the eligibility check. Inconsistencies were discussed to reach consensus. Due to the timescale of the project, it was not possible to check study eligibility of all articles by the second independent reviewer, which might have impacted the methodological validity of this review.

The TIDieR checklist [1] was used to report interventions' key elements, which is beneficial for the replication of reviewed interventions in research and clinical practice. However, due to variable adherence to CONSORT guidelines [61] and being unable to contact some study authors for further information, some interventions could not be described in as much detail as needed to repeat the intervention. It should be noted that four studies were published prior to the TIDieR checklist publication [1], which could limit their adherence to these guidelines. The review included study designs, which might provide weaker evidence for intervention effectiveness, such as a case and pre-post studies. Many studies had small sizes, did not include control groups and/or did not follow participants up after treatment. Most reviewed studies were assessed to be of fair or poor quality or posed high risk of bias. Overall, the evidence of effectiveness across studies was weak and it is not possible to draw robust conclusions about intervention effectiveness.

Clinical and Research Implications and Recommendations

This review found that peer befriending and volunteering show some effectiveness at addressing social isolation for individuals living with ABI. However, the evidence is too weak to make robust recommendations for clinical practice. There is some tentative evidence that connecting individuals within their communities might be beneficial.

The review highlights the need for more research into interventions addressing social isolation in individuals living with ABI, in particular including ABI presentations other than TBI and post-stroke aphasia and their effectiveness. Addressing social isolation as a primary aim of interventions and more detailed descriptions of underpinning theory would be beneficial. More high quality RCTs are needed especially those comparing intervention types and controlling for factors like delivery setting, intensity, and duration. Given the limited reporting of theory underpinning the included interventions, it might be helpful to further develop our understanding of the processes involved in developing social connectedness following ABI to inform future intervention development. Theories such as Social Identity Theory [62], the Y-shaped model for rehabilitation [63], or the GENIAL model [64, 65] have been shown to be relevant to social support and connectedness [66] and have been used for intervention development [67]. Using the TIDieR checklist to report intervention elements would support replication of studies in research and also facilitate the use of interventions in clinical practice. Given the limited focus on interventions formally evaluated through peer reviewed research in this review, it would be beneficial to conduct further research to describe interventions that are routinely available in clinical and community settings through a scoping review of the grey literature or qualitative research in both NHS and third sector neurorehabilitation settings. More research is needed to investigate suitable and valid outcome measures to assess interventions in the ABI population.

Conclusion

The review identified interventions addressing social connection and isolation for adults living with ABI and summarised their key elements and effectiveness. Overall, there is little research addressing this issue in the ABI population. Only a small number of heterogenous studies with variable quality were included, which made it difficult to draw firm conclusions about the interventions’ effectiveness. Evidence suggests that social support intervention, as opposed to skill-based or traditional therapeutic interventions, might be more effective in reducing social isolation or improving social connection. More research is needed to develop interventions addressing social isolation, underpinned by theory, and to evaluate their effectiveness with appropriate outcome measures.

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Chapter 3. Bridging Chapter

This chapter summarises the findings from the systematic review and explains the rationale of the empirical paper based on these findings.

The systematic review identified published interventions addressing social isolation following acquired brain injury (ABI), their key elements and effectiveness. The findings of the review suggest some tentative evidence of the effectiveness of social support interventions; however, due to heterogenous interventions and variable study quality, no firm conclusions can be drawn. In addition, most studies did not report detailed theory to underpin the intervention elements related to social connectedness. The review concluded that more interventions based on theory are needed. The empirical study aims to support our understanding of the processes involved in maintaining and/or sustaining social connectedness following ABI, which can be used as a framework for clinical practice and intervention development. In addition, the study explores practices used by individuals living with ABI, family members/carers and community ABI support people to support these processes, which could provide further insights into practices used in different contexts and how practices can be further developed.

Chapter 4. Empirical research study prepared for submission to Disability and Rehabilitation

“My connections are stronger with people”: A grounded theory exploration of stakeholder perspectives on successful social connection after ABI

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Abstract

Purpose: Individuals living with acquired brain injury (ABI) often have poor psychosocial outcomes, including feeling socially isolated. The study aims to develop our understanding of key processes involved and practices used by individuals living with ABI, family members/carers and community ABI support people to maintain and/or develop social connectedness.

Method: Six focus groups involving 23 individuals drawn from those living with ABI, family members/carers and community ABI support people were conducted. Processes and practices were explored using Grounded Theory and findings were presented in a model.

Results: Four interlinked processes were identified to be involved in developing and/or maintaining social connectedness: understanding of oneself and from others, acceptance of oneself and from others, rebuilding confidence and creating safe spaces. Practices used slightly differed both within and between participant groups.

Conclusions: The study proposes a framework of processes underpinning the development and/or maintenance of social connection, alongside current practices, which can be used to guide clinical practice.

Introduction

Social connectedness can be defined as “the sense of belonging and subjective psychological bond that people feel in relation to individuals and groups of others” [1]. Social connectedness is understood as a core human need [2] and has been linked to more positive life outcomes [1]. For example, social connectedness has been found to be associated with a longer life expectancy [3] and better cognitive health [4]. Social inclusion, support and participation, constructs associated with social connectedness [1], have been found to positively predict emotional and physical wellbeing in the general population as well as in people with various health conditions or disabilities [5-7]. Due to the associated health implications, social isolation has been recognised as a public health problem in the general population and individuals with various health conditions or disabilities can be at an increased risk of social isolation [8]. This can be due to disorder-specific factors, such as cognitive bias in depression [9] and positive symptoms in psychosis [10], both linked to social withdrawal, or communication difficulties in ABI [11]. Other factors can be observed across populations, such as stigma towards the condition [12, 13] or the impact of impairments on mood and motivation [10, 14]. Although there is no overarching predictive model of social isolation across disorders, research on predictive factors has been conducted for specific populations and theories such as Social Identity Theory [15] have been used to explain social isolation.

Whilst the findings might also be applicable to other conditions, Conneeley [16] identified that the nature of the impairment (e.g., cognitive, physical or communication difficulties), the response of others to the individual’s condition (e.g., preconceptions, fears), as well as general social network changes can be linked to breakdowns in social relationships in individuals with acquired brain injury (ABI), creating an increased risk of poorer psychological wellbeing and social isolation for people living with ABI [5]. A decline in social life, loss of friendships [11, 17] and difficulties to maintain and/or develop new social connections can lead to an increase in responsibilities and associated stress for family carers [6], which can also put a strain on family relationships.

A sense of belonging to social networks after ABI has an impact on adjustment post-injury [11] and individuals' physical recovery [6]. A study by Dhand and colleagues [6] found that an individual's baseline network size was associated with their physical functioning at three and six months after stroke. In addition, it has been found that social isolation might increase the risk of a second adverse event in stroke survivors [18]. However, there are many factors that act as barriers to social connectedness, including practical barriers [19] or barriers more directly linked to the individual and impairments due to their injury. For example, research showed that individuals experiencing post-stroke aphasia were more likely to be socially isolated [20] and that it is often the subjective experience, rather than the actual impact of the injury that is affecting social interactions [5]. It is suggested that the perceived changes in one's functioning may reduce individuals' confidence to engage in social roles and activities [21].

However, research showed that not all individuals with ABI experience poor outcomes and social isolation [22] and some facilitators of social connection were highlighted. For example, engaging in meaningful activities with people who accept the person and their ABI [5], and where the individual experiences a sense of belonging [23], tend to create a feeling of social connectedness. Research suggests that individuals with ABI who had more positive social connections also engaged in more other social interactions and community activities [19]. Berger and colleagues [24] found that activity-based community groups could improve individuals' wellbeing by providing opportunities for social connection, amongst others. Group membership can help individuals to feel like they belong and are important to others [25] by contributing to a person's sense of self [15].

The importance of social connectedness for individuals' wellbeing and their engagement in further social interactions highlights the need for interventions and rehabilitation programmes that focus on facilitating social connections. Neurorehabilitation approaches are often set up to reduce psychological and behavioural barriers to community and social integration; however, this might not be enough to facilitate social connection [26]. Rehabilitation services may address the need for social connections by offering therapies within social contexts, by developing mentoring schemes or by linking with third sector organisations for group activities [20]. Nevertheless, limited funding for long-term health service support (for example within the National Health Service (NHS) in the UK) highlights the demand for additional or alternative ways of facilitating social connections for individuals with ABIs. This, in addition to the long-term negative impacts experienced by those living with ABI in relation to social connectedness and participation, show a need for a shift from commonly more problem-oriented frameworks within healthcare to a more prevention-focused way of working. However, more research is needed to understand what processes are involved in maintaining existing and developing new social connections following ABI and how health and care services can support this.

This project forms part of ongoing research about enhancing wellbeing following brain injury, with an overall aim of co-developing a structured resource or programme with key stakeholders that specifically focuses on enhancing, maintaining and developing social connection for people living with ABI, taking account of the person, their context and community. Work to date has indicated the importance of social connection for wellbeing [24]. The purpose of this project is to continue building on our understanding of social connection post brain injury for this co-developed resource by better understanding the key processes involved and practices used by individuals living with ABI, family members/carers and community ABI support people to maintain and/or develop social connectedness.

Research Questions

1. What are the key processes involved in maintaining and/or developing social connections following brain injury from the perspective of people living with ABI, family members/carers of people living with ABI, and community ABI support people with a range of experiences of social connection?
2. What are the shared and divergent practices and processes being used by people living with ABI, family members/carers of people living with ABI, and community ABI support people that help people living with ABI maintain and develop social connections?
    a. What are the facilitators of and barriers to addressing social connection for people living with ABI from the perspective of people living with ABI, family members/ carers of people living with ABI, and community ABI support people?

3. What current ABI rehabilitation processes and practices could be improved, changed, or developed to impact the maintenance and/or development of social connections following brain injury that involve diverse community stakeholders and family members? How might these processes be implemented in different contexts?

Method

Design

This project used qualitative methods, involving focus groups (FG) informed by Constructionist Grounded Theory [27]. This work is underpinned by a social constructionist perspective, which holds that knowledge and our understanding of the world are shaped by culture, context and society [28]. It emphasises understanding social processes from the perspective of those who experience them and the existence of more than one account of reality, which highlights the importance of the rich narratives of different people.

Ethics

Ethical approval was granted by the UEA Faculty of Medicine and Health Ethics Committee (reference: 2020/21-059; Appendix E). Written informed consent was gained from all participants. The consent procedure was adapted to facilitate the inclusion of those living with ABI by providing more accessible information and offering telephone and/or video calls to support understanding. All available information relating to participants has been anonymised and pseudonyms are used to protect participants' anonymity.

Sampling

Participants were individuals living with ABI, family members/carers of individuals living with ABI and community ABI support people (including healthcare professionals and employees of third sector organisations) to explore various perspectives relating to the research aims. In line with Grounded Theory research, purposive sampling was planned to be used to ensure that a variety of perspectives were included in the focus groups [27]. While aiming to recruit participants with a variety of experiences and perspectives, purposive sampling was not possible as planned due to the project's timeline and convenience sampling was employed.

All eligible participants were required to be able to give informed consent; be over 18 years old; have access to a networkable device that supports video conferencing and the internet connection needed to attend online focus groups; live in the UK; and speak English fluently. Eligible individuals living with ABI must have sustained their injury more than six months prior and over the age of 17 and not have cognitive or emotional difficulties of such severity as to prevent participation in the study with adaptations and accommodations or cause significant risk of distress. Eligible family members and carers were individuals who have a family member or are caring for an individual who sustained an ABI more than six months ago and when older than 17 years old. Eligible community ABI support people were rehabilitation professionals, support staff working with adults with ABI (including paid and voluntary support staff), individuals working in community groups where adults living with ABI are supported or individuals involved in decision-making about community projects where adults with ABI are supported.

Recruitment Procedure

Participants were recruited from third sector organisations, through social media (Appendix F), the research team's professional networks, professional bodies, as well as word-of-mouth. Key contacts in organisations and professional bodies were contacted about this project and, if they agreed to support the project, shared brief information with potential participants by verbal or written communication, including accessible presentations. Interested individuals could contact the lead author directly or complete a consent to contact form (Appendix G) that was returned to the research team. Participants had the opportunity to discuss the study with the lead author prior to signing the consent form (Appendix H).

Data Collection

A short questionnaire was given to participants to capture demographic data, including information to aid sampling (Appendix I).

Qualitative data was collected in FGs, allowing participants to link concepts through group discussions, which elicited a wide range of views and perspectives [29]. Throughout recruitment and data collection adaptations and accommodations were used to support participants with communication and cognitive difficulties to take part [30], including supportive communication strategies.

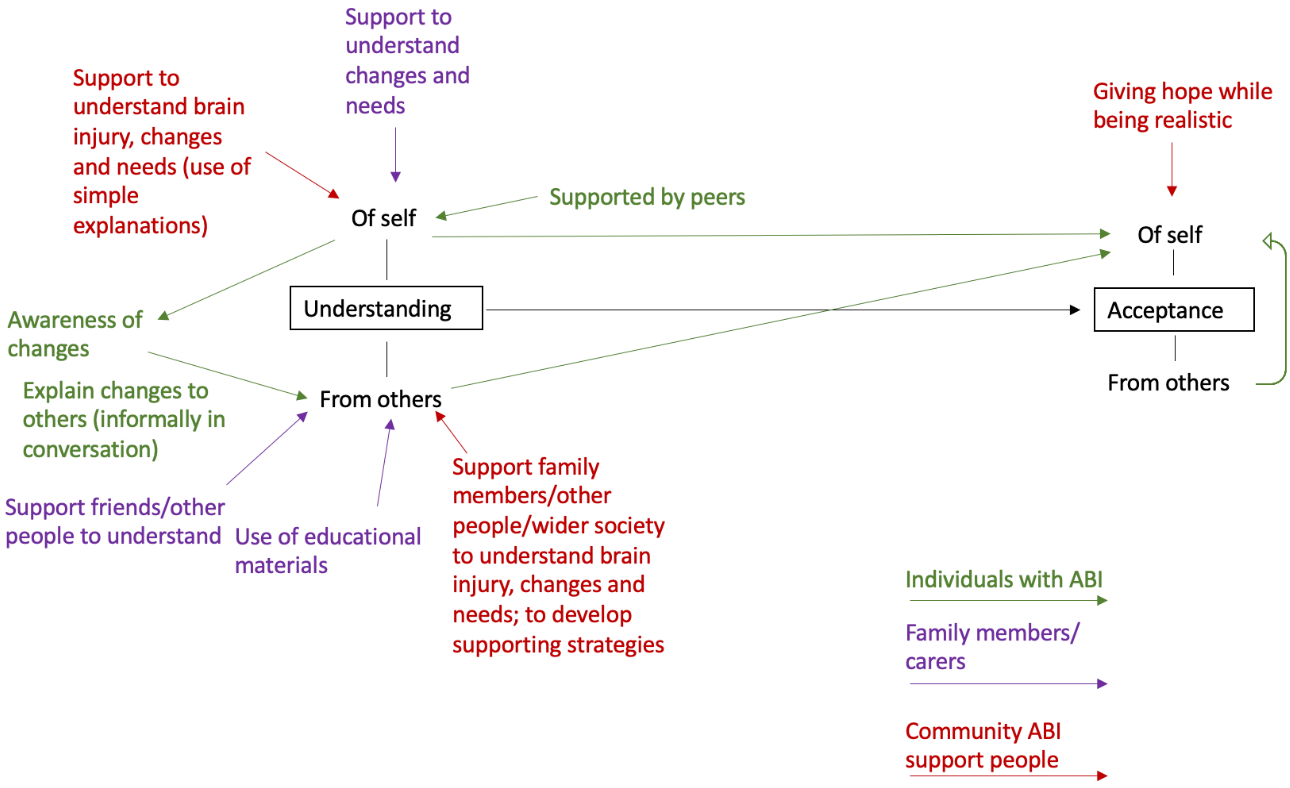
Each FG was attended by four to six participants. The initial FGs were participant group specific, which allowed for a safe space for each group to argue their points freely and to avoid potential power imbalances between participant groups. The subsequent FGs were joint discussions to start developing practical ideas to guide rehabilitation practice, which considers everyone's perspectives. Two participants per participant group were invited to mixed FGs based on their availability. Focus groups lasted 90 minutes with a break. Topic guides were developed, to guide the FGs, relating to the research questions, through discussion with supervisory panel members and iteratively by data collected in previous FG in line with Grounded Theory [27] (Appendix J). Topic guides were used flexibility and discussions were guided by participants' responses. All FG meetings took place online. FGs were led by the lead researcher (LW) with a second research team member joining all FGs.

Data Analysis

FGs were transcribed verbatim by the lead author (LW). Initial coding was conducted by the lead author after each focus group and tentative categories were developed after the group-specific groups. Focussed codes and redefined conceptual categories were taken back to mixed FGs for the next iterations of the GT process. Throughout the FGs, initial codes evolved into focussed codes and categories [27]. Throughout this process, the codes, categories and their relationships were discussed within the research team to involve multiple perspectives to ensure overall credibility of the data. Preliminary analysis models were presented at the mixed focus groups for member checking and co-construction of the grounded theory model. Examples of preliminary models including processes and practices are shown in figure 4.1. Reflective notes were written throughout the data collection and analysis process to create more transparency. The data analysis processes are outlined in figure 4.2 alongside the data collection and Intervention Mapping [31] stages. There are a range of approaches to methodological quality assurance in qualitative research, but Yardley's [32] approach was chosen due to its open-ended, flexible principles, which are in keeping with the ethos of qualitative research.

Figure 4.1

Preliminary analysis models showing processes and practices involved



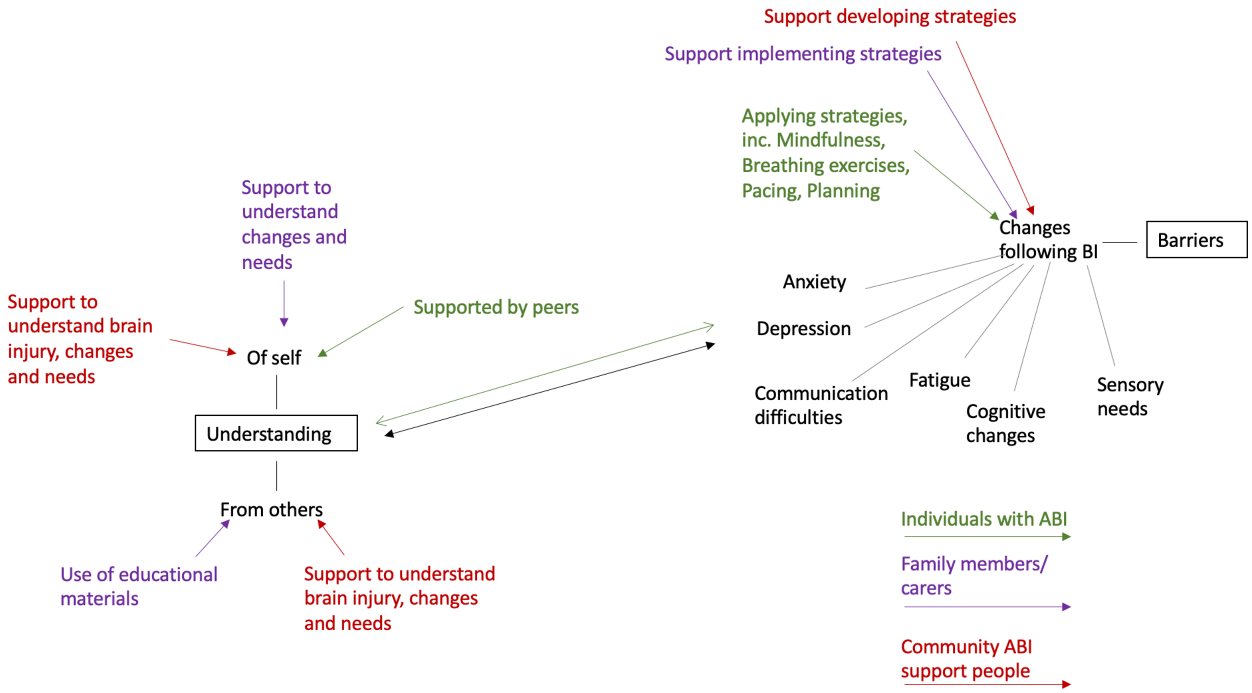
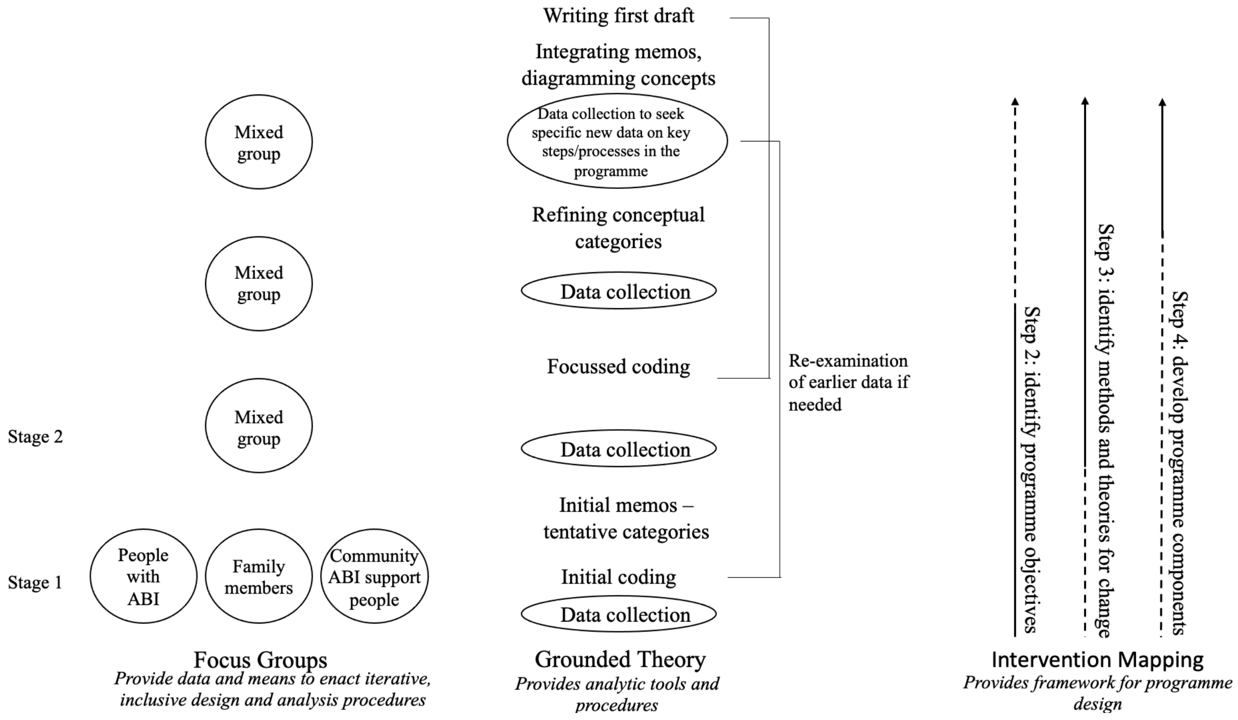

Support developing strategies
Support implementing strategies
Applying strategies, inc. Mindfulness, Breathing exercises, Pacing, Planning
Changes following BI
Barriers
Anxiety
Depression
Communication difficulties
Fatigue
Cognitive changes
Sensory needs
Support to understand changes and needs
Support to understand brain injury, changes and needs
Of self
Supported by peers
Understanding
From others
Use of educational materials
Support to understand brain injury, changes and needs
Individuals with ABI
Family members/ carers
Community ABI support people

Figure 4.2

Data collection and analysis process.



Grounded Theory diagram adapted from Charmaz [21]

Participant Demographics

Thirty-one individuals contacted the researcher of which 23 participants gave consent (people living with ABI n=7; family members/carers n=7; community ABI support people n=9). Five individuals were identified to not be eligible pre-consent, one post-consent and two individuals stopped responding to communication post-consent. Two participants only took part in one focus group and did not stay enrolled until the end of the project due to not being eligible (one family member) and withdrawing consent (one individual living with ABI). Participant demographics are displayed in tables 4.1, 4.2 and 4.3.

Table 4.1

Participant Demographic Information of Individuals Living with ABI

Gender	Age	Nature of ABI	Time since injury (years)	Ethnicity
Male	54	Brain tumour	5	White British
Female	60	Encephalopathy due to lead poisoning	2	White British
Male	53	Stroke	7	White British
Female	41	Brain Infection	8	White British
Female	78	Stroke	3	White British

Table 4.2

Participant Demographic Information of Family Members/Carers

Gender	Age	Relationship to person with ABI	Nature of ABI of family member/cared for	Time since their injury (years)	Ethnicity
Male	77	Spouse	Stroke	2	White British
Male	24	Son	Brain Infection	5	Black/African/Caribbean/Black British
Male	52	Spouse	TBI	5	White British
Male	62	Parent	TBI	Over 10	White British
Female	29	Cousin	Brain tumour	2	Black/African/Caribbean/Black British
Female	42	Spouse	Stroke	4	White British

Table 4.3

Participant Demographic Information of Community ABI Support People

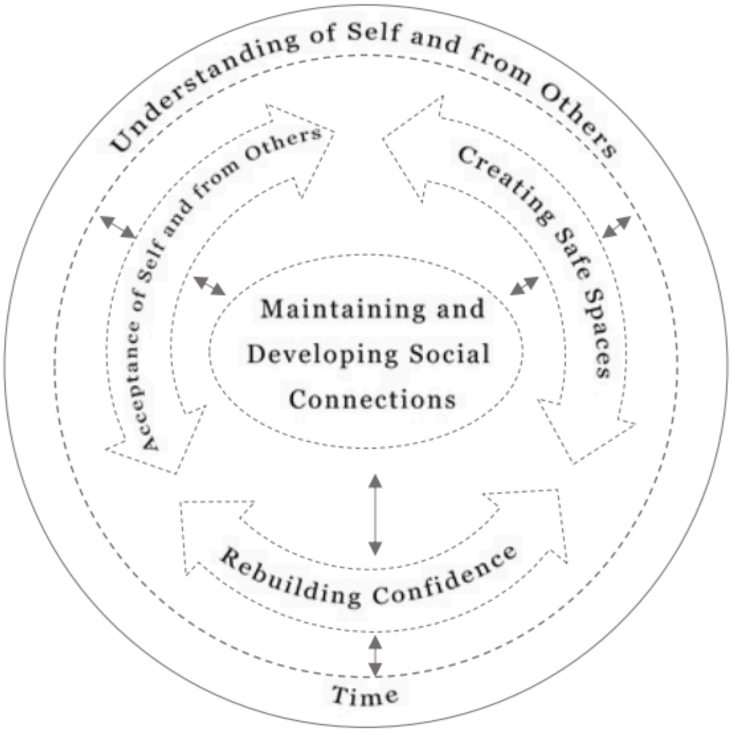
Gender	Age	Profession	Time working with ABI (years)	Work context	Ethnicity
Female	32	Music Therapist	4	Rehabilitation	White British
Female	33	Speech and Language Therapist	13	Third sector	White British
Female	31	Clinical Psychologist	6	Rehabilitation	White British
Female	41	Occupational Therapist	21	Third sector	White British
Male	70	Brain Injury Case Manager	22	Community	White British
Female	47	Outdoor Educator	10	Third sector	White British
Male	68	Retired	20	Third sector	White British
Female	63	Speech and Language Therapist	35	Third sector	White British
Female	40	Clinical Psychologist	3	Rehabilitation	White British

Results

Participants described various processes and practices involved in maintaining and developing a feeling of social connectedness after ABI. The model of how people maintain and/or develop social connectedness following ABI was co-constructed with participants and the research team (figure 4.3). It shows the process of understanding of self and from others as a crucial part of feeling connected. Rebuilding confidence, acceptance of self and from others, as well as creating safe environments in ABI-specific settings and in the community were also described as processes important to move towards feeling connected; while all processes influence each other. Practices used by individuals living with ABI, family members/carers and community ABI people to foster those processes and ultimately to move towards social connections are outlined below and presented in table 4.4.

Figure 4.3

Grounded Theory Model of How People Maintain and Develop Social Connections



Underlying Mechanisms

All participants agreed that the processes involved in becoming more connected develop over time and becoming socially connected takes time. Understanding, both of self and from others, appeared to underlie all processes. It was felt that understanding one's brain injury and subsequent needs or difficulties was needed to develop and use supportive strategies to feel more in control and independent. Understanding or awareness from others was also needed to allow the individual to take more control to build more confidence. Rebuilding confidence facilitates becoming more socially connected and having social connections will further increase the person's confidence and improve their own understanding of themselves and their injury, as well as the understanding of others who they have become connected with.

Participants described that understanding themselves, as well as feeling independent and in control, helped to develop self-acceptance. Some participants felt that understanding of the impact of brain injury from others was not needed, if they accepted what the person told them about their needs and the impact the brain injury had. Self-acceptance and acceptance from others facilitate becoming more connected to others and, in turn, feeling more connected helps to feel accepted.

Understanding and acceptance from others play a significant role in creating safe spaces for individuals living with ABI. Accessing safe spaces with opportunities for social interactions can support rebuilding confidence. Increased confidence, having a good understanding of oneself and of strategies to use to create safety for oneself could help individuals to access further opportunities for social connection in the community.

Understanding

The theme 'understanding' appeared to underly and be influenced by all processes involved in moving towards social connection and included the two subthemes: understanding oneself and understanding from others. The overall sense of this theme is captured in this quote from Jessica (*community ABI support person*):

> *I think, understanding helps well and helping people understand and then helping others around them understand what's going on. I think that can be a real barrier to connectedness, feeling misunderstood and and lonely as a result.*

Understanding oneself

Individuals living with ABI described how gradually developing an understanding of the impact of their brain injury and how it changed them as a person has helped them to feel better about, and more connected to, themselves. Having a good understanding of their "new self" was felt to be helpful for explaining to other people how they have changed as a person and their needs following ABI to support other people's understanding, which participants identified as an important step in becoming connected to others. A community ABI support person added:

> *Because through understanding oneself that gives a context for understanding other people. (Richard; community ABI support person)*

Some individuals with ABI described how social connections built on trust allow honest communication about changes following ABI. Having honest conversations might in turn further deepen these relationships. All participants agreed that peers with ABI play a crucial role in developing an understanding of oneself, as seeing and hearing about peers' experiences helps to reflect on ones' own changes following ABI. One participant described how meeting peers helped her to recognise the impact of her ABI.

> *And it and it was just like had a light bulb moment. I just it just kind of woke me up really to to make me realize and kind of see. I don't really know if I was*

> *oblivious to it or I'm not sure I just I just kinda thought I was like I was before. (Claire; individual living with ABI)*

All individuals with ABI talked about the challenges of fatigue, cognitive changes, sensory needs, communication and/or mental health difficulties following ABI as potential barriers to social connectedness. Individuals differed in what techniques and strategies they found most beneficial to overcome these barriers, including mindfulness, breathing exercises, pacing, and planning. Individuals living with ABI reported applying these strategies independently and some family members explained supporting their loved one with these strategies.

> *I did a wonderful course of mindfulness* [at the brain injury unit] *which I use all the time and it really helps my anxiety if I get to a place where I'm really, really anxious (Ann; individual living with ABI)*

Understanding from others

Individuals living with ABI described that feeling understood by others enables them to feel more comfortable, which allows them to be their true self without trying to hide their difficulties. Not having to "*pretend that I'm somebody else*" (Claire; *individual living with ABI*) and being able to be their true self felt crucial in maintaining or developing connections with others. All individuals explained that some pre-injury family members and friends understand their needs and the impact of the injury better than others, which makes maintaining these connections easier. Most participants felt best understood by others who had sustained a brain injury. This emphasises the importance of interactions with peers following ABI to develop a sense of belonging and social connection; however, two individuals with ABI explicitly stated that social connections with non-peers are also needed. A family member explained how a good understanding of the pre-injury social network is important to keep the relationships going.

> *Uhm, [partner] has an existing network of friends […] it's giving [partner] the chance to continue the relationship which she had with them, albeit in a slightly changed form […]. (Harry; family member)*

One participant living with ABI explained that others do not need to fully understand the injury, as long as they are aware of it, as well as trust and accept what the individual is telling them about their needs.

> *[…] whereas someone else, another member of peer group we have known just as long, just, I don't know if he gets it more. He accepts what I'm saying. (Bill; individual living with ABI)*

All participants explained that the understanding of oneself and from others takes time to develop; however, it was identified by all participant groups that receiving accessible information early on in the ABI pathway, both for the individual who sustained an ABI as well as the people in their social network, might be beneficial to support the process of understanding to enable maintaining social connectedness.

> *It takes time and erm looking within yourself to actually see how the injury affects you. And that takes weeks, months and years. (Ann nodding; individual living with ABI) Only then can you understand how it affects you so so therefore*

> *then, er, only then can you tell other people how it you know, how it affects you. (Donald; individual living with ABI)*

Rebuilding confidence

All participants talked about rebuilding confidence to “feel ready” to focus on social connections again and emphasised various ways to rebuild confidence. One individual with ABI and a family member talked about how feeling in control of a situation leads to feeling more confident. Another individual living with ABI and a family member both highlighted the importance of feeling independent before feeling confident to seek out social connections.

> *I think until that time I wasn't really ready, if I’m honest, it's because I I think I was a lot more erm not shielded, but I I couldn't really speak to other people or I need somebody with me. (Claire; individual living with ABI)*

Attending ABI groups was also seen as helpful in increasing independence, as well as motivation to try new things, enabling more opportunities of social connections.

Participants described the importance of peers in rebuilding one’s confidence and some individuals with ABI felt that interacting with peers helped them to build the confidence to interact with non-peers.

> *Ann (individual living with ABI): like being with other people with a brain injury because they get it without any worry-*
>
> *Claire (individual living with ABI): Yeah.*
>
> *Ann (individual living with ABI): so your anxiety goes. No anxiety at all. But obviously that's you have to mix with other people as well, but it's a really good way to get into the the confidence of being in a group socially, give you the techniques like mindfulness to deal with the anxiety.*

One participant detailed that peers with ABI are able to normalise and validate their experiences, which increases their confidence to explain these to non-peers and, therefore, might lead to feeling more connected with others.

Individuals with ABI felt that having had the confidence to seek out one social interaction and having had a positive experience increased their confidence to seek out further opportunities for social connections.

> *that's all you need is that one connection to build that confidence to build more connections. (Theresa; community ABI support person)*

Acceptance

Acceptance of self

Acceptance of self and from others was described to be important to feeling connected. Some individuals with ABI explained that accepting their new self results in worrying less or being less conscious about changes post-injury and allows them to be more themselves and relaxed, as they do not try to hide the impacts of the injury. They described feeling happier and more open to explain changes to others, leading to stronger connections.

> *I think perhaps my connections are stronger with people, but only with certain people. (Claire; individual living with ABI)*

One individual living with ABI explained that they are accepting that they can do the same activities as prior to their ABI but slightly differently and that this is the same for social relationships. A family member also wondered if accepting oneself might help the individual living with ABI to stop wondering *"if you're normal or not, if you doing things the right way or not*" (Shirley) and a community ABI support person explained:

> *it's all the things that have happened that make you doubt that you don't know a thing about yourself anymore. Uhm, you know acceptance starts to bring it back in. (Richard; community ABI support person)*

Some community ABI support people felt that, in their experience, a lack of independence and control as well as lack of understanding can make acceptance more difficult. All participants felt that acceptance is a process that develops over time.

> *Keep moving forward keep you know, keep adjusting, adjusting to life with a brain injury, there's good days and bad days, but gradually the the acceptance does get easier. (Donald; individual living with ABI)*

Acceptance from others

Most participants living with ABI felt that others needed to accept their new self and family members observed that acceptance from others helps their loved ones to feel more comfortable, which helps them to be more themselves. One person living with ABI felt that others do not necessarily need to understand the impact of their brain injury, as long as they accepted it. A family member shared a similar observation:

> *(…) and all of a sudden if there's something that's a little bit off with that person, they, the general public, maybe just don't, just don't get it and I think from maybe an acceptance point of view that if if if people understand what's happened to that person, they might not understand why that person is acting that way, or why and maybe their speech is slightly slurred and things like that but maybe they accept that person a bit more and go Oh well, actually they're*

> *not being rude or they're not doing this or that, you know." (Tony; family member)*

This highlights the importance of awareness and acceptance of brain injury, and its impact on the person, in the general population as an important part of developing social connections in the community.

Creating safe spaces

Individuals living with ABI talked about the importance of feeling safe to maintain and/or develop social connections. They explained that feeling safe enables them to have honest conversations with others about their needs, they can trust others to respond to their needs and can be their true self in social interactions. Additionally, they described that when feeling safe, interactions require less effort; thus, having a smaller impact on fatigue.

Participants felt that it was the role of healthcare professionals to create these spaces within ABI-specific services or settings. Community ABI support people explained that safe environments enable individuals with ABI to be themselves without feeling the need to hide their difficulties, which is important in connecting with others. However, there was an awareness that not all ABI groups suit every individual, which might hinder developing social connectedness in these contexts.

Opportunities for social connections can feel like risky situations, emphasising the importance of safety, and why feeling prepared for these situations can help. This was discussed between a community ABI support person and individual with ABI:

> *Jessica (community ABI support person): So it sounds like, uhm, part of social connectedness is being able to take a risk. I don't know. I don't know whether it feels like that. Sometimes, like reaching out to others and how important it is to feel safe, and whether all that preparation and knowing, you know, the environment in order that helps with that sort of element of safety. So people can then take take the risk. Uhm, I don't know. I guess it's more of a thought or a question.*
>
> *Bill (individual living with ABI): I think you're right. Whenever you open your mouth, someone who not met before, it is a risk you don't know how what the reaction is, you're gonna get, whether you're you've got brain injury or not. And I guess when you've got a brain injury that other things that they make, you worry about the reaction that you will get.*

Participants talked about community ABI support people's role in actively facilitating social connections as part of their role and all participants described something captured by this participant when he said:

> *there's a danger that we think, well, because everybody got an ABI, they're all gonna get on, well, well, before they had the ABI, they probably didn't like each other. Why would they like each other afterwards? (Jim; family member)*

One individual with ABI explained that having a "*kind*" and "*trusted*" (Claire; *individual living with ABI*) person at ABI-specific settings would help them to feel safe. A community ABI support person took this further, stating that each individual should have a case or support worker who supports linking them into the community throughout their adjustment to living life with ABI. This could facilitate maintaining and/or developing social connectedness as an ABI experienced person would be able to respond to the individual's needs when they arise.

Practices

Overall, participants in each participant group used similar practices and most divergent practices were described within the group of community ABI support people due to different professions and different contexts in which they worked. All community ABI support people supported individuals to overcome barriers to social connection through developing strategies and/or sharing information and providing safe, understanding opportunities for social connections, though in different contexts. All emphasised using a patient-centred approach in their work. Community ABI support people's practices mostly differed in the group size, as one described organising big groups for smaller groups to develop naturally, one person explained for service users to meet in small groups, whereas someone else actively links two to three individuals together within a small group. Discourses of practices used by most community ABI support people were empowering of the individuals, emphasising their voices and choices, and supporting them to move towards independence.

All individuals with ABI spoke about the benefits of using strategies developed with healthcare professionals; however, differed in which they found most useful. All individuals valued interactions with ABI peers in ABI specific settings and most participants talked about peer interactions within the context of jointly engaging in activities, which appeared to play an important role in forming connections. Participants' accounts were more oriented towards the future and their own adaptation rather than dwelling on the past.

Family members appeared very supportive and involved in the care of their loved ones; however, differed somewhat in the intensity of their involvement. Some family members talked about the importance of representing the individuals’ voice in the early stages but also allowing them to regain control and independence when possible, portraying a more empowering relationship. Accounts from others, while also supporting independence and encouraging to do more, appeared to be guided by a strong need to protect their loved ones. Most family members appeared proactive in seeking out further information about ABI and raising awareness within their wider communities.

All participant groups commented on the large variability in ABI service provisions across the UK and the need for long-term support following ABI, as individuals with ABI highlighted that needs and social circumstances might change over time.

Table 4.4

Practices Used by Individuals Living with ABI, Family Members/Carers, and Community ABI Support People

	Understanding of Self and from Others	**Rebuilding Confidence**	**Acceptance of Self and from Others**	**Creating Safe Spaces**
Individuals living with ABI	• Explaining needs and impact of BI to others (in general and in day-to-day situations) • Learning about peers' experiences to reflect on own injury • Having honest conversations	• Interacting with peers/attending ABI groups/shared activities in ABI groups • Returning to pre-injury activities (with adaptations if needed) • Using a gradual approach • Applying strategies to manage needs and changes due to BI (e.g., anxiety, fatigue, communication)	• Explaining needs and impact of BI to others • Realising abilities/skills through return to activities	• Planning and preparing for situations in the community • Planning options to independently leave/have a quiet space when with people less known or who understand less well • Explaining needs and impact of BI to others • Adapting social interactions to own needs (e.g., avoiding busy places, take into account mental effort of interaction) • Using a gradual approach
Family members/ carers	• Supporting to develop understanding by pointing out changes to the individual • Seeking out educational materials • Sharing information with others to best accommodate the person's needs	• Encouraging to do more by building on available skills • Highlighting progress • Supporting to make tasks/activities achievable • Supporting and allowing the person to have a voice (regain control)	• Sharing information with others for them to be aware of the person's needs • Giving hope while being realistic	• Sharing information with others for them to be aware the person's needs • Providing practical supports
Community ABI support people	• Sharing accessible information • Support developing	• Highlighting progress • Support developing	• Normalising experiences/changes in needs	• Showing understanding, acceptance, being non-judgmental

	strategies to overcome potential barriers (e.g., mindfulness, pacing, planning) • Support/practise how to explain needs/changes due to BI to others • Normalising experiences/changes in needs	strategies to overcome potential barriers • Encouraging to do more by building on available skills • Practising skills, strategies, activities (inc. adaptations if needed) • Supporting and allowing the person to have a voice (regain control) • Support to start conversations between people in shared activities	• Supporting realisation and rediscovery of abilities • Encouraging discovery of the ‘new self’	• Setting clear expectations of situations by providing accessible information • Providing opportunities to practice social interactions/conversations • Using a gradual approach • Providing opportunities to meet peers in bigger groups, in small groups, or link 2-3 individuals together in an activity • Adapting activities to person’s abilities • Taking time to build good rapport

Discussion

The grounded theory analysis of focus groups provided an understanding of the processes involved and practices used by individuals living with ABI, family members/carers and community ABI support people to help individuals with ABI to maintain and develop social connectedness. Participant groups talked about similar processes that felt important in moving towards becoming socially connected and about various ways in achieving this. There were some variations in practices used both between and within participant groups. Participants described understanding of self and from others as a crucial process and that this is underlying the processes of accepting of self and from others, rebuilding confidence and creating safe spaces while maintaining and/or developing social connectedness. These processes are interlinked and develop over time with periods of feeling more socially connected or less. Individuals living with

ABI used strategies developed with healthcare professionals; however, preferred different strategies. All valued opportunities to meet peers, especially in activity-based groups. Family members differed somewhat in their involvement, but all encouraged their loved ones to do more by building on their abilities. Community ABI support people appeared to use the most divergent practices due to different professions and contexts of their work; however, practices used were patient-centred and motivated to empower individuals.

The described processes, as well as ups and downs in social life [33], fit within the wider body of literature relating to social connectedness and social isolation following ABI. A good understanding, both of self and from others, of the impact of ABI and changes in needs is often reported in the context of navigating the individuals' social worlds and to impact their connections with other people [16, 34, 35]. Some of the processes and practices used to achieve better understanding have also been described in the literature. For example, understanding of oneself is supported through feedback from others [36], meeting peers and working with clinicians, which normalise individuals' experiences as being part of their condition [26]. In line with the importance of understanding from others, it has been reported that feeling misunderstood can worsen the adverse effects of ABI and individuals might try to hide their symptoms, which might lead to societal withdrawal [37] and social isolation [16]. Häggström and colleagues [23] also reported that explaining one's needs and the impact of the injury was used to facilitate other people's understanding to maintain and/or develop social connectedness.

Participants' accounts of developing acceptance of their new self and wanting to feel accepted by others has also been reported previously [33, 38]. It has mostly been linked to the reconstruction of a positive self-identity [38], as feeling accepted and understood by others might reduce the sense of self-discrepancy in one's identity, which allows individuals to be themselves and the sense of needing to hide their difficulties might reduce. This might allow for stronger social connections. Accepting oneself facilitates acceptance from others, which has reported previously in relation to self-disclosure of health information [33]. Social contact with others has been found to support developing a sense of acceptance [11] and, more specifically, acceptance from others in social encounters has been reported to support accepting oneself and a sense of being valued [38], further supporting the process of maintaining and developing social connectedness.

The importance of creating, psychologically and socially, safe environments to enable social connectedness, as well as its link to the process of understanding, was also found in other studies [24, 26, 33, 39]. In line with this study's findings, safe environments were often linked to interventions or group activities with other ABI survivors [33, 35], as these are environments where individuals feel comfortable [33], supported and understood by peers and staff [26]. Safe environments have also been reported to challenge individuals outside their comfort zones [26], in line with this study's participants description of taking risks to enable social connectedness, highlighting safety as a condition needed for engaging in challenges and to promote confidence of trying new things. The importance of safety in the process of developing belonging is in line with Maslow's [2] hierarchy of needs. In addition, safety has been associated with good vagal tone, which enables social connection, as well as positive emotion and physical health [40].

Participants in this study highlighted the importance of rebuilding confidence for social connections. Loss of confidence in social interactions has been discussed in the ABI literature in relation to communication and physical [33], as well as cognitive difficulties [16]. Caregivers and ABI-specific group interventions, in line with this study's findings, were described to support rebuilding independence and confidence [26, 33]. Rebuilding confidence appears to be crucial for "feeling ready" to re-join a social life or participation in the community [24, 33, 39], while "feeling ready" or having the confidence to take the first step is leading to increased confidence for further social situations that create opportunities for social connectedness.

The processes highlighted in this grounded theory are interlinked, leading to becoming more socially connected, which, in turn, facilitates the processes further. For example, participants in this study described the importance of connecting with peers to build confidence to develop connections in the wider community. In line with Social Identity Theory [15], the newly developed social group membership might support developing the person's own sense of identity, which might increase confidence to seek out further social interactions or be generalised to other social contexts such as existing friends, families or community networks [41].

This study's findings support previous research about existing social contacts and frequency of social activities, suggesting that more social contacts led to more frequent engagement in social and community activities [19], as the processes to maintain and develop social connectedness are often supported by pre-injury friends, family members and/or community ABI support people. All participants in this study had some existing social contacts or some support through ABI services.

Supports provided by rehabilitation services, clinicians, family, friends, and the wider community can support adjustment to living life with a brain injury [38], as well as feeling socially connected, which has been emphasised as a key component of experiencing wellbeing [42]. The current study provides information on practices to facilitate, or remove barriers to, social connectedness. Overall, data from this qualitative study suggest the need for longer term community support following ABI, as opposed to time-limited approaches, which is in line with the social model of rehabilitation [39] and research suggesting better outcomes following ABI with longer term support [43]. It is suggested that accessible information should be provided to the individual and their wider social network at various points after the injury when needed. As proposed previously by Douglas and colleagues [44], social-relational aspects should be incorporated into neuropsychological assessment to understand individuals' social difficulties and to tailor rehabilitation to their social connectedness needs. Based on this study's grounded theory framework, this might involve adjustment support to develop self-acceptance and rebuild confidence, for example through therapeutic interventions based on the Y-shaped model developed by Gracey and colleagues [45]. Notably, it has been suggested that this process can be further supported through peer interactions, highlighting the importance of ABI groups in rehabilitation settings [24, 26, 39]. Berger and colleagues [24] found that individuals feel ready to attend opportunities to socially connect in ABI groups at different stages of their rehabilitation, further emphasising the need for longer term rehabilitation. In addition, it might be helpful for other services or healthcare providers, such as primary care settings, to be aware of opportunities to socially connect in the local community (e.g., social prescribing), as they might have longer term contact with individuals and might be able to offer these opportunities at different points following ABI.

Strengths and Limitations

The social constructionist grounded theory [27] allowed for an in-depth exploration of the processes and practices involved in becoming socially connected following ABI, which would have been challenging to explore in a quantitative study. Collecting data in participant group specific focus groups as well as combined focus groups allowed for a safe space for each group to share their experiences, as well to start developing practical ideas to guide rehabilitation practice, which considers everyone's perspectives. To our knowledge, no study to date simultaneously explored the processes and practices involved in becoming socially connected following ABI from the perspective of individuals living with ABI, family members/carers and community ABI support people. Adaptations were made to ensure inclusion of people with cognitive and communication difficulties.

The study was designed to use purposive sampling to hear about the experience of participants of different backgrounds and varying levels of social connectedness. Due to the timeline of the project, convenience sampling was employed. Due to challenges reaching individuals living with ABI who do not feel socially connected through third sector organisations and social media, most individuals reported feeling somewhat socially connected; however, all described a reduction in social networks and feeling less connected to some people, which provided an account of experiences of social isolation. Some individuals, who are more socially isolated, might have not heard about the research or felt unable to take part in the study, as focus groups as the data collection method had a ‘social element’ to it and might have felt inaccessible to some. In addition, most family members were involved in some voluntary ABI work or very engaged in the rehabilitation process of their loved one, which might have limited diversity with regards to the social context of family members. No paid carers took part, whose perspectives might have differed to those of family members due to them facilitating social connectedness in a paid capacity rather than to a loved one. The sample was ethnically less diverse than the UK population and there were limited insights into more diverse ways in which non-ABI community groups or cultural communities might be experienced by people with ABI.

Clinical and Research Implications

Knowledge of the processes involved in maintaining and/or developing social connectedness has important implications for clinical practice and intervention design. The study proposes that social connectedness can be achieved through acceptance and by rebuilding confidence as well as creating safe spaces, which are underpinned by understanding of the self and from others. Healthcare and community settings can support each of these processes directly and by facilitating the understanding of existing social networks to support these processes. In holistic neuropsychological rehabilitation similar processes (e.g., therapeutic milieu, shared understanding, sense of safety) are facilitated through various group activities and shared responsibilities within the centre [46, 47], which could be adopted to support social connections. Neurorehabilitation services might be able to specifically focus on the social connectedness of service users and work collaboratively with service users and local communities to overcome potential barriers. Community ABI support people and family members would be well placed to support individuals to move through the different stages of gaining sufficient understanding, confidence and independence before beginning to join groups or activities, which might initially be ABI-specific groups before joining opportunities in the wider community.

Further research is needed to gather insight about the processes of social connectedness and practices used across different contexts to understand their diversity, especially relating to those who are disconnected or marginalised. For example, individuals feeling disconnected could be identified in NHS services, including GP practices, and asked for their views on this topic or in relation to the results of this study in individual interviews. Capturing the views of individuals who do not access any brain injury services will be challenging; however, the voice of this group is extremely important, as they are likely to feel more isolated. The processes identified in this study can be used to develop an intervention programme used by neurorehabilitation or ABI-specific services to improve social connectedness following ABI. For example, an intervention programme could be developed to focus on each of these processes.

Conclusions

Based on the accounts of individuals living with ABI, family members and community ABI support people, this study suggests that acceptance of oneself and from others, rebuilding confidence and creating safe spaces are important processes involved in developing and/or maintaining social connectedness, which are underpinned by understanding of oneself and from others. The four identified processes are interlinked and develop over time, while having social connections further fosters these processes. These processes can be facilitated by providing relevant information, normalising of experiences, and adopting a gradual approach of encouraging to build on available skills as well as availability of opportunities to engage in activity-based groups to meet peers with ABI and people in the wider community.

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Chapter 5. Extended Methodology

This chapter outlines an extended methodology for the empirical study, including further details of methodological processes and considerations, and how these were adapted to support the inclusion of those living with brain injury throughout the research. In this chapter, the author outlines her research position and reflections on the process of conducting this research.

Stakeholder Involvement / Patient and Public Involvement

The needs and priorities of individuals living with acquired brain injury (ABI) have been considered throughout the research process. The supervisory group included a family member of an individual living with ABI and a healthcare professional working in clinical practice, who advised on the project throughout the process. For example, the family member highlighted the importance of family involvement in the study and provided feedback about the length of research activities as well as how best to use video meeting platforms to optimise focus groups online. The wider supervisory group was also involved throughout the data collection and analysis process by guiding the development of topic guides for the last two focus groups and to discuss the developing analysis. Three of the four members of the supervisory panel attended 1-2 focus groups each. This is in line with the principles of patient and public involvement (PPI), where end-users of research should be included throughout the research process to ensure that the research is meaningful and appropriate (INVOLVE, 2012).

Ethical considerations

Informed Consent

Participants were given detailed information about the study (Appendix K) and the opportunity to ask questions about it prior and during their participation. Written informed consent was sought on an online form (Appendix H). Support to complete the online form was offered to all participants. The consent form explicitly outlined what the participant consented to, including clarification that withdrawal of consent to participate in future groups was possible; however, their data could not be withdrawn once a group had finished as this would impact other group members' data. Full consent was required for every item (except item 11: consent to being contacted regarding opportunities to contribute to future studies on this topic by members of this research team), on the online form by selecting yes or no, before consent to study participation was accepted.

Adaptations to support inclusion for people living with acquired brain injury

People living with brain injury can often present with cognitive and communication difficulties (Hilari et al., 2021), which can pose barriers to participation across the research process (Shiggins et al., 2022). As a result, people with communication and cognitive difficulties have often been excluded from research (Ryan et al., 2021; Townend et al., 2007), which prevents the voices of all end-users of the research being heard and impacts the generalisability of findings (Townend et al., 2007). The authors were conscious of this and wanted to ensure that this research reflected, and meaningfully included, all those who live with brain injury, rather than a sub-group of the population who are cognitively and communicatively able. As a result, adaptations were made throughout the research to ensure that people's specific needs were accommodated for, and inclusion supported.

Consent procedures

Accessible information sheets, consent forms and a presentation for recruitment purposes, using communicatively accessible formatting (also known as aphasia-friendly) were used to support the inclusion of people with cognitive and communication difficulties in this study. LW received training on how to develop information using aphasia friendly guidelines (Rose et al., 2014; Rose et al., 2011) and these were reviewed by a qualified speech and language therapist (supervisor CS). Individuals had the option to discuss the information sheets to facilitate understanding and were offered to complete the consent form with the researcher's support via email, video or phone call, depending on the person's preferred communication medium.

Recruitment

Third sector organisations working with individuals with communication difficulties were specifically contacted as recruitment sites of potential participants and a brief, aphasia-friendly presentation of the study was prepared to be used in groups at these sites. The eligibility criterium of 'no cognitive or emotional difficulties of such severity as to prevent participation in the study with adaptations and accommodations or cause significant risk of distress' was assessed based on the clinical judgement of the key contact in the organisation and by the lead researcher during the initial contact with the potential participant.

Data collection

Support to use the video conferencing programme was offered to participants by sending step-by-step instructions via email and all participants were offered one-to-one practice sessions (Ownsworth et al., 2020). These were used to identify the needs of the person and how their involvement could be supported, to identify access difficulties and to test the raise hand, chat and captions functions. Throughout the focus groups, participants were facilitated to participate by using supportive communication strategies (Kagan, 1998; Paterson & Scott-Findlay, 2002) with adaptations to online focus groups (Topping et al., 2021). These included refocusing the conversation when side-tracked, scaffolding techniques (Simmons-Mackie et al., 2013), allowing participants more time to respond when needed, use of raise hand function on the videoconferencing platform or by raising one's own hand in the video when needing more time to initiate speech, using the chat function or using pen and paper to facilitate communication. The groups were facilitated by the lead author with the support of another member of the supervisory team (FG, CS and JA) to focus on non-verbal cues or communication to ensure all participants were able to participate (Topping et al., 2021). Video recordings were taken of the focus groups, so non-verbal communication could be noted during transcription and analysis.

Individuals living with ABI often experience fatigue after periods of sustained attention, which can impact their ability to process information (Johansson et al., 2009) and to participate in focus groups. As it has been reported that it takes significant amounts of energy to focus on group discussions (Paterson & Scott-Findlay, 2002) and in line with previous PPI feedback, focus groups were scheduled for a maximum of 1.5

hours. Breaks were scheduled with the input of participants, and it was offered that participants could take a break by turning off their microphone and video whenever needed (Topping et al., 2021).

Data management

In line with the Data Protection Act (Data Protection Act, 2018) and the General Data Protection Regulation (GDPR, 2018), all information from and about participants obtained during their involvement in the project was kept confidential. Video recordings were taken using Microsoft Teams' recording function and recordings were saved securely on password-protected servers. Participants were made aware that their contributions during FG discussions would not be anonymous to participants and researchers present during the FGs; however, all contributions were be rendered anonymous after transcription. All recordings were deleted once the data was transcribed.

Distress

There was a possibility that discussions about difficulties with feeling socially connected to others could have caused distress for some participants. Participants were made aware of this prior to providing informed consent (Appendix K). Support was offered within the researcher's ability, as someone with advanced skills in supporting people with mental health issues, during and after the session. Participants received a debrief sheet to normalise emotional reactions and to provide contact information for voluntary organisations that could provide mental health support, for example Samaritans, and NHS services (Appendix L).

Research Design and Underlying Theory

Social constructionism is in line with the perspective that knowledge and our understanding of the world are shaped by culture, context and society (Kim, 2001). It acknowledges the existence of more than one account of reality (Dickerson & Zimmermann, 1996) and cautions against singular accounts, which might silence rather than empower individuals. In addition, it suggests that processes arise within socially constructed contexts (Charmaz, 2006). Individuals living with ABI live in different contexts, which vary in terms of support, resources, economic factors and cultural diversity; all of which will influence the individual's experience of living with an ABI. Therefore, social constructionism fits well with the underlying nature of this project, the fundamental perspectives of Intervention Mapping (IM), and GT (Levers, 2013).

This project drew on IM (Bartholomew-Eldredge et al., 2016) and Constructionist Grounded Theory (GT; Charmaz, 2014). Previous research conducted as part of this overall body of research completed step 1 of IM by investigating the experience of people with ABI about accessing and making use of community groups and by conducting a systematic review of correlates and predictors of social isolation and connectedness (Berger, 2020). The current study, as well as this thesis' systematic review, built on this previous research by focusing on step 2 (identifying who and what needs to change in order to prevent the problem) and step 3 (identifying theories and methods that can facilitate change). In addition, some suggestions for step 4 (design of the programme) were offered through this project.

Recruitment procedures

Recruitment of individuals living with ABI and family members/carers of individuals living with ABI via third sector organisations and community groups

Key contacts of organisations were contacted with an introductory letter (Appendix M) and, when agreed to support recruitment, specific options were discussed. Key contacts either approached the person directly to inform them of the study, ascertain if interested and if so obtained 'consent to share contact details' (Appendix G) with the researcher; or advertised the study (physical poster, or email / newsletter with brief overview of the study, Appendix F) providing contact information so the researcher could be contacted directly.

Recruitment of community ABI support people through third sector organisations and community groups

Key contacts of organisations were contacted with an introductory letter (Appendix M). When agreed to support recruitment, they were provided with information to share with staff in the organisation via email and individuals were asked to contact the researcher directly.

Recruitment of community ABI support people through professional bodies

Professional bodies were contacted with an overview of the study (Appendix N) and asked to distribute to their members. Individuals were asked to contact the researcher if they were interested in taking part in the study.

Recruitment of all participants via social media

The study's flyer and a brief introduction to it (Appendix F) was shared on relevant social media platforms.

Data Collection and Analysis

As outlined in Chapter 4, six focus groups (FG) were completed in total. The first three group meetings were participant group specific (individuals living with ABI, family members/carers, community ABI support people) and then there were three mixed FGs including up to two participants of each participant group. Individuals of these groups were included in this research, as all three stakeholder groups play an essential role in social connection following ABI and their practices often impact each other's practices and experiences.

In line with Grounded Theory (Charmaz, 2014), the process of data collection and analysis was iterative with regular checking of transcripts, and codes with participants (Charmaz, 2014). FGs were initially coded by the lead author (LW) by using phrases reflecting processes and actions (Charmaz, 2014). Codes from the three participant-group specific FGs were studied together and refined into tentative categories. These were combined with initial codes from the fourth FG and developed into focussed codes. Data from the last two FGs was combined with previously collected data to redefine categories.

Data from the first three FGs, and then combined with data from each subsequent group, was displayed visually (Appendix O). At the beginning of each mixed FG, visual representations of data from previous FGs were shared and participants were invited to critique and share further experiences. Participants were invited to share experiences which were in line with the data presented but also to share different experiences to avoid confirmatory evidence only. Through this co-construction of our understanding, visual representations developed from mind maps into the grounded theory model presented in Chapter 4.

Each stage of the data collection was informed by previous codes through changes in topics in the topic guides and presenting collected data. Reflective notes were written throughout data collection and analysis to create more transparency.

Methodological Quality Assurance

Yardley's (2000) approach to methodological quality assurance was chosen, as the open-ended, flexible principles, align well with the ethos of qualitative research. It fits well with social constructionist research due to its consideration of power imbalances, for example. It evaluates research against four principles: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance.

There are various elements to address sensitivity to context. The empirical data has been discussed within the context of existing literature to place it within the theoretical context. Participants (and researchers) were invited to introduce themselves at the beginning of the FGs to provide some information about themselves and the context of their experiences. Questionnaires used for sampling purposes provided some further information about individuals' contexts. I was aware of potential power imbalances between participants and myself but also between participant groups. Power imbalances have previously been reported in research and healthcare settings (Joseph-Williams et al., 2014), which might have reflected into FGs. To address imbalances between participants, there were some separate FGs to begin with and during mixed

FGs, each participant was given the opportunity to share their experiences and knowledge, if they wished. The project's aim was to co-construct a GT model, which was emphasised by inviting participants' critique to visual presentations of the data, giving more balance to the participants' voices.

Commitment and rigour were addressed through prolonged engagement with the relevant literature, both topic and method specific, and by in-depth discussion with the research team members, who are experienced, both clinically and in research, in wellbeing following ABI and the methods used within this project. Triangulation was used to achieve a multi-layered understanding of the topic by including individuals living with ABI, family member/carers and community ABI support people. To fully achieve completeness of the data analysis, it would have been beneficial to discuss the final model with participants. Due to the timeline of this project, it was not possible to share the model as part of the analysis process; however, it will be shared with participants as part of the dissemination process.

The study was discussed in the supervisory team and reviewed by another member of the researcher's school to align the research questions, philosophical perspective, method of investigation for coherence of the study. The researcher tried to create transparency of the data collection and analysis process by sharing excerpts of the coding process (Appendix P), further quotes for each theme (Appendix Q) and initial visual maps (Appendix O). Reflective notes were written throughout the process. Theoretical and clinical implications of this project, and the thesis portfolio more broadly, were discussed.

Researcher position and reflections

I am a 29-year-old, White German Trainee Clinical Psychologist currently living in the East of England. My first work experience as an Assistant Psychologist was within a neurorehabilitation service for individuals living with Traumatic Brain Injury (TBI). The team's work was underpinned by a Positive Psychology approach and Martin Seligman's phrase "building what's strong rather than fixing what's wrong" is something that stuck with me from this job. Service users were offered opportunities to attend various groups within the service and the wider community. Conversations with service users and colleagues showed how important these groups were for various reasons; however, it mostly stood out to me how much individuals valued the opportunity to meet and connect with peers. Throughout further professional roles, I learned more about the impact of brain injury on individuals' lives, wellbeing and sense of connection, and about the huge variability of ABI service provision across the country. Personally, I highly value feeling well connected to people around me and I am aware how important my feeling of belonging to social groups is, especially at times when life feels more challenging. This personal as well as my previous work experience inspired me to learn more about how individuals' sense of belonging and connection after brain injury is supported across the country and drew me to this research project.

Throughout the focus groups, it struck me that individuals living with ABI, despite acknowledging their losses, appeared to speak less of their difficulties following brain injury and focussed on sharing experiences of what strategies they have learned and what they have found helpful while adjusting to life with a brain injury. This felt very different to some qualitative research on similar topics that I read previously and made me reflect on participants' stages of adjustment, but also on how I phrased questions and guided discussions throughout the focus groups.

All participants talked about the importance of understanding and peer support, which was emphasised by participants offering support and normalising other group member's experiences, not only between participants of the same participant group but also between individuals living with ABI and family members. This observation highlighted how important it was to combine participant groups in mixed focus groups not only for data collection purposes but also for the participants' experience. One individual living with ABI fed back how helpful they found hearing the perspectives of people with slightly different experiences and backgrounds as well.

Hearing participants talk about what helps them to feel connected to others made me reflect on my own experiences as well, as I have not thought about what helps me to feel socially connected before starting this research. It appeared that some participants might have had similar reflections, for example a family asked, "don't we all want to feel accepted?".

During the write up of this project, I noticed how participants' use of language shaped my writing. At times, I found myself typing words such as journey, recovery or lived experience as these terms are used in the literature but then deleting them as participants described them to not truly represent their experiences. They explained that a journey suggests that there will be an endpoint, recovery has a conjunction of being back to how one was before the injury. Individuals living with ABI preferred the term 'adjustment', which was used throughout this portfolio.

Chapter 6. Critical Appraisal and Discussion

In this chapter, the findings of the systematic review and empirical study will be summarised and discussed in the context of the wider literature. How these papers contribute to our understanding of improving social connectedness and reducing social isolation following brain injury will be outlined. The strengths and limitations of this thesis portfolio will be discussed, before suggesting implications for clinical practice and future research.

Summary of Main Findings

The thesis aimed to increase our understanding of the processes and practices, including available interventions, involved in maintaining and sustaining social connectedness and reducing social isolation for people living with Acquired Brain Injury (ABI).

The systematic review identified interventions currently available that address social isolation in adults living with ABI and appraised the evidence of their effectiveness. Eleven interventions were included in the systematic review. Overall, only a small number of heterogenous studies with variable quality was available (e.g., small sample sizes, outcome measures used were not validated in the ABI population), which made it difficult to draw firm conclusions about the interventions' effectiveness. Interventions could be grouped into social support, communication and psychological interventions; however, most interventions were not based on theory. There was some evidence that social support interventions, more specifically peer befriending and volunteering, might be effective in reducing social isolation.

The empirical study explored the processes involved in maintaining and/or developing social connectedness following ABI and the practices used by individuals living with ABI, family members and community ABI support people. These aims were addressed by using a qualitative method, involving six focus groups informed by Constructionist Grounded Theory (Charmaz, 2006). The initial three focus groups were attended separately by individuals living with ABI, family members/carers and community ABI support people. Two individuals from each participant group were invited to the remaining three focus groups. These data suggested acceptance of self and from others, rebuilding confidence and creating safe spaces to be important processes involved in developing and/or maintaining social connectedness, underpinned by understanding of self and from others. The identified processes develop over time and impact on each other in a bi-directional way, while having social connections further nurtures these processes. Similar practices were described to be used by participants in each group. Community ABI support people appeared to use the most divergent practices due to different professions and contexts of their work; however, practices used were motivated by the same values in line with improving social connection and wellbeing. The Grounded Theory model developed through the empirical study can be used to inform elements of future interventions as well as practices in neurorehabilitation to maintain social connection and reduce social isolation.

The two papers complement each other and contribute to the Intervention Mapping (IM) framework by investigating available interventions that target social isolation while also investigating mechanisms that foster social connectedness and, therefore, might prevent social isolation.

Integrating Findings within the Literature

When mapping the interventions included in the systematic review onto the key components highlighted in the empirical paper, most reviewed interventions appear to be in line with one or two of the components of the empirical study. Communication interventions (e.g. Marshall et al., 2016) often support individuals to rebuild confidence to communicate (rebuilding confidence) and to develop their understanding of their needs (understanding of self) and helpful communication strategies (understanding of self; rebuilding confidence). Interventions delivered in groups (Dahlberg et al., 2006) provide opportunities to meet ABI specific peers (understanding) and to socialise in safe spaces (creating safe spaces). Only one social support intervention explicitly emphasised developing strategies to support adjustment to living with ABI (Hilari et al., 2021). This is in line with all processes highlighted by participants in the empirical study, as it supports understanding and acceptance, allows the person to rebuild confidence through developing strategies while in a safe space with ABI peers. Participants in the empirical study also felt that brain injury education at various stages during the adjustment to living life with ABI is important; however, no intervention explicitly described an educational component about brain injury for the individual living with ABI or people in their social network.

The systematic review and empirical study both emphasise the role of peers with ABI in reducing social isolation and promoting a sense of social connection. This is in line with findings of Hughes and colleagues' (2020) systematic review on ABI peer support that highlighted that individuals value peer support for the opportunity to obtain friendships, share coping strategies and receive more information about brain injury.

Being able to share resources and information with people with a shared experience of ABI promotes social capital (Kemp et al., 2017), describing links between individuals and uniting people from various backgrounds (Putnam, 2000), as well as develops social cohesion (Elliott et al., 2014). Social cohesion is defined as ‘community’ achieved through geographical space by sharing values and interactions (Elliott et al., 2014) and has been described to create a context for positive connections with others (De Vries et al., 2013) but also to stimulate feelings of belonging and acceptance (Elliott et al., 2014). This connection between acceptance, peer support and feeling of social connection was also found within the empirical study. Here, peer support was mostly offered through groups and interactions in neurorehabilitation services or brain injury charities. Previous qualitative research also highlighted the positive impact of psychosocial and community groups on social connectedness and acceptance (Berger, 2020; Wilkie et al., 2021). Community groups are often formed around a specific activity (such as arts or sports groups) and were found to provide opportunities to connect with other people (Attard et al., 2015; Berger, 2020), to experience a sense of accomplishment (Hyer et al., 1996) and to experience positive affect (Berger, 2020; Phinney et al., 2014). It is of note that participants in the empirical study referred to peer support that occurs organically while engaging in group activities, such as during community groups, rather than to structured peer befriending interventions, as investigated in studies in the systematic review. However, in line with accounts from participants in the empirical study, there is no “one-size-fits-all” approach for group participation and research suggests that attending groups may not be as beneficial if not attended at the right time (Berger, 2020; Lanyon et al., 2019), if the individual cannot identify a tangible benefit (Lanyon et al., 2019) or if there is insufficient support, in particular communication support, as highlighted by individuals with severe aphasia (Lanyon et al., 2019). This highlights the importance of a person-centred approach to social connection following ABI, which was also emphasised by community ABI support people in the empirical study.

The empirical study highlighted that becoming socially connected or a sense of social connectedness is not only depending on the individual but greatly influenced by people around them through understanding, acceptance and supporting a feeling of safety. It also emphasised how people other than the individual engage in practices that support social connectedness for the individual living with ABI. This is in line with previous research by Berger and colleagues (2020), which emphasised the importance of practical and emotional supports to facilitate access to community groups. The reviewed interventions utilised some practices highlighted in the empirical paper and, as discussed, supported some of the underlying processes of becoming socially connected. Nevertheless, these interventions mostly focussed on the individual rather than considering social connectedness as a phenomenon influenced by the people around them and emphasising the role of communities.

The empirical study suggested that developing and/or maintaining social connectedness takes time. Most therapeutic models used in rehabilitation programmes and described in the literature, as well as interventions reviewed in the systematic review, are short-term interventions (Douglas et al., 2006). Given the findings of the empirical study, this may raise the question whether short-term interventions can be effective in supporting social connectedness. Especially, if not provided at the right time when the individual feels ready to engage in these opportunities (Berger, 2020) or if there are no further opportunities to engage in the community to continue building on the experience from the short-term intervention. This is in line with reports highlighting the lack of long-term community support (Salas et al., 2020), which was aimed to be addressed with the National Service Framework for Long-Term Conditions (Department of Health and Social Care, 2005). For example, Coetzer (2008) outlined a long-term model of community rehabilitation, incorporating some principles of holistic rehabilitation into a long-term, low-intensity community setting. It also highlighted the benefits of community-based rehabilitation to support generalisation of skills and drawing from strengths and support of communities (Coetzer, 2008). Salas and colleagues (2020) also describe a model of long-term social rehabilitation where a safe relational environment is provided for individuals to stay socially and cognitively active (Salas et al., 2020). The model provides long-term support, in line with suggestions from the empirical paper, throughout the chronic phase of ABI with a focus on counteracting social isolation and promoting wellbeing following ABI (Salas et al., 2020).

Neurorehabilitation practices (Cullen et al., 2018; Tulip et al., 2020) increasingly draw upon models of wellbeing that adopt principles linked to Positive Psychology (PP), such as Seligman's (Seligman, 2011) PERMA model of wellbeing and the GENIAL (Fisher et al., 2019; Kemp et al., 2017) model, reflecting a shift to move towards wellbeing rather than reducing impairment (Tulip et al., 2020). In the empirical paper, some participants talked about how feeling accepted and understood, led to feeling able to be themselves (linked to self-acceptance), and to closer connections and "feeling good", which fits with elements of Seligman's (Seligman, 2011) model of wellbeing. This further supports findings by Berger and colleagues (2020) about how social connection can improve wellbeing and mood. Additionally, Berger and colleagues

(2020) found that factors leading to wellbeing are interlinked, rather than distinct, and suggested that improvements in one area (e.g., becoming more connected) can lead to a virtuous cycle of increased activity and connection, which may lead to wellbeing in other areas. In the empirical study, some individuals living with ABI also talked about this cycle of positive connections and experiences leading to motivation and confidence to do more and engage in more contexts with opportunities for more social connections, which further supports this finding while using data drawn across family members and community ABI support people. Family members and community ABI support people appear to support this process by encouraging the individual to do more by building on their available skills, as well as by supporting the individual to realise and rediscover abilities and interests.

The GENIAL (Fisher et al., 2019; Kemp et al., 2017) model also highlights the role of socio-contextual factors supporting or restricting the experience of wellbeing (Gibbs et al., 2022), emphasising the need to look beyond the individual and their neurorehabilitation service at how communities might be able to support individuals with ABI. Looking at resources available within the individual, their families and communities might also address some of the discussed issues, such as reviewed interventions focussing mostly on the individual rather than incorporating resources around them as well as being time limited. Asset-based approaches to healthcare (Hopkins & Rippon, 2015) suggest that people can move towards wellbeing and health by identifying and drawing from the resources available to them within their communities. Asset-based approaches would recommend for community organisations, health and social care to work together to identify and mobilise resources to support health and wellbeing (Marmot et al., 2010). There are various examples showing this type of joint working. For example, in the UK, social prescribing (Public Health England, 2022) has been introduced, where health and care professionals prescribe community activities, or resource facilitation has been developed and evaluated in the USA (Trexler & Parrott, 2018). Resource facilitation describes the partnership between an individual living with ABI and their social network, and a facilitator with local knowledge, who support to navigate systems to achieve agreed goals (Trexler & Parrott, 2018). It mostly focuses on return to work following ABI but has also shown promising results in increasing participation at home and in the community (Trexler et al., 2010).

Strengths and Limitations of the Thesis Portfolio

A strength of the overall thesis is how the two studies, and their different methodologies complement each other to explore the complex phenomenon of social connectedness and how it can be fostered following ABI. The systematic review was conducted based on a protocol reviewed by the supervisory team and PROSPERO reviewers. It reviewed quantitative studies to gain a good understanding about the effectiveness of current interventions. Using the TIDieR checklist (Hoffmann et al., 2014) to synthesise and analyse the findings of relevant studies could have provided important information about specific intervention elements that contribute to the interventions' effectiveness. In addition, due to the quantitative nature of the studies, important information about the interventions' specific social contexts or circumstances to maximise access and outcomes might have not been captured.

There are some limitations for the systematic review. Due to limited intervention studies published, the inclusion criteria were relatively broad, including studies measuring social isolation as secondary outcomes. Due to the timeline of the project, the systematic review only included peer-reviewed literature and, therefore, interventions published in the grey literature might have been missed. This might pose a risk of bias due to only detecting studies that are published and potentially missing studies with insignificant outcomes due to publication bias. In addition, only papers published in English were reviewed.

Using a qualitative methodology in the empirical paper allowed for people to share their subjective experiences, which allowed for a more nuanced understanding of social connectedness following ABI (Hennink et al., 2020). Using a constructionist grounded theory methodology (Charmaz, 2014) enabled an in-depth exploration of the processes and practices involved in maintaining and developing social connectedness, drawing upon discursive resources, terms and phrases used in a specific context, used by individuals living with ABI, family members and community ABI support people. Conducting focus groups online allowed participants from various contexts in the UK to take part as well as enabled inclusivity of participants that might have been unable to travel to the focus groups. However, it limited participation to individuals who had access to online platforms and were able to use it with support. Efforts were made to facilitate participation and make the research process accessible for individuals with cognitive and communication difficulties. Participant facing documents were adapted and all participants were offered the opportunity to discuss information via email, telephone or video call. Test calls were offered to reduce stress due to technological aspects. Various functions of the video platform (e.g., chat box, hands up, live captions) were explained to participants verbally and in writing and a second researcher attended all focus groups to watch for non-verbal signs to support inclusivity.

The ABI population is highly heterogenous (Bruns Jr & Hauser, 2003) due to differences in people's individual impairments, contexts, personal circumstances, settings and also sense of social connectedness. Due to the timeline of the project and some recruitment difficulties, purposive sampling was not possible to be proactively selective to ensure a diversity of the sample, which would have been helpful for driving the analysis (e.g., negative case analysis) and enhancing transferability of findings. The ethnic diversity of participants did not reflect the UK population, indicating a lack of people from minoritized backgrounds in this research, and individuals who might be or feel excluded from NHS services or research and those who experience health inequalities were not represented in this research. This indicate a gap in our understanding about different types of community activities that might be more focused about specific religious or cultural practices.

Holding a social constructionist position in the grounded theory study meant that the researcher influenced the analysis and resulting theory, as themes and quotes of more meaning to the researcher may have been given greater emphasis. To be more transparent about influences by the researcher, as well as decisions made, the researcher used notes, diagrams, and discussions with the wider supervisory team. Initial diagrams of the emerging analysis were brought to the three mixed focus groups to co-construct the analysis with participants. It would have been helpful to check back the final theory with participants (Doyle, 2007), however, this was not possible due to the timeline of the project. While writing up the results, the author regularly reviewed participants' quotes to ensure that the theory is grounded in the focus group data and reflects participants' accounts.

Implications for Clinical Practice

There is a large variety of rehabilitation service provision and funding, availability of brain injury organisations and structures as well as cultural, community and activity groups across the UK, highlighting the need to focus on the specific social context when drawing from this thesis's findings.

Peer relationships

The systematic review and the empirical paper highlighted the beneficial impact on social connectedness of spending time with peers. In line with previous research (e.g., Berger, 2020), the empirical paper emphasised that individuals feel ready to meet peers at different points after ABI and that their experience of social connection might change over time. This highlights the need to offer opportunities to meet with peers at various points during the adjustment process and potentially requiring extended follow-up in ABI settings.

Community resources

The grounded theory suggests a framework to inform clinical practice and factors to consider when supporting an individual to become more socially connected. For example, it stresses the importance of good understanding both of the individual themselves and from others, highlighting the need for early and continuous education about ABI (Hart et al., 2018), its impact and related factors. Using accessible language or metaphors is important for the individual's own understanding but also to enable individuals to share information with their social networks. Again, providing information and education can be helpful at various time points throughout the acute and chronic phases, as individuals' needs may change or different challenges occur (Hart et al., 2018). To support other people's understanding, it may be helpful to provide support to the individual in how to communicate and explain the impact of their brain injury to their social network or provide opportunities for members of the social network, and the wider community, to access further information.

The empirical study supported Berger and colleagues' (2020) findings that accessing community groups leads to a virtuous cycle of increased social connection, motivation and activity. Most participants in this empirical study talked about peer connections occurring in the context of activity-based groups, rather than less or unstructured social groups. Both emphasising the importance of encouraging activity-based groups offered within brain injury-specific environments and in the individuals' communities. Engaging in activity- or skill-based groups might further improve wellbeing due to a sense of accomplishment.

Asset-based approach

Asset-based approaches to healthcare are suggested to be used for region-specific detailed recommendations for clinical practice, which will ensure that they are informed by individuals living ABI and other local stakeholders to provide the best possible opportunities. This further emphasises the importance of good links between different services ranging from acute to community rehabilitation, third sector as well as social care. This is in line with the NHS Long Term Plan (2019) for Integrated Care Systems, which aims to bring together local organisation to improve population health and might include practices such as social prescribing. Good communication between different health and care providers has been shown good patient outcomes following ABI (Hawley et al., 2000). Having a seamless service provision with different intensity of support might facilitate individuals' integration into their communities.

Theoretical Implications and Future Research

The thesis suggests that more intervention studies looking at improving social connectedness following ABI are needed, in particular studies of higher quality and with a primary aim of improving social connectedness. To further improve the quality of intervention studies and to better understand effectiveness, it would be useful for interventions to be underpinned by our theoretical understanding of social connectedness. In addition, there is a need for more validated outcome measures of social isolation and/or social connectedness to be able to determine intervention effectiveness. Further, it might be useful to complete a systematic review of intervention studies including qualitative studies with a focus on the nuances of intervention delivery across different contexts to further improve our understanding about inclusiveness and adaptations that might be needed.

It would be helpful to see if the grounded theory model of developing and/or maintaining social connections following ABI and the practices used are also found in different contexts. The model suggests a framework to inform clinical practice and could be used to develop interventions aiming to foster social connectedness. In line with the Intervention Mapping approach (IM; Bartholomew-Eldredge et al., 2016), this thesis and previous work by Berger and colleagues (2020) covered the first three steps of IM. However, further information on when and in what context an intervention should be implemented and how it should address social isolation is needed before moving onto the next steps in the approach, which involves co-developing specific programme components (step 4) with individuals living with ABI, family members/carers and community ABI people. For example, the intervention might involve a training programme addressing all four processes identified in the GT that would be delivered to community group facilitators in order to broaden opportunities of social connections during the adjustment phase in individuals' communities. Alternatively, an intervention might involve resources for acute and community services to offer support linked to all four processes that can be tailored to an individual's needs. The intervention or programme would be implemented (step 5) over a period of time and across different contexts and evaluated (step 6). Given the limited availability of outcome measures validated in the ABI population, this step requires careful consideration and mixed methods might be employed to evaluate the intervention.

Conclusion

The thesis suggests that understanding of oneself and by others, acceptance of oneself and by others, rebuilding confidence and creating safe spaces are important processes involved in developing and/or maintaining social connectedness following ABI. These processes develop over and, therefore, take time. The thesis highlights the important role of the individual living with ABI as well as of family members, community ABI support people and also peers in the process of fostering social connectedness by using various practices. It suggests that published interventions aimed to improve social connectedness following ABI often address only one or two of these processes; however, drawing from this thesis’s findings, interventions or service models could explore integration of all four described processes.

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Appendices

Appendix A

Search Strategy

APA PsycInfo searched on EBSCOhost Research Databases

Concept 1: brain injury

S1 TI ("brain injur*") OR AB ("brain injur*")

S2 ABI

S3 TBI

S4 TI (stroke) OR AB (stroke)

S5 "brain h#morrhage"

S6 "brain tum#r"

S7 "brain infect*"

S8 encephalitis

S9 "head injur*"

S10 "head trauma"

S11 "cerebrovascular accident"

S12 CVA

S13 "brain aneurysm"

S14 "carbon monoxide poisoning"

S15 "hydrocephalus"

S16 hypoxi*

S17 anoxi*

S18 meningitis

S19 DE "Brain Injuries" OR DE "Traumatic Brain Injury"

S20 DE "Brain Damage" OR DE "Periventricular Leukomalacia"

S21 MM "Cerebrovascular Accidents"

S22 MM "Brain Lesions (Disorders)"

S23 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22

Concept 2: social isolation

S24 "social network"

S25 “social isolat*”

S26 lonel*

S27 "social connect*"

S28	friends*
S29	"social inclus*"
S30	"social participat*"
S31	befriending
S31	"social support"
S32	"community integration"
S33	"social activit*"
S34	"community group*"
S35	MM "Social Isolation"
S36	MM "Social Connectedness"
S37	MM "Belonging"
S38	MM "Loneliness"
S39	DE "Social Networks" OR DE "Online Social Networks"
S40	MM "Social Inclusion"
S41	MM "Participation"
S42	MM "Friendship"
S43	MM "Social Support"

S44 S24 OR S25 OR S26 S27 OR S28 OR S29 OR S30 OR S31 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43

S45 S23 AND S46

S46 MM “Dementia”

S47 S45 NOT S46

<u>Medline searched on EBSCOhost Research Databases</u>

Concept 1: brain injury

S1 TI ("brain injur*") OR AB ("brain injur*")

S2 ABI

S3 TBI

S4 TI (stroke) OR AB (stroke)

S5 "brain h#morrhage"

S6 "brain tum#r"

S7 "brain infect*"

S8	encephalitis
S9	"head injur*"
S10	"head trauma"
S11	"cerebrovascular accident"
S12	CVA
S13	"brain aneurysm"
S14	"carbon monoxide poisoning"
S15	"hydrocephalus"
S16	hypoxi*
S17	anoxi*
S18	meningitis
S19	(MH "Brain Injuries+")
S20	(MH "Brain Damage, Chronic+")
S21	(MH "Stroke+")
S22	(MH "Hypoxia, Brain+") OR (MH "Encephalitis+")
S23	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22

Concept 2: social isolation

S24	"social network"
S25	"social isolat*"
S26	lonel*
S27	"social connect*"
S28	friends*
S29	"social inclus*"
S30	"social participat*"
S31	befriending
S32	"social support"
S33	"community integration"
S34	"social activit*"
S35	"community group*"
S36	S19 OR S29 OR S30 OR S31 OR S32
S37	(MH "Social Isolation+")
S38	(MM "Loneliness")
S39	(MH "Social Networking+")
S40	(MM "Social Inclusion")

S41 (MM "Social Participation")

S42 (MM "Friends")

S43 (MH "Social Support+")

S44 (MM "Community Integration")

S45 S24 OR S25 OR S26 S27 OR S28 OR S29 OR S30 OR S31 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44

S46 S23 AND S47

S47 (MM ”Child”) OR (MM “Adolescent”) OR (MM “Infant”) NOT (MM “Adult”)

S48 (MM “Dementia”)

S49 S46 NOT S47 NOT S48

<u>CINAHL searched on EBSCOhost Research Databases</u>

Concept 1: brain injury

S1 TI ("brain injur*") OR AB ("brain injur*")

S2 ABI

S3	TBI
S4	TI (stroke) OR AB (stroke)
S5	"brain h#morrhage"
S6	"brain tum#r"
S7	"brain infect*"
S8	encephalitis
S9	"head injur*"
S10	"head trauma"
S11	"cerebrovascular accident"
S12	CVA
S13	"brain aneurysm"
S14	"carbon monoxide poisoning"
S15	"hydrocephalus"
S16	hypoxi*
S17	anoxi*
S18	meningitis
S19	(MH "Brain Injuries+")
S20	(MH "Brain Damage, Chronic+")

S21	(MH "Stroke+")
S22	(MH "Hypoxia, Brain+") OR (MH "Encephalitis+")
S23	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22

Concept 2: social isolation

S24	"social network"
S25	"social isolat*"
S26	lonel*
S27	"social connect*"
S28	friends*
S29	"social inclus*"
S30	"social participat*"
S31	befriending
S32	"social support"
S33	"community integration"
S34	"social activit*"
S35	"community group*"

S36	S19 OR S29 OR S30 OR S31 OR S32
S37	(MH "Social Isolation+")
S38	(MM "Loneliness")
S39	(MH "Social Networking+")
S40	(MM "Social Inclusion")
S41	(MM "Social Participation")
S42	(MM "Friends")
S43	(MH "Social Support+")
S44	(MM "Community Integration")
S45	S24 OR S25 OR S26 S27 OR S28 OR S29 OR S30 OR S31 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44
S46	S23 AND S47
S47	(MM ”Child”) OR (MM “Adolescent”) OR (MM “Infant”) NOT (MM “Adult”)
S48	(MM “Dementia”)
S49	S46 NOT S47 NOT S48

EMBASE searched on OVID Research Databases

Concept 1: brain injury

1 brain injur*.tw.

2 ABI.mp.

3 TBI.mp.

4 stroke.tw.

5 brain h#morrhage.mp.

6 brain tum#r.mp.

7 brain infect*.mp.

8 encephalitis.mp.

9 "head injur*".mp.

10 "head trauma".mp.

11 "cerebrovascular accident".mp.

12 CVA.mp.

13 "brain aneurysm".mp.

14 "carbon monoxide poisoning".mp.

15 "hydrocephalus".mp.

16 hypoxi*.mp.

17 anoxi*.mp.

18 meningitis.mp.

19 brain injury/

20 brain damage/

21 cerebrovascular accident/

22 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21

Concept 2: social isolation

23 "social network".mp.

24 "social isolat*".mp.

25 lonel*.mp.

26 "social connect*".mp.

27 friends*.mp.

28 "social inclus*".mp.

29 "social participat*".mp.

30 befriending.mp.

31 "social support".mp.

32 "community integration".mp.

33 "social activit*".mp.

34 "community group".mp.

35 social isolation/

36 loneliness/

37 social network/

38 social participation/

39 friend/

40 social support/

41 community integration/

42 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 40 or 41

43 22 AND 43

44 (child/ or adolescent/) not adult/

45 Dementia/

46 43 not 44 not 45

Appendix B

Measure of Social Isolation Used in Included Studies

Supplementary Table B.1

Measure of Social Isolation Used in Included Studies

Name of measure	Type of social isolation measured	Description of measure
Friendship Scale	Subjective	Explores people's subjective feeling of social isolation, if they feel able to relate to others and if they have other people they can contact for support
Social Connectedness Scale-Revised	Subjective	Explores people's subjective sense of closeness in interpersonal relationships, as well as difficulties developing and maintaining a feeling of closeness
Sense of Belonging Instrument - Psychological Experience subscale	Subjective	Explores people's subjective feeling of valued and accepted
University of California, Los Angles Loneliness Scale (UCLA)-Version 3	Subjective	Explores people's subjective feelings of loneliness and their frequency
Frequency of integrated social contacts	Objective	Counts the frequency of contacts
Social Network Analysis	Objective	Assesses the size of social network as well as closeness of the relationship
Lubben Social Network Scale-6	Objective	Assesses the size of social network and how many people they would approach for social support, and frequency of contact

Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF) social integration	Objective	Assesses at the person's social network and number of social contacts
Stroke Social Network Scale	Combined	Measures objective isolation (by assessing the social network size) and perceived social isolation (people's satisfaction with contact and exploring feelings of loneliness

Appendix C

Quality Appraisal Ratings for Included Studies

Supplementary Table C.1

Quality appraisal of randomized controlled trials

		Marshall et al. (2020)						**Hilari et al. (2021)**						**Struchen et al. (2011)**					
		Y	PY	N	PN	NA	NI	Y	PY	N	PN	NA	NI	Y	PY	N	PN	NA	NI
Domain 1. Randomisation 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?				*						*					*			
	Risk-of-bias judgement	Low risk						Low risk						Some concerns					
Domain 2. Deviation 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?					*						*						*	
	Risk-of-bias judgement	Low risk						Low risk						Some concerns					
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?				*							*						*	
	Risk-of-bias judgement	Some concerns						Some concerns						Low 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?					*						*							*
	Risk-of-bias judgement	Low Risk						Low 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?			*						*									*
	Risk-of-bias judgement	Low risk						Low risk						ome concerns					
Domain 6. Overall Bias	Overall risk-of-bias rating	Some concerns						Low risk						High risk					

		Dahlberg et al. (2007)						**Marshall et al. (2016)**						**Dede et al. (2019)**					
		Y	PY	N	PN	NA	NI	Y	PY	N	PN	NA	NI	Y	PY	N	PN	NA	NI
	1.1 Was the allocation sequence random?	*							*					*					

Domain 1. Randomisation process	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?						*				*					*			
	Risk-of-bias judgement	High risk						High risk						Low risk					
Domain 2. Deviation 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?					*						*						*	
	Risk-of-bias judgement	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?					*						*						*	
	Risk-of-bias judgement	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?						*						*				*		
	Risk-of-bias judgement	Low risk						High risk						Some concerns					
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?	*	*	*
	Risk-of-bias judgement	Low risk	Low risk	Some concerns
Domain 6. Overall Bias	Overall risk-of-bias rating	High risk	High risk	High risk

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

Supplementary Table C.2

Quality appraisal of pre-post designs with no control group

	Northcott et al. (2015)					**Tamplin et al. (2013)**					**Caute & Woolf (2010)**					**Lawrence et al. (2017)**				
	Y	N	CD	NA	NR	Y	N	CD	NA	NR	Y	N	CD	NA	NR	Y	N	CD	NA	NR
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?	*	*	*	*
Quality rating	Poor	Fair	Poor	Fair

Y = Yes, N = No, CD = Cannot Decide, NA = Not Applicable, NR = Not Reported

Supplementary Table C.3

Quality appraisal of case series

	Johnson & Davis (1998)				
	Y	N	CD	NA	NR
1. Was the study question or objective clearly stated?	*				
2. Was the study population clearly and fully described, including a case definition?	*				
3. Were the cases consecutive?		*			
4. Were the subjects comparable?		*			
5. Was the intervention clearly described?	*				
6. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?		*			
7. Was the length of follow-up adequate?	*				
8. Were the statistical methods well-described?		*			
9. Were the results well-described?	*				
Quality rating	Poor				

Y = Yes, N = No, CD = Cannot Decide, NA = Not Applicable, NR = Not Reported

Appendix D

Intervention Characteristics According to the TIDieR Checklist

Supplementary Table D.1

Intervention Characteristics According to the TIDieR Checklist

Author	**Brief name *(Item 1)***	**Rationale/Theory *(Item 2)***	**What (procedures and materials; *Items 3 and 4*)**	**Who provided *(Item 5)***	**How and Where *Items 6 and 7)***	**When and how much *(Item 8)***	**Tailoring and modifications *(Items 9 and 10)***	**Adherence and Attrition *(Items 11 and 12)***
Hilari et al. (2021)	Supporting wellbeing through Peer Befriending (SUPERB)	• Peer befriending is social and emotional support provided by people with living with a similar condition and can support individuals to bring about the desired change. This may improve psychosocial wellbeing for people with stroke and aphasia. • Peer befriending aims to support people move forward and develop strategies for adjusting to life after stroke. • Peer befriender training, supervision and visits were tailored to peer befrienders and participants' needs (inc. communication and	• The intervention includes peer-befriender visits for goal setting, problem solving, conversations, trips out, and joint activities to support developing strategies to adjust to living with stroke. • Peer-befrienders receive training based on an adapted peer befriending intervention manual from Connect-the communication disability network (now Re-Connect). • Materials: Handbook with key forms that need completing prior to and after visits. Materials to	• Peer befriender training and supervision: Speech and Language Therapist, Clinical Linguist • Peer befriending intervention: Peer befrienders have mild-moderate aphasia, >1-year post-stroke, be able to complete visits for 3-4 hours (inc. travel time), able to use public transport/drive, have positive personality characteristics (e.g., resilience, open with feelings, confident, able to approach others), must attend training and monthly supervision; work with 2-4	• Peer befriending intervention: organised by befriender; in a person's house; in the community (e.g., local cafe, stroke club). • Peer befriender training: face-to-face with 5 befrienders • Peer befriender supervision: face-to-face, up to 10 befrienders	• Peer befriending intervention: visits for min. 1h; at least 6 visits over 3 months, plus 2 follow-up visits in the following 6 months. • Peer befriender training: 5-6 hours across 2-3 days. • Peer befriender group supervision: monthly, 1-1.5 hours.	• Peer befriending training was revised from 6 to 5 hours following the first training session.	• Evaluation of fidelity of training, supervision and visits through ratings of video recordings; recording of attendance of all study components • Adherence: 24 (92%) attended at least two sessions, 21 (81%) attended all six sessions; 3 sessions were cancelled, 98% of sessions

		cognitive abilities, content, location).	support communication with people with aphasia	participants, no more than 2 at a time				happened as planned (n=116) or rescheduled (n=27) • Attrition: 4 participants withdrew after randomisation (7.14%)
Marshall et al. (2016)	EVA Park - individual therapy	• Computer therapy tools can tailor exercises to the individual's needs and has been shown to be effective for a range of language skills (e.g., verb production) (Furnas & Edmonds, 2014). • Virtual reality may be beneficial to aphasia therapy by providing an engaging environment, facilitating generalisation of therapy skills to the real work, and by offering opportunities to meet others with the potential to reduce social isolation. • The intervention is tailored to the participant's individual goals (at least 3 goals).	• Each participant is paired with a support worker who meets with them in the EVA park virtual reality for activities to work on their individual goals. • Support workers receive 4 hours of training prior to the intervention (inc. access to EVA park, navigation, interaction skills, communication activities) and weekly supervision from speech and language researchers. • Materials: laptop	• Speech and language therapists, experienced stroke group volunteers	• The intervention takes part at an agreed time and place in EVA park virtual reality, which is accessed from the participant's home.	• Daily sessions with support worker (25h in total). • Weekly 1-hour groups discussions with all participants and support workers. • Unlimited, independent access for 5 weeks.	• None reported.	• Time logged into EVA park is automatically recorded for each participant. • 10 participants completed all sessions (50%). The mean time spent in EVA park by participants was 40.85 hours (range: 14-100 hours). • No attrition.

Marshall et al. (2020)	EVA park - group therapy	• Telerehabilitation used to assess and treat people with aphasia is mostly delivered one-to-one; however, there is some evidence that virtual group interventions may also be effective in improving communication related quality of life (Pitt et al., 2019). • Groups were found to potentially increase social connectedness (Vickers, 2010). • Intervention included activities aimed to promote wellbeing and to address personal identity; activities in line with Positive Psychology and asset-based intervnetions. • Previous research on EVA park showed that participants valued the positive support and humour from meeting others in EVA park (Amaya et al., 2018).	• The intervention is based on accounts of support interventions (e.g., Attard et al., 2015; Shadden & Agan, 2004) and informed by discussions with an Advisor group. • Group activities focus on promoting wellbeing, giving participants experiences of communicative success and building social connections. • 14 sessions facilitated by a group co-ordinator and 2 volunteers with between session tasks. • Co-ordinators and volunteers receive two, 4-hour long training sessions and monthly supervision. • Materials: laptop	• Group co-ordinators with at least 3 years' experience in leading community groups for people with aphasia. • Volunteers with previous experience in working with people with aphasia	• Groups sessions run remotely in EVA park. • Training of co-coordinators takes place face-to-face; supervision takes place in a private area of EVA park.	• 14 group sessions (21 hours) delivered over 6 months (once a fortnight).	• The protocol advises 4 volunteers per group.	• The aim was to record 30 intervention session and for two study unrelated speech and language therapists to check them based on a fidelity checklist. • 18 sessions were checked for fidelity: the mean fidelity score was 1.76/2 and 81.9% of the applicable treatment components were fully present in the evaluated video. • Attrition: 14.7% did not complete the intervention, 20.6% did not complete all assessments

Northcott et al. (2015)	Solution focused brief therapy (SFBT)	• There is some evidence for the effectiveness of psychotherapeutic therapies for people with aphasia to improve mood (Hackett et al., 2008); however, there limited evidence to increase social activities. • There have been promising group interventions to improve social participation (e.g., Vickers, 2010) but there is less evidence for therapies for socially withdrawn people with aphasia. • The effect of SFBT on the social and emotional well-being of people with aphasia has not yet been evaluated. • Therapy is tailored to the individual's needs.	• The intervention is based on the model of SFBT as delivered at the BRIEF therapy centre in London (Ratner et al., 2012). • The first therapy session explores the participant's 'best hopes' following which the person is supported to describe 'their preferred future'. • Scaling questions are used, and homework tasks suggested to notice positive signs of change.	• Speech and language therapists trained in SFBT	• Sessions take place based on participants' preference (face-to-face or virtual).	• 3-5 therapy sessions, between 45-90 minutes each • Participants can choose the spacing of sessions.	• Choice was offered regarding spacing and location of sessions. • One spouse attended therapy sessions due to participant's preference.	• No attrition.
Tamplin et al. (2013)	"Stroke a Cord"	• Group music experiences offer a social opportunity to stroke survivors with aphasia that focuses less on verbal communication and has been found to have positive effects on mood in stroke survivors (e.g.,	• Rehearsals included 90 mins of singing and vocal exercises and 30 mins coffee break for rest and socialising. • The music therapist demonstrated and asked participants to join in with postural/breathing	• Managed and facilitated by three music therapists as well as volunteers • Assessment and recording of observational data, as well as organising finances and insurance: speech pathologist	• Group sessions • Mode of delivery not reported.	• Weekly 2-hour rehearsal	• None reported.	• Fidelity not reported. • Of 20 choir members, 13 took part in the research project.

		Magee & Davidson, 2002). • It is suggested that singing in a choir can offer greater benefits than singing alone or participating in a social activity (Bungay & Skingley, 2008). • Adaptations to participants' needs (e.g., adapting sounds, increase repetition of lyrics).	exercises and vocal warm-ups; encouraged participants to use sounds that were easy and accessible. • Materials: CD for home practice, songbooks, projector for lyrics.					• Attrition: 23%
Caute and Woolf (2016)	Voice recognition software (VRS)	• People with aphasia are at risk of social isolation (e.g., Parr, 2007) and difficulties with written communication can lead to reduced social participation. • There is some evidence that Voice Recognition Software (VRS) can be used to compensate for writing difficulties in aphasia, which can be generalised to improve social participation.	• Training Dragon to recognise the participant's voice; training in operating the software; developing strategies to monitor output and reading incoming emails; use of homework tasks to develop independence in new acquired skills • Materials: Dragon NaturallySpeaking Preferred V10 on a Samsung Netbook; instruction sheets; Read&Write9 Gold® assistive software	• Speech and language therapist	• Individual session. • Mode of delivery not reported.	• 16 one-hour therapy sessions, twice a week	• Adaptation during voice recognition: generating a list of words and phrases that would be useful rather than reading a passage of text continuously; difficulties understanding Dragon's text-to-speech function led to use of an alternative software • Adaptation of intervention schedule due to availability.	• No attrition. • Adherence and fidelity not reported.

DeDe et al. (2019)	Aphasia conversation treatment	• Aphasia is one of the most debilitating outcomes of stroke. • It is important to understand which treatment approaches are most effective for communication outcomes and if those treatments reduce social isolation. • Conversation treatment is unstructured, based on principles of naturalistic conversation (philosophical orientation described by Simmons-Mackie et al., 2014). • In line with the Life Participation Approach to Aphasia (LPAA Project Group, 2008) • Followed a socially oriented approach, encouraging meaningful, authentic conversations around functional topics. • Each individual has two goals that are identified before starting treatment. • Tailored to individuals'	• Each session begins with a general introductory question, then conversation is facilitated through the session with materials described. • Five conversation topic categories for treatment sessions: personal history, dining, travel, news/events, entertainment. • Use of supported conversation techniques to scaffold participation in conversations. Clinicians modelled multimodal communication throughout sessions. • Detailed training programme was offered to group facilitators. • Materials: Treatment manual; PowerPoint slide shows for each topic; communication support materials; fidelity checklists	• Trained graduate student clinicians under supervision of a licensed speech-language pathologists with previous experience of facilitating conversation treatment.	• Dyad or group setting. • In-person	• One-hour sessions, twice weekly for 10 weeks.	• None reported.	• Recording number of clinician models for multimodal communication strategies, number of conversation turns per individual and clinician. 20% of session are reviewed independently to determine reliability of coding. • Reliability of conversation turns was deemed acceptable. Clinicians modelled use of strategies at least 3 times in 93.5% of sessions. • Attrition: 10.87% did not complete testing post-intervention, 21.74% did not complete follow-up after 11 months

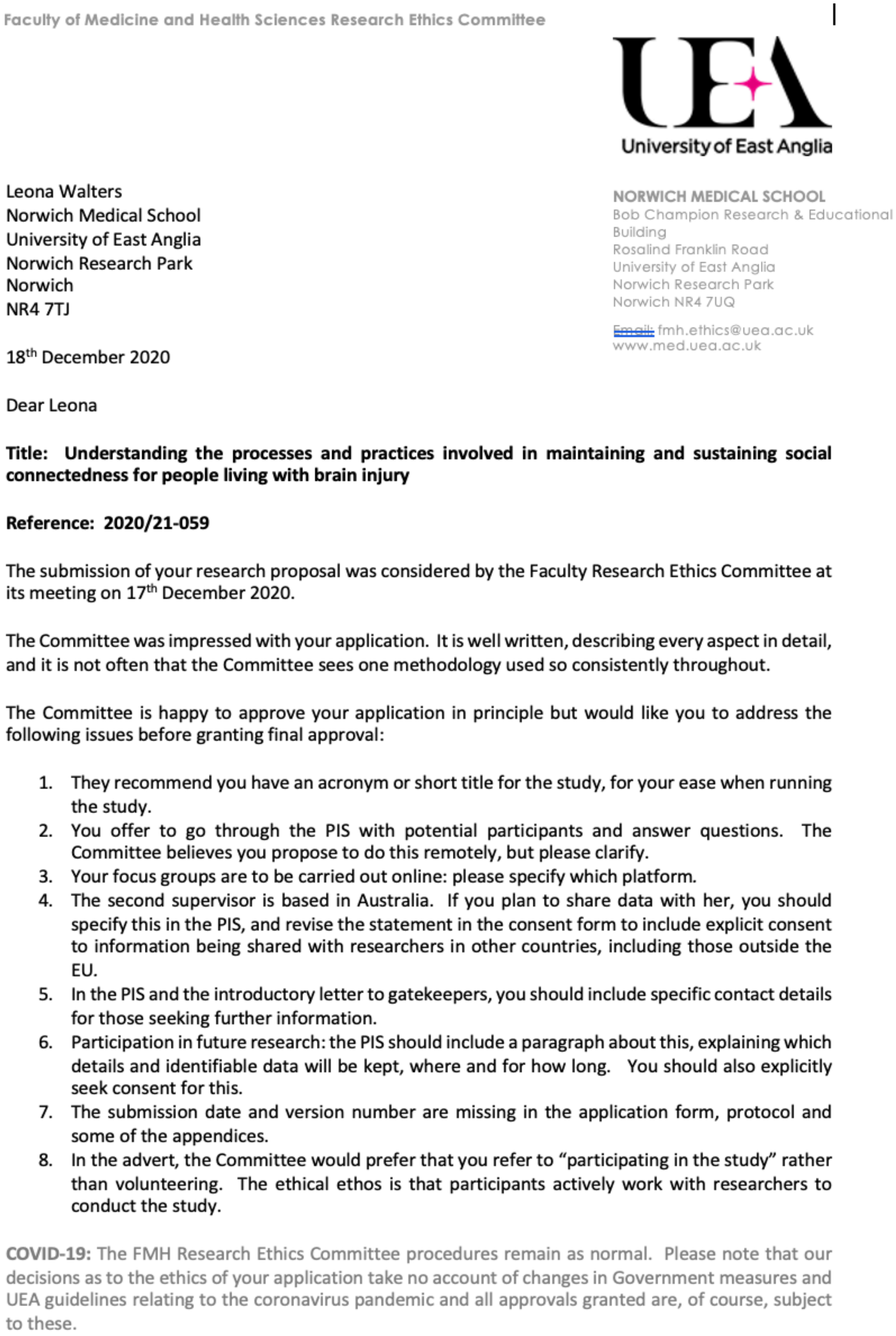
		communication needs and individualised goals.						
Dahlberg et al. (2007)	Social communication skills group	• Social communication difficulties can contribute to loss of meaningful relationships, which can lead to social isolation and loneliness (Ylvisaker & Feeney, 2001). • Research shows that individuals with TBI often experience difficulties in social communication skills.	• Session format: review of homework, introduction of session topic, guided discussion, small group practice, group problem solving and feedback, (family) homework. • Sessions cover practising skills related to goal setting, being a good communicator, goal-specific strategies, social problem-solving within group and at home. • Materials: Social Skills and Traumatic Brain Injury: A Workbook for Group Treatment (Hawley & Newman, 2006); video equipment for feedback	• 2 group leaders from different clinical backgrounds (i.e., social work and speech pathology)	• Face-to-face in a living room-type setting, one session in the community. • Group with up to 8 group members	• weekly 1.5h meeting for 12 weeks	• None reported.	• Across all treatment arms, 8 participants discontinued the intervention (attrition: 15.38%), 4 participants did not start the intervention.
Struchen et al. (2011)	Social peer-mentoring program for persons with TBI	• Peer mentoring has been used in different populations to improve community integration and social relationships (e.g., Barrett & Randall, 2004).	• Social mentors complete extensive assessment and a 2-hour training. • Social mentors are matched to peers based on 4 criteria	• Social mentors • On-call trial therapist to provide support to mentors.	• Increasing social networking through outings in the community, phone calls and emails, and/or social visits to the partner's house.	• Active peer mentoring takes place for 3 months and each pair is expected to have at least 2 outings per month.	• None reported.	• Recording of in-person contacts for each mentor-peer pair to determine the intensity of intervention.

		• For people with TBI, it has been used in rehabilitation settings; however, there is limited evidence for its use of improving social integration. • Social mentoring programs might be beneficial to increase social network opportunities for individuals who have difficulties maintaining and developing social networks. • The mentoring outings are tailored to mentor and partner's interests.	(geographical proximity, age, gender, interests). • Mentor and peer have regular interactions to increase social networking. • Mentors complete a monthly log sheet to record mentoring activities and have weekly support calls to discuss mentor-partner relationship. • Materials: written manual ('Making connections after brain injury: A guide for social peer mentors')		• The contacts take place in the community, at people's houses or online/on the phone.			• Adherence: Only half of the pairs met twice a month (50%). • Attrition: 8.3% (1 participant left due to dissatisfaction with peer match)
Johnson and Davis (1998)	Supported relationships program	• Studies have focused on improving social skills (e.g., Braunling-McMorrow et al., 1986) to reduce social isolation in individuals with disability, inc. TBI; however, this does not always support developing social relationships (Haring & Breen, 1992). • Many studies on supported relationships have been done in school settings rather than in the	• Baseline observations are conducted for 4-7 weeks. • Individual is matched with 4 potential community partners. • Community partners receive training to complete Social Contact Surveys (SCS) after each meeting with individual. • Daily phone call by research team to the participants to complete SCS. Weekly phone call	• Community partners • Research team (inc. researchers and research assistants)	• Initial meetings with individuals and the introductory meetings of individuals and community partners (approx. 1h) took place at the participants' home, further meetings took place at either person's houses or in the community.	• Meeting between individual and community partner at least once per week for 4 weeks; optional meetings following the 4-weeks intervention phase.	• One participant had a one week break during the intervention due to being out of town.	• Interobserver agreement calculations for phone calls to analysis SCS. • Reliability calculations of individual and community partner reporting. • Interobserver agreement was 100% across all phases.

		community, though some programmes showed promising results (e.g., Circles; Forest & Pearpoint, 1992). • Adaptation of intervention schedule due to availability.	to ask about satisfaction with the programme, to offer practical support. • Follow-up 1 phase (4 weeks): Phone calls to individual (daily) and community partner (weekly) to gather information about activities. Follow-up 2 phase (4 weeks): daily phone calls to individuals. • Materials: Videotape shown to community partners presenting examples of how TBI may impact a person's life; handout "Head Injury: A Guide for the Patient and Family" (Jones & Lorman, 1988).					• Reliability ranged between 86.7-100%. • Attrition at follow-up phase 1: 33%
Lawrence et al. (2017)	The Mission Continues Fellowship Program	• Veterans with TBI are at risk of feeling lonely and socially isolated (Kersel et al., 2001). • Volunteering programmes have been found to have positive effects on health and psychosocial factors in elder populations (Jenkinson et al., 2013) and in veterans (Matthieu et al., 2017).	• Individuals complete leadership, networking, goal-setting, and autobiographical writing exercises during orientation. • Goal-setting curriculum is completed throughout the programme with support of a peer mentor from The Mission Continues staff.	• The Mission Continues (US national non-profit organisation) administers a civic service programme in a local non-profit organisation in the individual's hometown.	• Formal volunteering (usually involves an orientation, a well-defined role and duration on the volunteering time, and provides living expenses). • Local non-profit organisation in the individual's hometown.	• 20h per week for 26 weeks	• None reported.	• Not reported.

Appendix E

Ethical Approvals



Faculty of Medicine and Health Sciences Research Ethics Committee

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Leona Walters
Norwich Medical School
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18th December 2020

Dear Leona

Title: Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Reference: 2020/21-059

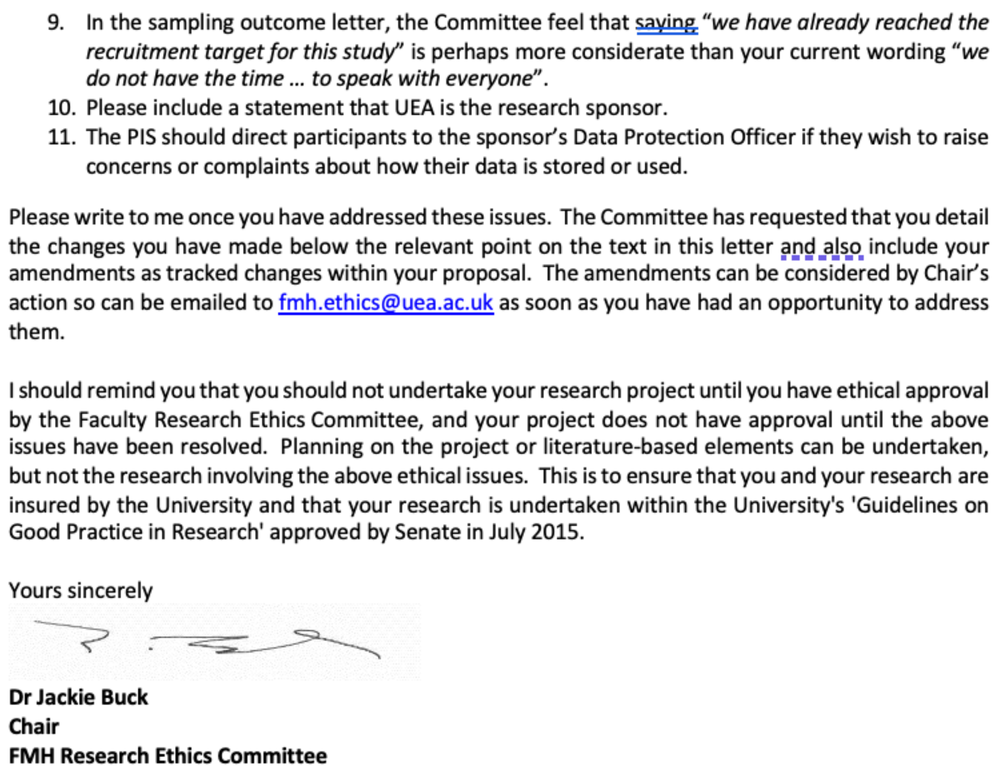
The submission of your research proposal was considered by the Faculty Research Ethics Committee at its meeting on 17th December 2020.

The Committee was impressed with your application. It is well written, describing every aspect in detail, and it is not often that the Committee sees one methodology used so consistently throughout.

The Committee is happy to approve your application in principle but would like you to address the following issues before granting final approval:

1. They recommend you have an acronym or short title for the study, for your ease when running the study.
2. You offer to go through the PIS with potential participants and answer questions. The Committee believes you propose to do this remotely, but please clarify.
3. Your focus groups are to be carried out online: please specify which platform.
4. The second supervisor is based in Australia. If you plan to share data with her, you should specify this in the PIS, and revise the statement in the consent form to include explicit consent to information being shared with researchers in other countries, including those outside the EU.
5. In the PIS and the introductory letter to gatekeepers, you should include specific contact details for those seeking further information.
6. Participation in future research: the PIS should include a paragraph about this, explaining which details and identifiable data will be kept, where and for how long. You should also explicitly seek consent for this.
7. The submission date and version number are missing in the application form, protocol and some of the appendices.
8. In the advert, the Committee would prefer that you refer to “participating in the study” rather than volunteering. The ethical ethos is that participants actively work with researchers to conduct the study.

COVID-19: The FMH Research Ethics Committee procedures remain as normal. Please note that our decisions as to the ethics of your application take no account of changes in Government measures and UEA guidelines relating to the coronavirus pandemic and all approvals granted are, of course, subject to these.



9. In the sampling outcome letter, the Committee feel that saying "*we have already reached the recruitment target for this study*" is perhaps more considerate than your current wording "*we do not have the time … to speak with everyone*".
10. Please include a statement that UEA is the research sponsor.
11. The PIS should direct participants to the sponsor's Data Protection Officer if they wish to raise concerns or complaints about how their data is stored or used.

Please write to me once you have addressed these issues. The Committee has requested that you detail the changes you have made below the relevant point on the text in this letter and also include your amendments as tracked changes within your proposal. The amendments can be considered by Chair's action so can be emailed to fmh.ethics@uea.ac.uk as soon as you have had an opportunity to address them.

I should remind you that you should not undertake your research project until you have ethical approval by the Faculty Research Ethics Committee, and your project does not have approval until the above issues have been resolved. Planning on the project or literature-based elements can be undertaken, 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

Dr Jackie Buck
Chair
FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

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Leona Walters
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18th February 2021

Dear Leona

Title: Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Reference: 2020/21-059

Thank you for your email of 15th February 2021 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can 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 that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics 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 arrange to send us a report once your project is completed.

Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee

Faculty of Medicine and Health Sciences Research Ethics Committee

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Leona Wolters
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20th July 2021

Dear Leona

Title: Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Reference: 2020/21-059

Thank you for your email of 29th June 2021 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can 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 that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics 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 arrange to send us a report once your project is completed.

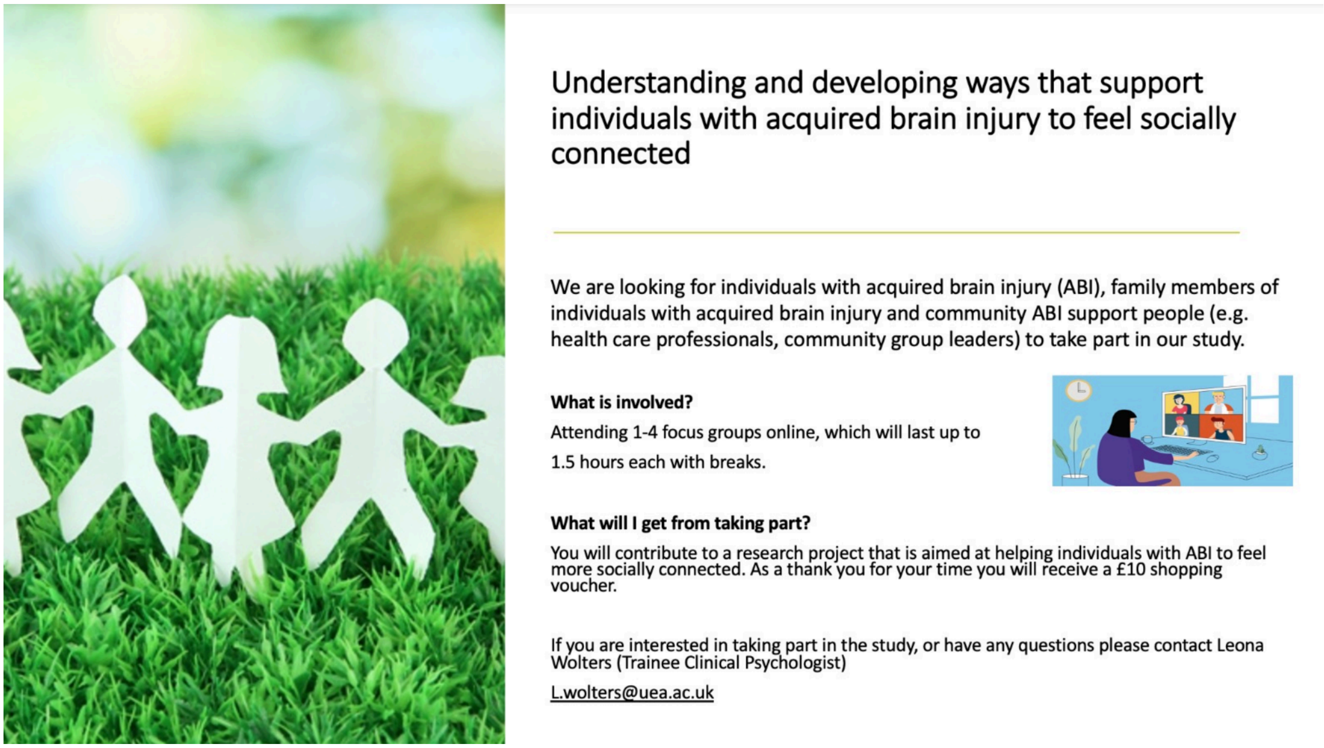
Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee

Appendix F

Recruitment Posters

Social media poster



Understanding and developing ways that support individuals with acquired brain injury to feel socially connected

We are looking for individuals with acquired brain injury (ABI), family members of individuals with acquired brain injury and community ABI support people (e.g. health care professionals, community group leaders) to take part in our study.

What is involved?

Attending 1-4 focus groups online, which will last up to 1.5 hours each with breaks.

What will I get from taking part?

You will contribute to a research project that is aimed at helping individuals with ABI to feel more socially connected. As a thank you for your time you will receive a £10 shopping voucher.

If you are interested in taking part in the study, or have any questions please contact Leona Wolters (Trainee Clinical Psychologist)

L.wolters@uea.ac.uk

Recruitment flyer

Understanding and developing ways that support individuals with acquired brain injury to feel socially connected

We are looking for individuals with acquired brain injury, family members of individuals with acquired brain injury and community ABI support people (e.g. health care professionals, community group leaders) to take part in our study.

What is involved?

Attending 1-4 focus groups:

- to help us understand more about social connections after brain injury.
- to think about ways that help maintain and/or develop relationships.

Each group session will take around 1.5 hours with breaks.

What will I get from taking part?

You will contribute to a research project that is aimed at helping individuals with acquired brain injury to feel more socially connected. As a thank you for your time you will receive a £10 shopping voucher.

How do I participate in the study?

If you are interested in taking part in the study, or have any questions please contact the research team.

L.wolters@uea.ac.uk

Appendix G

Consent to Contact Form

Faculty of Medicine and Health
Sciences,

University of East
Anglia,

Norwich NR4
7TJ

l.wolters@uea.ac.uk

CONSENT TO CONTACT FORM

Title of Project:

Understanding and developing ways that support individuals with acquired brain injury to feel socially connected

Name of Researcher:

Leona Wolters, 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 Participant	Date	Signature

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 H

Informed Consent Form

Faculty of Medicine and Health Sciences,

University of East Anglia,

Norwich NR4 7TJ

l.wolters@uea.ac.uk

Please select yes or no to each statement below and electronically sign by typing your name and date at the bottom.

CONSENT FORM

Understanding and developing ways that support individuals with acquired brain injury to feel socially connected

Version 3 (29/06/2021)

Ethics Approval Reference: 2020/21-059

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

   Yes/no

2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason, without my care, employment/volunteer status or legal rights being affected.

   Yes/no

3. I understand that I may not be selected to take part in the focus groups.

   Yes/no

4. I consent for the focus groups to be video recorded.

   Yes/no

5. I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.

   Yes/no

6. I understand who will be able to access my data, including members of the research team in other countries.

   Yes/no

7. I understand how this research will be written up and published. I understand how my contributions in the group chats will be used in publications.

   Yes/no

8. I understand that absolute anonymity cannot be guaranteed due to the use of direct quotes, but that the utmost care will be taken to anonymise and remove identifying information.

   Yes/no

9. I understand that I can change my mind and withdraw my consent without giving any reason. It will be my responsibility to contact the researcher to let her know if I wish to withdraw my information. I understand that data from group chats cannot be deleted.

   Yes/no

10. I consent that my anonymised data may be accessed and further analysed by other members of the research team in the future.

    Yes/no

11. I consent to being contacted regarding opportunities to contribute to future studies on this topic by members of this research team.

    Yes/no

12. I agree to take part in the above study.

    Yes/no

To electronically sign the consent form, please type your name:

___________________ Date: _____________

When completed: 1 for participant; 1 for researcher site file

Faculty of Medicine and Health Sciences,

University of East Anglia,

Norwich NR4 7TJ

l.wolters@uea.ac.uk

Please select yes or no to each statement below and electronically sign by typing your name and date at the bottom.

CONSENT FORM

Aphasia-friendly version

Understanding and developing ways that support individuals with acquired brain injury to feel socially connected

Version 3 (29/06/2021)

Ethics Approval Reference: 2020/21-059

1. I confirm that I have **read and understood** the information sheet dated… (version…) for the above study. I have had the opportunity to **consider the information**, **ask questions** and have had these **answered to my satisfaction**.

   I have read and understood the information sheet.

Yes/no

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

   I understand that I do not have to take part.

   Yes/no

3. I understand that I **may not be selected** to take part in the focus groups.

   Yes/no

4. I consent for the focus group to be **video recorded**.

   Yes/no

5. I understand how my **data will be stored**.

   Yes/no

6. I understand who will be able to access my data, including members of the research team in other countries.

   I understand who can access my data.

   Yes/no

7. I understand how this research will be **written up and published**. I understand how my contributions in the group chats will be used in publications.

   I am happy for my anonymised data to be used in publications.

   Yes/no

8. Absolute anonymity cannot be guaranteed due to the use of direct quotes but **great care** will be taken to **anonymise** and **remove identifying information**.

   I understand that absolute anonymity cannot be guaranteed.

   Yes/no

9. I understand that I **can change my mind** and withdraw my consent **without giving any reason**. I will need to **contact the researcher** if I want to withdraw my information. I understand that **data from group chats cannot be deleted**.

   I understand that I can stop contributing but data from previous group chats cannot be deleted.

   Yes/no

10. I consent that my **anonymised data** may be accessed and **further analysed** by other members of the research team **in the future**.

    I am happy for my anonymised data to be used in the future.

    Yes/no

11. There might be opportunities to take part in projects about this topic in the future.

I am happy to be contacted for future studies.

Yes/no

12. **I agree to take part in the study.**

Yes/no

To electronically sign the consent form, please type your name:

____________________ Date: _____________

When completed: 1 for participant; 1 for researcher site file

Appendix I

Sampling Questionnaires

Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Thank you for taking the time to complete this survey. Please provide/select the answers that fit best your current situation. Your study ID can be found in the email that included the link to this survey.

Study ID: ……..

Date of completion: ……..

Individuals with ABI

Age:

Gender: male/female/other/prefer not to say

Ethnicity *(as recommended by the Office for National Statistics):*

White: English/Welsh/Scottish/Northern Irish/British; Irish; Gypsy or Irish Traveller; Any other White background, please describe

Mixed/Multiple ethnic groups: White and Black Caribbean; White and Black African; White and Asian; Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British: Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background, please describe

Black/ African/Caribbean/Black British: African; Caribbean; Any other Black/African/Caribbean background, please describe

Other ethnic group: Arab; Any other ethnic group, please describe

Living arrangement: living alone/supported living/living with a spouse or partner/living with family/living with friends/other

If other, please state __________________

Type of brain injury: TBI/illness or infection/stroke/tumour/hypoxia/other

If other, please state __________________

Time since injury: __ years __ months

Choose the option that **best describes** how / if opportunities to socially connect with others were offered to you (for example, community groups, online platforms):

I had **many opportunities** to connect with others offered to me.

I had **a few opportunities** to connect with others offered to me.

I had **no opportunities** to connect with others offered to me.

If you had opportunities offered, when were they offered:

During my rehabilitation.

After my rehabilitation.

Other: ___________

Who offered them?: ___________

In the past, …

I attended a community group designed for people living with a brain injury (for example, any Headway group, an Aphasia group, a choir designed for people living with a brain injury).

Yes/no

If yes: How often did you attend the group? Weekly/monthly/yearly/occasionally

If yes: Was it online or face-to-face?

If online: Please specify: The group has always been online./The group has been online due to Covid-19.

If yes: Why did you stop attending the group?

If no: Why did you not attend a group? I did not have the opportunity./Other reason. Please specify.

I attended a community group **not** specifically designed for people living with a brain injury (for example, a church choir, a community gardening group, an exercise or sports club).

Yes/no

If yes: How often did you attend the group? Weekly/monthly/yearly/occasionally

If yes: Was it online or face-to-face?

If online: Please specify: The group has always been online./The group has been online due to Covid-19.

If yes: Why did you stop attending the group?

If no: Why did you not attend a group? I did not have the opportunity./Other reason. Please specify.

Currently,

I am attending a community group designed for people living with a brain injury (for example, any Headway group, an Aphasia group, a choir designed for people living with a brain injury).

Yes/no

If yes: How often do you attend the group? Weekly/monthly/yearly/occasionally

If yes: Is it online or face-to-face?

If online: Please specify: The group has always been online./The group is online due to Covid-19.

If no: Why are you not attending a group? I do not have the opportunity./Other reason. Please specify.

I am attending a community group **not** specifically designed for people living with a brain injury (for example, a church choir, a community gardening group, an exercise or sports club).

Yes/no

If yes: How often do you attend the group? Weekly/monthly/yearly/occasionally

If yes: Is it online or face-to-face?

If online: Please specify: The group has always been online./The group is online due to Covid-19.

If no: Why do you not attend a group? I do not have the opportunity./Other reason. Please specify.

Choose the option that **best describes your current situation**:

I am **currently** participating in a (community) group.

I have participated in a (community) group **in the past**.

I have **never** participated in a (community) group.

Choose the option that best describes how you feel **in relation to your family**:

I feel **more connected** to my family than I felt before my injury.

I feel **as connected** with my family as I felt before my injury.

I feel **less connected** to my family than I felt before my injury.

Other:

Choose the option that best describes how you feel **in relation to your friends** you have **from before your injury**:

I feel **more connected** to my friends than I felt before my injury.

I feel **as connected** with my friends as I felt before my injury.

I feel **less connected** to my friends than I felt before my injury.

Other:

Choose the option that best describes how you feel **in relation to people** you have met s**ince your injury**:

I find it **as easy to connect** to new people as I found it before my injury.

I find it **harder to connect** to new people than I found it before my injury.

Other:

Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Thank you for taking the time to complete this survey. Please provide/select the answers that fit best your current situation. Your study ID can be found in the email that included the link to this survey

Study ID: ……..

Date of completion: ……..

Family members and carers

Age

Gender: male/female/other/prefer not to say

Ethnicity *(as recommended by the Office for National Statistics):*

White: English/Welsh/Scottish/Northern Irish/British; Irish; Gypsy or Irish Traveller; Any other White background, please describe

Mixed/Multiple ethnic groups: White and Black Caribbean; White and Black African; White and Asian; Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British: Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background, please describe

Black/ African/Caribbean/Black British: African; Caribbean; Any other Black/African/Caribbean background, please describe

Other ethnic group: Arab; Any other ethnic group, please describe

Relationship to individual with ABI: parent/spouse/sibling/child/carer/other

Type of brain injury: TBI/illness or infection/stroke/tumour/hypoxia/other

Time since injury: __ years __ months

Choose the option that best describes the situation of your family member/the individual you care for, with regards to opportunities to socially connect (for example, community groups, online platforms):

They had **many opportunities** to connect with others offered to them.

They had **a few opportunities** to connect with others offered to them.

They had **no opportunities** to connect with others offered to them.

If they had opportunities offered, when were they offered:

During their rehabilitation.

After their rehabilitation.

Other: ___________

Who offered them?: ___________

In the past, …

My family member attended a community group designed for people living with a brain injury (for example, any Headway group, an Aphasia group, a choir designed for people living with a brain injury).

Yes/no

If yes: How often did they attend the group?

Weekly/monthly/yearly/occasionally

If yes: Was it online or face-to-face?

If online: Please specify: The group has always been online./The group has been online due to Covid-19.

If yes: Why did they stop attending the group?

If no: Why did they not attend a group? They did not have the opportunity./Other reason. Please specify.

They attended a community group **not** specifically designed for people living with a brain injury (for example, a church choir, a community gardening group, an exercise or sports club).

Yes/no

If yes: How often did they attend the group?

Weekly/monthly/yearly/occasionally

If yes: Was it online or face-to-face?

If online: Please specify: The group has always been online./The group has been online due to Covid-19.

If yes: Why did they stop attending the group?

If no: Why did they not attend a group? They did not have the opportunity./Other reason. Please specify.

Currently,

My family member is attending a community group designed for people living with a brain injury (for example, any Headway group, an Aphasia group, a choir designed for people living with a brain injury).

Yes/no

If yes: How often do they attend the group? Weekly/monthly/yearly/occasionally

If yes: Is it online or face-to-face?

If online: Please specify: The group has always been online./The group is online due to Covid-19.

If no: Why are they not attending a group? They do not have the opportunity./Other reason. Please specify.

My family member is attending a community group **not** specifically designed for people living with a brain injury (for example, a church choir, a community gardening group, an exercise or sport club).

Yes/no

If yes: How often do they attend the group? Weekly/monthly/yearly/occasionally

If yes: Is it online or face-to-face?

If online: Please specify: The group has always been online./The group is online due to Covid-19.

If no: Why do they not attend a group? They do not have the opportunity./Other reason. Please specify.

Choose the option that best describes your family member/the individual you care for in relation to other people:

They have **lost friends** and/or **feel more isolated** since sustaining the injury.

They have **increased their social network** or **sense of connection** with others since sustaining the injury.

There seems to be **no difference** in their sense of connection or social network since sustaining the injury.

Choose the option that best describes **your** current situation:

I had **many opportunities** to connect with others in an ABI related context offered to me.

I had **a few opportunities** to connect with others in an ABI related context offered to me.

I had **no opportunities** to connect with others in an ABI related context offered to me.

Choose the option that best describes **your** current situation:

I am **currently** attending an ABI related group.

I have attended an ABI related group **in the past**.

I have **never** attended an ABI related group.

Understanding the processes and practices involved in maintaining and sustaining social connectedness for people living with brain injury

Thank you for taking the time to complete this survey. Please provide/select the answers that fit best your current situation. Your study ID can be found in the email that included the link to this survey

Study ID: ……..

Date of completion: ……..

Community ABI support people

Age

Gender: male/female/other/prefer not to say

Ethnicity *(as recommended by the Office for National Statistics):*

White: English/Welsh/Scottish/Northern Irish/British; Irish; Gypsy or Irish Traveller; Any other White background, please describe

Mixed/Multiple ethnic groups: White and Black Caribbean; White and Black African; White and Asian; Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British: Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background, please describe

Black/ African/Caribbean/Black British: African; Caribbean; Any other Black/African/Caribbean background, please describe

Other ethnic group: Arab; Any other ethnic group, please describe

Profession:

Work context: acute hospital / rehabilitation / third sector / Other: _____

Area of UK:

Years of experience working with people with ABI

Is social connection/ isolation a focus of your assessments with people with ABI?

Yes/no

If so, how?

Is social connection/ isolation a focus of your intervention with people with ABI?

Yes/no

If so, how?

Are you supporting individuals with brain injury to connect in their communities?

Yes/no

If so, how?

Is this a key part of your job role?

Yes/no

If yes, please describe to what extent it is a key part of your job role:

Appendix J

Sample Topic Guide

First focus group with individuals living with ABI

- Introductions
- 'Housekeeping' – information will be anonymised; meeting will be video recorded; turn on captions if helpful; difficulties in online meetings (raise hand); let me know if conversations bring up difficult feelings
- Reminder of the purpose of the groups

- What has helped you to maintain relationships in your community?
    - Tell me about your relationships with your family and friends.
    - Have the relationships changed since your injury? If so, how? What is different now? How have you changed in the relationship? How has the other person changed in the relationship?
    - What did you do to keep the relationship going? What did other people do to keep it going?
- What has helped you to develop new relationships in your community?
    - Tell me about a time when you met new people after your injury.
    - How did this come about?
    - Did you make friends?
    - Were you able to keep the friendship going?
    - What helped you do that?/ What has stopped you do that?
- What has helped you to find out about opportunities in your community to build more relationships?
    - Who has told you about these opportunities?
    - Did you find out yourself? Where?

- What support did you receive in order to enhance/maintain/develop social connections?
    - Where did you receive this?
- What support would you have liked to receive?

Appendix K

Participant Information Sheet

Faculty of Medicine and Health Sciences,

University of East Anglia,

Norwich NR4 7TJ

l.wolters@uea.ac.uk

PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: 2020/21-059

Title: Understanding and developing ways to support individuals with acquired brain injury to feel socially connected

You are being invited to take part in our research. We want to make sure that you understand the study before you agree to take part so please read this information sheet carefully; it provides answers to some of the questions that you may have about the study. You can ask the researchers any questions about the study or meet with them to discuss the project before you decide if you would like to take part.

What is the purpose this study?

We know that people with an acquired brain injury (ABI) can find it harder to feel connected to friends and family and also to make new friends. Feeling connected to other people is important for wellbeing and can also have an influence on rehabilitation and physical recovery.

We would like to find out more about how feeling connected with other people after brain injury is viewed by people living with a brain injury, their family members, and by people in the community working with individuals with a brain injury.

We would also like to better understand what is currently done to help foster social connections, and what could be done to improve it. The information you give us will help us better understand how to help people develop or maintain social connections.

Why have I been invited to take part?

You have been invited because

- you have sustained a brain injury when you were 17 years old or older and have been living with the injury for 6 months or more, or
- you are a family member or carer of someone living with a brain injury (sustained aged 17 or older and been living with it for at least 6 months), or
- you are working with someone who is living with a brain injury (sustained aged 17 or older).

What will taking part involve?

- Once you have considered this information, you will need to sign a consent form to take part in this project.
- We ask you to provide some demographic information on an online survey.

- We ask you to join one focus group discussion with up to 5 other people who have had a brain injury; who has a family member with a brain injury; or who supports individuals with a brain injury in the community.
- You may also be invited to up to 3 further focus groups. Individuals with a brain injury, family members of people with a brain injury and people who support individuals with a brain injury in the community will take part in these groups together.
- Group discussions will take place on an online video call platform.
- We will provide support for you to be able to access this online video call platform prior to the first focus group.
- Meetings will last a maximum of 1.5 hours with breaks as needed.
- You may attend between one and four of those meetings. Unfortunately, due to time constraints we may not be able to invite everyone who is interested in taking part in the study to every focus group. We will let you know if this is the case.
- The focus groups will be video recorded.

Do I have to take part?

No. Taking part in this study is optional. It is entirely up to you to decide if you want take part or not. Your decision will not affect your current or future care, support or employment.

We encourage you to speak to family, friends or your care team to help you decide if you wish to take part. You can ask questions about the study before deciding whether or not to participate or we can meet with you to discuss the project further.

If you decide to take part, you may withdraw from the study at any time without giving a reason. However, you cannot withdraw your data once a group has finished, as this would impact other group members’ data.

Will everyone who is interested be able to take part?

Unfortunately, it may not be possible to include everyone who is interested. This is due to time constraints of the research study. We will let you know as soon as we can if we can include you in the study.

Will what I say be anonymous?

- Other participants in the group will hear what you are saying. However, the transcripts of the discussions will be made anonymous by using pseudonyms.
- A lot of care will be taken not to include information that could identify you. However, in this type of research quotes are used to support the points made by the researcher.
- There is a small chance that people who know you well may guess which quotes belong to you if they know you are participating in the study. Therefore, we cannot guarantee 100% anonymity.

How will you keep my information secure?

- The video recordings will be stored on password protected secure university servers.
- The recording will then be typed up and all information that could identify you will be removed or changed. The original recordings will then be destroyed.
- Any personal information will be stored on password protected secure university servers.
- The personal information you have given (e.g., your email address) will be destroyed once you have completed the study, unless you consented to be contacted about future related projects.

Who will have access to the research data?

Research data, including personal information such as your name and email address, can be accessed by the main researcher (Leona Wolters), her primary supervisor (Dr Fergus Gracey), both based at the University of East Anglia, and her secondary supervisor (Dr Ciara Shiggins), based at La Trobe University, Melbourne, Australia.

Anonymised research data will be shared with the wider supervisor team.

What will you do with the research findings?

- It is important to share research results because they might be interesting or useful to other people.
- The research findings of this study will be shared with participants.
- The findings will also be written up in a doctoral thesis, which will be publicly accessible via the UEA library. A report of the findings could be published in an academic journal or presented at a research conference. Anonymised quotes of your contributions might be used in publications.

Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research; however, you will have the opportunity to contribute to our understanding of brain injury, which may help develop ways to better support people in the future. As a thank you for your time, you will receive a £10 shopping voucher from Love2shop.

Are there any potential risks in taking part?

There might be a minimal risk for you participating in the study, as you might find some discussions distressing. If you should experience any distress, please let someone in the research team know. They will provide you with information of where you could seek support. You will also be provided with a de-briefing sheet and links to useful resources and support services.

Participation in future research on similar topics

If you are interested in participating in future studies on this topic, you can indicate this on the consent form (item 11). If you select '*yes*' on the consent form, the research team will keep your name and contact details, such as telephone number and/or email address. Your information will be stored securely on a password-protected spreadsheet on the university system of the Data Custodian (Dr Fergus Gracey). Your contact information will be kept for a maximum of up to ten years.

Who has reviewed the study?

This study has been reviewed by, and received ethics clearance through, the Faculty of Medicine and Health Sciences Research Ethics Committee (reference number: 2020/21-059).

Who has sponsored the study?

The University of East Anglia is the research sponsor.

Who do I contact for further information?

Leona Wolters (Trainee Clinical Psychologist)	L.Wolters@uea.ac.uk

Dr Fergus Gracey (Clinical Associate Professor in Clinical Psychology)	F.Gracey@uea.ac.uk
Dr Ciara Shiggins (Post-doctoral research fellow)	c.shiggins@latrobe.adu.au

What if I have a Concern or Complaint?

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

Professor Niall Broomfield (Head of Department of Clinical Psychology and Psychological Therapies, University of East Anglia): N.Broomfield@uea.ac.uk

If you wish to raise concerns or complaints about how your data is stored or used, please contact:

Ellen Paterson (Head of Information Compliance and Data Protection Officer, University of East Anglia): E.paterson@uea.ac.uk

Faculty of Medicine and Health
Sciences,

University of East
Anglia,

Norwich NR
4 7TJ

l.wolters@uea.ac.uk

PARTICIPANT INFORMATION SHEET

Aphasia-friendly version

Ethics Approval Reference: 2020/21-059

Title: Understanding and developing ways to support individuals with acquired brain injury to feel socially connected

You are being **invited to take part in our research**. We want to make sure that you **understand the study before you agree to take part.** Please read this information sheet carefully.

This **sheet provides answers to some of the questions that you may have** about the study. **You can ask the researchers any**

questions about the study **or meet with them** to discuss the project before you decide if you would like to take part.

1 Aim of the study

We know that people with an acquired brain injury (ABI) can find it harder to feel connected to friends and family and also to make new friends. Feeling connected to other people is important for wellbeing and can also have an influence on rehabilitation and physical recovery.

The aim of this research is **to develop our understanding of social connectedness in people living with acquired brain injury**.

The information you give us will help us **better understand how to help people develop or maintain social connections.**

2 Why have I been invited?

You have been invited because

- you have **sustained a brain injury** when you were **17 years old or older** and have been **living with the injury for 6 months or more**, or

- you are a **family member or carer of someone living with a brain injury** (sustained aged 17 or older) for more than 6 months, or
- you are **working with someone who is living with a brain injury** (sustained aged 17 or older).

3 What do you have to do?

- Once you have considered this information, you will need to **sign a consent form** to take part in this project.
- We will ask you to provide some **demographic information** on an **online survey**.
- We will ask you to attend **focus groups** on an online **video platform**. Other group members will be:
    - people who had a brain injury
    - family members of people with a brain injury
    - people who work with individuals with a brain injury.

- In the first focus group, each of these groups will meet together.
- In later focus groups, we mix these groups of people.

- There will be **up to six (6) people** per focus group.
- These group chats will be **video recorded**.

- You could be asked to attend **one (1) to four (4)** focus groups. Unfortunately, due to time constraints, we **may not be able to invite everyone** who is interested to every focus group. If this is the case, we will ask people with **different perspectives** to attend in order **to gain a diverse understanding**.

4 How much time will it take?

One focus group will last no more than **1.5 hours with breaks as needed**.

5 Do I have to take part?

No, and your decision will not affect your current or future care or support.

You can **withdraw** yourself from the study **at any time.** We will stop contact and destroy any personal information we have of yours.

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

We encourage you to speak to family, friends or your care team **to help you decide** if you wish to take part. You can **ask questions** about the study before deciding whether or not to participate.

6 Can everyone take part?

Unfortunately, due to time constraints we **cannot guarantee that everyone who shows an interest can take part,** but we will be as inclusive as possible.

7 Confidentiality

- Other group members will hear what you say.
- I will only use **pseudonyms** when writing up the results. Your **name and address** will **not** be used when writing up the results.
- I will use **direct quotes** when writing up the results. If someone knows you very well, there is a **small chance that they might recognise you**.

8 How will my data be kept safe?

- All data and recordings will be stored on **password protected secure university servers**.
- The original **video recording will be destroyed** as soon as possible.
- My supervisory team will be able to see your data but nobody outside this research project will be able to see it.
- Your **personal information (e.g., email address) will be destroyed** once the study is completed. We will keep it for future projects if you have agreed to be contacted again.

9 Who has access to the data?

- Research data, including personal information (e.g., your name and email address) can be accessed by the main researcher (Leona Wolters) and her supervisors (Dr Fergus Gracey and Dr Ciara Shiggins).
- Leona Wolters and Dr Fergus Gracey are based at the University of East Anglia, United Kingdom, and Dr Ciara Shiggins is based at La Trobe University, Melbourne, Australia.
- The wider supervisory team has access to anonymised data.

10 What happens to the data?

It is **important to share research results** because they might be interesting and **useful to other people** to better understand the impact of brain injury and how best to support people in the future.

Only pseudonyms will be used when sharing the results.

The results will be shared:

- in a **doctoral thesis**, which is **publicly accessible** via the UEA library
- with **other participants**
- in **published journals**
- at **conferences**

11 Advantages of taking part?

There are **no direct benefits to you**; however, you will have the opportunity to contribute to our understanding of brain injury, which may help develop ways to better support people in the future. As **a thank you** for your time, you will receive a £10 shopping **voucher** from Love2shop.

12 Risks of taking part?

There are **minimal risks**, as you might find **some discussions distressing**. If you should experience any distress, please let someone in the research team know. They will **provide you with information of where you could seek support**.

13 Participation in future studies

You may take part in future studies on this topic. If you would like to be considered for future studies, you can let us know by selecting '*yes*' for item 11 on the consent form.

If you select '*yes*', we will:

- keep your name and contact details (telephone number and/or email address).
- keep your contact details for up to 10 years.

- securely store your information on the university system of the Data Custodian (Dr Fergus Gracey).

14 Who has reviewed the study?

This study has been reviewed by, and received ethics clearance through, the Faculty of Medicine and Health Sciences Research Ethics Committee (reference number: 2020/21-059).

15 Who is the sponsor of the study?

The **University of East Anglia** is the sponsor of this study.

16 Who do I contact for further information?

Leona Wolters (Trainee Clinical Psychologist)	L.Wolters@uea.ac.uk
Dr Fergus Gracey (Clinical Associate Professor in Clinical Psychology)	F.Gracey@uea.ac.uk
Dr Ciara Shiggins (Post-doctoral research fellow)	c.shiggins@latrobe.adu.au

17 I want to take part – what do I do?

Contact **Leona Wolters** at l.wolters@uea.ac.uk

18 I want to complain – I'm not happy with the researcher or this study

Contact **Niall Broomfield** at N.Broomfield@uea.ac.uk

I want to complain – I'm not happy with how my data is stored or used

Contact **Ellen Paterson** (Head of Information Compliance and Data Protection Officer, University of East Anglia) at E.paterson@uea.ac.uk

Appendix L

Debrief Sheet

The debrief sheet will be send out via email after each focus group. During the group, participants will be made aware that they will receive this.

Please note, this email inbox is not monitored 24/7. If you are in distress, please contact any of the options below.

Dear participant,

Thank you for attending today's focus group. Your contributions are very important to develop our understanding of social connections after brain injury and to develop practical ways that may help people with brain injury to have more valuable social relationships in their communities.

Topics, such as losing important friendships or relationships with family members, can feel upsetting for some people. You might have had similar experiences yourself. It is quite normal that these discussions can have an influence on how you feel. You might feel sad or anxious after these discussions. Sometimes you might feel better after a few hours or doing something you enjoy. But sometimes this could have a longer impact on how you feel, and it would be important to speak to someone about this.

Please see some information about where to access further psychological support at the end of this email.

Yours sincerely,

Leona Wolters

Who to contact for support

- **Samaritans:** 116 123 – free helpline open 24 hours a day, 365 days a year, to listen to anything that is upsetting you
- **Headway:** 0808 800 2244 – free helpline available Monday to Friday, 9am to 5pm. Headway is a service specifically tailored to people with brain injury.
- **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. If you need to speak to a GP after your surgery closes, you should be directed to an out-of-office service. You may find this information either on their answering machine message or on their website.
- **Healthcare Service:** If you are currently under the care of a neurological rehabilitation team, mental health team or other service, it's a good idea to speak to them about your experiences.
- **Mind:** 0300 123 3393; info@mind.org.uk, Text: 86463 – lines are open 9am to 6pm, Monday to Friday (except bank holidays)
- **SANEline:** 07984 967 708 or support@sane.org.uk – leave a message and someone will get back to you as soon as they can *(They currently experience difficulties with their usual helpline so I need to check their website regularly to update the information.)*
- **Accident & Emergency (A&E):** If you're experiencing a mental health emergency, you should contact A&E by calling 999.

Appendix M

Introductory Letter to Recruitment Sites

Understanding and developing ways to support individuals with acquired brain injury to feel socially connected

Dear {name of key contact at the organisation},

My name is Leona Wolters and I am a second-year trainee of the Doctoral Clinical Psychology programme at the University of East Anglia (UEA), Norwich, UK. I am conducting a study building on our understanding of social connectedness in people living with acquired brain injury (ABI), under the supervision of Dr Fergus Gracey at the UEA and Dr Ciara Shiggins (Centre of Research Excellence in Aphasia Recovery and Rehabilitation, Australia). This study is also guided by a supervisory panel including Dr Zoe Fisher (Traumatic Brain Injury Service, Swansea) and Julia Ajayi (PPI member). This project is part of a larger body of research which aims to co-develop a structured resource that will support people living with ABI to enhance, maintain and/or develop social connections. The study will build on completed research lead by this team that shows how important this topic is to people living with ABI, and how for some finding the right community connections can enhance life post-injury.

In order to develop this resource, we need to explore and better understand the different perspectives and experiences of those with first-hand experience of acquired brain injury. We hope this means that our new understandings and any ideas we develop will represent the views, experiences and priorities of those who the resource is intended for. Therefore, in this study we are recruiting **people who have a brain injury, family**

members and people in the community who support people with brain injury (for example, healthcare professionals or volunteers/professionals supporting ABI community groups).

In order to answer the research questions, we will run a series of **focus groups**. The first focus group will be participant group specific, followed by three mixed focus groups. People will be invited to participate in one to four focus group sessions. I would like to recruit four to six participants per group, and I have contacted different ABI related organisations to facilitate recruitment. Please see attached the Participant Information Sheet for a more detailed description of the project.

This study has received full ethical approval from the Faculty of Medicine and Health Sciences Research Ethics Committee (reference number: 2020/21-059). We would be very grateful for the opportunity to recruit participants through {service/local group}. Please do not hesitate to get in touch via l.wolters@uea.ac.uk if you have any further questions about this project. I would also be happy to meet with you to discuss this project further.

Thank you very much for reading and considering this invitation. I look forward to hearing from you.

Best wishes,

Leona Wolters

Appendix N

Introductory Letter to Professional Bodies

To be sent alongside Participant Information Sheet

Understanding and developing ways to support individuals with acquired brain injury to feel socially connected

To whom it may concern,

My name is Leona Wolters and I am a second-year trainee of the Doctoral Clinical Psychology programme at the University of East Anglia (UEA), Norwich, UK. I am conducting a study building on our understanding of social connectedness in people living with acquired brain injury (ABI), under the supervision of Dr Fergus Gracey at the UEA and Dr Ciara Shiggins (Centre of Research Excellence in Aphasia Recovery and Rehabilitation, Australia). This study is also guided by a supervisory panel including Dr Zoe Fisher (Traumatic Brain Injury Service, Swansea) and Julia Ajayi (PPI member). This project is part of a larger body of research which aims to co-develop a structured resource that will support people living with ABI to enhance, maintain and/or develop social connections. The study will build on completed research led by this team that shows how important this topic is to people living with ABI, and how for some finding the right community connections can enhance life post-injury.

In order to develop this resource, we need to explore and better understand the different perspectives and experiences of those with first-hand experience of acquired brain injury. We hope this means that our new understandings and any ideas we develop will represent the views, experiences and priorities of those who the resource will be intended for. This does not only include recruiting people who have a brain injury and their family members, but importantly also people in the community who support people with brain injury (for example, healthcare professionals or volunteers/professionals supporting ABI community groups).

In order to answer the research questions, we will run a series of focus groups. The first focus groups will be participant group specific, followed by three mixed focus groups. People will be invited to participate in one to four focus group sessions, and I would like to recruit four to six participants per group. Please see attached the Participant Information Sheet for a more detailed description of the project.

I would be very grateful if you would be willing to disseminate this email with members of your organisation.

Please do not hesitate to get in touch if you have any further questions about this project, or if you would like to take part.

I look forward to hearing from you.

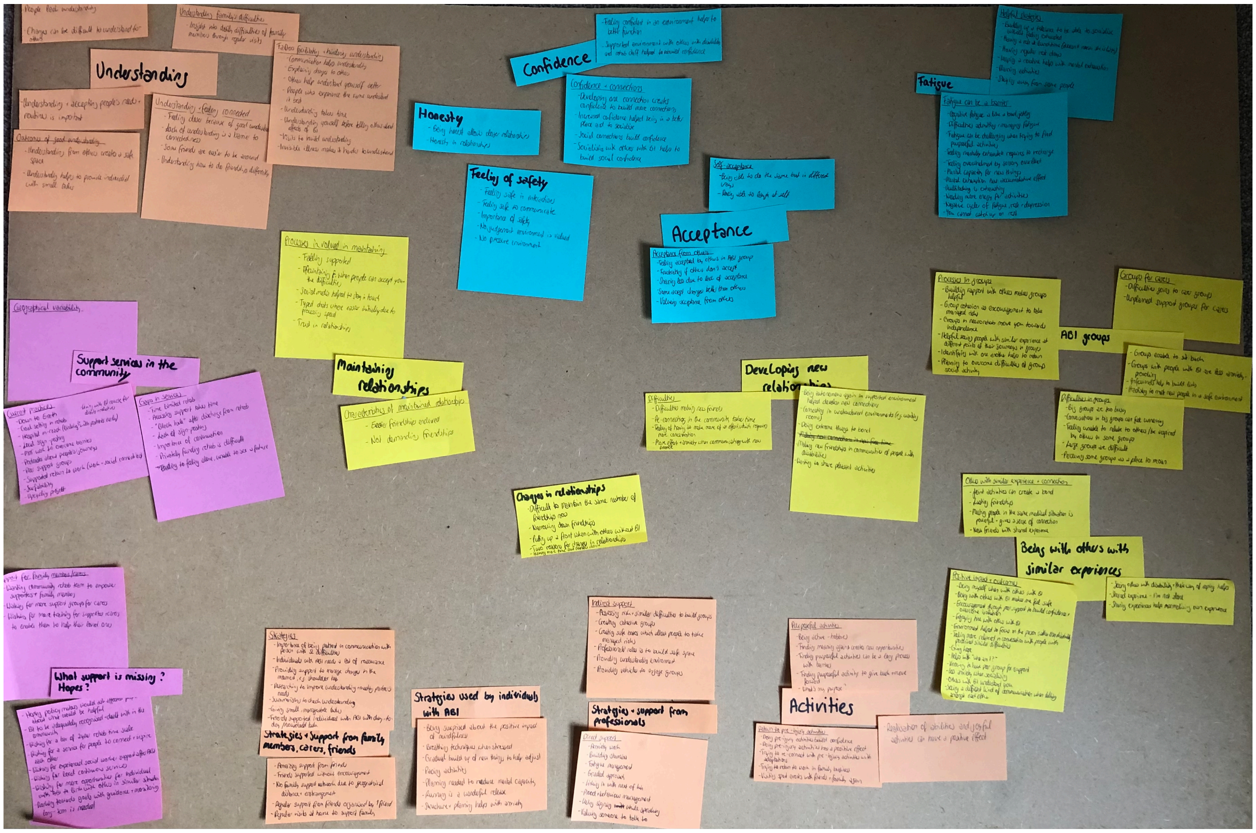
Best wishes,

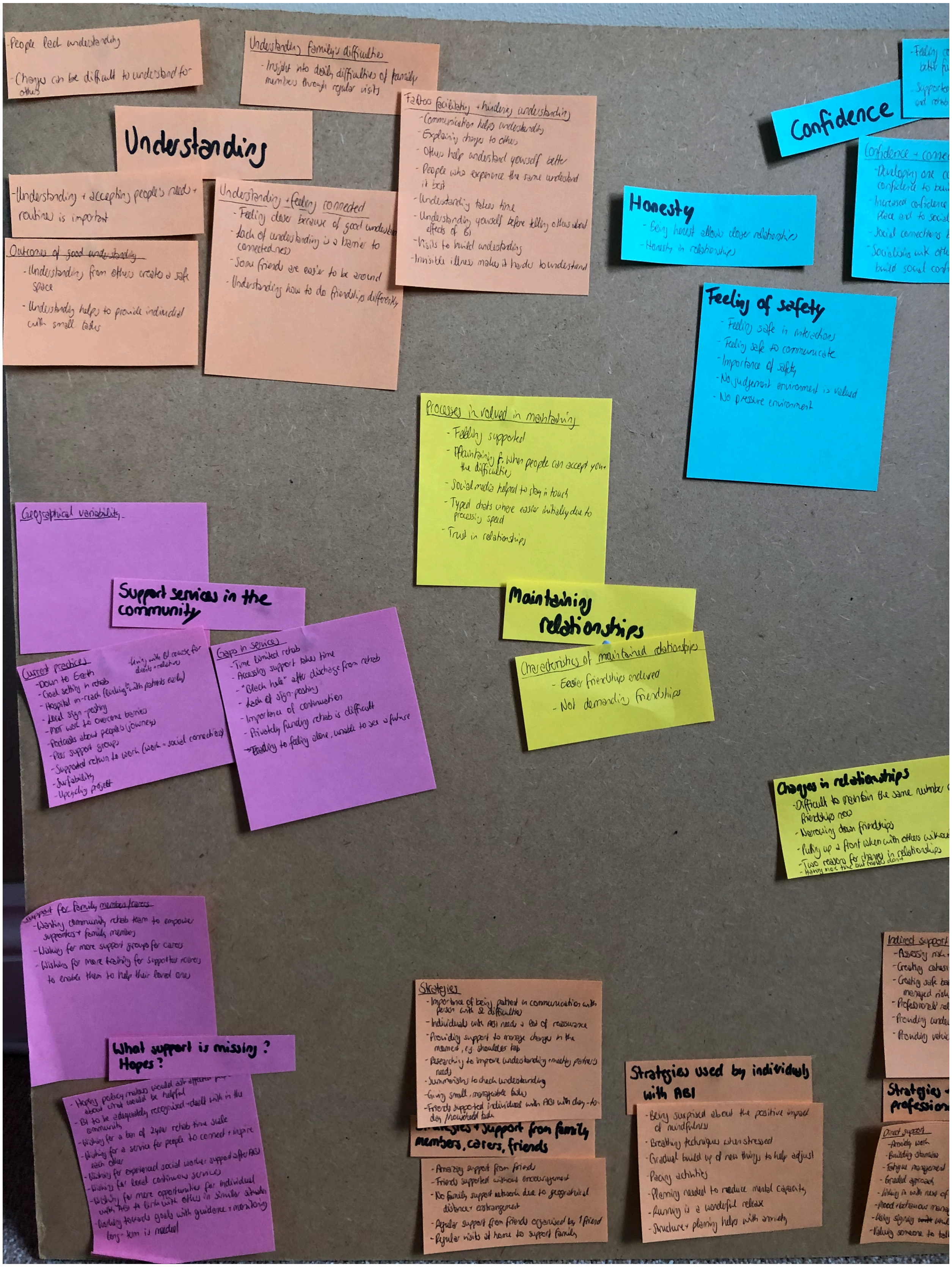
Leona Wolters

Appendix O

Example of Diagrams Used to Assist Development of Theoretical Codes and Model

Example of diagram showing tentative categories (full board and split in two halve for eligibility)





- People lack understanding
- Changes can be difficult to understand for others

Understanding family's difficulties
- Insight into daily difficulties of family members through regular visits

Understanding

- Understanding + accepting people's needs + routines is important

Outcomes of good understanding
- Understanding from others creates a safe space
- Understanding helps to provide individual with small tasks

Understanding + feeling connected
- Feeling close because of good understan
- Lack of understanding is a barrier to connectedness
- Some friends are easier to be around
- Understanding how to do friendships differently

Factors facilitating + hindering understanding
- Communication helps understanding
- Explaining changes to others
- Others help understand yourself better
- People who experience the same understand it best
- Understanding takes time
- Understanding yourself before telling others about effects of BI
- Visits to build understanding
- Invisible illness makes it harder to understand

Confidence

- Feeling c
  bette fu
- Supporte
  and rehab

Confidence + conne
- Developing one c
  confidence to bui
- Increased confidence
  place and to social
- Social connections
- Socialising with oth
  build social conf

Honesty
- Being honest allows closer relationships
- Honesty in relationships

Feeling of safety
- Feeling safe in interactions
- Feeling safe to communicate
- Importance of safety
- No judgement environment is valued
- No pressure environment

Processes involved in maintaining
- Feeling supported
- Maintaining f. when people can accept your the difficulties
- Social media helped to stay in touch
- Typed chats where easier initially due to processing speed
- Trust in relationships

Maintaining relationships

Characteristics of maintained relationships
- Easier friendships endured
- Not demanding friendships

Changes in relationships
- Difficult to maintain the same number
  friendships now
- Narrowing down friendships
- Putting up a front when with others withou
- Two reasons for changes in relationships
- Having more time but friends don't

Geographical variability

Support services in the community

Current practices
Living with BI course for clients + relatives
- Down to Earth
- Goal setting in rehab
- Hospital in-reach (linking in with patients early)
- Local sign-posting
- MOT work to overcome barriers
- Podcasts about people's journeys
- Peer support groups
- Supported return to work (work = social connection)
- Surfability
- Upcycling project

Gaps in services
- Time limited rehab
- Accessing support takes time
- "Black hole" after discharge from rehab
- Lack of sign-posting
- Importance of continuation
- Privately funding rehab is difficult
→ Leading to feeling alone, unable to see a future

Support for family members/carers
- Wanting community rehab team to empower supporters + family members
- Wishing for more support groups for carers
- Wishing for more training for supporters + carers to enable them to help their loved ones

What support is missing? Hopes?

- Hoping policy makers would ask affected peo about what would be helpful
- BI to be adequately recognised + dealt with in the community
- Wishing for a ben of 24hr rehab time scale
- Wishing for a service for people to connect + inspire each other
- Wishing for experienced social worker support after ABI
- Wishing for local continuous services
- Wishing for more opportunities for individuals with ABI to link with others in similar situations
- Working towards goals with guidance + monitoring long-term is needed

Strategies
- Importance of being patient in communication with person with SL difficulties
- Individuals with ABI need a lot of reassurance
- Providing support to manage changes in the moment, e.g. shoulder tap
- Researching to improve understanding + meeting partner's needs
- Summarising to check understanding
- Giving small, manageable tasks
- Friends supported individuals with ABI with day-to-day/household tasks

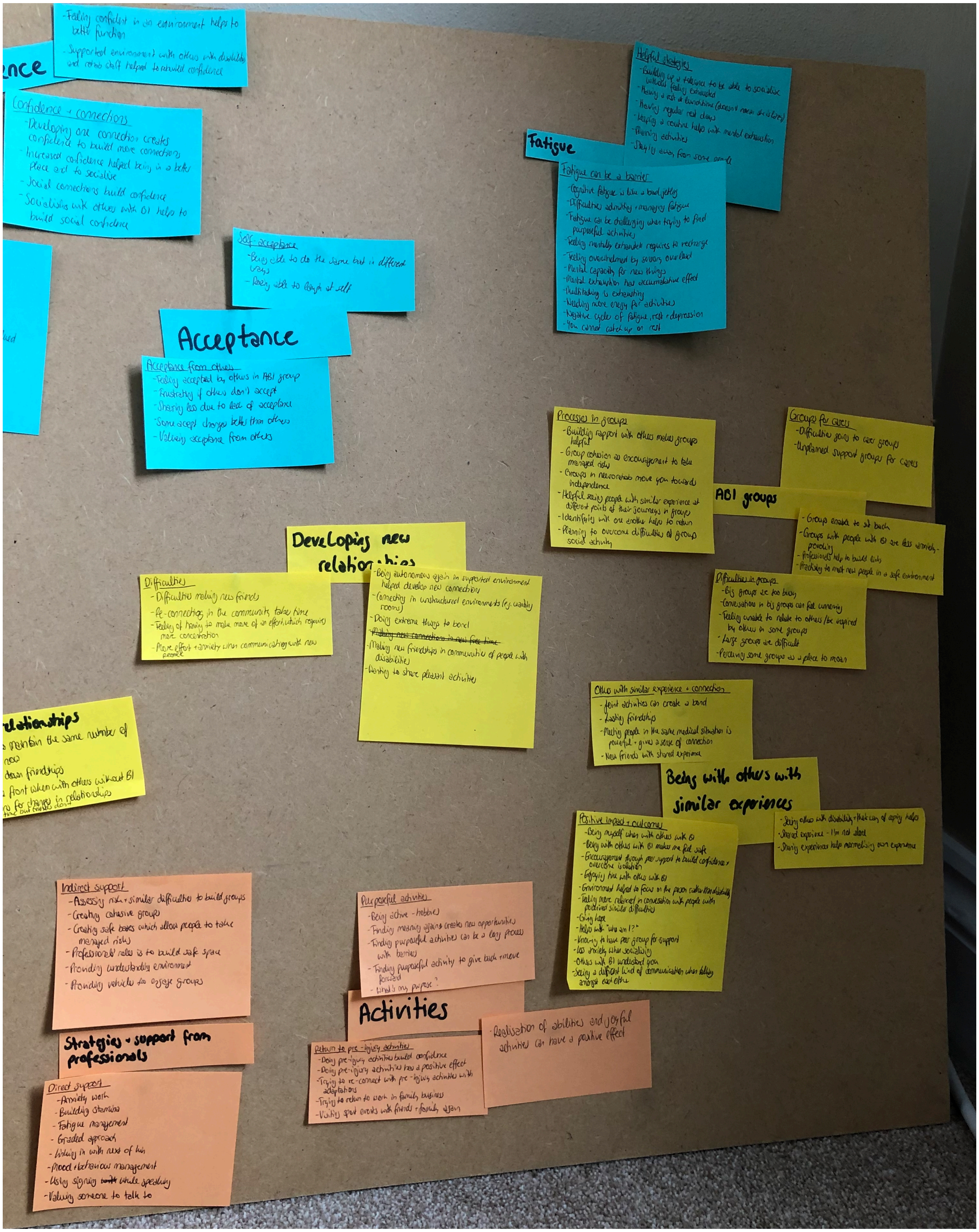
Strategies + support from family members, carers, friends
- Amazing support from friends
- Friends supported without encouragement
- No family support network due to geographical distance + estrangement
- Regular support from friends organised by 1 friend
- Regular visits at home to support family

Strategies used by individuals with ABI
- Being surprised about the positive impact of mindfulness
- Breathing techniques when stressed
- Gradual build up of new things to help adjust
- Pacing activities
- Planning needed to reduce mental capacity
- Running is a wonderful release
- Structure + planning helps with anxiety

Indirect support
- Assessing risk
- Creating cohesi
- Creating safe ba
  managed risk
- Professionals' rol
- Providing unde
- Providing vehic

Strategies + professiona

Direct support
- Anxiety work
- Building stamina
- Fatigue management
- Graded approach
- Linking in with need of
- Mood + behaviour manag
- Using signing ~~with~~ and
- Valuing someone to tal



nce

- Feeling confident in an environment helps to better function
- Supported environment with others with disabilities and rehab staff helped to rebuild confidence

Confidence + connections
- Developing one connection creates confidence to build more connections
- Increased confidence helped being in a better place and to socialise
- Social connections build confidence
- Socialising with others with BI helps to build social confidence

Self-acceptance
- Being able to do the same but in different ways
- Being able to laugh at self

Acceptance

Acceptance from others
- Feeling accepted by others in ABI group
- Frustrating if others don't accept
- Sharing less due to lack of acceptance
- Some accept changes better than others
- Valuing acceptance from others

Fatigue

Helpful strategies
- Building up a tolerance to be able to socialise without feeling exhausted
- Having a rest at lunchtime (doesn't mean she is lazy)
- Having regular rest days
- Keeping a routine helps with mental exhaustion
- Planning activities
- Staying away from some people

Fatigue can be a barrier
- Cognitive fatigue is like a bad jetlag
- Difficulties admitting + managing fatigue
- Fatigue can be challenging when trying to find purposeful activities
- Feeling mentally exhausted requires to recharge
- Feeling overwhelmed by sensory overload
- Mental capacity for new things
- Mental exhaustion has accumulative effect
- Multitasking is exhausting
- Needing more energy for activities
- Negative cycle of fatigue, rest + depression
- You cannot catch up on rest

Developing new relationships

Difficulties
- Difficulties making new friends
- Re-connecting in the community takes time
- Feeling of having to make more of an effort, which requires more concentration
- More effort + anxiety when communicating with new people

- Being autonomous again in supported environment helped develop new connections
- Connecting in unstructured environments (e.g. waiting rooms)
- Doing extreme things to bond
- ~~Making new connections in new free time~~
- Making new friendships in communities of people with disabilities
- Wanting to share pleasant activities

elationships
maintain the same number of
now
down friendships
front when with others without BI
for changes in relationships
time but friends don't

ABI groups

Processes in groups
- Building rapport with others makes groups helpful
- Group cohesion as encouragement to take managed risks
- Groups in neurorehab move you towards independence
- Helpful seeing people with similar experience at different points of their journeys in groups
- Identifying with one another helps to return
- Planning to overcome difficulties of group social activity

Groups for carers
- Difficulties going to carer groups
- Unplanned support groups for carers

- Group enables to sit back
- Groups with people with BI are less anxiety-provoking
- Professionals help to build links
- Practising to meet new people in a safe environment

Difficulties in groups
- Big groups are too busy
- Conversation in big groups can feel unnerving
- Feeling unable to relate to others / be inspired by others in some groups
- Large groups are difficult
- Perceiving some groups as a place to moan

Being with others with similar experiences

Others with similar experience + connection
- Joint activities can create a bond
- Lasting friendships
- Meeting people in the same medical situation is powerful + gives a sense of connection
- New friends with shared experience

Positive impact + outcomes
- Being myself when with others with BI
- Being with others with BI makes me feel safe
- Encouragement through peer support to build confidence + overcome isolation
- Enjoying time with others with BI
- Environment helped to focus on the person rather than disability
- Feeling more relaxed in conversation with people with perceived similar difficulties
- Giving hope
- Helps with "who am I?"
- Knowing to have peer group for support
- Less anxiety when socialising
- Others with BI understand you
- Seeing a different kind of communication when talking amongst each other

- Seeing others with disability + their way of coping helps
- Shared experience - I'm not alone
- Sharing experiences helps normalising own experience

Strategies + support from professionals

Indirect support
- Assessing risk + similar difficulties to build groups
- Creating cohesive groups
- Creating safe bases which allow people to take managed risks
- Professionals' role is to build safe space
- Providing understanding environment
- Providing vehicle to engage groups

Direct support
- Anxiety work
- Building stamina
- Fatigue management
- Graded approach
- Linking in with next of kin
- Mood + behaviour management
- Using signing ~~with~~ while speaking
- Valuing someone to talk to

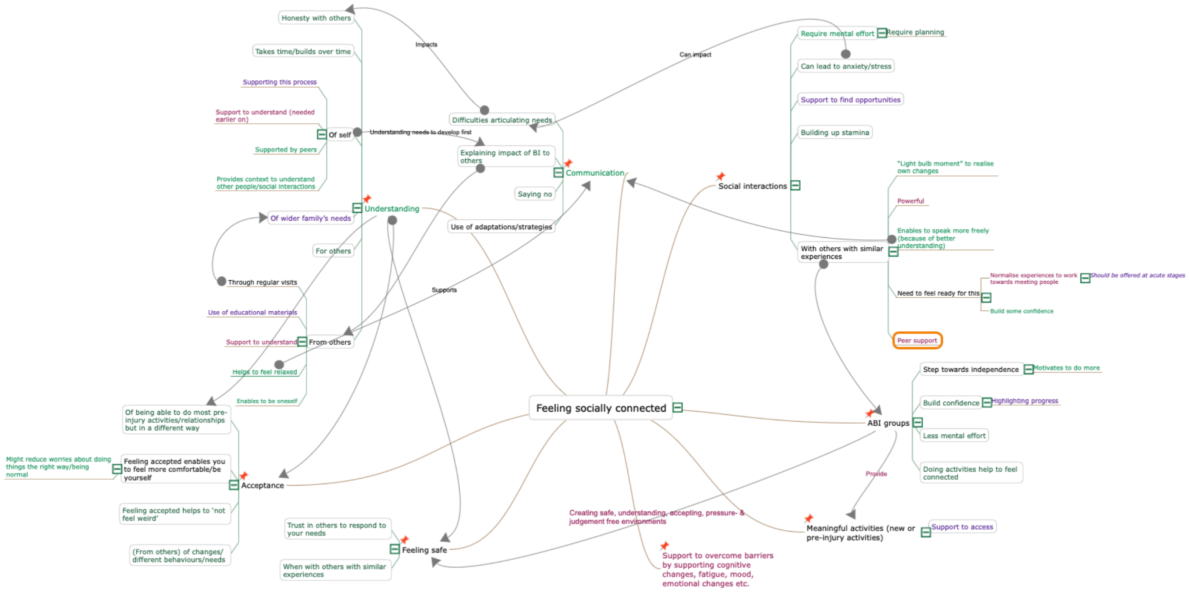
Activities

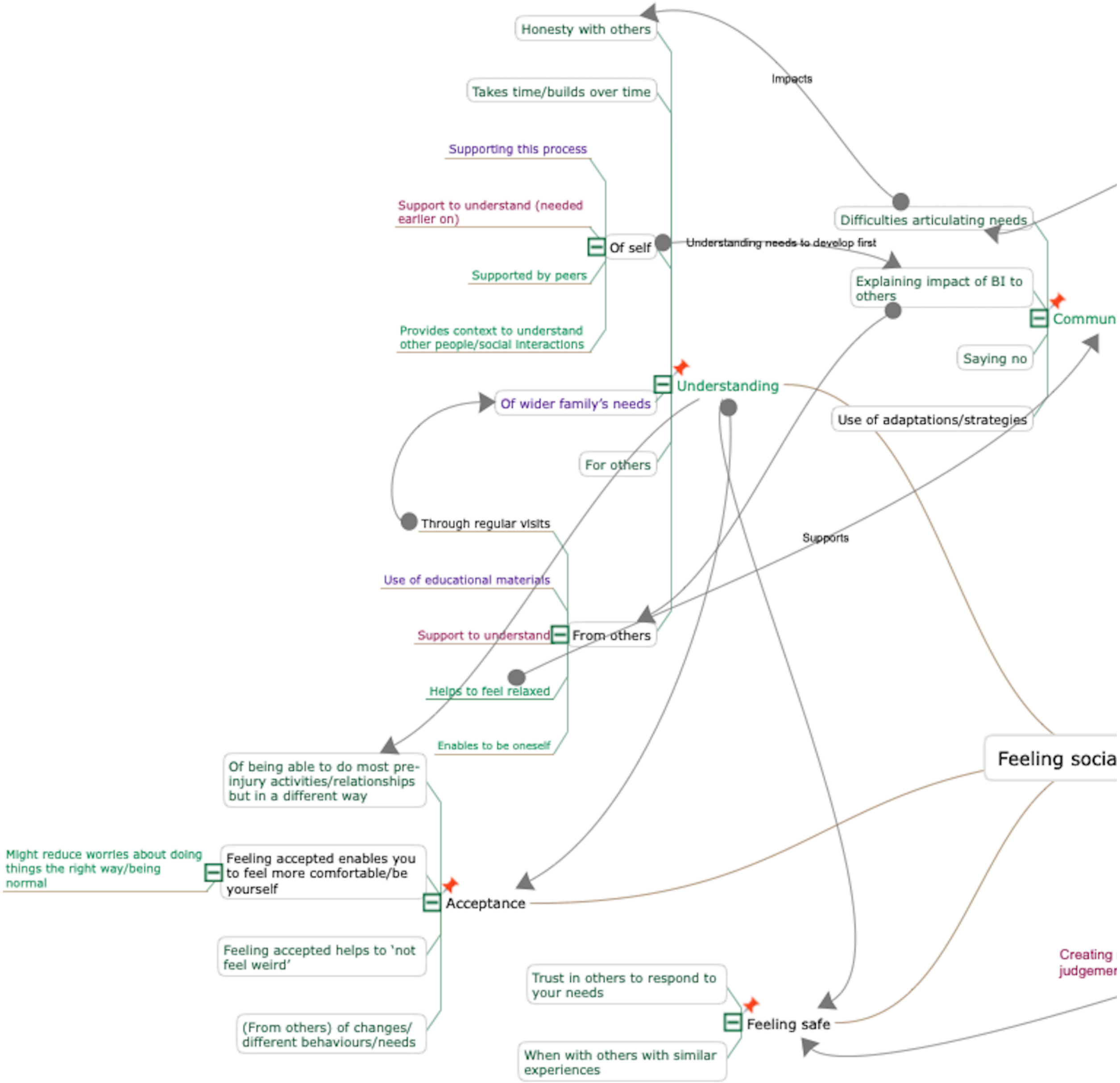
Purposeful activities
- Being active - hobbies
- Finding meaning again creates new opportunities
- Finding purposeful activities can be a long process with barriers
- Finding purposeful activity to give back + move forward
- What's my purpose?

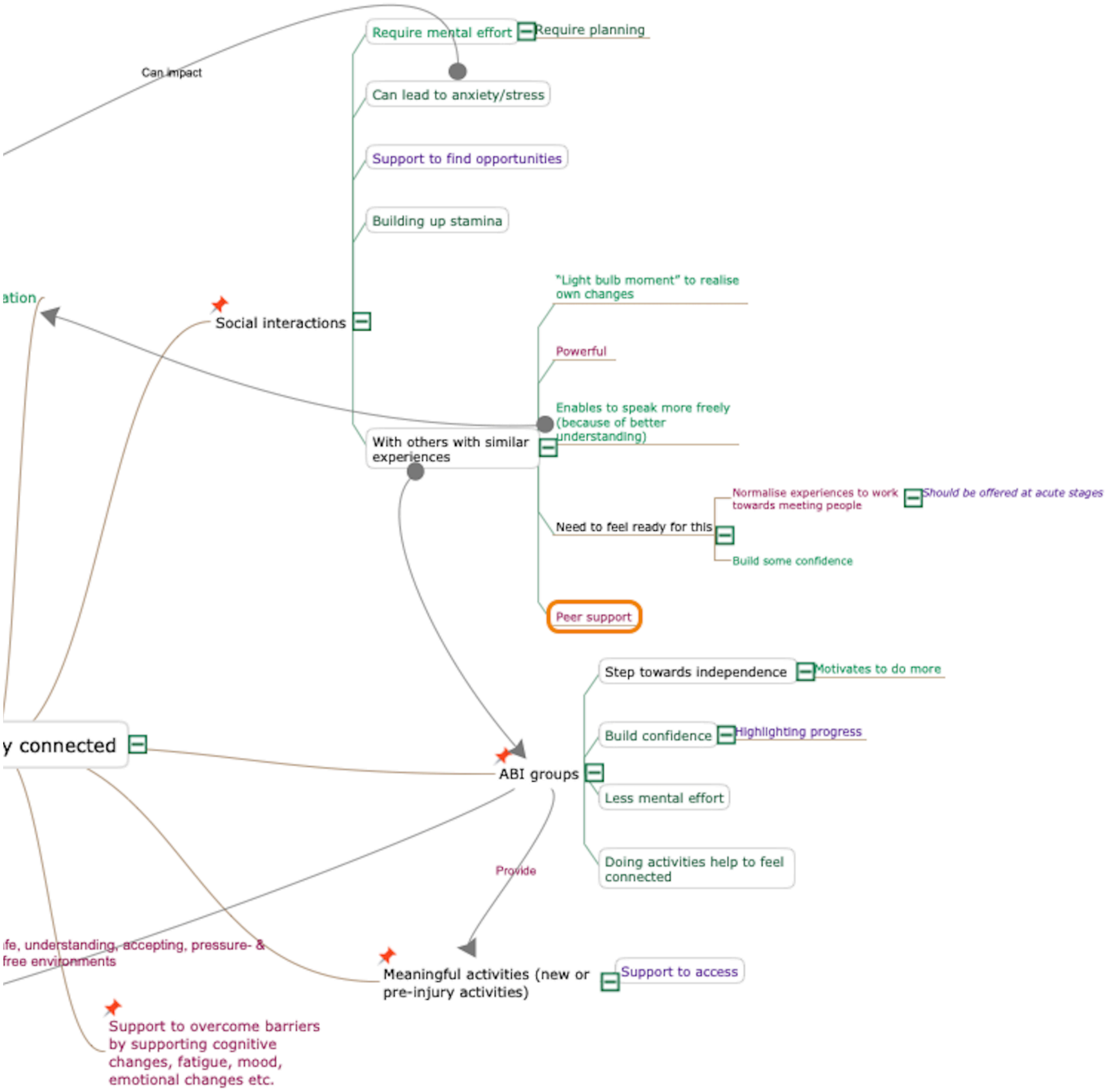
Return to pre-injury activities
- Doing pre-injury activities build confidence
- Doing pre-injury activities has a positive effect
- Trying to re-connect with pre-injury activities with adaptations
- Trying to return to work in family business
- Visiting sport events with friends + family again

- Realisation of abilities and joyful activities can have a positive effect

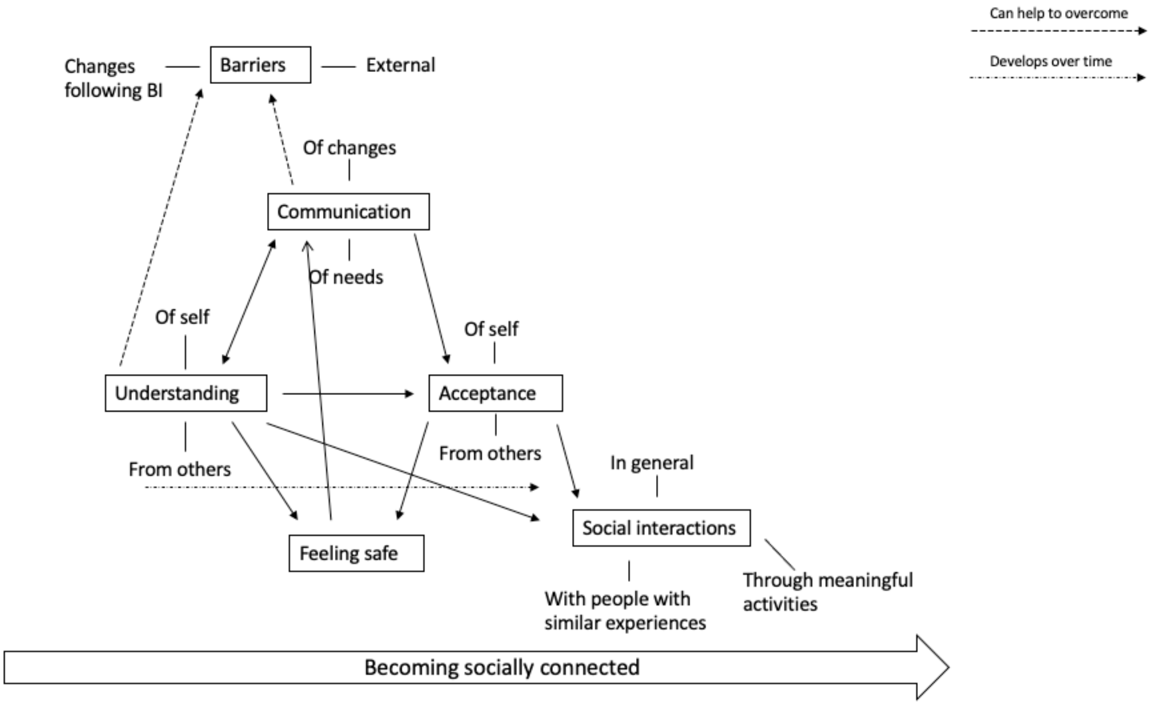
Example of diagram showing categories and links between them (whole diagram and split in two halve for eligibility)

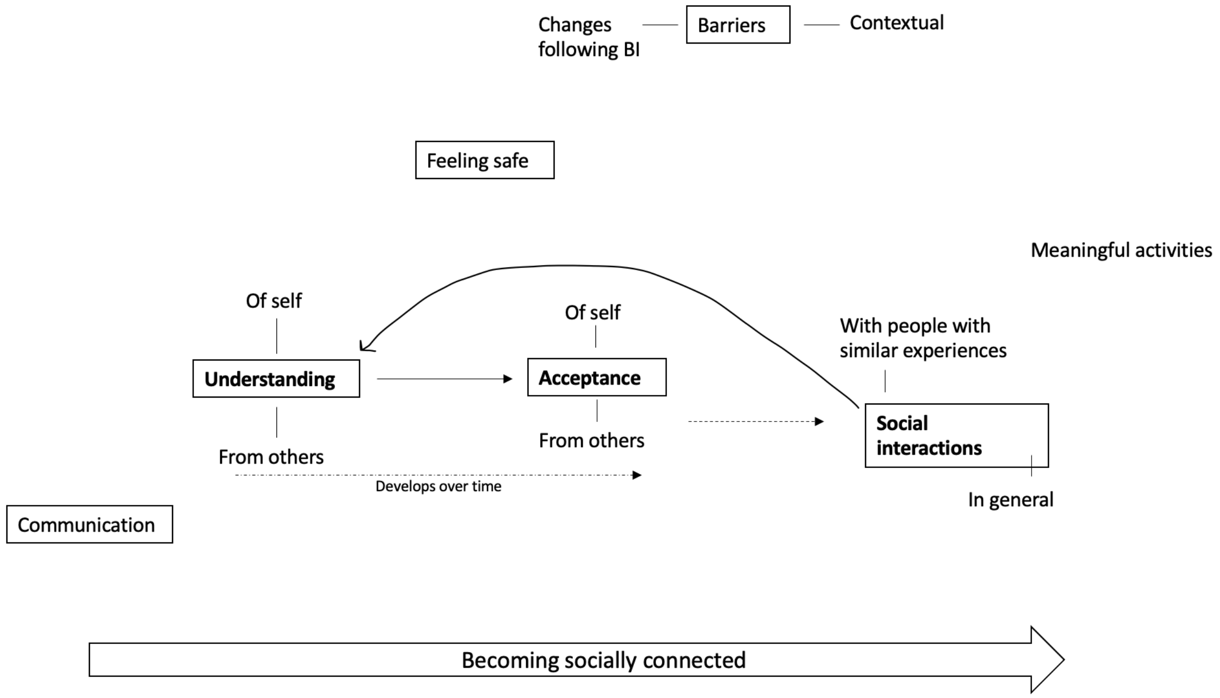


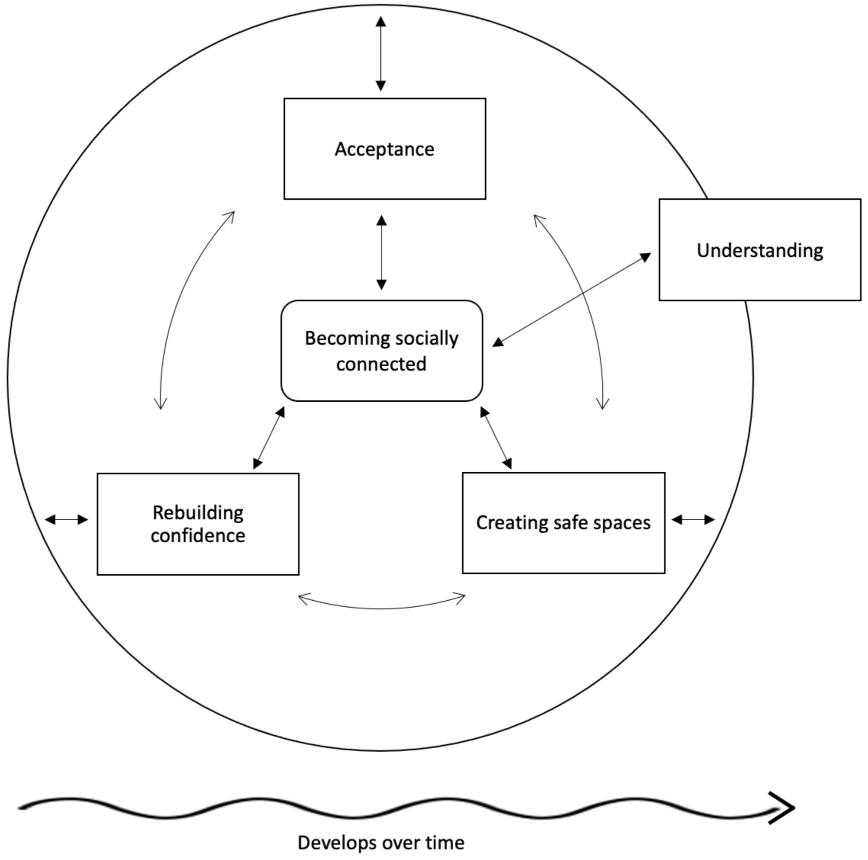

Honesty with others
Impacts
Takes time/builds over time
Supporting this process
Support to understand (needed earlier on)
Difficulties articulating needs
Of self
Understanding needs to develop first
Supported by peers
Explaining impact of BI to others
Commun
Provides context to understand other people/social interactions
Saying no
Understanding
Of wider family's needs
Use of adaptations/strategies
For others
Through regular visits
Supports
Use of educational materials
Support to understand
From others
Helps to feel relaxed
Enables to be oneself
Of being able to do most pre-injury activities/relationships but in a different way
Feeling socia
Might reduce worries about doing things the right way/being normal
Feeling accepted enables you to feel more comfortable/be yourself
Acceptance
Feeling accepted helps to 'not feel weird'
Creating judgemer
Trust in others to respond to your needs
Feeling safe
(From others) of changes/ different behaviours/needs
When with others with similar experiences


Can impact
Require mental effort
Require planning
Can lead to anxiety/stress
Support to find opportunities
Building up stamina
ation
Social interactions
"Light bulb moment" to realise own changes
Powerful
Enables to speak more freely (because of better understanding)
With others with similar experiences
Normalise experiences to work towards meeting people
Should be offered at acute stages
Need to feel ready for this
Build some confidence
Peer support
Step towards independence
Motivates to do more
y connected
Build confidence
Highlighting progress
ABI groups
Less mental effort
Doing activities help to feel connected
Provide
ife, understanding, accepting, pressure- & free environments
Meaningful activities (new or pre-injury activities)
Support to access
Support to overcome barriers by supporting cognitive changes, fatigue, mood, emotional changes etc.

Examples of model development



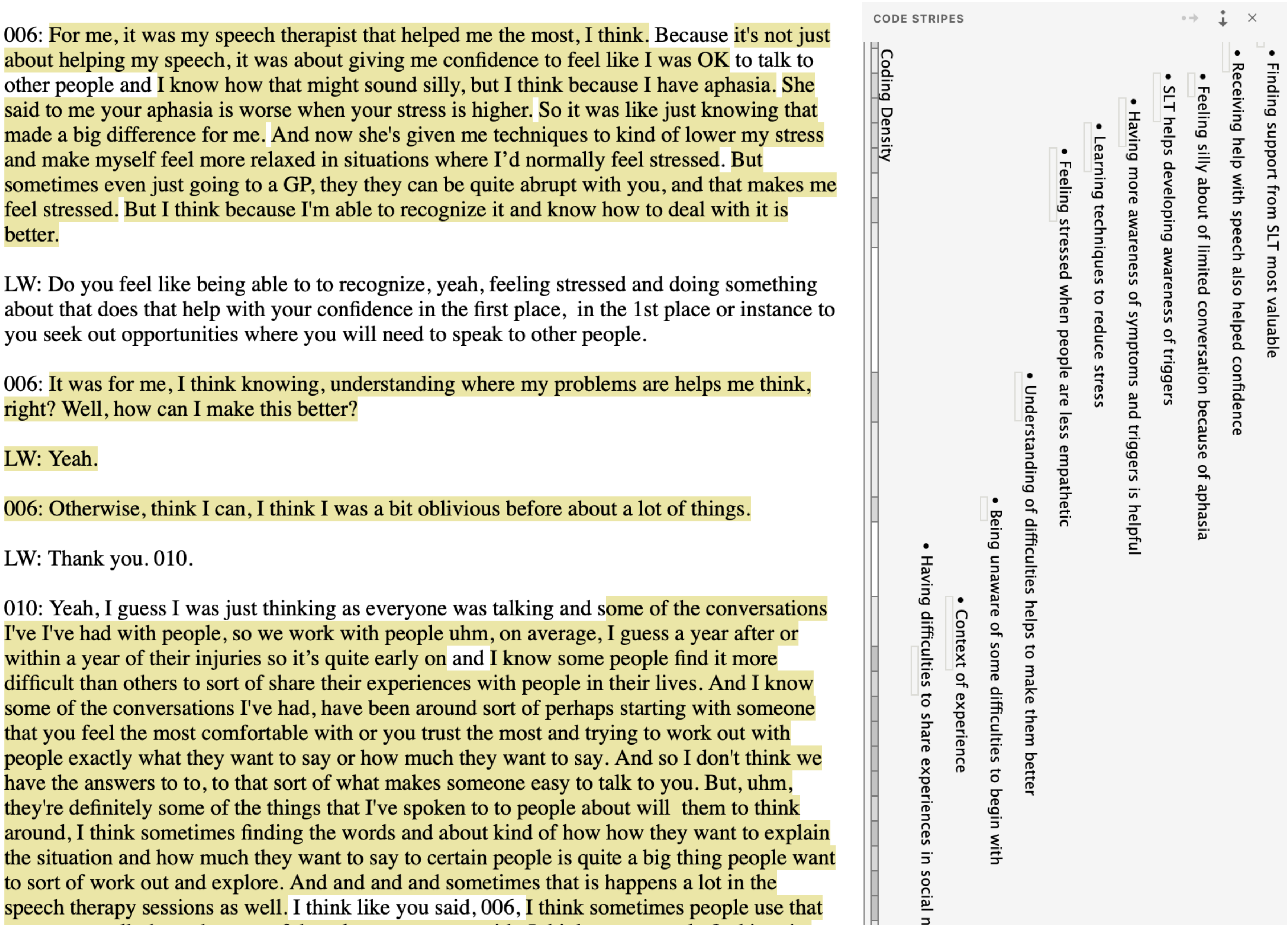

Changes following BI
Barriers
Contextual
Feeling safe
Meaningful activities
Of self
Understanding
From others
Of self
Acceptance
From others
With people with similar experiences
Social interactions
In general
Develops over time
Communication
Becoming socially connected


Acceptance
Understanding
Becoming socially connected
Rebuilding confidence
Creating safe spaces
Develops over time

Appendix P

Excerpt of Transcript with Initial Coding

Excerpt of focus group 6: Discussion included two individuals with ABI (005 – Bill; 006 – Claire), two community ABI support people (009 – Emma; 010 – Lauren) and the lead researcher (LW)



006: For me, it was my speech therapist that helped me the most, I think. Because it's not just about helping my speech, it was about giving me confidence to feel like I was OK to talk to other people and I know how that might sound silly, but I think because I have aphasia. She said to me your aphasia is worse when your stress is higher. So it was like just knowing that made a big difference for me. And now she's given me techniques to kind of lower my stress and make myself feel more relaxed in situations where I'd normally feel stressed. But sometimes even just going to a GP, they they can be quite abrupt with you, and that makes me feel stressed. But I think because I'm able to recognize it and know how to deal with it is better.

LW: Do you feel like being able to to recognize, yeah, feeling stressed and doing something about that does that help with your confidence in the first place, in the 1st place or instance to you seek out opportunities where you will need to speak to other people.

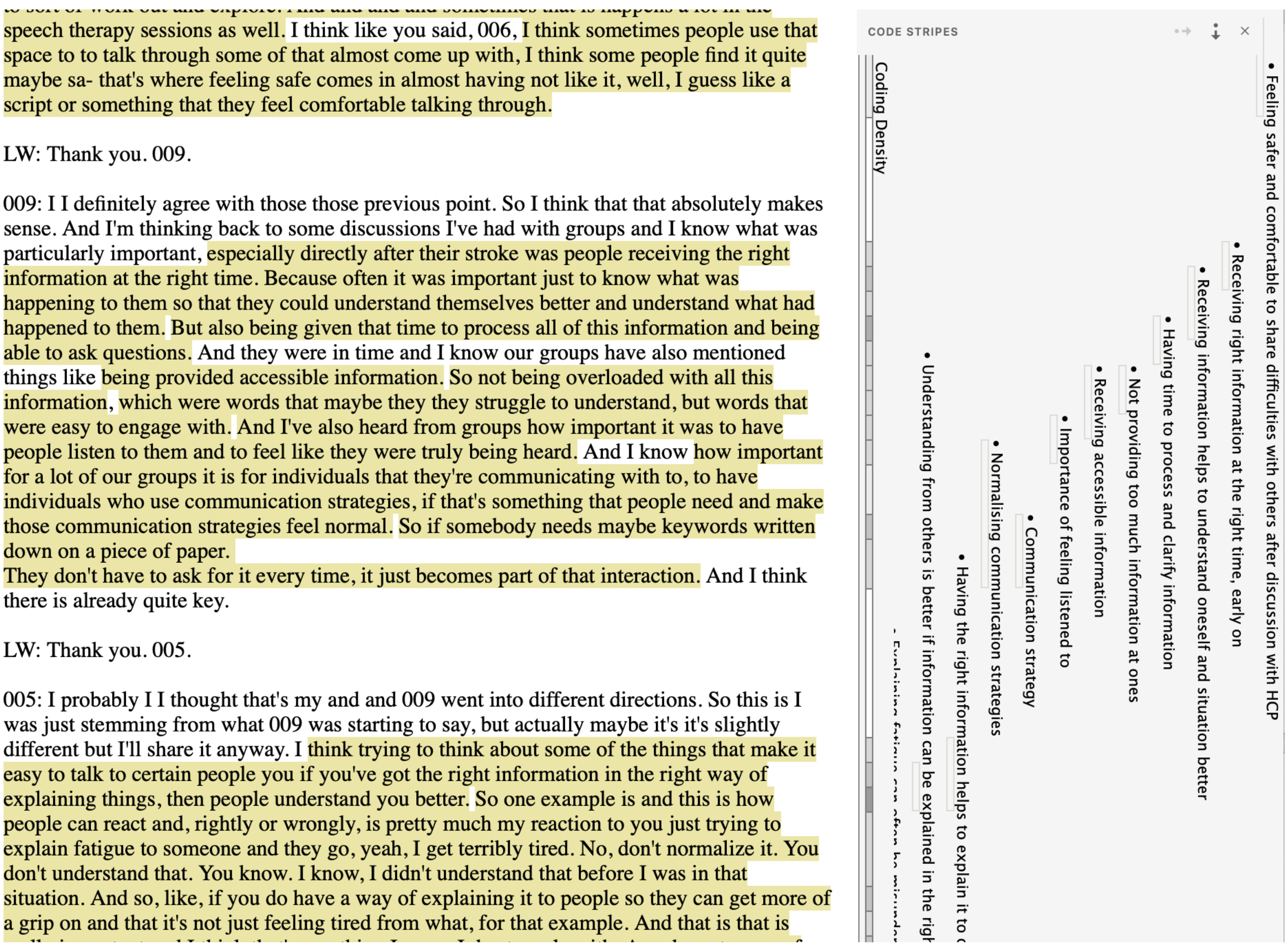
006: It was for me, I think knowing, understanding where my problems are helps me think, right? Well, how can I make this better?

LW: Yeah.

006: Otherwise, think I can, I think I was a bit oblivious before about a lot of things.

LW: Thank you. 010.

010: Yeah, I guess I was just thinking as everyone was talking and some of the conversations I've I've had with people, so we work with people uhm, on average, I guess a year after or within a year of their injuries so it's quite early on and I know some people find it more difficult than others to sort of share their experiences with people in their lives. And I know some of the conversations I've had, have been around sort of perhaps starting with someone that you feel the most comfortable with or you trust the most and trying to work out with people exactly what they want to say or how much they want to say. And so I don't think we have the answers to to, to that sort of what makes someone easy to talk to you. But, uhm, they're definitely some of the things that I've spoken to to people about will them to think around, I think sometimes finding the words and about kind of how how they want to explain the situation and how much they want to say to certain people is quite a big thing people want to sort of work out and explore. And and and and sometimes that is happens a lot in the speech therapy sessions as well. I think like you said, 006, I think sometimes people use that



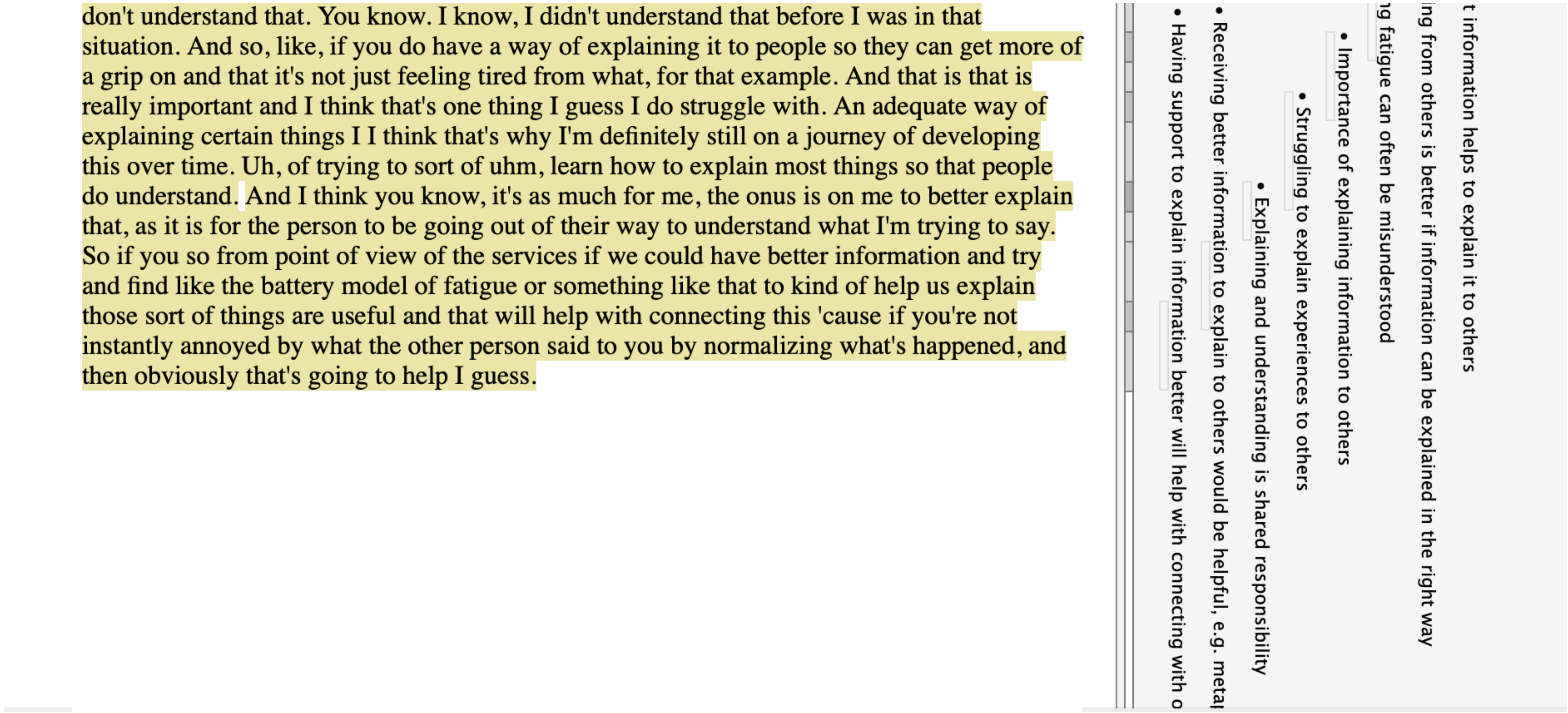
speech therapy sessions as well. I think like you said, 006, I think sometimes people use that space to to talk through some of that almost come up with, I think some people find it quite maybe sa- that's where feeling safe comes in almost having not like it, well, I guess like a script or something that they feel comfortable talking through.

LW: Thank you. 009.

009: I I definitely agree with those those previous point. So I think that that absolutely makes sense. And I'm thinking back to some discussions I've had with groups and I know what was particularly important, especially directly after their stroke was people receiving the right information at the right time. Because often it was important just to know what was happening to them so that they could understand themselves better and understand what had happened to them. But also being given that time to process all of this information and being able to ask questions. And they were in time and I know our groups have also mentioned things like being provided accessible information. So not being overloaded with all this information, which were words that maybe they they struggle to understand, but words that were easy to engage with. And I've also heard from groups how important it was to have people listen to them and to feel like they were truly being heard. And I know how important for a lot of our groups it is for individuals that they're communicating with to, to have individuals who use communication strategies, if that's something that people need and make those communication strategies feel normal. So if somebody needs maybe keywords written down on a piece of paper.
They don't have to ask for it every time, it just becomes part of that interaction. And I think there is already quite key.

LW: Thank you. 005.

005: I probably I I thought that's my and and 009 went into different directions. So this is I was just stemming from what 009 was starting to say, but actually maybe it's it's slightly different but I'll share it anyway. I think trying to think about some of the things that make it easy to talk to certain people you if you've got the right information in the right way of explaining things, then people understand you better. So one example is and this is how people can react and, rightly or wrongly, is pretty much my reaction to you just trying to explain fatigue to someone and they go, yeah, I get terribly tired. No, don't normalize it. You don't understand that. You know. I know, I didn't understand that before I was in that situation. And so, like, if you do have a way of explaining it to people so they can get more of a grip on and that it's not just feeling tired from what, for that example. And that is that is



don't understand that. You know. I know, I didn't understand that before I was in that situation. And so, like, if you do have a way of explaining it to people so they can get more of a grip on and that it's not just feeling tired from what, for that example. And that is that is really important and I think that's one thing I guess I do struggle with. An adequate way of explaining certain things I I think that's why I'm definitely still on a journey of developing this over time. Uh, of trying to sort of uhm, learn how to explain most things so that people do understand. And I think you know, it's as much for me, the onus is on me to better explain that, as it is for the person to be going out of their way to understand what I'm trying to say. So if you so from point of view of the services if we could have better information and try and find like the battery model of fatigue or something like that to kind of help us explain those sort of things are useful and that will help with connecting this 'cause if you're not instantly annoyed by what the other person said to you by normalizing what's happened, and then obviously that's going to help I guess.

Appendix Q

Examples of Quotes within Theoretical Codes

Understanding

Understanding of self

"I hadn't really spotted that in myself up to a couple years ago when my wife raised it" (Bill; individual living with ABI)

"It takes time and erm looking within yourself to actually see how the injury affects you. And that takes weeks, months and years. (Ann nodding) Only then can you understand how it affects you so so therefore then, er, only then can you tell other people how it you know, how it affects you." (Donald; individual living with ABI)

"I think it was just the awareness, so I think I think it just gradually got more and more aware of a lot of things and I just feel, I feel better for knowing." (Claire; individual living with ABI)

*"(...) just to be told in the plain, you know a plainest language. I was like. OK, so that's why didn't you know? Dinner, simple task. But now it is, it's draining because you're still building pathways and I was like oh **** yeah think about it, it makes sense." (Donald; individual living with ABI)*

"Because through understanding oneself that gives a context for understanding other people. And the difficulty, very often everybody is different and I don't wish to generalize. But the difficulty after having had a brain injury. Is that you can no longer rely predictably upon yourself to interpret. So constantly being thrown back into: Did I get it right? Is it me? (...) But if you can't really understand

> *what's happened to yourself then it's almost like random chatter which comes at you from other people because she can't put him to a coherent framework." (Richard; community ABI support person)*

> *"I think I've got better overtime, so I've got better to understood myself. (...) I feel like I've gradually got used to the way things are. I do think I'm able to tell people now what my issues are." (Claire; individual living with ABI)*

> *"First of all, let's just try and normalize all these phenomena that people invariably express about you know, problems so you know the holes in memory. Or uhm, feeling suddenly irritating when you didn't feel before uhm (...) And it there's almost audible after a while a sense of relief that comes up 'it's not just me then' and that I think is really important." (Richard; community ABI support person)*

Understanding from others

> [What helped to maintain those friendships? …] "*I think that since I started communicating more, especially with my parents, they understand more of how I feel, so rather me just doing something and they not understanding why I'm doing it. I'm saying I'm doing this because I'm tired or I'm doing this because I can't cope with my surroundings or,- erm, I think feeling safe enough to do that is important." (Claire; individual living with ABI)*

> *"I know some people find it more difficult than others to sort of share their experiences with people in their lives. And I know some of the conversations I've had, have been around sort of perhaps starting with someone that you feel the most comfortable with or you trust the most and trying to work out with people exactly what they want to say or how much they want to say. (...) I think sometimes finding the words and about kind of how how they want to explain the*

situation and how much they want to say to certain people is quite a big thing that people want to sort of work out and explore." (Jessica; community ABI support person)

"…but for them [others] to understand is part of nature, without being nasty, that takes time more so than it would in a normal if you are a normal person making friendships, you know so so sometimes that that's a barrier." (Donald; individual living with ABI)

"I actually made the effort to acquire some books on brain injury rehab and and that has been very helpful. It's helped me to gain a better understanding of what her needs might be so I could then see how they were for her and if they were helpful, then to engage them. If they weren't, then obviously not." (Harry; family member)

"Erm, but actually she [Tony's partner] sort of realises that she does that as well so often in in new situations will probably pre-empt or or with the conversation saying I don't mean to be rude, but I I sort of say things as it is. It's not that I'm not caring about it or I'm intentionally trying to insult you. It's just that I I say things as it is sorting due to the injury so." (Tony; family member)

"I don't know what it is about the understanding if I'm honest, I just feel like it makes me feel more relaxed it knowing that somebody knows how I feel or knows what erm, issues I have. (…) Like if if it's some understanding when I go in there, it makes a big difference for me and I feel relaxing to go in. So I'm able to talk and Say things as a as a need to." (Claire; individual living with ABI)

> *"In the case of [Harry's partner], erm, it's really a case of helping people to understand erm, how the stroke has impacted upon her? So that they're actually able to have the best kind of conversation with her because I think I'd certainly detected early on that if [Harry's partner] didn't understand something, she wouldn't acknowledge that to others." (Harry; family member)*

Rebuilding confidence

> *"The groups the groups in the brain injury I did Surfability with the brain injury unit, which was absolutely, it's just a really good way to get into doing something else, and to motivate you to then take the next step and to do it more independently away from their brain injury unit." (Ann; individual living with ABI)*

> *"Until that time I wasn't really ready, if I'm honest, it's because I I think I was a lot more erm not shielded, but I I couldn't really speak to other people or I needed somebody with me. (...) Whereas now, I feel more confident, even just. I still I still. I'm nervous about doing things that perhaps I feel people don't understand how I feel nervous about it, but I'm all out as you do something now and just think Oh well, it doesn't matter what they think. But I still do worry a little bit." (Claire; individual living with ABI)*

> *FG (researcher): And did that confidence spill over to other people or other situations?*
>
> *Claire; individual living with ABI: I suppose it has, I suppose it has because it because I feel happier and more confident in those situations. It makes me push myself a bit more in, in everyday life. (...)*

> *[Family member's partner went to an ABI-specific event] "They really came out of themselves. They seem to have an increased level of confidence, they their*

> *speech seemed to improve as well, and it was really quite remarkable" (Harry; family member)*

> *"But you can kind of feel like a bit of a fraud at times or or just that things that are happening to you. You've got no frame of reference from before. It is something completely new and and that the peer network allows you to normalize that. And if you know that what you're feeling is real 'cause other people saying that back to you, that gives you more confidence in to explain it to a non-peer group, I would say." (Bill; individual living with ABI)*

> *"What we aim to do at [removed for confidentiality] the charity that I manage looking at supporting people as individuals to be doing more, using what skills they've got." (Helen; community ABI support person)*

> *"His parents have been really good, if I'm honest, uhm so he goes up and sees them sort every couple of weeks. Uhm, they live up in Leeds and so he gets the train on his own. Like again things like that which he couldn't do to start with he's obviously built his confidence" (Rebecca; family member)*

> *"I mean, for [John's daughter] obviously the experience of being at [inclusive college] was really good because then she was in an environment where she wasn't being dragged around by mum and dad trying to arrange things." (John; family member)*

Acceptance

Acceptance of self

> *"She's [Tony' partner] got this nice great mantra that actually it's not, uhm, recovering back to uh, where you were, because actually that will never happen.*

> *You know, I think that sort of assumes people realize that then that's a lot better for them. But actually it's sort of recovering to a, to a life that's worth living again" (Tony; family member)*

> *"I feel like I'm happy. I feel like I'm happy now. Whereas I've not been before because I was always conscious of my issues and worried about what other people thought, whereas now I kind of think I've got to accept it and I've just got to get on with what I can do rather than what I can't do. (Researcher: Has that changed anything for you in relation to you connections or friendships with other people?) I think perhaps my connections are stronger with people, but only with certain people. So people that I feel understand me and uhm, my parents, my sister, my close friends. People who have also had encephalitis. Or who have the same difficulties. (...)" (Claire; individual living with ABI)*

> *"A lot of people have said to me in the past, initially, especially in the early days after their injury, there was this huge loss of independence and they they weren't in control of the decisions that were being made and that that made acceptance rather challenging and difficult. And as they started to reclaim that independence and control that also played a role in acceptance (Emma; community ABI support person)*

> *Uh, you know keep keep keep keep moving forward keep you know, keep adjusting, adjusting to life with a brain injury, there's good days and bad days, but gradually the the acceptance does get easier. (Donald; individual living with ABI)*

Acceptance from others

> *"So what I value is that people would just accept what little I do say to them at times I guess. So for me with friends, friendship groups. Uh, I don't get a lot of*

> *pushback on saying. 'Actually, no, I can't do that, so stop pestering me' and the people kind of get that" (Bill; individual living with ABI)*

> *[Acceptance], I think, you know that's the longer term thing really because that really that is about others, clinical others and others in, you know, in the family and then friends but also others in the wider world having some understanding of what Brain injury is. (Richard; community ABI support person)*

> *"I think from maybe an acceptance point of view that if if if people understand what's happened to that person, they might not understand why that person is acting that way, or why and maybe their speech is slightly slurred and things like that but maybe they accept that person a bit more and go Oh well, actually they're not being rude or they're not doing this or that, you know." (Tony; family member)*

> *"If you're not limping or whatever, it it's very hard to understand what's going on for folks. So I find that I find certain friends easy to go out with because they accept what I'm doing (...)." (Bill; individual living with ABI)*

Creating safe spaces

> *"I think one of the things that I do which doesn't necessarily maybe it helps, maybe it doesn't help. You can see it both ways in how I manage uhm, people don't understand what I need. I make sure I've got a way out when I need it. (...) And I'd say like if I'm away and with people, I don't know that well, I just make sure that I've got the ability to be independent. And if I need to go, I can. You know, I know how to get home. I know they had to get to where I want to go. And so. Yeah, I I guess maybe I do pre warn people that I might do that as well done as well." (Bill; individual living with ABI)*

“Being with other people with brain injury being in the brain injury unit is probably the place I feel sort of the most safe.” (Ann; individual living with ABI)

“But the thing that we get back time and time again. Is that: uhm, we're not being judged and we're not being judged by anyone in the group for being ourselves, and that that's all it is. It's that acceptance, you know, and no one's gonna say there is obviously with brain injury, there are many physical, visibly physical impairments.” (Theresa; community ABI support person)

[What helped to maintain those friendships? ...] “Yeah, just just the same as Donald said just trusting people and and feeling like you’re safe to, like to just be honest.” (Claire; individual living with ABI)

“I think what perhaps he needs to do a little bit more is to connect with people in in a similar situation to him. There is some groups that he's been going to, which again is virtual, but it's kind of a daytime one where, uhm run by local charity that he's getting to talk to people in a, you know, similar situation. It's a young persons’ brain injury group, so that's been quite beneficial just to have.” (Rebecca; family member)

“But when you actually have people who you need to say, yeah, that happened to me. This is what I did, and yeah, that's not so weird. (...) And then that allows you know a feeling of ‘gosh, I'm normal’, but also a feeling of of connectedness with those other people. (...) I think that's really, really important. I think the role of peer support is probably you know you can't have it too soon, can't bounce people into it before they're ready, but I think it's ultimately probably at least as important, if not more important than, um, you know the explanation

> *from you know some sort of clinician or some sort of professional." (Richard; community ABI support person)*

> *"There were about seven or eight people who had suffered strokes (...) They seem to have an increased level of confidence, they their speech seemed to improve as well, (...) And it's I think it's something to do, I think it's something to do with the confidence which they then felt because they felt they probably weren't being judged because they were amongst their contemporaries, amongst their peers." (Harry; family member)*

Time

> *"I mean it takes honestly honestly time. But also a lot of work with NHS and and and private sector" (Donald; individual living with ABI)*

> *"I was gonna say about it does develop over time. I think it's a really good thing to have that time margin in there because understanding your your brain injury, when it's yours it takes a lot of time, so of course it takes time for the people to get as well." (Bill; individual living with ABI)*

Appendix R

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