

PAPER ONE: SYSTEMATIC REVIEW

The Efficacy of Interventions that Facilitate Social Participation on Outcomes of Social Participation and Quality of Life in Adults with Acquired Brain Injury

PAPER TWO: EMPIRICAL PAPER

Improving Peer Relationships for Adolescents with Acquired Brain Injury:

Using Intervention Mapping as a Framework to Identify Targets for Intervention

Submitted by Mr Scott Ankrett, to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology, May 2020

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Shalas

Signature:

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SCHOOL OF PSYCHOLOGY DOCTORATE IN CLINICAL PSYCHOLOGY

PAPER ONE: SYSTEMATIC REVIEW

The Efficacy of Interventions that Facilitate Social Participation on Outcomes of Social Participation and Quality of Life in Adults with Acquired Brain Injury:

A Systematic Review

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Abstract

Background and aims. Social participation is a key determinant for health and wellbeing across the lifespan, and is a frequent goal for rehabilitation. Acquired brain injury (ABI) is a leading cause of death and disability worldwide that can result in persistent difficulties within cognitive, emotional, behavioural, physical, and social domains that contribute to chronic disability and restricted participation. Consequently, survivors are at higher risk of social isolation and reduced quality of life (QoL). The social participatory goals of rehabilitation are increasingly advocated for to support QoL and minimise disability post-ABI. The aim of this review was to explore the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adult survivors of ABI. The synthesis of available evidence might support rehabilitation professionals to consider how to improve such outcomes in post-acute settings.

Methods. A systematic review was conducted to locate, appraise, and synthesise evidence relating to the review questions. Appropriate intervention studies were identified using a pre-determined search strategy. These were then assessed for inclusion against pre-defined eligibility criteria to investigate the efficacy of their interventions on the target outcomes for this review, social participation and QoL.

Results. Of the 1119 possible articles identified in the initial search, 12 studies met the inclusion criteria for this review. Data were then extracted and methodologies were critically appraised. Intervention programmes were grouped according to intervention methods, and included peer-mentoring, community integration, leisure activities, outpatient neuropsychological rehabilitation, intensive cognitive rehabilitation, and health-promotion. Seven of the 12 studies found statistically significant differences on at least one target outcome following intervention. Four of

these identified efficacy on both social participation and QoL, and varied in methodological design and quality.

Conclusion. Currently, there is limited evidence for the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL for adults with ABI. The varying objectives, quality, and potential bias of the 12 included studies limits the conclusions that can be drawn. Social participatory interventions appear to have objective and subjective benefits for adults post-ABI. Appropriate intervention methods (i.e., delivery and focus) to support target outcomes is uncertain from the limited literature included in this review. However, interventions that showed efficacy on both target outcomes (four of the 12) were multifaceted and intensive. Rehabilitation of social participation to support social participation and QoL post-ABI may benefit from supporting participants to develop the skills and self-belief needed to actively participate in social activities that are important to them, however, further evidence is needed. Considerations for future research and clinical implications are outlined.

Introduction

The World Health Organisation (WHO; 2001) conceptualises disability as impairment, activity limitations, and restrictions in participation. Accordingly, the British Society of Rehabilitation Medicine (BSRM) and the Royal College of Physicians (RCP) in the United Kingdom (UK) define rehabilitation as "a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological, and social function" and that services should consider "the use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society" (BSRM & RCP, 2003, p. 7).

Social participation is defined as "...a person's involvement in activities that provide interactions with others in society or the community" (Levasseur, Richard, Gauvin, & Raymond, 2010, p. 2148). This definition was established to address the lack of consensus within the health literature, which often uses similar concepts interchangeably to describe social participation. These include social engagement (i.e., participation in social activities; Bassuk, Glass, & Berkman, 1999), community integration (i.e., engagement in activities in home, social, and productive environments; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), and social integration (i.e., mutual engagement in social activities with others; Lefebvre, Cloutier, & Levert, 2008).

To support the definition and conceptualisation of social participation, Levasseur et al. (2010) conducted an inventory and content analysis across 43 identified definitions of social participation across a broad range of disciplines. They proposed a taxonomy comprising of six levels containing the different types of social activities that contribute to social participation: (1) doing an activity in preparation for

connecting with others; (2) being with others but feeling alone; (3) interacting with others without doing a specific activity; (4) doing an activity with others; (5) helping others; and (6) contributing to society. This suggests that a person's social participation can be viewed on a continuum from passive to very active (Levasseur et al., 2010; Piškur et al., 2014).

Social participation is a fundamental determinant for health and wellbeing (Levasseur et al., 2010), viewed as important for children's development, positive adult mental health, and healthy aging in the elderly (WHO, 2002). Regarded as a key outcome in rehabilitation (Gerber, Garago, & McMackin, 2016; Piškur et al., 2014), social participation has been separated into objective and subjective outcomes. Some authors refer to it as the number (objective) of social contact hours an individual receives (Shattuck, Orsmond, Wagner, & Cooper, 2011). Others, view social participation as the amount of meaningful (subjective) experiences an individual has with others (Boutot & Bryant, 2005). Thus, one may not engage in many social activities but regards these as meaningful for wellbeing (Piškur et al., 2014).

Social participation is a particular concern following acquired brain injury (ABI), a leading cause of death and disability worldwide (Jolliffe, Lannin, Cadilhac, & Hoffman, 2018; Menon & Bryant, 2019). In the UK alone, there were 348,453 recorded hospital admissions for ABI between 2016 and 2017, approximately 954 admissions per day (Headway, 2018). Moreover, prevalence rates are likely to be an underestimation due to inconsistent recording procedures and those not requiring admission being omitted from figures. ABI can result from a variety of mechanisms that result in damage to the structural integrity of the brain. These include traumatic brain injuries (TBI), caused by road traffic accidents, falls, or assaults; or non-traumatic injuries, caused by stroke, brain tumour, hypoxic injuries, or infections (Barber et al.,

2018). Enhancements in medical science have increased the survival rates for people with severe ABI (Holloway & Tasker, 2019), and the sequela that contribute to chronic disability are increasingly recognised.

Survivors may experience far reaching impairments in cognitive, emotional, behavioural, physical, and social domains. There is evidence to show difficulties with attention (Sinclair, Ponsford, Rajaratnam, & Anderson, 2013), executive functioning (Niemeier, Marwitz, Lesher, Walker, & Bushnik, 2007), insight and awareness (Fleming, Strong, & Ashton, 1996), memory (Hutchinson & Marquardt, 1997), identity (Carroll & Coetzer, 2011), mood (Gould, Ponsford, Johnston, & Schönberger, 2011), lability, aggression, disinhibition (Eames & Wood, 2003), mobility (Cubis et al., 2018), and interpersonal relationships (Yeates, 2013) following ABI. Similarly, individuals can experience significant losses in life roles as well as restricted participation in domestic, vocational, community, and leisure activities (Brown, Gordon, & Spielman, 2003; Goverover, Genova, Smith, Chiaravalloti, & Lengenfelder, 2017).

Post-ABI, individuals are more likely to experience increased social isolation, loneliness, and depression (Bombardier et al., 2010; Douglas, Dyson, & Foreman, 2006; Salas, Casassus, Rowlands, Pimm, & Flanagan, 2018). Unsurprisingly, quality of life (QoL) and satisfaction with functioning is often affected post-ABI, resulting in deteriorating mental health and further restricted participation (Goverover et al., 2017; Kalpakjian, Lam, Toussaint, & Merbitz, 2004). In addition to the impact of ABI, community and cultural factors may also influence social participation post-injury. These include social economic status and access to community resources (Ashida, Kondo, & Kondo, 2016), living in rural areas (Douglas, Dyson, & Foreman, 2006), engagement in health promoting behaviours (Hyyppä & Mäki, 2003), religion and

ethnicity (Tam & Neysmith, 2006), and family and community views towards disability (Saetermoe, Scattone, & Kim, 2001).

Adults with TBI have previously reported significantly less social participation in leisure and recreational activities (Fleming et al., 2011; McLean, Jarus, Hubley, & Jongbloed, 2014), reduced friendship quality, and higher social isolation when compared to non-injured adults (Flynn, Mutlu, Duff, & Turkstra, 2018). Furthermore, Cubis et al. (2018) identified that those who perceived higher levels of functional and cognitive impairment following brain tumours were more likely to experience a loss in social group membership and poorer psychological wellbeing.

WHO (1998) define QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 1570). Accordingly, if participation in social activities is of value to individuals, unfulfillment in this area is likely to affect life satisfaction. Indeed, social support and community integration has previously been shown to be significantly associated with QoL measures (Kalpakijan et al., 2004), and participation in leisure activities has been significantly associated with increased satisfaction with life (Pierce & Hanks, 2006).

Similarly, health-related QoL (HRQoL) gives reference to subjective perspectives on the impact of a health condition on wellbeing and functioning within physical, psychological, social, and domestic domains (Cella et al., 2012). Such experiences are likely to be key drivers for rehabilitation and contribute to overall value of treatment for individuals. The Quality of Life after Brain Injury Instrument (QOLIBRI; von Steinbüchel et al., 2010), a measure of HRQoL, has previously shown positive relationships with the social aspects of the Community Integration Questionnaire (CIQ; Willer et al., 1993) in ABI populations (Gerber et al., 2016). The CIQ is an objective

measure of a person's level of integration in home, social, and productive activities (Willer et al., 1993), and is frequently used to measure social participation in ABI populations (Gerber et al., 2016).

The relationship between social participation and QoL has previously been recognised (Geber et al., 2016), particularly on subjective measures of social participation. McLean et al. (2014) identified that enjoyment and satisfaction with performance in social activities were significantly associated with QoL in their sample with TBI, but the diversity and frequency of activities were not. Subsequently, it has been concluded that rehabilitation should focus on supporting individuals to engage in meaningful social activities to maximise QoL and minimise disability (Cicerone, 2004; Eriksson, Kottorp, Borg, & Tham, 2009; McColl, 2007; McLean et al., 2014). Whilst it has been suggested that QoL may improve with increased meaningful social participation (Goverover et al., 2017; McLean et al., 2014), the causal relationship between the two outcomes is yet to be explored.

Rationale and Aims for Review

Rehabilitation aims to maximise an individual's ability to participate in valued activities and increase wellbeing, despite the presence of impairments (BSRM & RCP, 2003; Hart & Evans, 2006). Accordingly, rehabilitation goals need to focus on what is important to the individual with ABI (Wilson, 2017). The chronic consequences of ABI can have significant implications for social participation and QoL, and the social goals for rehabilitation are becoming increasingly recognised (Gerber et al., 2016).

There is a rationale to review the efficacy of interventions that facilitate social participation for adults with ABI on outcomes of social participation and QoL. Furthermore, it seems pertinent to identify suitable methods (i.e., intervention delivery

and focus) within the evidence-base to achieve this. A synthesis of available evidence could support rehabilitation professionals to: (a) understand the interplay between social participation and QoL; (b) consider how best to support these outcomes in post-acute rehabilitation; and (c) review outlined considerations for future intervention research.

A limited number of systematic reviews have been conducted to explore the efficacy of community, leisure, and social participation interventions in ABI populations. Tate, Wakim, and Genders (2015) reviewed the efficacy of community-based social activity programmes for people with TBI on outcomes of mood and QoL, but not social participation. The authors only found two studies with sufficient scientific rigour to show efficacy of the interventions on target outcomes. The limited number of available studies was recognised and it was concluded that interventions need to be specific, structured, goal-driven, intensive, and conducted over a period of months. More recently, Lee, Heffron, and Mirza (2019) explored the efficacy of interventions focusing on community and leisure participation for individuals following stroke. They also recognised the limited number of available studies to show an effect on measures of participation, depression, and HRQoL. It was recommended that future interventions should focus on social participation and community activities beyond leisure.

This review aims to extend the work of Tate et al. (2015) and Lee et al. (2019) to explore the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adults with ABI. As recognised by Levasseur et al. (2010), the ABI literature equally uses interchangeable terms, such as social participation (McLean et al., 2014), leisure activities (Fleming et al., 2011), and community integration (Gerber et al., 2016); with the latter concerning itself with a

person's activity, and physical and social inclusion in community life (Winkler, Unsworth, & Sloan, 2006). Community integration has largely been replaced by 'participation' in rehabilitation literature (McLean et al., 2014).

For this review, *social participation* was defined as 'any engagement in activities that provides interaction with others within society or a community' (Levasseur et al., 2010). The use of this definition will allow for the inclusion of intervention studies using terms such as community integration, leisure activities, and peer-mentors, both in an individual and group setting, if all other inclusion criteria is met. This review aimed to answer the following questions:

- 1. What is the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adult survivors of ABI?
- 2. Does increased social participation result in improved QoL post-ABI?
- 3. What are the psychological processes that support social participation and QoL post-ABI?

Methods

A systematic review aims to locate, appraise, and synthesise empirical evidence relating to specific research questions to provide evidence-based answers (Boland, Cherry, & Dixon, 2017). This review adhered to the guidelines provided by the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocol (PRISMA-P; Moher et al., 2015).

Eligibility Criteria

The population, intervention, comparator, outcome, and study type (PICOS) framework was used to determine eligibility criteria (Table 1) for study characteristics, as recommended by the PRISMA-P checklist (Moher et al., 2015).

Table 1

PICOS Eligibility Criteria for the Inclusion and Exclusions of Studies in the Review

In	clusion	Exclusion		
Population	 Adult population (>18 years) Population with ABI (various aetiologies, may include stroke if population referred to as ABI) 	 Non-adult populations (specified children or adolescent population / or older adult population) Population exclusively referred to as stroke Population without ABI (i.e., progressive neurological conditions/ neurodevelopmental or learning/ intellectual disabilities) Population with primary mental health needs/ focus 		
Intervention	 Studies or interventions facilitating/ increasing social participation for participants (i.e., supporting inclusion in activities with others) 	 Studies without a primary focus increasing social participation for participants (i.e., return to work, individual self-help) 		
Comparison n/	'a	n/a		
Outcomes	 Studies that report social participation (including community integration, leisure satisfaction) and QoL as separate outcomes Studies that report outcomes relating to social participation and QoL/ HRQoL QoL may be reported as subjective well-being or satisfaction with life Studies may report additional outcomes, as well as social participation and QoL 	 Studies that do not report outcomes relating to social participation or QoL Studies that only report outcomes relating to social participation or QoL Studies that only report outcomes in mood domains 		

Study designs

- Peer-reviewed articles
- Quantitative studies
- Randomised controlled trials (RCT)
- Longitudinal/ prospective studies
- Single-case experimental designs (SCEDs)
- Qualitative studies

- Clinical case studies
- 'Grey literature' (due to time restrictions)
- Discussion or opinion papers
- Conference abstracts
- Book chapters
- Papers published in foreign language with no available English translation
- Study proposals

Population. Identified participants were adults (>18 years) with ABI. Studies that outlined a minimum inclusion age of 16 years were included if the sample was stated to be adults and the reported mean age suggested the majority of participants to be above the age of 18 years. The term "stroke" was excluded from the search strategy due to the recent review by Lee et al. (2019) with this population in this topic area. Participants with stroke aetiologies were only included if studies identified the sample to be exclusively ABI.

Intervention. Studies were included if the intervention promoted engagement in activities in a social, group, or community setting; in line with the definition of social participation. Studies were included if they referred to community integration, leisure activities, or peer-mentoring and aimed to increase participation with others.

Comparator. No restrictions were placed upon comparator criteria, allowing for the inclusion of randomised controlled trials (RCT), and within prospective and single-case experimental designs.

Outcome. Studies were included if they measured outcomes relating to both social participation (including community integration, leisure satisfaction) and QoL (including HRQoL). Studies that only reported one of these outcomes were excluded

due to the review questions. Studies may also refer to QoL as subjective well-being or satisfaction with life (Skevington & Böhnke, 2018).

Study designs. Only peer-reviewed studies were included in this review. Due to time constraints and the large number of possible articles identified from searching the ProQuest database, grey literature was not included.

Information Sources

The following electronic databases were searched to identify eligible studies: PsycINFO, Medline, Embase, CINAHL, Web of Science, Psychology and Behavioural Collections, and the Cochrane Library. Studies were also added from initial scoping searches and reference lists within publications were hand-searched for further relevant papers, as recommended by the National Institute for Health and Care Excellence (NICE, 2012).

Search Strategy

The Cochrane database and the International Prospective Register of Systematic Reviews were checked to confirm that the review questions had not yet been investigated. An initial scoping search was conducted to provide an overview of the available literature and relevance to the review questions. The reading of key texts and previous reviews allowed for the generation of further specific search terms (Lee et al., 2019; Levasseur et al., 2010; Tate et al., 2015). Final search terms were refined with consultation and supervision from researchers and clinicians, as recommended by the Cochrane Online Library guidance (Thomas, Kneale, McKenzie, Brennan, & Bhaumik, 2019).

The search terms in Table 2 were used to search for relevant studies across the identified databases. Using these terms in conjunction with Boolean operators and truncation symbols optimised the search strategy (Higgins & Green, 2011). All

databases were searched in December 2019 and all identified citations were exported into the reference management software, Mendeley.

Table 2

Key Search Terms used in Review

Individual Search Terms (Titles and Abstracts)

- 1. "interventio*" OR "progra*" OR "rehabilitation" OR "treatment" AND
- "social participation" OR "participation" OR "social engagement" OR "social integration" OR "re-integration" OR "leisure activities" OR "community activities" OR "social networks"
 AND
- "adul*" OR "adult survivors" OR "adulthood" AND
- 4. "traumatic brain injury" OR "TBI" OR "acquired brain injury" OR "ABI" OR "head injury" OR "brain tumo*" OR "CNS infection" OR "meningitis" OR "encephalitis" AND
- 5. "quality of life" OR "QoL" OR "health related quality of life" OR "HRQoL" OR "subjective well-being" OR "SWB"

Study Selection

All identified articles (titles and abstracts) were initially screened against the outlined PICOS criteria. Studies that were considered appropriate were then included for full text screening to assess their eligibility against the inclusion and exclusion criteria. Six studies were randomly selected at the full text stage to be reviewed by a second-rater. They were asked to make a yes/no decision as to whether the study was to be included or excluded, based on the PICOS criteria. Inclusion criteria was discussed to address any queries. This yielded 100% inter-rater reliability (Cohen's K = 1).

Appraising Quality and Risk of Bias in Studies

As recommended by Moher et al. (2015), the validity and methodology of each full text article was assessed. Consistent with previous systematic reviews exploring interventions conducted with ABI populations (Krasny-Pacini, Chevignard, & Evans, 2014; Mahen, Rous, & Adlam, 2017; Ross, Dorris, & McMillan, 2011), an appraisal checklist was used to assess the quality of quantitative methodology (Mahen et al., 2017). This appraisal tool was developed primarily using the Consolidated Standards of Reporting Trials (CONSORT) guidelines, with further added items specific to ABI that could impact upon the validity of results, such as time since injury (accounting for recovery processes). This checklist has previously been reported to have high interrater reliability (Krasny-Pacini et al., 2014; Mahen et al., 2017). Studies that employed mixed-method designs were assessed on the basis of the most prominent methodology. Accordingly, all included studies were assessed using the same appraisal tool.

Studies were assessed against the 27-item criteria. A score of 1 was awarded if the criterion was met, and 0 if it was not met or not possible to ascertain. Consistent with previous reviews (Krasny-Pacini et al., 2014; Mahen et al., 2017; Ross et al., 2011), studies were considered to be "high" quality if they met 75% of the specified criteria. Studies that met between 50% and 74% were deemed to have "moderate" quality, and those that met less than 50% were considered to be "lower" quality. To assess the reliability of the chosen appraisal checklist, an independent researcher rated three (25%) randomly chosen studies using the same checklist. A comparison of quality scores from both researchers yielded an almost perfect agreement (Cohen's K = .91). The appraisal checklist was not used as an assessment tool to exclude

included studies on the basis of their quality, and all studies contributed towards the overall discussion of evidence.

Data Synthesis

The synthesis is provided in a narrative format due to the variation in included studies, as recommended by the Centre for Reviews and Dissemination (CRD; 2009). Data were extracted from each full text article based on (1) study population; (2) suitable design; (3) intervention description; (4) outcome measures; and (5) results and conclusions regarding intervention efficacy on target outcomes, social participation and QoL.

Where possible, the effect sizes (ES) on target outcomes were also extracted or calculated using Hedges g (Hedges & Vevea, 1998), adapted by Morris and DeShon (2002). Hedges g was calculated as a standard difference between means and has previously been used in research (Cicerone et al., 2008) and other systematic review articles to investigate efficacy of interventions in ABI populations (Krasny-Pacini et al., 2014; Mahen et al., 2017). Calculating ES allows for the exploration of the magnitude of reported statistical significance that exist between and within experimental groups.

ES was interpreted as small when $g \ge .2$, medium when $g \ge .5$, and large when $g \ge .8$ (Cohen, 1988). Figure 1 displays the formulas used for calculating ES (Morris & DeShon 2002). If articles provided insufficient information to be able to calculate ES, the results were analysed on the basis of what was reported. The reporting of ES supported the narrative of the evidence for intervention efficacy. Due to the diversity of studies, intervention type, designs, and rigour, a meta-analysis of the results was not conducted (CRD, 2009).

The formula below was employed for ES calculation in single group pre- and post-intervention research designs:

• ES = (Mpost, exp - Mpre, exp) / SDpre, exp

The formula below was employed for ES calculation in independent group pre- and post-intervention research designs:

ES = [(Mpost, exp - Mpre, exp) / SDpre, exp] - [(Mpost, com - Mpre, com) / SDpre, com]

The formula below was employed for ES calculation in independent group post-intervention designs:

ES = (Mpost, exp – Mpost, com) / SDpost, *pooled

In these formulas, M is the mean, exp is the experimental group, com is the comparison group, pre is the pre-intervention score, post is the post-intervention score, SD is the standard deviation, and * is weighted.

Figure 1. The formulas used for calculating ES (Hedges *g*) for included studies.

Results

The review process and the number of identified and screened articles are detailed in Figure 2. The database search yielded a total of 1084 potentially suitable records. An additional 35 records were added from other sources identified through scoping searches, resulting in a total of 1119 records. After removing duplicates (n=400), 719 articles were screened against the pre-defined PICOS criteria. Articles were excluded following title and abstract screening, leaving 36 records. The remaining full-text studies were assessed for eligibility, of which 12 were included in the review. The extracted information relating to the PICOS criteria, outlined review questions, and critical appraisal is summarised in Table 3 below.

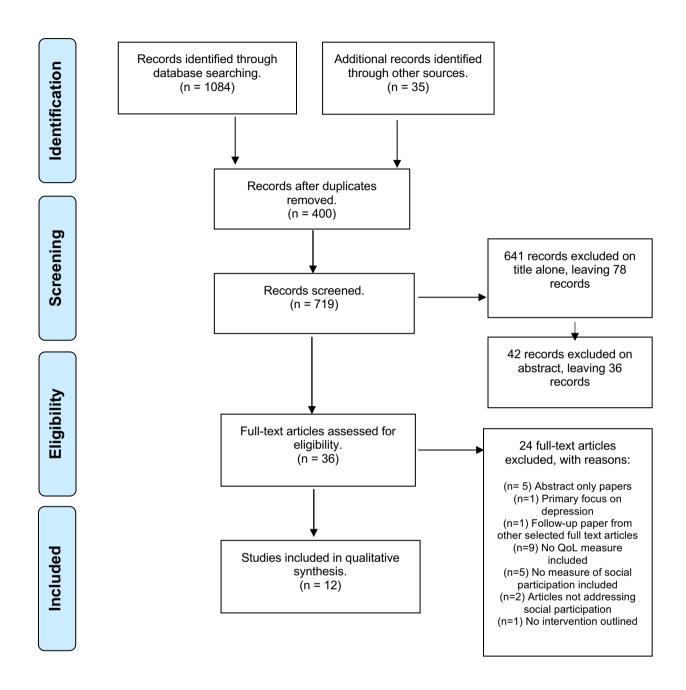


Figure 2. Results of search strategy and screening process for systematic review using PRIMSA flow diagram.

Table 3
Summary of Studies Included for Analysis in Alphabetical Order

No., Authors, and Country	Design	Participants (Pts.) Sample type, n, (mean age), severity of injury (GCS/PTA).	Intervention Summary	Outcome Measures	Main Findings and Conclusion	Critical Appraisal Quality Rating (%)
1. Brands, Bouwens, Gregório, Stapert, & van Heugten (2013). The Netherlands.	Prospective cohort study. Data collected pre (T0), post-intervention (T1), and 6-month follow-up (T2).	ABI (n=26) (44.6 years) ABI aetiologies: Stroke (n=9) TBI (n=10) Haemorrhage (n=4) Tumour (n=1) Infection (n=1) Hypoxia (n=1) Severity not reported. Relatives (n=23) (50.1 years).	A process-oriented neuropsychological rehabilitation group aimed to promote adjustment and meaningful living post-ABI. Group and individual sessions guided by individual goals. Emphasis on group dynamics and process. Relative group focused on psycho-education, emotional adjustment, and expectations. Length of group varied according to individual needs. Mean duration of 8 months, range 2 to 19.5 months. Sessions ran weekly for 1hr 45min.	Participation CIQ HRQoL SA-SIP	There were no significant differences on outcomes between T0 and T1 for pts with ABI. T0 to T1: $CIQ (p = 1)$ $SA-SIP (p = 1)$ No significant differences were identified at 6-month follow-up on both measures (T1 to T2). Participation in the programme did not increase levels of participation or QoL for pts with ABI. The group did have positive effects on the attainment of individual goals across group and individual sessions.	Strengths: Representative sample. Use of validated measures. ABI determined by medical documentation. Intervention described in detail. Inclusion of relatives to support insight and environmental aspects of QoL. Intervention tailored for individual everyday needs. Inclusion of follow-up measures to assess if effects were maintained. Weaknesses: Lack of control group. Effect sizes not provided. Variation in intervention duration and dosage complicates data interpretation.

						Quality rating: Moderate (63%)
2. Brenner, Braden, Bates, Chase, Hancock, Harrison- Felix, Hawley, Morey, Newman, Pretz, & Staniszewski (2012). United States of America.	RCT. Data collected at pre (T0), post-intervention (T1), and 3-month follow-up (T2).	TBI (n=74) (43 years) Pts were randomised into two conditions: (1) intervention (n=37); and (2) waiting list (n=37). Injury severity: PTA mean 148.81 days (control) and 146.91 days (intervention).	A 12-week group health and wellness intervention to improve health promoting behaviours. 12 sessions in total, lasting for 1.5 hours. The structure of each session was to: (1) enhance learning and take advantage of the group process; (2) review concepts and homework; (3) introduce a new health and wellness-related topic; (4) solve problems regarding barriers; and (5) enhance self-efficacy for health promotion behaviours. Pts in the control group did not receive a treatment for 6-months.	Participation PART-O QoL Diener SWL Scale HRQoL SF-12	A significant time-by-treatment interaction was evident on measures of social participation (<i>p</i> < .001) and satisfaction with life (<i>p</i> = 0.22). These were attributed to estimates across time, not treatment. No significant treatment effects were apparent on measures of QoL, HRQoL, and participation. Insufficient information to calculate ES. Efficacy of group health-promotion intervention on outcomes of participation and QoL was not supported.	Strengths: Representative sample. Inclusion of control group. Intention to treat analysis. Use of validated measures. TBI determined by medical documentation. Sample at least 6- months post injury. Weaknesses: Unequal groups pre- intervention. Means and SD not reported for outcomes. Effect sizes not included. Assessors not blind to conditions. Follow-up data not reported. Quality rating: Moderate (74%)
3. Carbonneau, Martineau, Andre, &	A mixed methods, pilot, experimental study.	TBI (n=3) (39.3 years) Severity not	The Leisure Education Programme was designed to foster awareness of, and participation in new meaningful	Participation KAS MPAI-4 LSS	Insufficient information to calculate ES. No statistical analysis conducted.	Strengths: Use of manualised intervention. Use of validated
Dawson (2011).	Data collected at pre (T0) and	reported. Significant others	ways to pursue leisure, build skills in relation to individual leisure	HRQoL SIP	Results reported individually for participant one (P1), two (P2), and three (P3).	measures. Sample at least 6- months post injury.

Canada.	post- intervention (T1), and 1- month follow- up (T2).	(n=2)	pursuits, and increase leisure satisfaction. The programme was offered on a one-to-one basis, and involved 10 weekly 2-hour sessions. As well as the individual sessions, pts were asked to engage in six periods of leisure activities by themselves.		Leisure satisfaction improved for all three pts at T1 and T2. Frequency in leisure participation improved for P1. P2 and P3 level of leisure participation had returned to baseline at T2. P1 reported improvement on the MPAI-4 and SIP at T1 and T2. P2 showed improvement on the SIP at T1, and all measures at T2. P3 showed small improvements on the SIP and MPAI-4 at T1 and T2. Qualitative benefits outlined for pts, such as change in family role, improved leisure confidence and QoL, and development of friendship. Leisure is important for adults with TBI and provides a basis for further research in this area.	Qualitative experiences provided by pts. Weaknesses: Small sample size. Opportunity sample. Information of how TBI was determined not included. Lack of control group. Statistical analysis not conducted. Short follow-up period. Quality rating: Low (41%)
4. Cicerone, Mott, Azulay, & Friel (2004). United States of America.	Non-randomised controlled intervention trial. Data collected pre (T0) and post-intervention (T1).	TBI (n=56) Moderate to severe injury (89% of pts). GCS/PTA data not reported. Pts were split into two conditions: Intensive cognitive rehabilitation programme (ICRP) and standard	ICRP pts received an intensive highly structured cognitive and psychosocial intervention programme. The programme lasted for 16 weeks and was provided in small groups of 5 to 8 pts. The ICRP focused on group and individual cognitive remediation and interpersonal communication skills, as well as group psychotherapy. Interpersonal group process was emphasised.	Participation CIQ HRQoL QCIQ & satisfaction with cognitive functioning (QCOQ Scale).	A significant main effect of time on total CIQ scores was identified (p <.001), with both ICRP and SRP groups improving post-intervention. Pts in the ICRP showed greater improvements on the CIQ from T0 to T1 when compared with SRP pts (p = .021; g = .69; M). ICRP CIQ T0 to T1 (g = 1.13; L). SRP CIQ T0 to T1 (g = .44; S).	Strengths: TBI determined by medical documentation. Representative sample. Intervention described in detail. Use of validated measures. Effect sizes provided. Weaknesses: Some SRP pts less than 6-months post-injury.

rehabilitation programme (SRP).

ICRP (n=27) (37.8 years)

SRP (n=29) (37.1 years).

The ICRP was conducted for 4 days per week, for 5 hours per day. ICRP participants received 15 hours of group and individual therapies per week and 1 day per week for community participation.

SRP pts received less intense standard neurorehabilitation with support of multiple therapeutic disciplines. Treatment content and duration was determined by individual needs. SRP pts engaged in 15 hours per week of treatment.

SRP pts expressed greater satisfaction with community functioning (p =.03, g = -.57; M) and cognitive functioning (nonsignificant) at T1 than ICPR pts. This was attributed to time after injury differences between ICRP (mean 33.9 months) and SRP (mean 4.8 months) pts and level of awareness.

Outcomes on the QCOQ scale were significantly related to post-intervention total on overall CIQ (r_s = .42, p = .001), home integration (r_s = .41, p = .002), and social integration (r_s = .36, p = .007). This relationship was particularly evident in the ICRP group (r_s = .55, p = .005) compared with SRP participants (r_s = .36, p = .051). Authors suggested the role of self-efficacy (satisfaction with functioning) for social participation.

The ICRP indicated significant clinical benefits in social participation for pts with TBI. QoL was not related to social participation, but satisfaction with cognitive functioning was (improved by ICRP). Self-efficacy may play an important role in rehabilitation post-TBI.

Unequal differences between groups preintervention (time since injury a pre-intervention CIQ scores). ES between groups interpreted with caution. Lack of randomisation of pts.
Lack of blinding for pts and therapists.
No longer term follow-up.

Quality rating: Moderate (70%)

S. Cicerone, Mott, Azulay, Sharlow- Galella, Ellmo, Paradise, & Friel (2008). United States of America. ICRP (n=34) (38.7 years) ICRP (n=23) Unknown (n=2) Moderate (n=6) Severe (n=23) Unknown (n=2) Injury severity: Mild (n=6) Severe (n=17) Unknown (n=1) Injury severity: Mid (n=6) Moderate (n=10) Severe (n=17) Unknown (n=1) GCS/PTA data not reported. Same intervention as Cicerone et al. (2004), with additional modules to support cognitive and emotional self-efficacy (supporting interpersonal relationships). Participation CiCQ QoL PQOL The two treatments provided 15 hours per week of therapy for 16 weeks. Pts in the ICRP condition initiated treatment simultaneously in small groups of 5 to 8. The ICRP focused on holistic neurorehabilitation, integrative interventions for cognitive, behavioural, emotional, and interpersonal difficulties. Specific self-evaluation and social problem-solving sessions included. Sessions ended with reflection of group process. Additional modules for supporting denotional self-efficacy (supporting interpersonal relationships). The two treatments provided 15 hours per week of therapy for 16 weeks. Pts in the ICRP condition initiated treatment simultaneously in small groups of 5 to 8. The ICRP focused on holistic neurorehabilitation, integrative interventions for cognitive, behavioural, emotional, and interpersonal relationships). The STD programme was conducted as a comprehensive, inter-disciplinary, day programme. Treatment orientated to specific deficit areas. Pts in this group received a limited amount of group sessions per week (<3 hrs).	There was a significant time by treatment (ICRP vs STD) interaction for overall CIQ ($p=.42$, $g=.60$; M), particularly on the social aspects of the CIQ ($p=.011$, $g=.46$; S), attributed to the gains made by ICRP pts. There was a significant time by treatment interaction on the PQOL ($p=.49$, $g=.30$; S), caused by significant improvements by the ICRP condition T0 to T1 ($p=.004$, $g=.36$; S). The ICRP condition maintained gains from T1 to T2. T2 functioning for ICRP pts remained significantly different from T0 for the CIQ ($p=.018$, $p=.59$; M) and PQOL ($p=.023$, $p=.33$; S), identified through paired sample t tests. Pts in the STD showed significant improvement on the CIQ between T1 and T2 ($p=.044$, $p=.27$; S), attributed to significant improvements made on the productivity sub-scale ($p=.016$, $g=.40$; S). There were no significant changes on PQOL in STD pts from T1 to T2. Pts in the ICRP condition reported valuing peer support and cohesion, fostered through group

6. Douglas, Dyson, & Foreman (2006).
Australia.

Prospective design.

Data collected pre (T0) and postintervention (T1). TBI (n=25) (36.95 years).

All pts reported to have severe TBI (PTA range 48 days to >120 days). Pts participated regularly in leisure activities over a six month period. Activities were facilitated by regional lead agencies who provided disability services in the community (not ABI specific).

Lead agencies coordinated several leisure activities offered within their own service or the local community for pts with TBI.

Pts were split into three groups at post-intervention data collection, representing their level of activity across the 6-month intervention period: (1) no change in activity (NA); (2) no sustained change in activity (NSA); and (3) sustained activity (SA).

The results supported the efficacy of an intensive holistic rehabilitation on outcomes of social participation and QoL for people with TBI.

Participation CIQ

QoL QoL measure

No statistically significant differences were identified across the three groups on outcome measures of social participation (p = .80) or QoL (p = .95) prior to the intervention.

A significant main effect for time (T0 to T1) across the groups was evident (p = .02), attributed to significant differences shown by the SA group (n=7) in social participation between T0 and T1 (p = .013, g = .81; L).

There was no statistically significant effects on measures of QoL. Those within the SA and NSA did show improvements towards significance.

SA pts reported significant improvements in social participation, and non-significant improvements in QoL. SA pts qualitatively reported gains with sense of self and confidence, belonging, and friendship.

Engagement in regular leisure and social activities has the potential to support improvements in social participation and QoL for adults with TBI.

Strengths:

TBI determined by medical documentation. Use of validated outcome measure for participation. Qualitative experiences provided by pts.

Weaknesses:

Inclusion/ exclusion criteria not reported. Volunteer sample. Small sample size. Intervention not described in detail. Dosage of activities not reported. Categorisation of pts post-intervention resulting in sample bias. Lack of control group. QoL measure not validated. Effect sizes not reported. No longer term followup.

Quality rating: Low (44%)

7. Geurtsen, Martina, van Heugten, & Geurts (2008). The Netherlands.	Prospective cohort study. Data collected at pre (T0), post-intervention (T1), and 12 month follow-up (T2).	ABI (n=24) (28.5 years, range 17-51 years) ABI aetiologies: TBI (n=18) Stroke (n=3) Tumour (n=2) Infection (n=1) TBI pts injury severity: GCS mean 5.9 (range 3-8).	The Brain Injury Programme (BIP) aimed to improve community integration through treatment using three modules: (1) independent living (e.g., executing tasks in domestic life), 100 hours per-person; (2) social-emotional (e.g., psychoeducation and social skills to maintain social relationships), 110 hours per-person; and (3) vocational (e.g., work and leisure tasks), 44 hours per-person. Pts received a combination of small group and individual sessions. The intervention aimed to support pts to achieve balance in daily life across family, work, leisure, and social domains. The mean duration of the BIP was 198.9 days (range 112 to 382 days).	Participation CIQ HRQoL EQ-5D EuroQoL Health	Significant time effects (T0 to T2) were evident for CIQ ($p < .001$) and EQ-5D ($p < .001$), but not EuroQoL Health ($p = .183$). T0 to T1: CIQ ($p = .001$, $g = .82$; L) EQ-5D ($p < .001$, $g = -1$; L) EuroQoL Health ($p = .013$, $g = .83$; L). These were maintained at 12-month follow-up. T1 to T2: CIQ ($p = 1$, $g =08$; S) EQ-5D ($p = 1$, $g = .06$; S) EuroQoL Health ($p = 1$, $p = .15$; S) Although a control group was not used, results provided support for the efficacy of a residential community reintegration programme on outcomes of social participation and QoL in adults with ABI.	Strengths: Representative sample. ABI determined through medical documentation. Use of validated outcome measures. Intervention described in detail. Inclusion of follow-up measures to assess if effects were maintained. Evidence of intervention generalisability (vocation and independent living). Weaknesses: Small sample size. Lack of control group. Sub-domains of CIQ not presented. Quality rating: Moderate (66%)
8. Geurtsen, van Heugten, Martina, Rietveld, Meijer, & Geurts (2011). The Netherlands	A prospective cohort study with a 3-month waiting list control and 12-month follow-up. Data collected at inclusion (T0), pre-intervention 3	ABI (n=70) (25.1 years) ABI aetiologies: TBI (n=47) Stroke (n=7) Tumour (n=10) Infection (n=4) Hypoxia (n=2) TBI pts injury severity:	The Brain Integration Programme (BIP). See intervention description for study seven above (Geurtsen et al., 2008). Total intervention time was 254 hours per person. Mean intervention duration was 196.2 days (range 44 to 357 days).	Participation CIQ QoL WHOQOL- BREF HRQoL EQ-5D EuroQoL Health	Data were available for 67 of the pts at T3. No significant differences were identified during the waiting list control period. A significant overall effect of time was identified (<i>p</i> < .001) for all outcome measures together. A significant effect of time (T0 – T3) was identified for each outcome measure.	Strengths: Representative sample. Adequate sample size. ABI determined through medical documentation. Effects of spontaneous recovery accounted for during control period. Use of validated outcome measures. Intervention described in detail.

months later (T1), postintervention (T2) and at 12 month followup (T3).

GCS mean 7.5

(range 3-15).

T0 to T3: CIQ (p < .001, g = .95; L)EQ-5D (p < .001, g = -.36; S) EuroQoL Health (p < .001, g = .58; WHOQOL-BREF overall (p < .001, g = .80; L)

T1 to T2: CIQ (p < .001, g = .58; M) EQ-5D (p = .008, g = -.61; M) EuroQoL Health (p < .001, g = .55; M) WHOQOL-BREF overall (p = .008, g = .52; M). All significant changes

were maintained at follow-up (T3).

T2 to T3: CIQ (p = 1, g = .09; S) EQ-5D (p = .85, g = .30; S) EuroQoL Health (p = .85, g = -.43; S) WHOQOL-BREF overall (p = .97, g= -.23; S).

The intervention was efficacious for improvements in QoL and social participation for adults with ABI.

Inclusion of follow-up measures to assess if effects were maintained. Evidence of intervention generalisability (vocation and independent living).

Weaknesses:

Lack of control group. Sub-domains of CIQ not presented.

Quality rating: Moderate (70%)

9. Hanks, Rapport, Wertheimer, & Koviak (2012). United States of America.	RCT Final data collected 12-months post-intervention.	TBI (n=96) (38.46 years) Significant others (n=62) (40.9 years). Treatment: Mentored TBI (n=47) Injury severity: GCS mean 9.39 Control TBI (n=49) Injury severity: GCS mean 9.80	Pts were randomly allocated to peer mentor or control. As significant others (SO) were included, there were 4 possible groups: (1) TBI mentor and SO mentor (2) TBI mentor and SO no mentor (3) TBI no mentor and SO mentor (4) TBI no mentor and SO no mentor. The mentors and mentees were requested to meet/ talk at least weekly for the first month, biweekly for the next 2 or 3 months, and then monthly for the remainder of the year. The control group was discharged to the community and received the usual socialisation following discharge. Final data collection occurred 12 months after mentoring was completed (24 months from baseline).	Participation CIM HRQoL SF-12	There were no statistically significant differences between TBI groups on measures of participation following the intervention ($p = .35$, $g =19$; S), identified through t test. There was a significant difference on a measure of HRQoL between TBI groups following the intervention ($p = .04$, $g = .42$; S), identified through t test. TBI mentees reported better emotional coping, physical functioning, and less somatic symptoms and less chaotic life styles when compared to controls post-intervention. TBI Mentees qualitatively reported feeling less alone through the support of their mentors. Mentors supported mentees with helpful management of emotions. The programme was reported to be helpful for individuals with TBI for HRQoL when compared to controls. Efficacy cannot be established due to lack of pre and post-intervention data (not collected).	Strengths: Representative sample. Use of control sample. Use of validated outcome measures. Assessors blind to treatment conditions. Intervention described in detail. Mentors had to complete a curriculum of training. Qualitative experiences provided by pts. Effect sizes reported. Weaknesses: Pre and post- intervention data not reported, complicating interpretation of efficacy. Time since injury for pts not reported. Limited intervention dosage. Characteristics of mentors not included. Analysis not suitable to determine efficacy. Poor randomisation process.
						Quality rating: Moderate (74%)

10.	Prospective	ABI (n=12)	A week long, residential,	Participation	Insufficient information to calculate	Strengths:
Mitchell,	design.	(36 years).	intensive, leisure education	LSS	ES.	Intervention described in
Veitch, &			programme called "Pushing the			detail.
Passey	Data collected	ABI aetiologies:	Boundaries".	QoL	Statistically significant	Use of validated
(2014).	pre (T0) and	TBI (n=10)		WHOQOL-	improvements on measures of	outcome measures.
	post (T1)	Non-TBI (n=2)	The intervention programme	BREF	participation and QoL from T0 to	Intervention included
Australia.	intervention,		aimed to provide leisure activities		T1.	individual goal planning.
	and 3-month	Medium to severe	through groups and provided			Qualitative experiences
	follow-up (T2).	ABI (GCS/PTA data	participants with the opportunity to		T0 to T1:	provided by pts.
		not reported).	trial a range of sporting and		LSS $(p = .02)$	
			recreational activities to increase		WHOQOL-BREF environment ($p =$	
			leisure satisfaction within their		.03)	Weaknesses:
			own communities. Intervention			Effect sizes not
			also included sessions on social		Statistically significant	reported.
			communication skills.		improvements on measure of	Means and SD not
					participation and QoL from T0 to	reported.
			Intervention objectives were: (1)		T2.	Lack of control group.
			for participants to trial a range of			Small sample size.
			recreational activities with support		T0 to T2:	Volunteer sample.
			so that they might participate in		LSS (p = .002)	Information of how ABI
			some similar activities within their		WHOQOL-BREF (all domains):	was determined not
			own community; and (2) for		Physical $(p = .008)$	included.
			participants to improve their		Psychological (p = .02)	Short follow-up period.
			communication skills to enable		Social relationships ($p = .02$)	0 - 12
			them to meet new people and		Environment ($p = .01$)	Quality rating: Low
			build friendships in their own			(48%)
			community.			
					Four pts reported that they were	
					participating in leisure activities at	
					home that were more meaningful to	
					them than their original goals.	
					Participation in the programms	
					Participation in the programme resulted in statistically significantly	
					improvements in social participation	
					and QoL 3-months post-	
					intervention.	
					into vention.	

					Findings supported the concept that social participation is important in the lives of adults with ABI.	
11. Rasquin, Bouwers, Dijcks, Winkens, Bakx, & van Heugten (2010). The Netherlands.	A prospective cohort study conducted with repeated measures. Data collected pre (T0) and post-intervention (T1), and 6-month follow-up (T2).	ABI (n=27) Relatives (n=25) (49.5 years total) ABI aetiologies: Stroke (n=9) TBI (n=5) Haemorrhage (n=3) Tumour (n=4) Epilepsy (n=1) Infection (n=2) Thrombosis (n=1) Hypoxia (n=1) Mixed (n=1) Severity not reported.	Group outpatient cognitive rehabilitation programme. Groups had a maximum of 7 pts. Programme lasted for 2.5 hours and ran for 15 weeks. Programme aimed to help pts gain insight into the consequences of brain injury, offer cognitive strategies for daily life, support the learning of social skills, learn how to control emotional reactions, and to enhance self-efficacy.	Participation CIQ HRQoL SA-SIP	No significant effects were identified for QoL at T1 (p = 1) or at T2. No significant differences identified using the CIQ at T1 or at T2. Insufficient information to calculate ES. Although participants attained individual goals, this did not result in higher participation levels or better QoL.	Strengths: Representative sample. Inclusion of follow-up measures to assess if effects were maintained. ABI determined through medical documentation. Use of validated outcome measures. Weaknesses: Data for secondary outcome measures not reported. Effect sizes not reported. Lack of control group. Some pts less than 6- months post-injury. Quality rating: Moderate (56%)
12. Struchen, Davis, Bogaards, Hudler-Hull, Clark, Mazzei, Sander, & Caroselli (2011).	Pilot RCT. Data collected pre (T0) and post-intervention (T1).	TBI (n=41) (31.7 years) Three pts groups: (1) Social peer mentors (SPMs; n=11) (2) peer partners (PPs),treatment group (n=12)	Peer-mentor intervention. SPMs were assessed for mentor suitability and completed extensive training around intervention content. Mentees were randomly assigned into PPs (treatment) or WLPPs (control). SPMs were matched with PPs to facilitate skill-building in the planning of social activities, participate jointly in social events	Participation CHART-SF SAI QoL Diener SWL scale	No statistically significant interaction effects were found for social participation between T0 and T1 (p = .16). Social participation for PPs moved towards significance at T1. No statistically significant interaction or main effects of time and/or group were noted on measures of social network size	Strengths: Representative sample. Use of control sample. Appropriate randomisation of pts. Use of validated outcome measures. Mentors had to complete a curriculum of training. Qualitative experiences provided by pts.

Unites States of America.

(3) waiting list controls (WLPPs) (n=18).

PPs and WLPPs injury severity: GCS mean 6.3 (range 3-15).

within the community, build social networks for PPs, and develop social communication skills through regular contact through face to face meetings or telephone. Mentors were expect to meet with PPs face-to-face, twice per month, over a 3-month period.

social activity level, or satisfaction with social life.

PPs did show non-significant improvements regarding satisfaction with social activities and perceived social support at T1 when compared WLPPs.

PPs reported higher perceived levels of social support than WLPPs at T1 (p < .05, g = .60; M).

No significant main or interaction effects were observed with satisfaction with life (p = .81).

87% of PPs felt that mentors had been helpful for social participation and decreasing loneliness.

Pts reported qualitative benefits for social participation following the peer-mentoring intervention, though not statistically supported.

Weaknesses

Small sample size.
Some pts less than 6-months post-injury.
Limited intervention dosage.
Effect sizes not reported.
Follow-up data not collected.
Pts were not blind to condition.

Quality rating: Moderate (63%)

*Note: GCS = Glasgow Coma Scale (Teasdale & Jennett, 1974), PTA = post-traumatic amnesia. ABI severity classifications: Mild (GCS 13-15; PTA <24 hours), moderate (GCS 9-12; PTA 1-7 days), and severe (GCS 3-8; PTA >7 days). Pts = participants, ABI = acquired brain injury, TBI = traumatic brain injury, QoL = quality of life, HRQoL = health-related quality of life, RCT = randomised controlled trial, SD = standard deviation, ES = effect size, g = Hedge's g, L = large ES, M = medium ES, S = small ES, CIQ = Community Integration Questionnaire (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), SA-SIP = Stroke Adapted Sickness Impact Profile (van Strated et al., 1997), Diener SWL Scale = Diener Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985), SF-12 = The Medical Outcomes Study 12-Item Short-Form Health Survey (Ware, Konsinki, & Keller, 1998), PART-O = The Participation Assessment with Recombined Tools-Objective (Whiteneck et al., 2011), KAS = Katz Adjustment Scale (Katz & Lyerly, 1963), MPAI-4 = Mayo Portland Adaptability Inventory (Malec & Lezak, 2003), LSS = Leisure Satisfaction Scale (Ragheb & Griffith, 1982), SIP = Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gilson, 1981), QCIQ and QCOG = The Quality of Community Integration Questionnaire and satisfaction with cognitive functioning

(Cicerone, Mott, Azulay, & Friel, 2004), PQOL = Perceived Quality of Life Scale (Patrick, Danis, Southerland, & Hong, 1988), QoL measure = a self-rated QoL measure (Hadorn, Sorenson, & Holte, 1995), EQ-SD = EuroQoL (including health visual analogue scale; Dolan, 1997), WHOQOL-BREF = The World Health Organisation Quality of Life Scale Abbreviated (World Health Organisation, 1996), CIM = The Community Integration Measures (McColl, Davies, Carlson, Johnston, & Minnes, 2001), CHART-SF = The Craig Handicap Evaluation and Reporting Technique - Short Form (Craig Hospital Research Department, 1999), SAI = The Social Activity Interview (Struchen et al., 2011).

Characteristics of Included Studies

The included studies recruited a total of 522 participants with ABI (range 3 – 96) and 112 significant others. The most frequently reported aetiology was TBI (studies 2, 3, 4, 5, 6, 9, & 12). Studies reporting an ABI population (1, 7, 8, 10, & 11) included TBI, stroke, tumour, haemorrhage, infection, hypoxia, epilepsy, and sinus thrombosis aetiologies. All participants were adults with a mean age range of 25 to 49.5 years.

All studies utilised interventions that promoted engagement in activities with others. The delivery of the interventions included groups (studies 1, 2, 4, 5, 6, 7, 8, 10, & 11), one-to-one (study 3), and through peer-mentors (studies 9 & 12). Interventions varied in duration and ranged from one to 78 weeks (19.5 months).

All included studies measured outcomes relating to social participation, QoL and/or HRQoL. The review's target outcomes were not always the primary outcomes of the included studies. Measures of social participation included outcomes related to community integration, social inclusion, social activity, and leisure satisfaction. The most frequently used measure of participation was the CIQ (seven of 12). QoL and HRQoL measures explored psychological well-being, social relationships, physical abilities, life participation, health status, and life satisfaction.

Of the 12 studies, four (2, 5, 9, & 12) used RCT designs. One study (study 4) used a non-RCT design. Six studies (1, 6, 7, 8, 10, & 11) employed prospective designs with pre and post-intervention measures, one of which used a waiting list control period (study 8). Study 3 utilised a mixed-method design.

One study (5) was deemed to have high methodological quality and was at lower risk of bias due to appropriate random allocation of participants, blinding of outcome assessors, and consideration of confounders at baseline. A moderate quality

rating was given to eight studies (1, 2, 4, 7, 8, 9, 11, & 12). Three studies (3, 6, & 10) were deemed to have a low overall quality and a higher risk of bias.

Critical Appraisal: Intervention Method and Efficacy on Target Outcomes

Intervention methods included peer-mentoring (studies 9 and 12), community integration (studies 7 and 8), leisure activities (studies 3, 6, and 10), outpatient holistic neuropsychological rehabilitation (studies 1 and 11), intensive holistic cognitive rehabilitation (studies 4 and 5), and health-promotion (study 2). Seven of the 12 studies (4, 5, 6, 7, 8, 9, and 10) found statistically significant differences on at least one target outcome post-intervention. Four of the 12 found statistically significant improvements on both target outcomes from pre to post-intervention (studies 5, 7, 8, and 10).

Peer-mentoring. Studies 9 and 12 utilised peer-mentoring interventions to support social participation and QoL for participants with TBI. A strength of these studies was the use of an RCT design to determine intervention efficacy against a control group. Study 9 identified a significant difference in HRQoL between mentored participants and the control group at 12-months post-intervention. Mentor discussions focused on three areas: (1) emotional well-being; (2) post-TBI QoL; and (3) community integration. Mentees indicated greater physical functioning and emotional coping than controls, and qualitatively reported greater ability to cope and reduced loneliness. However, a significant limitation of study 9 was the omission of pre and post-intervention data, and a time-by-treatment interaction was not investigated to determine intervention efficacy. Thus, identified differences may have already existed between groups pre-intervention. No significant differences in social participation were identified between groups 12-months post-intervention. The intervention dosage (i.e.,

intensity and focus) was reported to be low, with an average of five mentee-mentor sessions and the majority conducted via telephone.

Study 12 did not show efficacy on outcomes of social participation. Reduced intervention dosage was also a limitation of the study, limiting identified efficacy. Half of mentees in study 12 did not achieve the minimum requirement of two in-person mentor sessions per month. Improvements in QoL were not identified post-intervention and mentees reported significantly greater levels of depression. This was attributed to increased self-awareness through mentorship. A similar unintended consequence of mentoring was noted by study 9 in mentored significant others.

Community integration. Study 7 and 8 found the Brain Injury Programme (BIP) to be efficacious on outcomes of social participation, QoL, and HRQoL for adults with ABI, with medium and large ES. The BIP was well described in studies and the intervention 'dosage' per-person was provided. The ES on target outcomes post-intervention in study 7 were substantial given the small sample size, and the effects were maintained at follow-up. Participants also reported improvements relating to employment and living situation at follow-up, suggesting intervention generalisability. A control sample was not used as a comparator and the validity of intervention efficacy could not be fully determined.

Study 8 assessed the BIP using a larger sample size and a 3-month waiting list control period pre-intervention to account for possible spontaneous recovery bias during the intervention period. Significant improvements on target outcomes were identified from pre to post-intervention, and across time; with medium and large ES. Improvements were maintained at follow-up. A lack of control group remained a limitation of the study.

Leisure activities. Studies 3, 6, and 10 used leisure-based interventions to support participants to engage in leisure and group-based activities within their communities. All three studies were deemed to be of low quality and at a higher risk of bias. A limitation was the use of small, volunteer (studies 6 and 10) and opportunity (study 3) samples, increasing sample bias. Study 6 reported significant improvements with large ES on a measure of social participation post-intervention in one participant sub-groups (sustained activity). As participants were clustered into groups according to levels of sustained activity post-intervention, the reported effect is likely to have been influenced by participant motivation. Information on intervention 'dosage', methods, and content was not reported.

Study 10 identified significant improvements on both target outcomes across time for participants with ABI. Participants qualitatively reported benefits from engagement in the residential programme, including increased confidence to build friendships. Although promising, intervention efficacy was interpreted with caution due to the small volunteer sample and lack of control group.

Outpatient holistic neuropsychological rehabilitation. Studies 1 and 11 conducted a weekly outpatient intervention. Though both studies identified significant improvements in individual participant goals, efficacy for the interventions on measures of social participation and QoL was not supported.

Intensive holistic cognitive rehabilitation. Studies 4 and 5 assessed the efficacy of their intensive cognitive rehabilitation programme (ICRP) against a control group receiving standard multidisciplinary neurorehabilitation. A strength of these studies was the inclusion of a control group for comparison of ICRP efficacy. The studies used validated outcome measures and information relating to intervention methods, content, and 'dosage' was provided.

Study 4 identified greater improvements in social participation for the ICRP group (with large ES) post-intervention when compared to controls, but not HRQoL; with controls reporting greater satisfaction with functioning. There was a significant difference between groups pre-intervention (time post-TBI) due to lack of randomisation. Consequently, the authors suggested that ICRP participants were less likely to report greater satisfaction due to greater awareness of difficulties than controls. This bias complicated the interpretation of intervention efficacy. Through a rigorous RCT design, study 5 provided high-quality evidence for the efficacy of the ICRP when compared to the control group. Participants in the ICRP made greater significant improvements on outcomes of social participation (medium ES) and QoL (small ES) than controls. These were maintained at 6-month follow-up. The comprehensiveness and complexity of both interventions was suggested by the authors to have affected the accuracy of ICRP efficacy (enhanced treatment as usual).

Health promotion. Study 2 was the only included study to focus on health promotion. The adapted health and wellness group programme did not show efficacy on secondary outcomes relating to participation and QoL for individuals with TBI. Authors recognised that the randomisation process failed to equate group differences pre-intervention.

Discussion

This review aimed to synthesise evidence for the efficacy of interventions that facilitated social participation on outcomes of social participation and QoL in adult survivors of ABI. A total of 12 studies, utilising a variety of intervention methods were included.

Question One: Efficacy of Interventions on Target Outcomes

Currently, there is limited evidence (four of 12 studies) to support the efficacy of social participatory interventions on outcomes of social participation and QoL. These studies varied in quality, duration, settings, and intervention method. On the basis of the results provided by the methodologically stronger studies (studies 5, 7, and 8) there is support for the efficacy of multifaceted interventions on both target outcomes in adults with ABI. A feature of these interventions was intensity (i.e., 'dosage', duration, and focus). Indeed, the need for neurorehabilitation interventions to be intensive to support efficacy has previously been recognised (Tate et al., 2015). Though intensive, the sample bias in study 10 resulted in caution when interpreting efficacy. Additional studies reporting improvements in social participation post-intervention (4 and 6) were also interpreted cautiously due to risk of bias.

In support of intensity, studies 1 and 11 reported the detriment of their low-intensity interventions on outcomes of social participation and QoL when compared to efficacy of high-intensity interventions (Cicerone et al., 2008). Similarly, studies 9 and 12 recognised the limitations of reduced face-to-face contact and joint outings in their peer-mentoring interventions. The challenging life dynamics (Eames & Wood, 2003), level of motivation, and mobility (Douglas et al., 2006) for individuals post-ABI are recognised barriers for treatment participation that merit further consideration in future

intervention design, alongside wider cultural factors such as social economic status (Ashida et al., 2016) and ethnicity (Tam & Neysmith, 2006) of participants.

The qualitative insights provided by other studies suggested that involvement with others allowed participants to feel less lonely, try new things, and build confidence to develop friendships (studies 6, 9, 10, and 12). Social isolation and loss of friendship is well recognised post-ABI (Bombardier et al., 2010; Flynn et al., 2018), and social-participatory interventions appear to be subjectively beneficial for people with ABI.

Question Two: Does Increased Social Participation Result in Improved QoL?

The findings from studies 5, 7, 8, and 10 identified improvements on both target outcomes post-intervention, which were maintained at follow-up. However, the suggestion that increased meaningful social participation improves QoL (McLean et al., 2014) was not directly tested in these studies, possibly because this was not the primary objective of all reviewed interventions. Though this review question cannot be answered by the included studies, it does suggest direction for future research exploring the possible causal relationship. The findings from the stronger studies (5, 7, and 8) provide an opportunity for secondary data-analysis to explore if post-intervention social participation was a predictor for improvements in QoL at follow-up.

The use of subjective measures of social participation may be more appropriate to evaluate causation than objective measures, because these have shown stronger relationships with measures of QoL (McLean et al., 2014). However, the use of subjective measures for both target outcomes requires careful attention as they may assess the same, or overlapping, constructs; particularly the social domains of QoL. Consequently, determining a causal relationship may be difficult. Future intervention studies exploring causality may benefit from multiple data collections in a sufficient

sample size with appropriate measures, and focus on content that is congruent with participant values and goals (Cicerone et al., 2004; Eriksson et al., 2009).

Question Three: Psychological Processes that Support Social Participation and QoL

Study 4 proposed that perceived self-efficacy supported improvements in social participation and HRQoL. Findings indicated that higher participation was significantly associated with improved satisfaction with cognitive functioning following the ICRP intervention. Indeed, perceived disability and reduced functioning have previously been associated with reduced participation and QoL (Cubis et al., 2018; Gerber et al., 2016). Study 4 suggested that community functioning (objective) and satisfaction with functioning (subjective) were separate aspects of participant experience that must be considered (Cicerone et al., 2004). This differentiation has been recognised in the wider literature (McLean et al., 2014; Piškur et al., 2014). Furthermore, they suggested objective measures of functional outcomes and QoL to be moderated by the subjective meaning and value assigned by participants, facilitated by perceived self-efficacy and satisfaction with performance.

Self-efficacy has previously been defined as an individual's beliefs and judgements around perceived abilities and competency to complete a specific task, or attain a level of achievement (Dijkers, 1997). Additional modules to support self-efficacy were added to the ICRP in study 5. Participants significantly improved on measures of social participation and QoL when compared to controls from pre to post-intervention. This offered support to the suggestion made by study 4. QoL may improve alongside social participation if participants feel confident and competent to engage in activities with others. Thus, enhancing subjective experiences (Cicerone et al., 2008).

Study 12 provided insights into the negative emotional consequences of increased awareness through peer-mentoring. Reduced awareness is common post-ABI (Fleming et al., 1996) and may be protective for HRQoL (Cicerone et al., 2004). Increased awareness through peer-mentoring may negatively affect mood, and subsequently QoL. The association between depression and HRQoL post-ABI has previously been recognised (Goverover et al., 2017). Supporting participants in this regard may be pertinent and clinically beneficial.

Strengths and Limitations of Current Review

To current knowledge, this is the first systematic review of the efficacy of interventions that facilitate social participation within an exclusively ABI population. ABI is a leading cause of disability (Jolliffe et al., 2018) and a number of survivors are admitted for rehabilitation. Social participation and QoL are key outcomes within rehabilitation (BSRM & RCP, 2003), and the synthesis of the available evidence to improve such outcomes may provide helpful insights for rehabilitation professionals and their clients.

Lee et al. (2019) recommended that interventions should focus on community and social activities beyond leisure. The definition of social participation used in this review (Levasseur et al., 2010) allowed for the inclusion of multiple intervention methods that facilitated activities with others, rather than one similar concept (i.e., community integration or leisure). This allowed for comparisons of efficacy to be made across several evidence-based interventions.

There are limitations of grouping studies together to discuss evidence relating to overall social participation, a term that appeared to be scarcely used within the reviewed studies, yet frequently used in the rehabilitation literature (Goverover et al., 2017; McLean et al., 2014). Consequently, included studies may not have explicitly

aimed to improve social participation, as defined in this review. Similarly, the inclusion of a variety of target outcome measures leaves caution around the validity of the review's interpretation of reported improvements relating to social participation. Overall improvements on the social domain of the CIQ may have related to elements of community integration without others, such as shopping or individual leisure activities (Willer et al., 1993). Moreover, as studies 7 and 8 only reported overall CIQ scores, and not the separate domains, inferred improvements in social participation may not have been supported. Reported improvements may have related to engaging in more home or productive activities such as employment, a focus of the BIP.

Finally, whilst the chosen appraisal checklist allowed for wider considerations for intervention quality with ABI populations, it does not ask if pre and post-intervention data was collected. Consequently, study 9 may have received a higher quality rating than what other assessment tools may have provided.

Clinical and Theoretical Implications

Rehabilitation. The results from this review suggest the need for rehabilitation of social participation to be intensive (studies 5, 7, and 8) and meaningful (studies 4 and 5) for individuals with ABI to support improvements in social participation and QoL. Individual goal setting that accounts for personal values is fundamental in rehabilitation (Wilson, 2017). The most suitable intervention method to support outcomes remains unclear due to limited evidence, however, future interventions may benefit from facilitating meaningful activities with others and providing skills to support confidence and continued engagement. Although cautiously interpreted, this might comprise leisure activities (study 10), social skills (studies 7, 8, and 10), modules for self-efficacy (study 5), and ongoing peer-mentoring (studies 9 and 12).

Outcome measures. The variety of included outcome measures relating to social participation highlights the need for the development and validation of a more specific measure in future studies. The CIQ is frequently used in intervention studies with ABI populations, however, only a limited number of items relate to friendship, leisure, and social activity. To work towards a measure of objective and subjective experiences of social participation (Levasseur et al., 2010) for those with ABI, a new measure could explore the number of social activities and the value the person perceives from it (Cicerone et al., 2004). Such a measure, the Social Activity Interview (SAI), was developed by Struchen et al. (2011) and included items around social network size, perceived importance of social activities, and satisfaction with social life.

Self-efficacy. Although limited, there is some evidence to suggest that perceived self-efficacy may support improvements with social participation and QoL post-ABI (studies 4 and 5). The taxonomy proposed by Levasseur et al. (2010) could provide a useful guide and goal-setting framework for rehabilitation professionals to support clients to build confidence and perceived competence to engage meaningfully in social activities with others that fall within the more active levels (four, five, and six).

Recommendations for Future Research

Recommendations are presented in Table 4.

Table 4

Recommendations for Future Research

Recommendations

 Future intervention studies investigating efficacy on outcomes of social participation and QoL might benefit from focusing on content and activities that are meaningful for participants, and providing skills to promote continued engagement and satisfaction with performance (multifaceted).

- To explore the causal relationship between increased social participation and improved QoL, future studies may want to consider using suitable outcome measures and collecting data across several time points post-intervention.
- To develop and validate a specific social participation measure for the ABI population that includes objective and subjective sub-scales (i.e., the SAI).
- Future intervention studies assessing intervention efficacy would benefit from using RCT designs with sufficient sample size.
- Future interventions should be delivered intensively and over a number of months, consistent with previous recommendations (Tate et al., 2015).

Conclusion

Currently, there is limited evidence for the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL for adults with ABI. The varying objectives, quality, and potential bias of the 12 included studies limits the conclusions that can be drawn. Nevertheless, social participatory interventions appear to have objective and subjective benefits for adults post-ABI. Appropriate intervention methods (delivery and focus) to support outcomes is uncertain from the limited literature included in this review. However, the four studies that identified efficacy on both target outcomes used multifaceted and intensive interventions. The suggestion that increased meaningful social participation improved QoL was not tested in the included studies. Future intervention studies exploring this relationship would benefit from rigorous methodology and the use of carefully chosen subjective measures. Rehabilitation of social participation to support social participation and QoL post-ABI may benefit from supporting participants to develop the skills and self-belief needed to actively participate in social activities that are important to them, however, further evidence is needed.

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SOCIAL PARTICIPATION AND QOL IN ADULTS WITH ABI

Appendices

Appendix A: Quality Appraisal Scores for Included Studies

Table A1

Quality Criteria Scores for Included Studies

Criterion/ Study	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	Total
Brands et al. (2013)	1	1	0	1	1	1	1	1	0	1	1	0	1	1	1	1	1	0	1	0	1	0	0	1	0	0	0	17/27
Brenner et al. (2012)	1	1	1	1	1	1	1	1	1	1	0	0	1	1	1	1	0	0	0	0	1	1	1	0	1	1	1	20/27
Carbonneau et al. (2011)	1	0	0	0	0	1	1	0	1	1	1	0	1	0	1	0	0	0	0	0	1	0	0	1	0	0	1	11/27
Cicerone et al. (2004)	1	1	0	1	1	1	1	1	0	0	0	0	1	1	1	1	1	1	1	0	1	1	0	1	1	0	1	19/27
Cicerone et al. (2008)	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	25/27
Douglas et al. (2006)	1	1	0	1	0	1	1	1	0	1	0	0	0	1	1	1	1	0	1	0	0	0	0	0	0	0	0	12/27
Geurtsen et al. (2008)	1	1	0	1	0	1	1	1	1	1	1	0	1	1	1	1	1	0	1	0	1	0	0	1	1	0	0	18/27
Geurtsen et al. (2011)	1	1	0	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	0	1	0	0	0	1	0	0	19/27
Hanks et al. (2012)	1	1	0	1	1	1	1	1	0	0	1	1	1	1	1	0	1	1	1	0	1	1	1	1	1	0	0	20/27
Mitchell et al. (2010)	1	1	0	0	0	1	1	0	0	1	1	0	1	1	1	1	1	0	0	0	1	0	0	0	1	0	0	13/27
Rasquin et al. (2010)	1	1	0	1	0	1	1	0	0	1	1	0	1	1	1	1	1	0	1	0	1	0	0	1	0	0	0	15/27

Struchen et	1	0	0	1	0	1	1	1	0	0	0	0	1	1	1	1	1	0	1	0	1	1	1	1	1	0	1	17/27
al. (2011)																												

SOCIAL PARTICIPATION AND QOL IN ADULTS WITH ABI

Appendix B: Journal of the International Neuropsychological Society Publication

Guidelines

https://www.cambridge.org/core/journals/journal-of-the-international-neuropsychological-society/information/instructions-contributors



SCHOOL OF PSYCHOLOGY DOCTORATE IN CLINICAL PSYCHOLOGY

PAPER TWO: EMPIRICAL PAPER

Improving Peer Relationships for Adolescents with Acquired Brain Injury:

Using Intervention Mapping as a Framework to Identify Targets for Intervention

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Abstract

Background and aims. Adolescence is a time for significant social development, facilitated by successful peer relationships. Those with reduced social skills are at risk of being rejected or victimised by peers, and can face significant emotional ramifications and implications for quality of life (QoL). Peer relationships for adolescents with acquired brain injury (ABI) have been largely under-recognised in the paediatric neuropsychology literature. Previous interventions aiming to improve social skills (needed for peer relationships) in this population have shown inconsistent efficacy and the targets for intervention are unclear. The intervention mapping (IM) framework offers a systematic and iterative protocol for the co-production of interventions through engagement with key stakeholders. This consists of six steps for intervention design, implementation, and evaluation: (1) creating a logic model of the target problem; (2) stating programme objectives; (3) programme design; (4) programme production; (5) implementation plan; and (6) evaluation plan.

This study aimed to: (a) develop a collaborative understanding of peer relationship difficulties for adolescents with ABI; and (b) seek the views of adolescents and other key stakeholders on what might be required to improve peer relationships post-ABI, and what intervention the goals might be. Qualitative methodology was used to support these aims. The findings of this study can inform the co-development of a meaningful intervention to support peer relationships and QoL in adolescents with ABI using the IM protocol in future research.

Method. Consistent with IM protocol, a planning group comprising four ABI clinical-researchers provided consultation at each stage of the study. First, the planning group completed a survey to develop an initial logic model. This is a framework for understanding peer relationship difficulties following ABI, the

determinants (or contributing factors) for these, and the long-term impact on QoL for adolescents. Focus groups and semi-structured interviews were then conducted with four stakeholder groups to develop an in-depth understanding of peer relationship difficulties post-ABI, the impact of these, and the determinants contributing to such difficulties, and to further develop the initial logic model: (1) adolescents with ABI (n=4); (2) parents of adolescents with ABI (n=7); (3) adults who sustained an ABI in adolescence (n=2); and (4) specialist practitioners (n=3). Perspectives were also obtained from stakeholders concerning what might need to change to support peer relationships post-ABI and what the targets for intervention might be. Qualitative data from focus groups and interviews were analysed using thematic analysis.

Results. The analysis of stakeholder conversations yielded 11 themes, grouped into two domains: (1) understanding peer relationship difficulties (e.g., dropped and excluded, a need to belong, restricted independence); and (2) supporting peer relationships (e.g., building understanding, meaningful social connection). The logic model underwent six iterations following planning group and stakeholder feedback. This was provided by stakeholders in the focus groups and interviews, and by planning group members and stakeholders through further member-checking procedures following the analysis.

Conclusions. Adolescents with ABI were reported to experience difficulties with peer relationships. At an important time for social development, peer rejection can increase feelings of isolation, loneliness, shame, and hopelessness. This can have further implications for mental health, peer relationships, and QoL. The individual, psychological, behavioural, and environmental determinants for peer relationship difficulties are broad. A meaningful intervention would need to be multifaceted attempting to build understanding in others, facilitate meaningful social opportunities,

offer early support post-injury, and help manage psychological wellbeing. A primary focus would be to empower adolescents post-ABI. The presented logic model provides a robust understanding of peer relationship difficulties for adolescents with ABI that can be used to guide intervention development in future research.

Introduction

Adolescence represents a time for significant social development (Blakemore, 2008), marking the growth of independence and social identity through peer relationships, group membership, and belonging (Ownsworth, 2014; Tajfel, 1978). Subsequently, adolescents may be more sensitive to peer acceptance and rejection (Steinberg & Morris, 2001).

Successful peer relationships can be protective for mental health and resilience (van Harmelen et al., 2017). Conversely, difficulties with peers can have significant social and emotional ramifications (Anderson et al., 2013), including loneliness, anxiety, and depression (Parker & Asher, 1987). Those with reduced social skills, physical disabilities, and difficulties with mood are at higher risk of peer rejection (King, MacDonald, & Chambers, 2010; Olweus, 1993; Vannatta, Gartstein, Zeller, & Noll, 2009).

Acquired brain injury (ABI) is a leading cause of death and disability worldwide (World Health Organisation, 2006), with an annual incidence rate in England of 400 per 100,000 for children younger than 15 years (Hospital Episode Statistics, 2013). ABI refers to several injury mechanisms that disrupt brain integrity after birth, and can result in persistent physical, cognitive, emotional, social, and behavioural impairments (Anderson, Brown, Newitt, & Hoile, 2011). Common causes of ABI include traumatic brain injury (TBI), caused by falls, assaults, and road traffic accidents; and non-traumatic injuries, caused by stroke, infection, hypoxia, and tumours (Barber et al., 2018).

Children and adolescents with ABI may have difficulties with fatigue, attention (Catroppa, Anderson, Godfrey, & Rosenfeld, 2011), executive functioning (Wade et al., 2010), memory (Mandalis, Kinsella, Ong, & Anderson, 2007), processing speed,

intelligence (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012), communication (Turkstra, Politis, & Forsyth, 2014), social functioning (Greenham et al., 2018), behaviour (Cole et al., 2008), and emotion regulation (Vasa et al., 2015). The often 'hidden' nature of these difficulties (Simpson, Simons, & McFadyen, 2002) can result in limited support and understanding from educational, social, and family environments (Keetley, Radford, & Manning, 2019). Consequently, children and adolescents with ABI may follow a different developmental trajectory to their peers and face secondary consequences for quality of life (QoL) including difficulties with identity, mood, and relationships; alongside future challenges with education, occupation, and criminal justice (Anderson, Brown, & Newitt, 2009; Arroyos-Jurado, Paulsen, Ehly, & Max, 2006; Sariaslan, Sharp, D'Onofrio, Larsson, & Fazel, 2016; Williams, 2012). Research into the social outcomes of adolescents with ABI is expanding (Tousignant et al., 2018; Sirois et al., 2019), however, there is a scarcity of research exploring the intricacies of peer dynamics, which remain poorly understood.

To understand the determinants (or factors) that influence peer relationships following ABI, the underlying processes for adequate social functioning must be considered. The Socio-Cognitive Integration of Abilities Model (SOCIAL; Beauchamp & Anderson, 2010; Anderson & Beauchamp, 2012) offers a theoretical biopsychosocial framework to understand the development of the social skills needed to build and maintain peer relationships throughout childhood and adolescence (Figure 1). The model is supported by empirical evidence of social dysfunction (disorders that are social in nature) in three clinical populations; autism spectrum disorder, schizophrenia, and TBI.

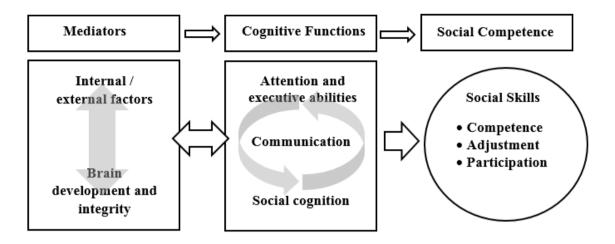


Figure 1. A version of the SOCIAL model re-created with the original author's permission (Beauchamp & Anderson, 2010).

The SOCIAL model assumes that social skills develop in the context of typical brain maturation within a supportive family and social environment. The model outlines the mediators and cognitive determinants (or functions) that can shape and facilitate successful social skills. Difficulties with social skills are suggested to result from disruption in the development or function of these mediators and determinants (Table 1).

Table 1

Mediators and Cognitive Determinants Outlined by the SOCIAL Model

Mediators and Cognitive Determinants	Description
Internal and external factors	Inclusion of genetics, temperament, personality, values, attributes. External factors relate to environment such as social economic status, social interactions, family environment, culture, and activities.
Brain development and integrity	The development of the social brain network and brain maturation.
Attention/ executive function	Sustaining attention to evaluate a situation and consider suitable actions with adequate processing speed. Ability to think flexibly and rationally to perform goal directed behaviour. Ability to self-monitor progress and inhibit responses.
Social cognition	Understanding social information through theory of mind, perspective taking, moral reasoning, and emotional recognition.
Communication	Utilisation of gestures, comprehension and production of language. Understanding of non-linguistic signals, such as volume, intonation, pitch (for sarcasm, and humour).

In the model, social skills encompass three social constructs. Social competence refers to the child's coordination of multiple sensory processes and resources in interactions to meet social demands (Anderson et al., 2013; Yeates et al., 2007), allowing for the development and maintenance of peer relationships over time (Iarocci, Yager, & Elfers, 2007). Social adjustment is defined as the degree to which children can adapt their social behaviour to perform competently (Crick & Dodge, 1994). Finally, social participation encompasses the number and quality of valued activities a child engages in with others in social environments (Fougeyrollas et al., 1998; Wade et al., 2018).

Neural correlates associated with the 'social brain' include the anterior cingulate, superior temporal, and ventromedial, orbital, and dorsolateral prefrontal

cortex (Blakemore, 2008; Garrigan, Adlam, & Langdon, 2016). These areas undergo significant development throughout adolescence and are the most vulnerable in brain injury, particularly TBI (Yeates et al., 2007).

Children and adolescents with TBI have been reported to have difficulties with theory of mind (Turkstra, Dixon, & Baker, 2004), empathy (Dennis et al., 2013), and social participation, competence, and adjustment (Anderson et al., 2013; Sirois et al., 2019; Yeates et al., 2014). Yeates et al. (2012) found that children with TBI (8 to 13 years) reported higher peer rejection-victimisation than those with orthopaedic injuries, and were less likely to have mutual friendships. The psychological difficulties associated with peer rejection may be protected against if children and adolescents with ABI have at least one friend (Heverly-Fitt et al., 2014).

There are a limited number of intervention studies aiming to improve social skills in adolescents with ABI. Wade et al. (2018) piloted an app-based peer coaching intervention to help adolescents (14 to 22 years) attain social participation goals. Post-intervention, participants reported higher levels of confidence in their social participation, however, did not rate the programme as very useful overall.

Barrera et al. (2018) conducted an RCT to explore the efficacy of a social skills intervention on outcomes of social competence and QoL in young brain tumour survivors (8 to 16 years). This was an eight week group-based intervention and included topics such as friendship making, managing bullying, conflict resolution, and empathy. Those in the experimental group showed significant improvements in self-rated empathy scores when compared to control participants. However, no intervention effect was observed in parent and teaching ratings of empathy, or on outcomes of QoL.

In a systematic review conducted with a non-ABI population, Andrews, Falkmer, and Girdler (2015) found strong evidence for improving community participation (including peer relationships), self-esteem, and QoL in child and adolescents with neurodevelopmental conditions. The authors recommended that participants should complete interventions with typically developing peers, and that future interventions should facilitate friendships alongside recreational participation and work on both individual (social skills) and environmental (community support) factors to support participation.

In summary, research within paediatric neuropsychology is beginning to investigate the social skills needed for peer relationships post-ABI. Currently, targets for intervention remain unclear and intervention efficacy is inconsistent. Reviewed evidence for improving peer relationships has used non-ABI populations (Andrews et al., 2015). The additional difficulties associated with ABI, such as loss of identity (Ownsworth, 2014), understanding from others (Keetley et al., 2019), and 'hidden' difficulties (Simpson et al., 2002), and their impact on peer relationships remain largely unknown.

There is a rationale to work with stakeholders to understand the complexities of peer relationship difficulties for adolescents with ABI, the impact of these, and what might be needed to improve peer relationships. This 'bottom up' approach would allow for the co-development of a meaningful intervention to support peer relationships and QoL post-ABI, and can provide insights into the intervention priorities for stakeholders. Indeed, interpersonal relationships have previously been reported to be the highest priority for adolescents with TBI (Sirois, Boucher, & Lepage, 2014).

The Medical Research Council (MRC) recently published guidelines for the development of interventions to promote worthwhile effects (MRC, 2019). In this

process, existing evidence for intervention should be considered and relevant theories identified or developed. Furthermore, to promote meaningfulness and clarity around intervention aims, the development process can involve collaboration with experts, community members, and other key stakeholders to firstly understand the target problem for intervention and its determinants (Fernandez, Ruiter, Markham, & Kok, 2019; Kok et al., 2015).

In line with MRC guidelines, the intervention mapping (IM) framework (Bartholomew-Eldridge et al., 2016) offers a structured and iterative protocol that guides the design of health promotion interventions. This comprises six steps (Table A1; Appendix A) which provide a map for intervention design, supported by theoretical and empirical knowledge (O'Connor, Blewitt, Nolan, & Skouteris, 2018). Steps one to four focus on the development of the intervention. Step five centres on the implementation of the intervention, and step six evaluates the intervention and its implementation (Fernandez et al., 2019).

A logic model is developed in step one, providing a framework to describe and understand the target problem for intervention, its impact on QoL, and its determinants. An environmental approach is used to identify determinants at an individual, community, and social level. This process includes: (1) involving stakeholders; (2) searching empirical literature to identify determinants of behaviour; (3) identifying theories on determinants; and (4) conducting research to explore unanswered questions (Fernandez et al., 2019).

IM employs community-based participation and co-design of interventions through systematic engagement with stakeholders who will benefit from participation, such as service users and practitioners. Stakeholders are engaged in every step to promote equity in decision-making. This ensures that the intervention suits population

need and context (Fernandez et al., 2019). IM has previously been utilised for improving social networks for diabetes management in minority families (Vissenberg et al., 2017), and communication between hospital staff and disabled children (Gumm et al., 2017).

The efficacy of interventions to improve social participation and QoL in adults with ABI has been suggested to be supported by the meaning and value of the intervention attributed by participants (Ankrett, 2020). Qualitative methodology is well suited for the collection and exploration of stakeholder experiences of peer relationship difficulties for adolescents with ABI, and what they think is needed to improve them. This methodology can consider what is meaningful to stakeholders and explore the heterogeneity of experiences. These experiences can inform the gap within the paediatric neuropsychology literature, and provide insights for the development of a logic model (step one) for the future design of a meaningful intervention using the IM protocol. Findings may also provide further insights into the determinants for social skill difficulties outlined by the SOCIAL model. The development of relevant theories for intervention design is recommended by the MRC (2019).

Aims and Research Questions

This study aimed to: (a) develop a collaborative understanding of peer relationships for adolescents with ABI; and (b) to seek the views of adolescents and other key stakeholders on what might be needed to improve them, and what the intervention goals might be. Due to financial and time limitations of the Doctorate in Clinical Psychology (DClinPsy), this study's qualitative methodology was informed by

the IM protocol, rather than prescriptive to it. Accordingly, focus group and interview schedules were developed with guidance from IM and the SOCIAL model.

For this study, *peer relationships* comprises relationships of varying quality (Heverly-Fitt et al., 2014), including negative (victimisation), neutral, and positive (friendships). Given the potentially ambiguous meaning of peer relationships for stakeholders, 'friendships' was encouraged for accessibility. *Stakeholders* describes participant groups that would benefit from the intervention (i.e., service users and providers). The following research questions (RQs) were proposed:

- 1) What are peer relationships like for adolescents with ABI, as described by stakeholders?
- 2) What do stakeholders believe the key determinants for peer relationship difficulties in adolescence to be following ABI?
- 3) What do stakeholders think needs to change to improve peer relationships for adolescents with ABI?
- 4) What do stakeholders think the intervention goals should be?

Methodology

Design

Qualitative methodology was employed utilising both focus groups and interviews. Thematic analysis (TA; Braun & Clarke, 2006; 2013) was the chosen method of data analysis as the study endeavoured to identify commonalities within stakeholder experiences and perspectives. Through TA, the researcher systematically identifies the salient themes or patterns of meaning that emerge from data items, alongside researcher reflexivity and judgement, which are then compared across the

data set. Themes are not 'discovered' but actively crafted to capture something important within the data that is relevant to the RQs (Braun & Clarke, 2006; 2016; 2019; Joffe, 2012).

Though the methodology seeks to understand the experiences of the adolescent ABI population, there is limited research into the topic area, and the depth, exploration, and interpretation of individual meaning was not required at this stage. Accordingly, TA was chosen over interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009).

Participants

Planning group. In line with IM protocol, a planning group was established comprising four clinical-researchers within the field of neuropsychology who provided consultation at various stages of the study. Members were contacted individually and invited to participate.

Stakeholder groups. Purposive sampling was used to recruit stakeholder participants who had experience of peer relationships for adolescents with ABI. Four stakeholder groups were invited to participate: (1) adolescents with ABI (12-17 years); (2) parents of adolescents with ABI; (3) adults who sustained an ABI in adolescence; and (4) practitioners working with adolescents with ABI. Both focus groups and interviews were employed due to time restrictions and the difficulties encountered when recruiting this population. Interviews allowed for increased breadth of recruitment.

Recruitment strategy. The study was advertised by charity organisations using a recruitment poster which was shared on social media. Potential stakeholders were asked to contact the researcher via email or through the study's webpage. A consent to contact form (Appendix B), participant information sheet (Appendices C to

H), and consent to participate form (Appendix I) were then sent for completion. A total of 27 potential stakeholders expressed interest in the study, of which 16 consented to participate (Tables 2, 3, & 4). To protect confidentiality, all identifiable information has been removed and all names used are pseudonyms.

Table 2

Parent and Adolescent Stakeholders

Parent	Adolescent	Adolescent Age (years)	Age at Injury	Type of ABI	Data Collection Method
Harriet Martin	Jessica	13	<1 month	Stroke	Focus group
Charlotte	Sarah	13	4 years	Infection	Focus group
Carol	Beth	13	10 years	ТВІ	Focus group
Lucy	Luke	13	8 years	Haemorrhage	Joint interview
Kelly	Did not participate	14	12 years	TBI	Interview
Shirley	Did not participate	15	12 years	TBI	Interview

Table 3

Adults with ABI Stakeholders

Adult with ABI	Age (years)	Age at Injury (years)	Type of ABI	Data Collection Method
Louise	27	13	Stroke	Interview
Ben	41	16	TBI	Interview

Table 4

Practitioner Stakeholders

Practitioner	Occupation	Years of ABI experience	Data Collection Method
Hannah	ABI Co-ordinator	4.5 years	Interview
Ella	Educational Psychologist	>5 years	Interview
Jackie	Occupational Therapist	>17 years	Interview

Ethical Considerations

Ethical approval was granted by the School of Psychology Research Committee at the University of Exeter (Appendix J). Contact was made with potential stakeholder participants upon completion of consent to contact forms. Stakeholders were required to read and sign a consent form prior to their participation. Confidentiality and anonymity procedures were reiterated within the focus groups and interviews. Stakeholders were informed when confidentiality may be broken in the interest of safety.

Procedure and Data Collection

Stage one: Planning group survey. Planning group members were sent a survey to complete comprising open-ended questions seeking perspectives in line with the RQs (Appendix K). Their responses were analysed separately to inform the initial development of the logic model of peer relationship difficulties (Appendix L) for stakeholder feedback. The logic model was created using the multifactorial precede approach. Here, the target problem for intervention, and its impact upon QoL, is understood to be influenced by individual and environmental determinants. In contrast to the traditional use of logic models (i.e., input and output), the logic model used by

IM provides a visual representation of possible influential determinants for the target problem, and the relationships between them. These derive from stakeholder experiences and perspectives, and are used to identify meaningful targets for intervention.

Stage two: Stakeholder focus groups. Two focus groups were held at the University of Exeter. Parents and adolescents with ABI participated in separate focus groups to promote homogeneity within each group. These were facilitated by two researchers who moderated group discussions around the topic areas, guided by a focus group schedule (Appendix M). The moderator role was maintained by facilitating group discussions and allowing each stakeholder to speak, rather than asking questions for a direct response (Braun & Clarke, 2013).

The topics for discussion included: (a) experiences of friendships for adolescents with ABI; (b) the difficulties associated with ABI and the impact of these on friendships; (c) educational, social, and community understanding of ABI; (d) psychological changes following ABI and the impact on friendships; (e) behavioural changes following ABI; (f) feedback on the planning group logic model of peer relationship difficulties; (g) what change is needed to improve peer relationships; and (h) perspectives on intervention design, methods, and goals. Additional prompts were included to probe for further discussion, if required. Focus groups lasted between 55 and 90 minutes.

The focus group schedule was piloted with four adolescents without ABI to explore the clarity and meaningfulness of the questions, and to observe how adolescents responded. This supported the amendment of the schedule following feedback and researcher reflections (Appendix N). A question regarding the nature of ABI was removed. This was due to time limitations within the focus groups and the

relevance of the question to the outlined RQs. Additional amendments included the modification of terms (i.e., cognition to thinking, and peer relationships to friendships), and including examples of changes in thinking, mood, and behaviour to support topic discussions. Feedback from the pilot group suggested that the topic areas were understandable and suitable for adolescents.

Stage two continued: Stakeholder interviews. Interviews were completed face-to-face or via telephone or Skype, depending on stakeholder preference and location. These were completed by the researcher and guided by an amended version of the focus group schedule to protect consistency of topic conversations. Interviews lasted between 50 and 110 minutes. The schedule was piloted with a psychological practitioner prior to interviews.

Transcription. All focus groups and interviews were audio-recorded and transcribed verbatim. Transcription services were required for the three data items, the remaining seven items were transcribed by the researcher. The data set was listened to prior to transcription, supporting researcher immersion. Researcher reflections and notes were made during focus groups, interviews, and data immersion.

Data Analysis

It was recognised that the type of data collected from focus groups and interviews differed. Within focus groups, stakeholders engaged in interactional discussions and were able to build on the perspectives of others. This allowed for themes to be built upon by the group, as well as for conflict of opinion to be shared. In contrast, interviews provided a question and response conversation between the researcher and the stakeholder. Due to time limitations and limited focus group data, the data were analysed collectively. This allowed for similar emergent themes from the two data collection methods to be analysed and further explored.

Transcripts were read and re-read (Braun & Clarke, 2006; 2013). Initial thoughts and codes were recorded prior to the analysis. Data were analysed using NVivo qualitative software (QSR International) through inductive TA. This bottom-up approach allowed for codes and themes to emerge from what was communicated in the data. Although questions were guided by theory (IM and SOCIAL), apparent themes within the analysis were data driven and naturalistically occurring (Joffe, 2012). This allowed the researcher to be open to new emerging concepts within the field of research. To ensure fidelity to the methodology, data analysis was completed following detailed guidance (Table 5) outlined by Braun and Clarke (2006; 2013).

Table 5
Steps for Thematic Analysis (Braun & Clarke, 2006)

Step	Description
Familiarisation with the data	Transcribing, reading, and re-reading data. Forming initial ideas.
2. Generating initial codes	Systematically working through whole data sets to produce initial codes to identify features of relevant data.
3. Searching for themes	Sorting codes into possible overarching themes and sub-themes.
4. Reviewing themes	Checking if themes work and are coherent with coded extracts.
5. Naming and defining themes	Refining each theme and defining the story the analysis tells.
6. Producing the report	Final analysis of data extracts in line with the outline research questions and literature. Producing and report of the analysis.

Transcripts were systematically and iteratively coded to identify prominent themes which were relevant to the RQs. A complete coding process was utilised and all relevant data were coded (Braun & Clarke, 2013). This was completed by systematically working through whole data items. Codes were then examined and reviewed to inform key themes. This was a continuous process until no new codes or themes were identified.

The data analysed from stakeholder focus groups and interviews informed the first revision of the logic model of peer relationship difficulties, consistent with IM methodology. In this process, the data from communicated stakeholder experiences (i.e., codes) were organised by the categories within the logic model (i.e., determinants, target problem, and impact on QoL). These categories were consistent with some of the pre-determined topics for discussion within the focus groups and interviews to support the outlined RQs. Organising the data according to the logic model categories provided a visual representation of the possible relationships between different parts of the data. This supported the development of themes to explore and interpret stakeholder experiences and perspectives, and how they connected to other themes.

Credibility Checks

To ensure that the analysis was trustworthy (Nowell, Norris, White, & Moules, 2017), a number of credibility checks were utilised. There was prolonged engagement with the data, including multiple rounds of analysis and several researcher transcriptions. A reflective journal was used to note down thoughts and assumptions, which were regularly reviewed during the research process to support researcher reflexivity. Analytic processes were discussed amongst peers and codes were

reviewed by two independent researchers through the sharing and critical discussion of two coded transcripts.

Member checking procedures were used to gain feedback on emerging themes to encourage trustworthiness of the interpretations (Braun & Clarke, 2013). A summary of themes (Appendix O) and the revised logic model of peer relationship difficulties were sent to stakeholders with a request to send their feedback to the researcher via email. Stakeholders were asked to comment and reflect on the 'fit' between the interpretations made and their discussed experiences, and the relevance of the logic model to their own experiences. These were also shared at a local ABI parent group for feedback on accessibility of information and relevance of the logic model of peer relationship difficulties. Feedback from the stakeholders that were able to provide feedback was enthusiastic, with parents reporting a feeling of relief that their child's complex experiences had been captured, understood, and presented within the themes and logic model. No inappropriate interpretations were reported by stakeholders and the decision was made to cease member checking procedures.

Epistemology and Researcher Reflexivity

To promote credibility, qualitative research requires a disclosure from the researcher around epistemological perspective, experience, assumptions, and biases that may influence analytic conclusions (Braun & Clarke, 2013; Joffe, 2012; Yardley, 2000). This study adopted a social constructionist position. Here, it was assumed that knowledge about the experience of peer relationship difficulties for adolescents with ABI is subjective and socially constructed by those who experience these, as well as by those who aim to understand these difficulties (Schwandt, 2003). From this position, knowledge was accessed and constructed through personal accounts and perspectives, described through language, and influenced by social contexts (Braun

& Clarke, 2013). Thus, the knowledge and experiences of peer relationship difficulties described in this study were constructed by the stakeholders and the researcher throughout the research process.

Reflexivity refers to the researcher's critical self-evaluation of their role and position within the research process and the creation of knowledge (Bradbury-Jones, 2007). Accordingly, it was important to consider the role of myself, the researcher, in the construction of data. Here, I acknowledge a number of factors that influenced the analysis. These became apparent through the research process, supported by discussions with my supervisors and peer researchers regarding my motivations for the research.

I am a white male completing a DClinPsy thesis study. My personal reasons for conducting this research came from a multitude of personal and clinical experiences. I have personal experiences of peer relationship difficulties in the context of a physical health condition. Furthermore, during adolescence, I witnessed a friend's involvement in a road traffic accident, and subsequently had experience of being a supportive peer to an adolescent with an ABI. Finally, I have worked therapeutically with children, adolescents, adults, and families following ABI, many of whom experienced peer relationship difficulties post-injury. Accordingly, I hold multiple perspectives in relation to this study; as an adolescent with a health condition, as a friend of an adolescent with an ABI, and as a clinician. I have continuously considered these throughout the analysis, alongside the potential biases that are unique to me.

Discussions with peer researchers and research supervisors, alongside the keeping of a reflective journal, surfaced my assumptions when approaching the analysis. These included the assumptions that adolescents with ABI want to be treated as normal, peers find it difficult to understand ABI, and that successful peer

relationships are a priority for adolescents. I regularly reviewed my reflections during the analysis and discussed these with peer researchers and supervisors, and the impact of these upon the analysis. For example, it was important for me to be mindful of not just attending to stakeholder experiences that matched my own. Similarly, there was a need for me to notice and manage my own position within the interpretations of the themes, and to consider if research themes and ideas were supported by the data set. The awareness of my preconceptions helped me to manage my subjectivity in the research process through an awareness of my own position. This also supported me to attend openly to stakeholder experiences (Starks & Trinidad, 2007) and for new themes to emerge.

Results

Themes

The analysis from stakeholder accounts yielded 11 themes (Table 6) organised into two domains: (1) understanding peer relationships difficulties (RQ one and two); and (2) improving peer relationships (RQ three and four). Some presented data excerpts have been modified to remove superfluous information that did not affect the overall meaning (Braun & Clarke, 2013; Sandelowski, 1994b). For the purpose of the results, *adolescents* refers to those with ABI, and *peers* and *friends* is used for non-injured adolescents.

Table 6

Domains and Themes

Domains	The	Themes		
1.0 Understanding Peer	1.1	Dropped and Excluded		
Relationships	1.2	Isolated and Alone		
Difficulties	1.3	A Need to Belong		
	1.4	No one Understands		
	1.5	Restricted Independence at a Time for		
		Growth		
	1.6	Loss of Past-Self		
	1.7	Challenges with Acquired Status		
2.0 Improving Peer	2.1	Building Understanding		
2.0 improving Feel		G		
Relationships	2.2	Meaningful Social Connection		
	2.3	Support for the Journey		
	2.4	Empowerment		

1.0 Understanding Peer Relationship Difficulties

The following themes capture stakeholder understandings of peer relationship difficulties for adolescents and the key determinants that contribute to these.

1.1 Dropped and Excluded

A pervasive sense of loss was portrayed by all stakeholders when describing friendships for adolescents. Parents and practitioners spoke particularly of the hardships adolescents experienced when attempting to maintain or re-integrate into friendship groups post-injury. Beth described these losses as feeling "dropped" by peers, depicting a powerful and emotive image associated with this loss.

"I have only got three friends because all the friends I seem to make keep on dropping me and being horrible." (Beth, adolescent)

"I could deal with the fact that I had a brain injury. It was losing all the friends that I couldn't deal with." (Louise, adult)

A common determinant for this loss emerged where adolescents 'drifted' from friends whilst recovering from injury. Consequently, adolescents felt left behind by peers, as they continued in their social development outside of school.

"You're sick all the time which means you're off sick even more than you already were, so things go on and people develop friendships in school, and you're missing it all. I had a best friend when I fell ill and I came back after not being sick and she'd made a new best friend." (Louise, adult)

Parents and practitioners emphasised the rejection and exclusion that adolescents can experience from peers. This appeared to result from peer frustration towards acquired cognitive and behavioural difficulties, such as impulsivity and forgetfulness. Being perceived as weird appeared frequently within the data, capturing the negative label that adolescents can attract when returning to school whilst navigating acquired difficulties. For example, difficulties interpreting social cues (social cognition) may result in inappropriate responses or behaviours. Peers may find this difficult to comprehend due to the often 'hidden' nature of ABI, and consequently find adolescents undesirable to be around at a time of increased sensitivity to peer acceptance.

"...they don't want to be the one who hangs out with the one who's just a bit weird." (Hannah, practitioner)

"When I am trying to be sarcastic, my voice doesn't sound it at all so people just think I am being really weird. I sometimes take people seriously and then they will be like, 'It was a joke,'" (Beth, adolescent)

1.2 Isolated and Alone

Isolation for adolescents was felt to be a significant consequence of exclusion or victimisation from peers. Parents spoke of their children subsequently becoming dependent on the family or withdrawing onto online platforms. This perpetuated feelings of isolation. Kelly spoke of her son's world becoming increasingly "insular and narrow", and other parents shared their concerns for their children's futures.

"...they do become so socially isolated they look more and more to the family, they spend more time by themselves or with adults, they lose their ability to act with age appropriate peers, the peers move on with everything" (Lucy, parent).

1.3 A Need to Belong

The importance of connection and belonging in adolescence was acknowledged by adult-aged stakeholders, recognising this to be a basic human need. Sarah spoke of a best friend being there for emotional support. Without this, adolescence was reported to be an extremely difficult time to be alone.

"You need to have a community in which you feel you belong, other than your family, other than mum and dad." (Charlotte, parent)

"Somebody who is nice to you, supports you if you are upset, makes you feel happy." (Sarah, adolescent)

Successful peer relationships were felt to be important for psychological wellbeing by some stakeholders. Louise powerfully shared a strong preference for successful peer relationships over academic performance. Parents suggested that this need was overlooked by educational environments primarily focusing on academic achievement.

"I wouldn't have cared if I got my GCSE's as long as I still had my friends at school. I would rather I had peer interventions from psychologists at school than I had for educational stuff. I would rather I left school with no GCSE's and didn't get bullied." (Louise, adult)

Parents, practitioners, and adults described a sense of desperation for adolescents to not be perceived as different by their peers. Charlotte, a parent, described how adolescents want to fit in and be accepted by their friends.

"...all they desperately want is to fit in and be, not super popular, but have a little crew. No, just a have normal crew of kids that are the same as them, and that are accepting of them." (Charlotte, parent)

Considering this, parents spoke of the differences in their treatment priorities compared to their children's. Shirley, a parent, shared her desire for her daughter to receive support for her cognitive difficulties in school, yet spoke of her daughter's reluctance through fear of appearing different. Other parents echoed this.

"Kids want to be normal as a teenager. They don't want to stand out, and by having some form of injury [...] you want to be as normal as possible and I think that's quite hard." (Carol, parent)

Through wanting to be part of something, parents spoke of how adolescents adjusted their friendship preferences post-ABI. Kelly and Lucy described how their children began to connect with peers who had similar educational and social challenges. Though this strategy supported social competence, it felt as though adolescents had limited choice in this adaptation. This appeared to subsequently impact upon social status, with practitioners describing adolescents as being placed into the "special educational needs group" in the minds of their peers and resulting in further exclusion.

"...some of his friends are with him because they are the ones who find the playground stressful as well." (Lucy, parent)

It emerged that a desire to belong can increase vulnerability from others. Adolescents were reported to become susceptible to undesirable social influences in an attempt to connect with others. Vulnerabilities can be further compounded by difficulties with social cognition and understanding the intentions of others. Shirley

shared concerns for her daughter's safety in this regard. Adolescents may also undertake a new role of being comical, entertaining, or useful to a new group of peers, increasing risk of exploitation from peers encouraging the provocation of teachers or engagement in criminal behaviour.

"Her trust in people and just believing everything everybody says. She doesn't seem to have that little thing inside to say, "Hang on a minute, that's not quite right", she doesn't have that." (Shirley, parent)

"...they're very keen to be part of something. So, they might get drawn into activities that are inadvisable or down-right dangerous, just in an attempt to be part of the group." (Jackie, practitioner).

1.4 No One Understands

A powerful theme for peer difficulties surfaced from stakeholder accounts surrounding the lack of understanding about ABI, and the associated assumptions and stigma. All stakeholder groups felt that others misunderstood ABI and its implications. This included peers, but also parents of peers, teachers, and the wider community. This incomprehension was recognised to be influenced by the 'hidden' difficulties associated with ABI in contrast to a physical injury or disability, and adolescents talked about a lack of support at school.

"They don't tell kids that this person has a brain injury or stop bullying them.

They don't say anything about me, like how to treat me. It is horrible." (Sarah, adolescent)

"I came back looking the exact same, so it was like nothing had happened."

(Louise, adult)

Parents spoke of the assumptions and stigma their children experienced. There was frequent reference to peers perceiving difficulties as non-existent, or used as a mechanism to miss school or receive special attention. Parents described often 'battling' with schools and other parents in an effort to 'prove' their children's difficulties. This reflected the challenges within the adolescent's educational and social environment that impacted upon relationships with peers. Some stakeholders, however, reported positive experiences with friends despite a lack of understanding.

"...we've got parents who are very much like, "Oh, she's just making a drama," or "Just pull yourself together," or "Is she really dizzy?" and "Does she just not want to be at school?." (Charlotte, parent)

"My few good friends that I have got are really understanding. I don't think they fully understand what is happening, but they are really supportive and they will help me." (Beth, adolescent)

1.5 Restricted Independence at a Time for Growth

Parents, practitioners, and adults with ABI suggested that adolescents are restricted in their opportunities for typical peer interaction, contributing to difficulties with peer relationships. This was particularly apparent for adolescents who sustained severe injuries, requiring specialist educational environments.

"...they've gone from what was their typical trajectory to being completely taken out of their cohort of peers. So they don't, certainly in their school hours, they don't have access to those peers anymore. I doubt how much access they have outside of school." (Ella, practitioner).

Adolescents who remained in their educational environment were reported to experience over-protection from family members and teaching staff, adding further restrictions for peer relationships. Stakeholders spoke of how having a teaching assistant could lead to further isolation from peers. Having an adult by one's side can be a signal of difference for peers, inviting curiosity and possible rejection. Jackie shared how peers can exclude adolescents through a reluctance to socialise with an ever-present adult.

"...no one is going to come and tell you a secret or include you in on something if there's an adult sitting there. So, no one's going to come over and give you all the gossip and dish the dirt if you've got an adult there, so you miss all that."

(Jackie, practitioner)

Opportunities for peer interactions were further affected by physical and cognitive difficulties. Parents, practitioners, and adults highlighted the impact of physical fatigue on meeting peers outside of school. Similarly, difficulties with memory and planning abilities restricted adolescent's capacities to independently meet up with friends. Consequently, there appeared to be a reliance on parents to

facilitate social activities. If parents were unavailable, opportunities for peer interaction were missed.

"...you had to be accompanied everywhere, because if I forgot what I was doing or where I was then I was going to be like a deer in the headlights, not knowing what to do." (Louise, adult).

1.6 Loss of Past Self

A commonality surfaced around the grief adolescents and parents can experience following injury, grieving for what could have been. Changes in identity appeared to be frequent for adolescents following a loss of sports, academic abilities, peer groups, and family roles. Adolescents were reported to find this difficult to adjust to, and felt hopeless and uncertain about the future, affecting QoL. Ben shared experiences of referring to the "old" and "new" version of himself. Kelly spoke of her son using a new name entirely. The impact of this resonated more if adolescents were able to remember their abilities before injury and finding themselves in conflict with the new sense-of-self.

"Very lonely, very depressed, you don't have that sense of achievement anymore, you've completely lost your identity, and, it just, it can lead to very downward spiral." (Louise, adult)

"...if they were younger than you, you were like the 'big brother', the younger person over takes you and they're allowed to go out at night or walk home from school and you're still not." (Jackie, practitioner)

1.7 Challenges with Acquired Status

A number of determinants for peer relationship difficulties presented within cognitive, emotional, and behavioural domains. Parents and practitioners spoke about the lability that adolescents can present with, rapidly switching between intense emotions which peers can respond negatively towards.

"...their mood and anxiety and not being able to keep on top of their emotions and having outbursts in school, which obviously leads to them being picked on even more and becoming even more socially isolated." (Hannah, practitioner)

The emotional sequela of ABI appeared to be significant for adolescents in stakeholder accounts. Anxiety and uncertainty towards new situations increased avoidance and withdrawal, further restricting social participation. Consequently, adolescents were reported to spend more time with the family or alone. Similarly, a loss of hope and confidence was noticed that presented as further barriers for motivation for being with friends. Ben and Louise, both adults with ABI, spoke about the denial and shame that they experienced towards their physical and psychological status post-ABI.

"...she's lost loads of confidence, so that makes it really hard to make friends when you're really, really inward." (Charlotte, parent)

"I knew there was something wrong with me, it kind of brought a shame on you. So you didn't want people to know because they looked at you as if you were an attention seeker." (Louise, adult)

2.0 Improving Peer Relationships

The following themes comprise stakeholder perspectives on what might need to change to improve peer relationships for adolescents, and what the goals of an intervention might be.

2.1 Building Understanding

There was a strong commonality shared around the need to increase understanding about ABI in others around adolescents. Parents, practitioner, and adults spoke of the benefit of teachers and peers receiving education around the impact of ABI and what the adolescent might be experiencing. This was hoped to reduce the assumptions and stigma shown by others that negatively impact upon peer relationships. This education and understanding may promote acceptance from others and facilitate compassion within the system around the adolescent, supporting social inclusion.

"...because it's not talked about, I would love for them to do a massive assembly in the school and say, "This is what goes on," [...], so that it's not such a taboo thing and so children aren't so frightened about it..." (Charlotte, parent)

2.2 Meaningful Social Connection

When considering the limited opportunities for peer interactions, parents advocated for meaningful social activities. Here, stakeholders reflected on being with others with ABI and participating in activities with non-injured friends. Ben recognised the benefit of being with others with ABI, promoting a sense of commonality and normalisation. However, some parents and practitioners felt it to be more important to

facilitate fun activities with peers. Louise reflected on her experience in adolescence, subsequently stating that solely socialising with others with disabilities would have furthered peer exclusion.

"I didn't really like the whole pushing me to surround myself with other people with brain injury. Didn't like that because [...] I wanted to be normal." (Louise, adult)

Stakeholder perspectives suggested that adolescents would benefit from having a space to talk openly about their emotions. Parents felt that having someone of a similar age to talk to was important for adolescents, recognising that professionals involved post-injury were mostly middle-aged.

"Somebody that understands the mood that you are feeling." (Beth, adolescent)

2.3 Support for the Journey

Parents and adults reported feeling lost post-discharge, with many unanswered questions and concerns for the future. It was recognised that professional support fell away and parental help-seeking relied on family resources. Subsequently, early support, assessment, and education for the family about ABI was advocated for to support school re-integration and care planning.

"...you're not informed on who you are now or what struggles you might deal with, which means then your peers aren't informed of who you are now and

what struggles you might be having to deal with. You don't even know, how are they meant to know?" (Louise, adult).

2.4 Empowerment

Parents, practitioners, and adults felt a need to support adolescents to change their relationship with ABI. They suggested that adolescents can feel powerless and hopeless in the context of injury. Kelly recognised the persistent negative messages that adolescents can experience from those around them that perpetuated feelings of hopelessness and shame.

"...all they're hearing in messages is "You're making it up" "You're skiving" they're being rejected by their peer groups, they're finding it really hard to interact with their peer groups, and they're worrying about future relationships..." (Kelly, parent).

Subsequently, it was suggested that an intervention needed to support and build on the strengths of adolescents, fostering confidence despite ABI. Jackie reflected on her experiences of empowering adolescents to become experts in themselves.

"You're empowering them to say to a teacher "I'm not being lazy, I've got an initiation problem", it just changes the whole world." (Jackie, practitioner)

Logic Model of Peer Relationship Difficulties

The logic model of peer relationship difficulties presented in Figure 2 offers a framework to understand stakeholder experiences of peer relationship difficulties for adolescents with ABI, its determinants, and the impact upon QoL. The planning group's responses on the survey informed the initial logic model (Appendix L). This was then discussed and reflected on by stakeholders. Data analysed from stakeholder focus groups and interviews informed the first revision of the initial logic model of peer relationship difficulties. The revised model was discussed in research supervision, and was then shared with the planning group for feedback and reflection around the organisation and interaction of the data (i.e., suitable determinant categorisation). This resulted in four more revisions, until no further feedback was provided and a consensus was reached by the planning group. The fifth iteration of the logic model was then shared with stakeholders for feedback around the credibility of what was presented in the logic model and their communicated experiences. This resulted in a sixth and final revision (Figure 2) after improving the accessibility of terminology. No further feedback was provided by stakeholders and no further revisions to the model were made.

The logic model of peer relationship difficulties (Figure 2) shows the variety of peer relationship difficulties that adolescents can experience and the long-term impact on QoL, as described by stakeholders. As presented, these difficulties were perceived as being influenced by the interactions between the outlined determinants. These may maintain peer relationship difficulties, or be further influenced by these difficulties, as represented by the bi-directional arrow. For example, being excluded from social activities (peer relationships difficulties post-ABI) may be influenced by emotional lability and withdrawal (behavioural determinants), time away from peers during

recovery, and the attitudes and assumption of others (environmental determinants). Being excluded from social activities may further influence mental health and mood (psychological determinants), and a reliance on parents (environmental determinants). Adolescents may experience a loss of friendship group over time (peer relationships difficulties post-ABI) and reduced QoL, influenced by isolation and feelings of loneliness.

Supporting these determinants may be the focus of future meaningful interventions to improve the outcomes of adolescents, such as through emotional support, education for others, supporting contact with peers during recovery, and facilitating activities with others; as suggested by stakeholders.

DETERMINANTS TARGET PROBLEM QUALITY OF LIFE Peer Relationship Difficulties **Behavioural Determinants** Quality of Life **Biological Determinants** Post-ABI · Academic challenges [reduced · Acquired physical difficulties Avoiding social situations motivation at school] · Age of Injury Behaviour that challenges · Appearing the same but perceived as · Difficulty with acceptance and Gender Emotional lability [unpredictability] different ['hidden' disability] adjustment Help-seeking ability Unmet desire to be with friends Genetics · Employment challenges · Injury characteristics [type, severity, location] Motivation and initiation Exclusion from social activities · Future uncertainties Withdrawal [self-isolating] · On-going health difficulties [epilepsy] Extensive planning for plans with peers Increased dependence on family · Sleep difficulties [medication, transport, safety, reliance on Isolation and reduced social · Tiredness and physical fatigue contact [engagement and Forced friendships/ similar level [SEN] participation] friends [social adjustment] Loneliness Friends moving on whilst away **Environmental Determinants** · Mental health difficulties · Friendship prioritised over grades Frustration/ uncertainty from friends · Reduced independence and Family Environment confidence · Labelled as weird Personal and Psychological Family expectations · Reduced physical health · Loss of friend groups Family openness to share difficulties · Risk of harm from others [criminal Determinants · Loss of sports and hobbies Family resources [education and knowledge] iustice1 Family structure and coping Peer victimization Risk of harm to self Family understanding · Reduced opportunity to participate in · Poorer sleep quality Financial resources activities [community and social Expectations for recovery · Tiredness and fatigue Reliance on parents participation] Maturity [post-injury] Sibling adaptability · Reduced quality of friendships · Openness to share with friends · Restrictions on available activities Perfectionism traits School Environment · Unable to keep up with friends Academic demands · Vulnerability to social influences [trusting Psychological Available school resources others, spotting danger, taken advantage of Cognitive abilities (insight, memory, Challenges of schooling environment · Wanting to belong, fit in, and be 'normal' planning, attention, processing] Experience of school re-integration Moving schools/ transitions Cognitive fatigue Communicative ability Over-protection from others Reliance on adults ITA, teachers1 Emotional dysregulation Time away from peers [acute phase and appointments] · Feeling misunderstood Understanding from others [peers, teachers] Grieving past self Teacher modelling responses to adolescent . Mental health [anxiety, depression] Popularity at school Mood [anger, frustration] Overstimulation Social and Community Environment · Perceived change in identity Attitudes and assumptions of others [stigma] Resilience/ coping resources Community and professional support Influence of social media [challenges to, and maintenance of Social cognition [ability to process and peer relationships) respond to social information] Location and available services Peer acceptance and adjustment · Social skills [post-injury] Peer parent attitudes and modelling Trauma of injury/ recovery Socialising online with friends

Figure 2. Logic Model of Peer Relationship Difficulties for Adolescents with ABI (6th Revision).

Discussion

This study aimed to collaborate with key stakeholders to: (a) understand peer relationship difficulties for adolescents with ABI (adolescents); and (b) seek their perspectives on what might be needed to improve them and what the intervention goals might be, to inform the development of a meaningful intervention.

The complexities of peer relationship difficulties for adolescents have largely been under-recognised, and the qualitative insights provided in this study inform this gap within the paediatric neuropsychology literature. The analysis, alongside planning group responses, informed the development of the logic model, outlining the difficulties adolescents can experience with peer relationships (target problem for intervention), its impact upon QoL, and its determinants. This offers a robust framework to guide future intervention design using the IM protocol (Bartholomew-Eldridge et al., 2016; Fernandez et al., 2019).

Stakeholders supported that adolescents face difficulties in maintaining peer relationships (Anderson et al., 2013; Ryan et al., 2013; Turkstra et al., 2004; Yeates et al., 2007), which are represented in the logic model. Peer rejection and exclusion was also recognised, consistent with Yeates et al. (2012). Stakeholder insights suggested this to result from peer separation during recovery, restricted peer interactions, and the negative assumptions associated with the 'hidden' difficulties associated ABI (Simpson et al., 2002).

Stakeholder conversations and planning group perspectives indicated the determinants for peer relationship difficulties (shown in the logic model) to be broad. Consistent with previous research, difficulties with cognition (Anderson et al., 2012), social cognition (Tousignant et al., 2018), misunderstanding (Keetley et al., 2019), emotional lability (Vasa et al., 2015), and perceived changes in identity (Ownsworth,

2014) were identified to negatively influence peer relationships. Stakeholders reported the lack of understanding about ABI to be an important determinant for peer difficulties. Some adolescents may return to school appearing unscathed, yet can present as very different to peers due to acquired cognitive, socio-cognitive, and emotional difficulties (Simpson et al., 2002). This may invite negative assumptions from peers towards the 'realness' of difficulties, resulting in further rejection or peer frustration. Similarly, the emotional consequences associated with ABI (Sariaslan et al., 2016) and a change in identity (Ownsworth, 2014) reduced motivation for social participation, perpetuating feelings of loneliness (Parker & Asher, 1987) and dependency on the family. These, and further implications for QoL are represented in the logic model, including future academic and vocational concerns (Sariaslan et al., 2016), reduced confidence, and risk of early contact with the criminal justice system (Williams et al., 2012), as reported by stakeholders.

The notion that adolescence is a time for belonging (Blakemore, 2008), peer emotional support (van Harmelen et al., 2017), and social identity (Tajfel, 1978) was supported. This was a recognised difficulty for adolescents within the themes and logic model. Successful peer relationships were a priority for some stakeholders over academic achievement, a priority previously reported by Sirois et al. (2014). To support belonging and peer acceptance, adolescents have an apparent priority to appear 'normal', and may adjust friendship preferences to perform competently (Anderson & Beauchamp, 2012). This may also increase vulnerability for exploitation from others, compounded by socio-cognitive difficulties and understanding intentions of others (a determinant in the logic model). Difficulties with theory of mind have previously been recognised post-ABI (Turkstra et al., 2004).

The themes and logic model provided in this study offer guidance for the development of a future intervention, and stakeholders offered their perspectives on what is needed to support the needs of adolescents. Their participation in intervention planning supports understanding the context for intervention and population needs to promote intervention efficacy (Fernandez et al., 2019; MRC, 2019). Stakeholder accounts suggested a preference for intervening within the adolescent's educational, community, and social environment. Individual interventions may be unappealing due to the threat of appearing different and subsequent peer rejection. An intervention may need to be multifaceted to support adolescents at an individual (emotional support) and environmental level (building understanding), consistent with recommendations made by Andrews et al. (2015). This could include providing education and resources about ABI to peers and schools, facilitating meaningful social activities with friends, offering emotional support, and early assessment and signposting post-injury. Empowering adolescents post-ABI was identified to be an important intervention goal.

Theoretical Implications

Within the SOCIAL model, social skills and functioning (i.e., competence, adjustment, and participation) are recognised to be fundamental for successful peer relationships (Beauchamp & Anderson, 2010). The model assumes that social skills are mediated by typical brain development within a supportive environment, and that the presence and integrity of social skills are facilitated by cognitive determinants (i.e., attention/ executive functioning, social cognition, and communication). The determinants spoken about by stakeholders in this study offer support for the mediators and cognitive determinants identified by the SOCIAL model. For example, challenges within an adolescent's external environment (i.e., peer rejection, misunderstanding, and stigma), and difficulties with cognitive and socio-cognitive

abilities were described by stakeholders as key influential determinants for peer relationship difficulties for adolescents with ABI within the themes and logic model. The presented interactions between these determinants are consistent interactions proposed within the SOCIAL model.

Emotional difficulties (i.e., anxiety, hopelessness, shame, and lability) were also described by stakeholders to be influential determinants for peer relationship difficulties within the themes and logic model, impacting upon social competence and motivation for social participation. Emotional determinants appear to be omitted from the SOCIAL model. It could be argued that the presence and integrity of social skills and functioning, in the context of typical brain development and a supportive environment, may also be influenced by emotional determinants (i.e., regulation, mood, and mental health). These determinants may have an important reciprocal role for facilitating successful peer relationships, which in turn, could support emotional difficulties for adolescents. Indeed, successful peer relationships in adolescence can be protective for mental health and resilience (van Harmelen et al., 2017).

The suggested interactions between the mediators and determinants in the SOCIAL model are supported by empirical evidence from TBI, autism spectrum disorder, and schizophrenia populations. The findings from this study may provide the foundation for further research exploring the relationship between social skills and mood in ABI populations. With further evidence, future revisions of the SOCIAL model may consider the inclusion of emotional determinants. As suggested by stakeholders, reduced social skills may invite stigma from the external environment and restrict participation. This may further reduce mood and influence social adjustment and participation.

Clinical Implications

The findings suggested that adolescents can experience difficulties with peer relationships and mental health, though they may not volunteer these difficulties through fear of appearing different. Consequently, their needs could be overlooked. Practitioners can hold this in mind and routinely enquire about an adolescent's mental health, alongside being curious about their support network beyond the family.

The risks and vulnerabilities associated with ABI and a need to belong were identified. This awareness can support clinicians to formulate risk and intervene appropriately. This awareness could also be shared with commissioners to seek funding for additional community resources to support social belonging for children and adolescents, such as youth clubs. Indeed, those with ABI are at higher risk of early contact with the criminal justice system (Williams, 2012).

Stakeholders suggested that peers should be involved and educated in the post-acute phase of rehabilitation to prevent adolescents 'drifting' from friends. This may maintain peer relationships and promote social inclusion throughout rehabilitation, absence from school, and educational re-integration. Social media platforms could support peer communication.

Some stakeholders shared their priority for successful peer relationships over academic achievements. This understanding may inform rehabilitation goal planning and educational learning plans to support adolescents to engage and participate meaningfully with friends, subsequently supporting QoL.

The importance of building understanding about ABI for those around the adolescent (i.e., peers, teachers) was identified as a key part of a meaningful intervention. Understanding could be supported through the creation of online resources or videos made by adolescent stakeholders with ABI. Social media could

facilitate an adolescent-led project to disseminate informative videos. This may simultaneously empower adolescents to become the experts.

The National Acquired Brain Injury in Learning and Education Syndicate was set up in 2018 to ensure that children and adolescents get the educational support they need. One strategic aim is to raise awareness of the educational difficulties associated with ABI amongst policy makers. The findings from this study can support this aim.

Strengths and Limitations

The methodology of this study promoted collaboration with planning group members and key stakeholders to co-produce the logic model of the target problem for intervention through a rigorous process. Utilising member-checking procedures throughout the study promoted the credibility of the findings and interpretations made. An additional strength included piloting the focus groups and interview schedules, allowing for the observation of responses and suitability to support the research aims.

A limitation includes the use of focus groups and interviews due to time restrictions and the difficulties encountered when attempting to recruit from the paediatric ABI population. Though focus groups and interviews were of a similar length, stakeholders who were interviewed had increased opportunity to contribute findings. Conversely, the richness of the data collected in interviews was limited due to question and response nature of the conversation. Stakeholders in the focus groups were able to construct opinions, share and build on each other's experiences, and discuss topics beyond scheduled topics that provided further insights. Future research exploring commonalities in adolescent and parent experiences of ABI may benefit from solely using focus group methodology. This methodology promotes connectivity and peer support to an often isolated population. It may encourage social interaction

and the sharing of social pressures amongst adolescents with ABI. Furthermore, it may allow parents and adolescents with ABI to feel less isolated in their experiences. The normalisation and commonalities discussed amongst participants could promote the disclosure and sharing of experiences beyond an interview setting. In addition, the analysis of focus group data will allow for exploration of how emergent themes are built upon by other stakeholders, and allow for further analysis of differences in opinion.

The parent and adolescent sample used within this study consisted of sample bias. All adolescents were aged 13 years and originated from a white middle-class background. This would have influenced adolescent and parental experiences following ABI, such as resources, access to services, and educational environments. This may contrast with experiences from stakeholders originating from BME or working-class backgrounds. Thus, findings from this study may not be generalisable to all adolescents with ABI. Future research should consider recruiting stakeholder participants from diverse backgrounds. This may be achieved through close working between the researcher and statutory services to seek support for recruitment, such as social care (i.e., youth services), the National Health Service, and the Department for Education. This could support recruitment from a wider and more diverse population, beyond those who are supported by charity organisations. Barriers to participation in research may be considered and supported, particularly for hard to reach communities. Outreach to potential participants could build trust (i.e., building a rapport and managing expectations from the outcome of the research) and provide opportunities to discuss the potential risks of participation (i.e., anonymity, discrimination, and social status).

Adolescent stakeholders had limited representation due to the small sample size and their apparent reservations in conversation. Consequently, their perspectives may not have emerged as strongly in the analysis when compared to other stakeholder groups. Future research should consider using a larger sample of adolescents with ABI.

Conclusion

Adolescents with ABI were reported to experience difficulties with peer relationships. At an important time for social development, peer rejection can increase feelings of isolation, loneliness, shame, and hopelessness. This can have further implications for mental health, peer relationships, and QoL. The individual, psychological, behavioural, and environmental determinants for peer relationship difficulties are broad. Reported stakeholder experiences offer new clinical and theoretical insights for the paediatric neuropsychology literature. A meaningful intervention would need to be multifaceted attempting to build understanding in others, facilitate opportunities for meaningful social connection, offer early support post-injury, and help manage psychological wellbeing. A primary focus would be to empower adolescents post-ABI. The presented logic model provides a robust understanding of peer relationship difficulties for adolescents with ABI that can be used to guide intervention development in future research.

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Appendices

Appendix A: Steps of Intervention Mapping

Table A1.

Intervention Mapping Steps (O'Connor, Blewitt, Nolan, & Skouteris, 2018)

	Step	Tasks	
1.	Logic model of the problem	 Establish and work with a planning group Conduct a needs assessment to create a logic model of the problem Describe context of intervention (population and setting) State programme goals 	
2.	Programme outcomes and objectives – logic model for change	 State expected outcomes Specify performance objectives for behavioural and environmental outcomes Construct matrices of change objectives Create a logic model of change 	
3.	Programme design	 Generate programme themes, components, and scope Choose theory – and evidence-based change methods Select practical applications to deliver change methods 	
4.	Programme production	 Refine programme structure Prepare plans for programme materials Draft messages and materials Pre-test, refine, and produce materials 	
5.	Programme Implementation Plan	 Identify potential programme users State outcomes and performance objective for programme use Design implementation interventions 	
6.	Evaluation plan	 Write effect and process evaluation questions Develop indicators and measures for assessment Specify the evaluation design Complete the evaluation plan 	

Appendix B: Consent to Contact Forms

Participant Consent Form

CONSENT TO BE CONTACTED

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Consent to be contacted for more information about participation in the above study.

I consent to be contact by the researchers involved in this study about the opportunity to take part and ask any questions that I might have about the research process and what is expected of me.

I understand that being contacted does not mean that I am obliged to take part in the research and that I am free to change my mind at any time.

I am happy for the researchers above, at the University of Exeter, to securely store the contact details that I provide for the purposes of informing me about the research study.

Only researchers from the University of Exeter will have access to your contact details, which will be kept for 5 years before being destroyed. All personal information will be kept securely on a password protected university server.

You will receive a	copy of this sig	ned documents	for your records.

Name of Person:
Signature Person:
Date:

Signature of Researcher Obtaining Consent/ Assent to be con	ntacted
Date	ə:
PROVIDED CONTACT DETAIL	LS
Preferred means of contact (phone/ text/ email/ post):	
Preferred times of day for contact (if by telephone):	
Telephone Number:	
Email Address:	
Postal Address:	

Participant Consent Form

YOUNG PERSON CONSENT TO BE CONTACTED

Improving Peer Relationships in Adolescents Following Acquired Brain Injury:
Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Consent to be contacted for more information about participation in the above study.

I consent to be contact by the researchers involved in this study about the opportunity to take part and ask any questions that I might have about the research process and what is expected of me.

I understand that being contacted does not mean that I am obliged to take part in the research and that I am free to change my mind at any time.

I am happy for the researchers above, at the University of Exeter, to securely store the contact details that I provide for the purposes of informing me about the research study.

Only researchers from the University of Exeter will have access to your contact details, which will be kept for 5 years before being destroyed. All personal information will be kept securely on a password protected university server.

You will receive a copy of this signed documents for your records.

Name of Young Person:
Signature of Young Person:
Date:
Signature of Parent or Guardian

Date:
Signature of Researcher Obtaining Consent/ Assent to be contacted
PROVIDED CONTACT DETAILS
Preferred means of contact (phone/ text/ email/ post):
Preferred times of day for contact (if by telephone):
Telephone Number:
Email Address:
Postal Address:

Appendix C: Adult Stakeholder Participant Information Sheet (Focus Groups)

Participant Information Sheet

STAKEHOLDER PARTICIPATION

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir \ Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child's developmental trajectory when compared to their peers, with developmental 'gaps' becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known out the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various 'stakeholders' who have experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

What type of data is being collected?

The study will be collecting data using questionnaires, surveys, and focus group discussions. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity. Each questionnaire will come with a set of instructions on how to complete them. A focus group is a group discussion around a particular 'focus' topic.

What will participation in focus groups involve?

There will be around six to eight people in each focus group with one facilitator. You will be asked to have a group conversation to express your views and form opinions. The group will be audio recorded and all information is kept confidential. The group will last for approximately 1 to 1.5 hours. For this study, we are interested in hearing your views about the social experiences of adolescents with ABI and to use your experiences to help us design an intervention programme which will aim to improve relationships with peers. There are no right or wrong answers to the questions we will ask you. The questions will aim to explore your experiences and views towards the research topic.

When will the focus group be?

It can be really difficult to arrange a time, date, and location for everyone to get together at the same time. We will propose a date in the near future and ask that you contact the researcher as soon as possible to confirm your attendance. If you cannot attend for any reason, please let us know as soon as possible. We ask that you arrive promptly to allow adequate time for the focus group. Refreshments will be provided on the day.

What will happen on the day?

You will be welcomed on arrival and offered refreshments whilst we are waiting for everyone to arrive. We will ask you to bring with you the questionnaires we will send to you **2 weeks** prior to the focus group. You will then be asked to sign a consent form to state that you are happy to continue with the focus group. You will be unable to participate without this. The facilitator will ensure that everyone is seated and explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. You will then be given the opportunity to ask questions. Once everyone is happy, the audio recording will begin and the group will commence. Following the group, you will be provided with debrief sheet which will contain further information about support if you require it.

What are the benefits of taking part?

This study offers and innovative approach which values the participation of 'experts by experience'. Your perspectives and consultation will allow for the development of an intervention programme to improve peer relationships for others experiencing ABI. You will have the opportunity to meet others in a similar situation to you and share experiences. As a thank you for sharing your time, we will give you a £10 Amazon voucher.

Are there any risks?

The questions are likely to talk about sensitive topics which may be difficult to share. If you become upset by the information spoken about within the focus group, there will be information provided about services where you could access support. You are able to withdraw from the study at any time with no consequence.

Will my information be kept private?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code.
 No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.
- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

- If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.
- This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that you, or someone else, was at risk of harm. In such cases, we would talk to you about this first and risk procedures will be followed. We may also make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Further information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix D: Young Person Participation Information Sheet (Focus Group)

Participant Information Sheet

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.



We would like to ask you to take part in our research study. It is really important that we give you all the information you need before you say 'yes' or 'no'. Please could you read the information on this page carefully about what you will be asked to do. If it is easier, you can ask someone else to read it with you, like your parents. You can always ask us for more information at any time. The contact details can be seen below.

What is the study about?

Sometimes, teenagers who have had a brain injury can find it hard 'connect' with their friends. This may be for a number of reasons, ranging from difficulties with memories to feeling that friends do not understand you. We would like to hear more about your experiences with friends and think about how we could help. We also want to hear about what's important to you.

Why am I being asked to take part?

We would like you to be in the study because you are the experts. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has had a brain injury to take part.

Do I have to?

No, you do not have to take part if you do not want to. It's up to you and your parents. You can say yes or no.

What will happen in the study if I say yes?

If you say yes, we will give you and your parents more information on the study. If you are happy to continue, we will invite you to come to the University of Exeter one day and meet other teenagers with brain injuries. We will ask you to have a group discussion in response to some questions that we will ask the group, there are no right or wrong answers. The group will last for around one hour and refreshments will be provided.

In the group, we will ask you to tell us about the difficulties some teenagers with brain injuries may face with friendships, and the other difficulties with this. We also want to ask you for your advice about what would help.

What's good about taking part?

You are the 'experts' in social experiences following brain injury. You will be helping us to understand what it is like for teenagers and what problems they might have. You can talk to us about what is meaningful and important to teenagers. We can think together about how we might be able to help teenagers who have difficulties with their friends. You will be able to meet other people your age and share experiences. You will also get a £10 Amazon voucher as a thank you for coming along.

What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time you feel that you might be upset, you can stop. If you want to, there will be people there who you can talk to and further information about support will be provided. If you want to leave the group at any point, you are more than welcome to.

Will my information be kept private?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code.
 No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.
- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
- If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (<u>sa675@exeter.ac.uk</u>) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.
- This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

We may have to break confidentiality if you say something that worries us. We will follow risk procedures and might have to tell someone else, such as your parents, what you have said to keep you safe. If we do this, we will talk to you first and provide you with support around accessing local services. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix E: Parent Participant Information Sheet (Focus Group)

Information Sheet for Parents of Potential Participants

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child's developmental trajectory when compared to their peers, with developmental 'gaps' becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known out the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various 'stakeholders' who have in some way experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

We would like to ask your child to take part in the research study. It is really important that we give you all the information about what your child is expected to do before you provide consent for them to participate. You can always ask us for more information at any time. The contact details can be seen below.

Why is my child being asked to take part?

We would like your child to be in the study because they are the 'experts' we would like to hear from in the development of this intervention. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has to take part and offer their expertise.

What type of data is being collected and how?

The study will be collecting data using questionnaires, surveys, and focus group discussions. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity (children with brain injury only). Each questionnaire will come with a set of instructions on how to complete them.

A focus group is a group discussion around a particular 'focus' topic. Your child will be asked to attend a focus group at the University of Exeter to meet with others their age and with similar experiences (date to be confirmed). There will be between 3 and 6 people in their focus group with one group facilitator. They will be asked to have group conversations in response to some questions, there are no right or wrong answers. For this study, we are interested to hear about experiences of children with brain injury regarding their friendships with others, what needs to improve, and how teenagers would like it to be done so that is meaningful for them. This information can then help design an intervention. The group will be audio recorded and all information is kept confidential. The group will last for approximately 1 hour, refreshments will be included.

What will happen on the day?

You and your child will be welcomed on arrival and offered refreshments whilst we are waiting for everyone to arrive. We will ask you to bring with you the questionnaires we will send to you **2 weeks** prior to the focus group (children with brain injury only). You will then be asked to sign a consent form to state that you are happy for your child to continue with the focus group. They will be unable to participate without this. The facilitator will ensure that everyone is seated and then explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. Following the group, you and your child will be provided with a debrief sheet which will contain further information about support if you require it.

Do they have to?

No, they do not have to take part, it is completely up to you and your child. If you choose not to participate, that's okay. This will not impact your child's care.

What's good about taking part?

Your child is the 'expert' in social experiences following brain injury. They will be helping us to understand what it is like for teenagers and what problems they might have. They can talk to us about what is meaningful and important to teenagers when thinking about friendships. We can think together about how we might be able to help teenagers who have difficulties with their friends. Your child will be able to meet others their age and share experiences. They will also get a £10 Amazon voucher as a thank you for coming along.

What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time your child feels that they are becoming upset, they can stop. If they want to, there will be people there who they can talk to and further information about support will be provided. If they want to leave the group at any point, they are more than welcome to, no problem.

Will information be confidential?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your child's information remains private is important to us. We will do the following to protect their privacy in this research study:

- All personal and research related information about your child will be stored on a secure password protected university server. No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your child's personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be coded with a unique participant identification code. All participant identification codes will be

stored electronically on a password protected database, stored on a secure password protected university server.

- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
- If you would like your child's data to be removed once they have taken part in the study, please request this in writing to the chief investigator (<u>sa675@exeter.ac.uk</u>) within 1 year following their participation.
- This outlined information will be given to your child again on the day of their participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that your child, or someone else, was at risk of harm. In such cases, risk procedures will be followed and we might have to tell you or someone else about what they have said in the interest of safety. We may also support you to make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix F: Adult Stakeholder Participant Information Sheet (Interviews)

Participant Information Sheet

STAKEHOLDER PARTICIPATION

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir \ Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child's developmental trajectory when compared to their peers, with developmental 'gaps' becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known out the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various 'stakeholders' who have experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

What type of data is being collected?

The study will be collecting data using questionnaires, surveys, focus group discussions and individual interviews. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity. Each questionnaire will come with a set of instructions on how to complete them.

What will participation in interviews involve?

Interviews will be conducted face to face at the University or via technology (Skype or telephone), dependent on demographic locations. Interviews will last for approximately 1 to 1.5 hours and will be conducted one to one with the chief investigator. You will be asked to express your views and share experiences in response to the interview schedule. The questions will aim to explore your experiences and views towards the research topic. There are no right or wrong answers, we are just interested in hearing about your experiences. For this study, we are interested in hearing your views about the social experiences of adolescents with ABI and to use your experiences to help us design an intervention programme which will aim to improve relationships with peers. The interview will be audio recorded and all information is kept confidential.

When will the interview be?

If you are interested in taking part and have provided consent to be contacted, you will be contacted individually by the chief investigator to arrange a suitable time for your interview. If you cannot attend on the day, please let us know as soon as possible and we can rearrange.

What will happen on the day?

Face to face interviews

If you are attending in person at the university, you will be welcomed by the chief investigator at the time specified on your individual interview invitation. Refreshments will be provided for you. You will be asked to bring with you the questionnaires that will be sent to you prior to the day. There will be an opportunity to ask further questions, and if you are happy, you will be asked to sign a consent form to continue with the interview. You will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and you will be asked a number of open ended questions to hear about your experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how your data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and you will be provided with a £10 Amazon voucher as a thank you for your time.

Interviews via technology

If you are attending the interview via Skype or telephone, you will be contacted at the time of your interview, specified on the interview invitation. Once you have provided consent to contact for the study, the chief investigator will ask you which form of technology you find most preferable and support will be given to use the technology if required. You will be asked to return the questionnaires sent to you either by post or scanner. On the day, there will be an opportunity to ask questions, and if you are happy you will be asked to complete a 'consent to take part' form electronically via the study's online webpage (link below) or via email. You will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and you will be asked a number of open ended questions to hear about your experiences and opinions. These interviews will be audio recorded and all information will be

confidential. Please see below regarding how your data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and you will be sent (via email) a £10 Amazon voucher as a thank you for your time.

Link for online consent form:

http://psychology.exeter.ac.uk/research/centres/ccnr/getinvolved/clinical/brain-injury/

What are the benefits of taking part?

This study offers and innovative approach which values the participation of 'experts by experience'. Your perspectives and consultation will allow for the development of an intervention programme to improve peer relationships for others experiencing ABI. You will have the opportunity to meet others in a similar situation to you and share experiences. As a thank you for sharing your time, we will give you a £10 Amazon voucher.

Are there any risks?

The questions are likely to talk about sensitive topics which may be difficult to share. If you become upset by the information spoken about within the interview, there will be information provided about services where you could access support. You are able to withdraw from the study at any time with no consequence.

Will my information be kept private?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.
- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
- If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.
- This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that you, or someone else, was at risk of harm. In such cases, we would talk to you about this first and risk procedures will be followed. We may also make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Further information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix G: Young Person Participation Information Sheet (Interviews)

Participant Information Sheet

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury:
Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.



We would like to ask you to take part in our research study. It is really important that we give you all the information you need before you say 'yes' or 'no'. Please could you read the information on this page carefully about what you will be asked to do. If it is easier, you can ask someone else to read it with you, like your parents. You can always ask us for more information at any time. The contact details can be seen below.

What is the study about?

Sometimes, teenagers who have had a brain injury can find it hard 'connect' with their friends. This may be for a number of reasons, ranging from difficulties with memories to feeling that friends do not understand you. We would like to hear more about your experiences with friends and think about how we could help. We also want to hear about what's important to you.

Why am I being asked to take part?

We would like you to be in the study because you are the experts. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has had a brain injury to take part.

Do I have to?

No, you do not have to take part if you do not want to. It's up to you and your parents. You can say yes or no.

What will happen in the study if I say yes?

If you say yes, we will give you and your parents more information on the study. If you are happy to continue, we will invite you to come to the University of Exeter one day to sit and have a conversation with the chief investigator about your experiences. If you live far away, this can also be done via telephone or Skype. You will be asked to share your experiences and opinions in response to some questions about peer relationships (friendships) following brain injury. There are no right or wrong answers, we just want to hear about your opinions and what is important to you. The interview will last for around one hour and refreshments will be provided.

We will ask you to tell us about the difficulties some teenagers with brain injuries may face with friendships, and the other difficulties with this. We also want to ask you for your advice about what would help.

What's good about taking part?

You are the 'experts' in social experiences following brain injury. You will be helping us to understand what it is like for teenagers and what problems they might have. You can talk to us about what is meaningful and important to teenagers. We can think together about how we might be able to help teenagers who have difficulties with their friends. You will also get a £10 Amazon voucher as a thank you for coming along.

What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time you feel that you might be upset, you can stop. If you want to, we can talk about what might be upsetting you as this can often help. Further information about support will also be provided. If you want to leave the interview at any point, you are more than welcome to.

Will information be kept secret?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code.
 No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.
- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
- If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (<u>sa675@exeter.ac.uk</u>) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.
- This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

We may have to break confidentiality if you say something that worries us. We will follow risk procedures and might have to tell someone else, such as your parents, what you have said to keep you safe. If we do this, we will talk to you first and provide you with support around accessing local services. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix H: Parent Participant Information Sheet

Information Sheet for Parents of Potential Participants

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child's developmental trajectory when compared to their peers, with developmental 'gaps' becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known out the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various 'stakeholders' who have in some way experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

We would like to ask your child to take part in the research study. It is really important that we give you all the information about what your child is expected to do before you provide consent for them to participate. You can always ask us for more information at any time. The contact details can be seen below.

Why is my child being asked to take part?

We would like your child to be in the study because they are the 'experts' we would like to hear from in the development of this intervention. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has to take part and offer their expertise.

What type of data is being collected and how?

The study will be collecting data using questionnaires, surveys, focus group discussions, and individual interviews. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity (children with brain injury only). Each questionnaire will come with a set of instructions on how to complete them.

What will participation in interviews involve?

Interviews will be conducted face to face at the University or via technology (Skype or telephone), dependent on demographic locations. Interviews will last for approximately 1 to 1.5 hours and will be conducted one to one with the chief investigator. Your child will be asked to express their views and share experiences in response to the interview schedule. The questions will aim to explore their experiences and views towards the research topic, peer relationships following ABI. There are no right or wrong answers, we are just interested in hearing about your child's experiences. For this study, we are interested in hearing their views about the social experiences of adolescents with ABI and to use these to help us design an intervention programme which will aim to improve relationships with peers. The interview will be audio recorded and all information is kept confidential.

When will the interview be?

If you are interested in your child taking part and have provided consent to be contacted, you will be contacted individually by the chief investigator to arrange a suitable time for their interview. If they cannot attend on the day, please let us know as soon as possible and we can rearrange.

What will happen on the day?

Face to face interviews

If your child is attending in person at the university, they will be welcomed by the chief investigator at the time specified on your individual interview invitation. Refreshments will be provided. They will be asked to bring with them the questionnaires that will be sent prior to the day. There will be an opportunity to ask further questions, and if they are happy, they will be asked to sign a consent form to continue with the interview. They will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and they will be asked a number of open ended questions to hear about their experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how their data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and they will be provided with a £10 Amazon voucher as a thank you for their time.

Interviews via technology

If your child is attending the interview via Skype or telephone, they will be contacted at the time of their interview, specified on the interview invitation. Once you both have provided consent to contact for the study, the chief investigator will ask which form of technology your child would find most preferable and support will be given to use the technology if required. You (or your child) will be asked to return the questionnaires sent to them either by post or scanner. On the day, there will be an opportunity to ask questions, and if you are both happy they will be asked to complete a 'consent to take part' form electronically via the study's online webpage (link below) or via email. They will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and they will be asked a number of open ended questions to hear about their experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how their data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and they will be sent (via email) a £10 Amazon voucher as a thank you for their time.

Link for online consent form:

http://psychology.exeter.ac.uk/research/centres/ccnr/getinvolved/clinical/brain-injury/

Do they have to?

No, they do not have to take part, it is completely up to you and your child. If you choose not to participate, that's okay. This will not impact your child's care.

What's good about taking part?

Your child is the 'expert' in social experiences following brain injury. They will be helping us to understand what it is like for teenagers and what problems they might have. They can talk to us about what is meaningful and important to teenagers when thinking about friendships. We can think together about how we might be able to help teenagers who have difficulties with their friends. They will also get a £10 Amazon voucher as a thank you for coming along.

What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time your child feels that they are becoming upset, they can stop. If they want to, they can use some time to discuss how they are feeling and information about support will be provided. If they want to leave the interview at any point, they are more than welcome to, no problem.

Will information be confidential?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research

team, further information may be obtained from the University's Data Protection Officer by emailing <u>dataprotection@exeter.ac.uk</u> or at <u>www.exeter.ac.uk/dataprotection</u>. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: <u>p.r.baxter2@exeter.ac.uk</u>).

Making sure that your child's information remains private is important to us. We will do the following to protect their privacy in this research study:

- All personal and research related information about your child will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your child's personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.
- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.
- All questionnaires and transcriptions used in the study will be marked with your child's unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.
- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.
- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
- If you would like your child's data to be removed once they have taken part in the study, please request this in writing to the chief investigator (<u>sa675@exeter.ac.uk</u>) within 1 year following their participation. All information related to your child's participation in this study can then be removed using their unique ID code.
- This outlined information will be given to your child again on the day of their participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that your child, or someone else, was at risk of harm. In such cases, risk procedures will be followed and we might have to tell you or someone else about what they have said in the interest of safety. We may also support you to make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix I: Consent to Participate Sheets

Participant Consent Form

STAKEHOLDER INTERVIEW PARTICIPATION

Improving Peer Relationships in Adolescents Following Acquired Brain Injury:
Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Please tick as appropriate:

I confirm that I have read the information sheet dated 30/07/19 (version 3) and understand what is expected of me in this study.	
I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.	
I understand that I am participating on a voluntary basis and that I am free to withdraw at any time without consequence.	
I understand that the information about me will be kept confidential and may only be viewed by members of the research team.	
I understand that in the interest of safety, if a risk issue is identified by the chief investigator they may have to contact my GP. I understand that they will talk to me about this first.	
Name of GPTelephone Number	
I understand that all collected information about me will be anonymised and that there will be no identifiable information published following this study.	
I agree that my contact details can be kept securely for the research team to contact me about the findings of the study.	
I give my consent to participate in the interview for this study.	

Signature:
Date:
Signature of researcher taking consent:
Signature:
Date:

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

Ethical approval number: eCLESPsy000805

Parent/ Guardian Consent Form

PARENT/ GUARDIAN

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Please tick as appropriate:

I confirm that I have read the information sheet dated 16/04/2019 (version 2) and understand what is expected of my child in this study.	
I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.	
I understand that my child is participating on a voluntary basis and is free to withdraw at any time without consequence.	
I understand that the information about my child will be kept confidential and may only be viewed by members of the research team.	
I understand that all collected information about my child will be anonymised and that there will be no identifiable information published following this study.	
I agree that my contact details can be kept securely for the research team to contact me and my child about the findings of the study.	
I understand that my child's GP will be informed of their participation in this study and I agree to this	
I give my consent for my child to participate in the focus group for this study.	
I agree that my contact details can be kept securely and used by researchers from the University of Exeter to contact me about future research projects. (please tick or leave blank)	
Name of Participant:	

Name of Parent:
Signature:
Date:
Signature of researcher taking consent:
Signature:
Date:

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

Ethical approval number: eCLESPsy000805

Child Assent Form

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K. I have read or heard the participant information sheet I have had the opportunity to ask questions about my involvement which have been answered I understand what I would have to do in the study I know that all the information about me will be kept secret I know that I am allowed to leave the study at any time Would you like to take part in the study? YES NO

Name of Participant:....

Name of Parent: (please also complete the attached parental consent form)
Signature:
Date:
Signature of researcher taking assent/ consent:
Signature:
Date:

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

Ethical approval number: eCLESPsy000805

<u>Participant Consent Form</u> (Young Person aged 16 years +)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K. Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Name:

Please tick as appropriate:

I confirm that I have read the information sheet dated 04/01/2018 (version 1) and understand what is expected of me in this study.	
I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.	
I understand that I am participating on a voluntary basis and that I am free to withdraw at any time without consequence.	
I understand that the information about me will be kept confidential and may only be viewed by members of the research team.	
I understand that all collected information about me will be anonymised and that there will be no identifiable information published following this study.	
I agree that my contact details can be kept securely for the research team to contact me about the findings of the study.	
I understand that my GP will be contacted about my participation in this study and I agree to this.	
I give my consent to participate in the focus group for this study.	
I agree that my contact details can be kept securely and used by researchers from the University of Exeter to contact me about future research projects. (please tick or leave blank)	

Signature:
Date:
Signature of researcher taking consent:
Signature:
Date:
Date:

Appendix J: Ethical Approval Confirmation

Dear Scott Ankrett,

Application

eCLESPsy000805 v3.3

ID:

Improving Peer Relationships in Adolescents Following Acquired

Title:

Brain Injury: Designing an Intervention Through Intervention

Mapping.

Your e-Ethics application has been reviewed by the CLES Psychology Ethics Committee.

The outcome of the decision is: Favourable

Potential Outcomes

Favourable: The application has been granted ethical approval by the Committee. The application will be flagged as Closed in th To view it again, please select the tick box: View complete					
The application has been granted ethical approval by the Committee conditional on certain conditions being met, as detable, with conditions: below. Unless stated otherwise, please resubmit the requeste amendments via the online system before beginning the research.					
Provisional:	You have not been granted ethical approval. The application needs to be amended in light of the Committee's comments and resubmitted for Ethical review.				
Unfavourable:	You have not been granted ethical approval. The application has been rejected by the Committee. The application needs to be amended in light of the Committee's comments and resubmitted / or you need to complete a new application.				

Please view your application <u>here</u> and respond to comments as required. You can download your outcome letter by clicking on the 'PDF' button on your eEthics Dashboard.

If you have any queries please contact the CLES Psychology Ethics Chair: **Nick Moberly** <u>n.j.moberly@exeter.ac.uk</u>

Kind regards, CLES Psychology Ethics

Appendix K: Planning Group Survey

Planning Group Survey

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping

Dear Planning Group member,

Thank you for accepting the invitation to provide consultation for the above study, as part of my Doctorate in Clinical Psychology research thesis. As you may recall, you will be asked to provide consultation at various stages of the study (timeline outlined in appendices; Appendix A).

As part of Phase 1, I would like to ask you to complete this open-ended survey, aiming to gain your perspectives on the multiple possible determinants which influence peer relationships following acquired brain injury (ABI) in young people. Your responses will be collated to inform a logic model.

The logic model is created using the multifactorial precede approach (Green & Kreuter, 1999). Using this approach, the target problem for intervention (peer relationships), and its impact upon quality of life, is understood to be a result of a number of determinants or factors. Determinants include personal, biological, environmental, cultural, and interpersonal factors which may influence peer relationships following ABI.

Please try to answer the questions as openly as possible. Your answers will be transcribed and analysed to inform the initial development of the model. I will then provide feedback to the planning group as a whole. The developed logic model will then be shared with stakeholders in focus group sessions for their feedback and for re-development. Stakeholders will include adolescents with ABI, parents, peers, and practitioners.

Questions

- 1. How long have you worked within the field of acquired brain injury (ABI*)?
 - Has this largely been with adults or young people?
 - Mainly in a research, clinical, or community role?
 - · Particular areas of specialty?
- 1. For this study, ABI will refers a number of injury mechanisms resulting in disconnection or structural damage within the brain, its neurons, and neuronal pathways after a typical period of development. Causes of ABI within the paediatric population include TBI, infection, stroke, hypoxia, tumour, radiation treatments, non-accidental injury, and secondary swelling.
- 2. What do you think are common difficulties experienced by young people with ABI?
 - e.g., cognitive, social, behavioural, emotional.
- 3. What challenges can these difficulties cause in everyday life for young people with ABI?
- 4. What is your perspective on the importance of peer relationships in adolescence in general?
- 5. How do you think peer relationships are affected following ABI in young people?
 - e.g., What might change? How will sequela of ABI influence changes? What will the consequences be?
- 6. In your experience, what is the impact of peer relationship difficulties on quality of life in young people with ABI.
 - e.g., What aspects of their lives will be affected? What are the ongoing psychological implications?
- 7. Which biological determinants do you think influence peer relationships following ABI in young people?
 - e.g., age, sex, brain development, genetics, health difficulties, pain, injury type (mechanism and severity), post-medical interventions (radiotherapy, surgery)?
- 8. Which personal determinants do you think influence peer relationships following ABI in young people?
 - e.g., personality, sense of self, social skills, pre-injury factors?

- 9. Which psychological determinants do you think influence peer relationships following ABI in young people?
 - e.g., cognition (e.g., memory, attention, processing speed, executive functioning, visuospatial, fatigue, awareness), communication, social cognition, mood (PTSD, anxiety, depression), resilience, coping skills?
- 10. Which environmental factors do you think influence peer relationships following ABI in young people?
 - e.g.., family functioning, educational support, peer understanding, social relationships, engagement, societal understanding, on-going community support (healthcare and social)?
- 11. Which behavioural factors do you think would influence peer relationships following ABI in young people?
 - e.g., impulsivity, inappropriate behaviour, aggression, social isolation?
- 12. How do you think young people with ABI can be supported to improve peer relationships?
- 13. Is there anything else that you think is important to discuss which the questions have not covered?

Thank you.

Further information

If you would like to know more about the study or ask any further questions, please do not hesitate to get in touch with myself (sa675@exeter.ac.uk) or Prof Anna Adlam (a.r.adlam@exeter.ac.uk).

Thank you for taking the time to complete this survey.

Please return your completed version via email using the addresses above.

Warm wishes.

Scott Ankrett Trainee Clinical Psychologist

University of Exeter sa675@exeter.ac.uk

Appendices

Appendix A: Outline Timeline of Planning Group Involvement Across Study

- 1. Forming of the planning group (March 2019)
- 2. Surveys sent for completion (March/April 2019)
- 3. Consultation in Phase 1 feedback on first draft of logic model of the problem (a model which outlines the determinants which influence peer relationships following ABI) developed from planning group responses (May 2019)
- **4.** Consultation in Phase 2 feedback following stakeholder focus groups and feedback on revised logic model of the problem (re-developed with stakeholder input). **(December 2019)**
- **5.** Consultation in Phase 3 feedback on qualitative analysis of the study, providing a completed logic model of the problem, suggested determinants for change, and intervention themes and aims (**February 2020**)
- 6. Thesis submission for examination (May 2020)
- 7. Thesis viva (July 2020)
- 8. Submit manuscript for publication (by September 2020)

Appendix L: Logic Model of the Problem (1st Draft) for Focus Groups and Interviews

DETERMINANTS PROBLEM: PEER RELATIONSHIPS AFTER ABI QUALITY OF LIFE Biological Behavioural **Everyday Difficulties** Peer Relationships and ABI Quality of Life Determinants **Determinants** of ABI Peer victimisation and rejection Difficulty with acceptance Age of Injury o Behaviour that Vulnerability to social o Seen as 'different' [to others and [from self and others] influences [intensions Injury characteristics challenges compared to pre-injury] o Change in identity [type, severity, Fixed thinking of others, gangs, crime] o Uncertainty from peers on how o Increased dependence on location] Emotional control o Academic challenges to interact with teenager with family Motivation [mood] o Grieving past identity Gender ABI Isolation and reduced On-going health issues Avoiding social and abilities o Ability of peers to be able to social contact situations [self- Opportunities to adapt to changes in personality Mental health difficulties isolating] participate in activities o Ability to manage stressful social o Loneliness Personal Feeling misunderstood o Risk of harm to self situations **Determinants** Social skills Cognitive barriers to friendships Environmental o Maturity [multifactorial] o Social communication difficulties Determinants o Personality o Quality of interaction and Family relationships o Popularity at school relationship and support o Social skills [pre-injury] Peer support and o Time away from peers and Stability in identity reintegration adaptability [pre-injury] Social avoidance and isolation Community support due to mood and understanding **Psychological** Location and available Determinants o Cognitive abilities services o Family openness to o Communicative ability share difficulties o Mental health and Parental coping mood o Family, school, and o Resilience peer understanding Determinants = factors that can influence everyday Social cognition [ability to process and difficulties for teenagers with ABI and their friendships. respond to social information]

Appendix M: Focus Group Schedule for Adolescents

Adolescent Focus Group Schedule

Introduction – 5 Minutes

"My name is Scott and this is NAME, and we're here today to have a conversation and be creative"

"The aim of this group is for us to have a discussion about friendships following brain injury in teenagers. We want to hear about the good things and the bad things"

"As you are the experts, we also want to ask for your help and tell us what would be useful to help you and other young people with brain injuries to build friendships"

"We will work together for around one hour and I will ask the group some questions. I hope that we can have a discussion around these and make some notes together using this big piece of paper and coloured pens. There are no right or wrong answers, we are just here to hear each other's opinions"

"To help me remember what has been said in the group, I will use this to record the session, but only the research team and transcription services will listen to this. You can talk to your family and friends about what you have said in the group. You can also talk about what others have said but you cannot use their names, as their opinions may be personal to them"

"The only time I will tell someone about what you have said in this group is if you share something that worries us, something which may result in either you or someone else getting hurt, but I will talk to you about this first"

"Some of what we speak about today might make you feel sad or angry, if you find this difficult, please let me know and we can stop and have a break. You

can then either carry on in the group or leave the room. If you feel too sad to carry on, that's okay."

"Do you have any questions?"

Respond to questions

Open Question – 10 Minutes

"Okay let's get started"

"Let's talk about friendships, what are these? Why are they important?"

• What are your experiences of these after ABI?

"Thinking about some of the difficulties that young people can experience following brain injury how can these influence friendships?

- "Changes in thinking"
- (attention, memory, executive functioning, fatigue)
- "Changes in ability to communicate to others"
- "Changes in mood"
- (sadness, anger, worry, PTSD)
- "Changes in behaviour?"
- (impulsivity, aggressive, withdrawn)

Key Questions – 35 Minutes

Determinants

Social Factors

"Let's talk about school...do you think schools, teachers or friends, understand brain injuries?"

"Do you think that schools provides enough support to help other young people in class to understand brain injury"

"What do you think other children think about brain injury, do you think this affects friendships?"

"Does ongoing medical support affect friendships?"

"Do you think there are enough opportunities for teenagers with brain injuries to meet new friends? Or be with their friends?"

Psychological Factors

Cognition

"Changes in thinking are common following brain injury, people may experience changes in their ability to remember things, problem-solve, communicate, or concentrate. Let's talk about how this can affect friendships"

"What's your experience of this?"

- Remembering what friends have said?
- Keep up with conversations
- Tiredness gets in the way of being with friends?

Social Cognition

What about processing and responding to social situations?

Interacting with friends

- Understanding how friends are feeling
- Understanding jokes
- Upsetting friends without knowing why

Mood

"Changes in mood are common for everyone. Following brain injury, people may experience strong feelings of sadness, worry, or anger, which can affect being with friends"

"What's your experience of this?"

Behaviour

"What about behaviour with friends following brain injuries?"

- Isolation?
- Unacceptable behaviours?
- Aggressive behaviours?
- Acting without thinking?

Quality of Life

"How do you think all of these difficulties which we have discussed so far affect quality of life for teenagers?"

BRIEF TASK

Logic Model of the Problem

"Here is a diagram which has partly been filled in by some people who have worked a lot with young people with brain injuries. Here, we are trying to understand what can influence friendships and how this can affect day to day life."

Talk through model.

"Does this make sense, are there any questions?"

"Now, although these people have worked a lot with young people with brain injuries, they have not had one themselves. I need your help to see if we need to make changes to this to ensure that this is meaningful for you"

"Do you think that there is anything missing from this?"

Prompts:

- "Do you think that this has included everything we have spoken about so far?"
- "Does anything need re-wording or deleting?"
- "Is there anything that you do not agree with?"

What Needs to Change?

"Okay, what needs to change to help build friendships following brain injury? What do you think can help?"

Prompts:

- "What about awareness and understanding?"
- "What about increasing opportunities and practice?"
- "What about learning new skills?"
- "What about help with thinking?"

- "What about help with mood?"
- "What about help with behaviours?"

Meaningful Intervention Design

"If you were being supported with friendships at school or hospital, what would be most important to you?"

Prompts

- "Would this be online or in person?"
- "How long would you like this to be?"
- "Would you like this to be individual or in a group?"
- "Would you like this to be delivered by a teacher, psychologist, or young adult?"
- "What type of goals would you have, or hopes following the support?"

Ending – 5 Minutes

"Okay, thank you, that's all the questions I have. I think we have had a really good discussion and spoken about some really important things (summarise key points)."

"Are there any questions?"

"How is everyone feeling? Does anyone have any concerns?"

"Thank you so much for taking part in the group and helping me with this project"

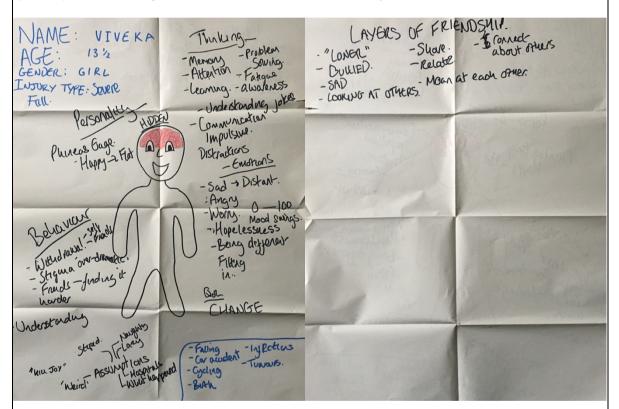
Provide thank you cards with £10 Amazon voucher.

Provide debrief and additional resources sheet.

Appendix N: Reflections Following Piloting of Schedule

15/04/19 | Focus Group Piloting

Piloted the focus groups schedule (adolescents) with four adolescent females without ABI (2 aged 15, 2 aged 13). The purpose of the piloting was to assess the accessibility of the draft schedule, checking with the participants the meaningfulness of the questions for their age range and to see if how they responded to the questions was suitable for the research questions. The challenge with this is that the schedules were designed for individuals with extensive experience of ABI in adolescence. As such, a significant amount of time was spent attempting to get the participants to consider themselves to have an ABI or to imagine being a character who had an ABI. For this, we created a character called Viveka (see below) and built up her story, allowing the participants to imagine what life would be like if they were Viveka.



The consequence of doing this is that we spent a large amount of time talking around the brain injury in the paediatric population. Similarly, the first questions asked for perspectives on common difficulties following brain injury. This resulted much time being spent on a question which wasn't related to the research questions. As a result, I amended the focus group to exclude this question. This is with the assumption that those coming to the focus group will have a good understanding of ABI, saving time and relevance for the study.

Other questions on the schedule appeared to be accessible to the piloting group, and they did not report any difficulties understanding the questions. I expect that a significant amount of time may be taken when explaining the logic model within interviews and focus groups. To account for this, I will make a summary sheet of

the logic model and send this to stakeholders prior to their participation. The piloting group presenting with no difficulties in being able to talk about friendships in adolescence and think about how having an ABI might alter peer dynamics. As suggested by the piloting group, no further changes are required on the schedule.

Out of the conversation with the piloting group, some interesting topics arose. Assumptions from peers appeared to be a potential barrier for friendships in young people with ABI. The piloting group said that without understanding, assumptions may be made, such as "she's sensitive, she's a drama queen" which may affect the ability to connect with others. Similarly the group offered some helpful suggestion around how an intervention programme should be delivered to people of their age, based on their experiences of what they have found helpful at their school, such as not having an external person come deliver an assembly, opting for more of an in depth teaching and rationale, co-delivered by a teacher and independent person.

Key points from discussion:

- Lack of understanding from staff and students
- Assumptions: taking things personally
- Understanding jokes hard to lighten mood around brain injury, may be easier to withdraw from peers
- Jealousy from peers 'special treatment' without communication and understanding as to why.
- Difficulty 'fitting in'
- Family can be over protective
- Social anxiety
- Increased impulsivity for arguments
- Memory problems causing tension
- Friendships are important at school someone to rely on and share things with, provides understanding
- More likely to get bullied without friends, no one stands up for you
- Feel left out
- Less likely to be motivated at school
- Friends are someone who you can share problems with, moan at, relate to
- Workshop would be better than an assembly (no pointless work sheets)
- Lack of understanding from friends, assumptions:
 - What happened?
 - Lazy, naughty, using it as an excuse
 - Rumours if the child is unpopular
 - Faking illness bringing a doctor's note for friends (?)
 - No physical difficulties invisible injuries.
 - Less likely to be invited to things "kill joy", have to be more careful around what you're saying.

Appendix O: Theme Summary for Stakeholder Feedback

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Theme	Description
DOMAIN ONE: UNDERSTANDING	This domain encompasses an understanding of what peer relationships are like following ABI in adolescence, and what causes difficulties with peer relationships, as described by stakeholders.
Dropped and Excluded	This theme captures stakeholder experiences of adolescents feeling dropped by friends following brain injury. Stakeholders describe the loss of friendships, influenced by friends moving on whilst the adolescent is away recovering. In addition, when re-integrated back into social contexts, peers can perceive adolescents as weird, or frustrating, influenced by behavioural, cognitive, and social cognitive consequences of ABI. As such, peers are more likely to reject adolescents or exclude them from social activities, as for many teens this is a stage of important social development and sensitivity to social acceptance.
Isolated and Alone	This theme describes the feelings of isolation and loneliness of adolescents following ABI, resulting from the exclusion by friends.
A Need to Belong	This is an important theme that follows stakeholders identifying the importance of peer relationships for belonging. Adolescents following ABI have a strong desire to fit in, appear normal, and be accepted in some capacity. As such, adolescents can make adjustment to friendship groups, such as relating to those with similar needs, or becoming vulnerable to undesirable influences.
No one Understands	Stakeholder accounts suggested that difficulties with peer relationships are compounded by people's lack of understanding around ABI and how individuals may change, although look the same. This is the difficulty with ABI as they are often termed 'invisible injuries' whereby survivors appear the same to others but act differently. Without education and understanding of this, people around adolescents can make assumptions or becoming victimising towards them (stigma).
Restricted Independence at a Time for Growth	Adolescents following ABI experience significant restrictions on their lives compared to their peers. This is at a time of important social development, as such, adolescents can fall behind when compared to their peers. Such restrictions include over-protection, always having a TA, and reliance on others.
Loss of Past-Self	Following ABI, adolescents experience significant change in terms of their identity. They may not be able to continue with previous career aspirations, may lose sporting identity, and lose and overall sense of self amongst friends and family. This comes with significant emotional ramifications and adolescents attempt to adapt to their new identities post-injury.
Challenges with Acquired Status	This themes encompasses the conflicts and difficulties adolescents face following ABI, in terms of mood, emotions, behaviours, and

cognition. There is a sense of loss of previous abilities as well as challenges in their new way of being. This can impact upon peer relationships through responses to behaviours, withdrawal, or cognitive challenges.

DOMAIN TWO: SUPPORTING

This domain encompasses themes from stakeholder accounts regarding what needs to change to improve peer relationships and what outcomes the intervention should focus on.

Building Understanding

This theme captures the need for increased understanding around ABI within the adolescents educational, social, and community contexts. This may include teaching training, education sessions, online resources, videos, apps, to help build understanding and acceptance.

Meaningful Social Connection

Stakeholders identified a need for more opportunities, however, not just an objective amount of opportunities but subjectively meaningful opportunities. These include, being with friends, meeting others, peer mentoring, doing fun activities, having someone to talk to.

Support for the Journey

Within this theme, stakeholders felt the need for early support following ABI. Often, stakeholders felt isolated and unsure of the future following discharge from hospital. Furthermore, lack of assessment resulted in lack of understanding within contexts. Within this, it would be important to consider anxiety management, knowledge, and realistic expectations.

Empowerment

An intervention needs to empower adolescents in the context of ABI. Often they received negative messages from their contexts which can result in feelings of shame. Empowering adolescents may include validation, normalisation, knowledge, hope, and opportunities for adolescents to become the experts, such as using social media to describe experiences or to teach others about ABI. An increase in confidence may support relationships with peers.

Appendix P: Domain One Theme Building Tables

1.0 Understanding Peer Relationships following ABI in Adolescence							
1.1 Dropped and Excluded	1.1.1 Friends moving on/ Loss of friends/ Loss of sports/ being included I have only got three friends because all the friends I seem to make keep on dropping me and being horrible. (FG) You know when you put on your thing it said about grieving the because she really does remember what she was like 2½ years ago to how she is now and what her friendship groups were like, and now she doesn't really see anybody that she was at primary school with. (FG) the move to secondary school further alienates you because your able friends, although they might have supported you in primary school, when you get to secondary school they move on and meet other people and your further dropped really. (I) so you're sick all the time which means you're off sick even more than you already were, so things go on and people develop friendships in school, and you're missing it all, like I had a best friend because she can't go through school every single day without somebody (I) So then I missed out on that big time and then all of my friends that I went to it with all got on the teams and then I didn't get to go, and then obviously you grow apart from	1.1.2 Falling behind/ not keeping up/ schooling environment/ SEN group But then you don't achieve what they're achieving and you're kind of being left behind. Then that will, the whole mood thing will just breakdown your friendship and they just don't want to be around you if you're not happy. (1) and often they can't after brain injury because they can't keep up with it cognitively, or physically sometimes, erm, and so they get put into another group in the mind of their peers, they get put into the SEN group (1) I wanted to be with my friends, I got moved back a year. I really struggled with that. Because then I wanted to do 10 GCSE's, you weren't allowed to, I struggled with that (1) I didn't know them before they had their brain injuries, but for these two who have had a real severe impact, the difference is massive for them because they've gone from what was their typical trajectory to being completely taken out of their cohort of peers, so they don't, certainly in their school hours, they don't have access to those peers	arrangements are made within a group, and then the young person with a brain injury forgets or cant plan and organise that, so doesn't turn up, then friends get annoyed and you don't get asked again. (I) And she is a bit like [name], so you have to repeat conversations, and so new friends or other friends are like, "Well, I've told you that already," or "Why are you asking me that," and so then they sometimes maybe get frustrated quicker than(FG) for maybe the first 4 years, like I would have had the same conversation with you in the space of half an hour like three time. Erm, and, you know, people would tell you that you had upset them and you will have forgotten and you go and speak to them and that will upset your friend further and they"ltell you that they don't want you to do something and you'll forget and you'll go do it, and so grudges held left right and centre but you're completely unaware of this. If that makes sense.(8) Eccuse you can't actually remember what the issue has been. (II)	Yes. I make fun of it. Then they say I am even weirder because I am making fun of it. It is not something to make fun of, but when I have got nothing else to do about it, it is better to make fun of it than just be sad about it all the time. (FG) When I am trying to be sarcastie, my voice doesn't sound it at all so people just think I am being really weird. I sometimes take people seriously and then they will be like, 'It was a joke,' or something. (FG) No, and she has no filter, [name], sometimes, so she says things that are – 'inappropriate' is probably too strong – but in the wrong context, and so then the other kids are like, "Well, that's a weird thing to say," and then she's like that, "Oh, did I?" (FG) They just think she's a bit odd. (FG) Their friends, while they don't purposely want to isolate this person, knows there is something different about them and just wants to kind of get on with everybody else and fit in everybody else, so they don't want to be the one who hangs out with the one who's just a bit weird. (I) Erm, I think the word 'weird' comes up quite a lot because, this is without physical disability, the young people, the peers are aware that this person is different but can't really understand all the invisible things, so they would say 'weird' and	people with a brain injury don't see that it's slowly going wrong until it's completely gone wrong or someone's completely left them (1) so if a girl vaguely smiles at them, they like, over-step the mark because they think "oh, she likes me" erm this touching and being touched in schools is a massive problem for young lads, particularly with brain injury because they don't read the green flags or stop sign very well and they miss judge it. (1) But it kind of continued a wee bit, not on the same level, but obviously, you know, she took a mobile phone from someone's room, she used it, it was still just lying on her desk, it wasn't like she was trying to hide it or steal it, but it was on top of her desk (1) if you've got no empathy into their situation and how it's devastating for them how their boyfriend has dumped them and you not understanding that, and all you're caring about is the fact that your shoes don't fit, that kind of thing, then you're not going to get included in conversations, your friends are not going to come to you and talk about things if you've got no understanding on their level of what their experiencing. So, of course you're going to get left out of that.	I have got some friends that I thought were my friends, but then they are really nice to me when I am dizzy and stuff. Then they are caring and trying to look after me, but as soon as I am not they don't hang out with me at all. I question now almost all of my friends. Do you actually like me or do you just feel sorry for me? (FG) But she doesn't really seem to keep them. She flitters from one person to another, and, you know, someone, she seems to think that someone is her friend after a day, you know what I mean. So that's an issue with her, but she hasn't got a problem really making friends. But she really just flitters from one to another. She doesn't seem to hold onto them. (I) she just sort of falls out with somebody, because she makes friends easily, she makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend and then falls out with them, makes another friend she had since the accident, she's got new friends now, as I said, she seems to make friends easily, but they don't last. They're sort of quick friendships, there's nothing to them if you know what I mean? (I)	No, there was nothing there until I started to get bullied at school, and then CBIT came in, Nadia came in a spoke to them but before that, no, there is nothing, like no conversations about what way I could maybe be coming back, how different I would maybe be, nothing like that it was just I came back. And then, when I started to get bullied, that 's when CBIT came in, and tried to explain it, but it was kind of too late by that stage. Everybody had kind of made up their mind and that was that. (1)
	and then dovlously you glow have them because of that. (I) Well(sigh), just because, you know, she seems to have lost everything previous to the accident, you know, all of her friends and, she's lost all them (I) Erm, no, I think it's the whole you're missing from school for so much and then, that's when everybody plans things, if they're even doing something after school or they're doing something that weekend, they plan it whilst they're in school and you're not there for that planning stage, therefore you just don't get invited, and that's it. So you're already missing that peer interaction from school, but you're also missing any type of interaction outside of school. (I)	anymore, erm, erm, I doubt how much access they have outside of school (I)	Well, sometimes they get annoyed with her and this is probably why she makes short friendships, crm, and doesn't sort of keep them (I)	Immstote lings, so they worked say whith a missay "oh, he's really weird since he's been back", or whatever. (I) I mean, because they can be so cruel now kids, you know, (name) gets called weirdo and stuff she laughs it off and then other times she's really upset about it. (I) Either they think they're bad, or they're daft, or they're just weird, maybe that's what they're thinking? (I)	an old school friend who lives just around the corner just happened to knock on the door, he's never done it before, just knocked on the door, Itel thim in, and he'd come round to see (name) and came to see if he wanted to play. (name) was like "go away". He was really rude. (I) Yes, when they are saying something I will be like, 'Why are you saying that? That is a bit weird to say.' Then I realise that they are just joking. (FG) Well, she's to the extremes. She doesn't seem to have any empathy now (I)		

1.2 Isolated	1.2.1 Feeling isolated	1.2.2 Difficulties meeting up	1.2.3 Mental health/ trauma	1.2.4 Reing alone
1.2 Isolated and Alone	Their friends, while they don't purposely want to isolate this person, knows there is something different about them and just wants to kind of get on with everybody else and fit in everybody else, so they don't want to be the one who hangs out with the one who's just a bit weird. (I) I think that's the issue that people have, is that they just changed so much and they just don't fit into those friendships groups anymore and then they just end up being really isolated and in so many families and children with adolescence, that was the hardest thing that they found for them, not kind of mourning for the child that they lost but seeing their children being kind of sad and lonely. (I) Yeah, like I said it's the hardest thing, it's not like the loss of the academic ability or even the loss of the physical side of things, it's that isolation and	1.2.2 Difficulties meeting up with friends You're also not allowed to do the same things that your peers would have been able to do like, like I wasn't allowed outside for like six months (laughter). You know because I was, it was feared that I got hit in the head, so I didn't go out and then I wasn't allowed to play hockey and I was a big sporting person, so I wasn't allowed to play noteky, I wasn't allowed to play netball, I wasn't allowed to play anything in case I got hit on the head. (I)	It sounds, it sounds, really awful but, erm, the, whenever you go to the doctors and go to the doctors and whatever and see them and stuff like this and they say "oh yes, you suffer for post-traumatic stress disorder, because of your brain injury" I'm like, "no, I didn't suffer from post-traumatic stress disorder because of my brain injury", I could deal with that fine. I could deal with the fact that I had a brain injury. It was losing all the friends that I couldn't deal with. (I) Low mood obviously does, is socially isolating because you don't, it's a lot of effort isn't it if you want to keep up a social life and if you, if in your mind it's been proven that actually no one wants to be with you then why bother? You don't do it do you? (I) But then because you're so low mood, when if you're around people when you feel like you want to be around them, they don't want to be around you. Like, nobody wants to be around someone that's not happy, and then also you're so frustrated that, obviously you're angry, and your anger shows. (I)	And then we've had to move her schools again because the school that she was in couldn't really accommodate her so she's gone to knowing nobody, and really, she really needs a better friendship network and she finds it really hard. Whether she would have always found that hard I don't know, but she's certainly lonely, and more lonely probably than she would have been if she hadn't banged her head and could actually stay in a classroom. (FG) if you are not connecting with people of your own age in an appropriate way, then you can feel very isolated and lonely, and you're going to be able to achieve anything else, like, you're not going to be to progress in school if you're going into school and feeling very socially isolated, and anxious, and depressed. (I) He's not even wanted to have that kind of interaction, it's almost like my family, my dog, and if you talked to him which hopefully you will, it's "milly this, milly that, milly everything", his dog, his brothers, his dog, his swimming, his art, it's just, his world has narrowed. And it carries on now when I see how narrow it's got. I
	child that they lost but seeing their children being kind of sad and lonely. (I) Yeah, like I said it's the hardest thing, it's not like the		when you feel like you want to be around them, they don't want to be around you. Like, nobody wants to be around someone that's not happy, and then also you're so frustrated that, obviously you're angry, and your	He's not even wanted to have that kind of interaction, it's almost like my family, my dog, and if you talked to him which hopefully you will, it's "milly this, milly that, milly everything", his dog, his

1.3 A Need to Belong	1.3.1 Wanting to be with friends/belonging	1.3.2 Fitting in and being normal	1.3.3 Vulnerability	1.3.4 Similar level friends	1.3.5 Moving schools	1.3.6 Friends over grades
	You need to have a community in which you feel you belong, other than your family, other than num and dad. As you're growing older you need to have something, whether it's just who you play football with, somebody else who actually is helping you in some ways to move on to becoming an adult. (I) They just need to feel like they belong to something, whether it's one friend or five friends, or certainly for us it is. She just needs to feel accepted and normal, that's her daily thing — (FG) I think that when you are younger, they don't matter, like friends, you know, you come be friends with Tommy one day and Deliah the next. It's not, you know they're just who you hang about with but as you get older and you go through different situations, scenarios and boyfriends, girlfriends, parties, you all those kinds of things, sports clubs, hockey, netball, all that, you need to have a structure of friends otherwise you'll be isolated. (I) so whether the children there won't like social interaction and some of them will, and I think they are aware that, for the particular children with the acquired brain injuries want the social interaction and I think that is something that they do come to me to ask for help with (I) there is this overriding sense of, of her need for the right peer group. Erm, and that probably does play quite a significant role in her lack of quality of life. (I) But having a breakdown in peers and losing all those friends, and not having somebody to go through the experience withmakes it ten times harder. (I) Okay, erm, friendships are really important throughout childhood, erm, but I think the nature of friendship in the teenage years becomes really much more important because of identity, because young people in the teenage years want to be seen to belong to a certain group (I)	I think that's the issue that people have, is that they just changed so much and they just don't fit into those friendships groups anymore and then they just end up being really isolated (f) Yes, do I fit in? Yes, exactly. Kids want to be normal as a teenager. They don't want to stand out, and by having some form of injury—whatever it is, or dyslexia or anything—you want to be as normal as possible and I think that's quite hard. (FG) Yes, because she's so vulnerable—And they're desperate to be liked.—and so desperate to fit in, and desperate to look cool, whatever that is. And they don't understand what any of this is, (FG) Because kids don't get it, do they? That's the thing. And all they desperately want is to fit in and be—not super-popular—but have a little crew—No, just a have normal—crew of kids that are the same as them, and that are accepting of them. (FG) "The reason you're not is because you've banged your head and you're not as normal as everybody else," and so she will be very upset this evening, I already know, by just making her even more aware of how she's not normal. (FG) Erm, yeah particularly for one of them, a desire to be part of that group in terms of, erm, it's really hard to put into words, er, to have some aspect of normality, like, em, so around her siblings, she wants to be wearing pants because she know that that's what they do, so there's that sense of wanting to be 'normal' (1) You've got this child who, all they want to do, is just fit in and they can't. (1) (name) then refused to engage with her because, and this is very important for your study, because he didn't want to appear different. (1) And if my peers and my friends who, you would like to think, would want to take it in, if it was like a week-long I think that they would. I didn't really like the whole pushing me to surround myself with other people with brain injury. Didn't like that because, like CBIT did that and I love CBIT and everything, but I wanted to be normal. (1) You yet kind of want to forget about it	No, not safe opportunities, and that brings in the problem with teenagers with brain injuries being so easily led, because they're very keen to be part of something, so they might get drawn into activities that are inadvisable or down-right dangerous, just in an attempt to be part of the group. (I) I think it does. Yeah, and if they've been dropped from, if they were quite academic and they were with a fairly driven academic group prior to injury, they now can't keep up with those friends maybe and so therefore they might resort to another group of friends where they can be funny or be useful in some way, or, then they end up in trouble and that's a real slippery slope for them. (I) Yes, because she's so vulnerable -And they're desperate to be liked and so desperate to fit in, and desperate to look cool, whatever that is. And they don't understand what any of this is. (FG) You can't regulate yourself, bang, and then you're in real trouble. But that's what some of the groups of boys find so funny, you know, they will wind somebody up and then watch them hit the teacher, or chuck something at the teacher. Apparently that's hilarious, you know (laughter), it's horrible isn't it. (I) And it's the safety really, I worry about them and she's 15 now, obviously friendships with boys that are similar, but she's at an all-girls school thankfully, but erm, yeah I'm worrying over her, she seems to just do everything on impulse, and it's that impulse thing that seems to not be regulated now. (I) Yeah, I think that would be my main thing, her safety. Her trust in people and just believing everything everybody assys, she doesn't seem to have that little sort of thing inside you to say, "hang on a minute, that's not quite right", she doesn't have that. (I) Oh yeah, I mean she'll definitely, that's definitely a major worry for me, around men basically because she's a good-looking girl and she's attractive and she would just go with anybody I'm sure if she got left to her own devices without thinking. (I)	One boy, because he's the only kid that's just chilled, and he's a little bit quieter and a little bit slower, and even though they were friends at school, now they're really good friends just because they're now on about the same sort of pace. (FG) And because the girl was French, even though she spoke really good English she was just slower at her processing because it was a foreign language, and they just got on brilliantly because she was actually on a par. But the girl only stayed for a term. (FG) And actually I think some of those are the vulnerable kids at school, [name] is in a separate unit and they come to the unit rather than having to face all the kids in the playground. So it's like his situation has helped them. (I) But as I said, some of his friends are with him because they are the ones who find the playground stressful as well. But it seems to have children who have got – which suits him brilliantly – anxiety, not fitting in at school or whatever. We've never found an activity where he can go and interact with peers who have no brain injury. (I) Erm, but I know he's, erm, the only friendships I would say that he's kept, have been, bizarrely, erm (sigh), a child called (name), that he was friends with at his primary school, who's got ADHD, who also has problem making friends, and they've been able to rekindle their friendships over Fortnite online (I)	And then we've had to move her schools again because the school that she was in couldn't really accommodate her so she's gone to knowing nobody, and really, she really needs a better friendship network and she finds it really hard. (FG) I was going to say to you, think back to when it was really hard to get friends. Because [name], we've got him into a school now where he's made some new friends but for a long time after your injury it was a bit hard, wasn't it? (I) Well, yes. See, I've done as much as I can to try and get people in to help them. Because I think they understand. So we have specifically chosen the school based on their special needs record and what they can offer. (I) so I left erm went to college, but a lot of people in colleges were coming from secondary schools in which people had classroom assistants and people had learning difficulties so there wasn't a judgement and no one knew me before so this is who they knew me as, and that was that. (I)	Yeah, so, my focus would be off all the other clinical crap and more onto making sure that those peer relationship don't break down. (I) Our whole experience of the brain injury, the thing that has upset us the most as parents was friendships. So we have based his school and most of his educational healthcare plan not on the academic side but on the friendship side. So that, for us, was kind of like we don't care if he doesn't come out with any formal qualifications, or few;; we want him to have friends. And so for us, that has always been the most important thing. And so that's why high school has been working for you;; because you have found some friends. But we identified that as the most difficult thing for him. (I) I would n't have cared if I got my GCSE's as long as I still had my friends at school. I would rather I had peer interventions from psychologists at school that I had for educational stuff. I would rather I had fer orducational stuff. I would rather I left school with no GCSE's and didn't get bullied. (I) That peer relationship is more key to an adolescence than their ability to succeed at school or to be better. (I)

1.4 No one	1.4.1 Environmental understanding	1.4.2 Assumptions and attitudes	1.4.3 Invisible injury/	1.4.4 Peer acceptance	1.4.5 Support received
understands		of others	Appearing the same		
	My new school that I am at now is. I moved school because the school I was at wouldn't have a meeting about my concussion. It was a really rubbish school so we moved and now the school are really supportive. They have a special area that I can go to and it is really good now. (FG) And we had a friend, and her daughter – this happened – and her daughter decided she did want to go, and we said, "Well we could watch it from the house so then it's not quite so intense," and she was like, "Oh, but she really wants to go down to the field with everybody." So, they're going to go, so [name] stayed on her own. And I was like, "That's pretty crappy friendship," but that's what some of the parents can be like as well, that they just go, "Well, she's just being not wanting to join in," and it's like, "Well no, she would love to. If anything, she'd love to go down there," so(FG) No, I chose to leave school because of it. So I, from about 13 to 14 I was in school maybe one day a week two days a week. My first day back at school, after 6 months off. Je ots at down to do a key stage 3 exam paper, and I was like "are you scrious?" (laughter), like that's by a teacher, so teachers didn't understand. (I) Erm I think that if you have a brain injury you, it can break down a relationship because your friends do understand, there's like a lack of understanding there. Erm, but in the same way, peoples brain injuries, like myself, you don't pick up on the same social norms and social cues anymore. (I) Erm, and your frustration shows and then the fact that your peers don't understand your brain injury so can't understand your frustration, then it's the same thing of "ah, you're alright, there's nothing wrong with you' and that is what you would always get. (I) Well the, if you go from like the very beginning, the lack of information leads to lack of support following brain injury which means that there's that lack of not having support there means you're not informed on who you are now ow what struggles you might be having t	And I think that comes out in the education system, quite often parents getting constantly questioned around their child's disability; "Is it real? Are you sure i's real? Are you not over-exaggerating? Are you sure you haven't made it up?" (FG) and then the recovery, erm, they can start to kind of assume that everything will kind of go back to how it was and they start to step away (I) But I think about his primary school when he went back. I think they just thought he was going to go back to normal, how he used to be, and they were just like well we'll just carry on until he's okay. I, erm, the school kept saying they were on the side, but they literally expected every week that it would magically go back to normal (I) his friends were then saying that he was skiving, it was because the lessons were boring, I think they resented that (name) could leave a really boring lesson. (I) Then you're getting out of school, you're going to all these appointments, you're getting special treatment, why you not palying on the hockey team anymore, why you not going to this…if you look the same. And then I think that develops, like a bit of grudge, like your friends and your peers begin to begridge you, because they don't think it's fair. (I) What we've got, is we've got parents who are very much like, "Oh, she's just making a drama," or "Just pull yourself together," or "Is she really dixzy?" and "Does she just not want to be at school?" She loves school, she's a real grafter, and I think because you can't see a broken leg or blood or whatever (FG) And I think because you can't see a broken leg or blood or whatever (FG) Oh, you're totally disbelieved, or I feel I am, by all sorts of professionals. Because she is 95% there, but that 5% is massive. And it is like, "Well, I" m not sure that is what happens," and I'm thinking, "I'm telling you, that's what appens," and I'm thinking, "I'm telling you, that's what appens," on I'm thinking, "I'm telling you, that's what appens," on I'm thinking, "I'm telling you, that's wha	in some ways it's easier and better that he has a physical disability because they can see that something has happened to him and maybe make more allowances. (I) Whereas I came back looking the exact same, so it was like nothing had happened. Yeah, and that was hard for people to respond to I guess? Yeah, that pushes into the lack of understanding. (I) if you have a brain injury, that's obviously not a tumour, then they don't expect a difference, and you come back and you don't look any different, so that's the big problem. (I) Totally. I think because you cannot see something physical. If she'd been sat there with her crutches and her foot in cast, everybody would have stayed up at the house with her." But because they couldn't see it And then parents feed it back to the children, don't they? (FG) I guess, the fact that I would have healed and then presented as (name) again, but you know, my injury being invisible, it wouldn't have been so obvious to my friends, erm of, you know, that there would be any after effects, there would be, you know, things that would affect me following that injury. Does that make sense? (I) And this of course massively affects friendships, because these kids are looking at these other children who generally look quite normal, 99%, but then they'll go into this funny little zone and they're like, "What is going on there?" (FG) Particularly as you've got a physical disability, so people can see something has happened to you. But that's not always the case it, is, I think just the brain thing, and non-visible disability, is really difficult. I see people looking at these other children who generally look quite normal, 99%, but then they'll go into this funny little zone and they're like, "What is going on there?" (FG) Particularly as you've got a physical disability, so people can see something has happened to you. But that's not always the case it, is, I think just the brain thing, and non-visible disability, is really difficult. I see people looking at us when he's	There's some Down's, there's a cerebral palsy girl in another year. There's only 20 in each year. There's and with Michael's syndrome in my son's class. So, in every class pretty much there's someone, and they're so good at that school at including them all and it doesn't make any difference, and I think it comes – (FG) Yes. So [name] has a sister with special needs so we have found that anyone who's had some kind of experience has been very empathetic. I'm just thinking about I wondered whether you went back—this is what I thought but you may say this isn't true—you were a bit scared of some of the boys when they were playing in the playground, about being knocked (I) Erm, I think young people that have had more experiences of being around difference of any sort are better equipped for dealing with it. So, for example, school that are attached to a special school or have got special ed units within these chool, or just schools that are very inclusive and have a range of, erm, needs within them, I think young people gused to that really quickly, I think it's when they are separated and they don't have any access to difference that problems occur. (I) Yeah, it's really sad, and I think it not as much of an issue in younger children, because younger children almost seem to be more accepting of things. They're kind of much less self-aware and kind of see people with a brain injury or any kind of disability or additional need as needing a little bit of extra help and not worrying about upting themselves out to do that. So, kind of when they reach adolescence that they start worrying about upting themselves out to do that. So, kind of when they reach adolescence that they start worrying about upting themselves out to do that. So, kind of when they reach adolescence that they start worrying about upting themselves out to do that. So, kind of when they reach adolescence that they start worrying about upting themselves out to do that. So, kind of when they reach adolescence that they start worrying about upting t	My school is actually good at supporting me because if I am down in the dumps or somebody has hurt me, I can go straight to the quad and they have a hub there who I can tell. (FG) No. My school doesn't do that. They don't tell kids that this person has a brain injury or stop bullying them. They don't say anything about me, like how to treat me. It is horrible. (FG) Well, mine happened at primary school, the injury happened at primary school so I think my primary school suddenly stepped up. I've never looked at it from any other I'm sure I probably could do something but I haven't. And so, she then returned in Year 6 and they put an awful lot of stuff in place, but only because of what had happened. And then we went to a local secondary school. They refused to do anything; they wouldn't even have a meeting (FG) Yes, I mean, I don't know;; you're the first people I've met, ever, since she's banged her head in three years. (FG) back into these social groups, and it's kind of at that point, when everything else has fallen away from families in terms of support, the child goes back to school and everybody expects it to be as it was, and it wasn't, and that's when things become very apparent and very quickly (I) Erm, a bit, but I don't, when children get to adolescence, the ongoing support they get is minimal. It depends obviously at what point they had their injury, if 5 they have it during adolescence then they we still got a lot of support, but especially here in Wales, it kind of, after they leave the neurorehab pathway in the hospital, their medical input is really minimal, you don't have any community neuropsychs or anything like that, you just kind of get your once yearly appointment with your neurologist and then it's just kind of, get on with it, and here's CBIT's number (laughter) (I). Well, yeah, it's crap. The hospital is amazing and it's got a really good programme, but once you get out into the community that's it, there are no services, and I don't know what that is like across the others area

1.5 Restricted	1.5.1 Reliance on	1.5.2 Always	1.5.3 Over-	1.5.4 Restrictions on	1.5.5 Physical	1.5.6 Feeling anxious	1.5.7 Time away from
	-	having a TA			difficulties/	1.5.0 Feeling anxious	
independence	others	naving a 1A	protection	meeting friends			appointments
at a time for					tiredness		
growth							
	He would pretty much like me to be	And then I think he was always	No, and we wouldn't feel	they've gone from what was their typical trajectory	physical abilities, obviously, if	I would be terrified at the same time that I am going	We do some after school, don't we? Which
	around all the time. That's another thing I guess. We've spent an	with an adult. And I think it was really hard. A lot of the friends	comfortable letting her go and do that, including the buses and -	to being completely taken out of their cohort of peers, so they don't, certainly in their school hours,	they have any limitations physically, that can affect their	to get rejected. (FG)	means that you don't get as long on the Xbox with your friends. (I)
	unnaturally long time together. As	you had didn't really talk to you	Because we'd say she's a little bit -	they don't have access to those peers anymore,	friendships because they cant	Yes, or if you just don't get along. Just to go up to a	
	in, when you're in hospital, we lived together 24 hours a day, didn't	then did they, except for a couple of girls who were very kind. (I)	age-wise - behind, isn't she? (FG)	erm, erm, I doubt how much access they have outside of school (I)	ride their bike round to their mates house or, erm, maybe get	new person and start talking to them, I probably wouldn't be able to do that because I would be	Erm, you also have a million and one appointments a week, which means you 2
	we? And so from our point of view, just having an opportunity to be in a	[Name]'s sort of okay, but sorry,	I'm completely trying desperately to do the right thing and sometimes	No, because there's no, there's nothing out there.	on a bus anymore or whatever so the physical limitations affect it.	scared. (FG)	miss so much school because of that appointment, and your immune system is shot
	safe environment doing something	this came up in [name]'s life the	I'm thinking, "Am I sheltering her	There's nothing. That's why your intervention is	(I)	So, the first day back to school coming up, she's	to hell, so you're sick all the time which
	else with kids his own age would be a great, great thing for us. (I)	other day. It's that [name]'s live is full of middle-aged women,	too much? Should I be more forceful and go 'Do you know	so important because, I mean you can't even do, unless you knew CBIT, you lived near to their	nothing was acceptable and then	already flapping about it, "Where do I have to go? I don't know which classroom it is, I don't know how	means you're off sick even more than you already were, so things go on and people
	they do become so socially isolated	[laughter] and I'm putting my hand up there, that I am a	what? No phones today, you can't ring me from school"" – because	head office that they were an active, CBIT could put on family days locally, and they have coffee	headaches everything, like I lost a lot of function on my left side	to get there, de de de de de de," and I have to email the teacher and say, "Please can somebody just	develop friendships in school, and you're missing it all (I)
	they look more and more to the family, erm, they spend more time	middle-aged woman. Because she has TAs and that, and they're	she's got free access so she can just text me whenever she's having a	mornings for the parents or whatever else, there is no opportunity to meet anybody. (I)	and stuff like that as well so it made just doing stuff in school	take her to one side and just explain what's happening for today?" (FG)	That you get out of school, or like even if
	by themselves or more time with	all mainly middle-aged women,	wobble. Do I say, 'Nope, suck it		every day really tiring. (I)		you're going to an appointment, it's not fair.
	adults, they lose their inability to act with age appropriate peers, erm,	and actually I know one of the things is that [name] responds a	up, get on with it, crack on,' and I don't know which is the right thing	You're also not allowed to do the same things that your peers would have been able to do like, like I	And even if there is the off	Huge, because she analyses everything. So, she will analyse why someone's talking to her. And if they're	You know, I was in on Wednesday and then Thursday I wake up and I've had a banging
	the peers move on with everything (I)	lot better if it's somebody who is a bit younger. (FG)	- (FG)	wasn't allowed outside for like six months (laughter). You know because I was, it was feared	chance that you do get invited to something outside of school, the	being nice to her, "Are they being nice to me because they're being nice to me? Are they being nice to me	headache all night and I'm not coming in, well you were in yesterday so what's wrong
			We've probably, around the time when he should have been having a	that I got hit in the head, so I didn't go out and	idea that you can only go for an	because they feel sorry for me? Are they being nice	with you? (I)
	you have to rely on your parents more because they're obviously a	Even if he goes to the lesson and meets his TA there. Because we	bit more independence, he was	then I wasn't allowed to play hockey and I was a big sporting person, so I wasn't allowed to play	hour because of how tired you are is probably pretty high up	to me because they want something?" (FG)	Yeah, yeah, and it's the same thing with the
	bit eughh (sigh) cautious about letting you out on the train by	have identified that it can be difficult with your friends (I)	actually quite ill so I think then we've been a bit Well, not just us	hockey, I wasn't allowed to play netball, I wasn't allowed to play anything in case I got hit on the	there (I)	Yes, [name]'s the same. So, she's worried because she's going back to school that she's got five –	jealousy from the school absence and your appointments were always during school
	yourself or something like that, you know, in case you forget where you	Actually, I think on-going	but on advice from others we've been very cautious about how	head. (I)	Or silly things when you're really, really fatigued, all social	they've tried to keep as many of the same teachers as possible – but she has got five new ones. "Are they	hours and sporting hours and not everybody with brain injury will be into sport, but like it
	are, and you get lost and you can't	learning support in class, which	much he can do on his own. (I)	Yeah, it's really stupid things that you don't think	norms just go out of the window	going to pick on me?" "No, they're not picking on	was the only thing that I felt like part of a
	make your way from the train station to the cinema. They've got	is necessary, but I think that gets in the way a lot, particularly if	we've been too over protective. (I)	about though, like I wasn't allowed to go to the cinema for ages because they kind of treat you, I	because you're so tired. You know, you might be in a situation	you, they're just talking to you." "Do they know about me? Do they understand? I'm going to have to	team in, was if I was out playing sport, I was always missing it, which meant that I didn't
	those fears in them as well, so they want to then make sure that they	the enabler is not skilled because they don't know when to	For good reason to begin with but	don't know if everybody is the same, but in my case they kind of treat you like you're epileptic for	where it's inappropriate to do this, or you need to be putting on	stay in a lesson but I can't stay in a lesson because I get dizzy," (FG)	get on the team which then further led to me feeling isolated, if that makes sense? (I)
	take you from A to B to ensure that	withdraw or they hover around at	now I think we're a bit protective	a while. So, I wasn't allowed to school discos, I	a face, you just don't care, you're		-
	you are there safely, and you haven't had like a meltdown. You	playtime or whatever. (I)	and so we, perhaps, don't let you do as much as we would have done	wasn't allowed to the cinema, I wasn't allowed in anywhere with like ICT equipment (laugh) (I)	so tired. (I)	definitely in adolescent girls I've noticed it much, much, more, and their mood and anxiety and not	Erm, no, I think it's the whole you're missing from school for so much and then, that's
	have to rely on them being free too. (I)	Well, because no one is going to come and tell you a secret or	in the past. But we're working on that. (I)	Erm, you don't get those opportunities but at the	Initially, they said six months, but it's still, yeah, she's still	being able to keep on top of their emotions and having like outbursts in school which obviously leads	when everybody plans things, if they're even doing something after school or they're doing
	· ·	include you in on something if there's an adult sitting there. So,	.,	same time, what I was thinking, was that even if	(inaudible), she's quite a sporty girl but it's kind of forced, she's	to them being picked on even more and becoming	something that weekend, they plan it whilst
	People hang about in the streets then as well and you could always	no one's going to come over and,	makes these young people be identified as very vulnerable and so	you do get that opportunity, you're very restricted in your level of participation. (I)	always tired and I know	even more socially isolated, but they just can't seem to regulate the emotions they have to kind of fit in. (I)	they're in school and you're not there for that planning stage, therefore you just don't get
	hear them, but I just wasn't allowed out because I was either too tired	you know, give you all the gossip and dish the dirt if you've got an	there's that balance of people wanting to protect them I suppose.	Which is a big factor for peer isolation;; because	teenagers are always tired as 'well, this is the trouble we have	So, kind of when they reach adolescence that they	invited, and that's it. So you're already missing that peer interaction from school, but
	and needed my medication, there was a risk I could get hit in the	adult there, so you miss all that. Erm, you miss all the rude jokes	(I)	like you know, like I said you only go for an hour or you can only go for half an hour, or its decided	because it's all sort of muddling in together, but I mean she's	start worrying about what other people think and how you should behave and what your friends are doing	you're also missing any type of interaction outside of school. (I)
	head, there was nobody there that	and stuff like that, because it's		that you can't go at all. You know, so I, feel like,	never recovered the same. (I)	and that kind of stuff, and that's when it becomes	**
	could accompany me home and to where I was going. You had to be	like "oh, he's got her with her" or whatever, erm, the naughty bits		you know, there's kind of people out there that might still get the opportunity to participate in		difficult, high school age. (I)	Well, (name) didn't want to see psychologists again. She says that they were annoying, it
	accompanied everywhere, because if I forgot what I was doing or	of life you're completely discarded from because there's		activities, but then when they do, it might only be an hour when everyone else is there for five or six		He's definitely worries about what comes out of his mouth (I)	was annoying her, and obviously she had to take time out of school to see her (I)
	where I was like then I was going to	an adult sitting there. (I)		hours. You know, whatever. (I)		· ·	take time out of school to see her (1)
	be like a deer in the headlights, not knowing what to do. (I)	I had a classroom assistant at		Yes, [name]'s the same. She'd like to do it all, like		When you're meeting new people, or you're in a group situation, there is like, you know, pressures	
		school and that further led to isolation (I)		some of her friends will get a train from [town] to [city] and come shopping for the day;; she'd love		there to be funny or to talk a lot or to engage a lot and you become really paranoid about it because you	
				to do it but I think she knows and I know that the likelihood of her actually finding [laughing] her		know that you've got problems with communications, and then it almost causes a more	
				way back to the train station may happen, but		detrimental effect because you kind of overdo it then,	
				equally(FG)		because you're so paranoid. (I)	
				So I think it's been a bit restrictive really. (I)			
		1	I		l		

1.6 Loss of past self	1.6.1 Past self/ loss of identity/ loss of sports	1.6.2 Changing after injury	1.6.3 Maturity	1.6.4 Concerns for the future	1.6.5 Remembering before injury/ grief
Okay, erm, friendships are really important throughout childhood, erm, but I think the nature of friendship in the teenage years becomes really much more important because of identity, because young people in the teenage years want to be seen to belong to a certain group. (1) Erm, because it can, your, it can shape your identity of who you think you are, erm, that it's, cr, you've got someone of a similar, a peer who's going through similar things. (1)	Erm, it's just, it feels very unfair. Erm, nobody can tell you what's wrong with you, therefore nobody can explain to the people that you love what's wrong with you, and therefore how are they meant to understand it't therefore you get isolated. Very lonely, very depressed, you don't have that sense of achievement anymore, you've completed lost your identity, and, it just, it can lead to very downward spiral. (I) Then, it was, I need to go to A-levels, go to University and do the normal like adolescent thing, no you're not well enough to do that. So, then it was then you have to go to college then you were further isolated and that then caused more problems with your mood and then it goes on and to careers as well, like I can't work full time. (I) I know from talking to the kids that siblings actually highlight your demise as well. Because if they were younger than you, you were like the big brother, the younger person over-takes you and they're allowed to go out and get a girlfriend but you haven't got one. When that reaches its tipping point, then I would think that that her reduces your quality of life, because you're thinking "oh god, I used to be big brother, now I'm not." (I) his entire identity was through swimming, he had really close friendships with his swimming mates (I) he started to call himself, like Frank, erm, he said I'm not (name), he kind of had this rating of who he felt, and he's like "I'm not (name) anymore, I'm Frank" and then there was another one and I can't remember the other name that he gave, but it was almost like he was rating himself on, he was so not himself (I) Then, like, you're meant to be a high achiever, for example like over anybody else, but like you know I should have done this and should have done that and you have a constant comparison of where you should be, and you're not there. (I) You kind of deal with that whole loss of identity and get very depressed because you're not achieving what you could have achieved maybe a couple of months prior. Erm, then, you can	So, she's seen a few, but it's hard because she's changed; and she has changed, but has she changed because she's become a teenager is part of it, but she has changed from the child she was before she banged her head to how she is now? And she's lost loads of confidence, so that makes it really hard to make friends when you're really, really inward. (FG) And that's definitely what's changed, because for me obviously, your kids were quite a bit younger, but I had an I I year old wo was really savvy and really on it and up there, top of the class, blah blah blah, and literally within six months she can't remember the alphabet, she can't count to I ol and she's got a tutor, and she's not the cool kid in class that's selected for all the games because now when she throws the ball it doesn't quite go where it should. So, she's got a real personal battle. (FG) Yes, [name] was a completely normal child until she had the ADEM, and now she's not. And they were tipping her as being gifted and talented and things and all the rest of it because she was so bright, and now she's not [laughs]. And so yes, we've got the before and after – (FG) Yes, you see I kind of wish she didn't remember how she was before. And she doesn't remember all of it, and I don't remind her about all of it, but then I don't know what's the right thing to do, as a parent. (FG) you know, because me before my injury was (name) before my injury, I've always explained this to my wife, I said' o'h, you know, this is me now, and you know, this is the (name) now", and I remember the old (name), and I always say to her, "you never knew the old (name), and I always say to her, "you never knew the old (name), and I always say to her, "you never knew the old (name), he's just very pale, he's not the same child, basically. (name) is just not the same child. (I)	Erm, I suppose initially it would be, erm (sigh), my first thought might be that the brain injury might affect the level of, kind of, cognition and maturity, and that that might result in a young person behaving in a way that was less developmentally mature than their peers, and that that would have a significant impact(I) I think it, sometimes they become much more mature than their peers, so that causes separation. Sometimes their much less mature than their peers, and that causes a separation. (I) [That they've been through] and that their having to think about their life, whereas a sort of typical 14 year old, especially a lad, doesn't think about anything, it's the immediate isn't it? They're not thinking "how am I going to cope with this, what am I going to do?" so they don't have that sort of, those meta-cognitive thoughts, I don't think, younger tenage boys. Gifs might a little bit more, erm, but being a teenager is about being in the moment, and you can't be in the moment with a brain injury. (I)	Well, I worry for her in the future, I worry for her safety, erm, I worry for you know, about jobs in the future, erm, obviously she's not as academic as she was either, so that will affect her because she did have high expectations of herself when she was younger because she was always bright, and I did as well, because you know, I'm not very bright, she must have taken her brains off her father probably, but erm, that well, you know, that's all, we've had to sort of look at different options. (1) She was going to be a doctor or a vet, and I know a lot of kids want to do that, but she had the ability, certainly was a brightnow we're sort of thinking, she's going to sort of, she's failed her, well she passed her maths and English but I mean, honestly, she needs all A's, they need all A's, she's not going to be an A person now. We've had to come to terms with all that, we've had to look and change her direction, it's been a big thing for her as well, and now she doesn't know what she wants to do or what she can achieve, she's all over the place really.(1)	You know when you put on your thing it said about grieving the because she really does remember what she was like 2½ years ago to how she is now and what her friendship groups were like, and now she doesn't really see anybody that she was at primary school with. (FG) So I think his only point of reference now, although you can remember I know he can remember what you could do physically, like how you could walk and ride your bike and all that kind of stuff before you had your injury, I think it's harder for him to see how his speech and processing might have an effect. (1) R2: Yes, I think it's a hard thing for a child to go through really, particularly I think as well, Penny has always said, the thing about an acquired brain injury is they quite often remember how they were before and so they contrast how difficult it was before, to how it is now. (1) Yeah, I think she used, she's found stuff, we've been clearing out her room and stuff over a couple of days here when she's been home, and we found all this poetry, she used to write poetry and things like that, she can't do anything like that now. (1) She's never been able to sort of, think and, her imagination seems to have been affected or something, but she won competitions and everything at school for poetry and she just couldn't remember doing it, when she found it. And it was me who gets and because she can't remember (laughter), but obviously I can. (1)

1.7 Challenge	1.7.1 Mental health/depression/	1.7.2 Managing emotions/	1.7.3 Cognition/ communication	1.7.4 Mood/ Denial/	1.7.5	1.7.6 Responses to
with New	anger	behavior that challenges		shame/ openness/ loss	Withdrawal/	behaviours
Status	6			of confidence/	avoidance	
Status				adjustment	a vordance	
				adjustificht		
	Erm, also in relation to their mental health, but saying that, like I said, it's a lot more common knowledge now and people can	but definitely in adolescent girls I've noticed it much, much, more, and their mood and anxiety	Like I was at the weekend, I was down there was a local fair in my park and there was loads of music, then there was obviously all the rides and all the	For a long time he was in denial that anything Well he knew something had	'Please leave me alone. I want to be in my shell.' They are	Totally gets in the way of friendships because she snaps
	freely talk about it without feeling ashamed. (I)	and not being able to keep on top of their	flashing lights and I bumped into somebody that my friend knew, and they	happened but he's never wanted to talk	like, 'No, you are going to	this way and snaps that way, and
	you're not going to be to progress in school if you're going	emotions and having like outbursts in school which obviously leads to them being picked on	were talking to them and I just couldn't concentrate on the person, they were trying to introduce me to them and they're trying to make me talk to them and	about it. It's only recently that you'll talk about it, isn't it? Before he was like,	have to say.' I am like, 'No.'(FG)	tears this way and drama that way, and then back down, and
	into school and feeling very socially isolated, and anxious, and depressed. You're not going to be able to, kind of, you know	even more and becoming even more socially isolated, but they just can't seem to regulate the	engage with them but these just too much going on, way too much going on for me to actually have some sort of decent conversation with this person. (I)	"I don't want to" (I)	I think boys, I don't like	even I'm a bit like, "Where are we?" Now, another 13-year-old
	worry about going home and talking to your parents about it,	emotions they have to kind of fit in. (I)		And so their view of themselves is	putting people into boxes, but	kid, and then what they do is,
	because they're not going to understand, erm, and I think that, it's just life isn't it, it's going to have real massive impact on	No, no. She doesn't see it. When she does see	Erm, fatigue I think is a big one, they're too tired after a day at school that they can't still go to cubs or play football or whatever they used to do. Erm, so that	damaged and they have adjustment issues although they might be way after	in my experience the boys tend to kind of withdraw and	they go, "Oh, I can't be dealing with that, I'm just going to walk
	your mental health, and if you're already, kind of, behind and lagging behind, and then you've got all this depression and	it, she gets really agitated and starts arguing with you if you bring it up. So, I mean she	really needs to be reflected within the school time table so that they can still have a life outside of school (I)	the injury. The move to secondary school brings it all up again, I think. (I)	accept their new status without friends which is easy	away," and then they drop them. (FG)
	anxiety and rubbish social situation then, it just impacts	probably does know that things are happening	· ·		on the outside, so they'll kind	` '
	everything. (I)	but then she gets frustrated and takes it out on whoever is nearest, I think. (I)	You might meet somebody and they might be friendly, but not a friend as in she sees it, but she can't see that and that's what's come out of her head injury.	And she's lost loads of confidence, so that makes it really hard to make friends	of go home and play on their X-box and family will be	I've had several boys who are just totally bewildered by the
	And I think that's what kind of takes over. Yes, he did get himself into a couple of periods of really low mood and	Totally gets in the way of friendships because	She can't see the bigger picture, she can't sort of see beyond what she thinks, kind of thing. (I)	when you're really, really inward. (FG)	really worried about them (I)	police turning up at school and they could be excluded whilst it's
	"what's the point?", but he's picked himself up each time. But	she snaps this way and snaps that way, and	5 ()	it was Norman, but he was so removed	Erm, she does spend a lot of	investigated which they are
	it's harder and harder, and if I was having this conversation with you in another 18 months-time, I'd be very worried. (I)	tears this way and drama that way, and then back down, and even I'm a bit like, "Where are	If there is too much information, I can't take it in. In the nicest way possible, I will forget everything that we have said today. 10 minutes later I will forget	from himself, but he didn't feel like he could talk to teachers, nobody	time by herself and she does seem happy to be by herself	already trying to play catch up because they've got a brain
	Erm, obviously these two I didn't see them before the brain	we?" Now, another 13-year-old kid, and then what they do is, they go, "Oh, I can't be dealing	everything because I can't loads of information. (I)	understood, erm, he doesn't like talking to people so if anyone cornered him and	then I'm like that, but then she's more of a social person	injury, and then they'll may be out of school for a term, while
	injury, erm, but I'm aware that, that now they (sigh), there's a	with that, I'm just going to walk away," and	So, yeah, of course those things are going to come into factor if you, you know,	said "how are you (name)?", he would	when she's out (I)	that's investigated, and the girls
	lot of low mood, erm, and frustration, erm (sigh), kind of occasional glimpses of enjoyment and calmness, but those are	then they drop them. (FG)	can't remember in jokes that you had with your friends or you can't retain funny things that you said last week, yeah of course that's going to be a factor.	just go "fine" and that would be it, and he would shut down.(I)		are like "tehehe". (I)
	infrequent really. (I)	You can't regulate yourself, bang, and then you're in real trouble. (I)	If you're kind of getting lost when walking around college or what have you, then there will be people who kind of take the mick out of you for that (I)	Yeah, and I also feel that you're very		Erm, so it's that and then they just quite, can't, I mean a couple
	rm, and mood, you know, I think if you're feeling sad or low or	*		caught up in the emotions and you don't		of her friends that have stayed
	despondency, I'd say, is a big word for teenagers with ABI, rather than depression, I think they are just despondent that it's	Well, then because when she does get reported, she breaks down and, the teacher says that her	Whereas, if nobody talks to you at playtime, or the bell rings and everybody belts off somewhere, you can't remember where they said they were going and	want to open up and like, speaking from personal experience, I didn't want to		here have said they just can't get her sometimes (laughter).(I)
	happened, it's the "why me?, will I ever have a normal life?", you know, "will anyone ever marry me, will I get a job, will I	emotional thing is well over the top, she's like totally crying and it's not, it doesn't, it doesn't	nobody really wants to be with you because you're a bit weird, all the skills you give that child in the world aren't going to help are they. (I)	open up.(I)		
	be able to drive?" it's all those questions going on all the time,	seem to go with the punishment, you know, to		And tell people what was really going		
	and of course their peers aren't having all those questions (I)	the extreme. (I)	for maybe the first 4 years, like I would have had the same conversation with you in the space of half an hour like three time. Erm, and, you know, people	on, or how you were really feeling. You're half scared that someone may do		
	Low mood obviously does, is socially isolating because you don't, it's a lot of effort isn't it if you want to keep up a social	if anything sad happens, she doesn't really show that much emotion and yet, for silly	would tell you that you had upset them and you will have forgotten (I)	something or make you do something and you just don't want it at that time.		
	life and if you, if in your mind it's been proven that actually no	things, you know like getting caught doing	That's another thing that's come out of it, it's all that sort of stuff. It's all the	You have enough going on. (I)		
	one wants to be with you then why bother? You don't do it do you? Erm, but, I don't see, in that teenage group, I don't see	something, it's like to the extremes, and then her anger, you know she's got some bursts of	little stuff behind it all, and you know, I can say that's she's never done this before and this is part of the head injury, this sort of impulsive behaviour with	like I say 1996 it was common to know		
	depression so often as sadness or anger, a lot of anger, but not actually what I would call depression or what is diagnoses with	anger, they don't last long but its shear rage, you know it's, it's like, its uncontrolled, you	her. So they don't actually, until I sort of mention it, and they say "oh, okay then, we'll just keep an eye on it" sort of thing, erm, but if I don't say anything,	what depression was but now it's, you know, it's household knowledge you		
	depression, erm, I think the low mood is what I would call	know, and I have to say "hey, hey, calm down" and it will over the stupidest things. But that	they don't know so they just think she's being stupid. (I)	know, but back then, you know, you felt ashamed. Personally, I felt ashamed to		
	despondency where they just think "what's the point? I've tried, no one likes me" or "I can't play football anymore, so	has definitely been a big thing, that's a big	I only remember things when somebody speaks really slow. Not quick. (FG)	actually admit that, erm, I felt like I was,		
	what's the point?" if that was their big enjoyment. (I)	different. I think with her friends, that may be an issue because she blows up and you know,	I think the other thing with her with her friends - I don't know if your girls get	you know, there was something wrong with me(I)		
	Lack of hope is probably something I hear a lot of them expressing. Just, if there's no point then they would translate	that what I'm say, she just blows up, gets really angry and " I'm not speaking to them, I'm not	it - like when you get a gaggle of girls and they're doing the three or four-way conversations and they're all chit-chatting, she can only focus on one	if you've had a brain injury, you don't		
	that into "I can't be arsed", "big deal, what's the point, I'm	ever speaking to them again", over something	conversation. So, then she'll miss what's going on, and then she doesn't know,	feel like you belong and there's		
	never going to be". I think if their aspirations were high before injury then the fall is greater isn't it, but if they already,	really minute, it's like overreacting to everything. (I)	and then she feels really stupid because she doesn't know what they're talking about, and it just -(FG)	something wrong with you, inherently wrong with you, and then you start		
	you know, if they were going to be a pilot with the RAF or you know, they had something in their mind that that was all	Whereas, normally people know if someone's	if you're not able to kind of function on the same cognitive level as your	going down that negative spiral don't you of like "my life's ruined, my life's		
	they've ever wanted to do and then suddenly "well you can't	getting angry, whereas a child with a brain	friends, then you're going to have insight into that as well, and you're going to	over, and ra ra ra ra ra". (I)		
	do that now, you're going to have to think of something else". That's really hard. (1)	injury might be completely fine and then bang, it can change so quickly, and that can be hard	feel even more anxious and nervous about it, and so are your friends, and they're going to start and not include you in things. (I)	Nolike, I knew, I knew there was		
	It's that sort of thing, you know, she hides it that way, she	for other teenagers to understand (I)	when he gets tired, he, he struggles to find the words and then he's worried	something wrong with me, but it's like, it kind of brought a shame on you. So		
	doesn't like talking about it and when I mention it she gets		about that he'll come across as stupid (I)	you didn't want people to know because		
	really angry. You know, somebody's here and I say something happened, and she'll say you know, just get really angry about			they looked at you as if you were an attention seeker. (I)		
	it. (I)			(-)		
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