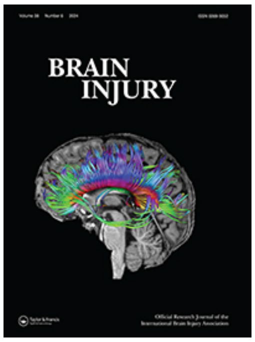

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Interventions to support children after a parental acquired brain injury: a scoping review

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ABSTRACT

Objective: This scoping review aimed to identify manualised programs and practice suggestions to support children's health literacy, behaviors and emotions after a parental acquired brain injury.

Methods: A systematic search of five scientific databases (PsychINFO, MEDLINE, ProQuest, Scopus, Cochrane) and gray literature occurred. Inclusion criteria included: studies and gray literature published 1989 to 2023, in English, child populations with relationship to parental acquired brain injury, identifying manualised programs or practice suggestions via content analysis approach.

Ethical considerations: No data were collected from human participants. All included studies, where relevant, demonstrated consent and/or ethical processes.

Results: Sixteen relevant studies and three gray literature resources (*n* = 19) were identified, including two studies that detailed manualised programs, and fifteen studies and two resource packs that included practice suggestions. Five common domains within practice suggestions were identified: systemic commitment (*n* = 17); family-centered approaches (*n* = 16); child-centered practices (*n* = 15); structured programs (*n* = 9); and peer support (*n* = 8).

Conclusions: More rigorous evaluation is required to test the potential benefits of manualised programs and practice suggestions. A systemic commitment at clinical and organizational levels to provide child and family-centered practices, structured programs, and access to peer support, early and throughout adult-health care settings, may help to meet the support needs of children.

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KEYWORDS
Parent; ABI; child; support; program; practice suggestion

Introduction

An acquired brain injury (ABI) encompasses different etiologies including stroke, the third leading cause of disability worldwide (1) and traumatic brain injury (TBI), estimated to impact sixty-nine million people worldwide each year (2). When an ABI occurs to a parent, family dynamics change (3–6). The predictability of family life is disturbed, and sense of security is altered as previous 'normality' takes on new meaning. Although definitive statistics are difficult to source, a report on the national brain injury study in the United Kingdom (7) indicated that 32% of people with TBI had children under the age of 18 years. Given the limitations to the setting of this study, these numbers could be higher.

Children experiencing parental ABI encounter a range of emotions and undergo a complex adaptational process due to interpersonal losses (8–10) including their secure and close attachments as part of parent-child subsystems. Shaping children's emotional and social development is the parent-child relationship, as supported by attachment theory (11) and the circle of security (12), which parental ABI can disrupt, impacting children's secure attachment dynamics and bonds with the parent. For example, the founding principles of the circle of security (12) identify that adults are a 'safe base' for children to feel confident to explore, and receive love and comfort when they return, which helps children develop positive schemas and a secure attachment style. However, the parent with ABI, if hospitalized, is absent and can have persistent impairments, while the non-injured parent can be preoccupied with new responsibilities (13,14). Dawes et al. (8) described these losses being in addition to significantly altered family dynamics and practical changes to routines, finances and recreational activities. These changes can result in children experiencing conflicting feelings of love, embarrassment, anger, sadness and worry toward their parent with ABI (9,10,14,15). Additional risks for children include increased prevalence of parental incarceration (16,17), child abuse (9,10), suicide (18,19), mental health and substance abuse (20), of or by the parent with ABI. In parallel to children's psychosocial adjustment, is stigma (21) and discrimination they may experience, known to manifest over time through social isolation, bullying and teasing, increasing risks of fractured peer relationships (22) and low school achievement (23).

Although children's needs following parental ABI have been described, most approaches to interventions within the ABI context are targeted toward adult family members, particularly spouses (24,25) with minimal consideration of dependent children. A survey study in a rehabilitation setting

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reported that only 19% of neurorehabilitation staff planned and focused interventions on affected children (26). Main reasons for clinicians' neglect of children's needs included little to no access to training, resources, or support structures. Dawes et al. (8) affirmed these findings, with children self-reporting feelings of being left 'in the dark' by clinical staff across all health-care settings. While similarities are noted between the needs of adults and children, there are fundamental differences with regards to delivery and age appropriateness of information, and the way discussion of feelings and learning from peers occurs (14). In a qualitative study with 14 children, Kieffer-Kristensen and Johansen (15) identified children's primary source of injury-related information was their non-injured parent, with siblings and grandparents also being important information sources. In a recent study by Rohleder et al. (14), children reported needing information to prepare for changes following ABI and an unknown future. This was supported by Dawes et al. (8) who expanded on information needs across children in different age ranges: younger children want information on the brain and older children want 'cause and effect' education, and means to provide this education, through staff and development of digital resources.

Within other parental illness literature, such as cancer (27–30) and mental health (31), child-focused interventions such as camps, art and play therapy, have been developed and evaluated showing significant intervention effects. There seems to be a paucity however, of literature focused on interventions to support children who have experienced a parental ABI. No systematic exploration, compilation and synthesis of evidence related to interventions for children after parental ABI has occurred to date. Filling this gap with a scoping review allows for mapping of evidence and the identification, exploring the breadth and depth of existing literature, and commonalities and differences of findings. Identification of key concepts and knowledge gaps can then be used to guide future research and inform the development of interventions for children after parental ABI. Therefore, the overall aim of this scoping review was to identify and map available literature pertaining to child-focused interventions in the ABI context. Specific objectives included to (1) synthesize interventions used to support children's health literacy, psychosocial adjustment, and (2) to present an overview of practice suggestions with regards to therapeutic approaches.

Methods

This scoping review was undertaking following a five-stage approach, as identified by Levac, Colquhoun and O'Brien (32), originally proposed Arksey and O'Malley (33): 1) identifying the research question, 2) identifying relevant studies, 3) selecting studies, 4) charting the data, and 5) collating, summarizing and reporting results. Reporting of the review was conducted in line with the Preferred Reporting Items for Systemic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). The study protocol was registered with the Open Science Framework (osf.io/sg45k) ().

Identifying the research question

The research questions were determined by concept, target population and health outcomes of interest (32) and were:

(1) What interventions are used to support children's health literacy and psychosocial adjustment after parental ABI?
(2) What practice suggestions are reported in the literature to support children's health literacy and psychosocial adjustment after parental ABI?

The concept explored was support and education through psychoeducational or didactic approaches directly targeted to children, or indirectly as part of a broader family intervention, that explicitly included targeting the welfare of children, delivered by manualised programs (i.e. performed according to specific guidelines and structure).

Practice suggestions pertaining to clinical approaches, interventions, or techniques were identified in observational study results (34) and in clinical resource packs. The target population was children, defined by the National Statement on Ethical Conduct in Human Research (35) and the United Nations Convention on the Rights of the Child (36) by age <18 years or mean age in studies being ≤18 years, and relationship of biology, acquisition, choice, or adoption to a parent who experienced an ABI.

Health outcomes of interest included increased health literacy, considering individual age-group differences to take on and understand information, in relation to the impact of ABI on their parent, family and self. The promotion of psychosocial adjustment, referred to children's adaptation and functioning in their environment (37), such as reduced levels of distress.

Identifying relevant studies

A comprehensive literature search of peer-reviewed studies occurred on 16 April 2019 in five electronic databases: PsychINFO, Medline, ProQuest, Scopus and Cochrane. Due to COVID-19 pandemic, and associated clinical work demands, a delay in study completion resulted in two additional searches run on 10 February 2023 and 13 March 2024. The three searches covered 1989–2019, 2019–2023, 2023–2024. Expert opinion on practice suggestions were included in the search due to previous research (8) identifying few interventional studies. A combination of key terms was developed by an experienced librarian and the research team, constructing search strings related to population, injury and intervention. Search terms were adjusted specific to the databases used, limited to studies published from the year 1989 onwards, and in the English language. The final search terms used can be found in Table 1.

Grey literature was searched in 2019 and 2024 by conducting broad and inclusive searches using a combination of specified search terms and keywords through Government and peak national or jurisdictional brain injury websites such as South Australia Health and Brain Injury South Australia who provide support to people with ABI or family members, Web search engines (Google), handsearching and consulting

Table 1. Search terms.

Population	'Parents' OR 'Adoptive Parents' OR 'Fathers' OR 'Foster Parents' OR 'Homosexual Parents' OR 'Mothers' OR 'Single Parents' OR 'Stepparents' OR 'Surrogate Parents (Humans)' OR 'Parent Child Relations' OR 'Father Child Relations' OR 'Mother Child Relations' OR 'Child of Impaired Parent' OR 'Parent Child Relations' AND
Injury	'Acquired Brain Injury' OR 'Acquired' OR 'ABI' OR 'Brain Injuries' OR "Traumatic" OR 'Traumatic Brain Injury" OR 'TBI' OR "Injur" OR 'Trauma' OR 'Damage' OR 'Contusion' OR 'Concus' OR 'Head' OR 'Crani' OR 'Brain' OR 'Skull' OR 'Hemisphere' OR 'Intracran' OR 'Cerebr' AND
Intervention	'Intervention' OR 'Counsel' OR 'Psychotherap' OR 'Clin' OR 'Psy' OR 'Beh' OR 'Therap' OR 'Fam' OR 'Group' OR 'Psychoanal' OR 'Cog' OR 'Psychodynam' OR 'Program' OR 'Workshop' OR 'Educat' OR 'Support' OR 'Early Interventions' OR 'Mental Health Services' OR 'Rehabilitation' OR 'Social Work' OR 'Student Health Services'

reference lists. Grey literature was screened for suitability and relevance to research question, with content reviewed and relevant information extracted. Subject specialists were contacted via e-mail to identify any potential additional resources. Any conflicts on inclusion regarding eligibility were discussed with a third researcher, until unanimous consensus was reached.

Study selection

Studies were eligible for inclusion if they were published from the year 1989 onwards, the study population were children who experienced a parental ABI and described either a child-focused intervention or practice suggestion. The year 1989 was selected due to the emergence of the literature focusing on children's needs after parental ABI (38–40). ABI was defined by the Australian Institute of Health and Welfare (41) as 'any damage to the brain that occurred after birth' (p. 1). TBI was defined by Menon et al. (42) as 'an alteration in brain function, or other evidence of brain pathology, caused by an external force' (p. 1638). No limitations were set on the setting, time-post ABI incident, stage of recovery, or injury occurring pre- or post-becoming a parent. Interventions were classified as any planned and systematically implemented activity which aimed at changing knowledge, attitude or behavior of a child (43). Practice suggestions were defined as any agency or individual activity or recommendation which aimed to directly support and educate children (44). Table 2 presents the criteria for inclusion and exclusion of studies in the review. Study selection occurred in two stages. Firstly, screening of title and abstract for concept, population and health outcomes was conducted independently by two reviewers. Next, full-text articles were screened for eligibility by the same two reviewers. Eligibility was not limited by study design; however, books, theses and opinion papers were excluded due to lack of empirical evidence and/or methodological rigor. Screening was completed in reference management software (Covidence) and in the case of a disagreement a third reviewer was consulted. Study selection is outlined in the PRISMA flow diagram (Figure 1) (45).

Charting the data

Data were extracted and collated in an Excel data charting form. Data were extracted by one author and checked for accuracy and completeness by a second author. Extracted information included (1) study characteristics, including publication year and country, study aim, study design, setting, and sample size (2), population characteristics, including age and gender (3), intervention characteristics, including intervention content as well as measurement tools used to evaluate the intervention (4), outcomes, and (5) practice suggestions.

For research question one, we collated information related to manualised program characteristics and study outcomes, noting whether this was child self-reported or by-proxy. To answer research question two, we used an analytical qualitative content analysis approach (46) by reading eligible studies carefully and repeatedly to achieve complete understanding of the data. Firstly, each study was read in its entirety. During second and subsequent reading, text was highlighted that appeared to describe a practice suggestion, with keywords noted in the margin. These keywords were used as preliminary codes to set up the charting form. All data within each preliminary code were examined. In three instances, codes were combined under a broad domain because the codes reflected more than one concept. Codes within domains were kept and are reflected in the findings.

Collating, summarising and reporting results

The three-step framework as recommended by Levac et al. was used to 1) analyze, 2) report the results of the review and 3) consider meaning (32,33). Initially, all studies were grouped by publication type being empirical research and gray literature resources. Information about the studies was analyzed, collated and summarized by category and reported numerically. Next, studies were grouped by intervention type into either manualised programs or practice suggestions. Once grouped, reporting of results occurred by identifying study data that related to the research questions. Manualised programs were

Table 2. Inclusion and exclusion criteria of the search strategy.

PCC	Inclusion Criteria	Exclusion Criteria
Population	Children who experienced a parental ABI	Any other relationship to ABI Any other parental illness such as cancer or mental health Family focus, with no indication of dependent child
Concept	Manualised programs/practice suggestions provided by any agency or individual, directly targeted to children after parental ABI	Medical intervention such as clinical trial
Context	Factors related to improved health literacy and psychosocial adjustment of children at any stage of parental ABI recovery	Factors relating to injured parent

PCC = population, concept, context; ABI = Acquired Brain Injury.

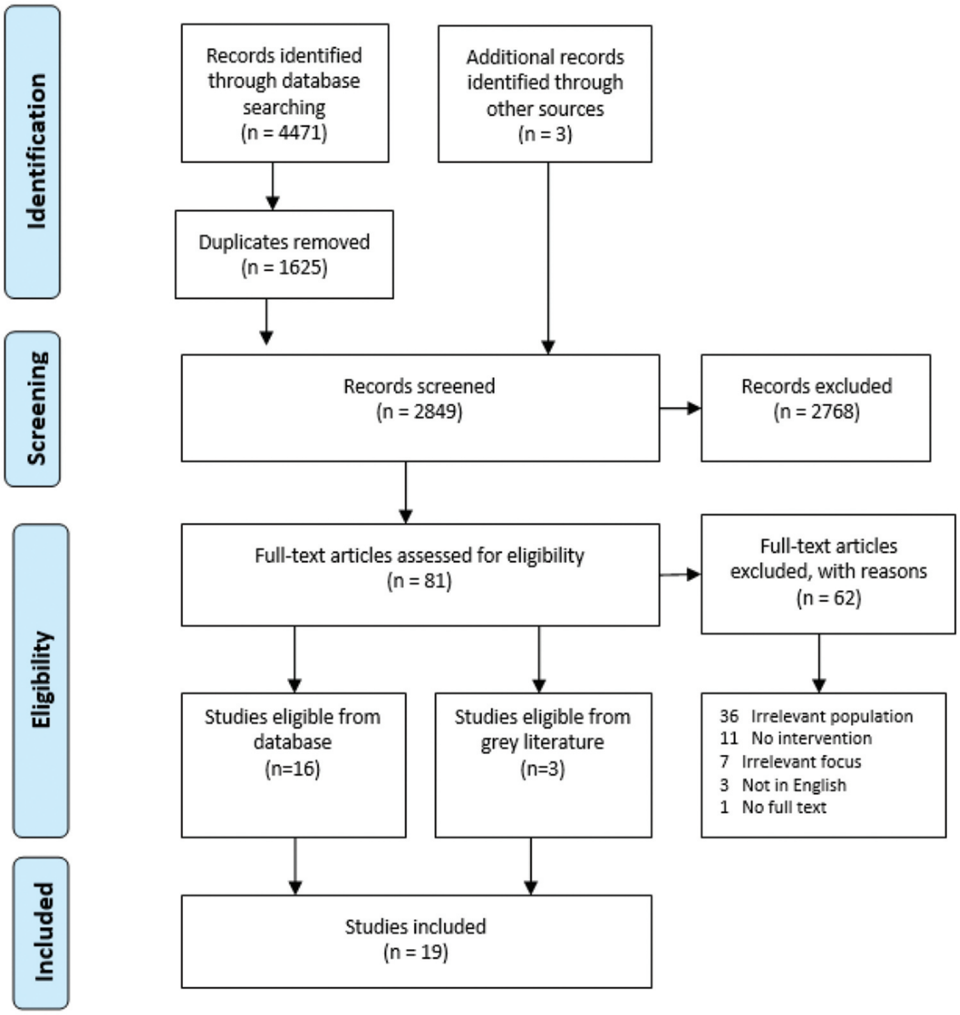

Figure 1. PRISMA flow chart.

analyzed and reported by study design, program content, delivery, facilitation, and outcomes. Practice suggestion content were analyzed by extracting exact words or statements from study findings in the results, discussion, or clinical implication sections. Inductive coding was conducted by KD and resulted in emerging practice suggestion concepts and domains, summarized qualitatively. Applying meaning to the results occurred with consideration of our scoping review purpose, to describe the manualised programs and present practice suggestion domains to illustrate interventions to meet the support needs of children after a parental ABI.

Results

The database searches identified 4471 studies and after removing 1625 duplicates, 2849 study titles and abstracts were screened for eligibility. A total of 2768 studies were excluded, and 81 studies were reviewed in full. Sixty-two studies were further excluded after reviewing the full text for reasons including irrelevant patient population ($n = 42$), no intervention detailed (no manualised program or practice suggestions) ($n = 16$), not in English ($n = 3$) and no full text available ($n = 1$). Sixteen studies were identified as eligible for inclusion in this scoping review, plus an additional three documents from the gray literature. Figure 1 outlines the selection of studies.

Characteristics of included studies

Study characteristics of the two manualised programs (see Table 3) and 17 practice suggestions (see Table 4) are detailed. Studies were conducted in Australia ($n = 6$), Canada ($n = 1$), Denmark ($n = 2$), England ($n = 1$), Finland ($n = 1$), Ireland ($n = 1$), Italy ($n = 1$), Japan ($n = 1$), United Kingdom ($n = 3$), USA ($n = 2$), and published between 1992 and 2023. Seven studies were qualitative (8,14,15,47,48,50,56), five quantitative (5,51,53–55) and four mixed-method designs (9,10,49,52). Grey literature sources included two resource packs (57,58) and one journal paper (39). Two studies used observation techniques (10,52), five interviews (8,14,15,48,50) and one combination of both (9). Three studies collected data from children only (9,15,51), two from adults (53,55) and eleven from mixed populations of children and adults (5,8,10,14,47–50,52,56,59). Twelve studies investigated children's self-report of experiences (5,8–10,14,15,47–50,56,59), one by observation of children (52), one by retrospective data (51) and two by parental survey (53,55).

Study sizes ranged from four (9) to 1532 participants (51) and a total number of 2153 children (52% male) were included

Table 3. Intervention characteristics for manualised programs.

	Intervention						
Study	Name/ type	Modules	Components	Facilitators	Delivery method	Outcome measures	Study results
Charles, Butera-Prinzi & Perlesz, 2007, Australia (10)	Multifamily Group Systemic intervention	1) grieving multiple and complex losses 2) restructuring family roles and responsibilities, 3) developing new identities, 4) creating new meaning	12 x 2-hour sessions over 6 months	Qualified allied health clinicians	Face-to-face in community setting (held in evenings)	**BASC** – a multi-dimensional measure evaluating various aspects of children, aged 4–18 years, behaviour and emotional distress from parent and child self-report. **GHQ-28** – a measure of depression, anxiety, somatic concerns and social dysfunction **DAS** – a measure of couple's functioning and relationship **FAD** – a measure of family assessment and functioning	**BASC** – finding clinically significant T-scores for 2 (*n*=9) children's self-reporting of emotions pre-intervention, decreasing at follow up for 1 child. Parental scale finding more clinically significant behaviours for children pre-intervention and an overall decrease for most at follow up **GHQ-28** - finding more psychological caseness for partners across all 3 timepoints, markedly more than person with ABI **DAS** - finding more dyadic dysfunction in T-scores amongst partners, than person with ABI **FAD** - finding more family dysfunction for partners than person with ABI across all timepoints
Wright, Roser, Smith, Gauld, Juipers & Kendall, 2007, Australia (47)	Brain Crew Psycho-educational intervention	1) Brain and brain injury 2) Physical changes, 3) Cognitive changes, 4) Behaviour and emotional changes, 5) Problem solving and coping strategies, 6) Review session	6 x 2-hour sessions over 6 weeks	Qualified allied health clinicians	Face-to-face in rehabilitation setting	Not Applicable	Qualitative interviews (2 weeks post) and focus groups (3 months post) Child quotes at 3-months: 'Really good fun' 'Gave us a chance to meet other kids in the same boat' 'Feel special and listened to' 'It helped me learn more about brain injuries which means I can understand what Mum was going through' 'Tell other kids that it is really good fun and you learn lots of things about brain injuries' 'It made it easier for me to go to school' 'I've learnt stuff to help deal with Dad's behaviour once he came home'

Note. BASC = Behaviour Assessment System for Children, GHQ-28 = General Health Questionnaire, DAS = Dyadic Adjustment Scale, FAD = Family Assessment Device.

Table 4. Study characteristics describing practice suggestions.

Study	Country	Study Aim	Design	Setting	Participants	Summary of Findings
PRACTICE SUGGESTIONS derived from Observational studies						
Butera-Prinzi & Perlesz, 2004, (9)	Australia	Raise awareness of children's needs after parental ABI	Mixed methods (qualitative [interview and observation] & quantitative)	Community	4 children (3 girls, 1 boy), aged 7 to 12 4 adults (4 injured)	Children are at risk of emotional and behavioural difficulties. Clinicians and researchers to question families about level of violence, often disclosed with ongoing involvement.
Gan, Campbell, Gemeinhardt & McFadden, 2006 (5)	Canada	Identifying predictors related to family functioning after brain injury	Retrospective observational study (quantitative)	Community & health setting	27 children (16 girls, 11 boys), aged 15 to 17 21 adults (21 injured)	Family unit and individual members reported significant distress in family functioning compared to the norm.
Coppock, Ferguson, Green & Winter, 2018 (48)	UK	To understand family's experiences and adjustment after parental ABI	Qualitative cross-sectional study	Community & health setting	5 children (1 girl, 4 boys), aged 8 to 16 6 adults (3 injured, 3 non-injured)	Post parental stroke, families experience uncertainty and renegotiate their roles and adjust to the losses. Psychosocial wellbeing of young people was negatively affected. Provision of adequate information, psychological and practical support was identified as critical.
Kieffer-Kristensen & Johansen, 2013 (15)	Denmark	To understand children's adjustment and coping from children showing high levels of post-traumatic stress symptoms	Qualitative cross-sectional study	Health setting	14 children (7 girls, 7 boys), aged 7 to 14	All children were affected by parental ABI with main findings indicating children suppressed their emotions to protect injured parent. Family-centred interventions that include children was recommended.
Kieffer-Kristensen, Teasdale & Bilenberg, 2011 (49)	Denmark	To examine children's post-traumatic stress symptoms and psychological functioning after parental ABI	Controlled study	Health setting	35 children (22 girls, 13 boys), aged 7 to 14	46% of children with parental ABI had post-traumatic stress symptoms, compared to 10% in diabetes group. Parents in ABI group reported more emotional and behavioural problems in their children, compared to norms.
Morenzo-Lopez, Holttum & Oddy, 2011 (50)	England	To explore the experiences of adolescents after parental ABI and the role of supportive relationships	Qualitative cross-sectional study	Community	9 children (6 girls, 3 boys), aged 3 to 20 (mean age 16.7) 3 adults (3 non-injured)	Adolescents experience a range of adaptational processes and require supportive relationships through parental figures and peer friendships to cope. Preventative interventions are recommended.
Niemela, Kinnunen, Paananen, Hakko, Merikukka & Karttunen, 2014 (51)	Finland	To investigate long-term consequences of parental ABI on children's use of psychiatric services	Retrospective clinical audit (population-based register study)	Community and health setting	1532 children, aged <21	22.5% of children with parent with TBI were treated in specialised psychiatric care. Adult health care services must have appropriate systems in place to address the psychosocial needs and support the welfare and development of children of patients with TBI.
Redolfi, Bartolini, Gugliotta, Maietti, Pietrapiana & Sapienza, 2017 (52)	Italy	To investigate children's emotional and behavioural distress	Mixed methods study (qualitative [observation] and quantitative)	Health setting	35 children (17 girls, 18 boys), aged 3 to 14 50 adults (25 injured, 25 non-injured)	63% of children showed signs of emotional suffering, which was underestimated by their parents based on a psychologist's assessment. Early intervention aimed at both parents and their children was recommended.
Rohleder, Lambie & Hale, 2017 (14)	UK	To examine children's emotional coping and support needs to determine optimal interventions	Qualitative cross-sectional study	Community	6 children (4 girls, 2 boys), aged 7 to 16 4 adults (2 injured, 2 non-injured) 3 staff	Children experience a variety of adaptive and maladaptive emotional coping and want credible validation and sharing of experiences with peers with lived experience of ABI. Interventions to include peer interaction to create credible validation of the specific distress experienced by children.
Takanashi, Sakka, Sato, Watanabe, Tanaka& Ooshio, 2017 (53)	Japan	To explore factors impacting mother-child's communication after father's brain injury	Quantitative cross-sectional study	Community	41 children (24 girls, 17 boys), aged 6 to 22 (mean age 17.9) 41 adults (41 non-injured)	Personal, social/family and illness-related factors were related to mother-child communication about paternal illness. Professionals should promote optimal family support functioning, connect families with external resources and assess families' interaction processes.
Dawes, Carlino, van den Berg & Killingtonl, 2020 (8)	Australia	To investigate the impact of familial ABI on children and adults, including their views of support provided, gaps and recommendations for future interventions.	Qualitative cross-sectional study	Rehabilitation	16 children (9 girls, 7 boys), aged 5 to 18 10 adults (3 injured, 7 non-injured)	Children and adults need to receive intervention in addition to the patient. To fill identified gaps, clinical staff need to provide more input and the development of technology was recommended.

(*Continued*)

Table 4. (Continued).

Study	Country	Study Aim	Design	Setting	Participants	Summary of Findings
Shrubsole, Pitt, Till, Finch and Ryan, 2021 (54)	Australia	Exploration of speech-language pathologist' perceived needs, current practices and barriers and facilitators to working with children of people with acquired communication disability.	Online survey	Hospital, rehabilitation and community	76 speech pathologists	75% of speech pathologists perceive the need to provide information and counselling to children, but 'rarely' or 'never' do due to barriers of access to children, lack of parental support, own capability (knowledge and skills) and own motivation (confidence).
Brickell, Wright, Sullivan, Varbedian, Gillow, Baschenis, French & Lange, 2023 (55)	USA	Examination of paediatric health-related quality of life (HRQOL) in families with one service member parent with traumatic brain injury	Quantitative cross-sectional study	Community	350 children (168 girls, 182 boys), mean age 11.5 (3.6 SD) 168 caregivers (167 female)	Many caregivers reported clinically elevated scores on all five paediatric HRQOL measures in the total sample (23.1–53.7%) and in 15- to 17-year-old subsample (23.6–61.1%). Poor veteran adjustment was associated with worse paediatric quality of life, impacted further by poor caregiver distress.
Ohan, Jackson, Bett, Garmer & Martini, 2023 (56)	Australia	To identify the experiences and needs of dependent children who have a parent with an acquired brain injury	Meta-synthesis	Rehabilitation and community	65 children (37 girls, 28 boys), aged 6 to 20 (mean age <18)	Four themes identified: 1) Sustained emotional toll (subthemes: i) initial shock and distress, ii) ongoing loss and grief, iii) Present-day stress and emotions) 2) Responsibilities change and children help out, 3) Using coping strategies (subtheme: Talking can help), and 4) Wanting information about the injury.
GREY LITERATURE						
McLaughlin, 1992 (39)	USA	To review literature regarding the adjustment of children who have a brain injured relative and develop appropriate treatment options.	Narrative review and activity group model development	Rehabilitation	Staff	Journal paper identifies literature related to children with brain injured relatives and provides an overview of a developed activity group model for children as an intervention to provide services, run concurrently with family groups, one evening per month
Butler, 2018 (57)	Ireland	Resource pack to support staff to be more inclusive of child relatives into rehabilitation program.	Clinical resource pack	Rehabilitation	Staff	A resource pack developed to strengthen family approach to rehabilitation, designed to provide staff with the tools and confidence to work with children
Webster, Daisley & Cardoso, 2003 (58)	UK	Resource pack aimed at rehabilitation staff working with children and practical strategies for including children in family interventions	Clinical resource pack	Rehabilitation	Staff	A resource pack developed for rehabilitation staff with a suggested range of practical strategies for including children in family interventions

in this review. Ethnicity of participants were detailed in four studies (8,48,55,56) and included Asian, European, Australasian, South African, Black American, and others. Socio-economic status was identified in seven studies by education level (5,49,53,55) and/or employment status (9,15,50,55), with majority of pABI having middle or higher education. Child participant ages varied from three (52) to 22 years (53) with all studies reporting the mean age of participants being ≤18 years. Studies that included data for children over 18 years (50,51,53,56) that did not separate clinical practice suggestions by age was included. Average age of the parent with ABI ranged from 26 (10) to 56 (48). Mean time since parental brain injury ranged from one (50) to 21 years (51), and four studies did not specify (8,14,47,52). Cause of brain injury included ABI (9,48), TBI (51,55) and mixed etiologies (8,10,15,49,50,52,53,56). Severity of injury ranged from mild to severe and five studies did not specify (8,9,14,47,53). A total number of 1903 injured parents were referenced across studies, with 1401 (73.6%) being fathers.

The studies and gray literature were grouped into manualised programs and practice suggestions. Two studies reported manualised programs tailored to children (10,47). A total of fifteen studies and two resource packs reported practice suggestions (5,8,9,14,15,39,48–58). Three sources focused on families (5,10,48), fifteen on children (8,9,14,15,39,47,49–52,54–58) and one on mother-child dyad (53).

Study results are presented in two sections, synthesizing findings regarding 1) manualised programs and 2) practice suggestions.

Manualised programs

Two studies detailed structured manualised programs (10,47), delivering systemic (10) and psychoeducational (47) interventions. The first study (10) used a mixed-method pre-post design ($n = 9$ children and 12 parents) to evaluate a 6-month Multi-Family Group Program (MFGP) targeting adults and children after parental ABI. The second study was qualitative ($n = 5$ children, 4 parents), exploring experiences with a program called 'Brain Crew,' a 6-week structured group program for children only (47).

Program content, delivery and facilitation varied. The MFGP (10) was a 6-month program, informed by the authors Bouverie Family tasks model of adaptation post-ABI. All 12 two-hour sessions involved parent and children's groups, conjoined family time, as well as time for person with ABI and partner. Brain Crew (47), informed by available literature, a survey of needs, and allied health expertise, was run alongside an existing family support program, in weekly two-hour sessions over a 6-week period (47). Both MFGP and Brain Crew were facilitated by qualified allied health clinicians. Specific content of the programs is detailed in Table 2.

Quantitative analysis of MFGP demonstrated improvements in most ($n = 6$) children's behaviors and emotions at 6 months, and less personal distress at follow-up ($n = 5$). The majority of parents (73%) reported levels of psychological equanimity on the General Health Questionnaire-28 post-MFGP which were not statistically significant. Missing data were noted in the MFGP publication: a table summarizing individual psychological well-being. Qualitative findings indicated the program led to increased understanding of ABI, clarification of misunderstandings and fears, and reduced feelings of isolation for children and parents.

Similarly, children attending Brain Crew (47), two-week post-attendance, also reported increased general education and having fun. At three months, children reported sustained benefits of peer connections, ABI education and a sense of being listened to. At the same time, parents identified prolonged benefits of enjoyment for their children, increased education, and links to support such as peers, teachers, counselors and the parents themselves. At all timepoints, children and parents report sustained coping for children.

Practice suggestions

Fourteen studies and three gray literature documents included practice suggestions for children after parental ABI (5,8,9,14,15,39,48–58). Through qualitative content analysis, five common domains within practice suggestions were identified: systemic commitment ($n = 17$); family-centered approaches ($n = 16$); child-centered practices ($n = 15$); structured programs ($n = 9$); and peer support ($n = 8$).

The findings are displayed schematically in Figure 2, including the interrelation between practice suggestion domains (arrows) which will be discussed below.

Systemic commitment (n = 17)

All studies and gray literature (5,8,9,14,15,39,48–58) recognized the need to routinely include children in automatic and holistic systemic support across two interconnecting spectrums: organizational and clinical. Both appears to impact on the ability to implement practice suggestions within the five identified domains, which is represented by the outer 'influences' circle in Figure 2.

Organisational support was identified in seven studies (8,9,48,50,51,54,56), relating to the establishment of clinical guidelines (51,54) to support clinicians to provide services (5) and agency liaison (48) such as with schools (9,14,15,39,48,50,57,58). Policy development to involve children was discussed in two studies (9,50), with five studies identifying the need for structured clinical approaches (15,49,52,53,56) to identify the presence of children in families (15,56–58). Six studies described research-based methodologies needed to establish clinical working methods such as feasibility of child-centered interventions being incorporated into treatment plans in adult health-care settings (51) and development of resources to match the needs of children (8,48,54–56), represented in Figure 2 by the 'clinical and policy development' arrow and connection to child-centered practice domain. Few studies (54,57,58) described raising awareness and introducing training for rehabilitation staff (54,58), to provide them with tools and confidence to work with children (57). Establishment of child friendly physical environments featured in both resource packs (57,58), such as a play area or family room.

Family-centered approaches (n = 16)

Fourteen studies (5,8,9,14,15,39,48–51,53–56) and two resource packs (57,58) reported on family-centered approaches with clinical practices aimed at whole families, through two main areas of education (5,8,14,53,54,56) and interventions (5,8,9,15,39,48–51,53,55–58).

Education related to specific ABI information for all family members (5,8,14,53), including brain injury knowledge, coping strategies and teaching of effective communication skills. One study recommended indirectly providing children with information and education through the injured or non-injured parent if access to them was a barrier (54).

Approaches were suggested to be family-centered and emphasized the importance of involving all family members, specifically children, not only the injured person or their adult carer in interventions (8,9,15,57) and family therapy (5,39,50,55). Support and intervention for the non-injured parent were identified as important (8,14,48,51,53,57,58) to improve their understanding of how their children can be affected and how to promote their coping and development. Inclusion of parenting and childcare goals for the injured parent featured in one resource pack (57).

Aims of family-centered approaches included promoting open communication (48,53) and maintaining relationships (57,58), improving families' problem-solving abilities to improve relationships (5,49), improve adaptation to change (55) and alleviating strain experienced by caregivers (5). Importantly, interventions were recommended to be individualized, based on family needs or wishes (8,50).

Child-centred practices (n = 15)

Child-centered practices were highlighted in thirteen studies (8,9,14,15,39,48–52,54–56) and two resource packs (57,58). It was recommended that children need to be routinely identified by clinicians (51,58), using structured assessments and screening of patient's family composition history (15,58), in order to receive early support (8,9).

Most (8,14,39,48,51,52,54,55,57,58) recommended children, from early to late adolescence, be provided with psychoeducation (55) and written age-appropriate ABI materials, in and throughout adult health care settings (8,48,51,56–58), including lists detailing long-term expectations and possible outcomes of a parent's injury (8,14,56,58). One resource pack developed a child-focused workbook (58) and scrapbook (57) to provide age-appropriate ABI information tailored to the injury and included rehabilitation and discharge goals. Both resource packs (57,58) encouraged interaction between the injured parent and children through exchanging of letters, telephone calls, Skype and photographs.

Nine studies (8,39,48–50,52,54–56) and two resource packs (57,58) recommended direct psychological intervention for

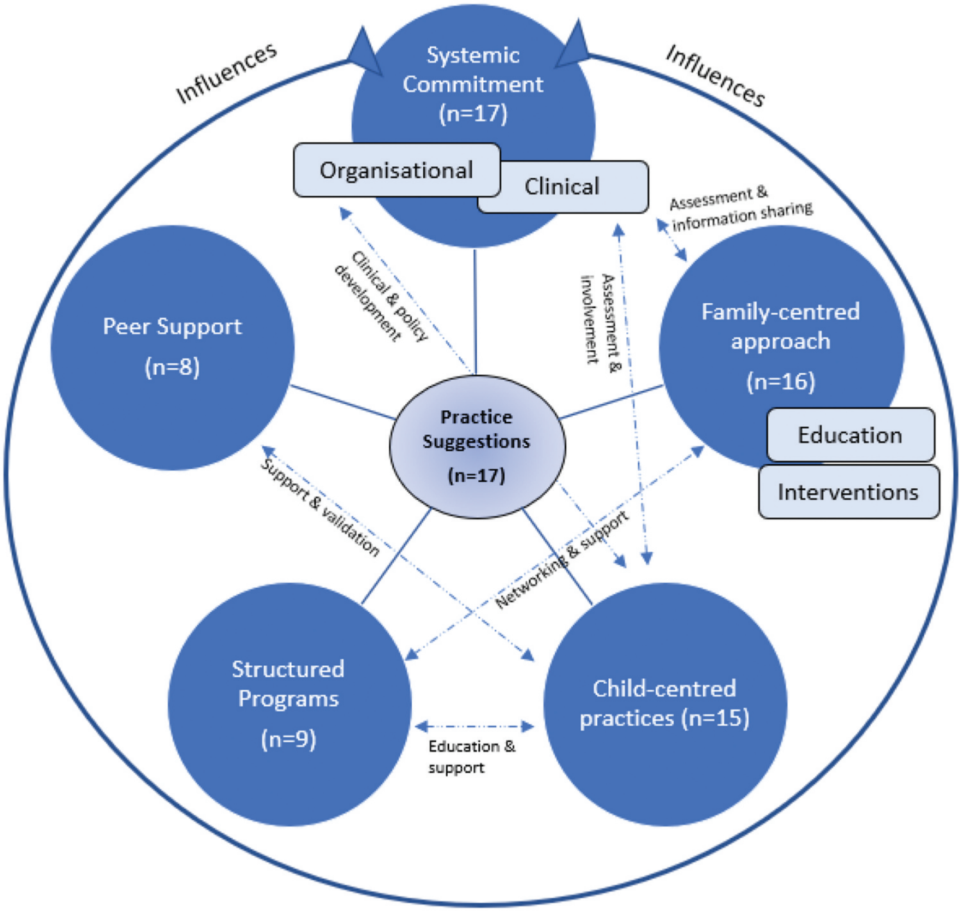

Figure 2. Schematic presentation of domains identified within studies reporting practice suggestions.

children to discuss the parents ABI to lower levels of traumatic stress. Other child-centered clinical practices (51) included the incorporation of children's needs in patient's treatment plans, invitation to attend meetings (8,15) and to provide age appropriate practical care to their parent with ABI, to a level children chose (8,39,57,58). Alternative modalities included play therapy and art techniques (39), and attendance in allied health therapy sessions (54,57,58). The resource packs described examples of child interventions informed by allied health, medical and nursing disciplines (58) and included answers to children's common questions (57).

The aims of child-centered practices involved the prevention of acute or delayed psychosocial difficulties (51), expression of emotions (39,57,58), reduction of trauma symptoms (49), facilitation of communication, to strengthen coping skills and to increase family bonds, self-efficacy and control (8,52).

Structured programs (n = 9)

Nine studies (5,9,15,39,48,50,52,53,55) with majority of children aged in middle-childhood (7 to 12 years) and adolescent (13 to 18 years) developmental ranges, recommended the use of structured programs for families, including child participants. Aims of programs were broad and included the provision of ABI information (48), teaching coping strategies and effective communication (5,48,55), developing awareness of children's needs (52), discussion of role changes (48) and building on families' strengths (5). Anticipated benefits of structured programs included opportunities for families to network (5,53) and receive reassurance, potentially reducing psychological distress and anxieties (48,52), as illustrated in Figure 2 by the 'networking and support' arrow and connection to family-centered approach domain.

Similar to family programs, structured programs specifically for children were recommended in five studies (15,39,50,52,55). Focus of structured children's programs included the provision ABI education material (15,39), information on parent's recovery trajectories and supporting children's emotions (9,52), as illustrated in Figure 2 by the 'education and support' arrow and connection to child-centered practice domain.

Peer support (n = 8)

Eight studies (8,9,14,15,39,50,55,56) with majority of children aged in middle-childhood developmental range (7 to 12 years) recommended peer support for children described twofold: firstly, as interaction with children in a similar situation to themselves, including siblings or other children having experienced parental ABI (8,9,14,15,39,56) and secondly, through existing peer friendships (50). Peer supports could validate children's emotions due to empathy through shared experiences (14,15,39) or a link to life before and after the parental ABI (50), as illustrated in Figure 2 by the 'support and validation' arrow and connection of peer support to child-centered practice domain.

Parents (14,50) and professionals (14) considered peer relationships as crucial support for children. Peers were able to fulfil different functions than adults, for example, provide a sense of continuity, compared to parents' competing priorities. Five studies (8,9,14,15,50) included the importance of peer relationships and engagement in social activities outside the home, such as sport. Two studies (8,14) recommended peer support modalities of lived experience videos, with one (14) further suggesting online and face-to-face peer mentoring. Some children indicated a desire to become mentors for other children (14).

Discussion

This review mapped and synthesized the available literature pertaining to interventions for children after a parental ABI. Two of the identified studies evaluated manualised programs and suggest initial feasibility for structured programs involving systemic (10) and psychoeducational (47) interventions. In addition, the review has identified and classified broad organizational and individual practice suggestions to work with children after parental ABI. This information may be helpful for adult-health services when considering holistic approaches to supporting the family as a unit and how to include children in interventions. The findings of this review also provide a foundation for further research.

The manualised programs in the two included studies demonstrated a reduction in behaviors and clarification of emotions at 6-months. It should be acknowledged that sample sizes were small, and results should be interpreted with caution, however similar intervention effects have been noted in children's internalizing symptoms in randomized control trials across other parental mental health literature (60–62). Within the same context, Santvoort et al.'s (63) study on a children's psychoeducational program found contrary results, with no significant intervention effects at follow up for children's emotions and behaviors. Of note, 70% of children at baseline had sub-clinical or clinical emotional and behavioral problems. These results raise the possibility of late intervention reach and timing of identification of children with serious problems, suggesting that early identification and referral to specialized programs may be a key factor in children's outcomes. This suggestion is supported by Steer et al. (64) who recommends early identification of children at risk, by providing staff training, resources and support at a systemic level. These recommendations align with our review findings.

Practice suggestions identified centered around five domains, including systemic commitment, family-centered approaches, child-centered practices, structured programs, and peer support, representing intervention characteristics to be considered by organizations and clinicians. These practice suggestions align with Bronfenbrenner's ecological systems theory (65), incorporating the microsystem, mesosystem, exosystem, macrosystem and chronosystem, by recognizing and addressing the multiple layers that influence children's development. Specifically, the microsystem level focuses on building positive relationships with children and their family by providing support (family-centered approaches and child-centered practices) and facilitating peer connections (peer support). At the mesosystem level, coordinated efforts and communication across settings such as hospitals and school (systemic commitment) and the provision of targeted programs (structured programs) can address children's needs.

Increasing children's health literacy was recognized as important within the context of three of the domains, requiring educational age-appropriate ABI materials and resources. Problematically, studies within this review emphasized the lack of available ABI resources and the need to develop such material (8,14,54). Reviews in other clinical populations such as parental mental illness (28) supports the need to provide information to children to increase their knowledge of the illness, dispel misconceptions and promote accurate interpretation of children's observations. Similarly, Niemelä, Hakko and Räsänen (66) found children self-reported being more aware and managing family reactions better by having information about the parental illness. Supporting children's health literacy could be considered as multifactorial: a combination of written information to support children's observations and their direct inclusion in child-centered practices identified and described in our review.

Our review findings did not identify practice suggestions specific to the management of children's behaviors. The lack of attention to interventions targeting children's behavior post-parental ABI is in contrast to parental illness literature, such as cancer (29,66–68), mental health (28,69), and serious physical illness (30,70,71) which explore children's behavior. To improve children's behavioral-emotional functioning in these cohorts, interventions focus on enhancing parent-child communication as a priority. In this context, studies contributing to three of the identified practice suggestion domains in this review mentioned the need to teach effective communication skills, which could be cautiously interpreted as supporting children's behavior.

The need to support children's emotions, specifically their stress, adjustment and coping, was an important finding in all identified practice suggestion domains. Approaches to children's emotional support varied from clinician-led, to peer support interventions, raising the question of which approach may be most beneficial to children. A systematic narrative review (66) of structured family ($n = 6$) and peer group interventions ($n = 5$) for children of parental cancer found no significant improvements in children's disenfranchised grief, anxiety and depression after family interventions. In contrast, written and verbal self-evaluations of the peer group intervention showed extremely positive satisfaction of content and ability of sharing feelings with peers. Supporting these findings is a web-based peer support platform for children with parental cancer (72). Children reported benefiting from sharing personal experience and providing support to each other, due to a lack of understanding in their direct environment. The collation of practice suggestions supports the development of online and face-to-face peer mentoring to validate children's ABI experiences through peer networks.

The scoping review findings revealed the need for organizational and clinical systemic commitment to increase clinicians' awareness of children's needs. Educating clinicians was found necessary to raise awareness and reduce anxiety of working with children. Training may reduce barriers that impact on work with children, such as negative attitudes or beliefs. Romer et al. (29) reviewed the implementation of a family-orientated consultation and liaison service for children of cancer patients in various hospital setting, finding physicians needed to be clinically convinced of the value of interventions, to stimulate the likelihood of referral. These results differ from the study by Shrubsole et al.'s (54), included in this review, who found that clinical staff identified the need to support children after parental ABI, but were faced with opportunity and motivation barriers, such as belief about their own capabilities, requiring training on how to deliver education to children. As identified by Webster and Daisley (26), training should encourage and enable clinicians to develop services for children, which in turn, can create a positive culture toward such work. Therefore, clinicians working with children could determine which intervention methods could reliably and widely be implemented in routine clinical practice and importantly, ensure collaboration with children and families to meet their individual support needs.

Strengths and limitations

Our findings provide insight into factors that may be important to consider when providing interventions to support children after parental ABI, a population that has received limited attention in the literature. A strength of this research is the inclusion of scientific as well as gray literature, and the wide inclusion criteria which allowed us to explore the perspectives from children, parents, and clinicians. Only two studies evaluating manualised interventions were identified; however, the comprehensive collation of identified practice suggestions provides a direction for clinical practice, policy, and research.

Although it is outside the scope of the used review methodology to critically appraise the literature (33), it is important to acknowledge that the review findings are limited by the dearth of research in this area, small sample sizes and lack of age-group delineation of support needs. Therefore, generalization of results to age brackets, more diverse familial relationships, ethnicity, socio-economic backgrounds, and injuries should be done with caution. Majority of studies were from Australia, presenting possible geographical bias, limited diversity, potential under representation of global issues and possible lack of transferability.

The search strategy limited studies to children of parents with an ABI. A search term targeting 'family' may have provided a broader perspective.

Future research

Injured parents in the studies included in this review were predominantly fathers with severe ABI. Further exploration into relational influences between the child and ABI parent across different stages of recovery and health settings would provide valuable insight. For example, the gender (specifically mother) and their family roles may indicate different support needs for children. Examining the support needs of children in the acute and sub-acute sectors may further contribute to increased knowledge of changing needs over time and supports required across the recovery continuum. Studies employing more rigorous study designs are needed to determine the efficacy of interventions targeted to the needs of children after a parental ABI. Future research should employ rigorous designs to evaluate the efficacy of interventions for children.

Conclusions

This review aimed to identify and map interventions to support children after parental ABI and provided an overview of manualised programs and practice suggestions. The findings of interventional studies cautiously suggest that manualised programs could be a feasible way to increase children's ABI health literacy, decrease behaviors and support emotions. Practice suggestions emphasized the need for systemic commitment at a clinical and organizational level to support clinicians to routinely provide child and family-centered clinical practices, including structured programs and access to peer support, early and ongoing throughout adult-health care settings. These results provide considerations for clinicians and may support informed decisions about their therapeutic approach that may meet children's needs. Results may also support future research which should include more rigorous evaluation, larger sample sizes, diverse hospital and community context and development of resources by co-design methodologies to meet children's needs.

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