



Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions

Kate Dawes, Ashley Carlino, Maayken van den Berg & Maggie Killington

To cite this article: Kate Dawes, Ashley Carlino, Maayken van den Berg & Maggie Killington (2020): Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions, Disability and Rehabilitation, DOI: [10.1080/09638288.2020.1766582](https://doi.org/10.1080/09638288.2020.1766582)

To link to this article: <https://doi.org/10.1080/09638288.2020.1766582>



© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 19 May 2020.



Submit your article to this journal [↗](#)



Article views: 477



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 1 View citing articles [↗](#)

Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions

Kate Dawes^{a,b}, Ashley Carlino^a, Maayken van den Berg^b and Maggie Killington^{a,b}

^aSouth Australian Brain Injury Rehabilitation Service, SA Health, Adelaide, Australia; ^b College of Nursing and Health Sciences, Flinders University of South Australia, Adelaide, Australia

ABSTRACT

Objective: To investigate the impact of familial acquired brain injury on children and adult family members, including their views of the support provided, gaps and recommendations for future interventions.

Research design: Qualitative exploratory study using a phenomenological approach.

Method: Twenty-six participants were recruited from 12 families across the South Australian Brain Injury Rehabilitation Service (SABIRS) and external community brain injury agencies in Adelaide, South Australia. Sixteen children aged 5–18 participated through ten semi-structured interviews. Ten adults attended six interviews. Following transcription and member checking, thematic analyses occurred with pooled data from all interviews undergoing open, axial and selective coding.

Main results: Analyses revealed four main themes: (1) help parents help their children, (2) improve family functioning by giving children meaningful roles, (3) staff: don't leave children "in the dark," and (4) support for children is not one size fits all.

Conclusions: Children and adults reported significant gaps in support offered by acute and brain injury services after familial acquired brain injury. Children and adults need to receive intervention in addition to the patient. To fill identified gaps, participants recommended more input by clinical staff including the use of technology; specifically, the development of age-appropriate applications, educational videos and interactive games.

ARTICLE HISTORY

Received 4 September 2019

Revised 4 May 2020

Accepted 5 May 2020

KEYWORDS

Children; family; acquired brain injury; support; adjustment

► IMPLICATIONS FOR REHABILITATION

- Providing intervention directly to children and non-injured adults by clinical staff as early as the Intensive Care Unit and sub-acute rehabilitation after parental acquired brain injury is recommended to support their adjustment and improve family functioning.
- The development of age-appropriate and engaging tools via the use of technology is proposed to fill consumers identified gaps in brain injury support and education which could widen access and provide a flexible approach for support to be available anywhere, any time.

Introduction



The effects of an acquired brain injury (ABI) are unpredictable and can instantaneously change the lives of the patient and their loved ones [1]. Although physical deficits can lead to significant disability, it is the changes to emotional control, behaviours and cognition that children and families report to be most traumatic [2,3]. In particular, emotional responses of the person with an ABI can often persist and provide increasing challenges for families over time [4–6].

Family burden and emotional distress, particularly in adult caregivers, are regularly reported in the literature [7–10]; however, there is a paucity of research investigating the impact of parental brain injury on children. Parental ABI is particularly traumatic for children due to changes within interpersonal relationships between children and their injured parent, as well as with the non-injured parent who is often pre-occupied with caring roles [1–3,10–12]. While ABI is not a terminal condition, children are significantly

vulnerable [2,8,13–15], with increased risk of childhood psychopathology as a result of their inability to understand the abstract nature of sequelae that can present following an ABI [2,16]. A study investigating the effects of parental brain injury on children's behaviour found that 92% of families experienced problematic behaviours with their children, such as increased aggression post-parental ABI [15]. It has also been shown that up to 54% of children display behavioural problems during their parents ABI rehabilitation [17].

Non-injured parents often struggle themselves with adjustment after their partners ABI and therefore are not well equipped to help their children [7,18]. Children often suffer in silence due to their fears of burdening family, and of not being understood [3,13,19]. Poor family coping has been linked to poorer rehabilitation outcomes [14,18–22] which in itself can have detrimental effects on parenting and children's adjustment.

Predictors related to successful adjustment after an ABI are the pre-morbid characteristics of the family, interpersonal

CONTACT Kate Dawes  kate.dawes@sa.gov.au  South Australian Brain Injury Rehabilitation Unit, 207-235 Hampstead Road, Lightview, 5085, South Australia, Australia

© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

relationships, severity of injury, and availability of support [1,11,23]. Support recommendations in the literature include long-term input by services, increased education and direct inclusion by clinical staff [6,7]. However, in practice children are habitually neglected by clinicians after parental ABI and receive minimal support, with one study showing that as little as 19% of children are being paid direct attention by clinical staff in a rehabilitation setting [14]. Numerous factors may contribute to this lack of direct attention such as staff's perceived lack of skills to address children's distress and limited scope within the workplace to undertake this work [14]. Lack of research which could guide clinical practice appears to be a significant barrier [12,13] making the best approach to intervention unclear.

The primary aim of this study was to investigate the perspectives of children and family members on their lived experiences when a family member has an ABI. Furthermore, to understand the best approach that can be implemented to provide support, we were particularly interested in the elements they believed would provide the optimum support system including content, mode, timing and location of support.

Methods

Research design

A qualitative, phenomenological approach was utilised through semi-structured interviews and open-ended questions. This methodology allowed for personal reflection and rich descriptive data to be gathered from children and family members to inform the research queries.

Recruitment sites included three departments within the state-wide hospital-based brain injury rehabilitation service, as well as through independent and peak body community brain injury support and advocacy services. Recruitment from the metropolitan hospital-based service included: (1) a sub-acute inpatient Brain Injury Rehabilitation Unit (BIRU) offering intensive goal-orientated interdisciplinary rehabilitation; (2) an outpatient medical clinic where medical reviews occur with patients after discharge from inpatient setting or upon community referrals; and (3) an ambulatory Brain Injury Rehabilitation Community & Home (BIRCH) service which provides community based, goal-orientated interdisciplinary rehabilitation programs for people who have sustained a traumatic brain injury (TBI). Ethics approval was granted by the Women's & Children's Health Network Human Research Ethics Committee (HREC/16/WCHN/136).

Study participants

Study participants included children and family members living in urban, suburban and semi-rural areas. Children were recruited across two defined age brackets, with eight children in each: (1) 5–10 years, and (2) 11–18 years, anticipating differences between the groups regarding their coping and support needs. Children under 5 years old were excluded due to difficulties articulating their experiences. A family member could include a parent, including the parent who sustained the ABI, a spouse or any interested significant other.

All participants were eligible if they: (a) had a close and continuing relationship with the parent with an ABI which was defined as involving close bonds of affection or friendship; (b) were linked with the South Australian Brain Injury Rehabilitation Service (SABIRS) or other external brain injury service; (c) had cognition and communication skills to enable participation; (d)

consented to a face-to-face interview as well as to the interview being audiotaped and transcribed.

SABIRS interdisciplinary staff identified potentially eligible participants during usual care assessments and interdisciplinary case meetings. Potential participants were given a brief verbal introduction to the study and those who expressed their interest were provided with an information sheet. Potentially eligible participants identified through external agencies were given the researcher's contact details for any questions should they wish to participate. A participant information sheet detailing the study aims and procedures was provided to all participants. All parents provided written informed consent for their own participation and for their child to be involved prior to study enrolment.

Interview methods

Interviews were conducted over 7 months by two experienced social workers with over 12 years combined clinical experience in sub-acute brain injury rehabilitation. Two researchers (KD and AC) conducted the initial interview to develop a consistent approach. Thereafter, interviews were performed by one researcher. Interviews were conducted in either the rehabilitation unit or participants' homes. An interview guide was developed based on a set of broad questions related to the research query (Appendix 1). Focus was multi-dimensional, including the participants understanding of events to date, their involvement within hospital and rehabilitation systems, changes within their families and future support recommendations. All participants were informed that the purpose of the study was to "tell their story" and that their answers might assist to help other children and families in the future by any recommendations to improve practice.

Interviews were conducted in English, audiotaped and transcribed verbatim. Scripts were provided back to the consenting participants for member checking. Field notes were also taken to identify emotive reactions and observations which were also analysed. The term "clinical staff" used in the interviews refers to nursing, treating doctors and social workers.

Results

A total of 26 participants (50% male), were recruited into the study and included families with Asian (31%), European (8%) and Australasian (61%) background. Sixteen children (50% in each age bracket, seven male and nine female) were interviewed and on five occasions, siblings were interviewed together. Mandatory support persons present during children's interviews included non-injured parents ($n=5$), parent with an ABI ($n=3$) and siblings aged 19 years of age or older ($n=2$). Interviews with the children ranged from 15 to 80 min, with children in the younger age bracket often including shorter answers such as "yes/no" compared to the older children.

Ten adults participated in the study. On two occasions, adults were interviewed in pairs and four adults were interviewed separately. Adult participants included three parents with an ABI, two husbands, two wives, two adult sons and one mother. Adult interviews ranged from 31 to 81 min. Data saturation was reached after the sixteenth interview. A list of participants can be found in Table 1.

Qualitative data analysis

Qualitative thematic analysis was undertaken, with the assistance of NVivo qualitative data analysis software; QSR International Pty

Table 1. Participant details.

Participant pseudonym	AGE	GENDER	REFERRAL SOURCE	Relationship to person with an ABI	ABI persons injury
Age group 5–10 years of age					
Chloe	6	Female	Ambulatory Rehabilitation	Daughter	Motor vehicle accident/TBI
Amy	6	Female	Inpatient Rehabilitation	Daughter	Brain tumour
Mohammed	7	Male	Inpatient Rehabilitation	Son	Subarachnoid haemorrhage
Laura	7	Female	Outpatient Medical Clinic	Daughter	Aneurysm
Rebecca	7	Female	Outpatient Medical Clinic	Daughter	Bacterial meningitis
Max	9	Male	Inpatient Rehabilitation	Son	Brain tumour
Scott	10	Male	Ambulatory Rehabilitation	Son	Subarachnoid Haemorrhage and ICA aneurysm
Ryan	10	Male	Inpatient Rehabilitation	Son	Subarachnoid haemorrhage
Age group 11–18 years of age					
Annabelle	14	Female	Ambulatory Rehabilitation	Daughter	Multiple cerebral aneurysm
Lola	14	Female	Inpatient Rehabilitation	Daughter	Brain tumour
Chase	15	Male	Ambulatory Rehabilitation	Son	Multiple cerebral aneurysm
Edward	16	Male	Inpatient Rehabilitation	Son	Subarachnoid haemorrhage
Alicia	17	Female	Ambulatory Rehabilitation	Daughter	Motor vehicle accident/TBI
Macy	17	Female	Community Brain Injury Service	Daughter	TBI (falling object)
Anita	17	Female	Inpatient Rehabilitation	Daughter	Brain tumour
Daniel	18	Male	Inpatient Rehabilitation	Son	Subarachnoid haemorrhage
Adults (19 years of age and over)					
Simon	Age information was not obtained	Male	Outpatient Medical Clinic	ABI	Bacterial meningitis
Brett	Age information was not obtained	Male	Inpatient Rehabilitation	Husband	Subarachnoid haemorrhage
Ian		Male	Outpatient Medical Clinic	ABI	Cerebral haemorrhage
Bianca		Female	Outpatient Medical Clinic	Wife	Cerebral haemorrhage
Garry		Male	Ambulatory Rehabilitation	Husband	Motor vehicle accident/TBI
Michael		Male	Inpatient Rehabilitation	Son	Brain tumour
Bridgette		Female	Community Brain Injury Service	Wife	TBI (falling object)
Peter		Male	Community Brain Injury Service	Son	TBI (falling object)
Donna		Female	Community Brain Injury Service	Mum	TBI (motorbike accident) + stroke
Cecily		Female	Inpatient Rehabilitation	ABI	Subarachnoid Haemorrhage

Ltd. Version 11. Data firstly underwent open coding by labelling and developing categories based on the properties, elements of the data and participants' exact words. Researchers generated 27 (KD) and 30 (AC) initial categories. Next, axial coding involved three researchers meeting to identify relationships amongst the open codes by using a deductive and inductive approach (KD, AC and MK). After 2 rounds of axial coding, 12 sub-categories were developed considering causes, interactions and sequences in the data. Finally, selective coding involved the three researchers (KD, AC and MK) meeting on three more occasions to further synthesise the data until consensus was reached, resulting in four final themes which they considered were a trustworthy account of the meaning of the data.

Themes:

1. Help parents help their children

In the view of 5/8 (62.5%) parents interviewed, clinical staff did not provide enough support to family members, particularly

children, as Donna (adult) stated, "we've done it tough ... it [lack of staff input] was absolutely horrendous." Instead, clinicians appeared to be focused solely on the parent with an ABI. An ABI was a new experience to all parents, and they appeared to struggle to understand the diagnosis and the enormity of their situation, resulting in sometimes misguided hope for a positive recovery. This hope extended to their children by providing them with positive outlooks and reassurance that everything "would be okay." Four out of eight (50%) parents wondered whether this approach was valid, and one participant queried, "maybe we're doing it wrong" (Brett, adult). It was evident that a number of parents did not want their children to go through their journey alone (6/8, 75%) but were unsure how to support them as they themselves were not offered guidance by clinical staff in the acute setting. In fact, like a number of other parents (5/8, 62.5%), Simon (adult) said, "there was just nothing offered." This was affirmed by 13/16 (81%) of all children who were not aware of any hospital-based supports. "I think a lot of doors got closed when his Mum had the accident because there wasn't those supports and ways for him [son] to

try and talk about his issues in the way he wanted to" (Simon, adult).

Not only was there a need for increased support during the hospital and rehabilitation phase, the two families who had experienced life in the community for up to 10 years post-ABI, reported a dire need for more support in the long term when formal services ceased as "it [life] just starts to get worse and worse" (Peter, adult). Garry (adult) reflected on his son's ongoing grief and stated "he was 16 when his mum had her accident and it wasn't until he was almost 24 that it came out that he was having such an emotional problem with it... the guilt of like when she initially had the accident and we were told that she was probably going to be a vegetable, thinking... 'maybe it would be better if she did die' and he lived with that guilt for all those years." From a child's perspective, Macy stated "when we got home, it just basically all, kind of, crashed and burned. It just wasn't the same and that is when it really hit, I think... just, like, not having the dad that we had before."

During interviews, the rawest expression of emotion observed by 5/8 (62.5%) of parents was when they discussed the negative impact of parental ABI on their children, often bringing them to tears. The impact was palpable for many parents who wanted to protect their children from trauma yet felt powerless to change the level of fear and uncertainty their children were experiencing as Simon (adult) stated "I think she [daughter] had a bit of time there to kind of, just wonder I guess, what was going on and I think there was some real fear there for her of the unknown and just that sense that, hang on, there's something going on here that's bigger than what I'm being told." Similarly, Bianca (adult) reflected "... at night, you can really feel the sadness in her [daughter]. There would always be tears, always."

Parents wanted "more education given to not only the kids, but the adults as well on how to handle kids" (Simon, adult) immediately after the ABI and for staff to be available for consultation at any time, not just business hours. Importantly, 3/8 (37.5%) of parents independently highlighted that they wanted to know how much information to disclose and how to answer their children's questions in an age-appropriate manner. "You don't want to tell them [children] nothing, you don't want to tell them everything and there's a big gap in the middle there" (Garry, adult).

Parents wanted to be offered information regarding how to spend quality time with their children, with other practical recommendations such as maintaining routines, the need for self-care and encouragement to focus on family bonding, not solely on the parent with an ABI. "I feel like I neglected my children" (Bridgette, adult) and "I did spend time with them [children], but I don't think I spent the time I needed to. The time I needed to, was sit on the lounge, watch a movie and when they need a cuddle, give them a cuddle and I probably didn't do that because I was too busy trying to fix everything for everyone" (Garry, adult).

Adults suggested support structures should include individual sessions with clinical staff for themselves and their children as first priority. Other support needs identified were access to information and adult mentors such as clinicians who can work with families across the continuum of recovery. Participants recommended social outlets such as coffee groups or "family days" during rehabilitation to link with peers, as well as separate spaces for families to bond and "learn how to be parents again together" (Garry, adult).

2. Improve family functioning by giving children meaningful roles

Children commented on their desire to be involved in the early recovery and rehabilitation process with 14/16 (87.5%) of children

attending the acute or rehabilitation setting early after the ABI. Five out of the eight children over the age of 11 wanted to understand what they could do to provide practical help to both the injured and non-injured parent." *I feel like when she [Mum with ABI] does come back [home], dad will probably have his focus on her again and take care of her, obviously, while the rest of us look after everything else the way we have been*" (Anita, child).

Children felt that "having a role" gave them purpose and meaning. Younger children's roles were related to seeing their parent with an ABI and spending time with them, typically after discharge from the Intensive Care Unit. By receiving opportunities and roles for children to be involved, they felt their emotions would be validated and they would be able to create real memories and bond with their families. Lola and Anita (children) discussed their pride in wanting to do a good job in their new roles to alleviate any concerns for the parent with an ABI. Designated roles assisted the older children to understand the perspective of the person with an ABI, "You get more understanding, kind of, and then you understand how hard it is for them [person with ABI]" (Macy, child). Roles also assisted in building positive relationships with the parent with an ABI. Macy (child) stated that when she assisted her dad at mealtimes in rehabilitation, "I think it really helped and it built our relationship, kind of, going back to how it used to be because it was spending more time together."

The older children appreciated their helping roles at home for the short term but appeared unsure about their roles in the long-term. To support their adjustment, children felt they needed information about possible recovery trajectories to better understand the nature and possible permanence of expected role changes as Anita (child) questioned "... how long until we can all relax a bit?" In Anita and her sibling's situation, roles helped "to mature us in a way... taking care of kids completely changed my outlook on it... I didn't realise how different it was to actually be responsible for other people."

At a hospital level, older children wanted to be included in conversations with medical staff which gave them the feeling of being important and involved. They expressed a desire to have a balance between the amount of time spent at home and at hospital to support their wellbeing.

Ten of the 16 children (62.5%) indicated that family discussions had taken place at home about changed family functioning. This involved the support of older siblings, grandparents, family friends and/or neighbours with practical tasks such as child care, household chores and transport during the phase of acute hospitalisation. The parents of four children had separated prior to their parent's ABI and these children expressed they did not notice changes to their care or family functioning.

3. Staff: don't leave children "in the dark"

The interview data gathered from the younger children indicated that they explored their parent's situation by visiting the hospital, rather than by asking questions. They sought information from their non-injured parent on issues they visually observed such as changed appearance and mobility limitations of the parent with an ABI.

The older children felt the need for more complex and candid information from clinical staff, such as recovery timeframes. Not having answers to their questions appeared to have a significant influence on their fear and uncertainty for the future.

All children and adults interviewed confirmed that, although children had queries and concerns, they did not ask clinical staff any questions. Children did not know what to ask, to whom and were "too scared." "I didn't really know what questions to ask and

didn't know – it's kind of like a school thing when kids don't want to ask a question because they think it might be stupid" (Peter, adult). A 7-year-old child reported that if she had a question, "I just normally kept that in my head" (Laura, child).

Across all ages, the most frequently asked question by children was "when will 'daddy' be home?" Children described feelings of being "left in the dark" by staff across all settings and stated that it would have been helpful to have received more attention and information regarding the diagnosis, possible long-term effects, causes and impact of an ABI. Peter (adult) stated, "... because our minds were, kind of, just festering a bit with negative thoughts and just not knowing was worse."

Children of all ages confirmed that the non-injured parent was the only source of information, especially in the acute setting when they typically had the most questions regarding the meaning of brain injury diagnosis and recovery.

Parents felt that the younger children kept to themselves as they are not naturally disposed to ask questions but would attempt to listen and interpret information themselves; sometimes misguidedly. This resulted in parental reports of hypervigilance, fear and resentment in their children. Simon (adult) stated "she [daughter] is more clingy to me and calls out for me in the middle of the night." Parents recommended additional staff training on how to provide information to all family members without the need to be asked, especially for medical staff in the acute setting. Parents felt that medical staff could use more visual education material and basic language with children and include them in family meetings as Garry (adult) reflected "it [family meeting] was very hard for the doctors. They didn't know how to talk to the kids."

4. Support for children is not one size fits all

The array of support approaches and content recommended by children and parents suggest that support for children is not "one size fits all" due to individual needs and learning styles. The younger children affirmed that they wanted general information about parental ABI and the brain, such as how it works. They also sought reassurance that an ABI was not contagious and wanted to hear other children's (peer) stories, including "how they [peers] feel too" (Ryan, child). They recommended different modalities to provide support such as technology, face-to-face programs, peer support, counselling and books.

Older children wanted brain injury "cause and affect" education and increased knowledge of how the brain works; including the different lobes, fatigue and memory. They wanted to know the impact of an ABI on their parent, specific to possible cognitive changes, and to understand medical information and diagnosis as Daniel (child) stated, "I didn't know what an aneurysm was." Pre-emptive information about changes to relationships, changes to finances and the focus being on the parent with an ABI was requested to best prepare for their experiences. Older children welcomed the use of technology, family education, peer support, ability to look up information and the option to talk face-to-face with clinical staff or via telephone. Older children highlighted the need for "respite" and time away from the parent with an ABI, along with the benefits of practical assistance such as help with food, cooking of meals and transport. Immediate support was recommended by older children, to begin in the Intensive Care Unit and continue for the long-term. Parents affirmed this immediate timing of support for the older children and recommended that younger children are provided with support once transferred to a neurosurgery ward. Like 90% of adults (9/10), Bridgette (adult) felt that direct support such as a "social worker that is definitely aimed

at the wellbeing of kids" with specialist knowledge about brain injury, was required.

Parents confirmed many of the children's support recommendations regarding content and modality. They wanted their children to learn in a visual, fun and interactive way so they were learning without realising as Simon (adult) suggested "anything that they're [children] enjoying they're more likely to learn... by something visual, so whether it's an App that they're sort of interacting with or whether it's a video or something that they're watching." Parents wanted to be prepared: prepared with knowledge and strategies for themselves, such as how to be equipped to manage possible adjustment issues their children may experience. They wanted to understand potential recovery trajectories so they could manage their current expectations and remain realistic about the possible changes to their spouse, relationships and family.

All participants felt the need for extending brain injury support and education to friends, schools, wider community and extended family members. The lack of education for surrounding family and friends resulted in the older children receiving misguided support which significantly strained personal and intimate relationships. Along with the essential need for face-to-face support from clinical staff, children of all ages and adults strongly recommended the development of age-appropriate digital tools for greater access to different modes of support; available anywhere, any time. Participants consistently recommended the use of iPads due to engagement and interactive capacities. The development of applications, educational videos and interactive games were the main priorities with suggestions of alternative digital modalities including Podcasts, YouTube videos and ability to personalise tools, such as "choose your own adventure" (Simon, adult).

Discussion

Findings from our study present a rich perspective from children, including those as young as 5 years of age, and their parents on what support is needed when a parent has sustained an ABI. Due to the gaps and possible solutions they identified, an inventory of recommended clinical practices, including content, locations, target populations and modalities were identified. The inventory has extended past the identification of children's risk factors for developing psychopathology and identifies personalised approaches and specific areas of knowledge required to enhance family adjustment.

Participants reported that education should be provided that improved their understanding of the brain and how it works as a way of supporting their children's adjustment. A study by Rohleder, Lambie and Hale [3] reported the importance of peer interaction to provide validation of feelings and experiences in their cohort of children after parental ABI. Our current study supports these findings, although peer interaction was not a major recommendation. Rohleder et al. [3] also identified the potential of technology for supporting children, including the development of lived-experiences videos and support groups via social media. Our current study expanded on their findings with the majority of our participants advocating for various age-appropriate technology applications that can be used any time, anywhere including educational videos, interactive games and personalised story books reflecting their journey.

We found that all children, independent of their perceived coping, required early and ongoing support due to their traumatic experiences which caused changes within relationships and family functioning. Our study recommends tailored and individualised

brain injury education which could be provided by clinical staff such as medical, nursing and social workers, to children as early as in the ICU setting. Likewise, community agencies with brain injury expertise need to consider how they could provide input as the participants reported their need for support, to continue after their discharge from formal rehabilitation services. Early and preventative intervention is supported by other studies [2,8,13,19,20], along with longitudinal studies that have demonstrated that support should occur from the first month up to 2 years [7,24,25] and even up to 10 years post ABI [5,6,26,27].

Family distress and how family's function over time is determined by numerous compounding factors such as social isolation, financial issues and the pressures of providing direct care-giving support [6]. Long-term support for families is recommended which may be met by community agencies with brain injury expertise and the development of digital tools to support increased access. A crucial aspect of long-term support would be ensuring relevant information on issues that families may experience over time, which our community participants highlighted.

Our study found that clinical staff were perceived by participants as unavailable and not proficient in supporting families, which suggests a need for specialised training for clinical staff in all settings regarding the needs of children and family members after parental ABI. In a national survey, Webster and colleagues [14] suggested that access to training and resources for clinical staff are predictors for the rate with which they address children's support needs after parental ABI, but that 77% of staff had not received this training or access to appropriate resources. Our study did not include clinical staff perspectives to verify why children are not receiving the support they require. The researchers suggest there may be various reasons to explain why clinicians do not appear to support children more effectively, such as seeing the patient as their sole client, lack of awareness of family support needs and the absence of clinical tools. We recommend further investigation from clinical staff's perspective in both acute and sub-acute settings as an area of future research.

Our study results have highlighted the need for education of non-injured parents on how to support their children which substantiates the study findings of Fisher et al. [21] who have proposed a theoretical framework to help guide a family-directed approach after brain injury. Fisher et al. suggest that the use of the "Family-directed Approach to Brain injury" (FAB) may assist in implementing education and inclusion of family members as "facilitators" throughout the rehabilitation phase and may address unmet support needs, which in turn may decrease their dependencies on health systems [21]. However, FAB focuses on family input with clinical staff for the benefits of the person with an ABI, not to the direct benefit of the children of parental ABI. We believe that interpretation of FAB lends itself to child cohorts as it aims to increase capacities of family members as active contributors in the recovery process, rather than providing them with information only. A family-directed or family-centred approach to brain injury could also guide and assist clinical staff in how to involve family members, particularly children in the rehabilitation process. Like FAB, a family-centred approach focuses on parents being positive role models and equal partners in the team providing support to their children which can increase parent's empowerment, control and responsiveness to all their family member's needs [28,29]. An integrated framework aimed at empowering parents, as agents of change, to meet their children's care needs has been described in the mental health literature [30]. Specifically, the "parent as agents of change model" attempts to break down barriers that families face when accessing services,

including parent's perceptions, attitudes and access to supports, with the focus on positive outcomes for their children. As our participants highlighted the desire to be involved and equipped with knowledge on actual and potential recovery trajectories, we suggest that these models may provide a basis to help parents help their children. But how do parents help themselves and gain access to mentors and socialisation opportunities as our participants recommended? Bellon et al. [31] suggest that coordinated, accessible and personalised services are needed in urban and remote areas so ABI peer support, support groups, information and social activities can be provided. In-person and online modalities for families are recommended due to their changing needs over time [31] which is supported by our research findings.

The current study results suggest that providing children with meaningful roles in order to become active participants in the recovery process is essential when supporting children's adjustment after a parental ABI. These findings are consistent with prior findings from a study exploring sibling adjustment after an ABI which demonstrated that the integration of meaningful responsibilities assisted the children to reclaim stability in their lives after they felt it was lost [31]. Restoring children's environments and assisting them to regain control appears to have benefits on children's adjustment and emotional development by increasing their sense of inclusion and positive involvement [31].

Study participants expressed a need for improved access to support and suggested that a variety of delivery modes may be needed to meet the need of both children and parents. The use of digital tools to facilitate flexible access was recommended. These suggestions are supported in the literature as it is clear that the use of e-Health technologies and digital tools is a progressive area within the literature [32]. Ninety percent of adolescents perceive the internet as a tool for communication and acquiring information [33]. In the hospital setting, Chin and Tsuei [34] investigated digital game-based learning as an educational tool for children with chronic illness and reported high levels of engagement. Similarly, a study evaluating acceptance and usability of a web-based e-Health intervention targeting parents of children with skin tumours to increase support, knowledge and understanding reported positive attitudes and high perceived usefulness (91.3%) of the interventions and delivery mode [35]. In addition, translation from therapist lead to computer-based interventions has occurred within cognitive-behavioural therapy practices targeting child anxiety and depression [36–39]. Internet-based programs have showed effectiveness of use and increased access to intervention. By increasing access to education, other stakeholders such as schools, extended family and friends may benefit and add to the support networks of families [8,13,19]. These results support our recommendation to develop age-appropriate digital tools, as proposed by participants in our study. Further research and investigation into clinical interventions that support and educate children after parental ABI may be warranted to assist translation of interventions from face-to-face towards digital tools.

Only two programs to support children after parental ABI have been published and described [22,26]. Both curriculums are presented in face-to-face group programs for children of inpatients within a rehabilitation setting. The basis for development of these models is unclear and appeared to lack consumer input. Our current study, which sought the consumer's perspective, suggests that the content of these models may not meet all the needs of the consumer and the modality may present numerous barriers; in particular, an inflexible approach, reduced access to children, geographic isolation, pre-set content, potential stigma and the

need for direct clinical staff to run the program. Our study suggests that alternative intervention methods are required which do not currently exist. We suggest the development, piloting and evaluation of age-appropriate digital tools for both parents and children as a priority. We hypothesise that in addition to increased involvement of “front line clinicians,” the use of interactive technology may increase consumer empowerment, accessibility and independent use, with subsequent improvement in services, cost reduction in therapy, and innovative and convenient practices.

All of the researchers involved in the analyses (KD, AC and MK) have worked in brain injury rehabilitation, ranging from four to over 30 years. This research was instigated because of researchers (KD and AC) firsthand clinical experiences of children being excluded from their parent’s recovery and wondering what support children would want, if given the opportunity to give their perspectives. Compounding the exclusion of children, was the absence of age-appropriate clinical tools for researchers (KD and AC) to use as social workers, when attempting to educate children about their parent’s brain injury. Prior to commencement of the study, it was hypothesised that the outcome may result in the development of clinical tools for use by social workers. Researcher (KD) is a mother to four dependent children and consequently places importance and beliefs around the need to engage with children which may have influenced the research. One of the researchers (MK) has lived experiences of brain injury: a sibling with a brain injury from birth and another sibling with a severe acquired brain injury in adulthood which may have influenced her perceptions.

Study limitations

There are a number of potential limitations to this study. In line with ethical conduct of research, all children were accompanied by a mandatory support person during interviews which may have impacted on the children’s responses. Our study had a relatively small sample size and although data saturation was reached, findings should be interpreted with caution when attempting to relate these findings to other contexts. Information on family income was not collected, consequently we are unable to discern whether there was an association between the nature of participants responses and their socio-economic status. When considering transferability of the study results, the study methods employed, characteristics of the clinical services and participant demographics should be taken into account. Finally, interviewing clinicians was beyond the scope of this study, instead clinician’s experiences and perceptions are being explored as part of a follow-up study.

Conclusion

This study has demonstrated that children and parents experience a lack of support and access to information to better understand the complex signs, symptoms and variation of family roles after a parental ABI. As every brain injury is different, so too is the impact on family members, highlighting the need for a flexible and multi-layered approach. Parents suggested the use of age-appropriate digital tools such as applications, educational videos and interactive games to facilitate personalised education and improve flexible access to support. Furthermore, we believe that educating clinical staff is of fundamental importance in raising awareness of family needs after an ABI. Being inclusive of the family in the acute and sub-acute phases of recovery should ensure family

education and support is offered to improve family adjustment and functioning.

Acknowledgements

Our heartfelt thanks to all study participants who generously gave their time and shared their unique stories in order to better inform practice and help children in the future.

Clinical trials registry

Australian New Zealand Clinical Trials Registry ID: ACTRN12617001419358.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Lifetime Support Authority (LSA) under Grant GA00015 (File No.: LSA0012 and Doc No.: LSA-D001155).

References

- [1] Florian V, Katz S. The other victims of traumatic brain injury: consequences for family members. *Neuropsychology*. 1991;5(4):267–279.
- [2] Kieffer-Kristensen R, Teasdale TW, Bilenberg N. Post-traumatic stress symptoms and psychological functioning in children of parents with acquired brain injury. *Brain Injury*. 2011;25(7–8):752–760.
- [3] Rohleder P, Lambie J, Hale E. A qualitative study of the emotional coping and support needs of children living with a parent with a brain injury. *Brain Inj*. 2017;31(2):199–207.
- [4] Brooks DN. The head-injured family. *J Clin Exp Neuropsychol*. 1991;13(1):155–188.
- [5] Brooks N, Campsie L, Symington C, et al. The five year outcome of severe blunt head injury: a relative’s view. *J Neurol Neurosurg Psychiatry*. 1986;49(7):764–770.
- [6] Ponsford J, Schönberger M. Family functioning and emotional state two and five years after traumatic brain injury. *J Int Neuropsychol Soc*. 2010;16(2):306–317.
- [7] Gan C, Gargaro J, Brandys C, et al. Family caregivers’ support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers. *NeuroRehabilitation*. 2010;27(1):5–18.
- [8] Kieffer-Kristensen R, Johansen K. Hidden loss: A qualitative explorative study of children living with a parent with acquired brain injury. *Brain Inj*. 2013;27(13–14):1562–1569.
- [9] Keenan A, Joseph L. The needs of family members of severe traumatic brain injured patients during critical and acute care: a qualitative study. *Can J Neurosci Nurs*. 2010;32(3):25–35.
- [10] Perlesz A, Kinsella G, Crowe S. Impact of traumatic brain injury on the family: a critical review. *Rehabil Psychol*. 1999;44(1):6–35.
- [11] Urbach JR, Sonenklar NA, Culbert JP. Risk factors and assessment in children of brain-injured parents. *J Neuropsychiatry Clin Neurosci*. 1994;6(3):289–295.

- [12] Lezak MD; National Head Injury Foundation. Living with the characterologically altered brain injured patient. Framingham: National Head Injury Foundation; 1978.
- [13] Butera-Prinzi F, Perlesz A. Through children's eyes: children's experience of living with a parent with an acquired brain injury. *Brain Inj.* 2004;18(1):83–101.
- [14] Guinevere W, Audrey D. Including children in family-focused acquired brain injury rehabilitation: a national survey of rehabilitation staff practice. *Clin Rehabil.* 2007; 21(12):1097–1108.
- [15] Pessar LF, Coad ML, Linn RT, et al. The effects of parental traumatic brain injury on the behaviour of parents and children. *Brain Inj.* 1993;7(3):231–240.
- [16] Thurman SK. Children of handicapped parents: research and clinical perspectives. Orlando (FL): Academic Press; 1985.
- [17] Visser-Meily A, Post M, Meijer AM, et al. Children's adjustment to a parent's stroke: determinants of health status and psychological problems, and the role of support from the rehabilitation team. *J Rehabil Med.* 2005;37(4): 236–241.
- [18] Walton KM, Ingersoll BR. Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: risk and protective factors. *J Autism Dev Disord.* 2015;45(9):2764–2778.
- [19] Moreno-Lopez A, Holttum S, Oddy M. A grounded theory investigation of life experience and the role of social support for adolescent offspring after parental brain injury. *Brain Inj.* 2011;25(12):1221–1233.
- [20] Sieh DS, Meijer AM, Visser-Meily JM. Risk factors for stress in children after parental stroke. *Rehabil Psychol.* 2010; 55(4):391–397.
- [21] Fisher A, Bellon M, Lawn S, et al. Family-directed approach to brain injury (FAB) model: a preliminary framework to guide family-directed intervention for individuals with brain injury. *Disabil Rehabil.* 2019;41(7):854–857.
- [22] Wright S, Gauld S, Roser J, et al. The brain crew: an evolving support programme for children who have parents or siblings with an acquired brain injury. *J Cognit Rehabil.* 2007; Fall:4–12.
- [23] Lezak MD. Brain damage is a family affair. *J Clin Exp Neuropsychol.* 1988;10(1):111–123.
- [24] Houtzager BA, Grootenhuis MA, Hoekstra-Weebers J, et al. One month after diagnosis: quality of life, coping and previous functioning in siblings of children with cancer. *Child Care Health Dev.* 2005;31(1):75–87.
- [25] Mosconi PD, Taricco M, Bergamini M, et al. Family burden after severe brain injury: the Italian experience with families and volunteer associations. *Patient.* 2011;4(1):55–65.
- [26] McLaughlin AM. Addressing the psychological needs of children with brain injured relatives: an activity group model. *J Cognit Rehabil.* 1992;10(2):12–18.
- [27] Jantz PB, Comerchero VA, Canto AI, et al. Traumatic brain injury and grief: considerations and practical strategies for school psychologists. *Contemp School Psychol.* 2015;19(3): 218–229.
- [28] Viscardis L. The family-centred approach to providing services. *Phys Occup Ther Pediatrics.* 1998;18(1):41–53.
- [29] Visser-Meily A, Post M, Gorter JW, et al. Rehabilitation of stroke patients needs a family-centred approach. *Disabil Rehabil.* 2006;28(24):1557–1561.
- [30] Olin SS, Hoagwood KE, Rodriguez J, et al. The application of behavior change theory to family-based services: improving parent empowerment in children's mental health. *J Child Fam Stud.* 2010;19(4):462–470.
- [31] Bellon M, Crocker R, Sando S, et al. Family support needs following acquired brain injury across metropolitan and regional/remote South Australia. *Brain Impairment.* 2015; 16(2):131–144.
- [32] Donovan CL, March S. Computer-based treatment programs for youth anxiety: a systematic review. *J Exp Psychopathol.* 2014;a1(1):130–156.
- [33] Tsai CC. Adolescents' perceptions toward the internet: a 4-T framework. *Cyberpsychol Behav.* 2004;7(4):458–463.
- [34] Chin JC, Tsuei M. A multi-modal digital game-based learning environment for hospitalized children with chronic illnesses. *Educ Technol Soc.* 2014;17(4):366–378.
- [35] de Graaf M, Totte J, Breugem C, et al. Evaluation of the compliance, acceptance, and usability of a web-based ehealth intervention for parents of children with infantile hemangiomas: usability study. *JMIR Res Protoc.* 2013;2(2): e54.
- [36] Cunningham M, Donovan CL, March S. Developing and delivering computer-based CBT for anxiety disorders in young people. 1st ed. Bowen Hills (QLD): Australian Academic Press; 2007. p. 83–97.
- [37] Spence SH, Spence SH, Donovan CL, et al. Online CBT in the treatment of child and adolescent anxiety disorders: issues in the development of BRAVE-ONLINE and two case illustrations. Queensland (Australia): Cambridge University Press; 2008.
- [38] March S, March S, Spence SH, et al. The efficacy of an internet-based cognitive-behavioral therapy intervention for child anxiety disorders. *J Pediatr Psychol.* 2009;34(5):474–487.
- [39] Calear AL, Christensen H. Review of internet-based prevention and treatment programs for anxiety and depression in children and adolescents. *Med J Aust.* 2010;192(S11): S12–S4.

Appendix 1

Interview guide for children

Primary Query: How did your (*Insert client's relationship*)'s brain injury/injury/illness affect you?

Opener: I understand that you have experienced brain injury in your family/your XXX has been hurt/went to hospital and I would like to talk more with you about this and how it has affected you (or ... how you feel). There is no right or wrong answers.

Main questions

1. What do you understand about your _____'s brain injury? (or for younger children 'what happened to your _____?')
2. Please tell me about your experience when you first became aware that your _____ had a brain injury/got hurt/went to hospital.
 - What were you told?
 - What happened in the hospital?
 - What happened in rehabilitation?
 - How did life change for you/how have your day's have changed? and your family?
 - Describe both good and bad aspects of your experience to date. (please tell me good and bad parts about everything you've been through)
3. How does your _____'s brain injury/injury/illness make you feel?
 - (Scared, devastated, embarrassed, understood, alone, supported, angry?)
 - Did you feel you could talk to people about your feelings?
 - If so, who?

If not, why?

How did you cope?

4. Who are the people affected by your _____'s brain injury/injury/illness?
 - How has your _____'s brain injury/injury/illness affected your relationship with you:
 - Mum/Dad?
 - Brother/Sister?
 - Extended family/Grandma/Grandpa?
 - Friends?
 - School?
5. What do you wish happened differently?
 - What would have helped you understand your _____'s brain injury/injury/illness better?
 - Did you feel 'part' of your _____'s recovery/rehabilitation?
 - Would it have helped you to link with other children going through the same thing? Why?
 - How do you best learn (auditory, tactile, visual, reading/writing, kinaesthetic, solitary, social)?
 - If a children's education program was offered while your XXX was in hospital, what:
 - Information should be included?
 - Who should be included (just kids?)?
 - How often should it be run and for how long?
 - Probing questions may include
 - Tell me more about
 - Please give an example of that ...
 - Why is that important to you?