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Main Title: Australian parent and sibling perspectives on the impact of paediatric acquired brain injury on family relationships during the first six weeks at home.

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Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

Data Availability Statement

The data that supports the findings of this study are not publicly available due to privacy or ethical restrictions.

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Main Title: Australian parent and sibling perspectives on the impact of paediatric acquired brain injury on family relationships during the first six weeks at home.

Abstract

This study explores the impact of paediatric acquired brain injury (ABI) on family relationships. Twenty-three families (n=18 mothers; n=7 fathers; and n=4 siblings) of children who sustained an ABI requiring treatment from inpatient acute and rehabilitation services reported on their perceptions regarding changes in family relationships since the injured child's return home. Thematic analysis of survey data was conducted. Family members (parents and siblings) described four themes: 1) negative changes in sibling interactions; 2) role changes arising from an increase in parental expectations of non-injured siblings; 3) family system challenges in balancing

needs within the parent-child dyad and sibling subsystems; and 4) supporting emotional responses within the family system. Findings reveal a critical time for families as they resume full care of the injured child at home. Clinical implications for social workers and other rehabilitation clinicians are explored.

Keywords: family, paediatrics, acquired brain injury, parents, siblings, relationships, community re-integration, transition, rehabilitation

Word Count: 5129 words

What is known about this topic?

- A paediatric acquired brain injury (ABI) event has a profound impact on the family system and disrupts its short and long-term functioning.
- Family functioning and child behavioural disturbances are predictive of child acquired brain injury social, emotional and participation outcomes.
- Rehabilitation services focus on child rehabilitation outcomes and community re-integration.

What this paper adds

- Focus on the impact of family relationships as the family system resumes care of the injured child at home.

- Important insights about family relationships changes post-ABI to expand on existing research on family functioning in the weeks following a child's return home.
- Important considerations for how rehabilitation services can include the family as part of the child's community re-integration transition

Introduction

Acquired brain injury (ABI) refers to damage to the brain (due to accidents, falls, strokes and infections) that occurs after birth (Laatsch et al., 2007) Children who sustain significant ABI can experience physical, cognitive and psychological losses and changes in functioning. Specialist paediatric rehabilitation services can assist a child to optimise their functional abilities and maximise their potential post-injury.

A paediatric ABI event can have significant impacts on the whole family system that surrounds and supports the child, disrupting the homeostasis of the system that existed prior to the injury (Analytis, Warren, & Ponsford, 2021; Bursnall, Kendall, & Degeneffe, 2018; Keetley, Radford, & Manning, 2019; Spina, Ziviani, & Nixon, 2005; Tyerman, 2015; S. L. Wade et al., 2002). ABI family research over the past two decades has shown an established relationship between family functioning and a child's post-injury social, emotional, participation and quality of life outcomes (LeBlond et al., 2021; Petranovich et al., 2020; Ryan et al., 2016; S. Wade et al., 2005; S. Wade, Zhang, Yeates, Stancin, & Taylor, 2016). Despite recognition that an ABI event can de-stabilise the family system and impact child outcomes, there is limited understanding of the process families undertake to re-organise and achieve a new homeostasis in the early stages post-injury.

Several studies have attempted to explain this changes in family relationships using the construct of family functioning in the first 12 months following a child's injury (Petranovich et al., 2020; Rivara, 1994; Rivara et al., 1992; S. Wade, Taylor, Drotar, Stancin, & Yeates, 1998; S. Wade et al., 2005; S. L. Wade et al., 2002). Families in these studies experienced instability, deterioration, and persistent problems

in family functioning in the initial period post-injury. One of the most challenging periods reported by families is the child's transition from hospital to home and the weeks and months that follow family reunification (Max et al., 1997; Robson, Ziviani, & Spina, 2005). During an injured child's hospital and rehabilitation admission, family members adapt their existing roles and tasks to ensure the needs of the family system are met. While intended as temporary, situation-specific adjustments to family life, re-negotiating further changes when the injured child returns home can prove problematic, with some families becoming 'stuck' in roles and patterns that no longer serve the needs of its members. For example, one parent, usually the mother, may continue to take on disproportionate responsibility caring for their injured child for months and even years post-injury (Clark, Stedmon, & Margison, 2008; Jordan & Linden, 2013; Robson et al., 2005). There can often be persistent issues related to parent coping, behavioural issues, inadequate resourcing that also adversely impact on the restoration of functioning to the family system (Keetley et al., 2019; Petranovich et al., 2020; S. Wade et al., 2005).

Family relationships have also been examined in the ABI research through the parent-child dyad using constructs of parenting styles and approaches as predictors of child outcomes (Clark et al., 2008; Moscato et al., 2021; Narad et al., 2019; Petranovich et al., 2020; Schorr, Wade, Taylor, Stancin, & Yeates, 2020). Parenting behaviours towards the child with the ABI have been reported to negatively change over time, with a reduction of warmth and involvement between relevant family members in the parent-child dyad (Narad et al., 2019). The bi-directional interactions within this parent-child dyad can impact on the child's behavioural outcomes, causing it to spiral negatively or positively, depending on the parenting approach (Moscato et al., 2021). Parents of

children with ABI, describe complex emotional responses associated with their child's ABI, such as grief, anxiety and guilt that manifest in their parenting approaches, the care they provided to their child and the quality of the parent-child relationship (Jordan & Linden, 2013; Yehene, Steinberg, Gerner, Brezner, & Landa, 2021). When they reported on parent-child dyads several years post-injury, mothers expressed a desire to re-build their relationship with their injured child, particularly if the child had had significant personality and behavioural changes post injury (Clark et al., 2008).

Family system resources are often redirected to focus on the injured child's acute care and rehabilitation immediately following an ABI, at the expense of time spent with non-injured sibling/s (Hickey, Anderson, & Jordan, 2016). Parents are often consumed with the care (direct and indirect) of the injured child, which limits energy to focus on the spousal subsystem and needs of the whole family system (Roscigno & Swanson, 2011). Other family system impacts include collective grief and loss responses; increased protectiveness of the injured child; isolation from others outside the family system; and loss of a predictable family future (Clark et al., 2008; Collings, 2008; Hickey, Anderson, Hearps, & Jordan, 2018a). Blame and guilt can also be felt by family members who believe they could/should have prevented the child's injury.

The unexpected nature of an ABI also impacts sibling relationships (Analytis, Warren, & Ponsford, 2020; Analytis et al., 2021; Bursnall et al., 2018; Tyerman, Eccles, Gray, & Murray, 2019). The ABI can challenge a sibling's world view, with their previous sense of meaning, safety and predictability contested. Siblings' perceptions of their parents as 'omnipotent' can also be shattered, exposing the parents' powerlessness to prevent the injury and personal vulnerabilities. That the injured child

has survived often gives hope to siblings that life will return to 'normal' (Analytis et al., 2020; Gent, 2011). As the injured child's care transitions through the phases from acute care - rehabilitation - return home, siblings report frustration and disappointment when faced with changes to family routines, structure and roles, decreased emotional and physical availability of parents, and increased caregiving responsibilities (Bursnall et al., 2018; Hickey et al., 2016). This is often compounded by feeling 'left out' of the recovery process; with limited injury information shared with siblings. Hope often gives way to a realisation that the injured child (and the family) will be ever changed and a new 'normal' needed (Tyerman et al., 2019). Consequently, the sibling subsystem is altered.

The extent of sibling subsystem changes post-injury appears to be largely dependent on the interactions that occur within the family system. With family resources being directed towards the injured child, the siblings feeling the loss of their parents' attention and support and a sense of isolation from within the family system (Analytis et al., 2020; Bursnall et al., 2018; Clark et al., 2008; Fay & Barker-Collo, 2003; Nodell, 1990; Robson et al., 2005; Sambuco, Brookes, & Lah, 2008; Swift et al., 2003; Tyerman et al., 2019). This is often exacerbated by sibling perceptions that their parents have changed their parenting style in favour of the injured child.

Sibling subsystem relationships may alter post-injury. In past studies, siblings have reported intense feelings of jealousy towards the personal attention directed at the injured child (Bursnall et al., 2018; Tyerman et al., 2019). Changes in an injured child's behaviour can leave siblings feeling embarrassed and socially isolated amongst their peers (Fay & Barker-Collo, 2003). Siblings experience a disruption to their

emotional equilibrium, are at-risk of adverse psychological outcomes with internalised feelings of worry, low-self-esteem and anxiety (Bursnall et al., 2018; Sambuco, Brookes, Catroppa, & Lah, 2012). These emotional responses are often exacerbated if siblings have been present or witnessed the injury event.

For this study, family relationships were defined by the Resiliency Model of Family Stress, Adjustment and Adaptation (the Resiliency Model) theme of *Changes in Family Patterns* definition (McCubbin, McCubbin, Danielson, Hamel-Bissell, & Winstead-Fry, 1993). *Family Patterns* are sets of attributes or clusters of behaviours that explain how the family system typically operates or behaves. These patterns also play a critical role in facilitating the development, restoration and/or maintenance of balance of the family system and the quality of the relationships between family members. This study describes the changes in family patterns and relationships related to a child's injury.

It is important to examine short-term adaptation in order to prevent long-term maladjustment for families caring for a child with ABI. This study will also explore family members' perceptions after discharge from inpatient rehabilitation and reunification with the whole family system of the impact of the child's ABI. This study aims to contribute to the existing knowledge about the family experience during an important transition period, with specific attention to family relationships.

Materials & Methods

Study Design

This study will report on quantitative and qualitative data obtained as part of a larger study conducted at The Royal Children's Hospital (RCH), a state-wide tertiary paediatric hospital in Melbourne, Australia. The RCH Human Research Ethics Committee (HREC 31212A) approved this study.

Participants

Parents and other family members (aged 18 years and over) with the responsibility of daily care of the injured child and siblings (aged 7-18 years) of children diagnosed with an ABI and admitted to inpatient rehabilitation between July 2012 and September 2015 were invited to participate at the time of the injured child's inpatient rehabilitation admission. A total of 47 families, including 75 family members (38 mothers, 26 fathers, one grandmother, three step-fathers and seven siblings) were enrolled into the larger study from which this sample is reported.

Eligible participants were identified via the hospital's rehabilitation service clinical meetings and approached once the child's admission to inpatient rehabilitation was confirmed.

Inclusion/exclusion criteria

Inclusion criteria were: (1) families of children aged 0-18 years who had recently sustained an ABI and requiring treatment from acute and inpatient rehabilitation; and (2) parents and other family members (caregiver) over 18 years with the responsibility of daily care of the injured child; 3) siblings aged 7 years and over. Exclusion criteria were: families of children (1) with an ABI from suspected physical abuse; (2) pre-existing ABI; (3) existing patient of the rehabilitation service and re-

admitted for inpatient services. Recruitment occurred between July 2012 and September 2015.

The injured children and families had access to social work and clinical psychology and neuropsychology professional as part of an interdisciplinary inpatient rehabilitation service treatment response. Following inpatient rehabilitation discharge, the contact with social work and other professionals was dependent on need, identified either by the rehabilitation service or family.

PROCEDURE

This study is part of a larger clinical intervention trial focused on family adaptation following ABI (Hickey et al., 2018a; Hickey, Anderson, Hearps, & Jordan, 2018b). The larger study collected data at three timepoints across the injured child's rehabilitation phases of care: T1 Inpatient Rehabilitation Admission; T2 Inpatient Rehabilitation Discharge; and T3 six week post Inpatient Rehabilitation Discharge. Families were recruited prospectively and sequentially as their child was admitted to the Inpatient Rehabilitation service. Parents or guardians of eligible siblings provided consent at T1 for their participation at T3.

At all three timepoints (T1, T2 & T3) in the larger study, parents and other adults who provide daily care for the injured child completed the 'Parent/Caregiver' surveys containing several repeat measures examining family adaptation. At T3, the 'Parent/Caregiver Survey' had an additional section pertaining to '*Changes in family relationships*'. At this same timepoint (T3), the siblings who had previously been

consented at enrolment into the study by their parent/guardian, also provided responses about changes to family relationships relevant to their role within the family. The relevant survey/s (T3) were handed to all enrolled participants of the larger study at their child's brain injury clinic review or posted to their home address (for families who did not attend the review clinic or had been transferred to a regional rehabilitation service). In addition to the sibling consent previously provided by parents at the time of recruitment into the larger study, siblings were also invited to confirm their willingness to participate at T3 by ticking the front page of the 'Sibling Survey' questionnaire. All participants were then provided with the relevant survey and a separate self-addressed envelope to ensure their responses to the surveys remained private and confidential in accordance with the ethical approval for this study.

Changes in family relationships section

The 'changes in family relationships' sections in the Parent/Caregiver and Sibling surveys were designed to obtain family member perceptions of changes (if any) that had occurred to family relationships since the injured child's return home at six-week post inpatient rehabilitation discharge. The sections contained three open-ended questions which focused on the family relationships according to 1) the sibling subsystem; 2) the parent-child dyad; and 3) the whole family system. For each question, participants provided quantitative data indicating 'yes' or 'no' as to whether there were impacts on family relationships. If they answered 'yes', they were asked then to describe their experience using free text responses (qualitative data) related to the question (See Table 2).

This study sought to obtain a multi-family member perspective on the changes to family relationships since the injured child's return home. There were no previous measures to capture this experience; therefore, three open-ended questions for the parents/carers and siblings to complete were developed by the researchers.

INSERT TABLE 2 HERE

Analysis

This paper will report on the changes in family relationships quantitative and qualitative data collected via 'Parent/Caregiver Survey' and 'Sibling Surveys' at T3. The number and proportion of 'yes' responses (quantitative data) to each of the three open-ended questions from the qualitative data is described. Thematic analysis of the qualitative data was conducted by the first author (LH) on the parent data and sibling data. Reflexive thematic analysis provided a description of the experience of the parents and siblings and reported patterns (themes) within the data (Braun & Clarke, 2006, 2019a, 2019b). Parent and sibling responses were analysed using a six-step process: (1) read data line-by-line, noting any initial ideas; (2) generated initial codes of features of the data related to the study aims; (3) collated codes into potential themes; (4) connections between themes were reviewed and noted, and (5) defined and named themes; and (6) producing the report (Braun & Clarke, 2006, 2019a, 2019b). Given the small data set there was considerable overlap between the coding stage and identifying the themes.

The themes described patterns in the data relevant to exploring family members' perceptions of the impact of the child's ABI on family relationships after

discharge from inpatient rehabilitation and reunification with the whole family system. To ensure the identification of themes were consistent and grounded in data, the themes were reviewed by the two co-authors (LH & BJ), any differences discussed, and consensus reached by the research group.

Results

In this study sample, 29 participants (18 mothers, 7 fathers and 4 siblings aged between 10 years and 15 years) from 23 patient families provided qualitative data. In total there were of 29 siblings across the 23 families. Of these 29 siblings, there was 18 siblings that met the eligibility criteria (aged 7 years and over) for this study. Parents (mothers and fathers) provided responses and therefore the term 'parents' will be used for reporting on the adult family member participants when describing this study sample hereafter. Family member demographics and patient characteristics, including the range of diagnoses, are presented in Table 1.

INSERT TABLE 1 HERE

Of the 29 respondents, 14 mothers, five fathers and three siblings (76%) indicated relationship changes in the sibling subsystem since the injured child's return home. Parent-child dyad relationships were also reported to have changed with 55% of respondents (9 mothers, three fathers, four siblings). A significant proportion 83% of family members in this study sample (16 mothers 6 fathers, two siblings) perceived changes family relationships in the six weeks since the reunification of the injured child with the whole family system.

The major themes relating to family member perspectives on sibling-sibling and parent-sibling dyad relationships and whole family relationship changes are described with interpretive comment. To ensure confidentiality in accordance with ethical considerations, participants for this study are identified by the family number and family member role. Parents and siblings reported the following themes that had affected the whole family system: 1) negative changes in sibling interactions; 2) role changes arising from an increase in parental expectation on siblings; 3) family system challenges associated with balancing needs within the parent-child dyad and sibling subsystems; and 4) supporting emotional responses within the family system. Verbatim quotes from the parent questionnaires are used to illustrate the complexities of their experiences, including the similarities and differences in perspectives from the participants.

Theme 1: Negative changes in sibling interactions

Parents reported negative changes to the sibling interactions in play with increased frustration and anger expressed by siblings towards each other. One father noted that his injured child was more aggressive, creating a need for increased parental supervision and monitoring of the sibling subsystem to ensure safety for all children.

> *'(Injured child) can be overemotional over small things depending on how tired he can be. Needs to be watched closely when he is tired to prevent something happening to his little brother'. Family 31, Father.*

Parents attributed these changes in the behaviour of the injured child since returning home to the ABI. Injury related changes such as cognitive fatigue, aggressive behaviour and communication challenges were all perceived as impacting on the sibling interactions.

> *'There are times where (injured child's) ABI impacts her ability to play/participate with her sisters' activity which can cause (injured child) to feel frustrated/sad at times'. Family 15, Father.*

Parents also reported siblings to have diminished coping in dealing with the injured child's challenging behaviours and this in turn negatively impacted the family system.

> *'The girls (siblings) seem to take turns in being able to cope and not cope with child's behavioural changes and the impact of these on our lives. They get very upset at times with him and with my husband and I'. Family 49, Mother.*

Parents also recognised the emergence of sibling jealousy, with non-injured siblings adversely responding to the increased attention and focus on the injured child.

> *'My other child feels jealous and gets upset all the time because attention is more focused on my impacted child'. Family 11, Mother.*

One sibling noted a decrease in the amount of contact with their injured sibling.

'I don't really get enough time with her because when I come home, she is resting or at an appointment'. Family 48, Sibling.

Theme 2: Role changes arising from an increase in parental expectation on siblings

Family members reported an increase in parental expectations on non-injured siblings which led to additional pressure, increased protectiveness, and a confusion of roles within the sibling subsystem. Parents' reported expectations on the sibling/s to mature and be actively involved in the injured child's recovery.

'His sibling is younger but has had to 'grow up' quickly, be more understanding, patient, tolerant, supportive. It has been challenging for him'. Family 50. Mother.

'I hear her telling him (injured child) the things he needs to do in the same tone of voice that I do (mum)'. Family 21, Mother.

One sibling also felt an increased responsibility to care for their injured sibling and educate others about their appearance and behaviour. Two siblings reported on their injured siblings' change in behaviour made it difficult to communicate and to support them.

'I feel like I'm in charge a lot more and need to take a lot more responsibility. I can't hurt him as much if we fight. When we go out, I make sure he wears a

helmet. Sometimes I have to explain his behaviour to strangers.' Family 50. Sibling.

Theme 3: Family system challenges associated with balancing needs in the parent-child dyad and sibling subsystems

Parents described changes in the parent-child dyad associated with the challenges of juggling the needs of the injured child whilst at the same time trying to meet the needs of other children with the family. Parents were aware that there had been a reduction in positive interaction in the parent-child dyad with the siblings of the injured child.

'My tolerance levels have decreased, have less patience with higher demands of children's behaviour also trying hard to spend time with each child is difficult due to 'business' and appointments and work.' Family 48, Father.

Parents described attempts to maintain both pre- and post-injury family routines and the toll this was taking on the family; specifically, changes in siblings' behaviour, engagement at school and negative impact of having restricted access to social and recreational activities.

Parents reported adjusting their parenting approach to accommodate the changed needs of their injured child. In making these adjustments, parents recognised an absence or lack of availability towards siblings.

'I probably have spent less time worrying about the 2-year-old needs as I've been more concerned with getting (injured) child back on track socially, every activity and encounter. I'm thinking about how he (injured child) perceives/experiences whatever we may be doing. The 2-year-old is expected to go with the flow.' Family 31, Mother.

One sibling felt that the injured child was favoured and given concessions for their behaviour, despite him being '*clearly in the wrong'*. This sentiment was echoed by another sibling '*there seem to be a lot more things that we do wrong and the stress that makes them become angrier quicker.' Family 49, Sibling.*

Theme 4: Supporting emotional responses within the family system

Parental emotional distress manifested in parents being ever watchful for positive signs their child was *'on the mend or back to normal'*.

'It has surprised me how his personality has changed. He's more emotional and so I need to change how I respond to him. Also, it's made me more emotional and more of a worrier'. Family 21. Mother.

Grief and loss were also expressed by parents related to the loss of the healthy child. *'It's very stressful and sad situation to be in, especially when prior to the injury our child was 100% healthy!' Family 10, Mother.* Another parent described the emotional impact of monitoring the child's progress post-ABI:

'It is hard to stop worrying about them and you do find yourself analysing everything significantly to try and determine things are on the mend or back to normal. It can be emotionally and mentally very difficult.' Family 15. Father.

All four siblings in this study affirmed that their relationship with their parents had changed since the injured child's return home. One sibling spoke of her reluctance to be at home and withdrawal from her family: *'When I go home, I get scared and I don't feel like talking to anyone' (Family 48, Sibling).* Another sibling described the impact on the whole family and in particular the fragility of his parents at the time of the accident:

'When it is really serious, I had to look after my mum a lot. For the first time ever, I saw my dad cry, it was difficult to understand everything. I felt like they forgot about me'. Family 50, Sibling.

These emotional responses, while often complicated, changed parents' perspectives on what was most important for their family moving forward: with the injury impacting on the family in 'many different ways' with a mix of challenges and gratitude surrounding the survival of the injured child.

'I'd rather he/we didn't have this challenge to face, but we've had to embrace it to move on with life and help our child with learning and getting ready for school next year.' Family 31, Mother.

While negative changes to family life were many, there were positive reflections from family members. Reflecting on the overall experience of having a child with a recently acquired brain injury, some parents experienced positive personal growth in response to this challenging experience *'I wish I knew then what I know now. It gets better' Family, 41 Father.* One sibling commented on the importance of remaining positive and trusting the treating team while another sibling response re-stated the challenges associated with the injured siblings change in mood and behaviour.

Discussion

The aim of this study was to explore the impact of a child with ABI on family patterns, specifically relationships, in the sibling subsystem, parent-child dyad and whole family system during the first six weeks of the injured child's return home. To the authors' knowledge, this is the first study to explore multiple family member perspectives on the changes in family relationships following a paediatric ABI. The study findings point to emerging family relationship difficulties relating to negative changes in sibling interactions; role changes arising from an increase in parental expectations of non-injured siblings; family system challenges in balancing needs within the parent-child dyad and sibling subsystems; and supporting emotional responses within the family system.

Parents and siblings in this study provided important insights into the emerging family patterns and relationship difficulties experienced by family systems as they re-organise to meet the changed needs of the injured child at home. In the sibling

subsystem, family members reported problematic patterns of interaction and negative emotional responses towards the injured child. These changes were perceived as adversely impacting on the quality of the sibling relationships within families. The experiences of family members' in this study is consistent with previous research and expert commentary on ABI sibling research (Gent, 2011; Nodell, 1990; Robson et al., 2005; Tyerman et al., 2019). The sibling relationship difficulties during the first six weeks of family reunification described by the family members in this study suggest that early post-ABI interventions focusing on non-injured siblings are needed (Hill & Brenner, 2019).

This study also highlighted the impacts of paediatric ABI on parent-child relationships and the complex task of family adaptation in the early weeks of reunification. Parents described the challenges of parent-child dyad with injured and non-injured children within the family. Within a relatively short period of time (six weeks post-inpatient rehabilitation discharge), the families in this study recognised these initial parent-child dyad changes in family patterns, similar to those reported by families in previous studies over several months or years (Bursnall et al., 2018; Clark et al., 2008; Jordan & Linden, 2013; Keetley et al., 2019; Tyerman et al., 2019). In their attempts to achieve a new balance in the parent-child relationships within the family, parents in this study sample described the complex process of shifting from pre-injury to new post-injury relationships with the injured child and their non-injured siblings. Parents and non-injured siblings described challenges and tensions associated with changes in the parent-child relationships. Given the brief elapsed time period from the injured child's inpatient rehabilitation discharge to family reunification, these challenges and tensions are to be expected.

What needs to be explored in future studies is how paediatric rehabilitation services can better prepare families about the changes in parent-child relationships they may expect and how these challenges and tensions can be managed in the early stages of reunification.

For many families in this study, the six-week period of reunification followed the injured child's lengthy acute and rehabilitation admissions. Parents and siblings perceived changes to the roles, responsibilities and patterns of interaction and communication within the family system with the injured child's return home. The prolonged acute and rehabilitation admissions for children with significant ABI may be an opportunity for paediatric rehabilitation services to deliver family support interventions that focus on family relationship issues as they arise.

The experiences of parents and siblings in this study draw attention to the systemic changes to family patterns post-injury and their ability to rebalance as a system while paying attention to the new structure required to manage the child's changed care needs. Although family members perceived these changes as necessary to meet their changed circumstances, they expressed emotional responses related to the child's ABI and resultant changes in family system relationships. The qualitative responses to the open-ended survey questions provide insights into these experiences. While the paediatric ABI family research has conducted qualitative research (Analytis et al., 2020, 2021; Bursnall et al., 2018; Clark et al., 2008; Roscigno & Swanson, 2011; Tyerman et al., 2019; Yehene et al., 2021), the use of qualitative research methods is needed to provide a rich and nuanced understanding of the family experience.

Parent and sibling descriptions of family relationship changes in the first six weeks of reunification align with previous studies (Collings, 2008; Keetley et al., 2019; Petranovich et al., 2020; S. Wade et al., 2005; S. Wade et al., 2016; S. L. Wade et al., 2002). The strength of this study, however, is the experiences of multiple family member perspectives, particularly those of fathers, who rarely report on their experiences following a child's ABI. What is important about the findings is that the families are beginning to recognise problematic issues that have been shown in previous studies to manifest as long-term maladaptive issues. Regardless of the role of the family member - mother, father, or sibling - the themes identified resonated with all who experienced this transition. In this sample, common themes were surfacing in the weeks following the child's discharge home. The findings from this study highlight that timely psychosocial family intervention is needed to ensure optimal family recovery trajectory following paediatric ABI.

Clinical implications

The findings of this study highlight the important role rehabilitation clinicians can play in supporting families in the transition to resuming care of the injured child at home. While the transition of the injured child from inpatient rehabilitation to home is a critical step for family recovery, this is also the point where rehabilitation clinicians typically start to reduce their involvement. This is not a timely response to the increasing needs of the injured child and family system. Assisting families to undertake the preparatory work before returning home is key to successful outcomes. This includes managing family expectations of the much-anticipated discharge. Proactive psycho-social interventions and resources need to be available to families as

they traverse the unfamiliar terrain that is unique to this transition process and will prevent emerging family relationship challenges and problematic issues from becoming entrenched.

Limitations

The quantitative and qualitative data collected via the survey format was limited. Despite this limitation, the findings in this study are similar to those of previous studies and as such the researchers are confident of the method of data collection used in this study. The open-ended survey questions offered participants an opportunity to share more details of their experiences. Unfortunately, more-in-depth exploration of family member perceptions about the changes in family relationships was not within the scope of this study.

The children of the families within this study were admitted to inpatient rehabilitation presented with different types of ABI. It was not possible to determine injury severity and its impact on family members' perceptions of changes in family relationships. Further, the nature and extent of social work and psychological interventions delivered to the participating families during the inpatient rehabilitation admission and following discharge is not reported. Therefore, it is not possible to draw any conclusions about the impact of these interventions on the experiences reported by family members.

Conclusions

In examining the experience of family members impacted by paediatric ABI, this study highlights important ramifications for rehabilitation services. The findings

give a vivid account of changes to the family relationships when a child is returned to the family system post injury and inpatient rehabilitation. The early identification of changes in the family relationships by family members suggests that the transition phase of family reunification is a further opportunity for social work and rehabilitation clinicians to provide interventions that will optimise a positive family recovery trajectory. Further research is needed to understand how rehabilitation and community-based services can provide post-inpatient rehabilitation support to families as they reintegrate their family system in the weeks following inpatient discharge.

Declaration of Conflicting Interest

'The authors declare that there is no conflict of interest'

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Table 1: Child characteristics and participant demographics

Patient Characteristics (N=23)		Participant demographics (N=29)	
Age (years), M (SD)	7.73 (4.54)	Mothers, n (%)	18 (62.1)
Gender [male], n (%)	17 (73.9)	Age, (years), *M* (SD)	33.0 (15.6)
Diagnosis, n (%)		Fathers, n (%)	7 (24.1)
Stroke	9 (39.1)	Age, (years,), *M* (SD)	42.7 (5.12)
Encephalitis	8 (34.8)	Siblings, n (%)	4 (13.8)
Traumatic Brain Injury	5 (21.7)	Gender of siblings[female], n (%)	3 (75.0)
Hypoxic Brain Injury	1 (4.3)	Age (years) M (SD)	11.75 (2.36)
Time in rehabilitation (days), (SD)	33.96 (28.93)	Parents highest educational level, n (%)	
Time at hospital (incl. rehabilitation) (days), (SD)	55.65 (39.15)	High school graduate	6 (24)
		University/College	13 (52)
		Post-graduate	4 (16)
		Not specified	2 (8)

Table 2: Open-ended questions

FAMILY MEMBER	QUESTIONS
Parent/caregiver	(1) 'Has your child's brain injury impacted on his/her relationship with your other children?' (2) 'Has your child's brain injury impacted on your relationships with the other children in your family?' (3) 'Is there anything else you would like to share about having a child with an acquired brain injury?'
Sibling	(1a) 'Has your brother or sisters brain injury changed your relationship with him/her?' (2a) 'Has your brother or sisters brain injury changed your relationship with your parents?' (3a) 'Is there anything else you would like to share about having a brother or sister with an acquired brain injury?'