

Experiences and needs of parents of critically injured children during the acute hospital phase: A qualitative investigation



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ARTICLE INFO

Article history:

Accepted 23 September 2016

Keywords:

Parents
Children
Injury
Trauma
Psychological distress
Family
Qualitative research
Emotional well-being
Interview
Hospital

ABSTRACT

Introduction: Physical injury is a leading cause of death and disability among children worldwide and the largest cause of paediatric hospital admission. Parents of critically injured children are at increased risk of developing mental and emotional distress in the aftermath of child injury. In the Australian context, there is limited evidence on parent experiences of child injury and hospitalisation, and minimal understanding of their support needs. The aim of this investigation was to explore parents' experiences of having a critically injured child during the acute hospitalisation phase of injury, and to determine their support needs during this time.

Methods: This multi-centre study forms part of a larger longitudinal mixed methods study investigating the experiences, unmet needs and well-being of parents of critically injured children over the two-year period following injury. This paper describes parents' experiences of having a child 0–13 years hospitalised with critical injury in one of four Australian paediatric hospitals. Semi-structured interviews were conducted with forty parents and transcribed verbatim. The data were managed using NVIVO 10 software and thematically analysed.

Findings: Forty parents (26 mothers and 14 fathers) of 30 children (14 girls and 16 boys aged 1–13 years) from three Australian States participated. The majority of children were Australian born. Three main themes with sub-themes were identified: navigating the crisis of child injury; coming to terms with the complexity of child injury; and finding ways to meet the family's needs.

Conclusions: There is a need for targeted psychological care provision for parents of critically injured children in the acute hospital phase, including psychological first aid and addressing parental blame attribution. Parents and children would benefit from the implementation of anticipatory guidance frameworks informed by a family-centred social ecological approach to prepare them for the trauma journey and for discharge. This approach could inform care delivery throughout the child injury recovery trajectory. The development and implementation of a major trauma family support coordinator in paediatric trauma centres would make a tangible difference to the care of critically injured children and their families.

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Introduction

Physical injury is a leading cause of death and disability among children worldwide and from the age of five, unintentional injuries are the largest threat to a child's survival [1]. When a child is injured parents report a range of intense emotions [2–5]. Parents are often fearful and concerned about their child's survival,

distressed and emotional about witnessing their child's pain, and affected by seeing the changes in their child's appearance and behaviour [2]. During the acute hospitalisation and treatment period, parents of critically injured children are constantly interacting with hospital staff and under pressure to make difficult decisions about their child's treatment. They experience an unfamiliar and stressful environment characterised by noisy equipment and witnessing other injured children [3,4].

Several factors influence how parents react to the hospitalisation of their severely injured child. These include the severity of their child's injury, whether they witnessed or were involved in the incident that led to their child's injury, the parent's own mental

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health and existing coping strategies, the normal pattern of family functioning, and parental reactions to the busy demands of the hospital environment [6]. In the first days following their child's injury, parental anxiety can be raised to near panic levels [7], and rates of parental acute stress disorder are reported as ranging from 16% to 32% [2,8,9]. Around 20–40% of parents are at risk of developing depression or anxiety after the injury [10] and up to 47% of parents develop post-traumatic stress disorder (PTSD) [2,8,11,12].

Children are dependent on their families, especially their parents, to meet their physical, emotional and social needs. If parents of a critically injured child have reduced capacity to meet their child's needs there is a negative impact on the physical and psychological adjustment of their injured child [13,14] and the well-being of entire family unit can be threatened [9,11,15].

A synthesis of international injury literature on the experience of surviving life-threatening injury found that individuals, regardless of age, rely heavily on family to assist them through the injury trajectory [16]. While the literature investigates the central role played by parents in providing care and support for critically injured children and adolescents, and parents' role in influencing how children cope with their recovery [17–19], few studies have explored parents' experiences of having a critically injured child throughout the hospitalisation period and little is known about the experiences and needs of parents with critically injured children during this time. There is a subsequent lack of evidence-based literature or clinical guidelines on supporting parents following critical child injury. Evidence is needed to inform care provision to better meet the needs of parents and families during a child's hospitalisation, and improve parents' and children's well-being and outcomes.

Aims

This study aims to investigate the experiences of parents of critically injured children 0–13 years during the acute hospitalisation phase, and to identify parents' unmet needs and factors that contribute to or impede their needs being met during this time.

Method

This study forms part of a prospective longitudinal multi-centre study investigating the experiences, unmet needs and well-being outcomes of parents of physically injured children 0–13 years over the two-year period following injury [20]. This paper describes the qualitative findings from the acute hospitalisation (initial) phase of the study. An interpretive qualitative approach was used to investigate parents' experiences and needs. This design is useful for understanding how people interpret and make meaning of their experiences, and is appropriate when little is known about a phenomenon [21].

Participants and recruitment

To be eligible, parents needed to have a child aged 0–13 years who had recently been hospitalised with an Injury Severity Score (ISS) greater than 15 or required an Intensive Care Unit stay. Parents also needed to speak, read and write English and be aged 18 years or older. A purposive sample of parents of children aged 0–13 years admitted with severe injury were recruited from four specialist paediatric trauma hospitals across three different Australian States. Potential participants were identified by the trauma coordinator at each site during clinical rounds and study suitability was discussed with the clinical team prior to recruitment. The trauma coordinator is a senior nurse responsible for the coordination of patient care from resuscitation to discharge [22].

Data collection

Researchers liaised with trauma coordinators to arrange parent interviews in a quiet room in the hospital. A trained interviewer conducted semi-structured in-depth interviews. Topic areas included parent experiences of having a critically injured child; parents' main needs when their child was injured; how parent needs were/not met, and by whom. Interviews occurred between September 2014 and October 2015 and ranged between 12 and 60 min with an average of 37 min. Data saturation, where no new information was being gathered, was reached with 40 participants. Field notes were completed after each interview. Interviews were audio recorded and transcribed verbatim, and de-identified with pseudonyms assigned.

Ethical considerations

Ethical approval for the study was gained from the relevant University and Hospital ethics committees. Participants were provided with an information sheet and consent form and gave verbal and written consent prior to study participation. Confidentiality and participant rights to cease the interview at any time were discussed and all participants were provided with contact details for follow-up emotional support if required. It was anticipated parents might get upset during interviews and in the event this occurred, the trained interviewer followed an ethics-approved process in providing initial support [20].

Analysis

Transcripts were imported into NVIVO 10 and an inductive thematic approach was used to analyse data. Interviews were coded initially using descriptive and in-vivo codes within and across interviews [23]. Codes were collated and collapsed into emergent themes by two researchers and in an iterative interpretive process, compared and mapped across the dataset to result in the final themes [24].

Findings

Forty parents of thirty critically injured children participated in the study (see Table 1 for child demographics). Children were aged from 1 to 13 years (mean = 7 years) and included 14 girls and 16 boys. The majority of children were Australian-born (28 children, 93%). Twelve children had both their parents interviewed (i.e. 24 parents) and 18 children had one parent interviewed (16 parents, as two parents each had two injured children). Twenty-six interviews were conducted with mothers and 14 with fathers. Parents ranged in age from 24 to 53 years (mean = 40 years). The majority of parents were Australian born (28 parents, 70%) with seven parents (18%) born in another country and five for whom no details were given (12%). Three main themes, with sub-themes, were identified in analysis: navigating the crisis of child injury; coming to terms with the complexity of injury; and finding ways to meet the family's needs.

Navigating the crisis of child injury

Parents had a range of reactions to their child's injuries during the acute hospitalisation phase including feeling initial shock about the injury, dealing with their child's treatment, and the difficulties of balancing the hospital and home environments.

The shock of injury—'it's turned our world upside down'

All parents felt shock at their child's injury regardless of how the injury occurred. Parents empathised deeply with the pain their

Table 1
Child demographics.

Baseline	Number of Children
Girls	14
Boys	16
Age range of children	1–13 years (mean 7 years)
Range of Injury Severity Score (ISS)	4–50 (mean 23)
Median number of days in ICU (IQR)	2 (1–7)
Median number of days in hospital (IQR)	18 (10–68)
Mechanisms of Injury:	
Motor Vehicle Collisions	
Motor vehicle passengers	12
Run over by car	2
Scooter hit by car	1
Motorbike hit by car	1
Falls	
Roof	2
Scooter/Pedal bike	2
Ladder or bench	2
Road Collisions	
Pedestrian versus car	3
Pedal cyclist versus car	1
Pedestrian versus motor bike	1
Other	
Kicked by horse	1
Go cart incident	1
Burn	1
Total number of injured children	30

child experienced, with many expressing how difficult it was as a parent to see their child in such intense pain:

'I would often have to just walk away and cry a little bit because it was just so overwhelming to see them in that much pain and not be able to take the pain away or stop it.' (Mother, 7 year old girl, motor vehicle collision)

Many parents were emotionally traumatised by the impact of the injury on their child and felt great sadness, fear and grief. Others kept their emotions in check and acknowledged they would likely feel the emotions later. These parents focused on addressing the physical and emotional needs of their child rather than their own needs:

'I haven't dealt with it all. I know I'm going to have to, but at the moment I haven't had time to worry about that. It's about getting her right. Once she's right and she gets home, I can find myself a little corner and I'm going to crash hard then and I'll just let it all out then.' (Father, 7 year old girl, pedestrian versus car)

Dealing with treatment—'one day at a time'

Most parents saw it as their responsibility to understand the type of treatment their child received and to ask questions of staff about their child's progress. Many were focused on the daily hospital routine and weren't thinking much about the future. Most were satisfied with the level of information they received from staff and the manner in which information was delivered:

'His surgical team were really good in giving us as much information as they could. We've seen them on a daily basis, so we've been able to touch base with them constantly and say, is this what you'd expect for his recovery? Is he doing everything that's appropriate? So, it's been good to talk to those people.' (Mother, 1 year old boy, kicked by horse).

A few parents were critical of the information they were given. They believed that staff should have given them more information, but did not seek staff out to ask. For some, the full extent of their child's injury only became evident over time. As the nature of the treatment and recovery process unfolded, these parents gained a deeper understanding of the emotional effects of their child's

injury on the whole family. This was coupled with a growing awareness of the complex and longer-term impacts of their child's injury:

'There'll be a 'before this accident' kind of time and then after it . . . it will have a big impact for a long, long time.' (Mother, 7 year old girl, motor vehicle collision)

The difficulties of balancing hospital and home—'two worlds collide'

Regardless of how far parents lived from the hospital, there was always tension between caring for their hospitalised child versus meeting the demands of life and family outside the hospital. This was further complicated by the nature of the injury and whether other family members had been involved in, or witnessed, the incident. Even with family and community support, many parents felt stressed trying to run a household from the hospital, especially with the care of siblings. Some parent couples stayed at the hospital and relied on extended family and friends to care for other children. Others chose one parent to remain at the hospital once the initial crisis had passed with the other returning home to care for other children. The situation was more complicated for single and/or separated or divorced parents.

Some parents had financial concerns because they were unable to work as a result of their child's injuries. While some were eligible for carers or sick leave, others were forced to take unpaid leave. If the parent at the hospital was normally the home caregiver, their partner became responsible for caring for other family members as well as working. The financial impacts were more intense for families where parents were self-employed and had limited access to sick leave or other employee entitlements:

'The expense of being here, it ends up racking up over time "cos you've got to pay for all your own food and your bits and pieces. We've struggled money wise because we just bought a house, so the mortgage's dropped to one wage plus we've got other debts.' (Mother, 3 year old boy, motor vehicle collision)

Coming to terms with the complexity of injury

Parents progressively came to terms with the injury during hospitalisation, with a dawning understanding of how the injury was impacting both the injured child and the family.

As the child improves, the parents improve—'if s/he gets better, we get better'

After the initial shock of injury, parents gradually became accustomed to their child's injuries and began to understand the potentially profound impact of the injury on their lives. Some children improved rapidly in hospital and these parents were pleased their child would experience little or no long-term physical impairments. For others whose child had sustained more severe injuries, small improvements resulted in parents feeling less anxious and stressed and having hope for the future:

'The best thing for us is when he woke up and recognised us. That was awesome and just watching him, he's getting better every day.' (Father, 9 year old boy, Pedestrian versus motorbike)

Making sense of the injury event—'what if's and who's to blame?'

Over time, parents sought to construct meaning in relation to their child's injury and how it occurred. This meaning-making process varied depending on the circumstances surrounding the injury, who was involved and who parents viewed as responsible for causing the injury. This was particularly influenced by whether they blamed themselves and/or others for the injury event. Some interpreted the incident as being beyond anyone's control; it was seen as fate or an accident in which no one was at fault. If the injury

occurred through the child's own actions, parents usually did not blame the child but tended to blame themselves or others, for example they blamed others meant to be supervising the child, or blamed themselves for not fulfilling their parental role of protecting and keeping their child safe.

Half the parents (20/40) expressed responsibility for their own actions or those of a family member in relation to the injury event. In these cases for example, the parent or relative may have been the driver in a motor vehicle incident or felt they could have stopped the incident by their actions. These parents often experienced intense guilt and believed they were personally responsible for causing their child's injuries:

'It's been really, really hard seeing Charlotte in pain and upset, especially knowing that I caused that . . . Everyone keeps telling me that it was an accident, but it's really hard to remove myself from it all. So it's all been really difficult.' (Mother, 10 year old girl, motor vehicle collision)

Even if parents were not directly involved in the incident, they often felt deeply responsible for their child's injuries and queried themselves with a range of 'what if' questions in relation to their own behaviour. In other cases, where someone else was perceived as responsible for the injury, for example in a pedestrian incident, parents' blame and anger focused on the person who caused the injuries and why the incident occurred.

'My son was on an access visit with my ex . . . ? Then I found out that my ex had drugs on him, and went head on [with my son in the car] into another car, killed the people in that car, and he [my ex] didn't get injured. It's tough when it's something that should never have happened.' (Mother, 5 year old boy, motor vehicle collision)

Questions about the future—'a new normal'

The crisis of injury was initially all-consuming for parents with their focus on whether their child would live or die. Once their child was out of danger, other questions arose, often prompted by the prospect of hospital discharge. Parents began to question the longer term effects of the injury on their child's physical functioning and many were particularly concerned about the mental and emotional impacts of injury on their child. Parents saw the physical injuries as more easily fixed because of their visibility, and it was the emotional consequences that caused them greater concern:

'The main need really is about Lucy's needs and then everything else is secondary. It's really about her recovery and her mental well-being because that's the part that really concerns me. Physically she's improving, but mentally she's deteriorating.' (Father, 10 year old girl, motor vehicle collision)

Where the long-term physical impacts of the injury were likely to be severe, parents had begun to grieve the loss of the child they had before the injury. They mourned the loss of their hopes and dreams for that child, no longer likely to be fulfilled due to the consequences of injury.

'The only thing I care about is him and his health. I just love him so much and without him, my life would be worthless . . . and like every mum, I had plans for him to graduate, get married, one day to look after his children but, if that's not the path, at least he's got me beside him.' (Mother, 12 year old boy, motorbike hit by car)

Finding ways to meet the family's needs

Parents drew on a variety of resources to address their own and their child's and family's needs. A range of personal and external factors influenced how they sought support and accepted help.

Seeking support—'I couldn't have done this alone'

Factors influencing how parents sought support included the type and severity of injury, and the impacts on the child's physical, emotional, social and psychological well-being. Also important were where the injury event occurred, distance to the hospital, and the impact of the hospital environment on family members. Personal factors impacting on how parents sought support included the parent's perception of their own guilt/blame in relation to the child's injuries, their personal pattern of coping with stress and anxiety, their usual approach to communicating with others, and access to their everyday support networks.

Parents were offered a range of practical support options by staff including social workers, nurses and trauma coordinators. This included on site accommodation at Ronald McDonald House, reduced parking costs, help with insurance claims and in some instances, hospital meals. For siblings, there were opportunities to visit the Starlight room; a medical-free haven for sick children and their families to relax and have fun or participate in other activities at the hospital together with their injured sibling. Many parents sought support from family and friends, while others who were from rural areas with limited support networks at the hospital looked to hospital staff and other parents for support:

'Sometimes you've just got to walk out of that room. You just have to act like it's all quite normal, but you know you've seen something that's not what parents normally see. I usually just say to the nurse, 'I need half an hour to step outside'. I smoke, so I go downstairs and I've met so many other parents over the last six weeks and they're down there as well, that's usually who I talk to about it all. You look forward to that time to get down there and they just say 'how are you going?'' (Mother, 9 year old boy, burn injury)

Accepting help—'family, friends and hospital staff have been amazing'

Most parents were open to accepting help for their practical needs such as accommodation and parking. More difficult for some, was accepting support for their emotional needs. Some parents focused exclusively on their child's needs and did not seek help with their own emotional needs, preferring to defer this until later:

'I feel like I haven't got the strength to delve into those emotions yet. If I do then I'm going to fall apart. I know you can't skip over grief, but I'm in no position to be processing it all at the moment.' (Mother, 13 year old boy, fall from scooter)

Some accepted emotional support from family and friends in the form of hospital visits, phone calls, texts or facebook posts, and others received practical support from neighbours and friends:

'My sister and my mother have rallied and been incredibly supportive which takes a real weight off. I can only imagine what it's like for people that are here from further away with no family around, trying to handle it all alone.' (Father, 12 year old girl, other incident)

Parents differed in terms of how they used the support offered by hospital staff including nurses, doctors, trauma coordinators and social workers. Some found the support helpful, while others were more comfortable using their own support networks. Some felt they had not been offered much support from staff or not offered it in a meaningful way. The majority, however, recognised they had access to a range of resources if they needed them. In regard to discharge planning, many parents were unclear about what progress their child needed to achieve in order to be discharged. Most felt unprepared to take their child home. They sought greater clarity from staff about the practical aspects of caring for their child's needs at home as well as information about what to expect with their child's physical and emotional recovery.

Parents suggested improvements included incorporating a home visit prior to discharge where possible, and hospital staff initiating contact between families and local community services and support.

Discussion

This study identified several key findings on parents' experiences and support needs during the acute hospitalisation phase of children's critical injury. While physical care provision for their children was identified as being effective, the emotional needs of parents, children and the family as a whole were not well-addressed by hospital staff. Parents in this study perceived the clinical care their children received to be of high quality, but were concerned about the impact of injury on their child's emotional well-being. This is consistent with research on Australian paediatric trauma staff perspectives on care, where 92.5% of staff considered their hospital met the physical needs of injured children, but only 68.2% identified children's emotional and psychosocial needs as being met [25]. Given that 1 in 6 injured children will develop stress symptoms following injury [19], and post-traumatic stress symptoms are linked with poorer child health and functional outcomes [26], there is a clear need for preventive interventions for injured children's post-traumatic stress [27] to be provided during the acute hospitalisation phase.

In terms of parents' own well-being they also received greater support for their practical needs than their emotional needs. Practical resources in the hospital which helped parents during hospitalisation included access to accommodation, food and affordable parking. While these resources were not always deemed adequate and parents suggested improvements could be made, they considered them essential in their ability to support their children. A significant finding was that the emotional well-being needs of parents in this study were not fully addressed. In order to

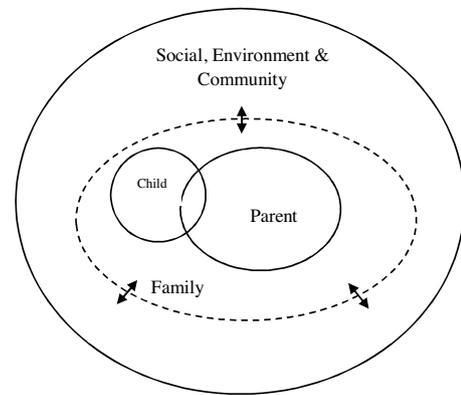


Fig. 1. The parent and injured child in context—framework for family-centred care provision.

prevent the known risk of mental and emotional distress for parents who do not receive effective intervention [10,28] it is essential that parents' emotional needs are recognised and addressed during the acute hospital phase. This is important not only in terms of parents' own well-being but for that of their child. Parents play a vital role in children's post-injury psychological outcomes [29], with a corresponding relationship between parent and child mental health. Poorer parental mental health and adjustment is associated with children's poorer psychological adjustment [30]. A related finding was that a number of parents in this study deferred or ignored their own emotional needs during the acute hospital phase. Suppressing emotions is a known risk factor for poorer mental and emotional outcomes and higher psychological stress symptoms following emotional trauma [31]. These findings indicate that both parents and injured children would benefit from targeted psychological trauma preventive

Table 2
Factors for family-centred anticipatory guidance frameworks for meeting family needs.

Child factors (injury and personal characteristics)	<ul style="list-style-type: none"> • Severity of injury and short/long term physical impairments • Circumstances of injury event • Consequences of the injury (physical/emotional) • Age of child and stage of development • Impact of injury on psychological well-being
Parent factors (emotional well-being, blame attribution)	<ul style="list-style-type: none"> • Self/other blame attribution by parent (present/absent) • Impact of child's injuries on parent (level of distress) • Personal understanding of how child is coping (physically, emotionally and behaviourally) • Personal resources including personal skills and coping mechanisms • Knowledge of and ability to access support networks (within hospital and external to hospital) • Quality of relationship with co-parent if partnered and/or significant others • Financial/employment concerns
Family factors (family functioning, and family environment)	<ul style="list-style-type: none"> • Parental relationships (partnered, divorced or separated, single) • Family structure (age, number and developmental stage of siblings, extended family) • Knowledge of and ability to access range of services and support (psychological, emotional and financial) • Consideration of the needs of all family members (in addition to needs of the injured child) • Financial and employment considerations and implications (self-employed/casual/part-time/full-time employment status)
Social, Environment and Community factors (social support, financial circumstances, school, community, and other external psychosocial influences)	<ul style="list-style-type: none"> • Level of integration of family/parents/child within their social environment and community • Willingness of community to help family with injured child and siblings (transport, meals, childcare, help at home) • Existence of support services and networks in their community • Knowledge of and ability to access support services and networks within the community • Geographic location of hospital in relation to home and social/community supports • Support of employers

interventions such as psychological first aid [32] during the acute hospitalisation phase.

A predominant finding was that half the parents in the study expressly referred to self or others in the attribution of blame for their child's injury event. This has further implications for parents' emotional well-being and for the family unit. Beliefs about the cause/s of illness are central to individuals' understandings of how illness occurs, and whether it could have been prevented. Beliefs are key determinants in how individuals explain an illness or injury and how they experience a sense of control over it [33]. Attributing causes of injury to others has a well-known association with poorer mental health and higher distress outcomes for injured patients [34,35]. Blame attribution has also been found to impact on compensation recovery from injury, with greater psychological healthcare utilisation and likelihood of seeking financial compensation [36]. This has implications for the current findings. While the literature has addressed blame attribution in the context of those who are injured, to our knowledge this study is the first to identify parental blame attribution in association with paediatric injury. These findings indicate that in order to reduce the risk of poorer parental mental health outcomes, there is a need to specifically address blame attribution in post-injury emotional support for parents of injured children, which is in addition to psychological trauma interventions such as psychological first aid. Given the identified link between parental and child psychological well-being, this would also assist in mitigating negative impacts on the family as a whole.

In terms of continuity of care, parents in this study identified a lack of discharge planning and hospital follow-up. This is supported by findings from trauma clinicians who recognised a lack of routine follow-up support services post-discharge for injured children and their families [25]. In order to prepare children, parents and families for the realities and practicalities of physical and emotional care post-discharge, it is vital that discharge protocols be developed and implemented as part of routine care. Parents and children would benefit from anticipatory guidance frameworks informed by a family-centred social ecological approach to prepare them for the trauma journey and for discharge. This approach could inform care delivery throughout the child injury recovery trajectory (see Fig. 1). Based on the study findings, factors to be incorporated into anticipatory guidance are outlined in Table 2.

Applying family-centred care principles such as planning care around the whole family, recognising all family members as care recipients, and partnerships in care between parents and staff [37], in care delivery for families of critically injured children can create positive changes for the family as a unit. To be successful, this needs to incorporate continuity of care across the injury recovery trajectory and engage with key stakeholders to promote successful implementation [38]. Parents in this study experienced a lack of continuity of care. They told their story multiple times to various staff across different hospital locations. A further recommendation for coordinated continuity of physical and psychosocial care is the inclusion of a major trauma family care coordinator role, which coordinates care provision for children, parents and family across the acute hospital phase and through to post-discharge follow-up. Informed by this study, this model is now being trialled by the research team at a paediatric trauma hospital in Australia: see www.paediatricinjuryoutcomes.org.au.

Conclusion

This study has investigated the experiences and support needs of one group of English speaking parents in one country. Findings may not be transferable to other contexts. Future studies need to include a broader group of parents. Further investigation is needed

on the impact of minor-moderate child injury on parents, the impacts of psychological first aid on parent and family well-being, and evaluation of the implementation of anticipatory guidance frameworks informed by a family-centred social ecological approach.

Conflict of interest statement

All authors state that they have no competing interests to declare.

Author contributions

KF: study design; data analysis and interpretation; drafting manuscript; critical revision.

AY: data analysis and interpretation; drafting manuscript; critical revision.

RM: study design; critical revision.

CV: data collection; critical revision.

KC: study design; data collection; critical revision.

Funding

The research is funded by the Day of Difference Foundation.

Acknowledgements

This research was funded by the Day of Difference Foundation. The authors would like to thank the parents who participated in the study and gave generously of their time at a difficult point in their and their family's lives. We also warmly acknowledge the vital support of the hospital trauma coordinators who recruited the parents.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.injury.2016.09.034>.

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