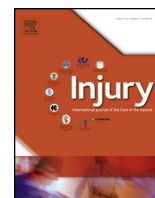




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## Experiences and needs of parents of critically injured children during the acute hospital phase: A qualitative investigation

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### 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

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