

Support for families with paediatric trauma

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- Background
- The Paediatric Critical Injury Research Program (PCIRP)
- Models of care delivery: Literature review
- Understanding existing practice clinician perspectives
- Support needs of parents of critically injured children

Background

- 1000+ injury admissions per week in children (double cancer, diabetes cardiovascular) (AIHW 2015)

 Children + parents - develop more PTSD symptoms following injury than of diabetes mellitus type 1 or cancer in the child (Landolt et al 2012)

 Embedded in the psychological support needs are day to day practical needs (accommodation, meals and transport, particularly rural/remote)

Background

- Trauma Centre expected minimum level of resources but this is varied (Leonard 2014)
- Research based on Family Centred Care, agree with principles, most places use
- Reduction in parental anxiety levels (increasing confidence, preparation, communication), BUT, staffing change ⁽³⁾, implementation and sustainability, nothing across span of care

Paediatric Critical Injury Research Program (PCIRP)

Chief Investigators:

Prof Kate Curtis (Usyd) Prof Kim Foster (ACU) A/Prof Rebecca Mitchell (Macq)







Three major gaps

- Where, how, and why?
- Systems of care?
- Parents?

Together we are answering these questions





Paediatric Critical Injury Research Program: 7 integrated studies

- **Study 1:** Review of international research on models of care delivery for severely injured children
- **Study 2:** Incidence of severe paediatric trauma in Australia
- **Study 3:** Experiences, unmet needs and outcomes of parents of physically injured children throughout the trauma journey: a longitudinal mixed methods study
- **Study 4A:** Understanding existing practice: Provision of care for paediatric trauma patients and their families in Australia

Paediatric Critical Injury Research Program: 7 integrated studies

- **Study 4B:** Implementation and evaluation of a pilot Family Care Coordinator
- **Study 5:** Identifying the needs of parents of severely injured children in Australia
- **Study 6:** Reviewing ambulance protocols to understand if severely injured children are being treated at the right hospital

Aim

 To examine and synthesize existing knowledge on the models and approaches of care delivery for critically ill children and their families

Review Questions

- How have models of care for families of critically ill children been evaluated?
- What is known about the outcomes of models of care that have been implemented for families of critically ill children?

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Models of Care Delivery for Families of Critically Ill Children: An Integrative Review of International Literature

Kate Curtis PhD^{a,b}, Kim Foster PhD^{a,c}, Rebecca Mitchell PhD^d, Connie Van PhD^{a,*}

- Method
 - Initial search generated 3296 articles
 - 334 abstracts screened and culled
 - 13 studies included for review
 - 1988 2015
 - Australia, Ireland, Thailand & United States

Results

- Reduced parental anxiety with FC model of care
 - Increased parental confidence, engagement & awareness
- Improved communication between parents & health professionals
 - ++ communication when shared care implemented
 - Better coordination, facilities, information
- Challenges for implementation
 - Assessing parent capacities
 - Need for increased staff training

No model reported that provided continuity of care from hospital through to recovery

Conclusions

- Models of care applying Family Centred Care principles can create positive changes in care delivery to critically injured children and family
- But, need a model which provides continuity of care across span of care: initial injury -> recovery periods
- Implementation challenging, but need to implement/evaluate models of care to support child & parent
- Engagement with key stakeholders essential

Study 4A: Understanding existing practice: Provision of care for paediatric trauma patients and their families in Australia

Aim

 To describe clinical staff opinions on the availability and suitability of resources to provide trauma care to children and their families and identify strengths, gaps and potential interventions to strengthen care

ORIGINAL ARTICLE

How is care provided for patients with paediatric trauma and their families in Australia? A mixed-method study

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Study 4A: Understanding existing practice

Method

- Mixed methods
- Phase 1: Interviews with 5 Trauma Coordinators in NSW, Victoria, South Australia and Queensland
- Phase 2: 22 question survey (based on interview results) to assess staff opinions on access to services and gaps in care, & open-ended questions.

Study 4A: Understanding existing practice

Quantitative results

- 214 clinicians completed the questionnaire
- 83.2% women
- More than half (57.9%) from NSW and nearly a quarter (22.9%) from South Australia
- Staff representative of trauma care workforce (53.7% nurses, 20.1% doctors, 25.7% allied health)

Study 4A: Quantitative results

- Ease of access to wide range of allied health services (57.1 93.2%): especially, Social Work (93.2%), play therapy (91.4%) and pain management services (89.7%)
- Least accessible services: clinical psychology/family counselling (10.5 %), mental health (10.2%), behaviour management services (9.1%)
- No sites had dedicated Social worker following injured child
 & family through hospital admission to discharge
- Easy to refer patients with paediatric trauma to outpatient services, especially for fractures and brain injury rehabilitation
- Least accessible outpatient services respite care and financial support

Study 4A: Qualitative findings

- 3 main categories from interviews and open ended survey responses
 - Strengths in care: teamwork; well-established trauma service; referrals to services; social work services for child & family
 - Gaps in care
 - Interventions to strengthen care





Gaps in care

 Lack of staff (including SW, PT, OTs). ED commonly identified as a setting where there was a large gap in social workers able to spend the time needed to support distraught family members

'...we had a little girl [in ED with severe head injuries after family member reversed over her with a car]... we had the social worker, myself and three ED nurses and we needed everybody because we had 20 family members there for 7 hours, and family members who were attempting to self-harm and hurt themselves...[due to grief]' (TC 1)

 Some services not available 24/7 (e.g. imaging or radiology after midnight) and a lack of rehabilitation services

'...we only have an inpatient rehabilitation service for brain injured patients. Those with complex injuries and physical disability do not have coordinated rehabilitation care from an allied health perspective...' (survey)

Gaps in care (cont)

- some specialty teams focus on their particular area not whole child
- lack of communication between specialty teams
- lack of coordination /continuity of care when children transition between teams or move from ICU to the wards

Different social worker for each ward, that can be 5 or 6



Gaps in care (cont)

- Follow up of families post-discharge esp. in rural areas.
- One hospital had no dedicated trauma outpatient clinic and another had a limited service
- Little or no formal follow-up policy for family psychosocial wellbeing

...you feel like you're sending them off, just this resource-rich place that you sit in where you offer them the world and then you send them off and say "see you later good luck" (TC 2)



Interventions to strengthen care

- Regular education and training on aspects of psychological first aid for staff

'The social work team in collaboration with the Trauma Service developed and implemented a 'response to trauma' workshop for all nursing staff to educate them on appropriate responses and interactions with children and families post a traumatic event. It also provides nursing staff with strategies relating to self-help and awareness in dealing with stressful situations' (survey)

- Social work service extended to provide onsite evening/weekend coverage in the ED

'...immediate psychosocial care [is impacted] when there is no emergency department social worker on duty and the on call social worker has to travel to the hospital. This situation can be improved if the social work service in the emergency department of the hospital was extended to being a 24 hour on site service' (survey)

Trauma nurse coordinator to provide continuing service throughout child's admission.
 Trauma coordinators, however, found this difficult to achieve with the competing priorities of their role

'If we had more staff, for example, a nurse case manager, we could have more clinical cover, we could cover Saturdays and Sundays... we could do more education... we could promote our guidelines and advocacy... we could ring [patients and their families] after discharge...the list is endless' (TC 3)

Study 3: Experiences, unmet needs and outcomes of parents of physically injured children throughout the trauma journey longitudinal mixed methods study

Aim

 To investigate the experiences, unmet needs and outcomes of parents of severely injured children 0-13 years over the two year period following injury.

Reduced parental physical and psychosocial wellbeing consistently predicts poorer child adjustment (Aspesberro et al., 2015)

- Objectives:
 - Explore parents' experiences of parenting an injured child in the acute hospitalisation phase, and at 6, 12, and 24 months following injury;
 - Identify parents' unmet needs and factors that contribute to, or impede, needs being met during the 24 months following injury; and
 - Measure parental quality of life, emotional distress, parenting stress, resilience and parent rating of their child's health in the acute hospitalisation phase, and 6, 12 and 24 months following injury.

Study 3: Longitudinal mixed methods parent study

Method

Prospective longitudinal study – embedded mixed methods design

Qualitative strand

- 40 semi structured interviews & surveys with parents of severely injured children 0-13 years. 4 hospital sites in Queensland, NSW & Victoria
- Inclusion criteria: over 18 years of age; can speak, read and write English, parents of recently injured & hospitalised child with Injury Severity Score (ISS) >15 or requiring Intensive Care Unit stay
- Exclusion criteria : parent under 18 years; non-English speaking, child injury ISS <15
- Initial face to face interview on site at baseline, telephone
 follow up at 6, 12 & 24 months

Preliminary Findings: Parent experiences

- Distress ++ at watching child experience pain and hurt
- Huge concerns about child's emotional well-being post-injury
- Parents & other family members experienced high emotional toll as a result of child injury event & hospitalisation/treatment
- Substantial impact on family's way of life & disruption to everyday routine for all family members
- However, grateful their child was alive and hospital care had been very good

'Everyone is really caring, nothing's too much of an ask, they'd do anything.' (Mother)

Preliminary Findings: Parents' needs

- Physical and practical needs including need for sleep, accommodation, parking & food
- Emotional support for themselves, for injured child & other family members (incl siblings)
- Information needs in relation to the injury, its impact on the child, the recovery process & role of parents in the process
- Financial needs especially for parents who were selfemployed, single parent, &/or on lower incomes

- Findings: Parental needs & hospital staff

- Mostly had very positive experiences of staff and the care they and their child received
- Staff were 'awesome' and 'fantastic' and parents were 'very grateful'

Unmet needs:

- Occasional clash with staff over child's care not perceived as met
- A few expressed concerns they felt went unheard by doctors & nurses
- Some parents believed staff did not react quickly enough to their child's physical distress

Parents' suggestions for improvement

- Hospital staff could support and encourage parents to take a break, & to express emotions
- Both parents allowed to stay overnight
- Better communication with parents about transition from hospital to home. More follow up after discharge
- Cheaper parking, better food choices and easy access to accommodation

'I definitely am thankful. I feel blessed and lucky. Lucky that we all came out of it because it could have ended so differently and I just really think the care we've got has been phenomenal, it's pretty amazing.' (Mother)

Discussion

- Physical needs of child met but not emotional. Nor for parents and family
- Child physically recovering, but not necessarily emotionally
- Ultimately the effect of the trauma may have developmental implications for child's future
- Child and parent wellbeing interdependent. Family unit affected
- Anticipatory guidance for parents
- Lack of continuity of care across injury/recovery hospital to community
- Need for coordinated family centred care over injury trajectory

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