

Experiences of caregivers of children who sustained moderate to severe traumatic brain injury (TBI) in early childhood



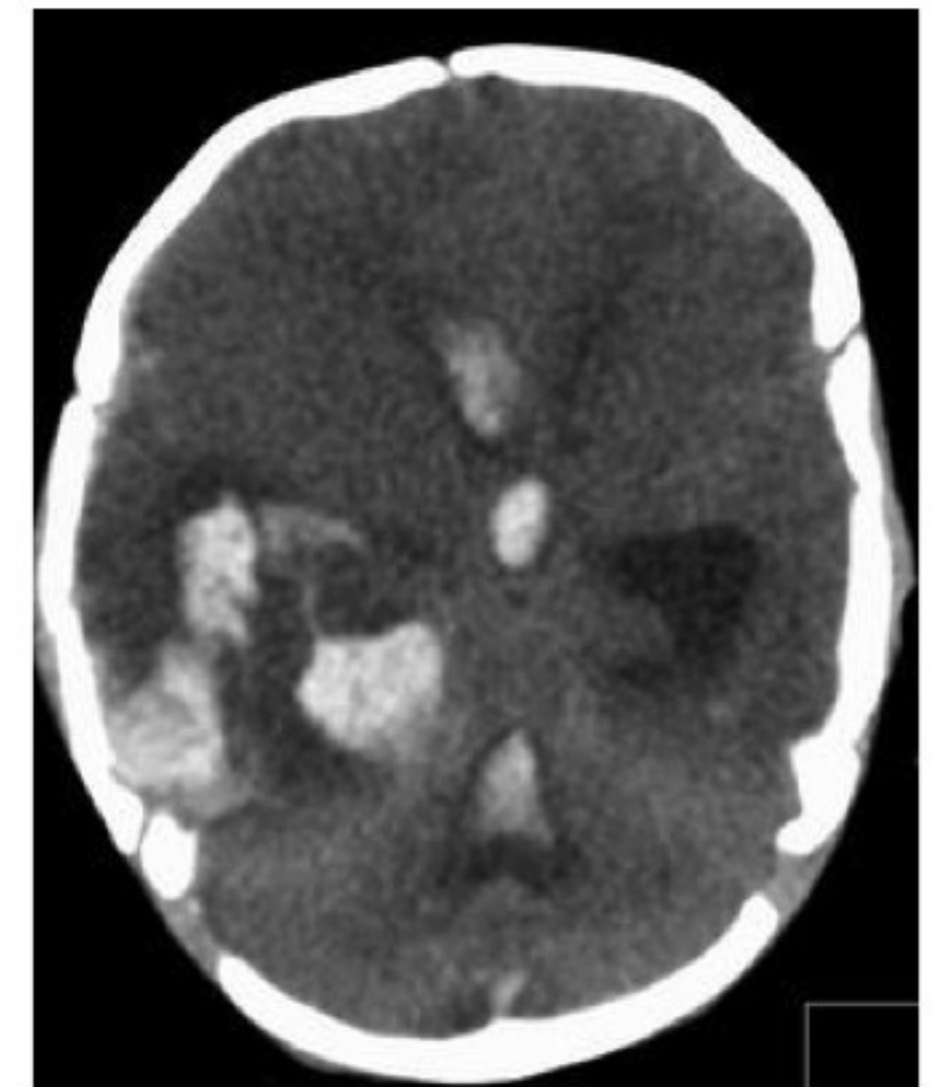
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STUDY RATIONALE

Traumatic brain injury:

- Leading cause of mortality and acquired neurological impairment in children
- ~ 33% of the population will sustain a TBI by 25 years of age (McKinlay, 2008)
- Neurobehavioural deficits can persist for several years following injury
- Ongoing difficulties can result in significant and persistent caregiver burden



Scant research exploring the healthcare and social service needs of children and their families following TBI sustained at an early age

METHODS

- Qualitative study using semi-structured interviews
- Explored the experiences of caregivers who supported a child following a moderate to severe TBI sustained < 2y of age
- Participants:
 - Caregivers of young children admitted to Starship Children's Hospital following structural TBI - *presence of skull fracture, intracranial haemorrhage, or cerebral injury reported on CT or MRI*
 - Exclusions: death during or after admission, and residence outside of Auckland
 - 50 children met the eligibility criteria and the caregivers of these children were approached by telephone to take part in the study



METHODS

- **Analysis:**

- Thematic, following guidelines recommended by Braun & Clarke (2006)

- **Interviews:**

- Carried out at the Starship Children's Hospital
- Māori researcher and a paediatric registrar
- Audio recorded and transcribed
- Participants were reimbursed for travel costs and supermarket vouchers as an acknowledgement of their involvement in the study
- Questions designed to cover 3 key areas

Table 1: Interview guide

Area of enquiry	Interview prompts
<i>Guide – Perceptions of appropriateness of services</i>	<ul style="list-style-type: none"> • Can you tell me which services you have accessed for support, starting from the time of their injury? • Are there any others you know about but haven't been able to access? • From your viewpoint, do you feel they have received the sort of help they needed to be as healthy as possible, to be at school/kindergarten/ kohanga reo if possible? • Do you feel that you have had enough support to care for them following their head injury?
<i>Guide – Experience of caring for a young child who has had a head injury</i>	<ul style="list-style-type: none"> • Can you tell me what it has been like for you caring for them since their head injury? • What sort of an impact do you think their head injury has had on your life? • What sort of an impact has it had on your family life?
<i>Guide – Perceptions of how services could be improved for families caring for and children who had sustained TBI</i>	What improvements do you think could be made to support families such as yours who are caring for young children with head injuries?
<p><i>Are there any other things you would like to talk about in relation to their head injury?</i></p> <p><i>Do you have any questions about anything to do with this study before we finish up?</i></p>	

RESULTS

- 21 Caregivers of 15 children interviewed: 16 female, 5 male; 9 were the child's mother; 11 Māori, 10 non-Māori
- 13/15 children had sustained inflicted brain injury
- 8 of those injured had sustained the injury > 10 years prior
- 6 of the children were living in foster care/with relatives

Table 2: Summary of categories and themes derived from participant interviews

Categories	Impact	Support	Information
Themes	Effects of the injury	Access to services and other supports	Lack of information
	Dealing with the processes at the time	Experiences of support	Recommendations and advice for others
	Coping strategies	Recommendations for better care	

RESULTS:

Impact

- Effects of the injury
 - Dealing with emotional and behavioural challenges post-injury
 - The emotional impact on families and caregivers
- Dealing with the processes at the time
 - CYF investigation
 - Judged unfairly
- Coping strategies
 - Resilience
 - Perseverance
 - Celebrating progress



RESULTS:

Support

- Access to services and other supports
 - Public and primary healthcare services; ACC and other government funded support services;
 - Non government and community organisations
- Financial support
 - Work and Income NZ support limited/inadequate
- Whānau/family and friends
 - Essential to fill service limitations
- Experiences of support positive and negative
- Recommendations for better care



RESULTS:

Information

- The lack of information is problematic
 - Frustration and anxiety regarding the lack of information about the injury and potential effects (short term and longer term)
 - The need for more information not only about the injury, but also support services and funding
- Recommendations and advice for others
 - Sharing specific pathways to accessing funding and support
 - The need to educate oneself: ACC process and funding access
 - The need to be proactive and prepared to fight
 - The need for a resource pack to inform caregivers of the services and funding available

KEY FINDINGS

- Impact of the TBI – broad range of difficulties
 - Service processes (healthcare and government agencies) impact significantly on whānau
 - Multiple stressors
- Whānau resiliency and strengths
- Treatment received and access to support services varied widely between participants
- Accessing support services and interventions; knowing the process was challenging and created further distress
- In order to access support services whānau were required to become 'health system experts'

CLINICAL IMPLICATIONS

1. Recommendations for better care

- Improved communication
- Improved access
- Advocacy
- Support managing challenging behaviours
- Longer term support
- Access to support groups/networks for caregivers; psychological support for caregivers

2. Accessing support services needs to be easier to reduce the significant distress

- ACC to investigate establishing a framework of core TBI support clinicians and accessible specialist services
- The need for standardised consistency in care and service delivery
- Improved access to education resources/information – ‘resource pack’
- Improved liaison between hospital and community services

RESEARCH IMPLICATIONS

- Additional research is required to identify the long-term issues and concerns for caregivers with children suffering the effects of TBI, and the development of guidelines for follow-up and monitoring
- Further investigation to establish what is the usual process of care for children with TBI in other parts of New Zealand
- Specific needs of Māori, Pacific, rural and other disadvantaged children with TBI to ensure services are developed that achieve equity of access and quality of service provision for these groups

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