

SKIBI – Supporting Kids In Brain Injury

Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions

Parental brain injury is particularly traumatic for children, who are significantly vulnerable and at risk of developing childhood psychopathology as a result of their inability to understand the abstract nature of symptoms that can present following the injury.

The primary objective of SKIBI was to investigate the impact of familial acquired brain injury on children and adult family members, including their views of the support provided, gaps and recommendations for future interventions.

Interviews with children and their parents were conducted and the results suggest clinicians should:

1. Help parents help their children. An acquired brain injury (ABI) was a new experience to all parents, and they struggled to understand the diagnosis and the enormity of their situation. Parents wanted targeted advice from clinicians on how to talk to their children immediately after the ABI. Importantly, parents wanted to know how much information to disclose and how to answer their children's questions in an age-appropriate manner.
2. Improve family functioning by giving children meaningful roles. Children commented on their desire to be involved in the early recovery and rehabilitation process. Children over 11 years wanted to understand what they could do to provide practical help to both the injured and non-injured parent. Children felt that 'having a role' gave them purpose and meaning.
3. Staff: don't leave children 'in the dark'. All children and adults interviewed confirmed that, although children had queries and concerns, they did not ask clinical staff any questions. Children did not know what to ask, to whom and were 'too scared'. Children described feelings of being 'left in the dark' by staff across all settings and stated that it would have been helpful to have received more attention and information regarding the diagnosis, possible long-term effects, causes and impact of an ABI.
4. Support for children is not one size fits all. The array of support approaches and content recommended by children and parents suggest that support for children is not 'one size fits all' due to individual needs and learning styles. The younger children recommended general information about the brain, such as how it works, reassurances that an ABI was not contagious and to hear peer stories. Older children requested more candid and specific information such as the different lobes, fatigue and memory. Children of all ages and adults strongly recommended the development of age-appropriate digital tools such as applications, educational videos and interactive games for greater access to different modes of support; available anywhere, any time.

Children and adults reported significant gaps in support offered by acute and brain injury services after familial acquired brain injury. To fill identified gaps, it will be important to facilitate flexible access and develop engaging digital tools in response to participant's recommendations.

Research Team

Maggie Killington PhD, Graduate Diploma Physio (neuro), APA Neuro-physiotherapist, Coordinator Research SABIRS, Senior Lecturer Flinders University.

Kate Dawes, Bachelor Social Work, Principal Clinician Social Work, SABIRS, PhD candidate Flinders University.

Ashley Carlino, Bachelor Social Work and Social Planning, Acting Principal Clinician Social Work, SABIRS.

Maayken van den Berg PhD, Senior Lecturer, Flinders University.

Reference: Kate Dawes, Ashley Carlino, Maayken van den Berg & Maggie Killington (2020) Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions, Disability and Rehabilitation, DOI: [10.1080/09638288.2020.1766582](https://doi.org/10.1080/09638288.2020.1766582)