

Parental Expectations and Experiences of Rehabilitation After Major Trauma - A Difficult Dichotomy

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Background

Physical trauma is a major source of death and disability in the paediatric population¹. Through the development of the major trauma networks which utilise a multidisciplinary approach to optimise the pathway of people after major trauma, there has been a reduction in mortality rates and improvement in the outcomes of severely injured patients^{2,3}. However, the specific issues around providing rehabilitation and long-term care to children after a severe injury is an area lacking in understanding⁴. Parents are seen as one of the three partners in paediatric rehabilitation along with the child and the professional⁵. This project aimed to gain an understanding of what the parents' hopes, fears and expectations are during their child's rehabilitation journey as a whole (from admission to discharge from services), as well as the challenges that rehabilitation brings, within the context of the major trauma patient.

Methods

Thematic analysis of semi-structured interviews were used to explore parents' experiences⁶. A relativist ontological standpoint was used which allowed the researcher to gain an understanding of each parent's interpretation of their journey, including their expectations and experiences, as these are likely to vary in each parent. In total 7 parents were interviewed. Each interview lasted between 60-90 minutes.

Findings:

An overarching theme of "Surviving a continuum of traumas" emerged which was central to the parents' experience. A non-finite circle was found of "Learning to expect" leading to the parent "Building conflicting expectations". "Devastation not rehabilitation" - the parent's experiences of rehab" emphasises the gain and loss felt by parents which fed into "The parent as an expert" which in turn provides a basis for future expectations building.

Surviving a Continuum of Traumas

Throughout the parents' journey the overriding theme was surviving continuing and multiple traumas.

"I don't think we even let ourselves think about anything, because it was just really like, 'Keep breathing,' and that's all you can do." - Participant 2
While this initial period appeared to resolve in all parents, the trauma continued in some form.

Learning to Expect

Expectations did not exist in a vacuum. They arrived from knowledge and experience. All parents described a previous lack of knowledge around rehabilitation after major trauma. This knowledge appeared to build over time as they developed a deeper understanding about their child's condition and about the healthcare systems. With this came expectations.

The parent as an expert

As the parent moved through their journey they often described a changing of roles and the requirement to take on new responsibilities. Specifically, they described elements of mourning for their child's loss, becoming an expert in their child and their condition, and becoming their child's advocate and rehabilitation professional.

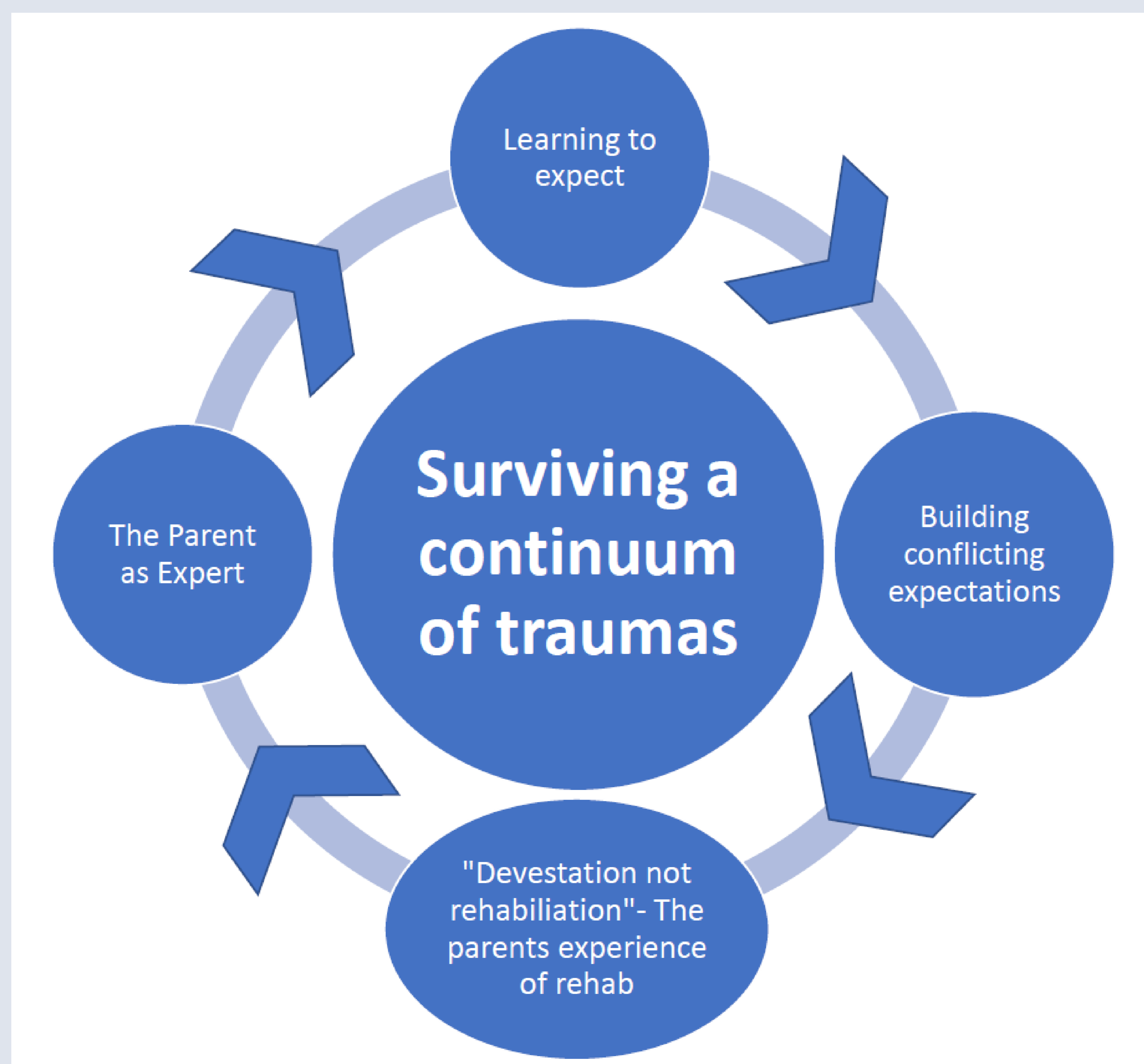


Figure 1. Thematic Map

Building conflicting expectations

Parents often found that those expectations that were present were often conflicting, with hopes for their child's recovery conflicting with their fear of the future.

"Devastation not rehabilitation"- the parent's experience of rehab

Rehabilitation post-injury was seen by parents in the light of the trauma that it causes as well as the progress that it enables their child to make. Parents stated that rehabilitation led to separation from family, negative impacts on siblings, financial hardship and demonstration of the child's disability. Parents saw rehabilitation as a long-term continuing process with no specific end.

Conclusion

Parent's expectations and experience of rehabilitation were intrinsically linked. Expectations were built on their previous experiences and these influence their expectations of future rehabilitation for their child. Rehabilitation was itself a traumatic experience. Although benefits were seen by parents, professionals should acknowledge and aim to address as possible the significant negative aspects associated with this process.