A narrative case study of family transition up to one year following head injury

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1. Introduction

There is widespread agreement that all members of a family may be profoundly affected by traumatic brain injury (TBI) (Jumisko et al., 2007). Changes associated with role change, stress, reduced social support, quality of life and relationship satisfaction all contribute to the non-injured members being considered an at risk population. However, the evidence base continues to suffer from a lack of prospectively designed studies that explore multiple contexts as those with TBI move through acute care, rehabilitation and community service provision (Verhaeghe et al., 2005, Yeates et al., 2007).

2. Research Questions:

“What are the changes experienced by non-injured family members during the first year of a family member’s Traumatic Brain Injury?”

“Within one family what are the effects of Traumatic Brain Injury up to one year following injury?”

3. Methods

Longitudinal Narrative Case study Design: Three cases recruited between August and December 2009 (N=9 non-injured family members see Figure 1).

Data Collection at 1, 3, 12 months: In-depth narrative interviews where participants were asked to describe the events and experiences that had been important to them.

4. Narrative Analysis

An in-depth, comprehensive analysis was conducted by the primary author and included detailed transcription and immersion in the data. The narrative analysis included commitment to the sequential and structural features of the extended account (Riessman, 2008). Narratives were also examined for biographical disruption, revision and reinforcement (Bury 1982; Williams 1990). Analysis was completed on three levels; the individual, the family and in-between family cases (Fig 2a/b). Rigour was enhanced through creating an audit trail, maintaining a reflective diary, peer review, and thick description.

5. Narrative Findings

Trauma Narratives were often raw and broken revealing dismay, fear and horror that families were left to make sense of.

“... because I couldn’t stop seeing her...and I just, we’d seen her at the hospital and [...] she just looked dreadful and I had to just keep looking at pictures, when I got up I had to sort of find some, well she’d got some photos by her bed and I sort of like got these photos and I had to look at them and say yeah that’s what she looks like.” [Case 2 mother T1]

“As much as [she] would like to forget it all... but I... I can’t ever forget it... because it’s, it’s part of...what has shaped...the future and... and has shaped me as a person...” [Case 3 husband T3]

Recovery Narratives portrayed how the injured person moved back to their pre-injury state. However, threatening this discourse of recovery was perception of how the injured person had changed.

“... a male nurse, said bluntly to me... he said ‘you know he will never go back to normal, he’ll never be himself’.” [Case 3 father T1]

Change was depicted as biographical disruption and was present in narratives alongside biographical attendance, revision, and reinforcement.

Autobiographical Narratives showed how powerful the experience had been, influencing family members’ own biographical sense of self. Biographical revision and personal growth were achieved in the absence of the injured person causing misalignment between family members.

“...he was just weak for a few weeks and woke up [laughs]... kind of... where we’ve all been kind of... grouped together, I guess, he wasn’t actually really a part of that [Case 1 adult child T1]

“...as much as [she] would like to forget it all... but I... I can’t ever forget it... because it’s, it’s part of...what has shaped...the future and... and has shaped me as a person...” [Case 3 husband T3]

Narratives of Suffering represented enduring sense of subjective loss, pain and distress over time. Suffering was also exacerbated when no purpose or positive meaning could be taken from the experience.

“...but he never saw her once... I can’t get over how dreadful... dreadful... I just think God... I can’t get over how the NHS is so awful... to people when they’re at home [...] I’ve been nursing since I was seventeen [...] if you had child who was ill they came and saw you... you find it difficult to speak... I just don’t... I’ve had to fight all the time...” [Case 2 mother T2]

Family Narratives depicted how all families pulled together in the acute period. Over time this unity was either sustained or the family pulled apart depending on whether the post-injury family was perceived has having more or less value than pre-injury.

“Erm... not that we weren’t close before... but we weren’t... like er... like we’d ring and talk about our lives and stuff but I didn’t feel as... connected...” [Case 2 sibling T2]

“it just... sometimes it’s not... you just want to break free... [laughs]... sometimes you want to break free and... you know you don’t want to hurt anyone, I wouldn’t do that to him but sometimes you feel... [exhale]... I’ve had enough...” [Case 4 wife T3]

6. Conclusion

Experiencing TBI as a non-injured family member can draw both positive and negative meaning. Change post TBI is multi-dimensional involving change as a symptom of the experience, not just a product of injury. Acute experiences of trauma and enduring suffering are present in families post TBI. Early interventions to support the family in transition are in need of exploring as a key part of working with families post-head injury.

7. References


