

“He is still my son.”

*Acquired Brain Injury:
The lived experience of family
members*

Mark Holloway DipSW MA

The Brain-Injured Family

- * Family affected by the ABI (Romano 1974, Lezak 1978).
- * Family have their own needs as a consequence, often unmet (Sinnakaruppan 2001).
- * Interventions can support family functioning (Kreutzer 2015).

Doctoral Research Questions:

- What is the experience of family members of their relative's ABI and of relevant services?
- How can professional practice best be informed by the experience and knowledge of family members? *(Holloway 2017)*

Why?

Relatives:

- Are likely to be in for the long-term.
- Know what we do not.
- Sometimes better placed to effect changes than professionals, often report dissatisfaction with services.
- Are not going away, they are integral.
- Their knowledge and experience may help us change our practice.

How to access all of this information?

1. Online survey of relatives (survey monkey).
2. In depth interviews with 16 relatives.
3. Inductive Thematic Analysis of the interviews. *(Braun and Clarke 2006)*

Confidentiality

- * All names, locations and specific personal details have been altered to prevent identification of any individual who took part in the research.

The Interviews:

- 16 interviews averaging 2+ hours each.
- 338,000 transcribed words in total.
- NVIVO used to code every phrase/sentence.
- 6 themes developed inductively.
- 1 over-arching theme.

The Inductively Derived Themes

1. The Context.
 2. The All Encompassing Challenge.
 3. Family Loss and Grief.
 4. The Unavoidable Burden.
 5. The Poor Experience of Services.
 6. Positive Support and Change.
- + *The relative as curator of narrative.*

1. The Context

- * The nature of severe brain injury impacts upon relatives and does so within a pre-accident context that affects how it is experienced.
- * During this period a number of family members were given very negative prognoses and were confronted with the decision to remove life-maintaining treatment

2. The All Encompassing Challenge

- * The impact of severe ABI is complex, far-reaching and extremely challenging.
- * *I don't really look ahead, I take each day. I honestly don't know. Life isn't easy, I'll admit life isn't easy, life is challenging... sorry, I get upset. I don't know, I really don't know.*

3. Family Loss and Grief.

- Ambiguous Loss, complex frozen lived grief.
- Grief/losses reside in past, present and future.
- Grief exacerbated by unavailability of burden.
- Ambivalence, feelings of love/hatred simultaneously (for services too).
- Value of life can be questioned.
- Relatives stop seeking support/explaining.

4. The Unavoidable Burden

- * Relatives' burden of care is unavoidable and difficulties are not limited solely to issues related to the brain injury.
- * *I couldn't walk away now. Whether I feel differently in five years time, or tomorrow, I don't know. There are lots of times when I want to walk away, but I couldn't, because I know he would do the same for me, I think that is what ... yes, if it was the other way round. What about me? I have got children and I have got to keep going, I haven't got any choice.*

5. The Poor Experience of Services

- * Difficulties experienced are exacerbated by formal and informal responses provided.
- * *The only contact I had with regards to brain injury was there was a scrap of paper with the Headway number stuck on a notice board. End of story. And in desperation, I phoned it.*

6. Positive Support and Change

- * **Positive change can occur and this can be supported by formal and informal structures; the relative plays a part in knowing how this can be achieved.**
- * *She (BICM) was the person that seemed most connected with the changes that had happened to him. She knew the things that he was finding difficult. She knew ways that he would be able to cope. She talked to him about ways that he could manage with the difficulties that he was finding.*

Relative as Curator of Narrative

- * Poorly defined (by me)
- * That over-arching sense that the relative is key to holding the narrative threads of the past, the present and the future. They are alone in being able to perform this task.

No simple binaries

- * Relatives coped, grew and managed at the same time as doing the opposite. They experience love and hate, hope and despair, gratitude and resentment....
- *simultaneously, a “doublethink” tear to the psyche that few others can truly grasp or understand.

Far from a simple tale

- * Hope, hard work, love and resilience co-exist with grief and loss in an inadequately supported environment, the burden felt is unavoidable.
- * Most participants noted that they wanted their experience to benefit the experience of others, that their travails will then not have been in vain.

So what do relatives say works?

- Rehabilitation/restoration of function/outcome is only one component. Process is integral and central.
- Continuity, knowledge, attitude and availability.
- Co-creation of person-specific knowledge.
- An “expert companion” on a life-long journey.
- Support to develop the new normal. This is a non-linear process, the development of a new narrative, experienced in hope.

T.S. Elliot

(from The Elder Statesman)

*There's no vocabulary
For love within a family, love that's lived in
But not looked at, love within the light of which
All else is seen, the love within which
All other love finds speech.
This love is silent.*

*With grateful thanks to all who
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to you for listening.*

mark.holloway@head-first.org

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