

Investigating the Relative's experience of Acquired Brain Injury and of Associated Services

Dr Mark Holloway DipSW MA DSW

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.

Confidentiality

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

What did the survey look like?

- Descriptor data: Age, cause of injury, time since injury, gender, living circumstances etc.
- Impairment level: Executive, cognitive, insight, behavioural disorder etc.
- Use of services, plus rating of them.
- Narrative responses to more open questions.

Results of survey

- * 110 respondents. 93F 17M.
- * Describing 85M and 25F.
- * Spread of ages, spread of years since injury.
- * 70% trauma, 86% live in community, 3.6% in FT work.
- * BICM highest rated service, SW the lowest.
- * 106 and 102/110 report cog' and exec' problems.
- * 62/110 report physical impairment.

Headline findings

- * Invisible impairments rated as more problematic
- * Correlations found with severity of invisible impairment and higher ratings for loss of insight (not for physical issues)
- * Increased loss of insight and behavioural difficulties were strongly correlated with loss of friendships by the family member (*correlation is significant at the 0.01 level, 2-tailed*).

Headline findings 2:

- * Assessment/judgement by appearance and not actual functioning was criticised.
- * Benefit of information and specialism was noted.
- * Valued professionals were considered humane and a “one-stop-shop”

Why was social work so poorly rated?

- * Lack of understanding of executive impairment, impact of poor/reduced insight
- * Lack of understanding of relatives' ongoing grief and ambiguous losses
- * Lack of capacity therefore to conceptualise the role as “manager” not simply “carer”

Results of survey 2

- *How has your relationship been affected by the brain injury?*
- We walk on eggshells now. He now has mental health difficulties, which we are told were brought on by the brain injury. He has tried to kill himself many times and he has also believed at one point that he needed to kill us and then himself....
- ***....He is not the same person any more, but he is still my son.***

Results of survey 3

- *Knowing what you know now, what would you do differently if you could go back to the time when your relative was first injured?*
- Pray for him to die rather than pray for him to live and possibly to die myself too.

Family knowledge:

- * *The one thing that should be different - is to recognise that family are the cornerstone of neuro-rehabilitation. If you lose them then you lose the best chance for the person with the brain injury!* (partner)
- * *I was included once I had found the way through to the correct people. The problem was knowing where to start and then being told to contact somewhere else.* (parent)

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mark.holloway@head-first.org

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