The Impact of Acquired Brain Injury on the Patients’ Family

Dr Mary E. Braine
University of Salford UK
Aims and objectives

- Background to the study
- Describe the rationale for the study
- Briefly outline the research study’s methodology
- Discuss the key themes identified
- Discuss the potential for future research and service provision
Background- The Injured (ABI person)

- Globally ABI is a leading cause of disability & can result in:
  - drastic alterations in identity & structure of self
  - functional changes in physical, cognitive & emotional capabilities
  - emotional / behavioral problems persisting for years after injury

- The long-term effects & cost implications unfold over time
- Impairment variable – ‘cognitive reserve’ (Stern 2007)
Emotional, Behavioral and Cognitive sequela following ABI

Behavioral Excesses
(Positive, Active)
- Agitation
- Restlessness
- Irritability “short-fuse”
- Anger Outbursts / Aggression
- Impulsiveness / Disinhibition

Behavioral Deficits
(Negative, Passive)
- Decreased initiation
- Apathy
- Loss of emotional drive
- Diminished self initiated
Emotional, Behavioral and Cognitive sequele following ABI

- **Impaired cognition** – attention, planning & reasoning, attention & concentration, problem solving, memory, verbal & design fluency, insight, self awareness, executive functioning

- **Mood disorders** – *‘traumatic insanities’* (Meyer 1904) depression (25% of TBI pts), manic features (9% of TBI pts), anxiety (11-70% of TBI pts)

- **Somatic symptoms** – pain, sleep disturbances, tinnitus, dizziness, visual changes etc.

- **Various terminology:**
  - Post-concussion syndrome (PCS)
  - Frontal lobe syndrome
  - PTSD
Rationale for the study

- Emotional, Behavioural & Cognitive sequelae following ABI (Challenging behaviour)
  - outstrips neurophysical sequelae as the major cause of disability posts injury
  - takes several forms is highly variable
  - may show only one form of challenging behaviour, whereas in others, ‘clusters’ of behaviours are evident
  - may change over time

- Literature dominated by a psychological or medical focus
  - Muriel Lezak (1978) – ‘Characterological altered brain injured patient’
Rationale for the study

- Dominance of quantitative research exploring families experience:
  - Global measures of psychological symptoms e.g. General Health Questionnaire
  - Global caregiver burden measures e.g. Caregiver Burden Scale, Caregiver Strain Index
  - Global family functioning measures e.g. Family Assessment Device, Brief Symptom Inventory

- The affect on the caregivers
  - focus on the whole family experience – none specifically on the affect of challenging behaviour
The non-injured injured - families

The ‘hidden patient’

- Presents a on-going major challenge for any family, affecting all one way or another
- The permanent transformation is a disturbing, if not devastating experience - nothing is certain and progress is uneven
- Normal life transition are drastically transformed
- Copying strategies are severely tested
The non-injured injured

- Behavioural, Emotional & Cognitive sequalea:- most difficult for carers to understand, predict, & treat of all the residual affects
- Caring for a person with ABI has been shown to negatively impact the caregiver
  - Psychological distress, anxiety & depression, increased stress & burden
  - Family strain & disruption – relationships & roles
  - Financial difficulties- unfolding over time

Bergen 2011
Aim of the study

- What are the experiences of those immediate family members of patients who have suffered acquired brain injury and present with challenging behaviour?
- What is the effect of the challenging behaviour on the family member?
Methodology

- Phenomenological - the lived experience of the people involved
  - descriptive - Husserl (1925/77)
  - rigorous, critical, systematic investigation of phenomena
  - transform the lived experience into a textual expression of its essence
  - Epochē (bracketing)
  - reduction to the essence of the experience
Method

- **Recruitment**
  - Recruitment from a North West Regional Neuroscience centre population 3.4M
  - Inclusion / exclusion criteria

- **Data collection**
  - In-depth, face-to-face, semi-structured interviews with individual family members (n=5)
  - Field notes using a proforma
Study participants

- ‘Family’ for the purpose of this study was defined as “…two or more individuals who depend on another for emotional, physical and economical support.” (Hanson 2001 p. 6)

- Sample
  - 5 female family members participated (4 partners & 1 mother)
  - Time since ABI injury (2 TBI’s & 3 SAH’s) 16 month – 12 years
  - All participants were living in the community with the injured at time of the interviews
Method

- **Data Analysis**
  - All interviews were recorded, transcribed verbatim and saved in rich text format
  - Giorgi (1985) and Colaizzi’s (1978) framework for analysis
  - Repeated systematic reading of the transcripts
  - Identify units/themes
Results

- Aggression: Unpredictability
- Emotionally Labile
- Memory loss: Repetition
- Adynamia: Slowness in tasks
- Attention seeking: Constant neediness

The behaviours of the person with ABI

Families experience

The enduring nature of the experience

Coping and Continually Enduring the Experience

Loss, loneliness, emotional turmoil, family upset, future, uncertainty
Results - Themes

● Seven inter-related themes emerged:
  ● First theme describes the behaviours that the carers encountered
  ● Six themes provide insight into the experiences of the carers:-
    ● Experienced emotions
    ● Loss
    ● Future concerns
    ● Family functioning
    ● Loneliness
    ● Adapting and coping
Theme - The emotional, cognitive and behavioural changes

- **Carers identified:**
  - Memory loss
  - Aggression
  - Repetition
  - Adynamia
  - Use of profanities, inappropriate remarks
  - Emotionally labile
  - Attention seeking
Theme – emotions experienced as a result of the persons behaviours

Huge emotional strain on individuals in the family:

- Emotional turmoil
- Lonely and despair
- Uncertainty
- Fear
- Embarrassment
- Saddened, feeling low in spirits
- Frustration, anger, self blame & guilt

Bergen 2011
Theme - Loss

- There is a sense of loss of the family member as they knew them, someone is "there-but not there", and how they imagined them in the future.

- Overwhelming sense of loss:
  - loss of a family member (loss of identity)
  - loss of normality
  - loss of hopes and dreams - ‘death of dreams’
  - loss of security

Bergen 2011
Theme - Loss

- The loss is ongoing - it is non-finite

“...because I lost my son that night. And you can’t grieve for it you can’t move on umm its there...every day.” P1

“...have lost that umm...somebody who... cares as much about the boys as I do... I miss that mostly....I miss that joint sort of thing making decision....” P4

“... I just sat on my bed and just read the papers. I’ve not being able to do that in three years.” P4

- Disenfranchised grief (Doka 1989)
- Ambiguous loss – ‘physically present but psychologically absent’ (Boss 2006)
Theme - Loneliness

- Being alone in their journey - sense of loneliness
- Perceived lack of understanding from society

“So…lonely and upsetting I think umm….It’s a very lonely place to be…it’s difficult to talk to people who haven’t been there. You can’t imagine what it is like.” P1

“But I means it is very difficult because for most of the time you are on your own….” P5
Theme - Future concerns

- Unpredictable future – great uncertainty
- Fearful for their future and the injured
- Stuck in the ‘now’
- Contemplation of ending life

“I don’t seem to be able to change his Behaviour, and that makes me fearful for his future.” P4

“I know you have to think of the future, but, I suppose that worries me because if I died I really don’t know what would happen to him.” P3
Theme - Future concerns

- Uncertainty about the future challenges the families' ability to map their future and move on – consequence of the impact of an ambiguous loss on everyday family life

- The ambiguity and uncertainty of the persons’ ABI has a profound effect on family dynamics and roles
Theme - Family functioning and roles

- Derailed family functioning
- Unexpected role changes
- Family resilience
- The effect of time

“So has your role changed?” (Researcher)

“Completely and utterly. Absolutely..” P3

“…there is no point to continuing in the way we are we need to change it if you want something to change…” P5

“…they never saw their dad he was always in the pub before the haemorrhage; they did not have a father...he goes to all the parents evenings now, he won’t miss them...he is at home now.” P2
Theme - Coping and adapting

- Endured coping with the ‘familiar stranger’ in a variety of ways:
  - Withdrawal from the public
  - Reading and ‘writing down’
  - Spirituality
  - Humour and laughter
  - Dealing with the behaviour, seeking understanding
  - Adaptive roles - fill in the absent roles
Theme - Coping and adapting

- Understanding and being aware of these potential positive effects on the family after trauma and adversity
  - For some they were “learning to live with unresolved grief,” and finding meaning in ambiguity itself
  - Need to adjust to life with the “new person”
  - Resilience - “the ability to stretch (like elastic) or flex (like a suspension bridge) in response to the pressures and strains of life.” Boss (2006)
Possible Implications

- Education - family assessment and family focused care
- Care delivery - recognise and met needs
- Recognize losses & assist in dealing with the emotions related to the loss:
  - Help actualize the loss
  - Help to identify and experience feelings
  - Help find meaning and emotional relocation
  - Help plan realistically for the future
  - Explore support systems
Implications

- Service
  - Timing: when services are provided they may not match the time of greatest stress for the carer
  - Ability of services providers to understand, provide resources and support the expanding needs of families post injury

Bergen 2011
Limitations

- Generalizability
  - qualitative study
  - sample size
  - participants

- Researcher bias
  - data collection
  - transcribing
  - describing the meaning of the experience
Future research

- Explores the demographic variables in relation to their experiences
- Other primary caregivers i.e. fathers, siblings, husbands, partners and other family members
- Interviewing parents of younger ABI victims together
- Longitudinal studies
- Explores the positive impact of the care giving
- Factors that influence the level of loss and grief experienced
Conclusions

- **Enduring the challenging behaviours was:**
  - both positive and negative
  - Enduring - time fails to emolliate the sense of uncertainty & loss for these carers
  - a solitary and stressful journey

- **The families experienced:**
  - a profound sense of loss
  - challenged their sense of security & safety
  - created a sense of uncertainty & unpredictability about their future, & the future of the ABI person

- **Support from informal & professional caregivers was not sufficient**
Thank you for listening