

Family Resilience and Adjustment for an Individual with an Acquired Brain Injury

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BACKGROUND

- Increasingly research suggests that the severity of brain injury, or indeed any medical disease is not the biggest predictor of adjustment and recovery.
- Rather personal and systemic factors have been shown to have predictive significance for both children and adults. (Sander et al, 2002)
- Research with children has shown that families – family functioning and family resilience processes (Walsh, 2015) – play a significant role in child outcome following an acquired brain injury and other neurological disorders and this has opened up new possibilities for neuropsychological interventions (McCusker et al., 2002; Greeff & Van der Walt, 2010; Heiman, 2002)
- Across different clinical presentations psychological interventions with families, as opposed to interventions with the individual themselves, improves outcomes for the individuals (Law et al., 2014).
- There is little, however, in the knowledge base with respect to how families influence outcomes for adults with ABI.
- The present research explores the processes that enable the family to help the Individual to adapt and adjust to life after an ABI.

OBJECTIVES

- To explore perceptions of the positive and negative influences on adjustment and recovery in individuals following an ABI from (a) the perspective of the individuals themselves and (b) the perspective of family members.
- To elicit themes through the shared meaning making which occurs in focus groups.
- To investigate how far themes relate to brain injury, service, individual and family factors.

METHODS

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|---------------------------|---|
| Participants | Focus group 1 and 2: 12 Individuals Nature of ABI: Stroke, TBI, Brain Tumour. Length of time after injury: Mean 6yrs |
| (7.1) | Recovery profiles: Pre-Injury: Employed 11 Student 1 Post-Injury: Employed 4, Unemployed 7, Retired (due to injury) 1. Age Profile: 28 – 68 yrs. old Mean 52 (12) |
| | Focus Group 3 and 4: 20 Family members Age Profile: 30 – 66 yrs. old Mean 58 (13) |
| Sampling: | The participants were recruited from Headway (Cork & Dublin) |
| Procedure: | A) Introductory session B) Group Discussions centred around three broad questions including: 1) <i>In thinking about how you have adjusted to life after an ABI, what are the things that have been helpful/unhelpful?</i> 2) <i>How has your family sometimes helped and sometimes hindered this process?</i> 3) <i>How has the ABI affected you as a family?</i> C) Presentation/Q & A |
| Data Collection: | Focus Groups Audio Recorded & Transcribed Average focus group length: 72 minutes |
| Analysis: | Thematic Content Analysis |
| Quality Assurance: | Thematic calibration was carried out on a subsection of the transcript where the researchers discussed and agreed upon appropriate labels for the data. |
| Ethical Approval: | Ethical approval was granted by the ethics boards in UCC and Headway. |

Individual's Themes

| Superordinate Theme | Subordinate Theme | Sample Quotation |
|----------------------------|-------------------------------------|---|
| Family Resilience | Meaning Making | <i>You go to a family event and... "Oh gee, you're looking great. You must be doing well... "Yeah, I'm perfect now." I just tell people that, I don't even go into it anymore.</i> |
| | Social Support | <i>And I think Headway saved my life. Yeah, I was just thinking the same. Saved my lived! It is the only place where I could come and say, "I feel this and this and this."</i> |
| | Communication | <i>I overreact to something-- And initially, he was kind of reacting in the way that I was reacting... whereas he has learned (to)...react very calmly. And I think that is so important; a calm response to somebody who's not calm.</i> |
| | Financial Resources | <i>...my partner's considerably older than me so I'll have to fend for myself at some point. So, I'm getting worried.... about my daughter's third level education and all that stuff.</i> |
| Individual Resilience | Acceptance | <i>When she (daughter) said, "I was like the mother,"... I understood the role change, screaming for being accepted back into my role as the mother of the house..... I have given myself into the independency of Pat (daughter)".</i> |
| | Managing Care Needs | <i>and that idea of writing a letter about your experience, would that be helpful? Absolutely! You just release a lot of the negative--Venting.... emotions inside you without screaming and shouting and beating someone up.</i> |
| Severity | Brain Injury | <i>And your physical disability, going back to work or driving will depend a lot on your physical disability.</i> |
| Understanding | Lack of understanding of the injury | <i>I would have found unhelpful would have been my children, is probably the lack of knowledge that they would have had about the difficulties that I was experiencing</i> |
| | Education | <i>...my two sisters want to get my two brothers together, because they feel that they have no understanding of what I'm going through...to talk to my doctor</i> |
| Adjustment | Interpersonal Relationships | <i>And we were sleeping in separate beds. My injury is three years ago....and that's a huge upheaval</i> |
| | Identity | <i>Yeah. That's where your identity, isn't it? And when that's gone you have to kind of find another one.</i> |
| Role changes in the family | Role Reversal | <i>We would've had the husband, the wife, and the children.... then there has been reversal, so it's my wife, and now my children, and now me</i> |

RESULTS

- There is a preponderance of themes relating to resilience including meaning making, social support, financial and community resources, acceptance, managing care needs, and communication.
- There is a shared experience in terms of the superordinate and subordinate themes for both the Individual and the family members. The shared superordinate themes consist of Family Resilience, Individual Resilience, Severity of injury, understanding, and adjustment. The subordinate themes include Meaning Making, Social Support, Communication, Acceptance, Managing Care Needs, Brain Injury, Identity, & Interpersonal Relationships.
- The acceptance of role changes and the establishment of new roles/Identities outside of the "sick role" is important for the individual.
- The cyclical stage of grief and stage in human development for the family members was noted as having a bearing on the Individuals recovery.
- The presence of empowerment and resilience in the themes suggest that there are clinical implications in terms of resilience promoting clinical interventions.

Family Member Themes

| Superordinate Theme | Subordinate Theme | Sample Quotation |
|----------------------------------|-------------------------------------|---|
| Family Resilience | Meaning Making | <i>A lot of it comes from reading the research. Even the (medical) professional themselves don't know. So, each individual case is different. So, you've got to get out there and learn it yourself, on your own case.</i> |
| | Social Support | <i>People are ready to come to hospital, and visit and do this and that. Well that stops. Friends are gone. Friends are gone.</i> |
| | Communication | <i>That I didn't involve them more and just say, "I can't manage on my own." years ago.</i> |
| | Community Resources | <i>The carers come in... and (he) goes to matches all over the country. And he goes to the club's matches.</i> |
| Individual Resilience | Acceptance | <i>He would love still to be working, but he knows now he can't... different people here in Headway, that kind of helped him to come to terms with the fact.</i> |
| | Managing Care Needs | <i>I'm asking myself why on earth I haven't just retired and go full time looking after her..... but that would be my entire life whereas at the moment at least I have work to go to. And I have an outlet.</i> |
| | Inner Strength | <i>I suppose you must have some inner strength you never knew you had for something.</i> |
| Severity/Symptoms | Brain Injury | <i>And your physical disability, going back to work or driving will depend a lot on your physical disability.</i> |
| | Mental Health | <i>My daughter totally rejected him. She ended up with anorexia for five years. She was at deaths door.</i> |
| | Physical Deterioration | <i>After about four or five years, Paul developed seizures, and from them he developed diabetes, the diabetes made him very nervous. He'd keep saying, "I can't do that because of the diabetes."</i> |
| Understanding | Lack of Understanding of the Injury | <i>I did not help my husband at all with the ABI, couldn't understand his behaviours, made no allowances for it. My kids made no allowances for it.</i> |
| Compensatory Recovery Strategies | Promote Mental Health | <i>We got a little dog, and he's made, with the dog, she's great company. He's out playing with her.</i> |
| | Reduce Risk | <i>I actually use a baby monitor, because I wouldn't hear the man in a fit, if I was downstairs and he was upstairs</i> |
| Adjustment | Interpersonal Relationships | <i>My daughter totally rejected him.... I had to throw Paddy out of the house</i> |
| | Identity | <i>And he found he's a lovely artist and he never knew it. And he paints, and draws. And if he's feeling a bit stressed, we kind of converted one of our rooms that he can paint, and draw, and leave all his stuff around if he needs to. He can get lost in that.</i> |
| Cyclical Stages | Stage in the Life Cycle | <i>So they're trying to treat me now as an old person. Rather than as somebody that's looking after somebody with a brain injury.</i> |
| | Stage of Grief | <i>...it is a kind of a grieving process of the person you had before to the new person you have now and grief brings a bit of anger, brings loss, brings all of those emotions</i> |

CLINICAL IMPLICATIONS

- The research highlights the importance of family-based interventions. The content of those interventions might include family resilience promoting programmes.
- These findings supports Headways approach which includes systemic interventions relating to psychoeducation, meaning making, overcoming adversity, communication, social network, acceptance, and the promotion of a new identity.
- Considering the influence that the ABI has on the psychological well-being and mental health of the whole family it is suggested that therapeutic interventions might be considered in conjunction with other interventions.

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