Life after brain injury: What happens when the health professionals leave?

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Content

• Original research question
• Methods
• Acknowledging the stories – room for more analysis
• Results
• Implications for practice
Enduring experience of TBI

Understanding the impact of traumatic brain injury on self-identity: establishing a framework for future measure development.

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Method

• Phase 1: Focus group meeting with people with TBI

• Phase 2: Refinement of measurement items and initial testing

• Phase 3: factor analysis, Rasch analysis & construct validity testing etc
Method

• Focus group in eight regions around NZ
• 4-9 people per group
• Emphasis on discussion of experiences and perspectives rather than measurement
• Grounded theory
Results

Participant characteristics (n=49)

• 34 men, 15 women; aged 21-79 years
• 34 NZ European, 13 Maori, 2 other
• Mild to severe TBI
• 6 months to 36 years post-TBI
Model under development

Being a coherent, whole person

Respect, validation and acceptance by others

Having valued place in the world

BEING AN INTEGRATED VALUED PERSON
## How I feel about myself...

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I know what is important to me</td>
<td>○</td>
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<tr>
<td>2. I have a clear idea of who I am</td>
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<td>3. I like the person that I have become since my injury</td>
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<td>4. I feel in control of the person I am</td>
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<td>5. I have become a better person since my injury</td>
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<td>○</td>
</tr>
<tr>
<td>6. I feel whole</td>
<td>○</td>
<td>○</td>
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</tbody>
</table>
Results

Surprising aspects to experiences:

• Duration of recovery period
  – significant confusion about self still felt at 3-4 years, for some at 10+ years

• Significant levels of self reported depression
  – Somewhat associated with changes in role and place in society; how viewed ‘self’

• Significance of social support groups
The extended duration of recovery period

*Like way back in those- the early years, you know, the first couple of years, you’re actually really not there anyway. You’re still just following your nose around. And your mind’s so confused, you know, so disrupted, that you’re still trying to find you. You’re still trying to find the same- the person you want to be, or can accept even yourself.*
The extended duration of recovery period

It took me – well all that five years I was still trying to be me. And couldn’t acknowledge why I couldn’t add up maths in my head, why I couldn’t work the computer when I’d been used to working untold screens at once, why I couldn’t read any factual information… And it wasn’t till I saw [the Brain Injury Field Officer], and she helped me accept that that me doesn’t exist. I’m now a different me
The significance of depression post-TBI

“I was thinking about medical people, and ACC, and things like that, when they dismiss you, or are patronising, or want to boot you, what that does to your sense of self is incredible… I don’t get depressed easily, but I have been suicidal a couple of times because of that, you know.”
The significance of depression post-TBI

“Sleeping pills, antidepressants- I never committed suicide, but I think about every day. Not so much now, in the last few weeks, but I go - I’ve been through periods where every single day I think about killing myself.”
The significance of depression post-TBI

“I tried committing suicide twice. And obviously I didn’t succeed on that either”
The important role of social support groups in long term recovery

“But that [Brain Injury Association] group, to me, has helped me in leaps and bounds. Because you are in a place where you’re so confused, you’ve lost a lot of power, you don’t have the confidence, and then… you sit down and you talk to people and you think I’m not a nutcase, or- you know, people are going through the same thing.”
For OT to consider

- Readiness for rehabilitation can often be years after we have stopped working with them
  - Welcome re-engagement with rehabilitation a long time down the track

- Screen for and consider depression during intervention

- Increase investment in community based group
  - OT involvement in such groups
Possible interventions

- Occupational Science (Klinger, 2005)
- Occupational Adaptation (Kielhofner, 2003)
- Identity-oriented goal training (McPherson et al., 2009)
- Application of Life Threads Model (Ellis-Hill et al, 2008)
- Mental health counselling to address existential crises resulting from TBI (Patterson and Statton, 2009)
- Narrative therapy (Morris, 2004)
- Expressive writing (Pennebaker and Chung, 2007)
- Social support groups/Peer mentoring
For debate

Does one need to have a clear sense of self (being) in order to be able to engage in occupation (doing)?
Questions

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References


References

