Cultivating recovery
Longitudinal qualitative findings from a study of recovery and adaptation after Traumatic Brain Injury

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Study design

- **Longitudinal qualitative** design
  - Utilized constructivist grounded theory methods (Charmaz)

- **Interviews** at 6, 12 and 24 months after TBI (btw 2010-14)
  - Also followed up sub-sample at 4 years (ending 2016)

- Participants: **people with TBI** (n=52), **significant others** (n=37)

- Analysis focusing on what **helped or hindered recovery and adaptation**
  - Cross-sectionally at particular timepoints (e.g. 6 months post injury)
  - Longitudinally across the narratives of participants over the two years
Participant demographics and characteristics

Qualitative research: *diversity* is key
– exploration of patterns, key time points, critical moments

• People with TBI: 16-85 years
• Significant other participants: 16-66 years
• Diverse life circumstances
  • Living situation
  • Work situation
  • For many, situations shifted during the study
• Across severities – experiencing problems at 6-mths
• NZ North Island residents (Hamilton & Auckland recruitment)
### Injured participants (n=52)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
<th>Pakeha</th>
<th>Maori</th>
<th>Asian</th>
<th>Pacific</th>
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<tr>
<th>Cause of TBI</th>
<th>Road traffic incident</th>
<th>Fall</th>
<th>Mechanical force</th>
<th>Assault</th>
<th>Mild</th>
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<th>Severe</th>
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<td>15</td>
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## Significant other participants (n=37)

<table>
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<td></td>
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<td>20</td>
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<tr>
<td>Relationship to injured person</td>
<td>Spouse / partner</td>
<td>Ex-partner</td>
<td>Asian</td>
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<td>2</td>
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<td>Child</td>
<td>Parent</td>
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<td>9</td>
<td>7</td>
<td>10</td>
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<tr>
<td></td>
<td>Friend</td>
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Analysis overview

• Coding of interviews focused on:
  • **Conditions** people found themselves subject to because of the TBI (e.g. life on hold)
  • **Actions** people took in response to the situations they were in (e.g. picturing a future)

• Coding represented the **range of experiences** described by the diverse sample,
  • Not every code is applicable to every participant’s situation.
  • Describe the scope of conditions and actions that were characteristic of TBI recovery and adaptation in our sample

• Higher-level categories were developed that grouped codes thematically

• Naming of categories aimed to capture **diversity of experiences** and both positive and negative examples
  • e.g. *Tension between life on hold and keeping up with life*
Two overarching themes: Relevant for both injured person and their family network

Room for recovery
The complexities of ‘accepting’ and learning how to allow for recovery of adaptation

Cultivating important resources
And the intricacies that affect their utility
Developing a concept of TBI recovery

Connectedness to others

... had both utility and complications in the context of each person’s life

Self as a resource

Sense of self was a resource that helped people cope (or even thrive) but was perpetually at risk

Developing a concept of Living with TBI

Cultivating resources for recovery and adaptation
Developing a concept of TBI recovery

<table>
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<th>Expectations</th>
<th>Knowledge</th>
<th>Appropriate timing</th>
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<tbody>
<tr>
<td>Developing understanding of what to expect</td>
<td>Acquiring knowledge about what supports could and should be available and why they were or were not being provided</td>
<td>Working out when and how families and communities should offer or withdraw supports to the injured person</td>
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Recovery for me/us?

For individuals and families who were able to develop a concept of what TBI recovery was for them, this acted as a kind of scaffolding for what they sought in the way of support, and how they adapted their lives to accommodate the effects of the injury.
For our participants, this was impeded by...

<table>
<thead>
<tr>
<th>Uncertainty</th>
<th>Whose responsibility?</th>
<th>Contradictions</th>
</tr>
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<tbody>
<tr>
<td>A lack of certainty or consensus from medical professionals about recovery trajectories and what was likely to be effective for the individual</td>
<td>Uncertainty regarding whose responsibility it was to gather information about what was to be expected</td>
<td>Even at 24 months, some participants still describing baffling contradictions in the opinions of GPs, specialists and case managers, making it impossible for them to figure out what ‘should’ be happening</td>
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You don’t know how long it’s going to take, **nobody gives you any information**, you don’t know whether it’s reliance on yourself and what you can even do to help yourself.

(Barbara, 12-mth)
The doctor just says it’s normal and you [the specialist] are saying that this is something terrible and I say you know [insurer] must have some experience but then I’ve got letters here [suggesting they are no help either].

(Gregory, 64 years, mild, 24-mth)
Developing a concept of living with TBI

Making sense of what happened predominated

For some, sense-making lasted years

Coming to an understanding of what to expect

• Influential people in their lives who
  • recognised the injury as a cause of long-term effects
  • accepted the changes ‘in their stride’
Connectedness to others: utility and complications

Being or becoming connected with other people can create reference points for understanding TBI recovery and living with TBI.

But relationships were not always easy, and TBI complicated this further.
[He’s got support from friends and parents] but he still needs support from somebody who’s been through it themselves, who can talk to him about it, understanding it.

(Mother of Tyler, 21 years, severe, 12-mth)
Self as an ‘at risk’ resource

• Sense of self played a variety of roles
  • *Life roles, sense of self and spirituality* contributed to
    • how the injured person and loved ones were able to cope with / adapt to effects of the injury
    • how people made sense of both the incident and the effects over time

• But sense of self also ‘at risk’
  • Self (re)constructed within changed social roles, occupations, and relationships as a result of the injury and its effects
“Self is an important symbolic arena in which the survivor’s post-injury existence is negotiated”
Gelech & Desjardins (2011)

Our study suggests this is true for individuals, whānau and family systems.

Acknowledgement & positive support of changes to enable development and maintenance of resources that enable people to recover from and live with TBI
## Recognition, acknowledgement, belief, understanding

<table>
<thead>
<tr>
<th>Importance</th>
<th>When lacking</th>
<th>Unintended lack</th>
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<tr>
<td>Need for what was happening for them to be recognized and acknowledged, and for others to genuinely believe and seek to understand their experiences</td>
<td>Lack of recognition, acknowledgement, belief and/or understanding could lead to significant disruption to people’s sense of self, and therefore to the personal resources being cultivated</td>
<td>From friends, family, neighbours, workplace</td>
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<tr>
<td></td>
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<td>From health professionals</td>
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My best friend, we’ve been friends for over 10 years [said] “you just made yourself so distant, you hid everything” and I didn’t realise I was doing it because I’m not a secretive person ...

She found it hard to cope with because [I was] not the person she knew. So I think the biggest thing is people understanding what it’s like, and that we’re not intentionally doing it to people - pushing them away ...

And [friends] can find ways to make it better for us.

(Hannah, 17 years, 12-mth)
Application to rehabilitation?

- People likely to **need to engage in processes of cultivating resources** in ways that are meaningful to them
  - People with TBI and significant others

- Roles of rehab professionals in helping that happen?
  - **Acknowledging, checking in, offering information and links**
  - Studies support multi-family group intervention – support developing concepts of TBI recovery and living with TBI (e.g. see Couchman et al, 2014)

- Roles of other support services?
  - Peer mentoring – peers have different relationship and different opportunities to share resources, information, experiences
References


TBI Experiences Research Group
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