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Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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Manuscripts

Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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Abstract

Objectives: To explore the acceptability of peer mentoring for people with a traumatic brain injury (TBI) in New Zealand.

Design: A Qualitative Descriptive study exploring experiences reported by mentees and mentors taking part in a feasibility study of peer mentoring. Interviews with five mentees and six mentors were carried out. Data were analysed using conventional content analysis.

Setting: The first mentoring session took place pre-discharge from the rehabilitation unit. The remaining five sessions took place in mentees' homes or community as preferred.

Participants: Twelve people with TBI took part: six mentees (with moderate to severe TBI; aged 18-46) paired with six mentors (moderate to severe TBI > 12 months previously; aged 21-59). Pairing occurred before mentee discharge from post-acute inpatient brain injury rehabilitation. Mentors had been discharged from rehabilitation following a TBI between 1 and 5 years previous.

Intervention: The peer mentoring programme consisted of up to six face-to-face sessions between a mentee and mentor over a six month period. The sessions focussed on building rapport, exploring hopes for and supporting participation after discharge through further meetings and supported community activities.

Results: Data were synthesised into one overarching theme: Making sense of recovery. This occurred through the sharing of experiences and stories; was pivotal to the mentoring relationship; and appeared to benefit both mentees and mentors. Mentors were perceived as valued experts because of their personal experience of injury and recovery, and could

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3 provide support in ways that were different to that provided by clinicians or family
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5 members. Mentors required support to manage the tensions inherent in the role.
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8 **Conclusions:** The insight mentors developed through their own lived experience,
9
10 established them as a trusted and credible source of hope and support for people re-
11
12 engaging in the community post-TBI. These findings indicate the potential for mentoring to
13
14 result in positive outcomes.
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18 **Trial registration:** International clinical trials registry platform (ICTRP) UTN: U1111-1142-
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20 7155
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23 24 **Keywords**

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27 Traumatic brain injury, peer mentoring, qualitative, feasibility, recruitment, retention
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Strengths and limitations of this study

- The use of qualitative interviews in this feasibility study enabled an in-depth exploration of the experiences of mentees and mentors engaged in a mentoring programme after traumatic brain injury.
- The study design was informed by our previous work trialling rehabilitation interventions with this population and incorporated robust methods to collect and analyse qualitative data.
- The intervention, developed using theory, evidence and consumer involvement; was delivered face to face and was flexible to the needs of both mentors and mentees.
- This was the mentors' first experience of mentoring following TBI, therefore, the benefits and challenges presented here may change in a larger trial where mentors have the opportunity to support more than one mentee.
- This study was designed to explore acceptability of peer mentoring and the efficacy of this intervention requires further investigation.

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Introduction

New approaches to supporting recovery and adaptation after Traumatic Brain Injury (TBI) have been called for, given recognition that it is more appropriately conceptualised as a 'long term condition than a single episode injury'.¹ Peer mentoring has been defined as 'support provided by individuals who have successfully faced a particular experience and can provide good counsel and empathic understanding to help others, with similar salient population characteristics, through a comparable experience'.^(p436)²³ Peer mentoring interventions generally include some degree of informational, appraisal, and emotional support.⁴ It has been used for over 50 years in mental health⁵ and is increasingly used in rehabilitation, for example with people with spinal cord injury²³⁶⁻⁸ and heart disease.⁴⁹

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3 The case for peer mentoring can be found in a number of psychological theories, such as
4 social cognitive theory¹⁰, and self-determination theory.¹¹ These propose that observing
5 others, feedback and modelling, and social exchanges that support autonomy lead to better
6 outcomes for those receiving the mentoring. Peer mentoring led to better adjustment after
7 spinal cord injury in a study in which mentors helped mentees to cope with practical,
8 emotional and identity challenges and project future possibilities.^{3 6} A review of peer
9 mentoring in heart disease showed that it led to increased self-efficacy, improved activity,
10 reduced pain, and fewer emergency room visits.⁹

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23 Peer mentoring for TBI is of particular interest with an estimated 10 million people
24 sustaining a TBI each year worldwide,¹² and over 70% of these experiencing wide-ranging
25 and significant problems that persist for many years after injury.¹³ Current services primarily
26 target the acute/sub-acute phase with only limited ongoing input.¹⁴ The burden this
27 situation poses to the individual and society prompts an urgent need to develop strategies
28 to improve long-term outcomes for people with TBI and their families. New Zealand has a
29 very high incidence of this condition (811/100,000).¹⁵ Many individuals with moderate to
30 severe TBI suffer significant on-going consequences in domains of physical, cognitive and
31 psychological functioning, and personality changes.¹⁶⁻²⁷ This variety of consequence makes
32 peer mentoring potentially challenging as candidate mentors may also be experiencing long-
33 term consequences of their TBI. Consequently, it is not surprising to find a limited range of
34 published research exploring peer mentoring in TBI. Three US-based studies exploring peer
35 mentoring in TBI report positive benefits on knowledge, quality of life general outlook,
36 behavioural control and return to work; however, design limitations and trial issues hamper
37 generalisability and adaptability of these findings.²⁸⁻³¹ Our study aimed to explore the
38 feasibility and acceptability of a peer mentoring intervention in the New Zealand context.
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3 This paper describes our approach and reports on the qualitative data collected to evaluate
4
5 the acceptability of the intervention.
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8 9 **Methods**

10 A Qualitative Descriptive³² methodology was employed to explore mentee and mentor
11 experiences of their participation in the peer mentoring intervention. This methodology is
12 particularly useful for guiding intervention development because it seeks to understand
13
14 particularly useful for guiding intervention development because it seeks to understand
15
16 complex experiences that are embedded within the human context.³³ We had funding to
17
18 include six mentees and six mentors. The study was conducted in Auckland, New Zealand /
19
20 Aotearoa where nearly all moderate-to-severe cases of TBI on the North Island have
21
22 inpatient rehabilitation with a single provider after their discharge from the acute hospital
23
24 services. This provider cares for between 100 and 150 people per year,³⁴ and was the sole
25
26 site of recruitment for mentees.
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32 Invitations to take on the role of mentor were sent by letter in batches to those identified as
33
34 eligible by the rehabilitation provider and followed up by phone to confirm eligibility. Letters
35
36 were also sent out from our research centre to those who had previously taken part in other
37
38 studies and expressed an interest in being involved in further research and fitted the study
39
40 criteria. Those people who met the eligibility criteria and expressed a desire to take up a
41
42 mentoring role were invited to attend a job interview. The interview panel consisted of
43
44 members of the research team (which included a psychiatrist with expertise in TBI). All
45
46 potential mentors also underwent a criminal record check. The mentors were paid on a
47
48 research assistant pay scale for their time on the project. Mentee recruitment was initiated
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50 by rehabilitation staff approaching all eligible participants and passing contact details of
51
52 those interested in hearing more about the study to the research officer (CC). The research
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3 officer then met with potential participants (and interested family members), explained
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5 what the study involved, discussed any concerns and took informed consent from those
6
7 willing to proceed. Participant eligibility criteria for both mentors and mentees are displayed
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9
10 in Table 1.
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15 Ethical approval was obtained from the New Zealand Health and Disability Ethics Committee
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17 (ref 13/NTA/99/AM05) and the University (ref 13/288).
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Table 1. In- and exclusion criteria		
Inclusion criteria	Mentees	Mentors
• Age (years)	≥15 years	≥18 years
• Moderate or severe TBI ^{35 36}	√	√
• Discharge from inpatient rehabilitation	Imminent	1-5 years previously
• Living in the greater Auckland region	√	√
Exclusion criteria		
• Unable to communicate in a way that enabled engagement with a mentor/mentee	√	√
• Medical condition that precluded their participation	√	√
• Discharge FIM Cognitive domain score* ≥24 ³⁷		√
• Ongoing alcohol or drug abuse problems, communication difficulties, known gang affiliations, concerns in terms of safety or security (clinical judgement)		√

* FIM: Functional Independence Measure, data obtained from the rehabilitation centre

** Moderate TBI: initial Glasgow Coma Scale (GCS) score 9-12 (of a possible 15) and/or post-traumatic amnesia (PTA) duration >1 but <7 days; Severe TBI: initial GCS <9 and/or PTA ≥7 days.^{35 36}

Intervention

Peer mentoring sessions were one-to-one and face-to-face, with the first session occurring pre-discharge in the rehabilitation setting and the remaining five in the community. It was intended the sessions would take place over a three month period and that three of the sessions would involve a pre-planned, supported participatory activity in the community, negotiated in advance by each mentee-mentor pair. Our approach was informed by our own research³⁸⁻⁴⁰ and by that of others.²⁸⁻³⁰ Table 2 displays the basic structure of the programme in more detail.

Table 2 The mentoring programme

Time point	Session purpose
One to two weeks before discharge from inpatient rehabilitation	Mentor meets with the mentee at the inpatient rehabilitation facility to get to know one another. Make provisional plans for meeting post discharge.
Two weeks after discharge	Mentor visits mentee at home, to re-establish connection, explore barriers and facilitators to participation, and support them to develop plan for social activities for the next couple of weeks.
Four weeks after discharge	Participate in mentor supported activity; check in with the mentee and discuss what has gone well over the last few weeks, what didn't go well? Plan further activities.
Six weeks after discharge	As for previous session
Eight weeks after discharge	As for previous session, reminder that next visit will be the last.
Ten weeks after discharge	Final visit. The mentor and mentee will review progress and the ending of mentee/ mentor relationship. A mihi whakamutunga (cultural blessing or prayer) will be offered for those who wish this.

Mentor training and support

Mentor training comprised of a two day interactive training workshop, with each day held one week apart (see the Appendix for an overview of the training programme). This included a mix of presentations, discussion, role play and skill-building activities, aiming to strengthen and build on the experience and skills of the mentors. Topic sessions included

1
2
3 the role of the mentor, experience of TBI, sharing experiences, and safety protocols.
4
5 Attention was paid to cultural protocols for the New Zealand context. For example, the
6
7 encouragement to use an opening and closing karakia (blessing or prayer) for meetings with
8
9 mentees when both parties agreed this was appropriate. Mentors had access to a resource
10
11 containing information on locally available services they could refer mentees to if
12
13 appropriate. Individual and group debriefing sessions were provided over the course of the
14
15 study to support the mentors in their role. This included provision for psychological and
16
17 psychiatric support.
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24 Data collection and analysis

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27 Semi-structured interviews with five mentees, and six mentors were conducted at the
28
29 conclusion of the mentoring relationship (one mentee was lost to follow- up). Researcher
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31 field notes, debriefing meeting notes, and mentor case notes (provided by three mentors)
32
33 supplemented these. An interview guide was used to inform the discussion for both
34
35 mentors and mentees. This focused on the mentoring experience, the timing of the
36
37 intervention, the perceived impact of the relationship, and suggestions for improving the
38
39 programme. Mentors were asked additional questions relating to the adequacy of the
40
41 training and support provided to them. Interviews were audio recorded and transcribed,
42
43 then checked for accuracy. Consistent with Conventional Content Analysis⁴¹, the interview
44
45 guide formed the initial frame for analysis. The core analysis group developed preliminary
46
47 codes by initially exploring the mentor and mentee data separately, and then looking for
48
49 patterns across the data sets. Developing findings were examined against the raw data and
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51 then presented to the wider team who helped extend the analysis, and reach agreement on
52
53 the final interpretation of data.
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Results

Letters were sent to 34 potential mentors, of whom nine were not contactable. The researcher discussed the study with 13 people who responded positively to the initial approach, with nine accepting the invitation for interview. All those interviewed were invited to attend mentor training. Eight mentors completed both training days with one dropping out after the first day due to work circumstances. They were employed by the university as casual staff and paid on an hourly basis. There were 12 potentially eligible mentee participants during the study period. Of these, nine agreed to talk further with the research officer, with six consenting to participate as mentees. The eight people who had attended the mentor training provided a pool from which six were successfully paired with the six consenting mentees. Mentor-mentee pairing was primarily on gender, and secondly by shared interest. Mentor availability was also a consideration. Demographic details of both mentors and mentees is provided in Table three.

Table 3. Demographics	Mentees (n=6)	Mentors (n=6)
Inpatient stay (mean days, SD)	72 (54.4)	N/A
Admission FIM score (mean, SD)	57.7 (26.2)	N/A
- Motor tasks	22.0 (5.7)	
- Cognitive tasks		
Age (range)	18-46 years	21-59 years
	Frequencies	Frequencies
Gender		
- Male	4	4
- Female	2	2
Injury severity		
- Severe	5	4
- Moderate	1	2
Ethnicity		
- Māori	1	1
- Māori / Samoan	1	
- New Zealand European	4	5
Employment		
• Studying	N/A	2
• Working full time		2
• Working part time		2

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3 Four mentees engaged in six peer mentoring sessions, with the remaining two engaging in
4
5 one only. One mentor lost contact with their mentee after a number of phone conversations
6
7 and did not manage to meet face to face after the initial visit in the inpatient setting. The
8
9 other was not available to take part in the mentor sessions due to unanticipated personal
10
11 circumstances but did contribute to the post intervention data collection.
12
13

14
15 The research officer called mentors following each mentoring session as per the agreed
16
17 safety protocol to 'check in' and enquire what had gone well, if there were any issues or
18
19 concerns, provide general reassurance and to remind mentors to maintain records of the
20
21 sessions. In addition to this, mentors took part in three face-to-face group debrief sessions
22
23 over the course of the study, led by members of the research team, and held on Saturday
24
25 mornings to accommodate those who were working or studying. Topics for the debriefs
26
27 were set by the mentors and included, for example, sharing experiences of the first meeting
28
29 with mentees (what went well, what were their concerns), appropriateness of community
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31 activities, how to conclude the mentoring relationship. Access to psychological and
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33 psychiatric support was available but not utilised.
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41 Peer mentoring: Making sense of recovery

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43 Data analysis revealed positive outcomes for both mentees and mentors. A key theme
44
45 identified in the analysis was that of making sense of recovery through shared experience
46
47 and stories. This sharing was pivotal to the mentor-mentee relationship with both parties
48
49 expressing benefit. Through stories of their lived experience of injury and recovery, mentors
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51 were perceived as valued experts and could provide support in ways that was different to
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53 that provided by clinicians or family members. This position posed some challenges to
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55 mentors who required support to manage the tension inherent in their role. These findings
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3 are discussed below with supporting quotes. Pseudonyms are used here, followed by the
4
5 mentor / mentee age.
6

7 8 **Sharing stories** 9

10 The essence of the peer mentoring intervention was to provide support from someone who
11
12 has had a similar experience.
13

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15 *It was very useful to have someone who has been through a similar*
16
17 *accident to myself. It really meant a lot to me (Mentee, Peter, 24)*
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19

20
21 Telling your own story was a key device this programme used to establish credentials and
22
23 facilitate the mentor / mentee relationship. The outcome of sharing these experiences was
24
25 something both mentors and mentees reflected on.
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29 *He wasn't asking me questions, he was a story teller. And that made me,*
30
31 *yeah rather than "how do you feel today?" Is what they [the clinicians]*
32
33 *asked me and I would go "oh yeah up and down like a rollercoaster I*
34
35 *guess." He would go 'oh yeah it's hard to explain isn't it?' [...]It was just,*
36
37 *like you say, an occasion to go out.[...] And that's what allowed me to have*
38
39 *someone who's a friendly expert, who had been through a brain injury, to*
40
41 *connect with. (Mentee: Dave, 45)*
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46 Similarly, mentors found it more beneficial to share their stories with other peer mentors on
47
48 the programme than people around them. Opportunities for this arose during the training
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50 programme and debrief sessions, as these mentors explained:
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3 *It was like a process of opening up to people who have been through the*
4 *same as yourself and I thought that was very helpful, just opening up and*
5 *just letting it out rather than bottling it up. (Mentor: Thomas 23)*
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11 *Listening to what everyone else was saying sort of gave me great*
12 *confidence that I wasn't the only one. (Mentor: John, 59)*
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14 Mentors as experts

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Returning home following discharge from rehabilitation is reportedly a difficult time as adjustments are made to changed circumstance. Mentees viewed their mentors as experts because they had experienced a TBI and attended inpatient rehabilitation and were now actively participating in life roles.

Because he had been through it. I guess I am just new at this. He made it flow. He was like a brain injury guru. [...] Because he had lived it and physically trained in that field, by being run over on his bike. [...] It was more progressively rehabilitating for me than [name of the rehab centre].
(Mentee: Dave, 45)

Even though mentors and mentees had different experiences of a TBI, they reported the sharing of experiences and stories enabled them to develop a connection, a sense of trust and in some cases a friendship.

It was like you had a connection maybe that was what it was, you have a connection. You have both been there and hearing what she had been through. (Mentee, Jane, 42)

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3 Mentees reflected their mentor provided an opportunity to talk through concerns and
4
5 worries with 'someone who had been there'. This was viewed as different from the support
6
7 provided by clinicians or family and friends. Using mentors as a sounding board helped
8
9 mentees to make sense of their experiences and what could be expected after a TBI.
10
11

12
13 *It was nice to have someone, outside your family. Because family are too*
14
15 *close to you and they seem to like be over protective. Whereas your buddy*
16
17 *[mentor] sort of understood where you were coming from, understood*
18
19 *what you were going through. And it was nice to be able to ask like any*
20
21 *questions that I had like 'is this normal? I'm doing this is this, you know*
22
23 *what's going on here?'* And get those answers. (Mentee: Kate, 45)
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28 The relationship between the pairs meant mentees felt comfortable sharing their
29
30 experiences, and contributed to a sense of trust and a willingness to discuss their difficulties
31
32 with more transparency than they might have with clinicians and family members. Kate
33
34 suggested the relationship with her mentor enabled her to open up:
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38 *You become friends in the way that you can actually openly communicate*
39
40 *to someone. That's where it changed. So instead of being careful about*
41
42 *what you say and you know being reserved, you could actually be totally*
43
44 *open and honest with someone that's not a psychologist.* (Mentee: Kate,
45
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48 45)
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51 Much of the discussion between mentees and mentors reportedly included talking through
52
53 issues they were reluctant to address with clinicians and believed their family members or
54
55 friends didn't understand. Mentors in turn revealed coping strategies they had found
56
57 helpful for issues raised such as dealing with fatigue, thinking about return to 'normal', and
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3 discussions about how to cope with social pressures regarding alcohol consumption
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5 following TBI. Discussions of such matters appeared to be facilitated by the relationship not
6
7 being bound by the systems and structures clinicians operate in and, unlike clinicians,
8
9 mentors had more time to be with mentees either in their own home or in the community.
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11 Mentors were conscious of their position and reported they were clear they were not acting
12
13 as clinicians and recognised they had to have boundaries in terms of the advice they could
14
15 offer.
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21 *But I shouldn't be giving him medical advice you know. I can't tell him*
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23 *what to do I can only tell him what I did [...] I can talk to him about that [*
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25 *alcohol consumption] but in that situation it should be more as a friend [...]*
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27 *because I don't want him thinking I've got some profound knowledge*
28
29 *about how your brain is going to affect your drinking after a year. (Mentor:*
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31 *Michael, 24).*
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39 Mentoring as a source of hope

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41 Meeting and talking with mentors provided mentees with a sense of hope for progress
42
43 beyond the difficulties they were facing immediately post-discharge and enabled them to
44
45 build their self-confidence. The mentees reported feeling pleased to learn their mentors
46
47 were now getting on with their lives and involved in activities such as university studies or
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49 returning to work.
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3 *Just how where he's come from, from his accident until now. How he's*
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5 *accomplished the things that he needs to do [...] What it helped me is he's*
6
7 *back to work. And that's where I want to be. [Mentee: Tony, 43]*
8
9

10 The mentors all expressed enjoying their role and developed caring supportive relationships
11 with their mentee. They appreciated reciprocity the role offered them in the opportunity to
12 give back and help someone.
13

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17
18 *I'd say it became a mutually beneficial relationship and one that to me meant a lot*
19
20 *because it was, to me it was watching him recovering. (Mentor: Louis, 23)*
21
22

23 The challenge of mentoring

24 Despite the mentees endorsement of the help and the inspiration of their personalising
25 stories during the intervention period, the mentors struggled with their own expectations of
26 the mentoring role. Some were concerned they needed more 'tools to do the job properly'
27 and were sometimes worried about the extent of the external support their mentee was
28 receiving. Frequent contact with the research staff was important to discuss these concerns,
29 to check in and ensure the mentee was safe and reassure the mentor that what they were
30 offering their mentee was valuable in its own right and was in keeping with the intentions of
31 the programme.
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46 *Watching some of the hard stuff he was going through and just kind of*
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48 *really bumming me out. [...] Everybody felt a bit of a pressure, a*
49
50 *responsibility to the person because we kind of get what it was like to go*
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52 *through what they went through and so you don't want to fail the person*
53
54 *you know. (Mentor: Michael, 24)*
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6 The valuable insights the mentors had into the challenges their mentees were experiencing
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8 that enabled them to establish connections and support their mentee, presented challenges
9
10 to the mentors as it prompted a revisiting of their own injury experiences and an
11
12 acknowledgement of their persistent residual symptoms.
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16 *Just because you know, you process your own head injury issues when you*
17
18 *are mentoring someone [...] sort of re thinking my own head injury and my*
19
20 *own thing to kind of try and be useful to him. [...] so some of that stress*
21
22 *probably wasn't at all out of my relationship with him was actually to do*
23
24 *with my own sort of, because like you say we are mentors because we*
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26 *have been through something that was kind of shit you know so we are*
27
28 *thinking about that difficult thing pretty deeply. (Mentor: Michael, 24)*
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36 Although they experienced these pressures over their concern for their mentee's situation
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38 and dealing with their own concerns, the mentors reported the support they received from
39
40 the research team helped them deal with these and be effective in their role.
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44 *I think even when (mentee) started being, even when he started being a*
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46 *little bit depressed, having you guys to call and just chat through things*
47
48 *and sort of, I had never really had a moment where I called you and no one*
49
50 *answered or something like that. It was always, there was always contact*
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52 *there. (Mentor: Louis, 23)*
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3 Another challenge concerned the intended community activities and the planned time
4 frames. These community activities were not always practical as some mentees had ongoing
5 medical problems that restricted their mobility or lack of access to transport. Therefore,
6 more mentor visits were at the mentees' homes than proposed in the programme. Where
7 community activities did occur, they typically included meeting up in a café, or browsing
8 shops together. Timeframes were stretched by circumstances, for example surgery for
9 associated injuries resulting in temporary mentee unavailability. Mentors were encouraged
10 by the research team to use the programme flexibly in response to the mentees preference,
11 which was considered a strength by many.
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24 The peer mentoring was provided as a time limited relationship, which for most mentors
25 was not a problem as they felt their mentee had moved along in their recovery or they had
26 nothing more to offer. However, for others, the consequence of the relationship being, and
27 becoming, more personal created difficulty and concern about ending the series of sessions.
28 These concerns were raised as a topic for discussion by mentors at each of the debriefing
29 sessions and mentors reported they needed this discussion to support them in withdrawing
30 from the formal mentoring relationship. Nevertheless, ending the mentoring relationship
31 appeared to result in a sense of loss.
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44 *We did talk about, in the last session that we might see each other again,*
45 *and then all of a sudden I am not a mentor anymore. (Mentor: Michael,*
46 *24)*
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52 Regardless, overall both the mentors and mentees reported the experience as beneficial.
53 The opportunity to connect with others in a similar situation provided comradeship and a
54 sense of hope:
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3 *I've just more than anything found like a friend. One that I can relate to.*

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5 *We have both had an injury. (Mentor: Sarah, 21)*

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9 *Because it helps you feel like you are understood and you are not the only*
10 *person going through this trouble but there have been other people who*
11 *have gone through similar things who are able to show you a glimpse of*
12 *hope that life gets better. (Mentee: Peter, 24)*
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21 Discussion

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26 The findings of this study indicate the peer mentoring relationship may be beneficial to both
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28 mentor and mentee through the sharing of experiences and stories, but also that mentors
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30 required support to manage the tensions inherent in the work. The time to talk and listen as
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32 well as the shared authentic experiences resonated with mentees, leading to feelings of
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34 hope and confidence as they re-engaged in the life post-discharge to the community.
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40 The strengths of this study include the use of qualitative interviews, which enabled an in-
41
42 depth exploration of the experiences of mentees and mentors engaged in a mentoring
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44 programme after traumatic brain injury. The intervention, developed using theory, evidence
45
46 and consumer involvement; was delivered face to face and was flexible to the needs of both
47
48 mentors and mentees. However, this was the mentors' first experience of mentoring
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50 following TBI, therefore, the benefits and challenges presented here may change in a larger
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52 trial where mentors have the opportunity to support more than one mentee. Furthermore,
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3 this study was designed to explore acceptability of peer mentoring and the efficacy of this
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5 intervention requires further investigation.
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10 Mentors required more support from the research officer than anticipated at the outset of
11
12 the study. For example, she supported them to maintain contact with their mentee during
13
14 the study period, assisted with scheduling visits when they experienced difficulties, and
15
16 provided assistance with negotiating the university's reimbursement procedures. The under
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18 recognised need for this level of support was in part due to lack of evidence for delivering
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20 this service with this population and will inform future study design and service models.
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26 Our exploration of mentees' experiences should be considered in light of them taking part in
27
28 a feasibility study. In addition, this was the first time each of our mentors had the
29
30 opportunity to work with a mentee. Findings might be different if this had been a routine
31
32 service or if mentors were more experienced in their role. This was a feasibility study and
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34 the findings are not designed to be transferable to other contexts, however, they have the
35
36 potential to inform future peer mentoring interventions for people following traumatic
37
38 brain injury and point to the potentially reciprocal benefits of the mentoring relationship. A
39
40 key feature of our study was the face to face delivery of the intervention. Although, in the
41
42 current study this was a culturally-located decision given this is a preferred method of
43
44 service delivery for New Zealand Māori (the indigenous population of New Zealand), we
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46 believe this to be a key component of this peer mentoring intervention, and one that helped
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48 create opportunities for developing connections and building the relationship.
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3 The stories our mentors used in their work with mentees were grounded in their own
4 experiences of recovery and living with consequences of TBI. The actual sharing of these
5 stories was a key component of the training workshops and debriefing sessions. Douglas and
6 colleagues (2015) suggest that supportive relationships that promote this sense of being
7 understood can facilitate people after injury to navigate their changed circumstances.⁴²
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9 Indeed, in our study, the sharing of stories helped both mentors and mentees realise they
10 were not the only ones in this situation and not alone in what they were going through.
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22 Mentees saw these stories as more authentic and more practically useful than receiving
23 advice from clinicians. This is similar to the findings of Veith et al. (2006), where mentees
24 saw professionals as forced into their life and as detached experts.³ Stories of people
25 becoming more active after spinal cord injury recorded by actors have also been used in a
26 study with people recently injured.⁴³ Although they used a different delivery mechanism,
27 people with spinal cord injury and healthcare staff considered the stories to be effective
28 tools for communicating the message regarding reengaging in activity after injury. They
29 considered those in the stories to be credible messengers, who were emotionally realistic
30 and provided context. Stories have also been shown to be key in the success of mentoring in
31 a number of other settings, including mental health.^{5 44} In our study, the relationship that
32 developed through this sharing led to mentees feeling able to express their concerns in a
33 more honest and intimate way than perhaps would have occurred with clinicians.
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53 The role of the mentor is different to that of a lay person in the community. This is because
54 mentors share the same experience (of an injury and of the associated traumatic experience
55 for example) and can be part of created social networks. Mentors are also different from
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3 paraprofessionals, who are lay people who have received extensive training and have
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5 essentially become professionalised.⁴ We took care not to professionalise the mentoring
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7 role and provided only limited education about the consequences of TBI to mentors, instead
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9 giving primacy to their own personal experiences of TBI. The 45-minute education session,
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11 led by a rehabilitation consultant, was material all mentors had previously received as an
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13 inpatient during their rehabilitation. This approach is different from other peer mentoring
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15 programmes in which mentors received more education about TBI from a clinical
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17 perspective.^{28 30 45}

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24 In our study mentees talked about a sense of hope that came from being with their
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26 mentors; hope for the future, and hope of recovery. This potential outcome is distinct from
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28 other studies of peer mentoring after TBI.²⁸⁻³⁰ Hope or hopefulness as a potentially
29
30 important outcome is considered in a conceptual analysis by Bright and colleagues.⁴⁶ Our
31
32 findings are similar to research in spinal cord injury, which showed that mentors helped
33
34 newly injured people see future possibilities.⁶ The authors described this in the context of
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36 temporality and conceptualised disabled peer mentors as bridges in the temporal disruption
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38 of newly injured persons. Similarly, in a study with people on acute stroke units, hope was
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40 also identified as a key outcome of a peer mentoring programme.⁴⁷

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47 The mentoring relationship appeared to benefit the mentors by allowing them to be, and to
48
49 be seen, as able to make a meaningful contribution, thus promoting a sense of self-value.
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51 Douglas and colleagues (2015) report on the social isolation frequently reported by people
52
53 with TBI, and describe rehabilitation as a 'social-relational affair' (p154).⁴² They suggest that
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55 through social interactions we build our sense of self, and that social interactions and
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3 expressive social support are essential elements for recovery after major injury.⁴² Similarly,
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5 qualitative accounts of the experience of recovery captured over two years following TBI,
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7 support this notion that recovery is a social relational process where people draw support
8
9 from others to make sense of recovery and life after TBI.²⁷ This is consistent with concepts
10
11 previously been discussed by others, such as relational autonomy, where autonomy is
12
13 argued to occur within and because of relationships.⁴⁸ Peer mentoring is one approach that
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15 explicitly attends to this important aspect of recovery.
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22 In conclusion, sharing experiences and stories seem key to successful peer mentee-mentor
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24 relationships after TBI and led to benefits for mentees. This approach does not replace
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26 clinical input, but provides something distinctly different and valuable. The efficacy of peer
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28 mentoring needs further investigation in TBI.
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Appendix Mentor training workshop

Day 1			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-10.00	Introductions, outline of the training, ground rules	Principal Investigator (PI rehab background), Research Officer (RO)	Discuss how the group wants to work together
10-10.30	Break		
10.30-11.00	The mentoring role and what we mean by participation	PI, RO, Co-investigator (health psychology background)	Brainstorm activities about participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful. *
11-12	Common challenges following TBI	Psychologist specialised in neurorehabilitation	Group discussion, including what helped and hindered managing these challenges.*
12-12.30	Common challenges following TBI	Rehabilitation specialist (medical doctor)	Presentation: same as that given to people prior to discharge. Topics covered included for example impact of head injury on the brain, recovery, impact of lifestyle choices on recovery (e.g. drugs and alcohol).
1.30-2.45	The mentoring relationship	Psychologist specialised in neurorehabilitation	Warm up exercise: 5-10 minutes, talk to your partner about yourself for 2-3 minutes; then listen to them for 2-3 minutes. Then be ready to introduce your partner to the group. Using flipcharts mentors drew aspects of their life after TBI they would be happy to share with a mentee.
2.45-3.15	Break		
3.15-4.30	The mentoring relationship	Psychiatrist with expertise in TBI, Neuropsychologist	Each mentor shared their story depicted in the flipchart - practising sharing their experiences. A 3-page outline of the mentoring role was also discussed. Discussion of culturally appropriate working in the NZ context.

* Summary was typed up and provided to mentors in their workbook

Day 2			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-9.45	Overview of the mentoring programme	Principal Investigator (PI), Research Officer (RO)	Summary was provided of participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful (from the previous week). Outline and rationale of the mentoring programme was presented.
9.45-10.30	Goals and setting them	Co-investigator (health psychology & nursing background)	Interactive workshop on goal setting and action planning using worksheets
10.30-11.00	Break		
11-12.30	The mentoring programme – in detail	PI, 2 ROs	Outline of each mentoring session was provided and discussed in workshop format
12.30-1.30	Lunch		
1.30-2.45	Project requirement, strategies for researcher safety	Co-investigator (health psychology background), PI and RO	Discussion of potential safety issues and how to manage them. Familiarisation with safety policy of the centre & note taking for the intervention.
2.45-3.15	Break		
3.15-4.30	Wrap up, questions, mileage claims	Principal Investigator (PI), Research Officer (RO), centre manager	Final question and answers session, explanation of keeping timesheets and mileage claims.

Author contributions

PK conceived of the study, led on study design, project management, data analysis and dissemination. NK, KMcP, MW, HE contributed to study design. CC, NK and DB contributed to the qualitative data analysis, MW and GS to the quantitative data analysis. CC, NK, DB, AF, KMcP, RS, HE, and GS contributed operationally (e.g. training, recruitment, data collection, mentor support and debriefing). PK drafted the manuscript and is the guarantor. All authors revised it critically for important intellectual content and approved the final version for publication. All authors agree to be accountable for all aspects of the work.

Competing Interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: PK, NK, HE, MW, KMcP had financial support from the Health Research Council of New Zealand for the submitted work; AF is an employee of ABI Rehabilitation New Zealand Limited; subsequent to the completion of this project and data analysis KMcP became the Chief Executive of the Health Research Council of New Zealand; all other authors declare no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Data sharing

Quantitative data from the study is not presented in the paper but can be obtained from the author, subject to the funder's permission.

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Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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Manuscripts

Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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23 Abstract

24 **Objectives:** To explore the acceptability of peer mentoring for people with a traumatic brain
25 injury (TBI) in New Zealand.

26 **Design:** A Qualitative Descriptive study exploring experiences reported by mentees and
27 mentors taking part in a feasibility study of peer mentoring. Interviews with five mentees
28 and six mentors were carried out. Data were analysed using conventional content analysis.

29 **Setting:** The first mentoring session took place pre-discharge from the rehabilitation unit.
30 The remaining five sessions took place in mentees' homes or community as preferred.

31 **Participants:** Twelve people with TBI took part: six mentees (with moderate to severe TBI;
32 aged 18-46) paired with six mentors (moderate to severe TBI > 12 months previously; aged
33 21-59). Pairing occurred before mentee discharge from post-acute inpatient brain injury
34 rehabilitation. Mentors had been discharged from rehabilitation following a TBI between 1
35 and 5 years previous.

36 **Intervention:** The peer mentoring programme consisted of up to six face-to-face sessions
37 between a mentee and mentor over a six month period. The sessions focussed on building
38 rapport, exploring hopes for and supporting participation after discharge through further
39 meetings and supported community activities.

40 **Results:** Data were synthesised into one overarching theme: Making sense of recovery. This
41 occurred through the sharing of experiences and stories; was pivotal to the mentoring
42 relationship; and appeared to benefit both mentees and mentors. Mentors were perceived
43 as valued experts because of their personal experience of injury and recovery, and could

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3 44 provide support in ways that were different to that provided by clinicians or family

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5 45 members. Mentors required support to manage the uncertainties inherent in the role.

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8 46 **Conclusions:** The insight mentors developed through their own lived experience established

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10 47 them as a trusted and credible source of hope and support for people re-engaging in the

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12 48 community post-TBI. These findings indicate the potential for mentoring to result in positive

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15 49 outcomes.

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18 50 **Trial registration:** International clinical trials registry platform (ICTRP) UTN: U1111-1142-

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23 52 **Keywords**

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26 53 Traumatic brain injury, peer mentoring, qualitative, acceptability, recruitment, retention

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Strengths and limitations of this study

- The use of qualitative interviews with both mentees and mentors engaged in a mentoring programme after traumatic brain injury to understand their experiences is a strength.
- The study design was informed by our previous work trialling rehabilitation interventions with this population and incorporated robust methods to collect and analyse qualitative data.
- The intervention, developed using theory, evidence and consumer involvement was delivered face to face and was flexible to the needs of both mentors and mentees.
- This was the mentors' first experience of mentoring following TBI. Therefore, the benefits and challenges presented here may change in a larger trial where mentors have the opportunity to support more than one mentee.
- This study was designed to explore acceptability of peer mentoring. The efficacy of this intervention requires further investigation.

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81 authors on this paper.

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83

84 Introduction

85 An estimated 10 million people sustain a Traumatic Brain Injury (TBI) each year worldwide.¹
86 New Zealand has a very high incidence of this condition (811/100,000, these figures include
87 people with mild to severe TBI).² While some people with TBI make functional gains over
88 time, many people deteriorate with time and often experience wide-ranging and significant
89 long-term problems with physical, cognitive and psychological functioning. Indeed, the
90 personal aftermath of TBI is characterised by disruption to a sense of self and personhood,
91 with usual markers of productivity and reciprocity in roles and relationships threatened.³ As
92 a consequence, many people report an enduring impact on social, community and
93 vocational participation, with many suffering social isolation.³⁻¹³ Major long-term costs to
94 society extend beyond acute healthcare to include compensation, support for
95 independence, social and physical rehabilitation.^{14 15} These findings suggest that more
96 effective strategies that facilitate enhanced participation for this population in the long term
97 are needed. However, current services, in New Zealand and elsewhere, primarily target the
98 acute/sub-acute phase with only limited ongoing input.¹⁶ In addition, rehabilitation services
99 largely focus on reducing impairment and improving activity (or reducing disability) with the
100 assumption that this will lead to improvements in participation.^{17 18} However, findings from
101 a longitudinal qualitative study exploring experiences of recovery over two years highlight
102 the importance of developing a concept of TBI and what it means to live in the context of
103 TBI, that are unique to the individual and which are socially and culturally located, for
104 successful re-engagement in meaningful activities.^{19 20} Individuals and their families in this
105 study highlighted that existing services (both in terms of their aim and purpose and the
106 timing of those services) failed to provide them with the necessary support to manage these
107 processes, leaving them to navigate and make sense of their recovery in isolation. These

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3 108 findings are consistent with arguments calling for new approaches to supporting recovery
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5 109 and adaptation after Traumatic Brain Injury (TBI), given recognition that it is more
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7 110 appropriately conceptualised as a 'long term condition than a single episode injury'.²¹
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13 112 Peer mentoring has been defined as 'support provided by individuals who have successfully
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15 113 faced a particular experience and can provide good counsel and empathic understanding to
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17 114 help others, with similar salient population characteristics, through a comparable
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19 115 experience'.^{22 23 (p436) 24} It has been used for over 50 years in mental health²⁵ and is
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21 116 increasingly used in rehabilitation, for example with people with spinal cord injury^{22 23 26-28}
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23 117 and heart disease.^{24 29} Empirical work in these populations has reported positive outcomes.
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25 118 For example, peer mentoring led to better adjustment after spinal cord injury in a study in
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27 119 which mentors helped mentees to cope with practical, emotional and identity challenges
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29 120 and project future possibilities.^{23 26} Likewise, a review of peer mentoring in heart disease
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31 121 showed that it led to increased self-efficacy, improved activity, reduced pain, and fewer
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33 122 emergency room visits.²⁹
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36 123 The case for peer mentoring can be found in a number of psychological theories, such as
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38 124 social cognitive theory³⁰, and self-determination theory.³¹ These theories propose that
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40 125 observing others, feedback and modelling, and social exchanges that support autonomy lead
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42 126 to better outcomes for those receiving the mentoring and were therefore selected as key to
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44 127 our programme. Peer mentoring interventions generally also include some degree of
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46 128 informational, appraisal, and emotional support.²⁴
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49 129 As noted above, many individuals with moderate to severe TBI experience significant on-
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51 130 going consequences in domains of physical, cognitive and psychological functioning, and
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131 personality changes.^{3-10 19 32-34} This variety of consequence makes peer mentoring potentially
132 challenging as candidate mentors may also be experiencing long-term consequences of their
133 TBI. Consequently, it is not surprising to find a limited range of published research exploring
134 peer mentoring in TBI.³²⁻³⁸ These studies report positive benefits on knowledge, quality of
135 life general outlook, behavioural control and return to work. However, design limitations
136 and trial issues hamper generalisability and adaptability of these findings.³²⁻³⁷ For example,
137 limitations include a lack of formal outcomes,³⁶ minimal detail provided limiting
138 replication,³⁷ lack of a control group,^{34 35} difficulties matching mentors with mentees,^{33 34}
139 costs of transport and social outings to participants,³³ and fewer sessions or contacts than
140 planned.^{32 33} As a consequence, a more robust evaluation of peer mentoring with people
141 with TBI is needed before tangible changes to practice and policy can be instigated.
142 However, before proceeding to a full trial for such a complex intervention it is important to
143 establish if the proposed intervention is acceptable, and if the study design is feasible.³⁹ Our
144 overarching study aim was to explore peer mentor and mentee views of the feasibility (e.g.
145 practicalities) and acceptability of a peer mentoring intervention in the New Zealand
146 context. This paper describes our approach and reports on the qualitative data collected to
147 evaluate the acceptability of the intervention with feasibility to be examined in a separate
148 publication.

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150 **Methods**

151 A Qualitative Descriptive methodology⁴⁰ was employed to explore mentee and mentor
152 perspectives and experiences of their participation in the peer mentoring intervention.⁴¹ In
153 Qualitative Descriptive studies researchers stay close to their data and to the surface of

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3 154 words and events.⁴⁰ This enables the explication and descriptive summary of complex
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5 155 experiences, which are valuable in their own right as end-products, but also to inform
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7 156 further study. As a consequence, Qualitative Descriptive methodology has been argued to be
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10 157 a useful approach for the development and refinement of interventions⁴¹ and so was well
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12 158 suited for the current study. The academic members of the research team consisted of
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14 159 people with a range of expertise in rehabilitation, physiotherapy, psychology, psychiatry,
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16 160 medicine, statistics, project management, data analysis and some personal experience of TBI
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19 161 or as a carer.
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24 163 The study was conducted in Auckland, New Zealand / Aotearoa. Due to the contracting of a
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26 164 single national funder of inpatient rehabilitation after Traumatic Brain Injury in New Zealand,
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28 165 nearly all moderate-to-severe cases of TBI in the North Island are treated at one of two site
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30 166 of a single provider after their discharge from the acute hospital services. This provider cares
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32 167 for between 100 and 150 people per year,⁴² and their primary Auckland site was the sole site
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34 168 of recruitment for mentees.
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40 170 We had funding to support inclusion of six mentees and six mentors. Invitations to take on
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42 171 the role of mentor were sent by letter in batches to those identified as eligible by the
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44 172 rehabilitation provider and followed up by phone to confirm eligibility. While staff involved
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46 173 in the clinical management of mentors were involved in helping to identify potentially
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48 174 eligible people, the actual recruitment of mentors was overseen and carried out by the
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50 175 research team. In addition to those identified by the rehabilitation provider, letters were
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52 176 also sent out from our research centre to those who had previously taken part in other
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54 177 studies, had expressed an interest in being involved in further research, and fitted the study
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3 178 criteria. Those who met the eligibility criteria and expressed a desire to take up a mentoring
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5 179 role were invited to attend a 'job' interview as this was a paid role. The interview panel
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7 180 consisted of members of the research team (which included a psychiatrist with expertise in
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9 181 TBI). The panel explored candidates' motivation for applying to become a mentor, any
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11 182 challenges they may foresee, how they might overcome these challenges, and what their
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13 183 support needs might be. All those offered the mentorship role underwent a criminal record
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15 184 check. The mentors were paid on a research assistant pay scale for their time on the project,
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17 185 and they were issued with a mobile phone to enable contact with their mentees and the
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19 186 research team at no cost to themselves and without the need to share their personal
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21 187 number.

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26 188 Mentee recruitment was initiated by rehabilitation staff approaching all eligible participants
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28 189 and handing them the study information leaflet. In this leaflet they were encouraged to
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30 190 discuss the study with their family. Rehabilitation staff passed contact details of those
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32 191 interested in hearing more about the study to the research officer (CC). The research officer
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34 192 then met with potential participants (and interested family member(s) if this was their wish),
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36 193 explained what the study involved, and discussed any concerns. This meeting took place at
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38 194 least 24 hours after the person had first been informed about the study, and in many cases
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40 195 the researcher followed up with a second visit to answer further questions and meet with
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42 196 interested family members. This process was used to ensure all potential mentee
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44 197 participants were able to take the time to consider their participation and discuss it with
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46 198 their family members, before providing consent. Eligibility criteria for both mentors and
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48 199 mentees are displayed in Table 1. The literature has shown that matching is important in
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51 200 peer mentoring.³²⁻³⁴ We had limited opportunities for matching due to funding constraints
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201 and being limited to work with six mentors, but we did match by gender, and where possible

202 shared interest (such as outdoor sports).

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For peer review only

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Table 1. Inclusion and exclusion criteria		
Inclusion criteria	Mentees	Mentors
• Age (years)	≥15 years	≥18 years
• Moderate or severe TBI ^{43 44}	√	√
• Discharge from inpatient rehabilitation	Imminent	1-5 years previously
• Living in the greater Auckland region	√	√
Exclusion criteria		
• Unable to communicate in a way that enabled engagement with a mentor/mentee	√	√
• Medical condition that precluded their participation	√	√
• Discharge FIM Cognitive domain score* ≥24 ⁴⁵		√
• Ongoing alcohol or drug abuse problems, communication difficulties, known gang affiliations, concerns in terms of safety or security (clinical judgement)		√

* FIM: Functional Independence Measure, data obtained from the rehabilitation centre

** Moderate TBI: initial Glasgow Coma Scale (GCS) score 9-12 (of a possible 15) and/or post-traumatic amnesia (PTA) duration >1 but <7 days; Severe TBI: initial GCS <9 and/or PTA ≥7 days.^{43 44}

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207 **Intervention**

208 Our approach was informed by our own research^{19 20 46-48} and by that of others.³²⁻³⁴ For
209 example, peer mentoring sessions were one-to-one and face-to-face (as opposed to by
210 phone). The research officer introduced the mentor to the mentee (and their family
211 members) prior to the first meeting. The first session occurred pre-discharge in the
212 rehabilitation setting and the remaining five in the community. Mentors were provided with
213 worksheets to support them with each session. It was also intended the sessions would be
214 time-limited and would take place in the initial stages following discharge, i.e. over a three
215 month period. Dyads started the intervention within two weeks of the mentee agreeing to
216 take part, and prior to discharge. Three of the sessions were intended to involve a pre-
217 planned, supported participatory activity in the community, negotiated in advance by each
218 mentee-mentor pair (to ensure dyads could focus on real life experiences of participation
219 and its challenges). Mentors were provided with petty cash to pay for any expenses during
220 such activities (up to NZ\$50 per activity).^{46-48 32-34} Table 2 displays the basic structure of the
221 programme in more detail.

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Table 2 The mentoring programme

Time point	Session purpose
One to two weeks before discharge from inpatient rehabilitation	Mentor meets with the mentee at the inpatient rehabilitation facility to get to know one another. Make provisional plans for meeting post discharge.
Two weeks after discharge	Mentor visits mentee at home, to re-establish connection, explore barriers and facilitators to participation, and support them to develop plan for social activities for the next couple of weeks.
Four weeks after discharge	Participate in mentor supported activity; check in with the mentee and discuss what has gone well over the last few weeks, what didn't go well? Plan further activities.
Six weeks after discharge	As for previous session
Eight weeks after discharge	As for previous session, reminder that next visit will be the last.
Ten weeks after discharge	Final visit. The mentor and mentee will review progress and the ending of mentee/ mentor relationship. A mihi whakamutunga (cultural blessing or prayer) will be offered for those who wish this.

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226 Mentor training and support

227 Mentor training comprised of a two day interactive training workshop, with each day held
 228 one week apart (see the Appendix for an overview of the training programme). This included
 229 a mix of presentations, discussion, role play and skill-building activities, aiming to strengthen
 230 and build on the experience and skills of the mentors. Topic sessions included the role of the

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3 231 mentor, experience of TBI, sharing experiences, and safety protocols. Skills in sharing
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5 232 experiences were developed by each mentor creating a pictorial map of their TBI journey, on
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7 233 their own then sharing this with the wider group. This helped the mentors to articulate their
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10 234 journey, decide what aspects they were willing to share and which ones they may not, and
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12 235 also gain insight into each other's journeys. This in turn helped them develop listening skills
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14 236 and empathy. We discussed ways of being respectful and keeping safe when visiting people
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17 237 in their homes. We established a safety protocol where mentors were required to notify the
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19 238 research officer of the time and date of their visits and check in (by phone) at the
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21 239 completion. Mentors were encouraged to share with the research team any concerns they
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23 240 had regarding the visit and any perceived threats to their own safety or the welfare of their
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26 241 mentee. We also took care not to professionalise the mentoring role as a key component
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28 242 was that mentors functioned as 'peers' not quasi health professionals. To that end we
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30 243 provided limited education about the clinical consequences of TBI to mentors, instead giving
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32 244 primacy to their own personal experiences of TBI. The 45-minute education session, led by a
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35 245 rehabilitation consultant (who was familiar to many of the mentors having been involved in
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37 246 their clinical management during their own inpatient stay), used material that all mentors
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39 247 had previously received as an inpatient during their rehabilitation. Attention was paid to
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42 248 cultural protocols for the New Zealand context. For example, the encouragement to use an
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44 249 opening and closing karakia (blessing or prayer) for meetings with mentees when both
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46 250 parties agreed this was appropriate; and the intervention being delivered kanohi te kanohi
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48 251 (face to face) which is a preferred approach for Māori.⁴⁹ Mentors had access to a resource
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51 252 containing information on locally available services they could refer mentees to if
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53 253 appropriate. Mentors were asked to make notes after every session with their mentee and
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56 254 were provided with a basic structure to do so.

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5 256 Mentors took part in three face-to-face group debrief sessions over the course of the
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7 257 intervention period, led by the principal investigator (PK) and accompanied by the research
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9 258 officer (CC) and one other member of the research team with psychology expertise (e.g.
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11 259 KMCP, DB, RS; each attending one session). These were held on Saturday mornings to
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13 260 accommodate those who were working or studying. Topics for the debriefs were set by the
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15 261 mentors and included, for example, sharing experiences of the first meeting with mentees
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17 262 (what went well, what were their concerns), practicalities of community activities, and how
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19 263 to conclude the mentoring relationship. Access to additional psychological and psychiatric
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21 264 support was available for individual mentors but not requested.
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29 266 Data collection and analysis

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31 267 Semi-structured interviews with mentees and mentors were conducted at the conclusion of
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33 268 the mentoring relationship, at the mentee and mentor homes, by one researcher (CC). She
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35 269 has over 10 years experiences of qualitative data collection and analysis, studying
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37 270 rehabilitation interventions in people with neurological conditions, in particular TBI (e.g.⁴⁸
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39 271 ⁵⁰). An interview guide (see table 3) was used to inform the discussion for both mentors and
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41 272 mentees. This focused on the mentoring experience, the timing of the intervention, the
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43 273 perceived impact of the relationship, and suggestions for improving the programme.
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45 274 Mentors were asked additional questions relating to the adequacy of the training and
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47 275 support provided to them. In both cases, the interview guide was used as a prompt to focus
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49 276 the conversation, but otherwise the interview was kept open, exploring topics raised by the
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51 277 participants in more detail as they arose. Interviews were audio recorded and transcribed
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3 278 verbatim by a contracted transcriber, then checked for accuracy by the researcher. They
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5 279 were anonymised prior to analysis.
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10 **Table 3. Interview guide (used flexibly)**
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12 **Mentees**

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- 15 • What was your experience of the mentoring project?
 - 16 • What was useful about the mentoring? What wasn't?
 - 17 • How has the relationship impacted on you?
 - 18 • If you had a mentor in the future what would you like them to focus on?
 - 19 • What sort of things would you like to talk to / do with your mentor?
 - 20 • When would have been the best time to meet up with your mentor? Prompts: the
 - 21 first meeting, after the first meeting, how often?
 - 22 • How did you find answering the questionnaires that CC asked you to complete?
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34 **Mentors**

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- 36 • Did you feel that the training workshops prepared you for your role as mentor?
 - 37 • What would you change about those workshops?
 - 38 • If we needed to cut these down to one day what would you suggest we cut out?
 - 39 • Or what should we add instead?
 - 40 • Did you feel that you received enough support for your role as mentor?
 - 41 • What would you change about the support you received?
 - 42 • How did you find the planning and write up requirements? How would you suggest
 - 43 that we do this in the future?
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3 282 The mentors were given a format for keeping visit notes, asking them to record the activities
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5 283 they carried out and reflect on what had gone well or not and what they would do
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7 284 differently next time. Mentors maintained in contact with their mentee by texts and phone,
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9 285 but these were not recorded as data. The researcher took field notes throughout the study
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11 286 to record her initial thoughts and reflections following post-visit phone debriefs with
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13 287 mentors, as well as following group debriefing sessions. She also noted when needing to
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15 288 provide mentors with practical support (such as connecting with their mentees). She
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17 289 collated the mentor notes, which supplemented interview data. Peer mentoring sessions
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19 290 were not observed as the team did not wish to interfere with the relational aspects of the
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21 291 intervention.
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28 293 Data were analysed drawing on Conventional Content Analysis.⁵¹ A core analysis group (PK,
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30 294 CC, NK and DB) was established, which was diverse in gender, ethnicity (New Zealand
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32 295 European, European and Australian) and professional background (rehabilitation,
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34 296 physiotherapy, health psychology, sociology and education). This group met several times to
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36 297 allow for an iterative and recursive approach to analysis before settling on the final
37
38 298 interpretation of data presented here. In the first instance, CC and PK listened to the audio
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40 299 recordings and read and re-read the transcripts to become familiar with the data. From
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42 300 there, data were read to identify key concepts relevant to the topic areas in the interview
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44 301 guide (e.g. broad experiences and perspectives of the intervention, the mentoring
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46 302 relationship, and feedback on specific aspects of the programme). This led to the
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48 303 development of a coding framework which formed the initial frame for analysis. Data were
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50 304 coded manually, deriving new codes where an existing code did not fit the existing
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52 305 framework. Code definitions developed, and then illustrative quotes were extracted into
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3 306 word tables. Each core analysis group member became familiar with a set of interviews in
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5 307 preparation for group analysis discussions where preliminary ideas and concepts derived
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7 308 from early coding were presented and discussed. Following each analysis session, CC
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9 309 returned to the raw data to test out our interpretation of data, further refine our coding,
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11 310 and categorise the data into meaningful themes. Triangulation was carried out with mentor
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13 311 notes and the researcher's notes from her discussions with mentors following their
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15 312 interactions with mentees, to check for trustworthiness. Interview data from mentors and
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17 313 mentees were initially coded separately before looking across data sets (i.e. within dyads,
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19 314 and across participant types) for patterns and meaningful clusters.
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25 316 **Patient and public involvement**

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28 317 Māori are the indigenous people of Aotearoa New Zealand and almost 17.5% of the New
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30 318 Zealand population identify as Māori.⁵² Researchers have a responsibility to ensure their
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32 319 research is of value and culturally responsive to Māori.⁵³ Therefore, guidance for the study
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34 320 was also sought from a University Mātauranga Māori committee, members of which are
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36 321 drawn from a wide range of Māori communities. Whilst people with recent TBI were not
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38 322 explicitly involved in the design of the study, seeking mentor and mentee experiences and
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40 323 perspectives was built into the design of the study to ensure their voice was formative to
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42 324 future related work. Further, mentors were appointed to paid positions and ongoing
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44 325 engagement with them through their training, debriefing and supervision sessions (see
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46 326 below for more detail) played a critical role in the operationalisation of peer mentoring in
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48 327 the current study.
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54 328 Ethical approval was obtained from the New Zealand Health and Disability Ethics Committee
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56 329 (ref 13/NTA/99/AM05) and the University (ref 13/288).
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330 Results

331 Letters were sent to 34 potential mentors, of whom nine were not contactable. The
332 researcher discussed the study with 13 people who responded positively to the initial
333 approach, with nine accepting the invitation for interview (36% of those contactable). The
334 main reason for not taking part as a mentor were other commitments. All those interviewed
335 were invited to attend mentor training. Eight mentors completed both training days with
336 one dropping out after the first day due to work circumstances (89% retention). Mentors
337 were employed by the university as casual staff and paid on an hourly basis.

338 There were 12 potentially eligible mentee participants during the study period. Of these,
339 nine agreed to talk further with the research officer, with six consenting to participate as
340 mentees. Six of the mentors who had attended the mentor training were successfully paired
341 with the six consenting mentees.

342 Demographic and disability data for mentors and mentees is provided in table 4. On
343 enrolment to the study all mentors were able to walk independently and without a walking
344 aid though many had ongoing physical and cognitive difficulties.

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Table 4. Demographics	Mentees (n=6)	Mentors (n=6)
Inpatient stay (mean days, SD)	72 (54.4)	N/A
Admission FIM* score (mean, SD)		
- Motor tasks	57.7 (26.2)	N/A
- Cognitive tasks	22.0 (5.7)	
Age (range)	18-46 years	21-59 years
	Frequencies	Frequencies
Gender		
- Male	4	4
- Female	2	2
Injury severity		
- Severe	5	4
- Moderate	1	2
Ethnicity		
- Māori	1	1
- Māori / Samoan	1	
- New Zealand European	4	5
Employment	Pre-injury	
• Studying	1	2
• Working full time	3	2
• Working part time	2	2

346 * FIM: higher scores denote greater dependency; total motor scores can range from 13 and
 347 91; total cognition scores 5 to 35.

1
2
3 348 Four mentees engaged in six peer mentoring sessions, with the remaining two engaging in
4
5 349 one only. One mentee lost contact with their mentor and the research team after the initial
6
7 350 mentoring session in the inpatient setting despite a number of attempts to arrange to meet
8
9 351 face to face. The other mentee was not available to take part in more than one mentoring
10
11 352 session due to personal difficulties that restricted her participation and which had not been
12
13 353 apparent during recruitment, but contributed to the post intervention interview data
14
15 354 collection. Five mentees and six mentors were interviewed at the end of the intervention
16
17 355 period, with an average duration of 45 minutes (range 15 to 60).
18
19
20
21 356

22
23 357 There were some deviations from the intended programme structure. For example, most
24
25 358 dyads took more than three months to start and finish the programme (up to six months,
26
27 359 see example in figure 1). This was mostly due to ongoing health issues the mentee was
28
29 360 experiencing (e.g. further surgery) or due to other commitments both for mentees and
30
31 361 mentors (e.g. work, study). Secondly, the intended community activities were not always
32
33 362 possible and as such, for some dyads more mentor visits were at the mentees' homes than
34
35 363 intended. We come back to these issues in the discussion.

36
37 364 The research officer called mentors following each mentoring session as per the agreed
38
39 365 safety protocol to 'check in' and enquire what had gone well, if there were any issues or
40
41 366 concerns, provide general reassurance and to remind mentors to maintain records of the
42
43 367 sessions. Written reflections were provided by four mentors, and although these were
44
45 368 generally brief, one mentor provided comprehensive written reflections for each session.
46
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51 369
52
53 370 Data from mentor notes showed that mentors and mentees undertook a range of
54
55 371 community activities, such as having their nails done, going for lunch, having coffee in a café,
56
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1
2
3 372 browsing for music, or going for a walk. Topics of conversations during the session were
4
5 373 wide-ranging, including going back to work, struggles with abstaining from alcohol and
6
7 374 drugs, feeling different, strategies for remembering to do things, and managing
8
9
10 375 relationships.

11
12 376

13
14 377 The next section explores the qualitative findings from the interviews. Pseudonyms are used
15
16 378 here, followed by the mentor / mentee age.

17 379 Peer mentoring: Making sense of recovery

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20
21 380 Positive outcomes were reported both by mentees and mentors. A key theme identified in
22
23 381 the analysis was that of making sense of recovery through shared experience and stories.

24
25
26 382 This sharing was pivotal to the mentor-mentee relationship with both parties expressing

27
28 383 benefit. Through stories of their lived experience of injury and recovery, mentors were

29
30 384 perceived as valued experts and could provide support in ways that was different to that

31
32 385 provided by clinicians or family members. This position posed some challenges to mentors

33
34 386 who required support to manage uncertainties inherent in their role. These findings are

35
36
37 387 discussed below with supporting quotes.

38 388 Sharing stories

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40
41
42 389 The essence of the peer mentoring intervention was to provide support from someone who

43
44 390 has had also experienced a TBI.

45
46
47 391 *It was very useful to have someone who has been through a similar*

48
49 392 *accident to myself. It really meant a lot to me (Mentee, Peter, 24)*

1
2
3 393 Telling your own story was a key device this programme used to establish credentials and
4
5 394 facilitate the mentor / mentee relationship. The outcome of sharing these experiences was
6
7 395 something mentees reflected on.

8
9
10 396 *He wasn't asking me questions, he was a story teller. And that made me,*
11
12 397 *yeah rather than "how do you feel today?" Is what they [the clinicians]*
13
14 398 *asked me and I would go "oh yeah up and down like a rollercoaster I*
15
16 399 *guess." He would go 'oh yeah it's hard to explain isn't it?' [...]It was just,*
17
18 400 *like you say, an occasion to go out.[...] And that's what allowed me to have*
19
20 401 *someone who's a friendly expert, who had been through a brain injury, to*
21
22 402 *connect with. (Mentee: Dave, 45)*

23
24
25
26
27 403 Similarly, mentors found it more beneficial to share their stories with other peer mentors on
28
29 404 the programme (as they had also had a TBI) than people around them. Opportunities for this
30
31 405 arose during the training programme and debrief sessions, as these mentors explained:

32
33
34
35 406 *It was like a process of opening up to people who have been through the*
36
37 407 *same as yourself and I thought that was very helpful, just opening up and*
38
39 408 *just letting it out rather than bottling it up. (Mentor: Thomas 23)*
40
41
42 409 *Listening to what everyone else was saying sort of gave me great*
43
44 410 *confidence that I wasn't the only one. (Mentor: John, 59)*

47 48 411 Mentors as experts

49
50 412 Returning home following discharge from rehabilitation is reportedly a difficult time as
51
52 413 adjustments are made to changed circumstance. Mentees trusted their mentors and viewed

1
2
3 414 them as experts because they had experienced a TBI and attended inpatient rehabilitation
4
5 415 and were now actively participating in life roles.
6
7

8 416 *Because he had been through it. I guess I am just new at this. He made it*
9
10 417 *flow. He was like a brain injury guru. [...] Because he had lived it and*
11
12 418 *physically trained in that field, by being run over on his bike. [...] It was*
13
14 419 *more progressively rehabilitating for me than [name of the rehab centre].*
15
16 420 *(Mentee: Dave, 45)*
17
18
19

20 421 Even though mentors and mentees had different experiences of a TBI, they reported the
21
22 422 sharing of experiences and stories enabled them to develop a connection, a sense of trust
23
24 423 and in some cases a friendship.
25
26
27

28 424 *It was like you had a connection maybe that was what it was, you have a*
29
30 425 *connection. You have both been there and hearing what she had been*
31
32 426 *through. (Mentee, Jane, 42)*
33
34

35 427 Mentees reflected their mentor provided an opportunity to talk through concerns and
36
37 428 worries with 'someone who had been there'. This was viewed as different from the support
38
39 429 provided by clinicians or family and friends. Using mentors as a sounding board helped
40
41 430 mentees to make sense of their experiences and what could be expected after a TBI.
42
43
44

45 431 *It was nice to have someone, outside your family. Because family are too*
46
47 432 *close to you and they seem to like be over protective. Whereas your buddy*
48
49 433 *[mentor] sort of understood where you were coming from, understood*
50
51 434 *what you were going through. And it was nice to be able to ask like any*
52
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1
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3 435 *questions that I had like 'is this normal? I'm doing this is this, you know*

4
5 436 *what's going on here?' And get those answers. (Mentee: Kate, 45)*

6
7
8 437 The relationship between the pairs meant mentees felt comfortable sharing their
9
10 438 experiences, and contributed to a sense of trust and a willingness to discuss their difficulties
11
12 439 with more transparency than they might have with clinicians and family members. Kate
13
14
15 440 suggested the relationship with her mentor enabled her to open up:

16
17
18 441 *You become friends in the way that you can actually openly communicate*

19
20 442 *to someone. That's where it changed. So instead of being careful about*

21
22 443 *what you say and you know being reserved, you could actually be totally*

23
24 444 *open and honest with someone that's not a psychologist. (Mentee: Kate,*

25
26
27 445 *45)*

28
29
30 446 Much of the discussion between mentees and mentors reportedly included talking through

31
32 447 issues they were reluctant to address with clinicians and believed their family members or

33
34 448 friends did not understand. Mentors in turn revealed coping strategies they had found

35
36 449 helpful for issues raised such as dealing with fatigue, thinking about return to 'normal', and

37
38 450 discussions about how to cope with social pressures regarding alcohol consumption

39
40 451 following TBI. Discussions of such matters appeared to be facilitated by the relationship not

41
42 452 being bound by the systems and structures clinicians operate in and, unlike clinicians,

43
44 453 mentors had more time to be with mentees either in their own home or in the community.

45
46 454 Mentors were conscious of their position and reported they were clear they were not acting

47
48 455 as clinicians and recognised they had to have boundaries in terms of the advice they could

49
50 456 offer.
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1
2
3 457 *But I shouldn't be giving him medical advice you know. I can't tell him what*
4
5 458 *to do I can only tell him what I did [...] I can talk to him about that [alcohol*
6
7 459 *consumption] but in that situation it should be more as a friend [...]*
8
9
10 460 *because I don't want him thinking I've got some profound knowledge about*
11
12 461 *how your brain is going to affect your drinking after a year. (Mentor:*
13
14 462 *Michael, 24).*

463

464 **Mentoring as a source of hope**

465 Meeting and talking with mentors provided mentees with a sense of hope for progress
466 beyond the difficulties they were facing immediately post-discharge and enabled them to
467 build their self-confidence. The mentees reported feeling pleased to learn their mentors
468 were now getting on with their lives and involved in activities such as university studies or
469 returning to work.

470 *Just how where he's come from, from his accident until now. How he's*
471 *accomplished the things that he needs to do [...] What it helped me is he's*
472 *back to work. And that's where I want to be. [Mentee: Tony, 43]*
473 *Because it helps you feel like you are understood and you are not the only*
474 *person going through this trouble but there have been other people who*
475 *have gone through similar things who are able to show you a glimpse of*
476 *hope that life gets better. (Mentee: Peter, 24)*

477

1
2
3 478 The challenge of mentoring
4

5 479 Despite the mentees endorsement of the help and the inspiration of their personalising
6
7 480 stories during the intervention period, the mentors struggled with their own expectations of
8
9 481 the mentoring role. Some were concerned they needed more 'tools to do the job properly'
10
11 482 and were sometimes worried about the extent of the external support their mentee was
12
13 483 receiving. Frequent contact with the research staff was important to discuss these concerns,
14
15 484 to check in and ensure the mentee was safe and reassure the mentor that what they were
16
17 485 offering their mentee was valuable in its own right and was in keeping with the intentions of
18
19 486 the programme.
20
21
22
23

24 487 *Watching some of the hard stuff he was going through and just kind of*
25
26 488 *really bumming me out. [...] Everybody felt a bit of a pressure, a*
27
28 489 *responsibility to the person because we kind of get what it was like to go*
29
30 490 *through what they went through and so you don't want to fail the person*
31
32 491 *you know. (Mentor: Michael, 24)*
33
34
35

36 492
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38
39 493 The valuable insights the mentors had into the challenges their mentees were experiencing
40
41 494 that enabled them to establish connections and support their mentee, presented challenges
42
43 495 to the mentors as it prompted a revisiting of their own injury experiences and an
44
45 496 acknowledgement of their persistent residual symptoms.
46
47
48

49 497 *Just because, you know, you process your own head injury issues when you*
50
51 498 *are mentoring someone [...]. Sort of re thinking my own head injury and my*
52
53 499 *own thing to kind of try and be useful to him. [...] so some of that stress*
54
55 500 *probably wasn't at all out of my relationship with him, was actually to do*
56
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58

1
2
3 501 *with my own sort of. Because like you say, we are mentors because we*
4
5 502 *have been through something that was kind of shit, you know, so we are*
6
7 503 *thinking about that difficult thing pretty deeply. (Mentor: Michael, 24)*
8
9

10 504

11
12
13 505 Although they experienced these pressures over their concern for their mentee's situation
14
15 506 and dealing with their own concerns, the mentors reported the support they received from
16
17 507 the research team helped them deal with these and be effective in their role.
18
19

20
21 508 *I think even when (mentee) started being, even when he started being a*
22
23 509 *little bit depressed, having you guys to call and just chat through things*
24
25 510 *and sort of, I had never really had a moment where I called you and no one*
26
27 511 *answered or something like that. It was always, there was always contact*
28
29 512 *there. (Mentor: Louis, 23)*
30
31

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33 513

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35
36 514 Another challenge concerned the intended community activities and the planned time
37
38 515 frames. These community activities were not always practical as some mentees had ongoing
39
40 516 medical problems that restricted their mobility or lack of access to transport. Therefore,
41
42 517 more mentor visits were at the mentees' homes than proposed in the programme. Where
43
44 518 community activities did occur, they typically included meeting up in a café, or browsing
45
46 519 shops together. Timeframes were stretched by circumstances, for example surgery for
47
48 520 associated injuries resulting in temporary mentee unavailability. Mentors were encouraged
49
50 521 by the research team to use the programme flexibly in response to the mentees preference,
51
52 522 which was considered a strength by many.
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3 523 The peer mentoring was provided as a time limited relationship, which for most mentors
4
5 524 was not experienced as a problem as they felt their mentee had moved along in their
6
7 525 recovery or that they had nothing more to offer as a mentor. However, for others, the
8
9
10 526 consequence of the relationship being and becoming more personal created difficulty and
11
12 527 concern about ending the series of sessions. These concerns were raised as a topic for
13
14 528 discussion by mentors at each of the debriefing sessions and mentors reported they needed
15
16 529 this support in withdrawing from the formal mentoring relationship. Nevertheless, ending
17
18 530 the mentoring relationship appeared to result in a sense of loss.

21
22 531 *We did talk about, in the last session that we might see each other again,*

23
24 532 *and then all of a sudden I am not a mentor anymore. (Mentor: Michael, 24)*

25
26
27 533 Regardless, overall both the mentors and mentees reported the experience as beneficial.
28
29 534 The opportunity to connect with others in a similar situation provided comradeship and a
30
31 535 sense of hope:

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33
34
35 536 *I've just more than anything found like a friend. One that I can relate to.*

36
37 537 *We have both had an injury. (Mentor: Sarah, 21)*

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39
40 538 The mentors all expressed enjoying their role and developed caring supportive relationships
41
42 539 with their mentee. They appreciated reciprocity the role offered them in the opportunity to
43
44 540 give back and help someone.

45
46
47 541 *I'd say it became a mutually beneficial relationship and one that to me meant a lot*

48
49 542 *because it was, to me it was watching him recovering. (Mentor: Louis, 23)*

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544 Discussion

545

546 The findings of this study indicate the peer mentoring programme was perceived to be
547 acceptable by both mentors and mentees. However, our experiences and that of our
548 participants highlight a number of key lessons for future related work. For example, there is
549 benefit to operationalising the intervention more flexibly than we initially intended. We
550 found that a rigid approach to the number and frequency of community participatory
551 activities is not always possible due to ongoing mentee health issues. Similarly, a 6-month
552 time frame is more appropriate for a programme consisting of six sessions to allow for the
553 complexity that mentees face post discharge in re-engaging with their home life. Further, it
554 is clear that mentors can sometimes require both practical support (e.g. to get hold of their
555 mentees and arrange times to meet) and emotional support (to help them navigate any
556 emotional response they might have to sharing their story and re-engage with their own
557 traumatic experiences in the sharing of those stories).

558

559 Although this study did not explicitly seek to explore programme benefits, both mentors and
560 mentees reported a number of perceived benefits. We found that the peer mentoring
561 relationship may be beneficial to both mentor and mentee through the sharing of
562 experiences and stories, but also that mentors required support to manage the uncertainties
563 inherent in the work. The time to talk and listen as well as the shared authentic experiences
564 resonated with mentees, leading to feelings of hope and confidence as they re-engaged in
565 the life post-discharge to the community.

566

1
2
3 567 Just over a third of mentors approached and contactable took part in the study. This level of
4
5 568 uptake could potentially impact upon feasibility of rolling this out to a larger study or service.
6
7 569 However, given some declined due to other (immediate) commitments it is possible that
8
9
10 570 when mentoring is embedded in routine service delivery (without the time constraints
11
12 571 associated with research) that more people would come forward.

13
14 572

15
16 573 Strengths of this study include the use of qualitative interviews, which enabled an in-depth
17
18 574 exploration of the experiences of mentees and mentors engaged in a mentoring programme
19
20 575 after TBI. The intervention was theory-based, and developed incorporating both evidence
21
22 576 and consumer (particularly Māori) involvement. An additional strength was delivering the
23
24 577 mentoring face to face and in a way that was flexible to the needs of both mentors and
25
26 578 mentees.

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31
32 580 While mentors reported some challenges, this was the mentors' first experience of
33
34 581 mentoring following TBI. Therefore, the benefits and challenges presented here may change
35
36 582 in a larger trial where mentors have the opportunity to develop experience through
37
38 583 supporting more than one mentee. Input into the study or intervention design were not
39
40 584 sought from people with recent TBI, which was a limitation. However, as noted in the
41
42 585 methods, engaging their perspectives was inherent in the study design, ensuring their
43
44 586 feedback is formative to future related work, which is consistent with the aims of the current
45
46 587 study.

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52 589 We experienced other challenges. Only four mentors recorded notes about their mentoring
53
54 590 sessions. During the debrief sessions it became apparent that taking such notes was often

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3 591 forgotten, or perceived as not necessary. Future research should consider the best
4
5 592 mechanisms for capturing such data.
6
7 593
8
9
10 594 Since this was a small study we were able to match on gender only, though we also took into
11
12 595 account shared interests. Ideally we would also have utilised the opportunity for matching
13
14 596 by ethnicity, an important approach especially for Māori⁴⁹ and future work needs to be
15
16 597 designed to enable this. We were also unable to pair by age or family circumstances due to
17
18 598 the small mentor group. This resulted for example in one single mentor in their twenties
19
20 599 mentoring a much older person with five children. However, they developed a very good
21
22 600 relationship and the differences in age or life experience for them was not of relevance. This
23
24 601 concurs with our previous research, which has shown that assumptions should not be made
25
26 602 concerning the type or level of support people need.⁵⁴
27
28 603
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30
31
32 604 Our mentors had previously sustained a moderate to severe TBI. Although they initially
33
34 605 appeared to be high functioning, several had ongoing physical and cognitive difficulties
35
36 606 whilst being part of our programme. For example, three required ongoing employment
37
38 607 support, many experienced significant levels of fatigue and irritability, and not all had been
39
40 608 able to return to driving. However, all were able to get to places to meet with their mentors
41
42 609 and develop a meaningful relationship. Thus we are not able to comment on the potential
43
44 610 mentoring ability of those with more severe residual disability following their TBI.
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46 611
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51 612 Mentors required more support from the research officer than anticipated at the outset of
52
53 613 the study. For example, she supported them to maintain contact with their mentee during
54
55 614 the study period, assisted with scheduling visits when they experienced difficulties, and
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1
2
3 615 provided assistance with negotiating the university's reimbursement procedures. The under-
4
5 616 recognised need for this level of support was in part due to lack of evidence for delivering
6
7 617 this service with this population and will inform future study design and service models.
8
9

10 618
11
12 619 Our exploration of mentees' experiences should be considered in light of them taking part in
13
14 620 a feasibility study. In addition, this was the first time each of our mentors had the
15
16 621 opportunity to work with a mentee. Findings might be different if this had been a routine
17
18 622 service or if mentors were more experienced in their role. This was a feasibility study and the
19
20 623 findings are not designed to be transferable to other contexts, however, they have the
21
22 624 potential to inform future peer mentoring intervention studies for people following
23
24 625 traumatic brain injury and point to the potentially reciprocal benefits of the mentoring
25
26 626 relationship. A key feature of our study was the face to face delivery of the intervention. In
27
28 627 the current study this was a culturally-located decision, given this is a preferred method of
29
30 628 service delivery for New Zealand Māori (the indigenous population of New Zealand). We also
31
32 629 believe this to be a key component of this peer mentoring intervention, and one that helped
33
34 630 create opportunities for developing connections and building the relationship.
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41
42 632 The stories our mentors used in their work with mentees were grounded in their own
43
44 633 experiences of recovery and living with consequences of TBI. The actual sharing of these
45
46 634 stories was a key component of the training workshops and debriefing sessions. Douglas and
47
48 635 colleagues (2015) suggest that supportive relationships that promote this sense of being
49
50 636 understood can facilitate people after injury to navigate their changed circumstances after
51
52 637 injury.⁵⁵ Others have suggested that relating to other survivors acts as a source of self-
53
54 638 cohesion in the process of identity re-construction.¹³ Indeed, in our study, the sharing of
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3 639 stories helped both mentors and mentees realise they were not the only ones in this
4
5 640 situation and not alone in what they were going through.
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7 641
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9
10 642 Mentees saw these stories as more authentic and more practically useful than receiving
11
12 643 advice from clinicians. This is similar to the findings of Veith et al. (2006), where mentees
13
14 644 saw professionals as forced into their life and as detached experts.²³ Stories of people
15
16 645 becoming more active after spinal cord injury recorded by actors have also been used in a
17
18 646 study with people recently injured.⁵⁶ Although they used a different delivery mechanism,
19
20 647 people with spinal cord injury and healthcare staff considered the stories to be effective
21
22 648 tools for communicating the message regarding reengaging in activity after injury. They
23
24 649 considered those in the stories to be credible messengers, who were emotionally realistic
25
26 650 and provided context. Stories have also been shown to be key in the success of mentoring in
27
28 651 a number of other settings, including mental health.^{25 57} In our study, the relationship that
29
30 652 developed through this sharing led to mentees feeling able to express their concerns in a
31
32 653 more honest and intimate way than perhaps would have occurred with clinicians.
33
34 654
35
36 655 We chose to use the terminology peer mentor over that of a lay person, since we concurred
37
38 656 with others that there are distinctive differences. A peer is someone 'who has had a
39
40 657 comparable experience' (p436).^{22 23} We do, however, acknowledge that the term 'lay' is also
41
42 658 used in self-management literature as people who have 'commonly, but not invariably,
43
44 659 themselves have a chronic disease, which may or may not be the same as that affecting
45
46 660 programme participants'.⁵⁸ We see the role of the mentor as different to that of a lay person
47
48 661 in the community. This is because mentors share the same experience (of an injury and of
49
50 662 the associated traumatic experience for example) and can be part of *created* social
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3 663 networks. Mentors are also different from paraprofessionals, who are lay people or lay-
4
5 664 leaders who have received extensive training to deliver more structured and educational
6
7 665 self-management programmes and have essentially become professionalised.^{24 58} This
8
9 666 approach is akin to that employed by other peer mentoring programmes in which mentors
10
11 667 received more education about TBI from a clinical perspective.^{32 34 59} There is no strong
12
13 668 evidence that such training impacts on health status, which provided us with the rationale
14
15 669 not to use this approach.⁵⁸ Further, we took a largely 'clinical perspective' in this study. A
16
17 670 sociological approach could reveal different insights and could be explored in further work.
18
19 671
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21
22
23 672 In our study mentees talked about a sense of hope that came from being with their mentors,
24
25 673 hope for the future, and hope of recovery. This potential outcome is distinct from other
26
27 674 studies of peer mentoring after TBI.³²⁻³⁴ Hope or hopefulness as a potentially important
28
29 675 outcome is considered in a conceptual analysis by Bright and colleagues.⁶⁰ Our findings are
30
31 676 similar to research in spinal cord injury, which showed that mentors helped newly injured
32
33 677 people see future possibilities.²⁶ The authors described this in the context of temporality and
34
35 678 conceptualised disabled peer mentors as bridges in the temporal disruption of newly injured
36
37 679 persons. Similarly, in a study with people on acute stroke units, hope was also identified as a
38
39 680 key outcome of a peer mentoring programme.⁶¹
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44 681
45
46 682 The mentoring relationship appeared to benefit the mentors by allowing them to be, and to
47
48 683 be seen, as able to make a meaningful contribution, thus promoting a sense of self-value.
49
50 684 Douglas and colleagues (2015) report on the social isolation frequently reported by people
51
52 685 with TBI, and describe rehabilitation as a 'social-relational affair' (p154).⁵⁵ They suggest that
53
54 686 through social interactions we build our sense of self, and that social interactions and
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2
3 687 expressive social support are essential elements for recovery after major injury.⁵⁵ Similarly,
4
5 688 qualitative accounts of the experience of recovery captured over two years following TBI,
6
7 689 support this notion that recovery is a social relational process where people draw support
8
9 690 from others to make sense of recovery and life after TBI.¹⁹ This is consistent with concepts
10
11 691 previously been discussed by others, such as relational autonomy, where autonomy is
12
13 692 argued to occur within and because of relationships.⁶² Peer mentoring is one approach that
14
15 693 explicitly attends to this important aspect of recovery. This was indeed found to be the case
16
17 694 in our study, with mentees re-engaging in activities with mentors' support, such as
18
19 695 contributing to activities within the church or leaving the home for a manicure or lunch.
20
21
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23 696
24
25 697 Peer mentoring interventions are also located within disability rights and advocacy (e.g. ^{63 64})
26
27 698 as a way of recognising, and utilising the expertise of those with experience of disabling TBI,
28
29 699 and supporting a non-clinical approach to supporting people to engage in life post TBI.
30
31
32 700 However, our peer mentoring intervention was not specifically conceptualised in this way.
33
34 701 Rather, as highlighted in the introduction, the intervention in the current study was
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36 702 underpinned by recognised gaps in service provision and informed by the experiences of
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38 703 people facing the enduring consequences of TBI. Likewise, there has been a recent interest
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40 704 in self-advocacy programmes for people with TBI and their families (e.g. ⁶⁵⁻⁶⁷). Self-advocacy
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42 705 can be defined as 'asserting your own needs and taking action to fulfil those needs'.⁶⁵
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44 706 Findings from such programmes are mixed but encouraging. One trial showed that advocacy
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46 707 behaviour improved both in a group taking part in a curriculum-based advocacy programme
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48 708 and one that was self-directed, and concluded that bringing like-minded motivated people
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50 709 with TBI is more important than programme structure or content in changing advocacy
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52 710 behaviour.⁶⁷ Similarly, the self-advocacy for independent life (SAIL) program showed

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3 711 improvements in self-efficacy, satisfaction with life and goal attainment both for those who
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5 712 took part in a curriculum-based programme and those who only accessed a workbook.⁶⁶
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7 713 However, neither study had a control group that did not receive an intervention, and the
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10 714 latter study was very small (n=12). Further, peer-advocacy or the role of peers in developing
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12 715 capability for self-advocacy was not explored in either study. Future research could consider
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14 716 the relevance of these findings for integration into TBI peer mentoring programmes.
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18 718 In conclusion, peer mentoring in the early stages post-discharge appeared acceptable to
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20 719 people with TBI, both as mentees and mentors. Sharing experiences and stories seem key to
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22 720 successful peer mentee–mentor relationships after TBI and appeared to lead to benefits for
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24 721 mentees. This approach is suggested to augment rather than replace clinical input, providing
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26 722 something valuable and distinctly different. This qualitative study is a first step in a larger
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28 723 programme of work aiming to examine the efficacy of peer mentoring in TBI. Our future
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30 724 work will more explicitly include the involvement of people with TBI and their families in the
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32 725 study design, and build on the experiences and inputs shared by the mentees and mentors in
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34 726 the findings of this study.
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729 **Figure 1. Example of mentoring timing**
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731 **Author contributions**

732 PK conceived of the study, led on study design, project management, data analysis and
733 dissemination. NK, KMcP, MW, HE contributed to study design. CC, NK and DB contributed
734 to the qualitative data analysis, MW and GS to the quantitative data analysis. CC, NK, DB,
735 AF, KMcP, RS, HE, and GS contributed operationally (e.g. training, recruitment, data
736 collection, mentor support and debriefing). PK drafted the manuscript and is the guarantor.
737 All authors revised it critically for important intellectual content and approved the final
738 version for publication. All authors agree to be accountable for all aspects of the work.

739 **Competing Interests**

740 All authors have completed the ICMJE uniform disclosure form at
741 www.icmje.org/coi_disclosure.pdf and declare: PK, NK, HE, MW, KMcP had financial support
742 from the Health Research Council of New Zealand for the submitted work; AF is an employee
743 of ABI Rehabilitation New Zealand Limited; subsequent to the completion of this project and
744 data analysis KMcP became the Chief Executive of the Health Research Council of New
745 Zealand; all other authors declare no financial relationships with any organisations that
746 might have an interest in the submitted work in the previous three years; no other
747 relationships or activities that could appear to have influenced the submitted work.

748 **Data sharing**

749 Quantitative data from the study is not presented in the paper but can be obtained from the
750 author, subject to the funder's permission.

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Figure 1 legend

The top image in this figure shows the intended duration of the peer mentoring programme (3 months) and frequency of sessions (every 2 weeks) for one of the study dyads. The bottom image shows the actual duration (6 months), and frequency (4-8 week gaps between sessions). The longest gap was due to the mentee requiring surgery.

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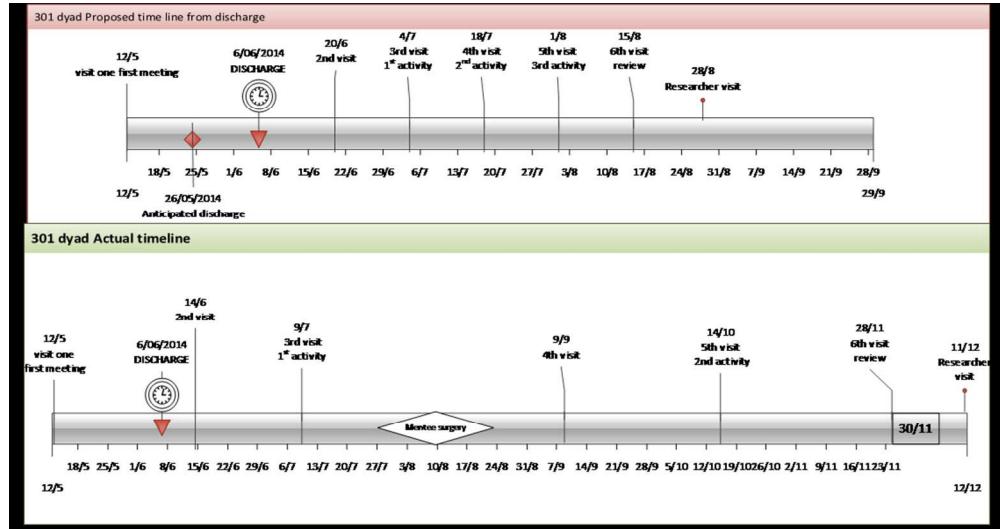


Figure 1. Example of mentoring timing

Appendix Mentor training workshop

Day 1			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-10.00	Introductions, outline of the training, ground rules	Principal Investigator (PI rehab background), Research Officer (RO)	Discuss how the group wants to work together
10-10.30	Break		
10.30-11.00	The mentoring role and what we mean by participation	PI, RO, Co-investigator (health psychology background)	Brainstorm activities about participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful. *
11-12	Common challenges following TBI	Psychologist specialised in neurorehabilitation	Group discussion, including what helped and hindered managing these challenges.*
12-12.30	Common challenges following TBI	Rehabilitation specialist (medical doctor)	Presentation: same as that given to people prior to discharge. Topics covered included for example impact of head injury on the brain, recovery, impact of lifestyle choices on recovery (e.g. drugs and alcohol).
1.30-2.45	The mentoring relationship	Psychologist specialised in neurorehabilitation	Warm up exercise: 5-10 minutes, talk to your partner about yourself for 2-3 minutes; then listen to them for 2-3 minutes. Then be ready to introduce your partner to the group. Using flipcharts mentors drew aspects of their life after TBI they would be happy to share with a mentee.
2.45-3.15	Break		
3.15-4.30	The mentoring relationship	Psychiatrist with expertise in TBI, Neuropsychologist	Each mentor shared their story depicted in the flipchart - practising sharing their experiences. A 3-page outline of the mentoring role was also discussed. Discussion of culturally appropriate working in the NZ context.

* Summary was typed up and provided to mentors in their workbook

Day 2			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-9.45	Overview of the mentoring programme	Principal Investigator (PI), Research Officer (RO)	Summary was provided of participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful (from the previous week). Outline and rationale of the mentoring programme was presented.
9.45-10.30	Goals and setting them	Co-investigator (health psychology & nursing background)	Interactive workshop on goal setting and action planning using worksheets
10.30-11.00	Break		
11-12.30	The mentoring programme – in detail	PI, 2 ROs	Outline of each mentoring session was provided and discussed in workshop format
12.30-1.30	Lunch		
1.30-2.45	Project requirement, strategies for researcher safety	Co-investigator (health psychology background), PI and RO	Discussion of potential safety issues and how to manage them. Familiarisation with safety policy of the centre & note taking for the intervention.
2.45-3.15	Break		
3.15-4.30	Wrap up, questions, mileage claims	Principal Investigator (PI), Research Officer (RO), centre manager	Final question and answers session, explanation of keeping timesheets and mileage claims.

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1 / 1-3
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	2-3 / 23-49

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	6-8 / 85-144
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	8 / 144-148

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	8 / 151-153
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	9 / 158-161 16 / 268-271
<p>Context - Setting/site and salient contextual factors; rationale**</p>	16 / 268
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	9-10 / 170-200
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	19 / 328-329
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	16-19 / 267-291

1 2 3 4 5	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	17 / 280-281
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	20 / 331-341
9 10 11 12	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	18-19 / 293-314
13 14 15 16	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	18-19 / 293-314
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	19 / 310-314

Results/findings

23 24 25 26	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	23-30 / 380-543
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	31-38 / 547-718

Discussion

32 33 34 35 36 37	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	31-38 / 547-728
38 39	Limitations - Trustworthiness and limitations of findings	32-33 / 568-603

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	40 / 740-747
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	5 / 72-75

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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Manuscripts

Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

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23 Abstract

24 **Objectives:** To explore the acceptability of peer mentoring for people with a traumatic brain
25 injury (TBI) in New Zealand.

26 **Design:** A Qualitative Descriptive study exploring experiences reported by mentees and
27 mentors taking part in a feasibility study of peer mentoring. Interviews with five mentees
28 and six mentors were carried out. Data were analysed using conventional content analysis.

29 **Setting:** The first mentoring session took place pre-discharge from the rehabilitation unit.
30 The remaining five sessions took place in mentees' homes or community as preferred.

31 **Participants:** Twelve people with TBI took part: six mentees (with moderate to severe TBI;
32 aged 18-46) paired with six mentors (moderate to severe TBI > 12 months previously; aged
33 21-59). Pairing occurred before mentee discharge from post-acute inpatient brain injury
34 rehabilitation. Mentors had been discharged from rehabilitation following a TBI between 1
35 and 5 years previous.

36 **Intervention:** The peer mentoring programme consisted of up to six face-to-face sessions
37 between a mentee and mentor over a six month period. The sessions focussed on building
38 rapport, exploring hopes for and supporting participation after discharge through further
39 meetings and supported community activities.

40 **Results:** Data were synthesised into one overarching theme: Making sense of recovery. This
41 occurred through the sharing of experiences and stories; was pivotal to the mentoring
42 relationship; and appeared to benefit both mentees and mentors. Mentors were perceived
43 as valued experts because of their personal experience of injury and recovery, and could

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3 44 provide support in ways that were different to that provided by clinicians or family
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5 45 members. Mentors required support to manage the uncertainties inherent in the role.
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8 46 **Conclusions:** The insight mentors developed through their own lived experience established
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10 47 them as a trusted and credible source of hope and support for people re-engaging in the
11
12 48 community post-TBI. These findings indicate the potential for mentoring to result in positive
13
14 49 outcomes.
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18 50 **Trial registration:** International clinical trials registry platform (ICTRP) UTN: U1111-1142-
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20 51 7155
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22 23 52 **Keywords**

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26 53 Traumatic brain injury, peer mentoring, qualitative, acceptability, recruitment, retention
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Strengths and limitations of this study

- The use of qualitative interviews with both mentees and mentors engaged in a mentoring programme after traumatic brain injury in order to understand their experiences is a strength.
- The study design was informed by our previous work trialling rehabilitation interventions with this population and incorporated robust methods to collect and analyse qualitative data.
- The intervention, developed using theory, evidence and consumer involvement was delivered face-to-face and was flexible to the needs of both mentors and mentees.
- This was the mentors' first experience of mentoring following TBI. Therefore, the benefits and challenges presented here may change in a larger trial where mentors have the opportunity to support more than one mentee.
- This study was designed to explore acceptability of peer mentoring. The efficacy of this intervention requires further investigation.

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74 interpretation of data, in the writing of the manuscript, nor in the decision to submit the
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78 Rehabilitation New Zealand (Auckland site) for supporting recruitment. The authors
79 acknowledge the contribution made by other members of the research team who
80 contributed to some aspects of the implementation of this project, but who are not named
81 authors on this paper.

83 Introduction

84 An estimated 10 million people sustain a Traumatic Brain Injury (TBI) each year worldwide.¹
85 New Zealand has a very high incidence of this condition (811/100,000, these figures include
86 people with mild to severe TBI).² While some people with TBI make functional gains over
87 time,³ many people deteriorate with time and often experience wide-ranging and significant
88 long-term problems with physical, cognitive and psychological functioning. Indeed, the
89 personal aftermath of TBI is characterised by disruption to a sense of self and personhood,
90 with usual markers of productivity and reciprocity in roles and relationships threatened.⁴ As
91 a consequence, many people report an enduring impact on social, community and
92 vocational participation, with many suffering social isolation.³⁻¹³

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3 93 Major long-term costs to society extend beyond acute healthcare to include compensation,
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5 94 support for independence, social and physical rehabilitation.^{14 15} These findings suggest that
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7 95 more effective strategies that facilitate enhanced participation for this population in the
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9
10 96 long term are needed. However, current services, in New Zealand and elsewhere, primarily
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12 97 target the acute/sub-acute phase with only limited ongoing input.¹⁶ In addition,
13
14 98 rehabilitation services largely focus on reducing impairment and improving activity (or
15
16 99 reducing disability) with the assumption that this will lead to improvements in
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19 100 participation.^{17 18} However, findings from a longitudinal qualitative study exploring
20
21 101 experiences of recovery over two years highlight the importance of developing a concept of
22
23 102 TBI and what it means to live in the context of TBI, that are unique to the individual and
24
25 103 which are socially and culturally located, for successful re-engagement in meaningful
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28 104 activities.^{19 20} Individuals and their families in this study highlighted that existing services
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30 105 (both in terms of their aim and purpose and the timing of those services) failed to provide
31
32 106 them with the necessary support to manage these processes, leaving them to navigate and
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35 107 make sense of their recovery in isolation. These findings are consistent with arguments
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37 108 calling for new approaches to supporting recovery and adaptation after Traumatic Brain
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39 109 Injury (TBI), given recognition that it is more appropriately conceptualised as a 'long term
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41
42 110 condition than a single episode injury'.²¹
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47 112 Peer mentoring has been defined as 'support provided by individuals who have successfully
48
49 113 faced a particular experience and can provide good counsel and empathic understanding to
50
51 114 help others, with similar salient population characteristics, through a comparable
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53 115 experience'.^{22 23 (p436) 24} It has been used for over 50 years in mental health²⁵ and is
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56 116 increasingly used in rehabilitation, for example with people with spinal cord injury^{22 23 26-28}

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3 117 and heart disease.^{24 29} Empirical work in these populations has reported positive outcomes.
4
5 118 For example, peer mentoring led to better adjustment after spinal cord injury in a study in
6
7 119 which mentors helped mentees to cope with practical, emotional and identity challenges
8
9
10 120 and project future possibilities.^{23 26} Likewise, a review of peer mentoring in heart disease
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12 121 showed that it led to increased self-efficacy, improved activity, reduced pain, and fewer
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14 122 emergency room visits.²⁹

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18
19 124 The case for peer mentoring can be found in a number of psychological theories, such as
20
21 125 social cognitive theory³⁰, and self-determination theory.³¹ These theories propose that
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23 126 observing others, feedback and modelling, and social exchanges that support autonomy
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25 127 lead to better outcomes for those receiving the mentoring and were therefore selected as
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27
28 128 key to our programme. Peer mentoring interventions generally include some degree of
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30 129 informational, appraisal, and emotional support.²⁴

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36 131 As noted above, many individuals with moderate to severe TBI experience significant on-
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38 132 going consequences in domains of physical, cognitive and psychological functioning, and
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40 133 personality changes.^{3-10 19 32-34} This variety of consequence makes peer mentoring
41
42 134 potentially challenging as candidate mentors may also be experiencing long-term
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44 135 consequences of their TBI. Consequently, it is not surprising to find a limited range of
45
46 136 published research exploring peer mentoring in TBI.³²⁻³⁸ These studies report positive
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48 137 benefits on knowledge, quality of life general outlook, behavioural control and return to
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50 138 work. However, design limitations and trial issues hamper generalisability and adaptability
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52 139 of these findings.³²⁻³⁷ For example, limitations include a lack of formal outcomes,³⁶ minimal

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3 140 detail provided limiting replication,³⁷ lack of a control group,^{34 35} difficulties matching
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5 141 mentors with mentees,^{33 34} costs of transport and social outings to participants,³³ and fewer
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7 142 sessions or contacts than planned.^{32 33} As a consequence, a more robust evaluation of peer
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10 143 mentoring with people with TBI is needed before tangible changes to practice and policy can
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12 144 be instigated. However, before proceeding to a full trial for such a complex intervention it is
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14 145 important to establish if the proposed intervention is acceptable, and if the study design is
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16 146 feasible.³⁹

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22 148 Our overarching study aim was to explore peer mentor and mentee views of the feasibility
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24 149 (e.g. practicalities) and acceptability of a peer mentoring intervention in the New Zealand
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26 150 context. This paper describes our approach and reports on the qualitative data collected to
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28 151 evaluate the acceptability of the intervention with feasibility to be examined in a separate
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31 152 publication.

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35 36 37 154 **Methods**

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39 155 A Qualitative Descriptive methodology⁴⁰ was employed to explore mentee and mentor
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42 156 perspectives and experiences of their participation in the peer mentoring intervention.⁴¹ In
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44 157 Qualitative Descriptive studies researchers stay close to their data and to the surface of
45
46 158 words and events.⁴⁰ This enables the explication and descriptive summary of complex
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48 159 experiences, which are valuable in their own right as end-products, but also to inform
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51 160 further study. As a consequence, Qualitative Descriptive methodology has been argued to
52
53 161 be a useful approach for the development and refinement of interventions⁴¹ and so was
54
55 162 well suited for the current study. The academic members of the research team consisted of

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3 163 people with a range of expertise in rehabilitation, physiotherapy, psychology, psychiatry,
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5 164 medicine, statistics, project management, data analysis and some personal experience of
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7 165 TBI or as a carer.
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11
12 167 The study was conducted in Auckland, New Zealand / Aotearoa. Due to the contracting of a
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14 168 single national funder of inpatient rehabilitation after Traumatic Brain Injury in New
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16 169 Zealand, nearly all moderate-to-severe cases of TBI in the North Island are treated by a
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18 170 single provider after their discharge from the acute hospital services. This provider cares for
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20 171 between 100 and 150 people per year,⁴² and their primary Auckland site was the sole site of
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22 172 recruitment for mentees.
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27
28 174 We had funding to support inclusion of six mentees and six mentors. Invitations to take on
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30 175 the role of mentor were sent by letter in batches to those identified as eligible by the
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32 176 rehabilitation provider and followed up by phone to confirm eligibility. While staff involved
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34 177 in the clinical management of mentors were involved in helping to identify potentially
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36 178 eligible people, the actual recruitment of mentors was overseen and carried out by the
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38 179 research team. In addition to those identified by the rehabilitation provider, letters were
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40 180 also sent out from our research centre to those who had previously taken part in other
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42 181 studies, had expressed an interest in being involved in further research, and fitted the study
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44 182 criteria. Those who met the eligibility criteria and expressed a desire to take up a mentoring
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46 183 role were invited to attend a 'job' interview as this was a paid role. The interview panel
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48 184 consisted of members of the research team (which included a psychiatrist with expertise in
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50 185 TBI). The panel explored candidates' motivation for applying to become a mentor, any
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52 186 challenges they may foresee, how they might overcome these challenges, and what their
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3 187 support needs might be. All those offered the mentorship role underwent a criminal record
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5 188 check. The mentors were paid on a research assistant pay scale for their time on the project,
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7 189 and they were issued with a mobile phone to enable contact with their mentees and the
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10 190 research team at no cost to themselves and without the need to share their personal
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12 191 number.

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16 193 Mentee recruitment was initiated by rehabilitation staff approaching all eligible participants
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18 194 and handing them the study information leaflet. In this leaflet they were encouraged to
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21 195 discuss the study with their family. Rehabilitation staff passed contact details of those
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23 196 interested in hearing more about the study to the research officer (CC). The research officer
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25
26 197 then met with potential participants (and interested family member(s) if this was their
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28 198 wish), explained what the study involved, and discussed any concerns. This meeting took
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30 199 place at least 24 hours after the person had first been informed about the study, and in
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32 200 many cases the researcher followed up with a second visit to answer further questions and
33
34 201 meet with interested family members. This process was used to ensure all potential mentee
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36 202 participants were able to take the time to consider their participation and discuss it with
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38 203 their family members, before providing consent. Eligibility criteria for both mentors and
39
40 204 mentees are displayed in Table 1. The literature has shown that matching is important in
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42 205 peer mentoring.³²⁻³⁴ We were able to match by gender, and where possible shared interest
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44 206 (such as outdoor sports).

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Table 1. Inclusion and exclusion criteria

Inclusion criteria	Mentees	Mentors
• Age (years)	≥15 years	≥18 years
• Moderate or severe TBI ^{43 44}	√	√
• Discharge from inpatient rehabilitation	Imminent	1-5 years previously
• Living in the greater Auckland region	√	√
Exclusion criteria		
• Unable to communicate in a way that enabled engagement with a mentor/mentee	√	√
• Medical condition that precluded their participation	√	√
• Discharge FIM Cognitive domain score* ≥24 ⁴⁵	-	√
• Ongoing alcohol or drug abuse problems, communication difficulties, known gang affiliations, concerns in terms of safety or security (clinical judgement)	-	√

* FIM: Functional Independence Measure, data obtained from the rehabilitation centre.

FIM discharge data were only used as an exclusion criteria for mentors.

210

211 Intervention

212 Our approach was informed by our own research^{19 20 46-48} and by that of others.³²⁻³⁴ For
213 example, peer mentoring sessions were one-to-one and face-to-face (as opposed to by
214 phone). The research officer introduced the mentor to the mentee (and their family
215 members) prior to the first meeting. The first session occurred pre-discharge in the
216 rehabilitation setting and the remaining five in the community. Mentors were provided with
217 worksheets to support them with each mentoring session. These worksheets helped them
218 to remember the focus of each session. It was also intended the sessions would be time-
219 limited and would take place in the initial stages following discharge, i.e. over a three month
220 period. Dyads started the intervention within two weeks of the mentee agreeing to take
221 part, and prior to discharge. Three of the sessions were intended to involve a pre-planned,
222 supported participatory activity in the community, negotiated in advance by each mentee-
223 mentor pair (to ensure dyads could focus on real life experiences of participation and its
224 challenges). Mentors were provided with petty cash to pay for any expenses during such
225 activities (up to NZ\$50 per activity).^{32-34 46-48} Table 2 displays the basic structure of the
226 programme in more detail.

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Table 2 The mentoring programme

Time point	Session purpose
One to two weeks before discharge from inpatient rehabilitation	Mentor meets with the mentee at the inpatient rehabilitation facility to get to know one another. Make provisional plans for meeting post discharge.
Two weeks after discharge	Mentor visits mentee at home, to re-establish connection, explore barriers and facilitators to participation, and support them to develop plan for social activities for the next couple of weeks.
Four weeks after discharge	Participate in mentor supported activity; check in with the mentee and discuss what has gone well over the last few weeks, what didn't go well? Plan further activities.
Six weeks after discharge	As for previous session
Eight weeks after discharge	As for previous session, reminder that next visit will be the last.
Ten weeks after discharge	Final visit. The mentor and mentee will review progress and the ending of mentee/ mentor relationship. A mihi whakamutunga (cultural blessing or prayer) will be offered for those who wish this.

230

231 Mentor training and support

232 Mentor training comprised of a two day interactive training workshop, with each day held
 233 one week apart (see the Appendix for an overview of the training programme). This
 234 included a mix of presentations, discussion, role play and skill-building activities, aiming to
 235 strengthen and build on the experience and skills of the mentors. Topic sessions included

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3 236 the role of the mentor, experience of TBI, sharing experiences, and safety protocols. Skills in
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5 237 sharing experiences were developed by each mentor creating a pictorial map of their TBI
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7 238 journey, on their own then sharing this with the wider group. This helped the mentors to
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9 239 articulate their journey, decide what aspects they were willing to share and which ones they
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11 240 may not, and also gain insight into each other's journeys. This in turn helped them develop
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13 241 listening skills and empathy.
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19 243 We discussed ways of being respectful and keeping safe when visiting people in their
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21 244 homes. We established a safety protocol where mentors were required to notify the
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23 245 research officer of the time and date of their visits and check in (by phone) at the
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25 246 completion. Mentors were encouraged to share with the research team any concerns they
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27 247 had regarding the visit and any perceived threats to their own safety or the welfare of their
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29 248 mentee. We also took care not to professionalise the mentoring role as a key component
30
31 249 was that mentors functioned as 'peers' not quasi health professionals. To that end we
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33 250 provided limited education about the clinical consequences of TBI to mentors, instead giving
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35 251 primacy to their own personal experiences of TBI. The 45-minute education session, led by a
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37 252 rehabilitation consultant (who was familiar to many of the mentors having been involved in
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39 253 their clinical management during their own inpatient stay), used material that all mentors
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41 254 had previously received as an inpatient during their rehabilitation.
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49 256 Attention was paid to cultural protocols for the New Zealand context. For example, the
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51 257 encouragement to use an opening and closing karakia (blessing or prayer) for meetings with
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53 258 mentees when both parties agreed this was appropriate; and the intervention being
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55 259 delivered kanohi te kanohi (face-to-face) which is a preferred approach for Māori.⁴⁹ Mentors
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3 260 had access to a resource containing information on locally available services they could refer
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5 261 mentees to if appropriate.
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9 263 Mentors took part in three face-to-face group debrief sessions over the course of the
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11 264 intervention period, led by the principal investigator (PK) and accompanied by the research
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13 265 officer (CC) and one other member of the research team with psychology expertise (e.g.
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15 266 KMCP, DB, RS; each attending one session). These were held on Saturday mornings to
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17 267 accommodate those who were working or studying. Topics for the debriefs were set by the
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19 268 mentors and included, for example, sharing experiences of the first meeting with mentees
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21 269 (what went well, what were their concerns), practicalities of community activities, and how
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23 270 to conclude the mentoring relationship. Access to additional psychological and psychiatric
24
25 271 support was available for individual mentors but not requested.
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30 272

31 273 [Data collection and analysis](#)

32
33 274 Semi-structured interviews with mentees and mentors were conducted at the conclusion of
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35 275 the mentoring relationship, at the mentee and mentor homes, by one researcher (CC). She
36
37 276 has over 10 years experiences of qualitative data collection and analysis, studying
38
39 277 rehabilitation interventions in people with neurological conditions, in particular TBI (e.g.⁴⁸
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41 278⁵⁰). An interview guide (see table 3) was used. This focused on the mentoring experience,
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43 279 the timing of the intervention, the perceived impact of the relationship, and suggestions for
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45 280 improving the programme. Mentors were asked additional questions relating to the
46
47 281 adequacy of the training and support provided to them. In both cases, the interview guide
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49 282 was used as a prompt to focus the conversation, but otherwise the interview was kept open,
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51 283 exploring topics raised by the participants in more detail as they arose. Interviews were
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3 284 audio recorded and transcribed verbatim by a contracted transcriber, then checked for
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5 285 accuracy by the researcher. They were anonymised prior to analysis.
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Table 3. Interview guide (used flexibly)**Mentees**

- What was your experience of the mentoring project?
- What was useful about the mentoring? What wasn't?
- How has the relationship impacted on you?
- If you had a mentor in the future what would you like them to focus on?
- What sort of things would you like to talk to / do with your mentor?
- When would have been the best time to meet up with your mentor? Prompts: the first meeting, after the first meeting, how often?
- How did you find answering the questionnaires that CC asked you to complete?

Additional questions for Mentors

- Did you feel that the training workshops prepared you for your role as mentor?
- What would you change about those workshops?
- If we needed to cut these down to one day what would you suggest we cut out?
- Or what should we add instead?
- Did you feel that you received enough support for your role as mentor?
- What would you change about the support you received?
- How did you find the planning and write up requirements? How would you suggest that we do this in the future?

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3 290 The mentors were given a format for keeping visit notes, asking them to record the activities
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5 291 they carried out and reflect on what had gone well or not and what they would do
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7 292 differently next time. Mentors maintained in contact with their mentee by texts and phone,
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9
10 293 but these were not recorded as data. The researcher noted when needing to provide
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12 294 mentors with practical support (such as connecting with their mentees). She collated the
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14 295 mentor notes, which supplemented interview data. Peer mentoring sessions were not
15
16 296 observed as the team did not wish to interfere with the relational aspects of the
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18 297 intervention.
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22
23 299 Data were analysed drawing on Conventional Content Analysis.⁵¹ A core analysis group (PK,
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25 300 CC, NK and DB) was established, which was diverse in gender, ethnicity (New Zealand
26
27 301 European, European and Australian) and professional background (rehabilitation,
28
29 302 physiotherapy, health psychology, sociology and education). This group met several times to
30
31 303 allow for an iterative and recursive approach to analysis before settling on the final
32
33 304 interpretation of data presented here. In the first instance, CC and PK listened to the audio
34
35 305 recordings and read and re-read the transcripts to become familiar with the data. From
36
37 306 there, data were read to identify key concepts relevant to the topic areas in the interview
38
39 307 guide (e.g. broad experiences and perspectives of the intervention, the mentoring
40
41 308 relationship, and feedback on specific aspects of the programme). This led to the
42
43 309 development of a coding framework which formed the initial frame for analysis. Data were
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45 310 coded manually, deriving new codes where an existing code did not fit the existing
46
47 311 framework. Code definitions developed, and then illustrative quotes were extracted into
48
49 312 word tables. Each core analysis group member became familiar with a set of interviews in
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51 313 preparation for group analysis discussions where preliminary ideas and concepts derived
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3 314 from early coding were presented and discussed. Following each analysis session, CC
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5 315 returned to the raw data to test out our interpretation of data, further refine our coding,
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7 316 and categorise the data into meaningful themes. The analysis was deepened through
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9 317 exploration of mentor notes and the researcher's notes of her conversations with mentors
10
11 318 following their interactions with mentees. Interview data from mentors and mentees were
12
13 319 initially coded separately before looking across data sets (i.e. within dyads, and across
14
15 320 participant types) for patterns and meaningful clusters.
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21 322 **Patient and public involvement**

22
23 323 Māori are the indigenous people of Aotearoa New Zealand and almost 17.5% of the New
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25 324 Zealand population identify as Māori.⁵² Researchers have a responsibility to ensure their
26
27 325 research is of value and culturally responsive to Māori.⁵³ Therefore, guidance for the study
28
29 326 was also sought from a University Mātauranga Māori committee, members of which are
30
31 327 drawn from a wide range of Māori communities. Whilst people with recent TBI were not
32
33 328 explicitly involved in the design of the study, seeking mentor and mentee experiences and
34
35 329 perspectives was built into the design of the study to ensure their voice was formative to
36
37 330 future related work. Further, mentors were appointed to paid positions and ongoing
38
39 331 engagement with them through their training, debriefing and supervision sessions (see
40
41 332 below for more detail) played a critical role in the operationalisation of peer mentoring in
42
43 333 the current study.
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49 334 Ethical approval was obtained from the New Zealand Health and Disability Ethics Committee
50
51 335 (ref 13/NTA/99/AM05) and the University (ref 13/288).
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336 Results

337 Letters were sent to 34 potential mentors, of whom nine were not contactable. The
338 researcher discussed the study with 13 people who responded positively to the initial
339 approach, with nine accepting the invitation for interview (36% of those contactable). The
340 main reason for not taking part as a mentor were other commitments. All those interviewed
341 were invited to attend mentor training. Eight mentors completed both training days with
342 one dropping out after the first day due to work circumstances (89% retention).

343 There were 12 potentially eligible mentee participants during the study period. Of these,
344 nine agreed to talk further with the research officer, with six consenting to participate as
345 mentees. Six of the mentors who had attended the mentor training were successfully
346 paired with the six consenting mentees.

347 Demographic and disability data for mentors and mentees is provided in table 4. On
348 enrolment to the study all mentors were able to walk independently and without a walking
349 aid though many had ongoing physical and cognitive difficulties.

350

Table 4. Demographics	Mentees (n=6)	Mentors (n=6)
Inpatient stay (mean days, SD)	72 (54.4)	N/A
Admission FIM* score (mean, SD)		
- Motor tasks	57.7 (26.2)	N/A
- Cognitive tasks	22.0 (5.7)	
Age (range)	18-46 years	21-59 years
	Frequencies	Frequencies
Gender		
- Male	4	4
- Female	2	2
Injury severity**		
- Severe	5	4
- Moderate	1	2
Ethnicity		
- Māori	1	1
- Māori / Samoan	1	
- New Zealand European	4	5
Employment	Pre-injury	
• Studying	1	2
• Working full time	3	2
• Working part time	2	2

351 * FIM: higher scores denote greater dependency; total motor scores can range from 13 and 91; total

352 cognition scores 5 to 35.

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3 353 ** Moderate TBI: initial Glasgow Coma Scale (GCS) score 9-12 (of a possible 15) and/or post-
4
5 354 traumatic amnesia (PTA) duration >1 but <7 days; Severe TBI: initial GCS <9 and/or PTA ≥7 days.^{43 44}
6
7
8 355 Four mentees engaged in six peer mentoring sessions, with the remaining two engaging in
9
10 356 one only. One mentee failed to meet again with the mentor after the initial mentoring
11
12 357 session despite a number of attempts to arrange a face-to-face meeting and eventually lost
13
14 358 contact with their mentor and the research team. The other mentee was not available to
15
16 359 take part in more than one mentoring session due to personal difficulties that restricted her
17
18 360 participation and which had not been apparent during recruitment, but contributed to the
19
20 361 post intervention interview data collection. Five mentees and six mentors were interviewed
21
22 362 at the end of the intervention period, with an average duration of 45 minutes (range 15 to
23
24 363 60).
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31 365 There were some deviations from the intended programme structure. For example, most
32
33 366 dyads took more than three months to start and finish the programme (up to six months,
34
35 367 see example in figure 1). This was mostly due to ongoing health issues the mentee was
36
37 368 experiencing (e.g. further surgery) or due to other commitments both for mentees and
38
39 369 mentors (e.g. work, study). Secondly, the intended community activities were not always
40
41 370 possible and as such, for some dyads more mentor visits were at the mentees' homes than
42
43 371 intended.
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49 373 The research officer called mentors following each mentoring session as per the agreed
50
51 374 safety protocol to 'check in' and enquire what had gone well, if there were any issues or
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53 375 concerns, provide general reassurance and to remind mentors to maintain records of the
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3 376 sessions. Written reflections were provided by four mentors, and although these were
4
5 377 generally brief, one mentor provided comprehensive written reflections for each session.
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10 379 Data from mentor notes showed that mentors and mentees undertook a range of
11
12 380 community activities, such as having their nails done, going for lunch, having coffee in a
13
14 381 café, browsing for music, or going for a walk. Topics of conversations during the session
15
16 382 were wide-ranging, including going back to work, struggles with abstaining from alcohol and
17
18 383 drugs, feeling different, strategies for remembering to do things, and managing
19
20 384 relationships.
21

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24
25
26 386 The next section explores the qualitative findings from the interviews. Pseudonyms are used
27
28 387 here, followed by the mentor / mentee age.
29

30 388

31 32 33 389 [Peer mentoring: Making sense of recovery](#)

34
35 390 Positive outcomes were reported both by mentees and mentors. A key theme identified in
36
37 391 the analysis was that of making sense of recovery through shared experience and stories.

38
39
40 392 This sharing was pivotal to the mentor-mentee relationship with both parties expressing
41
42 393 benefit. Through stories of their lived experience of injury and recovery, mentors were
43
44 394 perceived as valued experts and could provide support in ways that was different to that
45
46 395 provided by clinicians or family members. This position posed some challenges to mentors
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48 396 who required support to manage uncertainties inherent in their role. These findings are
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50 397 discussed below with supporting quotes.
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3 398 **Sharing stories**

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5 399 The essence of the peer mentoring intervention was to provide support from someone who
6
7 400 had also experienced a TBI.

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9
10 401 *It was very useful to have someone who has been through a similar*
11
12 402 *accident to myself. It really meant a lot to me (Mentee, Peter, 24)*

13
14
15 403 Telling your own story was a key device this programme used to establish credentials and
16
17 404 facilitate the mentor / mentee relationship. The outcome of sharing these experiences was
18
19 405 something mentees reflected on.

20
21
22
23 406 *He wasn't asking me questions, he was a story teller. And that made me,*
24
25 407 *yeah rather than "how do you feel today?" Is what they [the clinicians]*
26
27 408 *asked me and I would go "oh yeah up and down like a rollercoaster I*
28
29 409 *guess." He would go 'oh yeah it's hard to explain isn't it?' [...]It was just,*
30
31 410 *like you say, an occasion to go out.[...] And that's what allowed me to have*
32
33 411 *someone who's a friendly expert, who had been through a brain injury, to*
34
35 412 *connect with. (Mentee: Dave, 45)*

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39 413 Similarly, mentors found it more beneficial to share their stories with other peer mentors on
40
41 414 the programme (as they had also had a TBI) than people around them. Opportunities for this
42
43 415 arose during the training programme and debrief sessions, as these mentors explained:

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46
47 416 *It was like a process of opening up to people who have been through the*
48
49 417 *same as yourself and I thought that was very helpful, just opening up and*
50
51 418 *just letting it out rather than bottling it up. (Mentor: Thomas 23)*

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3 419 *Listening to what everyone else was saying sort of gave me great*
4
5 420 *confidence that I wasn't the only one. (Mentor: John, 59)*
6
7

8 421 Mentors as experts

9
10 422 Returning home following discharge from rehabilitation is reportedly a difficult time as
11
12 423 adjustments are made to changed circumstance. Mentees trusted their mentors and
13
14 424 viewed them as experts because they had experienced a TBI and attended inpatient
15
16 425 rehabilitation and were now actively participating in life roles.
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19
20 426 *Because he had been through it. I guess I am just new at this. He made it*
21
22 427 *flow. He was like a brain injury guru. [...] Because he had lived it and*
23
24 428 *physically trained in that field, by being run over on his bike. [...] It was*
25
26 429 *more progressively rehabilitating for me than [name of the rehab centre].*
27
28 430 *(Mentee: Dave, 45)*
29
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31
32 431 Even though mentors and mentees had different experiences of a TBI, they reported the
33
34 432 sharing of experiences and stories enabled them to develop a connection, a sense of trust
35
36 433 and in some cases a friendship.
37
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39
40 434 *It was like you had a connection maybe that was what it was, you have a*
41
42 435 *connection. You have both been there and hearing what she had been*
43
44 436 *through. (Mentee, Jane, 42)*
45
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47
48 437 Mentees reflected their mentor provided an opportunity to talk through concerns and
49
50 438 worries with 'someone who had been there'. This was viewed as different from the support
51
52 439 provided by clinicians or family and friends. Using mentors as a sounding board helped
53
54 440 mentees to make sense of their experiences and what could be expected after a TBI.
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3 441 *It was nice to have someone, outside your family. Because family are too*
4
5 442 *close to you and they seem to like be over protective. Whereas your buddy*
6
7 443 *[mentor] sort of understood where you were coming from, understood*
8
9 444 *what you were going through. And it was nice to be able to ask like any*
10
11 445 *questions that I had like 'is this normal? I'm doing this is this, you know*
12
13 446 *what's going on here?'* And get those answers. (Mentee: Kate, 45)

14
15
16
17 447 The relationship between the pairs meant mentees felt comfortable sharing their
18
19 448 experiences, and contributed to a sense of trust and a willingness to discuss their difficulties
20
21 449 with more transparency than they might have with clinicians and family members. Kate
22
23 450 suggested the relationship with her mentor enabled her to open up:

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26
27 451 *You become friends in the way that you can actually openly communicate*
28
29 452 *to someone. That's where it changed. So instead of being careful about*
30
31 453 *what you say and you know being reserved, you could actually be totally*
32
33 454 *open and honest with someone that's not a psychologist. (Mentee: Kate,*
34
35 455 *45)*

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39 456 Much of the discussion between mentees and mentors reportedly included talking through
40
41 457 issues they were reluctant to address with clinicians and believed their family members or
42
43 458 friends did not understand. Mentors in turn revealed coping strategies they had found
44
45 459 helpful for issues raised such as dealing with fatigue, thinking about return to 'normal', and
46
47 460 discussions about how to cope with social pressures regarding alcohol consumption
48
49 461 following TBI. Discussions of such matters appeared to be facilitated by the relationship not
50
51 462 being bound by the systems and structures clinicians operate in and, unlike clinicians,
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53 463 mentors had more time to be with mentees either in their own home or in the community.
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3 464 Mentors were conscious of their position and reported they were clear they were not acting
4
5 465 as clinicians and recognised they had to have boundaries in terms of the advice they could
6
7 466 offer.

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9
10 467 *But I shouldn't be giving him medical advice you know. I can't tell him*
11
12 468 *what to do I can only tell him what I did [...] I can talk to him about that [*
13
14 469 *alcohol consumption] but in that situation it should be more as a friend [...]*
15
16 470 *because I don't want him thinking I've got some profound knowledge*
17
18 471 *about how your brain is going to affect your drinking after a year. (Mentor:*
19
20 472 *Michael, 24).*

21 22 23 24 25 473 26 27 28 474 **Mentoring as a source of hope**

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30 475 Meeting and talking with mentors provided mentees with a sense of hope for progress
31
32 476 beyond the difficulties they were facing immediately post-discharge and enabled them to
33
34 477 build their self-confidence. The mentees reported feeling pleased to learn their mentors
35
36 478 were now getting on with their lives and involved in activities such as university studies or
37
38 479 returning to work.

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42 480 *Just how where he's come from, from his accident until now. How he's*
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44 481 *accomplished the things that he needs to do [...] What it helped me is he's*
45
46 482 *back to work. And that's where I want to be. [Mentee: Tony, 43]*
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49
50 483 *Because it helps you feel like you are understood and you are not the only*
51
52 484 *person going through this trouble but there have been other people who*
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3 485 *have gone through similar things who are able to show you a glimpse of*
4
5 486 *hope that life gets better. (Mentee: Peter, 24)*
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10 11 488 The challenge of mentoring

12
13 489 Despite the mentees endorsement of the help and the inspiration of their personalising
14
15 490 stories during the intervention period, the mentors struggled with their own expectations of
16
17 491 the mentoring role. Some were concerned they needed more ‘tools to do the job properly’
18
19 492 and were sometimes worried about the extent of the external support their mentee was
20
21 493 receiving. Frequent contact with the research staff was important to discuss these concerns,
22
23 494 to check in and ensure the mentee was safe and reassure the mentor that what they were
24
25 495 offering their mentee was valuable in its own right and was in keeping with the intentions of
26
27 496 the programme.
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31
32 497 *Watching some of the hard stuff he was going through and just kind of*
33
34 498 *really bumming me out. [...] Everybody felt a bit of a pressure, a*
35
36 499 *responsibility to the person because we kind of get what it was like to go*
37
38 500 *through what they went through and so you don't want to fail the person*
39
40 501 *you know. (Mentor: Michael, 24)*
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47 503 The valuable insights the mentors had into the challenges their mentees were experiencing
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49 504 that enabled them to establish connections and support their mentee, presented challenges
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51 505 to the mentors as it prompted a revisiting of their own injury experiences and an
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53 506 acknowledgement of their persistent residual symptoms.
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3 507 *Just because, you know, you process your own head injury issues when you*
4
5 508 *are mentoring someone [...]. Sort of re thinking my own head injury and my*
6
7 509 *own thing to kind of try and be useful to him. [...] so some of that stress*
8
9
10 510 *probably wasn't at all out of my relationship with him, was actually to do*
11
12 511 *with my own sort of. Because like you say, we are mentors because we*
13
14 512 *have been through something that was kind of shit, you know, so we are*
15
16 513 *thinking about that difficult thing pretty deeply. (Mentor: Michael, 24)*
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22 515 Although they experienced these pressures over their concern for their mentee's situation
23
24 516 and dealing with their own concerns, the mentors reported the support they received from
25
26 517 the research team helped them deal with these and be effective in their role.
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30 518 *I think even when (mentee) started being, even when he started being a*
31
32 519 *little bit depressed, having you guys to call and just chat through things*
33
34 520 *and sort of, I had never really had a moment where I called you and no one*
35
36 521 *answered or something like that. It was always, there was always contact*
37
38 522 *there. (Mentor: Louis, 23)*
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45 524 Another challenge concerned the intended community activities and the planned time
46
47 525 frames. These community activities were not always practical as some mentees had ongoing
48
49 526 medical problems that restricted their mobility or lack of access to transport. Therefore,
50
51 527 more mentor visits were at the mentees' homes than proposed in the programme. Where
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53 528 community activities did occur, they typically included meeting up in a café, or browsing
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3 529 shops together. Timeframes were stretched by circumstances, for example surgery for
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5 530 associated injuries resulting in temporary mentee unavailability. Mentors were encouraged
6
7 531 by the research team to use the programme flexibly in response to the mentees preference,
8
9 532 which was considered a strength by many.

10
11
12 533 The peer mentoring was provided as a time limited relationship, which for most mentors
13
14 534 was not experienced as a problem as they felt their mentee had moved along in their
15
16 535 recovery or that they had nothing more to offer as a mentor. However, for others, the
17
18 536 consequence of the relationship being and becoming more personal created difficulty and
19
20 537 concern about ending the series of sessions. These concerns were raised as a topic for
21
22 538 discussion by mentors at each of the debriefing sessions and mentors reported they needed
23
24 539 this support in withdrawing from the formal mentoring relationship. Nevertheless, ending
25
26 540 the mentoring relationship appeared to result in a sense of loss.

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30
31 541 *We did talk about, in the last session that we might see each other again,*
32
33 542 *and then all of a sudden I am not a mentor anymore. (Mentor: Michael,*
34
35 543 *24)*

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39 544 Regardless, overall both the mentors and mentees reported the experience as beneficial.
40
41 545 The opportunity to connect with others in a similar situation provided comradeship and a
42
43 546 sense of hope:

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46
47 547 *I've just more than anything found like a friend. One that I can relate to.*
48
49 548 *We have both had an injury.(Mentor: Sarah, 21)*

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3 549 The mentors all expressed enjoying their role and developed caring supportive relationships
4
5 550 with their mentee. They appreciated the reciprocity the role offered them in the
6
7 551 opportunity to give back and help someone.
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9

10 552 *I'd say it became a mutually beneficial relationship and one that to me meant a lot*
11
12 553 *because it was, to me it was watching him recovering. (Mentor: Louis, 23)*
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18 555 Discussion

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22
23 557 The findings of this study indicate the peer mentoring programme was perceived to be
24
25 558 acceptable by both mentors and mentees. However, our experiences and that of our
26
27 559 participants highlight a number of key lessons for future related work. For example, there is
28
29 560 benefit to operationalising the intervention more flexibly than we initially intended. We
30
31 561 found that a rigid approach to the number and frequency of community participatory
32
33 562 activities is not always possible due to ongoing mentee health issues. Similarly, a 6-month
34
35 563 time frame is more appropriate for a programme consisting of six sessions to allow for the
36
37 564 complexity that mentees face post discharge in re-engaging with their home life. Further, it
38
39 565 is clear that mentors can sometimes require both practical support (e.g. to get hold of their
40
41 566 mentees and arrange times to meet) and emotional support (to help them navigate any
42
43 567 emotional response they might have to sharing their story and re-engage with their own
44
45 568 traumatic experiences in the sharing of those stories).
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53 570 Although this study did not explicitly seek to explore programme benefits, both mentors and
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55 571 mentees reported a number of perceived benefits. We found that the peer mentoring
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3 572 relationship may be beneficial to both mentor and mentee through the sharing of
4
5 573 experiences and stories, but also that mentors required support to manage the
6
7 574 uncertainties inherent in the work. The time to talk and listen as well as the shared
8
9
10 575 authentic experiences resonated with mentees, leading to feelings of hope and confidence
11
12 576 as they re-engaged in life post-discharge to the community.

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14 577

15
16 578 Just over a third of mentors approached and contactable took part in the study. This level of
17
18 579 uptake could potentially impact upon feasibility of rolling this out to a larger study or
19
20 580 service. However, given some declined due to other (immediate) commitments it is possible
21
22 581 that when mentoring is embedded in routine service delivery (without the time constraints
23
24 582 associated with research) that more people would come forward.

25
26 583

27
28 584 Strengths of this study include the use of qualitative interviews, which enabled an in-depth
29
30 585 exploration of the experiences of mentees and mentors engaged in a mentoring programme
31
32 586 after TBI. The intervention was theory-based, and developed incorporating both evidence
33
34 587 and consumer (particularly Māori) involvement. An additional strength was the potential
35
36 588 replicability of the study and delivering the mentoring face-to-face and in a way that was
37
38 589 flexible to the needs of both mentors and mentees.

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40 590

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42 591 While mentors reported some challenges, this was the mentors' first experience of
43
44 592 mentoring following TBI. Therefore, the benefits and challenges presented here may change
45
46 593 in a larger trial where mentors have the opportunity to develop experience through
47
48 594 supporting more than one mentee. Input into the study or intervention design were not
49
50 595 sought from people with recent TBI at the time of commencing this research, which was a

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2
3 596 limitation. However, as noted in the methods, capturing their perspectives was a critical
4
5 597 component of the current research so that they may inform refinement of the core
6
7 598 processes (e.g. mentor training, mentor support and intervention delivery) for future
8
9 599 related work and peer mentoring service models.
10

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12 600

13
14 601 We experienced other challenges. As noted above, two mentees did not complete the
15
16 602 intervention, one did not stay in contact and the other had significant personal problems
17
18 603 that precluded ongoing participation although was able to contribute to the qualitative data
19
20 604 collection. Those who stayed in the study completed all sessions, which was a strength. Only
21
22 605 four mentors recorded notes about their mentoring sessions. During the debrief sessions it
23
24 606 became apparent that taking such notes was often forgotten, or perceived as not necessary.
25
26 607 Future research should consider the best mechanisms for ongoing participation and
27
28 608 capturing data about the content of sessions.
29

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33
34 610 Since this was a small study we were able to match on dyads gender only, though we also
35
36 611 took into account shared interests. Ideally we would also have utilised the opportunity for
37
38 612 matching by ethnicity, an important approach especially for Māori.⁴⁹ We were also unable
39
40 613 to pair by age or family circumstances due to the small mentor group. This resulted for
41
42 614 example in one single mentor in their twenties mentoring a much older person with five
43
44 615 children. Despite the limitations to our matching opportunities the mentor-mentee pairs
45
46 616 developed very good relationships and their differences in age or life experience was not of
47
48 617 relevance. This concurs with our previous longitudinal research with people with TBI, which
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50 618 has shown that assumptions should not be made concerning who would be the best match
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52 619 to provide mentorship.⁵⁴
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5 621 Our mentors had previously sustained a moderate to severe TBI. Although they initially
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7 622 appeared to be high functioning, several had ongoing physical and cognitive difficulties
8
9
10 623 whilst being part of our programme. For example, three required ongoing employment
11
12 624 support, many experienced significant levels of fatigue and irritability, and not all had been
13
14 625 able to return to driving. However, all were able to get to places to meet with their mentors
15
16 626 and develop a meaningful relationship. Our findings suggest that even those who
17
18 627 experience ongoing residual impairment following TBI are able to function well and safely in
19
20 628 a mentoring role. Regardless, we are not able to comment on the potential mentoring
21
22 629 ability of those with more severe residual impairment than our sample.
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26 630

27
28 631 Mentors required more support from the research officer than anticipated at the outset of
29
30 632 the study. For example, she supported them to maintain contact with their mentee during
31
32 633 the study period, assisted with scheduling visits when they experienced difficulties, and
33
34 634 provided assistance with negotiating the university's reimbursement procedures. The
35
36 635 under-recognised need for this level of support was in part due to lack of evidence for
37
38 636 delivering this service with this population and will inform future study design and service
39
40 637 models.
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46 639 Our exploration of mentees' experiences should be considered in light of them taking part in
47
48 640 a feasibility study. In addition, this was the first time each of our mentors had the
49
50 641 opportunity to work with a mentee. Findings might be different if this had been a routine
51
52 642 service or if mentors were more experienced in their role. This was a feasibility study and
53
54 643 the findings are not designed to be transferable to other contexts, however, they have the
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3 644 potential to inform future peer mentoring intervention studies for people following
4
5 645 traumatic brain injury and point to the potentially reciprocal benefits of the mentoring
6
7 646 relationship. A key feature of our study was the face-to-face delivery of the intervention. In
8
9
10 647 the current study this was a culturally-located decision, given this is a preferred method of
11
12 648 service delivery for New Zealand Māori (the indigenous population of New Zealand). We
13
14 649 also believe this to be a key component of this peer mentoring intervention, and one that
15
16 650 helped create opportunities for developing connections and building the relationship.
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20
21 652 The stories our mentors used in their work with mentees were grounded in their own
22
23 653 experiences of recovery and living with consequences of TBI. The actual sharing of these
24
25 654 stories was a key component of the training workshops and debriefing sessions. Douglas and
26
27 655 colleagues (2015) suggest that supportive relationships that promote this sense of being
28
29 656 understood can facilitate people after injury to navigate their changed circumstances.⁵⁵
30
31
32 657 Others have suggested that relating to other survivors acts as a source of self-cohesion in
33
34 658 the process of identity re-construction.¹³ Indeed, in our study, the sharing of stories helped
35
36 659 both mentors and mentees realise they were not the only ones in this situation and not
37
38 660 alone in what they were going through.
39
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41 661

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43
44 662 Mentees saw these stories as more authentic and more practically useful than receiving
45
46 663 advice from clinicians. This is similar to the findings of Veith et al. (2006), where mentees
47
48 664 saw professionals as forced into their life and as detached experts.²³ Stories of people
49
50 665 becoming more active after spinal cord injury recorded by actors have also been used in a
51
52 666 study with people recently injured.⁵⁶ Although they used a different delivery mechanism,
53
54 667 people with spinal cord injury and healthcare staff considered the stories to be effective
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3 668 tools for communicating the message regarding reengaging in activity after injury. They
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5 669 considered those in the stories to be credible messengers, who were emotionally realistic
6
7 670 and provided context. Stories have also been shown to be key in the success of mentoring in
8
9
10 671 a number of other settings, including mental health.^{25 57} In our study, the relationship that
11
12 672 developed through this sharing led to mentees feeling able to express their concerns in a
13
14 673 more honest and intimate way than perhaps would have occurred with clinicians.
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19 675 We chose to use the terminology peer mentor over that of a lay person, since we concurred
20
21 676 with others that there are distinctive differences. A peer is someone 'who has had a
22
23 677 comparable experience' (p436).^{22 23} We do, however, acknowledge that the term 'lay' is also
24
25 678 used in self-management literature as people who 'commonly, but not invariably,
26
27 679 themselves have a chronic disease, which may or may not be the same as that affecting
28
29 680 programme participants'.⁵⁸ We see the role of the mentor as different to that of a lay
30
31 681 person in the community. This is because mentors share the same experience (of an injury
32
33 682 and of the associated traumatic experience for example) and can be part of *created* social
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35 683 networks. Mentors are also different from paraprofessionals, who are lay people or lay-
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37 684 leaders who have received extensive training to deliver more structured and educational
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39 685 self-management programmes and have essentially become professionalised.^{24 58} This
40
41 686 approach is akin to that employed by other peer mentoring programmes in which mentors
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43 687 received more education about TBI from a clinical perspective.^{32 34 59} There is no strong
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45 688 evidence that such training impacts on health status, which provided us with the rationale
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47 689 not to use this approach.⁵⁸ Further, our approach to mentoring was largely informed by
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49 690 contemporary models of rehabilitation with a focus on participation as a key outcome of
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3 691 interest. A sociological approach could reveal different insights and could be explored in
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5 692 further work.
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10 694 In our study mentees talked about a sense of hope that came from being with their
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12 695 mentors, hope for the future, and hope of recovery. This potential outcome is distinct from
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14 696 other studies of peer mentoring after TBI.³²⁻³⁴ Hope or hopefulness as a potentially
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16 697 important outcome is considered in a conceptual analysis by Bright and colleagues.⁶⁰ Our
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18 698 findings are similar to research in spinal cord injury, which showed that mentors helped
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20 699 newly injured people see future possibilities.²⁶ The authors described this in the context of
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22 700 temporality and conceptualised disabled peer mentors as bridges in the temporal disruption
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24 701 of newly injured persons. Similarly, in a study with people on acute stroke units, hope was
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26 702 also identified as a key outcome of a peer mentoring programme.⁶¹
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32 704 The mentoring relationship appeared to benefit the mentors by allowing them to be, and to
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34 705 be seen, as able to make a meaningful contribution, thus promoting a sense of self-value.
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36 706 Douglas and colleagues (2015) report on the social isolation frequently reported by people
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38 707 with TBI, and describe rehabilitation as a 'social-relational affair' (p154).⁵⁵ They suggest that
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40 708 through social interactions we build our sense of self, and that social interactions and
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42 709 expressive social support are essential elements for recovery after major injury.⁵⁵ Similarly,
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44 710 qualitative accounts of the experience of recovery captured over two years following TBI,
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46 711 support this notion that recovery is a social relational process where people draw support
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48 712 from others to make sense of recovery and life after TBI.¹⁹ This is consistent with concepts
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50 713 previously discussed by others, such as relational autonomy, where autonomy is argued to
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52 714 occur within and because of relationships.⁶² Peer mentoring is one approach that explicitly
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3 715 attends to this important aspect of recovery. This was indeed found to be the case in our
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5 716 study, with mentees re-engaging in activities with mentors' support, such as contributing to
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7 717 activities within the church or leaving the home for a manicure or lunch.
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12 719 Peer mentoring interventions are also located within disability rights and advocacy (e.g. ^{63 64})
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14 720 as a way of recognising, and utilising the expertise of those with experience of disabling TBI,
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16 721 and supporting a non-clinical approach to supporting people to engage in life post TBI.

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18 722 However, our peer mentoring intervention was not specifically conceptualised in this way.

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20 723 Rather, as highlighted in the introduction, the intervention in the current study was

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22 724 underpinned by recognised gaps in service provision and informed by the experiences of

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24 725 people facing the enduring consequences of TBI. Likewise, there has been a recent interest

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26 726 in self-advocacy programmes for people with TBI and their families (e.g. ⁶⁵⁻⁶⁷). Self-advocacy

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28 727 can be defined as 'asserting your own needs and taking action to fulfil those needs'.⁶⁵

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30 728 Findings from such programmes are mixed but encouraging. One trial showed that advocacy

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32 729 behaviour improved both in a group taking part in a curriculum-based advocacy programme

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34 730 and one that was self-directed, and concluded that bringing like-minded motivated people

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36 731 with TBI together is more important than programme structure or content in changing

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38 732 advocacy behaviour.⁶⁷ Similarly, the self-advocacy for independent life (SAIL) program

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40 733 showed improvements in self-efficacy, satisfaction with life and goal attainment both for

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42 734 those who took part in a curriculum-based programme and those who only accessed a

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44 735 workbook.⁶⁶ However, neither study had a control group that did not receive an

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46 736 intervention, and the latter study was very small (n=12). Further, peer-advocacy or the role

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48 737 of peers in developing capability for self-advocacy was not explored in either study. Future
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3 738 research could consider the relevance of these findings for integration into TBI peer
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5 739 mentoring programmes.
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9 741 In conclusion, peer mentoring in the early stages post-discharge appeared acceptable to
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11 742 people with TBI, both as mentees and mentors. Sharing experiences and stories seem key to
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13 743 successful peer mentee–mentor relationships after TBI and appeared to lead to benefits for
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15 744 mentees. This approach is suggested to augment rather than replace clinical input, providing
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17 745 something valuable and distinctly different. This qualitative study is a first step in a larger
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19 746 programme of work aiming to examine the efficacy of peer mentoring in TBI. Our future
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21 747 work will more explicitly include the involvement of people with TBI and their families in the
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23 748 study design, and build on the experiences and inputs shared by the mentees and mentors
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26 749 in the findings of this study.
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3 752 **Figure 1. Example of mentoring timing**

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For peer review only

754 **Author contributions**

755 PK conceived of the study, led on study design, project management, data analysis and
756 dissemination. NK, KMcP, MW, HE contributed to study design. CC, NK and DB contributed
757 to the qualitative data analysis, MW and GS to the quantitative data analysis. CC, NK, DB,
758 AF, KMcP, RS, HE, and GS contributed operationally (e.g. training, recruitment, data
759 collection, mentor support and debriefing). PK drafted the manuscript and is the guarantor.
760 All authors revised it critically for important intellectual content and approved the final
761 version for publication. All authors agree to be accountable for all aspects of the work.

762 **Competing Interests**

763 All authors have completed the ICMJE uniform disclosure form at
764 www.icmje.org/coi_disclosure.pdf and declare: PK, NK, HE, MW, KMcP had financial support
765 from the Health Research Council of New Zealand for the submitted work; AF is an employee
766 of ABI Rehabilitation New Zealand Limited; subsequent to the completion of this project and
767 data analysis KMcP became the Chief Executive of the Health Research Council of New
768 Zealand; all other authors declare no financial relationships with any organisations that
769 might have an interest in the submitted work in the previous three years; no other
770 relationships or activities that could appear to have influenced the submitted work.

771 **Data sharing**

772 Quantitative data from the study is not presented in the paper but can be obtained from the
773 author, subject to the funder's permission.

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3 775 **Figure 1 legend**
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6 776 The top image in this figure shows the intended duration of the peer mentoring programme
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8 777 (3 months) and frequency of sessions (every 2 weeks) for one of the study dyads. The
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10 778 bottom image shows the actual duration (6 months), and frequency (4-8 week gaps between
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12 779 sessions). The longest gap was due to the mentee requiring surgery.
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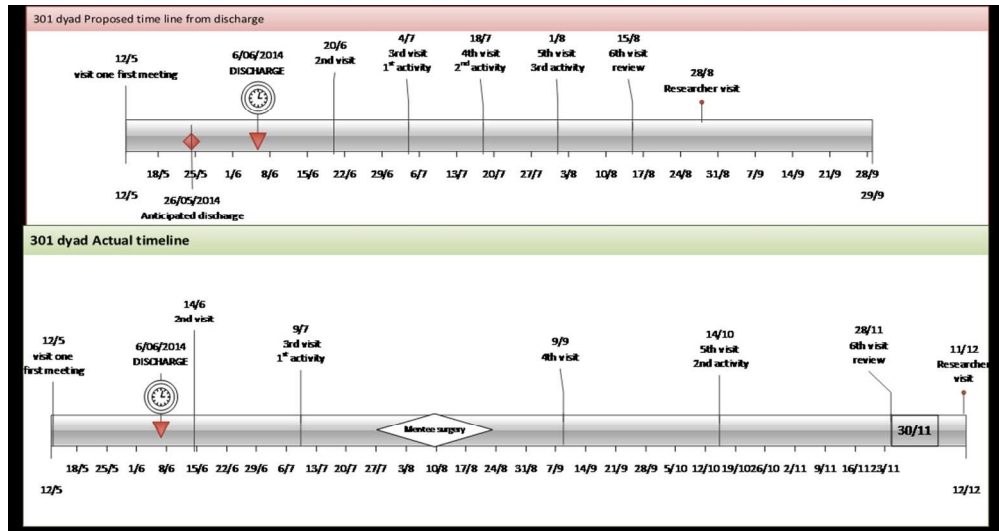


Figure 1. Example of mentoring timing

Appendix Mentor training workshop

Day 1			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-10.00	Introductions, outline of the training, ground rules	Principal Investigator (PI rehab background), Research Officer (RO)	Discuss how the group wants to work together
10-10.30	Break		
10.30-11.00	The mentoring role and what we mean by participation	PI, RO, Co-investigator (health psychology background)	Brainstorm activities about participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful. *
11-12	Common challenges following TBI	Psychologist specialised in neurorehabilitation	Group discussion, including what helped and hindered managing these challenges.*
12-12.30	Common challenges following TBI	Rehabilitation specialist (medical doctor)	Presentation: same as that given to people prior to discharge. Topics covered included for example impact of head injury on the brain, recovery, impact of lifestyle choices on recovery (e.g. drugs and alcohol).
1.30-2.45	The mentoring relationship	Psychologist specialised in neurorehabilitation	Warm up exercise: 5-10 minutes, talk to your partner about yourself for 2-3 minutes; then listen to them for 2-3 minutes. Then be ready to introduce your partner to the group. Using flipcharts mentors drew aspects of their life after TBI they would be happy to share with a mentee.
2.45-3.15	Break		
3.15-4.30	The mentoring relationship	Psychiatrist with expertise in TBI, Neuropsychologist	Each mentor shared their story depicted in the flipchart - practising sharing their experiences. A 3-page outline of the mentoring role was also discussed. Discussion of culturally appropriate working in the NZ context.

* Summary was typed up and provided to mentors in their workbook

Day 2			
Times	Topic	Led by	Activities
9.00-9.15	Arrive, refreshments		
9.15-9.45	Overview of the mentoring programme	Principal Investigator (PI), Research Officer (RO)	Summary was provided of participatory activities mentors themselves engage in, which ones they had difficulties with after their TBI and what support were or would have been helpful (from the previous week). Outline and rationale of the mentoring programme was presented.
9.45-10.30	Goals and setting them	Co-investigator (health psychology & nursing background)	Interactive workshop on goal setting and action planning using worksheets
10.30-11.00	Break		
11-12.30	The mentoring programme – in detail	PI, 2 ROs	Outline of each mentoring session was provided and discussed in workshop format
12.30-1.30	Lunch		
1.30-2.45	Project requirement, strategies for researcher safety	Co-investigator (health psychology background), PI and RO	Discussion of potential safety issues and how to manage them. Familiarisation with safety policy of the centre & note taking for the intervention.
2.45-3.15	Break		
3.15-4.30	Wrap up, questions, mileage claims	Principal Investigator (PI), Research Officer (RO), centre manager	Final question and answers session, explanation of keeping timesheets and mileage claims.

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1 / 1-3
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	2-3 / 23-49

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	6-8 / 85-144
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	8 / 144-148

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	8 / 151-153
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	9 / 158-161 16 / 268-271
<p>Context - Setting/site and salient contextual factors; rationale**</p>	16 / 268
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	9-10 / 170-200
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	19 / 328-329
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	16-19 / 267-291

1 2 3 4 5	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	17 / 280-281
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	20 / 331-341
9 10 11 12	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	18-19 / 293-314
13 14 15 16	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	18-19 / 293-314
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	19 / 310-314

Results/findings

23 24 25 26	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	23-30 / 380-543
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	31-38 / 547-718

Discussion

32 33 34 35 36 37 38	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	31-38 / 547-728
39	Limitations - Trustworthiness and limitations of findings	32-33 / 568-603

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	40 / 740-747
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	5 / 72-75

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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