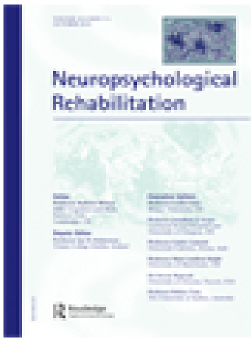

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Recovery and adaptation after traumatic brain injury in New Zealand: Longitudinal qualitative findings over the first two years*

Joanna K. Fadyl[a], Alice Theadom[a,b], Alexis Channon[a] and
Kathryn M. McPherson[a,c]

[a]Centre for Person Centred Research, Auckland University of Technology, Auckland, New Zealand; [b]National Institute for Stroke and Applied Neurosciences, Auckland University of Technology, Auckland, New Zealand; [c]Health Research Council of New Zealand, Auckland, New Zealand

ABSTRACT

Knowledge about the impacts of traumatic brain injury (TBI) and aspects that influence recovery and adaptation are key to understanding how best to provide appropriate services. Whilst injury experiences have been documented, factors that help or hinder recovery and adaptation over time and across injury severities remain unclear. We present overarching findings addressing these matters in a large longitudinal qualitative study of recovery and adaptation following TBI. People experiencing TBI ($n = 52$) and their significant others ($n = 37$) were interviewed at 6-, 12- and 24-months post-injury. Data were thematically analysed cross-sectionally and longitudinally. Two overarching themes were captured in the analysis: *making room for recovery* and *cultivating important resources*. Themes comprise circumstances and processes that changed and developed over time in different ways for different participants. Key complexities within the overarching themes included the notion of "acceptance" and the role it played in allowing for recovery and adaptation; and the concept of "self" as a resource aiding recovery, but one that is perpetually at risk due to the intersection between the functional and social effects of the injury. Developing concepts of TBI recovery and living with TBI were central processes across diverse participants, but necessarily individualised in how they could be enacted.

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KEYWORDS Traumatic brain injury; Recovery; Adaptation; Rehabilitation; Support; Qualitative; Longitudinal; New Zealand.

Introduction

Knowledge about the impacts of traumatic brain injury (TBI) and the aspects that influence a person's recovery and adaptation are key to understanding how best to provide

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CONTACT Joanna K. Fadyl jfadyl@aut.ac.nz Centre for Person Centred Research, Auckland University of Technology, Private Bag 92006, Auckland 1142, New Zealand

*On behalf of the TBI Experiences Research Group: Kathryn McPherson; Alice Theadom; Joanna Fadyl; Laura Wilkinson-Meyers; William Levack; Nicola Starkey; Nicola Kayes; Valery Feigin; Matire Harwood; Grant Christey.

Supplemental data for this article can be accessed at https://doi.org/10.1080/09602011.2017.1364653 appropriate and responsive rehabilitation, and wider supports. Research and practice in this field acknowledge that both experiences of recovery, and what is most important for facilitating improvement and adaptation, change over time (Brown, Lyons, & Rose, 2006; Malec et al., 2013). However, research providing insight into the characteristics of these changes, particularly with a longitudinal sample, is still very limited.

Following TBI, many people experience ongoing symptoms and struggle with everyday functioning (Langlois, Rutland-Brown, & Wald, 2006; Ponsford et al., 2014). This in turn impacts on the person's ability to return to employment, fulfil other social roles and can place a strain on close relationships (Lefebvre, Cloutier, & Josée Levert, 2008). On the positive side, increasing evidence of neural plasticity (DeFina et al., 2009; Levin, 2003) identifies potential for ongoing improvement and adaptation (Doidge, 2007; Powell, Ekin-Wood, & Collin, 2007). These factors in combination highlight the need to consider TBI as a chronic condition that continues to affect a person and their wider networks in the years following the injury, but where there remains capacity for positive intervention to facilitate recovery and adaptation (Malec et al., 2013; Ponsford et al., 2014).

Although there are now a number of cross-sectional qualitative studies exploring the impact of TBI, there is a paucity of studies that analyse recovery and adaptation over time for people experiencing TBI. The majority of qualitative studies in TBI are targeted to specific issues or sub-populations, and thus aim for samples of around 10–15 participants (Levack, Kayes, & Fadyl, 2010). Further, the majority of studies focus on data collection at a single point in time (Levack et al., 2010). These approaches and the existing studies are valuable for exploring particular aspects of experiences in-depth. However, when the goal is to investigate the range of experiences of recovery and adaptation across this relatively heterogeneous population, a larger sample and longer timeframe is required. Qualitative longitudinal research generally has been argued to be effective for exploring complex social phenomena in which there are important movements in experiences over time (Bidart, 2013). For a TBI population, this could be a powerful tool for identifying both broad patterns and critical moments to inform the design of key supports and rehabilitation interventions.

The overall aim of the *TBI Experiences Study* was to investigate the subjective experiences of recovery and adaptation over the first two years after having a TBI from the perspective of people with the injury and the family and/or friends most closely involved in their recovery (who we termed "significant others"). The specific research questions focused on what helped or hindered recovery and adaptation over time following TBI. Adaptation was conceptualised broadly to be a counterpoint to "recovery": a process of changing and reconceptualising activities and roles in response to life events.

Study design and methods

Study design

The design was a longitudinal qualitative descriptive study within a post-positivist epistemology (Thorne, Kirkham, & MacDonald-Emes, 1997). We employed data collection and analysis methods described by Charmaz (2006) as her social constructionist lens was consistent with our study, and the systematic approach to analysis and prior application for investigating chronic conditions indicated it was particularly appropriate. The full methodological approach is outlined in a partner paper (Fadyl, Channon, Theadom, & McPherson, 2017) and key details are provided below.

Participants and recruitment

Inclusion criteria for participants with TBI were: people over 16 years who had experienced a TBI classed as severe, moderate, or mild with persistent problems (emotional, cognitive or physical difficulties) at 6-months post-injury. People who could only contribute via an interview with support were included to maximise diversity, and this included some people with expressive communication difficulties.

Potential participants were identified through multiple routes: a population-based TBI incidence study (Feigin et al., 2013); patient support organisations; and TBI service providers in the Hamilton and Auckland regions of New Zealand. We selected TBI participants using purposive sampling (Patton, 2002), aiming for diversity in key characteristics of interest, including severity of injury, level of recovery, and ethnicity in order to maximise transferability of findings. Subjective aspects such as level of recovery and the presence of persistent problems were ascertained from formal assessment where this was available, or referrer description of the participant's situation, and then further explored during the interviews with participants. Theoretical sampling was not employed in this study as we did not intend to develop theory from the inquiry, focusing instead on patterns in experiences across a heterogeneous participant group.

The person who had a TBI was approached by a member of the study team who provided information about participating in the study and asked the person to give written consent. During the consent process, participants were also invited to nominate one or more significant other (16 years or over) to receive an invitation to participate. There were no additional criteria defining who could be nominated to participate as a significant other, although participants were asked to nominate someone who knew them well and was involved in their recovery.

Informed, written consent was sought from all participants, and each participant had a right to withdraw at any stage during the study. The study was approved by the appropriate regional and University ethics committees.

Data collection

The data was in the form of interviews at approximately 6, 12 and 24 months following the TBI. Although the study protocol specified time-points, we allowed a 3-month window (e.g., 6–9 months, 12–15 months) to respond to individual circumstances (Calman, Brunton, & Molassiotis, 2013). Interviews with the person experiencing TBI were either together with their nominated significant other or separate according to the preference of the person with TBI.

The interview guide was semi-structured, again allowing the research to be responsive to the person's particular experiences, and explore emerging patterns and themes that were becoming important to the analysis in later interviews. Each interview began with broad questions asking the participant(s) to describe their experiences following TBI and/or since the last interview, and then focused on aspects related to recovery and adaptation (see supplementary online material for interview guide). Interviews were audio-recorded and transcribed verbatim, and researcher notes regarding the interview were also collected to assist in reading of the data within the participants' wider contexts. The interviews took place at a location chosen by participants – most often at their homes.

Data analysis and interpretation

Data analysis was complex and multi-staged due to the large number of participants and the volume of interviews (up to 3 per participant). We have detailed our approach to data analysis and particular challenges and solutions in a partner paper (Fadyl et al., 2017). In summary, interviews were thematically analysed using techniques drawn from Charmaz (2006), with two distinct goals. These were 1) a synthesis of participants' experiences at particular time-points, aiming to capture issues of particular importance at specific time-points (cross-sectional analysis); and 2) an exploration of the insights from the journey over time from each participant, aiming to thematically describe the experiences and challenges that occurred over the recovery journey up to 2-years post-injury (narrative analysis).

Preliminary coding of the 6-month interviews was done by a team (AC, AT, JF, KM and an additional research assistant), to organise sections of text according to what participants were saying about the processes of and influences on recovery and adaptation (Charmaz, 2006). Initial codes were created as required based on the interview content and entered into a bespoke database (Fadyl et al., 2017). The content of codes was then further examined during group analysis sessions using constant comparison (Charmaz, 2006) to generate fewer, more interpretive codes and categories with comprehensive descriptions and relationships. Individuals in the core team working on the interpretive analysis represented different health disciplines (sociology, psychology, and nursing), meaning the discussions about interpretation of findings and code and category generation were cross-disciplinary and informed by a wide range of knowledge and literature. Once 12- and 24-month interviews were available for analysis, they were coded using the 6-month codes as a reference, but extending descriptions and revising code names to reflect the longitudinal nature of the data, as well as adding new codes as required. A manual mapping technique was used to record relationships between codes and themes and track the changes in both individual codes/themes and their relationships at the different time-points (6, 12 and 24 months). Once we had more than one interview available per participant, our comparison process expanded to incorporate both the longitudinal journey of the individual participant and the particular aspects of each time-point. All analysis decisions, including code generation and retirement, allocation and re-allocation of extracts to codes, and category discussions and decisions were documented in a database. Reports on these decisions were generated from the database and these, along with coding maps, were discussed with the study team and wider steering group for auditing and critique (also from a wide range of disciplines). We also gave regular presentations during the analysis period to a community reference group made up of health professionals currently working in TBI and people with personal experience of TBI, who gave input into decisions and provided consultation on application and dissemination of findings. For a detailed description of the analysis processes, challenges associated with the complexities of the study and strategies taken to ensure rigour, see Fadyl et al. (2017).

Findings

Over the course of the study, 52 people with TBI and 37 significant others (a total of 89 participants) took part in one or more interviews, gathering experiences relating to 53 different people with TBI. One person with TBI who was severely affected by their injury declined to be interviewed and instead offered that their significant other be contacted for interview. Details of participant numbers at each time-point are given in Table 1. Thirty-one TBI participants (60%) completed all three interviews, and 13 (25%) took part in two interviews. Eight TBI participants (15%) completed only one interview: 3 at the 6-month time-point and 5 at the 12-month time-point. Thirteen participants began participation at the 12-month time-point due to late referral. Reason for not continuing was loss to follow-up, including two participants who died during the study period.

Age at the time of injury for the participants with TBI ranged from 16 to 85 years (mean 45 years, median 46 years). Twenty-four out of 37 significant other participants provided their date of birth with their ages ranging from 16 to 66 years (mean of 44 years, median 47 years). Table 2 provides information about demographics and other characteristics of the participants with TBI. Table 3 gives demographic information and relationship to the injured person for significant other participants. In addition to the information in the tables, it is worth noting that participants were experiencing diverse life circumstances. For example, participants' living situations ranged from living alone, in a family home (some with dependent children), living in supported accommodation, to being homeless. For many, their situations shifted during the study.

Across all time-points, we conducted 48 joint interviews with the person with TBI and their significant other, 79 with the individual with TBI only, and 25 with the significant other/s alone. Most interviews were between 40 and 90 minutes long.

For this longitudinal analysis, we have focused on the overarching messages emerging out of the cross-sectional and narrative analysis of the interviews over the three time-points: 6-, 12- and 24-months post-injury. This looks at patterns over time and builds on baseline analysis at 6 months, which has been presented elsewhere (McPherson et al., 2017). Below we present the central themes that brought the analysis together, and within this a discussion of higher-level categories that were formed in the interpretation of the data. All themes were derived through the interpretive process described in the methods, across the whole range of participants. Pertinent quotes are presented as an illustration of the main points, drawn from instances where a participant provided a succinct description of their experiences. All names are pseudonyms.

Central themes

We identified two central themes. Both themes incorporate multiple elements that were crucial to helping or hindering recovery and adaptation for the participants. The theme *room for recovery* is presented as the context within which recovery and adaptation is allowed to occur, and could be seen to have many similarities with other life experiences that involve grief, acceptance and adaptation. *Cultivating important resources* comprised of four inter-related processes which arguably are more specific to the particular context of TBI.

Table 1. Number of participants at each time-point.

	6-month	12-month	24-month
Person with TBI	40	48	38
Significant other	22	24	20
All participants	62	72	58

Table 2. Characteristics of participants with TBI.

Characteristic	Subgroup	Number of participants
Gender	Male	39
	Female	14
Ethnicity[a]	Māori (Indigenous NZ)	13
	Pākehā (NZ European)	35
	Asian	2
	Pacific	2
	European	6
	Other	1
Cause of TBI	Road traffic incident	17
	Fall	20
	Mechanical force (accident)	7
	Assault	9
Severity of TBI[b]	Mild [mild, high risk]	26 [20]
	Moderate	8
	Severe	15
	Not known	4
Highest qualification	None	9
	High school	4
	Tertiary	23
	Postgraduate	2
	Not provided	15
Employment status at injury	Not in paid employment	15
	Part-time paid employment	3
	Full-time paid employment	21
	Information not provided	14

[a] Multiple ethnic identities are common in Aotearoa New Zealand. In line with recommended practice in NZ, all ethnicities reported are included (total response) (Cormack & Robson, 2010).

[b] Classified by the recorded duration of post traumatic amnesia (PTA). Mild with persistent problems at 6 months post-injury.

Room for recovery: the complexities of "accepting" and learning how to allow for recovery and adaptation for the individual and their family network

One of the most salient messages that came through from the study overall was that the need for recovery came with an imperative that room was created for that recovery in the life of the individual and their family network. For many initially, the incident of the TBI and acute symptoms and care automatically created that space (with participants talking

Table 3. Characteristics of significant other participants.

Characteristic	Sub-group	Number of participants
Gender	Male	6
	Female	31
Ethnicity[a]	Māori (Indigenous NZ)	6
	Pākehā (NZ European)	20
	Asian	2
	Pacific	2
	European	5
	Not provided	10
Relationship to injured person	Spouse / partner	19
	Ex-partner	1
	Child	9
	Parent	7
	Friend	1

[a] Multiple ethnic identities are common in Aotearoa New Zealand. In line with recommended practice in NZ, all ethnicities reported are included (total response) (Cormack & Robson, 2010).

about life going "on hold" (McPherson et al., 2017). However, as time progressed there needed to be a more active acknowledgement that recovery required time, resources and a reforming of the normal activities and processes of life. Thus, learning how to allow for recovery and adaptation also involved a process of "accepting" that the injury and its ongoing effects was now part of that person's life and the lives of those who were close to them. It wasn't until nearly 2-years post-injury for some that the gravity of this acceptance and adaptation became apparent. Because of this, the quotes given to illustrate "complexity of acceptance" mainly come from the 24-month interviews.

Complexity of acceptance. What we have termed the *complexity of acceptance* was conceptualised in a number of ways, and played different roles in different participants' lives, but generally formed an important part of the process of being able to *make room for recovery*. In some cases, accepting involved temporarily or permanently relinquishing aspirations. For some, knowing and coming to terms with the difficulties that they experienced as a result of their injury formed a way of determining the boundaries between what they can and can't do now, enabling them to focus on recovery. The very notion of "acceptance", however, was commonly an uncomfortable one – meaning many different things, both positive and negative:

> He let go of his dream and his [work] position knowing full well he wasn't going to get back up there, but he knew he had to change his lifestyle and that's why I say he was now looking "down there" instead of "up here" [applying for new jobs] and he is, I guess, angry about it. (Mother of Tyler [21 years, mild], 12-month interview)

> I had a really hard time accepting it because I never learned to compromise [before the injury], I also just said OK I want this and need this and I got it. Afterwards I realized it's not about getting what you want. You don't always get what you want. [Describes processes of making decisions post-injury and evaluating differently] Maybe now I'm taking more of a broken track, a worn out track, a road that is very bumpy, but so what? (Gary, 23 years, severe, 24-month interview)

Participants also articulated a difference between being resigned to the consequences of the injury and having accepted it, with acceptance as a more "graceful" recognition of what needed to be acknowledged in order to move forward:

> Accepting is much more graceful than being resigned […] What I want to be and what I should be in relation to my family: as a role model to my children and a partner to my wife, I can't be that and that's a tormenting thing to me. I am resigned to that. It's definitely not accepting. (Mark, 45 years, moderate, 24-month interview)

This acknowledgement often included specific reference to losses that resulted from the injury: particularly lost opportunities for life experiences and a loss of an anticipated future self. In the quote below, the mother of a participant with TBI reflected on the differences in life possibilities for her injured son compared with her other adult children:

> [Injured son] has lost all his … he can't make choices to the same extent, you know? I look at [my other adult children] – they can make good choices and bad choices but they can make choices, while [injured son] can't make those same decisions. (Mother of Carl [19 years, moderate], 24-month interview)

Allowing me to change what I normally do in order to manage, adapt and recover. In the early period following the injury, participants often had a concern with allowing for the "natural" course of recovery (McPherson et al., 2017). As time went on, for many the emphasis appeared to shift towards actions and strategies that actively created room for managing, adapting and recovering. People often described spending a lot of time and energy trying to find ways of managing that worked for them and their loved ones – including trialling different ways of doing things or organising everyday life, seeking and/or sorting out advice, and learning about how to negotiate the various aspects of their lives to maintain what was working for them.

In terms of *allowing me to change*, the different environments and relationships in the person's life came to take on huge importance in this context. Many participants described tensions when their family, friends and colleagues had to adapt their routines and behaviours to accommodate brain-injury related needs. In some cases this affected their relationships or employment. Some also described difficulty deciding what to prioritise when needs conflicted: for example, a need for peace and quiet conflicting with a need for social connection. Participants who were able to change what they normally did in a way that they could accept and make peace with that change experienced much less stress and anxiety about this aspect of *making room for recovery* than those who felt "forced" to make changes that profoundly affected their enjoyment of life or sense of self-worth:

> [Employer] was getting, starting to ask questions: well how long are you going to be on [reduced hours] sort of thing, […] it was brought to my attention that if I didn't get 100% clearance then potentially [company] could say "you haven't got a job because you are not fit to do the tasks you are employed for." So I found that a little bit disturbing but quite real […] although I've had no problems with my performance at work (Mark, 44 years, moderate, 12-month interview)

> [Talking about a change in activities to accommodate brain injury symptoms] I'm often asked why don't I go back to [club], but I've got enough in my life now that, I miss the comradery, the friendships that you make, yes, to some degree I do miss that, but you know there is only so many things you can do and I do more sailing now than I did, than I was able to when I was a [club] member. (James, 71 years, severe, 24-month interview)

Complications: the "tangle" of brain injury symptoms and competing demands. Two aspects further complicated the process of trying to allow for recovery and adaptation for participants. These related to the experience of symptoms and the complicated nature of their impact, and the complications of the person with TBI being in a position of needing support now, but life continuing on despite this.

Because a TBI may affect both physical and cognitive processes, the symptoms intermingled and interacted to affect a person's ability to do a whole variety of everyday things. Furthermore, symptoms of brain injury had an effect on the process of recovery, or the ability to cope with the process of recovery. There was a strong message from participants that changes in functioning cannot and should not be divided up into components (or divided cleanly into brain injury symptoms and changes as a result of other things) – it always affects the whole person:

> All I know is I can't remember how to do things. I know I've done them before, with varying degrees of competency, but now I just have no idea […] and it's quite weird because I don't have any sort of tentative indicators or benchmarks. […] and I'm saying all these things since the accident: "oh this happened since the accident, that happened since the accident" and everybody says "well, that's middle age, that's normal" … but I know, we know there was nothing wrong with that [before]. (Mark, 45 years, moderate, 24-month interview)

Self-management techniques, which are often seen to be a good way of managing chronic conditions, were complicated by this tangle of brain injury symptoms.

Where such strategies were implemented without consideration of this issue, people described feeling like they were failing to accomplish basic recovery. As such, any strategies needed to be a good fit with the challenges associated with other impairments. The interconnection between symptoms could also work in a positive way when treating one thing led to improvements with other things that were not the specific focus of treatment:

> It [physiotherapy] affects the motor control part of the brain or whatever and in turn it eventually affects my behaviour, mood and everything too. That has helped. (Gary, 23 years, severe, 24-month interview)

Additionally, although most participants with TBI and their significant others saw support as essential to coping, recovery and adaptation, a family or whānau's[1] ability to offer or provide support could be impacted on by any number of competing factors. Many families and whānau felt an expectation from professionals to be available wherever and whenever to provide support for their loved ones who had a TBI, without consideration of the other pressures (such as work, family and community commitments, financial concerns) that restricted their ability to do this:

> I was paying his rent, and I also had my granddaughter staying with me and supporting her as well. It was hard, and with my own injury [head injury 4 years earlier] as well I was struggling. (Mother of Tyler [22 years, mild], 24-month interview)

> The occupational [therapy], they were very intense therapy which is probably why they wanted him to go there [rehabilitation centre 5 hours' drive away] […] They kept wanting to keep him there and of course the longer he was there, the harder it was for me to rely on my family to go up there with me [drive me there]. (Partner of Edward [66 years, severe], 6-month interview)

In some cases, some members of a person's family were not willing (or able) to be supportive, and this could have negative effects for both the person with TBI and significant others:

> They [other family members] said clearly they didn't want their lifestyle to be interrupted. I asked them "only 1 hour per week, just commit to 1 hour per week, come and do things for him and with him, so he has something to look forward to" and they refused. (Wife of Henry [85 years, severe], 24-month interview)

Especially later on in the recovery and adaptation process, different family members often had different needs and/or wants and were motivated by different concerns. This could result in them wanting conflicting actions to be taken. In cases where these competing demands were resolved, participant accounts suggested this enabled a greater focus on recovery and adaptation. This resolution could happen in many different ways. In one example, conflicting needs between family members (managing needs of daughter with young children versus coping with symptoms and recovery) were resolved through simply getting more physical distance between the participant and her daughter. This enabled both a feeling of both less demand on the person with the TBI and more enjoyment of the time with her grandchildren:

> Richard [husband]: Our eldest daughter has moved 20 minutes further away so her needs are not quite so high.
>
> Linda: Or dependent on me. And like I am enjoying the grandkids a lot more now because their noise and that doesn't worry me like it used to. (Linda, 56 years, moderate, 24-month interview)

Cultivating important resources (and the intricacies that affect their utility)

When discussing what supports recovery and adaptation, an overarching theme that came through in the experiences of the participants was that there were a multitude of personal and social resources that they drew on to assist with the process. However, it was not possible to say that for everyone a particular resource or type of resource was always helpful, because of the intricacies of how potential resources manifested and played out in the context of each person's life. Thus, in the discussion below, we have talked about four processes of resource-finding or resource-creation rather than specific resources.

For each person (people with TBI and significant others), developing a concept of TBI recovery and developing a concept of living with TBI were processes that helped participants to make decisions or make sense of situations. Connectedness to others (family, friends, professionals, wider networks and animals) was seen to have both utility *and* complications in the context of each person's life. While other people were essential for being able to function or be safe in some situations, at other times this connectedness created circumstances where people felt frustrated, burdensome or vulnerable. Lastly, a person's sense of self was discussed as a kind of resource that helped people cope (or even thrive) but was perpetually at risk because of the significant functional limitations and social role adjustments associated with the injury and its effects.

Developing a concept of TBI recovery. Developing a concept of TBI recovery was something that happened slowly over the course of months or years following the initial acute treatment of the injury. Key issues included developing an understanding of what to expect (which in our data was dominated by a lack of certainty about functional prognosis, treatment and recovery trajectory); acquiring knowledge about what supports could and should be available and why they were or were not being provided; and working out when and how families and communities should offer or withdraw supports to the person with TBI.

After an initial period of trying to make sense of what had happened and what needed to happen now, by 12 months many participants were reflecting on a lack of understanding of what exactly TBI recovery was supposed to look like and how long it would take. For individuals and families who were able to develop a concept of what TBI recovery was for them (and keep it flexible enough to adapt when things changed), this acted as a kind of scaffolding for what they sought in the way of support, and how they adapted their lives to accommodate the effects of the injury. Support services themselves, particularly subsequent to acute rehabilitation, were helpful in developing and adapting this concept. However, accessing them was not always easy, and throughout the process there was a need for someone to be proactive in seeking and following up those supports (see also McPherson et al., 2017). Particularly as the time since injury got longer, many people felt that information about entitlement to services was (intentionally or unintentionally) withheld, and it was necessary to "hassle" to get referrals and information:

> Hassling [services] about things is probably an important thing to do because if you don't ask them they won't do anything (Niko, 25 years, severe, 24-month interview)

Longer-term support services could also be instrumental in helping families continually evolve their understandings of TBI recovery as things changed. In later stages, if formal support services were being provided, they were highly valued and helped individuals and families plan what to do when unexpected challenges arose, or to offer guidance and assurance when the recovery trajectory "dipped." Participants talked about how important it was to be able to perceive some sort of "progress" overall. However, in many cases, by 12 or 24 months formal support services had ended.

Participants and their families experienced a lot of confusion stemming from what appeared to be a lack of certainty and a lack of consensus from medical professionals about recovery trajectories and what was likely to be effective for the individual. There was also a lot of uncertainty regarding whose responsibility it was to gather information about what was to be expected, and even at 24 months some participants were still describing baffling contradictions in the opinions of GPs, specialists and case managers, making it impossible for them to figure out what "should" be happening. Participants often sought input from researchers on the study to help them try and piece together what TBI recovery should be and whether or not they were "achieving" important milestones. This lack of clarity and surety impeded an ability to develop a concept of TBI recovery:

> The doctor just says its normal and [the specialist is] saying that this is something terrible and I say you know [insurer] must have some experience but then I've got letters here [suggesting they are no help either]. (Gregory, 64 years, mild, 24-month interview)

> [Clinicians] typically have differing viewpoints or even a different understanding of what's going on. […] I think if somebody had said to me right at the outset "um this is going to be a huge learning experience for all of us. We're going to try a lot of things, some of them might work a little, some of them might be detrimental, we don't know. This is into the unknown" then I think I would have been better prepared for what we've been through. (Husband of Karen [61 years, mild], 12-month interview)

Developing a concept of living with TBI. Crucially, most of the participants and their families and communities had little concept of what a TBI was, and what it could mean, in the context of their lives at the point of injury. Despite being hugely important, developing this knowledge was difficult, given the major disruption to their lives that they were experiencing because of the TBI at precisely the time that they most needed to acquire this knowledge.

In the early months after the injury, participants engaged in processes of making sense of what had happened, including processing the impact of the incident that had resulted in the injury. For some participants, this sense-making lasted throughout the two years, especially in cases where the incident itself had been difficult to come to terms with (e.g., assault), or the effects of the injury had a profound influence on their self-identity or usual occupations (see also *self as an at-risk resource* section below). The following participant articulated at the 24-month interview how he was still unable to "mentalize" the incident, which was an assault. This affected his ability to "live with" the consequences:

> All your things that happen and come into it and so I haven't had the chance to mentalize them and file them, so it's hard to output what I need to and even little [carrying on with life] things are quite sensitive to what it's to do with. (Matthew, 37 years, mild, 24-month interview)

With regard to the effects of the injury itself, over the course of the two years, the participants with TBI in particular talked about coming to an understanding of what to expect, and coming to terms with the idea that some things would return to how they were before, while others would need to be accommodated:

> I feel better about it, and I know the answer will come back to me. If it's someone I'm talking to I'll just say "just leave that it will come back" and it does. (Mary, 76 years, severe, 24-month interview)

In contrast, as time since the injury extended, issues like the outward invisibility of the effects of TBI and the fact that brain injury is not a "discrete" injury but one that interacted (sometimes extensively) with other areas of life, became more significant. Because of this, having influential people in their lives who recognised the injury as a cause of long-term effects and understood and accepted the changes in their stride became increasingly important. As such, being connected to other people who had a concept of living with TBI that was aligned with that person's experience was key.

Connectedness to others: its utility and its complications. Participants talked about how relational processes – being or becoming connected with other people – can create reference points for understanding TBI recovery and living with TBI. This included people with lived experience of TBI (e.g., other people with TBI or their significant others) and others who had an understanding of aspects of the lived experience (e.g., people who had had similar disruptions in their lives). This connectedness extended to stories of others in the media. For significant others, connecting with others who understood what it was like to be a support person or carer provided the opportunity to talk with someone who was not their injured family member about what they were going through. The connecting needed to be with the right people, in the right format, and at the right time for the individual. Several participants talked about the idea of peer support as something that would be helpful, even when this wasn't available – extending a notion of the importance of personally valued re/connections that was crucial at the 6-month point (McPherson et al., 2017):

> [He's got support from friends and parents] but he still needs support from somebody who's been through it themselves, who can talk to him about it, understanding it. (Mother of Tyler [21 years, severe], 12-month interview)

The participant in the quote below talked about how different his experience of recovery was by 12-months post-injury because of a choice to connect to an ambient social environment which had been familiar to him growing up:

> [Going to home country to stay in a busy community has] been supportive. And yeah, you know, the ambience, because there I was staying alone, in New Zealand. Here you have everyone working around you, so you don't tend to get depressed, if you have people around you. (Gary, 22 years, severe, 12-month interview)

Connectedness to others was also about reciprocity – having the opportunity to help others as well as be helped by others. The participant in the following quote described a relationship that helped him through a very dark period in his recovery:

> One guy I always hung out with, he left the hospital the same day I left […] We've been able to support each other […] so yeah, things are coming right. (Tane, 24 years, severe, 24-month interview)

A lot of discussion of what "support" was and the various forms it took was present in the data from the study. Very early on after the injury, participants distinguished between a type of support that makes them feel "looked out for" and the type that is more focused on doing helpful things. The notion of "being looked out for" permeated throughout the findings as something that mediated a number of experiences – from health services engagement to employment experiences and family relationships. Feeling that a person who mattered in the process (be it a health professional, case manager, employer, or family member) cared enough to be "looking out" for the person with TBI or their close supports was highly valued.

Self as an at-risk resource. Another important process that came through in the participant accounts across the 2-year period was the way in which a sense of self played a variety of roles in recovery and adaptation after the injury. "Self" was talked about as a resource in the sense that life roles, sense of self, and spirituality contributed to how the person with TBI and their loved ones were able to cope with and adapt to the effects of the injury. For example, having a sense of one's self as adaptable, spiritual or having a particular type of life experience helped people navigate their recovery. These aspects of self also contributed to how people made sense of both the incident that led to the injury, and the effects experienced over time. In the quote below, Andrew talked about how his understanding of himself helped him see in a positive way why he didn't immediately take up strategies suggested by health professionals (as opposed to being non-compliant or lazy):

> I suppose some people, you know, someone says something and they say "ok", and they just start doing it, whereas I'm not like that, I don't do things just because people say, you know, I like to try and find out for myself, when something isn't working, then I'll look for a better way. (Andrew, 28 years, severe, 12-month interview)

However, "self" was something that participants also experienced as being "at risk", as their self was (re)constructed within their changed social roles, occupations, and relationships as a result of the injury and its effects. This linked back with the need participants had for what was happening for them as a result of the injury to be recognised and acknowledged, and for others to genuinely believe and (for significant people) seek to understand their experiences. A lack of recognition, acknowledgement, belief and/or understanding could lead to significant disruption to people's sense of self, and therefore to the resources that this sense of self entailed for adaptation and recovery:

> My best friend, we've been friends for over 10 years [said] "you just made yourself so distant, you hid everything" and I didn't realize I was doing it because I'm not a secretive person, I'm so honest […] she found it hard to cope with because you are not the person she knew. So again I think the biggest thing is making people understand what it's like, and that we're not intentionally doing it to people – pushing them away, it's just us without realizing. Yeah, and they [friends] can find ways to make it better for us. (Hannah, 17 years, severity unknown, 12-month interview)

Discussion

The findings presented here should be viewed as an overview of study findings from the perspective of drawing out key clinical implications from the longitudinal analysis. This research upholds and reinforces findings of recent studies showing a clear need to address disruption to lives and selves as an effect of TBI across the severity spectrum (mild to severe), and this as an ongoing process spanning years rather than months for many individuals (Couchman, McMahon, Kelly, & Ponsford, 2014; Knox, Douglas, & Bigby, 2016; Salas, Casassus, Rowlands, Pimm, & Flanagan, 2017; Sveen, Soberg, & Ostensjo, 2016). In taking a longitudinal approach across the first two years post-TBI, our study found that there were many ways of recovering, coping with and adapting to the effects of TBI for injured people, their families and whānau. However, our analysis identified that *making room for recovery* in different ways as things changed, and *cultivating important resources* (requiring an array of both information and supports) were valuable processes across participants and the variability in their injury characteristics and experiences, even though they might be enacted in different ways. Perhaps surprisingly, participants with injuries classified as "mild" described engaging in remarkably similar processes when it came to re/adapting to life as those with moderate and severe injuries – hence we did not separate these out in our analysis and interpretation. Identifying these as overarching needs could provide a useful framework for supporting people during the first two years following the injury across all injury severities.

The various processes that contribute to recovery and adaptation identified in the present study also further support findings from studies that have focused on aspects of long-term recovery and adaptation such as reconstruction of self-identity and life roles, and the importance and complexities of social connectedness (Gelech & Desjardins, 2011; Levack et al., 2010; Martin, Levack, & Sinnott, 2015; Nichols & Kosciulek, 2014; Salas et al., 2017; Sveen et al., 2016; Thomas, Levack, & Taylor, 2014). Our study brings together these and other elements in a way that offers a new conceptualisation of what recovery and adaptation after TBI entails over time from the perspectives of those living it (people with TBI and significant others). In particular, we highlight central issues around which supports may be organised to appropriately support individuals and their families and whānau in this process. This includes a clear need to revisit, revise and re-evaluate strategies and supports over time.

Participants in our study were drawn from one particular geographical area (North Island of New Zealand) which may be considered a limitation to findings. However, other studies that have explored elements of TBI recovery and adaptation in-depth across various countries show resonance with our findings, as discussed in this section. Whilst bringing together findings from the study as a whole necessarily sacrifices focused consideration of particular aspects of the experience of participants at any one time-point, it allowed a different type of richness and complexity to surface. Sub-analyses and secondary analyses on pertinent topics will address this further, for example a secondary analysis concerning sleep issues has already been undertaken (Theadom et al., 2016). Further, the study team is working on dissemination initiatives to provide both analyses and data together in an accessible way (e.g., online and mobile resources).

Although *making room for recovery* and the processes of *cultivating important resources* were discussed separately in the findings, there is a clear connection between these two aspects. For example, it seems likely there may be ways of supporting people to confront the complexities of acceptance and the complications caused by the tangle of symptoms (and competing demands for significant others), while concurrently helping them develop their concept of living with TBI. Such a resource could assist people to make informed decisions about these challenges.

Findings have clearly highlighted the importance of supporting a whole family system to develop a concept of TBI recovery, and a way of living with TBI, that is productive and supportive. However, this may be enormously difficult to do because of the nature of TBI. In the months (and years) following a TBI, participants and their significant others became consumed with (and at times exhausted by) coping and adapting. Thus, it is perhaps unsurprising people feel difficulties are intensified from lack of basic knowledge about TBI effects and recovery process (see also Gagnon, Lin, &

Stergiou-Kita, 2016). Existing acknowledgement, belief and understanding from friends, neighbours, health professionals, and others, seemed to suggest a greater chance that people in the midst of recovery and adaptation would receive the support and resources required. There are various ways in which this could be encouraged, and there would be value in pursuing more than one avenue.

Some studies have explored family involvement and even multi-family group intervention in the context of rehabilitation (Couchman et al., 2014; Forster et al., 2012; Kreutzer, Marwitz, Godwin, & Arango-Lasprilla, 2010). These interventions appear to support the development of shared conceptualisations of TBI recovery and/or living with TBI, and could arguably accelerate the process of developing these "resources." In the case of multi-family group therapy, the study by Couchman et al. (2014) found that the connectedness to people with lived experience outside their own family facilitated the sense of supportive connectedness through the experience of being believed and understood (resonating with the present study), and also opportunities for reciprocity. Peer mentoring has also been argued to achieve similar aims, albeit on a more individual scale (Hibbard et al., 2002).

Even with these sorts of supports in place, several recent studies emphasise that social interactions and relationships with people outside of the immediate family can be extremely difficult for people with acquired brain injury because the general public have little concept of what it is like to live with a brain injury. Social isolation is experienced, and social connections are found most easily with those who have lived experience (Couchman et al., 2014; Nichols & Kosciulek, 2014; Salas et al., 2017) or people in caring roles (Douglas, 2013). Alongside our findings about the importance for recovery and adaptation of having concepts of TBI recovery and living with TBI, this suggests that there is a need to help the general public become more aware of everyone's role in helping people recover and adapt after injury. Part of this would be in providing resources about living with TBI that they can easily access, to facilitate recognition, acknowledgement, belief and understanding of the everyday experiences of life after TBI. In turn, this may enable the GP, the case manager, the physiotherapist, and so on, opportunity to develop a better understanding about the experience of living with TBI in conjunction with their more clinical knowledges of the effects of TBI. It is conceivable that this may help mitigate some of the difficulties participants described with the communication of uncertainty about treatment outcomes.

Lastly, the concept of self as a resource for recovery and adaptation, yet one that is perpetually at risk, is important in the context of recent work exploring identity change and reconstruction after TBI. Previous work has focused on the extent and importance of changes in identity and sense of self and personhood after TBI (e.g., see Levack et al., 2014), while our findings contextualise this in terms of the role identity could play in recovery and adaptation, strongly supporting the notion articulated by Gelech and Desjardins (2011) that "self is an important symbolic arena in which the survivor's postinjury existence is negotiated" (p. 62). In particular, if this aspect of the injury is acknowledged appropriately and the process of dealing with changes is supported positively, this could powerfully enable people in developing and maintaining resources that help them recover from and live with TBI.

For practitioners specifically, who are dealing with the complexity of individual circumstances on a daily basis, this overarching picture could help to structure thinking about plans and review how rehabilitation and support services are being delivered over time. The knowledge that people have to continuously *make room for recovery* and *cultivate important resources* in ways that are meaningful to them in the context of their lives (and the discussion of how that might look for different people at different points in time) offers a way of framing what may be going on for a particular individual. In this discussion section, we have also offered some specific ideas regarding resources which may help operationalise these findings drawn from broader research in TBI.

Conclusion

The findings presented here support and extend the existing literature concerning TBI recovery and adaptation. While previous studies have focused on exploring particular aspects such as symptom impact, self-identity reconstruction, and negotiation of life roles, the overarching themes of this longitudinal study of a heterogeneous population offer critical insight into how these elements, and others, fit within a picture of recovery. The conceptualisation of recovery and adaptation from these findings could offer a framework for informing both future research about social processes of recovery and adaptation in this population, and the goals and structures of supports and services to optimise outcomes across the first two years post-TBI.

Note

1. Whānau is a Māori (indigenous language of New Zealand) term referring to an extended “family” and may involve networks of families that are closely related socially and economically.

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