

Wrestling with uncertainty between knowledge and experience after mild traumatic brain injury (MTBI)

A mixed methods study

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☐ Participants

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☐ Co-Investigators

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Background

- ❑ Education early after MTBI has some support
- ❑ MTBI symptoms can persist for some
- ❑ Educational information may have limited impact for this group
- ❑ Impact of mismatch between educational information and individual's own experiences/expectations?



Objectives of study¹

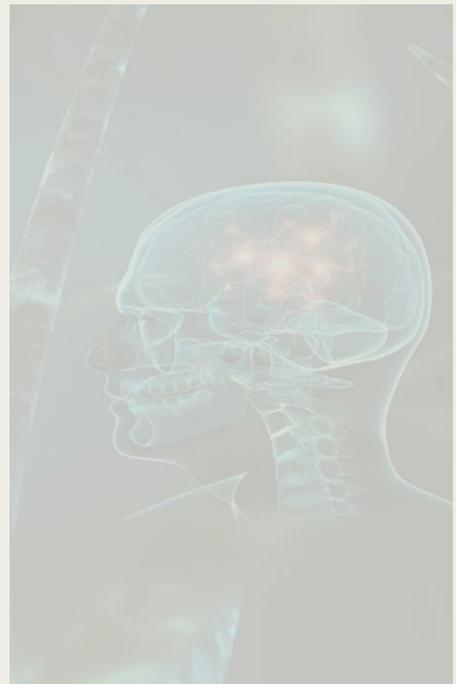
- ❑ “To explore recovery experiences and injury understandings in people who had either recovered or not recovered from an MTBI, using both quantitative and qualitative methods”
- ❑ “To investigate whether more in-depth analysis of participant experiences might extend quantitative evidence regarding the impact of early educational interventions on recovery from MTBI”

1. Snell et al., 2018. Wrestling with uncertainty after mild traumatic brain injury: a mixed methods study. Disability and Rehabilitation (in press)



Design, Participants and Setting

- ❑ Cross-sectional case control study with quantitative and qualitative data collected and analyzed concurrently
- ❑ Recruited from a Concussion Service in New Zealand more than six months after an MTBI
- ❑ Participants matched on age (± 5 years), gender, ethnicity and injury severity
- ❑ Participants (n = 76)
 - *Non-recovered group [NRG: n = 45, mean age 47.6; 58% female]*
 - *Recovered group [RG: n = 31; mean age 42.4; 55% female]*



Results Summary^{1,2}

- ❑ Non recovered participants
 - *Endorsed more anxiety and depressive symptoms*
 - *Held more negative expectations about their recovery (IPQ-R)*
 - *Felt less certain about their diagnosis (IPQ-R)*
 - *Endorsed greater use of avoidance and acceptance coping strategies (Brief COPE)*
 - *Engaged in limiting behaviours (BRIQ Limiting Behaviours subscale)*
- ❑ Qualitative findings highlighted participant attempts to better understand their recovery



1. Snell et al., 2017. What's wrong with me? seeking a coherent understanding of recovery after mild traumatic brain injury. *Disability and Rehabilitation*. 39(9):1968-75
 2. Snell et al., 2018. Untangling chronic pain and post concussion symptoms: the significance of depression. *Brain Injury*. Feb 1:1-10 [Epub ahead of print]

Wrestling with Uncertainty

- ❑ Participants attempted to integrate their internal experiences of injury recovery with external information received from other sources
- ❑ If there was a mismatch across sources, participants described increased anxiety and confusion about their health
- ❑ Four meta-sub-themes captured the essence of where the 'wrestling' with uncertainty was located:
 - *(not) knowing what is/was wrong*
 - *(not) knowing what to expect*
 - *(not) knowing if I've recovered*
 - *(not) knowing how symptoms could be managed*



(Not) knowing what is/was wrong

Meta-theme Overview:

Confusion and uncertainty about symptoms and diagnosis increased distress.

"I had an old friend who had a head injury and a year later, he actually died on the operating table because they found a brain tumor and I think "Gosh, maybe it's a brain tumor" ..."

(P 5: Male, Non recovered Group).



(Not) knowing what is/was wrong

It was mostly the concussion (causing the headaches). Like I'm pretty confident about that 'cos I see my muscle ache as contributing to the whiplash, like I felt a difference there ... but the headaches were different ...

(Participant 6: Female, Recovered Group).



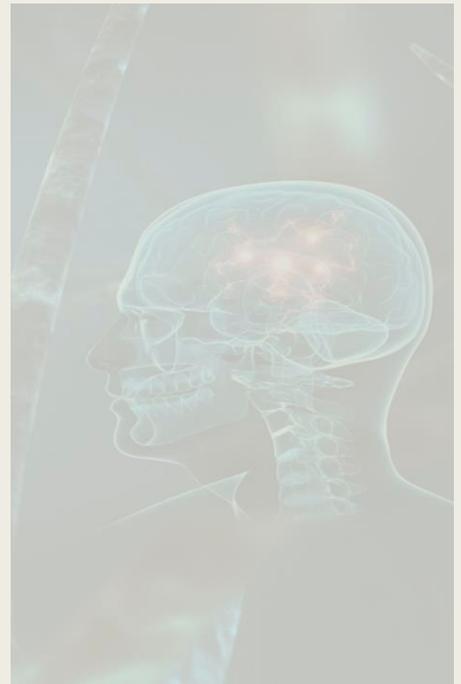
(Not) knowing what to expect

Meta-theme Overview:

Importance of knowing what to expect and how long it would all take. Uncertainty about recovery appeared associated with increased distress.

“Well, it was confusing, at one stage, we were going for early medical retirement, but my doctor wouldn't sign it off because there was still a possibility that the head injury might come right”

(P 1: Male, Non Recovered Group).



(Not) knowing what to expect

“Just to have that reassurance that what you were feeling and those kind of things that you experience are quite common and real... and it helped knowing that I was going to get better”

(P 8: Male, Recovered Group)



(Not) knowing if I've recovered

Meta-theme Overview

Determining recovery - participants described feeling uncertain about whether they had recovered or not. Both groups discussed taking their lead from others.

“I don't know, I really don't know. I used to come to appointments, I used to say to my boss and that, “How do you think I am?” and see how they saw me, people around me, compared to how I saw myself. So, yeah, it was just ... I really took my lead from them, from how they saw me because I didn't know...”

(P 4: Female, Non Recovered Group).



(Not) knowing if I've recovered

I remember saying to mum "I thought I was OK," you know. And she reassured me, "Well, you are probably OK but you know, you're not quite a hundred percent. Give it a little bit more time and it'll be for your benefit"

(P 8: Male, Recovered Group).



(Not) knowing how symptoms could be managed

Meta-theme Overview

Having strategies to manage their symptoms - non recovered participants appeared less confident and more concerned about making their symptoms worse by 'getting it wrong.'

"It's good to be told stuff. Up 'til then, it had been hazy ... I didn't want to do anything that was going to make me more tired or feel worse."

(P 3: Female, Non Recovered Group)



(Not) knowing how symptoms could be managed

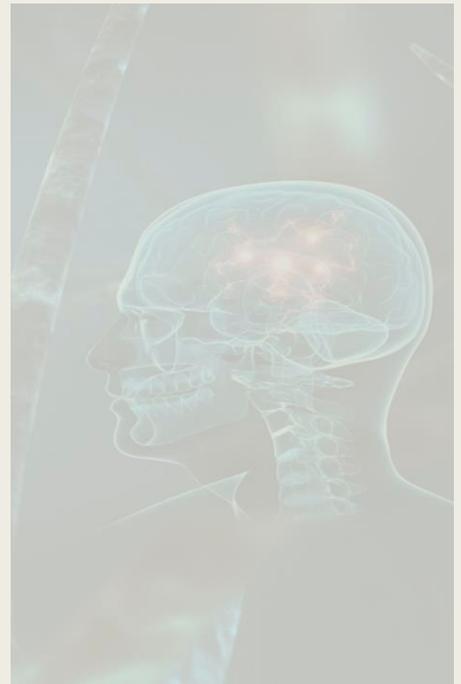
She [occupational therapist] gave me this sheet which had like my battery levels which I found really helpful. It's like "Where am I at? How am I gonna get my battery up?" It was just really helpful for me to have that visual aspect of where I was at...

(Participant 6: Female, Recovered Group).



Summary/ Discussion

- Consider interpretations made of educational information
- Consider how this information fits with experience and knowledge gained from other sources
- Conflicting information may set the stage for significant uncertainty
- Uncertainty can be distressing and risk invalidation



Implications for Rehabilitation

- ❑ Education and reassurance after MTBI may be optimised:
 - *When content is tailored to the individual*
 - *Subjective interpretations of information from formal and informal, internal and external sources are considered*
 - *Uncertainty regarding the diagnosis, expectations of recovery, and coping strategies, may offer specific targets for intervention*



Thank you for listening

Are there any
questions?

