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Establishing a person-centred framework of self-identity after traumatic brain injury: a grounded theory study to inform measure development

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ABSTRACT

Objective: To develop a theoretically sound, client-derived framework to underpin development of a measure reflecting the impact of traumatic brain injury (TBI) on a person's self-identity.

Design: Grounded theory, based on transcription of audio recordings from focus group meetings with people who have experienced TBI, analysed with constant comparative methods.

Setting: 8 different urban and rural communities in New Zealand.

Participants: 49 people (34 men, 15 women), 6 months to 36 years after mild-to-severe TBI.

Results: The central concept emerging from the data was that of desiring to be or having lost a sense of being an integrated and valued person. The three main subthemes were: (1) having a coherent, satisfying and complete sense of oneself, (2) respect, validation and acceptance by others and (3) having a valued place in the world.

Conclusions: This study reinforces the notion that change in self-identity is an important aspect of life after TBI, and provides information on what this concept means to people with TBI. In order to scientifically evaluate relationships between self-identity and other aspects of health (eg, depression, quality of life), and to test the effect of interventions to address problems with self-identity after TBI, a quantitative tool for evaluation of this construct is required. Themes from this research provide a foundation for the development of a measure of self-identity grounded in the language and experience of people with TBI.

Strengths and limitations of this study

- This study provides a theoretically sound foundation for the development of a measure of self-identity for people with traumatic brain injury (TBI), grounded in the language and experiences of people with TBI.
- Decisions regarding selection of participants for this study (who ranged in age, severity of injury and time since injury) increase the possible transferability of the study findings to other people with TBI, but restrict its specificity to particular life situations (eg, self-identity issues specific to young adults with TBI).
- Self-identity is culturally and historically situated, so the transferability of the study findings may be limited in non-Western countries.

INTRODUCTION

Evaluation of the effectiveness and cost–benefit of rehabilitation programmes is based on use of standardised outcome measures. It is therefore fundamental to decide which measures address outcomes of most importance. Selection of measures in any clinical context is dependent in part on the values ascribed to different outcomes, and in this regard, it has been noted that 'disabled people neither share the same priorities, preoccupations or perceptions of problems as their healthcare providers' (ref. 1, p.137). In order to identify outcomes that reflect the experiences of people with traumatic brain injury (TBI) we completed a qualitative metasynthesis of all research published between 1966 and June 2009 reporting on the lived experience of recovery and outcome following TBI.[2] In our review, 23 studies were identified representing the lived experiences of 263 people with TBI, and were included for data collection and analysis.

A key finding from this metasynthesis was that *loss* and *reconstruction* of self-identity and personhood were recurring themes in the narratives of people talking about their experiences of surviving TBI.[2] Data from this metasynthesis indicated the influence of

possible factors on change in self-identity including (1) loss of connection with one's body, (2) loss of memory of significant periods of life, (3) loss of one's place in the world and (4) existential crisis directly arising from brain injury, for example, a loss of sense of internal unity. What was missing from the results of this meta-synthesis however, and from the papers underpinning it, was a clear framework linking these themes and factors together for the purposes of clinical evaluation of self-identity after TBI.

It has been increasingly suggested that alterations to self-identity are associated with depression, anxiety, lower quality of life and a reduction in hope for a positive future.[3–5] A number of authors have begun extensive discussions on how these issues could be addressed in the clinical environment.[3–16] However, further research into the prevalence and impact of problems with self-identity, or on the effectiveness of rehabilitation interventions to positively influence self-identity after TBI, is currently limited by a lack of tools for operational evaluation and quantification of this construct.[2]

We therefore undertook a qualitative study that looked specifically at the recovery experiences of people with TBI regarding change in self-identity. We acknowledge from the outset that a number of established theories have already been proposed to account for the sense of loss or change in self-identity following disabling health conditions. These include Self-Discrepancy Theory,[4] Social Identity Theory,[7] Narrative Theory and theories of biographical disruption,[11][17] Relational Frame Theory,[14] Possible Selves Theory[10][18] and Erikson's stages of psychological development.[19] However, these theories are not specific to TBI nor do they immediately translate into measurement tools for clinical research. Furthermore, we did not wish to assume that all relevant factors associated with change in self-identity after TBI had already been identified. Therefore, for this study, we chose to draw on first person experiences, grounding the development of any new measurement items in the language of people who had survived and experienced life after TBI. Grounded theory was chosen as the

methodology for this work because of its emphasis on precisely this notion: the inductive development of theoretical frameworks regarding lived experiences from data (as opposed to starting with a theory or hypothesis that is then tested deductively through experimental methods).[20]

This study was intended as the first step in a programme of work developing a theoretically sound, psychometrically robust measure, grounded in the language used by people with TBI to describe and understand the impact of their injury on their self-identity. An overview of the planned process for measure development is provided in figure 1, although the study reported here refers to just the first step in this process. Specifically, the aim of this research was to develop a conceptual framework for the operationalisation of impact of TBI on self-identity, with the intent of using this framework to create measurement items in the future.

METHODS
Research design
This study employed grounded theory[20] to investigate the experiences of change and reconstruction of self-identity after TBI. Data collection involved focus group meetings with people who had survived TBI.

Participant selection and recruitment
To be included in the study, participants were required to be adults who had experienced a TBI after the age of 16, who had sufficient communicative abilities to contribute to a chaired group discussion and who reported experiences of personal or social changes resulting from TBI (even if these had subsequently resolved). Participants were required to be at least 6 months postinjury, but we also included people with decades of experience of life after TBI to ensure a breadth of perspectives. Participants were recruited from eight different regions in New Zealand via local organisations that supported people with TBI and their families in the

Figure 1 Planned process for measure development. TBI, traumatic brain injury.
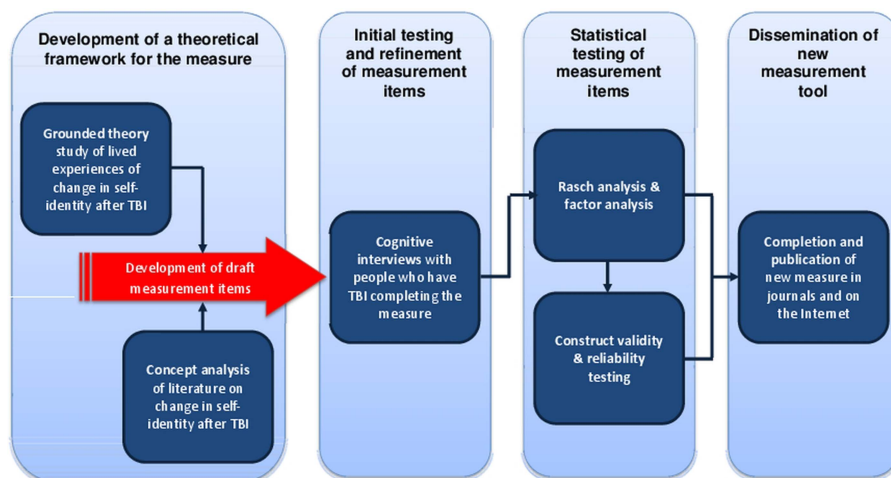
community. Purposeful sampling[20] was used to recruit people with TBI from a range of different backgrounds including men and women, people from urban and rural localities, different age groups, different ethnic backgrounds and people with different lengths of time since injury. As TBI is a particular problem for the Māori (the indigenous people of New Zealand), who have a much higher incidence of sustaining TBI compared with the non-Māori in New Zealand,[21] strategies were implemented to increase opportunities for the Māori to participate in this study. This included establishing two Māori-only focus groups in regions with proportionally higher Māori populations and with observance of tikanga (Māori protocol) during the meetings in order to create a respectful research environment and to facilitate participant connection with the research process.

Data collection

Written informed consent was obtained from all participants prior to data collection. One focus group meeting was held in each of the eight regional centres, with between four and nine participants per meeting. All focus groups were attended by two researchers (WMML and PB), with one researcher facilitating and chairing the meeting and the other researcher taking field notes, managing the audio recording and addressing any problems that participants had during the course of the meetings.

Each meeting lasted 90–120 min, with refreshment breaks after the first hour. Participants were invited to bring a support person along to the meeting. The role of these people was expressly to facilitate the participants voicing their own views rather than the support people contributing directly to the discussion. On the few occasions where support people did express their views during meetings, these were acknowledged, but were not included in the analysis.

During the meetings, the participants were invited to talk about how TBI and its consequences had (or had not) influenced their sense of who they were as people. This was summarised for participants as follows: "We are interested in how brain injury and life after brain injury affected: your sense of who you are as a person, your sense of identity, your sense of self, or what makes you 'you'?" Participants were also encouraged to discuss factors that they thought helped them or others regain a positive sense of self-identity after TBI and to introduce any other issues they felt were related to the topic. The focus group discussions were digitally recorded and transcribed verbatim.

As one of the principles underpinning this research, we wished to recognise the participants as experts in life and disability after TBI.[1] To do this, we stated at the beginning of each meeting that this was our intent, and we gave a $NZ50 gift voucher to each participant for their contribution to reflect this position. Reimbursement was also provided for travel expenses.

Data analysis

Consistent with the constant comparative method of grounded theory,[20] data analysis occurred concurrently with ongoing data collection. Data from each focus group were transcribed and analysed between meetings, influencing the refinement of questions in subsequent meetings. NVivo software (QSR International) was used to help manage the interview data and data coding. Each transcript was read and re-read, incorporating findings from additional focus groups as the study progressed.[20] Initial coding (open coding) was undertaken on a line-by-line basis, with subsequent analysis exploring the relationships between codes so as to develop higher order concepts.

To strengthen the credibility and trustworthiness of the analysis,[20] the initial coding was first undertaken independently by two researchers (WMML and PB). These two researchers then compared and debated their findings, along with personal reflection on the data collection and study process, before sharing the initial analysis for discussion and peer review with other members of the research team.

Opinion is somewhat divided among grounded theorists regarding the role of previously published literature in data analysis. Some researchers, notably Glaser,[22] have argued against prior reading when engaging in a new study, stating that an atheoretical position needs to be assumed when undertaking inductive qualitative analysis and that prior reading can impede sensitivity to new theoretical ideas. Other researchers, notably Strauss and Corbin[23] and Charmaz,[20] have indicated the value of preconceived theoretical concepts as starting points for looking at new data, but not as a means of providing an automatic framework on which to pin analysis. For this study, we chose to pursue the latter approach.

Negative case analyses—the purposeful exploration of 'instances that do not fit the emerging model' (ref. 24, p.174)—were used to further test and explore the emerging theory. Data collection continued until theoretical saturation, that is, when new data revealed 'no new direction, no new questions, and…no need to sample further' (ref. 24, p.174). The results below are presented with a small number of extracts from the focus group transcripts to illustrate key points. More extensive examples from the transcripts, along with information on the transcription conventions used, are available in the online supplementary appendix.

RESULTS
Overview

Forty-nine people from a range of different backgrounds (34 men and 15 women, aged 21–79 years, who were 6 months to 36 years post-TBI) participated in this study (see table 1). Given the length of time since injury, data on clinical measures of severity of injury (eg, Glasgow Coma Scale or Post-traumatic Amnesia scores) were not available for many of the participants. However,

Table 1 Participant characteristics

Gender	34 men, 15 women
Ethnicity	34 New Zealand European (1 who also identified in part as Samoan), 13 Māori (5 of whom also identified in part with one other ethnicity—eg, New Zealand European, Fijian, Chinese), 1 American and 1 Chinese New Zealander.
Age	Average 52.7 years (SD 11.9 years); range 21–79 years
Relationship status	20 married or living with a partner, 13 divorced or separated, 3 widowed, 13 never married
Occupation	31 unemployed (many doing part-time unpaid or voluntary work), 8 retired, 8 in part-time employment or part-time study, 2 self-described as 'home maker'
Highest education level	2 primary school (ie, elementary school), 23 secondary school (ie, high school), 18 undergraduate university, 6 postgraduate university
Age at accident	Average 40.4 years (SD 15.1 years); range 16–77 years
Time since accident	Average 12.7 years (SD 10.1 years); range 6 months to 36 years
Cause of accident	28 road accidents, 11 falls, 3 sports accidents, 3 assaults, 2 work accidents, 1 medical misadventure, 1 aeroplane accident
Duration of loss of consciousness	20 people were unconscious for less than a few hours (3 of whom were not admitted to hospital), 3 unconscious for several hours, 8 unconscious for several days, 18 unconscious for weeks to months
Admitted to hospital on injury?	46 yes, 3 no

participants reflected a wide range of severity of TBI with some people having had self-reported loss of consciousness of less than an hour and no hospital admission, through to those who had had months of hospitalisation and coma. Among the most impaired participants were three people who required 24 h supervision, two wheelchair users and many people who needed extra time or support from others when communicating to express or articulate their views.

The concept of loss or change in self-identity following TBI was one that clearly resonated with the groups involved, although the extent to which TBI was perceived to have changed a person's sense of self differed from individual to individual. Notably, coping with change in self-identity and personhood was an issue that many (but not all) participants continued to struggle with for many years, long after physical recovery from the initial injury had plateaued. For a number of participants, the problem of change in self-identity was not recognised until some years after injury, when formal health professional involvement had often ceased.

> It's probably only in the last year that I've actually accepted that other person [myself prior to my accident] was somebody else, and I'm a new me now. But that's a new thing to me. (Group 3, female, eight years after injury)

The central theme that emerged from this study was that of desiring to be or having lost a sense of being an integrated, valued person. There were three main themes underpinning this core construct:

1. Having a coherent, satisfying and complete sense of oneself;
2. Respect, validation and acceptance by others and
3. Having a valued place in the world.

In other words, our data suggested that in order to recover a robust, coherent and satisfying sense of self-identity after TBI, one needs to (1) regain a strong internal sense of who one is, and to feel like a complete person, (2) be treated like a person of worth by other members of one's community and by society at large and (3) feel like one has a place in the world where one 'fits' and that one values. An overview of these themes and their subthemes is provided in figure 2.

Having a coherent, satisfying and complete sense of oneself

For many participants, TBI resulted in a profound disruption to their sense of wholeness as a person. The abilities, skills and roles previously used by individuals to characterise personal attributes were no longer available to many participants, and loss of these self-descriptors resulted in some participants feeling very uncertain regarding who they were (or had become) after injury. Furthermore, self-knowledge of one's capacity and the life one might lead after TBI remained unclear for a long time (sometimes many years). This was in part due to uncertainty regarding a person's expected level of recovery following injury, but also due to the slow process of coming to terms with what TBI actually meant for them in their lives.

> I mean who the hell am I, you know? Really. I'm a writer, you know, I'm semi-retired so I could you know, write, and I have a book I've been writing from—for years, and now I can't write. So now, who am I? You know.
>
> Researcher: Yeah. So now who are you?
>
> I have no idea, really. (Group 1, female)

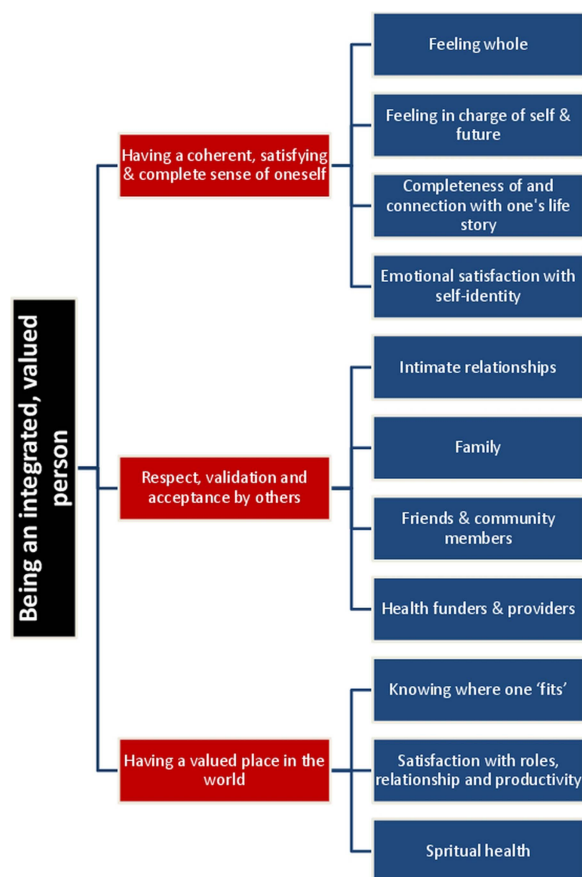A common experience reported by participants was feeling as if one's self-identity had become fragmented.

Figure 2 Overview of key themes related to issues with self-identity after traumatic brain injury.

Some participants spoke of their 'self' prior to TBI and their 'self' after TBI as two separate identities, and the need to resolve this disruption in self-concept.

> I'm probably like Dr Jekyll and Mr Hyde. There's two of us. And I don't get on too well with the other one. And we continually have disputes. (Group 2, male)

Similarly, some participants spoke of feeling as if they had an external identity, which presented to others in the world around them but which did not accurately portray their 'true' identity. These external identities could present acerbically or unpleasantly to others, or behaved in a manner inconsistent with one's perceived 'internal' identity.

Opinion was divided on whether successful recovery after TBI required acceptance of becoming a new person or whether continuing to strive to return to one's life prior to TBI was important. However all participants considered it very important to be in charge of development of one's self-identity after TBI, and that this should be directed by one's own values and preferences and not by those of others (eg, friends, family, health professionals, etc).

The degree of coherence of a person's self-identity appeared to be related to the completeness of his or her personal life story, in the sense of their objective knowledge and subjective experience of it. Some of the most remarkably pronounced disruptions to self-identity were described as resulting from retrograde amnesia and changes in the emotional connection that individuals had with aspects of their life prior to TBI.

> I got home after the accident; it was literally like I'd stepped into somebody else's shoes. I didn't know my wife, I didn't know where home was, and I thought the garage was a mess, and it was, I guess, just as I'd left it. So yeah, it was literally like I'd stepped into someone else's shoes. (Group 5, male)

However, coherence of self-identity seemed connected to the degree to which post-TBI experiences could be meaningfully integrated into one's life story. In this regard, TBI was not just associated with negative factors. Some participants described 'growing' as an individual after TBI, or feeling like a stronger or better person as a result of the injury experience (ie, being more giving, friendlier, being more empathic to those less well-off, etc).

Nevertheless, loss or changes in self-identity were sources of suffering for a number of participants. Significant depression and reports of past suicidal ideation were commonly associated by participants with loss or changes in self-identity. Learning to accept oneself and developing pride in one's achievements and who one had become after injury were described as important steps towards the reconstruction of a positive self-identity.

Respect, validation and acceptance by others

In addition to one's internal sense of self, a number of other key factors were associated with how people with TBI were treated by others, that is, intimate partners (eg, spouses), family, friends, coworkers, health service professionals (including insurance providers), as well as members of the general public. These 'others' could strengthen or undermine an individual's sense of self and their perceived status as a 'person' in society (ie, their sense of personhood).

While many participants discussed the collapse of their intimate relationships following TBI, others attributed at least some recovery of their sense of self to their spouse or to new intimate relationships formed after injury. Relationships with other family members (parents and children in particular) were also considered important to many. Opinion was divided as to whether it was possible for people without TBI to truly understand the lived experience of surviving this injury, but all participants sought validation and acceptance from intimate partners and family members, and when this was not available, expressed a sense of feeling depersonalised as a result.

> One of the difficulties I've got is really the family like accepting me for what I am now. Well it's like instead of

say being you know, the old fashioned head of the house-hold, it's like I'm just a—well not quite a nothing, but just don't have a lot of status. (Group 4, male)

The role of friendships after TBI was a subject of much discussion, with the respect, validation and acceptance provided by good friends contributing significantly to the participants' sense of being valued people. The participants discussed at length the common experience of social networks dramatically reducing after injury. At least part of the breakdown of previously valued relationships occurred for many individuals because of participants choosing to avoid social activities, either due to feeling unable to cope in those situations or due to changes in personal interests after TBI. However, equally, many participants described long-term friends withdrawing their involvement from their lives, with the view that TBI showed you who your 'true' friends were. Regardless of the reasons for these changes, loss and reconstruction of social networks contributed to a sense of having changed as a person, and thus to change in self-identity.

> I went sort of hermit-ish, and didn't want to socialize, 'cos of the way it affected me… Basically became a grumpy hermit… So over that period of a couple of years, people didn't want to know me 'cos I would never socialize. (Group 1, male)

Other social factors that contributed to a sense of changed status as a person related to how participants interacted with and were treated by people in their workplace, members of the general public and health sector employees. Funders (eg, insurers) and providers of TBI services (eg, care providers and health professionals) had the capacity to greatly influence a person's sense of self through their interactions with them. One particularly prominent issue here was when a participant's subjective experience of TBI was contradicted or disputed by funders or providers of health services. This included times when participants' capacity for functioning had been assessed as being much better or much worse than the participants themselves believed it was or experienced it to be. A number of participants reported occasions when they felt it had been implied (either directly or indirectly) that they were not applying themselves sufficiently to their recovery, were malingering or were even being fraudulent in their need for continued disability support or compensation. While these labels were frequently resisted, such experiences were invalidating and made participants question their own beliefs regarding who they were as individuals (ie, their integrity, their worth or their resilience). Conversely, being told by health professionals that one was not capable of achieving more in one's life after TBI (eg, in the workplace) could also significantly undermine a person's sense of self. Likewise, being treated disrespectfully by care providers, or being treated like a number or a case file rather than a person by insurance or health professions, were dehumanising experiences for the participants.

> I was thinking about medical people and [insurance managers], and things like that, when they dismiss you, or are patronising, or want to boot you, what that does to your sense of self is incredible…I don't get depressed easily, but I been suicidal a couple of times because of that. (Group 1, female)

Having a valued place in the world
Associated with social relationships was the notion of the importance of 'place' in the development of a robust, coherent sense of self-identity after TBI. For the participants in this study, 'place' did not refer so much to the physical environment in which they resided (although for a few people this was significant), but to a more abstract concept of one's place in the world. For some participants, TBI was followed by loss of one's previous place in society, then by a more extended period of trying to find a new place to 'fit'. Importantly, for reconstruction of self-identity to be satisfying, this new place had to be one that was valued by the individual, even if it was considerably different to their preinjury place in the world.

> And I think for me, yeah, I'm a very different person to who I was. I think it's- myself, you know, inside, is still me, but it's the- who I am in society, where I fit, that's what I don't know any more now. (Group 5, female)

Having a valued place in society related to one's social roles and to the ways in which a person felt productive or contributed to the lives of others. Maintaining a vocational identity was extremely important to some individuals, and among those who did not have paid employment, a large proportion still undertook regular unpaid work or strived to give of themselves in other ways (eg, cooking for elderly neighbours, supporting a friend in need or helping others new to the TBI experience).

Finally, for a few participants, one's place in the world was intimately linked to spiritual beliefs. For reconstruction of self-identity to be successful, the consequences of TBI had to make sense from a spiritual perspective. For some, the recovery experience had strengthened spiritual beliefs, and spiritual beliefs had in turn provided a framework for understanding life after TBI, making restoration of self-identity easier. For at least one other, however, TBI had resulted in spiritual crises, raising questions regarding whether this individual had failed to understand his role in life, and therefore his place in the world.

> So I wasn't only failing myself, I was failing my lord… And that was—another religious term, I suppose, but soul destroying… I still have the sense of failure and so on, which was a constant spiritual exercise for me, and the just striving to you know, again, in these religious terms, to serve my god better. And yes, redeem myself. (Group 6, male)

DISCUSSION

The results from this study advance understanding of the concept of change in self-identity after TBI and, more specifically, identify elements relevant to the experiences of people with TBI that could usefully contribute to a better understanding of that construct as a health outcome. Importantly, the findings from this study also provide a useful structure around which these elements can be grouped for the purposes of clinical evaluation and measurement development. At the top most level these elements relate to: one's internal sense of self; sense of self as arising from social interactions with others and sense of self as arising from one's experience of 'place' in the world. Notably, the notion of change in self-identity was something participants in this study found meaningful and stimulating. Eliciting data on this topic was relatively straightforward from mildly and severely impaired individuals, despite what might seem the abstractness of the concept.

While the results from this study could potentially have wider appeal than just to populations of people with TBI, the structure of our findings is naturally influenced by the choices we made as researchers, regarding which types of people we talked to and when we spoke to them. It has been argued that even the idea of possessing an individual identity is culturally and historically situated.[25] Any outcome measure resulting from this study is not necessarily going to be relevant to all people with TBI worldwide, with a particular question regarding relevancy for people in non-Western countries. Likewise, experiences of self-identity are likely to be influenced by life stage.[26] Our decision to recruit people with TBI from a wide range of ages produced findings that are more transferrable across life stages, but potentially reduced the specificity of findings relevant to particular life circumstances (such as during young adulthood for instance).

Our study could also be criticised for mixing data from people who have mild TBI with those who have moderate to severe TBI. While epidemiological studies support the assertion that mild TBI can for some people result in moderate to severe disability[27 28] (and indeed that the 'magnitude and societal ramifications [of mild TBI] are often underestimated' (ref. [29], p.489)), it is not necessarily the case that mild TBI will have the same type of impact on self-identity as does moderate or severe TBI. Furthermore, differences in presentation in terms of cognitive impairments and self-awareness may have influenced the type of data we gathered based on self-report from people with mild versus more severe forms of brain injury.

One additional consideration in this regard is the difficulty inherent in trying to evaluate the severity of a person's initial injury on the basis of historical records and self-report. In this study, we included three participants who were not admitted to hospital and who were only reported as having been unconscious for a short period. However, in all three cases, the TBI event (a car accident in two cases and a fall off a ladder for the third) was unobserved as the participants had been alone at the time. Furthermore, when the individuals in question first recovered consciousness, they did not immediately seek medical attention despite, or perhaps because of their state of confusion following their TBI. The actual severity of injury, including duration of confusion or post-traumatic amnesia, was therefore never assessed for these people. A prospective, longitudinal qualitative study could therefore have produced more robust data in terms of linking self-reported lived experiences to formal clinical assessment of severity and type of injury. However, such an approach would have been considerably more difficult from a pragmatic perspective, particularly when trying to seek input from people five or more years following TBI.

The findings from this study are in many ways consistent with previous TBI research.[3–16] Other researchers have also reported that loss and reconstruction of self-identity is an essential yet complicated variable to consider following TBI; that it is related to factors such as changes in functional abilities, social roles and perceived social status; that development of self-knowledge following TBI is difficult but crucial for successful restoration of a coherent self-identity and that self-identity is affected by thoughts about oneself and by interactions with other individuals or institutions in society.[2 3 15 30] Disruption of life narratives, including those resulting from loss of memory or lost emotional connections with people and things from the time prior to injury have also been identified as component parts of changes in self-identity following TBI.[3 8 15] Already interventions exist that could potentially have some positive influence over the reconstruction of self-identity after injury,[8 31 32] but again, some way of quantifying changes in self-identity is required in order to test the specific effects of such interventions.

Also of note is how findings from our study align with past research on the phenomenon of post-traumatic growth following TBI.[33–35] While only a small part of our total study findings, these reported experiences of positive psychological development following TBI should serve as a reminder regarding the potential complexity of interactions between trauma, loss, stress, coping, individual sense-making and personal growth following injury. It has been proposed that rather than focusing solely on 'fixing' problems, such as impairments (that may indeed be ultimately unresolvable for some people), it could be beneficial to place greater attention in rehabilitation on building on an individual's strengths and on fostering opportunities for post-traumatic growth.[35] Research in this area of clinical practice is however still very much in its infancy.

In terms of the future development of a measure of change in self-identity following TBI, our intention from here is to operationalise the concepts emerging from this study into measurement items, using the Patient-Reported Outcome Measurement Information

System Cooperative Group's guidelines[36] to develop and test these items prior to further statistical refinement (see figure 1). There will be a number of challenges associated with development of such measurement items. For example, data from this study suggest that there are multiple ways of being content with one's self-identity after TBI, and caution would be required when designing a measure in order to avoid being judgemental regarding the 'right' ways of recovering. As demonstrated by this study, change in self-identity after TBI is not necessarily negative in itself. Indeed, people can be expected to grow, adapt and develop throughout their lives, regardless of injury or disability. Similarly, while acceptance of change was considered by many participants to be important, unconditional acceptance of impairment or related difficulties is unlikely to be conducive to positive formation of a self-identity after injury, and some participants resisted outright the notion of having to simply accept their lot following TBI.

CONCLUSIONS

Results from this study support the notion that change in self-identity is a meaningful concept for people who have experienced TBI and one that is worth attempting to measure. Strength of, coherence of and satisfaction with self-identity are constructs that many people struggle with after TBI. In this study, difficulty with self-identity was associated for some participants with emotional suffering, depression and lower quality of life. Finding ways to clinically evaluate and quantify perceptions and experiences associated with self-identity is required in order to further advance and test hypotheses related to loss and reconstruction of self-identity after injury. The results from this study provide a theoretical foundation for the future development of such a measurement tool.

Data sharing statement Extra data (more detailed transcripts of focus group meetings, edited to preserve anonymity) are available by emailing: william. levack@otago.ac.nz.

REFERENCES

1. Hammell KW. *Perspectives on disability and rehabilitation: contesting assumptions; challenging practice*. Edinburgh: Elsevier Limited, 2006.
2. Levack WMM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disabil Rehabil* 2010;32:986–99.
3. Muenchberger H, Kendall E, Neal R. Identity transition following traumatic brain injury: a dynamic process of contraction, expansion and tentative balance. *Brain Inj* 2008;22:979–92.
4. Cantor JB, Ashman TA, Schwartz ME, *et al*. The role of self-discrepancy theory in understanding post-traumatic brain injury affective disorders: a pilot study. *J Head Trauma Rehabil* 2005;20:527–43.
5. Carroll E, Coetzer R. Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol Rehabil* 2011;21:289–305.
6. Douglas JM. Social linkage, self-concept, and well-being after severe traumatic brain injury. In: Jetten J, Haslam C, Haslam SA. eds. *The social cure: identity, health and well-being*. Hove and New York: Taylor & Francis Group, 2012.
7. Gracey F, Ownsworth T. The experience of self in the world: the personal and social contexts of identity change after brain injury. In: Jetten J, Haslam C, Haslam SA. eds. *The social cure: identity, health and well-being*. Hove and New York: Taylor & Francis Group, 2012:273–95.
8. Morris SD. Rebuilding identity through narrative following traumatic brain injury. *J Cogn Rehabil* 2004;22:15–21.
9. Ylvisaker M, Feeney T. Reconstruction of identity after traumatic brain injury. *Brain Impairment* 2000;1:12–28.
10. Ylvisaker M, McPherson K, Kayes N, *et al*. Metaphoric identity mapping: facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychol Rehabil* 2008;18:713–41.
11. Doering BK, Conrad N, Rief W, *et al*. Living with acquired brain injury: self-concept as mediating variable in the adjustment process. *Neuropsychol Rehabil* 2011;21:42–63.
12. Fotopoulou A. False selves in neuropsychological rehabilitation: the challenge of confabulation. *Neuropsychol Rehabil* 2008;18:541–65.
13. Hoogerdijk B, Runge U, Haugboelle J. The adaptation process after traumatic brain injury: an individual and ongoing occupational struggle to gain a new identity. *Scand J Occup Ther* 2011;18:122–32.
14. Myles SM. Understanding and treating loss of sense of self following brain injury: a behavior analytic approach. *Int J Psychol Psychological Ther* 2004;4:487–504.
15. Nochi M. "Loss of self" in the narratives of people with traumatic brain injuries: a qualitative analysis. *Soc Sci Med* 1998;46:869–78.
16. Yeates GN, Gracey F, McGrath JC. A biopsychosocial deconstruction of 'personality change' following acquired brain injury. *Neuropsychol Rehabil* 2008;18:566–89.
17. Hogan BA. Narrative therapy in rehabilitation after brain injury: a case study. *Neurorehabilitation* 1999;13:21–5.
18. Heller W, Mukherjee D, Levin RL, *et al*. Characters in contexts: identity and personality processes that influence individual and family adjustment to brain injury. *J Rehabil* 2006;72:44–9.
19. Coetzer R. Holistic neuro-rehabilitation in the community: is identity a key issue? *Neuropsychol Rehabil* 2008;18:766–83.
20. Charmaz K. *Constructing grounded theory*. London: Sage Publications Ltd, 2006.
21. Feigin VL, Theadom A, Barker-Collo S, *et al*. Incidence of traumatic brain injury in New Zealand: a population-based study. *Lancet Neurol* 2013;12:53–64.
22. Glaser BG. *Emergence vs forcing: basics of grounded theory analysis*. Mill Valley, CA: Sociology Press, 1992.
23. Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks: Sage Publications, 1998.
24. Morse JM, Richards L. *Readme first for a user's guide to qualitative methods*. Thousand Oaks: Sage Publications, Inc, 2002.

25. Sullivan M, West-Newman CL. Being: identity. In: Matthewman S, West-Newman CL, Curtis B, eds. *Being sociological*. New York: Palgrave Macmillan, 2007.
26. Erikson EH. *Childhood and society*. New York: W W Norton Company, 1963.
27. Thornhill S, Teasdale GM, Murray GD, *et al*. Disability in young people and adults one year after head injury: prospective cohort study. *BMJ* 2000;320:1631–5.
28. Whitnall L, McMillan TM, Murray GD, *et al*. Disability in young people and adults after head injury: 5–7 year follow up of a prospective cohort study. *J Neurol Neurosurg Psychiatry* 2006;77:640–5.
29. Feigin VL, Barker-Collo S, Krishnamurthi R, *et al*. Epidemiology of ischemic stroke and traumatic brain injury. *Best Pract Res Clin Anaesthesiol* 2010;24:485–94.
30. Conneeley AL. Transitions and brain injury: a qualitative study exploring the journey of people with traumatic brain injury. *Brain Impairment* 2012;13:72–84.
31. McPherson KM, Kayes N, Weatherall M. A pilot study of self-regulation informed goal setting in people with traumatic brain injury. *Clin Rehabil* 2009;23:296–309.
32. Patterson FL, Staton AR. Adult-acquired traumatic brain injury: existential implications and clinical considerations. *J Ment Health Couns* 2009;31:149–63.
33. McGrath JC. Posttraumatic growth and spirituality after brain injury. *Brain Impairment* 2011;12:82–92.
34. Ownsworth T, Fleming J. Growth through loss after brain injury. *Brain Impairment* 2011;12:79–81.
35. Rogan C, Fortune DG, Prentice G. Post-traumatic growth, illness perceptions and coping in people with acquired brain injury. *Neuropsychol Rehabil* 2013;23:639–57.
36. DeWalt DA, Rothrock N, Yount S, *et al*. Evaluation of item candidates: the PROMIS qualitative item review. *Med Care* 2007;45(Suppl 1):S12–21.