APPENDIX: SUPPLEMENTARY DATA

Key to transcription conventions:

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses (...) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Em dashes (–) were used in the place of hanging phrases resulting in an incomplete sentence, interruption by another speaker, or where the speaker made a meaningful pause.

Component parts of being an integrated, valued person after traumatic brain injury:

<table>
<thead>
<tr>
<th>Having a coherent, satisfying and complete sense of oneself</th>
<th>Knowing oneself</th>
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<tr>
<td>Feeling whole</td>
<td>Like way back in those – the early years, you know, the first couple of years, you’re actually really not there anyway. You’re still just following your nose around. And your mind’s so confused, you know, so disrupted, so – you know, that you’re still trying to find you. You’re still trying to find the same – the person you want to be, or can accept even yourself. (Group 2, male)</td>
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<td>Recognising or representing oneself in one’s actions &amp; behaviour</td>
<td>My kids were looking at me like I was nuts, my husband was looking at me like who’s this person I’m married to, and all that came out of me in a big lot of anger. I can remember one day, and I look at it and think, god, did I do that? My husband went away – we got a big four-car garage outside, and he went and locked himself in it. And what I did was bang on the door and say listen to me, and I’m screaming at him, you’ve got to listen to me. And I think myself, did I do that? (Group 3, female)</td>
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I would swear. And cos you know, you sort of – people go on cos they weren’t used to me swearing. So that didn’t feel nice, cos I knew that wasn’t me, like you know, the ‘me’ me. (Group 1, female)
| Feeling in charge of self & future | **Being in charge of developing new self-identity**  
You don’t want them [i.e. family members] to define you, because you know you’re going to have to be somebody new, you don’t want them defining what that is. (Group 1, female)  
And I’ve given myself that permission to get well, and be still, as you say. And to hell with the world and what’s going on around, and they don’t dictate my life for me, it’s me who has to dictate it- (Group 8, female) |
|---|---|
| **Problems with predicting future self**  
I think for newbies like me, it’s a really difficult question as to what is the new me, what’s the new normal? Because I don’t know how much I’m going to change in the future, I’ve done a lot of reading on neuroscience, neurologists, and it’s totally confusing. (Group 2, male) |
| **Being in control of behavior**  
And that puts another perspective on my relationship with my wife too, and I had the same – you were talking about you know, the impact on the family, and my wife – I was only thirty five then, you know, two kiddies just- well one was only a baby, and toddler. And yeah, my wife |
| Completeness of & connection with one’s life story | **Connection with pre-injury self**  
It frightened me, of course, when I woke up and I didn’t remember who they were. You know, my family, I didn’t remember their names, or who they were... My daughter came from England, and I didn’t know who she was, and it really frightened me. It took a long time to get that back... I couldn’t remember who I was and where I lived. Where we lived and all the rest of it. (Group 6, male) |
|---|---|
| **Recognition of & integration of post-injury changes to new concept of self**  
When you get later on with it... I think you get to a state where as I can turn around and joke about it all a lot more now. In fact I joke about it quite a bit... Once you get to that stage, you’re getting more to defining yourself too, with your brain injury. (Group 1, male)  
The fundraising that we were doing [for a local brain injury support group], like the first year when I was asked, I just did not want to be on the street, you know, wearing a brain injury vest. Just did not want to be seen as having a brain injury... I was embarrassed, denial, whatever... But yeah, it’s – yeah, things like I’m quite happy now to actually – to wear a high vis vest or something, brain injury on it. (Group 5, male) | |
| **Positive personal developments following injury**  
I think I’ve become a different person. Like probably stronger. More in depth, you know, like you think of things, you think more deeply about everything. (Group 4, female)  
I think I’m easy to get along with [since my TBI]. And that’s changed, because my personality changed completely, and before I wasn’t, apparently, so they tell me. I’m a lot more friendlier, which is a positive thing... I’m more easy going, I’m more open to anyone, you know. (Group 3, male)  
I think understanding myself, um, and- and as I said, you know, coming to terms with becoming a stronger person. It’s because of the change that I’ve undergone. (Group 8, female) | |
| **Ambiguous loss of a future self that never existed**  
I just know with my friends, they’re all- they were all just- just all my friends having partners, and then they were all engaged, and then they were all married, and now they’re all having kids, and yeah, it’s |
frustrating, I just think yeah, well I have no idea what I would have been like, but I just think I wonder if I would have been the same, if I’d found the person I wanted to be with, and I’d had children, who knows. (Group 5, female)

**Loss of characteristics and skills linked to past life**
The other thing was I spent half my life on boats, and I can’t even stand on the wharf without feeling sick. (Group 3, female)

Quite regularly I would get wild with the guy that was in this body, that couldn’t do what he knew he could do, and – which led on to deep depression, because I wasn’t achieving anything, I couldn’t make decisions for myself, even to the sense of budgeting, or balancing, a checkbook... from being independent to being dependent on other people was not me. (Group 2, male)

**Resilient aspects of pre-injury self**
Well I’ve always had a happy go lucky attitude... Like I’ve noticed being round people with head injuries, a certain amount of your personality will always come through. Before your head injury, it will still come through after your head injury. (Group 3, male)

I sort of think myself, I don’t think I’ve changed in the way that my sense of humor is exactly the same. (Group 5, female)

I guess the whole thing is I don’t know who I am. But there is – there is a person inside me, who’s sort of watching, that’s it... I think it’s just the basic me... [the] ‘me’ me, yeah (Group 1, female)

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### Self-esteem
Whether it’s an employment, or anything that you participate in, when people say like – you know, you introduce yourself, you know, it’s a pride in yourself, what do you do? (Group 1, male)

I find like now, I’m still got a little bit conscious of you know, working around outside [in the garden], because you know, cars driving past, they must wonder who this guy is... And like there’s no pride – there is no pride on being on [injury compensation], and like I guess, you know, that’s another reason for wanting to get back in the work place, you know, for a bit of self-esteem. (Group 5, male)

### Depression
Sleeping pills, antidepressants – I never committed suicide, but I think about every day. Not so much now, in the last few weeks, but I go - I've been through periods where every single day I think about killing myself. (Group 2, male)

### Respect, validation and acceptance by others

#### Intimate relationships
You reach a point where you’re trying to find where you were, you realise you’ll never be quite the same, but you try to find a balance where you can adjust to that... And a lot of that has to do also with your interaction with your partner. A loving and supporting wife. My previous wife was killed in the accident, so it was a complete new adjustment. I didn’t come to that situation [having a new intimate relationship] until six or eight years ago... Up until that time, I was just coping on my own but feeling that I was just a drain on society. (Group 6, Male)

I’ve had girlfriends, or partners, since about two years after my head injury. It’s good to have someone close like that. Understands you, I suppose, and can accept you being a bit goofy. (Group 1, male)

#### Family
I’m just disconnected, I mean I don’t have any family support because nobody gets it. It’s just because they think I’m somebody that I’m not anymore, you know. (Group 1, female)

I find arguing with my family hard... They don’t want to accept as much as I don’t want to accept, but I’ve just had yelling and screaming, you know, pretty much competitions with them, you know, ‘I’ve got no choice to accept it,’ excuse my language, but ‘I got no choice to accept it, you c*nts have to – you too’– you know. (Group 7, female)

#### Friends & community members
Adding on to that, another sad thing is friends you’ve known your whole life, not intentionally, they just drift away completely. All of a sudden you’re left high and dry on your own... You have your off days, you have your good days, so they might come round one week and you’re having
an extremely bad day, so they say there oh look, I’ll come back and see
you when you’re better, right, they might do the same thing the
following week. After about two or three weeks of that, that’s it. And
it’s so sad. (Group 3, male)

Yeah, and I’ve found like a lot of my closest friends are now reading
books on brain injury, and some of them come along to meetings to
support me, and like they are really into in. (Group 4, female)

Why is it important to you, that other people believe and appreciate
what’s going on for you?
A: It’s got to be, because –
B: Otherwise you’re not valid, are you
A: Well it’s not – it’s not only that I’m not valid, but you’re aware that
others are seeing you as, well, being a bludger, as you know, why aren’t
you working full time? (Group 6, two men talking)

I find it very difficult now to have conversations now with people, I’m
not sure how they’re looking at me, and I don’t know whether it’s me, or
it’s them relating to me in a different way... I don’t know. But I’ve got to
the stage where I shut off, because I think I’ll go to a social situation, and
I think there’s all this noise, there’s all these people talking at once, and
you can’t follow the conversation, so you just shut off, and you sit there
like a zombie, and everyone looks at you and thinks oh, there [she is],
she’s just sitting there again, and then after a while you think oh, I’m
going home. (Group 3, female)

Health funders and
providers

Being a ‘case’ or a ‘file’ rather than a person
I’ve now been put on to a permanent [insurance case manager] who’s in
[the city], cos I’m on a dead file – I thought it was cos I was dead when I
when I had my accident, and they got me back to life and that, but now I
guess - I’m on a permanent thing, and I’m dead, so it’s all in [the city]
now. You know it’s ridiculous. So they get you to a certain extent, you
have your own file. (Group 6, male)

Living experiences and beliefs about oneself challenged or disputed by
health funders or health professional
Oh, I went in to ask about some work – if I could have some work, have a
job, and um, I walked into [the insurance claims office] to do it, there
was, you know, a few people in there. And I asked out loud, you know,
‘have yous got any work?’ And um, my case manager at the time, said
you know, to everybody in there, and she says ‘oh, [mate], you can’t
work.’ And I was really blown away by that – that comment, you know.
And I just went outside, and I huffed and puffed, and kicked, and you
know. What a thing to say! ... Obviously they don’t know what they
know – they may know on paper what’s involved, but they don’t know, you know, about me. (Group 8, male)

There’s a tendency… in general, okay, you’ve had this injury, you aren’t able to do the things you used to do. But you can still go back to work. Okay, you were an architect but you can’t do that now, but you can get a job sweeping the floor for the local supermarket. Sorry, that just destroys the person even more. He needs to get something that somehow relates to his former job, in order for him to feel himself again. (Group 6, male)

Sometimes it makes you feel like you’re a fraudster. Sometimes it makes you feel like you’re just a whining prick… and – and when they do it, the way they do it, they’ll make you feel bad about yourself, because you’re putting your hand up, saying ‘hey, I’m not- I’m not coping, I need some help.’ (Group 7, male)

And then the woman at [the insurance organisation], all she reads [in the medical assessment] is she’s exaggerating and pretending she doesn’t have her balance, she’s normal, so therefore there’s nothing wrong with her. It actually started making me think well, maybe I am mad. Maybe I have lost the plot somewhere. (Group 3, female)

**Treatment by care provider**

I had one carer look after me, she said – and we didn’t get on too good in the finish. She used to keep the biscuit tins empty, the fridge empty of drinks, used to sit her big fat bum on my couch and just give me orders. I said to her one day, I said, I think you should find another job. She said, she’d get rid of me - you’ll end up going into a [nursing] home… I rely on my carers to look after me now, and I am much, much obliged what they do for me, the carers do an excellent job, they make me feel alive again. And I want to live. Whereas for a while there I was just thinking oh, I wish I died out there, I can’t handle this any longer. I was going downhill… Because, it makes life, having nice carers, makes life worth living. (Group 4, male)

**Having a valued place in the world**

**Knowing where one ‘fits’**

I don’t know why I like to do anything that I like to do, it’s like that’s gone anyway, so I’m just happy doing nothing. But yet I – oh, at the same time, I don’t fit with people that do nothing [i.e. unemployed people], so I’m kind of – here I am, I’m actually this person that’s doing nothing, but I see my – I still see myself as being the person I was, and I’m not, so I don’t fit with those people, but I don’t fit with the people that sort of do nothing either. (Group 5, female)
I didn’t really make sense of it, quite honestly… Big mystery, yeah, yeah… I used to sit there looking out at the farm, and – through the window, and I wonder what I do out there, what’s happening out there? It was difficult – ten years, it’s a long time. (Group 6, male)

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<th>Satisfaction with roles, relationship and productivity</th>
<th>Maintenance or change in roles within family</th>
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<tr>
<td>I can still communicate with my children, my grandchildren, even though I’m in a bloody chair. So I’m not pushing up bloody puha [a staple green vegetable of Maori, still eaten today] (Group 8, male)</td>
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<td>Since I’ve come home from [the rehabilitation unit], my wife is my carer… So that’s been a big whole change, my whole life, in reverse, really… She’s become more mum and dad type of thing really, and I’m just like a kid again sometimes. And it drives me nuts now. (Group 4, male)</td>
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<td>I was the bread winner for our family. And now my wife is that bread winner, and I’m the home keeper. (Group 1, male)</td>
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<td>I lost a lot of friends and family. I don’t have any family that ah, I think because of the behavioral issues I had right through all my head injuries and the dysfunction that came from my whanau [the Maori word for ‘extended family’], that in some ways contributed to that. Ah, ah, they don’t want to know me. And so I live a solitary life, pretty much. And I rely on very limited, ah, social, ah, connections with other people. (Group 7, male)</td>
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<th>The importance of productivity and contribution</th>
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<td>I would definitely kill myself if I thought I’d never get a job again. (Group 2, male)</td>
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<td>I finished up after twelve months on [injury compensation], and then just over twelve months back in the [the workplace] trying to cope, I finished up writing to [my boss] and saying I’m taking six months further out and – yeah, so on. In actual fact he wouldn’t hear of that, and sent my – transferred me, and I moved around various positions trying to find something that I could cope with, and I wasn’t coping anywhere. And in the finish, simply resigned. And the whole of that process was one of seeing myself as a failure. (Group 6, male)</td>
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<td>On the acceptance thing, with my part time voluntary work, I have got a lot of acceptance, because – excuse me, I’m – I am proud, yes I am proud, I am proud! Cos I am accepted at the [place] I work in. And I know I am different. Yeah. (Group 1, male)</td>
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It’s your self-pride, and you – you want to contribute, you know, you just want to contribute to your own life, anybody else’s, but you don’t… and your identity in yourself is - it’s just pride, I guess (Group 1, male)

**The importance of financial independence**
I struggle financially on the [disability benefit]... My self-esteem’s gone; my self-confidence. My mum wants me to stay on the benefit and earn pocket money walking dogs, and I’m just like well, it’s very well saying that, but I want to become independent again, you know. (Group 1, female)

**Enjoyment of new found solitude**
And since then, I can go in my back yard, and if I don’t see anybody, look at the cat in the grass, and I can sit and watch it. And I could never have done before. Cos all the boys are hyperactive in our family. And I was always on the go. And now I find that time by myself is the best thing in this world, cos I’ve got to have it, because otherwise people, and thought patterns - hat you think they’re thinking, just weighs you down. (Group 4, male)

| Spiritual health | How proud I am that through my head injury that I’ve developed faith, and trust in me. And that’s what the healing that I’ve seen happen for myself this year, has in the still and the quiet – that I call back on me and Te Atua [the Maori word for ‘god’]. (Group 8, female) |