

Title: Traumatic injury survivors' perceptions of their future: a longitudinal qualitative study

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Abstract

Aim: Persistent disability following traumatic injuries can disrupt future plans and create uncertainty about how to mitigate future impacts. It is unknown how or whether perceptions of the future change in the years after injury. Therefore, the aim of this study was to explore trauma survivors' perceptions of their future over time.

Methods: A longitudinal qualitative study, nested within a population-based longitudinal cohort study, was undertaken in Victoria, **Australia** with survivors of serious injury. Sixty-six seriously injured adults (≥ 16 years) without severe neurotrauma were interviewed at 3-years post-injury (n=66), and re-interviewed at 4 (n=63) and 5-years (n=57) post-injury. A longitudinal thematic analysis was performed.

Results: Many traumatically injured people had persistent physical and mental impacts. Participants reported being anxious about pain, mobility, work, housing and accommodation, social activities, and finances in their future. Others were hopeful and optimistic regarding their future and developed coping strategies and adopted new viewpoints.

Conclusion: Over time, most seriously injured people's perceptions of the future remained consistent. Some had enduring anxiety and others sustained hopeful approaches. Personalised and targeted interventions that address specific concerns could reduce anxiety and support positive adjustment following traumatic injury.

Key words: Trauma, Injury, Interviews, Disability, Ageing, Future expectations, Qualitative

Introduction

Traumatic injury is a leading cause of mortality, morbidity and permanent disability worldwide [1], and affects individuals of all ages, genders, ethnicities, and socioeconomic status [2]. In Australia alone, almost half a million people are hospitalised each year as a result of injury, and the numbers are rising [3]. People who sustain serious injury can face the sudden prospect of lifelong consequences. Such long-term consequences can pervade all aspects of an injured person's life, and include physical, psychological, social, financial, employment, and transport impacts [4, 5, 6, 7].

Recovery pathways vary for seriously injured people. Varying physical and mental consequences can occur from traumatic injuries such as to the head, chest, abdomen, and extremities [6, 8]. Many have difficulty with returning to, or sustaining return to, work over time [9, 10, 11]. Several longitudinal cohort studies examining functional and health related quality of life within the first 3-years of injury show a high prevalence of problems with self-care (18-24%), usual activities (47-55%), mobility (37-56%), pain and discomfort (50-63%), anxiety and depression (26-41%) [6, 8, 12], and cognitive disability (28-65%) [8, 13]. Given the persistent disability, and long and complex recovery pathways reported by seriously injured people [6], this is an important group to research to improve outcomes.

Significant changes in life circumstances can create uncertainty about the future and how to mitigate negative consequences in the future [14, 15, 16]. Uncertainty in some people can promote anxiety, diminish effective responses, and impede preparations for the future [14]. Future predictions are often based on a person's current state, past experiences, and the environment in which they are immersed [14]. A clearer understanding of how seriously

injured people perceive their future and manage uncertainty over time, could enhance service providers' efforts to deliver more effective, appropriately personalised, supportive care.

Previous studies that have explored the experience of recovery from traumatic injury and recovery expectations have broadly identified fears with respect to the future. These studies, however, have not generated detailed information about future beliefs or any actions taken over time to mitigate issues [17, 18, 19, 20]. While some studies have explored perceptions of the future, these have mainly been restricted to people with neurological conditions such as multiple sclerosis and traumatic brain injury (TBI) [21, 22, 23]. Further, these qualitative studies have focused on future concerns at a single point in time, and have outlined concerns without exploring participants' adaptive responses. The specific concerns of seriously injured people who have not sustained significant neurotrauma remain unknown. Therefore, this study aims to explore seriously injured adults' perceptions of their future including their concerns, anxieties, coping mechanisms, and sources of resilience over time.

Methods

Setting

This longitudinal qualitative study was undertaken in Victoria, Australia, with survivors of serious injury. The state of Victoria has an inclusive trauma system that ensures the most seriously injured patients are directed to the most appropriate hospital for their injuries [24]. Eight-one percent of trauma patients are definitively managed at one paediatric and two adult hospitals defined as major trauma services [25]. The population-based Victorian

State Trauma Registry (VSTR) monitors the trauma system by collecting data about all seriously injured hospitalised cases [24]. As part of routine data collection for the VSTR, trained interviewers follow-up participants by telephone at 6-months, 1-year and 2-years post-injury to capture long-term function, pain, health status, and return to work outcomes using validated questionnaires [24].

The RESTORE (REcovery after Serious Trauma—Outcomes, Resources use and patient Experiences) study is a population-based longitudinal cohort study that captures the experiences of seriously injured people at 3, 4 and 5-years post-injury through quantitative and qualitative methods [26]. This paper focuses on the nested longitudinal qualitative component of the RESTORE project. The study was approved by Monash University Human Research Ethics Committee (25/03/2014) and participating hospitals.

Survivors of serious injury routinely access health care for their treatment and recovery. In Australia, all citizens and permanent residents are entitled to health care and services through Medicare, the publicly funded national health system. More than half of Australian adults also purchase private health insurance [27]. In addition, for people injured in road transport crashes or work-related incidents in Victoria, no-fault third party insurers (the Transport Accident Commission [TAC] and WorkSafe Victoria) provide income support and funding for treatment and rehabilitation delivered either through Medicare or the private healthcare system. Injured people who claim funds from insurers are termed compensable.

Inclusion criteria

Individuals who were eligible to participate in the study, who agreed to an in-depth interview at 3-years post-injury, and were aged 16 or older at the time of injury, were included in the analysis. All RESTORE participants were registered with the VSTR, and

therefore met a seriously injured criteria. Injury is defined as serious if any of the following criteria are met: (i) death related to injury; (ii) an injury severity score (ISS) >12; (iii) admission to an intensive care unit (ICU) for >24 hours and requiring mechanical ventilation for at least part of their ICU stay, and (iv) urgent surgery is required [24]. **Individuals with severe TBI or spinal cord injury (SCI) were excluded from this study.** A severe TBI was defined as Abbreviated Injury Scale (AIS) score for the head region of at least 3 (a rating of serious or higher) and a Glasgow Coma Scale score of 3 to 8. People with mild or moderate brain injuries were included. Participants were required to be able to recall information about their injury and treatment, self-report, and be fluent in English (as available funding could not cover the cost of translation services). People with serious neurotrauma were excluded from the analysis as many were cognitively impaired and unable to self-report, and people with SCI were expected to have limited recoveries, which lead to very different perceptions of their future.

Procedures

At the final 24-month VSTR interview, participants with an injury date of from 1 July 2011 to 30 June 2012 were asked if they could be contacted again as part of the RESTORE project (Figure 1). The RESTORE project consisted of 2,609 survivors to hospital discharge who provided consent to participate after receiving a patient information and a consent form in the mail. RESTORE participants were telephoned at 3-years post-injury to repeat the questionnaires administered in the first 24-months of injury, as well as additional surveys exploring emotional impacts and environmental barriers. For the nested qualitative component of RESTORE, participants were invited to partake in a separately conducted semi-structured interview based on a purposive sampling criteria. The patient outcomes manager, who coordinated the follow-up interviews for the VSTR, sampled participants

based on age, gender, compensation status (yes/no), residential location (metropolitan or regional), and whether care was delivered at a major trauma service (yes/no). It was estimated that 40-60 participants should be recruited at 3-years post-injury to participate in one interview each year for the duration of the study. This recruitment estimate was selected to ensure the purposive sampling criteria were met, diverse experiences were captured, and to allow for the attrition of participants over the 3-year study timeframe.

Figure 1. RESTORE participant inclusion pathway for nested longitudinal qualitative study

One hundred and fifty-eight participants consented to participate in nested longitudinal qualitative component of the RESTORE study 3-years after injury. However, only 66 seriously injured adults met the inclusion criteria for this study. All interviews were conducted in English via the telephone by one of five trained qualitative interviewers between July 2014 and July 2017. The median interview time was 47 minutes 3-years after injury, 28 minutes at 4-years and 26 minutes at 5 years. The semi-structured interview guide explored a range of topics relating to long-term recovery such as experiences with compensation, employment, and finances, and how participants were managing with home life and activities [26]. The interview questions were based on the research aims, and previous qualitative research conducted in injured populations. The same questions were asked at each time point, however at 4-and 5-year post-injury interviews, participants were asked to limit their responses to the previous 12 months. Participants were specifically asked about their

impressions of how their recovery was progressing, and what helped or hindered this process. The final question was “Do you think the injury will impact on your future? If so, how?” Probes were used to clarify or further explore the respondents’ perceptions of their future. Consent was provided for all interviews to be audio recorded and transcribed. The project manager (SB) and interviewers held fortnightly meetings to discuss any potential interviewer biases, preliminary data, review initial themes, manage logistical issues, and to decide if further recruitment was indicated.

Data analysis

A thematic analysis was undertaken using a framework approach [28]. This approach was taken as it enabled the larger project team to collaborate and make important content and contextual contributions to the development of the framework. To manage and organise data, NVivo 10 (QSR International, Doncaster) was used. The analysis was performed by SB and a research assistant (who was also one of the interviewers) who are trained and experienced qualitative researchers. Iterative and inductive processes were used. To commence the analysis all transcripts were read in their entirety; once for familiarity, and a second time for content related to the aim of this study. While reading the transcripts, notes were made on repeated content, meaning and attitudes, enabling excerpts of transcripts to be grouped into themes and subthemes [28]. These themes and subthemes were reorganised as the transcripts were re-read and discussion took place between SB and the research assistant to resolve any discrepancies and to achieve consensus.

A longitudinal analysis was undertaken using a recurrent cross-sectional approach, which involved examining group level data and analysis through the comparison of different time points (3, 4, and 5-years post-injury) [29, 30]. Hence, the transcripts of participants who did

not complete interviews at all three time points were included in the analysis. A reflexive stance was maintained throughout data collection and analysis as outlined in Table 1.

Table 1 Qualitative validation criteria

Credibility and trustworthiness	This was achieved by having a large sample size and from maintaining detailed records of coding and theme development decisions. Additionally, themes were reviewed and refined by among a multidisciplinary project team [31].
Descriptive validity	The transcripts were read and referred to multiple times [32].
Triangulation	Multiple sources of data were used to produce the results; the interview transcripts, memos recorded during interviews, and the authors' involvement in developing themes expanded understanding. The authors' contribution included assisting to develop higher-level themes and subthemes, identifying gaps in the analysis, critiquing and developing the framework [33, 34].
Negative case analysis	Examination of data that did not support interpretations [35].
Researcher subjectivity	Examination and declaration of bias among interviewers and researchers [35].
Peer review debriefing	Peer review, regular meetings and debriefs with the project team were conducted during the project and analysis [31].

Results

Of the 66 seriously injured people interviewed at 3-years post-injury, 63 were interviewed again at 4-years and 57 participants at 5-years. Most participants were male (n=44), with a mean (SD) age of 49.9 (15.4) years, and road traffic crashes were the predominant cause of injury (Table 1). Forty-nine percent of participants were claiming compensation for their injury and two thirds lived in a major city. Most reported no disability in the week prior to

injury, and 36 of the 49 participants who were working prior to their injury had returned to work by 3-years post-injury (Table 2).

Table 2: Participant profile (n=66)

Descriptor		n (%)
Gender	Male	44 (66.7)
Age in years	16-39	18 (27.3)
	40-59	24 (36.3)
	60+	24 (36.3)
Injury group ^a	Chest and/or abdominal and other associated injuries	36 (54.6)
	Head and other associated injuries	13 (19.7)
	Multi-trauma and other associated injuries	10 (15.2)
	Orthopaedic injuries only	7 (10.6)
Cause of injury	Transport-related	36 (54.6)
	Falls	13 (19.7)
	Other ^b	17 (25.8)
Education ^c	University	15 (23.8)
	Completed high school	6 (9.5)
	Advanced Diploma	26 (41.2)
	Did not complete/ has not completed high school	16 (25.4)
Fund Source ^d	Compensable	32 (49.2)
	Non-compensable	28 (43.1)
	Private or other non-compensable	5 (7.7)
Region of residence ^e	Major cities	43 (66.2)
	Inner regional	16 (24.6)
	Outer regional/ remote	6 (9.2)
Injury Severity Score Median (IQR)		17 (14-24)
Charlson Comorbidity Index weight (CCI) ^f	None	47 (71.2)
Index of Relative Socio-economic Advantage and Disadvantage ^g	1 (most disadvantaged)	7 (10.8)
	2	8 (12.3)
	3	18 (27.7)
	4	19 (29.2)
	5 (most advantaged)	13 (20.0)
Pre-injury disability	No	58 (88.9)
	Yes	8 (11.1)
Returned to work at 36 months (of those working prior)	Yes	36 (73.5)

^aMulti-trauma and other associated injuries = includes multiple body region injuries (excluding serious neurotrauma), burns and other injuries that do not fit into any of the other groups.
Head and other associated injuries = head injury with Abbreviated Injury Scale (AIS) > 2 in addition to another injury.

Chest and/or abdominal and other associated injuries= chest and/or abdominal injury with AIS > 2 in addition to another injury.

^bOther=horse related; other threat to breathing; fire, flames, smoke; firearm; cutting, piercing object; struck by or collision with object or person; machinery; electricity; interpersonal violence and other specified and unspecified external cause.

Missing data: ^cn=3; ^dn=1; ^en=1; ^gn=1

^fCCI is a weighted index that considers the number and seriousness of comorbid diseases

The findings are described in relation to the three main themes and multiple subthemes identified in the analysis, complemented with illustrative excerpts extracted from interview transcripts. Each excerpt is linked to the patient's gender, age group at time of injury, injuries sustained, post-injury year the interview was conducted, and a unique identifying number. An asterisk indicates that further longitudinal excerpts related to the participant and theme are available in the supplemental online material.

Future outlook

An uncertain future

Many participants of all ages reported feeling uncertain and being worried and anxious about their future. Increasing awareness of the long-term consequences of their condition changed how respondents perceived their future. Furthermore, anticipated changes caused stress, including fears and anxieties about pain, independence and mobility that endured over time:

When you get out of bed in the morning... and you can't even move, and you're lying in bed and all you want to do is get up to go to the toilet, and even that's too hard if I'm like this now what am I going to be like in five years' time, 10 years' time?

*Male_16-29yrs_Multiple severe fractures and other injuries_yr3_#581**

In addition to their anxiety, some participants described feeling despondent about their future. Both young and older participants diagnosed with mental health issues such as depression or post-traumatic stress disorder (PTSD) expressed hopeless and bleak outlooks at multiple times post-injury. One participant who reported he had PTSD depicted a discouraging a future:

I'm just going to die one day, that's it. My future, there is no future, you just exist... I don't get enjoyment out of anything, I just exist. *Male_60-69yrs_Thoracic fractures and other injuries_yr4_#920**

Hopeful

Some participants reported persistent physical and mental impacts but revealed hopeful and optimistic attitudes in the face of an uncertain future. People who were hopeful focused on a range of approaches including what was in their personal control, what they were able to do and achieve, and on working around problems. A hopeful and positive outlook was associated with an enthusiastic way of living in the present alongside a pragmatic acceptance of uncertainty:

I want to get out and do things; I don't want it to slow me down. In the next 10 years I might have no problems. But after that I might have a breakdown of my new hip, I might get arthritis in the rest of my body. I don't know what's going to happen. But I'm going to be there... I'm just going to do things. *Female_40-49yrs_Pelvic and lower limb fractures_yr5_#519**

Others expressed optimism about their future and reported feeling 'lucky'. These perceptions were evident in people who reported a full recovery, as well as people who had persistent disability. People who visualised optimistic futures described positive attitudes, acceptance of (any) persistent disability, and a tendency not to dwell on losses. The injury event and recovery experience changed their perspective based on what could have been their future:

It's shown me that on that day I could have come home with no leg... I could have been a vegetable sitting in bed, but I was lucky that I have had [to] go through all this process. I can still feed myself, I can still play with the grandkids, so it's sort of

changed the way I look at it [*the future*]. I don't see things the way I used to.

Male_40-49yrs_Spine and lower extremity fractures_yr3_#509

Some participants were hopeful that there would be no impacts from their injury in the future. People who expected no impacts generally reported a full recovery and a return to their usual activities at the 3-year post-injury interview. However, cautious language was used such as 'shouldn't', 'wouldn't think so', 'hope', and 'don't anticipate', indicating a lack of confidence in their predictions:

I don't anticipate anything due to the injury that could cause me problems in the

future. *Female 60-69yrs_Head and other injuries_yr3_#992**

Future viewpoint over time

Most participants reported a similar perspective of their future at each follow-up time point. People who were hopeful about their future generally remained so, and people who believed their condition would worsen over time, continued to express this view. Similarly, people who were anxious and concerned about their future repeated these feelings at each interview. Despite describing small positive changes in her physical state over the study period, the following participant showed little variation in her fears of the future:

The future just scares the shit out of me. I don't know how I'm going to cope, I don't

know where I'm going to end up because I'm on my own so I've just got no idea

what's going to happen. *Female_50-59yrs_Multiple severe fractures and other*

injuries_yr3_#427

I'm so terrified of the future and all the rest of it. *Yr4_#427*

I fear for that *[the future]*. I hope like hell the doctors are all wrong and I don't get severe arthritis... and the fact that if it does happen it would limit my mobility even further and that's a real worry. Yr5_#427

Further, relatively few participants anticipated improvements in their condition over time. An exception to this was a small number of people who had a moderate TBI. These participants expected improvement and a reduction in TBI symptoms:

I'm optimistic that it'll keep improving ... The head injury, I've been told that could take up to 20 years for the brain to totally recover. *Male 60-69yrs_Head and other injuries_yr4_#441**

Concerns about and expectations of the future

Impact of ageing

For many injured people, the ageing process was a key concern when thinking about their future. Participants with varying levels of physical impairment expressed concern about how the related impacts could worsen as they got older. Numerous participants noted increasing losses in their strength, flexibility, fitness, balance, and mobility, and some described themselves as on a downward trajectory. Many predicted that their physical condition would continue to deteriorate, raising concerns about their mobility and independence as they aged:

My back is getting worse. There are some days I don't think my hips can carry me....

I'm frightened I'm going to end up in a wheelchair. *Female 50-59yrs_ Spine and thoracic fractures and other injuries_yr4_#377**

A prominent concern reported by many participants was the development of arthritis in the future. Pain and limited mobility were inter-related concerns. Many participants stated that their treating health professional informed them about the likelihood of arthritis in injured joints as they aged. For some, health professionals explained that joint replacements would be required in their future. This information weighed heavily on participants given their experiential knowledge of living with impaired mobility and function post-injury:

I've been told that I will need a knee replacement... *[but]* to delay that as long as possible because my outcome might not be as easy as it would be for someone who hasn't had the major trauma to that area... And I'm fully aware of what it's like to go back to not being able to use your legs. So that's something I'm not looking forward to. *Female_60-69yrs_Head injury, spine, pelvic and lower limb fractures_yr3_#475*

Concern about the development of arthritis and pain in their future was consistently reported up to 5-years post-injury:

The physio said that I will have arthritis, not necessarily soon but later on... so that's probably going to cause more pain down the track. *Female_40-49yrs_thoracic and lower limb fractures_yr4_#493**

Persistent pain and mental health issues

Many participants expressed concern about experiencing pain in their future. These concerns related to developing pain or expecting existing pain to worsen. A number of people stated they avoided thinking about this possibility:

So I try not to think about it often, but I see a pretty sort of uncomfortable life ahead as I get older. *Female_30-39yrs_Thoracic and lower limb injuries_yr3_#642**

Some participants discussed their psychological state and expectation that their condition would persist into the future and the need to find ways to manage it:

Well, my psychiatrist and my GP said it will impact for the rest of my life, especially when I come in to appointments, so agitated, shaking, DTs [*delirium tremens*], like an alcoholic, indescribable... you're crying and all that because you had a bad taxi guy. I know that's going to be a permanent thing for me. *Male_40-49yrs_Thoracic injuries and spinal cord contusion_yr3_#689**

Feeling powerless to change or plan the future

Most participants had attempted to improve their physical condition, but several found that physical activity aggravated and inflamed their injured joints, causing pain and discomfort. Of particular concern was an inability to exercise and regain fitness. As a result, some participants described feeling that their body dictated what could be achieved in the future:

I worry about what's going to happen in my future because my cardiovascular fitness is nowhere near what it was. And it's very difficult to change that because I get tired and my joints get stiff, and my feet swell... But this is nothing I can do anything about, and it's certainly not for lack of trying. *Female_30-39yrs_Multiple lower limb fractures, thoracic and other injuries_yr4_#426*

Similarly, 5-years after injury a different participant reported difficulty with attempts to improve their future physical state:

At a mainstream gym I kept getting injured and in the end I just stopped going, and that's actually been detrimental. I've lost a bit of fitness and strength because I didn't pursue it... Mainstream gyms don't always understand injury.... I definitely

won't be going into my old age as fit as I had hoped. *Female_60-69yrs_Head injury, spine, pelvic and lower limb fractures_yr5_#475*

While some injured people achieved a level of acceptance about their persistent impairments, many reflected on their frustration at their inability to control the flow on effects to their finances, social interaction, employment, living arrangements and plans:

I don't think it's *[the future]* going to get any better. My social life probably won't improve... I struggle a little bit financially... living by myself I'm paying a fairly high rent and I'm paying off my car, so I still have to work, or retire and use my super *[superannuation]*... The only way at this stage is to keep working, but my body is going to control that and not my willpower. *Male_60-69yrs_Spine and rib fractures, thoracic injury_yr3_#092**

Participants reported that managing and planning their financial future was a source of considerable concern and anxiety. Many perceived their finances to be regulated by injury insurers as their support was described as unpredictable. Typically, the amount and duration of financial support were not clearly defined by insurers. Participants also often questioned the physical and psychological sustainability of the hours and type of work they could perform over time. This created anxiety about sufficient income to cover current and future costs. As a result, some participants described feeling powerless to plan their retirement, find secure living arrangements, and address how they would pay for their needs in the future:

It's *[the injury]* never going to allow me to work correctly, so there'll be less income coming into the home.... and things can change, and I don't know what TAC [insurer]

might say in three months' time to what they're going to say today. *Male_40-49yrs_Thoracic injuries and spinal cord contusion_yr4_#689**

Future losses and opportunities

Younger participants perceived future losses and lost opportunities in relation to being active and caring activities (e.g., playing with children, taking care of older adults). Injured persons of all ages expressed losses related to recreational activities (e.g., travel, sports) and spoke of disruption to their short-term and longer-term life plans:

I'll never be able to run. And I start to think what about if I have kids one day and I want to play with them, I'm not going to be able to do certain things with them.

Male_30-39yrs_Multiple lower limb fractures and abdominal injuries_yr3_#851

Working age adults expressed dismay at lost opportunities with respect to future work and employment, life plans, and aspirations. Younger participants, in particular, wanted financial support to cover the costs of study and grappled with navigating their career plans:

I can't do what I wanted to do. And the fact is that I had to ditch my dream [career] goal, as I can't really do it. Something I've wanted to do for most of my life. *Male_16-29yrs_Thoracic and abdominal injuries and knee fractures_yr4_#664**

Ways of coping with concerns about the future

Living in the present

While many participants articulated coping strategies and mechanisms, these were not always linked to coping with concerns about the future. Where participants did link these strategies, some found ways to live with their concerns and regain some control over their

anxieties. Dealing with the persistent effects of their injuries day by day, or making only short-term plans and goals, enabled participants to live more in the present and adjust to the changes in their life. This enduring coping strategy prevented concerns about the future from becoming too overwhelming in the years after injury:

I don't make plans a long way out in the future, but I make little steps. *Female_50-59yrs_Thoracic, abdominal injuries, lower extremity fractures_yr3_#449**

Some participants reported that their pre-injury positive attitude was retained and practised in their post-injury life, while others referred to a new attitude post-injury. A positive outlook assisted participants to accept their level of function, focus on activities that were within their capability, optimistically appraise their progress, and adapt to their post-injury life. One participant described resilience in how he did not allow his persistent disability to control his future. Rather than waiting for his physical condition to improve, he applied his positive attitude and engaged in the activities that he wanted to do:

[My future physical state is] probably about what it is now. It only limits you if you let it, and I ain't letting it... If you've got a good set in your mind, that it *[the injuries]* aren't going to stop you, that you can do anything, you will do it. *Male_50-59yrs_lower extremity fractures_yr3_#553**

Preventive action

Some participants reported taking proactive steps to reduce the impacts of injury and the influence of ageing on their future. These actions mainly related to preventing or managing inflammation in injured joint/s and by active movement. Participants described being 'fit', 'mobile', and 'active' as their goal to mitigate physical deterioration and optimise their physical condition:

[The future] will depend on how hard you push it and how well you exercise and how well you keep it moving, don't put on excessive weight, and all that sort of stuff for the rest of your life.... you're only going to get out of it what you put into it. *Male_40-49yrs_Thoracic, abdominal and orthopaedic injuries_yr3_#394**

A number of participants described being more attentive to potential risks following their injury, to prevent future harm to themselves or loved ones:

I think it will make me more cautious. As my children get older, it will make me more cautious with them, getting to places and getting home from places. And just generally being aware that stuff can happen. *Female 30-39yrs_Skull fracture, head and other injuries_yr3_#130*

Looking for financial security

For some participants, lodging a common law claim for damages was an option if their injuries were caused by the negligence of another. Not all injured people who were eligible for this type of compensation pursued the option. Of the people who did, most described the action as an attempt to 'secure', 'ensure', or 'protect' their future, reflecting effort to regain some control over this aspect of their life. This was of particular importance given their restricted options for finding and retaining appropriate work:

I'm going to see my lawyer... *[but]* I want to have a career before I settle because if I don't have a future I don't know if any money is going to be sufficient for me to live my whole life, I need to have a reliable income. *Male_30-39yrs_Severe lower limb injuries_yr4_#105**

A different participant confirmed they were experiencing a similar issue 5-years after injury:

I'm actually going through a compensation process at the moment, trying to provide for myself in the future. *Female_31-49yrs_Lower limb fractures_yr5_#905*

Redefining normal and the future

For people living with persistent disability, this prompted some to set a new baseline for what they considered normal. Reducing stress by working towards or achieving acceptance of a 'new normal' position was a coping strategy used to inform attitudes and decisions by which future priorities and goals were made. This participant was able to reflect on her recovery progress as she relinquished unachievable goals and grew to focus on the things that were in her control:

I think there is a new normal, because my old normal can't be anymore.... probably about a year, year-and-a-half, when I sort of felt this is it, day in, day out... I think it sort of took me until then to realise that life wasn't going to be normal anymore... [you] need to make new goals because the ones that you had are not attainable any more. *Female_50-59yrs_Multiple fractures and abdominal injuries_yr3_#724**

Seeking information

To help cope with future uncertainty, some participants sought information from health professionals and injury insurers. Participants wanted to know how long insurers would provide financial support, how to prevent the development of secondary conditions and further injury, and continue their rehabilitation without professional support:

I [would have liked] some specialist information about the future of my injuries... I'd like to know things, like the bone injuries that I sustained, how I stand in regards to the future for maybe arthritis and osteoporosis. *Female_30-49yrs_Head, thoracic injuries, spinal fractures_yr4_#290**

Five-years after injury, a different participant confirmed wanting information about how to continue her rehabilitation:

I'm actually just hoping for a bit of direction ... I feel like I was thrown out of a [insurer funded] professional environment and then like off you go to the gym... I keep getting injured and sore and then I have to go sort that out. *Female_60-69yrs_Head injury, spine, pelvic and lower limb fractures_yr5_#475*

Discussion

This longitudinal qualitative study explored seriously injured people's perceptions of future. This novel study involved a large sample of injured people who were interviewed at three time points in the first 5-years of injury, with minimal attrition of participants over time. The result highlight that many participants of varying ages, genders, and in particular, people who sustained orthopaedic injuries, expressed concerns about persistent pain, physical impairment, and the impact of ageing in the future. However, different ways of coping with, and adapting to, these concerns were evident. These findings can inform the delivery of more effective, personalised, and supportive care which enhances adaptive coping. Given the uniformity in future outlooks for most people in the cohort, interventions to mitigate concerns about the future and associated anxiety should be targeted in the early years of recovery.

Sustaining serious injuries is a major 'disruption' in a person's life course [16]. Bury's concept of 'biographical disruption' [16], views chronic illness as disruptive experience to

the structures of everyday life, which provokes a re-evaluation of expectations and plans for the future [16]. Similarly, in our study, traumatic injuries interrupted the routine of daily life and the knowledge that supported assumptions about the future. This loss of normality has been noted in previous injury studies examining recovery in the first 6-months [19, 36, 37]. Our study identified the long-term nature of the disruption, related impacts on perceptions of the future, and for some, adjustment that enabled a positive orientation to the future.

In line with prior research into people living with SCI and TBI [38, 39, 40], resilience supported effective coping and adaption in our study. Resilience is the ability to positively adapt in the face of a traumatic event and ongoing uncertainty [41]. In our study, resilience was evident over time as injured people took positive actions to recover such as an optimistic outlook, living in the present, and performing actions that managed uncertainty such as seeking information. It is also possible that a positive pre-injury predisposition, or particular beliefs and values, and supportive social networks including family, friends, employers, and service providers also influenced positive outlooks [39, 42]. Psychologists can assist to strengthen these attitudes and actions post-injury, as well as personalise the process to develop other resilience behaviours such as problem solving, emotional management, and communication skills [38, 40]. For people with a pre or co-existing psychological disorders, strengthen resilience needs to be incorporated with other interventions and strategies [41]. As resilience can reduce emotional distress, gains can include better functional outcomes post-injury, improved social relationships, and return to work for people [43, 44, 45]. Additionally, as resilience is a relatively stable psychological

attribute [39], this could explain why injured people who were positively orientated to their future at 3-years post-injury, reported similar outlooks at 4- and 5-years.

Consistent with previous studies of adaption to disabling conditions, adjustment to an uncertain future in our study was exhibited through features of adaptive self-regulation [46, 47, 48]. Adaptive self-regulation is the adjustment of social-cognitive behaviours orientated to the achievement of goals [49]. This approach can help people to manage disruptions to their goals, adapt to new circumstances such as disability, and mitigate negative psychological outcomes [46]. In our study, many seriously injured people demonstrated adaptive self-regulation by re-evaluating and setting obtainable goals, such as financial goals and adapted their behaviour to reduce the risk of further injury. Further demonstrating effective self-regulation, some injured people recognised unattainable goals, such as career goals, and disengaged from these when they were clearly no longer achievable [47].

Conversely, some injured people did not regulate their goals in response to perceived future challenges, and persistent despondency and anxiety were described. This most often occurred in injured individuals with psychological issues who felt powerless to control their future. Psychological issues, such as depression and anxiety, have been previously identified to interfere with adjustment to disability by negatively affecting coping skills and by delaying or slowing acceptance [5, 50, 51]. As psychological and emotional wellbeing after injury supports productivity and long-term outcomes, such as health, employment status, and satisfaction with recovery [52, 53], timely access to appropriate mental health supports is a priority for seriously injured people.

To improve perceptions of well-being and alleviate feelings of helplessness about the future, health professionals (e.g., psychologists, occupational therapists) can support adaptive self-

regulation in injured people by assisting them to set realistic recovery expectations and goals [20]. Interventions that can enhance adjustment and adaptive self-regulation include acceptance and commitment therapy and mindfulness-based approaches [54]. These approaches involve developing an awareness and non-critical acceptance of experiences, recognising what is valued in life and learning how to set and achieve goals around those values, and changing responses to symptoms, instead of the symptoms themselves [54]. Self-management programs that use self-regulation and self-efficacy enhancing interventions (e.g., goal setting, actions plans, problem solving), could also be of benefit in an injury context [49, 55]. Additionally, adjustment and enhanced self-efficacy can be cultivated through peer support programs, as previously reported by people living with TBI and SCI [56, 57, 58]. Specifically, engagement with people who model desirable coping strategies, health behaviours and outcomes, and who have experiential knowledge of a health condition, could empower people with information, foster feelings of personal control, and improve resilience [59]. Future research should determine the impact and timeliness of interventions that mitigate concerns about the future on outcomes in injured people without significant neurotrauma.

A number of positive responses to persistent disability, such as optimism and hope for the future, were recorded in our study. Post-traumatic growth involves experiencing a positive personal change after a traumatic experience [60]. The struggle with the crisis leads to deep and profound changes in individuals [60]. This change can be a process or an outcome, depending on the stage of adjustment and acceptance of the person. Post-traumatic growth was evident in our study as some people had redefined their normal, accepted uncertainty, and had a new positive attitude and outlook. Similar findings have been reported by Ogilvie et al [18], as a new life perspective was gained following traumatic injury. In distinction to

resilience and adaptive self-regulation, post-traumatic growth involved a change in values and priorities, and willingness to pursue a new pathway [60]. Through a reduction in psychological distress, nevertheless, post-traumatic growth can support resilience and adaptive self-regulation through goal engagement and disengagement [40, 60]. In previous research conducted 13-years after injury, post-traumatic growth in people living with TBI was associated with social support, paid employment, high activity levels, and a sense of personal purpose [61]. For people living with SCI, access to support and community services, a positive attitude, the provision of equipment, and knowledge about their condition facilitated post-traumatic growth [62]. These findings highlight some environmental factors (e.g., equipment provision and service access) that could also support coping and adaptation in injured people without serious neurotrauma. However, in Victoria, access to services and equipment can be an inequitable system as injured people in receipt of compensation from injury insurers (people with transport or work-related injuries), or who have private health insurance, are financially supported.

Uncertainty and unpredictability about the course of the disability and finances can reduce coping and psychological adjustment and raise anxiety [4, 15, 63]. In our study, anxiety about an uncertain future was raised with respect to finances, career, and employment, which then introduced uncertainty about future housing and accommodation. Attending to modifiable factors in health and insurance systems that impact on coping and adjustment [64] could help mitigate some of these concerns. To alleviate the financial concerns of people receiving compensation, information from injury insurers about the amount and duration of financial support could be more transparent and definitive. For all injured people, access to financial, vocational, and social work support early after the injury event could mediate anxiety about financial, work and housing issues [4, 63]. Facilitating return to

work has benefits for societal and economic reasons, as well as for an individual's health and psychosocial status [53].

Seeking information was a coping method used by some to help adjust to future uncertainty. Access to appropriate information can promote a sense of security and be a source of empowerment for injured people [65]. However, people with adequate health literacy, have fewer problems accessing information and supports [66, 67, 68, 69]. As low health literacy and barriers to accessing information are common in this patient population [66, 70, 71], how and what information is communicated should be carefully consider for its impact on coping and adaptation. Given little evidenced-based information exists about injury and the development of arthritis, providing information about a problem that might not eventuate could unnecessarily raise anxiety levels and lower recovery expectations [72]. Future long-term follow-up studies are needed to identify the outcomes of these injuries in order to provide more accurate predictions. To optimise outcomes after injury, the findings of this study and others highlight the need for information about personalised coping strategies, preventing secondary conditions, and how to safely improve strength and fitness [66].

Limitations

This longitudinal qualitative study has provided comprehensive insights into how 66 seriously injured people perceived their future 3 to 5-years after injury. Nonetheless, some limitations to the study exist. Only people who were English speaking and did not have severe neurotrauma (TBI and SCI) participated in the study, meaning the views of people not included could differ. It is possible that non-English speaking people and people with severe neurotrauma experienced greater difficulty with their recovery (such as

understanding information or access to services), which could have resulted in different perspectives. Our cohort was a heterogeneous sample in terms of the types of injury and included people with mild or moderate head injury. Nevertheless all met a serious injury criteria. People who encountered negative issues with their recovery may have been more likely to participate in an interview. However, many people with self-reported full recoveries and no ongoing problems, contributed to the study. The study was conducted in Victoria, Australia, and therefore the findings might not be transferrable to other states and countries with different injury insurance schemes and funding sources for traumatically injured people.

Conclusion

Many seriously injured people were anxious about pain, disability, mobility, work, housing and accommodation, social activities, and finances in their future. Others allayed concerns with a hopeful approach to recovery and by using effective coping strategies. Our findings highlight that health, rehabilitation, occupational, social and insurance systems all have a role in shaping injured person's responses to their injury and recovery, and that developing adaptive coping mechanisms could foster optimistic future outlooks. For the many injured people concerned about their future, targeted and personalised interventions could reduce anxiety about specific concerns, such as pain, restricted mobility, and independence in turn alleviating worries about financial, employment, and housing plans.

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