

# **Exploring patient perceptions of barriers and facilitators of recovery following trauma**

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2<sup>nd</sup> April 2012

Research report #: 0412-023-R1D

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## Project Background

Traumatic injury is a leading cause of the global burden of disease (1, 2). While the identification of injury as a preventable disease, combined with advancements in the treatment of injuries, have contributed to a global reduction in injury-related death (1), injury continues to be a significant contributor to hospital, emergency care and rehabilitation costs. The percentage of preventable deaths is now very low with improvements in trauma care increasing the probability of surviving even severe injuries. This has placed a greater emphasis on determining the morbidity associated with injury and, in particular, establishing the degree of functional loss, ongoing disability and reduced health-related quality of life (HRQL) experienced by survivors (3).

The consequences of injury are many and varied, resulting in diverse patient outcomes and experiences with the recovery process (4). The Victorian State Trauma Registry (VSTR) and the Victorian Orthopaedic Trauma Outcomes Registry (VOTOR) are unique in their routine capture of long term outcomes following serious injury (5). These registries collect long term outcomes for approximately 5000 trauma survivors annually using standardised instruments and protocols, providing important quantitative data regarding the recovery and outcomes of trauma patients in Victoria, factors predictive of outcome, and the enabling the monitoring of outcomes over time. Factors predictive of poor patient outcomes and prolonged disability include female gender, pre-injury unemployment status, lower levels of education, receiving injury compensation, injury pattern and injury intent (6-9). While highlighting groups at risk of poor outcome, exploration of “why” and “how” these factors impact on patient recovery is not known, and requires a qualitative study approach.

Qualitative studies of barriers and facilitators to patient outcomes in injury are few, with most focusing on traumatic brain, spinal cord or burn injury (4, 10-14), or road trauma survivors (15). Others have focused on specific issues such as orthopaedic external fixation in adolescents (16) and the inpatient rehabilitation experience following orthopaedic trauma (17). The UK Burden of Injury (UKBOI) study included a qualitative component, sampling 89 participants for in-depth interviews to enable a qualitative assessment of the consequences of injury, and identification of barriers and facilitators for recovery (18). This study identified numerous themes, providing an insight into the recovery process for individuals. However, direct extrapolation of the findings to the

Victorian or Australian setting is not straightforward given substantial differences in health and trauma care delivery, access to rehabilitation, and compensation systems, and the perceived barriers and facilitators to recovery in the local context remain unknown. The information is important for informing improvements in trauma care delivery, understanding and meeting the needs of injured patients and in improving the interaction between injury patients and compensation and health care agencies.

## **Aims of the Project**

The primary aims of this project were to:

- i. Explore the individual and societal impacts of trauma experienced by survivors of serious injury.
- ii. Establish the facilitators and barriers to recovery for trauma survivors.

## Methods

### Setting

Victoria has a population of 5.4 million, representing 25% of the national census. To ensure timely and appropriate matching of the needs of the patient with the service providing definitive care, an inclusive, regionalised trauma system was implemented in 2000 (19). The Victorian State Trauma System (VSTS) coordinates pre-hospital services and acute care across the state. All 138 trauma-receiving hospitals have a level of designation. There is one paediatric and two adult hospitals defined as major trauma services (MTS). A single ambulance service provides a road and air ambulance services to the state.

The Victorian State Trauma Registry (VSTR) is a population-based registry collecting data about all major trauma patients in Victoria (20). The definition of major trauma used includes any of the following criteria: (i) death following injury; (ii) an Injury Severity Score (ISS) >15; (iii) intensive care unit (ICU) admission >24 hours and requiring mechanical ventilation; and (iv) urgent surgery. Since October 2006, the VSTR has followed-up all adult survivors to discharge at 6, 12 and 24-months post-injury by telephone interview (5).

The Victorian Orthopaedic Trauma Outcomes Registry (VOTOR) is a sentinel site registry, fully integrated with the VSTR, collecting data about all adult orthopaedic trauma patients with a length of stay >24 hours, and admitted to The Alfred, Royal Melbourne, Geelong and Northern Hospitals. All VOTOR patients are followed-up by telephone interview at 6 and 12-months post-injury using the same methodology as the VSTR patients.

### Participants and sampling

Participants were recruited from the VOTOR and VSTR patient group. Participants were eligible to take part in the study if they were registered by VOTOR or the VSTR and met the following criteria:

- i. Blunt trauma patients (representing >90% of VSTR patients and >95% of VOTOR cases).
- ii. 12 to 24-months post-injury.
- iii. Aged 18 years and over

- iv. TAC compensable or non-compensable patients
- v. Received definitive care at The Alfred or Royal Melbourne Hospital (the two adult Major Trauma Services).

Participants were excluded from the study if they had not completed the 12-month VSTR/VOTOR follow-up interview.

Purposeful quota sampling was used to ensure a range of ages, and injury severity, with the intention to ensure equal representation by gender and compensation status. Three age groups were used for sampling and these were 18-44 years, 45-64 years and  $\geq 65$  years. Within each age group, 20 participants in each sex were sampled, with 10 VSTR and 10 VOTOR participants within each age and gender group. Within each age, gender and registry group, 5 compensable and 5 non-compensable participants were recruited. The intention was to recruit a total of 120 participants with 60 of each sex, registry and compensable status evenly represented across the age groups.

## **Ethics statement**

The project was approved by the Alfred Human Research Ethics Committee (Project Number 71-11) and the Melbourne Health Human Research Ethics Committee (Project Number 2011.096).

## **Interviews**

Individual interviews were used, as opposed to focus groups, to enable participants to speak freely about their experiences and perceptions (21, 22). Eligible participants were invited to participate by VSTR and VOTOR follow-up staff at the 12 or 24-month post-injury interview. Patients interested in participating were then sent a participant information sheet and were followed-up by telephone by the project coordinator (Krystle Wilson) to confirm participation and arrange an appropriate time to complete the interview. Three experienced telephone interviewers were used for the project.

In-depth, semi-structured interviews were completed by telephone (21). A topic guide was used to provide interviewer prompts of key issues for exploration including family support, compensation and their experiences with compensation providers, experiences with health care providers, employer and financial impacts, among other factors (Table 1).

Participants provided verbal consent to take part in the study and each interview was recorded using a digital voice recorder with a telephone adaptor.

## **Analysis**

Data from the VSTR and VOTOR pertaining to age, sex, compensable status, injuries and outcomes were extracted to provide a detailed description of the study participants. Each interview was transcribed from the audio recording in preparation for analysis. Thematic analysis was used to identify important thematic groupings and the relationships between these groupings (21-23). The thematic analysis involved two main steps (22):

- i. Reading through each transcript, and listening to the recorded interview if appropriate, to make sense of the interview data.
- ii. Re-examination of the transcript as a component of all of the interviews to make sense of what was being said by the participants as a group.

Twenty-six interviews were double-coded to enable cross-checking of coding and interpretation of the data by independent researchers (24). Each researcher became familiar with the transcripts, generated initial codes and collated these codes into tentative themes. Two research meetings were held, involving four investigators (BG, JS, CG, NC), to discuss and develop the emerging coding frame prior to completion of the interview coding. The coding frame for themes was developed based on common topics, patterns, and relationships emerging from the transcripts. Two investigators (BG, CG) completed the coding of the remaining interviews (n=94), and the principal investigator (BG) applied the coding frame to the coded transcripts, allowing revision and refinement of themes as the themes were applied to all of the codes extracted from all interviews. The transcripts were revisited a number of times to compare and contrast participant experiences, and to ensure consistency of meaning of individual participant responses.

The thematic analysis is exemplified by quotes drawn from the participants' transcripts. These quotes provide an illustration of the themes emerging from the thematic content analysis. Quotes were drawn from a range of participants of different ages, genders, injury severity, and fund source. For each quote, a brief description of the respondent is provided to enable the quote to be interpreted in context.

**Table 1: Summary of the topic guide**

<b>Topic</b>	<b>Interviewer prompts</b>
Injury event	Can you tell me about your injury? How it happened?
Injury treatment	<p>How do you feel about the care you received?</p> <p>How could the treatment you received be improved?</p> <p>What information or advice did you receive about your injury?</p> <p>If you did not receive information, what information would you have liked to and from who?</p>
Experiences with compensation agencies (if relevant)	<p>Did you make a claim with TAC or WorkCover for your injury?</p> <p>Can you tell us about your experiences with TAC or WorkCover since your injury?</p> <p>Is there anything you feel could have been done differently by TAC/Worksafe to help your recovery?</p>
Experiences with private health insurer (if relevant)	<p>Did you make a claim with your private health insurer for your injury?</p> <p>Can you tell us about your experiences with your health insurer since your injury?</p> <p>Is there anything you feel could have been done differently by your health insurer to help your recovery?</p>
Work life	What impact did the accident have on your work life? Paid/unpaid?
Financial	What financial costs have you had as a result of your injury?
Home life	What impact has the injury has on your home life? Has the injury affected your ability to do things at home in any way?
Relationships	Has the injury affected your relationships with friends or relatives in any way?
Transport	Have you made any changes to the way you travel?
Health	What impact has the injury had on your general health? Have you had any other problems that you feel are as a result of your injury?
Emotional	What impact has your injury had on you emotionally?
Perception of recovery	<p>How well/quickly do you feel that you have recovered?</p> <p>How long did it take you to resume normal activity (if you have)?</p> <p>What helped the most?</p> <p>And the reverse, what if anything made it harder to recover?</p> <p>What would you like to have happened differently with your treatment?</p>
General view of impact of injury	How would you describe the impact that your injury has had on your life?

## Results

The volume and breadth of the themes was extensive. Many of themes inter-link. The findings presented in this report describe the main issues arising from the analysis.

### Profile of participants

The full quota of 120 participants was filled, but there were difficulties recruiting participants in particular categories (Table 2). In particular, there was under-sampling in the 65 years and over age group, and a small gender imbalance in the final participant group. The majority of participants reported no pre-injury disability, and 71 per cent were working prior to injury, which is consistent with the wider VOTOR and VSTR population.

**Table 2: Demographic characteristics of participants profile (n=120)**

Descriptor		
Age	Mean (SD)	48.6 (17.6)
	n (%)	
	18-44 years	48 (40.0)
	45-64 years	48 (40.0)
≥ 65 years		24 (20.0)
	n (%)	
	Male	63 (52.5)
Gender	Female	57 (47.5)
	n (%)	
Pre-injury employment	Working or studying	85 (70.8)
	Not working or studying	35 (29.2)
	n (%)	
Pre-injury disability	None	98 (81.7)
	Mild	13 (10.8)
	Moderate to severe	9 (7.5)
	n (%)	

There was a small over-representation of VSTR patients, and TAC clients, in the study cohort (Table 3). The median time since injury was 14 months. The percentage of participants experiencing severe functional disability at 12-months was very low, with more than half recording a “good recovery” on the GOS-E scale (Table 3). None of the participants reported moderate to severe pain at 12-months. The mean (SD) physical health (PCS-12) score of participants at 12-months post-injury was significantly lower than the mean (SD) of 48.9 (10.2) for the Australian population ( $t=7.59$ ,  $p<0.0001$ ), but the mean (SD) mental health (MCS-12) score of the participants was not different to the mean

(SD) MCS-12 score of 52.4 (8.8) for the Australian population ( $t=-0.24$ ,  $p=0.81$ ). Together, these findings suggest an outcome profile of participants towards the better end of the VSTR and VOTOR patient population. Given the requirement of the study to interview the participant directly, the bias towards higher functioning is not unexpected.

**Table 3: Injury and outcomes characteristics of participants (n=120)**

Descriptor				
Hospital of definitive care	n (%)			
	The Alfred		60 (50.0)	
	Royal Melbourne Hospital		60 (50.0)	
Registry	n (%)			
	VSTR		62 (51.7)	
	VOTOR		58 (48.3)	
Time since injury	Median (range) months		14.2 (12.8-19.7)	
Fund source	n (%)			
	TAC		62 (51.7)	
	Medicare		40 (33.3)	
	Private		16 (13.3)	
	WorkCover		2 (1.7)	
Mechanism of injury	n (%)			
	Motor vehicle		24 (20.0)	
	Motorcycle		21 (17.5)	
	Low fall		19 (15.8)	
	Pedal cyclist		16 (13.3)	
	High fall		13 (10.8)	
	Pedestrian		6 (5.0)	
	Struck by/collision with object or person		5 (4.2)	
	Horse-related		4 (3.3)	
Other		12 (10.0)		
Hospital length of stay	Median (IQR) days		6.2 (2.3-11.6)	
Discharge destination	n (%)			
	Home		75 (62.5)	
	Inpatient rehabilitation		45 (37.5)	
12-month outcomes	GOS-E	n (%)		
		Upper good recovery	24 (20.0)	
		Lower good recovery	40 (33.3)	
		Upper moderate disability	42 (35.0)	
		Lower moderate disability	28 (23.3)	
		Severe disability	5 (5.0)	
		Return to work*	n (%) Yes	62 (72.9)
		PCS-12	Mean (SD)	41.5 (12.2)
	MCS-12	Mean (SD)	52.6 (10.6)	

\* Of participants working prior to injury

Isolated lower extremity fractures were prevalent in the VOTOR participants, accounting for 40 per cent (n=23) of cases, following by upper extremity fractures (n=14, 24.1%), multiple lower extremity fractures (n=9, 15.5%), spinal fractures (n=5, 8.6%), and other injuries (n=7, 12.1%). Of the participants in the “other” injury category, three had sustained soft tissue or neural injuries, two had sustained multiple upper extremity fractures, while one case had sustained both upper and lower extremity cases, and the final participant had sustained spinal and upper extremity fractures.

Twenty-seven (43.6%) VSTR participants had sustained a serious head injury, defined as an injury to the head with an Abbreviated Injury Scale (AIS) severity score >2. Of these participants, 20 had also sustained other serious chest, abdominal or orthopaedic injuries. Forty per cent of the VSTR participants (n=25), had sustained serious orthopaedic injuries, with no other associated injury with an AIS severity score >2. The remaining cases has sustained chest or abdominal injuries only (n=4), or had sustained multiple injuries not involving a head injury (n=6).

## Thematic overview

All 120 participants contributed 2,542 codes across the key emerging themes (Table 3).

**Table 4: Key emerging themes**

Theme	Sub-theme
Medical care	Quality of care Communication Medical and clinical follow-up Pain management
Non-medical service support	(TAC, health insurance, etc.)
Social support	Support from family, friends, neighbours Impact on family, friends, neighbours
Emotional impact	
Financial impact	
Impact on work	Positive and negative support from employer Positive and negative impact on work
Issues with activities of daily living	
Impact on social and leisure pursuits	
Ongoing disability	
Impact on travel	
Resilience	
Impact on health	
Overall impact on life	
Recommendations for system improvement	

## Medical care

### Pre-hospital care

The care provided by ambulance paramedics was not commonly noted by the participants. Where pre-hospital care was discussed, most felt the care received was excellent. There was a perception of comfort and reassurance provided by paramedics.

#### **#96, 21yo male, TAC, motorcycle, upper extremity fracture, 13 months post-injury**

*".....I'm sitting there trying to hold my bone back from falling out of my arm. But once the ambulance had gotten there they were very professional and calm, and settled everything down, and knew exactly what they were doing, and kept me distracted until they'd given me the painkillers and assessed everything. But, no, they were very, very helpful."*

#### **#108, 57 yo male, Private, high fall, head and other injuries, 12 months post-injury**

*"The ambulance and paramedic care was fantastic."*

On the rare occasion that participants reported a negative experience with pre-hospital care, this related to delays in transportation to hospital.

#### **#68, 32 yo male, Private, low fall, spinal injuries, 16 months post-injury**

*"I can't understand how DHL or FedEx can insure a parcel, gets across the planet within 24 hours and a human being can't travel 3½ hours when they're in a medical emergency. In what's supposed to be a developed first world country."*

### Hospital care

The majority of participants reported positive or mixed experiences with their hospital care (n=98), and the number of participants reporting only negative experiences was low (n=22). When judging the quality of the care they received, participants factored in perceived treatment delays, the attitudes and attentiveness of hospital staff, general care provided, the communication provided in the hospital, and the hospital environment.

For many major trauma patients, commenting on the quality of hospital care was difficult as they had little recollection of their stay in hospital due to prolonged intensive care unit admissions, or the presence of post-traumatic amnesia following traumatic brain injury.

#### **#118, 80 yo female, TAC, motor vehicle, chest and abdominal injuries, 13 months post-injury**

*"I was in Intensive Care I think for two or three days. I don't remember much about it. I think they did very well for me, lifting me up and propping me up, two men, and I think they were very kind to me."*

The overall impression of the hospital care received was very good, though when participants did report negative impressions, these were often related to negative interactions with specific individuals.

**#5, 56 yo female, TAC, pedestrian, head and other injuries, 24-months post-injuries**

*“Look, I’ve got nothing but praise. I was so well looked after and everyone was so supportive. Yeah, it was just wonderful. I can’t believe how well we are looked after in our country.”*

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*“...cannot fault it. Absolutely magnificent.”*

**#47, 47 yo female, TAC, motorcycle, orthopaedic injuries, 14 months post-injury**

*“My level of care, I’ve never had...I’ve always felt very good about the level of care that I’ve received and felt very lucky to have that level of care.”*

*Promptness of treatment*

Delays to treatment were commonly reported (n=33) with many perceiving these delays prolonged their time spent in hospital and their overall recovery. Delays to surgery were prevalent in the interviews with orthopaedic trauma (VOTOR) patients, with many experiencing extensive delays to receiving surgical management of their injuries. These patients perceived their lesser seriousness of injury to be a key factor in the delays.

**#73, 48 yo male, Private, pedal cyclist, upper extremity fracture, 14 months post-injury**

*“I think the only issue I had is I waited three days for the operation because it was the Queen’s weekend, and all the surgeons were away. So every day I had to go to the hospital, 24-hour fasting before, sit and wait and then get sent home at 3:00 o’clock in the afternoon again, without the operation. So that happened three times. ....Well, it wasn’t the hospital’s fault to be honest because what happens with the long weekend, you hear a helicopter come over and it had serious trauma and in the big picture things it isn’t really serious trauma, it’s a bit annoying but it’s not life threatening. Every time there was an accident or a big crash or something you knew you were just going to get bumped again. It’s understandable but it’s one of the things.”*

**#37, 35 yo male, Medicare, low fall, head and other injuries, 14 months post-injury**

*“I had to be operated on but it was nearly six days before I was operated, in which time I had to fast the entire time because they kept saying, “Yeah, we’ll do it today”, and then something obviously a more desperate incident would pop up and they’d say, “No, we can’t do it now. Don’t eat, we’ll do it in the morning”. So you wait for the morning and, “Sorry, we can’t do it now, we’ll do it tonight, but don’t eat”.....I seemed to be left to pushed to the side because I wasn’t dying as such. But to me it was bad.....I thought every day I don’t get operated the longer it’s going to take to repair. So I became quite desperate and I lost quite a bit of weight. Yeah, it wasn’t the best hospital stay.”*

Delays experienced in the emergency department (ED) were also reported by participants. For many this involved long waits in the ED while the hospital staff located a bed.

**#88, 59 yo female, TAC, Pedestrian, upper extremity fracture, 12 months post-injury**

*“When we got to the hospital I think I remember I was taken straight in, I wasn’t left in the ambulance like other people are. But I was put in a sort of pre-emergency spot. It was Thursday, about 6-ish or 7-ish, and I actually didn’t receive any treatment...I was given painkillers but I wasn’t actually attended to as such for what was wrong with me until about 11:00 o’clock the next day. So I think that was a fairly long wait. I was cared for in the sense that I was given painkillers, but it wasn’t very good care. They were in a terrible mess.”*

**#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*“.....I was..... in considerable pain and discomfort, and it wasn’t possible to find a bed for me so I spent a lot of time on the trolley. It was not a good experience.”*

*Communication*

Even when participants reported that the care received was good, the majority (n=68, 56.7%) of participants reported issues with communication with medical, surgical and other hospital staff. In particular, ward rounds were disliked by participants due to the timing of the round, the lack of engagement of the patient, and the impersonal nature of the process. The breadth of issues with communication was extensive but the key issues related to:

- i. A lack of information about prognosis or incorrect prognosis
- ii. Inability to absorb information in the early phase post-trauma due to memory deficits, impaired comprehension due to medication, or being “too traumatised” to comprehend the information
- iii. Failure to explain the risks of treatment options sufficiently, or providing treatment options without sufficient information to make an informed decision
- iv. Conflicting information provided by clinicians
- v. Failure of clinicians to engage the patient in decision making.

**#44, 26yo male, TAC, motor vehicle, multiple lower extremity fractures, 14 months post-injury**

*“They fixed it up. I would have probably liked a little more explanation at the start of exactly what injury entailed. I understand the job of the doctors is to keep patients positive I guess, but I was told many times that the bone will be healed in six weeks time. And I was told that about four or five times.”*

**#114, 60 yo female, Medicare, high fall, multiple lower extremity fractures, 12 months post-injury**

*“...So they used to come to my bed, a lot of students. I’ll be quite honest, I didn’t know what the hell was going on when I look back. Just sort of everybody, “jungjung”, talking amongst themselves and then they disappear again, and then the next day it’d be the same thing and disappear again. Nobody tells me anything and I guess I was in shock, that I was too stupid to even ask anything.”*

**#75, 34 yo female, TAC, pedal cyclist, lower extremity fracture, 17 months post-injury**

*“...That morning there was also a massive ward round with probably six medical students and a whole lot of doctors. And so I didn’t really feel so able to ask the questions I wanted to ask. I didn’t even quite realise who to talk to, like who’s the boss out of the 12 people standing around my bed?”*

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*“.....Just that it was so early and there were so many of them. And a lot of them were students and so they would be talking amongst themselves about me and I was kind of like, “Hi guys, I am here and I am trying to...”, injured and unable to move and I know it’s my fault but just a little bit more sensitivity, like, maybe they could save discussions amongst themselves for when they either leave the patient or maybe some of them go outside and discuss it.”*

**#13, 51yo male, Medicare, low fall, multiple upper extremity fractures, 24 months post-injury**

*“..I don’t think anyone ever explained to me upfront what the risk of the operation was as far as long-term effectiveness of the treatment..... I would have preferred, in hindsight, that one had that discussion up front about well there is a big risk in trying to put these things back together that you will need a second operation. And now I find that there is still quite a high probability that I’d need a third operation. Again, I’m not experienced and I’m not sure what decision I would have made, especially in my condition at the time. But I just think it would have been better if someone had said up front that there are two treatment options: one is to try and reconstruct this with a fairly high chance that it won’t work, or we do this other thing.....”*

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*“...the way they said to me things take the neck brace off, no you’re not, put it back on, oh, you’re fine to go to work, no you’re not, you’re not a candidate for surgery, yes you are, no you’re not or now you’re on a priority list for surgery of this. They tell you something different every time you go there....”*

**Hospital environment**

A number of participants commented on the “business” of the hospital, the noise and activity interfering with sleep, lack of cleanliness of the hospital, and the poor food provided to the patients. The hospital volunteers were a highlight for a number of participants, who praised their compassion and attentiveness to the patients.

**#20, 61 yo female, Private, other mechanism, head and other injuries, 21 months post-injury**

*"...I just think what I can remember of the hospital, they were very pushed for time. They were very busy."*

**#101, 58 yo male, Private, pedal cyclist, knee injury, 12 months post-injury**

*"The people were absolutely frantic."*

**#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*"But I ended up in a ward with I think there were four or six people who were in an even worse state than me. Some of them very old and I think some of them probably a little bit demented, who woke up during the night screaming. There was in my case a light that constantly beaming in my eyes at night to ensure that I wouldn't get any sleep."*

**#99, 59 yo male, Medicare, high fall, lower extremity fracture, 13 months post-injury**

*"Oh, look, they are tremendous in that hospital. The only thing what was bad is the food was absolutely s%&#. But, that's not...look, the nurses, the doctor, everyone was so, so good. I just couldn't believe it. For the limited finances they get in there, how they can just go, go, go and look after everybody, and everyone seems to give everyone so much attention."*

**#68, 32 yo male, Private, low fall, spinal injuries, 16 months post-injury**

*"One other thing I wanted to mention was the volunteers at the Royal Melbourne were brilliant. I've got a lot of respect for them and somehow I'd like to do in the future is it's very hard for me right now to do it but I would like to in the future spend some time and volunteer some time to help because they provided invaluable service and they do it off their own back. I wish the health system was such that we didn't need volunteers."*

### *Pain management*

Pain was raised as an issue for 44 (36.7%) participants in the study. Poor pain control in the acute care phase, and a lack of continuity between inpatient and outpatient pain management were constant themes. There was also a perception of over-medicating for pain by a number of participants. The presence of pain impacted on the participant's behaviour, mood and recovery. There were also reports of pain medication impacting on mental acuity and return to work, and difficulties weaning themselves from pain medication.

**#100, 45 yo male, TAC, motorcycle, lower extremity fracture, 13 months post-injury**

*"..I don't like all the pill popping they give me; the painkillers and stuff. Some of them are like they shove them down your throat too often I think, even if you don't really need them."*

**#89, 41 yo male, WorkCover, other mechanism, orthopaedic injuries, 13 months post-injury**

*"...the problem being is I was in a lot of pain. Imagine four broken vertebrae, broken ribs and broken neck. And basically, I was on morphine, well, Oxycontin and all those. I was on different drugs everywhere. To tell you the truth, I was sort of drugged out of my head, which was basically driven on pain relievers I suppose. There were certain nights that I felt, "Jesus Christ, I'm still in pain, can I have more morphine?" They said, "No we can't because we've pumped in the max amount into you; that's understandable. I'm not an actual GP or anything."*

**#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*"...for many months I was on opiates...I was taking Oxycontin and so on, that's made my mind very sluggish. Initially, I could not complete a crossword in a day, so I didn't really get back to a reasonable level of work until just a few months ago really."*

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*"I've been living with chronic pain every day, you get grumpy, you get short-tempered."*

**#49, 25 yo female, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*"I don't know whether it's because they were short on staff or anything, but there were times where I'm in a lot of pain and I couldn't really...it took a long time to finally find someone to come help me and assist me with it."*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*"No, while I was in the hospital I had pretty much all the pain relief I needed. When they sent me home they virtually sent me home with no pain relief and that took a couple of months of seeing other doctors and stuff to get that prescribed for me again. I found it quite depressing at the time because I was in pain and I just felt like they suggested I'd be a drug addict."*

**#98, 26 yo male, TAC, motorcycle, multiple lower extremity fractures, 13 months post-injury**

*"So I was on pain medication for four months in the hospital, but they didn't wean me off it when I left. No, well, because I was still on it the doctor was still giving it me, he said he can't just stop it. And then I was taking it for another five months and after I tried to get off it."*

## Follow-up care and rehabilitation

### *Discharge from hospital*

Discharge from hospital care was a stressful time for a number of participants, and many felt ill-prepared for discharge either emotionally, physically, or due to a lack of information about what they could and could not do.

#### **#87, 33 yo female, Medicare, low fall, lower extremity fracture, 12 months post-injury**

*“Yeah, like, heaps of stuff, they just kind of tell you, “Okay, you’ve had your surgery, you’ve been here a week and a half, you can go home now”.”*

#### **#102, 60 yo male, TAC, motorcycle, multiple lower extremity fractures, 12 months post-injury**

*“Yeah, they bundle you up pretty quickly. Once word got around that I was out they pack you up and out the door pretty quick. They gave me some quick lessons on fractures and, “See you later”.”*

#### **#22, 60 yo female, TAC, motor vehicle, orthopaedic injuries, 19 months post-injury**

*“Okay, well, you now have to wait a while, but they don’t tell you why, and they don’t tell you what and what you should and shouldn’t do……. I think teaching you how to handle yourself I think could probably be improved……. And I know the nurses haven’t got time. It should be a physio’s job. They’re probably stretched to the limit as well. Just to teach you how to just manoeuvre yourself. When I got home friends gave me different things, like their parents had had, you know like those pick up things; those long and when you drop something because I couldn’t bend to pick anything up……. I was probably home roughly three weeks before someone turned up. And I managed to get an over-bed pully thing, so that I could lower myself and lift myself out of bed.”*

#### **#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*“So I think when they send you home, I think just your whole world’s been turned upside down and any instruction or anything like that that you’re given, you just don’t remember at all.”*

### *Inpatient rehabilitation*

Forty-five participants (37.5%) were discharged to inpatient rehabilitation, and to a number of different rehabilitation facilities. Participants reported opting not to go to rehabilitation due to the distance required for family members to travel to visit, and others expressing their need for rehabilitation but not having this option offered. Of those who went to inpatient rehabilitation, their experiences at rehabilitation were mixed, with patients reporting excellent care and perceived value from the experience, while others were not as positive about their rehabilitation experience. The latter reflected a lack of information given about the reasons for transfer to rehabilitation.

**#115, 63 yo female, Private, low fall, lower extremity fracture, 12 months post-injury**

*"I was discharged to a private rehab. They just put me down for public or private and I would just go to whichever had a bed. And I got terrific care there."*

**#80, 62 yo female, Medicare, struck by person, isolated head injury, 13 months post-injury**

*"I think the programs that they had ..... were very good for people like me. There was everything there and you're on a daily assessment, and I think that was just getting back into a routine of some description was very good for me."*

**#15, 78 yo male, TAC, pedestrian, head and other injuries, 24 months post-injury**

*".....but my treatment down in ..... I can only speak extremely highly of down there. They really got me up and moving about. My biggest fear was that I was not going to be able to walk and move about. But with their help and guidance we've managed to do that and I'm walking around. I limp but it's better than having to sit in a wheelchair or something."*

**#112, 67 yo male, Private, low fall, upper and lower extremity fractures, 12 months post-injury**

*".....And then they said, "You have to go to rehabilitation", which I wasn't very impressed with by that time...I wasn't in any pain, I hardly needed any pain relief at all, I didn't want it. My left wrist was okay, as long as I didn't move it too suddenly. I just wanted to get home, but they insisted that I go to the rehab, which I detested absolutely. .... I spent six weeks there and I hardly had more than four hours of therapy a week; it was just a waste of the time and a waste of bed...."*

**#28, 28yo female, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*"I think maybe more information about rehab because I was just given a list of two and I just chose one, and it was probably not a suitable rehabilitation facility. It was all old people and there was no people recovering from accidents. And I just felt a little bit out of place. It was the longest two weeks of my life."*

**#16, 56 yo male, Medicare, low fall, head and other injuries, 24 months post-injury**

*"Why aren't I at home? Nothing is happening. I'm not getting any treatment as such. I don't need half a dozen nurses or doctors around me changing dressings or sending me off for this, that and the other. I couldn't understand why I was there."*

### *Outpatient treatment*

The outpatient clinics at both The Alfred and Royal Melbourne Hospitals were universally disliked by participants. The major reasons for the almost wholly negative reports were the substantial delays in receiving an appointment, prolonged waiting times to be seen, the very limited time spent by clinicians, the lack of continuity of care, and the inability to see senior staff. A number of participants were able to address the long outpatient waits by changing to private care.

**#12, 37yo male, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*“The Outpatient system is an absolute disgrace. I live in ..... It’s 200 km from the Alfred. So I drive down there, sit in traffic, pay exorbitant amounts for parking, sit in the waiting room for over three hours and then spend 10 minutes with a different doctor to the one that was there last time. Have an argument about the whys and wherefores of the pain that I’m suffering, and then drive home again. I don’t understand why I can’t get an X-ray locally, have it sent to the Alfred and then talk on the phone about my pain. There is absolutely no reason why I had to drive a car down there and sit in a waiting room to spend 10 minutes face-to-face with someone to have a discussion; that’s just ridiculous, absolutely ridiculous.”*

**#77, 43 yo female, Medicare, low fall, upper extremity fracture, 15 months post-injury**

*“Mind you, the hospital appointments I found were pointless because you’d walk in, they’d go, “Oh, yeah, you’ll be fine, come back in six weeks”. I’d be sitting there for three hours....”*

**#105, 28 yo male, Medicare, low fall, upper extremity fracture, 12 months post-injury**

*“The only negative thing I’d have to say was the tremendous waiting in the outpatient room, and I completely understand the chaotic logistics of running a hospital. While I was sitting there I think there was a certain scheduled time for me to be there which was, for example, say 2:00 o’clock, and I think the last one I had to wait four hours I think. Now, that’s okay but there’s just one with all the other quite annoyed patients, there was no information provided whilst you’re waiting, so you just have to wait for infinity.”*

**#75, 34 yo female, TAC, pedal cyclist, lower extremity fracture, 17 months post-injury**

*“This is so hard to change but I would have liked to not have to wait hours in the outpatient clinic to be seen for five minutes by a really junior doctor, but that is the way it is, but it was pretty annoying at the time..... and I’ve spent five hours here to speak to a very junior doctor and get dodgy advice. So that’s it, I’m going to go private. So that’s been really good.”*

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*“.....and then when I had to go back again, which was six weeks, they couldn’t fit me in for another 10 weeks, and I’d been instructed that I had to go back because if the metalwork wasn’t...or my bone was healing, or the metalwork wasn’t put in properly that they’d have to do it again. So I was told not to go over that. So when they sent me the appointment, I said I’ve been told to come at six, not 10 weeks, that’s a month later. “We can’t fit you in anywhere”, so that’s when I went private.....”*

*Allied health follow-up*

Physiotherapy was specifically mentioned by 33 (27.5%) participants as important for recovery, while nine participants found benefit from seeing a psychologist or “counsellor”. Other forms of allied health such as chiropractic, osteopathy, occupational therapy and hydrotherapy were mentioned by participants as beneficial in less than 10 cases.

**#75, 34 yo female, TAC, pedal cyclist, lower extremity fracture, 17 months post-injury**

*“Seeing physios and being given exercises and doing them on a good day. It’s very hard to motivate yourself to do them exactly and as often as recommended. But I think they helped a lot.”*

**#108, 57 yo male, Private, high fall, head and other injuries, 12 months post-injury**

*“In terms of it being very professional of course, but also getting that balance between establishing a rapport, being someone you felt you could ask questions of. I thought the physio was excellent for that.”*

**#64, 45 yo male, Medicare, other mechanism, upper extremity fracture, 14 months post-injury**

*“I’ve been to counselling; I’ve done counselling probably for the last 12 months I suppose. I must admit, that has... a bit tough because I don’t normally do that sort of thing but it’s been really helpful.”*

**#9, 41 yo female, Private, other mechanism, orthopaedic injuries, 22 months post-injury**

*“I had some counselling, which I paid for, which was helpful.”*

**#10, 58yo female, TAC, Pedestrian, Upper extremity fracture, 25 months post-injury**

*“I ended up having some help from a psychologist because I got quite depressed because of a complete change of lifestyle and being socially isolated, etcetera, and I haven’t been able to work and in constant pain, and that was really, really helpful – really helpful.”*

## **Non-medical care**

### **TAC**

Just over half (n=62) of the participants were TAC compensable patients. Participant experiences with TAC were mixed. Many participants reported wholly negative experiences, although many were able to see the benefits of the system, particularly the financial support provided. A number of participants likened the TAC to a “bureaucracy”, “government department” or “insurance agency”, with their expectations of TAC consistent with their expectations of other government agencies and bureaucracies. Participants reporting positive experiences with TAC usually also reported areas that they felt could be improved.

Positive participant experiences with TAC were generally associated with the following themes:

- i. Single point of contact with TAC
- ii. A perception of “caring” by the TAC staff
- iii. Financial support provided by TAC

- iv. Good communication with participant, and between participant, TAC and service providers
- v. Rapid approval of services.

**#47, 47 yo female, TAC, motorcycle, orthopaedic injuries, 14 months post-injury**

*"It's all been good. I've always felt as if I've been looked after by the TAC. There have been a couple of times where they've questions things that I've asked for or something. When I've explained why I need those things they have followed through with them. As long as it's a reasonable request. There have been a couple of times where I haven't received a reimbursement and I've had to ring up and they've had some sort of computer glitch, but other than that no. Working with the TAC has been very good for me."*

**#97, 46 yo female, TAC, motorcycle, upper extremity fracture, 11 months post-injury**

*"They (TAC) are amazing I think. I suppose too because I've sort of tried to be polite and all that. Pretty much anything that I've needed (within reason) and they've sort of...I think they approved everything I need because it's sort of related to my accident.....I haven't really got anything bad to say about anything at the moment. It's been pretty accommodating..."*

**#82, 51 yo female, TAC, motor vehicle, upper extremity fracture, 13 months post-injury**

*"Exemplary. Naturally, when your income is threatened you just go into a tailspin and I remember I had the accident on the Friday, so maybe it was on the Saturday morning, there was a woman, a representative came from the Transport Accident Commission and said to me you can fill out all these forms and this, that and the other, and you will be eligible for a loss of income benefit. Which, to me, was just remarkable. I was so naive about that whole organisation. And, particularly because I was at fault in the accident I was just astounded that they were willing to give me that support. So that was great. Everybody that I have spoken to, and I do keep in communication with the TAC, everybody I've spoken to has been unbelievably kind. No-one has ever been moody or impatient with me, or with what I sometimes think might be silly questions, they've always been very helpful, explained everything they could."*

**#44, 26 yo male, TAC, motor vehicle, multiple lower extremity fractures, 14 months post-injury**

*"They've been excellent. As I said, you've got to understand you work with bureaucracies and you did have to repeat yourself a bit of time. If you can cancel that bureaucracy then great. There are improvements that could be made."*

**#5, 56 yo female, TAC, pedestrian, head and other injuries, 24-months post-injuries**

*"Well, they were nothing but supportive and quick to respond and they paid for everything without question. They were wonderful."*

Conversely, negative experiences with TAC involved:

- i. Lack of single point of contact, a constantly changing contact or failure of contact to communicate with participant.
- i. Lack of trust of participant by TAC
- ii. Perceived lack of compassion, concern or care by TAC staff
- iii. Difficult paperwork processes and difficulty “navigating” TAC processes
- iv. Pressure to return to work when participant not feeling ready
- v. Protracted and adversarial impairment assessment process.
- vi. Delays in receiving information, organisation of services and reimbursement.

The inability to communicate effectively with TAC was the most common complaint of participants, with many describing the frustration associated with accessing information from TAC. In many cases, this reinforced the participant’s perception that TAC did not care about their recovery. Participants commonly reported a lack of compassion or caring by TAC staff, and a perceived lack of understanding of the difficult situations participants were in.

There were very mixed reports of when participants would receive information from the TAC. For a number of participants, the information arrived many weeks after injury and there was difficulty getting reimbursed for services used in the meantime as TAC processes had not been followed. For many, the TAC “10 day rule” was highlighted by participants as an issue – where communication was almost always received on the 10<sup>th</sup> day but a resolution or decision had not been made. Waiting for reimbursement commonly caused significant stress and financial hardship.

Participants also reported considerable difficulty “navigating” TAC claims processes and understanding the paperwork requirements. Comprehending and completing the TAC paperwork was a clear issue for participants with ongoing cognitive issues following head injury, with little recognition of this issue by TAC claim managers and staff. A perception of constant requests for different paperwork was also considered problematic by participants with the question “Why didn’t they ask for this at the start?” raised commonly. The approval of treatment in small “batches” was considered a barrier to recovery as the re-approval process often led to periods without treatment.

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*“They need to sit you down and explain their system to you – across the board. I would ring TAC and speak to my case manager and then say in a month’s time I’d ring TAC again and try and speak to my case manager, and they’d say, “Oh, no, you’ve got a different case manager now, we’ll put you through”. So I’d have to speak to them and go right through all my details and claim and everything. They’d ask questions about everything and I think why do you have it now? Why can’t I just stay with the same claim manager because I’ve got a rapport with them, then you’ve got continuity, they know who you are, they know how you’re feeling at that time. They know if you’re having a meltdown or whether you’re coping fine or whatever. And then you just get lumped with new case managers.”*

**#62, 63 yo female, TAC, motor vehicle, orthopaedic injuries, 17 months post-injury**

*“When I was in the Epworth was the first time I had any contact from them, and I had a lady ring, who said she was my case worker. She said if I needed to talk to her to ring and ask for her. I think she might have even given me her extension number. Anyway, when I came out of hospital my partner actually had two or three accounts that he’d sent off to them.....So I rang them and wasn’t able to speak to my case worker, and the lady that I did speak to she only sorted out all the accounts difficulties, and I have never been assigned another case worker. I was never reassigned another...nobody bothered to reassign me another case worker, no-one has rung to talk to me about anything.”*

**#49, 25 yo female, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*“The main problem I’ve been having with TAC are the income claim issues. One of the main problems that has caused is because there was a lot of...I wasn’t aware of all the things that I was supposed to be doing, so I just wished that I was told quite clearly that this is what I should be doing, this is what’s happening”.*

**#95, 36 yo male, TAC, motorcycle, lower extremity fracture, 13 months post-injury**

*“TAC are a typical government department. They were hopeless, absolutely hopeless in their lack of information, what they expected me to do to get medical treatment I thought was a joke. When I got let out of hospital they only gave me a day’s worth medication, or two days’ worth of medication, sorry. And I was on medication for about 8 weeks after the accident. I had a lot of trouble with the TAC, and the local GP’s trying to get medication, trying to get the hospital, all that sort of thing was...that wasn’t very good.”*

**#73, 48 yo male, Private, pedal cyclist, upper extremity fracture, 14 months post-injury**

*“You just got to chase them up because it is a government department unfortunately.”*

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*“You go in there, I don’t know, they’re just not very compassionate, regardless of your situation; they’re not very helpful the people..”*

**#88, 59 yo female, TAC, Pedestrian, upper extremity fracture, 12 months post-injury**

*“They’ve got a lot of proformas. And then you get a letter from TAC that all look the same. And they’ll say things like...now let me think of some...I can’t think of the exact wording, but maybe I could just make it up because otherwise it’ll be totally wrong. But say you’re in two situations. I’ve got a broken arm, so they’ll probably say on my letter, “If you have a broken leg, then go south. If this doesn’t apply to you, go west”. Why don’t they take the broken leg out of my letter? They put it in there and when you read it you go, “Oh, what do I have to do now?” And you have to actually read the paragraph carefully to work out what applies to you because they just have a proforma. And if you have a look really carefully you might find a sentence on my letter that applies specifically to you. If you miss that you’re done for.”*

**#107, 59 yo male, TAC, pedal cyclist, head and other injuries, 12 months post-injury**

*“I suppose once again it’s probably a learning curve for myself and my doctor. There were delays in me starting rehab which if TAC had been more informative and all the paperwork and steps and hoops that I needed to jump through to start the rehab, I could have started my rehab a fortnight sooner.”*

**#107, 59 yo male, TAC, pedal cyclist, head and other injuries, 12 months post-injury**

*“The frustrating thing at the moment is I’m doing exercise physiotherapy to try to build up some shoulder strength, and evidently I can only get those in packets of five sessions. When the fifth session is a comparative against the first session to see whether I’m improving, and then that management plan has to be resubmitted to TAC for approval. So that means I do five weeks, have two or three weeks off while TAC approves the next session. I can’t do a continuous set of exercises, so I find that very frustrating.”*

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*“The relief when TAC actually comes through with something like they said. When you fight for your money then the day it comes through it’s just, oh, my God, that is just...I can grocery shop, I can feed my kids.”*

**#90, 30 yo female, TAC, motorcycle, lower extremity fracture, 21 months post-injury**

*“But TAC just kept on ..... one document from document from document and I supplied to TAC everything and just about two months ago they turned around and said we need a group certificate. And I said, “Why didn’t you ask for this at the start?”*

Dealing with TAC investigators, assessors, and TAC initiated medical assessments, were viewed negatively by participants. The behaviour of these TAC representatives was generally perceived as aggressive, antagonistic and negative, with the participants feeling this approach was unjustified given the degree of their injuries and their experiences with TAC. In general, there was a perception of mistrust by the TAC. For a small number of participants, dealing with a TAC investigator was their first direct experience with TAC.

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*"I haven't been treated the best with TAC to be honest. Got treated like a criminal when I got out. I had an investigator come out and investigate me, and being a passenger in a vehicle and asking me my alcohol limit. I mean, what's the relevance of me being a passenger, and 20-minute interview ended up going for 4½ hours..... He started interrogating me. "Was I drinking in the car?" I said, "You know I wasn't drinking because my blood alcohol..." we had a slab of beer in the car, it's not illegal to buy a slab of beer from the pub on the way home". And I said, "The driver's alcohol limit, my driver's alcohol limit was 00, mine was 00, and you know that from the hospital report, so why are you asking me that question?""*

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*".....and he was just really trying to intimidate me the whole time. He could clearly see I was legitimate. Within the first ten minutes he could have kicked it back a bit and not kept attacking the whole way, but he was totally inappropriate and the fact that he is in a care profession, he should have treated me as a patient. I know he was contracted by the TAC and he gets paid by them, but there was no bedside manner, there was no...it was just really bad."*

**#12, 37yo male, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*"TAC must seem to think that people are now trying to rot the system, and I'm sure that a lot of people are, but this is a clear-cut case of a broken leg. The rigmarole to go through to get approval for just some basic physio or whatever, and discussing further support after the incident is like pulling teeth."*

The issue of returning work created conflict between TAC and the participant in a number of cases. Participants experienced pressure from their TAC contacts to return to work despite the participant not feeling ready, or returning too soon and struggling to cope.

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*"I was having a lot of pushback from them. I was telling them that I wasn't coping at work and that I was thinking of resigning. And they wanted to...because obviously there's a back to work program and they thought maybe they could speak to my employer and see if I can go part-time. I said, "Look, I'd love to but I can't with this job, it needs to be full-time. Unfortunately, it's the way the role is."*

**#49, 25 yo female, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*"When I'm on the phone with them I start feeling this guilt on myself when they ask me questions like, "Have you returned to work yet? Why haven't you?" It just made me feel really bad about myself."*

An interesting finding was the perception of participants as being "cash registers" for health service providers, where recovery was a secondary aim after perceived financial gain for the health service provider. There was no blame for this attributed to the TAC, but the situation was perceived as a problem with the compensation system.

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*"...I would have liked to be treated like a human being instead of like a cash register number, to be honest, because some of them... just treated you as a cash register number and as long as they get their money, and haven't heard anything from TAC, they didn't care what treatment you got."*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*"...they couldn't make sure they were going to work because they tried anyway, and I don't know why they do that, is it to get more money from the TAC or what? But by doing that obviously it's holding me back a little bit."*

Some of the strategies used by the participants and their health care providers to avoid dealing with TAC were engaging legal representation to navigate the system, and using alternative funding (e.g. private health insurance and Medicare bulk billing) to limit contact and service claims with TAC. Participants reported that a number of health service providers were not willing to submit claims for treatment services to the TAC due to delays in payment, requesting that the participant use alternative payment methods.

**#29, 67 yo male, TAC, motor vehicle, chest injuries, 23 months post-injury**

*"TAC covered everything but my doctor seems to for some reason she put it through Medicare, so I don't know why, it must be quicker really for her."*

**#62, 63 yo female, TAC, motor vehicle, orthopaedic injuries, 17 months post-injury**

*"Yeah, the only thing I've had to get reimbursed from them is medication, because no chemist will send in to TAC because they don't pay them very quickly, so you have to pay them and then claim it."*

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*"At this stage I actually had to get my solicitor involved because I wasn't hearing back from them."*

Participants reflected on the TAC system as a whole and the impact that this had on their recovery and responses. Many identified the positive aspects of the financial support and provision of services as a clear benefit of the TAC system. Others believed that the compensation process was detrimental, creating conflict between the participant and TAC, and shifting the focus of the participant from recovery to impairment.

**#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*"I have been hard on the TAC but I realise that just the fact that they're there that when something like this happens to a person that they pick up the medical tabs that really is a very good system."*

**#44, 26yo, male, TAC, motor vehicle, multiple lower extremity fractures, 14 months post-injury**

*"The knowledge that many things were covered under the TAC, that provided solace."*

**#75, 34 yo female, TAC, pedal cyclist, lower extremity fracture, 17 months post-injury**

*"I suppose I might say going to medico-legal appointments puts the focus on impairment and what you can't do, and there is actually almost an incentive to focus on those things – the negative parts of it. I don't think it's had a really negative impact on me but I have at times wondered about my answers to their questions and think if there wasn't the potential for some gain, would I answer that in exactly that way? I tried to answer everything as truthfully as possible but you sit there being confused, going, well, I'm seeing a doctor but actually it's for the purposes of seeing if I'm eligible for a payout of some kind. That is pretty confusing. However, I'm really glad that there is a system of compensation if you have a certain degree of impairment; I think that is fair. So I don't think that should be taken away but there are some of the negative impacts of going through that medico-legal process.*

**#28, 28 yo female, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*"Going through a compensation process makes it harder to recover. I sort of regret that, I should have just like not tried to seek compensation. I think that hinders the recovery process."*

**Private health insurance**

Sixteen participants in the study had utilised private health insurance during their recovery, either to fund their initial care, or through their rehabilitation process. Participant experiences with private health insurance companies were mostly positive or indifferent. There were no reports of difficulties of dealing with private health insurance companies, but participants reported confusion in the hospital about whether to be treated as a private or public patient. A few participants initiated private care in the public hospital in an effort to reduce delays but most reported no change in the timeliness of care. Where benefits of private health insurance were perceived by participants was in the use of private health insurance for surgical follow-up and outpatient allied health treatment. Many initiated the use of private health insurance to avoid difficulties experienced with follow-up care in the public outpatient system. There was no clear consensus from privately insured participants regarding the overall benefit to recovery.

**#101, 58 yo male, Private, pedal cyclist, knee injury, 12 months post-injury**

*"....do you want to be treated as a private or a public patient? I said private. And then they went away and then about three days later they came back and said, do you want to be a private or a public? I said private. And I said, "What's the difference?" And they said, "Well I get the TV on and I get the use of a phone". And the money will help from the hospital."*

**#20, 61 yo female, Private, other mechanism, head and other injuries, 21 months post-injury**

*"I have to say I'm sure if I didn't have the private coverage things might have been different."*

**#36, 34 yo male, Private, high fall, orthopaedic injuries, 15 months post-injury**

*"...they've been good in the coverage side of things, that's for sure. I couldn't ask for better there really. I just thought I might have got...and I know these things take time so you can't push it...and I know there's a system, so I've just sort of been waiting it out really. The only thing for me I don't know whether I would have got any better or lesser service due to being in healthcare or not healthcare."*

**#94, 35 yo female, Medicare, pedal cyclist, upper extremity fracture, 13 months post-injury**

*"...the guy I was dealing with did ask me did I want to go private or public, and I said I was quite happy with either. He kind of made the decision that I'd get in earlier so I went public, and because it was considered an emergency case. Yeah, just sort of information with more options, but I think if you go private you have to go to a different hospital, but one of the surgeons that work here would have to fit you in, but I never got any of that information."*

**#45, 54 yo female, Private, low fall, upper extremity fracture, 14 months post-injury**

*".....And then when I had the second follow-up, I think it was then maybe only a couple of weeks I couldn't get it for the designated time, so that...if I had stayed in the public system I would have been out of work far longer."*

**#68, 32 yo male, Private, low fall, spinal injuries, 16 months post-injury**

*"...I had healthcare which covered that amount of the costs."*

## **WorkCover**

Only two participants in the study were covered by WorkCover. Both were treated as public patients and a WorkCover claim was successfully made after hospital discharge. Both participants reported similar issues to TAC participants with communication.

**#76, 29 yo female, WorkCover, other mechanism, head and other injuries, 17 months post-injury**

*"Well they're good as far as it pays for everything, but they're an absolute pain to communicate with, and everybody says they're impossible to get payments from. I was lucky, my physio was willing to do it but apparently practitioners don't like to work for them. Yeah, I used to have to ring them absolutely constantly, I could never get hold of them at all; they're always in meetings. In the end I dealt with them, I had three different consultants. So then the new one wouldn't know my case, so I had to go through it all again because it was pretty complicated from memory."*

**#89, 41 yo male, WorkCover, other mechanism, orthopaedic injuries, 13 months post-injury**

*"...And I made well over 30 calls to find out an answer when is all this going to get paid, when is it going to get approved. I had case managers, I had one went upstairs, she couldn't give a hoot; she was going upstairs and another one come in, he got the boot, and another one come in, I just got totally cocked around – excuse the French!"*

## **Social support and impact on social networks**

The importance of social support from family, friends, neighbours and the community for recovery was clear in the responses from the participants. Seventy per cent (n=85) of participants reported social support as a facilitator of recovery. Family, friends and neighbours provided considerable emotional support, assistance at home, assistance with transport, and financial support for those who needed it. Most assistance was required in the early stages after injury but many reported still requiring assistance, more than 12-months after injury. Loss of mobility, difficulties with self-care, activities of daily living and transportation were prevalent, requiring substantial help from family and friends. Many participants struggled with the loss of independence, placing strain on relationships with family and friends. Where the injured participant was the carer of another family member, the injury had a profound negative on the household. A number of participants reported re-defining of friendships and family members with the phrase “you learn who your real friends are” commonly used.

### **#3, 27 yo female, TAC, motorcycle, head and other injuries, 24 months post-injury**

*“When I first got out of hospital I went to stay with my mum and dad for probably a month or so, and then I ended up going home but I still couldn’t drive. I wasn’t allowed to drive yet. So, my sister would come around and take me to the supermarket and do that and mum would come and take me places so, yeah, that was pretty good..... I couldn’t have done it without them. They were awesome and I suppose they’re glad I’m alive.”*

### **#5, 56 yo female, TAC, pedestrian, head and other injuries, 24-months post-injuries**

*“...everyone really rallied and helped me which was really lovely. Family and my daughter came and lived with me for a bit and my husband came over from Adelaide, and family and other family and friends all rallied and helped out, so, yes, it did all...and they’re all in shock as well. But I had so much support.”*

### **#24, 72 yo female, Medicare, low fall, orthopaedic injuries, 19 months post-injury**

*“Well, I was greatly supported. I have an unmarried sister and she came in for 3½ months while I was in the brace and looked after the whole household and just moved in. And friends and relatives have been fantastic.”*

### **#41, 66 yo female, Private, low fall, upper extremity fracture, 14 months post-injury**

*“Oh, I felt bad, I felt awful because if you drive and you can’t get anywhere, and my friends sometimes they used to come and take me for coffee, but they got their own families and their own...they can’t just drop everything. They still took me a couple of times for coffee and they come visit me, help me to wash myself at the beginning because I couldn’t wash myself. I couldn’t even pull my pants up. It was so bad.”*

**#102, 60 yo male, TAC, motorcycle, multiple lower extremity fractures, 12 months post-injury**

*“Well, my family are magnificent.”*

**#94, 35 yo female, Medicare, pedal cyclist, upper extremity fracture, 13 months post-injury**

*“Initially, when my arm was in a cast and things like that. I remember, it’s weird, I remember asking my son to help me do my bra up and he was looking at me, like I am not touching your bra.....”*

**#82, 51 yo female, TAC, motor vehicle, upper extremity fracture, 13 months post-injury**

*“...so in my immediate discharge from hospital I did need assistance, so I came to stay with my father and his wife, and I hate being, you know, I’m fiercely independent, as many people are and I hated being of such a concern to them. So, basically, it’s just one of the motions that you worry that other people are so worried about you.”*

While most participants reported a strong social support network, a number of participants expressed the difficulties and impact on recovering of not having a social network to draw upon.

**#46, 57 yo female, Medicare, low fall, lower extremity fracture, 14 months post-injury**

*No, because my mum’s got dementia and my brother and my sister are looking after her, so I didn’t really have any support.*

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*“...so they just assume that you’re going to have help when you get home. And people can say, “Oh, look, I’m going to help, I’m going to pull my finger out and do this”, but they don’t. The day after I came out of hospital my kitchen...spaced out on medication, trying to cook for my kids and I was here alone because...yeah, everyone fusses while you’re in hospital and then when you get out everyone just goes back to usual.”*

**#64, 45 yo male, Medicare, other mechanism, upper extremity fracture, 14 months post-injury**

*“...Well, at the moment my mother’s very sick so it’s just a matter of time with her so I’m going through that. There’s not much at home, put it that way.”*

**#41, 66 yo female, Private, low fall, upper extremity fracture, 14 months post-injury**

*“Yes at the beginning I couldn’t do much; very little. Well, my family was upset of course and no-one could help so I had some...my husband is here but the man don’t do whatever...they do the way they think...and whenever they want to. So I had some help at home – it’s okay. I wasn’t expecting to have everything like the way it was. I took it that’s how it’s going to be and that’s it.”*

The impact of the injury on family and friends was extensive in many cases. Most participants conveyed the shock that family and friends experienced after the injury. The considerable strain placed on relationships with family and friends was often discussed.

Nine participants reported a positive impact on family and friends, while 54 reported a negative impact. The need for family and friends to take on a role as carer was the most commonly reported negative impact of the injury, although several participants also reported that family and friends were required to make medical decisions when the participant was unable. The latter situation was particularly stressful for the family member or friend. Many participants reported negative impacts on relationships with family and friends due to an inability to participate in usual social activities due to transport or physical limitations.

**#2, 30 yo female, TAC, motor vehicle, chest/abdominal injuries, 30 months post-injury**

*“...Even though, as families go, we get along pretty well together and we’ve always been in a family where everyone does everything; it’s not like one person does...my mum’s always worked, and even if she hadn’t, we’ve always been brought up to look after ourselves. So at the same time I feel like they can’t even have a night in together to themselves because I’m always there. They can’t have naked nights! Everyone wants that every now and again. I feel like I’m a bit of a strain on their relationship, and my relationship with them, so emotionally that’s quite difficult.”*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*“The only tears I’ve really shed through the whole ordeal was for my sister because she’s my next-of-kin and she had to make all the big decisions. She had to give permission for them to amputate the leg.....I was in a coma for two weeks so I was oblivious to all of that and she was worried about how I was going to react when I come around and all that kind of stuff.”*

**#52, 46 yo male, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*“It’s made it harder for her physically because being a female is not really built to...she had to do all the heavy stuff for the first six or eight months: bring all the firewood in, which wasn’t good.”*

## **Emotional impact**

Ninety per cent (n=108) of participants discussed the emotional impact of the injury. The emotional impacts were extensive ranging from: anxiety and depression; diagnosed post-traumatic stress disorder (PTSD); feelings of vulnerability, frustration, anger, isolation; sense of loss of independence and/or self-esteem; worry, fear, and a loss of confidence.

Fourteen participants reported issues with anxiety, depression or PTSD. For participants with previous anxiety or depression, the condition was compounded by the injury. A diagnosis of PTSD was confirmed for two participants. The anxiety and depression

experienced by participants often had a negative impact on relationships and was a clear barrier to recovery for most.

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*“Now, it’s been a bit of a rollercoaster ride. It’s been a year now, so PTSD has set in, so I’ve had times where I’ve been...so there’s obviously all the symptoms from the PTSD which is moodiness, being very emotional and just struggling with all sorts of parts of life.”*

**#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*“Although I’ve had episodes of depression before the accident, I’ve been much more depressed since, so that’s also been an obstacle.”*

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*“The injury caused a lot of, like I said, quite a bit of anxiety and depression, and so it’s kind of destroyed...it has destroyed my relationship at the time, for better or for worse.”*

**#2, 30 yo female, TAC, motor vehicle, chest/abdominal injuries, 30 months post-injury**

*“...I didn’t know until afterwards because of the brain injury I got elevated depression, anxiety. So sometimes that can be difficult.... Like, a lot of things that happen are just then, like, I guess depression is something a lot of people don’t understand.”*

Loss of confidence, fear and heightened caution were commonly reported by participants. In particular, road trauma victims reported being fearful, or being “hyper-alert”, when travelling on the road after the crash. Revisiting the site of the crash or injury event, or being placed in similar circumstances, was difficult for participants. For most participants, the additional vulnerability and fear passed with time, but for a number of participants, this fear was ongoing at the time of interview (>12-months after injury).

**#38, 55 yo male, TAC, motor vehicle, orthopaedic injuries, 15 months post-injury**

*“Oh, very nervy on it; I just think that every car that’s...because I got hit from the side on, I think every car is going to come through...at the crossroads and all that. A bit jumpy but, oh well.”*

**#37, 35 yo male, Medicare, low fall, head and other injuries, 14 months post-injury**

*“I do a bit of riding. As I said, the awareness part of it just more...having a decent look around what I’m doing. The night it happened it was a dark evening, I hit a speed hump I didn’t see because it was a bit dark. It was a silly thing. I don’t sort of ride at the night a bit, I suppose that’s one thing I’ve changed; I haven’t ridden at night since and I wear a helmet. The kids do too; I don’t have to argue with them anymore after they saw me.”*

**#30, 23 yo female, TAC, motor vehicle, head and other injuries, 20 months post-injury**

*“When you’re driving along the road and turn a corner and stuff, I will double check to make sure that there are no cars coming. I will just constantly be alert and constantly double check everything.”*

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*“I’m very, very sceptical when I drive now; very, very sceptical. Even that red light, and it goes grey and I look left and right in case some banana is going to go forward now, in case I get cleaned up again. You never stand outside to go for a bit of a walk around the house, with these young kids the way they fly on the road, and I’ll just, “Slow down fellas, you’re going to kill yourself”, but they just don’t care.”*

**#4, 63 yo male, Medicare, struck by person, other multi-trauma, 24 months post-injury**

*“I found for a long time if I go to a pub or use public transport I’d be a little nervous. I tend to....although it’s pretty rare these days, but I sort of look around a bit more than I ever would in the past.”*

A sense of vulnerability and a recognition of not being “bulletproof” was a consistent theme expressed by the participants. Many highlighted the simple circumstances in which the injury occurred and the shock that such severe injuries could happen so easily.

**#83, 34 yo female, Medicare, fall, upper extremity fracture, 13 months post-injury**

*“I realised that I wasn’t superman anymore, so that was a change.”*

**#13, 51yo male, Medicare, low fall, multiple upper extremity fractures, 24 months post-injury**

*“I feel quite vulnerable because I’ve only got one good arm now to defend myself.”*

**#33, 56 yo female, Medicare, low fall, multiple lower extremity fractures, 22 months post-injury**

*“I feel quite vulnerable with what goes on outside in the world, and I do feel that I’m a bit of a target, so I am a little bit scared travelling with a gammy leg and a walking stick. I still do it but I do find that that has been a bit of a hiccup for me.”*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*“I don’t feel so bulletproof anymore.”*

A common theme was the impact of a loss of physical independence, the associated feelings of inadequacy, and a perception of missing out on life due to the loss of independence. For many, the loss of independence resulted in a feeling of social isolation.

**#2, 30 yo female, TAC, motor vehicle, chest/abdominal injuries, 30 months post-injury**

*“I don’t have my independence and I guess with the fatigue side of things I can’t go out and meet a lot of folk, so a lot of my activities are during the day, especially when I was working I had basically no social life.”*

**#15, 78 yo male, TAC, pedestrian, head and other injuries, 24 months post-injury**

*"I just get annoyed with myself sometimes. Not being able to climb up on a ladder and do things like that. Like changing of a light globe overhead, you've got to wait till one of the young grandsons come in so they can change those sorts of things, where I'd just grab a stepladder and go up and do it myself previously. Just the odd little things around the place that makes you annoyed. You're mind says you can do it but the body won't let you."*

**#23, 76 yo male, TAC, other mechanism, orthopaedic injuries, 19 months post-injury**

*"It's just that you feel so useless that you can't do things."*

**#40, 39 yo male, TAC, motorcycle, orthopaedic injuries, 15 months post-injury**

*"I don't front up to that anymore. I've lost a bit of...probably more so now getting around; it's a little bit embarrassing actually now for me. That's how it sort of comes across. My wife says to me, "Oh, you don't have to be embarrassed about it". Then I think about it: no, I don't have to be embarrassed about it, but I just hate how everyone runs after me, I'm not that sort of bloke..... Probably more the way I think and how they come across. As soon as come in, someone comes running at you with a chair to sit down. They all mean well...it's nice to defend for yourself too. My words are, "Yeah, I'm right, I'll get it". I'm not a bloody invalid."*

Reduced self-esteem and self-consciousness were also reported by participants, often related to weight gain following long periods of reduced activity during their recovery, and the presence of visible scars from their injuries. While many expressed self-consciousness due to scarring, others considered their scars a reminder of what they had been through and survived.

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*"I have a story and I have a scar and I've survived something that was pretty...it kind of...I did something very stupid and I was lucky enough to make it through."*

**#37, 35 yo male, Medicare, low fall, head and other injuries, 14 months post-injury**

*"I was very conscious of the scarring and the whole look of it, but 12-18 months nearly down the track I've had corrective surgery and I'm pretty happy with the outcome now. I realised what it's going to be. There's a little bit of scarring left. I've sort of noticed that more than anybody else. In your own face."*

**#49, 25 yo female, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*"I do feel a little bit self-conscious with the scars on my body. That's the main thing really."*

**#75, 34 yo female, TAC, pedal cyclist, lower extremity fracture, 17 months post-injury**

*"But, negative impacts I suppose were, I think I've said like gaining weight through not being able to do exercise and that affecting my self-esteem and my confidence, and probably my mood."*

**#71, 30 yo female, TAC, motorcycle, lower extremity fracture, 15 months post-injury**

*"I put on 10 kg, I'm trying to drop that at the moment because that's my biggest issue. I'm not all that confident in myself at the moment."*

Anger and frustration were common emotional impacts of the injury reported by participants. Frustration at loss of independence, that the injury happened at all, and a loss of control of life were evident the participants' responses. Anger at self and others for the injury happening were clear.

**#12, 37yo male, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*"A combination of frustration and annoyance I suppose. You sort of reflect and think, well, it's a b%\$^#d that this happened but you just have to deal with it,.....so I just have to accept it, it's going to annoy me for the rest of my life, but things happen."*

**#18, 55 yo male, TAC, motorcycle, multiple lower extremity fractures, 23 months post-injury**

*"Very angry..... the guy that caused the accident, that knocked into me, I believe he was texting, and that made me right at the beginning, "Oh, there is nothing I can do now; it's an accident" but as time went on and I've discovered that my leg was that bad I had to undergo four operations and then I just feel I became more and more angry, but what will come that now because nothing that can be done. Nothing. That's the way it is and that's the way it is."*

## **Impact on activities of daily living, transport, and social and leisure pursuits**

More than half of participants reported that their injury impacted on their capacity to undertake simple activities of daily living, interfered with transport, and had a negative impact on participation in social and leisure activities. Ongoing disability was also commonly reported by participants. The duration of impact varied substantially depending on the severity of injuries sustained with participants with single upper extremity injuries generally reporting limitations for weeks rather than months, and participants with spine, lower extremity or major trauma reporting prolonged disability of greater than 6-months. For a number of participants, ongoing disability more than 12 to 24-months after injury was evident. Even for participants who had returned to doing their normal activities, many reported that activities now take longer and this needs to be factored into their day.

**#38, 55 yo male, TAC, motor vehicle, orthopaedic injuries, 15 months post-injury**

*"Well, you just go shopping where you allow half an hour you got to allow two hours, that sort of thing. You're just slow at everything. That bugs me a little; you just can't seem to get out of that rut, but anyway."*

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*“Look, I’m really sorry... but I kind of need you to help me pull my pants down so I can go to the toilet”. So there were a few different scenarios like that where I had to ask people to do things that really that person wasn’t really necessarily quite comfortable, but in that situation you can’t, you just have to forget about it.”*

**#113, 66 yo female, Medicare, low fall, lower extremity fracture, 12 months post-injury**

*“Well, there was nothing I could do around the house; I don’t work outside the house. My husband’s retired, so it wasn’t really a big handicap because he was really good. He’s not a gourmet cook but we got there. It’s frustrating because I have to sit for three months. I could shower myself, I could toilet myself; so that was a bonus.”*

Disruption to their usual mode of transportation was a particular concern for participants as this interfered with family schedules, work, and socialisation. Injured motorcyclists and pedal cyclists more commonly changed their mode of transportation with a number not returning to motorcycle riding or cycling due to concerns of family and friends.

**#9, 41 yo female, Private, other mechanism, orthopaedic injuries, 22 months post-injury**

*“...it was probably about four months where I couldn’t drive, and then there was probably a further two months where I couldn’t do long journeys. You miss out on a lot of things. It’s not good. How do you feel? Yeah, you feel you miss out on a lot of stuff because you can’t get in the car and go for a long drive. We had a four-wheel drive and in my brace I couldn’t get to the seat, so in the whole time I was at home for my recovery, I couldn’t go anywhere; I was housebound, so that wasn’t much fun.”*

**#49, 25 yo female, TAC, pedal cyclist, orthopaedic injuries, 14 months post-injury**

*“I actually learnt to drive after the accident because I couldn’t bike ride, I had to think of a different mode of transport for myself. So, yeah, that’s when I finally got it together and got my driver’s licence.”*

**#73, 48 yo male, Private, pedal cyclist, upper extremity fracture, 14 months post-injury**

*“I don’t cycle to work anymore. The wife won’t let me either. I had a few scraps, a few near misses and things. Then you realise when you wear a bit of lycra and ice cream carton on your head it’s probably not very good for safety. So now I ride a Vespa to work.”*

**#97, 46 yo female, TAC, motorcycle, upper extremity fracture, 11 months post-injury**

*“I can’t ride my motorbike anymore because my hand needs strength for the accelerator. My family would kill me personally if I got another one.”*

Sixty per cent of participants (n=72) discussed the impact of injury on their participation in social and leisure activities. The inability to participate in usual social and leisure activities was inter-linked with emotional issues. For many, the loss of capacity to participate in physical activity or social activities impacted on health, self-esteem and increased the

perception of social isolation. The importance of regaining the capacity to participate in sport, recreation and social activities on participant's emotional and physical recovery was clear.

**#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*"I used to play tennis, I don't do that anymore. I used to walk to and from work, so that'd be like an hour walk a day and I can't walk more than 20 minutes. I can't stand longer than 15 minutes which impacts on me going out now. So I'm reluctant to go out with friends because if there's nowhere for me to sit then I can't stay out all night. So I'm not going out as much, I'm not seeing my friends as much because of that. I'm not as active physically, so I'm not doing any sport."*

**#71, 30 yo female, TAC, motorcycle, lower extremity fracture, 15 months post-injury**

*"Well I don't ride with my mates anymore; I used to do a lot of riding. Impact on my friends I've actually not lost a lot of friends, ut hanging out with my friends has dropped a lot because I used to do a lot of hiking and stuff like that, surfing. And just because of the injury I had to stop a lot of it."*

**#57, 24 yo male, Private, struck by person, isolated head injury, 14 months post-injury**

*"I'm now....was the captain of a football team, and now I'm struggling to get back into the team; people have their doubts about what I can and can't do. Memory caused a lot of issues. It's just hard to get back to what I wanted to be. Everything's changed and made everything a lot different."*

**#20, 61 yo female, Private, other mechanism, head and other injuries, 21 months post-injury**

*"I used to dance every week, and I did art, scrapbooking, but I haven't been able to get back to them because I can't...with the vision, even though there's nothing wrong with the actual eyesight, it's just everything is still off centre."*

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*"Like a lot of my leisure activities...when you're an artist you don't really have leisure activities. Like being an artist is kind of your leisure activity, so, yeah, I could barely ride my bike anymore for a long time. Can't go roller skating because if I fall I could hurt my wrists really badly and they're already stuffed. So I had to sort of make a few changes of my leisure activities..... kind of took away a big part of my life really."*

## **Financial and employment impacts**

Eighty-one participants (67.5%) discussed the financial implications of their injury. Loss of income, treatment costs, alternative travel costs, replacing the damaged vehicle or bicycle, equipment, and assistance at home were some of the key costs reported by participants. Financial burden was predominantly reported by participants of working age, with loss of income the primary concern of participants. A prolonged inability to work resulted in huge financial impacts for many participants. A reliance on savings and loans from family

members or friends were common, particularly for those with prolonged absence from work and an absence of compensation. For participants reporting out of pocket costs for treatment, these were generally not extensive and were predominantly “gap” payments for privately insured participants seeking treatment from private practitioners. Needing to keep to a budget, and reduce the purchase of “luxuries”, were common themes discussed by the participants.

The financial implications of loss of income were generally much less for those covered by the TAC, although many discussed the shortfall between loss of earnings payments from the TAC and their usual income. The inability to earn an income due to injury resulted in reliance on welfare payments through Centrelink for a number of participants. The importance of income protection insurance was discussed by several participants, providing substantial financial support after injury. The loss of income was not only for the injured participant. Many participants reported that family members took extensive leave or left their employment to provide assistance to the injured participant.

**#4, 63 yo male, Medicare, struck by person, other multi-trauma, 24 months post-injury**

*“..I was on sort of rollover medical benefits through Centrelink (Newstart). That helped but it certainly doesn't go far.”*

**#9, 41 yo female, Private, other mechanism, orthopaedic injuries, 22 months post-injury**

*“..Once I returned home from hospital we had to pay for a carer to come each day and sit with me and the baby because I couldn't carry the baby or do anything for the baby, so we had to pay for a carer to come every day from 8 o'clock till 5 o'clock so that my husband could go to work, so he kept working..... So nearly four months of paying a person's wages to come and look after me at home and the baby was home, whilst I couldn't do anything. And there was no facilities at all that would take me and the baby to look after us. There's no council help, there's no government help.....My husband lost a lot of income because he was off work for at least a month and then on top of that we had to pay wages for another three months for someone to come in and act as a carer during the day while my husband went to work..... We're still paying it back now so the the effects for the couple of months that we spent that money the effects has sort of gone on for almost two years now.”*

**#13, 51yo male, Medicare, low fall, multiple upper extremity fractures, 24 months post-injury**

*“...I've just watched my savings dwindle to the point where I'm selling things to try and get by. I'm not at my last dollar yet, but things are looking a bit grim for the longer term....”*

**#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*"...The time she (wife) was at work I couldn't do anything. So when she came home the second day I said to her I can't do this, so she had to resign from her job and become a carer. So she lost a job that was paying a thousand plus a week to getting a Centrelink Carer's payment for me, which is not much."*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*".....It has been a little bit of a battle I suppose. I've had to just watch what I spend, run a tight budget, that kind of stuff, but I survived all that."*

**#37, 35 yo male, Medicare, low fall, head and other injuries, 14 months post-injury**

*"What I had was my work fund – fairly decent. So Income Protection Scheme through the union I'm in, that covered...not as much as obviously a full wage but enough to keep us afloat while I was out. I've got broken bones, payment at the end which helped when I went back to work...through that scheme as well. Yeah, I wouldn't have been able to...I could have been struggling without that, that's for sure."*

**#47, 47 yo female, TAC, motorcycle, orthopaedic injuries, 14 months post-injury**

*"No treatment costs because the TAC has covered that completely. They have also paid a wage subsidy to me, but of course I've lost 20% of my income and I don't get paid super or holidays or anything like that, so there's been a bit of a financial cost there."*

**#68, 32 yo male, Private, low fall, spinal injuries, 16 months post-injury**

*"...once everything else fell into place I was able to make a claim through Centrelink as well on sickness benefits."*

Eighty-five of the 120 participants (70.8%) were working prior to injury. Sixty participants reported that the injury had a negative impact on work, with only three participants reporting a positive impact on work. The duration of work limitations was related to the types of injuries sustained, and the type of work. Restricted work capacity ranged from weeks to months, with some participants still unable to return to work even two years after injury.

The participants reporting a positive impact on work resulting from the injury discussed using the injury as a motivator to change career. Positive support from their workplace or employer was expressed by 22 participants, with nine reporting substantial difficulties with their employer in trying to return to work.

Employer-related barriers to return to work included the employer not listening to the needs of the injured participant, not understanding their limitations, and placing unrealistic expectations on the injured participant. Additional barriers discussed by participants

included ignoring requests from the participant's GP for a change of duties, and the employer failing to approve sick leave requests. For one participant, modification of duties was seen as a huge barrier in their return to work as the "special duties" were new and stressful, and they felt that a return to their usual duties would have been beneficial to their recovery.

**#5, 56 yo female, TAC, pedestrian, head and other injuries, 24-months post-injuries**

*"...But instead of going back to my normal duties they gave me a special job to do because that job that was...at first you think that is a good solution, not to go...because I had a very high pressure job which is very busy but, in many ways, it would have been much better to go back to my comfort zone area rather than do something totally new. It was a special project, where I had to concentrate on something that I didn't know all that much about, and I think that made it harder at first but got through that as well."*

**#45, 54 yo female, Private, low fall, upper extremity fracture, 14 months post-injury**

*"...But something I did think of afterwards, my GP when I was heading back to work first, wrote a letter stating that I should only really do desk duties for a few weeks, and it would be reviewed. When I handed that to my unit manager I was told it wasn't worth the paper it was written on, which was quite disconcerting."*

**#120, 31 yo female, Medicare, low fall, isolated head injury, 11 months post-injury**

*"One of the things that I was very annoyed about, nothing to do with the hospital was just more that my work, they weren't very proactive about getting me back should I say...I felt ready to go back sooner but I still needed a gradual return to work, I understand that, but I really did feel they didn't really want me back..... If anything, I had less supervision than I had before the accident and was kind of expected to do more work."*

Positive support from employers manifested in different ways, ranging from being able to use sick leave, annual leave and long service leave entitlements, to providing a "back to work" program and alternative duties to accommodate the capacity of the injured participant. A number of participants reported that their employers supported them financially, generally through the additional percentage of salary not covered by TAC loss of earning payments.

**#3, 27 yo female, TAC, motorcycle, head and other injuries, 24 months post-injury**

*"...they were happy to have me back but I had to go on a back to work program. But they were happy to still have me there."*

**#11, 49 yo female, Medicare, other mechanism, head and other injuries, 25 months post-injury**

*"I was off work for five months, but I've been with the company for probably 25 years so I had long service leave, I had two years of annual leave that had accumulated, so I think it ended up that I had maybe three weeks where I didn't get any money."*

**#97, 46 yo female, TAC, motorcycle, upper extremity fracture, 11 months post-injury**

*"...My work has been fantastic: very supportive and everything..."*

**#111, 49 yo female, TAC, pedal cyclist, spine fractures, 12 months post-injury**

*"Oh, yeah, they were fantastic. My work paid 100% of my salary, and then TAC paid them back 80%, so my work lost 20%."*

**#107, 59 yo male, TAC, pedal cyclist, head and other injuries, 12 months post-injury**

*"Well, fortunately, I work for ....., so they looked after me excellently, so there was no financial loss of money. They paid full wages and TAC paid them the 80% or whatever it is they pay."*

Aside from the financial implications of prolonged absence from work, the negative impacts on work reported by participants included; reduced work capacity (e.g. hours and tasks), loss of employment, physical limitations preventing re-employment, insufficient retraining to address the mismatch between skills and physical abilities, and missing job opportunities or promotions while recovering from injury.

**#61, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*"My job function before I had the crash I was a senior team member, and those functions are somewhat diminished so it has affected my career in various ways as progression is concerned and possibly going into the future at this point. Because I haven't been full-on contact for a year and a half, and I'm only there part-time and I can't do the duties that I used to do. There's naturally going to be some overlooking, from management perspective, as far as my progression within the company."*

**#16, 56 yo male, Medicare, low fall, head and other injuries, 24 months post-injury**

*"But I have no formal training, no qualifications, so suddenly, where I was looking for another few years of staying in that and then just retiring, suddenly I'm unemployed for the first time in my life with no qualifications, and then you go in and say I'm 58, nearly 59, I've got steel plates holding my feet on, I can't think too much because I get a headache, I can't do anything, I've got no skills, I have trouble with the computer. They sent me off to a computer course to help me, and I was doing borders and colours on a Valentine's Day card. I said, no, I want graphs and charts. I want business planning, I want stock control, orders, delivery schedules, so they said, "Oh, yeah, you're in the wrong bit; this is more a social class"."*

**#40, 39 yo male, TAC, motorcycle, orthopaedic injuries, 15 months post-injury**

*"I'm a plumber and gasfitter by trade, which you've probably got the details there. That's the only thing I've ever done since I've sort of...since I left school. It's like the old saying, "You can't teach an old dog new tricks", so I really, really would like to go back to that. And then to what degree am I going to be able to do?"*

**#1, 40 yo female, TAC, motor vehicle, other multi-trauma, 24 months post-injury**

*"...I can never work again.."*

## **Resilience**

A positive attitude and resilience were considered a key facilitator of recovery for participants. Fifty-two participants raised the issues of adaptation, adjustment, acceptance, coping, self-motivation, faith and positivity as highly important for recovery. While most participants expressed regret that the injury had happened at all, the capacity to look forward and not dwell in the past was seen as important.

**#67, 58 yo male, TAC, motor vehicle, orthopaedic injuries, 14 months post-injury**

*"...my life's changed, you move on and you don't dwell on the past. Too many people live in the past. I don't complain if things aren't going right every day, about me accident."*

**#24, 72 yo female, Medicare, low fall, orthopaedic injuries, 19 months post-injury**

*"I'm in the very fortunate position of having a very strong faith and I really drawn upon the Lord, and I have been amazed at how well I've recovered..... I really feel that I've had God's hand on me in a very real way. To me it's been miraculous, it really has."*

**#53, 31 yo male, TAC, motorcycle, orthopaedic injuries, 14 months post-injury**

*"I suppose I just try to stay positive most of the time and just kept trying to just thing how I'm going to get through it."*

**#25, 61 yo female, TAC, motor vehicle, spinal fractures, 19 months post-injury**

*"Oh, it's in the past; nothing can be done to change it, so live with it."*

**#91, 20 yo female, TAC, motor vehicle, head and other injuries, 13 months post-injury**

*"I don't really look at the bad side of things so I just try and stay positive."*

## Impact on health

Thirty-five participants (29.2%) reported that the injury had impacted on their overall health. A negative impact on health was perceived by 27 participants, predominantly related to an inability to participate in physical activity and associated weight gain.

### **#27, 44 yo male, TAC, motor vehicle, orthopaedic injuries, 24 months post-injury**

*".....you can't do anything. You might be putting on a bit of weight but you can't...I used to be active: go and do the lawns, whipper snip, do this, do that, you get exercise, and now I can't do nothing; I walk from the lounge room to the kitchen and the lounge room, and that's about it."*

### **#65, 58 yo male, TAC, pedestrian, lower extremity fracture, 13 months post-injury**

*"...Although I've been getting back to gym in recent times, trying to do some gym work and the physiotherapy, it's not a fraction of what I used to do before. I've put on weight and all the rest of it..... This is worrying because my GP told me it will probably affect my life expectancy."*

For a small group of participants (n=8), the injury had a positive impact on the participant's health through improved management of a pre-existing condition, or an increase in physical activity as part of the rehabilitation program.

### **#44, 26yo, male, TAC, motor vehicle, multiple lower extremity fractures, 14 months post-injury**

*"Well, I'm probably a lot fitter because I'm exercising to build it back up again; that's probably been an unintended bonus."*

### **#91, 20 yo female, TAC, motor vehicle, head and other injuries, 13 months post-injury**

*"I didn't do anything beforehand, now I have to go to the gym and things for physio – local gym. They've got be start swimming. I try to get out and walk early and try and get the running up and stuff; it's a lot better since the accident."*

## Overall impact

More than half of participants (n=61) expressed that the injury had been a life changing incident. There was a strong feeling of being fortunate, a new appreciation for life, and enhanced emotional strength. Many expressed that the impact of the injury will be lifelong, that it had changed everything in their life, and had left a feeling of uncertainty about the future. Even participants who reported no disability related to their injury were still concerned about how the injury may impact them in the future.

**#3, 27 yo female, TAC, motorcycle, head and other injuries, 24 months post-injury**

*"...just that it's been a fairly major incident in my life I guess, I don't whether that's...something obviously I'm not going to forget it because I've got scars all over my body to remind me. I guess in a way I see myself as being a little bit stronger than what I thought I was."*

**#8, 27 yo female, Medicare, high fall, head and other injuries, 25 months post-injury**

*"...it's definitely increased my compassion for people who have injuries or who have in some ways injured and stuff like that. Now I notice when someone's got a brace on their leg I'll offer them help, because I know what it feels like to not be able to do things on your own."*

**#31, 38 yo male, TAC, motorcycle, orthopaedic injuries, 20 months post-injury**

*"I just appreciate life a lot more."*

**#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*"I'm going to have a massive scar on my neck, so I'll be reminded everyday for the rest of my life about what happened. I don't know, it's the unknown, isn't it? .....It's going to affect me for the rest of my life basically. You can't have something like that done and have no hint even of repercussion from it..... hopefully it is the end of a nightmare – a year-long nightmare."*

**#68, 32 yo male, Private, low fall, spinal injuries, 16 months post-injury**

*"And so I've got a new normal..... Oh, it is a defining point in my life, for a number of reasons. Like I was saying before, it's sometimes very hard for me to separate my physical injury with my emotional issues as well because they were so intertwined at the time. Because I changed my lifestyle I had to change my living arrangements, I had to change my career, everything changed."*

**#74, 75 yo female, TAC, other mechanism, spinal fractures, 19 months post-injury**

*"I don't think it will ever be...I'll never be the same."*

**#67, 58 yo male, TAC, motor vehicle, orthopaedic injuries, 14 months post-injury**

*"Yeah, I think I'm a pretty lucky person and I learnt a lot from it. Even though I 'm not a 100% it's taught me a lot. For a bloke who works six days a week, and 12 hours every day, to spend four months in hospital was a reality check..... I think they think I'm a better person for it, to be honest."*

## **Participant recommendations for improving trauma care and recovery**

Throughout the interviews, participants provided suggestions for how to improve trauma care and facilitate a better recovery for participants. The most common participant-reported recommendations were related to improved communication, particularly with TAC, surgeons, and the outpatient department.

### **TAC**

The recommendations for TAC made by the participants were improved communication, greater clarity and timeliness of information provided by the TAC, greater transparency in TAC processes, improved processes for obtaining medication, and a consistent point of contact with the claimant.

#### **#107, 59 yo male, TAC, pedal cyclist, head and other injuries, 12 months post-injury**

*"It was probably more clearer information on what information I need to provide back to TAC. They should have told me that I needed to get a letter from the doctor saying whatever, whatever, so in the end the doctor got in touch with TAC and says let's cut...Vince is the middle man, don't ring Vince, if you've got problems with my paperwork you come and ring me so we can short circuit the system. So he was bewildered by what he thought was un-required toing and froing between the parties."*

#### **#84, 26 yo female, TAC, pedestrian, lower extremity fracture, 12 months post-injury**

*"..To be done quicker. If they were more direct about what they required. I guess just being clear and transparent with the processes."*

#### **#55, 37 yo female, TAC, motor vehicle, spinal fractures, 13 months post-injury**

*"Why can't I just stay with the same claim manager because I've got a rapport with them, then you've got continuity, they know who you are, they know how you're feeling at that time."*

#### **#2, 30 yo female, TAC, motor vehicle, chest/abdominal injuries, 30 months post-injury**

*"Well, if they had more consistency in their treatment of their client I would have probably been able to gain more information about what and how they could assist me, whereas I have no idea, really, how and what they can assist me with because there is no real guidelines as to what, and I guess every case is different, but I don't have a clue, I don't know who to ask."*

#### **#98, 26 yo male, TAC, motorcycle, multiple lower extremity fractures, 13 months post-injury**

*"...like with the medication, they could have put it on an account or something like that because sometimes I couldn't afford to pay for it."*

## Hospital outpatients

Given the universal dislike expressed by the participants for the public hospital outpatients systems, a number of participants provided recommendations for improving the service for patients. These recommendations fell into two categories: (i) improved communication with the patients; and (ii) a change in the way consultations are conducted. In particular, participants requested being informed about the delays and waits in outpatients through announcements in the outpatient department, or through telephone or SMS messaging systems. Two participants felt that attendance at the clinic was not required and that updated images could be obtained locally, sent to the consultant, and followed-up by telephone.

### **#88, 59 yo female, TAC, Pedestrian, upper extremity fracture, 12 months post-injury**

*"I would have liked to have been briefed as early as possible in the hospital about the situation in the hospital. And so there's going to be some delay, but please let us know if you need anything, even though we are busy, let us know."*

### **#99, 59 yo male, Medicare, high fall, lower extremity fracture, 13 months post-injury**

*"They should have just told us in advance, "Look, you could be upward 2-3 hours wait"."*

### **#105, 28 yo male, Medicare, low fall, upper extremity fracture, 12 months post-injury**

*"Yeah, maybe a text update or something, how the waits going, there are all sorts of systems they could probably investigate."*

### **#12, 37yo male, TAC, motorcycle, lower extremity fracture, 24 months post-injury**

*"I don't understand why I can't get an X-ray locally, have it sent to the Alfred and then talk on the phone about my pain."*

## Other recommendations

Participants made other observations about potential improvements to the delivery of trauma care and factors that could facilitate recovery. These included:

- i. Greater compensation and support for victims of crime.
- ii. A single point of contact for follow-up and organisation of post-discharge care.
- iii. Improved communication with surgeons.
- iv. Greater organisation of home-based services.

## Discussion

Through in-depth interviews of 120 survivors of serious injury in Victoria, factors that helped and hindered patient recovery were explored. The interviews provided a wealth of information about the participants' experiences with the trauma system, their care and recovery. The narratives provided an unparalleled insight into the issues faced by injured participants as they attempt to recover, and provide valuable information for informing recommendations for trauma care in this state.

### Impacts of injury

The impacts of injury experienced by the participants in the study were many and varied. There were profound effects on physical function, activities of daily living, participation in social and leisure activities, and transport, for periods of weeks, months and years. These findings are consistent with cohort studies of trauma survivors (9, 25-28). Loss of independence and reliance on others featured heavily as themes, as did the emotional impact of physical limitations.

Emotional impacts were common, with anxiety, depression, PTSD, fear, vulnerability, loss of independence and loss of self-esteem featuring strongly in the participant responses. For many, the traumatic event was a life-changing experience, with lifelong repercussions, a finding consistent with other studies of trauma survivors (29). A sense of "lost time" due to the injury, and the potential for lifelong disability weighed on the participants, as did a concern for how the injury may impact them in the future (e.g. potential for osteoarthritis, loss of earnings, lifelong disability). For many, there was a shift towards a greater appreciation for life, and a feeling of being fortunate that the injury was not worse.

The financial repercussions of the injury were largely borne by participants of working age with no access to financial supports such as loss of earning payments from the TAC, or income replacement. While others have highlighted the financial issues faced by self-employed patients following injury (29), a number of participants in our study who were not self-employed still reported substantial financial hardship due to insufficient sick leave or accrued annual leave to cover the long absences from work. Even with income protection insurance, there was often a delay of weeks to months before the payments commenced. Where loss of earnings payments were received from TAC, many reported that they did not fully replace their income, and there were longer term implications for participants

through the inability to accrue sick leave, annual leave, and superannuation while receiving these payments. Overall, the number of participants reporting substantial out-of-pocket costs for medical treatment was very small, with most costs covered by Medicare, private health insurance, WorkCover and the TAC.

## **Facilitators of recovery**

There was consistency in patient perceptions of facilitators of recovery. The factors participants identified as helping in their recovery were a strong social support network, coordination of care, positive support from their employer, a positive attitude, and resilience. Faith, determination, physiotherapy, psychology and counseling, and good communication with health service providers and non-medical support were also perceived as being important in recovery.

The need for strong social support has been highlighted by other studies undertaken in road trauma, burn and orthopaedic trauma rehabilitation populations (15, 17, 29, 30). Disability is prevalent after injury, particularly early in the post-injury phase, with many requiring considerable assistance from family and friends for self-care, household duties, and travel. Therefore, the weighting of social support as the most prevalent facilitator of recovery is understandable.

Positivity, faith and resilience were considered important for recovery for participants as they adjusted to prolonged disability, financial hardship, and ongoing treatment. The reports of our study participants are consistent with a previous study of 79 road trauma survivors in Victoria, where “attitudinal resources” such as positivity, hope and belief were highlighted as key facilitators of recovery (15). The concepts of finding a “new normal” and adaptation to the situation were also consistent the findings of Harms (2004), as participants identified ways of coping with their experiences to date, and uncertainty into the future.

The value of physiotherapy, psychology and counselling in recovery was clearly articulated by participants, a finding consistent with the UK Burden of Injury study, and the study completed by Harms (2004). Harms (2004) who found that 35 per cent of study participants mentioned the value of physiotherapy, 24 per cent highlighted a counselor, and 12 per cent noted a psychologist, as assisting with recovery (15). Physiotherapists were generally praised for their communication, support, encouragement and the provision

of self-directed programs to participants. In our study, the delineation between counselor and psychologist was unclear at times, with participants unable to distinguish between the two. A lack of psychological support was highlighted as a barrier to recovery by Oster et al. in their study of 39 burn patients in Sweden (30). Given the prevalence of fear, anxiety, depression, PTSD, and hyper-vigilance noted by participants in our study, particularly road trauma victims, the perceived benefit of psychological support is not surprising.

Good communication with health service providers, and non-medical support such as TAC, was consistently highlighted as necessary for facilitating recovery. In particular, a consistent point of contact for treatment and follow-up was highlighted as a necessity for participants in this study. Participants appreciated clarity and timeliness of the delivery of information and services, manifesting as an identified facilitator of recovery.

## **Barriers to recovery**

Participants generally reported more difficulty in identifying clear factors that impeded their recovery. Nevertheless, a number of factors were highlighted by the participants in this study as being difficult during their recovery process. Participants highlighted issues with communication, treatment delays, a lack of coordination of care, pain, and financial hardship as factors impeding recovery following injury.

Persistent pain is common following injury (8, 31, 32), with pain at discharge a strong predictor of persistent longer term pain (8). As pain also impacts on function, return to work and health-related quality of life, pain management is important following injury. Pain as a barrier to recovery has been highlighted in qualitative studies of 39 burn patients, and 9 orthopaedic rehabilitation patients (17, 30). Consistent with our study, Oster et al. noted that participants reported difficulty in weaning of pain medication (30), while several participants in our study identified problems with obtaining appropriate pain relief after being discharged from hospital.

Delays to receiving definitive surgery in hospital, and delays in accessing outpatient care, were perceived by participants as prolonging their recovery. Prolonged waits for outpatient follow-up appointments were a common complaint of participants, with the end result being delays to receiving additional services (e.g. physiotherapy), delays in returning to work, and in one case, important delays in identifying a complication of treatment.

While many participants expressed understanding of how busy the public hospital system is, there was overall agreement that outpatient management was poor.

Most financial hardship experienced by participants related to an inability to work for prolonged periods. The loss of income associated with work absences had a negative impact on participant experiences after injury. Participants eligible for TAC loss of earning payments, those with extensive accrued leave entitlements, and participants with income protection insurance were largely protected from significant financial hardship. An additional barrier to recovery was an unsupportive workplace or employer. The increased physical and emotional stress of unrealistic expectations of employers and a feeling of being unwanted had a negative impact on participant recovery.

Poor communication from health service providers about prognosis was seen as a barrier to recovery for participants. A number of participants reported a stark contrast between their actual recovery trajectory and prognostic information provided by surgeons and other health care professionals, leading to frustration and disappointment with their outcomes. An additional issue with communication was receiving contradictory information from health service providers about management and treatment options. Several participants felt insufficiently informed to be making decisions about their treatment, leading to a lack of trust or faith in their clinical management. These findings are consistent with the study by Harms (2004), where road trauma survivors expressed the need for better communication and prognostic information when asked what they would have liked early in their rehabilitation (15).

The prevalence of anxiety, depression and PTSD was relatively low in the study cohort, but these factors had a negative impact on patient recovery. For many reporting anxiety and depression, this was a pre-existing condition which was exacerbated by the injury. The presence of anxiety and depression interfered with social relationships, and motivation to recover, while those with PTSD reported issues with fear, panic attacks and interruption of normal sleep patterns.

Many eligible for the TAC scheme experienced substantial difficulties with communication, navigation of the scheme, a sense of lack of trust, and delays in receiving approval for services and reimbursement of payments. Participants found dealing with TAC stressful, and many highlighted the TAC as a barrier to recovery.

## **Recommendations**

Clear themes emerged from the interviews to guide the identification of patients “at risk” of a difficult recovery process, and to make recommendations for improvements to trauma care delivery. Whilst not an exhaustive list of the learnings from this study, the key points are summarised in the following sections.

### **Vulnerable patient groups**

There were a number of factors that could be used to identify participants “at risk” for a difficult recovery process. In particular, patients without strong social networks, and those with pre-existing diagnoses of anxiety or depression are likely to experience physical and emotional hardship following injury. Provision of information about additional support and home services, and psychological support services are likely to be of benefit for these patients.

Participants of working age who do not have extensive leave accrual, those not covered by TAC or WorkCover, and patients without income protection insurance are likely to experience financial hardship. These participants could benefit by improved information about financial support services, budgeting, and work retraining.

### **Health service provision**

While most participants expressed satisfaction with their acute hospital care, and felt very lucky to receive the high quality of care that they did, there were a number of areas which could be improved to facilitate patient recovery, particularly with respect to discharge from hospital, and post-discharge follow-up. At the heart of these issues was poor communication, and the following recommendations are made based on the feedback from participants:

- i. Delays to surgery were common in the study cohort with many expressing that the reasons were not well explained, creating frustration and concern. Patients need to be kept informed of the delays and the reasons for the delays.
- ii. Participants expressed the need for clear information about prognosis. While many expressed an understanding that this could be difficult in some circumstances, general prognosis is important for setting participant expectations and easing concerns about their recovery process.

- iii. Participants highlighted inconsistency in information provided, and difficulties with identifying a key point of contact for information in the hospital. Patients should be provided with a key point of contact for information about diagnosis, management and prognosis.
- iv. Several participants highlighted the lack of explanation of treatment risks and treatment options. It is not sufficient to present treatment options without providing sufficient information for patients to make an informed decision, and ensuring the patient is fully informed should be a priority of treating clinicians.
- v. Discharge from hospital is a very stressful time for trauma patients and many felt ill-prepared for discharge. There was no consistency in the information provided to participants and delays to receiving services after discharge exacerbated the issues. Many expressed the need for a single point of contact to coordinate post-discharge recovery, and this represents a clear recommendation for improving trauma care.
- vi. The reasons for discharge to inpatient rehabilitation need to be conveyed to the patient.
- vii. Delays to receiving outpatient appointments, prolonged waits in outpatients, and dissatisfaction with the continuity of care and the clinicians seen, were clearly articulated by participants as barriers to recovery. While many participants expressed the need for a total restructure of outpatient delivery, others provided simple recommendations for improving the experience for patients:
  - a. Keep the patients informed about delays.
  - b. Investigate systems for early notification of participants about delays (e.g. SMS messaging systems).
  - c. Reduce the need for outpatient attendance through improved use of remote and telemedicine approaches, particularly for patients based in regional, remote and interstate locations.
  - d. Provide consultations of suitable duration to address patient questions.
  - e. Improve the continuity of care of the patient through consistency of clinician contact for follow-up (e.g. see the same surgeon each time).

## TAC

Sixty-two participants in the study were TAC clients, with more than 80 per cent discussing issues with dealing with the TAC. The overall perception of TAC was not as an organisation working to improve patient outcomes, but as a “bureaucracy” or “insurance company”. Consistent with the difficulties identified for medical care provision, poor communication was at the heart of participants’ negative experiences with TAC. The key factors that participants felt could be improved were:

- i. A consistent, single point of contact with TAC who is accessible to the client. While this is a simple recommendation, many participants identified constantly changing claims managers and failure to return calls as a negative impact on their recovery.
- ii. The provision of timely information. Despite the severity of injuries sustained by participants in this study, the timeliness of provision of TAC information to the client varied considerably. Participants reported receiving TAC information in the acute hospital, in rehabilitation, or not until they had returned home, sometimes many weeks after the injury.
- iii. Improved clarity and transparency about TAC processes and paperwork. The information provided to TAC was the same irrespective of injuries sustained. Those with cognitive deficits struggled to absorb, understand and retain the information provided. Nevertheless, even those without injuries resulting in cognitive deficits experienced significant issues in completing the paperwork to the satisfaction of the TAC.
- iv. Consistency of information provided to clients. Many participants reported inconsistency in the information provided, resulting in failure to provide the necessary documentation, and delays in approval of services and reimbursements. This was a major frustration of TAC clients.
- v. Increased timeliness of decision making about provision of services and reimbursement.
- vi. Improved empathy of TAC staff members. The injury event and aftermath was traumatic for many participants, and there was a general perception of TAC staff members lacking understanding and compassion for the client.

- vii. A perceived lack of trust of the client by the TAC was evident in many interviews. Participants expressed some understanding that this was due to some people reporting the TAC system, but all felt this was unjustified in their circumstances given the severity of the injuries they sustained. The lack of trust was evident when dealing with TAC investigators and medical assessors who were often behaved inappropriately in the minds of the participants.

Of note, the vast majority of participants in this study were injured prior to the introduction of the TAC2015 model which has a shifted focus to improved client outcomes. This study provides a strong foundation for evaluating the impact of the change in claims model on participant perceptions of the TAC and its role in their recovery.

## **Conclusions**

This study represents the largest qualitative study of trauma survivors undertaken to date. Through in-depth interviews of 120 survivors of serious injury in Victoria, factors that helped and hindered patient recovery were explored. The interviews provided a wealth of information about the participants' experiences with the trauma system, their care and recovery. Strong social support networks were considered highly important for patient recovery. Communication was at the heart of both positive and negative experiences with health service providers and the TAC. The narratives provided an unparalleled insight into the issues faced by injured participants as they attempt to recover, and provide valuable information for informing recommendations for trauma care in this state.

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