

Tilburg University

## Experiences of recovery and posthospital care needs of working-age adults after physical trauma

Roodbeen, Ruud T J; Lugtenberg, Marjolein; Pöstges, Heide; Lansink, Koen W W; Theeuwes, Hilco P; De Jongh, Mariska A C; Joosen, Margot C W

*Published in:*  
BMJ Open

*DOI:*  
[10.1136/bmjopen-2021-053330](https://doi.org/10.1136/bmjopen-2021-053330)

*Publication date:*  
2022

*Document Version*  
Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

### *Citation for published version (APA):*

Roodbeen, R. T. J., Lugtenberg, M., Pöstges, H., Lansink, K. W. W., Theeuwes, H. P., De Jongh, M. A. C., & Joosen, M. C. W. (2022). Experiences of recovery and posthospital care needs of working-age adults after physical trauma: A qualitative focus group study. *BMJ Open*, *12*(4), [e053330]. <https://doi.org/10.1136/bmjopen-2021-053330>

### **General rights**


Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

# BMJ Open Experiences of recovery and posthospital care needs of working-age adults after physical trauma: a qualitative focus group study

Ruud T J Roodbeen,<sup>1,2</sup> Marjolein Lugtenberg,<sup>1</sup> Heide Pöstges,<sup>1</sup> Koen W W Lansink,<sup>3,4</sup> Hilco P Theeuwes,<sup>4</sup> Mariska A C de Jongh,<sup>3,5</sup> Margot C W Joosen <sup>1</sup>

**To cite:** Roodbeen RTJ, Lugtenberg M, Pöstges H, *et al.* Experiences of recovery and posthospital care needs of working-age adults after physical trauma: a qualitative focus group study. *BMJ Open* 2022;**12**:e053330. doi:10.1136/bmjopen-2021-053330

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-053330>).

ML and HP contributed equally.

Received 11 May 2021

Accepted 12 March 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

## Correspondence to

Dr Margot C W Joosen;  
m.c.w.joosen@tilburguniversity.edu

## ABSTRACT

**Objective** To explore experiences of recovery after physical trauma and identify long-term needs for posthospital care.

**Design, participants and setting** A qualitative study was conducted consisting of seven online focus groups among working-age adults who sustained their injury between 9 months and 5 years ago. Trauma patients discharged from a level 1 trauma centre in the Netherlands were divided into three groups based on the type of their physical trauma (monotrauma, polytrauma and traumatic brain injury). Group interviews were transcribed verbatim, and thematic analysis was conducted.

**Results** Despite differences in type and severity of their injuries, participants all struggled with the impact that trauma had on various aspects of their lives. They experienced recovery as an unpredictable and inconstant process aimed at resuming a meaningful life. Work was often perceived as an important part of recovery, though the value attributed to work could change over time. Participants struggled to bring the difficulties they encountered in their daily lives and at work to the attention of healthcare professionals (HCPs). While posthospital care needs varied between and across groups, all people stressed the need for flexible access to person-centred, multidisciplinary care and support after hospital discharge.

**Conclusions** This study reveals that people with a broad variety of injury experience recovery as a process towards resuming a meaningful life and report the need to expand trauma care to include comprehensive support to live well long term. Person-centred care might be helpful to enable HCPs to take people's individual long-term needs and life situations into account. Furthermore, providing timely access to coordinated, multidisciplinary care after discharge is advocated. Integrated care models that span a network of multidisciplinary support around the person may help align existing services and may facilitate easy and timely access to the most suitable support for injured people and their loved ones.

## INTRODUCTION

Physical trauma, defined as injury to the human body with fatal or non-fatal consequences, is one of the leading causes of

## Strengths and limitations of this study

- This study adds that people with relatively minor physical trauma can also struggle to deal with disruptions to various aspects of their lives, even if only temporarily.
- Long-term recovery from trauma is an under-researched area, and our study extends evidence by demonstrating the need for ongoing interdisciplinary clinical support.
- Our findings may be relevant to other patients in trauma care, as they demonstrate similar experiences across a broad sample of people with different ages and different types of injuries and times since injuries.
- Conducting focus groups online reduced physical barriers and the time required to participate in our study, though it may also have led to the exclusion of people with limited digital literacy.

life-long morbidity and disability among working-age adults.<sup>1</sup> In the Netherlands, more than 75 000 people with physical injuries are hospitalised each year, of whom 97% survive.<sup>2</sup> In addition to physical difficulties, people with non-fatal injuries can encounter a wide range of psychosocial problems.<sup>3,4</sup> A proportion of them are unable to work for a longer period of time or have not returned to work after 2 years.<sup>5,6</sup>

The awareness of poor long-term outcomes for people with injuries has greatly increased in recent years.<sup>7,8</sup> Studies on unmet care needs during the early phases of recovery emphasise the importance of providing comprehensive care after hospital discharge. This includes physical and occupational rehabilitation<sup>9</sup> and psychosocial support.<sup>9,10</sup> In-depth knowledge about long-term care needs after physical trauma is, however, still scarce to date.

To gain a better understanding of these needs, it is necessary to take a closer look at how people experience their recovery after physical trauma in the long term. Previous studies have shown that recovery after injury can go far beyond physical healing and can be perceived as a process of reconstructing oneself as a person.<sup>11–13</sup> These studies, however, fall short of paying attention to work-related issues and focus predominantly on specific injuries or during the earlier stages of recovery. Little research has been conducted on experiences of people with a broad variety of injuries and their experiences of returning to work and resuming their lives in the long term.

The aim of the current study is to gain a deeper understanding of the experiences of recovery and the perceived long-term needs for posthospital care from the perspective of people with a broad variety of injuries. These insights will be valuable to help tailor the delivery of posthospital care to long-term needs and individual circumstances of people after physical trauma, potentially enhancing recovery.

## METHODS

### Study design

A qualitative focus group study was conducted among people after physical trauma. The theoretical framework underpinning this qualitative study is based on a phenomenological approach, focusing on describing meaning and significance of lived experiences.<sup>14 15</sup> Although the phenomenological approach traditionally focuses on lived experiences of the individual, group interviews in phenomenology have also been shown beneficial in stimulating discussion and opening new perspectives.<sup>16</sup> As such, the focus groups enabled us to obtain an in-depth understanding of the experiences and perceived needs of people with physical trauma, which can inform improvement initiatives in the future.<sup>14 15</sup> Furthermore, we chose to conduct focus groups because of the expected positive effects on the interactions between people.<sup>15 17 18</sup> Another advantage of focus groups is that the discussions may trigger memories and experiences of the different people and can be compared with those of others in the group, leading to richer information.<sup>15 17 18</sup>

### Context, researcher characteristics and ethics

Due to the COVID-19 pandemic, only online focus groups were feasible to avoid physical meetings in accordance with national recommendations for infection prevention. The study was designed and carried out in close collaboration with healthcare professionals (HCPs) making sure the research questions would be relevant to both trauma care professionals and their patients. Experienced qualitative researchers (HP, RR, ML and MCWJ) from Tilburg University carried out the data collection. These researchers had no prior relationship with anyone who participated in the focus groups. People were made aware that the researchers who conducted the interviews were

not involved in patient care and were informed about the aims of the focus groups. All participants provided online informed consent. The study was designed and presented according to the Standards for Reporting Qualitative Research.<sup>19 20</sup>

### Sampling strategy

Selection and recruitment of people for the focus groups were arranged by the Elisabeth TweeSteden hospital (ETZ), located in the South of the Netherlands, where people were hospitalised for at least one night to receive care after injury at a level 1 trauma centre. Potential participants were selected from the hospital's trauma register (MACJ and KL). All selected participants were formally discharged from inpatient services. Therefore, in this study, they are referred to as participants or people rather than patients. People were considered eligible if they were of working age (between 18 and 67 years), were injured between 9 months and 5 years ago and had an injury that was classified according to one of the following three categories:

1. Monotrauma, including one fracture of the upper or lower extremities and no other injury (independent of Injury Severity Score (ISS)), referred to as 'mono' in this study.
2. Mild to moderate traumatic brain injury (TBI), Abbreviated Injury Scale (AIS)=2 on severity (the AIS is an anatomically based severity scoring system, classifying each injury in every body region according to its relative severity (scores range between 1 and 6). Severity is used in this study as an indication).
3. Polytrauma (ISS  $\geq$ 15), referred to as 'poly' in this study.

During selection from the trauma register, information on ethnicity of participants was not available, and therefore, not considered. All participants eligible according to the previously mentioned conditions were invited to participate. People were distributed across different focus groups according to their respective trauma type to make it potentially easier for them to relate to each other and enhance interactions between the group members. Maximum variation sampling was applied using four additional characteristics: age, gender, time since the injury and occupation.<sup>15</sup> The intended number of focus groups depended on data saturation.<sup>15 21</sup> During the debriefing between researchers after the sixth focus group session, the summarising of preliminary themes, interpretations and ideas did not lead to new insights that could have contributed to answering the research question. Therefore, we decided to conduct a seventh and last focus group to validate this finding. In this last focus group, no new insights were found, indicating data saturation.<sup>15 21</sup>

### Selection of participants

The selected people received an invitation for the focus group and an information leaflet by email or mail. An invitation was sent to 611 selected people (187 mono, 153 TBI, 271 poly), of which 51 signed up to participate and 39 participated. The main reasons for not participating

after initial sign up were: (1) illness, (2) unavailability on the day and (3) preference to participate in another study. People could contact one of the researchers for questions and concerns (HP). All completed a web form, which also included an online informed consent form and six questions on demographics and participant characteristics (sex, age, time since injury, employment status, change of jobs since injury and the amount of actual and contractual working hours—see online supplemental appendix 1). Participants were compensated with a gift voucher of €40.

### Data collection

Seven online focus groups were conducted between October 2020 and January 2021 and facilitated by at least two members of the research team (HP, RR, MCWJ and ML). A topic guide was developed to structure the group interviews (HP, ML and MCWJ) (see online supplemental appendix 2). The participants were audible and visible during the focus group sessions that were hosted on Microsoft Teams, creating circumstances similar to face-to-face meetings. Prior to the focus groups, people received an email with technical instructions on how to participate. Sessions lasted approximately one and a half hours. All focus group discussions were audio-recorded with permission of the participants. After each session, the facilitators debriefed together and summarised preliminary themes, interpretations and ideas.

### Data analysis

All audio recordings were transcribed verbatim, and identifying characteristics were removed using pseudonymisation methods. Transcripts were managed using Atlas.ti,<sup>22</sup> and data were analysed in an iterative process moving back and forth between the coded extracts and initial data. A thematic analysis strategy was deployed, following the phases described by Braun and Clarke.<sup>21</sup> After each focus group, one researcher read and summarised each transcript prior to coding (HP). Next, one researcher created open codes based on all transcripts (HP). Without seeing initial codes, another researcher also coded six of these transcripts (RR). After these initial analyses, the researchers compared and discussed codes and preliminary themes until consensus was reached. Following consensus, one researcher (HP) identified more specific and detailed relationships between codes and organised them into main and subthemes. This was achieved by mapping the data against the predefined research questions about experiences of recovery, experiences of healthcare and posthospital care needs. This enabled us to gain a more in-depth understanding of the participants' experiences of the day-to-day practicalities of living with physical trauma and made it possible to see links between themes. The candidate themes were discussed and adjusted in a final meeting with the research team (RR, ML, MCWJ and MACJ). The next phase consisted of reviewing and refining the set of candidate themes (HP and RR), followed by checking them against the

**Table 1** Demographic information of participants of the focus groups

Focus groups (n=7)	Mean	Range	
Number of participants	6	4–7	
Type of trauma	Number		
Mono	3		
Poly	2		
TBI	2		
Participants (n=39)	Mean	SD	Range
Age (in years)	47.8	15.0	20–67
Sex	Number Percentage		
Female	19	49	
Male	20	51	
Employed			
Yes	27	69	
No	12	31	
Time passed after discharge			
Less than 1 year ago	9	23	
Between 1 and 5 years ago	30	77	

TBI, traumatic brain injury.

complete data set. Analysis was concluded by defining and naming each theme. Lastly, the results of the analyses were presented to trauma surgeons working at ETZ (KL and HT), and implications for clinical practice and future research were discussed. A coding scheme was created (tables 1–3), in which main themes and subthemes are presented. All (sub)themes that were identified during the analysis are illustrated by quotes, which were translated into English and edited, increasing readability without the loss of meaning or context.

### Patient and public involvement statement

Participants received a summary of findings in a leaflet after the study. No other patient or public involvement was carried out.

## RESULTS

### Participants

Seven focus groups were conducted with 39 people ranging from four to seven participants per group. Table 1 shows the demographics of the focus groups and included participants (see online supplemental appendix 3 for a description of demographics per focus group). Three focus groups were conducted for people with monotrauma, two for people with polytrauma and two for people with TBI. The average age of people was 47.8 years (SD 15.0), 49% were female and 69% were employed. At the time of the focus groups, 23% of participants were discharged from inpatient services less than 1 year ago

**Table 2** Experiences of recovery

Subthemes	Quotes
(1) Disturbances to daily life	<p><i>Disconnecting from people and surroundings:</i>            ‘When you are lying in a hospital bed in your living room, and your home is turned into a hospital(...), and you don’t go outside, you lack stimulation. When you can go outside again, you feel that this causes fear(...). There are all these things you have to deal with. It’s not just a bone that needs to recover, it’s a whole weirdness that overcomes you’. (3.5, female, 58 years old, mono)</p> <p><i>My life turned upside down:</i>            ‘My life has been turned completely upside down. There is nothing that is actually normal compared to what I had before. Before, I was a car mechanic and I had a good life, I had a good job, I had a nice family, I had... everything was perfect until I had the fall (meaning the injury). Then everything turned upside down. I lost my job and I lost my family. I’m trying to find different work now, however, it is not easy’. (6.4, male, 55 years old, TBI)</p>
(2) Dealing with an uncertain future	<p><i>Different stages:</i>            ‘I noticed that recovery had several phases. I felt that it went very fast in the beginning, in the sense that I could do certain things fairly quickly again. Then, suddenly, it went very slowly. You saw little change and thought it will get better again. You notice eventually that it gets better by the week’. (1.4, female, 20 years old, mono)</p> <p><i>Setbacks:</i>            ‘When I went back to see a physician, they said that I should be able to do most things again and I shouldn’t experience problems a year later (after the trauma). But this wasn’t the case, it went into the wrong direction really. Maybe this happened because I was overly enthusiastic and did too much. This can sometimes work against you’. (5.4, male, 59 years old, poly)</p> <p><i>Decisions with uncertain outcomes:</i>            ‘I’ve got an awful plate in my elbow, arm and forearm, with screws. They are still in my arm. I’m scared to get them removed, though it feels uncomfortable when I lean on my elbow. I’m able to accept a lot, so I think: so be it.(...) If I don’t get this removed, it’ll always trouble me. So, this is the question right now, what shall I do?’. (2.3, female, 64 years old, mono)</p> <p><i>Changed future plans and focus on work, when outcomes are known:</i>            ‘I had my accident during my last year at the university, so I never got to work properly. I’ll see whether I can do voluntary work in the future, but I think a full-time job that I have studied for won’t be possible anymore. (...) It’s full-time rehab right now, and only if I’m a bit further in this and have the surgery behind me, then I’ll see what I’m still able to do’. (4.6, male, 28 years old, poly)</p>
(3) Becoming independent	<p><i>Underestimating fatigue, returning to work too early:</i>            ‘I was somewhat recovered, but I couldn’t keep my concentration. When I first arrived at work, I was completely exhausted from driving my car for 45 minutes, and when I arrived, I had a cup of coffee and went home again’. (5.5, male, 53 years old, poly)</p> <p><i>Physical recovery out-of-sync with recovery from pain and fatigue:</i>            ‘Frequently, people tell me things, like, “are you still not working, are you still not better”? Because they can’t tell from the outside, but I can’t always bear the pain. You need to ignore these people, but that’s not always easy’. (1.4, female, 20 years old, mono)</p>
(4) Realising and accepting change	<p><i>Comforting realisations that situations are temporary:</i>            ‘I’m noticing improvement and what she also said to me in the beginning was: this will pass. Then you are so relieved.(...) And if it takes another five years, but then it will be over. Yes, that feels nice’. (7.1, female, 29 years old, TBI)</p> <p><i>Realising that temporary changes will be permanent:</i>            ‘I found it mentally difficult that it wouldn’t be completely fine again. I always assumed that it would be fine again, and that this will pass. It is very difficult to accept that this is the endpoint’. (5.3, female, 31 years old, poly)</p> <p><i>Accepting changed priorities:</i>            ‘My mountain bike was in the shed for a year. After one year, my friends asked whether I would go cycling with them again. Then I sold it (the bike), because there was some pressure from my family. My wife and two children who said, “dad, you better don’t do this” (riding his bike again). And it clearly wasn’t important enough in my life to do this again. So, the mountain bike is gone and I luckily do other sports again’. (5.5, male, 53 years old, poly)</p>

Quote numbering, the first number indicates the focus group number, and the second number the participant number of the specific focus group.

TBI, traumatic brain injury.



**Table 3** Experiences of healthcare

Subthemes	Quotes
(1) Preparing for discharge	'I was hospitalised for almost 14 days and then they said, "you can go home now". I could barely walk. My bed (at home) was upstairs, so some arrangements had to be made to put my bed back in order(...). It takes quite a lot of effort to arrange all those things. So, yes, you can go home, but you are thrown into the deep end, and you have to figure it all out by yourself'. (1.3, male, 41 years old, mono)
(2) Attention for work-related issues	'I don't think the physician asked me: "do you work, or what do you actually do?" I did bring it up myself, because at that time, I really wanted to work'. (3.5, female, 58 years old, mono) 'The rehabilitation has been completed, but there have been no changes yet. What will happen when I go back to work? Yes, I could still do with some support for that'. (6.6, female, 23 years old, TBI)
(3) Working through problems together	'Well, at first, I was feeling quite insecure, because one of my kidneys did not work well (because of the trauma), and he (the occupational physician) simply discussed the options with me. For example, how I could recognise when I am getting dizzy and was going too far(...). By doing so, he gives you some assurance and tools to organise your life. Those are some of the things you can discuss together (with your physician)(...). This provides you with support to resume your life and getting back to doing the right things'. (5.5, male, 53 years old, poly)
(4) Providing an estimated timeframe	'Back to managing expectations, she (the physician) did not set out any false expectations after surgery, yet she said: "well, if all goes really well, then you can do this and that at this point, then you can think this long until all functions should be back to normal, or this and that could happen instead". This gives me something to work with, a bandwidth, that allows me to think 'okay, now I have something to work towards'. (3.2, male, 57 years old, mono)

Quote numbering, the first number indicates the focus group number, and the second number the participant number of the specific focus group.

TBI, traumatic brain injury.

and 77% of participants were discharged between one and 5 years ago.

### Thematic analysis

The following three overarching topics were explored and structured the analysis: (1) experiences of recovery, (2) experiences of healthcare and (3) perceptions on posthospital care needs. While a more detailed analysis revealed that there is no one way of responding to and living with an injured body, several recurring subthemes revealed that these overarching topics were all linked to the matter of resuming a meaningful life after physical trauma.

### Experiences of recovery

In general, within this overarching topic, our analysis revealed that people with injuries experienced recovery as an unpredictable and inconstant process, often towards an uncertain future. While some understood recovery in terms of getting back to what they considered normal before the injury, others put the emphasis on living well despite physical trauma. This suggests that recovery took place along a continuum of temporary and permanent changes to life. All had in common that they perceived the final aim of recovery as being able to engage in meaningful activities and experience pleasure again.

Most important to me is to be able to live an independent life again and how this will involve work. Will I be able to experience joy again by doing things again instead of lying in bed? (3.5, female, 58 years old, mono)

All subthemes and quotes for this overarching topic are presented in [table 2](#), illustrating the problems that people encountered during their recovery, and the ways disruptions were resolved.

Despite differences in type and severity of their injury, all participants showed similarities in their description of the disturbances the physical trauma had on their daily lives (subtheme 1). The perceived disturbances ranged from feeling temporarily disconnected from other people and surroundings to feeling that their whole life had been turned upside down. Throughout the recovery process, people tried to resolve these disruptions in their day-to-day existence. Most people mentioned that they found it difficult to *deal with an uncertain future* (subtheme 2). While some described recovery in terms of several different stages, it was prominent from the discussions that recovery does not always follow a single path. People had to deal, for example, with setbacks. Others reached a crossroad where a decision with uncertain outcomes had to be made, such as whether to perform another surgery or whether to accept the current state. Furthermore, some people struggled to adjust to changed future plans and uncertain prospects of their recovery. When it was uncertain what level of ability a person would be able to regain, some people managed the situation by focusing on, for instance, rehabilitation and surgery first and considered anything to do with other activities, such as work, later when they had more certainty about the achievable outcome. *Becoming independent* (subtheme 3) was a recurring theme throughout all discussions. Over the course of the recovery trajectory, the level of functioning

improved for most people, and many regained the ability to do activities that were important to them. Some could, however, do only one or two activities at a time. They realised, for example, that they underestimated their lack of energy to perform the required number of tasks on a single working day and therefore realised they returned to work too early. Also, the progress made in terms of physical recovery visible on the outside could be out of sync with the slower improvements regarding inner feelings of pain and fatigue. Many participants mentioned a lack of acknowledgement for invisible impairments by people around them. Especially people for whom a full physical recovery was out of reach, saw *realising and accepting change* (subtheme 4) as an important part of recovery. For some, it was a comforting thought to think that their debilitating situation would pass at some point. This could, however, lead to difficulties later, when some discovered that their lives had changed permanently. The timing of this could vary between people and could happen many years after sustaining the physical trauma. To find a new balance, they had to let go of things that used to be integral and important in their lives. Also, recovery did not necessarily follow the progress achieved in terms of improved physical functioning. Some people accepted changed priorities. They decided against resuming an activity, or they worked fewer hours or not at all, even if they were physically able to return to their preinjury level. The experience of physical trauma had changed their outlook on life, and they counteracted the disruptions by reprioritising what they spend their time on.

### Experiences of healthcare

While the experiences of healthcare varied between and across groups, in general, it was apparent from the discussions that people with injuries encountered a lack of support after being discharged from hospital. They perceived a lack of acknowledgement and assistance to deal with the difficulties they encountered during recovery in their daily lives and at work. Although people were usually very satisfied with the care they received in hospital, they felt left alone, helpless, uncomfortable and unsupported after discharge, missing someone to discuss their day-to-day struggles with.

In the hospital, it was absolutely brilliant, [...] but then, I really experienced it as a black hole. You are at home, and you are lying there, and you can't do anything. You feel helpless and uncomfortable that you have to ask for everything. I really experienced this as unpleasant and I really missed some support with this. (5.1, male, 39 years old, poly)

Within this overarching topic, four specific subthemes were uncovered, as presented in [table 3](#).

Some people with injury felt insufficiently *prepared for their discharge* (subtheme 1) from hospital. They would have welcomed more support from HCPs to organise for a smoother transition while they were still hospitalised. There was a need for more practical support (eg,

arranging in house and home care) and a smooth transition of support to the primary care sector (eg, planning a transition appointment with a primary care physician). Many people also missed *attention for work-related issues* (subtheme 2) during conversations about recovery aims with HCPs. They mentioned that there was a lack of attention from the physician in the hospital, which they would have appreciated because returning to work was an important recovery goal to them. Some people also stressed that the rehabilitation programme was mainly focused on physical recovery without discussing work-related issues (eg, which impact has the lack of improvement on my working life). Those who did feel supported valued situations in which the difficulties they encountered in their daily lives were carefully attended to by the HCP. They highly regarded tailored support to their specific life situations that helped them to *work through problems together* (subtheme 3) with HCPs. This could be an occupational physician, surgeon, nurse or manager at work. People found it challenging to deal with uncertainties about their future. They worried about their recovery in terms of whether they could ever walk again, take care of their family or go back to work. They also worried about relapse of pain complaints. Given these uncertainties, they appreciated to be *provided an estimated timeframe* (subtheme 4) that sets out the possible range of their recovery prospects. This would give them some perspective for the future and feelings of hope.

### Perceptions on posthospital care needs

While the care needs in general varied between and across groups, it was apparent from the discussions that people with injuries missed timely access to multidisciplinary, person-centred care after being discharged from hospital. Some expressed a need for coordinated support up to several years after being discharged from hospital. [Table 4](#) provides an overview of four subthemes that represent means through which care could be tailored towards the particular needs and circumstances of a person.

At the moment that the discharge letter arrives, you are out. You have to sort it out yourself from then. I think it is important to see how the patient is getting on with life after half a year, a year or maybe after two years. If there are still issues and who you can go to (for support), I wouldn't know who. (4.2, female, 63 years old, poly)

Many people with minor to moderate injuries indicated a need for a lower threshold to *access multidisciplinary care* (subtheme 1) and would have appreciated to be provided with information about available multidisciplinary care and support. Those with more severe injury also stressed the importance of having timely access to specialist care at a later stage, especially at the moment when the limits of recovery were reached, and the realisation sunk in that a full physical recovery was not possible. These situations could arise up to several years after sustaining the physical trauma. Furthermore, people emphasised the need for

**Table 4** Perceptions on posthospital care needs

Subthemes	Quotes
(1) Easy and timely access to multi-disciplinary care	<p><i>Support with accessing multidisciplinary care:</i>            ‘I’ve had to arrange physiotherapy myself. They (HCPs) just didn’t pay any attention to the non-functional aspect. For example, what will it (the injury) do to you if... Or how to deal with your fear? Things like that, absolutely nothing. So, yes, it cost me a lot of energy handling things like this’. (3.5, female, 58 years old, mono)</p> <p><i>Providing information about available support:</i>            ‘It would be nice if someone could have a list of physiotherapists and said, “ok, this one is specialised in this, and that one is specialised in that”, and so on(...). It doesn’t have to be physiotherapy; it could also be about something else. Just, someone, like a type of social worker (who has the list), someone who knows about these kinds of things’. (2.5, male, 46 years old, mono)</p> <p><i>Timely access to specialist (secondary) care:</i>            ‘Yes, a possibility to have a short connection (easy access to an HCP) is important indeed, and in my experience not necessarily shortly after an accident, but especially after a little while, actually at the point when it is said that this is the maximum achievable level’. (1.3, male, 41 years old, mono)</p>
(2) Social support for themselves and their loved ones	<p><i>Focus on living well:</i>            ‘If you go there as a patient to see a physician, the conversation should not just be about that bone that is broken, but about everything that is related to that. The dependence, the pain you have, the feeling that makes you think, damn, I can’t do the things I want to do. They (the HCPs) do not ask you about those things(...). In my opinion, only asking “how are you” can already help and make you feel better, instead of someone asking, “how is the bone doing”?’ (4.5, male, 27 years old, poly)</p> <p><i>Opportunity to debrief with HCPs:</i>            ‘After receiving bad news, it might be nice to have someone (HCP) who is able to process the bad news with you(...). It might be nice to have someone who can explain the bad news in more understandable terms, or who can support you with processing that information’. (1.1, male, 20 years old, mono)</p> <p><i>Access to peer support:</i>            ‘I participated in that (meeting fellow patients) for a very short time and noticed that it can really benefit you, for example, hearing how other people deal with it (the injury) and tips and all that. With fellow patients you often notice that you only have to say a few things and you already understand each other. This is not always the case with healthcare staff’. (4.6, male, 28 years old, poly)</p> <p><i>Support for closest relatives or friends:</i>            ‘For my girlfriend, it was horrible(...). It ultimately meant that she ended up taking care of two people (our baby and me), which must have been difficult for her. And for that there is no support at all’. (2.5, male, 46 years old, mono)</p>
(3) A single point of contact in healthcare	<p><i>Case manager:</i>            ‘Someone who can manage the entire process, from IC (intensive care) to, eventually, the rehabilitation centre and beyond’. (4.6, male, 28 years old, poly)</p> <p><i>Someone who listens to the full story:</i>            ‘I am probably not that complex as a patient, so a case manager for me would be a bit of an overkill, but I do think that there is someone needed to keep a finger on the pulse, someone who you can talk to. In my case, I could not tell my story to my general practitioner either, which was very annoying’. (4.7, male, 64 years old, poly)</p>
(4) Alignment between different healthcare and work contexts	<p><i>Alignment between primary and secondary care:</i>            ‘Then you go back (to your general practitioner) because you notice all of a sudden that this is more than only physical, because the physical was already nicely restored. So, you notice other things (fatigue, problems with social relationships, etc.) and you go back to your general practitioner who is not specialised enough in this area, and therefore, not able to diagnose anything because they can’t see anything physical’. (7.3, male, 49 years old, TBI)</p> <p><i>Working across health and employment contexts:</i>            ‘There is an occupational physician who actually does not know who you are and there is a company that does know who you are(...) And both communicate with each other about you, and that’s not going to work if you are not engaged as a person with the support from mental healthcare’. (6.5, male, 61 years old, TBI)</p>

Quote numbering, the first number indicates the focus group number, and the second number the participant number of the specific focus group.

TBI, traumatic brain injury.

social support for themselves and their loved ones (subtheme 2) to help them deal with specific difficulties in their daily lives and at work. The most emphasised means to enhance

care included asking open-ended questions about life in general and taking time to listen. Other examples for social support included opportunities to debrief with





someone after bad news from a physician and access to peer support. Furthermore, many people felt their loved ones should have the opportunity to have access to support from HCPs, since the impact of physical trauma on their lives could be draining for them too. In addition, *a single point of contact (subtheme 3)* to help navigate the healthcare system was repeatedly identified. The suggestions ranged from having a case manager to just having one person who listens to their full story. Lastly, people felt that *a lack of alignment between primary and secondary care (subtheme 4)* hampered their access to adequate care at the right time. They struggled in situations when they faced unexpected problems that a general practitioner did not recognise. This was more often the case with non-physical issues, such as concentration problems, fatigue and social problems. Furthermore, some people felt a need for better alignment between the provision of care across healthcare and employment contexts to feel better supported in their work environment.

## DISCUSSION

In this focus group study, we explored experiences of people with a broad variety of injuries on their recovery trajectory, experiences of healthcare and perceptions on posthospital care needs. First, these people had in common that they struggled to engage in daily activities that were helpful for them to feel content with their lives. They experienced recovery as an unpredictable and inconstant process, often towards an uncertain future, with the ultimate goal to resume a meaningful life. Work was often perceived as an important part of recovery, though the value attributed to work seemed to change over time. Second, people with injury struggled to bring the difficulties that they encountered in their daily lives and at work to the attention of HCPs. Third, while post-hospital care needs varied between and across groups, all people with injury stressed the need for person-centred support that included: (1) easy and timely access to multidisciplinary care, (2) social support for themselves and their loved ones to deal with specific difficulties in their daily lives and at work, (3) a single point of contact and (4) alignment between care provision across healthcare and work contexts.

### Academic contribution

Previous research has shown that there is no one way of responding to physical trauma<sup>23</sup> and that the long-term outcomes can differ between various types of injury.<sup>24</sup> We found this reflected in the different rationales behind efforts towards recovery. The different rationales were, nevertheless, driven by the same motive, namely, to resume a meaningful life despite physical trauma. Our results also resonated with previous research that found that people recovering from TBI and life-threatening trauma experience their recovery as an unpredictable and inconstant process with the ultimate goal to reconstruct the various facets of oneself as a person.<sup>11 12</sup> This study

adds that people with relatively minor physical trauma can also struggle to deal with disruptions to various aspects of their lives, even if only temporarily.

This study adds insights to conventional approaches to recovery regarding health and work. Research on work disability after physical trauma is scarce, and existing studies on work across different health conditions focus on factors such as return to work and low sickness absence as the desired outcomes.<sup>25</sup> Our findings indicated a more nuanced and flexible approach that is sensitive to personal values and changes over time. We found that for many working-age adults, work was an integral part of life, while for some it was no more than a necessity. The value attributed to work could also change over the course of the recovery process. These kinds of complexities were also evident with regards to recovery in general, which did not necessarily follow the progress achieved in terms of improved physical functioning. Some participants decided against resuming an activity or they worked fewer hours or not at all, even if they were physically able to return to their preinjury level. Previous research has already shown that responses can change over the course of different recovery stages<sup>11</sup> and that people's outlook on their own quality of life can change in the wake of their recovery, which is known as 'responsive shift'.<sup>26 27</sup> While participants were generally satisfied with the support to optimise their physical health, our study highlights some neglected areas of conventional approaches that refer to recovery in terms of predefined outcomes. Our findings have indicated that recovery processes rather constitute day-to-day realities of life that are often rendered invisible during encounters with HCPs. Our research offers an alternative perspective that enables us to judge recovery not only by levels of activity and the speed of returning to work. The results of this study highlight the importance to consider whether people can deal with the kinds of problems that they encounter at a specific point in time and are able to engage in the kinds of activities that are important to them.<sup>28 29</sup>

This study also provides valuable insights into post-hospital care needs from the perspective of people with injuries and illustrates how perceived shortcomings such as insufficient support from HCPs to deal with concerns about uncertain futures might be addressed in practice.<sup>10 30</sup> According to people with injury in our study, person-centred care appeared to be crucial to feel supported by HCPs to live well despite physical trauma. Our data revealed various means to support a person-centred approach to help people deal with specific problems that they encounter under particular circumstances in their lives. This shares similarities with the concept of 'shared doctoring' that refers to tinkering together with the patient and possibly others to find the best solution at the point a problem arises.<sup>28</sup> Our study further contributes to the growing body of literature that draws attention to the need for timely access to coordinated, multidisciplinary care in the posthospital phases of physical trauma. This research supports previously identified

possibilities to improve care through providing flexible access to physical and occupational rehabilitation,<sup>9</sup> psychosocial support<sup>9 10</sup> and a single point of contact to help navigate the healthcare system.<sup>31</sup> Our results further suggest the importance of ensuring continuity of support through aligning primary and secondary care provision<sup>32</sup> and working across employment and health contexts.<sup>25</sup> This might be best achieved by adopting an integrated care model that centres a network of multidisciplinary care around a person's specific needs, which are better known from services for people with long-term conditions.<sup>33</sup> An example of a single point of contact to help people with traumatic injury to navigate the system and align primary and secondary care provisions are patient navigators.<sup>34 35</sup> These navigators could be licenced HCPs or lay health workers who provide guidance to people throughout their recovery process, explaining treatment and care options, managing medical paperwork, facilitating communication with different healthcare teams and providing support.<sup>36</sup> These navigators could potentially resolve some of the shortcomings indicated by the participants in our focus groups and improve healthcare utilisation.<sup>37</sup> Furthermore, peer support is another potential example of social support for trauma survivors that is flexible, constant and cost-effective at different stages of recovery. This is emphasised by a growing body of research that points to the potential for peer support to enable return to work and community integration.<sup>38 39</sup> Future research is needed to investigate the roles of both patient navigators and peers in the recovery process of people with traumatic injury and how these roles can be coordinated with HCPs to enhance support.

### Strengths and limitations

The methodological considerations of this study relate to our sampling and data collection methods. A strength of our study is the inclusion of people with a broad variety of physical trauma who sustained their injuries up to 5 years ago, which has helped to make our findings applicable to most people seen at a trauma centre. Using maximum variation sampling enabled us to obtain the most variable sample of participants for the focus groups in terms of age, gender, time since injury and return to work. By using a multidisciplinary research team including health scientists, a communication scientist, a psychologist, an epidemiologist and trauma surgeons, the data were illuminated and interpreted from different angles, which adds to the quality of our research. Additionally, interactions and discussions between participants during focus groups can be challenging. However, because all participants were active and all engaged in conversation during the focus groups, we did not perceive the group discussions or interactions to be too challenging for participants. Furthermore, due to the COVID-19 pandemic, we were forced to host the focus groups online. This turned out to have both advantages and disadvantages. Providing the opportunity to join focus groups online reduced physical barriers and the time required to participate

in our study, improving accessibility. Organising online focus groups, however, may have led to the exclusion of people with limited digital literacy.<sup>40 41</sup> We tried to mitigate this risk by offering digital testing sessions prior to the group sessions and by allocating a designated person to provide technical assistance during the focus groups. Due to the online group format and our exclusion of people with severe brain injury, the perspectives from people with severe communication and cognitive difficulties are missing from this study. Also, during selection of participants using the trauma register, information on ethnicity was not available, which may have resulted in an ethnically homogeneous population. More research is needed to include and further investigate a more ethnically diverse population by sampling purposefully, conducting individual instead of group interviews and using communication aids. Furthermore, in general, the depth of experiences and needs that are achievable using focus groups are limited. To achieve saturation of (sub)themes, more research is needed using individual instead of group interviews. Additionally, although the topic 'work' was a key subject in the topic guide (see online supplemental appendix 2), we were not able to elicit information from participants detailed enough to fully understand work experience. Although we were able to gather and implement many other relevant insights in this study, future research is needed to provide a more in-depth and detailed insight into work experiences and the impact physical trauma has on return to work.

### IMPLICATIONS

This study indicates an overall need to expand physical trauma care to ongoing interdisciplinary clinical support including integrated, multidisciplinary, person-centred care and support for people to live well in the long term after hospital discharge. According to people with injury in our study, person-centred care that takes their individual needs and life situations into account would be helpful for their recovery. Our results suggest a need for systemic change to provide care that is centred around a person's long-term needs. Integrated care models that span a network of multidisciplinary support around the person can help align existing services and ensure easy and timely access to the most suitable support for people with injury and their loved ones. Future research should assess and include the perspectives of HCPs and hospital administrators to explore the practical implementation of the proposed suggestions for systemic changes found in this study.

### Author affiliations

<sup>1</sup>Tilburg School of Social and Behavioral Sciences, Tranzo Scientific Center for Care and Wellbeing, Tilburg University, Tilburg, Noord-Brabant, The Netherlands

<sup>2</sup>Research Department, Breuer&Intraval Research and Consultancy, Groningen, The Netherlands

<sup>3</sup>Department Trauma Topcare, Elisabeth-TweeSteden Ziekenhuis, Tilburg, Noord-Brabant, The Netherlands

<sup>4</sup>Department of Trauma Surgery, Elisabeth-TweeSteden Ziekenhuis, Tilburg, The Netherlands

<sup>5</sup>Brabant Trauma Registry, Network Emergency Care Brabant, Tilburg, The Netherlands

**Acknowledgements** We would like to thank everyone who participated in our focus groups for sharing their personal experiences and insights so openly and generously. We would also like to thank Thymen Houwen for his administrative support during the recruitment phase and Miel Vugts for providing feedback on an earlier version of this article.

**Contributors** MCWJ, as guarantor, accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. MCWJ, MACJ, KL and ML designed the study. HP, ML, RR and MCWJ performed the data collection. HP and RR analysed the data. HP, ML, RR, MACJ, KL, HT and MCWJ interpreted the data. HP and ML wrote the first version of the manuscript. All authors revised versions of the manuscript, and all approved the final version.

**Funding** This study was funded by the The Netherlands Organisation for Health Research and Development. (ZonMw, Dutch: Nederlandse Organisatie voor Wetenschappelijk Onderzoek), grant number 842004001.

**Competing interests** None declared.

**Patient and public involvement** Participants received a summary of findings in a leaflet after the study. No other patient or public involvement was carried out.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants. Ethical approval for this study was obtained from the Ethics Review Board (ERB) of the School of Social and Behavioral Sciences of Tilburg University (RP301). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request. The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

#### ORCID iD

Margot C W Joosen <http://orcid.org/0000-0001-5064-7302>

## REFERENCES

- WHO. Injuries and violence: the facts 2014. Switzerland, 2014. Available: <http://www.who.int/>
- Landelijke traumaregistratie. 2015-2019 [national trauma registration 2015-2019]., 2020. Available: <https://www.lnaz.nl/nieuws/publicatie-ltr-rapport-2015-2019>
- de Munter L, Polinder S, Haagsma JA, *et al*. Prevalence and prognostic factors for psychological distress after trauma. *Arch Phys Med Rehabil* 2020;101:877–84.
- Karabatzakis M, Den Oudsten BL, Gosens T, *et al*. Psychosocial problems following physical trauma: a systematic review. In: . Psychosocial screening after physical trauma (dissertation), 2020.
- Kendrick D, Dhiman P, Kellezi B, *et al*. Psychological morbidity and return to work after injury: multicentre cohort study. *Br J Gen Pract* 2017;67:e555–64.
- Vles WJ, Steyerberg EW, Essink-Bot M-L, *et al*. Prevalence and determinants of disabilities and return to work after major trauma. *J Trauma* 2005;58:126–35.
- Haider AH, Herrera-Escobar JP, Al Rafai SS, *et al*. Factors associated with long-term outcomes after injury. *Ann Surg* 2020;271:1165–73.
- Nasirian S, Engström M, Forsberg A, *et al*. Recovery and quality of life after trauma: a 6-month follow-up study. *J Trauma Nurs* 2020;27:327–34.
- Silvester LA, Trompeter AJ, Hing CB. Patient experiences of rehabilitation following traumatic complex musculoskeletal injury – a mixed methods pilot study. *Trauma*;88:146040862098812.
- Visser E, Den Oudsten BL, Traa MJ, *et al*. Patients' experiences and wellbeing after injury: a focus group study. *PLoS One* 2021;16:e0245198.
- Ogilvie R, McCloughen A, Curtis K, *et al*. The experience of surviving life-threatening injury: a qualitative synthesis. *Int Nurs Rev* 2012;59:312–20.
- Levack WMM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disabil Rehabil* 2010;32:986–99.
- Rees S, Tutton E, Achten J, *et al*. Patient experience of long-term recovery after open fracture of the lower limb: a qualitative study using interviews in a community setting. *BMJ Open* 2019;9:31261.
- Boeije HR. *Analyseren in kwalitatief onderzoek: denken en doen [analyzing in qualitative research: thinking and doing]*. Boom Koninklijke Uitgevers, 2005.
- Wester FPJ, Renckstorf K, Scheepers PLH. *Onderzoekstypen in de communicatiewetenschap [research designs in communication science]*. 2nd edition. Alphen aan den Rijn: Kluwer, 2006.
- Bradbury-Jones C, Sambrook S, Irvine F. The phenomenological focus group: an oxymoron? *J Adv Nurs* 2009;65:663–71.
- Barbour RS, Morgan DL. *A new era in focus group research: challenges, innovation and practice*, 2017.
- Krueger RA, Casey MA. *Focus groups: a practical guide for applied research*. 5th edition, 2015.
- O'Brien BC, Harris IB, Beckman TJ, *et al*. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.
- Peditto K. Reporting qualitative research: Standards, challenges, and implications for health design. *HERD* 2018;11:16–19.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- Scientific software development GmbH. ATLAS.ti 2019.
- Rosenberg G, Zion SR, Shearer E, *et al*. What constitutes a 'successful' recovery? Patient perceptions of the recovery process after a traumatic injury. *Trauma Surg Acute Care Open* 2020;5:e000427.
- Dahm J, Ponsford J. Comparison of long-term outcomes following traumatic injury: what is the unique injury? *Injury* 2015;46:142–9.
- Cancelliere C, Donovan J, Stockendahl MJ, *et al*. Factors affecting return to work after injury or illness: best evidence synthesis of systematic reviews. *Chiropr Man Therap* 2016;24:32.
- Schwartz CE, Stucky B, Rivers CS, *et al*. Quality of life and adaptation in people with spinal cord injury: response shift effects from 1 to 5 years Postinjury. *Arch Phys Med Rehabil* 2018;99:1599–608.
- Sprangers MAG, Schwartz CE. *Integrating response shift into health-related quality of life research: a theoretical model*. in: Pergamon: Social Science and Medicine, 1999: 1507–15.
- Mol A. *The logic of care: health and the problem of patient choice*, 2008.
- Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. *Sci Technol Hum Values* 2009;34:55–76.
- Braaf S, Ameratunga S, Ponsford J, *et al*. Traumatic injury survivors' perceptions of their future: a longitudinal qualitative study. *Disabil Rehabil* 2020;42:2707–17.
- Gabbe BJ, Slaney JS, Gosling CM, *et al*. Patient perspectives of care in a regionalised trauma system: lessons from the Victorian state trauma system. *Med J Aust* 2013;198:149–52.
- Wiertsema SH, van Dongen JM, Geleijn E, *et al*. The transmurale trauma care model (TTCM) for the rehabilitation of trauma patients is effective in improving patient related outcome measures: a non-randomized controlled trial. *BMC Health Serv Res* 2019;19:819.
- Baxter S, Johnson M, Chambers D, *et al*. The effects of integrated care: a systematic review of UK and international evidence. *BMC Health Serv Res* 2018;18:1–13.
- Eliacin J, Fortney SK, Rattray NA, *et al*. Patients' and caregivers' perspectives on healthcare navigation in central Indiana, USA after brain injury. *Health Soc Care Community* 2021. doi:10.1111/hsc.13275. [Epub ahead of print: 20 Jan 2021].

- 35 Rosario ER, Espinoza L, Kaplan S, *et al.* Patient navigation for traumatic brain injury promotes community re-integration and reduces re-hospitalizations. *Brain Inj* 2017;31:1340–7.
- 36 Robinson-White S, Conroy B, Slavish KH, *et al.* Patient navigation in breast cancer: a systematic review. *Cancer Nurs* 2010;33:127–40.
- 37 Ali-Faisal SF, Colella TJF, Medina-Jaudes N, *et al.* The effectiveness of patient navigation to improve healthcare utilization outcomes: a meta-analysis of randomized controlled trials. *Patient Educ Couns* 2017;100:436–48.
- 38 Dorstyn D, Murphy G, Potter E, *et al.* How peer support can assist job-seekers with a disability move into work. *The Australian Journal of Rehabilitation Counselling* 2020;26:7–11.
- 39 Gassaway J, Jones ML, Sweatman WM, *et al.* Effects of peer mentoring on self-efficacy and hospital readmission after inpatient rehabilitation of individuals with spinal cord injury: a randomized controlled trial. *Arch Phys Med Rehabil* 2017;98:1526–34.
- 40 Heijmans M, Brabers A, Rademakers J. *Hoe gezondheidsvaardig is Nederland? Factsheet Gezondheidsvaardigheden - Cijfers 2019 [how 'health literate' is the Netherlands? Factsheet health literacy - figures of 2019]*. Utrecht, 2019. [www.nivel.nl](http://www.nivel.nl)
- 41 Sørensen K, Van den Broucke S, Fullam J, *et al.* Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;12:80.