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Perceived Changes in Quality of Life in Trauma Patients: A Focus Group Study

Nena Kruithof, MSc ■ Marjan Johanna Traa, PhD ■ Maria Karabatzakis, MSc ■ Suzanne Polinder, PhD ■ Jolanda de Vries, PhD ■ Mariska Adriana Cornelia de Jongh, PhD

ABSTRACT

Quality of life (QoL) following a physical trauma is still insufficiently known from a patient perspective. The aim of this study was to qualitatively report perceived changes in QoL after trauma. Focus groups were conducted. Patients admitted to the hospital were eligible for inclusion if they had a lower extremity trauma, severe injuries, or severe traumatic brain injury (TBI). Patients 75 years or older were invited. To analyze the perceived changes in QoL, open coding was used. Patients ($n = 20$, $M = 55$ years) reported comparable consequences. In the first month posttrauma, physical limitations, independency, pain, and anxiety predominated. Later, patients experienced problems with acceptance. The patients' feelings of the need to have control over their own situation, their own expectations, and a social network were

related to QoL. Compared with the other patient groups, TBI patients reported more psychosocial consequences, and elderly patients reported more difficulties in performing (social) activities. Quality of health care was considered an important aspect in the patients' perceived QoL, and adequate aftercare was missed according to the patients. The impact of a trauma influences QoL in different health domains. Further improving the quality of aftercare may positively influence trauma patients' perceived QoL. These results indicated that TBI patients and elderly patients deserve specific attention regarding QoL.

Key Words

Focus groups, Nonfatal outcome, QoL, Qualitative methods, Trauma

According to the World Health Organization, trauma is a major and worldwide problem and continues to place a tremendous burden on public health (World Health Organization, 2016). The trauma mechanism and trauma type can be diverse, and there is a large variety of factors, including regarding age, gender, and socioeconomic status, that indicate the

heterogeneity of the population. Recently, the inhospital mortality rate of trauma patients in the Netherlands was 2% (Berden & Leenen, 2015). Consistent with this finding, a large proportion of patients survive their trauma and have to address the remaining physiological and physical changes, which can have a large effect on the patients' life. For example, physical limitations can lead to difficulties in performing daily activities or to problems in partnership or other social relationships.

Quality of life (QoL) is a subjective phenomenon; it aims to measure the patients' satisfaction with their functioning. QoL is a multidimensional concept, including both positive and negative aspects of life. It incorporates a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment (WHOQOL-Group, 1994).

However, little is known about the factors that play a role in the patients' perceived QoL after trauma. Uncertainty about recovery was considered stressful for trauma patients who reported longer-term pain, resulting in a large decrease in QoL (Sleney et al., 2014). Furthermore, injury, specifically in the elderly, can lead to an ongoing process of isolation and activity restrictions via insecurity, misgivings, and fear, which negatively influence their QoL (Ziden, Scherman, & Wenestam, 2010).

Conducting focus groups is necessary to understand trauma patients' QoL because focus groups can provide a

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deeper understanding of complex insights. Therefore, the aim of this study was to gain more insight into changes in perceived QoL after trauma via a direct exploration of the patients' point of views.

METHODS

This study was approved by the Ethics Committee Brabant (the Netherlands), Project Number NL50258.028.14. The study was performed in accordance with the 1964 Helsinki Declaration.

Participants

Adult patients were selected by one author (N.K.) from the Brabant Trauma Registry (BTR) database. Patients were selected based on severity and type of injury using the Abbreviated Injury Scale (AIS) and the Injury Severity Score (ISS). The AIS is used to define the anatomical region and severity of separate injuries in detail (range 1–6). The ISS is used to assess the overall trauma severity ranging from 1 to 75. An ISS of 16 or more is considered severely injured (Gennarelli & Wodzin, 2006).

Patients were eligible to participate if they were admitted in 2014 to a ward or the intensive care unit (ICU) of the Elisabeth-TweeSteden Hospital (Tilburg, the Netherlands), a Level 1 trauma center. The group of included patients had to be a representative sample of the trauma population. To meet this criterion, patients who were invited to attend a focus group were randomly selected based on sex, age, and type and severity of the trauma. The trauma population is a heterogeneous population. Therefore, four different subgroups of patients were created that represented, in our opinion, a good reflection of the total population. We recruited (a) patients ages 18–64 years with a blunt trauma of the lower extremity, with an ISS less than 13 and without other serious injuries; (b) patients 75 years or older with an ISS less than 16; (c) patients ages 18–64 years with a blunt trauma, with an ISS 16 or more (i.e., severely injured); and (d) severe traumatic brain injury (TBI) patients ages 18–64 years with an AIS head 4 or more and admitted to an ICU. Exclusion criteria were (1) preexisting severe cognitive deficits and (2) an insufficient knowledge of the Dutch language. Purposive sampling was used, meaning that the recruitment of patients was completed after the intended number of patients and sufficient diversity between the patients in the focus groups was achieved. Because of the small number of patients selected from the BTR who were willing to participate, additional patients were selected by a trauma surgeon (K.W.W. Lansink, MD, PhD) via screening of medical health records.

Procedure

In the focus group, the participants discussed and debated their experiences about a specific topic. Additional focus groups were conducted if the most recent group

provided new information until a focus group no longer provided new information (saturation point is reached) (Baarda, de Goede, & Teunissen, 2009). Before participation, all patients signed an informed consent form. The focus groups were conducted by two researchers (N.K. and M.T.).

Audio records were made during each focus group. A script was developed and the average scheduled duration of each focus group was 2 hr. During the focus groups, three questions were included:

1. "What is QoL in your opinion?"
2. "Which short- and/or long-term consequences did/do you experience after your trauma?"
3. "Which aspects or facets determine your QoL after your trauma?"

If a different subgroup of patients (e.g., TBI patients, severely injured patients, or elderly patients) reported consequences that were related to their specific type of injury or age, then these consequences were reported separately in the Results section.

Data Analysis

To analyze perceived changes in QoL, open coding was used. All audio-recorded data were transcribed verbatim. Two authors (N.K. and M.K.) independently read and coded each of the transcripts using Microsoft Word and Excel. First, the researchers determined the beginning and the end of each fragment using track changes. Second, the researchers independently determined why each fragment was considered a meaningful whole (i.e. text that belongs together and addresses one issue or idea). Third, the researchers independently judged whether the fragment was relevant to the research topic. If this was the case, then the codes were assigned to the text fragment. Fourth, using Excel, the different fragments were compared to examine whether the multiple fragments in the text addressed the same topic and should therefore receive the same code (Boeije, 2010; Glaser & Strauss 1967). Any discrepancies in coding were resolved via discussion until a consensus was reached or by consulting a third author (M.T.). In the text, the major and important findings of the focus groups are outlined.

RESULTS

In total, 98 patients were invited to participate in the focus groups (see Figure 1). TBI patients showed large willingness to participate. Therefore, two focus groups were created with this group of patients (Round 1: $n = 5$; Round 2: $n = 7$). Because of the small number of interested patients in the remaining groups, it was necessary to combine the groups. Two focus groups with severely injured patients and elderly patients were combined (Round 1: $n =$

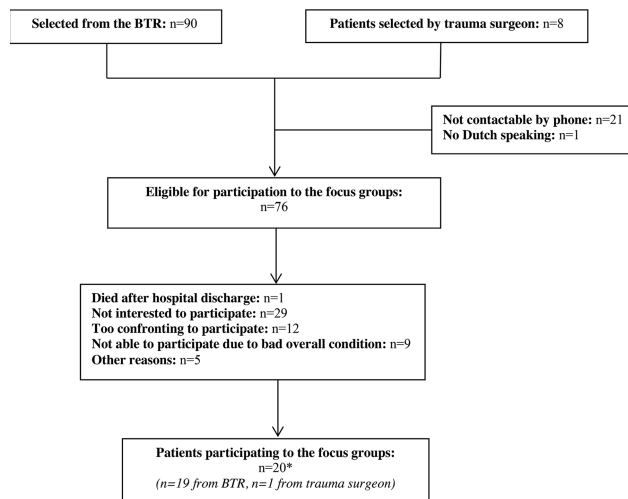


Figure 1. Trauma patients invited to participate in the focus groups. *Of these participants, four were accompanied by their informal health caregiver because of patients' poor physical or psychological functioning. BTR = Brabant Trauma Registry.

4— $n = 3$ severely injured, $n = 1$ elderly—and Round 2: $n = 4$ — $n = 2$ severely injured, $n = 2$ elderly). Twenty patients participated in the four focus groups.

Table 1 provides an overview of the demographic characteristics of the participants. Three TBI patients and one elderly patient were unable to attend the focus groups without the assistance of an informal caregiver because of their poor functioning. Therefore, partners of these patients were allowed to accompany the patients. Partners were not actively involved during the focus groups, although at the end of each focus group, the partners were given the opportunity to submit remarks.

Definition of QoL According to Trauma Patients

First, patients were asked to provide a definition of the term “QoL” (see Table 2). Participants emphasized that QoL is a subjective phenomenon and incorporates different aspects; for the participants, QoL mainly incorporated not being dependent on someone, enjoying life, and being able to perform activities of daily living.

Consequences and Perceived Changes in QoL After Trauma

During the discussions, the two leading questions “Which aspects of facets determine your QoL after your trauma?” and “Which short- and/or long-term consequences did/do you experience after your trauma?” often overlapped in the answers the participants provided. Therefore, these results were combined (see Table 3).

Overall QoL and Health

These results showed that most patients irrespective of trauma severity, trauma mechanism, or age reported the

TABLE 1 Demographic Characteristics of the Focus Group Participants

	<i>M ± SD, Range</i>
Age ^a (years)	55 ± 16, 28–81
ISS98	23 ± 10, 6–45
Length of hospital stay, (days)	18 ± 19, 2–86
Time since injury (months)	17 ± 2.46, 13–21
	<i>n (%)</i>
Gender	
Male	12 (60)
Female	8 (40)
Educational level	
University degree	4 (20)
Bachelor's degree	5 (25)
Senior secondary vocational education and training	6 (30)
Preparatory secondary vocational education	5 (25)
Household	
Single household	6 (30)
Multiperson household	14 (70)
Injury cause	
Road traffic injury	11 (55)
Fall	7 (35)
Work-related	1 (5)
Sports-related	1 (5)
Injury mechanism	
Blunt	20 (100)
Penetrating	0 (0)
ICU admission	
Yes	16 (80)
No	4 (20)
Currently working	
Yes	10 (50)
No	10 (50)
<i>Note.</i> ICU = intensive care unit; ISS98 = Injury Severity Score 98. ^a Time of the trauma.	

same consistent consequences, including many physical, psychological, social, and environmental issues. Nearly all of the patients stated that their QoL had been changed after the trauma. In the focus groups, five patients stated that they were still rehabilitating. In the first month posttrauma, nearly all patients reported that their

TABLE 2 Trauma Patients' Thoughts About the Term "QoL"**Quotes**

"The way you live your life and how you deal with it. ... Whether you need help of someone else and whether you can live more or less independently." (Female, 81 years, fall, elderly patient)

"Being together with other people, enjoying life, having fun, getting help from others when necessary and being satisfied. I find it really important that I can do whatever I need to do, or want to do, without suffering any pain." (Female, 61 years, sports-related accident, severe injury)

"Being independent ... enjoying the things you are still able to do." (Female, 64 years, road traffic accident, severe TBI)

"I think mainly about the normal things of life, whether they are still possible ... Can you cook, can you do the laundry, can you take your children to school, in fact the very normal daily things, can you manage those, yes or no? ... For me, QoL means being independent." (Male, 43 years, road traffic accident, severe TBI)

Note. QoL = quality of life; TBI = traumatic brain injury.

own feelings (ie, their emotional perception or attitude such as anger or sadness) and their own expectations largely influenced their recovery. Eight participants clearly indicated that their feeling of having control over the situation positively influenced their recovery, and other patients agreed with this statement. In the long-term, patients experienced difficulties with accepting their remaining disabilities and their new life. Patients acknowledged that they have to live with the long-term physical and psychological consequences of their injury. Three patients stated that they did not allow their injury to play a dominating part in their remaining lives. However, most patients concluded that their trauma has changed their life because the consequences of their injury had a negative impact.

In comparison to other patient groups, TBI patients reported more psychosocial consequences such as personality changes. Two elderly patients stated that QoL was highly related to their age. For these patients, increasing health problems, loss of function, and a high risk of being dependent on someone else were seen as normal parts of their aging process. Compared with the other patients, all three elderly patients reported less functional impairments but reported more problems in performing (social) activities.

Physical Health

All groups thoroughly discussed the physical consequences. The overall consequences were comparable among all groups. An important cause of the physical limitation was pain. All participants stated the importance of being independent. Performing activities of daily living, such as getting dressed, was considered very important. Patients frequently reported a lower level of energy and reduced work capacity. All TBI patients reported memory impairments, fatigue, sleeping problems, difficulties with stimulus processing, and speech difficulties (e.g., aphasia).

Psychological Health

Patients reported several psychological consequences that mainly included negative feelings. Fear of receiving a new trauma was present for most participants. Some patients emphasized that their injury negatively influenced their emotional well-being; the trauma affected their lives dramatically because they were unable to return to their normal physical functioning as before their injury. Nearly all participants expressed that the psychological shock after trauma still remained even after more than 1 year posttrauma. Except for a few patients, the changed life situation led to problems with acceptance. Patients described disappointment over the remaining limitations. In contrast, in each of the focus groups, at least one participant spoke about the positive aspects of their trauma (ie, posttraumatic growth). Because of the trauma, the patients can see and enjoy the little things more easily in life.

All TBI patients reported that they still experience many psychological problems of which irritability was considered to be the most important. Other reported psychological problems were sadness and difficulties with emotion regulation (e.g., crying more easily for no reason).

Social Relationships

Except for one TBI patient, all patients stated how important family and friends were for their recovery. The possibility to obtain assistance from others was considered very important during recovery. Soon after their trauma, most patients received abundant of social support, and the patients felt positively overwhelmed by this support. However, for one elderly patient, a loss of mobility resulted in activity restrictions and a more isolated life on the long-term posttrauma. The consequences of the trauma were not limited to the patients. TBI patients shared that their physical and psychological consequences affect not only themselves but their family members as well. Relatives stated to the patients that their personalities have been changed.

TABLE 3 Trauma Patients' Perspective on Perceived Changes in QoL

General QoL and health

- "I've to look at the here and now and which steps I want to be able to take for tomorrow and well the old stuff, it will never be the same again anyway. So, let all that go and enjoy the little normal things in life. But it's much easier said than done." (Male, 43 years, traffic accident, severe TBI)
- "I have now reached a point where I have to act or think about the activities that I can perform rather than the things I cannot do. And I think that you've come a long way when you can do that." (Male, 80 years, fall, elderly trauma patient)
- "I've put my life as it was before my trauma behind me and I went on with other things. I had to do it for my own good." (Male, 46 years, fall, severe injury)
- "I felt down and self-absorbed but at a certain moment I changed my mind. I thought Damn it! Come on, look at it from a different perspective! From that moment, I made huge steps forward ... I am absolutely certain that psychological functioning influences physical functioning." (Male, 46 years, fall, severe injury)
- "Recovery is more, I rather think it is more about your psychological functioning than about the physical area, the one cannot function without the other..." (Female, 42 years, road traffic injury, severe injury)
- "It's nice that people take good care of you physically during your hospital stay. They helped me very well. But actually, many things come after that part. And that doesn't all have to be negative Acceptance, that did not happen until one year after my trauma... after the second opinion when I heard that nothing could be done about it It's hard to know that you are powerless to do anything about it." (Female, 42 years, road traffic accident, severe injury)

Physical health

- "I live with constant pain, ad nauseam." (Male, 37 years, road traffic accident, severe TBI)
- "My 'battery' is always empty... ." (Male, 43 years, traffic accident, severe TBI)
- "I was always in a hurry and doing things quickly, and now I take a little more time." (Female, 81 years, fall, elderly patient)
- "I'm tired, I'm extremely tired. I'm tired and I can't sleep." (Male, 37 years, road traffic accident, TBI)
- "I notice that I can go to bed very tired and still lie awake for three or four hours." (Female, 64 years, road traffic accident, severe TBI)
- "I had to use a wheelchair and I was devastated about that." (Male, 79 years, fall, elderly trauma patient)
- "After my accident I became dependent on other people... . Independency is clearly important to me." (Male, 43 years, work-related accident, severe injury)
- "Before my accident I did everything by myself. Now I need help with almost everything." (Male, 56 years, road traffic accident, severe injury)
- "I thought that I received very good medical care during the entire process and I actually still think so today." (Male, 56 years, road traffic accident, severe injury)
- "In my opinion the care I received was really very good, and particularly the facilities in the hospital, which have improved so much that I really didn't mind being in hospital." (Male, 79 years, fall, elderly trauma patient)
- "Many activities were rather exhausting because I received many external stimuli and I really couldn't handle them yet." (Male, 28 years, road traffic accident, severe TBI)

Psychological health

- "My life now is much better than my life before my trauma. Always being busy and having to do 100.000 things at the same time, and now I just can't do it anymore." (Female, 64 years, road traffic accident, severe TBI)
- "I'm currently working hard to achieve everything that's possible for me, I refuse to become a victim because of my trauma." (Female, 58 years, fall, severe TBI)
- "I've learned how nice it can be to just look outside and watch the birds." (Female, 61 years, sports-related injury, severe injury)
- "About 'what happened yesterday'? Before my accident I would just know that immediately. Now I've to really search my memory, what happened yesterday. That's new for me." (Female, 61 years, road traffic accident, severe TBI)
- "What did I do to my partner and children? I was the one who climbed onto that motorcycle." (Male, 43 years, road traffic accident, severe TBI)
- "Balance and recovery of the body and automatic compensation of the body. I think it is rather surprising that my body ... just nice to see how my body has recovered." (Female, 42 years, road traffic accident, severe injury)
- "I've got another scar and that seems to be attractive." (Male, 56 years, road traffic accident, severe injury)
- "The realization that my accident happened and that it can happen again." (Female, 61 years, sports-related injury, severe injury)

(continues)

TABLE 3 Trauma Patients' Perspective on Perceived Changes in QoL (Continued)

"The only thing for me is that I have become extremely cautious at work. Nothing has actually changed, but what happened is constantly at the back of my mind." (Male, 43 years, work-related accident, severe injury)

"Fear of pain. Purely based on ignorance, really." (Female, 42 years, road traffic accident, severe injury)

"The things I did before in one day, I would not mind doing them in three days now. But the fact that I just can't do them anymore, that's really painful." (Male, 56 years, road traffic accident, severe injury)

"I've really become more emotional but I don't see that as a shortcoming or a flaw. Nowadays I'm more guided by my intuition." (Male, 43 years, road traffic accident, severe TBI)

Social relationships

"My trauma led to unexpected consequences; changes in my relationship with my partner and my children. And there is a new kind of fear: will it be all right again?" (Male, 43 years, road traffic accident, severe TBI)

"Since my accident I like to be on my own." (M, 37 years, road traffic accident, TBI)

"They say: 'Oh, I recognize your situation, I really do' but they are healthy!" (Female, 64 years, road traffic accident, severe TBI)

"Well if you break a leg and they take a radiograph then you need to get a plaster cast. I think that they think they understand my situation but they don't." (Female, 58 years, fall, severe TBI)

"People sometimes don't understand my situation. They say: 'Oh, you look great! You can do everything now'." (Female, 81 years, fall, elderly patient)

"A lot of people paid attention to my situation, I had never experienced that before. Everybody wanted to know how I was doing. People asked: 'Can we do anything to help?'. That was really overwhelming! ... Then I started thinking; this is really great, to have people around me who are concerned about me, who did not just ask how I was doing and then disappear into thin air but who kept calling me all the time, that was really wonderful!" (Male, 79 years, fall, elderly trauma patient)

Environment

"I'm more aware of the dangers, I've become more cautious." (Female, 42 years, road traffic accident, severe injury)

"After my accident, our house was remodeled, so we can now sleep downstairs... I can do everything downstairs, so I don't have to go upstairs anymore, which would be difficult anyhow." (Female, 81 years, fall, elderly trauma patient)

"After my accident I needed a modified car and I needed to start all over again learning how to drive a car. It cost me a lot of money that I didn't take into account beforehand. ... After all, the counterparty compensated all these costs. But imagine that you've to pay the costs all by yourself!" (Male, 56 years, road traffic accident, severe injury)

"I would have preferred the orthopaedic surgeon to say: 'Let's plan another appointment half a year from now, so we can make a new X-ray and check how you are doing, and what possible consequences there might be, positive or negative'. And that did not happen! The treatment just ended. That's really important to me." (Male, 79 years, fall, elderly trauma patient)

"A few months after my accident I had a standard bone scan and that was all fine. My shoulder also recovered very well, but my head just would not heal. ... I suffer from my brain injury. I immediately got the results of the bone scan, but I said 'I would rather have had my head examined'." (Female, 81 years, fall, elderly trauma patient)

"Bureaucracy slows everything down. Frustration about the municipality... All those troubles with the public authorities, that it takes forever and that you are actually actively opposed by them." (Male, 46 years, fall, severe injury)

"A trauma can teach you to become healthy again." (Male, 43 years, road traffic accident, severe TBI)

"For a long time I was dependent on a taxi, or on a scoot mobile, or I had to ask my family or friends to drive me. Loss of mobility is really terrible." (Male, 56 years, road traffic accident, severe injury)

"I wasn't eligible for a compensation for the costs for a taxi ... I couldn't do anything; I was not allowed to drive a car or to ride a bike. However, I had to go to therapy. My neighbour aged 80 took me to therapy in his car." (Female, 64 years, road traffic accident, severe TBI)

Note. TBI = traumatic brain injury.

All TBI patients emphasized that it was difficult to explain their situation over and over again to others. They shared the view that their psychological symptoms were often not taken seriously by others who are unable to understand the problems that face TBI patients.

Environment

Different changes in the environmental domain (e.g., access to and quality of health care and financial resources) were discussed. All participants stated that good communication skills and empathy of health care providers positively

influenced their recovery process, and this contributed indirectly to the trauma patients' perceived QoL. However, nine patients clearly felt that they were not well informed about their situation. TBI patients emphasized that health care professionals should more involve their close relatives. Furthermore, all patients stated the importance of an appropriate follow-up. However, aftercare in the sense of outpatient monitoring was often not offered although the patients felt that they needed it. The lack of a follow-up indirectly influenced the patients' QoL negatively.

Eight patients felt that the laws and regulations were not fitted to their situation. Examples included difficulties during their process to return to work (RTW) or by requesting a parking license for disabled people. Patients' shared experiences focused predominantly on the cumbersome procedures and incomprehension of the public authorities. Insufficient financial resources also had a negative influence on the patients' QoL. In particular, in the elderly group, patients had to (partially) pay for medical aids such as a walking aid or braces in the bathroom. Two patients had difficulties into paying for these aids.

All patients who were employed before their injury reported difficulties with RTW. Large difficulties with RTW were specifically reported by TBI patients. Participants who worked before their injury stated that having a job is not only an aspect of physical or psychological health; these patients felt that RTW was associated with having a place in the society again.

Participants agreed that good transportation facilities made it easier to be active and social. Nine participants became long-term or permanently dependent on others to bring them to social activities, leading to a reduction in perceived QoL. This aspect was particularly important for elderly patients.

Partners' Experiences of Changes in QoL After Trauma

Four patients were unable to attend a focus group without the assistance of their caregiver. Partners were shortly given the opportunity to report the consequences that they experienced (see Table 4). Partners reported consequences that overlapped with the patients' reported consequences. All partners would like to be more actively involved and would like to have more information about the patients' hospital stay and expected recovery process. Furthermore, all partners stated that the trauma influenced their lives as well since they had to accept their new lives as being a partner of a person with disabilities.

The partners of TBI patients named several psychosocial consequences that the patients did not mention in precise detail during the focus groups, for example, personality changes. The partners stated that the patient was not always aware of the consequences of the brain injury, and subsequently, they had to confront the patient with

TABLE 4 Perceived Changes in QoL of Trauma Patients' Partners

Quotes Partners

"His trauma has serious consequences for us; we are not able to go on holiday anymore, he now can't take a shower without assistance and he can't walk anymore." (Partner of male, 80 years, fall, elderly trauma patient)

"(My husband) had his last surgery nine weeks ago. And I realize that I only started to come to terms with it after that operation. Before that, there just was no space for it" (Partner of male, 43 years, road traffic accident, severe TBI)

Note. TBI= traumatic brain injury.

these changes. Moreover, some of the psychological consequences of the TBI patients were perceived differently by partners. For example, one partner stated that his relative had severe difficulties following a storyline; however, the patient partially agreed with this.

DISCUSSION

This study shows that trauma influences patients' QoL in different health domains. Most of the physical, psychological, social, and environmental consequences after a trauma are the same in all patients irrespective of age, trauma mechanism, or severity. Time after the injury plays an important role in the patients' way of experiencing QoL. In the first month posttrauma, patients stated that their feelings and expectations largely influenced their recovery and QoL and vice versa. Participants stated that their feeling of having control over the situation positively influenced their recovery, although some patients felt that they had no control on their recovery. Furthermore, physical limitations, independency, pain, and anxiety dominate. In the long-term, patients experienced difficulties with accepting their remaining disabilities.

Trauma patients stated that QoL is largely dependent on independency and being able to perform daily activities. Throughout the recovery process, it became evident for patients that some consequences would remain for the rest of their lives. However, some patients stated that the trauma had positively changed them, by increasing the potential to see and enjoy more easily little things in life. Perceived changes in QoL in trauma patients showed similarities with changes in QoL in other patient groups. For instance, trauma patients reported difficulties in accepting their new life, and this was also found in patients with Parkinson's disease, stroke, or in patients after a kidney transplantation (Crawford, Low, Manias, & Williams, 2016; Den Oudsten, Lucas-Carrasco, & Green, 2011; Numminen et al., 2016).

The emotional impact of the consequences of a trauma can differ per person. Consistent with the literature, the

feeling of having control over the situation, the patients' own expectations, and attitude (e.g., belief in own ability to address with problems) can have a large influence on perceived QoL (Gregorio, Gould, Spitz, van Heugten, & Ponsford, 2014; Luszczynska, Benight, & Cleslak, 2009; Martin, Byrnes, McGarry, Rea, & Wood, 2016; Wielenga-Boiten, Heijenbrok-Kal, & Ribbers, 2015). For example, problem-solving persons might encounter problems with adjusting to their limitations, as they may find it difficult to accept their situation. This study reveals that stage of life also plays an important role. Because of their advanced age, elderly patients stated that their needs and desires were reduced regarding functional outcome. For the working-age population, RTW was clearly important, which confirms conclusions from previous trauma research (Gabbe et al., 2014).

Furthermore, this study underlines the importance of a strong social network and sufficient societal support. A good social network is vital because patients often experience difficulties with daily activities such as self-care. Reductions in QoL can be expected when there is lack of social support. This finding is consistent with earlier studies demonstrating that social support tends to be of great importance to the well-being and recovery process of trauma patients (Gustafsson, Persson, & Amilon, 2002; MacKenzie et al., 1998; Sleney et al., 2014; van Delft-Schreurs et al., 2014). With regard to societal support and finances, the patients often feel that they stand alone. Patients become dependent on others because of the different laws and regulations from the public authorities, and this outcome is consistent with an earlier study among spinal cord injury patients (Levins, Redenbach, & Dyck, 2004). As in the case of other patient groups (Den Oudsten et al., 2011; Mayer, Nasso, & Earp, 2017), some trauma patients experience difficulties in buying medical aids. To optimize the patients' QoL, public authorities (e.g., government authority) should improve standard processes by taking into account the patients' individual needs.

This study revealed that trauma can also have a negative impact on the partners' life, specifically in TBI patients. Partners of TBI patients have to alert their relative about the acquired shortcomings and this outcome is consistent with previous research (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017; Lefebvre, Cloutier, & Josee Levert, 2008). Moreover, in earlier studies, caregivers reported changes in relationships with patients, which negatively influenced their QoL (Kratz et al., 2017; Lefebvre et al., 2008).

Quality of health care is an important aspect in the patients' perceived QoL. Participants emphasized the need of appropriate aftercare in the form of outpatient monitoring to identify their remaining problems. This finding is consistent with earlier research among different patient groups in which a good quality health care system had a large influence on the patients' QoL (Den Oudsten et al., 2011; Sleney et al., 2014; Volker et al., 2017).

The results of this study indicate that more awareness in health care settings is necessary to optimize trauma patients' QoL. In recent studies, the role of a case manager or nurse coordinator has proven to be effective not only in oncology patients but also in patients with acquired brain injury (Azar et al., 2017; Bruner-Canhoto, Savageau, Croucher, & Bradley, 2016). From hospital admission until discharge, a case manager can function as a first contact person for patients, and before leaving the hospital, a conversation with the case manager is offered to the patients. This case manager can provide information about the trauma and expected recovery while taking into account the patients' expectations. In addition to care coordination, it is recommended to extend the standard aftercare to screen the remaining problems that the patients have to address, for instance trauma-related psychosocial or emotional issues (e.g., adjustment issues or a posttraumatic stress disorder). A large proportion of the patients suffer from psychological impairments, which can have a large negative effect on their recovery and QoL (Kenardy et al., 2017). For example, after 3 months, a follow-up appointment with a case manager can be offered to support and advise patients and their relatives to accept their new life situation. A less invasive alternative is that this extended aftercare can be offered by a general practitioner to signpost patients. If necessary, the patients can be referred to an appropriate (health) service.

Previous studies concluded that specialized trauma nurses have a significant impact on the care and management of trauma patients during their hospitalization (Walter & Curtis, 2015). Trauma nurses can play an important role during the patients' hospitalization because the nurses can inform and advise patients and their relatives when they are uncertain or worried about their future.

This study has its limitations. It was necessary to combine the different subgroups of patients who were created beforehand because of the small number of patients who were willing to participate. Subsequently, this small number might have led to response bias. Another limitation is selection bias because only Dutch-speaking participants could participate. Reported QoL might be underestimated because several patients stated that their participation was too confrontational, and others were unable to attend the focus group because of their bad overall condition. Despite these conditions, the included participants demonstrated a large range of characteristics in age, trauma mechanism, and severity.

This study provides recommendations for future research. First, the patients' own expectations had a large influence on perceived QoL. Therefore, more research is necessary to examine the patients' information needs with regard to symptoms and recovery. Subsequently, information protocols can be developed. Second, research should focus on the psychological well-being of family members

confronted with an injury of their relative, especially in TBI patients. Third, patients with the same clinical condition can report different QoL scores. Researchers should take into account trauma patients' feeling to have control over the situation and the patients' own expectations when examining QoL. Lastly, this study indicated the necessity for specific attention for two specific injury groups when examining patients' QoL (i.e., elderly patients and TBI patients). The main focus in elderly patients needs to be on measuring the changes on the (social) activity level. For TBI patients, the focus should be on psychosocial problems.

CONCLUSION

Time since injury plays an important role in the patients' way of experiencing QoL. This study shows that trauma influences QoL in different health domains. The trauma patients' social network and quality of health-care play an important role in the patients' QoL experience. Trauma nurses can play an important role in improving trauma patients' perceived QoL by informing and advising patients.

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KEY POINTS

- Trauma influences the patients' QoL in different health domains. Most of the physical, psychological, social, and environmental consequences after trauma are the same in all patients irrespective of age, trauma mechanism, or severity.
- Time since injury plays an important role in the patients' way of experiencing QoL. In the first month posttrauma, patients state that their feelings and expectations largely influenced their recovery and QoL and vice versa. Participants state that their feeling of having control over the situation positively influenced their recovery, although some patients felt that they had no control on their recovery. Furthermore, physical limitations, independency, pain, and anxiety dominate. In the long-term, patients experience difficulties with accepting their remaining disabilities.
- Quality of health care, the ability to have control over the situation, the patients' own expectations of recovery, and a social network are vital issues influencing perceived QoL.

REFERENCES

- Azar, J. M., Johnson, C. S., Frame, A. M., Perkins, S. M., Cottingham, A. H., & Litzelman, D. K. (2017). Evaluation of interprofessional relational coordination and patients' perception of care in outpatient oncology teams. *Journal of Interprofessional Care, 31*(2), 273–276.
- Baarda, D. B., de Goede, M. P., & Teunissen, J. (2009). *Basisboek Kwalitatief Onderzoek—Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek*. Groningen, the Netherlands: Noordhoff Uitgevers.
- Berden, H. J. J. M., & Leenen, L. P. H. (2015). *Landelijke Traumaregistratie 2010-2014: Rapportage Nederland*. Landelijk Netwerk Acute Zorg.
- Boeije, H. (2010). *Analysis in qualitative Research*. London: SAGE Publications Ltd.
- Bruner-Canhoto, L., Savageau, J., Croucher, D., & Bradley, K. (2016). Lessons from a care management pilot program for people with acquired brain injury. *Journal for Healthcare Quality, 38*(5), 255–263.
- Crawford, K., Low, J. K., Manias, E., & Williams, A. (2016). Healthcare professionals can assist patients with managing post-kidney transplant expectations. *Research in Social & Administrative Pharmacy, 13*(6), 1204–1207.
- Den Oudsten, B. L., Lucas-Carrasco, R., Green, A. M., & Whoqol-Dis Group. (2011). Perceptions of persons with Parkinson's disease, family and professionals on quality of life: An international focus group study. *Disability and Rehabilitation, 33*(25–26), 2490–2508.
- Gabbe, B. J., Slaney, J. S., Gosling, C. M., Wilson, K., Sutherland, A., Hart, M., ... Christie, N. (2014). Financial and employment impacts of serious injury: A qualitative study. *Injury, 45*(9), 1445–1451.
- Gennarelli, T. A., & Wodzin, E. (2006). AIS 2005: A contemporary injury scale. *Injury, 37*(12), 1083–1091.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. New York: Ladine de Gruyter.
- Gregorio, G. W., Gould, K. R., Spitz, G., van Heugten, C. M., & Ponsford, J. L. (2014). Changes in self-reported pre- to postinjury coping styles in the first 3 years after traumatic brain injury and the effects on psychosocial and emotional functioning and quality of life. *The Journal of Head Trauma Rehabilitation, 29*(3), E43–E53.
- Gustafsson, M., Persson, L. O., & Amilon, A. (2002). A qualitative study of coping in the early stage of acute traumatic hand injury. *Journal of Clinical Nursing, 11*(5), 594–602.
- Kenardy, J., Heron-Delaney, M., Hendrikz, J., Warren, J., Edmed, S. L., & Brown, E. (2017). Recovery trajectories for long-term health-related quality of life following a road traffic crash injury: Results from the UQ SuPPORT study. *Journal of Affective Disorders, 214*, 8–14.
- Kratz, A. L., Sander, A. M., Brickell, T. A., Lange, R. T., & Carozzi, N. E. (2017). Traumatic brain injury caregivers: A qualitative analysis of spouse and parent perspectives on quality of life. *Neuropsychological Rehabilitation, 27*(1), 16–37.
- Lefebvre, H., Cloutier, G., & Josee Levert, M. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury, 22*(7–8), 535–543.
- Levins, S. M., Redenbach, D. M., & Dyck, I. (2004). Individual and societal influences on participation in physical activity following spinal cord injury: A qualitative study. *Physical Therapy, 84*(6), 496–509.
- Luszczynska, A., Benight, C. C., & Cleslak, R. (2009). Self-efficacy and health-related outcomes of collective trauma, a systematic review. *European Psychologist, 14*, 51–62.
- MacKenzie, E. J., Morris, J. A. Jr., Jurkovich, G. J., Yasui, Y., Cushing, B. M., Burgess, A. R., ... Swiontkowski, M. F. (1998). Return to work following injury: The role of economic, social, and job-related factors. *American Journal of Public Health, 88*(11), 1630–1637.
- Martin, L., Byrnes, M., McGarry, S., Rea, S., & Wood, F. (2016). Posttraumatic growth after burn in adults: An integrative literature review. *Burns, 43*(3), 459–470.
- Mayer, D. K., Nasso, S. F., & Earp, J. A. (2017). Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. *Lancet Oncology, 18*(1), e11–e18.
- Numminen, S., Korpjaakko-Huuhka, A. M., Parkkila, A. K., Kulkas, T., Numminen, H., Dastidar, P., & Jehkonen, M. (2016). Factors influencing quality of life six months after a first-ever ischemic stroke: Focus on thrombolysed patients. *Folia Phoniatrica et Logopaedica, 68*(2), 86–91.

- Slaney, J., Christie, N., Earthy, S., Lyons, R. A., Kendrick, D., & Towner, E. (2014). Improving recovery—Learning from patients' experiences after injury: A qualitative study. *Injury, 45*(1), 312–319.
- van Delft-Schreurs, C. C., van Bergen, J. J., de Jongh, M. A., van de Sande, P., Verhofstad, M. H., & de Vries, J. (2014). Quality of life in severely injured patients depends on psychosocial factors rather than on severity or type of injury. *Injury, 45*(1), 320–326.
- Volker, A., Koch-Gallenkamp, L., Jansen, L., Bertram, H., Eberle, A., Holleczeck, B., ... Brenner, H. (2017). Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. *Acta Oncologica, 56*(2), 190–197.
- Walter, E., & Curtis, K. (2015). The role and impact of the specialist trauma nurse: An integrative review. *Journal of Trauma Nursing, 22*(3), 153–169.
- WHOQOL-Group. (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health, 23*, 24–56.
- Wielenga-Boiten, J. E., Heijenbrok-Kal, M. H., & Ribbers, G. M. (2015). The relationship of health locus of control and health-related quality of life in the chronic phase after traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 30*(6), 424–431.
- World Health Organization. (2016). *Violence and injury prevention*. Retrieved from http://www.who.int/violence_injury_prevention/media/news/2016/18_09/en/
- Ziden, L., Scherman, M. H., & Wenestam, C. G. (2010). The break remains—elderly people's experiences of a hip fracture 1 year after discharge. *Disability Rehabilitation, 32*(2), 103–113.