



In-depth assessment of quality of life and real life impact of mild traumatic brain injury in elderly by means of a focus group study



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ABSTRACT

Traumatic Brain Injury (TBI) in the elderly population leads to more severe consequences than in young patients. However, the impact that TBI has on elderly patients' Quality of Life (QoL) has not been thoroughly investigated and is still unclear. Therefore, the main objective of this study is to qualitatively investigate changes in QoL after mild TBI in elderly patients.

A focus group interview was conducted with 6 mild TBI patients, with a median age of 74 years old, admitted to the University Hospitals Leuven (UZ Leuven) between 2016 and 2022. The data analysis was performed following the guide provided by Dierckx de Casterlé et al. in 2012, using Nvivo software.

Three themes emerged from the analysis: functional disturbances and symptoms, daily life after TBI, and life quality, feelings and satisfaction. The most reported factors that deteriorated QoL 1–5 years post-TBI in our cohort were the lack of support from partners and families, changes in self-perception and social life, tiredness, balance disturbances, headache, cognitive deterioration, changes in physical health, senses' disturbances, changes in sexual life, sleep problems, speech disturbances and dependence for daily life activities. No symptoms of depression or feelings of shame were reported. The acceptance of the situation and hope for improvement were shown to be the most important coping mechanisms for these patients.

In conclusion, mild TBI in elderly patients frequently leads to changes in self-perception, daily life activities and social life 1–5 years after the injury, which could contribute to a loss of independence and QoL deterioration. The acceptance of the situation and a good support network seem to be protective factors for these patients' well-being after TBI.

1. Introduction

Traumatic Brain Injury (TBI) is a life changing event and one of the main causes of disability worldwide (Fleminger and Ponsford, 2005), frequently leading to long-term physical, cognitive, emotional, behavioral and social problems, and QoL deterioration (Carroll et al., 2004; Gouin and Kiecolt-Glaser, 2011; Hoofien et al., 2001; van Baalen et al., 2003; Dijkers, 2004).

It is known that in elderly patients, TBI's consequences are more severe than in younger patients, even when the TBI is classified as mild (Thompson et al., 2006; Dijkers et al., 2013; Kelley-Quon et al., 2010). The ageing process usually results in a deterioration of the molecular and cellular functions (Kirkwood, 2005), limiting physiological reserve and leading to higher comorbidities (Rockwood and Mitnitski, 2011). Therefore, recovery in elderly patients can be complicated by these

factors (Albrecht and Wickwire, 2020; Albrecht et al., 2017, 2019), and these patients have the highest emergency department admission, hospitalization and mortality incidences (Taylor et al., 2017).

After a TBI, patients can experience anxiety (Hatch et al., 2018), depressive symptoms (Hatch et al., 2018), posttraumatic stress disorder (PTSD) (Hatch et al., 2018) or even a self-identity disruption (Bryson-Campbell et al., 2013), that can last months or years after the accident (Lippert-Grüner et al., 2007). Even in mild TBI cases, cognitive symptoms, such as reduced concentration and memory, and a lack of energy are frequent (Johansson et al., 2009).

TBI patients usually report significantly variable ratings for QoL assessments after the injury, most probably due to the high amount of factors on which a person's QoL depends (Williams and Willmott, 2012; Corrigan et al., 2001; Ergh et al., 2003; Kozlowski et al., 2002; Baumann et al., 2007; Branca and Lake, 2004; Dahlberg et al., 2006; Pierce and

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Hanks, 2006).

The main contributing factors for QoL have shown to be mental health, emotional and neurobehavioral status, cognitive functions, sleep quality, autonomy, energy levels, relationships, employment, and higher levels of independence and social participation, among others, which are usually affected in these patients (Williams and Willmott, 2012; Corrigan et al., 2001; Ergh et al., 2003; Kozłowski et al., 2002; Baumann et al., 2007; Branca and Lake, 2004; Dahlberg et al., 2006; Pierce and Hanks, 2006).

Previous studies have shown that patients who have longer hospital stays or need more medical care are usually less satisfied with their general health and recovery after TBI and have lower QoL (Polinder et al., 2016). Nevertheless, up to date, little is known about how patients cope with the long-term consequences following TBI (Allanson et al., 2017) and the impact that TBI has on elderly patients' QoL is still unknown, mainly due to the lack of a standard QoL measures for older adults (Hunt et al., 2019). Furthermore, the patients' heterogeneous symptoms are not usually the focus during early rehabilitation and, to date, have not been included in TBI clinical guidelines (Bryant et al., 2010). Therefore, the main objective of this study is to qualitatively investigate the difficulties that elderly patients with a mild TBI suffer after injury and how those affect their QoL, in order to better understand the impact of TBI on elderly patients' lives.

2. Methods

In order to perform a qualitative in-depth investigation of the QoL changes that elderly patients experience after a TBI, a focus group study was designed and approved by the UZ Leuven/KU Leuven Ethics Committee.

For this study, patients admitted to the University Hospitals Leuven (UZ Leuven) between 2016 and 2022 with a mild TBI diagnose, ≥ 65 years old, were eligible to participate in the study. Patients were excluded if they were < 65 years old, had a moderate or severe TBI, were admitted to UZ Leuven before 2016, had a diagnose of any other disease which could affect the patients' QoL, suffered cognitive disturbances caused by any other pathology, had previous alcohol/drugs abuse, or had communication difficulties. Only patients who were fluent in Dutch were eligible for the study.

The eligible participants were selected from UZ Leuven registry by one researcher (RG) and contacted by telephone or e-mail. After the study explanation was provided, patients had to provide informed consent form (ICF) to be included in the study. Only after signing the ICF patients were contacted by telephone or e-mail to schedule the focus group interview. The groups' sample size was set to a maximum of 10 patients.

The interview took place in UZ Leuven in May 2022 and lasted a total of 90 min. The topics of the interview guide encouraged the participants to describe experienced problems in their daily life after TBI, in order to better understand how those changes have affected their QoL. The English translation of the used interview guide, originally in Dutch, can be read in [Appendix A](#).

During the interview, two moderators were present (BD and RG). The first moderator (BD) conducted the meeting and led the discussion. The second moderator (RG) recorded the interview and took notes of the conversation.

The session started by asking the participants to provide a brief autobiography and to share with the group how the injury had happened. Then, the interview guide [[Appendix A](#)] was used to steer the conversation. Follow-up questions to specific comments, not present in the initial guide, were also asked in order to stimulate the conversation flow and obtain interesting details to answer the researchers' main research question.

The interview was digitally recorded using a smartphone and transcribed verbatim in a Word document. The patients' data was pseudonymized and data analysis was performed following the guide

provided by Dierckx de Casterlé et al. in 2012 (Dierckx de Casterlé et al., 2012), using paper methods and Nvivo software.

3. Results

For this study, one interview was performed with 6 patients (4 males and 2 females), with a median age of 74 years old (range 66–82 years old). The patients' age at the moment of the accident ranged between 65 and 77 years old and 2 patients had a GCS of 14 at admission, 2 of 15 and for the other 2 patients the GCS was unknown.

Four of the patients had the TBI due to a bicycle accident, one had a fall accident and one an accident with a horse. Two of the patients reported remembering very little or nothing about the accident and three described having a trauma that was apparently serious or being picked up from the accident scene for near dead. The interview was performed 1–5 years post-TBI for these patients.

The analysis resulted in 17 codes, which were organized in 3 categories and 14 sub-categories [[Table 1](#)].

Three interrelated themes emerged from the analysis (Fleminger and Ponsford, 2005): functional disturbances and symptoms (Carroll et al., 2004), daily life after TBI, and (Gouin and Kiecolt-Glaser, 2011) life quality, feelings and satisfaction.

3.1. Functional disturbances and symptoms

The patients reported having suffered functional disturbances and different symptoms after the injury. The most common ones were balance problems, headaches, cognitive deterioration, changes in physical health, senses' disturbances, changes in sexual life, sleep problems, and speech disturbances.

The most common cognitive alterations suffered in this cohort were short-memory deteriorations.

This can be observed in the following examples:

"I have the impression that I'm a bit, not firm enough, when I have to do something. Sometimes I'm just treading water on the plants and I have to hold on to it to keep my balance. That is a bit less, I think, than before." (Patient 4, GCS 15, 2 years after TBI)

"That headache ... I'm constantly in pain, and even combing my hair, going to the shop ..." (Patient 5, GCS 15, 1 year after TBI)

"To get something, I go to the kitchen, to the garage, for that bottle of milk or water and then all disappears. Yes, I went to get something, but what ... and then I turn back." (Patient 5, GCS 15, 1 year after TBI)

3.2. Daily life after TBI

Patients reported difficulties in their daily life after the TBI. Although

Table 1
Categories and subcategories that emerged from the qualitative analysis.

Categories (n = 3)	Subcategories (n = 14)
Functional disturbances and symptoms	Balance problems Headache Cognitive deterioration Physical health Senses' disturbances Sexual life Sleep problems Speech disturbances
Daily life after TBI	Daily life activities Support and help
Life quality, feelings and satisfaction	General life satisfaction Changes in social life Self-perception Acceptance

they reported to be independent and active in their daily lives and thought they were lucky during their recovery process to achieve their current status, they experienced some changes in their daily lives.

Activities such as cleaning or driving were the most affected ones in these patients and external cleaning help or transportation was needed. This can be seen in the following example:

“Yes, absolutely, less independent ... I can't drive my car anymore ... now I have a driver, and yes, that means less independence.” (Patient 5, GCS 15, 1 year after TBI)

However, the most important difficulty these patients reported was the lack of support and understanding of the patients' situation by partners and family, which was an big source of discomfort.

Some of the patients' reports were:

“That I have this ... I accept that to myself, I know it is like this, but my husband doesn't. I don't dare to say I'm tired, I don't dare to sit down, I cannot go to rest because he starts to bother me. He's always going to say what I'm forgetting, or what I have to change. He thinks I'm demented after the fall. I can't believe it. I don't get any support.” (Patient 5, GCS 15, 1 year after TBI)

“I don't have a very cooperative husband either. That support is not always there. I think that for all of us ... that understanding of people who are outside is completely different.” (Patient 6, GCS of 14, 1 year after TBI)

Therefore, lack of support and understanding, and the inability to perform certain tasks, such as cleaning, or driving, were reported to be the main elements affecting QoL in our cohort.

3.3. Life quality, feelings and satisfaction

The patients reported to be generally satisfied with their lives and to feel good at the moment of the interview:

“My quality of life is good, actually. I feel loved by a lot of people. And yes, I do get upset when certain things go less well, but globally I'm happy.” (Patient 4, GCS 15, 2 years after TBI)

However, despite the general satisfaction, they reported some changes in their life that were referred as QoL-disturbing. Importantly, many patients reported not being the same person as before, mainly attributing those changes to higher irritability levels and a reduced interest in social life post TBI, which usually made the patients feel uncomfortable, bad, very emotional, with difficulties to cope, going too far and/or unhappy:

“I am very irritable. I am not the same person as before ... I used to be calm and quite easy going, but now I react very often to everything. I am very irritable, and I have never been like this.” (Patient 5, GCS 15, 1 year after TBI)

“I used to be social, but I am not interested anymore ... after I fell, that actually broke. So that social isn't ... anymore. I had these friends, that used to be real friendship, but then I don't feel at home there anymore.” (Patient 3, unknown GCS, 3 years after TBI)

Despite these difficulties, most patients reported having accepted their current situation and seemed optimistic and with hope for an improvement of the situation and none of the patients reported feelings of shame or depression when specifically asked.

4. Discussion

TBI is widely known to be a life changing event (Bury, 1982). In elderly, even in mild TBI cases, patients suffer multiple difficulties in their lives after the accident (Albrecht and Wickwire, 2020; Albrecht et al., 2017, 2019; Taylor et al., 2017), which was supported by our findings.

We qualitatively analyzed changes in QoL in 6 patients with mild TBI 1–5 years post TBI. The most reported factors that deteriorated QoL in these patients were balance problems, headache, cognitive deterioration, changes in physical health, senses' disturbances, changes in sexual life, sleep problems, speech disturbances, changes in self-perception and social life, tiredness, dependence for daily life activities, and lack of support and understanding. These symptoms have also been reported by previous studies considering changes in QoL in adults with TBI (Williams and Willmott, 2012; Jones et al., 2011; Kalpakjian et al., 2004; Andelic et al., 2018; Sveen et al., 2016; Parcell et al., 2008).

In our cohort, multiple patients reported changes in their social life and lack of support and understanding from other people, which was affecting their QoL. Brown et al. (Andelic et al., 2018) already showed that social participation is a key factor for a higher QoL in patients with a TBI (Williams and Willmott, 2012) and the correlation between social support and higher levels of QoL has also been shown in previous studies by Jones et al. (2011) and Kalpakjian et al. (2004).

These social life changes were described associated to changes in self-perception in our cohort. Mainly due to the lack in social interest, patients reported to not recognize themselves anymore. They said they were “not the same as before”. This has also been frequently reported in TBI patients in the past, as when comparing their actual life with pre-injury life situations, they usually perceive not having the same abilities or feelings as in the past (Sveen et al., 2016).

Furthermore, most of our included patients had problems to sleep. Sleep disturbances are a well-known challenge in TBI (Parcell et al., 2008). However, the influence of the lack of sleep in the other reported symptoms is still unclear and further investigation would be necessary to clarify it.

Despite all these important changes that the patients described 1–5 years post-TBI, none of the patients reported symptoms of depression and all of them described being globally satisfied with their lives. A previous systematic review and meta-analysis published by the authors in 2021, showed that 2.6–4.8% of the elderly patients with mild TBI develop depression symptoms (Gavrilu Laic et al., 2021). However, this was not the case in our cohort. Even those patients who reported more complaints and worse support networks described using the acceptance of the situation and hope for improvement as mechanisms to cope.

It is important to take into account that in this study we only considered mild TBI cases. Therefore, the results cannot be extrapolated to more severe injuries. Although a direct correlation between GCS and QoL has not been found (Siponkoski et al., 2013; Colantonio et al., 1998), we should consider that the group of patients that were included in our study was quite homogeneous in terms of functional outcomes and favorable recovery and the results should be carefully interpreted. Probably, having included mild TBI patients with worse recovery or more severe TBI cases would have led to different outcomes.

In previous studies considering more severe TBI cases, Brown and Vandergoot (Brown and Vandergoot (1998) found that patients with lower GCS presented higher subjective QoL decades post-injury. Furthermore, Kalpakjian et al. (2004) found that, whilst the mean QoL score in severe TBI patients was lower than the average and significantly lower than in non-disabled patients, nearly half of the patients scored in the average or high range 5 years post-injury. Therefore, the literature regarding a possible association between the severity of TBI and QoL is still controversial and unclear (Hofhuis and Spronk, 2014). To date, no direct correlation between GCS and QoL scores has been found (Siponkoski et al., 2013; Colantonio et al., 1998). However, it is known that GCS might not be that reliable for TBI injury classification in elderly, as these patients have an increased risk for intracranial injuries presenting a delayed mass effect, leading to secondary deterioration (Hofman et al., 2001; Stiell et al., 2001; Haydel et al., 2000). Thus, the correlation between QoL and other clinical parameters should be further investigated in elderly.

Regarding changes over time post-injury, we did not find big differences between patients interviewed 1 and 5 years post-TBI. Previous

studies have shown that TBI patients adapt over time and present a better QoL in the long-term after injury (Brown et al., 2011). Nevertheless, it would be interesting for future studies to consider shorter and longer times post-injury to better understand changes in QoL over time.

This study is, to the authors knowledge, the first qualitative study on QoL after mild TBI specific for elderly patients. However, it is important to consider that it has some limitations. First, the included sample size is quite low. This has to do with the fact that the group of interest is composed of patients of a high age and frequently a high comorbidity rate, which made the interest for participation lower. Furthermore, the recruitment was performed during the covid-19 pandemic and patients were more afraid to come to the hospital for non-essential procedures. Therefore, the number of performed interviews was limited to one. Second, only mild TBI patients were included in the study. Although 80% of the elderly patients are classified as mild (Stein et al., 2018) and the included cohort could be representative of the elderly TBI phenomenon, there is a lack of representation in our cohort of moderate and severe TBI patients and our results cannot be extrapolated to them. Future studies specific for those injury severities in this population are required to be able to understand the changes in QoL by injury severity.

From the results obtained in this study we saw that, even though the patients were globally satisfied with their lives 1–5 years post-TBI, they suffered from multiple complaints that changed their life and self-perception after the injury.

We believe that these results can be very valuable in clinical practice. Up to date, evidence for QoL changes in elderly patients with TBI is rather scarce (Brown et al., 2017) and a qualitative approach is very useful to thoroughly understand the patients' experience.

In our cohort, the acceptance of the situation and a good support network were described as protective factors for the patients' well-being after TBI. Therefore, more efforts to provide psychological assistance and a support network for these patients after injury should be put. Patients should not have the feeling of being left alone and should be followed-up after hospital discharge and receive rehabilitation (Sveen et al., 2016). Finally, future studies to thoroughly investigate QoL in elderly patients, considering all injury severities, are necessary to improve the clinical care and outcomes of these patients.

5. Conclusion

Mild TBI in elderly patients frequently leads to changes in self-perception, daily life activities and social life 1–5 years after the injury, which could contribute to a loss of independence and QoL deterioration. The lack of support and inability to perform certain daily tasks are important factors for QoL deterioration in elderly TBI patients. The acceptance of the situation, optimism, and a good support network seem to be protective factors for these patients' well-being after TBI.

Authorship confirmation statement

All authors contributed to the study conception and design. The focus group interview was performed by Bart Depreitere and Rebeca Alejandra Gavrilă Laic. The qualitative analysis was performed by Rebeca Alejandra Gavrilă Laic. The first draft of the manuscript was written by Rebeca Alejandra Gavrilă Laic. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Author(s') disclosure statement(s)

The authors declare that they have no competing interests.

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Appendix A. Supplementary data

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