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Health, wellness, and safety concerns of persons with moderate-to-severe traumatic brain injury and their family caregivers: a qualitative content analysis

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ABSTRACT

Background: Persons with moderate-to-severe traumatic brain injury (TBI) face issues with health, wellness, and safety that affect their ability to independently manage their care, even for individuals who are ≥75% independent in activities of daily living. These issues often lead to increased family involvement in managing the person's condition after discharge home.

Purpose: We explored health, wellness, and safety concerns after discharge home from inpatient rehabilitation from the perspectives of persons with TBI who are ≥75% independent in activities of daily living and their family caregivers.

Materials and methods: We interviewed 27 persons with TBI and family caregivers and used conventional content analysis to analyse the data.

Results: Seven themes related to health, wellness, and safety encompassed participants' experience. Health themes included: (1) attempting to manage medications and (2) navigating mental health difficulties. Wellness themes included: (1) working to stay physically active, (2) dealing with sleep and sleeplessness, and (3) adjusting to changing social relationships. Safety themes were: (1) addressing mobility challenges and (2) compensating for complications with cognitive functioning.

Conclusions: Findings can guide the development of tools, supports, and resources to promote health, wellness, and safety of persons with TBI as they recover after discharge home.

IMPLICATIONS FOR REHABILITATION

- Findings on numerous concerns related to health, wellness, and safety suggest the need for implementation or development and testing of tools, supports, and resources to promote health, wellness, and safety of persons with traumatic brain injury as they recover after discharge home.
- Our findings can be used to educate healthcare providers and increase awareness of the nuanced challenges patients and families face after discharge home.
- Findings can also be used by providers to educate patients and families on realistic expectations for life after discharge.

Introduction

Traumatic brain injury (TBI) is defined as a “bump, blow or jolt to the head, or a penetrating injury that disrupts the normal function of the brain” [1]. Each year, over 69 million people sustain a TBI globally [2]. Across the world, North America has one of the highest incidence rates of TBI [2], with over 2.7 million people sustaining a TBI in the United States (USA) each year. Subsequently, more than 275,000 people in the USA sustain a moderate-to-severe TBI that requires a hospital stay of two or more days [1]. Typically, patients with moderate-to-severe TBI require acute medical care and inpatient rehabilitation to address functional impairments and deconditioning [3]. Even after inpatient rehabilitation, many persons with moderate-to-severe TBI transition to home and community settings with residual impairments in cognition, physical functioning, behaviour, or emotion that lead to long-term disability and varying levels of dependency [4,5]. They also have substantially increased safety risks while carrying out instrumental activities of daily living [6,7]. Disability and associated safety risks limit self-management of health, wellness, and safety for persons with TBI and often require increased family involvement in managing the person’s care, daily activities, and general recovery [8–10].

When available, family caregivers play a large role in helping persons with TBI transition back home from the hospital [11,12], including assisting with decision-making during the hospital stay and providing physical, instrumental, and emotional support after discharge [13,14]. However, compared to family caregivers of patients with other diagnoses, family caregivers of persons with TBI feel less prepared to care for and address the needs of the person with TBI [15]. Family caregivers of persons with TBI also report unmet needs after discharge home [16,17] related to difficulties navigating the healthcare system post-discharge [10] and limited preparation on how to care for and address the needs of the person with TBI [18]. In addition, family caregivers report difficulty in assisting the person with TBI to self-manage their health, likely because persons with TBI have numerous post-discharge challenges and may lack awareness of their own needs [18].

Research shows persons with TBI and their families have difficulty adjusting to life after discharge home, including adapting to...
cognitive impairments [19,20], managing emotions [19,21,22], using effective coping strategies [23,24], and safely regaining independence [24]. Persons with TBI experience numerous challenges that can affect mental health and quality of life [25,26] such as an inability to return to driving, work, school, or hobbies [25–27]. These post-discharge challenges for persons with TBI can lead to social isolation, anxiety, and depression [28,29].

Although qualitative and quantitative research has been conducted on challenges persons with TBI and their family caregivers face after discharge, many of which are listed above, research on post-discharge health, wellness, and safety for this population is still emerging, especially for individuals that are ≥75% independent in activities of daily living but may still struggle to manage instrumental activities of daily living [19,20,23,28]. In addition, there is limited qualitative research on the perspectives of persons with TBI and their family caregivers on their post-discharge health, wellness, and safety concerns. According to the World Health Organisation, health is defined as “a state of complete physical, mental, and social well-being and not merely the absence of disease” [30]. In contrast, wellness is considered to be subjective (often based on the individual’s perception) and encompasses multiple areas such as emotional, intellectual, physical, social, psychological, and spiritual dimensions [31,32]. Finally, safety is defined as being protected from danger, risk, or injury [33]. Issues with health, wellness, and safety may influence post-discharge outcomes for persons with TBI, affect recovery of persons with TBI, and increase burden on family caregivers [34–37].

Aim of paper
The purpose of this study was to explore post-discharge health, wellness, and safety concerns from the perspectives of persons with moderate-to-severe TBI discharged home from inpatient rehabilitation who were ≥75% independent in activities of daily living and their family caregivers. We provide a conceptual model that describes our participants’ specific health, wellness, and safety concerns, which is useful in understanding patient and family post-discharge adjustment and transition needs. These findings can be used to guide implementation or development and testing of resources, supports, and tools that promote health, wellness, and safety to be used by persons with TBI and their family caregivers during recovery after TBI.

Methods
Study design
We conducted an exploratory, qualitative study of the health, wellness, and safety concerns of persons with moderate-to-severe TBI discharged home from inpatient rehabilitation and their family caregivers. We chose to conduct a qualitative study because qualitative research of the perspectives of persons with TBI and their families on their concerns and needs can provide pertinent insight into areas where additional support may be needed [38]. In addition, qualitative research, in general, can be used to support, refute, extend, and provide further or new explanations for research using quantitative research methodologies [39–41]. Finally, sole use of quantitative research methodologies may not allow for full, in-depth descriptions of the experience of persons with TBI and their family caregivers [39,41]. We used the consolidated criteria for reporting qualitative research criteria (COREQ) guidelines to report our findings [42].

Recruitment
We recruited participants between October 2016 and May 2017. All patients were recruited from an inpatient rehabilitation hospital in the Southeastern region of the USA. Recruitment began after patients were discharged home from inpatient rehabilitation and had completed an intervention focused on improving safety in the home. We included caregivers who were involved in supporting persons with TBI after discharge to provide supplemental information. We selected this sample to obtain foundational insights about the perspectives of patients with TBI and family caregivers on health, wellness, and safety concerns.

Inclusion and exclusion criteria
Persons with TBI were eligible to participate if they: 1) were age ≥18 years; 2) had been diagnosed with a moderate or severe TBI (severity determined by initial Glasgow Coma Scale score of 3–12 at scene of injury or initial hospital presentation); 3) were discharged home after receiving inpatient rehabilitation; 4) were able to carry out ≥75% of self-care activities (e.g., eating, dressing, and hygiene) independently, based on Mayo-Portland Adaptability Inventory Abilities subscale (Part C-Participation) [43]; 5) lived in a private residence; and 6) were able to communicate in English. Persons with TBI were not eligible to participate if they: 1) were receiving one or more outpatient therapies at the time of recruitment, had a diagnosis of mild TBI or prior neurological disorders or could not communicate in English. Family caregivers were eligible to participate if they were: 1) age ≥18 years; 2) living in the private residence with the person with TBI; and 3) able to communicate in English. Family caregivers were not eligible if they had previously sustained a TBI, did not live with the person with TBI, or could not communicate in English.

Ethical considerations
The participating Institutional Review Board approved this study before initiation. All participants were able to provide informed consent, which was determined based on the above-listed inclusion criteria. A signed informed consent form was obtained from each participant before beginning the qualitative interview.

Data collection and analysis overview
We used conventional content analysis to analyse our qualitative data. We selected conventional content analysis because this analysis technique is suitable for exploration in an area where little is known and could benefit from further description [44].

Specific data collection procedures
Our research team collectively developed a semi-structured interview guide to direct the collection of data on health, wellness, and safety concerns from the perspectives of persons with TBI and their family caregivers that were not previously discussed in the literature or warranted further study (see Table 1). The interview guide was piloted before use in this study. The priori definitions of health, wellness, and safety that guided our data collection (and subsequent analysis) came from the literature and were defined in the introduction section [30,32,33].

Participants were interviewed in a private conference room at a rehabilitation facility. When only a person with TBI was recruited, private interviews occurred; when both a person with TBI and their family caregiver agreed to participate, both were
interviewed simultaneously due to limitations of scheduling and transportation of both parties. Two researchers conducted all interviews (KA and NT). Following the tenets of conventional content analysis as described by Hsieh and Shannon, our interviews began with a broad and open-ended question about participants’ health, wellness, and safety concerns to allow participants to tell us information that was meaningful to them [44]. Next, we asked specific questions about post-discharge concerns in a number of areas. Throughout each interview, we asked participants to provide more information by using prompts such as “could you give me an example?” or “tell me more about that.” All interviews were audio recorded, transcribed verbatim, and ranged from 45 to 90 minutes. Each participant was compensated $25 each at the completion of the interview.

Specific data analysis procedures
All authors engaged in the data analysis, with experience in qualitative research methodologies ranging from two months to 8 years. We conducted our data analysis in two phases: preparation and organisation [44,45]. Within the preparation phase, we attempted to get a sense of the data as a whole by reading through each transcript while listening to the audio recording and making marginal notes about important topics discussed by participants related to health, wellness, and safety [44,45].

Next, we began the organisation phase, where we read through each transcript line-by-line and categorised the data [44,45]. We reorganised each transcript into a data analysis table with six columns. We independently reread each transcript and completed the data analysis table. Within the data analysis table, column 1 was the speaker [person with TBI, family caregiver, or interviewer(s)] and column 2 contained the quote. We highlighted quotes in column 2 that were specific to health, wellness, and safety. In column 3, we wrote keywords or notes about the quote, including a summary of what was highlighted or thoughts that came to mind while reading. In column 4, we indicated whether the quote was related to health, wellness, or safety concerns. In column 5, we suggested a name for a code related to the category or theme that fit with the corresponding data. In column 6, we suggested a sub-category or sub-theme related to the category. After coding each transcript independently, we each wrote a memo as part of our audit trail, which described our coding selections, with accompanying quotes from each participant. Next, we met to discuss the coding and memos written for each transcript. We discussed the coding of each transcript until agreement was reached. We allowed our data to drive our coding, as directed by Hsieh and Shannon, who indicate categories and names of categories should come directly from the data [44].

We illustrate our coding process with the following example. The first interview question we asked each participant was, “When you were first discharged from the hospital, what were your health, wellness, and safety concerns?” A person with TBI responded:

Trying to navigate my house because I broke my hip, so I was using the walker and having to navigate around things. And getting in and out of the car was something that we practiced a couple of times.

After reading the above quote, we conducted the following coding process:

- In column 2, we highlighted “navigated my house because I broke my hip,” “using the walker,” “navigate around things,” and “getting in and out of the car.”
- In column 3, we wrote, “difficulty navigating house and transferring in/out of car.”
- In column 4, we wrote “safety” to indicate the quote was related to safety concerns.
- In column 5, we wrote “mobility” as the suggested category.
- Finally, in column 6, we wrote “navigating home” and “using assistive devices” as the suggested sub-categories.

We coded all data in a similar fashion throughout the first iteration of the organisation phase.

After coding each transcript, we created and revised a conceptual model that emerged from the data to illustrate the categories describing the health, wellness, and safety concerns of participants. For each new category, we collaboratively wrote a group memo describing the category, sub-categories, and quote exemplars from several participants. After all transcripts were coded, we edited our group memo and revised the conceptual model for consistency.

We continued to conduct our data analysis until saturation was reached, where no new or relevant categories were identified in additional interviews [46]. We increased the rigor of our qualitative research by: 1) conducting our data collection and analysis with a research team, 2) using an audit trail to describe the analysis decisions we made throughout the study, and 3) ensuring our categories covered a wide range of participants’ experiences with use of quotes from multiple participants [47,48].

Results

Sample characteristics
Our sample included 27 total participants (15 persons with TBI and 12 family caregivers). Most persons with TBI were men with a
mean age of 32 years and average time since injury (TSI) of 18 months. Most family caregivers were women with a mean age of 50 years. Detailed sample characteristics can be found in Tables 2 and 3.

**Overview of themes**

There were a total of seven themes that describe the concerns of persons with TBI who were ≥75% independent in activities of daily living that related to health, wellness, and safety, as well as family caregivers’ perspectives on these issues for these persons with TBI (see Figure 1). Health-related themes included: 1) attempting to manage medications and 2) navigating mental health difficulties. Wellness-related themes included: 1) working to stay physically active, 2) dealing with sleep and sleeplessness, and 3) adjusting to changing social relationships. Safety-related themes were: 1) addressing mobility challenges and 2) compensating for complications with cognitive functioning. The severity of participants’ concerns on these topics varied over time, as sometimes concerns were heightened or decreased.

Table 2. Sample characteristics for persons with TBI (n = 15).

<table>
<thead>
<tr>
<th>Demographic items</th>
<th>Mean</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>32</td>
<td>20–60</td>
</tr>
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<td>Time since injury (months)</td>
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<td>6–28</td>
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<td>Sex</td>
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<td></td>
</tr>
<tr>
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<td>66.7</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>33.3</td>
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<tr>
<td>Race</td>
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<td>White</td>
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<td>53.3</td>
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<tr>
<td>African American</td>
<td>5</td>
<td>33.3</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>1</td>
<td>6.7</td>
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<td>6.7</td>
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<td>Ethnicity</td>
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<td>Cause of injury</td>
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<td></td>
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</tr>
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<td>13.3</td>
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<tr>
<td>Education</td>
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<tr>
<td>High school diploma or GED</td>
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<tr>
<td>Post-injury living situation</td>
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<td></td>
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<tr>
<td>Living with parent</td>
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<td>46.7</td>
</tr>
<tr>
<td>Living with spouse/partner</td>
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<td>20</td>
</tr>
<tr>
<td>Living with other family</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Living with friend or roommate</td>
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<td>6.7</td>
</tr>
<tr>
<td>Geographic location of residence</td>
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<tr>
<td>Suburban</td>
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<td>53.3</td>
</tr>
<tr>
<td>Rural</td>
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<td>26.7</td>
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<tr>
<td>Other</td>
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</tr>
<tr>
<td>Post-injury employment</td>
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<td></td>
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<tr>
<td>Student (part- or full-time)</td>
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<td>13.3</td>
</tr>
<tr>
<td>Employed (part- or full-time)</td>
<td>4</td>
<td>26.6</td>
</tr>
<tr>
<td>Unemployed</td>
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<td>46.7</td>
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<tr>
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<td>13.3</td>
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<tr>
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<td>25.6</td>
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<td>$50 000–$74 999</td>
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<td>6.7</td>
</tr>
<tr>
<td>$75 000–$99 999</td>
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<td>13.3</td>
</tr>
<tr>
<td>$100 000 or more</td>
<td>4</td>
<td>26.7</td>
</tr>
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</table>

Table 3. Sample characteristics for family caregivers of persons with TBI (n = 12).

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<th>Demographic items</th>
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</tr>
</thead>
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<td>Age (years)</td>
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<td>Sex</td>
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<td>83.3</td>
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<tr>
<td>Race</td>
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<td></td>
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<td>White</td>
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<td>58.3</td>
</tr>
<tr>
<td>African American</td>
<td>3</td>
<td>25</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Other</td>
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<td>8.3</td>
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<tr>
<td>Ethnicity</td>
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<td></td>
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<tr>
<td>Not Hispanic or Latino</td>
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<td>91.7</td>
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<tr>
<td>Hispanic or Latino</td>
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<td>8.3</td>
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<tr>
<td>Relationship to patient</td>
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<td></td>
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<tr>
<td>Spouse/partner</td>
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<td>16.7</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
<td>58.3</td>
</tr>
<tr>
<td>Other (e.g., relative and friend)</td>
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<td>25</td>
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<tr>
<td>Education</td>
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<td>High school diploma or GED</td>
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<td>Some college, no degree</td>
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</tr>
<tr>
<td>Bachelor’s degree</td>
<td>6</td>
<td>50</td>
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</table>

Figure 1. Conceptual model.
Health concerns

Attempting to manage medications

The theme “attempting to manage medications’ describes the process of the person with TBI and family caregiver trying (and often struggling) to manage the person's medications (e.g., prescribed medications, vitamins, and supplements). Persons with TBI attempted to administer their medications either independently or with family caregiver assistance. Approaches used to manage medications were often influenced by the person's level of cognitive impairment, the number of prescribed medications to be managed, switching doctors or medications, and the person's or family caregiver's personal beliefs about the benefits of medication. As time went on after discharge, persons with TBI and family caregivers developed or discovered strategies to assist with medication management, which often improved the medication management process.

All persons with TBI and family caregivers described use of medication supports to manage the person's medications, including obtaining assistance from family caregiver(s) or use of organizational support (e.g., pillboxes, reminder alarms, and routine for arranging medications). When describing his routine for arranging his medications, one person with TBI stated,

I had a list of all the medications that I needed to take, and then I had them all lined up in the medicine cabinet in my bathroom so that I know which ones. These are the morning, and these are middle of the day, and these are at night. (Person with TBI #101, below mean age, below 18 months TSI)

Independent and family caregiver-assisted medication administration led to either successful/safe or unsuccessful/unsafe medication administration. In successful/safe medication administration, the person with TBI or family caregiver remembered to have the person take the medication(s), including taking the correct medication with the correct route, dose, time, and frequency. Successful/safe medication administration typically had positive consequences (e.g., a desirable therapeutic effect), but sometimes came with unwanted side effects. Unsuccessful/unsafe medication administration could occur if the person with TBI: 1) did not take their medication(s), 2) had problems administering the medication(s), and 3) took the incorrect medication(s). If the person did not take their medication(s), it was typically because they forgot to take it, intentionally chose not to take it, or forgot to refill their prescription and ran out of their medications. Problems administering medication stemmed from difficulty swallowing pills. One participant stated, “I just hate taking it, because as soon as it goes in my mouth, it’s stuck right here [points to throat], and I can’t do nothing about it” (Person with TBI #107, below mean age, above 18 months TSI). In addition, if the person with TBI took the incorrect medication(s), it was often because they took the wrong dose of the correct medication, took the correct medication at the wrong time, or took the wrong medication altogether. Many persons with TBI had substantial problems remembering to take their medications, emphasized in a family caregiver's statement, “Medication management is a solid problem. He misses far too many medications, multiple times every week, sometimes once or twice a day, or even more” (Family caregiver #111, below mean age, parent). Unsuccessful/unsafe administration had the consequences of a desirable therapeutic effect (intended) or side effects (unintended).

Navigating mental health difficulties

This theme focused on concerns related to the person with TBI’s emotions or behaviour. Most persons with TBI and family caregivers described concerns about the person’s mental health; however, some persons with TBI had more severe problems with mental health than others. A condition that seemed to influence the presence of mental health problems for the person with TBI was the person's pre-injury mental health (i.e., those with pre-injury mental health difficulties may also have had post-injury mental health difficulties). Mental health difficulties tended to fluctuate after discharge for persons with TBI; these difficulties could get better for some or worse for others over time.

Persons with TBI and their family caregivers described multiple triggers for mental health issues including social difficulties and physiological problems they perceived to trigger mental health issues; they also described use of strategies to cope with mental health difficulties. Social difficulty triggers described by persons with TBI and family caregivers included decreased social engagement, limited social support, lack of independence, trust issues, negative feedback from family members and friends, and problems with returning to parenting. When reflecting on problems returning to parenting, one person with TBI stated, “I always feel stressed. Just being a parent but not about being allowed to be a parent is hard” (Person with TBI #102, above mean age, above 18 months TSI). While discussing how decreased social engagement affected her husband's mental health, a family caregiver stated, “After the hospital, he was just at home. Which was really hard for him because he was just used to going to work and giving it his all at work and then he had to stay home” (Family caregiver #109, below mean age, spouse). The person with TBI affirmed the family caregiver’s statement by replying, “Yes, it was an identity crisis. I didn't have anywhere to go. I didn't have people calling me, like, 'Where are you? Why aren't you here?' It wasn't the same life I had. I started to feel depressed” (Person with TBI #113, below mean age, above 18 months TSI).

Persons with TBI and family caregivers also described physiological changes they perceived could trigger mental health problems, such as overstimulation and problems sleeping. Sometimes, persons with TBI and family caregivers attributed physiological triggers to be the cause of specific mental health problems such as obsessive-compulsive disorder, manic episodes, stress, anxiety, depression, suicidality, and anger/frustration. However, some persons with TBI were not sure what the cause of their mental health issues was. One person with TBI stated, “There were several boiling points of stress and anxiety that I didn’t understand. I didn’t understand what I was dealing with. Mentally is where I was affected most with my TBI, is what I’ve come to discover but I don’t know where it came from” (Person with TBI #113, below mean age, above 18 months TSI). In contrast, some family caregivers were unsure if the behaviours they observed were due to a true mental health problem or if it was a common occurrence in the TBI recovery process. A family caregiver stated, “I think, when you're that stressed, that can also cause depression and some depression is sleeping a lot…So trying to gauge what is the sleeping that he's doing? Is it really due to the brain still healing or is it due to depression?” (Family caregiver #102, above mean age, parent).

To deal with mental health problems, persons with TBI used a variety of coping strategies such as medications, physical activity or meditation, distractions, and talking to others. Medications that were used to treat mental health problems were typically prescribed by a healthcare provider, such as a depression or anxiety medication. When using physical activity or meditation to cope, persons with TBI engaged in physical activity or led themselves through breathing exercises. When discussing use of physical activity as a coping mechanism, a person with TBI shared,
“Walking, running, all physical [activity] helped my stress management and anxiety” (Person with TBI #113, below mean age, above 18 months TSI). Some persons with TBI used hobbies as a distraction, while others engaged in napping, playing with pets, listening to music, cooking, watching TV, browsing the web, reading or listening to audiobooks, fishing, being outdoors, and self-reflection to cope with mental health issues. When talking with others as a coping strategy, persons with TBI talked with licensed mental health counsellors, friends, or family members.

Wellness concerns

Working to stay physically active

The theme “working to staying physically active” focused on concerns of persons with TBI and their family caregivers on engaging in intentional exercise. Persons with TBI engaged in a broad duration and intensity of physical activity from limited to no physical activity to heavy physical activity on a regular basis. Physical activity often occurred at the gym, inside or outside the home, or in the surrounding community. Multiple conditions influenced engagement in physical activity including family caregiver encouragement, pre-injury physical activity level, prescribed physical activity level at inpatient rehabilitation discharge, and the person’s level of motivation to be physically active.

Persons with TBI who had limited engagement in physical activity cited multiple reasons for not engaging in physical activity including psychological factors, environmental factors, physical limitations, pain, and lack of financial resources. Psychological factors included lack of interest and insecurities about body appearance or performance. Environmental factors included no desire to be outside and concerns about having to deal with extreme weather. Physical limitations included headaches or physical pain when exercising. When describing the pain that occurs with physical activity, a person with TBI stated, “If I just jog right there, sometimes it will make my head hurt. So, then that’s why I just walk” (Person with TBI #105, above mean age, below 18 months TSI). Another person with TBI stated, “I like exercise. But it’s just painful” (Person with TBI #109, below mean age, below 18 months TSI). Occasionally, persons with TBI described lack of financial resources as the reason for decreased physical activity, such as not having the money to pay for the cost of a gym membership.

Persons with TBI who had high engagement in physical activity regularly engaged in: cardio/aerobic exercises, weight lifting, swimming, adaptive sports, walking, yoga/stretching, and exercises guided by a personal trainer. These persons described positive benefits of physical activity, including the perception of having a routine schedule, a personal drive to maintain wellness, and use of exercise as a coping strategy. The perception of having a routine schedule allowed persons with TBI to have something to look forward to and often prevented feelings of boredom. Individuals who perceived physical activity gave them a personal drive to maintain wellness made consistent improvements and progress towards returning to their pre-injury level of physical activity and wellness. When perceiving exercise as a coping strategy, persons with TBI felt they could expend energy, escape temporarily from stressors, have an opportunity to enjoy outdoor stimulation, and enjoy personal interactions with others. A person with TBI who exercised regularly as a coping strategy stated, “Three times a week I go to a normal gym. It’s the same gym that I did a lot of my physical therapy through, so my therapists are still there, that type of thing. I see them so I’ve got a social network” (Person with TBI #103, above mean age, above 18 months TSI).

Dealing with sleep and sleeplessness

This theme focused on concerns of persons with TBI related to getting a good night’s rest at home, as well as persons’ and family caregivers’ perspectives on changes the person made to try to improve their sleep. Although problems with sleep occurred throughout the post-injury timeline, many persons with TBI and family caregivers indicated the person had worse sleep initially after discharge home with some improvements over time. One family caregiver stated, “When we first came home, he couldn’t get any sleep. It was ridiculous. So that affected basically everything because he was so exhausted” (Family caregiver #102, above mean age, parent). The majority of participants had a genuine interest in understanding and improving their sleep quality.

Persons with TBI who had problems sleeping described issues with sleep quality (e.g., difficulty falling asleep or staying asleep or a sporadic sleep schedule) or problems with other health issues that affected their sleep (i.e., anxiety and pain). When describing problems with sleep, a person with TBI stated, “It’s hard for me to fall asleep, and then it’s hard for me to stay asleep” (Person with TBI #104, above mean age, below 18 months TSI). These problems often led persons with TBI to feel daytime fatigue. Sometimes, those who felt fatigued made lifestyle and medication changes to try to improve their sleep. Lifestyle changes included increasing physical activity, improving sleep habits (e.g., decreasing amount of naps during the day), and altering diet (e.g., decreasing amount of caffeine, changing nutrition, and alcohol consumption). Medication changes included using a variety of sleep and non-sleep medications or supplements. A person with TBI who tried a variety of sleep aids, stated, “I’ve used Melatonin, Valerian root. You name it, I’ve tried it. It hasn’t worked” (Person with TBI #110, below mean age, above 18 months TSI). Other medication changes included changing the dose, timing, and frequency of non-sleep medications; or changing to a different non-sleep medication altogether. When describing changes to non-sleep medications to improve sleep, a person with TBI stated,

My sleep is usually affected more so by the medications that I take, and that really has the biggest effect on if I’m going to sleep well or not. Like right now, I’ve started a medication recently that causes restless legs. I remember the first night that I took the medication, I was tossing and turning all night and couldn’t get to sleep. But once I get the dosages correct, then I didn’t have the same problems. (Person with TBI #101, below mean age, below 18 months TSI)

Adjusting to changing social relationships

This theme focused on the person with TBI’s attempt, ability, and desire to interact with other people, including family members, friends, and acquaintances. Persons with TBI engaged in in-person social interactions with others in the home or community or while using technology such as email, social media, or cell phones. Attempts to socialise with others typically increased over time after discharge home. The person with TBI’s desire to socialise and actual level of social interactions was often influenced by their mental health and pre- and post-injury perceptions of the trustworthiness of others.

Some persons with TBI and their family caregivers described problems with socialising. Those who had problems socialising often wanted to engage in social activity but had difficulty doing so or preferred to not socialise to prevent social problems from occurring. Instead, these persons chose to only socialise with family members. One person with TBI stated, “I didn’t engage in any really social stuff because social stuff was stressful. I did a lot of
socializing with my family, though. It felt safer to talk with them” (Person with TBI #110, below mean age, above 18 months TSI).

Those with no desire to socialise had limited social interactions pre-injury or had feelings of not belonging post-injury. When discussing why social interactions were limited, one person with TBI stated, “I found at the beginning, I felt I was being judged” (Person with TBI #112, above mean age, below 18 months TSI). Another person with TBI stated, “I’m very antisocial. It’s a choice” (Person with TBI #104, above mean age, below 18 months TSI). In contrast, those who had a desire to socialise but had difficulty doing so described challenges with socialising due to: 1) access (e.g., proximity to friends and problems securing transportation); 2) cognitive impairments that decreased cognitive processing and speed of response or caused problems with word finding; 3) anxiety while socialising, even with familiar people, or in unfamiliar social situations; 4) problems making good friends or the “right type” of friends; 5) busy schedules; and 6) limited privacy. Those who had limited social interactions expressed feelings of social embarrassment, isolation, or boredom.

Safety concerns

Addressing mobility challenges

The theme “addressing mobility challenges” focused on the person with TBI’s ability to engage in physical movement in any environment, including maintaining balance and transferring from one location to another. Reports of mobility challenges were associated with low levels of physical activity and level of involvement in physical or occupational therapy. Presence of mobility challenges varied; some participants had no mobility challenges after discharge, others had persistent mobility challenges, and a few individuals had improvements in mobility as time went on. Individual and environmental factors caused mobility problems. Individual factors included difficulties with depth perception and musculoskeletal issues (e.g., problems with vision, balance and walking, back pain, bearing weight, muscle tone/weakness, and spasticity). When referring to her daughter’s problems with balance, one family caregiver stated, "I’m concerned about her stumbling and walking into stuff" (Family caregiver #108, above mean age, other).

In contrast, environmental factors described by persons with TBI and family caregivers included difficulty with transfers in and around the home and community due to lack of a safety bar to assist with a transfer and untrained people improperly assisting with a transfer. When talking about nerves related to transferring into or out of the tub, one person with TBI stated, "I also still had a little bit of concern because when I have a bath and I have a Jacuzzi tub and getting in and out of it, I know that I was very nervous about that at the beginning, but I still had some residual nervousness around getting in. (Person with TBI #108, below mean age, below 18 months TSI)

In addition, problems navigating the home and community arose when lighting was dim or when the person was moving from one type of terrain to another (e.g., walking from carpet to hardwood floor, gravel to sand, and sidewalk to street).

To prevent unintentional injury and harm caused by mobility issues, persons with TBI and their family caregivers used various mobility supports, including making their home accessible, using assistive equipment, and providing caregiver assistance. To make the home accessible for the person with TBI, the family caregiver often moved the person's bed to the first floor of a multi-level home, purchased and used a portable toilet, or installed stair railings or a stair lift. Specific examples of assistive equipment used by persons with TBI included a walker, wheelchair, cane, gait belt, or prosthetic leg. One person with TBI talked about how their home was made accessible for them, stating, "Well, I was living in the living room because we have a two-story house. I couldn’t get up the stairs, so I was seriously living in the living room (laugh)—we put a bed in there. We had some sort of portable toilet. It was wild. (Person with TBI #111, above mean age, below 18 months TSI)

When necessary, family caregivers or paid caregivers assisted the person with TBI by monitoring them while they were bathing, walking on flat surfaces and stairs, or transferring from one location to another.

Compensating for complications with cognitive functioning

The theme “compensating for complications with cognitive functioning” focused on cognitive problems for persons with TBI that were typically caused by the initial injury, including issues with memory, organisation, attention, awareness, impulsivity, judgement, and executive functioning (e.g., initiation and planning). Issues with cognitive functioning varied from person to person and over time; these issues often manifested as difficulties with instrumental activities of daily living such as medication management, preparing food, shopping, and child rearing. Most persons with TBI and family caregivers had concerns about cognitive functioning; persons with TBI who had no concerns about cognitive functioning usually lacked insight into their cognitive impairments based on family reports.

Persons with TBI attributed problems with cognitive functioning to consequences of the initial injury. While some persons’ cognitive functioning got better over time, others had severe, persistent issues and a few maintained the same level of cognitive functioning. One family caregiver stated, "We still struggle with the planning, and attention, memory, those things. So, it was just really heightened when he first was home” (Family caregiver #112, above age, spouse). Primary safety consequences of cognitive problems included poor execution of tasks (e.g., errors with medication management) and unintentional injury or harm. Although family caregivers described problems with the person’s attention, some persons with TBI described their attention could be influenced by the perceived value of the object that required their attention. For instance, if the person with TBI would rather be on social media than listen intently to his/her parent who was speaking, the family caregiver perceived the person had problems with attention, as this family caregiver stated, "He’ll listen for a while, but next thing you know he’s on that phone. So, it’s like he can only pay attention so long, then he’ll check out for a little while. Then he’ll come back. I don’t know if he does this with other people or just because I’m Mom. I’m not sure, but I really feel like it’s more of a choice” (Family caregiver #102, above mean age, parent).

Most persons with TBI described using a combination of strategies to compensate for problems with cognitive functioning, such as memory aids, use of a structured environment, time management/planning, organisational aids, or intermittent supervision. When using memory aids, persons with TBI and family caregivers described using mental repetition and photos or screenshots of information stored in their cell phone. A comprehensive calendar also helped some persons with TBI remember important information. Others used tools to research forgotten information including browsing on the web or searching Facebook to find a person’s name and picture. One person with TBI shared, "I will say that Facebook really helped me at the beginning. I went through all my friends and did the facial recognition thing, so that was really cool.” A family caregiver who
perceived she could help to improve the person with TBI’s memory, stated, "I’m still working on getting his memory back. And, like I said, I’ve got to get better. Been doing all right. I keep notes and everything with me, a lot of notes, and he’s working on note-wise" (Family caregiver #112, above mean age, spouse). Cognitive games/exercises were also used to improve cognitive function and included games designed to monitor cognitive progress or increase mental stimulation (e.g., Lumosity) or games used for leisure (e.g., video games).

When using a structured environment to compensate for problems with executive functioning, family caregivers would set the person’s daily schedule and ensure they had something to do most of the time so they wouldn’t get bored. When using time management/planning, the person with TBI set goals, created to-do lists, and used planners or calendars to create their own schedule. These time management/planning tasks were often done independently or with family caregiver assistance. When using organisational aids, family caregivers described using a color-coding system to record the person’s schedule on a calendar or using whiteboards to record pertinent information in a location accessible to both the person with TBI and family caregiver. Finally, intermittent supervision was used for persons with TBI who had what was perceived by family caregivers to be mild issues with impulsivity and judgement, such as accompanying the person with TBI when walking near moving vehicles or crossing the street as a precautionary measure to prevent unintentional injury and harm.

**Discussion**

The purpose of this study was to describe post-discharge health, wellness, and safety concerns from the perspectives of persons with moderate-to-severe TBI discharged home from inpatient rehabilitation who were ≥75% independent in activities of daily living and their family caregivers. Findings showed seven themes related to health, wellness, and safety, including: 1) attempting to manage medications, 2) navigating mental health difficulties, 3) working to stay physically active, 4) dealing with sleep and sleeplessness, 5) adjusting to changing social relationships, 6) addressing mobility challenges, and 7) compensating for complications with cognitive functioning. Participants provided rich descriptions of problems they encountered after discharge home from inpatient rehabilitation in each of these areas, as well as strategies they used to deal with these issues.

Our findings contribute to the literature by providing contemporary qualitative perspectives of persons with TBI and family caregivers on health, wellness, and safety concerns, particularly because these three topics are important to recovery after TBI. Our findings depart from prior research that explored perspectives of persons with TBI and their family caregivers separately by including the perspectives of both persons with TBI and family caregivers, which allows comparison of perspective and experience. Our research also adds to the TBI literature on medication management, mobility, and cognition. More specifically, our findings on medication management provide nuanced evidence about the difficulties persons with TBI and their family caregivers experience in managing medications, including consequences of unsafe/unsuccesful medication administration. Although research in other patient populations shows patients and families struggle with medication management [49,50], limited research on the experience of medication management for persons with TBI and their family caregivers has been conducted. Our findings provide rich data on medication management challenges specifically for persons with TBI and their families, which are often coupled with complications with cognitive functioning, as well as additional insight into where medication management breakdowns may be occurring for them. In addition, the majority of research on safety in the TBI literature is quantitative and has described problems with safety for persons with TBI, such as issues with unintentional injury and harm [35], as well as caregivers’ perceptions of high safety concerns related to travel and finances [19]. Our findings add to the literature on safety by providing patient and family perspectives on issues with cognition and mobility that can affect the persons’ safety. Similarly, although there is both historic and recent research that has shown persons with TBI deal with complications of cognitive impairments [20,51,52], our findings expand on prior research by providing detailed descriptions of cognitive difficulties persons with TBI face and the compensatory strategies they use. Likewise, although mental health issues are well documented in the TBI literature [29,37,53], our findings add to the literature with perspectives of persons with TBI regarding post-discharge mental health issues, triggers, and coping strategies used. Finally, sleep is an important aspect of recovery for persons with TBI evidenced by emerging research on sleep disturbances and disorders in patients with TBI [54–57]. Our findings add to the limited qualitative research on sleep after TBI by describing sleep difficulties of persons with TBI and the strategies they have used to try to improve their sleep. Our participants had a genuine interest in understanding and improving their sleep quality, which calls for resources to be developed that can aid individuals in doing so.

Like other studies [16,17,25,26,58,59], our findings emphasise the plethora of post-discharge challenges persons with TBI and their family caregivers face. Our findings contribute to the literature by describing the challenges of being mostly independent in activities of daily living but still needing support in other facets of life. Multiple problems with self- and family-management of health were shared by our participants, such as problems with managing medications or dealing with mental health triggers [4,60]. Similar to other research [61–63], our findings show, in order for persons with TBI to feel well again after injury, they have a desire to engage in important activities, such as physical activity and socialising with friends. As many of these challenges are common after TBI, especially for individuals who are ≥75% independent in activities of daily living, it is important for persons with TBI and family caregivers to have appropriate resources, supports, and tools that promote health, wellness, and safety to use in managing the person’s care, daily activities, or general recovery.

**Practice and research implications**

Our findings have implications for educating and increasing healthcare providers’ awareness about the numerous post-discharge challenges this population experiences. We also recommend use of our findings by providers to educate and prepare persons with TBI and their family caregivers to set realistic expectations for life after discharge home from inpatient rehabilitation. For example, pre- and post-discharge education and training for patients and families related to medication management, compensation for cognitive challenges, and improving safety in the home and community are warranted based on our findings. We also recommend providers use our findings to help persons with TBI and family caregivers set goals and achieve goals as they recover after TBI [64]. For example, patients with limited levels of physical activity and/or mobility may wish to work with healthcare...
providers to set goals to increase exercise to improve their wellness. In addition, there are many currently available resources, supports, and tools, such as assistive technologies, provider support, and safety assessment measures that can help persons with TBI set goals in numerous areas of concern [52,65–68]; we recommend providers, patients, and families use these tools to promote health, wellness, and safety. Finally, researchers and clinicians may also use these findings to provide direction for implementation or development and testing of resources, supports, and tools to promote health, wellness, and safety of persons with TBI and their family caregivers after discharge home from inpatient rehabilitation.

Limitations

First, interviews with related persons with TBI and family caregivers occurred simultaneously in the same room. Interviews with both parties present may have limited their desire to speak freely about their concerns. However, multiple post-discharge concerns were shared, which provide a foundation for the challenges persons with TBI and their family caregivers face post-discharge related to health, wellness, and safety. Second, our sample included persons with TBI and family caregivers who completed a post-discharge intervention focused on improving safety in the home and community. One can only assume that persons with TBI and family caregivers that do not undergo this intervention may have the same, if not more, post-discharge concerns and less provider support in addressing these concerns. Third, six patients with TBI in our sample lived in a household within an income of ≥$75 000 (USD) per year, and their financial resources may have influenced their post-discharge concerns. However, regardless of access to financial resources, patients and families reported numerous concerns. Finally, although our findings may not be generalisable to all patients with TBI and family caregivers, our findings provide informational representation of patients with TBI and family caregivers who have concerns about health, wellness, and safety issues after discharge home from inpatient rehabilitation.

Future research

Future researchers may wish to conduct longitudinal research on how health, wellness, and safety concerns for persons with TBI and their family caregivers change over time to provide clinicians and researchers with guidance on a timeline of their needs. Future research is also needed to explore resources, supports, and tools desired by persons with TBI with varying levels of dependency and their family caregivers to address their concerns related to health, wellness, and safety. Finally, future research is needed to determine how financial resources influence patient and family concerns post-discharge.

Conclusion

Our findings describe the numerous challenges persons with TBI and their family caregivers face related to health, wellness, and safety after discharge home. These results can be useful in increasing awareness for providers, providing direction for patient/family education from providers, and providing direction for researchers across the world to implement or develop and test appropriate resources, supports, and tools that promote health, wellness, and safety to be used in managing the person’s care, daily activities, or general recovery.

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