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## Women Family Members' Experiences of Involvement in Adult Inpatient Traumatic Brain Injury Rehabilitation

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# Women Family Members' Experiences of Involvement in Adult Inpatient Traumatic Brain Injury Rehabilitation

## **Abstract**

*Background:* Traumatic Brain Injury (TBI) rehabilitation is an intensive process aimed at reducing disability. The experience of care is lived not only by the patient with TBI, but by the family as well.

*Methods:* Five women family members of patients with TBI were interviewed. Based on a descriptive qualitative approach informed by phenomenology, thematic analysis was completed to draw a general sense of family members' description of their involvement.

*Results:* Two themes were identified: Wearing different hats and a balancing act, that highlight the many roles undertaken by the women family members as well as the difficulties they encountered.

*Conclusion:* Occupational therapists may assist the health care team in an attempt to identify strategies to lessen the burden on the family.

## **Comments**

Disclosure Statement: The authors report no conflict of interest.

## **Keywords**

head injuries, inpatient, involvement, family, women family members, rehabilitation, traumatic brain injury

## **Cover Page Footnote**

This research project was completed with the assistance and support of the staff at the rehabilitation facility. We would like to thank the participants for sharing their experiences with us.

Traumatic brain injury (TBI) is one of the leading causes of death and lifelong disability and is recognized as a global “silent epidemic” (Arango-Lasprilla, Quijano, et al., 2010; Chan, Parmenter, & Stancliffe, 2009; Man, 2002, p. 1025). TBI is an important public health issue that is associated with extended medical care and lost productivity, along with other serious and persistent consequences (Foster et al., 2012). TBIs warrant worldwide attention, as they are associated with considerable costs that are increasing as more individuals survive severe brain injuries (Foster et al., 2012). The estimated prevalence rate of TBI in Canada in 2012 was 100 to 300 per 100,000 individuals, with approximately 17,000 hospitalizations annually (Brain Injury Advocates of Canada, 2012).

Road traffic injuries and falls are the primary causes of TBI, followed by violence and collisions with moving or stationary objects (Brain Injury Advocates of Canada, 2012). The cause and the type of injury are often associated with specific impairments. Structural imaging findings, posttraumatic amnesia, loss of consciousness, and the *Glasgow Coma Scale* (GCS) are used to classify the severity of the injury as either mild, moderate, or severe (Agency for Healthcare Research and Quality, 2012). The injury may cause different problems, depending on which parts of the brain were most damaged (Arango-Lasprilla, Ketchum, et al., 2010). A wide range of studies have explored the spectrum of functional short- or long-term changes affecting the physical, affective, social, intellectual, and spiritual dimension of the patient with TBI (Degeneffe, 2001). Physical problems may include motoric deficits, pressure ulcers, bladder and bowel incontinence, as well as chronic pain (Arango-Lasprilla, Ketchum, et al., 2010). Psychosocial sequelae may include decreased life satisfaction, lower perceived social support, and reduced marital stability (Arango-Lasprilla, Ketchum, et al., 2010). Possible behavioral and emotional changes include impaired executive functions, deficits in attention, mood disorders, anxiety disorders, and suicidality and substance abuse, among other changes (Arango-Lasprilla, Ketchum, et al., 2010). In addition, the patient often faces decreased employment opportunities and increased costs associated with lasting disabilities. Such changes affect the extent to which a person can manage daily activities of self-care, productivity, and leisure in an independent manner (Holmqvist, Kamwendo, & Ivarsson, 2012).

Patients with TBI are admitted to inpatient rehabilitation for an average of 12 to 109 days, depending on demographic and injury characteristics (Arango-Lasprilla, Ketchum, et al., 2010). Rehabilitation is a long-term, problem-solving process that involves the coordination of a team of health care professionals and is aimed at reducing disability and handicap resulting from a disease or injury (Chua, Ng, Yap, & Bok, 2007). Therapies may include occupational therapy, physiotherapy, speech-language pathology, and neuropsychology. Occupational therapists are frequently involved in providing strategies to improve the client’s daily function and occupational performance in activities of daily living (ADLs), instrumental activities of daily living (IADLs), work, school, leisure, and social participation. Given the intensive demands of the rehabilitation process, the experience of care is lived not only by the patient, but also by the family (Chan et al., 2009).

There is increasing acknowledgement of the powerful role of the family in rehabilitation (Arango-Lasprilla, Quijano, et al., 2010; Man, 2002). The literature suggests that the family, not the institution, provides most of the care to TBI survivors (Degeneffe, 2001). As such, in addition to the patient, the family can be considered as one of the most important members of the rehabilitation team (Foster et al., 2012; Sander, 2014). Better outcomes are associated with a strong therapeutic alliance between the family and the health care professionals (Foster et al., 2012). It is believed that patients can

experience better recovery when the family is fully involved during rehabilitation (Foster et al., 2012; Man, 2002).

To date, most of the research on families and TBI rehabilitation has focused on how the brain injury affects families. Family members often experience significant distress and compromised quality of life in the wake of the neurobehavioral changes imposed by TBI (Rivera, Elliott, Berry, & Grant, 2008). Family members typically face high levels of stress, burden, social isolation, role changes, and other psychosocial health problems that generally do not lessen with time (Barclay, 2013; Degeneffe, 2001). The challenges and distress experienced by family members can impact the rehabilitation process as well as the recovery of the person with TBI (Sander, 2014). Families often report difficulties in absorbing the realities of TBI and repeatedly perceive a lack of support and information from the medical and rehabilitation team (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005). In addition, families are faced with increased responsibilities, financial strain, reduced social events, and the absence of sexual intimacy. The stressors often cause the family members to experience extreme fatigue, irritability, anger, depression, anxiety, isolation, and hostility. They are required to manage intense stress and emotions, to cope with loss and change, to problem-solve effectively, to focus on accomplishments, and to set reasonable goals, all while recognizing the importance of taking care of themselves. The lives of the families are often plagued by stigma, which limits their opportunities to maintain or reintegrate into their activities (Rivera et al., 2008).

Despite the consensus that families should be involved in the rehabilitation process to optimize outcomes and that key strategies to facilitate this involvement should be put in place (Foster et al., 2012; Shaw, Chan, & Lam, 1997), few studies have examined the families' experiences of involvement. Keenan and Joseph (2010) examined family involvement in critical and acute care and aimed to identify the changing needs of family members over time. Various family members identified "involvement in care" as a theme, and families explained being physically involved by providing hands-on care for their loved one (Keenan & Joseph, 2010, p. 26). Family members described being involved as a patient advocate and in planning for the future. Some participants described being extremely involved in all aspects of the patient's care and described that their "needs didn't matter" (Keenan & Joseph, 2010, p. 29). Jumisko, Lexell, and Soderberg (2007) explored the overall meaning of living with a family member with TBI. Analysis of interviews with eight family members resulted in one major theme: "Fighting not to lose one's foothold" (p. 358), with six subthemes that related to the unknown nature of the situation and the need to accept the changes imposed by the injury.

Recent research has also targeted the description and interpretation of the overall experience of inpatient brain injury rehabilitation (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Ishikawa, Suzuki, Okumiya, & Shimizu, 2011). Fleming, Sampson, Cornwell, Turner, and Griffin (2012) interviewed 20 patients and 18 family members to better understand how inpatient brain injury rehabilitation is lived by patients and their caregivers. They identified three important themes: (a) the rehabilitation context and physical environment of the inpatient ward, (b) the emphasis on structured activities and meaningful occupations in the rehabilitation unit, and (c) the support and adjustment of families and patients to optimize outcomes. Ishikawa Suzuki, Okumiya, and Shimizu (2011) interviewed 15 family members and identified seven themes that painted a picture of the caregiving experience of family members of patients receiving inpatient rehabilitation in a region in Japan. Some of the themes identified by family members included spending time with the patient with a TBI,

accepting the patient's disabilities, and being devoted to caring for the patient with a TBI, despite their emotional distress.

Despite the acknowledgment that families are involved in certain aspects of rehabilitation, little is known regarding the experience of involvement from the family's perspective. To begin to fill this gap, this study explored how families described their experience of being involved in adult inpatient TBI rehabilitation.

The goal of this study was to add to the understanding of family involvement in inpatient TBI rehabilitation through the examination of family involvement at one Canadian rehabilitation unit. For the purpose of this study, we have combined Foster et al. (2012) and Eggenberger and Nelms' (2007) definitions of "family". More specifically, the definition of family we use honors the premise that the family social system may extend beyond the traditional view and will broadly include all those who influence recovery, including family members, friends, and significant others who may take on a care giving role.

## **Method**

### **Study Design**

To address the above-mentioned objective, we adopted a constructivist perspective and employed a descriptive qualitative approach informed by phenomenology. We chose a descriptive qualitative approach, as we wanted to obtain a comprehensive description of a specific situation as experienced by individuals (Lambert & Lambert, 2012). In addition, we chose phenomenology to inform the approach, as phenomenology seeks to understand how individuals construct meaning as they experience a phenomenon (Creswell, 2013). Adopting this approach allowed for an analysis of themes, hence providing a precise comprehension of how the participants experienced their involvement in adult inpatient TBI rehabilitation. Acknowledging that we experience a phenomenon with and through others and that the meaning we construct has its roots in human interaction, a constructivist perspective allowed for a more accurate understanding of the experience (Creswell & Miller, 2000). The following research question guided this study: How do family members describe their experience of being involved in adult inpatient TBI rehabilitation?

### **Setting**

We conducted the study at a rehabilitation center in Canada. The targeted program for this study was the Acquired Brain Injury (ABI) Service.

### **Participants**

Convenience sampling was employed and subjects were selected based on their availability during the data collection period (Patton, 1990). We recruited five family members of patients with a TBI admitted to the ABI inpatient service program of the rehabilitation facility. We selected only one member per family to maximize the diversity of experiences described by the participants. The family selected and identified the participant.

### **Data Collection**

The triage nurse approached eligible family members shortly following the patient's admission to the ABI inpatient service program. Families were provided with a short explanation of the goal of the study. If they expressed interest, they were asked to provide their name, telephone number, and verbal consent acknowledging that this information could be passed on to the occupational therapy student conducting the study.

After receiving written informed consent, we conducted two semi-structured interviews with the family members in a quiet and private room at the rehabilitation center to gather the participants' descriptions of their experiences of being involved in adult inpatient TBI rehabilitation. We first interviewed the participants when the patients were approximately at midstay to ensure that meaningful involvement occurred before data collection.

At least 2 weeks later and prior to the participants' family members' discharge, we conducted follow-up interviews with the participants to further explore previous responses and to ensure that any unclear or ambiguous ideas were well understood by the interviewer. We collected data from October to December. We audio recorded the interviews and transcribed them verbatim for analysis.

### Data Analysis

We used *ATLAS.ti7*, a qualitative data analysis software, to help organize the data obtained from the interviews. We first read the transcripts, focusing on the subjective experience as described by the participants. We attempted to draw a general sense of the family members' description of their involvement. We then coded the data for meaning units and organized these meaning units into themes. Finally, redundant themes were regrouped to develop the final themes (Whitting, 2002).

### Data Validation

We used specific strategies to evaluate the credibility of the findings (Creswell & Miller, 2000). First, we used clarification as a strategy that required the researcher to comment on past experiences and biases that may shape the interpretation of the study (Creswell, 2013). In addition, we used member checking to increase the trustworthiness of the data (Carlson, 2010). During the second interview, we specifically asked the participants to confirm certain responses from the initial interview, providing them with an opportunity to assess the adequacy of the data. We also used peer debriefing to support the credibility of the findings (McBrien, 2008).

### Results

The triage nurse approached seven participants who met the inclusion criteria. Of the seven participants, five were interested and consented to participate. The participants were all women in their early 20s to mid-60s and were either a mother or a spouse of a patient admitted to the inpatient ABI ward with a primary diagnosis of TBI. We interviewed each participant twice. The first interview took place at approximately two weeks following admission, and the follow-up interview took place approximately two weeks after that. See Table 1 for participant characteristics and pseudonyms.

**Table 1**

*Participant Characteristics and Pseudonyms*

Pseudonym	Relationship to patient
Sara	Mother
Melanie	Spouse
Kathleen	Mother
Sandra	Spouse
Cheryl	Spouse

### The Overall Experience

The overall experience of having a family member suffer a TBI was described as an overwhelming, life-changing experience. The participants described feeling shocked and having to deal

with ongoing uncertainties in their attempt to support the patient with a TBI through the health care process, including the acute care and rehabilitation phases. Sara, the mother of a patient with a TBI, provided context early in the initial interview and stated, “It was really a shock to me.” Cheryl also described that, “It just all happened so fast,” and that she felt she was “still in shock.” Sandra described specific examples and explained that even though she noticed her husband’s improvements, his future progress remained unknown: “But, umm, you know, he might not be 100% as to what he was before the accident . . . and I think we have to accept that.” The participants also described having to “mentally prepare for the journey.” Melanie and Kathleen both stated that they know their experience of being involved will continue beyond their involvement in inpatient TBI rehabilitation. In addition, all of the participants identified and explained the necessity of learning to accept the situation and the importance of learning to be patient throughout the rehabilitation journey. Finally, even though the participants described the idea differently, the family members agreed that they would “not wish this experience on others.”

### **Qualitative Themes**

Two main themes emerged from the analysis of the interviews: (a) wearing different hats and (b) a balancing act. The primary themes relate to the family member’s experience of being involved in adult inpatient TBI rehabilitation and are supported by specific statements.

**Wearing different hats.** The participants described their involvement in inpatient rehabilitation in different ways. Family members explained undertaking and physically participating in certain tasks at the rehabilitation center, providing ongoing emotional support for the patient with a TBI, and being the main source of information for other professionals in the patient’s circle of care. The family members’ involvement was described as one that varies from one day to the next but also as one that remains constant: “There were so many different roles that I had to play and so many things that I had to do.”

**Constant presence.** The participants described different ways in which they had been involved in their family members’ rehabilitation, but the five family members elaborated on their role as a constant presence. The family members specifically described being involved in ways that required them to undertake various duties and to learn numerous responsibilities or skills that are often associated with the roles of health professionals. The participants described having to “wear different hats” and having to provide continuing care and services for the patient in a variety of ways. Throughout their journey at the rehabilitation center, the participants referred to themselves as the constant presence for the patient. Four of the five participants described their involvement as something that was continuously changing but also as something that revolved around the fact that the patient was their top priority. When describing her constant involvement, one woman said, “I’m always here and I always will be.” Another participant described her feelings related to her constant involvement as: “Like I want him to know that I’m always gonna be there no matter what.” In addition, the participants identified being physically and emotionally present for the patient, but also acting as an important source of information and link between the patient and the other individuals from the patient’s social circle and rehabilitation team.

**Providing emotional and physical support.** In their role as a constant presence, the participants described being involved in the care of the patient with a TBI by wearing many hats and by undertaking physical responsibilities that often resembled the roles of health care professionals. For example, every participant described her involvement when assisting the patient with ADLs, IADLs,

transfers, and repositioning. Melanie explained being involved in her husband's care: "I had been doing, umm . . . total care with him; all his morning care" and "he is so used to me doing all the care for him, he's become kind of shy. He wants me to do things as opposed to the nurses." Kathleen stated, "I still do change his sheets on his bed" and "I brushed his teeth, I looked after all his hygiene." In addition, two participants described being involved by bringing the patient home-cooked meals, doing the patient's laundry, completing the patient's paper work, escorting the patient to appointments, and assisting in the patient's medication administration at the rehabilitation center.

The family members participating in the study also described their experience of being physically involved in therapies, including speech-language pathology, occupational therapy, and physiotherapy: "They have been teaching me to do his feeds independently." On her side, Cheryl said, "With physio, if I can watch her do what she does with him, then I can, you know . . . pay attention and then when he gets out of here I'll be more helpful." She also reported helping out in therapies: "I get his weights and stuff like that and they want to make sure that I can do the transfers well 'cause we go from the car to the house." In short, every participant described being involved in a different way, but they all reported physically attending therapies and assisting, observing, learning, and receiving education from the staff.

Providing care, empathy, love, trust, encouragement, and reassurance are a few of the many terms the participants used when describing their involvement in inpatient TBI rehabilitation. Another of the many hats worn by the participants included providing constant emotional support and remaining mindful of their family member throughout their journey. Mothers and wives described being "on-call 24 hours per day, seven days per week." They identified always being available to provide the patient with emotional support, whether it be in person or by telephone. Sara explained, "I told him, 'If you need me, you can call me. I am always available.'" Kathleen elaborated on her experience of having to provide constant emotional assistance and support to her son, even when she was not on the ward: "Yesterday, he called me five times between 8:30 and 11:30 and four times between 1:30 and 3:30 . . . he needed my help."

Family members described being involved in encouraging the patient, in facilitating his independence, and in developing techniques and learning strategies to assist with behavior management. Cheryl described her experience as a constant emotional presence and referred to it as something that required a lot of energy. She then identified how she was involved in that role: "I'm constantly re-boosting his ego, constantly telling him, you know, 'I'm proud of you. You're doing really well. You're staying focused. You're doing good.' And I keep telling him, 'I'll always be there. But you have to be able to do it on your own, too'."

**Being the patient's voice.** The participants described keeping the patient's pertinent rehabilitation information together with the goal of relating it to extended family members, friends, or other professionals. The participants used different descriptors, but every participant mentioned constantly communicating with staff and being "the patient's voice." The family members established communication with staff early in the rehabilitation journey, as the family members recognized that the patient's progress may impact their involvement following discharge. Melanie stated, "I communicate a lot with them because, for example, his progress in physio will affect my transfers and my involvement when I bring him home." Family members also explained communicating with the staff at the rehabilitation center to better understand what may be done to better prepare for weekend passes and for the transition into the community. In that sense, five of the participants described receiving education



from the staff, and three of the participants described preparing their home to accommodate the patient's needs.

Women family members also highlighted their experience of being involved not only as a constant intermediate, or messenger, between the patient and the staff at the rehabilitation center, but also between the patient and the patient's friends, extended family members, or other contacts in the community. From early in the rehabilitation, family members were asked to observe and to comment on the patient's progress: "They ask me [quoting staff]: 'How do you find him? Is he doing much better?'" They were also faced with responsibilities that went beyond their involvement with the patient at the rehabilitation center. Sandra described her role as similar to that of a secretary when attempting to relay the patient's progress to the rest of the family: "The phone calls at night whenever [I] got home, umm, sort of letting everyone know how he was doing and stuff... I spent an awful lot of time on the phone after my day should've been over." In addition to explaining how they communicated with family and friends, the participants explained their experience of being involved with insurance companies, lawyers, and other individuals in the community.

As time went on, the family members identified trying to take measures to reduce the amount of duties, tasks, and roles they had to undertake. Family members described that this change in involvement was possible as staff got to know the patient better, as they established an "involvement routine," and as the patient progressed.

**A balancing act.** There were many ways in which family members described striving to find a balance. The participants described having a difficult time finding a balance between their involvement in their family members' rehabilitation and their other responsibilities and occupations. This affected the family members' emotional well-being and led to a feeling of exhaustion and burnout among the participants.

**Finding time to fulfill occupational roles.** When illustrating their experiences of being involved in their family member's TBI rehabilitation, the participants used various descriptors to portray their struggle with finding a balance. Melanie said, "I think the most difficult part right now is finding a balance," and Cheryl explained that, "It's been challenging balancing my job, my kids, and being here for him . . . . I have no me time." Two of the participants explained taking their work with them and working at the rehabilitation center while visiting the patient. The other three participants indicated having to "stop everything [else]" to be fully involved and to provide for their family members.

In describing their struggle to find balance, the five participants expressed their desire to "take a step back" and to "learn to pull away" from their involvement in their family member's inpatient rehabilitation. Kathleen explained trying to be involved in every aspect of her life: "I'm still juggling way too many balls," and stated that this often led to her "doing everything half ass." Another participant described "really trying to pull away a bit" and later acknowledged the importance of and the difficulties associated with taking a step back from her involvement: "He'll work it out and I've got to learn to pull away from that, too."

**Fatigue and exhaustion.** While attempting to be involved in their family member's rehabilitation, as well as in their other life commitments, the participants often associated their experience with fatigue and exhaustion. Melanie stated, "I'm involved about as much as I can be," and another participant stated, "It's just mental exhaustion." All five of the participants illustrated their experience of being involved at the rehabilitation center as tiring and exhausting as a result of everything that they had to do. Sandra described the short-term impact of her attempt at remaining involved in her

husband's rehabilitation while struggling to find a balance: "Whenever I go home at night anymore, I usually make a cup of coffee and feed the pets and fall asleep on the couch." A few of the participants also discussed the long-term impact of their involvement on their own health, as well as on their physical and emotional well-being: "It's just I think I'm getting to the point where I'm getting burnt out . . . it's been a lot." Another woman asserted, "It's starting to catch up."

### Discussion

This qualitative study has helped illuminate how family members describe their involvement in adult inpatient TBI rehabilitation. The interviews with women family members regarding their experiences of being involved in adult inpatient TBI rehabilitation and an analysis of their experiences revealed two main themes to describe the essence of the experience: "Wearing many hats" and "a balancing act." The overall experience of being involved in adult inpatient TBI rehabilitation was described as being constant, ongoing, and requiring many roles. The participants were engaged in the care of the patient with a TBI while they were on the unit but also when they were off the unit. This made it difficult to find a balance between being involved in the care of the patient with a TBI and remaining engaged in other responsibilities. Family members described this constant involvement as a factor that ultimately led to a state of physical, emotional, and mental exhaustion.

Overall, the findings of the study demonstrate that the experiences of involvement in inpatient TBI rehabilitation may be described differently by everyone and that every family member may be impacted by TBI in different ways. Therefore, it may be inadequate to generalize how all families described their experiences of being involved in inpatient TBI rehabilitation. This is consistent with the findings of Cavallo, Kay, and Ezrachi (1992), who identified that while all brain injuries impact the entire family, not all families react to or are affected by it in the same way. Similarly, every participant in our study described the overall experience of being involved as one that was overwhelming, life-changing, shocking, and full of uncertainties. Specifically, the participants described having to deal with ongoing uncertainties throughout the rehabilitation journey. Uncertainty has been identified by family members living with a patient with a TBI in the community (Lefebvre et al., 2005) and research has also confirmed that close relatives live with a great deal of uncertainty for a long time following the injury (Bond, Draeger, Mandleco, & Donnelly, 2003).

In 2007, Jumisko and colleagues explored the overall experience of living with a family member with a TBI and identified "getting into the unknown" (p. 358) as an important subtheme that emerged from a phenomenological hermeneutic interpretation of the data. Although this study examined the meaning of the family members' experiences on a larger scale, it found that close relatives were in a state of shock and disappointment when they realized that their loved-ones may never be able to take part in achieving the dreams and life-plans established prior to the injury. Ishikawa et al.'s (2011) study aimed to present a general picture of the experience of caregiving, and identified "accepting the disability and constructing a care system" (p. 76) as an important element of family experience. Even though the objective of the above-mentioned study was different, this is consistent with the findings of our study, as every participant described having to prepare for the journey and learning to accept the true impacts of the injury.

Findings from Fleming et al.'s (2012) study titled *Brain Injury Rehabilitation: The Lived Experience of Inpatients and their Family Caregivers* aimed to describe the inpatient rehabilitation from the family's perspective. In this study, the family members identified that their primary role is to support the patient with a TBI and that they also provide the patient with ongoing emotional support.

The primary role of providing support for the patient with a TBI was described in depth by our study participants, with every family member elaborating on having to wear many hats and having to provide ongoing and constant support for the patient with a TBI.

In addition, family members from our study described their experience of providing care, completing ADLs, and being involved in completing other physical responsibilities for the patient with a TBI. This type of involvement is congruent with the results presented by Ishikawa et al. (2012), which identified that spending time with and providing care for the patient with a TBI are important elements of the family experience. Some examples of care provision were highlighted in Degeneffe's (2001) study and found that the duties that family caregivers undertake can be extensive and may include assistance with ADLs and medication administration, among other responsibilities.

The findings of our study presented a description of the women family member's experiences of providing emotional support and encouragement for the patient with a TBI, as well as facilitating the patient's independence. This role was undertaken in the context of inpatient TBI rehabilitation, but this has also been highlighted in a study exploring the types of caregiving supports that are provided by siblings to the patient with a TBI at least 6 months post-injury (Degeneffe & Burcham, 2008). Ishikawa et al. (2011) also identified that family members are often involved in providing emotional support and assisting to facilitate the independence of the patient with a TBI. The vital role of family members in providing constant emotional support to patients with a TBI is well recognized in the literature (Fleming et al., 2012; Ishikawa et al., 2011; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007).

The participants in Jumisko et al.'s (2007) study identified constantly being available and "on call" (p. 359) for the patient with a TBI. This is consistent with findings from our study and specific descriptions of family members who provided ongoing emotional support for the patient with a TBI, even when they were away from the hospital. This often led to a state of fatigue and exhaustion among the participants in our study. Although Man (2002) and Barlcay (2013) present their findings in regard to family functioning in the community, the feelings of psychosocial distress, burnout, exhaustion, and overall lack of energy are consistent with the findings of our research.

### **Future Research**

The findings from this study contribute to a preliminary understanding of the specific experience of women family members' involvement in adult inpatient TBI rehabilitation. However, it is necessary to broaden the study to include additional types of patient-caregiver relationships, particularly those in which men are the family caregiver. In addition, future research should also explore what family members perceive as specific actions that may be undertaken to lessen the burden. On that note, it would be interesting to explore how family members feel the treatment team and other individuals in their support system could lessen the overwhelming nature of their involvement. Finally, future research exploring the experience of involvement in rehabilitation during other phases of rehabilitation, such as acute care or outpatient brain injury services, may be an important contribution to the literature.

### **Implications for Occupational Therapy Practice**

The description of the family members' experiences has identified several areas relevant to clinical practice. First, this study highlighted the importance of supporting family members as they seek to learn more about brain injury and how they can help with rehabilitation. Second, family caregivers are often fatigued, exhausted, and burnt out as a result of everything that they have to do. As members of the health care team, occupational therapists could assist in the identification of key strategies that may lessen the burden on family members. As a team, health care professionals could review their

approach to the delivery of services and identify specific ways in which they could assist in the completion of tasks that are being completed by the family members. Occupational therapists have a great understanding of the impact that the social and institutional environments may have on an individual and his or her family. Given this understanding, it would be appropriate for occupational therapists to assist in the development of individualized care plans and other strategies that could alleviate sources of burden on families. Occupational therapists may also assist in assessing family needs and in identifying the areas in which it is mandatory to provide support and act as a constant resource for family members. By frequently evaluating the needs of the family, we may support family members in their attempt to stay involved in their other important responsibilities throughout their involvement in the rehabilitation of the patient with a TBI. This may indirectly assist in lessening the burden.

### Study Limitations

This study has limitations. The sample used in this study reflects the experience of five women family members of patients with a TBI from one brain injury rehabilitation center in Ottawa, ON, Canada, during the 2 months of recruitment. The sample is limited in its gender diversity and in the variation of the family members' relationships to the patient with a TBI. The transferability of the findings of this qualitative study need to be considered in this light, and it is important to note that the findings may not generalize to other contexts.

### Conclusion

This study aimed to explore the specific experience of being involved in adult inpatient TBI rehabilitation. The findings highlighted many similarities among the participants, but the overall experience of being involved differed from one family member to the next and varied throughout the rehabilitation journey. Specifically, being involved in adult inpatient TBI rehabilitation is characterized as an ongoing engagement in the completion of various roles, including physical tasks, emotional support, and communication with the health care team and other community resources. The women family members characterized their constant involvement as a struggle to find a balance between their engagement in the rehabilitation of the patient with a TBI and their other responsibilities. This struggle often leads to a state of exhaustion and burnout among family members. Overall, the findings provide an important contribution to the literature by examining the experience of being involved in adult inpatient TBI rehabilitation. The clinical practice implications of these findings highlight that health care professionals should examine specific strategies that are aimed at reducing the burden on family members. Future research should include additional types of patient-caregiver relationships and may be extended to explore the experience of involvement during other phases of rehabilitation.

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