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Research Article

Towards a better understanding of the impact of the sequelae of TBI on the social participation of seniors

Abstract

Background: The multiple sequelae caused by traumatic brain injuries (TBIs) can considerably reduce the ability of seniors to resume their activities of daily living and their leisure activities, and to return to meaningful relationships so they can participate in the life of their community.

Purpose of the study: This article aims to put forward the perceptions of older participants about the sequelae they themselves identify as consecutive, short or medium long term, with their TBI and consequently, the limitations they experienced in terms of their social participation.

Results: The findings reveal a correspondence between the multiple sequelae of the TBI identified by the participants and those documented in the scientific writings. These sequelae could be grouped according to the limitations found in the operational framework's three spheres of activities related to social participation: those that promotes self-realization through an autonomous and independent everyday life; through pastimes and leisure activities; and through relationships with others.

Main findings: The findings are innovative compared with what is generally described in the scientific literature, since existing studies offer few concrete examples of the limitations encountered in terms of social participation due to sequelae following a TBI. Four sequelae namely memory loss, loss of balance, lack of motivation or apathy and fatigue, appear to have many impacts on a variety of activities which could explain their significance for participants.

Conclusion: The findings pave the way for new research avenues that focus on analyzing social participation opportunities of older adults by reinforcing their capacities.

Potential implications: Results provide benchmark for health care and social services professionals for the mobilization of most effective resources and services to help seniors to engage in rewarding, meaningful social participation activities.

Introduction

Seniors often express a desire to remain in their living environment for as long as possible, even if their autonomy and functional mobility are limited [1]. This calls for the implementation of public policies promoting cohesive, adapted environments, and programs or interventions focused on optimizing active aging and social participation [2- 5]. Highly valued by seniors [6], social participation is considered a protection factor for mental health and cognitive functioning, and contributes to maintaining social skills and quality of life [4,5,7,8]. It is defined as the optimal involvement of individuals in meaningful activities that provide opportunities for them to thrive in their daily lives, leisure activities and social interactions [4,9,10]. It is a complex process based on

mutual, equal, meaningful and quality interactions between individuals and their social environment and within their community, where individuals are the principal actors in their lives and fully exercise their rights [11].

In this context, seniors who have a traumatic brain injury (TBI) represent an at-risk group. Indeed, over the last ten years, the prevalence of TBIs has significantly increased in the elderly population [12,13], with individuals over 75 years of age representing the majority of emergency room cases, hospitalizations, and fatalities resulting from a TBI [12]. According to the Center for Disease Control, 62% of TBIs in seniors are caused by falls as opposed to traffic accidents, which account for 17% of cases [14]. Compared with younger adults, seniors suffering from a TBI must overcome additional challenges since they are at greater risk of experiencing functional decline after the injury due to disabilities associated with normal aging [15-21]. These factors increase the risk of additional falls [21] and may considerably limit seniors' ability to resume their activities of daily living, to return to their meaningful interpersonal relationships, and to participate socially [9,20].

The social participation context specific to these seniors is given little consideration in the scientific literature. Studies focus primarily on very young or middle-aged adults, and very few touch on the particular situation of seniors with a TBI, who are almost systematically excluded from research protocols. Conversely, the few studies that focus on this population tend to describe the very broad impacts of the injury [17] and share few concrete examples concerning the effects of each type of sequela on social participation. They do highlight some difficulties in completing activities of daily living and attribute these to cognitive sequelae, but do not draw an explicit link between these difficulties and the obstacles faced when performing varied activities that are meaningful to the individual [18,22].

This article aims to provide a general overview of the obstacles to social participation from the perspective of seniors who have sustained a TBI, according to the different sequelae they associate with their injury. Although we recognize that it may be difficult for seniors to differentiate sequelae resulting from the TBI from those associated with the normal aging process [17,20], this article wishes to present the perceptions of older adults about the sequelae resulting from their TBI and the impact on their social participation.

Conceptual framework

The article relies on the operationalization of the concept of social participation in light of a review of writings by Hardaker [9]. The concept centers on three main spheres of activities related to the social participation of seniors who have a TBI.

Autonomous and independent daily living: To be able to participate socially, seniors must be able to function in an enabling environment that will allow them to meet their own challenges. They must be able to perform their activities of daily living as autonomously and independently as possible [4].

Hobbies and leisure activities: Seniors must be able to participate in the recreational, social, cultural, and spiritual activities that are meaningful to them. These activities may vary according to their abilities (e.g. spending time at a senior citizen day center, volunteering, going to the movies or a coffee shop) [5].

Relationships with others: Maintaining or fostering social and family relationships can motivate seniors to get involved in the life of their community. The presence and support of others is in fact considered one of the fundamental pillars of social participation [4,5]. In light of this operational framework, we can assume that seniors having a TBI can have an optimal social participation when they autonomously and independently accomplish activities of their choice, in a context of equal, positive and motivating relationships with others and in a vitalizing and welcoming personal and social environment.

Methods

The data were collected during the first phase of a longitudinal qualitative study that aimed to adapt, implement and assess the *Personalized citizen assistance for social participation* program (APIC) with seniors who have a TBI. In conjunction with the existing community resources, the APIC offers support to seniors to promote their social participation through mentoring to help them carry out the daily living and leisure activities that are meaningful to them [23,24]. The APIC study relies on the constructivist paradigm [25] and offers opportunities for learning and reflection. It takes into account the perspective of seniors on the support they received during the course of the program in order to identify the best ways to promote their social participation. It has been approved by the Research Ethics Board of the APIC's partner institutions.

Population

Participants were intentionally selected based on specific criteria and for the purposes of diversity [26]. The criteria were as follows: have participated in the APIC program for a twelve months period, have sustained a mild or moderate TBI; be 65 or older; live at home or in an intermediate resource. Recruitment took place in partnering rehabilitation centers in the Greater Montreal area based on a review of medical records and referrals from clinicians in TBI programs. The sample consisted of 11 participants (Table 1), including 7 women and 4 men, ranging in age from 65 to 96 years (average age is 78). Most participants lived alone because they were separated/divorced or widowed, and several had children. Generally, they had a complicated mild TBI 2 to 4 years ago, for an average of 3.5 years (the highest number of years: 9). According to the available data (3 missing data), the TBI was most often caused by a fall (N=8), and in one case by a traffic accident (N=1). The majority of participants had co-existing health problems, sometimes pre-existing (e.g. arthritis, CVA, diabetes, heart problems) (Table 1)

Data collection

Semi-structured interviews, lasting approximately 60 minutes, were conducted at the home of the participants

with the aim of documenting the impact of the TBI on their social participation prior to the start of the APIC intervention. Interviews were audio-recorded and subsequently transcribed verbatim, and were conducted using a validated grid adapted to the elderly clientele [27]. The grid was developed using two recognized measurement tools: the *Activities of Daily Living Scale* (ADL scale v.5,) [28] and the *Profile of Leisure Activities v.3.0* [29]. The *ADL Scale* is used to assess participants' perceived changes to social participation and the performance of activities of daily living. The *Profile of Leisure Activities* assesses the level of involvement in leisure activities. A questionnaire which included general socio-demographic (e.g. age, sex, marital status) and health (e.g. comorbidities, treatment, medication) questions was administered at the end of each interview.

Analysis

A thematic content analysis [30] was conducted to obtain a detailed understanding of the elderly participants' perceptions and experiences regarding the obstacles to social participation they encountered due to the sequelae resulting from their TBI. The data collected during the semi-structured interviews were analyzed using pre-determined and emerging categories. When necessary, sub-categories associated with different characteristics of the sequelae mentioned were established in order to group the collected data in the most discerning way possible (e.g. physical or emotional fatigue; psychomotor retardation or expression abilities) [31]. The categories (and sub-categories) were grouped in a table per participant according to the operational framework's three main spheres of activities of social participation. This led to the identification of recurring themes, divergences, and constants. A researcher and a research professional ensured the internal validity of the analyses by reaching a consensus on the codification and interpretation of the data.

Results

Prior to the APIC-intervention, participants identified multiples sequelae resulting from their TBI. These sequelae could be grouped according to the operational framework's three spheres of activities related to social participation: those that promotes self-realization through an autonomous and independent everyday life; through pastimes and leisure activities; and through relationships with others. It is important to note that participants mentioned at least three sequelae affecting their social participation, and that some types of sequelae were highlighted by a larger number of participants, including fatigue (N=9 participants sur 11), loss of balance (7 participants sur 11), memory problems (6 participants sur 11), and apathy (6 participants sur 11) (Table 2).

Limitations experienced in terms of autonomy in everyday life

All the participants faced limitations to their daily autonomy and level of independence, and all expressed, to varying degrees, difficulties in performing personal tasks and domestic duties (Table 3).

The vast majority mention fatigue (lack of energy, vitality, muscle weakness or drowsiness), lack of interest and motivation (apathy), memory loss, loss of balance, and in isolated cases, increased sensitivity to noise, visual impairments (double vision, loss of visual field) and a state of confusion or inattention as factors limiting their ability to complete household tasks. Among the household chores that are the most difficult to accomplish for those suffering from fatigue, visual impairments or related physical injuries sustained at the time of the TBI (back pain) are tasks that involve carrying heavy objects, bending down or being higher up, those that require a lot of physical strength (washing windows, mopping floors) or that take a long time. A lack of motivation or interest in action as well as fatigability (somnia) are expressed in others by a tendency to stay in bed until late in the day, to take less care of their appearance, or to abandon tasks. Participants also describe being slower in their movements since the TBI and consequently have difficulty getting up or out of bed. Because of inattention problems (or confusion), some experience difficulty maintaining their efforts when it comes to completing tasks, whereas others, due to memory losses, encounter difficulties with planning, especially when it comes to cooking more complicated recipes or managing

Table 1: Sample

	N	%
Sex		
Female	7	64%
Male	4	36%
Civil status		
Married	4	36%
Divorced/separated	5	46%
Widowed	2	18%
Number of years since the injury		
2 years or less	3	27%
Between 2 and 4 years	7	64%
More than 4 years	1	9%
Type of TBI		
*1 missing data		
Mild	1	10%
Complicated mild	6	60%
Moderate	3	30%

Table 2: Frequency of onset of sequelae identified by participants (N=11)

Definitions - Sequelae	N	%
Fatigue (e.g. muscle weakness, sleepiness)	9	75%
Loss of balance (e.g. dizziness, vertigo, physical instability)	7	58%
Memory impairments	7	58%
Apathy (e.g. lack of motivation, lack of initiatives)	7	58%
Speech impairments	4	33%
Confusion (e.g. disorientation, disorders of consciousness, feeling of strangeness)	4	33%
Visual impairments (e.g. double vision, loss of visual field)	3	25%
Irritability	3	25%
Increased sensitivity to noise	2	16%
Slowness (of movements)	2	16%
Loss of sense of smell	1	8%

appointments (e.g. medical). Others are hesitant to run errands or go to the bank, and avoid cleaning higher surfaces because of their loss of balance, fearing falls or injuries. Certain have difficulty cleaning properly or have a tendency to knock over objects due to visual impairments and others cannot tolerate noise or feel dizzy when it is too noisy and must develop strategies to perform household chores (e.g. use earplugs while vacuuming).

When faced with all of these difficulties, family seems to occupy a central support role in the domestic sphere. A large majority of participants receive practical help from their families (e.g. spouse, children) for the preparation of meals, the performance of household chores (e.g. housekeeping) or to get around (e.g. getting to medical appointments). These participants appreciate this support. However, some more than others seem to be in the middle of contentious family situations, especially when it comes to the management of their personal finances. These participants hesitate to share their needs and expectations with their children, who hold the purse strings, for fear of upsetting them or no longer receiving help. Added to this are the difficulties in obtaining what they need from their loved ones when they desire it (purchase of the desired food products; dirtiness and untidiness of the residence and criticisms made to the daughter who is slow in cleaning the house).

In addition to the family support received, some participants, less autonomous when it comes to personal care, also benefit from services offered by the Local Community Services Centers. They receive the help of an occupational therapist to adapt their equipment at home or professional help to wash themselves, clean or take their medication. However, it is rare for participants to have access to other types of services, with the exception of one senior who receives a meal delivery service twice a week, and of another who sometimes uses her residence's catering service. Finally, certain participants sometimes have a difficult time consulting a healthcare professional (e.g. a doctor), are not aware of the available services, and have trouble obtaining equipment (e.g. waiting to receive prostheses/hearing aids, glasses) because of financial difficulties or because there are delays in accessing certain services (e.g. optometrist).

Limitations experienced in hobbies and leisure activities

All the participants report that the TBI is accompanied by mourning and disconnects regarding their aspirations and lifestyles. They all regret not being able to take part in satisfying recreational or productive activities (Table 4). Memory loss, loss of balance, lack of motivation (apathy), fatigue, increased sensitivity to noise, and visual impairments are among the most important sequelae noted by participants. Some also find it difficult to no longer be able to read because of memory loss or use a computer less often because they have trouble retaining new information or tend to forget it. The loss of balance prevents others from doing physical exercises at home (e.g. stationary bike). Several participants who were regularly active prior to the TBI also had to abandon the recreational (e.g. dancing, walking) or sport (e.g. working out, tennis)

Table 3: Perceptions of TBI sequelae and limitations experienced in activities of daily living.

TypeS OF SEQUELAE	Limitations ON ACTIVITIES OF DAILY LIVING	VERBATIM EXAMPLES
Memory losses	Difficulty preparing meals, making complicated recipes, managing medical appointments	<i>I used to have a good memory. Now I walk to the fridge and I don't know what I'm looking for. (8)</i>
Confusion OR inattention	Difficulty maintaining focus on tasks	<i>Normally, my motto is "I finish what I start". But with the state I'm in now, I can't find the energy, the motivation to finish things. (14)</i>
Apathy OR Lack of motivation	Lack of interest in performing tasks Difficulty tackling the day, finishing tasks	
Loss of balance	Difficulty running errands, cleaning higher surfaces, bending down Difficulty preparing meals, tendency to knock objects over	<i>I'm scared I'll fall if it's too high. (...) Before, I cleaned my table... There was no problem. (10)</i>
Physical fatigue (muscle weakness, low energy)	Difficulty carrying heavy objects, completing longer tasks or those that require physical strength	
Loss of dexterity	Difficulty getting dressed	
Increased sensitivity to noise	Difficulty vacuuming	<i>I always have ear plugs... it's the damn vacuum, when I turn it on... And I know it's too loud, and I feel like hitting everything. (3)</i>
Visual impairments	Tendency to knock over objects, difficulty cleaning	
Fatigability or somnolence	Tendency to stay in bed or difficulty getting up	

Table 4: Perceptions of TBI Sequelae and limitations experienced in hobbies and leisure activities

Types OF SEQUELAE	Limitations ON PASTIMES OR LEISURE ACTIVITIES	VERBATIM EXAMPLES
Memory losses	Difficulty reading or using a computer Difficulty engaging in volunteer activities	<i>I can't commit to something where I have to give medication at 4 p.m., and the lady won't take her pill at 4 p.m. because I forgot. (3)</i>
Confusion (orientation) Apathy OR LACK OF MOTIVATION	Difficulty getting around outside Difficulty to leave the house or participate in leisure activities	
Loss of balance	Fear of falls Difficulty getting around, taking walks, doing physical exercises	<i>Sometimes, I lose my balance, and I walk like a duck. And I walk much slower than before. (4)</i>
Physical fatigue (muscle weakness, low energy)	Difficulty remaining standing for longer periods when getting around, walking for long periods	<i>Like taking walks by myself. I did it once or twice, but just in front of the shopping center and I was already getting tired. I sat down, but I felt like crying. (1)</i>
Loss of dexterity	Difficulty knitting	
Increased sensitivity to noise	Difficulty going to the movie theatre, watching television	<i>I have to be careful with my vision in my left eye... If it was up to me, I would always go off on my own, but my children always say: "Mom, we don't like it. We would like you to always have someone with you." (11)</i>
Visual impairments	Difficulties with orientation when getting around, going to the movie theatre, watching television, completing puzzles, sewing, knitting Avoid walking alone	

activities that they used to take part in. An increased sensitivity to auditory stimuli as well as visual impairments impact their ability to go to the movies, watch television, complete puzzles, and perform activities that require fine motor skills (e.g. knitting, sewing).

Several participants report a lack of motivation (apathy) to resume activities. Two of the four male participants, who were employed or socially involved (e.g. volunteer work), now state that they are deprived of opportunities to socialize, feel useless and unproductive within society, and have lower self-esteem. These participants say they lack the enthusiasm to once again take up activities. Some female participants, who were very active and independent before their TBI, find it difficult that they are now unable to drive and have to rely on their loved ones to get around.

A large majority of participants find it difficult to get around outside their home, in particular because of loss of balance, and more rarely due to fatigue (difficulty staying up), visual impairments, physical symptoms (e.g. knee or leg pain), and/or problems with orientation. Several fear falling when they are getting around, a fear that is particularly strong in participants whose TBI was caused by a fall. One of them is in fact excessively apprehensive due to the circumstances surrounding her TBI: a physical assault followed by a fall when she was out. To face their fear of falling, some participants use avoidance strategies, i.e., they no longer use public transit or avoid going out alone. This insecurity is a recurring theme for several participants and increases depending on the climate, icy sidewalks, and the cold, which discourage the majority of participants from leaving their houses.

Nevertheless, some participants are able to overcome their apprehensions when getting around by adopting more adaptive strategies: not rushing, avoiding being encumbered. Certain participants rely on paratransit; however, not everyone agrees on this mode of transportation. Some participants avoid this service because they are worried about the wait or have trouble planning their outings ahead of time. Others prefer the transportation services provided in day centers since these services follow a better planned, set schedule. Nevertheless, certain participants never leave their house alone, and those who still have their driver's license following the TBI are now more cautious when driving. They avoid driving at night, choose to go to nearby places they know well, organize their trip, or avoid rush hour.

Limitations experienced in interpersonal relationships

Participants report significant difficulties in maintaining satisfying interpersonal and social relationships. The relationship limitations experienced by participants (Table 5) include trouble following conversations if people are speaking too quickly, or if more than one person is speaking at the same time, due to memory loss, trouble concentrating, or an increased sensitivity to noise. Those who have a tendency to search for their words during conversations highlight trouble communicating. They consequently feel excluded from conversations. Others are apprehensive of getting involved

Table 5: Perceptions of TBI Sequelae and limitations experienced in interpersonal relationships

Types OF SEQUELAE	Limitations EXPERIENCED IN INTERPERSONAL RELATIONSHIPS	VERBATIM EXAMPLES
Memory losses Apathy OR LACK OF MOTIVATION	Difficulty following conversations, getting involved in volunteer activities for fear of being judged Feeling embarrassed or excluded in social situations Lack of motivation to interact with others, to renew past relationships or create new ones	<i>Since my accident, it's always a little hard to remember names. Sometimes, I'll run into people and they'll ask me how I am. I say, "I'm doing well." But I don't remember their face. I'm a little uncomfortable. I can't remember. (5)</i>
Expression difficulties or trouble communicating	Tendency to search for words and to feel excluded from conversations Difficulty being understood by others when trying to communicate	<i>Like this morning, I can't understand him, and sometimes I just don't know what he wants. And then he goes and gets ready. And then I realize he thought he was going to the CLSC. (Spouse; (13)</i>
Increased sensitivity to noise Confusion OR inattention	Difficulty following conversations Always having to ask people to repeat themselves and feeling embarrassed	<i>I think it's my attention. I don't pay attention. (...) But I think I'm distracted. I'm lost in my thoughts and then someone talks to me and I miss the first few words, and I ask them to repeat themselves (12)</i>

in volunteer activities for fear of exasperating others, being judged, or forgetting the instructions given because of their memory loss. Some participants feel embarrassed when they find themselves in social situations and are unable to remember individuals who know them, or because they have difficulty following the conversations due to language difficulties. Others hesitate to get involved because of behaviors deemed unacceptable or inappropriate, including aggressiveness, anger, and irritability that are sometimes manifested in front of others and that they have trouble controlling.

All of these difficulties hinder participation in activities that could provide opportunities for participants to socialize and develop a new social network. Leaving the house less often, taking part in less leisure activities as well as boredom can all lead to demoralization, weariness, and feelings of worthlessness in seniors. These feelings are expressed, to varying degrees, by all participants, who all find social isolation and the lack of interaction alarming with negative effects on their wellbeing. Even though they live in residences, some participants also lament the lack of meaningful social relationships, with the situation more apparent for those who have little contact with their immediate family. These participants suffer from loneliness and feel the need to interact and communicate. Others complain about the lack of communication with the spouse, son or daughter they live with (e.g. only a few minutes of interaction a day) or the fact that they feel excluded from their social circle.

At the outset, several participants expressed the need for company and relationships with others. The vast majority need to speak, converse, communicate what they feel, which is sometimes difficult to do with a loved one. They need support

to develop new relationships within the community or to renew old ways of connecting. Some participants require professional emotional and psychological support (psychologist, psychiatrist), but unfortunately do not have access to these services for financial reasons.

Discussion

The aim of this article was to establish an overview of the obstacles to social participation experienced by seniors who had sustained a TBI, according to the various sequelae they associate with their injury. The study reveals a correspondence between the multiple sequelae of the trauma identified by the participants and those documented in the scientific literature, in particular fatigue, loss of balance, memory and visual impairments, speech and hearing problems, confusion, apathy, personality or behavioral changes, as well as physical symptoms [13, 19, 32, 33]. Participants allude to one or several of these sequelae as sometimes recurring factors limiting their social participation activities. However, the findings go beyond what is generally described in the scientific writings, which offers few concrete examples regarding the impact of the various sequelae of the TBI on the social participation of seniors. To our knowledge, only the quantitative studies conducted by Rappoport et al. [18] and Powell et al. [22] establish associations between cognitive impairments (e.g. language problems, executive function deficits, memory loss) and lower performance levels when completing basic activities of daily living in seniors with a TBI. The nature of the present study allows the researchers to *qualitatively* record the impact of the specific sequelae of TBI on the abilities of the elderly participants to take part in various social participation activities, an avenue that has yet to be properly explored.

In this regard, the study identifies the types of sequelae of TBI that are mentioned most frequently by participants when referring to limitations in the different spheres of activities of social participation used in our operational framework, namely memory loss, loss of balance, lack of motivation (or apathy) and fatigue. These four sequelae appear to be a significant part of participants' experience, to a much greater extent than confusion, slowness, speech impairments, hearing problems, loss of smell, irritability. The importance of each of these four sequelae is reflected in the scientific literature focused on adults with a TBI, regardless of age [2,17, 19,20,33-38]. In a mixed research design study conducted by Dumont [2] with 53 adults below the age of 50 who sustained a TBI, fatigue was identified as the most persistent and frequently mentioned sequela associated with obstacles to work, leisure and social activities. Memory problems [35] were also recognized as having a significant impact on the performance of complex tasks, on the ability to read, and on the retention of information. With fatigue [2,33,35], these difficulties were mentioned, in higher proportions, in the great majority of studies reviewed by Dumont [2] as factors that hindered social participation. Other studies that have specifically focused on apathy or loss of balance also showed some effects on social participation in adults with TBI [34]. The adverse effects of apathy were highlighted as a barrier to interest in activities of daily living

[36]. Mobility difficulties related to loss of balance were recognized as affecting the capacity to function in everyday complex environments. These difficulties were associated with a slower pace and cautious behaviors when getting around on foot [38]. To our knowledge, to this day no study illustrates the impacts between fatigue, memory loss, loss of balance or apathy and the limitations on social participation experienced by seniors with a TBI, which is clearly emphasized in the many accounts of participants. These four sequelae appear to have many impacts, and on a variety of activities in at least two of the three spheres of activities of social participation of the study's operational framework, which could explain their significance for participants, compared with other types of sequelae such as confusion, slowness, speech impairments, hearing problems, loss of smell or irritability. Rather, these others sequelae seem to limit participants with regard to specific targeted activities, and over which they appear to have a greater feeling of control. Confronted with visual or hearing impairments (increased sensitivity to noise), some recounted, for example, their use of active compensation strategies, (e.g. taking steps to access the services of an optometrist, wearing earplugs when vacuuming).

Furthermore, the analyses reveal that, for all participants, the conditions were not ideal for them to fully engage in their social participation in a satisfying way following the TBI. The portrait that initially emerges post-TBI is of a daily situation that leaves little room for the activation of the seniors, with regard to their ability for self-realization through an autonomous and independent life, through hobbies and leisure activities of their choice, and through meaningful social and interpersonal relationships. In addition to a number of aggravations, participants also mention difficulty lifting objects that are heavy or placed too high, a tendency to knock over objects, performing tasks more slowly, and trouble getting out of bed, and taking less interest in their appearance. These obstacles to basic activities of daily living are identified in some studies focused on adult or elderly TBI populations [13,20,22,39,40]. Obstacles to self-realization through hobbies and leisure activities also emerged, including problems reading or using a computer, and difficulty watching television or knitting. These activities carried out at home were identified as meaningful and rewarding for seniors which is documented in the writings [41]. Also important to note is the fact that many participants regretted the difficulties they experienced walking, getting around outside, and using public transit. Several of them also expressed their fear of falling when getting around, specifically because of a loss of balance, which occurs frequently in individuals with a TBI, regardless of age [19,37,38]. Insecurity and fear of suffering a fall are cause for concern for seniors with or without a TBI and are described as determining factors when choosing a neighborhood or a place to visit [5,7,42-47]. Being able to move, getting out, and planning outings are essential to seniors since they promote improved cognitive and functional abilities, better quality of life, and physical health [7,8,48].

Finally, the analyses revealed that all participants felt excluded from social life. Several of them reported loneliness or social isolation as well as strategies to avoid situations

where there would be social interaction. These difficulties are documented in scientific literature [49,50]. Some participants indicated that they now avoid participating in organized social activities (e.g. volunteering) or informal ones, either because they had difficulty following conversations in groups due to memory loss or increased sensitivity to noise, or because they were embarrassed when they exhibited uncontrollable aggressive or inappropriate behaviors in social situations. This is of concern given that being engaged in satisfactory interpersonal relationships is viewed as a powerful indicator of social participation [6,19,51,52], whether these relationships take place in the privacy of the home, in the neighborhood, during sport or leisure activities, or through an involvement in the community [6]. The living environment, including family, is in this regard recognized as providing positive support to people with a TBI [19,53–55]. However, some participants seemed to experience a contentious family situation, and were dependent financially, emotionally and for support [50], which could hinder their rehabilitation and social participation [19,51]. Faced with this finding, interventions or programs need to be put in place in order to help loved ones find the best ways to meet the demands and needs of seniors with a TBI, to inform them on the appropriate supervision to provide, and to ensure they live and evolve alongside them in a positive environment [53].

Strengths and Limitations

The scientific rigor of the study, supported by the high level of data saturation and the triangulation of the analyses, led to a thorough understanding of participants' perceptions of the concrete impacts of the sequelae of TBI on the social participation of elderly participants, which makes this an original and innovative study for the rehabilitation sector as well as the fields of geriatrics and public health.

Yet, the sampling method used calls for some caution when it comes to the generalization of the findings. In fact, it is possible that the study's participants exhibit disabilities or personal characteristics that distinguish them from other seniors with a TBI who refused to participate in the APIC program (because they didn't have the time, they already had access to adequate support, or did not feel the need to receive help with their social participation). The data collected do not shed light on this matter. On the other hand, the present data were collected before the APIC intervention. Thus, it is possible that the overall picture of the sequelae associated by participants to the TBI will change over time to reflect the evolution of the assistance, and consequently participants may identify other types of sequelae that hinder their social participation. Those that seemed less important at the outset may progressively take on greater importance. Finally, this article focused on the sequelae that participants themselves associated with their TBI. These findings are important to mention, while keeping in mind that it is difficult, impossible even, to determine whether the sequelae mentioned are a result of the injury, or of a degenerative process due to normal aging, which began before the injury [17,20].

Conclusion

Several interventions have been implemented to promote the social participation of seniors, with or without a TBI, by offering support to engage in meaningful activities. These formal support resources take various forms (mentorship, respite care, friendly visits, home support, help engaging in activities, advocacy, transportation, etc.) and take place in various contexts: education, work, community life, activities of daily living, and leisure activities (assistance schedule). These resources generally do not focus on promoting the person's strengths, developing their abilities, or self-determination. Also, they are not systematically concerned with the values, interests and personal life project of the accompanied seniors. In order to improve the assistance provided, the innovative *Personalized citizen assistance for social participation* program (APIC) was developed, implemented and assessed. This new method of assistance and support, focused on developing skills and self-determination, and creating community ties, contributes to the improvement of seniors' autonomy and social participation.

Results of this study will be of a precious help to APIC assistants as they present concrete examples of how the TBI sequelae may affect social participation. They can lead to new research avenues analyzing seniors' social participation opportunities considering their capacities and limitations. Results provide benchmark for health care and social services professionals for the mobilization of most effective resources and services to help seniors to engage in rewarding, meaningful social participation activities.

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References

1. Association québécoise d'établissements de santé et des services sociaux [AQESSS] (2011) 6 cibles pour faire face au vieillissement de la population. (Eds). Montréal, Québec: AQESSS.
2. Dumont C (2003) L'identification des facteurs qui vont favoriser la participation sociale des adultes présentant des séquelles de traumatisme crânio-cérébral. Doctorat en santé communautaire, Université Laval: Faculté médecine, Département de santé communautaire. [Link: https://goo.gl/JjGm6b](https://goo.gl/JjGm6b)
3. Institut national d'excellence en santé et services sociaux [INESS] (2015) L'automatisation des personnes en perte d'autonomie liée au vieillissement. Québec: Gouvernement du Québec.
4. Raymond E, Gagné, D Sévigny A, Tourigny A (2008) La participation sociale des aînés dans une perspective de vieillissement en santé: Réflexion critique appuyée sur une analyse documentaire. Québec, Canada: Gouvernement du Québec.
5. Organisation mondiale de la santé [OMS] (2007) Guide mondial des villes-amies des aînés. Genève: Organisation mondiale de la santé. [Link: https://goo.gl/ZAhfSz](https://goo.gl/ZAhfSz)
6. Levasseur M, St-Cyr Tribble D, Desrosiers J (2009) Meaning of quality of life for older adults: importance of human functioning components. *Archives of Gerontology and Geriatrics* 49: e91-e100. [Link: https://goo.gl/CpwQ5a](https://goo.gl/CpwQ5a)

7. Dahan-Oliel N, Gélinas L, Mazer B (2008) Social participation in the elderly: What does the literature tell us? Critical Review in Physical and Rehabilitation Medicine 20: 159-176. [Link: https://goo.gl/gZrAd4](https://goo.gl/gZrAd4)
8. Richard L, Gauvin L, Gosselin C, Laforest S (2008) Staying connected: neighbourhood correlates of social participation among older adults living in urban environment in Montréal, Québec. Health Promotion International 24: 46-57. [Link: https://goo.gl/PKudhW](https://goo.gl/PKudhW)
9. Hardaker, N (2011) Pragmatic evidence based review. Community integration in moderate to severe traumatic brain injury. New Zealand: Accident Compensation Corporation. Prevention.
10. Levasseur M, Richard L, Gauvin L, Raymond E (2010) Inventory and analysis definitions of social participation found in the aging literature: proposed taxonomy of social activities. Social Science & Medicine 71: 2141-2149. [Link: https://goo.gl/5bKQn8](https://goo.gl/5bKQn8)
11. Fédération québécoise des centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement [FQCRDITED] (2013) La participation sociale des personnes présentant une déficience intellectuelle ou un trouble envahissant du développement: Du discours à une action concertée. Document d'orientation. Québec: Gouvernement du Québec. [Link: https://goo.gl/tx8p1N](https://goo.gl/tx8p1N)
12. Faul, M, Xu, L, Wald, MM, Coronado, VG (2010) Traumatic brain injury in the United-States. Emergency department visits, hospitalizations and deaths 2002-2006. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. [Link: https://goo.gl/uPqETK](https://goo.gl/uPqETK)
13. Leblanc, de Guise E, Gosselin N, Feyz M (2006) Comparison of functional outcome following acute care in young, middle-aged and elderly patients with traumatic brain injury. Brain Injury 20: 779-790. [Link: https://goo.gl/rmSfzG](https://goo.gl/rmSfzG)
14. Centers for Disease Control and Prevention [CDC] (2006) Web-based injury statistics query and reporting system; [Internet; downloaded document on December 15, 2015]
15. Frankel JE, Marwitz JH, Cifu MMA, Kreutz JS, Englander J, et al. (2006) A follow-up study of older adults with traumatic brain injury: Taking into account decreasing length of stay. Archives of Physical Medicine Rehabilitation 87: 57-62. [Link: https://goo.gl/7ZYnEc](https://goo.gl/7ZYnEc)
16. McIntyre A, Mehta S, Janzen S, Aubut J, Teasell RW (2013) A meta-analysis of functional outcome among older adults with traumatic brain injury. NeuroRehabilitation 32: 409-414. [Link: https://goo.gl/XaMKTI](https://goo.gl/XaMKTI)
17. McIntyre A, Janzen S, Teasell R (2014) Traumatic brain injury in older adults. Topics in Geriatric Rehabilitation 30: 230-236. [Link: https://goo.gl/dw4wFY](https://goo.gl/dw4wFY)
18. Rappoport MJ, Herrmann S, Shammi P, Kiss A, Phillips A, et al. (2006) Outcome after traumatic brain injury sustained in older adulthood: a one-year longitudinal study. Am. J. Geriatr Psychiatry 14: 456-465. [Link: https://goo.gl/BhXR6j](https://goo.gl/BhXR6j)
19. Sendroy-Terrill M, Whiteneck GG, Brooks CA (2010). Aging with traumatic brain injury: Cross-sectional follow-up of people receiving inpatient rehabilitation over more than 3 decades. Archives of Physical Medicine Rehabilitation 91: 489-97. [Link: https://goo.gl/XqqsQF](https://goo.gl/XqqsQF)
20. Yi A, Dams-O'Conno K (2013) Psychosocial functioning in older adults with traumatic brain injury, NeuroRehabilitation 32: 267-273. [Link: https://goo.gl/i2cftV](https://goo.gl/i2cftV)
21. Benker, DG (2003) Fear of falling in ambulatory older adults screening and interventions. Master of Nursing, Washington State University. [Link: https://goo.gl/jwL5of](https://goo.gl/jwL5of)
22. Powell JM, Temkin NR, Machamer JE, Dikmen SS (2007) Gaining insight into patients' perspectives on participation in home management activities after traumatic brain injury. American journal of occupational Therapy 61: 269-279. [Link: https://goo.gl/asUYcQ](https://goo.gl/asUYcQ)
23. Lefebvre H, Levert MJ, Bottari C, Gélinas I, Croteau C et al. (2011) Un accompagnement personnalisé d'intégration communautaire en soutien au développement de la résilience: vers un modèle. Réseau international sur le Processus de production du handicap [RIPPH] 19: 103-111. [Link: https://goo.gl/bTNm7T](https://goo.gl/bTNm7T)
24. Therriault PY, Lefebvre H, Guindon A, Levert MJ, Briand C (2013) Accompagnement citoyen personnalité en intégration communautaire: un défi pour la santé mentale? 38: 165-188. [Link: https://goo.gl/XYrAh](https://goo.gl/XYrAh)
25. Muchielli, A (2005) Le développement des méthodes qualitatives et l'approche constructiviste des phénomènes humains. Recherches qualitatives Hors Série 1: 7-40.
26. Lavoie-Zajc L (2007) Comment peut-on construire un échantillonnage spécifiquement valide? Recherche qualitative Hors série no 5: 99-111. [Link: https://goo.gl/GdcwEp](https://goo.gl/GdcwEp)
27. Levert MJ, Gélinas I, Lefebvre H, McKerral M, Roy O (2012-2014) Préserver l'autonomie fonctionnelle des personnes âgées ayant subi un traumatisme craniocérébral: Adaptation, implantation et évaluation de l'intervention d'Accompagnement personnalisé d'intégration communautaire [APIC]. Montréal, Québec, Canada: Fonds de recherche du Québec - Santé. 35: 229-241. [Link: https://goo.gl/5RjJVy](https://goo.gl/5RjJVy)
28. Dutil E, Bottari C, Vanier M, Gaudreau C (2005) Profil des AVQ. Description de l'outil Version 5. Québec: Les Éditions Emersion. [Link: https://goo.gl/hA71RY](https://goo.gl/hA71RY)
29. Dutil E, Bier N, Gaudreault C (2006) Le profil du loisir, un instrument prometteur en ergothérapie. Revue canadienne d'Ergothérapie 4: 326-336. [Link: https://goo.gl/Um7t7x](https://goo.gl/Um7t7x)
30. Paillé P, Muchielli A (2012) L'analyse qualitative en sciences humaines et sociales (3e éd.). Paris: Armand-Colin.
31. Deslauriers, JP (1991) Recherche qualitative. Guide pratique. Montréal, Québec: Chenelière/McGraw-Hill.
32. Ashman TA, Cantor JB, Gordon WA, Sacks A, Spielman L et al. (2008) A comparison of cognitive functioning in older adults with and without traumatic brain injury. Journal of Head Trauma Rehabilitation 23: 139-148. [Link: https://goo.gl/wACLZu](https://goo.gl/wACLZu)
33. Brown M, Gordon WA, Spielman L (2003) Participation in social and recreational activity in the community by individuals with traumatic brain injury 48: 266-274. [Link: https://goo.gl/YWErmu](https://goo.gl/YWErmu)
34. Andersson S, Finset A (1999) Apathy and depressed mood in acquired brain damage: relationship to lesion localization and psychophysiological reactivity. Psychological Medicine 29: 447-456. [Link: https://goo.gl/18kDVM](https://goo.gl/18kDVM)
35. Draper K, Ponsford J, Shönberger M (2007) Psychosocial and emotional outcomes 10 years following traumatic brain injury. Head Trauma Rehabilitation 22: 278-287. [Link: https://goo.gl/JSJZLw](https://goo.gl/JSJZLw)
36. Finset A, Anderson S (2000) Coping strategies in patients with acquired brain injury: relationships between coping, apathy, depression and lesion location, Brain Injury 14: 887-905. [Link: https://goo.gl/HY3oPP](https://goo.gl/HY3oPP)
37. Katz DI, White DK, Alexander MP, Klein RB (2004) Recovery of ambulation after traumatic brain injury. 2004; Archives of Physical Medicine Rehabilitation 85: 865-869. [Link: https://goo.gl/BL6zWx](https://goo.gl/BL6zWx)
38. McFayden BJ, Cantin JF, Swaine B, Duchesneau G, Doyon J, et al. (2009) Modality-Specific, Multitask locomotor deficits persist despite good recovery after a traumatic brain injury, Archives of Physical Medicine Rehabilitation 90: 1596-1606. [Link: https://goo.gl/BhTFJL](https://goo.gl/BhTFJL)
39. Lamontagne ME, Poncet F, Careau E, Sirois MJ, Boucher N (2013) Life habits performance of individuals with brain injury in different living environments. Brain Injury 27: 135-144. [Link: https://goo.gl/8YovvH](https://goo.gl/8YovvH)

40. Provencher V, Desrosiers J, Demers L, Carmichael PH (2015) Optimizing social participation in community-dwelling older adults through the use of behavioral coping strategies. *Disability Rehabilitation*. Online: 1-7. [Link: https://goo.gl/mPCaok](https://goo.gl/mPCaok)
41. Edward DE, Christiansen C (2005) Occupational Development. In Christiansen, C, Baum, C, editors. *Occupational Therapy: Performance, participation and well-being*. NJ: Slack. [Link: https://goo.gl/pJk4Ka](https://goo.gl/pJk4Ka)
42. Andonian L, MacRae A (2011) Well older adults within an urban context: strategies to create and maintain social participation. *The British Journal of Occupational Therapy* 74: 2-11. [Link: https://goo.gl/kfmx41](https://goo.gl/kfmx41)
43. Arrif T, Rioux L (2011) Les pratiques des espaces verts urbains par les personnes âgées. L'exemple du parc de Bercy. *Green spaces' practices by the elderly people. The case of Bercy park. Pratiques psychologiques* 17: 5-17. [Link: https://goo.gl/ffK2mh](https://goo.gl/ffK2mh)
44. Bruce DG, Devine A, Prince RL (2002) Recreational physical activity levels in healthy older women: The importance of fear of blame. *American Geriatrics Society* 50: 84-89. [Link: https://goo.gl/YAbkd1](https://goo.gl/YAbkd1)
45. Buffel T, Phillipson C, Scharf T (2012) Ageing in urban environments: developing "age-friendly" cities. *Critical Social Policy* 32: 597-617. [Link: https://goo.gl/G2WQhm](https://goo.gl/G2WQhm)
46. Clarke P, Ailshire JA, Bader M, Morenoff JD, House JS (2008) Mobility disability and the urban built environment. *American Journal of Epidemiology* 168: 506-513. [Link: https://goo.gl/R3Aznf](https://goo.gl/R3Aznf)
47. Michael YL, Green MK, Farquhar SA (2006) Neighborhood design and active aging. *Health Place* 12: 734-740. [Link: https://goo.gl/mG6X3i](https://goo.gl/mG6X3i)
48. Hanson HM, Schiller C, Winters M, Sims-Gould J, Clarke P et al. (2013) Concept mapping applied to the intersection between older adults outdoor walking and the built and social environments, *Preventive Medicine* 57: 785-791. [Link: https://goo.gl/kSybBB](https://goo.gl/kSybBB)
49. Freund A, Baltes PB (2003) Pour un développement et un vieillissement réussis: Sélection, optimisation et compensation. *Revue québécoise de psychologie* 24: 27-52. [Link: https://goo.gl/Us2mAH](https://goo.gl/Us2mAH)
50. McLean AM, Jarus T, Hubley AM, Jongbloed L (2014) Associations between social participation and subjective quality of life for adults with moderate to severe traumatic brain injury. *Disability and Rehabilitation* 36: 1409-1418. [Link: https://goo.gl/zGWFAe](https://goo.gl/zGWFAe)
51. Gilmour H (2012) Social participation and the health and well-being of Canadian seniors. *Statistics Canada. Health Reports* 23: 3-11. [Link: https://goo.gl/bSmWvn](https://goo.gl/bSmWvn)
52. Godelief MJ, Mars MA, Gertrudis IJM, Kempen IM, Proot IM et al. (2015) Characteristics of social participation as defined by older adults with a chronic physical illness, *Disability & Rehabilitation* 30: 1298-1308. [Link: https://goo.gl/AEq9FW](https://goo.gl/AEq9FW)
53. Lamontagne ME, Ouellet MC, Simard JF (2009) A descriptive portrait of human assistance required by individuals with brain injury. *Brain Injury* 23: 693-701. [Link: https://goo.gl/NnhLbb](https://goo.gl/NnhLbb)
54. Lefebvre H, Cloutier G, Levert MJ (2008) Perspectives of Survivors of Traumatic Brain Injury and their Caregivers on Long-term Social Integration. *Brain Injury* 22: 535-543. [Link: https://goo.gl/A8jDFm](https://goo.gl/A8jDFm)
55. McColl MA, Carlson P, Johnson J, Minnes P, Shue K, et al. (1998) The definition of community integration: Perspectives of people with brain injuries. *Brain Injury* 12: 15-30. [Link: https://goo.gl/X23j1q](https://goo.gl/X23j1q)