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Family experiences up to seven years after a severe traumatic brain injury–family interviews

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ABSTRACT

Purpose: To explore the experiences of being a family with one member suffering from severe traumatic brain injury (STBI) up to 7 years earlier through narrative family interviews.

Methods: There are few studies where a family as a unit, including persons with STBI, are interviewed together. This study used a family systems research approach following a qualitative interpretative design. Therefore, 21 families with a total of 47 family members were interviewed. Qualitative content analysis was used to reveal categories with sub-categories and a theme.

Results: “From surviving STBI towards stability, through the unknown, into a new everyday life and a new future as a family” characterized the implicit message. The results revealed two categories both with three subcategories. The first category characterized the rapid change from a normal everyday life to one of uncertainty and finally to one of stability, and the second category described how it is to adapt as a family after STBI.

Conclusions: Long-term experiences of STBI show the importance for the whole family of belonging to a context, having a job, and having something to belong to as a way to achieve stability. Families’ feelings of loneliness and lack of treatment and support are challenges for professionals when trying to involve families in care and rehabilitation.

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Severe traumatic brain injury; long-term perspective; family interviews

► IMPLICATIONS FOR REHABILITATION

- A sense of belonging, having a purpose and a social network are important within families.
- Professionals can provide information and can help to eliminate misunderstandings for individuals with severe traumatic brain injury and their families.
- It is important for rehabilitation professionals to undertake a thorough family assessment.
- This assessment will support families become involved in the process of rehabilitation.



Introduction

Traumatic brain injury (TBI) is a major public health problem globally and is a leading cause of long-term disability in people of working age [1]. The overall annual incidence of mild to severe TBI (STBI) in Sweden, among about 10 million inhabitants, is estimated at 250–354 000 persons/year [2,3], while STBI with Glasgow Coma Scale (GCS) <9 [4] is estimated to be 2% in an earlier study from northern Sweden [2].

STBI causes great personal suffering and involves high costs for the individual and the community [5,6]. Changes in one family member’s life after severe illness affect the family as a whole [7], and families of severely injured persons often have difficulties to adapt to the new situation [8]. Systemic changes are thus needed within the family unit to restore functional stability and to improve family satisfaction and wellbeing [8,9]. Possible future disabilities or in worst cases death can be a reality. Caregiving partners are at greater risk for emotional distress and higher levels of burden [10]. To manage this situation, strategies of keeping the family together have been described [11–12]. From the acute

phase, continuous information and being involved are of importance for a family after STBI [12–14], and about 1 year after the injury family members reported being embedded within the experience of a relative’s brain injury [15]. Family responsibilities do not fade away with time, and the long-term impact of TBI might require external help [15,16]. STBI sufferers comprise a heterogeneous group with varying prognoses [17] and impacts on the person with STBI in terms of behavioral, psychosocial, physical, and cognitive impairment, the latter often being invisible at first sight. This makes it difficult for the family and others in the community to understand the level of severity of these problems [17–18].

There are some studies focusing on experiences described by persons with STBI [19] and other studies that have focused only on relatives [10,20,21]. Family members’ separate experiences of a severe injury and STBI show that relatives make sacrifices and experience anxiety and that distress is put on the family [22]. It has also been found that people with TBI 7 or more years after the injury mostly had integrated the consequences of the injury

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Table 1. Demographics and injury characteristics for persons with severe traumatic brain injury (STBI) in northern Sweden ($N=21$).

	Median (range)
GCS* year 2010–2011	5 (3–8)
<i>Hospital care</i>	
Intensive care (days)	14 (3–39)
Specialized rehab (days)	35 (0–127)
Total (days)	62 (16–250)
Age (years)	49 (27–70) N (%)
<i>Gender</i>	
Male	14 (66)
Female	7 (33)
<i>Diagnosis</i>	
Diffuse brain injury (S062)	6 (29)
Focal brain injury (S063)	2 (10)
EPH* (S064)	4 (19)
Traumatic SDH* (S065)	7 (33)
Traumatic SAH* (S066)	1 (5)
Other (S068)	1 (5)
<i>Cause of injury</i>	
Fall	9 (43)
Traffic	8 (38)
Sport	3 (14)
Unknown	1 (5)

*EPH: epidural hematoma; SDH: subdural hematoma; SAH: subarachnoid hematoma; GCS: Glasgow Coma Scale [4].

into their lives and felt at peace with the situation [23]. We have only found one study following a family systems approach where formerly severely injured persons and their family members were interviewed together after treatment in an intensive care unit [24]. However, there are studies of TBI families that take a holistic and a family-centered perspective even if family members are interviewed separately. The importance of narratives is highlighted [15,25], and it has been found that family-systems conversations and research (i.e., the family members are together) broadens the knowledge of how it is to be a family where one member is suffering from various illnesses. In a review it was shown that families evaluated and described the importance of being gathered in the same interview, thus learning from each other and creating a common family story [26]. It would, therefore, be of interest to gain more knowledge about how families experience life after STBI and how the family members together create a family story for adapting to the situation a long time after the STBI.

Aim

To explore the experiences of being a family with one member still suffering from STBI up to 7 years after the initial injury event.

Method

This study used a family systems research approach [26] following a qualitative interpretative design. The method relies on linguistic (verbatim text) rather than numerical data and employs meaning-based rather than statistical forms of data analysis [27].

Definitions

The family is who they say they are, or a family can be a group of two or more individuals who identify themselves as a family [28,29]. A family can consist of subgroups like dyads or triads, for example, couples, siblings, or a person with STBI and a child. In this study the terms family and families are used to refer to when all the members in the family including the one suffering from STBI shared an experience, i.e., being a family with emotional

bonds. For individual experiences, the concept of the injured person or the family member was used.

Participants and setting

Thirty-seven injured persons with STBI were admitted during 2010–2011 to the Regional Neurotrauma Center at Umeå University Hospital in northern Sweden, covering a geographical area comprising almost half of the total area of Sweden. These 37 persons were recruited prospectively as a part of the Swedish-Icelandic multicenter Probrain study ($n=114$) involving five of six university hospitals in Sweden and one in Iceland [30,31]. Inclusion criteria for the Probrain study were persons aged 18–65 years with acute STBI and GCS 3–8. The exclusion criterion was death within 3 weeks of injury. Assessments after 3 weeks, 3 months, and 1 year included clinical examination using the framework of the International Classification of Functioning, Disability and Health (ICF) [32].

Survivors from the 37 persons with STBI from northern Sweden were part of this follow-up study at 5.5–7.5 years (mean 6.5 years) after the injury. Nine persons were deceased, six of whom died within the first year, thus 28 injured persons were available to participate. Three persons declined participation, one had full recovery and wanted to leave this event behind, one gave no reason and decided not to participate, and one was not able to be a part of a family interview because of lack of time and behavioral problems. Two were not reachable, and two had no family member who could participate and were therefore excluded. Thus, 21 persons with STBI participated in the study, and 21 family systems interviews were held with a total of 47 participants of which 26 were family members. For demographic and injury characteristics, see Table 1. Characteristics of the person with STBI at the time of injury and at follow-up are described in Table 2. The family members were partners living together with the one suffering STBI ($n=13$) and former partners ($n=1$), grown up or young children ($n=4$), including two still living with their parent and two children living in the same town, and parents ($n=6$). None of the parents lived with their children at time of injury or at follow-up. Finally, two personal assistants were included. One person with STBI could not participate because of disorder of consciousness and ongoing infection, but a grown-up child and two personal assistants participated. Fifteen interviews were carried out at the home of the injured person, one interview was conducted at the injured person's workplace, and two interviews were conducted at the authors' office. Three interviews were conducted by telephone or by videoconference due to the great distances in northern Sweden. The injured person or their legal trustee was contacted by the first author (MS), who had been in contact with the families in earlier follow-up studies [33–37].

Data collection

The injured person or a legal trustee decided who should be invited to the family interview. The participating families decided the time and place for the interview. The injured person (or the legal trustee) and family members gave written informed consent. Two of the authors were present during the interviews, and one (B-IS) performed the family interviews. A family systems approach [28,38] was used during the interviews, i.e., the interviews were based on seeing the family as an entity and that the family as a system influenced the experience of having STBI in the family. The interview started with a question that first invited the injured

Table 2. Marital status, employment and livelihood, personal support, and driving license at time for injury in 2010–2011 and at follow-up up to seven years later ($n = 21$).

	Time of injury N (%)	Follow-up N (%)
<i>Marital status</i>		
Unmarried without underage children living at home	4 (19)	4 (19)
Unmarried with underage children living at home	1 (5)	0
Married/cohabitating without underage children living at home	9 (43)	10 (48)
Married/cohabitating with underage children living at home	6 (29)	5 (24)
Married/cohabitating with grown child living at home	1 (5)	1 (5)
Compulsory care in the case of abuse	0	1 (5)
<i>Employment and livelihood</i>		
Worker or being a student	17 (81)	10 (48)
Sick leave	3 (14)	9 (43)
Welfare payment	1 (5)	1 (5)
Other	0	1 (5)
<i>Personal support</i>		
Personal assistance 24/7	0	2 (10)
Homecare service several times daily	0	2 (10)
<i>Driving license</i>	16 (76)	13 (62)

person and then the rest of the family to narrate from their perspective their experience from the time of the injury event and then during the 7 years that had passed. This made it possible to listen and learn from each other. They were also asked open-ended questions such as “When you listen to your mother, what do you think?” or “What is the biggest change in your family?” Further, the interviews followed certain themes of the injury trajectory and how the family had coped during the various phases throughout the 7 years that had passed. During the interview the family members were encouraged to fill in passages and help each other to remember. The interview time varied between 36 and 64 min, and all interviews were tape-recorded and transcribed verbatim covering a total of 489 pages.

Ethical consideration

The study was approved by the Ethical Review Board Umeå, Sweden, No 2016/444-31. Many of the families showed compassion and sorrow. Some of them also cried now and then during the interview. In such cases they were asked if they wanted to take a break or even stop the interview, but no one did. If they had wanted to stop the interview, we had the possibility to arrange for a meeting with a psychological counselor. As a benefit from the interviews, others also told that this was considered as something very good for the soul and that this was the first time they could be together and listen to each others' stories.

Data analysis

Qualitative content analysis is a widely used method to explore interview texts because the data contain both manifest text and a latent meaning [39,40]. The inductive analysis of the text uses both the manifest descriptions and an interpretation of the latent meaning. This means that the text is analyzed trying to put the authors' pre-understanding aside. The first author read the whole text several times in order to grasp a sense of what it was all about. The co-authors also read the text, and the first impressions and understandings of the text were discussed among the authors. Thereafter, the first author identified meaning units relevant for the purpose of the study. By coding the meaning unit, the text was condensed, i.e., codes were generated from the meaning units without losing the content. After further discussions among the authors, the codes were amalgamated according to similar content and sorted into categories and subcategories. These categories constituted the manifest content and were

intended to be as complete and mutually exclusive of the text as possible. Throughout the entire process, the analysis went back and forth between codes, meaning units, subcategories, and categories. Together the authors co-created the interpretation of the manifest content leading to two main categories and six subcategories. The analysis also resulted in a theme covering the latent meaning of the text.

Results

The theme “From surviving STBI towards stability, through the unknown, into a new everyday life and a new future as a family” characterized the implicit message in the text. All families emotionally described the shocking experience of the injury even though it had occurred up to 7 years earlier. There were various outcomes for the injured persons, but the families described quite similar experiences at the beginning but after some years they led their lives in different ways.

The following results are presented with two categories both with three subcategories. The first category is characterized by the rapid change from a normal everyday life into one of turmoil, striving from uncertainty to stability, and the second category describes how it is to adapt as a family after STBI.

Striving from uncertainty to stability

To be thrown as a family from a common everyday life to a near death experience and then to gradually adapt to the new situation was described in three subcategories: Mobilization and to be a guardian, Struggle with loneliness, and To achieve stability.

Mobilization and to be a guardian

Families described the strength of being gathered together and how with love they coordinated their responsibilities. Mobilization helped them to feel that they had a mission and helped them to support each other. Family members that avoided gathering did so because they could not stand the situation, but there was also a description of their own belief that it might be better for the injured person if they avoided the acute situation. Young children were excluded from the acute phase in some families, but that was not always wanted by the children, especially adolescents. The families guarded the patient, they were alert, and they learned and watched the medical equipment. After transitioning to the next level of care, uncertainty appeared, and families

described a lack of information. The closest family member, often a partner or a mother, took the responsibility for discussions with healthcare personnel authorities. Mothers and partners took the role of carer, took control of the situation, and sought to keep the family together. Other family members sometimes had to stand back. To manage the role of carer, it was necessary for family members to partly give up their own needs.

The mother of a son who sustained a STBI at age of 23 described the first weeks with her former partner and the father to their son: " ... *and then there was a lot of waiting and we could support each other during that time and talk about common things from the past and also be able to lift each other up a little bit and share old memories, maybe you remember things and can be a little happy sometimes. It was actually great. If I had gone there alone, I do not think that I would have had the energy*".

Struggle with loneliness

Struggling with loneliness within the families was described by all families. Partners still felt alone with their experience from the acute phase 7 year earlier. The injured person also avoided talking about this situation because they were unconscious at the time or had prolonged amnesia and had to refer to others. Thus, they did not describe the same strong emotional feelings. By not having their own story, they described a feeling of loneliness. The injured persons also talked about the lonely struggle with reduced self-confidence living with their disability, new opportunities for living conditions, and for some guilt and sorrow for what their family had experienced. The other family members described painful feelings of loneliness because of people's difficulty in understanding the common endeavor after STBI and how persons in their network had successively dropped out when recovery slowed down. Returning to work or school was described as one goal to break the loneliness and isolation and to achieve a meaningful everyday life. Families saw improvement over the years and sought help for rehabilitation, although there were descriptions that brain injury rehabilitation was offered for the first year but no longer than that. Families had to deal with authorities, for example, the social insurance system for themselves or the injured person, and for some families this was a lonely on-going struggle without any support.

To be accepted and to accept "the new you" were not obvious among the injured persons. Self-chosen loneliness was described, and the injured persons often withdrew themselves in different situations and declined invitations for gatherings. Family members as caregivers felt lonely and saw nobody else to relieve the burden. To struggle with loneliness had a considerable cost for family caregivers, but for the injured person the attention by the caregivers was valuable.

The wife of a husband who sustained a STBI at the age of 42 years and who lived in a rural area: "*And I have to say, that it is, one thing, I really need to get out of this conversation; and this is, for the injured person, to come home, instead of being in a hospital or institution, I highly recommend it. It has made him very good! Instead of living inside four walls at the hospital, but I do not strongly recommend it, for the relatives. Because it has been a shitty time. I couldn't take jobs or anything for the first five years, so I have missed everything that is part of the pension system. Eh, it is an incredible amount of pressing and searching all the time. You are constantly investigating.*"

To achieve stability

Stories about how to achieve stability differed. Families, beliefs, and outside networks were important. Earlier experiences of how to handle difficult situations in the families and the ability to mobilize strength such as using humor, thinking positively, keeping up with physical activity, writing a diary, or using social media were described. The ability to look forward and manage reorientation was important. Stability was in some families described as a stagnation, and searching for a change was desirable.

Alcohol and drugs as part of the family were included in these discussions. Often this new situation became a turning point and limited further abuse. It was described by the family members that if this trauma had not happened, maybe their injured relative would have died because of their substance abuse, and even though living with a severe disability, family members said that this was a better way to be a family than before. The injury increased closeness and stability. Depending on how the recovery progressed, the families went more and more back to old roles that encouraged stability. In some cases, if the relationship was unequal, a decision to take a step aside and separate, but still be close together, was decided on.

A mother of a son who sustained a STBI at age 25, said: "... *There is a completely different sense of humility today without your abuse than it used to be. You had it before, but with what has happened you are much tenderer now. Yeah, a little softer. I don't know, it's just a greater feeling of closeness.*"

Son: "*hearing this makes me want to cry.*"

To adapt as a family after STBI

The second category concerned adapting as a family after STBI and had three subcategories: To be as usual, To be somewhat unusual, and To be quite unusual, with a perspective from today towards the future.

To be as usual

Families described how the journey back to a normal life occurred unexpectedly quickly. A milestone for normality was coming back to work and getting a driver's license. The experience to be back as usual seemed to be easier for those who were on sick leave or who were unemployed before their injury. This self-perceived life-satisfaction of being as usual and their gratitude for being back at a full-time job was a recurring message, but several described how they had returned to work too early. To be as usual was also related to the outside networks expectations and confirmation of the injured person today, and sometimes there were small changes remaining but families felt that everything was as usual. The family system had been restored. For the future, the injured person just wanted to take care of their family and to get on with their daily life. To live in the present and not worry about the future was an explicit goal. Several families told how they did what they could do and did things more often together. Even though everything was all right so far, there were families describing a fear of further deterioration like dementia.

A person who sustained a STBI at age 21 and afterwards completed university studies and today works in a full-time job said: "*The only thing I notice from the injury today is that, if I sleep too little, then I have difficulties to find words and I often say the wrong words. So that's the only, yes, remaining problem, but my current partner does not notice anything*".

To be somewhat unusual

To be a somewhat unusual family led to changes in the family system and to new responsibilities and roles in the family. During the recovery phase, the family had to deal with the injured person's confusion, irritability, and other changes to their personality. The injured persons were often more positive of their recovery, but in the family interviews they heard another description of how the family perceived them today. This description caused interesting discussions between all family members, and in some of the families they had never spoken about this before. Family members were more negative, but they also described a deeper relationship and how positive personalities could be strengthened such as being softer and more caring. Children to an injured parent carefully described the change in personality of their parent. A common reflection was that this is how things are, that they are somewhat unusual.

To be somewhat unusual and having unspoken pressure and expectations about being as usual, for example, working full-time, were described with tears. A hope for having children turned into sorrow because this could not be fulfilled. Families could not imagine that they could be responsible for additional children. Partners to the injured person described the situation today as a perfect way of living even though somewhat unusual, and this was especially the case for men, while women had more worries. Families planned and made actions to facilitate common activities, such as travelling and keeping up their interests and continuing to be a part of different social and sports activities. They had found a balance in life and described that they had a good social life and good possibilities for leisure even though being somewhat unusual.

A male partner to a woman who sustained a STBI at age 22, and who were a couple when the incident occurred, said: *"I think we live a perfect life"*.

The injured woman: *"So I have come to realize that I will probably not be so much damn better, but it is just to learn to live like this ... but the wish that I had was to find some work, so I can work a little or something, so I have something to do, and not be at home all the time."*

To be quite unusual

To be quite unusual was described by the families as being limited, set on pause, or even that life had stopped. Self-confidence was affected among the injured persons. To be a child in families with STBI and having a parent that no longer behaved as usual was described as difficult. The other parent then took a greater responsibility for the children. There were children who in a humble way stated that *"this is how it is for us, and this is how my parent is"*.

As time went by, limitations became more obvious as the injured person's condition seemed stable. For the injured there were limitations to their ability to take care of themselves and to make their own decisions and to be independent. Family members, a mother, a partner, or a grown-up child had to take big responsibilities for the injured person. They saw no other solution and did it with love, but also from a sense of duty. This was described as a locked-up situation. Family members underlined the wish to sometimes live their own life and let the injured live their life just like it was before.

When family members took time for themselves, they had a bad conscience for the injured person. Seven years after the injury, some of the family members missed professional support for themselves. This situation was described as emotionally

demanding and stressful. The quite unusual families had given up their endless efforts to get help from outside networks such as help from social workers and the possibility for rehabilitation. They had resigned themselves to their situation.

For the future, these families described a wish that the disability and the whole situation would not become worse. There were worries about how to manage to keep the family relationship intact. The injured persons tried to give different solutions to release family members from these worries. Discussions went on in the families, and it became clear that the solution was not just for the injured person, but also for the whole family. To get a formal responsible person for support or to find another accommodation was for the future. Support over the years seemed extra important and differed depending on, for example, the age of the injured person.

A mother to a son, who sustained a STBI at age 50, said: *"They (the children) don't want to have any contact with their dad. They think it is too difficult to visit him, and that is hard for my son and is hard for me."*

The injured son: *"I'm so alone. Why did I do that, why am I injured?"*

Totally, the families described hopes for the future in various ways even if they generally hoped that everything would go well or at least not be worse than today. There was hope for a better future but also anxiety about being left alone. Actions for the future are concrete, and actions for the future are also an opportunity to challenge yourself and try new things.

Discussion

In the present study of family experiences up to 7 years after STBI, families as a unit together instead of individuals were studied. The most important finding was their common struggles over these years – "From surviving STBI towards stability, through the unknown, into a new everyday life and a new future as a family", which is the implicit message in the text. The results showed a rapid change for families from a normal everyday life before STBI, and their striving through uncertainty to stability and their adaptation as a family after STBI. Striving from uncertainty to stability, from ordinary life to a rapid change, permeated almost all of the results. The transitions for individual close family members have been described earlier [41], but also with the whole family in mind, even if the injured person was left behind [15]. Still, there is an absence of studies focusing on the process of transition for STBI families as a whole with the injured person included, especially in a long-term perspective. Our study, like other studies, confirms that prognoses after STBI differ [42] and that even many years after STBI disability some minor or more prominent needs and changes still exist [43]. Families in our study, as long as up to 7 year after injury, described unmet needs and lack of professional support to alleviate the burden and sense of loneliness or social isolation. This is in line with previous studies that have shown high and persistent family needs up to 2 years after injury [44,45].

Mobilization and to be a guardian was the first subcategory, describing, for example, the importance of having a family who could provide a sense of security for persons with STBI. This was also described earlier [46] among other persons who have been critically ill. We also found how important it was for the families to be included and involved in care and the importance of receiving consistent information. This was also seen in a study that summarized the needs of family members to patients with STBI during their neuro-intensive care [12]. The results in our study

pointed at the importance that staff checked that the given information was correctly understood by family members to individuals with STBI, which was also found in another study [46]. The families had not been offered special targeted information about STBI adapted for young children or teenagers. It has been reported that adolescents having a parent with chronic medical conditions have an increased risk of, for example, internalizing problems, adverse caregiving characteristics, and stress [47]. This is something to be aware of, and offering such information is recommended.

A common experience was that the families took responsibility in the short and the long term, sometimes seen as life-long. Taking responsibility for an injured family member was done out of natural love, and as a moral obligation, but also because no one else was there. Further, mothers and female partners were in the majority when it came to taking the role of guarding and being the closest caregiver. This is also reported by others [48,49]. In the beginning, the responsible family members often changed their professional lives so that they could be near or take care of the injured person, leading to increased financial strain. TBI has great impact and stress on partners [10]. Caregivers' initial needs were very similar, but like in another recent study they varied widely already at 6 months [49] because of the different outcomes of the STBI.

To struggle with loneliness was the second sub-category in our study. Loneliness was still present 7 years after injury, demonstrating a before and after mood. It was said to be a lonely ongoing struggle without support. The loneliness among the injured persons related to not remembering what had happened and to others in the family not being able to share the experience. Loneliness in our study can be compared with what is reported in another study as feelings of isolation within the families [25]. Loneliness was also described as a dominant feeling and was either individual or shared and sometimes self-chosen. The lack of a common life with experiences of friends who had successively dropped out were also described. The loss of friendship following STBI and other social contacts is also described by others [50].

Further, the results of our study showed that their lonely struggle concerned the support that families received or did not receive from outside, for example, lack of further rehabilitation from health care and increased community services. This has also been reported by others [45]. A study including family members to persons with STBI concluded that experiencing loneliness was an independent predictor for increased burden [44]. Other studies of family members to STBI patients have described the long-term needs for both the injured persons and their families [9,12,20].

To achieve stability was the third subcategory and consisted of the importance of being able to mobilize strength, having the ability to look forward, managing reorientation, and acceptance. Stability was in some families described as stagnation, and searching for a change was desirable. On the other hand, the illness and the progress of recovery often increased closeness and the ability of families to achieve stability and return to old family roles. This can be compared with what is described as a strengths-based process unfolding over time towards a more holistic view of outcomes, such as reframing and positive appraisal [51] and to feel greater closeness underpinned by mutual respect, empathy, and understanding [15].

To strive from uncertainty to stability is a process of being thrown into chaos and slowly adapting to a new situation. Support is fundamental to be able to go through the ordeal and reach stability. Professional support by giving adequate information is one way to ease the transition, and support from both

family members and professionals can decrease loneliness and help to achieve stability. Closer relationships and better communication were aspects that helped the families to achieve stability even if STBI sometimes negatively affected family relations. Families were important for stability, but barriers were also seen, such as confronting substance abuse. This is also in line with what others have described [52]. Substance abuse before the injury had ceased in almost all of the families and contributed to stability. Substance abuse disorders are the most common pre-injury psychiatric diagnosis among individuals with TBI and the third most common psychiatric diagnosis post-injury [53]. There is a suggestion for screening individuals with TBI for drug and alcohol use after an injury in order to facilitate proper interventions if necessary [54].

Families, including children, need professional help to understand the recovery process after STBI and to get a chance to talk about it in order to avoid misunderstandings. In an earlier study, post-traumatic stress symptoms were identified in children with a parent who suffered from acquired brain injury [55]. Professional support also increases the possibility for the injured person to be closer to the situation or if necessary to reduce a sense of shame. Professional support that manages stress and anxiety might be important for these families [56], and as reported in this study also in a long-term perspective. To be ignored and treated with disrespect are reprehensible, but unfortunately this has been described earlier among persons with severe disability after STBI [57]. It is of importance to listen to STBI families' narratives independently of the injured person's outcome. Changes after the injury are not limited to the injured person, and family members are also changing as a result of their experiences. Thus they need help to understand the family situation [15].

We suggest that families should be addressed with long-term help and provided with professional support in line with results from other studies [10,45,48]. To invite families to health-promoting conversations, an experience-based intervention [38] might be a release and help for the families to improve their well-being. In a review study, the use of personal narrative approaches in addressing loss of identity following TBI were supported, and health care professionals were encouraged to help families build a strengths-based identity for individuals with TBI by telling and sharing their stories [58]. This approach is also something we recommend for the whole family together. To help families to realign and reconstruct themselves post-injury might be a helpful strategy for rehabilitation [25]. A problem also described in our study was that STBI survivors demonstrated limitations in verbal expression and narration and thereby perhaps do not experience the positive result expected from these interventions [50].

In order to adapt as a family after STBI, we identified three possible ways of interpreting the results of the family system and the family's adaptation to their situation after the STBI, up to 7 years after the injury. The three ways are linked to the injured person's recovery and to becoming a family unit again, demonstrating, for example, family functions and family strategies. Further research is needed to see if this interpretation can be found in other families as well.

The first way described the family as being as usual again and with an unexpectedly fast recovery. The family system had been restored and they lived their daily life in the present, which also included a goal for the future. A severe injury like this in the family could also be a source of concern and strength for the future. The second way described the family as somewhat unusual, describing how the family functioned nearly as it was before, and even if the social life was reduced, it was still good enough. The

injured person might still have some kind of behavioral problems that influences family daily living leading to, for example, stress, but even so these families had found a balance in life and a good possibility for leisure time. The third way described families as quite unusual, which covered a new way of living often with severe problems, and these families continued to struggle with a lack of self-confidence and burdensome changes in daily life. Family members felt anxious about how things would be for them, especially if they could no longer be the caregiver for the injured person.

These three ways of presenting family systems and adaptation have not, as far as we have seen, been described in this way before. Therefore, we have not discussed and compared this part of our results with other studies. The intention is that our results are one way to elucidate how STBI families adapt to the situation and serve as a way to illustrate family illness trajectories up to 7 years after the STBI. We believe that presenting our results in this way might be an eye opener for further research concerning families living with STBI.

Study strengths and limitations

This family system study can be seen as having a nearly total participation of families after STBI. All persons with STBI who were eligible from northern Sweden and who had participated in earlier follow-up studies were invited to participate together with their family members. The heterogeneous group of interviewed families gave a broad and varied, but also in many ways a common picture of their experiences up to 7 years after the incident. Thus, the results can be transferable to other families suffering from STBI.

The interviews were mostly conducted in the homes of the families, representing a safe and well-known environment. They had met the first author in earlier follow-up studies, which also contributed to a trustful interview situation in which they helped each other to narrate their illness story and thereby also learned from each other. There might be a risk of bias because the first author knew the families from before. However, the last author who performed the family interviews was unaware of the illness history of each family, thus limiting the risk of bias.

The authors' pre-understandings, i.e., knowledge of the participants (MS), medical knowledge of STBI rehabilitation (MS, B-MS), and knowledge of family systems and reactions under severe conditions (B-IS) is important to be aware of and to try to hold back. The internal consistency in this inductive study is shown through a thorough description of the analysis process and is strengthened with quotations from the text thus strengthening the trustworthiness, transferability, and quality of the study.

Individual family members did not always agree about what was talked about in the narratives, and some things were also unknown to the others. There were things that they had never discussed before. Because these interviews in some cases clarified things between the participants, the conversation then continued in, as we interpreted it, a forward direction.

Family interviews, including the family member with STBI, and the analysis focusing on the family as a system showing family strength and limitations was unique for studies on STBI families.

Conclusions

After 7 years, families with a member suffering from STBI described how they strived from uncertainty to stability and how they adapted as a family. It is important to provide a thorough

family assessment of family members' experiences of living as a family with STBI in order to understand which types of interventions families should be offered from professionals. Information and support in the short and long term were essential because STBI meant a change for the worse, but sometimes also for the better. There is a need to eliminate misunderstandings and that the families together with professionals understand the expected recovery process after STBI. Offering long-term rehabilitation and emotional conversational support to the whole family is recommended.

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