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Traumatic Brain Injury as an Invisible Disability: Institutional Barriers in Medical, Social and Financial Services in Finland

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Abstract: People who sustain traumatic brain injuries (TBIs) often experience unmet rehabilitation needs. The aim of our research was to explore how the invisible aspects of traumatic brain injury affect the experiences of survivors of TBI in accessing the necessary medical, social, and financial assistance. Using Giorgi's descriptive phenomenological inquiry, we purposefully sampled 11 participants who had experienced TBI when aged 13–27 for interviews. The time since their injuries ranged from 7 to 37 years. Three key themes emerged: (1) lack of knowledge and guidance in medical services, (2) lack of social service assistance, and (3) battles with insurance companies. Our findings show that, due to the hidden nature of TBI-related disabilities and a general lack of societal knowledge about TBI outcomes, survivors face significant difficulties in accessing essential medical, social, and financial services. This study underscores the critical need to address the challenges faced by youth survivors of TBI, as their injuries occur during a pivotal developmental phase when they are developing psychosocial skills, pursuing education, and transitioning into the workforce. Delays or lack of proper medical, social, and financial support hinder rehabilitation and the successful reintegration of these youth into society.

Keywords: traumatic brain injury (TBI); invisible disability; advocacy; phenomenology

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Received: 27 September 2024
Revised: 30 January 2025
Accepted: 3 February 2025
Published: 6 February 2025

Citation: Engström, O.E.; Katsui, H.; Ned, L. Traumatic Brain Injury as an Invisible Disability: Institutional Barriers in Medical, Social and Financial Services in Finland. *Disabilities* **2025**, *5*, 18. https://doi.org/10.3390/disabilities5010018

1. Introduction

Traumatic brain injury (TBI) is a global public health concern and a chronic disability that affects about 55 million people worldwide [1]. TBI is associated with a host of long-term physical, behavioral, social, and cognitive problems [2]. TBI is brain damage or a change in brain function due to external forces, including vehicle accidents, falls, episodes of violence, and contact sports [3]. It is one of the most common types of accidents among children, young adults, and older people and is a leading cause of death and disability [4]. Pediatric TBI has unique characteristics compared to adults due to age-related anatomical and physiological differences, injury patterns linked to physical abilities, and challenges in neurological evaluation. Research shows that children exhibit specific pathological responses to TBI with distinct neurological symptoms, prompting significant efforts to understand their pathophysiology [5].

While research on the life-long impact of pediatric traumatic brain injury is limited, existing studies indicate that TBI acquired during childhood and adolescence is a chronic health condition that has a negative long-term impact on quality of life [6–8]. Compared to adults, the consequences of TBI pose a greater risk for children and youth who are undergoing a vulnerable developmental stage [9–12]. During this period, youth develop higher-order cognition—a stage characterized by the accumulation of cognitively, psychologically, and socially demanding experiences that are vital for acquiring social interaction skills [13]. That is why neuropsychological impairments during childhood and adolescence have greater consequences, as they occur during critical developmental stages. Such impairments (e.g., attention deficit, difficulties with emotional self-regulation, memory problems, cognitive fatigue) are present across all types of TBI, from mild to severe, and manifest in areas such as academic performance and psychosocial functioning [12,14]. Consequently, they may also contribute to secondary conditions, such as oppositional defiant disorder (ODD) and attention deficit hyperactivity disorder (ADHD) [7]. These findings highlight the need for specialized rehabilitation programs and long-term follow-up care for youth who have suffered TBI.

A person who has sustained TBI is often referred to as a survivor. This term acknowledges the severity of their life-threatening experience and its long-term impact, which requires resilience and support [15,16]. Existing research indicates that survivors of TBI often encounter rehabilitation needs that have not been met [17], with their social care personnel and caregivers needing long-term support and guidance [18,19].

A variety of rehabilitation services for survivors of TBI is provided during inpatient and outpatient care. These include neuropsychological services, speech therapy, physical and occupational therapy, and psychological and vocational services. Unaddressed cognitive impairments and issues with emotional and social skills are the most common unmet needs in pediatric TBI rehabilitation [8]. Some research shows that psychological and educational services as well as speech therapy are lacking across all injury severities [7,12,20]. A few studies point out that it is children with mild TBI who have the highest unmet rehabilitation needs [8,20]. These issues can be attributed to insufficient research on the long-term outcomes of pediatric TBI [12] and the hitherto predominant focus on physical rehabilitation [8].

Within the frame of disability studies, our study looked at experiences of young people with TBI in different domains of their lives. Several themes came up across all domains, one of which is invisibility. This article reports on the theme of TBI as an invisible disability, which is an umbrella term for chronic physical, mental, neurological, psychological, or cognitive conditions or impairments that are not immediately observable but that can significantly impact a person's daily activities [21–23]. Some examples of invisible disabilities, aside from TBI, are rheumatoid arthritis, multiple sclerosis, chronic pain, mental illness, chronic migraine, stroke, post-traumatic stress disorder, attention deficit hyperactivity disorder, and mitochondrial disease [24,25].

Why is it important to address an invisible disability? The lack of visibility of someone's condition can lead to incorrect assumptions about their health and hasty conclusions about their disability status [26]. Research on invisible disability is still insufficient, but some existing studies indicate that people with invisible disabilities often face more negative attitudes than those with visible markers, such as assistive devices like wheelchairs or white canes [27,28]. Traumatic brain injury, as an invisible disability, is subject to similar challenges. The mistrust regarding the existence of disability among survivors of TBI stems from the public's lack of knowledge about TBI and its outcomes [29], highlighting the need to educate those who interact with survivors of TBI in their daily lives [30]. The invisible nature of traumatic brain injury can create challenges in social settings, where individuals with TBI often face misunderstandings [31] and unintentional invalidation of their struggles [32,33], which, as we already mentioned, leads to unaddressed rehabilitation needs. The objective of this study was to examine how the invisible aspects of TBI affect survivors' experiences in accessing the medical, social, and financial assistance they require.

2. Methodology

The Nordic countries, being welfare states with significant investments in healthcare, often position disability research within a paternalistic state framework, distancing it from addressing the needs most relevant to individuals with disabilities [34]—the very needs that people with disabilities wish to express themselves. This is why we chose to apply qualitative research using Giorgi's descriptive phenomenological method [35] to investigate the experiences narrated by survivors of TBI in seeking or attempting to access medical, social, and financial services. Following this method, descriptions of experiences are first presented by the participants. Next, the first author engages in a scientific phenomenological reduction while adopting the perspective of disability studies. This is followed by an analysis of the raw data to identify the fundamental structure of the experience, which is then described at a different level from the initial description [36].

2.1. Participants

We chose three criteria to select participants for our research—TBI, age of the injury, and long-term experience after the injury. Research participants were purposefully sampled [37] with the criteria that they had sustained mild, moderate, or severe TBI during youth and were between the ages of 13 and 27 when they acquired TBI. The diagnosis of TBI and its severity were self-reported by participants of our study.

Our choice is based on the previous studies about the higher-order cognition development during the youth—an active stage of accumulation of cognitively, psychologically, and socially demanding experience vital for developing skills for social interactions [13,38] and the evidence that TBI experience during youth carries increased risks of various health and social consequences [39–43].

So far, only a few studies have explored the long-term impact of TBI outcomes [41,44,45], with most research focusing on the short-term consequences of TBI on survivors' lives and limiting the post-injury period to 6 months [46]. The existing body of literature also highlights the need for studies on the long-term impact of TBI on survivors [47,48], emphasizing the importance of investigating and treating TBI as a chronic condition [49]. All but one of the participants in our research have more than 10 years of post-injury experience, which helps us to understand the long-term challenges of TBI.

The exclusion criterion was 'unable to speak independently about their own experiences'. It was essential for participants to articulate their personal experiences, as hearing their reflections on long-term experiences was a key component of the study.

Participants were recruited through the Traumatic Brain Injury Association (Aivovammaliitto), Finnish Disability Forum (Vammaisfoorumi), and Tatu Ry—the organization that arranges peer activities for children and young people with innate or acquired disabilities. In the written consent, participants were informed that no compensation would be provided to avoid response bias. However, after the interviews were completed, they received a modest monetary honorarium as a token of appreciation for their time and contribution to the study.

A total of 11 participants were recruited for personal phenomenological in-depth interviews, taking into consideration the recommended number of 10 for phenomenological research [50,51]. The demographic information of the participants is provided in Table 1 below. We reported the participants' ages at the time of injury as ranging from 13 to 27 years and at the time of the interview as ranging from 27 to 61 years to ensure pseudonymity. The post-injury period refers to the number of years that have passed from the year of the injury to the year when the interview was conducted for this research. The participants are named P1–P11 in this article.

Table 1. Participants demographics.

Participant	Post-Injury Period	Self-Reported Severity of Injury	Sex
P1	37	severe	female
P2	11	moderate	male
P3	21	moderate	male
P4	19	moderate	female
P5	30	severe	male
P6	25	moderate to severe	female
P7	48	severe	female
P8	12	moderate	male
P9	7	moderate	female
P10	22	mild to moderate	male
P11	10	severe	female

2.2. Data Collection

The interviews were conducted by the main researcher between May and June 2023. She is a grant-funded doctoral researcher in social policy and disability studies at the University of Helsinki and a white woman, aged 49 at the time of the interviews. Her ethnic background is the same as that of the participants in this study. The interviewer's age and experience of motherhood provided insight into interpreting participants' experiences in relation to their developmental stages before and after injury. The interviewer's previous knowledge, gained through several years of independent research into TBI and reading other survivors' stories, informed her understanding of the context. While she was aware of the general themes that might arise, she refrained from guiding participants with her questions, allowing them to tell their stories freely. This approach led to unexpected placements of topics within their narratives. For instance, while responding to a general question about their experiences in school and work, participants shared stories about insurance battles and challenges with medical services.

A phenomenological in-depth interview was conducted applying a 3-step approach [35,52]. The first step of the interview consisted of the same descriptive questions for all participants: How did TBI affect your relationship with family and friends? How did TBI affect your school and work experience? Do you still face any challenges today? These 1st step questions were offered as a written assignment to allow participants to answer them at their own pace. The questions were asked and answered via email. All participants completed this assignment within one to two weeks.

The second step of data collection was the audio interview. The interview consisted of structural questions based on each participant's individual answers to the 1st step questions. The third and final step of data collection included extra questions for clarity. Some participants answered these questions during the second step interview or in written form, via email, after the interview. The examples of 2nd step questions during the interview and 3rd step questions during the same interview or via email after the interview are presented in Table 2 below.

The interviews were audio recorded using a secure university platform allowing for the recording of sensitive data. The interviews were kept shorter than one hour upon the guidance of the Ethical Review Board due to the possibilities of emotional distress, and also physical and cognitive fatigue of the interview participants with TBI. Writing assignments and interviews were completed in the Finnish language and translated into English. All the data were immediately transcribed verbatim and pseudonymized, and identifying data were removed. Correspondence was deleted immediately upon receiving emails after saving the data. Audio recordings of interviews were deleted once they had been transcribed.

Table 2. Examples of 2nd and 3rd step questions.

Participant	2nd Step Questions	3rd Step Questions
P3	Did doctors understand your challenges?	How would a better understanding of your TBI and its outcomes by doctors and insurance companies affect your life?
P4	What help did you try to get?	What help do you think you needed back then? What help do you still need?
P6	What did doctors tell you? How did they explain brain injury to you? Did you try to explain your symptoms to doctors and how did they respond?	What help would you have needed from doctors during your first years of rehabilitation and still need now?

2.3. Data Analysis

Data analysis followed a descriptive phenomenological method as outlined by Giorgi and Giorgi [36]. First, the data were read several times to obtain a holistic overview. During the ensuing step, the description of the participants' experiences was divided into meaning units to reveal the significance of an experience by analyzing detailed and extensive descriptions. Then, the meanings shared by the participants were interpreted in a way that highlighted the disabling environment, rather than focusing directly on the participant's individual life or personal circumstances. The final step was to apply an imaginative variation to transform meaning units in order to determine their essential aspects. The most consistent meanings associated with the experience were described to form the overall structure. The three following themes, representing the invisibility of TBI conditions, emerged: (1) lack of knowledge and guidance in medical services, (2) lack of social service assistance, and (3) battles with insurance companies.

3. Findings

To underscore the critical need for comprehensive medical, social, and financial support, we begin this section by outlining the diverse symptoms self-reported by participants following TBI. For all participants, TBI resulted from a traffic accident. Four self-reported symptoms or conditions were shared by most participants: cognitive fatigue, mental health issues, burnout, and memory problems. The specific mental health issues varied among participants and included depression, difficulty regulating emotions, suicide attempts, issues with alcohol consumption, experiencing mentally tough situations, suicidal thoughts, flat affect, anger, eating disorders, and post-traumatic stress disorder. Only one participant reported seeking and receiving psychological help.

Each participant also reported experiencing additional symptoms or conditions—or combinations of two to three symptoms—that were not necessarily shared with others. These included balance issues; blurry vision; confusion; difficulty reading; trouble understanding directions, place, and time; dizziness; epileptic seizures; migraines; lack of memory of the accident immediately after it occurred; unawareness of TBI-related outcomes or disabilities after the accident; concentration problems; resistance to being labeled as disabled; sensitivity to colors, light, loud sounds or voices; difficulty getting up in the morning; sensitivity to smells; sleep disturbances; a tendency to get lost; a tendency to make mistakes; and episodes of unconsciousness.

3.1. Issues with Medical Services

This theme described survivors' experiences of medical personnel's lack of knowledge, guidance, and explanation about TBI, which left them confused about their symptoms.

The lack of support led to mistrust, misdiagnoses, delayed rehabilitation, burnout, and secondary disabilities, emphasizing the critical need for timely and accessible rehabilitation services. Three subthemes related to participants' experiences of accessing medical services were identified under this theme: (1) lack of knowledge about TBI among medical personnel; (2) insufficient guidance provided by medical personnel; (3) delayed rehabilitation.

3.1.1. Lack of Knowledge About TBI Among Medical Personnel

Most survivors reported that they experienced medical personnel's lack of knowledge about TBI during their long-term life experience following TBI:

> *In encounters with health care personnel, I notice a lack of knowledge about brain injury and its associated diseases, which causes frustration and unnecessary visits to doctors.* (P1)

TBI symptoms could even be interpreted as different diagnoses:

> *I talked to a psychiatrist about renewing my medication [prescription], which was earlier issued by a neurologist outside [name of the hospital], which is like an ADHD medication, but it is prescribed to some survivors of TBI, because of fatigue as the main condition. He didn't agree to renew it . . . When I said that I don't have ADHD, that I have moderate TBI, he somehow denied that I had it.* (P2)

3.1.2. Insufficient Guidance Provided by Medical Personnel

When dealing with medical services, survivors also encountered a lack of guidance and explanation. For instance, the medical staff did not explain what TBI is and what consequences it might have on a survivor's life:

> *I was told right away [about the TBI diagnosis], but I didn't realize it myself in that situation. I would have liked the matter to have been discussed in more detail later. [The doctors] did not go through anything. They just went through things quickly and wrote a letter and asked how I was doing.* (P8)

The lack of explanation and guidance from medical personnel left participants feeling confused about their own symptoms:

> *The matter [damage] was belittled by the neurologist. And then that neuropsychologist in [town name] also [said that] the brain regenerates well. . . . I wasn't told anything about the brain injury right away, and then at home I just started wondering why miraculously I didn't remember something. What's wrong?—I asked the orthopedist . . . That's how I got to that neuropsychologist for tests. Not right away.* (P3)

> *No one even told me about this brain injury; I was just told that yes, you have a brain injury. I was told that for now, you just try to recover and go back to work. . . . I was so completely confused . . . I was so shocked myself and I didn't even understand what TBI is . . . So I just went to work, but then I kept wondering why I had such a strange, confused feeling, of course, because I had those symptoms so strongly and I should probably have been on sick leave for a year because I had such massive fractures and the brain injury.* (P4)

3.1.3. Delayed Rehabilitation

Lack of knowledge and guidance led to situations when the survivors did not understand their own challenges or the source of the symptoms they experienced as well as mistrust from doctors, wrong diagnoses, and delayed rehabilitation. When talking about rehabilitation, survivors mostly referred to neuropsychological rehabilitation and physiotherapy. Even though most of the survivors reported on receiving rehabilitation, a few reported not receiving rehabilitation: *'But I didn't get any rehabilitation. No one told me what it meant . . . and . . . my sick leave was over . . . and then you just went to work'.* (P4)

Some survivors mentioned that rehabilitation was delayed, and in some cases, they had to fight for it:

> . . .*at that time there was no magnetic resonance imaging yet, I think . . . Would you have seen any brain bleeding then? . . . I have subsequently received neuropsychological tests. I have received rehabilitation afterwards. . . . but when they have come like 16 years late. If I had received it, then [after the injury] . . . I could have avoided a lot of things. Not such horrible things.* (P6)

> . . . *[what needs to be changed] the persons with disabilities would be offered all possible rehabilitation right away. In many cases, people with disabilities have to demand rehabilitation, and it takes too much energy, and thus many people don't get it.* (P8)

Delayed or unreceived rehabilitation put negative pressure on the personal and social relationships of some of the participants:

> *I got into rehabilitation that same year [2 years after the injury]. We got divorced after that rehabilitation. Maybe that rehabilitation should have been much earlier. Then she would have understood where all that came from . . . I myself didn't understand what it was all about . . .* (P3)

Many participants felt something was wrong after the accident, highlighting the need for rehabilitation. However, rehabilitation was not automatic, particularly for those with mild or moderate TBI. Participants often had to discover, pursue, and demand rehabilitation services, which were not always provided promptly. Delayed rehabilitation caused confusion, burnout, and sometimes secondary disabilities. Survivors reported prolonged struggles in understanding their condition due to these delays, emphasizing the critical need for timely and accessible rehabilitation services.

3.2. Deficiency in Social Service Support

This theme illustrated survivors' struggles in accessing social services due to providers' lack of knowledge about TBI and understanding of their challenges, leaving survivors without proper guidance on available support and how to access it. The following two sub-themes were uncovered: (1) lack of TBI awareness among social services personnel; (2) lack of guidance on services and support for survivors of TBI.

3.2.1. Lack of TBI Awareness Among Social Services Personnel

The survivors experienced issues when trying to access social services as persons with disabilities. Social services are similarly important to the participants because they are the ones expected to connect them to social and disability services. However, the problems are similar to those with medical services—social service providers lack knowledge about TBI and hence lack understanding of the challenges faced by survivors:

> *There was a whole family present [at family counselling once] . . . but of course, they [family] didn't understand the part about the brain injury themselves, the family counselor didn't understand the part about the brain injury either, especially when I had not received a proper rehabilitation yet.* (P3)

In social services, there is a lack of understanding that managing complicated tasks and dealing with multiple entities is a difficult cognitive challenge for a person with TBI:

> *I dealt with many, many different officials [of National institution providing social services] in the course of a couple, of 3 months . . . it's a very bureaucratic . . . really bureaucratic machinery . . . which is [for person with] brain injury isn't quite right, it's . . . difficult [to grasp].* (P2)

3.2.2. Lack of Guidance on Services and Support for Survivors of TBI

Furthermore, according to the participants, they often lacked guidance about what help and services survivors of TBI are entitled to and where and how to seek the help.

Some participants expressed a wish to get the help of a social worker to learn what support they are entitled to, to get childcare assistance, and navigate application processes:

> *I called the municipality's social service, if it would be possible to get any childcare assistance. We don't have anything [they answered]. . . . I didn't understand how to apply for any help. There should be someone, a social service worker or someone like that, who should take care of these people with disabilities, because at some point one is so tired of that job [of seeking help].* (P1)

> *There were a lot of challenges with the brain injury, and I didn't really get help from anything. . . . I didn't even know where to go for help. I didn't have anything like treatment contacts or anything. . . . I mean, that was already the first problem in my opinion, that no one, even a social worker or someone, told me how this works.* (P4)

Participants reported difficulties navigating the social service landscape and expressed a desire for guidance and assistance in these matters.

3.3. Battles with Insurance Companies

This theme highlighted survivors' prolonged battles with insurance companies, which often dismissed their symptoms as unrelated to TBI and manipulated the process to reach negative decisions. Three sub-themes have emerged: (1) experience as a fight; (2) denial of connection between symptoms and injury; (3) manipulation of the decision-making process.

3.3.1. Experience as a Fight

Confusion with medical services and ambiguity of diagnosis led to delayed or denied insurance compensation. Almost all survivors reported long fights with insurance companies: '*I had been fighting for this pension for 4 years.*' (P7); '*we had a lawsuit against the insurance company for a long time [9–10 years]*' (P10). Survivors described this experience as draining both financial resources and their own stamina, keeping them in a state of victimhood:

> *Fighting with the insurance company for compensation, and after it fails, dealing with [the Social Insurance Institution of Finland]. This creates an experience of otherness and passivity in the face of faceless bureaucracy as only a victim and not an actor.* (P2)

> *There were a lot of challenges with the brain injury, and I didn't really get help from anywhere. In addition, I had to fight with the insurance company for rights and compensations for years, which took my ability to work to zero.* (P4)

3.3.2. Denial of Connection Between Symptoms and Injury

Almost half of survivors explained that insurance companies insisted that '*all the symptoms are not the cause of the crash*' (P3); '*After a year, they just said that these symptoms were not caused by that injury.*' (P4) and denied the causal connection between the reported symptoms and TBI:

> *. . .now I have this [condition] which was diagnosed back in [5–7 years after the injury] related to this brain injury; now the insurance company says that it is not a causal connection.* (P1)

> *They [insurance company] think that when I have these symptoms, such as fatigue and exhaustion, sensitivity, and difficulty in controlling emotions, they think that the reason*

> *for bothering is not justified . . . They also consider that it is not possible to prove a causal connection for sure, that it would be due to a brain injury.* (P2)

3.3.3. Manipulation of the Decision-Making Process

Some survivors thought that insurance companies manipulated the process towards a negative decision:

> *But in my opinion . . . they can suddenly turn a positive decision into a negative one. This is what I have heard about from many [other people].* (P1)

> *The insurance company canceled my contract. . . . They had a loophole in it. It was in the small print in the insurance [contract] that if it became too expensive, then they could cancel it.* (P9)

P5 reported a paradox of disability notion manipulation:

> *Some people consider me too disabled and on the other hand some consider me too healthy to be disabled.* (P5)

The interpretation of disability was used when P5 applied for monetary support from the municipality and an insurance company. These entities interpreted the participant's degree of disability differently and rejected the applications for financial support. More precisely, P5 asked for financial support from the insurance company for re-education and received a negative response:

> *The insurance company considered me 'too disabled to ever return to working life'. Disability services were denied by municipality stating that 'I am too healthy to be [categorized as] disabled'. Many people know too little about brain injury, you know. They have no information.* (P5)

Insurance companies usually provided their own doctors to work on customers' cases, and the decisions of these doctors could conflict with the statements of survivors' doctors, who diagnosed them:

> *The insurance company stated that my study performance is proof that the post-traumatic brain injury condition was not moderate, that it is mild at most . . . But none of this is supported by [my] neurologists. My neurologists have always talked about a moderate brain injury . . .* (P2)

In sum, battles with insurance companies that lasted for several years were a collective experience for the survivors. The two main issues named were that insurance companies denied the causal connection between survivors' symptoms or conditions and TBI and the perception that insurance companies manipulated the decision-making process towards negative decisions. Such decisions made by the insurance company led to the denial of insurance compensation and drained personal financial and health resources. The negative psychosocial effect of the issues with insurance companies was highlighted by many participants.

4. Discussion

The experiences of adult participants of our research who had sustained TBI during their youth were important for understanding the long-term challenges following the injury. Our findings show that the invisible nature of traumatic brain injury and a lack of knowledge about the long-term outcomes of traumatic brain injury pose challenges for survivors of TBI regarding receiving appropriate medical, social, and financial services. For example, our data showed that the invisible nature of TBI made it challenging for the interviewed survivors to ask for and receive the appropriate assistance, as was also found in Lingsom [27]. The interviewed survivors of TBI were faced with difficulties in claiming the status of a person with disabilities and obtaining the services required because of the invisible nature of their disabilities. They are often viewed as people with capacity and in no need of assistance in various contexts. However, people with TBI do need disability services but cannot get them due to the deterioration of their social communication skills and their lack of an advocate to help them express their needs comprehensively [53,54].

These issues may be attributed to the lack of understanding of TBI conditions, which, combined with incorrect guidance from primary care physicians—who describe mild TBI as an uncomplicated diagnosis with the expectation of a quick recovery—results in survivors being left to manage their symptoms on their own without clear guidance [33]. Additionally, some health professionals misjudge the impact of TBI on survivors' behavior and deny the required treatment [29]—an experience reported by some participants of our research. During the post-acute phase there is a more pronounced need to negotiate the out-patient healthcare services, but due to cognitive impairment, the survivors of TBI face difficulties in communicating their own need for treatment, rehabilitation, and assisting services [55].

Some Brain Injury Associations, e.g., [56], which carry out the mission of educating and supporting survivors of TBI and their families, advocate for the classification of TBI as a chronic condition. Our data support such a view of TBI and show that TBI results in long-term and persistent conditions that are often not acknowledged by medical professionals, thus leaving survivors with limited support in managing their life-long disability.

The symptoms described by survivors of TBI are sometimes disregarded or misdiagnosed. Lack of knowledge might result, for example, in wrongful assessment of the abilities of survivors of TBI and hence the appropriate treatment [30,57]. Insurance companies commonly disregard traumatic brain injuries [58]. Sometimes, the reason is that symptoms are overlooked for months or years after the injuries. Usually, insurance companies reject cases of severe TBI and appoint their own doctors to make a diagnosis. There are cases of neuropsychologists hired by the insurance company downplaying the impact of TBI, and it generally becomes much harder to prove the severity of TBI outcomes if the correct medical assessment is delayed [58]. Almost all participants experienced such battles with insurance companies.

The study findings also highlight that the disability of survivors of TBI is often unacknowledged when they attempt to access medical, social, or financial assistance. Additionally, the fatigue and social difficulties they experience make it challenging to advocate for themselves against the institutions providing such services. As a result, their invisibility is reinforced. Our data indicates that TBI leads to many negative and tangible consequences for survivors. We see two main reasons for the challenges faced by the participants in our research in gaining access to medical, social, and financial services: the ambiguity of the disability status of TBI and communication problems.

The first reason for obstacles in gaining access to medical, social, and financial services is the non-existent status of disability for those who struggle with the challenging outcomes of TBI. According to the Finnish Disability Service Act [59], a person with disabilities is someone who faces long-term or permanent physical, psychological, social, cognitive, or sensory challenges that affect their lives as a result of an injury or illness. The traumatic brain injuries of participants happened during a period when TBI was seen as purely an injury with prospects of full recovery, but even today, it is still emerging as a chronic condition [49]. Thus, before a survivor of TBI can claim a customer plan [59] after assessments of their service needs, TBI needs to be officially recognized as a long-term challenging condition.

Individuals with invisible disabilities such as TBI face additional burdens in proving their need for assistance, as their conditions are not always evident to bureaucratic systems.

They often encounter institutional mistrust. Welfare and healthcare systems operate with rigid definitions of disability, demanding visible markers of impairment as proof [60]. This approach can exclude individuals with less visible conditions like TBI, foster mistrust, and create obstacles in accessing services. The ambiguity surrounding TBI highlights the need for greater attention to survivors' lived experiences. Medical and social institutions should be more receptive to these personal narratives to better understand and address the challenges faced by individuals with invisible disabilities.

This takes us to the second obstacle to obtaining the required services, which is a communication issue. As our data show, survivors of TBI lack the knowledge and cognitive strength to communicate their own needs in a comprehensible manner to medical, social, and financial institutions. We see that advocacy is a missing empowering tool for participants in negotiating and receiving the required services. In disability studies, the importance of self-advocacy is well discussed [61–63]. Self-advocacy is understood as the act of advocating for one's needs, preferences, and choices [64,65]. Skills in self-advocacy are important for survivors of TBI [66,67] to be able to explain the ongoing challenges related to TBI. Advocacy is needed, especially through the post-acute phase of rehabilitation and reintegration into society after the injury. However, due to their cognitive disabilities, survivors of TBI have a range of needs that are difficult to fulfill on their own.

Many health and social care representatives, such as social workers, play advocacy roles due to the nature of their profession [68]. However, our research lacked stories about social worker input. When asked if they had a case worker or disability service assistant, all the participants answered negatively. Social workers are sometimes assigned to people with disabilities, but issues arise with survivors of TBI due to a lack of knowledge about TBI outcomes and needs [69].

The obstacles TBI survivors face in accessing necessary services stem from both the lack of recognition of their disability and communication barriers. The invisibility of TBI as a disability often prevents survivors from receiving the medical, social, and financial support they need, as their condition is not always recognized by institutional systems. Furthermore, survivors frequently struggle to effectively communicate their needs due to cognitive challenges, increasing the difficulty of navigating these systems. While some social care professionals, such as social workers, may play an advocacy role, our research found a lack of reported involvement from them in the survivors' experiences. We see a need for tailored training for social workers who are specialized in disability services and have knowledge of TBI, as well as ensuring the availability of these professionals. This would enable social workers to assist survivors in expressing their requirements and accessing support, acting as advocates and key points of contact to guide survivors through the service systems.

The obstacles mentioned can delay access to critical rehabilitation, social services, and financial support, especially for young survivors of TBI. This issue is particularly significant for those transitioning into adulthood, as they may lack the practical skills needed to communicate effectively with societal institutions. Adolescence and youth are also critical periods for developing psychosocial skills essential for sustaining adulthood [13,38]. If young survivors of TBI experience delays or are not provided with the proper medical, social, and financial assistance during this time, they may face significant gaps in their development, which could have long-term consequences on their well-being and independence.

5. Limitations of the Study

There are a few limitations that must be taken into account when considering the results of our study. This is qualitative research with a phenomenological approach, and we cannot make claims about the generalizability of our findings. It is still possible that participants' experiences correspond to those of other survivors of TBI in social and institutional settings.

This study is based on the self-reflections and recollections of survivors of TBI. Due to memory issues, we leave space for discrepancies in the information provided. All participants in the interview mentioned that they were social by nature. That means that our results might not fully represent the challenges of survivors who are, for example, shy or have deficits in communication skills or more severe cognitive impairments. In this regard, we should assume that the situation of survivors of TBI could generally be different and perhaps worse.

One limitation of this study is that the diagnosis of participants was self-reported, which may introduce potential biases. Participants' self-assessment of their condition may not always align with clinical diagnoses, and there is a possibility of overreporting or underreporting due to personal perceptions or social desirability. Future studies could benefit from including clinical assessments to validate self-reported diagnoses.

Our results present a roadmap for further investigations of TBI as an invisible disability and, in conjunction with this, unmet rehabilitative needs such as cognitive and psychosocial rehabilitation. We recognize the need for further longitudinal study on a larger scale to understand the dynamic of recovering after youth TBI and survivors' needs at different stages of the long-term post-injury phase. Such an approach to investigation would guide the development of more holistic rehabilitation programs and disability services design.

6. Conclusions

The invisible nature of TBI outcomes, combined with a lack of knowledge about TBI among medical and social services professionals, as well as a lack of guidance and assistance, makes it difficult for survivors to receive the services they require during the chronic phase post-injury. This often results in their disability going unacknowledged, complicating their understanding of their own symptoms in the first few years after the injury. Consequently, survivors face challenges in accessing rehabilitation, disability services, and financial compensation. These difficulties make it hard for them to explain their challenges to the public and navigate their lives effectively. Medical follow-ups during the chronic phase of recovery, along with advocacy by a social worker specializing in disability services and knowledgeable about TBI, would make it easier for survivors of TBI to communicate their needs and have those needs met. Such assistance is crucial, especially for survivors of TBI who sustain injuries during youth, the most important developmental stage for acquiring psychosocial skills and education and determining future employment or disability pension outcomes.

Author Contributions: Conceptualization, O.E.E.; methodology, O.E.E.; validation, O.E.E. and H.K.; formal analysis, O.E.E.; investigation, O.E.E.; writing—original draft preparation, O.E.E.; writing—revisions and editing, O.E.E., H.K. and L.N.; supervision, H.K. and L.N.; project administration, O.E.E. and H.K.; funding acquisition, O.E.E. All authors have read and agreed to the published version of the manuscript.

Funding: This work was supported by Suomen Kulttuurirahasto (the Finnish Cultural Foundation), grant number 00230303, awarded on 30 January 2023.

Institutional Review Board Statement: Ethical approval for research was obtained from the Ethical Review Board in the Humanities and Social and Behavioural Sciences at University of Helsinki. Ethical Review Statement 20/2022, 17 February 2022.

Informed Consent Statement: Prior to the interviews, and in accordance with the ethical principles of the University of Helsinki, all participants were given the following documents to consent to voluntary participation in the research: research information for research participants, informed consent, and data protection statement/notification of scientific research EU General Data Protection Regulation Articles 12–14. All data has been pseudonymized. The first step of the interview was set up as a written assignment to reduce participants' stress connected to traumatic events.

Data Availability Statement: The data are classified as sensitive due to the TBI diagnosis; therefore, we are not sharing them with others.

Acknowledgments: We are grateful for the participation of the 11 TBI survivors in this study. Without them and their life stories, this study would have been impossible. We appreciate the help of the Finnish Traumatic Brain Injury Association (Aivovammaliitto), the Finnish Disability Forum (Vammaisfoorumi), and Tatu Ry in recruiting participants for our research.

Conflicts of Interest: The authors declare no conflicts of interest.

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