Striving to become familiar with life with traumatic brain injury

Experiences of people with traumatic brain injury and their close relatives

Eija Jumisko
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To Oula, Anna-Maria and Hanna-Reetta

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Striving to become familiar with life with traumatic brain injury: Experiences of people with traumatic brain injury and their close relatives.

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ABSTRACT
The overall aim of the doctoral thesis was to elucidate the meaning of living with traumatic brain injury (TBI) for people with TBI and for their close relatives. The data were collected by means of qualitative research interviews with people with moderate or severe TBI (I, III, IV) and their close relatives (II, III), and were then analyzed using a phenomenological hermeneutic interpretation (I, II, IV) and thematic content analysis (III).

This study shows that living with moderate or severe TBI means living with a perpetually altered body that changed the whole life and caused deep suffering, where feelings of shame and dignity competed with each other. People with TBI lost their way and struggled to achieve a new normalcy. Losing one’s way included experiences of waking up to unknown, missing relationships and experiencing the body as an enemy. Struggles to attain a new normalcy included searching for an explanation, recovering the self, wishing to be treated with respect, and finding a new way of living. Feeling well, for people with moderate or severe TBI, means that the unfamiliar life with TBI has become familiar. This included finding strength, regaining power over everyday life, being close to someone and being good enough. People with TBI felt well when they reconciled themselves with the circumstances of their life, that is, they formed a new entity in that life where they had lost their complete health.

Living with a person with moderate or severe TBI means that close relatives fight not to lose their foothold when it becomes essential for them to take increased responsibility. They struggled with their own suffering and compassion for the person with TBI. Close relatives' willingness to fight for the ill person derived from their feeling of natural love and the ethical demand to care and be responsible for the other. Natural love between the person with TBI and close relatives and other family members gives them the strength to fight.

People with TBI and their close relatives had experiences of being avoided, being ruled by the authorities, being met with distrustfulness and being misjudged. They also searched for answers and longed for the right kind of help. People who listened to them, believed them and tried to understand and help them were appreciated.

This thesis shows that people with TBI and their close relatives experienced deep suffering where they struggled between evil and good, suffering and desire. They had moments of hopelessness but they strived to become familiar with a life with TBI. Their suffering was alleviated when they were able to understand their experiences, experienced love and had someone to share their suffering with, and felt satisfaction and happiness. People with TBI and their close relatives have experiences of suffering of care. It is crucial that they meet professionals who have knowledge about TBI and really understand the suffering it causes for them as individuals and as a family.

Keywords: traumatic, brain injuries, family, family members, qualitative research, interviews, phenomenological, hermeneutics, interpretation, content analysis, suffering.
ORIGINAL PAPERS

This doctoral thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


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INTRODUCTION

This doctoral thesis focuses on the meaning of the lived experiences involved in daily life with traumatic brain injury (TBI) from the perspective of people with moderate or severe TBI and their close relatives. This knowledge is fundamental for people with TBI and their close relatives so they can receive help.

A life-world perspective

The German philosopher Edmund Husserl introduced the concept of the life-world, the world of the lived experience. The life-world is the world people live daily and experience pre-reflectively, without conceptualizing, categorizing, or reflecting on it. This world is often taken for granted (van Manen, 1990). Further, Merleau-Ponty (1945/1997) pointed out that it is by means of the body that people have access to the life-world. When it is healthy, the body carries out people’s projects in the world and they are not aware of it. The body is invisible, forgotten, or surpassed because ‘I am my body’ and there is no separation between the body and the self. The body can be objectified and become present for oneself and other people in certain situations. For instance, during sexual arousal or sports activities, people become aware of their body and enjoy it. In illness, people are forced to be aware of the body and experience it as an alien presence (Toombs, 1993). Because the body is present in everything a person does, every change in the body also changes that person’s being in the world (Merleau-Ponty, 1945/1997).

The life-world is a phenomenological concept because phenomenology is concerned with lived experiences (Dahlberg & Drew, 1997). According to van Manen (1990, p. 9), in phenomenological research, the researcher asks ‘what is this or that kind of experience like?’ It can be understood as a description of a phenomenon in a way that reveals the structure of lived experience in a hitherto hidden way. Lived experience can only be grasped as a past presence and never in its immediate presence because it is difficult to reflect on it while it is being lived through. Through mediations, conversations, and other interpretative acts, its meaning can be made explicit. Dahlberg and Dahlberg (2004) noted that, in life-world research, the task is to ’explore the
invisible by using the visible as a point of departure.' According to Bengtsson (2005), it is possible to achieve enlarged and deepened knowledge about the life-world of other people because it is never totally foreign to us. People always understand and communicate with each other through their life-worlds. They also transmit aspects of the life-world from one generation to another.

**Living with chronic illness**

Irrespective of whether the illness is acute or chronic, the person suffering from it is forced to confront life’s vulnerability and unpredictability. With the occurrence of moderate or severe TBI, the person moves rapidly from being healthy, through a life-threatening episode, to a state of having a chronic illness. This change is so rapid that the afflicted person and their close relatives may find it difficult to understand what has happened (cf. Duff, 2002).

According to Corbin and Strauss (1987), the main issue for people with chronic illness is the failure of their body, which profoundly changes their lives. Studies (e.g., Backman, del Fabro Smith, Montie & Suto, 2007; Heuer & Lausch, 2006; Kanervisto, Kaistila & Paavilainen, 2007; Lütze & Archenholtz, 2007; Olsson, 2007) showed that the body becomes a barrier to performing activities in daily life in a desired way. People with chronic illness are forced to pay attention to the body and structure their everyday life according to the body's limitations involving fatigue and lack of energy.

Isaksson and Ahlström (2006) and Whitehead (2006) noted that the time before getting the diagnosis is experienced as frightening and filled with agony. Experiences of receiving the diagnosis vary from shock, fear, anxiety, sorrow, and uncertainty to relief after getting an explanation and confirmation of the illness symptoms. According to Toombs (1993), people with illness experience loss of control in life and to them, the future disappears because the goals they had before their illness become unachievable and they are preoccupied with the demands of the here and now. Strandmark (2004) maintains that the essence of deficient health is powerlessness, when the ill person experiences worthlessness and suffering and when the illness restricts the ability to live life as they hoped. The treatment brings added difficulties as time is spent travelling to
and from clinics, and undergoing tests and treatments that may be exhausting (Kleinman, 1988). A fundamental form of suffering in chronic illness is the loss of self when the person with the illness loses their former self-image without simultaneously developing an equally valued image (Charmaz, 1983; 1987). Living one day at a time allows focusing on the illness and treatment and gives a sense of control and a way to relinquish one's past visions of the future (Charmaz, 1997).

Life with chronic illness requires a lot of diligence and vigilance (Corbin & Strauss, 1987). Olsson (2007) argued that the inability to go on to live one's life as expected can be seen as restricted freedom in everyday life and, at the same time, a feat for freedom in everyday life exists. A feat for freedom involves choosing to involve oneself in everyday life rather than to withdraw from it. Thorne and Paterson (2000) state that coming to terms with chronic illness involves a process of mastery and normalization. Living with it shifts from experiencing the illness as being in the background of consciousness to that of overwhelmingly experiencing it as a thing that dominates one's whole life. Experiences of hope give energy and power (Lohne & Severinsson, 2006). Finding new perspectives in life and personal development and growth are the positive dimensions of living with a chronic illness (e.g., Kanervisto et al., 2007; Lohne & Severinsson, 2006; Mayan, Morse & Eldershaw, 2006; Whitehead, 2006).

**Being a close relative of a person with chronic illness**

Close relatives are extremely important to a person with chronic illness. They increase the ill person's feeling of safety (Kanervisto et al., 2007) and motivation to participate in occupation (Isaksson, Lexell & Skär, 2007). Living with a person with chronic illness has a threatening effect on the lives of the close relatives. Close relatives experience total disruption in their life when their family member sustains a serious illness (Öhman & Söderberg, 2004). Studies (Chang & Horrocks, 2006; Öhman & Söderberg, 2004) showed that close relatives want to be near and to do as much as they can for the person with chronic illness. They experience distress, frustration, ambiguity, anxiety, and suffering because they must handle their own life situation on a daily basis while dealing with additional situations related to the chronic illness (Svavarsdottir, 2006). Chang and Horrocks (2006) reported that close relatives living with a person with a
mental illness had to endure embarrassing and aggressive behavior from the person with the illness. They also experience pervasive and strong stigma.

Close relatives to people with chronic illness are more housebound and experience a shrinking life (Kanervisto et al., 2007; Öhman & Söderberg, 2004). They must continually shift the patterns of their life and act to accommodate and change their dreams and hopes to suit the realities of the person with illness (Chesla, 2005). Grant and Davis (1997) noted that close relatives of a person with a serious chronic illness experience loss of the familiar and autonomous self because they were forced to assume new roles and responsibilities and to restrict their activities to fit in with the person with the illness. They experience fear and uncertainty about the future and try to live one day at a time (Öhman & Söderberg, 2004). A review (Lim & Zebrack, 2004) showed that the role changes, responsibility, and caregiving demands are difficult to resolve and often become a source of chronic strain for the close relatives. Chronic illness complicates the relationships within the family. In a study (Isaksson, Skär & Lexell, 2005), close relatives of women with spinal cord injury took too much responsibility and the women with illness felt that they were treated like a child. They emphasized that, in order to maintain their role as an adult, they should take responsibility for their relations with close relatives.

**Traumatic brain injury**

Traumatic brain injury can be seen as a chronic illness that results from an external trauma following rapid acceleration/deceleration or violent contact of forces with the head (Kushner, 1998). The primary injury from a TBI, after the initial impact, can lead to contusions, epidural and subdural hematomas, and skull fractures (Lovasik, Kerr & Alexander, 2001). Physiological responses to primary injury like cerebral edema, increased intracranial pressure (ICP), cerebral ischemia, hypotension, and infection are the most common causes of secondary injury (Nolan, 2005; Zink, 2005).

Traumatic brain injury can be classified as mild, moderate, or severe, according to the Glasgow Coma Scale (GCS), which is the most common method for classifying the severity of the injury (Lovasik et al., 2001). Lovasik et al. (2001) stress that TBI is a
significant world health problem despite declines in occurrence. The overall incidence rate in Europe is about 235/100,000/year (Berg, Tagliaferri & Servadei, 2005). The main causes of TBI are falls, traffic accidents, violence, and sports accidents (Lovasik et al., 2001; National Institutes of Health [NIH], 1998). Fall is the most common cause in northern Europe and road traffic accident in southern Europe. Except in the UK, violence-related injuries are not as great a problem in Europe, differently from USA (Berg et al., 2005). According to Nolan (2005), those at highest risk for TBI are infants between 6 months and two years, males between 15 and 30 years, young children in school age, and the elderly. In Sweden, about 15,000 individuals are hospitalized every year as a result of TBI and a majority of them sustain a mild TBI (Lexell, 2007). In a study in Norrbotten (Jacobsson, Westerberg & Lexell, in press), the majority of people with TBI were older and sustained mild TBI as a result of a fall. The highest occurrence of falls was in the 70–79 age group. There was a strong association between traffic accidents, severe TBI, and young age. The majority of people sustaining TBI were men.

A large number of people with mild TBI may not go to hospital at all or are discharged without followup. The person with moderate or severe TBI often has associated injuries and continuing medical and surgical needs (Das-Gupta & Turner-Stokes, 2002). The focus of TBI management is to control the ICP and cerebral perfusion pressure and prevent complications (e.g., cardiovasculary, pulmonary, and musculoskeletal) (Nolan, 2005; Zink, 2005).

Gordon et al. (2006) mention several studies that reveal the benefits of early rehabilitation. In Sweden, TBI rehabilitation is based on the philosophy of interdisciplinary, team-based, and goal-oriented services that aims to reduce disability and improve functioning within a person's environment and from his/her perspective. Most people with TBI are in need of both in-patient and outpatient services with emphasis on community reentry and vocational training (Lexell, 2007). Further, family intervention as part of the rehabilitation process is crucial (e.g., Nolan, 2005; Verhaeghe...
et al., 2005; Zink, 2005). Research on the outcomes of various rehabilitation programs is complicated and still in its infancy (Gordon et al., 2006; Lexell, 2007).

**Living with a traumatic brain injury**

People with TBI are confronted with various long-lasting problems. A TBI may result in physical impairment, cognitive, emotional, and behavioral problems that all impact on a person’s interpersonal relationships. Physical consequences can vary, for example, reduced motor function, headache, sleep disturbances (Hibbard, Uysal, Sliwinski & Gordon, 1998; NIH, 1998), and fatigue (Brewin & Lewis, 2001; Paterson & Stewart, 2002). One of the most common cognitive impairments is that of impaired memory, which people with TBI have described as an unpleasant and frightening experience that makes daily life more difficult (Brewin & Lewis, 2001; Johnson, 1995; Nochi 1997; Price–Lackey & Cashman, 1996; Strandberg, 2006). Conneeley (2002) demonstrated that a memory loss resulted in a feeling of being a 'stranger' and outside the experiences of other people. Difficulties in concentration, in language use, and in visual perception are also common (NIH, 1998). According to Schretlen and Shapiro (2003), cognitive functioning improves during the first 2 years after moderate or severe TBI but can be markedly impaired even after that.

Reviews (Antonak, Livneh & Antonak, 1993; Gordon et al., 2006; Morton & Wehman, 1995) showed that people with TBI may suffer from anxiety and depression for many years after the injury. Antisocial behavior, that is, aggression, mood swings, quick temper, obsessiveness, lack of sexual restraint, and attention-seeking behavior may also occur (Das-Gupta & Turner-Stokes, 2002; Gordon et al., 2006; Wood, Liossi & Wood, 2005). Emotional problems, especially depression associated with cognitive impairments, have an important impact on daily life and family functioning (Martin, Viguier, Deloche & Dellatolas, 2001). Studies (Brooks, Campsie, Symington, Beattle & McKinley, 1986; Malia, Powell & Torode, 1995) showed that personality changes remained many years after the injury and were often first detected at home (Johnson & Balleny, 1996). Self-awareness deficits, especially in social behavior, are common after TBI. Self-awareness is often increased over time but may also be chronic. Diminished
awareness is a risk factor for behavioral disturbance and a limiting factor in recovery and rehabilitation outcome. People with better self-awareness of their deficits show better treatment outcome and a more successful return to work (Bach & David, 2006). The persistence of the disability and deterioration or development of a new disability after previous recovery are strongly associated with high ratings for depression, anxiety, stress, and low self-esteem (Whitnall, McMillan, Murray, & Teasdale, 2006).

NIH (1998) reports that the risk of suicide, abuse, unemployment, financial problems, and divorce is high among people with TBI. Especially unpredictable patterns of behavior and mood swings after a head injury impose a great burden on relationships between spouses and may contribute to relationship breakdown (Wood et al., 2005). Reduced social contact lead to increased loneliness and decreased social network (Morton & Wehman, 1995; Strandberg, 2006). Loss of friends and difficulties in establishing new contacts give rise to feelings of hatred, frustration, and disappointment (Crisp, 1994). Nochi (1998a; 1998b) described how people with experience of TBI sense loss of themselves because of memory loss, difficulties in figuring out what they can do in their surroundings, and when they compare themselves now with their pre-injury selves and interact with other people in society. According to Strandberg (2006), the experience of rapidly losing independence, autonomy, and becoming dependent on others is hard to accept. People with TBI experience an identity crisis, uncertainty, and role changes that all change the person. Chamberlain (2006) noted that the loss of the recognizable self is a great source of sorrow and suffering. Limitations in verbal expression hinder their resolution and recovery. They have a need to make sense of their experience and to reconstruct themselves (Nochi, 1997; 2000).

In short, sustaining TBI has devastating consequences for people with the illness and they are confronted with various long-lasting problems. Most of the research in the area has a quantitative approach.

**The experiences of feeling well in people with traumatic brain injury**

Sustaining TBI is a great challenge to quality of life (QOL) and life satisfaction. Reviews (Dijkers, 2004; Gordon et al., 2006; Johnston & Miklos, 2002) indicated
decreased QOL and life satisfaction in people with TBI. The severity of the injury is not necessarily a predictor of perceived QOL or life satisfaction. There are several studies (e.g., Hicken, Putzke, Novack, Shere & Richards, 2002; O'Neill et al., 1998; Pierce & Hanks, 2006; Steadman-Pare, Colantonio, Ratcliff, Chase & Vernich, 2001; Warren & Wrigley, 1996; Webb, Wrigley, Yoels & Fine, 1995) that have described factors that influence QOL or satisfaction with life in people with TBI. They showed that improved physical functioning, perceived mental health, participation in work and leisure, and social support increased QOL and satisfaction with life. According to Gordon et al. (2006), people with higher education, socioeconomic status, and steady employment before TBI report better QOL, community integration, and productivity than people with violent etiology, psychological problems, and minority status before TBI. Wood and Rutterford (2006) noted that the very long psychosocial outcome following severe TBI may be better than expected. Most participants in their study lived independently or had a full- or part-time employment and reported themselves as only 'slightly dissatisfied' with their life.

Johnston and Miklos (2002) stated that research on subjective QOL has been less common than research on functional or activity outcomes based on measurements with various instruments. Functional status and activity are observable and can be measured by professionals. These measurements are a part of QOL but they do not assess the person's feelings, values, and whether she/he is satisfied with the functional status and activity level (e.g., ability to manage activities of daily living like household management). Child care or work skills are often impaired after TBI, but the relevance of these items varies by gender, age, personal lifestyle, culture, and other circumstances. Dijkers (2004) advertised for doing qualitative research that explores the experience of QOL.

According to Dijkers (2004), only qualitative research has indicated some positive effects of TBI, although it is often limited to a 'feeling of being glad to be alive.' Living with TBI is experienced to contribute to personal growth. This involves gaining insight into the self and others, being aware of one’s own humanity and mortality, reordering
values, becoming a better human being in a moral sense, and stopping abuse of alcohol or drugs (Conneeley, 2002; McColl et al., 2000; Nochi, 1998a; 2000; Strandberg, 2006). People with TBI experience that they have more time to notice and appreciate their surroundings and all the wonderful elements in the world (McColl et al., 2000). Studies (Conneeley, 2002; Layman, Dijkers & Ashman, 2005; McColl et al., 2005; Strandberg, 2006) indicate that the relationships between people with TBI and their family members often deepen and become stronger. Further, they may experience greater closeness to other people (McColl et al., 2000) and get new friends through their injury (Strandberg, 2006).

Confidence and hope in recovery is described as one positive dimension in living with TBI (Chamberlain, 2006; Johnson, 1995; Nochi, 1998a; 1997; Strandberg, 2006). Comparing their losses or limitations to other people who are more ill increases feeling well in people with TBI because it is a reminder that they have something to be grateful over (McColl et al., 2000). Levack, McPherson and McNaughton (2004) investigated the feeling of success in the workplace following TBI. People with TBI described enjoyment when they achieved their personal goals, were meaningfully occupied, and had a sense of having done something 'worthwhile for one's money' independent of hours worked or pay earned. According to Strandberg (2006), those who have lived with the injury for more than 7 years talked about it differently; the injury was integrated to their identity and daily life and they felt peace. The experience of personal autonomy and control, and the integration of limitations into the self are involved in the subjective experience of QOL (Conneeley, 2003).

In short, there is a lot of quantitative research in QOL and life satisfaction. These studies indicate that sustaining TBI decreases feeling well in people with TBI. Qualitative research reveals some positive dimensions that strengthen feeling well with TBI.
Being a close relative of a person with traumatic brain injury

Close relatives to persons with TBI are confronted with extensive challenges and they often show great willingness to adjust their lives to fit in with the needs of the person with TBI (e.g., Carson, 1993; Duff, 2002; 2006, Layman et al., 2005; Simpson, Mohr & Redman, 2000). They are forced to re-evaluate and reconcile themselves to the person with TBI (Chawalisz & Stark-Wroblewski, 1996; Duff, 2002; Kneafsey & Gawthorpe, 2004) and feel great sorrow because of the loss of the person they knew (Carson, 1993; Guerrire & McKeever, 1997; Smith & Smith, 2000). Close relatives experience great uncertainty both during the time the person with illness is in critical condition and afterward. Uncertainty is caused by unknown effects of the injury, personality changes of the person with TBI, negative encounters with health care professionals, and inconsistent and defective information and explanations (Bond, Draeger, Mandleco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002; Kao & Stuifbergen, 2004).

Studies (Degeneffe, 2001; Lovasik et al., 2001; Verhaeghe et al., 2005) indicate that close relatives experience significant levels of stress, anxiety, depression, social isolation, and loss of personal freedom. They felt exhausted as they tried to cope with being responsible for the person with TBI and for meeting other life demands (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002; Simpson et al., 2000). The ill persons’ personality changes and behavioral and cognitive problems are especially disturbing (e.g., Anderson, Parmenter & Mok, 2002; Florian, Katz and Lahav, 1989; Junque, Bruna & Mataro, 1997; Knight, Devereux & Godfrey, 1998; Wood et al., 2005). Reviews (Perlesz, Kinsella & Crowe, 1999; Verhaeghe et al., 2005) showed that different relationships with the person with TBI create different types of burden. Spouses experience more role changes, a decrease in financial and parenting support, and loss of sexual intimacy and empathic communication with the person with TBI. Concerns about the children in the family are also common. Parents experience worry about the future of their adult child with TBI and are likely to negotiate issues of dependence and independence when their child recovers. Other family members, such as children and siblings of a person with TBI, also experience increased responsibility and psychological distress. According to Perlesz, Kinsella and Crowe (2000), primary caregivers, especially
mothers and wives, are at greatest risk of distress and low family satisfaction. Male relatives often report their distress in terms of fatigue and anger. Negative emotions that close relatives experience as a consequence of caregiving demands awaken feelings of guilt (Knight et al., 1998).

While the neurobehavioral disability of the person with head injury may impose distress on the partner, it does not necessarily affect the stability of the relationship between spouses (Wood et al., 2005). Caregiving can be experienced as positive and uplifting as it offers a sense of family unity and deepened relationships (Knight et al., 1998; Layman et al., 2005). In a study (Perlesz et al., 2000) of primary, secondary, and tertiary carers to people with TBI, a great proportion of participants were not distressed and reported good family satisfaction. Layman et al. (2005) showed that older people with TBI and their partners related various relationship changes to ageing and not to the TBI. They were strongly committed to live together despite the illness.

A family with a person with TBI is forced to negotiate their habits, roles, goals, and communication patterns in order to maintain marital and familial harmony (Duff, 2006; Kao & Stuifbergen, 2004). Close relatives have a great need for information, emotional, and practical support (e.g., Bond et al., 2003; Crisholm & Bruce, 2001; Duff, 2006; Johnson, 1995; Smith & Smith, 2000). They also have a need to feel hope and to be able to make sense of their experiences (Carson, 1993; Duff, 2006; Johnson, 1995; Smith & Smith, 2000). The consequences of TBI are complex and vary across the lifespan with new problems occurring as a result of new challenges and ageing. People with TBI and their close relatives need access to support and rehabilitation throughout the course of their recovery, which may last for many years after the injury (Duff, 2006; Kolakowsky-Hayner, Miner & Kreutzner, 2001; NIH, 1998).

In short, living with a person with TBI changes profoundly the lives of the close relatives. They experience various kinds of burden as they try to adjust their lives according to the TBI.
The experiences of treatment from other people

Good treatment from other people is crucial to the ill person's self-confidence and strength to live with TBI (Strandberg, 2006). However, several studies (e.g., Backhouse & Rodger, 1999; Chamberlain, 2006; Conneeley, 2002; Darragh, Sample & Krieger, 2001; Guilmette & Paglia, 2004; Paterson & Stewart, 2002; Strandberg, 2006; Swift & Wilson, 2001) showed that other people, including families and professionals, have misconceptions about TBI and lack the knowledge and understanding of the ill person's changed situation and the long-term nature of TBI. Nochi (1998a; 1998b) indicated that people with TBI are stigmatized and their autonomy and integrity are questioned. They may be regarded as abnormal, crazy, lazy, malingering, unintelligent, mentally retarded, or incapable (Kao & Stuifbergen, 2004; Nochi, 1998b; Paterson & Stewart, 2002; Simpson et al., 2000). People with TBI experience that they are not treated as individual persons but are classified into pre-existing categories (Nochi, 1997; 1998a; 1998b). Swift and Wilson (2001) showed that people without external sign of injury were treated as if they were healthy and met high expectations. In contrast, those with obvious physical disability were underestimated because they were thought to have intellectual disabilities. People with TBI feel that they are living in an unsympathetic society (Paterson & Stewart, 2002) and their sense of self is threatened by labels the society imposes on them (Nochi, 1998a). Paterson and Scott-Findlay (2002) argued that the small amount of qualitative research in the experience of people with TBI reveals researchers' underlying assumptions about the dependency of survivors of people with moderate or severe TBI and their inability to narrate their experiences.

Close relatives receive inadequate instrumental, emotional, and professional support (e.g., Duff, 2006; Kolakowsky-Hayner et al., 2001; Paterson, Kieloch & Gmiterek, 2001; Smith & Smith, 2000) and lack understanding of their problems with other people (Backhouse & Rodger, 1999; Swift & Wilson, 2001). They experience it as painful when other people discuss their relative's injury in public or behind their backs (Kao & Stuifbergen 2004). The health care system is experienced as complex and there is no one who takes the responsibility for helping them in navigating through the system (Duff, 2006; Smith & Smith, 2000). Close relatives feel that they are on their own and have to fight to ensure help and support (Smith & Smith, 2000). According to
Ragnarsson (2006), people with TBI and their close relatives have, for a long time, felt that their burden is poorly recognized by health care professionals. They protect themselves from the bad treatment from other people, stigma and shame associated with brain injury by lying, hiding or concealing vital facts about the injury or withdrawing themselves from their social networks (Kao & Stuifbergen, 2004; Nochi, 1998b; Simpson et al., 2000). Other people with similar injuries and professionals with special knowledge about TBI understand better their needs and have a greater ability to give relevant help and support (Kao & Stuifbergen, 2004; Strandberg, 2006).

In short, other people often lack knowledge and have difficulties in understanding what people with TBI and their close relatives are going through. Their needs are not always met by professionals.

**RATIONALE FOR THE DOCTORAL THESIS**

Several studies, mostly quantitative, already exist that show what consequences a TBI has for both the injured person and for their close relatives. Especially the negative consequences of TBI are well reported. Previous research indicates that they have a great need for various kinds of support, but these needs are not always met. Both the people with TBI and their close relatives lack understanding from other people of their profoundly changed situation. It is therefore important to gain more knowledge about the meaning of the lived experiences involved in daily life with TBI from their perspective. This knowledge increases the understanding of how it is to face daily life with the consequences of TBI. The main task for nursing is to help and support the person with TBI and their close relatives based on their needs in daily life. When people with TBI and their close relatives experience that they, both separately and together, are understood, they also have better opportunities to get help and support that promote their dignity and health and alleviate their suffering in daily life.
AIMS OF THE DOCTORAL THESIS

The overall aim of the doctoral thesis was to elucidate the meaning of living with TBI in people with moderate or severe TBI and in their close relatives. From the overall aim, the following specific aims were formulated:

Paper I to elucidate the meaning of living with TBI in people with moderate or severe TBI;

Paper II to elucidate the meaning of close relatives’ experiences of living with a person with moderate or severe TBI;

Paper III to describe the treatment from other people as experienced by people with moderate or severe TBI and their close relatives;

Paper IV to elucidate the meaning of feeling well for people with moderate or severe TBI.

METHODS

This thesis has a life-world perspective; it investigates the meaning of the lived experiences involved in daily life. Different methods are used in order to answer the specific aims. According to Bengtsson (2005), the life-world perspective is qualitative, but it is possible to use different methods that are consistent with each other and adequate for the research question at hand.

Setting

The research investigation was performed in the northern part of Sweden and included people living with moderate or severe TBI (I, III, IV) and their close relatives (II).

Participants and procedure

People with traumatic brain injury (I, III, IV)

In this study, the criteria for participation were that the person had sustained a moderate or severe TBI and he/she had the capacity, interest, and desire to narrate his/her experiences. They also had to have lived with the injury for at least 3 years in order for them to be considered experts in what it means to live with TBI. The participants were recruited by the Swedish Association of Brain Injured and Families, a
psychologist, and a nurse working in two different acute care hospitals. They telephoned possible participants and, after receiving their permission, sent them a letter with information about the study and a reply form on which they could give their informed consent. In total, 17 people with moderate or severe TBI were contacted, of whom 12 chose to participate in the studies presented in Papers I and III (Table 1). After receiving their permission, I telephoned each one and arranged a time and place for the research interview. Two of the people with TBI lived with their parents, two with their partners, and eight alone or with their children, five had a personal assistant. They had lived with the TBI between 3.5 and 13 (md=7) years. Five of the participants had an employment or studied; seven of the participants were unemployed or retired.

In the study presented in Paper IV, 12 people with moderate or severe TBI who participated in the studies presented in Papers I and III were sent a letter, including information about the study and a reply form on which they could give their informed consent. Eight of them chose to participate in the study (Table 1). I telephoned each one in order to arrange a time and place for the research interview. Two of the participants lived alone, five with their family (children and/or partner), and one with his parents. Four had a personal assistant or companion. The participants had lived with TBI for between 7 and 15 years (md=10) years. All of the participants had an employment or were students before the injury. After sustaining TBI, all of them were sick-listed for a long time and they could not continue with their employment or their education. At the time of the study, four participants had an employment after a long rehabilitation period and/or reeducation. One of the participants returned to an employment similar to what he had when he was healthy.

Close relatives (II, III)

In connection with arranging the interviews with the people with TBI (I, III), I asked their permission to send a letter to one of their close relatives with whom they had frequent close contact during their illness and who could tell me about experiences of living with a person with TBI. Eleven of the participants had close relatives whom I contacted by mail; in the letter, I included information about the study and asked if they would like to participate. Eight close relatives (Table 1), who had lived with the
person with moderate or severe TBI for between 4 and 13 years (md = 8) years, returned their written agreement. I then arranged for a specific time and place for the research interview. Two of the close relatives lived in the same household as the person with TBI. Five of the participants had upper secondary education and three had received university education. Two participants lived in the same household as the person with TBI. Six of the people with TBI had sustained TBI in a traffic accident and two during a fall.

Table 1 Overview of the participants, data collection and data analysis

<table>
<thead>
<tr>
<th>Paper</th>
<th>I, III</th>
<th>II, III</th>
<th>IV</th>
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</thead>
<tbody>
<tr>
<td>People with TBI</td>
<td>n=12</td>
<td>n=8</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
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</tr>
<tr>
<td>Age, years</td>
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</tr>
<tr>
<td>Median</td>
<td>40</td>
<td>41</td>
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<tr>
<td>Range</td>
<td>23-50</td>
<td>29-53</td>
<td></td>
</tr>
<tr>
<td>Cause of TBI</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Traffic accident</td>
<td>7</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Fall</td>
<td>3</td>
<td>2</td>
<td></td>
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<tr>
<td>Assault</td>
<td>2</td>
<td></td>
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<tr>
<td>Data collection</td>
<td>Two interviews</td>
<td>Interviews</td>
<td></td>
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<tr>
<td>Data analysis</td>
<td>PH, TC</td>
<td>PH</td>
<td></td>
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Close relatives

<table>
<thead>
<tr>
<th>n=8</th>
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<tbody>
<tr>
<td>Female</td>
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<td>Male</td>
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<td>Age, years</td>
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<tr>
<td>Median</td>
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<tr>
<td>Range</td>
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<tr>
<td>Relationship with the person with TBI</td>
</tr>
<tr>
<td>Parent</td>
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<tr>
<td>Partner</td>
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<td>Sibling</td>
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<td>Daughter</td>
</tr>
<tr>
<td>Data collection</td>
</tr>
<tr>
<td>Data analysis</td>
</tr>
</tbody>
</table>

PH= phenomenological hermeneutic interpretation
TC= thematic content analysis

Data collection

The data were collected by means of qualitative research interviews (Table 1). Kvale (1997, p. 13) stresses that ‘the aim of the research interview is to obtain descriptions of
the interviewee’s life-world in order to interpret the meaning of the described phenomena. A research interview is characterized by an inequality of power because it is the researcher who has control over the situation. It is an instrumental dialogue probing the interviewee with descriptions, narratives and texts in accord with the aims of the study. The researcher initiates the interview, decides on the topic, poses the questions, and also closes the interview (Kvale, 2006). Ricoeur (1976) argued that mediating one’s immediate experience to another is impossible, but mediating the meaning of it is possible. When people are speaking, they indicate what they mean and the private experience becomes public.

*Interviews with people with traumatic brain injury*

Interviewing people with TBI can be problematic because they may have cognitive impairments, become fatigued and distracted during the interview situation, and be unable to effectively recall or articulate their experiences (Paterson & Scott-Findlay, 2002). The interviews with people with TBI (I, III, IV) were, therefore, planned according to suggestions made by Paterson and Scott-Findlay (2002)—that is, concrete and more direct questions (instead of broad open-ended ones) might help the interviewees to narrate.

To obtain data that were as rich and complete as possible, the participants were interviewed twice in the studies presented in Papers I and III. At the first interview, they were asked to talk about their daily life before and after the injury. This involved questions about treatment and the care that they received. Questions phrased in a way that Paterson and Scott-Findlay recommended (2002) were used to encourage the interviewees to narrate their experiences—for example, ‘Can you tell a story about when you…’, ‘Can you tell me about the worst/best experiences when you…’ and ‘Can you give an example of when …’. Further, the interviewer asked followup questions using the themes and words the interviewee used, for example, ‘You told that it was up and down, can you tell me more about it’. Before the second interview, I listened to the tape recordings of the first interview and planned supplementary questions. The second interview always started with a common recall of the first interview (I, III). The
average length of the first interview was 75 minutes and that of the second was 60 minutes.

In the study presented in Paper IV, the interview questions were pretested with a person with TBI in order to evaluate the phrasing of the questions. Questions such as 'Can you tell me what in your everyday life makes you feel good,' 'Can you give an example when you felt well,' and 'Has the injury changed your thinking about feeling well?' were used to encourage the interviewees to narrate. The average length of the interview was 60 minutes.

The data collection took place during 2003 (I, III) and 2006 (IV). The participants were interviewed in their homes (I, III, IV), except one of the participants who was interviewed at my workplace (I, III).

**Interviews with close relatives**

Papers II and III report findings based on interviews of close relatives of people with moderate or severe TBI (Table 1). An interview guide with such themes as life before and after the injury, encountering other people, and any care received was used. The interviews started with an invitation to 'please tell me about your experiences when X was injured'. In order to encourage communication, I used follow-up questions that Kvale (1997, pp. 124–125) recommended, for example, 'what did you think then,' 'please tell me more about that,' and 'can you give an example.'

All close relatives were interviewed in their homes. Two interviews took place by phone because of geographic distance. All the interviews were tape-recorded and transcribed verbatim. The interviews lasted approximately 80 minutes. The data collection took place during 2003 (II, III).

**Data analysis**

The data were analyzed using a phenomenological hermeneutic interpretation (I, II, IV) and thematic content analysis (III) (Table 1). The different methods for data analysis
were relevant, bearing in mind the specific aims of the studies. Treatment from other people is one dimension in living with TBI (I). However, I found it important to write a separate article about treatment from other people (III) because both people with TBI and their close relatives had negative experiences from it.

**The phenomenological hermeneutic interpretation**

Phenomenology is an approach that attempts to grasp the essence of a phenomenon. Essence means the inner nature, the true being of a thing; 'what makes a thing what it is and without which it would not be what it is' (van Manen, 1990, p. 177). In phenomenological hermeneutic, the aim is to study the essence of a phenomenon, but, in order to make it explicit, there must be interpretation. Ricoeur (1976) argues that the interpretation is an understanding applied to a written expression of the lived experience. The text has a semantic autonomy as it is ‘liberated from the narrowness of the face-to-face situation’ (Ricoeur, 1976, p. 31). The aim is not to understand the author's intention or spiritual life but what the text is all about (Ricoeur, 1976; 1993).

The interview texts presented in Papers I, II, and IV were analyzed using a phenomenological hermeneutic interpretation inspired by Ricoeur (1976) and developed by Lindseth and Norberg (2004). Interpretation is an ongoing movement between the whole and the parts of the text (the hermeneutic circle), and between understanding and explanation (Ricoeur, 1976; 1993). In the face-to-face situation, we ask for explanation if we do not understand. The text is explained through its structure and internal relations. Explanation and understanding is a prerequisite of each other; explanation is crucial to understanding the text and the explanation is completed through understanding (Ricoeur, 1993).

The phenomenological hermeneutic interpretation used (I-II, IV) consists of three phases: naïve understanding, structural analyses, and comprehensive understanding. First, the text is read several times as open mindedly as possible in order to grasp its meaning as a whole. This is the first surface interpretation, the naïve understanding of the text (Lindseth & Norberg, 2004; cf. Ricoeur, 1976). It is guessing the meaning of the text and it is important because the text is mute (Ricoeur, 1976). The second phase
is the structural analyses, which aim to explain the text as objectively as possible and to validate the naïve understanding. Structural analyses appear as the mediation between a surface interpretation and the deepened interpretation achieved during the third phase, the comprehensive understanding. In this final phase, the text is again interpreted as a whole based on the preunderstanding of the authors, the naïve understanding, the structural analyses, and the literature. This leads to a new enlarged and deeper understanding of the phenomena being studied (Lindseth & Norberg, 2004; cf. Ricoeur, 1976).

The interview texts were read several times in order to grasp the meaning of living with a TBI (I, IV) and living with a person with TBI (II). After gaining a sense of the whole, a naïve understanding was constructed. In the structural analysis, the interview texts were divided into meaning units, which were a sentence, paragraph, or several pages with the same meaning. The meaning units were then condensed and abstracted to produce formulated meaning units. The formulated meaning units were sorted into different groups according to similarities and differences in meaning. The groups were then compared with each other and organized into themes with subthemes. In the last phase of the interpretation, the text was again viewed as a whole. The naïve understanding, the results of the structural analyses, and the researchers’ preunderstandings were brought together into a comprehensive understanding that was reflected on (I-II, IV).

The thematic content analysis

Thematic content analysis is a form of qualitative content analysis. According to Sandelowski (2000, p. 339), qualitative content analysis aims to produce a ‘descriptive summary of an event, organized in a way that best contains the data collected and that will be most relevant to the audience for whom it was written.’ It is the least interpretive of the qualitative analysis approaches. The researcher stays closer to the data and the surface of the worlds and events than researchers conducting grounded theory or phenomenological research. In qualitative content analysis, there is an effort to understand both the manifest and latent content of the data. Downe-Wamboldt (1992) stated that the manifest content describes the visible, surface, and obvious components
of the text. The latent content is the underlying meaning, the tone or implied feeling, in the text.

Qualitative content analysis is a systematic approach where the researcher moves back and forth between the whole and the parts of the texts, between the text and output of content analysis (Downe-Wamboldt, 1992). The following steps were taken during the analysis of data presented in Paper III. The interview texts were read several times in order to obtain a sense of the content. Second, meaning units containing the participants’ experiences of the treatment from other people were identified. Each meaning unit was condensed, that is, shortened while still preserving the core. Next, the condensed meaning units were sorted into categories according to similarities and differences in content. In this step, the condensed meaning units extracted from the interview texts with people with TBI and close relatives were brought together because they described similar experiences. The category system was refined several times, meaning units that were not especially easy to sort out gave insights for revisions. According to Downe-Wamboldt (1992), the researcher creates a set of categories based on the data and those samples of the texts that are not easily classified provide insights for revisions of the category system. In the next step, the categories were then compared to identify themes. Baxter (1994) stated that themes are threads of meaning recurring in domain after domain. After identifying the themes, the interviews were read again to verify the emerging categories and themes. Downe-Wamboldt (1992) states that, by returning to the original text, the researcher can strengthen the validity in analysis.

Ethical considerations
All participants gave their written informed consent to participate and again verbally before the interviews started. They were guaranteed confidentiality and anonymity in the presentation of the findings and were also reassured that participation was entirely voluntary, and that they could withdraw from the study at any time. This study was approved by the Ethics Committee at the University (I-III) and by the Regional Ethical Review Board (IV).
According to Oliver (2003), a researcher can never be sure about the consequences of a study for the participants but it is important to do as much as possible to minimize the risk of causing harm. The interviewee may see the interviewer as a friend with a good education and who may be in a position to offer adequate help or advice. There is a risk of role conflict if the interviewee asks for help from the researcher in an area outside the limit of the research. In this study, I met people with TBI three times (I, III, IV), which may have increased the risk of a role conflict because the interviewees and I learned to know each other better. The participants (I-IV) were conscious that I and my supervisors were nurses and a physician, but that, in this connection, we were researchers. I received some questions about care when I collected data for studies presented in Papers I and III, and answered them by directing the participants to make contact with a suitable professional or agency.

Participating in a research interview can be experienced as intruding (Oliver 2003), exhausting (Paterson & Scott-Findlay, 2002), and it can awaken powerful, painful, and sad memories (Dyregrov, 2004; Newman, Walker & Gefland, 1999). A researcher must have the ability to facilitate communication about sensitive themes without hurting the interviewee’s feelings (Kvigne, Gjengedal & Kirkevold, 2002). Gadamer (1960/1994, p.16) stated that it is by 'tact' that we understand a special sensitivity and sensitiveness to situations and how to behave in them. 'Tact' helps to avoid the intrusive and the violation of the other person's intimate sphere. I tried to be tactful in the interview situations by being observant of the needs and comfort of the participants. When asking about items that seemed to be especially sensitive for the interviewee, I emphasized that they do not have to answer or continue the interview if they do not want to. Many of the participants were touched by memories when they narrated their experiences, but no one wanted to terminate the interview or withdraw from the study. The participants themselves chose the locations for the interviews and it is assumed that this increased their feeling of security and their ability to narrate their experiences.
After the interview, I stayed a while with the participants, giving them an opportunity to discuss further any matters of personal interest and to reflect on experiences during the interview. They found it important to participate in order to be able to help others in the same situation. They also said that it was a relief to talk about their experiences to someone who took the time to listen to them. This is in line with several studies (Cook & Bosley, 1995; Dyregrov, Dyregrov & Raundalen, 2000; Dyregrov, 2004; Peel, Parry, Douglas & Lawton, 2006) where being given the opportunity to talk about experiences and help others in the same situation were the positive experiences of participating in a research interview. Frank (1995, p. 54) stated that ‘whether ill people want to tell stories or not, illness calls for stories.’ He argues that telling stories about one’s experiences in living daily with the illness gives a voice to suffering and increases the understanding of other people. According to Kvale (2006), interviews give voice to common people as they are allowed to present their life-world in their own words.

FINDINGS
The results of the four Papers are presented separately. In the respective Papers, the major themes are marked with italics. The findings are presented in Table 2.
### Table 2 Overview of the findings in Papers (I-IV)

<table>
<thead>
<tr>
<th>Paper</th>
<th>Themes, subthemes, and comprehensive understanding (I, II, IV)</th>
<th>Categories and themes (III)</th>
</tr>
</thead>
</table>
| **Paper I** | Losing one's way  
Waking up to the unknown  
Missing relationships  
Experiencing the body as an enemy | Struggling to attain a new normalcy  
Searching for an explanation  
Recovering the self  
Wishing to be met with respect  
Finding a new way of living |
| | Perpetually altered body changed the whole life and caused deep suffering where feelings of  
shame and dignity competed with each other. | |
| **Paper II** | Fighting not to lose one's foothold  
Getting into the unknown  
Being constantly available  
Missing someone with whom to share the burden  
Struggling to be met with dignity  
Seeing a light in the darkness | Close relative's willingness to assume care for the injured person is derived from their feeling of  
natural love and to be responsible for the other. They struggle with their own suffering and  
compassion. Natural love and hope gave the strength to fight. |
| **Paper III** | Being excluded  
Being avoided  
Searching for answers  
Being ruled by the authorities | Missing confirmation  
Being misjudged  
Meeting distrustfulness  
Longing for right kind of help |
| **Paper IV** | The unfamiliar becomes familiar  
Finding strength  
Regaining power over everyday life  
Being close to someone  
Being good enough | Feeling well, for people with TBI, is to be reconciled with the circumstances of life with TBI,  
that is, finding a new life and forming a new entity in that life where they lost their complete  
health. This involves accepting themselves and experiencing a renewed communion with  
other people. |
Paper I

The meaning of living with moderate or severe traumatic brain injury

This study elucidates the meaning of living with TBI in people with moderate or severe TBI. This study showed that living with moderate or severe TBI means living with a perpetually altered body that has changed the whole life and caused deep suffering, where feelings of shame and dignity competed with each other. This was seen in the themes losing one’s way and struggling to attain a new normalcy. Losing one’s way was dominated by feelings of shame and loss of dignity. Struggling to attain a new normalcy was dominated by managing feelings of shame and re-establishing dignity.

Losing one’s way was related to participants’ experiences of waking up to the unknown, missing relationships, and experiencing the body as an enemy. Memory loss covering several months or years was experienced as being like losing everything and going down to the bottom or into a deep cave. People with TBI had difficulties knowing what was true or false, which made them afraid and anxious. They could not talk about their experiences or feelings to anyone because they often lacked sufficient ability to formulate their thoughts. They were forced to realize that they had to begin to learn everything anew and were helpless and dependent on other people in a way they had never before experienced. Participants felt sorrow and shame when they realized how much they had been changed and when people they had many contacts with before the injury abandoned them. They longed for relationships but sometimes chose loneliness by avoiding situations where there was a risk of making a fool of themselves and feeling ashamed. There was always someone who stayed with the participants and gave them an opportunity to feel the love and solidarity that alleviated their suffering and supported feeling of dignity. Within the family especially, they were able to find consolation in terms of being believed, accepted, and supported. In spite of deepened relationships within the family, people with TBI felt loneliness in their illness. They experienced the body as an unfamiliar and a frightening enemy. Sometimes, headache and fatigue governed their whole body and confined them to bed. An inability to feel thirst, hunger, temperature, or the lack of a sense of taste made life boring. They were afraid of smelling unpleasant and of suffering further injuries. The struggles to gain control over the body were intensive and time-consuming.
Struggling to attain a new normalcy was related to the participants’ search for an explanation and their experiences of recovering the self, wishing to be met with respect and finding a new way of living. People with TBI strove to understand what had happened and how seriously ill they were, and sought explanations and information. They blamed themselves or other people for their injuries and felt bitter, but they were also grateful to have survived. Participants struggled to know themselves and their surroundings and wondered whether they were the same people as before the injury. They experienced an inability to control feelings and reactions and had difficulties in understanding other people’s emotions. Unintentionally coming into conflict with other people made them feel ashamed and guilty. Feelings of being less clever and having a bad memory were experienced as frustrating, embarrassing, and frightening.

People with TBI felt they were living with a hidden handicap and were forced to struggle to be understood and respected by other people. Insulting encounters seemed to increase their feeling of shame and the struggle to be met with dignity demanded a lot of energy. Participants strove to be able to accept the injury because to do so made life easier to live. Hopes of recovery carried them forward and they seemed to have an enormous will to live, and the courage and strength to encounter suffering. It took many years to be able to understand what had happened and to learn to live with TBI. After all the struggles, they were proud of themselves and felt grateful to have developed as human beings, which supported a feeling of dignity. In spite of finding a way of living with TBI, there was always a longing to be healthy, independent, and free from the struggle with the illness. If they regressed, they felt depressed and thought it would have been better to die.

**Paper II**

The meaning of living with a person with moderate or severe traumatic brain injury

This study elucidates the meaning of close relatives’ experiences of living with a family member with moderate or severe TBI. Living with a person with TBI means that close relatives were forced to fight not to lose their foothold when it becomes essential to take on
increased responsibility. The close relatives’ familiar life collapsed and they entered into an unknown life, steered by the illness. Information about the ill person’s injury was experienced like a shock. Participants felt panic, anxiety, and disappointment when their future plans and dreams with the ill person were ruined, causing them deep suffering. They struggled between hope and despair as the ill person’s condition varied and were at the hospital beside the person with TBI as much as they could be. The experience of uncertainty with regard to the survival of the ill person was experienced as terrible and anxiety-ridden. Close relatives felt that they had entered a vacuum in which everything they considered important lost its value. After the critical phase, they gradually realized that the person with TBI was totally changed and they were forced to become acquainted with that changed person. This was experienced as hard and time consuming. It was difficult to accept the ill person’s helplessness and participants felt great sorrow because they had lost the person they knew before the injury.

Close relatives were willing to do everything to support the ill person, which was interpreted to derive from their feelings of natural love and the ethical demand to care and be responsible for the other. They were constantly available for the person with TBI, adjusted their life according to the needs of the ill person, and wanted to be sure that she/he felt as well as possible because she/he was a fine person and worthy of their involvement. The increased responsibility for the ill person changed as the injured person got better, but it never ended. Involvement with the person with TBI changed the close relatives’ opportunity to be with other family members, which made them feel anxious and gave them a bad conscience. It was important to be able to discuss things at length with other family members who were also forced to change their lives. Everyone in the family supported the ill person and each other, giving close relatives strength. Close relatives felt that their relationships with the person with TBI and the family deepened. Natural love between close relatives, the person with TBI, and other family members seemed to alleviate the suffering of the former.

Close relatives struggled with their own suffering and compassion for the person with TBI. They wanted to be strong and balanced the demands they felt were made on them because they had their work, family, and sometimes also the ill person’s children
to take care of. They felt exhaustion but placed their own well-being second because being able to support the person with TBI was most important. Close relatives missed someone to share the burden with, people who offered to help and appreciated their efforts to manage daily life with the ill person. They felt that they were rather alone and were disappointed with significant others who were engaged only at the beginning and with the help they received from social and healthcare personnel. Participants discovered that other people found it difficult to understand the ill person because the illness was often invisible and struggled to ensure that the person with TBI and they themselves were understood and met with dignity by other people. Getting help and encountering people who met both the ill person and their close relatives with respect gave relief and increased the latter’s feeling of security.

Close relatives never lost hope for a better future, which both gave them the courage to suffer and alleviated it. The relationships to significant others remained good or even deepened if the latter asked how they felt, offered to help, and appreciated their efforts to manage the daily life. Natural love between the ill person and close relatives seemed to make their objectives the same, that is, the ill persons’ well-being. Seeing the ill person making progress and finding a new way of living increased their hope and gave them the strength to continue the fight. If the ill person felt well, the whole family felt well. They understood that the ill person would never be the same as before the injury, but they were happy to have more good than bad days. Close relatives had moments when they felt bitterness after giving so many years to the ill person but they were, above all, proud of themselves because they did not give up but managed to fight. In time, they were able to look forward to the future and make new plans.

**Paper III**

*The experiences of treatment from other people*

This study describes the treatment from other people as narrated by people with moderate or severe TBI and their close relatives. The thematic content analysis of the interview texts revealed two themes: *being excluded* and *missing confirmation*. Both themes included experiences where the participant’s dignity might have been violated.
Being excluded was related to participants’ (people with TBI and close relatives) experiences of being avoided, searching for answers, and being ruled by the authorities. Other people began to behave differently and avoided the person with TBI. People with TBI experienced that they were afraid and lacked courage to talk with them. People with TBI felt bitterness when they lost many contacts they had before the injury. Also, close relatives lost friends. Participants felt lucky when their closest, longstanding friends remained. They appreciated relatives and neighbours who asked how they felt and offered help. People with TBI were treated best by children and adolescents who were open, honest, and natural.

Participants wanted to have clear explanations and information, without strange terms or medical terminology. People with TBI described that the personnel gave evasive or unclear answers when they wanted to have information about their treatment or prognosis or asked for more rehabilitation. Receiving any or varying explanations about the care made them feel that the personnel did not know what they were doing or they lied to them. Close relatives felt dreadful if they were informed about the prognosis in a way that removed their hope. They wanted more information about the brain injury, their rights, and where to find help for themselves. Continuous, open, and honest information adjusted to their needs facilitated the participants’ life.

Participants experienced that authorities made decisions without listening to them and felt a fear of authorities’ power. They experienced that authorities saw them as a burden and treated them like an object. They appreciated freedom to express their opinions but missed more opportunities to contribute to care and rehabilitation. People with TBI experienced that home-help service, transportation service, and personal assistants worked at set times without consideration of their needs. Close relatives described that it was annoying to see that the injured person was forced to adjust to the personal assistants. A good personal assistant was the one who worked in the way the ill person wanted and who had a good contact with the family.

Missing confirmation was related to participant’s experiences of being misjudged, meeting distrustfulness, and longing for the right kind of help. People with TBI described that
they were approached as if they were drunk, a little child, less freaky, stared at, laughed at, or denied admission to shops or restaurants. It was insulting and terrible to meet other people, including authorities, who classified them as a ‘hopeless case.’ In contrast, some people made as great demand on the person with TBI as if she/he was healthy, this made the ill person feel bad. Misjudgements from other people were so tough that people with TBI thought committing suicide. Being treated with respect and receiving encouragement were crucial.

It was insulting to be questioned and controlled by the authorities—for example, close relatives felt that the social insurance office and their employer questioned their need to report sick. They described that it was a pleasure if the employer and the colleagues supported them and they felt free to be off work when they needed to. Participants experienced that other people had difficulties understanding their life situation, especially if the person with illness looked healthy. People with TBI tried to explain what they had gone through but were not always believed. It was easier to be in contact with others with similar experiences and life situation.

Participants described many examples of insufficient care and rehabilitation, for example, the ill person was not examined thoroughly or did not get help with her/his needs. The rehabilitation was good if it was meaningful and according to the ill person’s needs. People with TBI experienced that they received only a worse kind of rehabilitation if the personnel did not listen to their wishes. Participants experienced rehabilitation being focused mostly on the physical aspects, but they did not receive enough help or opportunities to talk about their feelings. It was alarming that health care personnel did not always have enough knowledge about rehabilitation of people with TBI. Close relatives were disappointed because they were often seen as a resource for the ill person and not as someone who also needs long-lasting help. Participants wanted healthcare personnel to take time to know them and be sensitive. Close relatives experienced that it was important to be able to fight for one’s rights to get relevant help.
Paper IV

The meaning of feeling well in people with moderate or severe traumatic brain injury

This study elucidates the meaning of feeling well for people with moderate or severe TBI. This study showed that feeling well for people with TBI means that the unfamiliar life with TBI becomes familiar and that they reconcile themselves with the circumstances of their life. This involves accepting themselves and experiencing a renewed communion with other people.

People with TBI emphasized their own responsibility of feeling well and they seemed to take a decision to treat themselves and to do everything they could to feel well, for example, they trained different skills and developed routines that facilitated feeling well in the daily life. Feeling well was described to be fragile and to demand 'hard work.' Participants found strength for self-treatment from their will to live and feel well, positive thinking, curiosity, belief, and confidence in life. They became stronger when they met others who felt well despite the injury, when they achieved results, and when they could do things they had not done for several years. Furthermore, travelling or moving to another environment where they could rest from the ordinary and having enough money to do things gave strength and made them feel well. Other people gave them ideas, proposal, and help 'on the way.' People with TBI felt well when they had people to talk about the injury with and when they got encouragement and help with activities in daily life. Professionals who engaged to know them and gave the help they needed increased their sense of feeling well.

Feeling well seemed to mean awareness of all that is good and healthy in one's life. People with TBI described that they felt well when they were fairly healthy and lived as ordinary a life as possible; when they could sleep, wake up, breathe, see, eat, write, be outside, listen to music, or take care of their children. They valued deeply and were glad about their body, moments, and people they took for granted when they were healthy. Paying attention to the 'hidden harmony of health' and richness in the world is seen as one form of self-treatment that helped the participants to feel well.
Feeling well was to regain power over and steer one’s everyday life instead of letting others, like personal assistants, do that. This included that people with TBI had control over their daily life and managed to remember ordinary things such as canceling of reservation of transportation in time. They experienced that feeling well was possible when they were conscious of, accepted, and got used to living according to the limitations caused by the injury. They felt well when they understood that they could not be the same as before the injury but instead focused on carrying out their possibilities. People with TBI felt better when they lived day by day without special expectations or worries about the future.

People with TBI experienced feeling well when they were close to someone and felt that they were good enough without need to pretend. To feel well was to be loved, to be popular, and to be able to engage in other people's lives, that is, being confirmed and confirming other people. People who accepted and appreciated people with TBI as they were confirmed them and made them feel well. Also, pets were a source of confirmation and feeling well. Being confirmed by someone and confirming someone helped participants to understand that they, despite the injury and their limitations, were still worthy. This is proposed to help them to accept themselves, which was described to be important for feeling well.

Feeling well and being reconciled with the circumstances of TBI implied transformation, finding a new life, and forming a new entity in that life where they had lost their complete health. This was not simple, and it demanded courage to confront the demands caused by the injury. This was seen, for example, in the participants' descriptions of how they needed courage to be with other people because of their limitations and the shame they felt.

**COMPREHENSIVE UNDERSTANDING AND REFLECTIONS**

The overall aim of this thesis was to elucidate the meaning of living with TBI for people with moderate or severe TBI and for their close relatives. The findings showed that people with TBI and their close relatives could not live the life they had taken for granted before the injury, but were forced to live a different everyday life (I–IV).
According to Toombs (1993), illness changes one’s being in the world and ‘the taken-for-granted quality of life is called into question. Sustaining illness implies facing personal vulnerability and loss of wholeness. In this thesis, TBI changed being in the world for both the people with TBI and their close relatives. This caused them deep suffering where they struggled between evil and good, suffering and desire. They had moments of hopelessness (the evil) but they strived to become familiar with a life with TBI (the good). People with TBI and their close relatives found it difficult to understand their profoundly changed lives, and felt a sense of deep sorrow and loneliness. Their suffering was alleviated when they understood their experiences, experienced love and had someone to share their suffering with, and felt satisfaction and happiness. These experiences of desire gave them strength (I-IV).

The familiar life people with TBI and their close relatives were used to live collapsed and they experienced fear, panic, anxiety and disappointment (I, II). According to Eriksson (1993; 1994/2006) people experience suffering of life when the life one is used to live is suddenly more or less taken away. It is suffering in relation to one's total life situation; what it means to live and to be among other people. It involves the threat of annihilation and feelings of fear and despair. People with TBI experienced that they waked up to the unknown where the only thing they certainly knew was, for example, that they had pain. Because of memory loss, several months or years of their lives had disappeared and this was experienced as losing everything and going down to the bottom or into a deep cave. They had difficulties to know what was true or false and they could not either talk about their experiences to anyone (I). Close relatives’ life changed without warning and the information about the ill person’s injury was a shock. They lost the person they knew before the injury and were perplexed and embarrassed. The uncertainty of the survival of the person was experienced as terrible. They felt that they had entered a vacuum where everything they had once considered as important had lost its value (II). I suggest that these experiences mean that people with TBI and their close relatives had difficulties to understand their life when one of them sustained a TBI, i.e. they experienced some kind of darkness in the understanding of life. Rehnsfeldt and Eriksson (2004) state that suffering challenges one’s understanding of life. At the onset of a sudden life change, the person may experience darkness in
understanding of life that means that the person does not understand life anymore. This causes unbearable suffering due to its inexpressibility and sense of hopelessness. However, close relatives tend to hold on to hope from the beginning (II); hence their understanding of life may not have been as dark as it was for the people with TBI.

Suffering of life includes a great sorrow over losing the life that was planned (Lindholm & Eriksson, 1993). In this thesis, people with TBI and their close relatives experienced great sorrow as they were forced to abandon the life they had planned (I, II). Feelings of sorrow alternated with feelings of satisfaction and happiness (I–IV). This is interpreted to mean that people with TBI and their close relatives experienced chronic sorrow. Olshansky (1962) presented the concept of chronic sorrow as a normal response to ongoing loss. Burke, Eakes, and Hainsworth (1999) stated that chronic sorrow is the presence of pervasive grief-related feelings that occur periodically throughout the lives of people with chronic illness, their close relatives, and the bereaved. They (1998) contend that any experience of significant loss may result in chronic sorrow. The loss may be ongoing without any predictable end or more circumscribed, such as the death of a loved one. The sorrow is not constant, but is interwoven with periods of neutrality and satisfaction (Burke et al., 1999; Teel, 1991). The presence of chronic sorrow has been acknowledged in people with chronic illness (e.g., Ahlström, 2007; Hayes, 2001; Isaksson, Gunnarsson & Ahlström, in press; Lichtenstein, Laska, & Clair, 2002; Lindgren, 1996) and in their close relatives (Eakes, 1995; Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Lindgren, 1996; Mallow & Bechtel, 1999).

People with TBI described that the state of feeling well was fragile (IV) and particularly when they regressed they felt sad (I). It was hard not to be respected by other people or to hear their children say that their greatest dream was for their parent to regain her/his health (I, III). Close relatives felt an increased responsibility, were worried about the ill person’s future as they were themselves getting older, and felt sorrow for the ill person’s loneliness and especially when she/he was treated with disrespect by others (II, III). All these experiences can be interpreted as events that may have triggered the participants’ feelings of sorrow when they were reminded of their permanently altered life compared
to people living without a serious illness in their family. According to Burke et al. (1999), common triggers of chronic sorrow for the person with illness and their close relatives are events like anniversaries associated with the illness, management crises, comparisons with norms, and experiencing a disparity between oneself and healthy people. Further, ceaseless caregiving and responsibility for the ill person triggers chronic sorrow in close relatives. Teel (1991) noted that the symbolic death of a loved one and the loss of dreams often cause chronic sorrow, because there are daily reminders of relationships and dreams that have been lost. The person with illness remains within the environment but is not the same. This study suggests that the close relatives experienced the symbolic death of a loved one because they had lost the person they knew before the injury. The person with TBI remained within the family but was not the same (II).

People with TBI and their close relatives suddenly entered a world steered by the illness which other people found difficult to understand (I, II, III). People with TBI felt sorrow when people they had many contacts with before the injury had now abandoned them and they missed the earlier relationships. At the same time, they sometimes preferred not to be in active contact with others, because of the risk of making a fool of themselves and feeling ashamed (I). Being alone in a strict silence facilitated feeling well as it gave them an opportunity to rest (IV). Close relatives felt loneliness and missed someone to talk with (II, III), but sometimes they appreciated an opportunity to be alone (II). It seems that people with TBI and their close relatives suffered because of the loneliness, but at the same time, they sometimes chose loneliness. According to Eriksson (1994/2006), loneliness becomes suffering when a person is too lonely, but not to be allowed to be alone or in privacy when one needs it can also involve suffering. The suffering person often prefers being alone despite longing for a communion with other people.

People with TBI and their close relatives had experiences of being ruled, mishandled, and meeting distrustfulness in contacts with professionals in social, healthcare, and other institutes. They were afraid of the professionals' power and emphasized that it was important to have knowledge, courage, and to be persistent in order to get the help
they needed (III). They described many examples of insufficient care and rehabilitation (I, II, III). These experiences mean that the participants experienced suffering of care, that is, suffering experienced in the caring situation because of violation of the person's dignity, condemnation and punishment, assertion of power, or omitted care or non-caring (Eriksson, 1993; 1994/2006). Eriksson (1994/2006, p. 34) stated that 'to be forced to ask help for the most basic needs, to experience that no one sees or understands what one needs, not to experience one's full worth as human being, is suffering'. Not receiving the care they needed may have increased the suffering of loneliness experienced by people with TBI and their close relatives.

People with TBI and their close relatives were in some way alone with their situation despite connectedness to someone else and the help that they got. People with TBI felt lonely in their illness (I) and close relatives did not want to show the person with TBI how badly they felt themselves (II). Furthermore, people with TBI emphasized that it was they themselves who had the responsibility for their feeling well (IV). Eriksson (1994/2006) stated that suffering of life includes insights about absolute loneliness. Every human being is in some way alone with his/her suffering and must confront it alone. Tillich (1973) stated that being alive meant being in a body separated from others and therefore being alone. It is our destiny to be alone and to be aware of it. Younger (1995) named this kind of loneliness an existential aloneness that, according to Andersson (1986), may follow from the awareness of life’s finiteness and an experience of meaninglessness or a dramatic event. People with TBI experienced that they had been given a lesson in the unpredictability of life (I) and close relatives experienced that they had learned the basic truths about life (II). This can be interpreted to mean that the dramatic event, where one of their own sustained TBI, made them more aware of life’s finiteness and they felt an existential loneliness. Florian and Krulik (1991) noted that a life-threatening illness may expose a person to existential loneliness that even substantial social support cannot alleviate.

People with TBI and their close relatives had moments of hopelessness, but overall, they retained their hope. People with TBI took a decision to treat themselves and to do everything they could to feel well (IV). Having hope and hating to give up was their
mainspring, even though they sometimes felt that their struggle was meaningless and that it would have been better to die (I). They emphasized that it was important to think positively, to have a strong will and to trust one’s possibilities (I, IV). Close relatives sometimes hovered between hope and despair but they never lost hope for a better future with the person with TBI. They wanted to do everything they could for the ill person and struggled to be strong and to cope with the fight (II). People with TBI and their close relatives felt joy and pleasure when the ill person got better and felt well (I, II, IV). This enhanced their hopes (I, II) and gave them strength (IV).

According to Eriksson (1993; 1994/2006) good suffering involves hope and struggle toward integration in order to once again be a whole person. The evil suffering is evil throughout and the person experiences hopelessness. The suffering person chooses to make her suffering a means for development and growth, or into a limiting factor. It is apparent that people with TBI and their close relatives struggled for the good suffering. They strived hard in order to be able to experience an alleviated suffering, and in this they needed each other and other people. Eriksson (1993; 1994/2006) stated that the prerequisite for suffering to become a means of growth is that the suffering person has someone to share the suffering with.

Love between family members increased feeling well for people with TBI and their close relatives. Despite conflicts, their relationships with each other and within the family deepened (I, II, IV). People with TBI felt well when they could talk about the injury with their family (IV) and they recovered themselves by listening to their family member's stories about themselves before the injury (I). Also, close relatives felt that it was important to discuss things at length within the family (II). According to Öhman (2003, p. 37) 'the meaning of living with serious chronic illness at home can be understood as a need to exist in a relationship, an ability to share the illness experience, suffering and loneliness'. Feeling of togetherness provides alleviation, support, and consolation both to the one who is ill and to her/his close relatives. Lindholm, Rehnfeldt, Arman, and Hamrin (2002) found that being in close contact with each other implies not only a matter of discussing the difficult things but of sharing the seriousness that brings the person with the illness and their close relatives closer together. According to Eriksson (1994/2006, p. 87) love is the fundamental power that
is needed to alleviate suffering. The suffering person needs to experience 'acts of love over and over again'.

Relationships with other people outside the family remained good or deepened if the participants felt that the latter enquired about how they felt, supported them, offered help, and appreciated their efforts to manage their daily life (I–IV). People with TBI and their close relatives felt lucky when their closest, longstanding friends remained (III). It was a pleasure to meet professionals who took time to get to know them, were kind, interested in them as persons, believed in them, encouraged them, and did everything to help them (III, IV). Öhlen (2001) stated that other people can facilitate alleviation of suffering when they see the suffering person in her/his vulnerability and render help with genuine engagement and interest. According to Eriksson (1993; 1994/2006) alleviating suffering in caring situations prerequisites that the suffering person feels that she/he is treated with dignity, is understood, and gets the care and treatment needed.

People with TBI and their close relatives searched for explanations and for continuous open and honest information (I–III). This can be interpreted to mean that they tried to make sense of and to understand their life. According to Söderberg, Lundman and Norberg (1999), finding explanations and understanding the meaning and coherence in illness brings relief, makes it easier to accept the illness, and contributes to living a life with dignity. Edvardsson, Sandman, and Rasmussen (2005) found that being able to understand one’s experiences promotes the feeling of safety. This involves experiencing honest answers and actions without conflicting messages or contradictory actions. In this thesis, finding explanations and being able to understand, for example, the treatment or reason for memory deficits was a relief and increased the sense of feeling well (I–IV). In contrast, receiving evasive, unclear, and contradictory explanations and information was experienced as confusing (III). Close relatives felt that it was important for healthcare personnel to convey bad news in a polite manner without depriving them of hope (II, III). Öhlen (2001) stated that in order to be understood in one’s existential situation, the suffering person needs honest answers to questions about
illness. This does not mean an absolute honesty but honesty that the suffering person is able to encounter without losing hope.

It appeared that the changes caused by TBI were gradually experienced as an inescapable reality and something to make best of. In time, the participants understood that their lives never would be the same and they found a way of living with TBI (I, II, IV). People with TBI felt well when the unfamiliar life of living with TBI became familiar and they could reconcile with the circumstances of their lives. They regained power over everyday life by being conscious of their limitations and altering their lives according to them. Feeling well was, above all, to be fairly healthy and to live as ordinary life as possible (IV). Close relatives altered their own lives in order to be able to support the ill person. The increased responsibility for the ill person changed when the person got better, but it never ended. In spite of this, close relatives were able to look forward to the future and make new plans. They felt good when the ill person felt well and were happy to have more good days than bad days (II). Close relatives also felt well when the unfamiliar life of living with the person with TBI became familiar. Öhleen (2001) found that an alleviation of the suffering can be experienced in a place of refuge, that is, being at home in oneself, in a familiar world where the changes and hindrances caused by the illness are experienced as a part of life and something to make the best of. In this thesis, becoming familiar with a life with TBI may have taken several years. People with TBI experienced that it took many years to be able to understand what had happened, and to learn to live with it (I). Close relatives experienced that becoming acquainted to living with the changed person was a time-consuming effort (II).

Participants' experiences of alleviated suffering, that is being able to understand their experiences, experiencing love, and having someone to share their suffering with were important sources of pleasure, satisfaction, and happiness for them (I–IV). They were proud of themselves because they did not give up in the face of adversity and developed as human beings (I, II). These experiences, I suggest, are signs of the good desire which gave them strength. According to Eriksson (1993; 1994/2006) and Herberts (1993) suffering always includes desire. In desire there is striving after the good and it can be
used as a motive power in the struggle against evil. In good desire the person experiences joy in life, meaning, and strength. Evil desire means that the person is driven by passion and is unable to decide about life.

CONCLUDING REMARKS
This thesis showed that people with TBI and their close relatives experienced deep suffering where they struggled between evil and good, suffering and desire. They had moments of hopelessness but they strived to become familiar with a life with TBI. Their suffering was alleviated when they were able to understand their experiences, experienced love, had someone to share their suffering with, and felt satisfaction and happiness. Becoming familiar with a life with TBI may have taken several years. In this time, people with TBI and their close relatives met professionals whose duty was to alleviate their suffering, but this thesis showed that they had experiences of suffering of care. People with TBI and their close relatives can experience alleviated suffering when they meet professionals who have knowledge about TBI and really understand the suffering it causes for them as individuals and as a family. This thesis provides knowledge that helps us to recognize and understand their suffering. People with TBI and their close relatives may not use the word ‘suffering’ when they narrate their experiences of suffering. Therefore, we must look for the cues that tell us about it. Seeing and recognizing the cues of suffering presuppose that there is the will and courage to be near the suffering person.

METHODOLOGICAL CONSIDERATIONS
The data were collected by means of qualitative research interviews. This is a relevant method as the aim of the study was to elucidate the meaning of living with TBI from the perspective of afflicted people and their close relatives. The sample of close relatives consisted mostly of women (II). The sample of people with TBI consisted of more men than women but is in line with the prevalence of TBI (I, III, IV). Jacobsson et al. (in press) described the demographics, injury characteristics, and outcome of TBI in northern Sweden in people who had been transferred for neurosurgical care from 1992
to 2001. The study comprised 250 men, of whom 107 had sustained moderate or severe TBI. From 82 women, 34 had sustained moderate or severe TBI.

The sample (I–IV) was heterogeneous concerning, for example, the participants age, time they had lived with TBI/person with TBI, and the reason and severity of the injury. However, the demographic characteristics of the participants were secondary to their knowledge of the phenomena and their ability and willingness to narrate their experiences. I do not believe that the findings in general had been so much different even though the characteristics of the participants had been more heterogeneous (sex) or homogenous (other characteristics).

Participants’ experiences were influenced by their memory and retrospective interpretation. The findings may have been influenced by the fact that people with TBI (I, III, IV) had memory deficits and could not narrate their experiences immediately after the injury or their discharge from the hospital, and close relatives (II, III) said that they could not narrate everything in detail, because so many years had passed since the person had sustained the injury. On the other hand, TBI occurs suddenly and dramatically and it may take time to realize what it actually means. Therefore, time for interpretation may have increased awareness of the lived experience of TBI. According to Lindseth and Norberg (2004) getting true narratives presupposes that the interviewees are aware of their lived experiences. The participants had a strong desire to narrate their experiences and it is argued that they shared the most significant experiences in living with TBI as these appeared to them at the time of the interview. Wiklund, Lindholm, and Lindström (2002) stated that narratives always entail chosen parts of the participant's life-world. It is a reconstruction of life in the way it is perceived by the interviewee.

All participants had lived with TBI/person with TBI for many years and their knowledge of the phenomena was apparent. In spite of memory deficits even people with TBI narrated a rich and experiential story of their experiences which contributed to a new understanding of the phenomena under study. I felt that I got whole stories with a clear beginning and end (I-IV). Sandelowski (1995, pp. 179, 183) stated that
'adequacy of sample size in qualitative research is relative’ but a good principle to follow is that an adequate sample size is one that permits a deep analysis which results in ‘a new and richly textured understanding of experience’. All contacted participants did not want to participate and it is unknown why they refused. However, in the end there was no need to try to contact more participants, as the data was sufficiently rich for our purposes (I–IV).

Kvale (1997) argues that establishing a good dialogue is the researcher’s responsibility. I am a nurse used to communicating with people who are ill and with their close relatives but, on the other hand, I had no experience of conducting research interviews with people with TBI. This, however, was compensated for by carefully planning the interviews and following the recommendations of Paterson and Scott-Findlay (2002) (I, III, IV). I felt that I managed to create a permissive climate in which the interviewees could freely narrate their experiences. People with TBI sometimes found it difficult to concentrate, formulate their ideas, felt fatigued, or had headache that made the interview situations more difficult. Interviewing them twice in studies presented in Papers I and III was crucial from the ethical point of view and can be seen as a form of prolonged engagement that facilitated the study (cf. Guba & Lincoln, 1989). In the study presented in Paper IV people with TBI were interviewed only once, because I had met the interviewees before (I, III). The interviewees and I knew each other and had a trusting relationship. I could prepare the interviews taking into account each participant's condition (e.g., ability to narrate, patterns of fatigue) and the interviewees were acquainted with my interview procedure. According to Paterson and Scott-Findlay (2002) prior meetings with the participants facilitates the study because it helps the researcher to take account of participants' characteristics, abilities, and strength to participate in the research interview.

Close relatives (II, III) were interviewed once, because they did not have the same problems in narrating as those with TBI. Taking time and using suggestions presented by Kvale (1997) encouraged their narrations. The interviews of close relatives were comprehensive, but it is possible that another interview would have added new information and promoted a deeper understanding of the phenomena.
The interview texts were analyzed using a phenomenological hermeneutic interpretation (I, II, IV) and thematic content analysis (III). Phenomenological hermeneutic interpretation (I, II, IV) proceeded through several stages, where the whole confirmed the parts and the parts confirmed the whole. According to Ricoeur (1976) the structural analysis, as the objective stage in the interpretation process, serves as a kind of validation. Thematic content analysis (III) also proceeded through several stages, moving back and forth between the whole and the parts of the texts and checks of accuracy of analysis. Downe-Wamboldt (1992) stated that moving back and forth between the text and the output of content analysis provides for refining and validating the analysis.

The studies (I–IV) were carried out by three researchers who were experienced nurses and a physician who worked with people with chronic illnesses or chronic disability, such as TBI. All were also researchers in this field. I argue that these preunderstandings facilitated the studies. According to Lincoln (1995), detachment and author objectivity are barriers to the quality of the study. The researchers' preunderstandings give them a horizon to engage with the horizon of the text (Geanellos, 2000) and an insufficient preunderstanding prevents the grasping of the essential meanings in the text (Lindseth & Norberg, 2004). Gadamer (1960/1994, p. 302) stated that the horizon 'is the range of vision that includes everything that can be seen from a particular vantage point'. To acquire a horizon means that one tries to look beyond what is close at hand in order to see it better, in a larger whole, and in truer proportion. However, preunderstandings lead to errors when the researchers are not sensitive to the text's alterity and ignore the actual meaning of the text if it is not what they imagine it to be. It is important to be 'aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings' (Gadamer, 1960/1994, p. 269).

The researchers were careful that their preunderstandings did not lead to bias and strived for openness in data collection, data analysis, and documentation of findings (I–IV). According to Dahlberg and Drew (1997), openness is the central concept in life-world perspective because it supports objectivity in research. In the data collection, I tried to be open and sensitive to what the participants conveyed in the interview.
situation. I checked my understanding with the interviewees and asked follow-up questions especially when I was unsure about what they meant (I–IV). Lindseth and Norberg (2004) believe that, when stories are told, both the teller and the listener take part in constructing meaning but it is important that the listener refrains from judging and concluding. In this situation the listener is open to the meaning in the experience.

In the data analysis, the researchers strived for openness by discussing the analysis and asking themselves questions like ‘is this what the participants’ really mean or is it something else, have we missed something’. The analysis and findings in studies presented in Papers I, II, and IV were discussed with other colleagues. Sandelowski (1998) noted that outsider experts are critics who ask the right questions and help researchers to see data in a new way. The findings presented in Papers I, II, and IV are based on the most probable phenomenological hermeneutic interpretation the researchers could achieve and it is always possible to argue for or against this interpretation. According to Ricoeur (1976), the interpretation arrived at must be more probable than any other interpretation. The findings presented in Paper III are based on thematic content analysis where the researchers strived for as accurate an analysis as possible. Downe-Wamboldt (1992) stated that ‘multiple meanings are always present in data—there is no right meaning, only the most accurate meaning from a particular perspective’.

Researchers must be sensitive to their original life-world descriptions and notice that the language used should be close to a phenomenon and its essence (Dahlberg, 2006). Lindseth and Norberg (2004) stated that the findings should be presented in everyday language close to the lived experience and, for example, metaphors can be used to convey the interpreted meaning. In this study, I have tried to stay close to the lived experience by constantly checking the interpretation and presentation of findings against the interview texts (I–IV). Metaphors have been used in some themes to convey the interpreted meaning. The procedure, context, and findings are presented as accurately as possible (I–IV) to help the reader to judge the trustworthiness, including transferability, of the study (cf. Guba & Lincoln, 1989).
SUMMARY IN SWEDISH-SVENSK SAMMANFATTNING

Oavsett om en sjukdom är akut eller kronisk konfronteras den sjuke personen med livets sårbarhet och oförutsägbarhet. Vid en medelsvår eller svår traumatisk hjärnskada (THS) sker en förändring från att ha varit frisk till att ha en kronisk sjukdom så snabbt att den sjuke personen och dennes närstående har svårt att förstå det som har hänt (cf. Duff, 2002). Denna avhandling fokuserar på innebörden i upplevelsen av att leva med THS utifrån berörda personers och deras närståendes perspektiv.

Rational

Ett flertal studier, de flesta med kvantitativ forskningsansats, har visat att en THS kan leda till långvariga fysiska, kognitiva, emotionella och beteendeförändringar hos den sjuke personen. Dessa förändringar påverkar hela livet för personen med THS och dennes närstående, framförallt de negativa konsekvenserna av THS är väl rapporterade. Tidigare forskning visar även att personer med THS och deras närstående har ett stort behov av olika slags stöd men deras behov är inte alltid uppfyllda. Andra människor i omgivningen har svårt att förstå hur mycket deras liv har förändrats. Därför är det viktigt att få mer kunskap om vad det innebär att leva med en THS och med en person med THS. Denna kunskap är grunden till att personer med THS och deras närstående har större möjligheter att få hjälp och stöd.

Syfte

Det övergripande syftet med denna doktorsavhandling var att belysa innebörden i att leva med en medelsvår eller svår THS utifrån de berörda personernas och deras närståendes perspektiv. Avhandlingen består av fyra delstudier.

Metod

Denna studie utfördes i norra delen av Sverige. I delstudier I och III intervjuades 12 personer, 10 män och 2 kvinnor. Deltagarna hade en medelsvår eller svår THS och de skulle vilja och kunna berätta om sina upplevelser. De var mellan 23–50 år (md=40) och hade levt mellan 3.5–13 år med skadan (md=7). Två personer med THS levde med föräldrar, två med partners och åtta levde ensam eller med sina barn. Fem deltagare

I delstudierna II och III intervjuades 8 närstående, 1 man och 7 kvinnor. Deltagarna var närstående till personer med THS som deltog i delstudie I. Deltagarna var mellan 28-56 år (md=45) och de var; föräldrar (n=3), partners (n=2), syskon (n=2) och en dotter (n=1). De hade levt med person med THS mellan 4-13 år (md=8). Närstående intervjuades en gång, de intervjuerna genomfördes år 2003.

År 2006 tillfrågades 12 personer med medelsvår eller svår THS som deltog i delstudier I och III att delta i delstudie IV. Åtta av dem valde att delta i en intervju. De var mellan 29-53 år (md=41) och hade levt med THS 7-15 år (md=10). Alla deltagare hade ett arbete eller var studerande innan de skadades, men efter THS kunde ingen av dem fortsätta med sitt arbete eller studier. Efter en lång rehabilitering och/eller utbildning hade 4 av deltagarna arbete vid tiden för denna studie. En av dem kunde återvända till ett liknande arbete som han hade innan han drabbades av THS.


Resultat

**Delstudie I: Innebördens innebörd i att leva med en traumatisk hjärnskada**

I delstudie I var syftet att belysa innebördens innebörd i att leva med en medelsvår eller svår THS. Studien visar att leva med en medelsvår eller svår THS innebar att leva med en för evigt förändrad kropp som förändrade hela livet och orsakade djupt lidande, där känslan av skam och värdighet konkurrerade med varandra. Detta framkom i de två temanat **att förlora sin väg** och **att kämpa för en ny normalitet.** Att förlora sin väg innebar upplevelser av att vakna upp till det okända, sakna relationer och att kroppen var en fiende. Att förlora...

De upplevde att deras relationer med familjen fördjupades. Personer med THS upplevde kroppen som en fiende som de aldrig kunde lita på och de kämpade med att återfå kontroll av kroppen.


Personer med THS upplevde att de levde med ett dolt handikapp och var tvungna att kämpa för att bli förstådda och respekterade av andra människor. Kränkande bemötande av andra människor verkade öka deras känsla av skam. De förlorade aldrig hoppet och hade en stark vilja att leva. Det tog flera år att förstå vad som hade hänt och lära sig ett sätt att leva med THS. Efter all kamp med sin sjukdom var de stolta och tacksamma över att de hade kunnat utvecklas som människor vilket tolkades som att det förstärkte deras känsla av värdighet. Trots att de kunde hitta ett sätt att leva med THS fanns en längtan till att vara frisk och fri från kampen med THS. De blev deprimera och tänkte att det hade varit bättre att dö om de förstått...
Personer med medelsvår eller svår THS är ofta långa tider på sjukhus och rehabiliteringsenheter, men denna studie visar att de verkade vara ganska ensam i sitt lidande och behöver mer hjälp och stöd i sitt dagliga liv.

**Delstudie II: Innebörden i att leva med en person med traumatisk hjärnskada**

I delstudie II var syftet att belysa innebörden i att leva med en person med medelsvår eller svår THS. Studien visar att innebörden i att leva med en person med medelsvår eller svår THS för närstående är att strida för att inte förlora sitt fotfäste när de var tvingade till ett ökat ansvar. De närståendes liv kollapsade, vilket innebar djupt lidande för dem. De pendlade mellan hopp och förtvivlan när den sjuka personens tillstånd varierade och de var på sjukhuset från morgon till kväll. Så småningom kunde de se att personen med THS var helt förändrad och att lära känna personen på nytt var tidskrävande. Det var svårt att acceptera den sjuka personens beroende och närstående kände sorg över att de förlorat personen de en gång kände.

Närstående ville göra allt de kunde för att stödja person med THS vilket verkade utgå från deras kärlek för den sjuka personen och det etiska kravet för att ta hand om hon/han. De ordnade sitt eget liv så att de kunde konstant vara tillgängliga för personen med THS eftersom hon/han var deras bästa vän, en fin person och värd all deras engagemang. Närståendes möjligheter att umgås med andra människor begränsades när den sjuka personen tog så mycket av deras tid. De upplevde ett dåligt samvete för att inte ha lika mycket tid till andra familjemedlemmar som också var tvingade till ett förändrat liv. Alla inom familjen stöttade varandra och naturlig kärlek inom familjen lindrade närståendes lidande.

Närstående kämpade med sitt eget lidande och medlidande för den sjuka personen. De ville vara starka och kunna ta hand om sitt eget arbete, familj och ibland även den sjuka personens barn. Närstående kände utmattning men de ville inte tänka på det eftersom det viktigaste var att den sjuka personen mådde bra. De upplevde att de var ganska ensam och de var besvikna på stöd och hjälp som de fick av andra människor, inklusive hälso- och sjukvårdspersonal. De saknade framför allt någon att prata med. Alla ville inte prata om sina upplevelser utan föredrog att vara ensam. Andra människor hade...
svårt att förstå den sjuka människan eftersom skadan ofta var osynlig och närstående fick kämpa med att person med THS och de själva skulle bli bemötta med respekt. Att bli bemött med respekt var en lättnad och ökade närståendes känsla av trygghet.

Att aldrig förlora hoppet för en bättre framtid verkade ge närstående mod och lindra deras lidande. Naturlig kärlek mellan den sjuka personen och närstående gjorde att de kämpade mot samma mål vilket var den sjuka personens välbefinnande. Att se person med THS göra framsteg och finna ett sätt att leva med sin sjukdom gav närstående styrka att fortsätta med sin strid. De kände ibland bitterhet över att de offrade så många år för person med THS men framförallt var de stolta att de inte gav upp utan klarade av striden. Närstående i denna studie hade mod och styrka att lindra den sjuka personens lidande, men de själva hade svårt att finna hjälp och stöd som lindrade deras eget lidande.

**Delstudie III: Bemötandet från andra människor**

I delstudie III var syftet att beskriva hur personer med medelsvår eller svår THS och deras närstående upplever bemötandet från andra människor. Studiens resultat beskrivs med hjälp av två teman **att vara utanför** och **att sakna bekräftelse**. Båda teman beskriver upplevelser där deltagarnas värdighet var hotad.


Deltagarna saknade tydliga förklaringar och information. Personer med THS beskrev att vårdpersonal var undvikande och gav otydliga svar på frågor om behandling, prognos och rehabilitering. Att inte alls få förklaringar eller få varierande förklaringar


Att bli ifrågasatt och kontrollerad av olika myndigheter upplevdes kränkande; till exempel närstående till personer med THS hade upplevelser av att försäkringskassa och arbetsgivare ifrågasatte deras behov av att vara sjukskriven. De upplevde en lättnad när arbetsgivare och kollegor var stödjande, de kände en frihet av att vara sjukskriven. Personer med THS och deras närstående upplevde att andra människor hade svårt att förstå deras livssituation speciellt om personen med THS hade inga synliga, fysiska skador. Personer med THS försökte förklara vad dem hade upplevt
men de blev inte alltid trodda. Det var lättare att vara i kontakt med människor i liknande situation.

Deltagarna beskrev många exempel på otillräcklig vård, omvårdnad och rehabilitering; till exempel personer med THS blev inte alltid ordentligt undersökta eller fick hjälp med sina grundläggande behov. Personer med THS och deras närstående upplevde att rehabilitering fokuserades på fysiska aspekter men att de inte fick tillräckligt med möjligheter att diskutera om deras känslor. Rehabilitering beskrevs som god i fall den var meningsfull och utifrån den sjuka personens behov. Rehabilitering som inte var utifrån deras behov ökade deras lidande. Närstående var besvikna eftersom de själva fick ingen hjälp och stöd utan sågs endast som en resurs till person med THS. De beskrev att det var viktigt att ha en förmåga att kämpa för att få relevant vård, omvårdnad och rehabilitering för personen med sjukdom, och de själva. Deltagarna var bekymrade när de insåg att hälso- och sjukvårdspersonal inte alltid hade kunskap om rehabilitering av personer med THS.

Det är viktigt att myndigheter, inklusive hälso- och sjukvårdspersonal reflekterar över hur de kan utveckla sitt arbete så att personer med THS och deras närstående upplever att de bemöts med värdighet. Bemötandet av personer med THS och deras närstående kan bli bättre när andra människor har mer kunskap om THS och hur det är att leva med sjukdomen. Detta är en utmaning för hälso-och sjukvården.

**Delstudie IV: Innebörden i att må bra**

I delstudie IV var syftet var att belysa innebörden i upplevelsen av att må bra hos personer med medelsvår eller svår THS. Studien visar att personer med THS må brat när livet med THS blev familjärt och när de kunde försonas med det som hade hänt. Detta innefattade att dem accepterade sig själva och upplevde en förnyad gemenskap med andra människor.

Personer med THS poängterade deras eget ansvar i att må bra. De verkade ta ett beslut att göra allt vad de kan för att må bra. De tränade olika förmågor och utvecklade rutiner som underlättade det dagliga livet och gjorde att de mädde bra. Personer med THS
beskrev att det krävde ’ett hårt arbete’ att må bra eftersom det var lätt att återigen bli ledsen. Deras vilja att må bra, samt deras positiva tänkande, tro och nyfikenhet för livet gav dem styrka. De fick kraft när de träffade andra som trots THS mådde bra. Att träning gav resultat och de kunde göra saker som de inte hade gjort på flera år gav ytterligare kraft. För att må bra var det viktigt att andra människor hjälpte i det dagliga livet, pratade med dem, gav idéer och förslag, och uppmuntrade. Att resa till en annan miljö där de kunde vila från det ordinära och ha tillräckligt med pengar för att göra olika saker upplevdes viktigt för att må bra.

Att må bra verkade innebära en medvetenhet om allt det goda och friska i ens liv. Personer med THS beskrev att de mådde bra när de var relativt friska och kunde leva ett så vanligt liv som möjligt; att de kunde sova, vakna upp, andas, se, äta, skriva, vara ute, lysna på musik eller ta hand om sina barn. De uppskattade djup och var glada över saker som de tog för givet när de var helt friska.

Personer med THS upplevde att de mådde bra när de återigen kunde själva styra sitt dagliga liv i stället av andra människor. Att må bra var att ha kontroll över sitt dagliga liv och själv komma ihåg saker, som till exempel att avbeställa färddjursförråd. Personer med THS upplevde att de mådde bra när de var medvetna om, accepterade och blev vana med att leva utifrån deras begränsningar. De förstod att de inte kunde bli som innan skadan utan fokuserade på att leva utifrån sina möjligheter. Det var viktigt att leva en dag i taget utan speciella förväntningar eller bekymmer om framtiden.

Att må bra innefattade upplevelser av att vara nära någon och att vara tillräckligt bra och duga som man är. Personer med THS mådde bra när de var ålskade, omtvickta och kunde engagera sig i andra människor dvs. att de var bekräftade och kunde bekräfta andra människor. Detta hjälpte dem att förstå att de, trots sina begränsningar, var värdefulla, och de kunde acceptera sig själva. Även sällskapsdjur var en källa för bekräftelse och hjälpte personer med THS att må bra.

Att må bra och försonas med livet med THS innebar att personer med THS formade ett nytt liv och en ny enhet av det livet där de förlorade sin fullständiga hälsa. Detta var
inte enkelt vilket syns till exempel i deras beskrivningar om hur de behövde mod att vara med andra människor därför att de kände skam på grund av deras begränsningar.

**Fördjupad förståelse och reflektioner**

Syftet med denna doktorsavhandling var att belysa innebörden i att leva med en medelsvår eller svår THS utifrån de berörda personers och deras närståendes perspektiv. Resultaten visade att personer med THS och deras närstående inte kunde leva det livet som dem tog för givet innan skadan utan de tvingades till ett annorlunda dagligt liv där livet med THS blev sättet att leva. Detta innebar ett djupt lidande där de kämpade mellan det onda och det goda, mellan lidandet och lusten. De hade stunder av hopplöshet (det onda) men de strävade efter att bli familjär med livet med THS (det goda). De hade svårigheter i att förstå deras totalt förändrade liv och upplevde sorg och ensamhet. Deras lidande lindrades och de fick kraft när de förstod deras upplevelser, hade någon att dela sitt lidande med och upplevde kärlek, samt kände lycka och tillfredsställelse.


Personer med THS och deras närstående hade upplevelser av att vara styrda, missbedömda och mistrodda av olika myndigheter. De var rädda för deras makt och beskrev att det var viktigt att ha kunskap, mod och vara envis för att få relevant hjälp. Personer med THS och deras närstående beskrev flera exempel på otillräcklig vård, omvårdnad och rehabilitering. Dessa upplevelser tolkades som att de upplevde
vårdlidande vilket innebär lidande i relation till vårdsituation på grund av kränkning av
personens vårdighet, fördömelse och straff, makttutövning samt utebliven vård (jmf.
ensamhet.

Trots att personer med THS och deras närstående upplevde samhörighet med någon
och fick hjälp verkade de uppleva ensamhet i lidandet. Detta tolkades som att de
upplevde existentiell ensamhet. Andersson (1986) menar att existentiell ensamhet kan
framkallas av medvetenhet om livets ändlighet, av en upplevelse av meningslöshet eller
en dramatisk händelse. Personer med THS upplevde att de fick en påminnelse om livets
oförutsägbarhet och närstående att de hade lärt sig om livet vilket kan tolkas som att
den dramatiska händelsen där en av dem fick en THS gjorde de medvetna om livets
ändlighet. Enligt Florian och Krulik (1991) kan en livshotande sjukdom leda till
menar att varje människa är på något sätt ensam i sitt lidande och måste konfrontera
lidandet ensam.

**Lindrat lidande**

Denna studie visar att personer med THS och deras närstående upplevde hopp och de
gjorde allt de kunde för att må bra. De upplevde stor glädje när personen med THS
menar att i det goda lidandet upplever människan hopp och för en kamp för en
integration till att återigen bli en hel människa. Det onda lidandet är alltigenom ont och
den lidande människan känner hopplöshet. Det är uppenbart att personer med THS
och deras närstående strävade efter det goda lidandet. De kämpade för att uppleva ett
lindrat lidande och i det behövde de andra människor.

Kärlek inom familjen gjorde att personer med THS och deras närstående kunde må bra.
De klarade av konflikter som uppstod inom familjen och fick fördjupade relationer med
varandra vilket lindrade deras lidande. Det var viktigt att diskutera mycket inom
familjen. Relationer till människor utanför familjen förblev goda eller fördjupades om
de frågade hur de mådde, stödjade, erbjöd hjälp och uppskattade deras strävan att klara


Avslutande reflektion

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REFERENCES


In K. Eriksson (Ed.), Möten med lidanden [Encountering suffering]. Reports from the
published 1994)
analysis]. In K. Eriksson (Ed.), Möten med lidanden [Encountering suffering]. Reports
from the Department of Caring Science 4/93 (pp.29-54, 187-188). Åbo: Åbo Akademi.


children. Social Science & Medicine, 32, (811), 1291-1296.

University of Chicago Press.

Trans.). New York: The Continuum Publishing Company. (Original work published
1960)

analysing research texts. Nursing Inquiry, 7, 112-119.

Gordon, WA, Zafonte, R., Cicerone, K., Cantor, J., Brown, M., Lombard, L., Goldsmith, R.,
Journal of Physical Medicine & Rehabilitation, 84, 343-382.

Nursing, 3, (1), 36-52.

Publications.


Hayes, M. (2001). A phenomenological study of chronic sorrow in people with type 1

in individuals with traumatic brain injury living in the community. Journal of Head
Trauma Rehabilitation, 13, (4), 47-57.


The Meaning of Living with Traumatic Brain Injury in People with Moderate or Severe Traumatic Brain Injury

Eija Jumisko, Jan Lexell, Siv Söderberg

Abstract: A traumatic brain injury (TBI) extensively affects the injured person's daily life. Research based on the perspectives of people with TBI can increase understanding of the challenges they face and the possibility of supporting them in managing their lives. The aim of this study was to elucidate the meaning of living with TBI as narrated by the people with moderate or severe TBI. The data were collected by means of qualitative research interviews with 12 participants who had lived with TBI for 4–13 years. A phenomenological hermeneutic method was used to interpret the transcribed interviews. The study showed that people with TBI had lost their way and struggled to achieve a new normality. Losing one's way included experiences of waking up to unknown, missing relationships and experiencing the body as an enemy. Participants' struggles to attain a new normality included searching for an explanation, recovering the self, wishing to be met with respect, and finding a new way of living. Living with TBI seems to mean living with a perpetually altered body that changed the whole life and caused deep suffering, where feelings of shame and dignity competed with each other. Participants seem to be quite alone in their suffering and need more support from healthcare professionals.

Research based on the perspectives of people suffering illnesses can increase understanding of the challenges they face in their daily lives. Listening to those who are ill is essential to obtaining an insight into the world of illness. Furthermore, care developed from the perspective of those who are ill probably has the best chance of succeeding (Söderberg, 1999).

Sustaining a traumatic brain injury (TBI) means that the person's whole life suddenly changes. The physical, cognitive, emotional, and social consequences of TBI have been presented in numerous quantitative studies (Antonak, Livneh, & Antonak, 1993; Lovasik, Kerr, & Alexander, 2001; Morton & Wehman, 1995). Researchers using qualitative methods have focused on a variety of perspectives of living with TBI (Brewin & Lewis, 2001; Crisp, 1994; Gutman & Napier-Klemic, 1996; Johnson, 1995; Nochi, 1997, 1998a, 1998b; Paterson & Stewart, 2002; Price-Lackey & Cashman, 1996). In spite of this knowledge, there are studies that show that people with brain injury experience a lack of understanding from those around them, including professionals, of the implications the injury has for their lives (Backhouse & Rodger, 1999; Darragh, Sample, & Krieger, 2001; Swift & Wilson, 2001). Therefore, more studies are needed to describe how people with TBI experience living with illness. This kind of knowledge will increase the possibilities of supporting people with TBI in managing their own lives. Thus, the aim of this study was to elucidate the meaning of living with TBI in people with moderate or severe TBI.

Background

TBI has an extensive effect on the person's daily life. Most affected people are between 15–24 years old, 75 years and older, or 3 years and younger. The prevalence is higher among males (National Institutes of Health [NIH], 1998), and the injury is often the result of an external force or a rapid acceleration/deceleration of the brain (Kushner, 1998). The main causes of TBI are motor vehicle accidents, falls, violence, and sports accidents (Kushner; NIH). TBI can be classified as mild, moderate, or severe (Kushner). Studies have shown that people with TBI can suffer lifelong physical, cognitive, emotional, and social difficulties (Hibbard, Uysal, Sliwinski, & Gordon, 1998; NIH, 1998). There can be a variety of physical consequences, such as reduced motor function, headache, and sleep disturbances (Hibbard et al.; NIH). People with TBI also have described experiences of overwhelming fatigue (Paterson & Stewart, 2002). Unpleasant and frightening experiences for people with TBI are poor memory (Brewin & Lewis, 2001; Johnson, 1995; Nochi, 1997; Price-Lackey & Cashman, 1996) and a feeling of losing themselves (Nochi, 1997, 1998a, 1998b).

Studies have shown that people with TBI suffer from depression and anxiety for many years after the injury (Antonak et al., 1993; Morton & Wehman, 1995; NIH, 1998). Problems with aggression, agitation, learning...
difficulties, and altered emotional control also are described (Lovasik et al., 2001; NIH). The emotional problems have an extensive influence on the person’s daily life (Florian, Katz, & Lahav, 1989; Martin, Viguer, Deloche, & Dellatolas, 2001). The personality changes remain for many years after the injury (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Malia, Powell, & Torode, 1995) and are often first detected at home (John-son & Balleny, 1996).

According to the NIH Consensus Statement Online (1998), the risk of suicide, unemployment, divorce, financial problems, and abuse are higher among people with TBI when compared to the general population. They also have difficulties in maintaining friendships and social support and participating in leisure activities. Reduced social contact and social support lead to a prolonged loneliness (Morton & Wehmam, 1995). Loss of friends and the failure to establish new contacts give rise to feelings of hate, frustration, and disappointment because good contacts with close relatives are no substitute for the loss of friends (Crisp, 1994). People with TBI often become dependent on their close relatives. Several studies have described various experiences of bearing a burden among close relatives (Allen, Linn, Gutierrez, & Willer, 1994; Brooks et al., 1986; Florian et al., 1989; Koskinen, 1998; Liss & Willer, 1990; Lovasik et al., 2001).

To summarize, the literature shows that people with TBI confront various long-lasting problems after their injury, and their relatives feel a great burden. The literature also shows that people with TBI need a great deal of support for a long time after the injury in order to manage their lives.

Method

Sample and Setting

The criteria for participation were that the person had a moderate or severe TBI and the capacity, interest, and desire to narrate her or his experiences. The participants also had to have lived at least 3 years with their TBI, by which time they are considered to be “experts” in what it means to live with TBI (Holloway & Wheeler, 2002; Robertson-Malt, 1999).

Twelve people (2 women and 10 men) with moderate or severe TBI, between 23 and 50 years old, participated in the study. Two participants lived with their parents, two with their partners, and eight alone or with their children. Five participants had a personal assistant. Seven of the participants had been injured in a traffic accident, three during a fall and two because of an assault. The participants had lived with TBI for between 4 and 13 years (M = 7 years).

The patient association for people with brain injuries, a psychologist, and a nurse working at two different hospitals in northern Sweden recruited the participants. They telephoned the prospects, and, after receiving their permission, they sent them an information letter including a reply form giving informed consent. In total, 17 people were contacted; 12 chose to participate. After receiving the participants’ permission, the first author telephoned each one in order to arrange a day and place for the interview.

Data Collection

Because the aim of the study was to elucidate people’s experiences of living with TBI, data were collected by means of qualitative research interviews (Kvale, 1997). In order to obtain data that was as rich and complete as possible, the participants were interviewed twice (Paterson & Scott-Findlay, 2002). At the first interview, they were asked to talk about their daily lives before and after the injury. The interview technique was planned according to suggestions made by Paterson and Scott-Findlay. Questions such as “Can you tell a story about when you...,” “Can you tell about the worst/best experiences when you...,” and “Can you give an example of when it happened to you...” were used to encourage the interviewee to narrate his or her experiences. Before the second interview, the interviewer listened to recordings of the first interview and planned supplementary questions. The second interview always started with a common recall of the first interview. Eleven participants wanted to be interviewed in their homes and one participant at the interviewers’ work place. All the interviews were recorded and transcribed verbatim. The average length of the first interview was 75 minutes and of the second 60 minutes. The data collection took place during the spring 2003.

Ethical Considerations

All participants gave their informed written consent when asked about their willingness to participate and verbal consent before starting the interviews. They were given a guarantee of confidentiality and anonymity in the reporting of the findings. The interviewer was sensitive to the needs and comfort of the participants during the interviews. After the interview, the interviewer stayed a while with the participants, giving them an opportunity to reflect on experiences during the interview and to further discuss any matters of personal interest or need (Paterson & Scott-Findlay, 2002). The ethical committee at the university approved the study.

Data Analysis

The data were analyzed using a phenomenological hermeneutic method inspired by Ricoeur’s philosophy (1976). The interpretation consists of three phases. The first phase is a naive understanding, the first superficial interpretation, of the text in order to gain a sense of the whole. The second phase is the structural analysis where the text is divided into meaning units and analyzed in detail in order to explain what the text says and the validation or invalidation of the understanding gained from the naive understanding. The third phase, the comprehensive understanding, is the interpretation of the text as
a whole based on the preunderstanding of the authors, the naïve understanding, the structural analysis, and the literature. This leads to a new deeper understanding of the phenomena being studied (Ricoeur, 1976). The preunderstanding is based on the authors’ experiences as nurses and as a physician working with people with chronic illnesses and as researchers in this field. The authors were constantly aware of preunderstanding and interpreted the interviews as open-mindedly as possible.

**Findings**

**Naïve Understanding**

The texts from the first and the second interview were seen as a whole. The texts were read several times in order to gain an overall impression and naïve understanding of the meaning of the phenomenon under investigation.

Contracting TBI was experienced as suddenly being in a place steered by the illness. Both a part of the past and the future disappeared. The worst aspect was the feeling of getting lost. An intensive search for explanations was central to the lives of the participants. Life also became a struggle to return to what one was, or perceived one was before the injury. The greatest hindrance seemed to be that their own bodies could betray them indiscriminately. There also was a need for familiar structure in daily life. Living with a personal assistant meant security, but it also meant a loss of one’s own life. Living with TBI was experienced as living with a hidden handicap, not being believed, being forced to struggle for understanding, and having a feeling of being offended. Getting help could take many years and it seemed to be difficult to admit to having a permanent brain injury. Being stuck in the past and feelings of bitterness and a constant longing to be as one was before hindered the participants from finding a meaningful life. Not only shame and sorrow but also pride and pleasure were expressed.

**Structural Analysis**

To explain the structure of the text, it was divided into meaning units composed of a sentence, paragraph, or several pages with the same content. The meaning units were condensed and abstracted to formulate meaning units. The formulated meaning units were organized into groups according to similarities and differences in meaning. The groups were compared to each other and organized into themes and sub-themes. The structural analysis resulted in two main themes (losing one’s way and struggling to attain a new normalcy) with seven sub-themes and validated the understanding gained from the naïve understanding. The themes are presented below and illustrated by quotations from the interview text.

**Losing One’s Way**

The theme losing one’s way was constructed from three sub-themes: waking up to the unknown, missing relationships, and experiencing the body as an enemy.

**Waking up to the Unknown.** The study participants described how they woke up in the hospital without knowing where they were, why, what their earlier life had been like, and what they had aimed at or dreamed about. Their family members were strangers. Because of memory loss, several months or years of their lives had disappeared. This experience was like losing everything and going down to the bottom or into a deep cave.

The only thing they knew for certain was, for example, that they had a terrible physical pain or that they saw a multitude of colors when they opened their eyes. They also had difficulties knowing what was true and false, and they had strong feelings of fear and anxiety. The participants could not talk about their experiences or feelings to anyone because they often lacked sufficient ability to formulate their thoughts.

I don’t remember anything about my life before the accident. …[W]hen I woke up, I couldn’t identify my mother, my brothers, and sisters, I couldn’t identify anything. …I didn’t know I was an almost 18-year-old girl. …I didn’t know what one should do as a human being.

The participants felt ashamed because they had become helpless and dependent on other people in a way they had never experienced before. They were confronted with their own inability to take care of their children, return to their ordinary homes, work, or have a drivers license. Their financial situation also became problematic. Living with a personal assistant meant safety and an opportunity to get outside the home, but also that they had lost their privacy. The participants were forced to realize that they had to begin to learn everything new.

I was forced to restart everything…talk and everything, there was nothing I could do when I woke up.

**Missing Relationships.** Study participants experienced loss of their friends. This was as an enormous source of sorrow. The inability to work resulted in minimal or complete lack of contact with colleagues; this was experienced as having the ground cut from under them or being pushed into a corner. The participants expressed disappointment and bitterness when they realized how people with who they had had many contacts with before the injury were never heard from. They felt used and expressed the suspicion that their friends avoided them because they were ashamed of being with them. They also described being jealous of other people’s friends. The participants consoled themselves by saying that sustaining a TBI is a way of finding out who your true friends are. When their contacts deepened and they received support from colleagues or friends, it warmed their hearts and they were appreciative. One’s dog also could be a real friend and supporter.

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It’s rather a big thing when so many friends leave...but then you can see who your real friends are. ...It’s no fun.

Participants described how they struggled to make contact with other people outside their homes. By not having family or friends, daily life could consist of watching television and consoling oneself by eating. Those who lived alone dreamed about finding a partner, but establishing new relationships was more difficult than before. They described how contact with the patients’ unions were important because that enabled them to meet other people, break the isolation and loneliness, and gain strength. It was important to meet other people, both those who were ill and those who were healthy. The people in the study said that it was sometimes better not to be in active contact with others, because there was always a risk that they might make a fool of themselves and feel ashamed.

I have become much quieter and shyer than before. ...I realize it especially at my work place when we are sitting and discussing things. I don’t say much, only if it really bothers me. ...I feel, let the others make the mistakes.

Participants experienced that they had been reminded of life’s vulnerability, which led to deepened relationships among members of the family. It was within the family that participants found consolation in terms of being believed, accepted, and supported. Children, in particular, gave a meaning to life and relieved loneliness. But not all participants received support from family members. Sometimes they found it impossible to continue to live together with their partners. They understood that it was difficult for the partner to accept that they were living with a person who was not the same as the one they had fallen in love with. The participants also expressed a fear of being a burden and that the partner was ashamed of them. It was crucial to be able to discuss openly all the problems that arose. In spite of living with a partner, participants felt lonely in their illness.

Experiencing the Body as an Enemy. Study participants felt that their body became unfamiliar, a frightening hindrance, and something they could never trust. They experienced a lot of pain, especially headache, and fatigue. Ordinary painkillers did not alleviate the headache, but they wanted to avoid stronger medication because that made their whole body feel strange. Sometimes, they felt that pain or fatigue governed their whole body and confined them to bed. Managing daily life demanded a great deal of concentration, which was exhausting. In turn, being fatigued made it hard to concentrate. Not being able to feel thirst, hunger, or temperature and lacking a sense of taste were also felt to be great losses and made life boring.

Lacking a sense of smell resulted in a fear of smelling unpleasant. Their bodies restricted their opportunities to live a normal life, to plan for the future, to be with family and other people, and pursue recreational activities. They also described a fear of suffering further injuries.

This bloody headache. ...it’s always there, it keeps on all the time, a little bit. You feel yourself often ...fatigued; I have always been so tired.

Participants described a struggle to gain control over their bodies. Training with and against one’s body was intensive and time-consuming. It was important to challenge one’s body. The participants trained mostly alone or with their personal assistant. It was also stimulating to train with other people who had different injuries.

Struggling to Attain a New Normalcy

The theme, struggling to attain a new normalcy, was constructed from four sub-themes: searching for an explanation, recovering the self, wishing to be met with respect, and finding a new way of living.

Searching for an Explanation. The study participants said that it took many years for them to be able to understand what had happened and how seriously ill they were. At the beginning they suspected that other people had injured them on purpose. They also blamed themselves for being injured, because the TBI was the worst thing that could happen in one’s life.

To live with this is just shit and once again, shit ...it’s something you do not wish to happen even to your worst enemy.

Participants sought explanations and information by reading medical journals, listening to stories about episodes in their lives, and participating in therapy aimed at stimulating their memory. Receiving clear, honest information from the nurses, seeing test results, getting explanations, and meeting other people with similar injuries were aids to understanding their illness. They struggled with bitterness when they felt that the whole or the best years of their lives had been ruined, but, on the other hand, they felt grateful to have survived and not been injured as badly as they might have been. Having survived was like a miracle.

I was injured on some hotel stairs, I slipped down, I don’t remember...after coming home from [the hospital], I wanted to go there and have a look what it was like...I felt it over the whole body, I don’t understand how I could have fallen and there is obviously no one who saw anything.

Recovering the Self. The participants struggled to know themselves and their surroundings. They wondered whether they were the same people as they were before the injury, and by listening to family members’ stories about themselves before the accident, and by
observing other people of the same age, they tried to formulate an identity. The participants had a feeling that they had lost something of themselves, usually something emotional, without being able to define it. Family members or friends also confirmed these changes. Participants experienced an inability to control feelings and reactions, particularly anxiety, frustration, anger, and aggression. They also described an inability to change their tune according to their feelings and difficulties in understanding other people's emotions. All this meant that the participants offended and, not on purpose came into conflict with other people, which made them feel ashamed and guilty. They struggled to be able to control their feelings and reactions.

I’ve really big problems with my temper. ...I can’t control my aggression when I feel offended. ...I get so bloody angry I can’t control it.

Participants described feelings that they were less clever and they were frustrated when they struggled to remember and learn things they had no problems with before. Forgetting things all at once or getting lost without any forewarning was embarrassing, frightening, and made them extra sensitive and suspicious. Living with a bad memory was described as being like an outsider in one’s own life. Life went on but they did not remember all the things that happened to them. Participants had difficulties following a discussion when they were among others, especially unfamiliar people. They felt that life became more dismal and cheerless or that they were living on a lower level.

Wishing to be Met with Respect. In spite of having physical signs of TBI, participants felt they were living with a hidden handicap. They had trouble expressing themselves and they struggled to be understood and respected by other people. They frequently described how they felt insulted by others, but children and young people treated them best, without prejudice.

It was insulting and exhausting to be checked constantly and inspected by various authorities in order to get a drivers license, an allowance for home equipment, or home help. They were afraid of the power of authorities over their lives. The participants searched intensively for help and rehabilitation where the personnel listened to them, respected their goals, and showed an understanding of their situation. Sometimes it took a long time to find this kind of help. Even getting the diagnosis of a brain injury could take several years, even though the person repeatedly sought help for the same problems.

Participants frequently felt that the personnel were not sufficiently qualified. Demands for more support and rehabilitation adjusted to their needs were common. If the participants did not find enough help from the traditional medical services, they continued to search for help from, for example, churches, alternative treatment forms, or from abroad. Finding help was seen as the turning of the tide, and it was an enormous relief and a source of gratitude. Support from relatives or having recourse through a lawyer were significant when their own strength was fluctuating.

When you feel there is something wrong, ...if they say it’s nothing, it’s important to believe in oneself and think no, hell, there is something wrong, [If] it’s not like it should be, look somewhere else.

Finding a New Way of Living. People with TBI had difficulties acknowledging that they had a brain injury because of prejudices held by themselves and other people; getting a brain injury means being more or less of a freak. It was hard to live with an altered appearance and, if possible, participants hid the visible signs of the injury. They struggled to be able to accept the injury because to do so made life easier.

It’s now almost 5 years ago actually. I should understand that I’ve got this injury and that I will never be normal again, but on the other hand it’s difficult for me to think in that way; it is like giving up.

Participants said that it was extremely important to think positively, to have a strong will and to trust one’s possibilities. Having hope and hating to give up were the mainspring. They set goals, struggled to attain them, and were hurt if other people did not believe in their opportunities. Making progress was a cause of enormous joy and motivated them to continue to struggle. It was also important to concentrate on living in the present.

If on the whole there is only a little idea, chance that one might return it’s usually much, much more than one can manage, more than one believes.

Fear of ruining their children’s lives was common. Participants felt sorry and anxious about not being healthy parents. It was hard to hear children say that their greatest dream is that their parent should be healthy. They were afraid that children took too much responsibility. It was therefore important to live as normal a life as possible. It increased the sense of well-being both for themselves and for those closest to them.

It took many years to learn to live with TBI and to find a little balance. Participants developed routines in order to manage daily life and avoid getting lost. They compensated for their poor memories by using memory aids and technical equipment, writing in a diary, and taking photographs. When they were unable to feel hunger, they ate when they saw other people eating.

In time, when there was obviously no other choice, living with TBI became a more natural part of their lives.
Participants found the courage to be as they were and said they lived a good life. Sometimes they found relief in art or writing, which was a way of expressing themselves. They were proud of themselves after all their struggles and felt grateful to have developed as human beings. They felt that they provided a lesson for other people of the unpredictability of life and wanted to communicate all that they had learned to others.

I think I've developed a lot because of my suffering. I've got more from it I think ... so, there is more good than bad.

In spite of finding a way to live with TBI, there was always a longing to be healthy, independent, and free from the exhausting, endless, and sometimes meaningless struggle. Particularly when they regressed, they felt enormously depressed and thought it would have been better to die. Support from people closest to them and the curiosity about life kept them alive. Participants felt at ease when they were in places where they could be more anonymous and only minimal demands were put on them.

It has been a real business to manage this 13 years, I need a little holiday [from the injury].

Comprehensive Understanding and Reflections

In the previous phase of the interpretation, the text was seen as a whole. The naive understanding, the results of the structural analysis, and the researchers' preunderstanding were synthesized into a new comprehensive understanding.

In this study, people with TBI lost their way and struggled to attain a new normalcy. Living with TBI seemed to mean living with a perpetually altered body that changed the whole of life and caused deep suffering. Losing one's way was predominated with feelings of shame and loss of dignity. Struggling to attain a new normalcy was predominated with managing feelings of shame and reestablishing dignity. Nevertheless, both feelings of shame and dignity were in some way present in each theme and it seems that participants fluctuated between these feelings.

The findings were interpreted in light of research about suffering carried out by Eriksson (1993, 1994) and Wiklund (2001). They maintained that suffering is a struggle with life and between good and bad, dignity and shame. In addition, literature was used that describes peoples' relation to their bodies in health and in illness (Corbin 2003; Leder, 1990; Van Maanen, 1998); shame (Kaufman, 1989); the meaning of life and suffering (Frankl, 1984/1994); and Frankl's reflections on encountering serious illness (1991/2002).

It seems that participants felt ashamed because they lost their familiar way of living. Kaufman (1989) stated that lack of control in one's life and loss of the dream self are activators of shame. According to Wiklund (2000), shame is always present in suffering as the opposite of dignity. When one's dignity is threatened, one experiences the shame of not being able to be the person one was intended to be. Edlund (2002) believed there is a difference between an absolute and relative dignity. Absolute dignity involves the holiness of human beings and is given to people by creation. Relative dignity is influenced by the culture and society and can be changed and demolished but also reestablished. In this study, it seems that the participants' serious illness was a threat to their relative dignity.

It appears that many people abandoned the participants. They felt they were not good enough and this again aroused feelings of shame. The feeling of not belonging or not being united with anyone increases suffering (Eriksson, 1993, 1994) and the feeling of shame (Wiklund, 2000). Nevertheless, there was always someone who stayed with the participants and gave them an opportunity to feel love. According to Eriksson (1993, 1994), the mediation of love supports dignity and alleviates suffering. In spite of a feeling of solidarity with someone, participants seemed to feel lonely. Eriksson (1994) maintained that absolute loneliness is felt when one discerns that only one can do anything for one's situation. It is then one must make a choice between struggling with illness or giving up. In this study, participants chose to struggle to be aware of their responsibility for their own well-being.

Participants longed for relationships, but they sometimes chose loneliness by avoiding situations where there was a risk of making a fool of themselves. It seems that participants were afraid of being ashamed. It may also be that the people who abandoned the participants felt the fear of shame, they were afraid of encountering the person with TBI in a clumsy way and therefore making a fool of themselves or only of increasing the ill person's shame. Kaufman (1989) stated: people often avoid someone who shames and just leave that person alone. According to Wiklund (2000), fear of shame isolates and increases the distance between people.

It seems that participants experienced their bodies as a hindrance to living a normal life. They were forced to pay attention to their bodies, to support them. They often avoid someone who shames and just leave that person. Frankl (2002) suggested that instead of striving to gain control of the body one should recognize the wonder of the body, trust it, and let it change according to its own wisdom. Then there is no
fight, only the possibility of change. According to Corbin (2003), learning to trust one’s body again can be time consuming and a feeling of bodily vulnerability with fear of relapse often remains. This is in line with this study’s findings, because participants seemed to be afraid of being injured again.

It appears that the participants’ search for explanation continued for many years, if it ever ended. They struggled against bitterness and were aware that it only led to feeling worse. According to Eriksson (1993, 1994), human attitude to suffering fluctuates between humility and bitterness. Humility helps one to survive suffering but bitterness leads to hatred of oneself and other people. In this study, it seems that participants chose humility.

The participants seemed to have an enormous will to live and the courage and the strength to encounter suffering.

It appears that participants’ increasing awareness of becoming another person made them feel a deep sorrow. Eriksson (1993, 1994) stated that suffering is always a form of dying when one is forced to abandon the potential one was born with. In this study, the participants appeared to experience a kind of dying when illness forced them to say goodbye to their ordinary selves. Frank (1991/2002) stated that the loss of the familiar body and ways of life must be mourned fully. “To grieve well is to value what you have lost. When you value even the feeling of loss, you value life itself, and you begin to live again” (Frank, 2002, p. 41).

The participants’ struggles to meet with respect seem to demand a lot of energy and courage. Eriksson (1993, 1994) and Wiklund (2000) stated that when a person encounters nonchallenge, the feeling of shame and the violation of dignity increase. According to Eriksson (1993, 1994), in order to alleviate suffering it is important to not to blame, not to use one’s power in a wrong way or to violate one’s dignity. It is worth reflecting on why the participants in this study were forced to struggle to be met with respect by various authorities, which should occur as a matter of course. Frank (2002) stated that for a truly intimate relationship, people need to share a personal history and to recognize each other’s differences.

It seems that the hopes of getting better carried the participants forward. However, they also had feelings of hopelessness and meaningless. According to Eriksson (1993, 1994), suffering has to have hope if it is to be alleviated. Good suffering involves a struggle for meaning and growth, but bad suffering means that person feels hopeless. This is in line with Wiklund (2000) who thinks that a person who is suffering can see their situation with “the eye of health” or with “the eye of suffering.” Regarding one’s situation with “the eye of health” means that the person is aware of difficulties but can look towards a horizon where communion and life dominates. Regarding one’s situation with “the eye of suffering” means that the horizon is dominated by alienation and death. It seems that in this study the participants strove to regard their situation with “the eye of health” (i.e., feeling hope and living as normal a life as possible), but they had moments when they saw with “the eye of suffering” (i.e., feeling of hopeless and meaninglessness). Wiklund (2000) considers that it is sometimes important to use both “eyes” because seeing only through “the eye of health” indicates a risk of idealizing suffering.

The participants seemed to have an enormous will to live and the courage and the strength to encounter suffering. Frankl (1984/1994) argued that the meaning of life is continually changing but it never disappears. He maintained that one can discover the meaning of life by performing an action, knowing one’s worth, and by suffering. The participants seemed to experience a meaning in life because they had goals they strived for (e.g., performing an action). They also had people they loved and felt loved by, and they struggled to reestablish their dignity (i.e., knowing one’s worth). Finally, it seems that the participants found meaning in their suffering when they realized they had developed as human beings. However, is it possible to claim that suffering has a meaning? The participants seemed to preserve their dream of returning to health. According to Eriksson (1993, 1994), suffering is wholly evil and the only meaning in suffering is to survive (Eriksson, 1994). Admitting that suffering has a meaning after all is a way of protecting the innermost part of oneself, alleviating suffering, and increasing the feeling of health (Eriksson, 1994).

Finally, this study emphasizes that living with TBI is not a process that starts with waking up to the unknown and ends with finding a new way of living. Each person experiences and encounters suffering in different ways, and this can vary from day to day or moment to moment. One day or moment the person may be full of feelings of hope, balance and dignity but another day or moment they may be overwhelmed by feelings of shame and loss of dignity.

Methodological Considerations

According to Lincoln and Guba (1985; Guba & Lincoln, 1989), trustworthiness in qualitative research means methodological soundness and adequacy. The strategies used should be appropriate for the reporting of the participants’ experiences. We argue that both the interviews as the method for data collection and the phenomenological hermeneutic method for data analysis were relevant choices, considering the aim of the study.

The sample consisted of more men than women but is in line with the prevalence of TBI. The interviewer and interviewees did not know each other before the interviews and therefore had no prejudices. On the other
hand, they were forced to build up a trusting relationship from the beginning. The participants chose the locations for the interviews and we assume that this increased their feeling of safety and their ability to narrate their experiences. The participants’ extensive experience of living with TBI, our careful planning of the interviews and interviewing every participant twice contributed to the depth and richness of the data.

Data analysis proceeded through several stages where the whole was confirmed by the parts and the parts confirmed the whole. The structural analysis as the objective stage in the interpretation process served as a kind of validation (Ricoeur, 1976). According to Ricoeur (1976), the interpretation arrived at must be more probable than any other interpretation. When interpreting texts we were careful not to let our preunderstandings steer us to prejudiced interpretation. We were open for different interpretations and also discussed interpretations with other colleagues. After these discussions we checked the accuracy of our interpretations and adjusted them if necessary. The final interpretation in this study is the most probable interpretation we could achieve.

The procedure, context, and findings of the study were presented as accurately as possible. The findings are illustrated with direct quotations from the interviews in order to show some of the raw data from which the findings emerged. In this way we help the reader to judge the accuracy of the interpretation and the transferability of findings to similar situations and participants (Lincoln & Guba, 1985; Guba & Lincoln, 1989).

According to Guba and Lincoln (1989), a study should result in a new insight into the phenomenon under study for both readers and participants. We believe that our study helps other people to understand more deeply what it means to live with a TBI and increases other people’s readiness to behave in a way that alleviates suffering for people with TBI. However, the authors cannot be sure whether this study will help the participants to achieve a better understanding of their world or to improve it.

Practice Implications

This study indicates that living with a TBI is living with a perpetually altered body that changes one’s whole life and causes deep suffering. People with moderate or severe TBI often spend long time in hospitals and rehabilitation settings. However, this study shows that the participants were quite alone in their suffering and they seem to need more support from professionals. Although professionals always have a will to alleviate suffering, they do not always have enough knowledge or courage to meet suffering humanity. It is essential to acknowledge that the act of healing requires the understanding of illness as lived (Warden Carrol, 1998) and what happens to one’s body happens to one’s life (Frank, 1991/2002). It is therefore important that professionals do not minimize the losses people with TBI experience, but recognize them and strive to understand how they think, what their aims are and what challenges they meet in their daily life. It is hoped that this study will help professionals not only to clarify their past understanding but also to see their practice in a new light. Seeing one’s practice in a new light can be the foundation for acting more carefully in order to be able to alleviate the suffering of people with TBI (Walton & Madjar, 1999).

Summary

It seems that the participants’ changed relation to their body changed their whole lives and caused suffering where feelings of shame and dignity competed with each other. The participants strived to manage their feelings of shame and to reestablish their dignity. It seems that they were quite alone in their suffering and they needed more support from other people, including healthcare personnel.

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References


Adlow: Liber Uitbldning.
Living With Moderate or Severe Traumatic Brain Injury

The Meaning of Family Members’ Experiences

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Traumatic brain injury (TBI) has long-lasting consequences not only for the individual with the injury but also for family members. The aim of this study is to elucidate the meaning of family members’ experiences of living with an individual with moderate or severe TBI. The data have been collected by means of qualitative research interviews with 8 family member participants. A phenomenological hermeneutic interpretation (Ricoeur, 1976) of the data reveal that family members struggle with their own suffering while showing compassion for the injured person. Their willingness to assume care for the injured person is derived from their feeling of natural love and the ethical demand to be responsible for the other. Hope and natural love from close relatives, the afflicted person, and other family members give the family members strength. It is important that professionals pay more attention to the suffering of close relatives.

Keywords: family; family members; traumatic brain injury; phenomenological hermeneutics; interpretation; responsibility; love; ethics; suffering; hope

Illness occurs within the relational context of family, friendships, and workplaces. Research has shown that chronic illness affects the relationship between the ill person and his or her family system, including both nuclear and extended family members, in various ways (Kuyper & Wester, 1998; Öhman & Söderberg, 2004; Purola, 2000; Söderberg, Strand, Haapala, &...
Lundman, 2003). Family members report putting themselves second to pro-
vide intensive support to the ill person (Engström & Söderberg, 2004; Öhman & Söderberg, 2004). When the illness is in a critical phase, family members describe that their whole existence is focused on the ill family member (Engström & Söderberg, 2004). Close relatives who live with someone with serious chronic illness feel a circumscribed personal freedom because living with the ill person takes much of their time and energy (Grant & Davis, 1997; Öhman & Söderberg, 2004).

The family member experiencing a moderate or severe traumatic brain injury (TBI) usually moves abruptly from a healthy state through a life-
threatening episode requiring acute care to a state of chronic illness. This change is so rapid and dramatic that relatives can only dimly understand the shift in condition from critical to chronic illness (Duff, 2002). Close relatives of individuals with TBI show a great willingness to adjust their lives to accommodate the needs of the injured person (Carson, 1993; Duff, 2002; Simpson, Mohr, & Redman, 2000). They may experience role changes and have to take on more responsibility than before the injury (Gill & Wells, 2000; Kneafsey & Gawthorpe, 2004; Perlesz, Kinsella, & Crowe, 1999). Close relatives engage in a process of reevaluation and reconciliation of the pre- and postinjury person with TBI (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002) and feel great sorrow because of the loss of the preinjury person (Carson, 1993; Smith & Smith, 2000). Emotional and behavioral changes in the injured person put great strains on close relatives (Florian, Katz & Lahav, 1989; Kneafsey & Gawthorpe, 2004). Family members also report loss of partnership, leisure time, and social contacts (Florian et al., 1989; Liss & Willer, 1990; Lovasik, Kerr, & Alexander, 2001).

Close relatives of people with TBI experience great uncertainty for a long time (Bond, Draeger, Mandelco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002). A review by Degeneffe (2001) found that the feelings of stress and burden among close relatives often do not lessen with time. Sometimes the responsibility for the injured person and the other demands of life are exhausting (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002; Simpson et al., 2000). Literature on family needs supports the importance
of hope (Carson, 1993; Johnson, 1995; Smith & Smith, 2000) and the need for information, together with the need for emotional and practical support (Bond et al., 2003; Smith & Smith, 2000). Several studies show that families do not get enough information or support (Paterson, Kieloch, & Gmiterek, 2001; Serio, Kreutzer, & Gervasio, 1995; Smith & Smith, 2000). According to Smith and Smith (2000), families experience the health care system as complex and feel that no one takes any responsibility for informing and supporting them, especially when the injured person returns to the community. They also believe that other people, including social and health care professionals, lack any understanding of their problems (Backhouse & Rodger, 1999; Swift & Wilson, 2001).

In summary, previous research using both quantitative and qualitative methods confirms that TBI has long-lasting consequences for close relatives. The research also shows that they experience various burdens and have a great need for different kinds of support; however, these needs are not always met. To meet the needs of these families, more knowledge is required about the experience of daily life with a person with TBI. The understanding gained from quantitative research is useful for predicting and enabling interventions to reduce harmful consequences of illness (Kneafsey & Gawthorpe, 2004). However, to provide holistic care, more understanding is needed about the meaning of living with a person with TBI from close relatives’ perspective. Thus, the aim of this study is to elucidate the meaning of close relatives’ experiences of living with a person with moderate or severe TBI.

Method

To explore the meaning of living alongside a family member with TBI, we chose a phenomenological hermeneutic method of interpretation inspired by Ricouer (1976). According to Ricoeur, language is a process whereby private experience is made public. The lived experience of one person remains private and cannot be transferred to another person in total, but its meaning can become public. By speaking to another person, people “point towards the unique thing” they mean (Ricoeur, 1976, p. 16).

Participants and Procedure

This report is part of a qualitative inquiry that aims to elucidate the experiences of living with TBI from the perspective of individuals diagnosed
with TBI (Jumisko, Lexell, & Söderberg, 2005) and their close relatives. We interviewed 12 people with moderate or severe TBI living in northern Sweden and asked permission to send a letter to one of their relatives with whom they had frequent close contact during the course of their illness and who could tell us about their experience of living with a person with TBI. The close relative did not have to live in the same household with the person with TBI. One of the individuals with TBI had no close relatives; thus, we contacted 11 close relatives by letter. The letter included information about the study and asked if the close relative would be willing to participate. Eight close relatives consented to participate, and they were then telephoned by the first author to arrange a time and place for an interview. The participants included 2 mothers, 1 father, 2 partners, 2 siblings, and 1 daughter. The family members ranged in age from 28 to 56 (median = 45) and had lived alongside the person with moderate or severe TBI between 4 and 13 years (median = 8 years). Five of the participants had received upper secondary education and 3 had received university education. Two participants lived in the same household as the person with TBI. The age of the person with TBI varied from 23 to 50 (median = 38). Six of the people with TBI had been injured in a traffic accident and 2 during a fall.

Data Collection

The data were collected by qualitative research interviews, which are appropriate for exploring the meaning of peoples’ experiences (Kvale, 1997). The participants were interviewed in their homes by the first author. An interview guide was used that included themes pertaining to life before and after the injury, the meeting of other people, and the care of the close relatives. Each interview began with the request: “Please tell me about your experiences when X was injured.” To encourage responses, the interviewer used follow-up questions such as “What did you think then?” “Please tell me more about that,” and “Can you give an example?” The interviews lasted approximately 80 minutes and were transcribed verbatim.

Ethical Considerations

All participants gave their informed consent and were provided a guarantee of confidentiality. The Ethical Committee at Luleå University of Technology in Sweden gave permission for the study.
Data Analysis

The text of the interview was analyzed using a phenomenological hermeneutic interpretation inspired by Ricoeur (1976). The interpretation consists of three phases: naïve understanding, structural analysis, and comprehensive understanding. First, the text is read several times as open-mindedly as possible to grasp meaning as a whole. This is the first superficial interpretation—the naïve understanding of the text. The second phase is the structural analysis aimed at explaining the text as objectively as possible and checking the naïve understanding. During the third phase, comprehensive understanding, the text is again interpreted as a whole based on the preunderstanding of the authors, the naïve understanding, the structural analysis, and the literature. This leads to a new, deeper understanding of the phenomena being studied (Ricoeur, 1976).

Findings

Naïve Understanding

Close relatives’ familiar world collapsed and they seemed to enter into an unknown life directed by the illness. They experienced great uncertainty during the period the injured family member was in a critical condition and when they realized how much their loved one had changed. Close relatives seemed to want to do everything to support the ill person. Finding a way to live with the person took a lot of their energy. They suffered with the ill person, and their well-being seemed to be associated with the well-being of the ill person. Feelings of fear, anxiety, and disappointment, but also of gratitude, pride, and pleasure, were expressed. Close relatives gained strength from their love for the afflicted person, from other family members, and from support given by other people. They experienced loneliness and observed that other people did not fully understand their changed situation. Feelings of anger were expressed about other people who met the ill person with non-chalance or in a way that was unfair. They reported that health professionals paid insufficient attention to their needs.

Structural Analysis

In the structural analysis, we divided the interview texts into meaning units, which included a sentence, a paragraph, or several pages with the same meaning. Next, we condensed and abstracted the meaning units to
formulated meaning units. The formulated meaning units were sorted into different groups according to similarities and differences in content. The groups were compared to one another and organized into themes and subthemes. The structural analysis resulted in one major theme with six subthemes and validated the meaning gained from the naïve understanding. The themes are presented below and further illustrated by quotations from the interviews.

**Fighting Not to Lose One’s Foothold**

The theme “fighting not to lose one’s foothold” was constructed from six subthemes: getting into the unknown, becoming acquainted with the changed person, being constantly available, missing someone with whom to share the burden, struggling to be met with dignity, and seeing a light in the darkness.

**Getting into the unknown.** Close relatives described how life changed without any forewarning. Information about the ill person’s injury was experienced as a shock, and the family members felt panic, anxiety, and disappointment when their future plans and dreams involving the ill person were ruined.

“It was very dramatic . . . it was awful, I came home . . . I knew that X [the ill person] would go early in the morning, she said she would . . . go to a solarium . . . because she would go away after school . . . and the next thing that happens is that the police came to my home and said there had been an accident. . . .”

Close relatives felt that they had entered a vacuum in which everything they considered important earlier had lost its value. Seeing the ill person bloody and bruised was unpleasant, and the technical equipment around the person was perplexing. They were at the hospital from early morning to late evening and hardly ate or slept. To be able to stay close to the ill person, the relatives reported to their employers that they were sick, which made their financial situation worse. The hospital was often far away from their home, and they were forced to stay at a hotel. If they could not afford accommodation, they lived in their cars.

Close relatives hovered between hope and despair as the condition of the ill person fluctuated. The experience of uncertainty with regard to the survival of the ill person was experienced as terrible and anxiety ridden. The relatives appreciated honest, clear, and continuous information about the condition of the ill person. It was important that bad news was conveyed in a polite manner and without depriving them of hope.
Becoming acquainted with the changed person. Close relatives gradually realized that the ill person had totally changed and were embarrassed about these personality changes. A cheerful and active person became one who was often depressed and preferred to be alone. The ill person lacked patience or lost all feelings of tenderness. Spouses described how their relationship with the ill person became more like that of a friend. Parents whose adult child was injured described how they had regained a little child that they needed to bring up to be an independent adult. The physical changes, such as the ill person’s perpetual fatigue and headaches, were also embarrassing. It was difficult to accept the person’s helplessness, and close relatives were sorry they had lost the person they knew before the injury.

“[H]e was totally different, he had the worst humour in the world . . . had no patience . . . and if something didn’t go as he wanted he was really angry and they [children] were very disappointed and it was really hard. . . . He could also shout and be angry with me . . . and if I didn’t always hear what he said . . . then the next time he shouted and it wasn’t only in a louder voice but much, much louder . . .”

Close relatives described how living with the changed person was like being on a roller coaster, and they struggled to be diplomatic and patient. They searched for information about TBI and ways to organize their daily life. Being given explanations, like meeting others involved in the same accident, was a relief. Finding a way of living with the changed person was time consuming, and sometimes it was impossible to continue to live in the same household with him or her.

Being constantly available. Close relatives felt that they had an important role because they were constantly on call. If they were at work, they went home for lunch to ensure that everything was all right. The person with TBI often called them either about something specific or just to talk. If they were not available, they knew that the person with TBI would become anxious and start to search for them. Close relatives felt that they should guide the ill person wisely to encourage him or her to live as normal a life as possible.

Close relatives described how it was crucial to be “pigheaded” and strong to manage daily life. They balanced the demands they felt were made on them because they had their work, family, and often the ill person’s children to care for. Close relatives experienced periods when they felt desperate and depressed. They did not want to burden the ill person by telling him or her about their feelings, because the ill person’s life was
much worse and seeing his or her suffering was extremely difficult. The ill
person was a fine person and worthy of their involvement. Close relatives
often suffered palpitations and other symptoms of burnout following the ill
person’s improvement.

“I was at the hospital a lot with X [the ill person]. . . . I worked nights . . . I
had my own kids and X [the ill person’s child] who needed a lot of help and
the telephone rang every day and people asked how was X. . . .”

Involvement with the ill person changed close relatives’ relationships
with other family members. Siblings who took care of the ill person’s
children said that their own children became jealous of the ill person or his
or her children. Close relatives felt that they did not always have enough
time for their relationship with their partners and felt they were drifting
apart, which resulted in feelings of anxiety. They felt that their privacy was
eroded if the ill person lived in their home, had a personal assistant, or spent
a lot of time with them in spite of actually living alone. Despite conflicts,
close relatives felt that their relationships with the ill person and other fam-
ily members were deepened, and they learned to appreciate their family
more. They understood life’s vulnerability and that they could lose one
another at any time. Everyone in the family tried to do his or her best to
facilitate the participant’s involvement with the ill person and to support the
ill person. It was important to talk to one another within the family.

*Missing someone with whom to share the burden.* Close relatives
described that they felt alone and were disappointed with significant others,
especially relatives, who were engaged only at the beginning. They wished
that significant others offered to help more often. Close relatives were also
disappointed with the help they received from social and health care per-
sonnel. They often had a need to talk about their experiences but felt that
the professionals seldom had time or rarely informed them of opportunities
for support. Close relatives sought help (e.g., from the church or a psychi-
atrist) or just accepted the situation because they had no energy or no idea
where to seek help. They expressed bitterness after sacrificing many years
to the ill person. Getting more support helped them to see their situation
more clearly and facilitated daily life. Not all participants wanted to talk
about their feelings, but they appreciated an opportunity to be alone.

“[O]ne hasn’t had an opportunity to talk to anyone. . . . I think I’ve missed it,
there is no one who listened or asked what you needed. . . .”
Struggling to be met with dignity. Close relatives discovered that it was difficult for significant others to understand the ill person because the illness was invisible. They protected the ill person from people’s curiosity and defended him or her following bad encounters. Close relatives felt that health care personnel did not have enough knowledge about caring for people with TBI and therefore felt insecure. They felt that personnel at the regional social insurance office, local authorities, or the insurance company treated the ill person nonchalantly. This made the close relatives feel angry, powerless, sad, and disappointed.

Close relatives reported that it was their duty to make demands and speak on behalf of the ill person. They said it was beneficial to have knowledge, authority, and courage. Close relatives felt that various professionals treated them with indifference and impatience when they advocated for the ill person. They expressed fear of the power of professionals because they felt they were subject to their control and in a weak position. Being controlled and being met with nonchalance and disbelief was frustrating and insulting.

“They don’t listen to us who are close to her and know what she needs . . . they must investigate here and there to see if she needs that help which she is entitled to . . . you must push and shove in order to get this help . . . it’s really wrong and . . . outrageous . . . that they don’t listen . . . but do what they want. . . .”

Seeing a light in the darkness. Close relatives described that the relationships to significant others remained good or were even deepened if they felt that the latter asked how they felt, offered to help, and appreciated the ill person’s and close relative’s efforts to manage daily life. They felt that it was a relief and eased their daily life when the ill person received help adjusted to his or her needs. Open and honest communication with professionals made them feel safe. Close relatives valued participating in group discussions with other people in the same situation or meeting professionals who took time to listen to them.

Seeing the ill person improving and finding a somewhat meaningful way of living increased hope and gave strength. If the ill person felt well, the whole family felt well. They understood that the ill person would never be the same as before the injury, but they were happy to have more good than bad days. In time, they were able to look forward to the future and make new plans. Close relatives were proud of themselves and the ill person because they had managed so well. They had learned a lot about life and had become more independent and strong.
“[T]hat you see him doing something he thinks for himself, hopes he can do some day . . . then you get strength . . . maybe he will manage something else as well. . . .”

Comprehensive Understanding and Reflections

In the last phase of the interpretation, the text was again viewed as a whole. The naïve understanding, the results of the structural analysis, and the researchers’ preunderstandings were brought together into a comprehensive understanding that was reflected on.

This study suggests that the meaning of close relatives’ experience of living with a person with moderate or severe TBI is a fight not to lose one’s foothold. They had to learn to know the ill person who had been changed by the TBI and were forced to take on responsibilities for which they were unprepared. Close relatives had to be constantly available to the person with TBI, and they had to be strong despite feeling alone and missing someone with whom to share the changed situation. Increased responsibility for the person with TBI changed the close relatives’ relationships with significant others, and they struggled to be treated with dignity. Close relatives managed their profoundly changed daily life with support from other family members and a hope for a better future.

Close relatives felt anxiety and sorrow when their relative was injured. They were forced to relinquish the life they had planned and instead find a new way of living with the changed person. The loss of this familiar life entailed great suffering. Eriksson (1993, 1994) argued that in its deepest essence, suffering is dying of sorrow for the loss of something important. Suffering also refers to fighting, where feelings of fear and despair are mixed with the willingness to fight for life. Close relatives’ struggles with feelings of fear and despair—mixed with the willingness to fight—are seen from the beginning, when they “got into the unknown.” May (1975/1984) argued that entering into the unknown requires the courage to go on in spite of despair. Close relatives talked about feelings of despair but carried on with the fight; this we regard as a sign of courage.

Close relatives were willing to do everything they could to support the ill person. They placed their own well-being second, because the ill person’s situation was much worse. This can be interpreted to mean that close relatives felt a deep compassion for the ill person. Eriksson (1993, 1994) stated that compassion entails sensitivity to another person’s pain or suffering and a preparedness to struggle for the other. According to
Lögstrup (1956/1992), every encounter between two people includes an ethical demand to take care of the other person’s life. He described the essence of natural love as a movement toward the other. Close relatives adjusted their lives according to the needs of the ill person and wanted to make sure that the person with TBI felt as well as possible because he or she was a person worthy of their involvement. We suggest that this is an expression that close relatives feel a natural love and an ethical demand to take care of, and be responsible for, the person with TBI. Therefore, they had no doubt about taking up the challenge of living with a person with TBI.

Close relatives struggled to be strong to support the person with TBI. They seemed to place their own suffering second because the ill person suffered much more. Lindholm, Rehnsfeldt, Arman, and Hamrin (2002) believe that significant others are torn between the suffering of the ill person and their own suffering. According to Eriksson (1993, 1994), the ability to feel compassion and alleviate the other person’s suffering can be limited by one’s own suffering. Suffering can be experienced as a threat that must be “buried” (Rehnsfeldt & Eriksson, 2004). Close relatives wanted to “bury” their own suffering from the person with TBI but found it important to be able to talk freely with other family members. They felt that relationships within the family deepened and that made it possible to cope with the changed situation. This we interpreted to mean that natural love within the family gave the close relatives the strength to fight. It alleviated their suffering and facilitated their feelings of compassion for the ill person.

The increased responsibility for the ill person changed when the person got better, but it never ended. Close relatives balanced their need to control the ill person and their need to support his or her independence. As mentioned earlier, Lögstrup (1956/1992) believed that the ethical demand means that one person holds another person’s life in one’s hands. The meaning varies from a passing feeling to the idea of holding the other person’s fate in one’s hands. One’s unselfishness and understanding of life provide information about the best way to take care of the other person without taking over his or her independence. In our study, close relatives almost had the ill person’s fate in their hands, but they seemed to have the wisdom to be cautious—not to take power from the ill person but instead to support his or her independence.

Close relatives fought to ensure that both they and the person with TBI were afforded dignity by other people. They missed people who gave attention to their changed situation in life, asked how they felt, believed in them, and offered help. Close relatives lacked confirmation of their experiences. According to Nåden and Eriksson (2000), confirmation consists of being
seen and trusted. Not being seen or taken seriously violates a person’s
dignity. Eriksson (1993, 1994) asserted that every suffering person has a
need to meet someone who can give him or her the feeling of being seen
to suffer uniquely. Difficulties in finding professionals who could help
the ill person and close relatives, and not being treated with respect by
professionals, can be regarded as suffering as a result of caring. Eriksson
(1994) stated that suffering from caring is a consequence of insulting
encounters, abuse of power, receiving incorrect care, or being left without
care. To be able to alleviate suffering, it is essential to supply whatever care
the suffering person needs. Meeting people who offered help and treated
both the ill person and their close relatives with respect was a relief and
increased the latter’s feeling of safety.

Close relatives never lost hope for a better future with the person with TBI.
Benzein (1999) claimed that hope as a human experience is always present.
She and her colleagues (Benzein, Saveman & Norberg, 2000) found two
major dimensions of hope: being in hope and having hope for something.
“Being in hope” relates to being, and “having hope” relates to doing. Hope
related to being includes a will to live and an awareness of one’s possibilities
in life, which provides energy and enables a person to make good and mean-
ingful choices. Hope related to doing is directed toward setting goals. It is
apparent that close relatives had hope related to being: a strong will to live
and to struggle, and awareness of one’s possibilities. They also seemed to
experience hope related to doing. Close relatives fought on because they had
a goal: the ill person’s improvement and well-being. Hope related to being is
an internal process and a prerequisite for hope related to doing, which is an
external process that nurtures hope related to being (Benzein et al., 2000).
Achieving goals (i.e., when the person with TBI improved), or hope related
to doing, increased hope for the close relatives and gave them the strength to
continue the fight (hope related to being). Lögstrup (1956/1992) stated that in
natural love, partners’ motives are the same, and taking care of each other
leads to happiness for all. We suggest that the natural love between the ill
person and the close relatives made their motives the same. Close relatives
felt well if the person with TBI felt well, which can be interpreted to mean
that taking care of the ill person led to well-being for both the person with
TBI and his or her close relatives.

In conclusion, this study suggests that living with a person with moder-
ate or severe TBI resulted in close relatives being forced to fight not to lose
their foothold when it became essential to take more responsibility. Their
willingness to fight for the ill person was based on feelings of natural love
and ethical demand. Natural love from close relatives, the ill person, and
other family members—along with hope—gave them the strength to fight. Close relatives struggled with their suffering and feelings of compassion. They had the courage and wisdom to alleviate the ill person’s suffering but had difficulty finding people who could alleviate their own suffering.

This study showed that professionals do not pay enough attention to the suffering of close relatives. Listening to the voices of close relatives who live with someone with TBI is central to understanding them on a more profound level and increasing the possibility of alleviating their suffering (cf. Chesla, 2005; Söderberg, 1999). This study can help other people become aware of and understand more deeply the experience of close relatives living with a person with moderate or severe TBI. This understanding will in turn increase the possibility that the close relatives will be treated with dignity and receive more help. If we alleviate close relatives’ suffering, we also alleviate the ill person’s suffering; the close relatives’ well-being can be decisive for the ill person’s well-being. We recommend research about close relatives’ experiences of well-being and nursing interventions that support their fight and alleviate their suffering. There is also a need for more knowledge about the changed relationships within a family when one person sustains a TBI.

**Methodological Considerations**

Participants had lived varying lengths of time with the person with TBI, but all of them were experts from whom we were able to obtain a rich understanding of the meaning of being a close relative of a person with moderate or severe TBI. The participants were mostly women; a greater number of male participants may have changed the findings. However, in this study the demographic characteristics of the participants were secondary to their knowledge of the phenomena and their ability and willingness to narrate their experiences.

Participants’ experiences may have been influenced by their memory and retrospective interpretation; TBI occurs suddenly and dramatically, and it may take time to realize what it actually means. Therefore, time for interpretation may have increased awareness of the lived experience of being a close relative of a person with TBI. According to Lindseth and Norberg (2004), receiving true narratives presupposes that the interviewees are aware of their lived experiences. The participants had a strong desire to narrate their experiences, and they may have shared their most significant experiences of living with a person with TBI as they occurred to them at the
time of the interview. According to Nunkoosing (2005), all stories are likely to change over time, and that “is always a problem when one is concerned with human experiences” (p. 702).

The interviewer was sensitive to the needs of the participants during the interviews; following the interviews, the participants had an opportunity to discuss further any matters of personal interest and to reflect on experiences covered during the interview. Participants were touched by memories when they narrated their experiences, but no one wanted to interrupt the interview. They found it important to participate to be able to help others in the same situation. For them, it was a relief to talk about their experiences.

Our preunderstanding as nurses and as a physician working with people with chronic illnesses, and as researchers, was important in that it allowed us to grasp essential meanings in the text; however, we were careful not to let it steer us to a prejudiced interpretation. We were sensitive and open to alternative interpretations, and freely discussed our interpretation in consultation with other colleagues. According to Ricoeur (1976), the interpretation arrived at must be more probable than other interpretations. The interpretation presented in this study is the most probable interpretation we could achieve. We have presented the procedure and the findings as accurately as possible to help the reader consider whether the findings can be transferred to similar situations (cf. Guba & Lincoln, 1989; Lincoln & Guba 1985).

References


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Paper III
RESEARCH PAPER

The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives

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Abstract

Purpose. The aim of this study was to describe the treatment from other people as experienced by people with moderate or severe traumatic brain injury (TBI) and their close relatives.

Method. Twelve people with moderate or severe TBI and eight of their close relatives were interviewed. The interviews were analysed using thematic content analysis.

Results. The results were described by the means of two themes: being excluded and missing confirmation. People with TBI and their close relatives had experiences of being avoided, being ruled by the authorities, being met with distrustfulness and being misjudged. They also searched for answers and longed for the right kind of help. People who listened to them, believed them and tried to understand and help them were appreciated.

Conclusions. This study showed a lack of treatment which promotes well-being of the people with TBI and their close relatives. They experienced bad treatment also from authorities. Therefore, we emphasize that authorities should continuously reflect on how to make their practice a place which promotes dignity. Treatment of people with TBI and close relatives may be improved by increased knowledge about TBI, living with it and being a close relative to a person with TBI. This is a challenge to health care and rehabilitation professionals.

Keywords: Brain injury, traumatic, relatives, treatment, experiences, interviews

Introduction

When a person sustains a traumatic brain injury (TBI), daily life for both the affected person and their closest relatives alters abruptly and profoundly. One study [1] claimed that living with TBI meant living with a perpetually altered body that changed the whole life and caused deep suffering, where feelings of shame and dignity competed with each other. Several studies showed that other people have poor understanding of the challenges that people with TBI meet [1–5]. According to Nochi [3,4], people with TBI experience a sense of loss of themselves not only because of their memory is affected but also when they interact with other people who stigmatize them as abnormal or powerless. Simpson et al. [6] found that TBI led to stigma and shame associated with a withdrawal of the community.

People with TBI often become dependent on close relatives for a long period of time. Close relatives show great willingness to adjust their life according to the needs of the person with TBI [6–9]. They experience uncertainty [8,10,11] and a sense of burden that often do not decrease with time [12]: they also feel that other people have difficulties to understand what they are going through [13]. They have a great need for information and emotional as well as practical support in order to be able to manage their changed life [14,15]. Several studies [2,10,15–17] showed that close relatives do not get enough information and help regarding future planning and options for the person with brain injury.
They experienced medical service as a complex system where no one has the main responsibility for supporting them [15].

In summary, previous research revealed that people with TBI and their close relatives experience that other people lack knowledge and understanding about how challenging living with TBI is. To the best of our knowledge there is a lack of studies focusing on how people with TBI and their close relatives experience treatment from other people. Increased knowledge about how people with TBI and their close relatives experience treatment enables them to be treated in a way that facilitates their daily life. Well-functioning relationships with other people are central to self-identity and self-respect [18,19] and can signify the difference between isolation and social integration [20].

Thus, the aim of this study was to describe the treatment from other people as experienced by people with moderate or severe TBI and their close relatives. According to Dolfe [21] treatment occurs on three levels. The collective level of treatment is seen in politics and laws that are expressions of society’s ideology. Politics and laws are then interpreted on the organizational level by various authorities. The third level is the individual level which is a reflection of treatment on the collective level and is expressed in personal meetings between people. This study focuses on the organizational and individual level of treatment.

Method

This study is within the naturalistic paradigm. In the naturalistic paradigm is the goal of research to understand how people construct reality within their context. The researcher wants to understand and document the day-to-day reality of the study participants. The findings are the result of the interaction between the researcher and the participants [22]. This study is a part of a qualitative inquiry aiming to elucidate the experiences of living with TBI from the perspective of people with moderate or severe TBI and their close relatives.

Participants and procedure

Twelve people with moderate or severe TBI and eight of their close relatives participated in the study (Table I). The severity of the TBI was defined by the injury classification (Glasgow Coma Scale) and the length of the loss of consciousness. Two people with TBI lived with their parents, two with their partners and eight alone or with their children. Five of them had a personal assistant. Two of the close relatives lived in the same household with the person with TBI. The participants had lived with TBI/the person with TBI for between 4 and 13 years (median 8 years).

The criteria for participation were that the person with TBI had a moderate or severe TBI and the capacity, interest and desire to narrate her/his experiences. They also had to have lived at least 3 years with their TBI, after which they were considered to be experts in what it means to live with a TBI (cf. [23]). The patient association for people with brain injuries, a psychologist and a nurse working at two different hospitals in northern Sweden recruited the people with TBI. They telephoned the participants and after receiving their permission, they sent them information including a reply form giving informed consent. In total 17 people were contacted of whom 12 chose to participate in the study. They were asked admission to send a letter to one of their close relatives who they had a lot of contact with during the course of illness and who could tell us about their experiences of living with a person with TBI. One of the persons with TBI had no close relatives. Consequently, we contacted 11 close relatives by mail, and informed them about the study. Eight of them chose to participate in the study. After receiving the participants’ permission, the first author telephoned each one in order to arrange a time and a place for the interview.

Ethical considerations

All participants gave their written informed consent (when asked about their willingness to participate) and verbal consent (before starting the interviews). They were given a guarantee of confidentiality and anonymity in the reporting of the findings. The Ethical Committee at the University approved the study.

Data collection

Interviews with people with TBI were planned according to suggestions made by Paterson and Scott-Findlay [24]. Questions such as ‘Can you tell a story about when you . . .’, ‘Can you tell about the worst/best experiences when you . . .’ and ‘Can you
give an example of when it happened to you...’ were used to encourage the participants to narrate their experiences. In order to get as rich data as possible the people with TBI were interviewed twice. Before the second interview, the interviewer listened to the tape-recordings of the first interview and planned supplementary questions such as ‘You told me about... how did you feel when it happened’. The average length of the first interview was 75 min and of the second interview 60 min.

Close relatives were interviewed once. The interviews started with the question ‘Please tell me about your experiences when X got injured’. Follow-up questions like ‘What did you think then’, ‘Please tell me more about that’, ‘Can you give an example’ were used (cf. [25]). The interviews lasted approximately 80 min.

The participants were interviewed by the first author in their homes and one participant at the interviewers’ working place. Three interviews were made by phone because of the long geographical distance. All the interviews were tape-recorded and transcribed verbatim. Interviews were performed with people with TBI and their close relatives on different occasions.

Data analysis

In order to achieve the aim of the study the data was subjected to a qualitative content analysis that is data-derived; in other words, there are no pre-existing codes but they are generated from the data themselves. The objective of the analysis is to understand both the manifest and latent content of data [26].

The following steps were taken during the analysis of the interview texts. The interviews were read several times in order to obtain a sense of the content. Secondly, meaning units containing the participants’ experiences of the treatment from other people were identified. Each meaning unit was condensed, i.e., shortening the meaning unit while still preserving the core. Next, the condensed meaning units were sorted out into categories according to similarities and differences in content (cf. [27]). The categories were then compared to identify themes, threads of underlying meaning recurring in meaning units and categories (cf. [28]). The interviews were reread in order to verify the emerging categories and themes. The third author checked the categorization performed by the first author. The checking was performed repeatedly during the process of analysis. This led to refining of the categories and themes, until consensus was reached.

Results

The analysis resulted in two themes with six categories (Table II).

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
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<tbody>
<tr>
<td>Being excluded</td>
<td>Being avoided</td>
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<tr>
<td>Searching for answers</td>
<td></td>
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<tr>
<td>Being ruled by the authorities</td>
<td></td>
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<tr>
<td>Longing for right kind of help</td>
<td></td>
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<tr>
<td>Meeting distrustfulness</td>
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<tr>
<td>Being misjudged</td>
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Table II. Overview of themes and categories.

Being excluded

The theme ‘Being excluded’ was constructed from the categories being avoided, searching for answers and being ruled by the authorities.

Being avoided

Participants experienced that many people were engaged in the beginning but after some time they distanced themselves. People with TBI described that other people were afraid and lacked the courage to talk with them. People they knew before the injury stopped to exchange greetings with them and instead looked away when they met them. They felt bitterness when they never heard from friends and colleagues they had had much contact with when they were healthy. Close relatives said that it was tough to see how the person with TBI tried to contact their friends but was rejected. Also, close relatives stated that they had lost friends. Participants described that they were lucky as their closest, long-standing friends remained. These friends tried to understand their situation and helped them. Others had a difficult time understanding how much the person with TBI had changed and wanted to see them as they were when they were healthy. Participants appreciated relatives and neighbours who asked how they felt and offered help to the whole family. They hoped to be met in an open, honest and natural manner. People with TBI experienced that children and adolescents treated them in that way but adults were cautious and spurious.

...sometimes you say something a bit wrongly and crazily but adults don’t say anything, but adolescents, they say something immediately, that's what I notice when I instruct them and... I say one thing and then I show it to them, and then they say to me ‘No, now you are wrong again, you say one thing and then you do just the reverse’, they are so enormously open... it’s the best treatment you can get... (Person with TBI)

Searching for answers

People with TBI described that their care had sometimes changed drastically and they did not receive any or varying explanations that made them
feel that the personnel did not know what they were doing or lied to them. They described that the personnel became evasive or gave unclear answers when they wanted to have information about their treatment, prognosis or asked for more rehabilitation. One of the persons with TBI said it was extremely insulting that when he asked for information about the operation and was told: ‘there’s no idea to explain to you because nothing yet goes into your brain’. People with TBI tried to obtain information and explanations by reading their medical records but it was difficult to understand the text. 

Close relatives experienced that they felt dreadful if health care personnel informed about the prognosis in a way that removed their hope. They experienced that they received insufficient information about the brain injury, their rights or where to find help for themselves. Participants felt it was frustrating if health care personnel used strange terms or medical terminology. Receiving continuous, open and honest information and explanations adjusted to their needs helped the participants to understand what had happened and facilitated their daily life. Close relatives hoped that they always obtained the same information as the person with TBI in order to be able to support the person with TBI.

... when we arrived at X [intensive care unit] we met the doctors who were nearest X [person with TBI] and they told us exactly how it was... and what they had done and it was really critical... we got really good information from all the personnel there... they were completely wonderful... they told about everything they did and instructed us about all those machines... (Close relative)

Being ruled by the authorities

Participants experienced that various authorities made decisions without listening to them and they expressed a fear of authorities’ power. Sometimes things, like home equipment, were arranged like they wanted only after their appeal to the county administrative court. They experienced pleasure if they felt free to express opinions but they missed more opportunities to contribute to the care and rehabilitation. Close relatives were called to meetings with rehabilitation personnel but found it difficult to say anything because they had not been informed about the purpose of the meetings. They experienced that authorities saw them as a burden and did not always want to meet them. People with TBI described that they were sometimes treated like an object and as if they did not exist by authorities.

... and not treat us like someone who is less knowing or incompetent or something like that, and ignore and belittle me but instead talk directly to me, not treat me as if I wasn’t really present. I’ve been treated like that... at a meeting... and her over there’... (Person with TBI)

People with TBI experienced that home-help service, transportation service and personal assistants worked at set times without consideration to their needs. Close relatives described that it was annoying to see that the person with TBI was forced to adjust to the personal assistant. Instead, a good personal assistant was described as someone who worked in the way the ill person wanted and who had good contact with the whole family.

Missing confirmation

The theme ‘Missing confirmation’ was constructed from the categories being misjudged, meeting distrustfulness and longing for right kind of help.

Being misjudged

Participants described that other people often thought that the ill person was drunk especially if she/he walked unsteadily. People with TBI experienced that they were approached as if they had been a little child, stared at and laughed at or denied admission to shops or a restaurant. They felt it was insulting to visit the bank, the post office, neighbours and relatives who had prejudices such as ‘getting brain injury meant being more or less freaky’. People with TBI stated that they had goals like being able to work again but the social insurance office, health care personnel or local authorities did not believe in them but instead talked about lowering the goals. It was annoying to be classified as a ‘hopeless case’. Participants appreciated if the employer made everything to facilitate the ill person’s return to work but employers who offered the person less qualified assignments only made them feel sad, disappointed and angry. Colleague’s opinions that the ill person should take the chance and retire were experienced as terrible. However, in contrast, some people made as great demands on the person with TBI as if she/he was healthy which made the ill person feel bad. Participants said that it was frustrating to hear that people gossiped and talked rubbish about the ill person. Bad treatment from other people was so tough that people with TBI had thoughts of committing suicide.

... I felt accused and distrusted in several places... shops and everywhere... My awful self-confidence became so bad that I thought what is the meaning of living and I remember the bridge at X and I thought I’ll jump off it... (Person with TBI)
Participants wished that other people would treat them with respect. Close relatives described that respect is about having courage, strength and knowledge in order to be able to understand. Participants experienced that it was important to receive encouragement and to meet people who believed in their ability to manage the situation.

... and then there were those who said that ... it’s really good that we were there [at the hospital] so much and thought that we did a good job and that we are really brave ... they thought that we did everything ... (Close relative)

Meeting distrustfulness

Participants described that it was insulting to be questioned and controlled by various authorities. They said that if the ill person with sickness benefit visited her/his working place, the social insurance office called the person in order to check why the person had been there. Close relatives felt that the social insurance office as well as their employer questioned their need to report sick. They experienced that it was a pleasure if the employer and colleagues supported them and they felt free to be off work when they needed. Those who took care of the ill persons’ children experienced visits of social authorities as burdensome because they felt as if they were being controlled.

... they [the insurance company] have even checked if he [the person with TBI] had borrelia ... Alzheimer’s disease and the devil knows what he has gone through, you know it’s insulting ... I think it’s bloody ... and still after eight years ... now I don’t know what inspection they’ll come with next ... last it was his leg ... there can’t be no one who has been inspected as much as he has been ... I’ve been angry ... he has sat and cried and been totally shattered ... (Close relative)

Participants felt that other people had difficulty understanding what it means to live with a TBI or being a close relative to a person with the illness. It was especially difficult if the person with the illness looked healthy. People with TBI tried to explain what they had gone through but were not always believed. It was insulting if someone argued that she/he knew what living with a TBI meant because they felt that no one who did not have the illness could really understand how much they had lost. They described that it was important to think that others’ deficient understanding and bad treatment could be due to their poor knowledge about brain injury. People with similar experiences were described as easier to be in contact with because they believed and understood the person with TBI better.

Longing for right kind of help

Participants said that it felt strange that the ill person was not examined thoroughly after the accident and did not receive the diagnosis of TBI until many years later, in spite of looking for help several times. They described that the ill person did not always get help with their needs like enough pain-relief, changing bandages, good bed equipment or help to get to the toilet. To experience that the health care personnel forgot the ill person or treated her/him in a rude manner or forced him/her to wait a long time before getting relevant aid was incomprehensible. Participants experienced that it was hard that personal assistants and home care personnel often changed.

... when we were at the emergency room the day he [the person with TBI] had a head ache and the pressure felt so unpleasant because it was in that area, but I think we weren’t particularly well treated, instead it was like he (the doctor) took one look at the wound, and yeah, a penicillin treatment, I don’t know really, both I and X felt that ... we didn’t feel ... that they really checked it out properly ... (Close relative)

People with TBI described that they received only worse of rehabilitation if the personnel did not listen to their wishes. They said it was frustrating and ridiculous to paint baskets instead of painting cars as healthy people or practice doing housework using the left hand instead of using the right one as healthy persons. Close relatives felt insecure when the person with TBI was sent home without having taking into account her/his need for home help, equipment or further rehabilitation. Participants experienced that rehabilitation was focused mostly on the physical aspects but people with TBI had not received enough help to work with their feelings. Close relatives experienced that it was alarming that the health care personnel did not always have enough knowledge about rehabilitation of people with TBI.

Close relatives were disappointed with the help they received. They experienced that they were seen as a resource for the ill person and not as someone who also needs help. If they received help, like a meeting with a welfare officer, the meeting was often brief or not adjusted to their needs. They missed practical support but above all someone to talk with. Close relatives said that they needed help as a family because everyone close to the ill person was affected in some way.

Participants said that it is crucial that health care personnel take time to get to know them. People with TBI said that it was a pleasure to meet health care personnel who was kind, interested in them as persons and did everything to help them. Participants experienced that the rehabilitation was good if
it was meaningful and according to the persons' needs. They said it was important to have knowledge, courage and be persistent in order to be able to fight for one's rights, like getting enough time with personal assistants, home equipment or referral to rehabilitation.

...I want to be met with respect for my problems...I've been in various rehabilitation places...X, it was the best place, they have helped me to put words on how I'm injured...nobody has understood me as well as they have...and they have helped me with means of assistance and things like that...and I've felt that oh hell how nice oh...they've been incredible...they have helped me to get going... (Person with TBI)

Discussion

The aim of this study was to describe the treatment from other people as experienced by people with moderate or severe TBI and their close relatives. The results were described by the means of two themes: being excluded and missing confirmation. Both themes included experiences where the participants' dignity might have been violated. Edlund [29] and Nordenfelt [30] mean that dignity on one hand is a universal or absolute quality that all human beings have to the same extent as long as they live. On the other hand, dignity is formed by the culture and society and depends on a person's self-image. This kind of dignity can be lost due to an illness that changes the person's body and being in the community. Sustaining a TBI is a threat to dignity [1] and disrespectful treatment from other people decreases the feeling of dignity. In contrast, being met with respect strengthens the person's feeling of dignity.

This study showed that other people began to behave differently and avoided the person with TBI. They were treated best by children and adolescents who were open, honest and natural. These findings are in line with other studies [19,31]. Avoidance by others leads to interaction experienced as obstructed [19] and increases the feeling of being alone and wounded, while being already wounded and vulnerable due to the illness [32]. Participants described that other people often were interested in the beginning but after some time they 'disappeared'. They felt lucky when people stayed at their side and offered help. Løstrup [33] means that in every encounter between people there is an unarticulated ethical demand to take care of the life of the other person in a way that best serves her/his interest. The demand is radical because the person confronted by it must him or herself determine how to do it and it may intrude disturbingly upon one's own existence.

It may be that being involved in the life of a person with TBI and their close relatives is so demanding and difficult that other people do not have the strength to do it. Rehnfeldt [34] means that it feels more allowed and simple to take part in another person’s suffering in the ‘acute phase’, but in the course of time it becomes too trying.

Participants experienced that they did not obtain enough information and explanations that would have helped them to make sense of their experiences and facilitate the daily life. According to Bond et al. [10] unmet needs of knowing was a main contributor to the close relatives’ intense feelings of anxiety and distress. Paterson et al. [17] showed that close relatives of survivors of TBI do not learn or recall all information the health care personnel tells them. The way of informing, its timing, consistency and relevance are significant if they are to listen to and remember the information. In this study participants described that health care personnel did not have enough knowledge about rehabilitation or did not listen to them. Having knowledge and listening to people with TBI and their close relatives are fundamental aspects in order to provide information adjusted to their needs.

Participants had experiences of being ruled by authorities and they wanted to contribute more to the care and rehabilitation. Experiences like being seen as a burden, treated like an object or seeing the ill person being forced to adjust him or herself to the personal assistant violate the person’s dignity. According to Corring and Cook [35], client-centred practice means that the person is valued as a human being by the authorities. Being involved in one’s care is seen as an aspect of the quality of care from both the ill person and the professionals’ view [36–38]. However, previous studies [39,40] and the present study emphasize that professionals need to be more aware of the persons’ desire to take part in the rehabilitation planning.

Participants described experiences of being misjudged and met with distrust and nonchalance by other people. According to Söderberg et al. [41] not being regarded as a credible person violates a person’s dignity. Participants appreciated people who listened to them, believed in them and did as much as they could to help and support them. Confirmation is defined as being seen and trusted [42], and as evidence that strengthens a person's positive self-assessment and feeling of human worth [43,44]. Being misjudged, met with distrust and nonchalance are expressions of disconfirmation, and disconfirming treatment undermines a person’s dignity [42].

In this study, participants had experiences of not receiving the care and rehabilitation they needed. They wanted health care personnel to take time to know them and to be sensitive. The results are in line with Schröder et al. [38] who showed that patients in psychiatric care valued a competent and committed staff, and being confirmed and
understood. Listening and empathy are forms of confirmation that increase the person’s security, confidence and feeling of dignity. It is worth to reflect on if the reason for not getting help or rehabilitation is that, whenever confirmation is absent, care and rehabilitation is not initiated [42]. Several studies (e.g., [45–50]) have shown that health care personnel’s ability to be genuinely concerned and truly present is crucial. Furthermore, to be taken seriously, believed and getting help are shown to be components of good caring [36,51].

Participants hoped that other people would treat them with dignity. The dignity of a person is worthy of respect from others [30] and it is frequently referred to in everyday conversation and as a right and a duty on the collective level of treatment; in politics, laws, professional codes and human rights frameworks. On the organizational and individual level the authorities seem to interpret the collective level of treatment in a various ways and sometimes in a way that the person with TBI and their close relatives experienced as disrespectful (cf. [21]). However, people are fallible and therefore they can degrade, devalue and humiliate each other [52]. People with TBI thought that bad treatment from other people could be due to their insufficient knowledge. Studies (e.g., [53–56]) confirm that people have deficient knowledge and misconceptions about living with a TBI. Deficient knowledge of how to treat a person with TBI and close relatives may cause fear and uncertainty that increases the gap between the ill person, close relatives and other people. The results point to the need of increased knowledge about TBI, living with it and being a close relative (cf. [21]).

Methodological considerations

The analysis was performed by the researchers who strove for neutrality and an as accurate description as possible of the procedure and the findings of the study. It should be considered that the study is based on interviews of people from a western culture and a study made in another culture may have lead to different findings (cf. [57,58]).

Conclusions

This study shows lack of treatment that promotes the well-being of the person with TBI and their close relatives. Their suffering is increased by insulting treatment from other people. It is alarming that they experience bad treatment also from authorities who should have more knowledge about ethics and treatment of people with TBI and their close relatives. On the basis of this study, it is imperative that authorities continuously reflect on how to make their practice a place which promotes dignity. Stress and lack of time may be the main reasons for not being able to get to know them and be sensitive to their needs; if so, how can these factors be controlled? Treatment of people with TBI and close relatives may be improved by means of increased knowledge about TBI, living with it and being a close relative to a person with TBI. This is a challenge to health care and rehabilitation professionals.

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References

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Paper IV
The meaning of feeling well in people with moderate or severe traumatic brain injury

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The meaning of feeling well in people with moderate or severe traumatic brain injury

Abstract

Primary objective

The aim of this study was to elucidate the meaning of feeling well for people with moderate or severe traumatic brain injury (TBI).

Research design

This study used a qualitative research approach, as the aim was to elucidate the meaning.

Methods and procedures

The data were collected through qualitative research interviews with two women and six men with moderate or severe TBI who had lived between 7 and 15 years with the injury. A phenomenological hermeneutic method was used to interpret the data.

Main outcomes and results

The meaning of feeling well for people with moderate or severe TBI was that the unfamiliar life with TBI became familiar. This included finding strength, regaining power over everyday life, being close to someone, and being good enough. People with TBI felt well when they reconciled themselves with the circumstances of their life and had formed a new entity in that life where they had lost their complete health.

Conclusions

This study showed that people with TBI needed a lot of strength to feel well. Professionals can support their feeling well by engaging to know them, and from this find the solutions that support the person’s feeling of well-being.

Keywords: traumatic, brain injuries, qualitative research, interviews, phenomenological, hermeneutics, interpretation, well-being.
Introduction

Sustaining a traumatic brain injury (TBI) brings about a major alteration of life both for the injured persons [1–6] and their family [7]. People with moderate or severe TBI usually move abruptly from a healthy state, through episodes that require acute care, to a state of chronic illness and disability. They are confronted with various long-lasting physical, cognitive, emotional, and social problems, and need rehabilitation throughout their recovery, which often last many years after the injury [8, 9].

TBI has various physical consequences, for example, reduced motor function, seizures, visual deficits, sleep disturbances, headache [9,10], and fatigue [11,12]. Some of the most persistent cognitive consequences are memory impairment and difficulties in concentration and attention [9]. Memory loss is experienced as a loss of self and being outside the experiences of other people [1, 2, 13]. Living with impaired memory is unpleasant, frightening, and makes daily life difficult [6, 11, 14–16]. Risk of suicide, divorce, long-term unemployment, and economic strain are common social consequences of TBI [9]. Disturbances in mood (e.g., depression, anxiety) and antisocial behavior (e.g., irritability) impose a great burden on relationships for people with TBI [8]. Impaired contacts with other people lead to increased loneliness and decreased social network [6, 17]. The experience of rapidly losing independence and autonomy is hard to accept [6]. According to Chamberlain [5], the loss of the recognizable self is a great source of sorrow and suffering. Several studies [e.g., 4, 5, 12, 13, 18, 19] have shown that other people, including families and professionals, have misconceptions and lack knowledge and understanding of living with TBI. People with TBI are often forced to struggle for finding help that facilitates their daily life and feeling of well-being.

It is well known that sustaining TBI leads to lower quality of life (QOL) and life satisfaction [20, 21]. There are also several studies [e.g., 22–27] that have described factors
that influence QOL and satisfaction with life in people with TBI. According to Dijkers [21], research in QOL after TBI is mostly based on objective measurements of functional status or activity outcomes. There is a need for qualitative research about the experience of QOL, because objective measurements do not reveal the person's feelings and values, and whether she/he is satisfied with her/his functional status and activity level.

Dijkers [21] noted that only qualitative research has indicated some positive effects of TBI: being glad to be alive, appreciating the little things in life, growth in a moral sense, insight into self and others, and ending self-destructive course or substance abuse. Deepened relationships within family [4–6, 13, 28, 29], new friends [6], and the experience of hope are other positive dimensions of living with TBI [1, 4–6, 14, 16]. Strandberg [6] showed that people who have lived seven years or more with TBI had integrated the injury into their lives and could feel a kind of peace.

In summary, considerable attention has been given to research consequences, QOL, and satisfaction with life in people with TBI. Most of the studies are quantitative and reveal negative aspects of living with TBI. However, their ability to increase one’s knowledge about feeling well in everyday life from the perspective of people with TBI is limited. Toombs [30, p. 90] stated that 'the act of healing requires an understanding of illness as lived'. Knowledge that provides an understanding of the meaning of feeling well for people with a TBI entails a possibility that they could receive support to feel well, despite their injury. To the best of our knowledge, there are no studies that focus on the meaning of feeling well for people with TBI.
Aim

The aim of this study was to elucidate the meaning of feeling well for people with moderate or severe TBI.

Methods

This study uses a qualitative research approach because we wanted to elucidate the meaning [cf. 31]. The data was collected by means of qualitative research interviews and analyzed using a phenomenological hermeneutic interpretation inspired by the French philosopher Ricoeur [32] and developed by Lindseth and Norberg [31]. According to Ricoeur [32], the lived experience of one person cannot be transferred directly to another person, but its meaning can be transferred. When people speak with each other, they point toward the unique thing of what they mean. The meaning is further revealed when the speech is transcribed to a text.

Participants and procedure

This study is a part of a qualitative inquiry aiming to elucidate the experiences of living with TBI from the perspective of people with moderate or severe TBI. The criteria for participation were: the person had sustained a moderate or severe TBI (based on their initial Glasgow Coma Scale score) and had the capacity, interest, and desire to narrate their experiences. Further, they should have lived with the injury for at least three years for them to be considered experts in what it means to live with TBI [cf. 33]. Twelve people with moderate or severe TBI from northern Sweden, and who participated in a previous study [4], were sent a letter including information about the study, and a reply form on which they could give their informed consent. After receiving their permission, the first author telephoned each one to arrange a time and a place for the interview.

Two women and six men with moderate or severe TBI, between 29 and 53 years (md = 41 years), chose to participate in the study. Two of the participants lived alone, five
lived with their family (children and/partner), and one participant with his parents. Four of them had a personal assistant or a companion. The participants had lived with TBI between 7 and 15 years (md = 10 years). All of the participants had an employment or were students before the injury. After sustaining TBI, all of them were sick-listed for a long time and they could not continue with their employment or education. At the time of this study, four of the participants had an employment after long rehabilitation and reeducation. One of the participants could return to an employment similar to what he had when healthy.

Data collection

Interviewing people with TBI can be problematic because they may, for example, have cognitive impairments or become fatigued and distracted during the interview [34]. Therefore, the interviews were prepared according to suggestions made by Paterson and Scott-Findlay [34]; e.g., the interviewer had to select concrete and direct questions instead of broad open-ended questions and be prepared to be flexible in the scheduling of the interview. The interview questions were piloted with a person with TBI to evaluate the phrasing of the questions. Questions such as 'Can you tell me what in your everyday life makes you feel good', 'Can you give an example when you felt well', and 'What would you tell to another person with TBI about feeling well' were used to encourage the participants to narrate their experiences. The interviewer (EJ) extracted the pivotal words or points of the interviewee's narrative on which she based her subsequent questions [cf. 34]. When narrating their experiences, the participants often asked for a question to be repeated because they wanted to be sure that they remembered the question right and answered it fully. The interviews were closed when the interviewees responded that they had no more to narrate about their experiences of feeling well. Debriefing after the interview provided participants an opportunity to discuss the research and matters of personal interest or need [34].
Seven participants were interviewed by the first author in their homes, and one participant at the interviewers’ workplace. The interviews were performed during the spring of 2006. The length of the interviews ranged between 45 and 77 minutes (md =55) and they were later transcribed verbatim.

Ethical considerations

All participants gave their informed written and verbal consent. They were given a guarantee of confidentiality and anonymity in the reporting of the findings. Approval for conducting this study was given by the Regional Ethical Review Board, Umeå, Sweden.

Data analysis

The phenomenological hermeneutic interpretation used in this study consisted of three phases; naïve understanding, structural analyses, and comprehensive understanding. First, the text was read several times as open-mindedly as possible to grasp its meaning as a whole. This was the first surface interpretation, the naïve understanding of the text. The second phase was the structural analyses, which aimed to explain the text as objectively as possible and to validate the naïve understanding [31, cf.32]. In this phase, the interview texts were divided into meaning units, which were a sentence, paragraph, or several pages with the same content. Next, the meaning units were condensed to formulated meaning units. The formulated meaning units were sorted into groups according to similarities and differences in meaning. The groups were compared with each other and abstracted to form the theme and subthemes. When formulating the theme and subthemes, we reflected on ‘what is the meaning of feeling well in this text’. The theme and the subthemes were then compared with the naïve understanding for validation. In the final phase, comprehensive understanding, the text was again interpreted as a whole, based on our preunderstandings, the naïve understanding, the structural analyses, and the literature [31, cf. 32].
Findings

Naïve understanding

Sustaining TBI seemed to mean a breakdown in feeling well for people with TBI. Feeling well appeared to demand courage, perseverance, and a lot of energy. The participants seemed to take a decision to do everything possible for feeling well. They had a will to look forward and a curiosity for life. They appeared to feel well when they themselves and other people understood that they would never be the same as healthy people. Living an ordinary everyday life in communion with other people seemed to mean feeling well for the participants. This everyday life involved being loved and having someone to love. Participants’ understanding of feeling well seemed to have changed in relation to when they had been healthy.

Structural analyses

The structural analysis resulted in one major theme with four subthemes. The themes are presented in the following text and illustrated by quotations from the interview texts.

The unfamiliar becomes familiar

The theme 'The unfamiliar becomes familiar' was constructed from four subthemes: finding strength, regaining power over everyday life, being close to someone, and being good enough.

Finding strength. Feeling well was expressed as demanding a lot of will, perseverance, energy, and positive thinking. Participants felt really bad when they understood how profoundly their life had changed. They said that the first thing to do was to take a decision to do something to feel well and enjoy life. They opined that only cowards committed suicide and 'if you give up you do not get nothing'. Their curiosity for what life could offer gave them energy to strive for feeling well. Meeting others with the
same kind of injury and who had made progresses strengthened their belief that feeling well is possible.

Feeling well was described to be delicate because 'it was so easy to again feel sad'. Participants said that feeling well demanded 'hard work', for example, they trained themselves in a lot of different skills such as walking or meeting other people. They expressed that it was wonderful and lovely and made them stronger when they achieved results and could do something they had not done for several years, such as going to a dance, walking, or driving a car. Participants felt well when they had a place and time to rest when they needed it. They relaxed when they were, for example, at a cottage with their family or in a strict silence. Traveling or moving to another environment made them feel well because it enabled them to be anonymous and gave a break from the ordinary. Having money to do different things was another aspect of feeling well.

… 13th January year 2000 it was then I felt quite well because I took my first steps…after sitting over two years in a wheelchair and to come up and take my first steps without falling down or something I felt like I was born anew…

Participants emphasized that it was they themselves who had the responsibility for feeling well but other people could give them ideas, proposals, and help on the way. They felt well when they had family, relatives, and friends who talked about the injury with them, and encouraged and assisted with activities such as preparing food, shopping, physical training, or contacts with professionals. Professionals who engaged to know them and help them with their everyday life supported their feeling of well-being. Participants described that they felt well when they got explanations to understand why they, for example, had impaired memory. Advice in breaking off relationships that deprived them of
energy, managing dwelling, and being able to move easily in the community were important for feeling well.

… they [siblings] have helped me to get started with things, they have helped me to look forward instead of backward… and all the time… they say if I do something wrong … and I’m grateful of that…

Regaining power over everyday life. Feeling well was above all for the participants to be fairly healthy and live as ordinary a life as possible, instead of having a lot of money or material things. They felt well when they could sleep, wake up, breath, see, eat, write, be outside, listen to music, or take care of their children. Participants expressed that they could deeply value and be glad about things that they earlier took for granted.

… it’s so much commonplace things that make me cheerful today because I’ve … come across so much misery… I think that when I have no opportunity to climb Mont Blanc or like that I find much more satisfaction at being able to go to my work with my wheelchair in a sunny weather…

It was described that feeling well was to have peace and harmony despite having a lot to do. Participants expressed that they strived to have as few musts as possible because musts made them go haywire and increased the risk of losing control. Having control and remembering was crucial for feeling well, because it made it possible to steer one’s own life and feel safe. Participants described that they developed routines that made it easier to self-remember instead of someone else, such as their personal assistant, reminding them. They felt well, were cheerful, and satisfied with themselves when they managed to remember ordinary things, such as canceling a reservation of transportation service in time. Participants described moments when they suddenly recalled something from their life before injury that made them really happy. They expressed that they felt better when they
were conscious of their limitations and lived day by day without special expectations or worries about the future.

.... I don't remember everything so I photograph and then I've written
diary since I was able to write again ... what I've done and little things like that but
it has been a great help so that you can go back ...... then I remember better and
feel that I've been there and I've done it... I feel it so because some things that
happens... that I don't remember what is retold, it's frightening and unpleasant...

Being close to someone. Participants described that they felt well when they were loved and had someone to love. Belonging in a family where people cared for each other was a great source of happiness. Participants appreciated the tenderness they got from their family more than ever before, and were careful to show their appreciation and love to the family members. Finding a partner was described to be an enormous source of happiness because they had doubted if there was anyone who wanted to live with a person with TBI. Being loved strengthened the participants’ feeling of well-being because they got self-confidence and felt that they really lived. Children were described to have cheerfulness that spread joy for people around. Pets were also expressed to be a source of unconditional love and happiness.

... I feel myself really happy when X's [wife] and my children come to us...
I feel myself really happy...

...she [the cat] is both company and I feel that I'm needed that I'm loved and that I have someone to show my love to... and she gives me so much
pleasure... because she is so funny, it's my third love...

Involvement in other people's lives and to give and receive pleasure was described
to be aspects of feeling well. Family and friends made participants feel well because they
could have nice activities together, and this gave them something other than themselves and the injury to think about. They expressed that they strived for maintaining contact with their friends and finding new friends, instead of those they lost after sustaining TBI. One way to find friends was to enroll in associations for other people with similar injuries.

**Being good enough.** Participants described that they felt well when they got used to living with the injury and accepting themselves. Feeling well involved being popular without a need to pretend. Participants expressed that they needed courage to be with other people because of their limitations and feelings of shame. They felt well when they were with people who took them seriously, were not ashamed of them, did not make too great demands upon them, and accepted that they could not always manage the things they should. It was described to be enormously delightful and nice when people greeted and remembered them. Participants experienced that it was safer and more comfortable to be in contact with people in similar situations because they ‘were at the same level’ and did never ‘make game of one’.

.... children, they understand they know me .... so they can respect what I have the strength to do...

.... few friends that I can trust.... they don't mind if I'm sour or sullen or don't have strength .... they stay anyhow and say 'aha it's that kind of day then we do something else or do nothing or meet next day', they take it as it is ... you can be like you are you don't have to pretend....

Participants expressed that they felt well when they were important, did something useful, and contributed to other people’s feeling of well-being. Being employed gave opportunities to be praised and feel that they were doing good work. It was the same for those who engaged in voluntary work that gave notable results and helped other people.
…you want feel that you are important… and appreciated it's … so hard at the beginning when you were only lying down …and it's also in some way that …. I mean when one only lies at home and feels sorry for oneself then one gets only more ill … when I got an opportunity to begin at work … I felt everything was better even though the headache is there…

Comprehensive understanding and reflections

This study suggests that the meaning of feeling well for people with moderate or severe TBI is that the unfamiliar life with TBI becomes familiar. This, we propose, means that feeling well for people with TBI is to be reconciled with the circumstances of their life, that is, finding a new life and forming a new entity in that life where they lost their complete health. This involves accepting themselves and experiencing a renewed communion with other people.

Participants emphasized their own responsibility for feeling well, and they seemed to take a decision to do everything possible for it; for example, they trained in different skills and developed routines that facilitated the feeling of well-being in daily life. Gadamer [35] stated that all have a responsibility to take care of and treat themselves, and it is important to have energy for self-treatment. In this study, participants seemed to find energy for self-treatment from their will to live and feel well, positive thinking, and a curiosity for life. According to Eriksson [36], health presupposes that the person wants health. Pauli [37] maintains that to be able to really live, not just exist, one must have a will to live. For people with illness or disability, a will to live often involves feelings of fear and horror. Therefore, they also need belief and confidence in life. Participants became stronger when they achieved results and could do something they had not done since they sustained the injury. This, we propose, strengthened their belief and confidence in life.
Feeling well was described to be 'a hard work' and it was important to get help and support from other people. Aristoteles [38] stated that active persons find the right and good things in life but they also need help. Being alone makes life a burden. To have other people to share both adversity and success is valuable and important for happiness.

Participants felt well when they were fairly healthy and lived as ordinary a life as possible. They valued deeply and enjoyed their body, moments, and the people they took for granted when healthy. This means that feeling well with TBI is to be aware of everything that is good and healthy in one's life. Gadamer [35] argued that health is a miracle of strong hidden harmony that involves happiness, feelings of well-being, and ease of life. It is a fact that people are not aware of, until it fails. Listening and paying attention to richness of the world is an important form of self-treatment.

The participants felt well when they regained power over their everyday life and could steer it by themselves. This involved consciousness of one's limitations and structuring daily life according to them. Gadamer [35] stated that to really recover means that the ill persons regain their place in daily life. According to Pauli [37], contracting an illness demands humbleness and great honesty of oneself, and a will to change things that one is obliged to. The person with illness must relinquish something, understand something new, and reconcile with one's mission in life. Eriksson [36] stated that reconciliation includes striving to carry out the possibilities in life. Participants seemed to feel well when they understood that they could not be the same as before the injury, but instead focused on carrying out their possibilities.

Participants felt well when they were loved, were popular, and could be involved in other people's lives. This means that feeling well is to be confirmed and confirming other people. According to Buber [39], every human being has a need to be present in other people's lives. This involves a desire to be confirmed by other people and an ability to
confirm fellow beings. Being able to serve and exist for one another enhances a feeling of dignity [36]. People who accepted and appreciated the participants as they were confirmed them and increased their feeling of well-being. Further, the participants felt well when they confirmed fellow beings. Also, pets were a source of confirmation and feeling of well-being. Being confirmed by someone and confirming someone seemed to help the participants to understand that they, in spite of their limitations, were still worthy. This helped them to accept themselves, and the participants described this as important for their feeling of well-being. According to Eriksson [36], reconciliation means accepting that one is not perfect, but still worthy. The reconciled person experiences a renewed communion with other people.

Feeling well and to be reconciled with the circumstances of TBI was not simple, but demanded courage to confront the demands caused by the injury. This was seen, for example, in the participants' descriptions of how they needed courage to be with other people because of the shame they felt. According to Eriksson [40], to be a human being means that one has courage to be what one really is. Also, a search for confirmation presupposes courage because one can never be sure if there is someone who will listen. Wiklund [41] stated that reconciliation takes place when the person has the courage to confront his/her suffering, and the discomfort, shame, and fear of rejection.

Study limitations

The findings are limited as the sample consisted of eight participants of Western culture, and who had lived many years with their TBI. The findings are transferable to similar situations and participants. The participants consisted of more men than women, which is in line with the prevalence of TBI [e.g., 9, 42, 43]. Participants' demographic characteristics were secondary to their knowledge of the phenomena and their ability and
willingness to participate in the study. They narrated rich and experiential stories, which made it possible to elucidate the meaning of the lived experience of feeling well. All contacted participants did not want to participate, for unknown reasons, but there was no need to try to contact more participants because the data was sufficient for the purposes of the study. Morse [44] opines that in determining the sample size, the researchers must consider that the data is target, contains less dross, and is rich and experiential.

This study was conducted in relation to our preunderstandings as nurses (EJ, SS), physician with experience of TBI rehabilitation (JL), and as researchers in the field. We were careful that these preunderstandings did not lead to bias, but instead increased the quality and trustworthiness of the study. It was crucial to be sensitive and open to the meaning in participants' experiences of feeling well in data collection, data analysis, and documentation of the findings. According to Lindseth and Norberg [31], the researcher must have sufficient preunderstanding to grasp the essential meanings of the text and. To achieve as truthful an interpretation as possible, the interpretation must be strict. Ricoeur [32, pp. 31-32] stated that a text is 'open to an indefinite number of readers and, therefore, of interpretations'. However, the interpretation presented must be more probable than any other interpretation. After confronting alternative interpretations and arbitrating between them we have presented the interpretation that we found most probable. No single fundamental truth of feeling well with TBI was found, because 'the whole truth can never be fully understood' [31].

Conclusions

Findings of phenomenological hermeneutic interpretation can be used if they affect people's way of perceiving life [31]. This study helps people with TBI and professionals to enhance their understanding and awareness of possibilities about feeling
well. It may strengthen people with TBI when they understand that feeling well with the injury is possible. Professionals’ enhanced understanding about feeling well facilitates supporting people with TBI. The people with TBI needed a lot of strength to feel well and professionals who engaged to know them supported their feeling of well-being. Therefore, we emphasize that professionals carefully investigate the needs and wishes of the person they care for and from this, together with the person with TBI, find the solutions that support the person’s feeling of well-being.

Further studies should be conducted to gain more knowledge about feeling well with TBI, for example, in people who have lived a short time with the injury and in the family members of people with TBI.

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References


2.
[10] Hibbard MR, Uysal S, Sliwinski M, Gordon WA. Undiagnosed health issues in
individuals with traumatic brain injury living in the community. Journal of Head Trauma
[15] Price-Lackey P, Cashman J. Jenny's story: reinventing oneself through occupation and
[16] Nochi M. Dealing with the "void": traumatic brain injury as a story. Disability and
[17] Morton MV, Wehman P. Psychosocial and emotional sequelae of individuals with
[18] Backhouse M, Rodger S. The transition from school to employment for young people
with acquired brain injury: parent and student perceptions. Australian Occupational Therapy


Translation of: Urdistanz und beziehung.


