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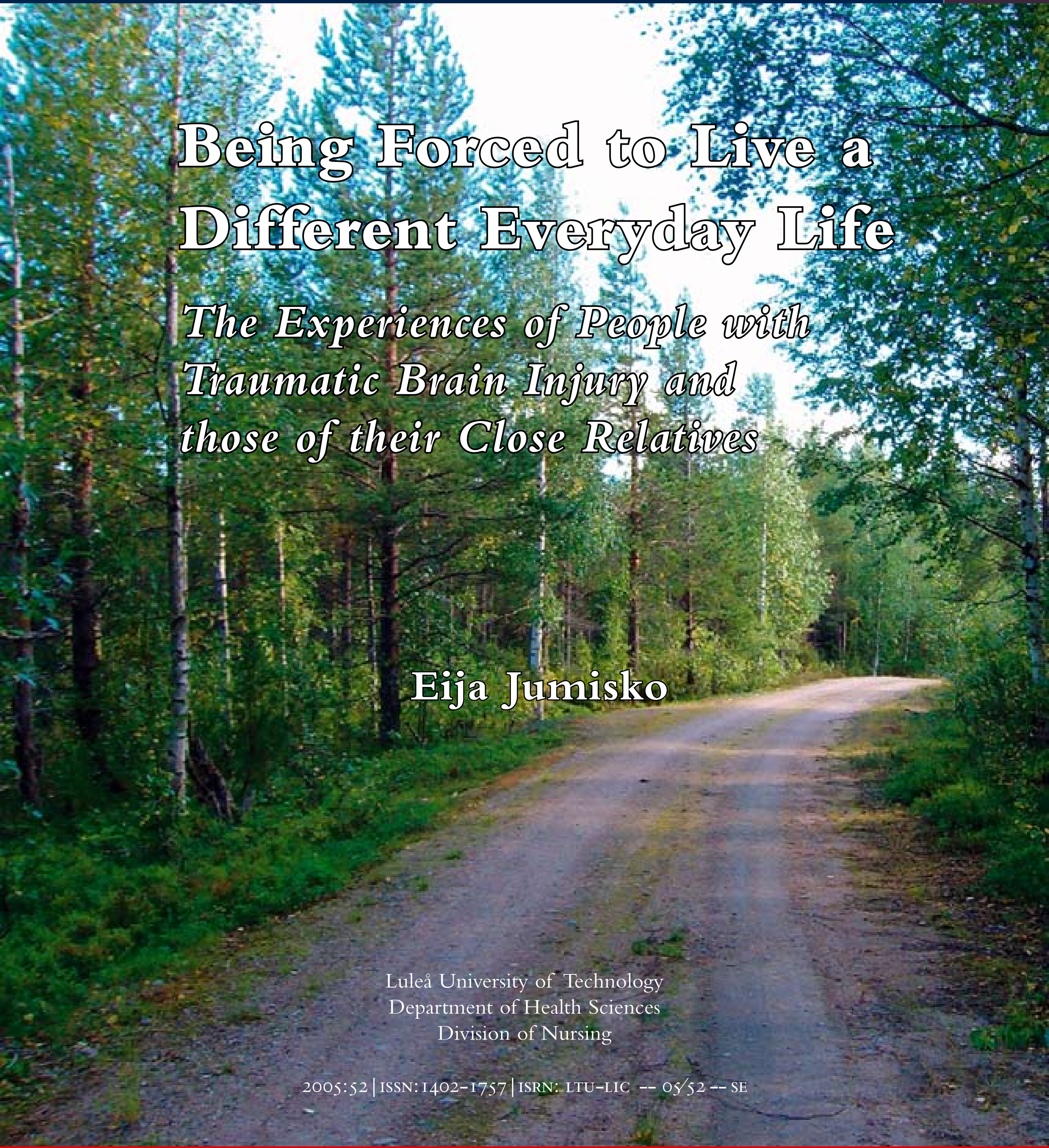

Being Forced to Live a Different Everyday Life

The Experiences of People with Traumatic Brain Injury and those of their Close Relatives

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To Anna-Maria and Hanna-Reetta

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PAPERS I–II

Being forced to live a different everyday life: the experiences of people with traumatic brain injury and those of their close relatives

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ABSTRACT

The overall aim of the licentiate thesis was to elucidate the meaning of living with traumatic brain injury (TBI) in people with TBI and their close relatives. The data were collected by means of qualitative research interviews with people with moderate or severe TBI (n=12) and their close relatives (n=8), and were then analysed using a phenomenological hermeneutic interpretation.

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 met with respect, and finding a new way of living.

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, close relatives and other family members gave them the strength to fight.

The comprehensive understanding revealed that people with moderate and severe TBI and their close relatives were forced to live a different everyday life where enduring uncertainty, chronic sorrow and loneliness, but also retaining hope were all present. They were rather alone in their suffering and their need for help, both as individuals and as a family, remained great even many years after the injury.

Keywords: lived experienced, traumatic brain injury, close relatives, shame, dignity, natural love, ethical demand, uncertainty, chronic sorrow, loneliness, hope, qualitative research interview, phenomenological hermeneutic

ORIGINAL PAPERS

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

I Jumisko, E., Lexell, J., & Söderberg, S. (2005). The meaning of living with traumatic brain injury in people with moderate or severe traumatic brain injury. *Journal of Neuroscience Nursing, 37*, (1), 42-50.

II Jumisko, E., Lexell, J., & Söderberg, S. Fighting not to lose one's foothold: the meaning of close relatives' experiences of living with a person with moderate or severe traumatic brain injury. Manuscript submitted.

The paper has been reprinted with the kind permission of the journal.

INTRODUCTION

This licentiate thesis focuses on the meaning of the 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 kind of knowledge is fundamental to being able to encounter and care for these people in a way that will profoundly facilitate their daily life for many years after the date of the injury. Therefore, this thesis uses a phenomenological hermeneutic approach in order to investigate the life-world of people with TBI and their close relatives.

A life-world perspective

Phenomenology was first described by a German philosopher Edmund Husserl who 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 and understand and communicate with each other. 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 arouse or sport 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).

According to van Manen (1990, p. 9) in phenomenological research the researcher asks 'what is this or that kind of experience like'? It is an approach that attempts to grasp the essence of a phenomenon and articulate the structures of meaning embedded in lived experience. The term essence can be understood as a description of a phenomenon in a way that reveals the structure of lived experience in a hitherto hidden way. Laverty (2003) noted that the study of phenomena in phenomenology means returning to taken-for-granted experiences and perhaps finding new or forgotten meanings. According to van Manen (1990) 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.

In order to grasp the essence Husserl (1913/2004) believed that the researcher must bracket out all presuppositions about the nature of the phenomenon. Later, Heidegger developed phenomenology towards hermeneutics which is a theory of interpretation. Hermeneutics became an approach to analysis of texts where pre-understanding was seen as necessary to shape the interpretive process (Koch, 1996; Laverty, 2003). Hermeneutics has an intermediary task to reveal the hidden, unfamiliar or forgotten meaning of the lived experience (Bengtsson, 1998).

The impact of chronic illness on daily life

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 that the failure of their body that changes their lives. Charmaz (1983, 1987) stated that 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. In one study (Grant & Davis, 1997) of close relatives of a person with a serious chronic illness they experienced 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.

According to Toombs (1993) loss of control in life causes considerable anxiety and fear. The ill person may feel that 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) noted 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). Living with chronic illness requires a lot of diligence and vigilance (Corbin & Strauss, 1987) and shifts from experiencing the illness as being in the background of consciousness and the overwhelming experience that the illness dominates one's whole life (Thorne & Paterson, 2000).

Traumatic brain injury

Traumatic brain injury can be seen as a chronic illness that is a result of 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. The injured brain tissue leads to a cascade of cellular events that contribute to secondary injuries. According to the Glasgow Coma Scale (GCS), the most common method for classifying the severity of the injury, TBI can be mild, moderate or severe (Lovasik, Kerr & Alexander, 2001). Large number of people with mild TBI may not go to hospital at all or are discharged without followup (Das-Gupta & Turner-Stokes, 2002).

According to Lovasik, Kerr and Alexander (2001) TBI is a significant world health problem despite declines in occurrence, because of more efficient recording of injuries, improvements in automobile production and the use of safety equipment during sports and other activities. They estimate that the annual incidence rate for TBI in the USA, Australia, Ireland and the United Kingdom is about 95/100,000. According to Berg, Tagliaferri and Servadei (2005) the overall incidence rate in Europe is about 235/100 000/year.

The main causes of TBI are traffic accidents, falls, violence and sports accidents, and the prevalence is much higher among males. Substance abuse, particularly in young adults, is also an important risk factor for sustaining TBI (Lovasik, Kerr & Alexander, 2001; National Institutes of Health [NIH], 1998). Traumatic brain injury is most common in infants and preschool children, young adults and elderly people (Bruns & Hauser, 2003). In a study in Norrbotten (Jacobsson & Lexell, manuscript) the majority of people with TBI were older and had sustained mild TBI as a result of a fall. Young people sustained TBI following traffic accidents. Moderate TBI was most common in the age groups 60 to 69 years and severe TBI in 0 to 19 years. Also in this study the majority of people sustaining TBI were men (Jacobsson & Lexell, manuscript).

Living with a traumatic brain injury

People with TBI confront various long-lasting problems. A TBI may result in physical impairment, cognitive, emotional and behavioural problems that all impact on a person's interpersonal relationships. Physical consequences can vary e.g., 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 a very unpleasant and frightening experience that has a great influence on managing their daily life (Brewin & Lewis, 2001; Johnson, 1995; Nochi 1997; Price-Lackey & Cashman, 1996). 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 two years after moderate or severe TBI but is markedly impaired even after that.

Reviews (Antonak, Livneh & Antonak, 1993; Morton & Wehman, 1995) showed that people with TBI may suffer from anxiety and depression for many years after the injury. Aggression, lack of sexual restraint and attention-seeking behaviour may also occur (Das-Gupta & Turner-Stokes, 2002). Emotional problems, especially depression associated to cognitive impairments has 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).

According to NIH (1998), the risk of suicide, unemployment, divorce, financial problems, and abuse is high among people with TBI. Reduced social contact and social support lead to increased loneliness (Morton & Wehman, 1995). 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. They have a need to make sense of their experience and to reconstruct themselves (Nochi, 1997; 2000). Several studies (e.g., Backhouse & Rodger, 1999; Darragh, Sample & Krieger, 2001; Swift & Wilson, 2001) showed that people with TBI feel that other people, including professionals, lack understanding of their changed situation. Nochi (1998a; 1998b) demonstrated that people with TBI were stigmatized and their autonomy and integrity were questioned.

In short, sustaining a TBI has devastating consequences for the daily life of people with the illness and this is only partially understood by other people. Even close relatives to the person with illness may experience a total change in their daily life.

Being a close relative of a person with traumatic brain injury

Close relatives often show great willingness to adjust their lives to fit in with the needs of the person with TBI (Carson, 1993; Duff, 2002, 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). Several studies (Bond, Draeger, Mandleco & Donnelly, 2003, Crisholm & Bruce, 2001, Duff, 2002) demonstrated that close relatives experience great uncertainty for a long time.

Close relatives reported high levels of stress and being burdened that often do not lessen with time (Degeneffe, 2001; Florian, Katz & Lahav, 1989). The ill persons' personality changes were experienced as especially disturbing (Florian, Katz and Lahav, 1989; Junque, Bruna & Mataro, 1997). A review (Perlesz, Kinsella & Crowe, 1999) 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 to person with TBI, also experience increased responsibility and psychological distress (Perlesz, Kinsella & Crowe, 1999).

According to Lovasik, Kerr and Alexander (2001) close relatives reported significant levels of 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, Mohr & Redman, 2000). Close relatives had a need to feel hope and to be able to make sense of their experience (Carson, 1993; Johnson, 1995; Smith & Smith, 2000). They also have a great need of information, emotional and practical support (Bond et al., 2003; Smith & Smith, 2000), but studies showed that they receive inadequate information (e.g., Paterson, Kieloch & Gmiterek, 2001; Smith & Smith, 2000) and that other people lack any understanding of their problems (Backhouse & Rodger, 1999; Swift & Wilson, 2001).

Close relatives of a person with TBI experience various kinds of burden as they try to adjust their lives according to the needs of the ill person. According to NIH (1998) the consequences of TBI are complex and vary across the lifespan with new problems occurring as a result of new challenges and aging. People with TBI and their close relatives need access to rehabilitation throughout the course of their recovery, which may last for many years after the injury (NIH, 1998). Immediate post-acute rehabilitation usually needs to be provided in an acute hospital setting because the person with moderate or severe TBI often has associated injuries and continuing medical and surgical needs (Das-Gupta & Turner-Stokes, 2002).

In short, when one person within a family sustains a TBI it has devastating consequences for the whole family, but other people have difficult to understand their situation.

RATIONALE FOR THE STUDY

Several studies already exist that show what consequences a TBI has for both the injured person and for their close relatives. Previous research shows that they have a great need of various kinds of support but these needs are not always met. Both the people with TBI and their close relatives seem to lack understanding from other people of their profoundly changed situation. It is therefore important to gain more knowledge about the meaning of living with TBI from their perspective. Kleinman (1988) stated that 'an inquiry into the meanings of illness is a journey into relationships'. The meanings of illness are shared, negotiated and form an integral dimension of lives lived together. Understanding the influence of the illness on the family necessitates understanding the family itself and not just the illness (pp. 185-186). Kleinman believes (1995, p. 184) that professionals often minimize the impact of serious illness in the 'interpersonal space of everyday life'. Deeper understanding of the challenges that people with TBI and their close relatives, both separately and together, are forced to meet is a basis for being able to facilitate their healing and wellbeing in everyday life. It increases the possibility for them both as persons and as a family to get more help from other people, including professionals.

AIMS OF THE STUDY

The overall aim of the licentiate 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:

- to elucidate the meaning of living with TBI in people with moderate or severe TBI,
- to elucidate the meaning of close relatives' experiences of living with a person with moderate or severe TBI.

METHODS

This study has a qualitative approach because this facilitates the acquisition of a rich understanding of the meaning of living with a TBI in everyday life from the perspective of people with the injury and their close relatives (cf. Denzin & Lincoln, 2000, pp. 8-10).

Setting

The research investigation has performed in the northern part of Sweden and included people living with moderate or severe TBI (I) and their close relatives (II). Jacobsson and Lexell (manuscript) estimate that annually approximately 260 people in Norrbotten sustain a TBI that requires neurosurgical and/or neurointensive care and on average 14 of them sustain a moderate or severe TBI. Norrbotten has five acute care hospitals and everyone with TBI requiring neurosurgical and/or neurointensive care is transferred to the University Hospital of Northern Sweden located about 16o kilometres south of the county border of Norrbotten.

Participants and procedure

People with traumatic brain injury

In this study the criteria for the participation were that the person had a moderate or severe TBI and the capacity, interest and desire to narrate their experiences. They also had to have lived with the injury for at least three years in order for them to be considered experts in what it means to live with TBI (cf. Robertson-Malt, 1999). The participants were recruited by the Patient Association for People with Brain Injuries, a psychologist and a nurse working in two different acute care hospitals. They telephoned the possible participants, and after receiving their permission sent them a letter including 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 study (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 hade lived with the TBI for between 3,5-13 (median=7) years.

Close relatives

In connection with arranging the interviews with the participants (I) I asked their permission to send a letter to one of their close relatives with whom they had a lot of contact during their illness and who could tell me about experiences of living with the person with TBI. Eleven of the participants had close relatives whom I contacted by letter which 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 4-13 (median= 8) years, returned their written agreement and were then telephoned in order to agree a time and place for the research interview. Two of the close relatives lived in the same household as the person with TBI.

Table 1 Characteristics of the participants

Participants	n, sex	Age, yrs	Cause of TBI	Relationship with the person with TBI
People with TBI	12 Male 10 Female 2	Median 40 Range 23-50	Traffic accident 7 Fall 3 Assault 2	
Close relatives	8 Female 7 Male 1	Median 45 Range 28-56		Parents 3 Partner 2 Sibling 2 Daughter 1

Data collection

The data were collected by means of qualitative research interviews. According to Kvale (1996/1997, p. 13) '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'. 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.

A research interview is a social situation and a meeting between two or more people but it is characterized by an inequality of power because it is the researcher who has control over the situation (Kvale, 1996/1997). Interviewing people with TBI can be problematic because they may have e.g., cognitive impairments, become fatigued and distracted during the interview situation and unable to effectively recall or articulate their experiences (Paterson & Scott-Findlay, 2002). The interviews with people with TBI (I) were, therefore, planned according to suggestions made by Paterson and Scott-Findlay (2002). In order to obtain data that were as rich and complete as possible the participants were interviewed twice. At the first interview, they were asked to talk about their daily life before and after the injury. Questions such as "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 it happened to you…" were used to encourage the interviewees to narrate their experiences (cf. Paterson & Scott-Findlay, 2002). 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).

Close relatives of people with TBI were interviewed once (II). An interview guide with such themes as life before and after the injury, encountering other people and any received care was used (I, II). The interviews of close relatives (II) started with a the invitation to 'please tell me about your experiences when X was injured'. In order to encourage communication I used follow-up questions such as 'what did you think then', 'please tell me more about that' and 'can you give an example' (cf. Kvale, 1996/1997).

Eleven people with TBI (I) and all close relatives (II) were interviewed in their homes. One of the participants with TBI was interviewed at my working place (I). Two interviews with close relatives took place by phone because of geographic distance (II). All the interviews were tape-recorded and transcribed verbatim (I, II). The average length of the first interview with people with TBI was 75 minutes and of the second 60 minutes (I). The interviews with close relatives lasted approximately 80 minutes (II). The data collection took place during the spring 2003 (I) and autumn 2003 (II).

The phenomenological hermeneutic interpretation

The interview texts were analysed using a phenomenological hermeneutic interpretation inspired by Ricoeur (1976) and developed by Lindseth and Norberg (2004). Ricoeur (1976) argues that the interpretation is an understanding applied to a written expression of the lived experience. The text represents the objective side of the meaning because it has a semantic autonomy as it is 'liberated from the narrowness of the face-face situation' (Ricoeur, 1976, p. 31). The text is free from its author, context and audience. Interpretation is a movement from what the text says to what it talks about and an ongoing movement between the whole and the parts of the text, and between understanding and explanation (Ricoeur, 1976).

The interpretation 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 and the author’s intention is beyond readers’ reach (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 deep interpretation achieved during the third phase, the comprehensive understanding. In this final stage 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 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) and living with a person with TBI (II). After gaining a sense of the whole a naive understanding was written down. In the structural analysis the interview texts were divided into meaning units, which were a sentence, paragraph or several pages with the same content. The meaning units were then condensed and abstracted to produce formulated meaning units. The formulated meaning units were sorted in to different groups according to similarities and differences in meaning. The groups were then compared to each other and organized into themes and sub-themes. 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).

Ethical considerations

All participants gave their informed consent by letter when asked if they were interested in participating, and again verbally before the interviews started. They were given a guarantee of 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.

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 remit of the research. In this study, I met people with TBI twice (I) which may have increased the risk of a role conflict because the interviewees and I learned to know each other better. The participants (I, II) were conscious that I and my supervisors were nurses and a doctor, but that in this connection we were researchers. I received some questions about care 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). 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. I was sensitive to the needs and comfort of the participants during the interviews and 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. Many of the participants were touched by memories when they narrated their experiences but no one wanted to interrupt the interview or withdraw from the study. 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) 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.

FINDINGS

The results of the two papers are presented separately. In the respective Papers the major themes are marked with italics. The themes and comprehensive understanding in each Paper are presented in Table 2.

Table 2 Overview of the findings in the Papers

Paper	Themes	Sub-themes	Comprehensive understanding
I	*Losing one's way*	Waking up to the unknown Missing relationships Experiencing the body as an enemy	Perpetually altered body changed the whole life and caused deep suffering where feelings of shame and dignity competed with each other. (Corbin, Eriksson, Frank, Frankl, Kaufman, van Manen, Wiklund)
	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	
II	*Fighting not to lose one's foothold*	Getting into the unknown Becoming acquainted with the changed person Being constantly available Being strong Missing someone to share the burden with Struggling to be met with dignity Seeing the light in the darkness	Willingness to fight for the ill person derived from feeling of natural love and ethical demand. Close relatives struggled with their own suffering and compassion for the ill person. Natural love and hope gave the strength to fight. (Eriksson, Levinas, Lögstrup, May)

Paper I

The meaning of living with moderate or severe traumatic brain injury

The first paper 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 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 were forced to realize that they had to begin to learn everything a new 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 was intensive and time-consuming.

Struggling to attain a new normalcy was related to 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 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 the 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

The second paper elucidates the meaning of close relatives' experiences of living with a person with moderate or severe TBI. Living with a person with TBI mean 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. 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. After the critical phase, close relatives 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 their best friend, a fine person and worthy of their involvement. Close relatives worried about the future and felt inadequate. 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 lenght with other family members who were also forced to change their lives. Everyone in the family supported the ill person and each other that gave 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 was a 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. Natural love between the ill person and close relatives seemed to make their objectives the same i.e., 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. 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.

COMPREHENSIVE UNDERSTANDING AND REFLECTIONS

This licentiate thesis aimed to elucidate the meaning of living with a TBI from the perspective of people with moderate or severe TBI and their close relatives. This study suggests that the meaning of living with traumatic brain injury in people with TBI and their close relatives is to be forced to live a different everyday life. It includes enduring uncertainty, chronic sorrow and loneliness. Illness changed the life of people with TBI and their close relatives so much that they experienced separation from others and loneliness. They long for relationships but sometimes choose loneliness which can be seen as a way to protect themselves (people with TBI) or the person with TBI (close relatives). People with TBI and their close relatives retained hope which was both a positive attitude toward living and hope of achieving goals. Their hope was strengthened by affirming relationships and provided the toughness needed to combat the illness. Being forced to live a new everyday life meant deep suffering for people with TBI and their close relatives. Their need for help both as persons and as a family is great, even many years after the injury but they seemed to be rather alone in their struggle.

Being forced to live a different everyday life

People with TBI lost their familiar body and experienced their body as an enemy. They were forced to become aware of their body, to pay attention to it and live with its limitations (I). According to Toombs (1993) illness is experienced as a disruption of the lived body which is a threat to the self. The person with illness becomes unwillingly aware of the 'diseased body' that they cannot escape. Habitual acts such as walking, running, cooking and eating, which were performed unthinkingly before, now become effortful and the body is experienced as an opposing force. Illness changes one's being in the world and 'the taken-for-granted quality of life' is called into question (p. 20). In this study the TBI changed being in the world for both the people with TBI and their close relatives. They could not live the life they had taken for granted before the injury, but were forced to live a different everyday life which included enduring uncertainty, chronic sorrow and loneliness but also retaining hope (I, II).

Enduring uncertainty, chronic sorrow and loneliness

This study argues that people with TBI and their close relatives were thrust into a novel and complex everyday life, where they had difficult structuring the meaning of all the events and predicting the outcomes accurately. People with TBI experienced waking up to the unknown, struggling to recover themselves and wondering if they were the same as before the injury. They were uncertain whether they were good enough and fluctuated between feelings of shame and dignity (I). Close relatives' fought not to lose their foothold, which included experiences of entering an unknown life and uncertainty about how to live with the changed person (II). These findings show that people with TBI and their close relatives lived with uncertainty which, according to Conrad (1987), is a common experience in illness. Mishel and Braden (1987) argue that uncertainty occurs when people are unable to assign definite value to events, to predict outcomes accurately or to structure the meaning of events connected with the illness.

According to Mishel (1988, 1990) uncertainty can be judged as an opportunity or a danger. If it is seen as a danger there is an expectation of a negative outcome while if it is seen as an opportunity a positive outcome is implied. When the alternative is negative certainty, as with an illness with a known downward trajectory, uncertainty can be viewed as an opportunity and strategies to maintain uncertainty are implemented. Managing short-term uncertainty and living with continual uncertainty may result in personal growth (Mishel, 1990). Experiencing uncertainty as an opportunity or a danger is not a static condition but can change with time during the illness (Neville, 2003). This study suggests that people with TBI and their close relatives experienced uncertainty both as a danger and an opportunity. They seemed to feel anxiety and fear when they were faced with the unknown future (I, II) which can be interpreted to mean experience of uncertainty as danger. At the same time, if they do not know all the devastating consequences of living with TBI (negative certainty), uncertainty is an opportunity. People with TBI and their close relatives found a way to live with TBI/the person with TBI and they felt that they knew more about life and appreciated each other more than before (I, II). This is interpreted to mean that enduring and managing a life with uncertainty gave them an opportunity to view life differently and to grow as human beings. According to Mishel (1990), when one no longer focuses on the value of continual certainty, predictability and mastery as the normal way of life, uncertainty provides an opportunity for growth and a change towards a new view of life.

Neville (2003) stated that uncertainty often remains constant for people with chronic illnesses but they are able to find a way to tolerate and endure it. People with TBI and their close relatives had no choice other than to find a way in which to tolerate and endure uncertainty. It is crucial to understand that living with the uncertainty that people with TBI and their close relatives were forced to endure meant suffering deeply. According to Charmaz (1999) loss of control, certainty and an anticipated future cause suffering. People with TBI and their close relatives sought for explanations (I, II) which can be seen as a way to make sense of and to structure the meaning of the illness event. Being able to do this helps to reduce the feeling of uncertainty (cf. Conrad, 1987). According to Söderberg, Lundman and Norberg (1999) finding explanations and understanding the meaning and coherence in illness brings relief. It makes it easier to accept the illness and contributes to living a life with dignity. Edvardsson, Sandman and Rasmussen (manuscript) found that being able to understand what happens involves being able to understand one's experiences and promotes the feeling of safety in the environment. In this study people with TBI and the close relatives experienced that finding explanations and being able to understand was a relief (I, II). Although people with TBI experienced guilt and bitterness, they did not fix on these thoughts but strove to think positively (I). Frank (2002) noted that ill people tell stories themselves about what is happening to them that influences their attitude towards living with the illness. They have to choose carefully the stories they use. Sometimes it is better to believe that the illness just happened because, for example, asking 'why me' can lead to a sense of past inadequacy and guilt that only increases the person's suffering.

People with TBI and their close relatives experienced significant loss as they were forced to abandon the life they had planned. This caused them sorrow. The times of sorrow alternated with times of satisfaction and happiness especially when the ill person got better (I, II). Olshansky (1962) presented the concept of chronic sorrow and identified its presence in parents with a mentally defective child. He stated that chronic sorrow is a normal response to ongoing loss and its intensity varies in different times, situations and families. Burke, Eakes and Hainsworth (1999, p. 374) 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 type of significant loss experience 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, Eakes & Hainsworth, 1999; Teel, 1991).

According to Burke, Eakes and Hainsworth (1999) common triggers of chronic sorrow for the person with illness and their close relatives are the anniversary events associated with the illness, comparisons with norms and experiencing a disparity between oneself and healthy people. Further, ceaseless care-giving and responsibility for the ill person triggers chronic sorrow in close relatives. People with TBI felt joy and were proud when they improved and found a new way of living but their sorrow could have triggered by events which reminded them of what they had lost, e.g., they felt it was hard to be met without respect by other people or to hear their children say that their greatest dream was for their parent to regain her/his health (I). 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 the relationship and the 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 lost the person they knew before the injury. The person with TBI remained within the family but was not the same. Close relatives felt an increased responsibility, were worried about the ill person's future as they were getting older and felt sorrow for the ill person's loneliness and when she/he was treated badly by other people (II). All these experiences can be interpreted as events that triggered the close relatives' feeling of sorrow when they were reminded of their permanently different life compared to people living without their loved one having a serious illness (cf. Burke, Eakes & Hainsworth, 1999).

It is suggested that the life of people with TBI and their close relatives changed so much that they experienced separation from others and loneliness. People with TBI and their close relatives suddenly entered a world steered by the illness and lost relationships to significant others (I, II). They missed the relationships (I) and someone to share the burden with (II). Close relatives' opportunities to make new contacts were limited because of the increased responsibility for the person with TBI (II). According to Toombs, Barnard and Carson (1995) to live with chronic illness is to experience a sense of 'differentness', loneliness and separation from others. People with chronic illness are preoccupied with experiences that are alien to the self and demand their whole attention; 'there is no time off for being sick' (Agich, 1995, p. 148). Spending a lot of time on a medical regimen also sets the ill person apart from others (Charmaz, 1983). In this study people with TBI and their close relatives seemed to be preoccupied with those experiences of living with TBI that demanded their whole attention, including spending a lot of time on medical regimens. Their time, strength and ability to be together with significant others were severely limited (I, II).

Younger (1995) stated that people experience relationships along a continuum that ranges from alienation to a full sense of connectedness. Loneliness is one step along the continuum from alienation and is the feeling of being alone in spite of longing for others. People with TBI and their close relatives missed relationships but at the same time they sometimes chose loneliness (I, II). People with TBI felt that it was sometimes better not to be in active contact with others, because of the risk of making a fool of themselves and feeling ashamed (I). Killeen (1998) uses the term 'aloneness', which contains a choice in wanting to be yourself whereas in 'loneliness' there is no choice. Close relatives sometimes appreciated an opportunity to be alone (II) which may be a sign of their need to turn inwards. According to Younger (1995) turning inwards is a response to hurt and a need to make sense of what has happened. It helps to address the question of ‘why’.

According to Lyons and Sullivan (1998, p. 141-142) illness violates the implicit ‘relationship contract’ that existed when everything was healthy. Illness forces the person with illness and her/his significant others into ‘relationships schema formatting’ where everyone must reflect on who they are, what expectations they have of the relationship and how they can contribute to the relationship. Despite conflicts people with TBI and their close relatives found that their relationships with each other and within the family deepened (I, II). This is interpreted to mean that they managed to format a new relationship schema within the family. Close relatives felt 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’. Lindholm, Rehnsfeldt, Arman and Hamrin (2002) found that being in close contact with each other is 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. In this study, love between family members made it possible to experience connectedness and togetherness within the family which alleviated the suffering of people with TBI and their close relatives. Younger (1995) stated that experiencing connectedness includes recognizing unity between the self and others and a sense of being a part of a group. Öhman (2003) maintains that a feeling of togetherness provides alleviation, support and consolation both to the one who is ill and to her/his close relatives.

People with TBI and their close relatives were in some way alone with their suffering despite the connectedness they seem to felt to someone else. People with TBI felt lonely in their illness (I) and close relatives did not want to show the person with TBI how badly they themselves felt because they wanted to protect them from their suffering (II). Eriksson (1994) argues that every human being is in some way alone with their suffering and must confront it alone. Tillich (1973) stated that being alive means 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 about life (II). This can be interpreted to mean that the dramatic event, where one of them sustained a TBI, made them more aware of life's finiteness and they felt 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 lacked understanding from other people and were forced to struggle to be treated with dignity. This made it more difficult to get help that facilitated daily life and alleviated suffering. They felt that even professionals lacked understanding of their situation and the knowledge to help them (I, II). All these experiences may have increased the feelings of loneliness experienced by people with TBI and their close relatives. According to Tillich (1973) loneliness includes the pain of being alone. He argues that people can feel alone in a crowd if they feel misunderstood, despite their desire to make themselves understandable. Cassel (1991) noted that perhaps the discomfort the suffering causes is one explanation for the withdrawal of many people. Roxberg (2005) found that sometimes professionals consciously chose not to engage in seeing the cues of suffering because they were occupied with their own suffering and had no strength to engage in others' suffering. Further reasons suggested were the lack of courage and knowledge.

Retaining hope

People with TBI and their close relatives retained their hope. People with TBI said that having hope and hating to give up was their mainspring. It was important to think positively, to have a strong will and to trust one's possibilities (I). Close relatives sometimes hovered between hope and despair but they never lost hope for a better future with the person with TBI and they struggled to be strong and to cope with the fight (II). It seems apparent that people with TBI and close relatives had hope related to being; a strong will to live, to struggle and an awareness of their possibilities. Benzein (1999, p. 35) believes that hope as human experience is always present. She and her co-authors (2000) found two major dimensions of hope; being in hope and having hope for something. Being in hope was related to being and hoping for something related to doing. Hope related to being includes a will to live and an awareness of one's possibilities in life which gives energy and enables the person to make good and meaningful choices. Hope related to doing is directed towards setting goals and it seems that people with TBI and their close relatives also experienced this dimension of hope. Natural love between close relatives and the ill person made that their goals were the same i.e. the ill person's wellbeing and independence that together they struggled to achieve (I, II).

According to Benzein et al. (2000) experiencing meaning in life is a prerequisite for hope related to being. Hope related to being is an internal process and a prerequisite for hope related to doing, an external process that nurtures hope related to being. In this study, people with TBI experienced a meaning in life because they had goals to strive for and people they loved and felt loved by (I). In turn, close relatives' willingness to fight for the ill person derived from feelings of natural love and ethical demand (II). Achieving goals, i.e. when the person with TBI improved (hope related to doing), increased hope for people with TBI and their close relatives, and gave them the strength to continue the struggle (hope related to being).

People with TBI and their close relatives had strong mutual relationships that together with other affirmative relationships (e.g., when they were met with dignity and received the help they needed) in all probability nurtured their feeling of hope. These relationships were crucial because they also met people who did not believe on their chances of improvement (I) or that they could take the responsibility for the ill person (II). Close relatives felt that it was important for healthcare personnel to convey bad news in a polite manner without depriving them of hope (II). Relationships including faith, affirmation and support nurture hope (Benzein et al., 2000; 2001), but hopeless people instil hopelessness in those around them (Barnard, 1995). According to Agich (1995) professionals' understanding of the meaning of hope is often limited; there is no hope if there is no effective treatment, cure or return to normality. He maintains that ‘hope is a virtue defining one’s bearing toward the future’ and to hope is ‘to experience forthrightly and with fortitude whatever comes one’s way’ (p. 143). This is close to Benzein’s et al.’s ‘hope related to being’ that also reveals one’s positive attitude towards living. People with TBI and their close relatives were proud because they did not give up but got on with the struggle (I, II). Charmaz (1999) stated that people with illness ‘gain pride in knowing that their selves have been put to test of character, resourcefulness and will. They know they gave themselves to struggles and lived their loss with courage’.

CONCLUDING REMARKS

This study showed how people with TBI and their close relatives experienced suffering as persons and as a family. Suffering is always individual and if we want to alleviate it we must know the suffering person and the family. Gaining total knowledge of a person/family is impossible (cf. Cassel, 1991) and the suffering person/family may not use the word ‘suffering’ when they narrate their experiences of suffering. Therefore, we must look for the cues that tell us about their suffering. It is crucial to take the time to listen to the stories of people with TBI and their close relatives and to be be entirely present in encounters with them (cf. Öhman & Söderberg, 2004). More knowledge about suffering and how it is experienced by different people and in various contexts helps to develop our ability to recognize the cues indicating suffering. Understanding more profoundly, for instance, the meaning of uncertainty, chronic sorrow, loneliness and hope facilitates the development of an ability to listen, understand and support people with TBI and their close relatives in their everyday life. Lack of time should not be a reason for not listening to the stories of people with TBI and their close relatives.

Further, seeing and recognizing the cues that indicate 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 people with TBI consisted of more men than women but is in line with the prevalence of TBI (I). The sample of close relatives consisted mostly of women (II). It is a weakness that the sample was dominated by either men (I) or women (II) and a more heterogeneous sample 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 were influenced by their memory and retrospective interpretation. The findings may have been influenced by the fact that people with TBI (I) had memory deficits and could not narrate their experiences immediately after the injury or their discharge from the hospital, and close relatives (II) said that they could not narrate everything in detail, because so many years had passed since the person 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. Nunkoosing (2005) stated that the interviewee chooses the aspects she/he is most interested in narrating. All stories are likely to change over time and that 'is always a problem when one is concerned with human experiences' (p. 702).

All participants had lived with TBI for many years and their knowledge of the phenomena was apparent. In spite of memory deficits they narrated a rich and experiential story of their experiences which contributed to a new understanding of the phenomena under study. The data were relevant and did not contain much useless material. 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.

Kvale (1996/1997) 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 traumatic brain injuries. This, however, was compensated for by carefully planning the interviews and following the recommendations of Paterson and Scott-Findlay (2002) (I). I felt that I managed to create a permissive climate in which the interviewees could freely narrate their experiences. I tried to be open and sensitive to what the participants conveyed in the interview situation and felt that I got whole stories with a clear beginning and end. Kvigne, Gjengedal and Kirkevold (2002) stated that 'openness on the part of the researcher is a prerequisite in order to gain access to the informant's life-world'. 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.

People with TBI sometimes found it difficult to concentrate, formulate their ideas, felt fatigue or had headaches that made the interview situations more difficult. Interviewing them twice was crucial from the ethical point of view and can be seen as a form of prolonged engagement that facilitated the study (cf. Lincoln & Guba, 1985; Guba & Lincoln, 1989). Close relatives (II) 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 (1996/1997) 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 analysed using a phenomenological hermeneutic interpretation which proceeded through several stages, where the whole confirmed the parts and the parts confirmed the whole. The structural analysis, as the objective stage in the interpretation process, served as a kind of validitation (cf. Ricoeur, 1976). The analysis (I, II) was carried out by three researchers who where experienced nurses and physician who worked with people with chronic illnesses. All were also researchers in this field. These preunderstandings facilitated the interpretation of the meaning of the

texts. Lindseth and Norberg (2004) maintain that insufficient preunderstanding prevents the grasping of the essential meanings in the text. According to Lincoln (1995) detachment and author objectivity are barriers to the quality of the study. However, it was important to be careful not to allow preunderstandings to prejudice the interpretation. This was prevented by striving to be open to different interpretations and by discussing interpretations with other colleagues. Sandelowski (1998) noted that outsider experts are critics who ask the right questions and help the researcher to see the data in a new way. After discussions with colleagues the accuracy of theinterpretations was checked and adjusted. According to Ricoeur (1976), the interpretation arrived at must be more probable than any other interpretation. The interpretation (I, II) presented is the most probable interpretation the researchers could achieve and it is always possible to argue for or against this interpretation.

According to Lindseth and Norberg (2004) the findings should be presented in everyday language close to the lived experience and, for example, metaphors can be used in order 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. Metaphors have been used in some themes in order to convey the interpreted meaning. The procedure, context and findings in the study are presented as accurately as possible in order to help the reader to judge the trustworthiness, including transferability, of the study (Lincoln & Guba, 1985; Guba & Lincoln, 1989).

SUMMARY IN SWEDISH-SVENSK SAMMANFATTNING

Att tvingas till att leva ett annorlunda dagligt liv: de drabbade personerna och deras närståendes upplevelser av att leva med en traumatisk hjärnskada.

Oavsett om en sjukdom är akut eller kronisk konfronteras den sjuka 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 sjuka personen och dennes närstående har svårt att förstå det som har hänt (Duff, 2002). Denna licentiatavhandling fokuserar på innebörden i upplevelsen av att leva med en THS utifrån de berörda personers och deras närståendes perspektiv. Avhandlingen har en fenomenologisk hermeneutisk forskningsansats eftersom det är livsvärlden som är i fokus.

Fenomenologi beskrevs först av Edmund Husserl, en tysk filosof, som introducerade begreppet 'livsvärld', värld av levd erfarenhet. Med livsvärlden menas den värld som vi dagligen lever i och som vi ofta tar för given (van Manen, 1990). Merleau-Ponty (1945/1997) menar att det är via kroppen människan har tillgång till livsvärlden. Även kroppen tas för given och människan tänker inte på dess existens förrän någonting händer med den. Sex eller sport aktiviteter är exempel på när vi blir medvetna om kroppen i positiv mening men när vi drabbas av en sjukdom blir vi tvungna att vara medvetna om kroppen (Toombs, 1993). Kroppen är närvarande i allt vad vi gör och varje förändring i den ändrar också vår livsvärld (Merleau-Ponty, 1945/1997).

I fenomenologin är det viktigt att 'gå till sakerna själva', att försöka se det väsentliga i ett fenomen och tydliggöra innebörden av den levda erfarenheten (upplevelsen). Husserl (1913/2004) menade att det är viktigt att forskaren sätter sin förförståelse inom parentes och utforskar fenomenet utan förutfattade meningar. Senare utvecklades fenomenologin mot hermeneutiken som är en tolkningslära av texter. Tolkning med hjälp av forskarens förförståelse ansågs vara en nödvändighet för att kunna belysa den levda erfarenheten (Koch, 1996; Laverty, 2003). Hermeneutikens uppgift är att avslöja den gömda, okända eller glömda meningen i den levda erfarenheten (Bengtsson, 1998).

Rational

Ett flertal studier har visat att en traumatisk hjärnskada kan leda till långvariga fysiska, kognitiva, emotionella och beteendeförändringar hos den sjuka personen. Förändringarna som påverkar hela livet för personen med sjukdomen och dennes närstående. 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 kunna bemöta och vårda personer med THS och deras närstående på ett sätt som stödjer dem, både som person och familj, i det dagliga livet.

Syfte

Det övergripande syftet med denna licentiatavhandling var att belysa innebörden i att leva med en medelsvår eller svår THS utifrån de berörda personernas och deras närståendes perspektiv. Avhandlingen består av två delstudier. I delstudie I var syftet att belysa innebörden i att leva med en medelsvår eller svår THS. I delstudie II var syftet att belysa innebörden i att leva med en person med medelsvår eller svår THS.

Metod

Denna studie utfördes i norra delen av Sverige efter att den hade godkänts av universitetets etikkommitté. I delstudie I intervjuades tolv 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 (median=40) och hade levt mellan 3,5-13 år med skadan (median=7). Två personer med THS levde med föräldrar, två med partner och åtta ensam eller med sina barn. Fem deltagare hade en personlig assistent. Intervjuerna genomfördes utgående från rekommendationer gjorda av Paterson och Scott-Findlay (2002). Alla deltagarna intervjuades två gånger för att få in rikt intervjumaterial (data).

I delstudie II intervjuades åtta närstående, 1 man och 7 kvinnor. Deltagarna var närstående till personer med THS som ingick i delstudie I. De var mellan 28-56 år (median=45) och de var; föräldrar (n=3), partner (n=2), syskon (n=2) och en dotter (n=1). De hade levt med person med THS mellan 4-13 år (median=8). Närstående intervjuades en gång. Intervjuerna med personer med THS genomfördes våren 2003 och med närstående hösten 2003.

Alla intervjuer bandinspelades och skrevs därefter ut ordargrant. Intervjutexter analyserades med en fenomenologisk hermeneutisk metod inspirerad av Ricoeur (1976) och utvecklad av Lindseth och Norberg (2004). Intervjutexter lästes igenom flera gånger för att kunna förstå innebörden i att leva med en THS och leva med en person med THS. Efter att fått en naiv förståelse av innebörden skrevs detta ner. Därefter gjordes en strukturanalys vilket syftar till att förklara texten och bekräfta den naiva förståelsen. Texten delades in i meningsbärande enheter som bearbetades och delades in i olika grupper utifrån likheter och olikheter i innebörden. Grupperna jämfördes och organiserades i teman och subteman. I den sista tolkningsfasen granskades texten återigen som en helhet med hjälp av forskarens förförståelse, den naiva förståelsen, strukturanalysen och litteraturen. Detta ledde till en fördjupad förståelse av innebörden i att leva att leva med en THS/leva med en person med THS.

Resultat

Innebörden i att leva med en traumatisk hjärnskada

Denna studie 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 temana *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 är en fiende. Att förlora minnet för flera månader eller år upplevdes som att förlora allt och att gå i botten eller en djup grotta. Personer med THS insåg att de hade blivit lika hjälplösa som små barn och att de måste börja allting på nytt. De upplevde sorg och skam när de förstod hur mycket de hade förändrats och när människor som de hade mycket kontakt med före olyckan inte längre tog kontakt med dem. Personer med THS saknade relationer med andra människor men valde ibland att vara ensam för att undvika att göra bort sig och skämmas. Relationer där de kände sig älskade verkade stärka deras känsla av värdighet. 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.

Kamp för en ny normalitet innebar upplevelser av att söka efter förklaringar, att återfinna sig själv, att önska sig att bli bemött med respekt och att hitta ett nytt sätt att leva. Personer med THS ville förstå det som hänt och deras sökande efter förklaringar kunde fortgå under flera års tid. De klandrade sig själva eller andra människor och kände bitterhet men även tacksamhet över att de hade överlevt. Personer med THS kämpade med att lära känna sig själva och upplevde att de hade svårt att kontrollera en del känslor eller förstå andra människors reaktioner. De hamnade i konflikt med andra människor utan att mena det, vilket gjorde att de kände skam och skuld. Att känna sig mindre klok och leva med ett dåligt minne upplevdes frustrerande och skrämmande.

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.

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.

Innebörden i att leva med en person med traumatisk hjärnskada

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 varierande 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 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 ensammen och de var besvikna på stöd och hjälp som de fick av andra människor, inklusive hälso- och sjukvårdspersonal. 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.

Fördjupad förståelse

Syftet med denna licentiatavhandling var att belysa innebörden i att leva med en medelsvår eller svår THS utifrån de berörda personers och deras närståendes perspektiv. Personer med THS förlorade sin familjära kropp och var tvungna att ta hänsyn till kroppen och leva med dess begränsningar. Det innebar att personer med THS och deras närstående tvingades till att leva ett annorlunda dagligt liv där livet med THS blev sättet att leva. Detta innehåller uthärdandet av osäkerhet, kronisk sorg och ensamhet, men även bibehållandet av hoppet. Sjukdomen förändrade deras liv så mycket att de upplevde separation från andra människor och ensamhet. De längtade efter relationer med ibland valde de ensamheten för att skydda de själva (personer med THS) eller person med THS (närstående). Hoppet var en positiv attityd mot livet samt hopp för att nå mål. Den förstärktes av bekräftande relationer och gav personer med THS och deras närstående styrka till att kämpa med sjukdomen. Att tvingas till ett annorlunda liv innebar djupt lidande. Personer med THS och deras närstående var i behov av hjälp både som enskild person och familj under flera års tid.

Att uthärda osäkerhet, kronisk sorg och ensamhet

Personer med THS och deras närstående upplevde osäkerhet när de kastades in i ett svårt och komplex liv med sjukdomen där de hade svårt att strukturera och förstå det de tvingades att leva igenom. Mishel (1988, 1990) menar att osäkerhet kan upplevas både som ett hot och en möjlighet. I denna studie framkom att personer med THS och deras närstående upplevde ångest och rädsla när de hamnade i en okänd värld, vilket kan tolkas som att osäkerhet var ett hot. Samtidigt, så länge de inte visste alla förödande konsekvenser av THS kunde osäkerhet framstå som en möjlighet. Personer med THS och deras närstående var stolta över att de inte gav upp kampen och upplevde att de i och med det kunde växa som människor. Uthärdandet av osäkerhet gav dem en möjlighet att lära sig att se livet med andra ögon. Trots att osäkerhet framstod som en möjlighet är det viktigt att förstå att osäkerhet som personer med THS och deras närstående tvingades till att uthärda innebar ett djupt lidande. De sökte efter förklaringar vilket tolkades som ett sätt att minska osäkerhet och lindra lidande.

Personer med THS och deras närstående förlorade det familjära livet vilket orsakade dem sorg. Kronisk sorg presenterades först av Olshansky (1962) som menade att det är en normal respons till en omgående förlust. Enligt Burke, Eakes och Hainsworth (1999) kan personer med kronisk sjukdom och deras närstående uppleva kronisk sorg, vilket betyder återkommande sorg. Sorgen är inte konstant utan varvas med perioder av neutralitet och välbefinnande. Känslan av sorg kan framkallas av årliga händelser kopplat till sjukdomen, jämförelser med samhällets normer och upplevelser av att vara annorlunda än friska människor. Närståendes sorg kan framkallas av upplevelsen av evinnerligt vårdande och ansvar för den sjuka personen. I denna studie framkom att personer med THS var stolta över att de förbättrades men de upplevde sorg när de blev påminda om vad de hade förlorat; de upplevde till exempel att det var svårt att bli bemött utan respekt eller att inte kunna vara den friska föräldern deras barn önskade. Närstående upplevde ett ökat ansvar, var bekymrade över den sjuka personens ensamhet och framtid, och kände sorg över när denne blev illa bemött av andra människor. De hade förlorat personen de kände och den förändrade personens närvaro i deras omgivning var en ständig påminnelse om deras förlust och annorlunda liv. Tider med sorg varierades med lycka och välbefinnande speciellt när den sjuka personen blev bättre.

Livet för personer med THS och deras närstående ändrades helt vilket medförde en upplevelse av separation från andra och ensamhet. De var upptagna att försöka leva med

THS och hade mindre tid, styrka och förmåga att vara tillsammans med andra människor, trots att de saknade relationer. Samtidigt valde de ibland ensamhet. Personer med THS upplevde att det ibland var bättre att vara ensam för att minska risk för att göra bort sig och känna skam. Närstående uppskattade ibland möjligheten att vara ensam vilket kan tolkas som att de hade behov av att vara med sig själva. Younger (1995) menar att människan vill vara med sig själv för att kunna ställa frågan varför och försöka förstå det som har hänt.

Personer med THS och deras närstående klarade av konflikter som uppstod inom familjen och fick fördjupade relationer med varandra vilket lindrade deras lidande. Närstående upplevde att det var viktigt att diskutera mycket inom familjen. Trots att personer med THS och deras närstående upplevde samhörighet med någon 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 dem medvetna om livets ändlighet. Enligt Florian och Krulik (1991) kan en livshotande sjukdom leda till existentiell ensamhet som inte ens ett socialt stöd kan lindra. Eriksson (1994) menar att varje människa är på något sätt ensam i sitt lidande och måste konfrontera lidandet ensam.

Denna studie visar att personer med THS och deras närstående saknade förståelse från andra människor och tvingades till att kämpa för att bli bemött med respekt. De upplevde även att olika myndigheter saknade förståelse för deras situation och kunskap för att hjälpa dem. Att inte bli förstådd och bemött med respekt ökar känslan av ensamhet och lidandet. Enligt Tillich (1973) kan ensamhet vara smärtsamt. Roxberg (2005) fann i sin studie att ibland ville vårdare inte se den andres lidande eftersom de var upptagna med sitt eget lidande eller saknade mod och kunskap. Detta är i överensstämmelse med Cassel (1991) som menar att se den andres lidande är obekvämt vilket gör att många drar sig undan.

Att bibehålla hoppet

Personer med THS beskrev att de strävade efter att aldrig förlora hoppet och att de hatade att ge upp. Närstående pendlade ibland mellan hopp och förtvivlan men förlorade inte hoppet för en bättre framtid. Benzein et al. (2000) har beskrivit två dimensioner av hopp: hopp relaterat till varande och hopp relaterat till görandet. Hopp relaterat till varande innefattar en vilja att leva och en medvetenhet om ens möjligheter vilket ger energi och förmåga att göra meningsfulla val. Hopp relaterat till görandet innebär att människan strävar efter att nå mål. Personer med THS och närstående hade hopp relaterat till varandet dvs. en stark vilja att leva och kämpa samt en medvetenhet om sina möjligheter. De hade även hopp relaterat till görandet eftersom de hade mål som de strävade efter att nå. Naturlig kärlek mellan dem gjorde att det viktigaste målet för dem båda var den sjuka personens välbefinnande. Benzein et al. (2000) menade att upplevelsen av mening i livet är en förutsättning för hopp relaterat till varande vilket är en intern process och förutsättning till hopp relaterat till görande. I denna studie verkade personer med THS och deras närstående uppleva mening med livet eftersom de hade varandra och mål att kämpa för. När person med THS förbättrades och gjorde framsteg (hopp relaterat till görandet) ökades deras hopp vilket det gav dem styrka att kämpa vidare (hopp relaterat till varandet). Personer med THS och deras närstående hade en stark relation med varandra vilket tillsammans med andra bekräftande relationer stärkte deras hopp. Dessa relationer var viktiga eftersom de också mötte människor som inte trodde på den sjuka personens möjligheter att bli bättre eller närståendes möjligheter att ta hand om person med THS. Det är viktigt att vårdare förstår dimensionen av hopp som är mycket mer än en effektiv botande behandling.

Avslutande reflektion

I denna studie berättade personer med THS och deras närstående om deras upplevelser av lidandet som personer och familj. Lidandet är alltid personligt och vi måste känna den lidande personen och familjen för att kunna lindra deras lidande. Den lidande personen använder inte alltid ordet lidande trots att hon/han lider. Därför är det viktigt att lyssna på personen och lära känna igen signaler som antyder hennes/hans lidande. Mer kunskap och en djupare förståelse om lidandet hjälper vårdaren i att utveckla sin förmåga att känna igen dessa signaler. Brist på tid bör inte vara ett hinder för att lyssna på den lidande personen. Att känna igen lidandets signaler kräver kunskap men även vilja och mod att vara nära den lidande personen.

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Paper I

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

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***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 normalcy. 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 normalcy 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 5 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

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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, Viguier, 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 (Johnson & 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 & Wehman, 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 naive 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 naive 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 naive 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.

> [I]t'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 on 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 (2000). 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 Manen, 1998); shame (Kaufman, 1989); the meaning of life and suffering (Frankl, 1984/1994); and Frank'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 and they seemed 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 that 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, allow for their bodies' weaknesses, and live its pain. According to Leder (1990), loss of ordinary body function means that one becomes aware of it as an alien presence and instead of just acting from the body one acts toward it. Van Manen (1998) stated that it is a challenge to everyone to develop a livable relation with their own body. In this study, participants struggled with their bodies and it seems that their bodies were almost like a battlefield. Frank (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 way 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 nonchalance, the feeling of shame and the violation of dignity increase. According to Eriksson (1993, 1994), in order to alleviate suffering it is important 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 strived 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 had 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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Paper II

Fighting not to Lose one's Foothold: The Meaning of Close Relatives' Experiences of Living with a person with Moderate or Severe Traumatic Brain Injury.

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Abstract

When a family member sustains a traumatic brain injury (TBI) it has long-lasting consequences for close relatives. Research based on close relatives' daily lives can increase our understanding of the challenges they face and the possibilities of supporting them. The aim of this study was to elucidate the meaning of close relatives' experiences of living with a person with moderate or severe TBI. The data were collected by means of qualitative research interviews with eight participants who had lived with a person with moderate or severe TBI for 4-13 years. A phenomenological hermeneutic method of the interview texts revealed that close relatives fought not to lose their foothold when it became essential to take an increased responsibility. Close relatives seem to struggle with both their own suffering and compassion for the person with TBI. Their willingness to fight for the afflicted person seems to derive from their feeling of natural love and the ethical demand to care and be responsible for the other. Natural love between close relatives, the afflicted person and other family members, and hope seem to alleviate the suffering of close relatives and give them the strength to fight. Close relatives have the courage and wisdom to alleviate the afflicted person's suffering but have difficulty in finding professionals who could alleviate their own suffering and facilitate their daily lives. It is important that professionals pay much more attention to the suffering of close relatives.

Key words: close relatives, traumatic brain injury, interviews, phenomenological hermeneutic interpretation, suffering, natural love, ethical demand.

When people contract an illness it happens within the context of family, friendships and workplaces. The threat of loss of relationships is always present (Lyons & Sullivan, 1998). Several studies (e.g. Kuyper & Wester, 1998; Purola, 2000; Söderberg, Strand, Haapala & Lundman, 2003; Öhman & Söderberg, 2004) have shown that chronic illness affects close relatives' relationships with the person afflicted and other people in various ways. Studies (Engström & Söderberg, 2004; Öhman & Söderberg, 2004) revealed that close relatives put themselves second and did everything to support the ill person. When the person was critically ill their whole existence was focused on that person (Engström & Söderberg, 2004). Close relatives living with someone with serious chronic illness felt an increased responsibility for the care of that person and a circumscribed personal freedom because living with the ill person took most of their time and energy (e.g. Bolmsjö & Hermeren, 2003; Grant & Davis, 1997; Öhman & Söderberg, 2004).

With the occurrence of a moderate or severe TBI (traumatic brain injury) the person afflicted usually moves from a healthy state, through a life-threatening episode and acute care to a state of chronic illness. This change is so rapid and complete that relatives can only dimly understand the shift in condition from critical to chronic illness (Duff, 2002). Close relatives of people with TBI show a great willingness to adjust their lives to accord with 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 (Gill & Wells, 2000; Kneafsey & Gawthorpe, 2004; Perlesz, Kinsella & Crowe, 1999). Close relatives are engaged in a process of re-evaluation and reconciliation of the pre-and post-injury person with TBI (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002) and feel great sorrow because of the loss of the pre-injury person (Carson, 1993; Smith & Smith, 2000). Emotional and behavioural changes in the ill person especially put great strains on close relatives (Florian, Katz & Lahav, 1989; Kneafsey & Gawthorpe, 2004). Reviews (Florian, Katz & Lahav,1989; Liss & Willer, 1990; Lovasik, Kerr & Alexander, 2001) report that close relatives of people with TBI experience a loss of partnership, leisure time and social contacts.

Close relatives of people with TBI experience great uncertainty for a long time (Bond, Draeger, Mandleco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002). A review (Degeneffe, 2001) shows that the feelings of stress and burden among close relatives often do not lessen with time. Sometimes the responsibility for the afflicted person and the other demands of life are exhausting (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002; Simpson, Mohr & Redman, 2000). Close relatives need to feel hope and be able to make sense of their experience (Carson, 1993; Johnson, 1995; Smith & Smith, 2000) and they need a lot of information, together with emotional and practical support (Bond et al, 2003; Smith & Smith, 2000). Several studies (e.g. Paterson, Kieloch & Gmiterek, 2001; Serio, Kreutzer & Gervasio, 1995; Smith & Smith, 2000) show that they do not get enough information or support. According to Smith and Smith (2000) they 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 feel that other people, including social and healthcare professionals, lack any understanding of their problems (Backhouse & Rodger, 1999; Swift & Wilson, 2001).

In summary, the literature reveals that when a family member sustains a TBI it has long-lasting consequences for close relatives. They experience various burdens and are in great need of support for a long time. In spite of this knowledge the needs of close relatives are not always met. This might be due to insufficient understanding of the problems relatives face in their daily lives. There seems to be a lack of studies describing the meaning of living with TBI from the perspective of close relatives and within the context of daily life. We believe that this kind of studies increase the understanding of what it means to live with a person with TBI. A better understanding of close relatives' daily lives is fundamental in being able to help them. Thus, the aim of this study was to elucidate the meaning of close relatives' experiences of living with a person with moderate or severe TBI.

Method

As we wanted to elucidate the meaning of experiences we chose a phenomenological hermeneutic method inspired by Ricouer (1976). According to Ricoeur (1976) 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 somebody, people 'point towards the unique thing' they mean (Ricoeur, 1976, p. 16). Fixing an oral discourse in text makes text autonomous and free from its author, context and the audience. The autonomous text says more, and says different things, than the author consciously meant; the text has a surplus of meaning (Ricoeur, 1976).

Participants and Procedure

This study was part of a qualitative inquiry aiming to elucidate the experiences of living with TBI from the perspective of people with TBI (Jumisko, Lexell &

Söderberg, 2005) and their close relatives. We interviewed twelve people with moderate or severe TBI living in northern Sweden and asked permission to send a letter to one of their close relatives with whom they had had a lot of contact during the course of their illness and who could tell us about the experience of living with a person with TBI. One of the people with TBI had no close relatives, thus we contacted eleven close relatives by letter, included information about the study and asked if they were willing to participate. Eight of them sent their written agreement and they were then telephoned by the first author to arrange a time and place for an interview. The participants comprised two mothers, one father, two partners, two siblings and one daughter. They were aged between 28-56 years (md 45 years) and had lived with the person with moderate or severe TBI for 4-13 years (md 8 years). Two lived in the same household as the person with TBI.

Data Collection

The data were collected by qualitative research interviews, which are appropriate for the study of the meaning of peoples' experiences (Kvale, 1997). The participants were interviewed by the first author in their homes. Two interviews took place by a speaker phone because of the long geographic distances involved. An interview guide, with such themes as life before and after the injury, meeting of other people and the care of the close relatives, was used. The interviews started with the request to 'please, tell me about your experiences when X was injured'. In order to encourage responses the interviewer used follow-up questions such as 'what did you think then', 'please, tell me more about that', 'can you give an example'. The interviews lasted approximately 80 minutes and were transcribed verbatim.

Ethical Considerations

All participants gave their informed consent by letter when asked about their interest in participating, and also verbally before starting the interviews. The participants were given a guarantee of confidentiality and anonymity in the presentation of the findings. They were reassured that participation was entirely voluntary and that they could withdraw from the study at any time. After each interview the interviewer 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. The Ethical Committee at University approved the study.

Data Analysis

The interview text was analysed using a phenomenological hermeneutic method inspired by Ricoeur (1976). The interpretation 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 superficial interpretation, the naïve understanding of the text. The second phase is the structural analyses 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 analyses and the literature. This leads to a new, deeper understanding of the phenomena being studied (cf. Ricoeur, 1976).

Findings

Naive Understanding

Close relatives experienced a shock when the family member sustained the TBI, and had many vivid memories of that time. They hovered between hope and despair during the period the person was in a critical condition. Close relatives suffered with the ill person and their well-being and dreams were associated with the well-being of the ill person. They seemed to be confused and sad when they realized how much the person with TBI had changed and they strove to understand and learn to live with the person. Feelings of fear, anxiety, uncertainty, disappointment and fatigue but also of gratitude, pride and pleasure were expressed. Close relatives seemed to gain strength from their love for the afflicted person, from other family members and from support given by other people. They experienced that other people seemed to find it difficult to understand their changed situation. Close relatives seemed to be quite alone in their struggle. They became advocates for the ill person and wanted to do everything to shield and support them. Feelings of anger when other people met the ill person with nonchalance or in a way that was unfair were expressed. It seems that professionals paid insufficient attention to the needs of close relatives.

Structural Analysis

In the structural analysis we divided the interview texts into meaning units, which were a sentence, paragraph or several pages with the same content. 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 meaning. The groups were compared to each other and organized into themes and sub-themes. The structural analysis resulted in one major theme 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 texts.

Fighting not to Lose one's Foothold

The theme 'fighting not to lose one's foothold' was constructed from seven sub-themes; getting into the unknown, becoming acquainted with the changed person, being constantly available, being strong, missing someone to share the burden with, 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 persons' injury was experienced like as a shock and they 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 I heard her leaving home...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 where everything they had considered important earlier had lost its value. Seeing the ill person bloody, bruised and looking like a package was unpleasant and they understood that the situation was serious. All the technical equipment around the ill person was perplexing and it took time to get used to it. Close relatives were at the hospital from early morning to late evening and hardly ate or slept. They were beside the unconscious, ill person and gradually began to take care of her/him; they talked, sang, massaged and watched over the person.

> …and week after week passed… I don't know how I have lived...I went from the patient hotel to the intensive care unit, there and back, but what did I do... I don't know …

Close relatives hovered between hope and despair as the condition of the ill person varied. The uncertainty about the survival of the ill person was experienced as terrible and anxiety-ridden. They 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. Being at the hospital a lot and participating in the care of the ill person helped them to understand the information. In order to be able to stay close to them the relatives reported 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 car. Close relatives expressed gratitude for being allowed to be at the hospital whenever they wanted.

Becoming acquainted with the changed person. After the critical phase, close relatives gradually realized that the ill person had totally changed and were embarrassed about these personality changes. They felt that the ill person was special and had changed in their manner. A cheerful and active person became one who was often depressed and preferred to be alone. The ill person could have no patience and get angry about small things. Close relatives felt that the ill person had lost all feelings of tenderness. Spouses described how their relationship with the ill person became more like that between friends. Parents whose adult child was injured described how they had again got a little child who they should bring up to be an independent adult. The physical changes, such as the ill persons' perpetual fatigue and headaches, were also embarrassing. It was difficult to accept the person's helplessness and close relatives were sorry that they had lost the person they knew before the injury.

> … he 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 person who had changed, especially at the beginning, was like being on a roller coaster. They found it difficult to understand why the ill person changed especially if she/he had no diagnosis of head injury from the beginning. Close relatives struggled to understand the afflicted person and tried to be diplomatic and patient. Their days became unpredictable and they adjusted their life according to the needs of the ill person. They were disappointed because they could not do things together with the ill person as they had planned.

> …sometimes if he had been worse we [the children and me] went away and did something together because it must be... if he needed to rest, a little peace and quiet because of children in this age … they run a lot …

Close relatives described wondering how the person had become ill. Being given explanations, and meeting others involved in the same accident, were a relief and helped them to understand. They did not have information about the illness and searched for it and ways to organize their daily life in order learn to live with the ill person. Finding a way of living with the changed person was hard, time consuming and sometimes it was impossible to continue to live in the same household with them.

Being constantly available. Close relatives experienced that when life changed for the whole family everyone took a more responsibility. Spouses took the whole responsibility for housework and children, siblings took care of the ill person's children and the daughter took the main responsibility for the housework and for younger siblings. They found it difficult to make demands on and trust the ill person who no longer had the same strength as before they were ill.

Close relatives felt that they had an important role as they were constantly on call. If they did not live in the same household as the ill person they visited them regularly. If they were at work they went home at lunch time in order to check that everything was all right. The person with TBI often called them either about something specific or just to talk. Close relatives described how they also functioned as the ill person's extra memory; for example they knew the ill person's bank code. If they were not available they knew that the person became anxious and started to search for them.

> One must go shopping with him and things like that because he doesn't know what to buy...even though you write a list.

Close relatives described how they tried to guide the ill person wisely in order to encourage them to live as normal a life as possible. They were anxious about the future and felt inadequate. Close relatives expressed great sorrow about the ill person's loneliness, wished that she/he had more friends and could find someone to live with and they were unsure if they were doing enough to help the person to find friends or a partner.

> …X:s loneliness is the most difficult thing… it's really hard... …and then you have the feeling that…I'm still…healthy and strong but gradually I'm getting old and perhaps won't have enough strength, what's going to happen then. There's some kind of anxiety about it.

Close relatives' involvement with the ill person changed their relationships with other family members. Those who took care of the ill person's children said that their own children became jealous of the ill person or her/his 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 and a bad conscience. They felt that their privacy was eroded if the ill person lived at home, had a personal assistant or spent a lot of time with them in spite of actually living alone. Despite conflicts close relatives felt their relationships with the ill person and other family members were deepened. Everyone tried to do his or her best in order to facilitate the participant's involvement with the ill person and to support the ill person. It was important to talk to each other a lot within the family and especially when they had no one else to talk to.

> …its the family that had made it possible to manage this…

Being strong. Close relatives described themselves as people who took responsibility for other peoples' well-being, wanted to have control and were not allowed to be weak. They balanced the demands they felt were made on them because they had their work, family and also the ill persons' children to take care for. Being sick-listed for a long time was financially impossible and therefore they worked in spite of constant anxiety about the ill persons' condition. They also tried to be careful so they did not neglect the needs of other family members.

> …I was at the hospital a lot with X [the ill person]…I worked nights…I had my own kids and X [the ill persons' child] who needed a lot of help and the telephone rang every day and people asked how was X…

Close relatives described how it was crucial to be 'pigheaded' in order to manage daily life; once they had decided to support the ill person they would not give up. They felt they must help, not to feel self pity or think about their own needs, because the ill person's life was much worse and seeing her/his suffering was extremely difficult. The ill person was their best friend, a fine person and worthy of their involvement; instead they had to believe in the ill person's improvement.

Close relatives had periods when they felt desperate and depressed. They did not want to burden the ill person by telling her/him about their feelings, but sometimes wanted to break out when everything revolved around the ill person's well-being. Close relatives did not acknowledge their exhaustion and often suffered palpitations and other symptoms of burnout after the ill persons' improvement.

> …when one went to bed in the evenings one was completely done …so if you were allowed to fall asleep in good time…fell asleep very quickly…otherwise you lay awake half the night thinking and then you had a headache in the morning and then lay there with the migraine half the day… it was like a vicious circle…

Missing someone to share the burden with. Close relatives felt that they were rather alone and were disappointed with significant others who were engaged at the beginning, but gradually stopped helping. The opportunity to create new contacts was limited because the afflicted person took so much of their time. Close relatives hoped that significant others would help them by discussing things with them and giving practical help like taking care of the children or the ill person so that they could be away for a while. They wished that significant others offered to help more often because they did not always have the energy to look for help and were also too proud to ask for it.

> …my sister… and my brother…became perhaps a little, if one can say colder …

Close relatives were disappointed with the help they got from social and healthcare personnel. They often had a great need to talk about their experiences but felt that the professionals seldom had time for them or informed them about the opportunities to get support. Having constantly changing home-help service personnel or a personal assistant who did not get on well with the ill person and the family was felt to be an obstacle. Close relatives sought help from, for example, the church or a psychiatrist or just accepted the situation because they had no energy or no idea where to seek help.

> …one 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…

Close relatives expressed bitterness after sacrificing many years to the ill person. Getting more support had helped them to understand, see their situation more clearly and facilitated daily life. Not all participants wanted to talk about their feelings with professionals or with significant others but they appreciated an opportunity to be alone.

Struggling to be met with dignity. Close relatives discovered that significant others found it difficult to understand the ill person because the illness was often invisible.

They protected the ill person from people's curiosity and defended them when they had bad encounters. Conflicts with other relatives about the care of the ill person and their distrust of the participant's ability to carry out the care were experienced as being difficult to cope with. Being questioned or dismissed by their employer when they needed sick listed was insulting. Close relatives did not want other people to pity them; instead they wanted to be met in a kind, honest, open and a natural manner.

It was important to be able to trust the healthcare personnel's knowledge and willingness to do everything to help the ill person. Close relatives felt that the healthcare personnel did not always have enough knowledge about caring for people with brain injuries and they therefore felt insecure. Seeing the ill person treated in a rude manner was frightening. They were especially worried when they realized that the planning for the ill persons' care after the acute phase was inadequate and that there would be no long term follow-up after discharge from the hospital.

> …those different rehabilitation …settings where X [the ill person] has been you can feel that …my experience is that there are actually not so many people who have a lot knowledge about this kind of brain injury…

Close relatives felt that various professionals, such as personnel at the regional social insurance office, local authorities or the insurance company, treated the ill person nonchalantly. This made them feel angry, powerless, sad, frustrated and disappointed. They said that it was impossible to understand why the ill person did not get the help she/he needed. Close relatives felt it was their duty to make demands and speak on behalf of the ill person. They demanded and sought for treatment and rehabilitation adjusted to the needs of the ill person, fixed an appropriate place to live and a financial supervisor for the person.

Close relatives said it was beneficial to have knowledge, authority and courage. They felt professionals treated them with indifference when they fought for the ill person. They described that professionals became inpatient with their questions and opinions, and that they were forced to go to the county administrative court in order to get the help they needed. They expressed fear of the power of the professionals' because they felt they were subject to their control and in a weak position. Being controlled, met with nonchalance and disbelief was frustrating and insulting. They felt that how they themselves were treated was of secondary importance; the most important thing was that the ill person was treated with respect.

> …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 to her…but do what they want…

Seeing a light in the darkness. The contacts between close relatives and 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 cope with the daily life. They felt it was a relief and eased their daily life when the ill person was cared by good personnel and received help adjusted to her/his 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 with a social welfare officer.

> …the physiotherapist …oh what a guy, it's like that I admire …that they engage in, not like with a package but with a person and …I felt he took pleasure, comfort in his work …
>
> …I have talked a lot with social welfare officers…it was good I got you know…understood his [the ill person] situation…before then you didn't know if he rambled or how it was…

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 a future and make new plans. Close relatives were proud of themselves and the ill person because they had managed to cope so well. They said that they had learned a lot about life, appreciated their family more than before and had become more independent and stronger.

> …that 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 responsibility they were not used to or prepared for. Close relatives had to be constantly available to the person with TBI, and had to be strong despite feeling alone and having no one to share the changed situation with. Increased responsibility for the person with TBI changed their 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 never-ending hope for a better future.

The familiar life of the close relatives collapsed and they 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 with the person with TBI entailed great suffering. Eriksson (1993, 1994) argues that in its deepest essence suffering is dying of sorrow for the loss of something important. Suffering also means fighting where feelings of fear and despair are mixed with the willingness to fight for life. Close relatives were willing to do everything they could to support the ill person. They placed their own well-being second because the ill persons' situation was much worse. This can be interpreted to mean that close relatives felt a deep compassion for the ill person. According to Eriksson (1993, 1994), compassion entails sensitivity to another person's pain or suffering and a preparedness to struggle for the other. Compassion presupposes love and the courage to take responsibility and to sacrifice something of oneself. Levinas (1982/1997) argues that seeing the face of the other implies a demand to take care of and responsibility for the other without expecting reciprocity. According to Lögstrup (1956/1992) every encounter between people includes an ethical demand to take care of the other person's life. He described the essence of natural love as a movement towards the other. Close relatives adjusted their life according to the needs of the ill person and wanted to make sure that the person with TBI felt as well as possible because she/he 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 instead of giving up and escaping from the situation. May (1975/1984) argue that entering into the unknown requires the courage to go on in spite of despair. Without courage, love is only a question of dependence on other people. Close relatives talked about feelings of despair but carried on with the fight, this we regard as a sign of courage.

It seems that close relatives struggled to be strong because it was most important for them to be able to support the person with TBI. 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. Lindholm, Rehnsfeldt, Arman and Hamrin (2002) believe that significant others are torn between the suffering of the ill person and their own. Suffering can be experienced as a threat that must be must be 'buried' (Rehnsfeldt & Eriksson, 2004). Close relatives struggled not to show their exhaustion to the ill person but found it important to be able to talk freely with other family members who were also forced to change their lives. Everyone in the family tried to do their best to support the person with TBI and the participant's engagement with her/him. In spite of conflicts, close relatives 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 on. It alleviated the suffering of the close relatives 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 her/his independence. Lögstrup (1956/1992) stated that the ethical demand means that one holds the other person's life in one's hand. This varies from a passing feeling to holding the other person's fate in one's hands. One's unselfishness and understanding of life provide the information about the best way to take care of the other person without taking over her/his independence. In our study close relatives almost had the ill person's fate in their hands but they seemed to have wisdom to be cautious, not to take power from the ill person but instead to support her/his independence.

Close relatives fought to ensure that the person with TBI and they themselves were understood and afforded dignity by other people. They missed people who gave some attention to their changed situation in life and 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) considers that every suffering person has a need to meet someone who can give him or her a feeling of being seen in their unique suffering. Listening and empathising are forms of communication, which make confirmation possible (Nåden & Eriksson, 2000). Råholm, Lindholm and Eriksson (2002) stated that 'it is in dialogue that the deepest suffering can be rendered' and to confirm the suffering human being means to 'communicate closeness and offer time and space'. Feeling abandoned when seeking help produces a feeling of being worthless and increases suffering (Eriksson 1993, 1994; Lindholm & Eriksson, 1993; Råholm, Lindholm & Eriksson, 2002). In this study close relatives felt they were mistrusted and abandoned by significant others who kept their distance or questioned their needs and ability to take care for the ill person. They also had difficulty finding professionals to whom they could talk about their experiences with and thus alleviate their suffering. Close relatives realized that the ill person did not always get the care he/she needed and when they fought for the person they were treated badly by professionals. Difficulties in finding professionals who could help them and not being treated with respect by professionals can be regarded as suffering from 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. In order to be able to alleviate suffering it is essential no to abuse power but instead to supply whatever care the suffering person needs. It is clear that close relatives were forced to struggle to find people who shared an understanding of the challenges they met in their daily lives. 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. According to Lögstrup (1956/1992) other people's attitudes can make one's world 'wide or narrow, light or dark, changing or monotonous, threatening or safe' (pp. 50-51).

Close relatives never lose hope for a better future with the person with TBI. According to Eriksson (1993, 1994) having hope gives the courage to suffer and also alleviates that suffering. Lögstrup (1956/1992) stated that in natural love partners' motives are the same and taking care of each other leads to happiness for all. Giving up the care of the other person torments the remaining one for the rest of her/his life. We suggest that the natural love between the ill person and their close relatives made their motives the same i.e., the ill person's well-being. Close relatives said that seeing the ill person making progress and finding a new way of living increased their hope and seemed to give them strength to continue with the fight. They felt well if the person with TBI felt well, which can be interpreted to mean that taking care of the ill person led to happiness for both the person and their close relatives. Close relatives had moments when they felt bitter after sacrificing so many years to the ill person but above all they seemed to be proud of themselves because they did not give up but managed to cope.

In conclusion, this study suggests that close relatives' willingness to fight for the ill person was based on feelings of natural love and ethical demand. Natural love between close relatives, the ill person and other family members, and 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 to finding people who could alleviate their own suffering. Close relatives' need for help is long lasting and this study showed that professionals do not pay enough attention to the suffering of close relatives which can sometimes be even greater than the ill persons' suffering. It is important that professionals have the courage to admit that close relatives suffer and try to alleviate it (cf. Lindholm & Eriksson, 1993). Listening to the voices of close relatives living with someone with TBI is central in gaining an insight into their world, understanding them on a more profound level and increasing the possibility of providing help that would facilitate their daily lives (cf.

Söderberg, 1999). If we are able to alleviate close relatives' suffering we also alleviate the ill persons' suffering; the close relatives' well-being can be decisive for the ill person's well-being. This study helps other people to become aware of and understand more deeply the experience of close relatives living with a person with moderate or severe TBI. This understanding increases the possibility that close relatives will be treated with dignity and gets more help from other people, including professionals. Research is required in order to obtain more knowledge about close relatives' experiences of nursing interventions that support their fight and alleviate their suffering.

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 sample consisted mostly of women, because most of the people with TBI in this study were men.

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 but we were careful not to let it steer us into a prejudiced interpretation. We were sensitive and open to alternative interpretations, and freely discussed and adjusted 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 in order to help the reader consider whether the findings can be transferred to similar situations (cf. Lincoln & Guba 1985; Guba & Lincoln, 1989).

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