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Living With Moderate or Severe Traumatic Brain Injury

The Meaning of Family Members' Experiences

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

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

Illness occurs within the relational context of family, friendships, and workplaces. Research has shown that chronic illness affects the relationship between the ill person and his or her family system, including both nuclear and extended family members, in various ways (Kuyper & Wester, 1998; Öhman & Söderberg, 2004; Purola, 2000; Söderberg, Strand, Haapala, &

Editor's Note: In the Swedish language, "family members" is translated as "those who stand close"; therefore, the authors of this article have chosen the term "close relatives" to refer to both nuclear and extended family members.

Lundman, 2003). Family members report putting themselves second to provide intensive support to the ill person (Engström & Söderberg, 2004; Öhman & Söderberg, 2004). When the illness is in a critical phase, family members describe that their whole existence is focused on the ill family member (Engström & Söderberg, 2004). Close relatives who live with someone with serious chronic illness feel a circumscribed personal freedom because living with the ill person takes much of their time and energy (Grant & Davis, 1997; Öhman & Söderberg, 2004).

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

Close relatives of people with TBI experience great uncertainty for a long time (Bond, Draeger, Mandleco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002). A review by Degeneffe (2001) found that the feelings of stress and burden among close relatives often do not lessen with time. Sometimes the responsibility for the injured person and the other demands of life are exhausting (Chwalisz & Stark-Wroblewski, 1996; Duff, 2002; Simpson et al., 2000). Literature on family needs supports the importance

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of hope (Carson, 1993; Johnson, 1995; Smith & Smith, 2000) and the need for information, together with the need for emotional and practical support (Bond et al., 2003; Smith & Smith, 2000). Several studies show that families do not get enough information or support (Paterson, Kieloch, & Gmiterek, 2001; Serio, Kreutzer, & Gervasio, 1995; Smith & Smith, 2000). According to Smith and Smith (2000), families experience the health care system as complex and feel that no one takes any responsibility for informing and supporting them, especially when the injured person returns to the community. They also believe that other people, including social and health care professionals, lack any understanding of their problems (Backhouse & Rodger, 1999; Swift & Wilson, 2001).

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

Method

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

Participants and Procedure

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

Data Collection

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

Ethical Considerations

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

Data Analysis

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

Findings

Naïve Understanding

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

Structural Analysis

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

Fighting Not to Lose One's Foothold

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

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

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

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

Close relatives hovered between hope and despair as the condition of the ill person fluctuated. The experience of uncertainty with regard to the survival of the ill person was experienced as terrible and anxiety ridden. The relatives appreciated honest, clear, and continuous information about the condition of the ill person. It was important that bad news was conveyed in a polite manner and without depriving them of hope.

Becoming acquainted with the changed person. Close relatives gradually realized that the ill person had totally changed and were embarrassed about these personality changes. A cheerful and active person became one who was often depressed and preferred to be alone. The ill person lacked patience or lost all feelings of tenderness. Spouses described how their relationship with the ill person became more like that of a friend. Parents whose adult child was injured described how they had regained a little child that they needed to bring up to be an independent adult. The physical changes, such as the ill person's perpetual fatigue and headaches, were also embarrassing. It was difficult to accept the person's helplessness, and close relatives were sorry they had lost the person they knew before the injury.

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

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

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

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

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

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

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

> "[O]ne hasn't had an opportunity to talk to anyone. . . . I think I've missed it, there is no one who listened or asked what you needed. . . ."

Struggling to be met with dignity. Close relatives discovered that it was difficult for significant others to understand the ill person because the illness was invisible. They protected the ill person from people's curiosity and defended him or her following bad encounters. Close relatives felt that health care personnel did not have enough knowledge about caring for people with TBI and therefore felt insecure. They felt that personnel at the regional social insurance office, local authorities, or the insurance company treated the ill person nonchalantly. This made the close relatives feel angry, powerless, sad, and disappointed.

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

> "[T]hey don't listen to us who are close to her and know what she needs . . . they must investigate here and there to see if she needs that help which she is entitled to . . . you must push and shove in order to get this help . . . it's really wrong and . . . outrageous . . . that they don't listen . . . but do what they want. . . ."

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

Seeing the ill person improving and finding a somewhat meaningful way of living increased hope and gave strength. If the ill person felt well, the whole family felt well. They understood that the ill person would never be the same as before the injury, but they were happy to have more good than bad days. In time, they were able to look forward to the future and make new plans. Close relatives were proud of themselves and the ill person because they had managed so well. They had learned a lot about life and had become more independent and strong.

> "[T]hat you see him doing something he thinks for himself, hopes he can do some day . . . then you get strength . . . maybe he will manage something else as well. . . ."

Comprehensive Understanding and Reflections

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

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

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

Close relatives were willing to do everything they could to support the ill person. They placed their own well-being second, because the ill person's situation was much worse. This can be interpreted to mean that close relatives felt a deep compassion for the ill person. Eriksson (1993, 1994) stated that compassion entails sensitivity to another person's pain or suffering and a preparedness to struggle for the other. According to

Lögstrup (1956/1992), every encounter between two people includes an ethical demand to take care of the other person's life. He described the essence of natural love as a movement toward the other. Close relatives adjusted their lives according to the needs of the ill person and wanted to make sure that the person with TBI felt as well as possible because he or she was a person worthy of their involvement. We suggest that this is an expression that close relatives feel a natural love and an ethical demand to take care of, and be responsible for, the person with TBI. Therefore, they had no doubt about taking up the challenge of living with a person with TBI.

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

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

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

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

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

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

Methodological Considerations

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

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

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

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

References

Backhouse, M., & Rodger, S. (1999). The transition from school to employment for young people with acquired brain injury: Parent and student perceptions. *Australian Occupational Therapy Journal, 46,* 99–109.

Benzein, E. (1999). *Traces of hope.* Doctoral dissertation, Umeå University, Sweden.

Benzein, E. G., Saveman, B.-I., & Norberg, A. (2000). The meaning of hope in healthy, nonreligious Swedes. *Western Journal of Nursing Research, 22*(3), 303–319.

Bond, E. A., Draeger, C. R. L., Mandleco, B., & Donnelly, M. (2003). Needs of family members of patients with severe traumatic brain injury. *Critical Care Nurse, 23*(4), 63–72.

Carson, P. (1993). Investing in the comeback: Parents' experience following traumatic brain injury. *Journal of Neuroscience Nursing, 25*(3), 165–173.

Chesla, C. A. (2005). Nursing science and chronic illness: Articulating suffering and possibility in family life. *Journal of Family Nursing, 11*(4), 371–387.

Chwalisz, K., & Stark-Wroblewski, K. (1996). The subjective experiences of spouse caregivers of persons with brain injuries: A qualitative analysis. *Applied Neuropsychology, 3,* 28–40.

Crisholm, J., & Bruce, B. (2001). Unintentional traumatic brain injury in children: The lived experience. *Axon, 23*(1), 12–17.

Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health and Social Work, 26*(4), 257–268.

Duff, D. (2002). Family concerns and responses following a severe traumatic brain injury. *Axon, 24*(2), 14–22.

Engström, Å., & Söderberg, S. (2004). The experiences of partners of critically ill persons in an intensive care unit. *Intensive and Critical Care Nursing, 20,* 299–308.

Eriksson, K. (1993). Lidandets ide [The idea of suffering]. In K. Eriksson (Ed.), *Möten med lidanden* (pp. 1–27, 184–187). Åbo, Sweden: Åbo Akademi.

Eriksson, K. (1994). *Den lidande människan* [The suffering human being]. Arlöw, Sweden: Liber Utbildning.

Florian, V., Katz, S., & Lahav, V. (1989). Impact of traumatic brain damage on family dynamics and functioning: A review. *Brain Injury, 3*(839), 219–233.

Gill, D. J., & Wells, D. L. (2000). Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing, 25*(2), 48–53.

Grant, J. S., & Davis, L. L. (1997). Living with loss: The stroke family caregiver. *Journal of Family Nursing, 1*(1), 36–52.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage.

Johnson, B. P. (1995). One family's experience with head injury: A phenomenological study. *Journal of Neuroscience Nursing, 27*(2), 113–118.

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, 36*(6), 20–28.

Kneafsey, R., & Gawthorpe, D. (2004). Head injury: Long-term consequences for patients and families and implications for nurses. *Journal of Clinical Nursing, 13,* 601–608.

Kuyper, M. B., & Wester, F. (1998). In the shadow: The impact of chronic illness on the patient's partner. *Qualitative Health Research, 8*(2), 237–253.

Kvale, S. (1997). *Den kvalitativa forskningsintervjun* [Interviews]. Lund, Sweden: Studentlitteratur.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lindholm, L., Rehnsfeldt, A., Arman, M., & Hamrin, E. (2002). Significant others' experience of suffering when living with women with breast cancer. *Scandinavian Journal of Caring Sciences, 16,* 248–255.

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences, 18,* 145–153.

Liss, M., & Willer, B. (1990). Traumatic brain injury and marital relationships: A literature review. *International Journal of Rehabilitation Research, 13,* 309–320.

Lögstrup, K. E. (1956/1992). *Det etiska kravet* [The ethical demand]. Göteborg: Bokförlaget Daidalos AB.

Lovasik, D., Kerr, M. E., & Alexander, S. (2001). Traumatic brain injury research: A review of clinical studies. *Critical Care Nursing Quarterly, 23*(4), 24–41.

May, R. (1975/1984). *Modet att skapa* [The courage to create]. Stockholm: Bonniers Grafiska Industrier AB.

Nåden, D., & Eriksson, K. (2000). The phenomenon of confirmation: An aspect of nursing as an art. *International Journal for Human Caring, 4*(3), 23–28.

Nunkoosing, K. (2005). The problems with interviews. *Qualitative Health Research, 15*(5), 698–706.

Öhman, M., & Söderberg, S. (2004). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research, 14*(3), 396–410.

Paterson, B., Kieloch, B., & Gmiterek, J. (2001). “They never told us anything”: Postdischarge instruction for families of persons with brain injuries. *Rehabilitation Nursing, 26*(2), 48–53.

Perlesz, A., Kinsella, G., & Crowe, S. (1999). Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology, 44*(1), 6–35.

Purola, H. (2000). *Kotona asuvan aivoverenkiertohäiriöpotilaan ja hänen omaisensa kokemuksia selviytymisestä* [Experiences of home-dwelling stroke patients and their relatives about coping]. Doctoral dissertation, University of Oulu, Finland.

Rehnsfeldt, A., & Eriksson, K. (2004). The progression of suffering implies alleviated suffering. *Scandinavian Journal of Caring Sciences, 18,* 264–272.

Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning.* Fort Worth, TX: Christian University Press.

Serio, C. D., Kreutzer, J. S., & Gervasio, A. H. (1995). Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation, 10*(2), 32–45.

Simpson, G., Mohr, R., & Redman, A. (2000). Cultural variations in the understanding of traumatic brain injury and brain injury rehabilitation. *Brain Injury, 14*(2), 125–140.

Smith, J. E., & Smith, D. L. (2000). No map, no guide. Family caregivers’ perspectives on their journeys through the system. *Care Management Journals, 2*(1), 27–33.

Söderberg, S. (1999). *Women’s experiences of living with fibromyalgia: Struggling for dignity.* Doctoral dissertation, Umeå University, Sweden.

Söderberg, S., Strand, M., Haapala, M., & Lundman, B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing, 42,* 143–150.

Swifth, T. L., & Wilson, S. L. (2001). Misconceptions about brain injury among the general public and non-expert health professionals: An exploratory study. *Brain Injury, 15*(2), 149–165.

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