Struggling for freedom—lived experiences of being a relative of a stroke survivor in the first six months after hospital discharge

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Abstract
The aim of this study was to illuminate the meaning of being a relative of a stroke survivor in the first six months after hospital discharge. The study is a part of a larger research project focusing on pedagogic strategies for relatives of stroke survivors. Qualitative interviews were performed with nine relatives of stroke survivors. The data were analysed by means of phenomenological hermeneutic analysis. In the analysis two main themes emerged; (1) awareness of the irrevocably altered life situation and (2) being strong in the altered life situation, which revealed that relatives are actively involved in “a struggle for freedom”, as they have no wish to adapt to the illness or its consequences. Instead, they want to choose their own way of life and write their own history. For that reason, they try to integrate the illness and its consequences by influencing and changing the stroke survivor, health professionals and their surroundings to suit their own needs. The results contribute to facilitating the health professionals’ work by showing that the relatives are free and independent human beings who have the capacity and power to create their own history. Focus should be directed towards identifying and supporting the relatives capacity to create history, and therefore, health professionals need to heed them.

Key words: Experiences, relatives, stroke, lifeworld, phenomenological hermeneutical method

Introduction
Stroke is the third leading cause of death and long-term disability in the adult population of the western world (Mackay, Mensah, Mendis & Greenland, 2004). In Sweden, approximately 35,000 people suffer a stroke each year (Riks-stroke, 2006). It is estimated that three out of four Swedish survivors return to their own homes (Socialstyrelsen, 2004) and more than half (60%) are dependent on help from relatives (Widén Holmqvist, von Kock & de Pedro-Duesta, 2000), which findings are consistent with international studies (see Dewey et al., 2002; Teel, Duncan & Min Lai, 2001). In a previous study (Wallengren, Friberg & Segesten, 2008) we found that, during the stroke victim’s hospitalization, relatives reached a “turning point”, where a life situation characterized by chaos turned into a search for order and stability. These findings called for further exploration of the relatives’ life after the survivors’ return to the home.

Research indicates that informal caregivers experience emotional and physical stress as a consequence of caring for survivors. In a literature review of 20 research articles focusing on informal caregivers, Han and Haley (1999) showed a 34 to 52% prevalence of depression, while Berg, Palomäki, Lönnqvist, Lehtihalmes and Kaste (2005) revealed a depression level of 30% (n = 98). Sit, Bong, Clinton, Li and Fong (2004) reported that approximately 40% (n = 102) experienced somatic symptoms such as musculoskeletal pain and headache. Other studies focused on the burden experienced by informal caregivers, and Blake, Lincoln and Clark (2003) as well as Tooth, McKenna, Barnett, Prescott and Murphy (2005) revealed that approximately 40 (n = 116) to 42% (n = 71) reported considerable...
burden. In another study, Scholte op Reimer, de Haan, Rijnders, Limburg and van den Bos (1998) disclosed that burden is a consequence of the heavy responsibility, restrictions on social life and uncertainty related to the survivors' care needs. There has also been extensive research on informal caregivers' roles after the stroke event. In a recent Canadian study (Silva-Smith, 2007), informal caregivers reported the necessity of changing the structure of life, such as the physical home environment, daily routines and social interaction with the survivors. DeLaune and Brown's (2001) study disclosed that female spouses were often obliged to perform traditional male activities and vice versa. Other studies focused on exploring the care provided by an informal caregiver to a survivor. In the study by Smith, Lawrence, Kerr, Langhorn and Lees (2004), informal caregivers reported feeling unprepared, abandoned and experiencing changed relationships as well as difficulty adjusting to their new role. Kerr and Smith (2001) revealed that informal caregivers experienced the home environment as problematic for maintaining the survivor's independence and were dissatisfied with the support provided by social services and general practitioners. Although there are many quantitative as well as qualitative studies about how informal caregivers' health, burden, role and provision of care are affected by the survivor's stroke, less is known about what it means to be a relative of a stroke survivor in the first six months after hospital discharge, irrespective of whether it was their own choice to be an informal caregiver. Therefore, this study investigates experiences of "being a relative of a stroke survivor" as this knowledge might assist professionals to support relatives after the survivor's return to the home.

The investigation

Aim

The aim of the study was to illuminate the meaning of being a relative of a stroke survivor in the first six months after hospital discharge.

Methodological approach

A qualitative approach was selected as the most appropriate for study of the phenomenon of "being a relative of a stroke survivor". A phenomenological hermeneutic approach (Lindseth & Norberg, 2004) inspired by the philosophy of Ricoeur (1976, 1998) was chosen, as it facilitates increased understanding of lived experiences and makes the meaning accessible to others. The phenomenological hermeneutic approach as described by Lindseth and Norberg (2004) involves both phenomenological and hermeneutic dimensions. The former comprises lived experiences of the phenomenon of interest, while the latter concerns the significance of the interpretation with the aim of increasing understanding of a specific phenomenon. The prerequisites for creating knowledge about human experience are that the individual communicates his/her lived experiences and that these are transferred to textual form. Knowledge can be created from these stories by means of a dialectic movement between the whole and the parts, from understanding to explanation and back to understanding as well as from what the text says to what the text talks about (Ricoeur, 1976).

Participants

Participants from an earlier study (Wallengren et al., 2008) were asked if they wished to participate in a follow-up interview. All were identified as a relative by the first time stroke survivor, had approximately six months experience of being a relative of a stroke survivor and they were able to speak and understand Swedish. Four relatives were excluded due to the death of the stroke survivor, two declined participation while one could not be contacted, thus, nine participants remained (Table I). As the two relatives who dropped out were men, there were more women than there were men in the study. We did not include more men, as we wanted to follow the relatives in their first six months after the stroke incident. A time and place for the interview was arranged when the relatives had agreed to participate. To ensure clarity, the interviewed person will be referred to as relative, Table I. Characteristics of the participants (n=9) in the study, who were selected by the stroke survivors.

| Relationship to stroke survivor | 5 |
|---------------------------------|---|
| Spouse                          | 5 |
| Daughter                        | 4 |
| Gender                          | 8 |
| Female                          | 8 |
| Male                            | 1 |
| Mean age (years)                | 63 (range: 47–80) |
| Civil status                    | 5 |
| Married to the stroke survivor  | 5 |
| Married/cohabiting              | 4 |
| Living situation                | 5 |
| Sharing household               | 5 |
| Not sharing household           | 4 |
| Education                       | 2 |
| Primary school                  | 2 |
| Secondary school                | 5 |
| University                      | 2 |
| Socio-economic status           | 5 |
| Retired                         | 5 |
| Employed                        | 2 |
| Unemployed                      | 2 |
the sick person as survivor and the health care professionals caring for the survivor as professionals.

Data collection

Narrative interviews were used in order to capture the experience of “being a relative of a stroke survivor”. The first author interviewed each relative on one occasion in his/her own home six months after the stroke survivor’s discharge from hospital. The interviews were conducted between April 2004 and October 2005. The relatives were invited to narrate, in their own words, what it was like to be a relative of a stroke survivor from the period after discharge from the stroke unit to the day of the interview. Follow-up questions were; “How did you feel then?” and “Tell me more about it?” The interviews were audiotaped, lasted between 30 and 90 min and were transcribed verbatim. Non-verbal expressions such as laughter and pauses were noted in the transcripts (Mishler, 1991; Streubert Speciale & Rinaldi Carpenter, 2003).

Ethical considerations

The relatives were informed about the study both orally and in writing, including the fact that the interview would be audiotaped. Special attention was paid to the relatives’ vulnerable life situation. We asked each of them to choose the time and place for the interview and told them to stop the interview if they became overwhelmed by emotions and that, if necessary, they could obtain emotional support from the first author after the interview. Furthermore, they were assured that their confidentiality would be respected and informed that they could withdraw from the study whenever they wished. Informed consent was also obtained. Approval for the study was granted by the Ethics Committee at Gothenburg University, Gothenburg, Sweden (T445-03).

Data analysis

The texts were analysed by a three-step method developed and presented by Lindseth and Norberg (2004): naïve interpretation, structural analysis and comprehensive understanding. The method is inspired by Ricoeur (1976) and has been used in nursing research by, among others, Rasmussen, Norberg and Sandman (1995), Lindahl, Sandman and Rasmussen (2003) and Wallengren et al. (2008).

Naïve interpretation. Each interview was repeatedly listened to and read as open-mindedly as possible, in order to gain a naïve understanding and a tentative interpretation of what it is like “to be a relative of a stroke survivor” in the first six months after hospital discharge. This first guess is important because it guides and provides ideas for the subsequent analysis (Lindseth & Norberg, 2004).

Structural analysis. In order to gain a deeper understanding of the content of the interviews, the structure of the text was systematically examined. First, narrative categories were analysed and the following were identified: dramatic units, principal characters, temporal ordering and scenes (Ricoeur, 1976, 1998). Second, a thematic analysis began by reading the text sentence by sentence. The text was divided into meaning units by excluding irrelevant words, after which the units were compared between interviews in terms of similarities and differences. Similar condensed meaning units were then abstracted and organized, and themes and sub-themes formulated (Lindseth & Norberg, 2004). An example of the steps used in the thematic analysis to obtain meaning units, condensed meaning units and sub-themes is presented in Table II.

Comprehensive understanding. When the initial naïve interpretation and subsequent structural analysis validated each other, we began to reflect on the text. By weaving the levels of data together, the authors reflected on pre-understanding, initial naïve interpretation and structural analysis. The text was considered as a whole and a more comprehensive interpretation was made to gain a new understanding (Lindseth & Norberg, 2004).

Rigour

In order to establish reliability, we chose participants who had experience of the research subject and a genuine interest in taking part in the interviews (Morse, Barrett, Mayan, Olson & Spiers, 2002). The first author (CW) tried to create a calm and relaxed atmosphere during the interviews, in order to make the relatives feel comfortable about expressing their feelings and experiences. The analysis was principally conducted by CW. CW and the third author (FF), discussed all the steps in the analysis process and the interpretations were scrutinized until consensus was achieved. Validity was established by carefully describing the characteristics of the participants as well as the data collection and analytic process (Streubert Speciale & Rinaldi Carpenter, 2003). According to Lindseth and Norberg (2004), the naïve interpretation is validated by the structural analysis and themes.
Findings

In the descriptions of the themes, the numbered subheadings in italics refers to the main themes, the underlined text to the themes and the text in italics to sub-themes. The numbers in brackets refer to the participants; text in brackets indicates the researcher’s comments while square brackets are used to clarify the language. An ellipsis (…) refers to omitted words or sentences.

Naïve interpretation

Despite their difficult situation, the relatives worked hard and systematically to increase the well-being of themselves and their family. A naïve guess was that relatives were “struggling to keep going”. The naïve guess suggested the direction of the structural analysis.

Structural analysis

The structural analyses seemed to validate the naïve interpretation, indicating that the relatives were “struggling to keep going”. An overview of the main themes, themes and sub-themes is presented in Table III.

1. Awareness of the irrevocably altered life situation

Struggling to maintain integrity

Relatives valued life due to its finiteness, as they were filled with doubt, uncertainty, fear, anxiety and worries as well as feeling unwell due to the realisation that life is finite. They described fearing that the survivor’s health

Table II. Example of meaning units, condensed meaning units and sub-themes grouped under the theme: Living in a public arena, which is one of the four themes that constitute the main theme: Awareness of the irrevocably altered life situation.

| Meaning unit | Condensed meaning unit | Sub-theme |
|--------------|------------------------|-----------|
| For the whole of March, April and most of May there were people here who gave him physical training five days a week. Twice a day, once in the morning and then later on [and] he was supposed to rest for an hour before the next session. For two-and-a-half months. [That] was very, very difficult. I felt like there was no place in the home where I could be alone. | Being deprived of one’s personal space | Living in a glass house |
| We cannot have a meal until it is very late. I also have mild diabetes. Thus I feel the effects of high insulin levels while my husband is sitting on his bed waiting and it’s not good when he has to sit there for ages. It leads to irritation. It sometimes happens that we are not finished until half past ten in the morning. That’s far too late. | Being controlled by others | Being obliged to follow another person’s schedule |
| It has been very tough as I have become somewhat restricted in my daily life. I sometimes think so. | Being restricted in life | Being imprisoned |

Table III. An overview of the main themes, themes and sub-themes, constructed from structural analyses of interviews with the participants (n = 9). The bold and underlined text refers to the main themes, the underlined text to the themes and the text in italics to sub-themes.

| Main themes | Themes | Sub-themes |
|-------------|--------|------------|
| 1. Awareness of the irrevocably altered life situation | Struggling to maintain integrity | Valued life due to its finiteness |
| | | Confronting my weak body |
| | Being circumscribed | Become more watchful and restricted |
| | | A feeling of distance |
| | | Experiencing linguistic limitations |
| | Living in a public arena | Living in a glass house |
| | | Being obliged to follow another person’s schedule |
| | | Being imprisoned |
| | Playing a minor role | Being treated as lacking in competence |
| | | Being unseen |
| 2. Being strong in the altered life situation | Finding solutions for life | Trying to avoid turning over |
| | Reclaiming the home | Declining professional help |
| | | Trying to convince other family members to adapt their home |
| | Guarding one’s life position | Trying to gain the professionals’ attention |
| | | Seeking human attention |
would deteriorate or that death would claim his/her body. The mere thought of him/her being ill again led to feelings of horror. They also described how the time after the survivor’s return home from hospital was filled with reflections about their own and others’ existence. They feared their own ill health or death, as they realised that their absence would mean disaster for the survivor. They also described the importance of other family members and friends and being afraid of losing their support. They were aware that their present life could change if the survivor was unable to remain in the home, which insight resulted in anxiety and uncertainty. The relatives narrated that they were engaged in confronting their weak bodies, as they had developed problems such as stomach pain, high blood pressure, fatigue, physical pain, and sleep disturbance as well as experiencing a lack of strength and energy as a result of the increased demands. The combination of anxiety about the finiteness of life, uncertainty about recovery and their efforts to provide support for their afflicted survivor had a weakening influence on their body. They considered that a weakened body that has reached the limit of its capacity and that is at breaking point is catastrophic, due to their awareness that the possibility for the stricken survivor to have a dignified life is dependent on their presence and strength. A weakened body makes it difficult to uphold the dignity of either oneself or the survivor, and someone who is absent cannot preserve any dignity whatsoever.

It worries me that if something happened to me and we hadn’t reached our goal that she would be unable to make herself understood and thus could not manage without me (5).

Being circumscribed. Many relatives described having become more watchful and restricted by the survivor due to his/her changed and disabled body, greater need of assistance and the fact that he/she exhibited more risk-taking behaviour. They assisted the survivor by using their own body, sensory organs, memory and voice. Being an extension of someone else’s body can be a source of panic, restriction, frustration as well as feelings of being on duty day and night. Other relatives stated that it was difficult and a burden to have to care single-handedly for someone who no longer has the ability to take care of himself/herself. Relatives, especially spouses, were of the opinion that it was hard to look after the house and family without the help of the survivor. Some reported that survivors who were previously sociable, outgoing and active had become passive, indifferent and lacked initiative. When the survivor was introverted and withdrawn, the relative experienced sorrow and a feeling of distance. Other relatives found that the relationship with other family members and close friends was negatively influenced and restricted, as the survivor was only able to socialize to a limited extent. This feeling became still stronger when the survivor was unwilling to integrate with other people due to his/her speech difficulties. Some relatives expressed that this linguistic limitation sometimes led to frustration, irritation, a tense atmosphere and conflict due to difficulty understanding each other.

There are so many things that I can no longer do. I just have to leave them. (Int.: Do you feel that you have lost some of your quality of life?)
Yes, when neither of us have enough strength to manage. It’s as if our lives are nothing but a strange kind of struggle to survive. We can do nothing about it (4).

Living in a public arena. Some relatives, mainly wives, related that at times they perceived their own home environment and private sphere as a public arena. They were living in a glass house. When the house was teeming with home help staff, rehabilitation personnel and community health professionals, they had no private place to which they could retreat in order to gather strength and just exist. They had little opportunity for integrity and privacy, which they experienced as draining, stressful and frustrating. They also perceived that they were less flexible, as they were obliged to follow another person’s schedule and that they could not choose when to eat, get up in the morning or go to bed at night. Other relatives, especially daughters, stated that having the home full of professionals created a sense of security and structure. They found it reassuring to know that there is human contact in the home. They gained strength and were calmer and more peaceful when a professional was present. A number of spouses stated that they felt imprisoned in their joint home, due to the fact that the survivor experienced a better quality of life there. The feeling of being locked up was even stronger due to other family members’ and friends’ homes not being adapted to the ill person’s functional impairments.

I know that one should be thankful for all the help that one receives, but it’s not always possible. For the whole of March, April and most of May there were people here who gave him physical training five days a week. Twice a day, once in the morning and then later on [and] he was supposed to rest for an hour before the next session. For two-and-a-half months. [That] was very, very difficult. I felt as if there was no place in the home where I could
be alone . . . It [was] very difficult to have so many people around. On top of that, the home nursing staff came to clean his catheter. So there were almost always strangers here (4).

Playing a minor role. Many relatives described that professionals treated them as lacking in competence in spite of being the ones who cared for and helped the survivor in his/her everyday life. They felt abandoned and left with a caring task that they were not always able to manage. One wife felt unseen by her husband and experienced not receiving sufficient appreciation from him, which made him appear like a stranger. Others felt that they were invisible to the rest of the family. One spouse stated that, although she had a great deal of contact with her daughter and son, she still felt very isolated. Some relatives considered that their situation was not always understood by other family members and friends, which led to feelings of being let down and abandoned.

Naturally I would have liked to talk to [the professionals] before they sent her home . . . She was not alone for a single night, I was there the whole time. Two days later they sent her home . . . They didn’t speak to me at all . . . They had absolutely no idea how it went . . . Annoying to see those notices everywhere . . . that there would be a follow-up and they will support you, one should be able to pose questions and they should provide supportive conversations. No, there was nothing whatsoever (7).

Finding solutions for life. Relatives became creative and innovative as they were trying to avoid turning over in their altered life. When thoughts about their life situation became overwhelming, they tried to think positively about the future or play with thoughts about the difficult things they had to face. A daughter mentioned that she sometimes thought that her suffering would be relieved by the death of the survivor. They found temporary mental space for positive feelings when they prevented or played with negative thoughts or engaged in positive thinking. Other relatives describe how they worked hard to train the survivor. The idea of working hard was that if they were struck by ill health or death, the survivor would have a better opportunity of continuing to live a good life without their assistance. Those who did not live with the survivor suffered from not knowing his/her present condition. They related that constant visits to the survivor either in person or by neighbours and children as well as regular phone calls prevented worries. One group of relatives reported that they feared having to move. They sanded the pathways, took up the carpets, removed the bathtub, and installed light fittings and an alarm for the cooker. Others described how they took the opportunity to regain energy. Spouses in particular tried to enjoy life when the opportunity arose. They took time to rest, went to bed earlier or went out on their own. Rest and short breaks from caring for the survivor acted as a temporary respite and allowed them to regain lost energy. However, many required a longer break in order to recoup lost energy and took the survivor with them to places where they knew that respite was available. Another way of gaining energy was sharing one’s life with others. A group of relatives narrated that they had to rely on the survivors’ ability if they wanted to visit a cinema or have a cup of coffee with friends. If they needed to get away for a longer period, they arranged a substitute, usually friends or children, to take their place. Some spouses, mainly wives, stated that they had resigned themselves to the restrictions in their life and felt no need to break away. They had actively renounced parts of their life and devoted themselves and their own time to the survivor. Some relatives employed their body and environment to better communicate with and understand survivors struck by aphasia. They created maps, texts and symbols and used body language and gestures to facilitate communication and understanding, thus reducing the level of irritation and misunderstanding.

You can’t be tied [to the survivor] for a long period of time.
(Int.: Have you started to train him?)
Yes, certain things . . . Like things on the table. For example, he can reach for [the milk] and take it but in the beginning he knocked it over and then I had to get down on the floor and wipe it up.
(Int.: Are these small elements of training sufficient to improve your everyday life?) Yes, they are absolutely essential. Otherwise you end up becoming irritated (2).

Reclaiming the home. The relatives strived to achieve security and harmony and reported that it was intolerable to live in a public arena. Some relatives, whose afflicted survivors received professional assistance, reclaimed their home by declining professional help. Other relatives allowed the survivor to recuperate at his/her own pace and declined professional help when they noticed that they were able to manage with only a small amount of assistance. Even if it meant more hard work, the benefit—to reclaim the home—was a more attractive option. They felt that they were able to plan their own time and follow their own tempo to a greater extent, thus
regaining their integrity, autonomy and privacy. In order to compensate for their confinement, some relatives were trying to convince other family members to adapt their home to suit the needs of the survivor, as this would give them a greater opportunity to reduce their sense of isolation.

Friday was the last day that we had the home help service ... I feel it’s best that we manage by ourselves in the mornings, otherwise we can’t plan our time ourselves. It actually affects me most (2).

Guarding one’s life position. Some relatives were trying to gain the professionals’ attention by making their voices heard. Relatives described how they questioned the care and treatment provided to the survivor and they criticized perceived deficiencies in the care. However, some relatives avoided seeking contact with the professionals and preferred to endure the situation, due to the fear of not being allowed to care for the survivor. Instead, they tried to look after themselves by using their common sense. Relatives who experienced not being seen or understood by the survivor or other close family members were seeking human attention. They told their family members how they felt and made them aware of their wish for support and confirmation. Others considered it pointless and opted to remain silent.

I asked to talk to a doctor ... It was something like; I suppose we can sit here on the edge of the bed. Do we have to sit here [among other patients], isn’t there a room we can use? Then I said, you haven’t performed any ECG. Couldn’t it be the heart? No, it was pneumonia. But the pain in his legs, what causes that? I thought that it might be due to poor circulation. No [doctor says], stroke can cause residual pain. Yes, but both his legs are affected yet only one was paralysed. I never received a proper answer to [my queries] (9).

Comprehensive understanding

Our interpretation of “being a relative of a stroke survivor” is that they seem to “struggle for freedom” in everyday life. Two main themes emerged to describe the relatives’ “struggle for freedom:” (1) “awareness of the irrevocably altered life situation” and (2) “being strong in the altered life situation”.

The result of this study was interpreted in the light of the theoretical thinking of the Brazilian pedagogue Paoulo Freire (1970, 1974), which can help us to widen and deepen our understanding of the human as an ontological being. Freire explains that all human beings have the capacity to define their own problems and to develop strategies for solving them. In addition, they have a free will to make their own choices. Human beings create their own history, as the chosen strategies lead to changes in themselves or the reality in which they live, i.e. the world. Freire holds that the capacity to create history is a sign of humanity. Since reality is a product of human strategies, the world is changeable. The human can either adapt to or integrate himself/herself in this changing world. How one adapts or integrates depends on the human being’s level of free will to make choices. If the human being is restricted by himself/herself or others when making choices, he/she will become passive and dependent and can only adapt to the world. According to Freire, he/she will become oppressed and controlled. When a human being loses the ability to create history, he/she also loses some of his/her humanity.

According to the results of this study, the relatives tried to create their own history in their “struggle for freedom”. When they confronted a changed situation such as the perception of living in a public arena, they started to reflect on how they could improve their unpleasant circumstances. They actively searched for different ways of handling the situation, as they wanted to make their own choices. The relatives’ efforts to turn their restricted life situation to one of freedom, living in a public arena to a situation of privacy as well as changing their feelings about being in a minor role can be interpreted as a “struggle for freedom”, as they tried to integrate the changed life situation within themselves and their way of life. In line with Freire, they are “real” humans, as they want to “write” their own history.

Discussion

The aim of this study was to illuminate the meaning of “being a relative of a stroke survivor” in the six first months after hospital discharge. The key finding is that relatives “struggle for freedom” in spite of their distress, as they do not want to adapt to the illness or its consequences. They want to choose their own way of life and write their own history and therefore try to integrate the illness and its consequences to meet their own needs. A previous study (Wallengren et al., 2008) revealed that, during the stroke victim’s hospitalization, the relatives reached a “turning point” where chaos moved towards order and stability. It is clear from the present study that after six months the relatives were still in a similar chaotic situation, as they expressed struggling to maintain integrity, being circumscribed, living in a public arena and playing a minor role. These results are supported by previous research (see Kerr & Smith, 2001; Blake et al., 2003; Sit et al., 2004;
Berg et al., 2005; Tooth et al., 2005). However, our results point to the relatives’ great ability and strength to create and co-create their life situation more clearly than in previous studies. Freire (1970, 1974) argued that human emancipatory power could result in the development of a more democratic and equal society. Thus, Freire’s thinking is multidimensional and can be used and contextualized in different ways. In this study, we especially focused on his reasoning about emancipation, as we believe that the possibilities it offers can help us to widen and deepen our understanding of the meaning of “being a relative of a stroke survivor” in an altered life situation. Freire’s theory has been used in a similar way in nursing by for instance Söderlund (1998) and Öhman (2003). We wish to emphasize that even if relatives have the capacity and strength to write their own history, they are still in need of support from the professionals. The vulnerability inherent in the altered life situation cannot be denied. It is also important to stress that the professionals’ authority is not threatened by strong and capable relatives and that they will always have an advantage when it comes to professional knowledge. Nevertheless, it is important to consider the relatives as experts on the subject of their own life and needs.

However, the relatives in this study also claimed that they had devoted themselves and their own time to the stroke survivor. This result supports the findings by Bäckström and Sundin (2007), who studied the meaning of being a middle-aged close relative of a stroke survivor. They found that relatives sacrificed themselves and disregarded their own needs. In line with the research on informal caregivers of stroke victims (De Laune & Brown, 2001; Silva-Smith, 2007) as well as informal caregivers of patients with other chronic diseases (Lindhardt, Bolmsjö & Rahm Hallberg, 2006; Goldsteen et al., 2007), our result confirms the different roles assumed by relatives. However, in the above-mentioned studies, the informal caregivers assumed different roles because they considered it their duty to take care of the survivor, while in the present study the relative assumed roles as a means to achieve freedom.

Limitations

One limitation of the present study is the eight to one prevalence of female relatives. This occurred because the survivors selected female more often than male relatives as participants and, of the three male relatives selected, two dropped out. However, research indicates that more females than males become caregivers (Henz, 2004), which is in line with social and societal values and traditions in Sweden. The comprehensive understanding of the present study is only one of many possible interpretations (Ricoeur, 1976) but the interpretation presented is the one we found the most meaningful.

Clinical implications

The professionals’ attitudes influence their way of acting towards the relatives. If professionals view the relatives as passive human beings, the risk of treating them as adaptive is greater. In line with Freire (1970, 1974), relatives who adapt have limited opportunity to change and grow as human beings. However, the situation changes if the professionals consider the relatives as active and reflecting subjects with the ability to make their own choices in their altered life situation. In our view, the professionals need to allow the relatives to play a leading role. Focus should be directed towards identifying and supporting the relatives’ capacity to create history as well as their efforts to integrate the illness and its consequences into their own life. In the words of Friberg, Pilhammar Andersson and Bengtsson (2007), professionals should be “following and letting oneself be followed” (p. 537).

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