

Long-term Experiences of Living with Stroke in a Family Context



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'Nobody who takes the hermeneutic problem seriously imagines that we can ever entirely understand the other or know what the other is thinking. More important is the fact that we seek to understand one another at all, and that this is a thoughtful path'.

Hans-Georg Gadamer (1995, p. 276)

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Preface and Pre-understanding

Years ago when I was working as a nurse I met Anne, an old lady suffering from an untreatable abdominal cancer. Anne had experienced a stroke many years ago and due to her aphasia, communication had become difficult. She needed time to convey her meaning and her speech was not easy to understand. I had to talk slowly and choose my words carefully. She was also paralysed and could not move her right arm, her right foot was weakened and her face was lopsided. Anne knew that she only had a short time left and her tears and trembling hands touched me and made me try extra hard to enter into her fragmentary speech to get to know her. I sensed that it was important to Anne to convey her message to me although this was a challenge for her at the very end of her life. She died a few days after being admitted to the ward.

My short encounter with Anne was an experience I never can or will forget. Anne painted a picture for me – a picture of her life after stroke. Most colours were black and grey; there were few rays of sunshine in her life. Anne recounted how she had been overlooked and stigmatised due to her disability. She felt loneliness and yearning to be accepted in spite of her impairments. Anne blamed aphasia for being ignored by healthcare workers when she tried to get help for her increasing abdominal pain. When she finally got attention it was too late. Anne felt that she had been neglected and rejected but I could not sense any bitterness. For me there was a deep meaning in Anne's fumbling words: 'If you want to help other people you have to be patient and take your time listening to them'. This meeting with Anne contributed to my development not only as a professional but, as I see it, also as a human being. This dissertation is the final result of my constructive encounter with Anne. Her lived experience provoked my interest in exploring the life-changing consequences of stroke.

My experiences as a member of a family which has lived through an incurable neurological illness, similar to stroke as it had a devastating influence on bodily functions, have also contributed to my pre-understanding of having a family member whose body function is declining. This took place while I was working on this study. These experiences have influenced my understanding of the interrelatedness of individuals within a family context.

My professional pre-understanding regarding stroke patients stems from working on my master's degree in practical knowledge and my special education as a geriatric nurse. I

conducted two observational studies and three interview studies with stroke patients with aphasia, their spouses and health care workers caring for patients with aphasia. I have not worked directly with stroke patients. I have mainly worked in surgical wards as a nurse and as a ward head nurse. As ward head I gathered rich experience in family nursing as one of my main obligations was to provide information and support for patients' families, especially during critical illness and death. During the last decade I have worked as a nursing teacher and have taught and supervised students working with stroke patients.

As stroke is a common and visible illness in the community my pre-understanding is certainly coloured by occasional encounters with stroke survivors and also by media discourses.

My various experiences have helped me to comprehend some of the complex needs of stroke survivors and people living with neurological diseases and their families. During interviews and observational studies when working on my master's degree I noticed that health professionals often failed to meet these needs in an appropriate manner. I wanted to know more about families' pathways through life in the aftermath of stroke.

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Abstract

Survivors of a major stroke have to live with serious and often lifelong disabilities. Stroke is a family illness as its various consequences affect all areas of life. Spouses have to take on new and demanding roles in addition to grieving the losses. Children show behavioural problems related to their parents' ability to deal with the consequences of stroke.

The overall aim of the study has been to illuminate the long-term lived experience of stroke within a family context. A phenomenological hermeneutic approach inspired by the philosophical concepts of Heidegger, Merleau-Ponty, Gadamer and Ricoeur facilitated interpretations of meaning of lived experience. Thirty-nine narrative interviews with stroke survivors, spouses and adult children who were minors at the onset of their parent's stroke provided descriptions of these families' life-world experiences.

Families were thrown from their familiar being-in-the-world and into transitional experiences called forth by the stroke and its life-changing consequences. Three phenomena manifesting themselves powerfully in these families' life-worlds and sharing threads across the three original papers emerged: firstly, communication; secondly, relationships; thirdly, identity.

Role changes, altered relationships, loss of appreciated activities and loss of independence called for open family communication to deal with these changes. The stroke's devastating effects on families' communication patterns complicated these efforts. Aphasia was perceived as the worst consequence of stroke. Feelings and thoughts remained undisclosed and shared problem solving became difficult. In addition stroke survivors' cognitive disabilities and changes in behaviour complicated communication. These problems created loneliness and distance between the family members. However, by means of its caring and supportive relationships, the family was perceived as a lifebuoy providing motivation and emotional support to go on with life in spite of serious disabilities. Through joining stroke and aphasia support groups, couples adapted more easily to changes and utilised new possibilities. Helping and being helped within family and support groups strengthened perceptions of self. Empathic and caring relationships with health care workers had a positive influence on hope and motivation whilst non-caring and disrespectful actions or premature prognosis were devastating for a couple's hope and well-being.

The meaning of bodily changes after stroke was interpreted as living an unfamiliar body and experiencing altered perceptions of self. The wide-ranging consequences of a stroke for the survivors and their family members forced them to reconsider their perception of self and threatened family identity. Adaptations and efforts to regain familiarity within an altered life-world were interpreted as experiences of transitions. There was a strengthened awareness of being mortal and existential threats surfaced during stroke families' transitions. Worries, fears, experiences of a limited life space and wavering experiences of time were blended with rays of hope for the future. Whilst short-term relationships felt apart, most couples in long-lasting or solidly built relationships experienced strengthened bonds, personal growth and extended boundaries leading to new values in life. These shifts were interpreted as experiences of self-transcendence.

In need of long-term guidance, stroke families missed professional support to help them prepare for the challenges in their post-stroke life. Spouses and children felt abandoned and regretted being left without emotional support and helpful information.

The phenomena in the life-world of long-term stroke families call for action by health care workers. Greater focus on post-stroke communication obstacles including aphasia is needed.

Extreme cautiousness is required when prognoses are revealed early in the stroke trajectory. Supportive actions strengthening all family members' concepts of self will be of great importance. Emotional and practical support that may mediate the existential challenges which arise during these families' transitions may help them to see new possibilities and values in life. More research is needed on parenting and on the situation for children in stroke families. It would seem to be of utmost importance to explore further what actions are needed to provide long-term guidance and support for stroke families.

Key words: stroke; couples; family; communication; relationships; identity; transition; self-transcendence; lived experience; phenomenology; hermeneutics

Norsk Sammendrag

Et slagtilfelle kan føre til et mangfold av alvorlige og sammensatte funksjonshemminger som kan vedvare hele livet. Tidligere forskning har vist at hele familien blir berørt fordi sykdommen har vidtrekkende konsekvenser på alle livets områder. Ektefellen må påta seg nye og krevende roller som kommer i tillegg til sorg over det som har gått tapt. Barn som lever sammen med en slagrammet forelder viser atferdsproblemer som er relatert til hvordan begge foreldre mestrer situasjonen.

Hovedhensikten med denne studien var å belyse livserfaringene til mennesker som lever med langvarige følger etter slag i et familieperspektiv. For å komme nær betydningen av den levde erfaring har studien en fenomenologisk hermeneutisk tilnærming basert på filosofien til Heidegger, Merleau-Ponty, Gadamer og Ricoeur. Datamaterialet baserer seg på tretton narrative intervju med slagrammede, ektefeller/partnere og voksne barn av slagrammede som ser tilbake på sine barneår sammen med en slagrammet forelder. Som følge av hjerneslaget ble familiene kastet ut av den livsverden de var fortrolig med og inn i langvarige og uforutsigbare endringsprosesser som ble fortolket som transisjoner. Det er tre fenomener som gjorde seg sterkt gjeldende i endringsprosessene til disse familiene. Fenomenene som gikk igjen i studien var kommunikasjon, relasjon og identitet.

Hjerneslaget medførte store endringer i rollefordelingen og i familieforhold for øvrig. Omsorgsbyrdene ble til dels store og den slagrammede ble avhengig av familiens hjelp, samtidig som hele familien trengte hjelp utenfra. Mange aktiviteter som familien hadde verdsatt måtte opphøre, noe som etterlot et stort savn. Kognitiv funksjonshemming og atferdsendringer hos den slagrammede var en stor belastning for ektefellen. God kommunikasjon er sett på som en forutsetning for å mestre disse utfordringene, men sykdommen viste seg å ha en negativ innvirkning på kommunikasjonsprosessene i familiene. Afasi ble betraktet som den verste av følgene etter hjerneslaget. Tanker og følelser kunne ikke lenger formidles og det var vanskelig for ektefellene å løse problemer i fellesskap. Det oppstod en distanse mellom familiemedlemmer, noe som ofte førte til ensomhet. Likevel ble familien oppfattet som en livbøye fordi nære og omsorgsfulle familierelasjoner ga støtte og motivasjon til å kunne fortsette med livet til tross for betydelige funksjonshemminger. Å bli medlem i en støtteforening var av stor verdi for å lære å tilpasse seg og gjøre bruk av sine ressurser. Selvbildet ble styrket når ektefellene mottok hjelp og kunne hjelpe andre både innenfor familiens rammer og i støtteforeningene. Empatiske og omsorgsfulle relasjoner med helsearbeidere ga motivasjon og håp mens respektløse eller likegyldige møter og forhastete prognoser virket ødeleggende på livsmotet.

De kroppslige endringene hadde stor betydning for de slagrammede. Deres erfaringer ble tolket som å 'leve en ukjent kropp' hvilket medførte en forandring i selvbildet. Konsekvensene av slaget påvirket ikke bare den slagrammedes identitet. Også andre medlemmer av kjernefamilien måtte revurdere sitt selvbilde og den samlede familieidentitet virket truet. For å kunne orientere seg på nytt i sin livsverden måtte familiene gi seg i kast med langvarige tilpasningsprosesser. Døden som en uunngåelig virkelighet kom nærmere og de ble konfrontert med eksistensielle utfordringer. Deres engstelser og bekymringer, endrede tidsbegreper og begrensninger i livsutfoldelse blandet seg med et spirende håp for en bedre fremtid. De fleste parene som hadde levd i langvarige og velfunderte forhold før slaget inntraff ble knyttet tettere sammen og opplevde personlig vekst og større frihet i forhold til tidligere begrensninger. Tidligere verdier i livet og syn på livet forandret seg. Disse endringene ble tolket som selv- transcendent.

Familiene uttrykte et udekket behov for hjelp til å kunne møte de langvarige utfordringene som ventet dem etter hjerneslaget. Spesielt ektefeller og barn følte at de ble overlatt til seg selv uten tilstrekkelig informasjon og emosjonell støtte fra helsepersonell.

Funnene i studien løfter frem fenomener som gjør seg gjeldende i livsverden til disse familiene og som helsepersonell bør være oppmerksom på. Det er viktig å støtte kommunikasjonsprosessene i disse familiene og legge mer vekt på afasi. Når prognoser skal formidles tidlig i sykdomsforløpet må det utvises stor varsomhet. Intervensjoner som støtter identitet vil være av stor verdi. Familiene trenger hjelp for å beholde nettverk og relasjoner samt viktige roller og aktiviteter. Emosjonell og praktisk støtte kan lindre de eksistensielle utfordringene som kommer til overflaten når familien gjennomgår transisjoner. Dette vil også kunne hjelpe familiene til å utvikle tettere bånd og hjelpe dem å se muligheter og finne frem til nye verdier. Det trengs mer forskning når det gjelder de utfordringer slagrammede blir stilt ovenfor når de skal fylle foreldrerollen. Også barns vilkår i familier som lever med slag er lite belyst. En større forskningsinnsats er påkrevd for å finne frem til langsiktige tiltak som dekker behovene som disse familiene gir uttrykk for.

Søkeord: Hjerneslag; parforhold; familie; kommunikasjon; relasjon; identitet; transisjon, self-transcendens; levd erfaring; fenomenologi; hermeneutikk

Original articles

The thesis is based on the following papers which hereafter will be referred to by their Roman numerals.

- I** Kitzmüller, G., Häggström, T., Asplund, K. Living an unfamiliar body – The significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, Health Care and Philosophy*, published online April 2012: DOI 10.1007/s11019-012-9403y, in press.

- II** Kitzmüller, G., Asplund, K., Häggström, T. (2012) The long-term experience of family life after stroke. *Journal of Neuroscience Nursing*, vol. 44(1).

- III** Kitzmüller, G., Asplund, K., Häggström, T., Gilje, F. The existential meaning of couples' long-term experience of living with stroke. *Illness, Crisis and Loss*, accepted October 2011, in press (2012, vol. 20(4)).

1.0 Background

This thesis focuses on being-in-the-world with reference to living with the long-term consequences of a stroke; this sudden and devastating illness often leads to long-lasting or even permanent life changes. The consequences of the illness affect not only the person hit by the stroke but also those surrounding this person within the family¹ context. The thesis attempts to illuminate the lived experience of stroke as expressed by stroke survivors, spouses and grown up children who recall their childhood experiences of living in a family hit by a stroke.

1.1 Stroke as a disease

To better understand the consequences of stroke for the life-world of stroke families, knowledge about stroke grounded in natural sciences provides an important background. The experience of being a stroke survivor, a caregiver or a child in such a family depends both on the severity of the stroke and on the internal and external resources available.

1.1.1 Pathology of stroke

Stroke, also called a cerebrovascular accident, is caused by the interruption of the blood supply to a person's brain, usually because a blood vessel bursts or is blocked by a clot that cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (Indredavik, 2004). The effects of a stroke depend on which part of the person's brain is injured and how severely it is affected. According to the WHO (2007) International Classification of Diseases and Health Related Problems (ICD10) stroke includes several categories of diagnosis including haemorrhages in different parts of the brain and cerebral infarctions due to occlusion and stenosis of cerebral and precerebral arteries. There is agreement on treating stroke patients in emergency medical services with priority dispatch (Adams, et al., 2007; Indredavik et al. 2010). Rapid neuroimaging by means of Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) is needed to differentiate between haemorrhages and clots, since clots may be treated successfully by means of antithrombotic medications within a time frame of 3-6 hours (Adams, et al., 2007; Indredavik, et al., 2010). Patients with haemorrhages have to be treated immediately, as lack of early, high-quality medical care has a

¹In this study 'family' refers to the nuclear family living together as the participants did in their family groups (mother and father or single parent and children) whereas 'extended family' refers to family members related to the members of the nuclear family (e.g. the parents or siblings of parents).

direct and potent impact on mortality and morbidity (Morgenstern, et al., 2010). There is strong evidence that the likelihood of death and disability in stroke patients within the first year can be significantly reduced through rehabilitation efforts immediately initiated and sustained across the health care continuum (Miller, et al., 2010). Admittance to specialised stroke units also reduces mortality and disability in such patients (Stroke Unit Trialists' Collaboration, 2007; Stevenson, 2005).

1.1.2 Stroke in an international context

According to existing research, 15 million people worldwide are diagnosed with stroke annually and five million of them remain permanently disabled (WHO, 2011). Stroke is the third most common cause of death in developed countries. Worldwide three million women and 2.5 million men die from stroke every year (Towfighi, Ovbiagele, & Saver, 2010; WHO, 2011). Although stroke is more common among men, women become more severely ill (Appelros, Stegmayr, & Terént, 2009; Eriksson et al., 2009). It is supposed that stroke prevalence will increase due to the ageing population in the industrialised countries even though incidence of stroke is declining due to better control of high blood pressure and decreased use of tobacco in these countries (WHO, 2011).

Low and middle-income countries shoulder 80 % of the disease burden but research on stroke appears to be insufficient or lacking in developing countries. A rising incidence is suspected in developing countries as these countries struggle with increasing prevalence of risk factors, especially diabetes (Feigin, 2005).

1.1.3 Stroke in Norway

Stroke is the third most frequent cause of death and the most common cause of disability in Norway (Ellekjær & Selmer, 2007). In 1997 there was an annual incidence rate of 3/1000 which translates into 15 000 new stroke patients every year, of whom 5000 die within the first three months (Ellekjær, 2000; Ellekjær & Indredavik, 1997). Approximately 11 000 first-ever strokes and 3500 recurrent strokes are expected in Norway annually and due to decreased mortality and small changes in incidence, the prevalence rate will increase in the ageing Norwegian population (Ellekjær & Selmer, 2007). Lifestyle factors contribute to the relatively high incidence (Russell, Dahl, & Lund, 2007). The cost to society is estimated at NOK 7-8 billion annually (Fjærtøft & Indredavik, 2007). Norwegian researchers have shown that

treatment of stroke patients in extended stroke units combined with early supported discharge improves functional outcome (Indredavik et al. 2000). National guidelines for treatment and rehabilitation of stroke patients were recently adopted in Norway (Indredavik, et al., 2010).

Approximately 50-60 000 Norwegians live with the consequences of stroke, 2/3 of them with multiple handicaps, e.g. paresis (75-85%), aphasia (20-25%) and cognitive or behaviour disorders (10-50%)(Indredavik, 2004). The body- and life-altering consequences of stroke inflict upon the survivors multiple losses, emotional burdens and life crises all of which clearly influence quality of life and well-being (Eilertsen, Kirkevold, & Björk, 2010; Kirkevold, 2002; Kvigne & Kirkevold, 2003; Kvigne, Kirkevold, & Gjengedal, 2004; Wyller & Kirkevold, 1999). There is scant scientific knowledge of the experience of living with the long-term consequences of stroke as a stroke survivor or a family member in Norway.

1.2 Literature review

Electronic searches were conducted using the following databases: CINAHL, PsycINFO and MedLine. Research papers and reviews from the years 1995-2011, mainly in English, were included. Additional references were sought from the citations of the identified papers. A few older studies were included as these studies were often cited in recent publications and considered as still valuable.

The review showed that the concept 'long-term' was used within a time range from six months to several decades post stroke. Most studies explored participants' experiences and conditions during the first year. It was decided to narrow the inclusion criteria to the same time span as in the current study (>3 years post stroke). Some of these studies had recruited both long-term (>3 years) and short-term stroke survivors or family caregivers and most included both spouses and adult children who were caregivers.

No long-term studies regarding existential issues and the influence of bodily alterations on self after stroke were found, and therefore such studies with a shorter time range (1-2 years) were included. The same decision was made regarding children's experiences and parenting after stroke as very few long-term studies were detected. Additionally three studies dealing with the impact of parental chronic illness (including stroke) on children were reviewed.

1.3 Being a long-term stroke survivor

A severe stroke attack influences a stroke survivor's health, quality of life and well-being. Bodily alterations following stroke threaten identity and seem to have devastating consequences on stroke survivors' social involvement and their sense of being accepted. Approximately one third of stroke survivors experience aphasia. For these stroke survivors communication becomes extremely difficult.

1.3.1 The long-term influence of stroke on stroke survivors' health, health-related quality of life and well-being

Long-term stroke survivors' health-related quality of life is known to be significantly lower than that of controls with regard to physical functioning, general health and role limitations and they are more likely to be dependent in basic activities of daily life (Hackett et al. 2006). The psychosocial and functional disabilities after stroke often have a chronic trajectory and cause severe disruptions to everyday life (Aström, Asplund, & Aström, 1992; Hochstenbach et al., 1996; Liman, et al., 2011; J. H. White, et al., 2007; Wilkinson, et al., 1997). Cognitive impairment is frequent and two thirds of stroke survivors do not recover from their cognitive impairment over the course of three years (Liman, et al., 2011).

Long-term (15-year) outcomes indicate that employment, social relations and leisure activities are affected and less than 40% of stroke survivors evaluate their quality of life to be good (Teasdale & Engberg, 2005). Adaptation to functional disabilities seems to depend on the availability of internal and external resources (Clarke & Black, 2005). If good life satisfaction is restored early after stroke it seems to remain later on (Aström, et al., 1992). However stroke survivors' long-term needs of rehabilitation and psycho-social follow-up services are obvious (Tariah, Hersch, & Ostwald, 2006).

According to Wyller & Kirkevold (1999) stroke survivors' quality of life does not necessarily correspond with the severity of bodily changes but more with how these changes are interpreted and with whether they apply pre-stroke criteria to their present life or utilise new criteria that are in accordance with being a stroke survivor. Fatigue, depression and unemployment are associated with poorer outcome in young stroke survivors' health-related quality of life (Naess, et al., 2006). Overall, depression and anxiety are reported to have a negative impact on stroke survivors' well-being (Aström, et al., 1992; Wilkinson, et al., 1997; Åström, 1996). In a study by Leys, et al. (2002) dependency and breakdown of marital

relationships are reported. Insufficient information and unmet clinical needs in addition to loss of income or increased expenses have a negative influence on stroke survivors' quality of life (McKevitt, et al., 2011).

Results of some long-term follow-up studies indicate that physical function and independence in activities of daily living remain stable (J. H. White, et al., 2007) whilst others reveal a decline in mobility status associated with inactivity, cognitive problems and depression increasing with age (Tuomilehto, et al., 1995; van de Port et al., 2006). Very long-term follow-up studies (>20 years) reveal greater mortality than in age- and sex-matched controls but stroke survivors' cognitive and functional abilities are nearly the same as in control groups (Gresham, et al., 1998) and their health-related quality of life is similar to that of the general population (C. S. Anderson, et al., 2004).

1.3.2 Struggling to maintain social relationships

Multiple losses of cognitive and physical ability combined with changes in personality lead to feelings of a profound loss of self and to social retraction (Murray & Harrison, 2004). This retraction is also caused by the negative feedback of others. The meaning of the disabled body is socially defined as it becomes the focus of the '*social gaze*' (Ellis-Hill, Payne, & Ward, 2000, p.730). Disrupted embodiment and loss of self-confidence have a negative influence on gendered identity and complicate the establishment and maintenance of gendered relationships (Murray & Harrison, 2004). In a study by Stone (2005) younger female stroke survivors experience being unable to meet other peoples' expectations. Feeling that their invisible disabilities are neglected by others leads to withdrawal from social settings, which covers up their disabilities even more.

Stroke survivors struggle to maintain their positions in the family as their family's perception of them as altered differs from their own perception of self (Wyller & Kirkevold, 1999). This discrepancy interferes with stroke survivors' role functioning and interactions within the family. The influence of social support and existing resources seems to be important for how well stroke survivors adapt to changes (Clarke & Black, 2005). Positive processes of meaning transformation after stroke hold the potential to strengthen family relationships and to allow the stroke survivor to feel competent and valued (Kessler et al. 2009).

1.3.3 Aphasia - losing the ability to understand and to be understood

Aphasia compromises language radically and thus makes it difficult to make sense of the impairment both within oneself and towards other people (Parr, 2001). Aphasia means losing the ability to tell about the 'sense of your world' (p. 279). Aphasia sufferers' social life as family members and parts of various networks is also affected (Parr, 2001). Aphasia mirrors itself in other peoples' negative responses, prejudices and stigmatisation, which thus determine the severity of the impact on the disabled person. Stroke survivors living with aphasia are exposed to social exclusion in various settings and these rejections have a deeply negative influence on identity and personhood (Parr, 2007). Young stroke survivors with severe aphasia show lower rates of employment than stroke survivors without aphasia, although many of them recover (Naess, Hammersvik, & Skeie, 2009). Not being able to return to working life lowers aphasic stroke survivors' financial status (Parr, 2001). Living with aphasia also means struggling with a deep anxiety about one's cognitive ability and being unable to make others aware of one's capacity of thinking and understanding (Nyström, 2009).

Dysarthria has a similar impact on stroke survivors' identity as these stroke survivors feel helpless, scared or frustrated and perceive themselves as abnormal or different from what they used to be (Dickson et al., 2008). Findings in this study also show that these stroke survivors retract from social settings and experience disruptions in their family relationships.

1.3.4. The consequences of stroke on body and self

Not being able to maintain intellectual or cognitive pursuits that have been an integral part of one's identity threatens stroke survivors' sense of self and calls for a renegotiation of who they have become after the stroke (Clarke & Black, 2005). The negative impact of stroke on self-esteem and self-concept is strongly associated with stroke survivors' depressive mood (Ellis-Hill & Horn, 2000; Vickery, Sepehri, & Evans, 2008). Due to the consequences of a changed body, a split between self and body is seen during the first post-stroke year (Ellis-Hill, et al., 2000). This split is commonly interpreted as a biographical disruption and a discontinuity of self (Becker, 1993; Ellis-Hill & Horn, 2000; Kaufman, 1988 a ; P. Pound, Gompertz, & Ebrahim, 1998). In addition to disrupted embodiment, the loss of appreciated skills and activities that form an integral part of a person's identity lead to a profound loss of self (Murray & Harrison, 2004). Being able to return to these self-defining activities restores

continuity in life after stroke (Clarke & Black, 2005; Montgomery, Booth, & Hutchinson, 2009).

Stroke survivors face dialectical tensions of discontinuity and continuity, being in control and out of control, and of experiencing one's self simultaneously as different and the same (Secrest & Thomas, 1999). Continuity of self is enhanced by integrating the same core self with new conditions on the physical, social and moral levels of self (Kaufman, 1988a). This process is facilitated by biographical work (Boylstein, Rittman, & Hinojosa, 2007; Faircloth et al., 2004; Häggström, 2004) that calls for the stroke event to be integrated in the biographical flow of stroke survivors' lives (Faircloth et al., 2004). Culture, age, social indicators and previous experiences of health and illness will influence the biographical flow of the lived self and determine how illness experiences are integrated (Faircloth et al., 2004; P. Pound, et al., 1998).

Female stroke survivors' bodily changes dramatically influence their interactions with the world and make them struggle to adapt to their altered roles and relationships (Kvigne, et al., 2004). Unable to fulfil their roles as mothers, wives and caregivers and instead being in need of care themselves forces these women to renegotiate their positions and roles. Kvigne & Kirkevold's (2003) findings indicate that female stroke survivors experience feelings of bodily strangeness as they perceive their bodies as limiting, unpredictable and unintelligible and in constant need of tools and remedies to function. Elderly female stroke survivors' perceptions of their bodies as weak and unreliable change their self-concept (Eilertsen, et al., 2010) and they feel unable to become themselves again due to disability and health decline (Hilton, 2002).

In a study by Lobeck, Thompson, & Shankland (2005) men's sense of self is severely threatened by loss of physical abilities and strength and by their own perception of altered appearance and weakened mental functions. For these men's identity it was important to regain independence and be a useful member of the community. Nevertheless male stroke survivors show significantly higher life continuity scores than women (Secrest & Zeller, 2003).

1.4 Being a long-term stroke survivor's family caregiver²

Long-term family caregiving often means significant lifestyle changes, loss of freedom and personal time and social isolation (P. D. Johnson, 1998). As caregiving interacts with working life, the caregiver also experiences increased financial strain (P. D. Johnson, 1998; Obe-om et al., 2006; Subgranon & Lund, 2000). The traumatic emotional impact of stroke on family caregivers persists after many years and the predominance of the caregiver role displaces other roles and activities leading to a devaluation of the self (Buschenfeld, Morris, & Lockwood, 2009). Constant worries and restraints in social life together with feelings of great responsibility for the stroke survivors' well-being are a heavy burden (Scholte op Reimer et al., 1998). Family caregivers are also concerned about future challenges as carers and these worries come in addition to burdens and alterations of roles which together contribute to a transformation of the relationship with the stroke survivor (Secrest, 2000). Stroke survivors' unmet needs and feelings of emotional distress and loneliness contribute more to caregivers' perceived burdens than the amount of care provided (Scholte op Reimer et al., 1998).

Nearly half of the spouses involved report dissatisfaction with life as their psychosocial functioning is poor and their depressive symptoms increase as time passes (Visser-Meily et al., 2009; Visser-Meily et al., 2008). According to Hartke & King (2002) lack of social involvement is the most difficult problem for long-term caring elderly spouses struggling with depression and loneliness. Poor physical health in caregivers and stroke survivors' cognitive, emotional and behavioural problems render family carers vulnerable to burn-out, with women and younger caregivers being most at risk (van den Heuvel et al., 2001).

According to P. D. Johnson (1998) perceived caregiver burden turns out to depend on the family relationship with the stroke survivor; spousal caregivers show greater satisfaction and less perceived burden than other family caregivers. Female family caregivers identify their most frequent stressors as stroke survivors' dependence, cognitive impairment, behavioural problems, fatigability and lack of social participation (A. Williams 1994; A. M. Williams, 1993). Hostility towards the care receivers is seen (A. M. Williams, 1993) and stroke survivors' cognitive deficits and communication problems contribute most to caregivers' negative feelings (P. D. Johnson, 1998). Due to deficient communication, family caregivers of

² As stated earlier (Section 1.2) most studies include both spouses and other family caregivers (adult children), therefore the term family caregiver was chosen.

stroke survivors living with aphasia must face emotional loneliness on top of their caregiver burdens (Nätterlund, 2010).

Positive consequences of caring have been mainly revealed in transcultural studies on long-term family caregiving after stroke. Family caregiving is seen as an integral and necessary task carried out with love, attachment and spirituality which strengthens family togetherness, cohesiveness and belonging (Pierce, 2001; Subgranon & Lund, 2000). Presence of family members during hospitalisation is seen as self-evident in some cultures and fundamental for surviving stroke (Häggström, 2004). When working together as a communicating and sharing team these families do everything to maintain their family systems (Pierce, 2001). Seeking harmony and reconciliation and receiving kinship and community support helps families to manage their problems (Lee & Mok, 2011; Subgranon & Lund, 2000). Although coping with the hardships of caregiving promotes family strength, the resilience in the family will determine self-development and maintenance of hope (Niyomathai et al., 2010). The longer carers maintain their role the more competent they feel; positive feelings of acceptance emanate and satisfaction with caregiving predominates (P. D. Johnson, 1998). Ethnicity and poverty play an important role in how caring is interpreted and performed (Pierce & Wiklinson, 1999).

1.5 The long-term consequences of stroke on the marital relationship

Although spouses' perceived burdens decrease after the first post-stroke years, their perception of harmony in the relationship and their satisfaction with sex life and social relations also decrease (Visser-Meily, et al., 2008). Male spouses and couples without young children or active coping strategies perceive their relationship to be better than female spouses, who consider caregiving as a duty and a part of their marital obligation (Visser-Meily, et al., 2009). Stroke survivors' loss of memory, depression and withdrawal represent a terrible loss for the marital relationship and often lead to estrangement (Secrest, 2000). According to P. D. Johnson (1998) partners of stroke survivors with cognitive disability experience loneliness and loss of the former companionship in spite of living as a couple. Loss of familiarity and intimacy represent other threats stroke couples must face (Buschenfeld, et al., 2009). Sometimes disabled husbands control their spouses' lives and limit their autonomy (Cecil, et al., 2011).

Stroke survivors are well aware of the stroke's negative impact on their marital relationship (H. S. Thompson & Ryan, 2009). They admit that their altered physical appearance, fatigue and uncontrollable emotions like irritability, anger, intolerance and anxiety have a negative influence on their relationships with their spouses. They perceive the physical alterations, dependence and loss of libido as a change from a marital relationship into a patient-carer relationship. Not being able to fulfil their roles and meet their partners' expectations call forth feelings of guilt and worthlessness and spousal overprotection and loss of physical intimacy add to their burden. Stroke survivors are distressed by being a burden to their spouses and show higher levels of self-perceived burden than care receivers with other illnesses, especially if they perceive low participation in family roles or feel socially disconnected (McPherson et al., 2010).

S.E. Williams (1993) found that aphasia has a negative influence on marital satisfaction. Spouses in long-term relationships with aphasic partners show a significantly greater number of negative attitudes toward their partners than members of a healthy control group (Zraick & Boone, 1991). Overprotection is seen in couples with aphasia and seems to occur more often if the stroke survivor has severe motor disabilities in addition (Croteau & Le Dorze, 2006). According to Croteau & Le Dorze (1999) female spouses of aphasic stroke survivors act in a more overprotective manner than wives of stroke survivors without aphasia. In a study by Zraick & Bone (1991) spouses perceived their disabled partners to be demanding, temperamental, nervous and confused. Aphasic stroke survivors' spouses appear to be more depressed than spouses of stroke survivors without aphasia (Zak, 1999).

Stroke couples experience stronger connection and congruence through sharing more domestic interests than before and the loss of their social network ties them together (Secrest, 2000). Dysarthria may bring partners closer together as the healthy partner supports the disabled partner's communication (Dickson, et al., 2008). An interrelatedness of stroke couples' occupational life strengthens their experience of we-ness (van Nes, Runge, & Jonsson, 2009).

1.6 The consequences of stroke on the parent-child relationship

1.6.1 From the parents' perspective

Mothers with stroke describe fatigue as an obstacle to being committed to their children's needs (Röding et al., 2003). The fathers in the same study revalue their fatherhood due to lost strength and increased vulnerability, but they also experience having more time for their children. Stroke survivors' concerns about childcare are a considerable source of anxiety and conflicts are seen between the disabled parent and the children (Teasell, McRae, & Finestone, 2000). The negative influence of aphasia and dysarthria seems to be substantial as these conditions weaken the sense of identity as a parent (Dickson et al., 2008; Parr, 2001). These parents experience insufficiency in being an emotional supporter, advisor or corrector and sometimes they feel incapable of bonding with their young children or stimulating their language development (Dickson, et al., 2008).

Healthy parents struggle with taking over the roles of the sick parent (Drummond et al., 2007) and they worry about the stroke's consequences for the children's relationship with the sick parent (Banks & Pearson, 2004; Nätterlund, 2010). Healthy parents conceal their emotions to spare their children and they try to combine their caregiver obligations with their parental obligations as well they can (Banks & Pearson, 2004).

1.6.2 From the children's perspective

Stroke survivors' children are exposed to long-term stress related to the depressions of both the disabled and the healthy parent and also to the perceived quality of the parents' marital relationship (Sieh, Meijer & Visser-Meily, 2010). Half of the children involved (aged 4-18 years) have clinical or subclinical problems from the beginning of their stroke parent's rehabilitation period and one third of the children still have problems one year later (Visser-Meily, et al., 2005). Only half of these children receive support from rehabilitation teams. Behavioural problems like withdrawal, somatic complaints, anxiety, depression and aggression are seen in one third of children aged 10-21 years, three years after stroke onset and almost two thirds of children involved assist their stroke parent in self care and mobility (van de Port, Visser-Meily, Post, & Lindeman, 2007). Children's achievements at school and their time together with friends are most affected by their caregiving obligations (Lackey & Gates, 2001). As they are afraid of being separated from their parents they do not complain about their huge responsibilities that steal their childhood (Metzing-Blau & Schnepf, 2008).

The consequences of being a child caregiver may also be positive, such as feeling more mature and needed and being proud of dealing with responsibilities (Lackey & Gates, 2001;

Metzing-Blau & Schnepf, 2008; van de Port, et al., 2007). Although caregiver obligations may knit children more closely and strongly to their families, changes in family dynamics and the experience of crisis, lack of knowledge and increased responsibility add to their tensions (Lackey & Gates, 2001).

A devastating effect on the parent-child relationship may be caused by aphasia as insufficient communication hinders adjustment and renegotiation of needs and emotions, creating distance in the parent-child relationship (Hallé, Duhamel, & Le Dorze, 2011; Harlow & Murray, 2001; Le Dorze, Tremblay, & Croteau, 2009).

Confronted with a parent's chronic physical illness children experience multiple stressors such as changes in parental self-esteem and personality traits, role changes and fear for the future (Barkmann et al., 2007). These children show higher risks of psychosocial maladjustment, which declines for boys but increases for girls during puberty. Girls also show significantly higher stress scores than boys (Sieh et al., 2010).

Adolescent and adult children in stroke families experience transitions and transformations in the relationship with the sick parent which cause considerable emotional strain (Fraser, 1999; Harlow & Murray, 2001; Le Dorze, Tremblay, & Croteau, 2009).

1.7 The existential meaning of stroke

Facing a stroke embraces the whole of the individual's being and gives rise to existential questions (Nilsson, Jansson, & Norberg, 1997). Stroke survivors face the existential threats of loss, distortion, fear and entrapment which have a permanent influence on life (Kaufman, 1988b). Stroke as an existential turning point raises crisis phenomena like emptiness, anxiety, discontinuity and despair (Nilsson, Jansson, & Norberg, 1999), Nevertheless such a crisis heightens the awareness of what really matters and calls for a redefinition of life (Eilertsen, et al., 2010). Facing aphasia increases existential loneliness that extends to all domains in life, disrupting identity and creating distance to other people (Nyström, 2006).

The maintenance of hope seems to be crucial for stroke survivors' well-being. According to Cross & Schneider (2010) stroke survivors are able to maintain their hope for future improvement many years after the stroke if they experience progress and support and are determined to keep a positive attitude. Elderly stroke survivors describe their hope as an inner

strength and a forward moving process requiring determination and effort (Bays, 2001). Bays found that goal achievement and family and spiritual connectedness are important factors in the hope-related patterns of these elderly people.

According to Lindquist & Dahlberg (2002) and Pierce (1994) stroke survivors' family members experience similar existential concerns such as anxiety, doubt, loneliness and uncertainty about the future. High levels of anxiety which remain high during the first months after a stroke are seen in both stroke survivors (De Wit, et al., 2008; Åström, 1996) and their caregivers (Greenwood & Mackenzie, 2010).

1.8 Rationale for the doctoral thesis

Family members have acquired a more important role as carers in Western countries as nowadays stroke survivors are discharged earlier than before and most of their rehabilitation process takes place in their homes (Palmer et al. 2004). More people experience a stroke due to ageing populations and people are living longer with the consequences of stroke due to better health care (WHO, 2011). Furthermore, the number of younger stroke patients still at the child-rearing stage may increase due to a higher incidence of lifestyle-related factors (Ferro, Massaro, & Mas, 2010; Putaala, et al., 2009). Reviews of family research on stroke reveal few investigations of stroke families (Evans et al., 1994; Palmer & Glass, 2003). Therefore there is an urgent need for further research in this field.

Searches updated in 2012 show that there is still very little knowledge about the long-term consequences of a stroke on family life. It therefore appears necessary to explore further the existential meaning of a stroke in a long-term perspective. The influence of bodily changes on self seems to have been sparsely explored and limited to females. More should be revealed about parenting and the parent-child relationship in stroke families. Knowledge of family life, identity and existential issues are important for health care workers who are supporting the rehabilitation efforts of families living with stroke.

Only the people who actually 'live' their illness or live with it in a family context are able to convey the meaning of these experiences. This insight is important when trying to understand ill people and their families within their life contexts and social relationships. Physiological knowledge and categorisation of diseases are necessary to optimise treatment but human

beings may easily be objectified if such an approach is the one and only basis for health care workers. Research into lived illness experiences may therefore add to health care workers' empathic understanding and expertise.

2.0 Aims

The overall aim of this thesis was to illuminate the long-term lived experience of stroke within a family context.

The research question of the thesis is:

What is the meaning of the phenomena revealed in the long-term lived experience of stroke survivors and their families?

The aim in Paper I was to illuminate the meaning of the long-term influence of bodily changes on the perception of self after stroke.

The aim in Paper II was to illuminate the long-term experience of family life after stroke of survivors, their spouses and children, particularly regarding marital and parent-child relationships.

The aim in Paper III was to uncover the existential meaning of couples' long-term experience of living with stroke.

3.0 Philosophical and theoretical framework

'Life-world' and 'lived experience' are key concepts in this thesis allowing access to phenomenology and hermeneutics, which are used as the philosophical foundation.

3.1 Life-world and lived experience

'Life-world' ('Lebenswelt') stems from Husserl, the founder of modern phenomenology (Bengtsson, 2006). Husserl saw life-world as the 'pre-given' world of 'immediate experience' (Husserl in van Manen, 1997, p.182)³ and maintained that our 'intentionality' is always directed towards the things and events which have meaning to us in our world (Dahlberg, Dahlberg, & Nyström, 2008, p. 47). With Heidegger, ontology and hermeneutics entered phenomenology (van Manen, 1997) and he transformed Husserl's term 'Lebenswelt'/'life-world' into 'Dasein'/'being-in-the-world' (Bengtsson, 2001; Heidegger, 1953/2001). This term refers to human interconnectedness with the world, which can be understood and investigated through 'concern' for various tasks or actions (Heidegger, 1953/2001), not through pure consciousness as claimed by Husserl (1958). As being is closely interwoven with 'having a world', human understanding will always be grounded in understanding the world (Heidegger, 1953/2001 p.52, 61, 152). Therefore Heidegger, in contrast to Husserl, maintained that our 'forestructures' (pre-understandings) cannot be ignored or bracketed but have to be seen as our foundational structure of understanding (McConnell-Henry, Chapman, & Francis, 2009).

According to Heidegger (2006, p.67) being a mortal human being means to dwell, cherish, protect and care. It also means being caught up in meaningful activities by using appropriate tools and being involved with concern with other beings and things ('Zeug'). Heidegger (1953/2001) emphasises temporality as a basic premise for this relationship between human beings and the world, as humans are always heading for future possibilities of 'becoming'.

Life-world and body are closely connected in Merleau-Ponty's (2002, p.167) existential phenomenology. He perceived the body as the 'anchorage' in the world (p.167) or the 'vehicle of being in the world' (p.94). Introducing the term 'être au monde', which may be translated as 'being in touch with the world' (Merleau-Ponty, 1994, p.vii), he highlights a

³ In the thesis the number of pages is included in the references not only with direct citations but also when indirect citations are close to the original text.

tight bond between human beings and the visible world. Merleau-Ponty (2002, p.xviii-xix) claims that we do not think the world but we live the world, are open to it and communicate with it through our senses.

The term 'lived experience' can be seen as a continuation of the term 'life-world' as all experiences take place in our life-world as our lived world. Lived experience involves our immediate, pre-reflective consciousness of life, a reflexive awareness that is unaware of itself (Dilthey in van Manen, 1997) and comes forth by actions, narrations and texts that convey meaning (Lindseth & Norberg, 2004). According to van Manen (1997, p.37) lived experience gathers hermeneutic significance as we are able to reflect on it and give memory to it. Therefore lived experience can be seen as an appropriate starting point for phenomenological hermeneutical research approaches (Bengtsson, 2006; Dahlberg, et al., 2008; Lindseth & Norberg, 2004; van Manen, 1997).

3.2 How to interpret phenomena of the life-world

Life-world has to be understood within the context of phenomenology as a philosophy. The term 'phenomenon' derives from Greek, meaning 'something that shows itself, or appears' (Heidegger, 1953/2001, p.28). The core theme of phenomenological investigations is to discover the essential meaning of a phenomenon, its 'essence', e.g. what makes the chair a chair (Lindseth & Norberg, 2004, p.146). Phenomena cannot appear unless they appear for someone. Being situated in living relations and shared situations, the phenomenological researcher is obliged to explore the actual category of lived experience in *all* its facets (van Manen, 1997). This endeavour requires interpretive researchers to take a critical stance to their pre-understanding to remain open for new insights (Gadamer, 1960/1990, p.271). Researching lived experience means investigating not only the aspects of the phenomenon that manifest themselves but also those parts that tend to be obscure (Heidegger, 1953/2001, p.36; van Manen, 1997).

Gadamer (1960/1990) states that the first hermeneutic condition of understanding is that something evokes one's interest (p.304). Thereafter one has to put into play one's pre-understanding and prejudices that may lead to misunderstandings; this means evoking and questioning one's prejudices (p.304).

Understanding and interpretation are seen as implicit processes of the life-world which cannot be captured by scientific methods alone but are dependent on the researcher's imagination and hermeneutical sense when addressing research questions (Gadamer (1960/1990, 1967). Tradition prefigures understanding and interpretation and is therefore always contextual, mediated by shared history, culture and language (Gadamer, 1995; Geanellos, 2000). Gadamer (1960/1990) sees the circular movement of understanding as the 'interplay of the movement of tradition and the movement of the interpreter' and as such the hermeneutic circle 'describes an element of the ontological structure of understanding' (p.298-299). An experience (Erlebnis) is something standing out from the continuity of life, which at the same time has to be understood within the wholeness of this continuity (p.75). According to Gadamer (p.364-365) understanding the other is a specific experience as the other is not an object but relates himself to the objects of the world in the same way as the 'understanding' subject does. To remain open to 'otherness' is the precondition of understanding other subjects (p.304). Acknowledging the other as someone who has something to tell is also a moral obligation and may facilitate balance in human relationships (p.365).

Ricoeur's (1976) interpretation theory adds the aspect of explanation to Gadamer's (1960/1990) hermeneutics of understanding. According to Ricoeur (1976), both understanding and explanation have their place within the hermeneutic circle and therefore the interpreter should have both a subjective and an objective approach to the text. Explaining a text means showing that a certain interpretation is more probable in the light of what we know; it is giving scientific knowledge to the text although it does not mean that one's conclusion is 'true' (p.78-79). Ricoeur describes the hermeneutic function of 'distanciation' that is applied when spoken language becomes fixated as a written text (p.25-44). According to Ricoeur texts should be freed from the author's intention and their original context to become available for new interpretation and meaning (p.30, p.92). Through the dialectical movement between understanding and explanation the initial step of distanciation is followed by appropriation of the formerly 'foreign' text (p.91). Ricoeur introduces the guess as the first step of understanding the meaning of a text (p.75). This initial guess has to be followed by the structural analysis which is a truth procedure representing the explanatory part of the interpretation (p.78-79). Guess and validation are both parts of the hermeneutic circle as subjective and objective approaches to the text, mediating between the parts and the whole and vice versa (p.79). Ricoeur's interpretation theory opens for alternative interpretations of a text but he underlines that the most probable interpretations amongst the text's limited fields

of possible constructions should be sought (p.79). In the final act of comprehending readers make the objectified text their own. The whole act of interpretation may be seen as an expedition from what a text says to what it speaks about: a direction of thought that is opened up by the existential force of the text (p.92).

3.3 Existence and meaning permeate the life-world

According to Merleau-Ponty (2001, p.298; 2002, p.vii) '*phenomenology is also a philosophy that puts essences back into existence*' and by existence he means '*the movement through which man is in the world and involves himself in a physical and social situation which then becomes his point of view on the world*'. Heidegger (1953/2001) called the structures typical of existence 'existentials' and in his existential analysis he explores these structures, such as hope, fear and concern. Merleau-Ponty (2002) perceived existentials as fundamental themes that run through the life-world of human beings like threads, examples being lived body, lived time, lived space and lived coexistence.

The research question in this thesis was: *What is the meaning of the phenomena revealed in the long-term lived experience of stroke survivors and their families?* Merleau-Ponty's and Heidegger's⁴ (1953/2001) existential phenomenology have been useful to arrive at a deeper meaning of illness experiences for the stroke survivor as an individual (I) and for stroke survivors, spouses and children within a family context (II, III). Ricoeur's (2001, p.296) statement about existential phenomenology explains why this philosophy may contribute to an understanding of the deeper meaning of being: '*...existential phenomenology makes the transition between transcendental phenomenology, born of the reduction of every thing to its appearing to me, and ontology, which restores the question of the sense of being for all that is said to 'exist'.*'

3.4 Phenomenology of self

Zahavi's (2000, 2005) and Gadamer's (1982) ideas were found useful in understanding and elaborating the concept of an embodied self.

3.4.1 Zahavi's notion of self

⁴ Neither Heidegger nor Merleau-Ponty called their philosophy '*existential phenomenology*' and Heidegger distanced himself from existentialism but described his work as an '*analytic of existence*'. The term '*existential phenomenology*' came into widespread use by their successors as Heidegger's and Merleau-Ponty's work hold many similarities (Wrathall & Dreyfus, 2006, p.31).

Drawing mainly on Husserl's phenomenological thoughts on consciousness and self, Zahavi (2000) claims that the core self or basic sense of self is linked to the 'first-person givenness' of experiential life. To be a self is to be acquainted with an experience from within, in the modality of what the experience is like, which constitutes the 'myselfness' of the experience (p.64). This subjectivity of experience retains the first-personal mode of givenness of an experience, self-awareness and egocentricity. Perceptual experience is only given to the subject and is not accessible to others (p.60-61). As a subject I am able to reflect both on the experience itself and to be aware of myself having the experience, in the sense of how it is experienced by me (p.56). I can also reflect about myself as the one who is thinking and acting. Additionally I am able to examine my actual self-awareness of the experience, i.e. how it feels having the experience. As a self my self-awareness bridges the gap between temporal distances and my memory allows me to recall past experiences as mine. Zahavi (2005) points to body awareness as the foundation of self-experience (p.202). Such awareness is seen as a given awareness that is a pre-linguistic form of self experience (p.204). As self, embodiment, inter-subjectivity and world are interrelated, the embodiment of our selves opens up to inter-subjectivity.

3.4.2 Gadow's phenomenological dialectic of body and self

According to Gadow (1982, p.86) our body and self are inseparable but not identical, as in terms of consciousness our body is still the other. Gadow's phenomenological quest aims at explicating four levels in a dialectical progression of relations between body and consciousness/self. The first level, called 'primary immediacy' (p.86), is my lived body experiences, my actions as me and my vulnerability in being exposed to and acted upon by the world. On the second level, 'disrupted immediacy', my body is experienced as the concrete otherness of the self when its incapacity is experienced by the self, i.e. when the body is unable to act as desired (p.90). Here body and self are in opposition to each other and the body is perceived as an object similar to other objects and at the same time as a part of the self. The experience of the objectified body facilitates a new reunion of body and self at the third level 'cultivated immediacy', characterised by harmony between the lived body and the object body, through the mastery of incapacities and limitations. On the fourth level, called 'aesthetic immediacy', a self-body unity is achieved by allowing the subject body to claim its own rights as it emerges in illness and ageing. The subject body is a part of the self that explores, gives meaning, aims at and values. The subject body is accepted by the self as one of the manifestations of self and the other parts of the self must learn to understand the body's

symbols. This new kind of interaction between the subject body as a part of self is crucial in illness and ageing where the body moves into the foreground of consciousness and expresses itself. In these cases the subject body claims its rights to awareness and consideration and gives meaning to human existence.

3.5 Hermeneutics of self

Ricoeur (2002) conceived self as a narrated self that constantly interprets its surroundings, abandoning itself to find itself through dialoguing with other selves and with texts. Human lives are readable as stories people tell about them and are more intelligible when narrative models of plots are applied (Ricoeur, 1992, p.114). Personal identity can only be expressed in the temporal dimension of human existence. Time becomes human time only when expressed narratively (Ricoeur, 1984, p.3). Ricoeur's (1992, p.16) theory of narrative identity discloses the dialectic of identity as sameness (*idem*) and selfhood (*ipse*). Sameness contains numerical identities (one and the same), qualitative identity (extreme resemblance) and uninterrupted continuity in the development of the 'same' individual, a kind of permanence in time. Selfhood maintains the individual's character as given by distinctive signs and dispositions that permeate in time and by which the person recognises himself and by which he is recognised by others as the one he 'is' (p.121). What matters to a person depends upon self-concern, which is constitutive of selfhood (p.137). Selfhood also encompasses an ethical dimension of 'keeping one's word', holding firm to the trust others place in a person's faithfulness (p.168). Narrative identity allows us to integrate diversity, variability, discontinuity and instability with permanence in time; these are features that seem to be its contrary in the domain of sameness-identity (p.140).

3.6 Family life course developmental framework

Definitions of the term 'family' have changed in accordance with the life cycle patterns of families (Carter & McGoldrick, 1999). Seccombe & Warner (in Chibucos, Leite, & Weis, 2005, p.9) provide a modern definition of the family: '*... a relationship by blood, marriage or affection, in which members may cooperate economically, may care for any children and may consider their identity to be intimately connected to the larger group*'.

The family life course developmental framework includes both family life course theory, individual life span theory and family development theory (White & Klein, 2008). Life course

refers to *'age-related life patterns imbedded in social structures and cultures that are subject to historical change'* (Elder in Chibucos, et al., 2005, p.11).

Family life course theory is the only theory so far developed to understand families; it aims to explain changes in families over time and to interpret the consequences of these changes on the whole family group (Chibucos, et al., 2005). Its purpose is to explain how the group adjusts, functions and conceives itself. Family is not only seen as a summation of its parts but as a dynamic organism where the group and the individuals influence each other and vice versa. There is thus an assumption that a life-threatening and disabling illness in one family member will influence the lives of all family members because their lives are linked together in one unit (Elder in Chibucos et al., 2005). The family's life cycle defines how families pass through their lives (e.g. marriage, child rearing stages, children leaving home, old age). Individuals' life cycles describe age-related biological and behavioural changes from birth to death (Chibucos, et al., 2005, p.11). The individual life cycles of all family members continually intersect with the whole family's life cycle and individual needs and preferences may conflict with the best interest of the family as a whole (McGoldrick & Carter, 1999). The definition of 'family' varies between cultures, as does the timing of life cycle phases and tasks and ceremonies that mark important transitions (Moore Hines et al., 1999). A family shares a common history and its relationships, boundaries, roles and psychological distances between members change as the family moves through time (Carter & McGoldrick, 1999).

According to White & Klein (2008) family development is defined by the norms of social systems as they change with time and within the same culture. These norms comprise roles that differ according to ethnicity and society. The family is affected by institutional norms along with the characteristics of its members and their inter-relationship. Individual choices and experiences affect the family as a whole. Family members may construct and change their rules, norms and social roles; this may in the long run lead to societal changes and altered societal norms. Timing of family events is related to the normative expectations of the social system and the event's timing may be as important as the event itself (e.g. a person at the child-rearing stage having a stroke). The chronological movement from one stage to another in a family's development is related to the age of family members and is marked by transitions (e.g. marriage, adolescents leaving home). Familial interactions differ according to the family developmental stages.

4.0 Methods

4.1 Researching lived experience - applying research methods within the philosophical framework

Using phenomenology as a philosophical framework for scientific studies' authors is not a straightforward process as a 'translation' into methods is needed. Researching lived experience called for suitable interview methods. A narrative interview method was chosen to obtain rich descriptions of participants' experiences of stroke and to reveal the implications of the illness for their life and family context (Lindseth & Norberg, 2004; Sandelowski, 1991,1994). In narrative interviews both the teller and the listener take part in the narrated experience and the researcher tries to get through to the meaning of the phenomenon to be investigated (Lindseth & Norberg, 2004).

Sharing the same horizon of history, tradition and language with all except one of the participants prepared the ground for being able to understand their life-world (cf. Gadamer, 1960/1990). Nevertheless my pre-understanding had to be questioned in order to understand the otherness of the participants' life-world (cf. Gadamer 1960/1990). To see this 'otherness' it was also necessary to keep a critical eye on prejudices concealed in research traditions and in the research background for this particular field.

During the interviews, Gadamer's (1960/1990; 1999) understanding of genuine dialogues was important to reach a new understanding as a result of the dialogue partners' melting horizons. Gadamer (1960/1990) emphasises the importance of the question to enhance understanding. Knowing that we do not know others' life-world prepares the ground for asking questions and listening to their life-world experiences with openness and humility. After the texts were transcribed the hermeneutical inquiry to search for the essential meaning of the text began. According to Lindseth and Norberg (2004) essential meanings lead us to lived truth and connect us to the ontological level of the life-world.

Different analytical procedures were chosen in Papers I, II and III in keeping with the three different aims and the different threads of the philosophical frameworks. It was supposed that this choice would facilitate a more thorough illumination of participants' lived experience and if possible reveal phenomena which stood out in their long-term experience of living with stroke. Interpretation was guided by Gadamer's (1960/1990) and Heidegger's (1953/2001)

principles of being reflective about the interpreters' forestructures in order to enter the hermeneutic circle correctly. The iterative movement between the parts and the whole grounded in the understanding of Ricoeur's (1976) interpretation theory was essential throughout the analytical procedures. Heidegger's (1953/2001) and Merleau-Ponty's (2002) philosophical concepts were helpful in making visible the existential and bodily groundedness of the life-world.

Reflecting on these concepts made it easier to grasp the interrelatedness of the illness experiences and the existentials in the participants' life-worlds, e.g. lived body, lived time, hope, fear and the experience of human finitude. The writing process was inspired by van Manen's (1997) and Lindseth and Norberg's (2004) ideas about phenomenological hermeneutical writing; here it is important to reveal the essence of lived experience and explore its meaning by using language reflectively in a way that emanates from the lived experiences.

4.2 The study

The study was conducted with a total of 42 participants (23 stroke survivors, 17 spouses and 2 adult children of stroke survivors who were minors at the onset of a parent's stroke).

Table 1. Overview of papers

Participants	Data collection	Method of interpretation	Philosophical underpinning
<i>Paper I:</i>			
<i>Living an unfamiliar body – The meaning of bodily changes' long-term influence on the perception of self after stroke</i>			
<i>n</i> = 23 all stroke survivors	Narrative interviews	Phenomenological hermeneutics based on Ricoeur's interpretation theory (Lindseth & Norberg, 2004)	Phenomenology (Merleau-Ponty, 2002) and interpretation theory (Ricoeur, 1976)
<i>Paper II : The long term experience of family life after stroke</i>			
<i>n</i> = 40 22 stroke survivors 16 spouses 2 adult children, minors at a parent's stroke onset	Narrative interviews	Phenomenological hermeneutics inspired by Fleming, Gaidys & Robb's (2003) analysis based on Gadamer's (1960/1990) hermeneutical principles and van Manen's (1997) approach to phenomenological themes	Hermeneutics (Gadamer, 1960/1990) and Phenomenology of lived experience (van Manen, 1997)

<i>Paper III: The existential meaning of couples' long-term experience of living with stroke</i>			
<i>n</i> = 40 23 stroke survivors 17 spouses	Narrative interviews	Interpretive phenomenology inspired by Benner (1985, 1994) and Benner & Wrubel's (1989) approach based on Heideggerian (1953/2001) phenomenology	Heideggerian (1953/2001) phenomenology and hermeneutics

4.2.1 Research setting and recruitment

The research was performed in rural and urban areas in six different counties in Southern, Central and Northern Norway. The data collection took place during 2009-2010. With one exception, a spouse from a non-Western country, all participants were ethnic Norwegians who had lived in Norway since they were born. The stroke survivors were recruited by leaders of local branches of the Norwegian Stroke and Aphasia Organisation and by leaders of home care nursing. These leaders were asked to undertake a sampling of stroke survivors using the following inclusion criteria: a minimum of three years post-stroke with disabling conditions, over 16 years of age, living at home, cognitively able to give informed consent and able to communicate in Norwegian.

The leaders were asked to recruit stroke survivors who had various illness experiences, different ages and who lived in a variety of social and family settings. The leaders were also asked to provide information on how many stroke survivors had been asked to participate but failed to do so.

Stroke survivors were asked to recruit spouses using the same criteria. The spouses must have lived with the stroke survivor for a minimum of three years after onset. Fourteen stroke survivors who still lived in couple relationships at time of interview recruited their spouses. One of the non-participating spouses refused due to his state of health. It is unknown whether the other spouses refused to participate or were not asked. Additionally, three spouses with severely disabled husbands who could not participate themselves were recruited. Participant recruitment was concluded when meanings emerging from the interview texts became redundant. Participating stroke survivors and spouses were asked to recruit their adult children with the following criteria: age below 16 at stroke onset and living with the stroke-affected parent for at least three years after onset. Four children matching the criteria were asked to participate and two agreed.

4.2.2 Participants

The sample consisted of a total of 42 participants (Table 2). There were no withdrawals during the study.

Table 2. Overview of the participants

	Stroke survivors n=23	Spouses n=17	Adult children (minors at onset) n=2
Gender	14 men 9 women	4 men 13 women	Characteristics withheld for ethical reasons
Age (at onset) (y)	30-40: <i>n</i> = 4 41-50: <i>n</i> = 6 51-60: <i>n</i> = 9 61-70: <i>n</i> = 4	30-40: <i>n</i> = 1 41-50: <i>n</i> = 7 51-60: <i>n</i> = 8 61-70: <i>n</i> = 1	
Time since onset (y)	3-5: <i>n</i> = 6 6-10: <i>n</i> = 11 11-15: <i>n</i> = 3 21-25: <i>n</i> = 3	3-5: <i>n</i> = 4 6-10: <i>n</i> = 8 11-15: <i>n</i> = 2 21-25: <i>n</i> = 3	
Family relationships			
Duration of marriage at time of interview (y)	<10: <i>n</i> = 1 10-30: <i>n</i> = 6 31-50: <i>n</i> = 11 > 50: <i>n</i> = 3		
Cohabitants (< 5 y) at time of interview (y)	<i>n</i> = 1 (at onset: <i>n</i> = 3)		
Steady relationship (< 5 y) at time of interview	<i>n</i> = 0 (at onset: <i>n</i> = 2)		
Families with minors at onset (<16 y)	<i>n</i> = 2		
Families with adult children at onset	<i>n</i> = 13		
Single mothers with minors (at onset)	<i>n</i> = 2		
Residual disabilities (stroke survivors)			
Paresis: <i>n</i> = 21 (dependent on sticks <i>n</i> = 9, of which dependent on wheelchairs outdoors <i>n</i> = 3; Aphasia: <i>n</i> = 11 (all with paresis); Neglect: <i>n</i> = 2; Emotional lability (self-reported): <i>n</i> = 8; Cognitive impairment (self-reported) <i>n</i> = 12, e.g. loss of memory, reduced ability to concentrate or orientate; Fatigue (self-reported): <i>n</i> = 5, Epilepsy: <i>n</i> = 6; Partial loss of eyesight: <i>n</i> = 2, Dependent on other people's help in Activities of Daily Living: <i>n</i> = 9. Several stroke survivors had generally recovered from decreased sensibility and apraxia			
Working status (stroke survivors)			
Full time employment before the stroke: <i>n</i> = 17			
Full time employment after stroke: <i>n</i> = 1			
Part time employment(<25%) after stroke: <i>n</i> = 5			

4.2.3 Interviews

The data collection (I-III) consisted of 39 narrative interviews (c.f. Lindseth & Norberg, 2004; Sandelowski, 1991, 1994). Seventeen were held individually with stroke survivors, eleven with spouses and two with adult children of stroke survivors who were minors at the onset of their parent's stroke. Six interviews were couple interviews because the stroke survivors preferred not to be interviewed alone mainly due to aphasia. After the couple interviews three spouses were interviewed individually. The interviewer commonly asked follow-up questions to elicit further and more nuanced descriptions of participants' experiences, to avoid misunderstandings due to participants' aphasia and to challenge premature interpretations coloured by the researcher's pre-understanding. Not all participants were able to provide rich narrations as some of the eleven stroke survivors with aphasia still had difficulty in verbalising reflections on their experiences. In these interviews more specific questions had to be asked, preparing the ground for shorter answers from participants with aphasia (cf. Philpin, Jordan, & Warring, 2005). In the couple interviews with participants with aphasia the spouses were ready to provide rich narrations both on behalf of their disabled spouse and of their own account. Mostly the stroke survivors expressed agreement with the spouses' narrations with words or nods. The interviewer was attentive to and documented expressions of disagreement and encouraged stroke survivors to express their own opinion.

The interviews started with an introduction of the interviewer and a short repetition of the study's aim and participants' rights. Participants were encouraged to ask questions about the study. Before responding to the broader questions aiming at narrative answers, participants were asked to provide personal information and data regarding the illness. They were invited into a dialogical conversation to convey further and more nuanced descriptions regarding the aims of the three studies (family life, couple relationship, parent-child relationship; the existential meaning of the illness, the meaning of living with bodily changes and the influence of these changes on self).

Interviews were conducted in participants' homes ($n=36$) or in hotel rooms (3). Each interview lasted between 60 and 210 minutes. Interviews were held in Norwegian, audio-recorded and transcribed verbatim by the first author. Pauses and various emotional expressions were documented in the transcripts. In addition the interviewer documented 'silent' data that were considered important, such as facial expressions, gestures and actions, in field notes during the interview (cf. Sandelowski, 1991). These field notes were considered during data analysis as part of the context of the text (cf. Mackey, 2005).

4.2.4 Data analysis and Interpretation

In Paper I only the stroke survivor's interview texts were analyzed. In Paper II all interview texts were analyzed (except for the interview texts of a spouse from a non-Western culture and a stroke survivor who were recruited later on). In Paper III all interview texts except for those of the adult children were analyzed.

Phenomenological hermeneutic interpretation inspired by Ricoeur (I)

The analysis in Paper I was guided by Lindseth & Norberg's (2004) phenomenological hermeneutics, inspired by Ricoeur's (1976) interpretation theory. This method aims at understanding meanings by interpreting transcriptions of narrative interviews and is commonly used in health sciences to illuminate lived illness experiences (M. Eriksson & Svedlund, 2006; Ervik, Nordøy, & Asplund, 2010; Haggström, Axelsson, & Norberg, 1994; Olsson, Skär, & Söderberg, 2010). The analysis was conducted in three steps following Lindseth and Norberg's (2004) suggestions.

Initially the text was read several times to gain an overall understanding of the meaning of the text. This first naïve understanding was written down and guided the next step, called the structural analysis (cf. Lindseth & Norberg, 2004). The texts were then broken down into meaning units of sentences or paragraphs which were condensed and compared across the texts. Similar meaning units were clustered and abstracted to themes and subthemes. Finally the naïve understanding was challenged by the results of the structural analysis. There was a reiterative process that made it necessary to return to the original texts and to refine the structural analysis and reformulate the naïve understanding until it was confirmed by the structural analysis (cf. Fagerberg & Norberg, 2009). This endeavour was also necessary to confront researchers' pre-understandings and to allow meanings embedded in the text to come forth.

During the third step, the comprehensive understanding, the themes and subthemes were reflected on in relation to the aim of the study. The interview texts were re-read and interpreted as a whole with the naïve understanding, the results of the structural analysis and researchers' pre-understanding in mind (cf. Lindseth & Norberg, 2004). By studying literature that contributed to the authors' understanding and through critical discussions of the findings the researchers tried to broaden their awareness of the meaning of the findings. The attempt to

achieve creative formulations that might open up for the reader's comprehensive understanding is an important task when using this method (cf. Lindseth & Norberg, 2004).

A Gadamerian-based interpretation (II)

The analysis in Paper II was guided by suggestions for Gadamerian hermeneutical analysis described by Fleming, Gaidys & Robb (2003) and van Manen's (1997) approach to phenomenological themes. Van Manen (1997, p.87-88) characterises phenomenological themes as a form of capturing the phenomenon one tries to understand by an open process of insightful invention, discovery and disclosure. There is the means to arrive at the notion and make sense of something but will always remain a reduction of that notion. According to van Manen, it is essential to be reflective, open to experience and sensitive to language in order to grasp the essential meaning of a phenomenon.

Gadamerian (1960/1990, 1967) hermeneutics emphasise the importance of questioning, experience, openness and reflection on pre-understandings (Binding & Tapp, 2008; Debesay, et al., 2008; Fleming, et al., 2003; Laverty, 2003). Using the hermeneutic circle as explained by Gadamer (1960/1990), moving back and forth between the parts and the whole of the text, is an important approach to gain understanding and to ensure sound interpretations (Annells, 1996; Fleming, et al., 2003). Gadamerian (1960/1990) hermeneutics have been used in qualitative studies by Bradley (2007), Fruiterman (2006), Stabell and Lindström (2003) and Tapp (2004).

Initially, all texts were read several times to gain an understanding of the text as a whole, which was written down. A written understanding of each interview text was formulated, confronted with the researchers' pre-understandings (Geanellos, 1998b) and held against the understanding of the text as a whole. The next step was to screen the texts for expressions of lived experiences which could illuminate the phenomenon. These expressions were condensed and clustered into four phenomenological themes (cf. van Manen, 1997). Finally, the themes were confronted with researchers' pre-understandings and compared with the understanding of the text as a whole again. Contextual notes were included to expand the meaning of the parts and to confirm the themes. Suitable quotes that illustrated different angles of the phenomenon 'family life after stroke' were selected to enhance readers' understanding.

A Heideggerian-based interpretation (III)

Benner's (1985, 1994) and Benner & Wrubel's (1989) approach to hermeneutic analysis, based on Heideggerian (1953/2001) interpretive phenomenology guided the analysis in Paper III. Benner (1985) describes three tenets of Heideggerian phenomenology: the self-interpretiveness of human beings as a constitutive element of the self, the person taking a stand on his or her own personhood and the meanings available to the individual as predetermined by language, culture and history. In addition temporality and concern are important features of Heideggerian phenomenology that hallmark Benner's (1994) approach. Paradigmatic cases and exemplars from interview texts help the researcher to look for important patterns of meaning and global characteristics across the whole text (Benner, 1985). This initial step facilitated further exploration of the text during the thematic analysis in order to arrive at themes and eventually subthemes. In Benner's (1994) approach member check is recommended to strengthen the findings. Methods inspired by Heideggerian (1953/2001) concepts have guided numerous studies on health and illness experiences and caring (Chesla, 1994; Kondora, 1993; Parsons-Suhl et al., 2008; Reed, 1994).

The entire text was read once again with the aim of Paper III in mind. Outstanding cases and exemplars were marked and scrutinised, and these helped the researchers to look for an existential meaning of being a stroke survivor and a spouse. This procedure facilitated finding patterns and themes when analyzing the whole text. Next a reflective reading-writing process started by writing summaries of the interview texts and posing questions as to their meanings. The next step was a thematic analysis, where parts of the texts related to the aim of the study were condensed, clustered and interpreted into themes. The first step of interpretation was close to the text while the second one aimed at a deeper level of interpretation.

According to Benner and Wrubel (1989, p.408) a constitutive pattern is a situation or concern that gives style to a participant's way of being-in-the-world. When comparing themes a constitutive pattern grounded in the themes was revealed, seen as the highest level of analysis. Member check (cf. Benner, 1994) was performed by discussing the themes and the constitutive pattern with four participants (two stroke survivors and two spouses) and a non-participating speech therapist who had worked with stroke survivors individually and in group therapy for many years. Their feedback was used to confirm the themes and to refine the final summary of the analyses.

4.2.5 Ethical considerations

The Regional Committee for Research Ethics for Northern Norway (P REK NORD 55/2008) and the Norwegian Social Science Data Services granted approval for this study. The research procedures were carried out according to the guidelines of the following institutions: Den nasjonale forskningsetiske komité for samfunnsvitenskap og humaniora [The National Committee for Research Ethics in the Social Sciences and the Humanities], 2006; Kunnskapsdepartementet [The Ministry of Education and Research], 2007 and the overall ethical principles of the Helsinki Declaration (World Medical Association, 2000).

Walker (2007) underlines the need for close adherence to ethical standards in phenomenological research as gaining access to participants' lived experience might easily intrude upon their private spheres. All participants gave their written informed consent to participate. There was no contact between the researcher and the participants before consent was given. Mediators who recruited the included participants were not informed about the participants' choice as to participation. Persons who received the informed consent letter were told that their decision would not be conveyed to the mediators. Participants were informed about their rights to withdraw without giving any explanation. Information about the study and the participant's rights were repeated at the start of each interview. This was important as some of the participants with aphasia had difficulty in comprehending written information.

Before starting the interviews the researcher made an effort to ensure the participants' cognitive ability to participate. Although the dramatic event that had changed participants' lives happened many years ago ($M=10$), it was essential to bear in mind that they were still vulnerable. According to Kirkevold & Bergland (2007) researchers have an ethical obligation to include frail and vulnerable participants in their studies to make their 'silent voices' heard. Participants were informed that sharing their experiences could evoke emotional distress and told where they could seek support if needed. Powerful expressions of emotion came forth during the interviews. Participants were encouraged to ask for the interviewer's help to seek such support if needed. None of them did so. The interviewer tried to end the interviews by gradually bringing the participant back to a more everyday communication setting by talking about common interests and daily life.

The interviewer made an effort to conduct the interviews in a cautious manner and tried to avoid misleading the participants to convey experiences they may later regret having recalled

(cf. Foss & Ellefsen, 2004). Being observant to participants' body language and other expressions of distress, the researcher was able to support participants by helping them to talk about their reactions or by suggesting a break in the interview. Using adjusted communication strategies to help participants to convey their thoughts and give them sufficient time to do so were important in these interviews. At the same time the interviewer avoided exposing participants' disabilities unnecessarily in order to protect their integrity and autonomy; this is of great importance in the case of participants living with cognitive disabilities (cf. Kirkevold & Bergland, 2007).

Another ethical challenge was to protect the adult children participants from being recognised as there were only two of them. Therefore most of their demographic information was withheld.

5.0 Main findings

The findings will be presented across the three articles to meet the overall aim of the study, which is to illuminate the long-term lived experience of stroke within a family context. An effort has been made to summarise the three different perspectives with the found meanings of living in a family context as a stroke survivor, a couple and a parent or child. An overview of the main findings is presented in Table 3.

Table 3. Overview of the main findings in Papers I-III

Aims	Themes
<p style="text-align: center;">Paper I</p> <p>To illuminate the meaning of bodily changes' long-term influence on the perception of self after stroke</p>	<p style="text-align: center;">1 main theme, 3 themes, 4 subthemes</p> <p>Main theme: Living with an altered perception of self Theme: Living a fragile body <i>Subthemes: Living a discomforting and vulnerable body</i> <i>Living a body in need of support</i> Theme: Living in increased attention to bodily functions Theme: Living a body that is 'not me' <i>Subthemes: Living a strange and unreliable body</i> <i>Living a body rejected by others</i></p>
<p style="text-align: center;">Paper II</p> <p>To illuminate stroke survivors', spouses' and children's long-term experience of family life after stroke, particularly regarding marital and parent-child relationships</p>	<p style="text-align: center;">4 themes</p> <ul style="list-style-type: none"> • The family as a lifebuoy (the essentiality of family support) • Absent presence (parent-child relationship) • Broken foundations (marital challenges) • Finding a new marital path (dealing with the changes)
<p style="text-align: center;">Paper III</p> <p>To uncover the existential meaning of couples' long-term experience of living with stroke</p>	<p style="text-align: center;">5 themes and 1 constitutive pattern</p> <p>Constitutive pattern: Struggling to adapt to an abruptly twisted and unfamiliar being-in-the-world Themes:</p> <ul style="list-style-type: none"> • Thrownness from the familiar being-in-the-world • Struggling to grasp rays of hope • Fear of dying, living and caring • Wavering experiences of time • Reinterpreting the life-world

5.1 The long-term experience of being a stroke survivor (I, II, III)

The force of the stroke was a strong and vivid memory to persist with, representing a break from stroke survivors' familiar being in the world as a healthy and independent person. Communication problems due to aphasia still complicated stroke survivors' lives and contributed to depressive reactions. These stroke survivors could no longer convey their life and illness stories on their own. Many of them were still dependent on devices to support their gait function and some were dependent on the help of other people, mainly their spouses, in their activities of daily living. Stroke survivors were reluctant to use the wheelchairs they had been provided with when leaving hospital and they exercised even harder to avoid using them.

Cognitive and emotional impairment were common and stroke survivors depended firmly on their families' support to endure these challenges. The stroke-ridden body was perceived as discomforting and vulnerable and in need of increased attention in order to perform. Being constantly alert to bodily functions consumed a huge amount of time and energy as did the attempts to speak and read if struggling with aphasia. The discomforting sensations of pain and fatigue strongly influenced many stroke survivors' well-being. Spasticity, epileptic seizures, emotional instability and other kinds of impairments intensified the feeling of living an unreliable body. Losing control over motor functions and sensations called forth feelings of estrangement and detachment as impaired body parts were perceived as 'not me'. Most stroke survivors became cautious in their way of living as they feared a second stroke or a fall.

Being deprived of using their language or other cognitive abilities gave rise to feelings of worthlessness and incompetence, which often led to withdrawal from social settings. Negative reactions towards their own non-cooperative body were enforced when they were stigmatised, rejected or ignored by others. Being dependent on others' help and on technical devices represented a loss of independence and self confidence. Not being able to meet the healthy spouses' expectations and being incapable of doing housework or odd jobs in the house had a negative impact on self-esteem.

The loss of bodily functions was strongly interconnected with the loss of important roles, social positions and networks. Gender roles that could no longer be maintained seemed to have a profound impact on the stroke survivor's self-esteem. Cognitive impairment was perceived as a threat to 'normality' and interfered strongly with a positive concept of self as

did loss of working life, especially for stroke survivors who were well educated and had held important positions.

Female stroke survivors' self-confidence suffered if the stroke had influenced negatively on their appearances. Sometimes the negative consequences of stroke were so devastating that the stroke survivor had a perception of not being the same persons any longer. Still grieving their losses, stroke survivors gradually learned to accept their disabilities and to integrate them into their self-concept. Their self-concept was supported if they managed to maintain or improve their bodily functions. Trying to continue with pre-stroke activities and helping others by joining peer associations had a positive influence on the sense of self. Through comparing themselves with peers, stroke survivors increased their empathic capacity and arrived at new perspectives on their own condition. The stroke survivors' interpretations of their self-concept depended on their former illness experiences, the extent of their life crisis and their stage of life. Health care workers' support was perceived as essential; by contrast their actions could have a negative effect on stroke survivors' perception of self if they acted in a discouraging, indiscreet or non-empathic manner.

5.2 The long-term experience of living with stroke in a family context (II, III)

Findings in Papers II and III revealed stroke families' experiences regarding couple and parent-child relationships. The findings concerning the parent-child relationship derived from the analysis of interviews with six parents whose children were minors at stroke onset, twenty-six parents who had adult children at onset and two adult children who were minors at the onset of stroke.

Couples considered aphasia to be the worst consequence of stroke as it was a hindrance to conveying thoughts and feelings and created emotional distance between spouses. Communication was perceived as extremely time-consuming and frustrating. Aphasia seemed to interfere strongly with couples' social activities because friends and acquaintances retracted. Stroke survivors' fear of being stigmatised by other people added to their withdrawal and made spouses struggle even harder to maintain an already shrinking network.

These couples could not share their reactions on the consequences of stroke and misunderstandings and conflicts arose. Even though most spouses supported their ill partner's independence, some female spouses were overprotective and limited aphasic stroke survivors'

possibilities to express themselves. Dealing with aphasia made couples realise that they had to develop new communication strategies. Aphasia deepened the gap between parents and children and sometimes caused withdrawal and anger in the child and despair in the ill parent.

Families also had to deal with other threats to communication. Both stroke survivors and spouses tended to hide their frustration and emotions in front of their partners. Healthy spouses' despair about their partners' cognitive and behavioural changes were disclosed only in individual interviews. There had also been negligible communication between parents and children about the illness and its consequences. Parents thought that their children did not want to talk about the event while one of the children's interview texts revealed an urgent need of someone to talk to at that time.

Stroke survivors' rehabilitation outcomes were facilitated by spouses who acted as nurses, physical therapists and loving and emotionally supporting partners. The healthy spouses' daily help and their ongoing search for the best treatment prevented institutionalisation. Stroke survivors considered spouses' supportive actions to be crucial and felt tremendous gratitude towards them. Nevertheless they regretted the huge responsibility and workload imposed on their spouses. To relieve spouses' burdens, stroke survivors gave up their own leisure activities or rehabilitation efforts that required help by the healthy spouses. Being a parent during the acute stage provided strong motivation to go on with life and to do one's best to recover. For most families with young children the support from other members of the extended family became crucial.

Although the family was commonly perceived as a lifebuoy, exceptions were seen. Living with a non-supportive spouse was profoundly disappointing for the stroke survivor. Healthy parents who did not receive support from their adult children felt disappointed and left alone with caregiving duties. In their experience, their adult children found it difficult to accept that the ill parent was not as before and some of the children denied the situation.

Sometimes stroke survivors' gratitude towards the healthy spouse was overshadowed by irritation and anger when they suffered from their own shortcomings and dependency or if the spouse acted on their behalf although they did not feel the need for help. The paradox of struggling for independence in their marriage and at the same time being dependent on the spouse was problematic for stroke survivors.

Suddenly becoming the spouse of a stroke survivor constituted a shift from a familiar to an unfamiliar sense of self. Caregiving around the clock was exhausting and gave rise to uncertainty and fear as to whether one would be able to provide the help needed in addition to other roles such as parenting, doing housework and working outside the home. Losing appreciated roles and activities threatened the self-image of the healthy spouse. Sometimes, due to changes in abilities, appearance and behaviour the ill spouse was perceived as a stranger. Some of the healthy spouses reacted with loneliness and despair and they perceived themselves as changed compared with their pre-stroke life. These spouses realised that their lives would never be the same.

During the acute stage spouses had been confronted with the threat of losing their partner and this fear persisted and made them refuse to leave the ill partner alone at home. Other overprotective actions that were grounded in healthy spouses' fear of losing the ill spouse were seen. Living with a depressive or even suicidal partner increased healthy spouses' fear tremendously. Fear, grief, increased workload and emotional despair led to sick leave and sometimes chronic illness in the formerly healthy spouses. Cognitive impairment could entail altered personality and childish or aggressive behaviour. For spouses it was extremely demanding to deal with their partners' cognitive disabilities and this threatened the marital relationship more than physical impairment. Some cognitive disabilities remained invisible to others; this increased the couple's burden as other people did not understand the impact of the impairment and expected too much.

More than half of the short-term relationships fell apart after the stroke while couples in long-lasting or seemingly stable relationships succeeded in adjusting better to the considerable changes post stroke. Most couples' relationships were strengthened by grieving losses together and finding new activities in common. If they joined peer associations together they managed to establish new networks and enter into supportive relationships.

The deeper meaning of the parent-child relationship was interpreted as the parents' absent presence. Both the sick and the healthy parent had to be absent during the acute illness trajectory and later on when rehabilitation targets claimed absence from home. Although later the parents returned home, their attention then seemed to be mainly directed towards the considerable life changes and less towards the needs of the children. Parents experienced that their children left home early in adolescence and moved to other parts of the country but did

not think of the stroke as a possible reason, unlike the participating children. Some parents reported psychosomatic reactions in their children but did not connect these complaints to the stroke experience.

Quotations from one child interview showed that this child had to undertake duties that were perceived as burdening. Female stroke survivors felt inadequate in their parenting role, which had a negative impact on their perception of self. Parents living as a couple did not think their children were suffering, as grandparents or other relatives took over their parental duties. Being a single mother and stroke survivor meant being more aware of their children's burdens. These mothers revealed that their children had later had behavioural problems, difficulties with concentration and learning deficits.

The impact of stroke on couples' lives seemed to give them a wavering experience of time and increase their perception of time as limited. Time was experienced as running too fast and healthy spouses lost precious time to live their own life due to their caregiving obligations and their partner's dependent state. Couples shared an existential fear of loss, dying or a worsening of the disabilities which could further limit their lives. In spite of being worried about the future, couples avoided looking forward directly after the stroke attack. Instead comparisons were made with their pre-stroke life. Later on most couples avoided looking back and rather tried to enjoy the present moment.

As time went by after the stroke event, the life-altering changes made couples reinterpret their views on life. A deeper appreciation of life and a shift in their view of certain values emerged. Money and possessions lost some of their value, while love, attachment and caring for each other and for other people became more important. Happiness emanating from close relationships that used to be taken for granted now became more appreciated. Comparing themselves to couples who had faced worse disabilities brought forth humility and gratitude and life was perceived as a precious gift. There seemed to be a shift from an individualistic to a more altruistic life view. Taking care of family and helping and supporting others in peer organisations were values that had gained greater importance.

The ability of health care workers to provide support and hope turned out to be crucial. Caring and supportive relationships with professional helpers strengthened stroke survivors' hope whilst premature and sometimes wrong negative prognoses made stroke survivors and

spouses lose hope and sometimes rehabilitation efforts were therefore given up. Most couples resisted an unfounded prognosis and often succeeded in their efforts to prove that the professionals' prognosis had failed. There was a common experience of missing professional support to master post-stroke life; here spouses and children were more negative than stroke survivors to the contribution of health care workers.

6.0 Theoretical and methodological considerations

Researchers within the interpretive paradigm do not expect to find a single fundamental truth (Lindseth & Norberg, 2004, p.151). Furthermore, qualitative researchers have different opinions on whether the same evaluation criteria should be used in quantitative and qualitative research. Following the suggestions of Lincoln & Guba (1985) parts of the qualitative research community suggest that 'trustworthiness' rather than validity should be established in qualitative research studies as this concept supports the qualitative paradigm (Graneheim & Lundman, 2004; Koch, 1996; Mishler, 1990). Drawing on these concepts, strategies were applied to achieve trustworthiness in all phases of the research project and to make the research process visible for the reader (cf. Sandelowski, 1993; Tobin & Begley, 2004). Credibility was sought by collecting rich and varied data, keeping to ethical standards, being thorough during data analysis and finding plausible interpretations through achieving a reflexive attitude.

6.1 Philosophical underpinning and theory

Although all of the three studies are guided by combinations of hermeneutics and phenomenology, different philosophical frameworks and different analyses in accordance with the philosophical concepts were chosen. Since all of these frameworks adhere to a life-world perspective - a fundamental concept in this study - it was possible to integrate the different concepts into a whole. The different views in the philosophical frameworks contributed to a comprehensive understanding of the whole. In the discussion sections of the articles phenomenological theories or theories close to phenomenology were chosen to illuminate more of the multiple facets of the phenomenon under investigation.

6.2 Trustworthiness of the sample

All participants except one of the spouses were ethnic Norwegians. This may have limited the study findings concerning the cultural aspect of living with stroke as an individual and as a family member. Participants were aged from 30-70 when suffering a stroke and thus the findings may not be representative of very young and very old stroke survivors in family settings.

Eleven stroke survivors lived with aphasia. The decision to include participants with limited communication abilities may be questioned as some of them could not provide rich accounts

of their experiences and their communication could easily be misunderstood. However aphasia plays a prominent role in the phenomenon of living with stroke, as 20-40% of stroke survivors and their families have to live with the serious consequences of this communication disorder (Poslawsky et al., 2010). To exclude the voice of this group due to their limited descriptions would have led to an incomplete picture of the phenomenon (cf. Kirkevold & Bergland, 2007). In addition researchers have a moral obligation to include people with communication disorders as this group is underrepresented in research settings (Philpin, et al., 2005). However the decision to include participants with aphasia made it necessary to carry out interviews with utmost care to ensure trustworthiness.

This study includes 42 participants. Phenomenological studies usually have few participants to facilitate in-depth analysis of the phenomenon under investigation (Sandelowski, 1995). On the other hand methodological papers point out that the sample should include rich variations to illuminate the phenomenon from different angles (Bowen, 2008; Morse, et al., 2002; Sandelowski, 1995; Silverman, 2006). Living with stroke as an individual and as a family member is multifaceted and depends on the kind and seriousness of residual disabilities, the age of the involved family members and their family stages. Therefore the decision was made to recruit sufficient numbers to provide a wide range of participants with regard to locality, age, gender and family setting. Redundancy of central themes in the interviews was an important criterion to end recruiting procedures (cf. Morse, et al., 2002). Unfortunately this criterion could not be achieved when recruiting adult children, since only four of the participating stroke survivors had minors at the onset of stroke and only two of these wanted to participate. Different recruitment procedures (e.g. advertisements) may have been more successful but were not applied. Although all parents who had minors at onset contributed with narrations about their children's reactions, the limitation to only two children can only give a hint about the experience of growing up with a parent with stroke.

6.3 Trustworthiness of the interviews

The first interview was used under supervision as a pilot interview to refine follow-up questions and improve the following interview procedures. Eleven stroke survivors lived with aphasia. Three of them needed the help of their spouses during the interviews, but only one of them had difficulty in understanding speech. The spouses who were interviewed together with these three stroke survivors had developed individual strategies to communicate with their

partners. In three other interviews stroke survivors and spouses were interviewed together according to their wish.

Three spouses were interviewed individually after the couple interviews. A comparison of these interviews showed that spouses expressed themselves more openly and emotionally when interviewed alone. In the individual interviews they conveyed experiences which they had held back during the couple interviews. The huge impact of the cognitive changes and altered personality on the couple's relationship were not disclosed in the couple interviews. Spouses explained that they wanted to spare their alert partners from their own emotions or did not want to criticise them. Spouses' tendency to hold back sensitive information during couple interviews is known from previous studies on couples' illness experiences (Harden, et al., 2002). Therefore combinations of interview methods are recommended to obtain both individual and shared perceptions (O'Rourke & Germino, 1998). Performing mainly individual interviews when focusing on couple perspectives may be questioned. Nevertheless important findings regarding the effect of cognitive and behavioural changes on the marital relationship would have remained undetected if only couple interviews had been conducted.

It is claimed that interviewees are not always willing to narrate about their experiences or that they even distort them in order to meet the interviewer's expectations (Lindseth & Norberg, 2004; Polkinghorne, 1988). Therefore a relaxed atmosphere was sought by taking time to introduce the interviewer and by validating participants' feelings and statements.

6.4 Trustworthiness of analytical procedures

In studies using combinations of phenomenology and hermeneutics the researcher's pre-understanding is considered essential to the interpretive processes (Fleming, et al., 2003; Laverty, 2003). Prejudices have to be provoked to be realisable in order to enter the hermeneutic circle in a fruitful way (Fleming, et al., 2003; Gadamer, 1960/1990; Geanellos, 1998a). This was done by means of reflections on the researchers' professional and personal experiences, earlier studies and theoretical knowledge on stroke. The first author's pre-understandings were written down and addressed throughout the interpretation process. Discussions with colleagues and mentors broadened the awareness of hidden prejudices and opened up for new understanding of interview texts (cf. Gadamer, 1960/1990, p.270-275; Geanellos, 1998a; van Manen, 1997). Pre-understandings were also explained to the readers

to make clear the basis for the interpretations (cf. Debesay, Naaden, & Sletteboe, 2008; Fleming, et al., 2003; Laverly, 2003).

The first interview was analyzed under supervision. The results of the analysis as a whole were discussed within the research team and with other research colleagues to enhance credibility. Field notes taken during the interviews that documented 'silent' data were used to arrive at the most probable interpretations. Deviant cases were considered important to reveal nuances of the phenomenon. To achieve thoroughness in the analytical process, re-reading procedures and reiterative motions between the parts and the whole were applied.

Member check was not considered appropriate because the study results have been synthesised and decontextualised from individuals (cf. Morse, 2002; Sandelowsky, 1993). Nevertheless in Study III the authors wanted to check if the synthesised analysis could be recognised by participants (two stroke survivors who were local leaders of peer organisations and two spouses) and by a health care professional experienced in working with stroke survivors in continuing therapy courses. All of them confirmed the core themes of the analysis and revealed related experiences during these dialogues.

6.5 Transferability

Although the transferability of results has to be considered thoroughly in qualitative research in relation to contextual similarity (Koch, 1996; Lincoln & Guba, 1985; Tobin & Begley, 2004) the essential concepts synthesised in this thesis indicate areas of importance for other stroke families and perhaps even for families living with other kinds of chronic illness.

Although the lived experience of stroke within a family setting seems to be alike in different cultures, different family constellations and patterns of caring relations will have an important influence on stroke survivors' and their families' life-world (Hägström, Norberg, & Huy, 1995; Pierce, 2001; Subgranon & Lund, 2000). These factors should be considered when transferring the core message of this Norwegian study to other cultures and settings. In-depth descriptions of the sample and the research context may facilitate the readers' evaluation as to whether aspects of the phenomenon may be transferred to their own settings.

7.0 Comprehensive understanding and reflections

The overall aim of this study was to illuminate the long-term lived experience of stroke within a family context. A phenomenological hermeneutic approach was chosen to shed light on the meaning of the long-term bodily changes on the perception of self after stroke (I), of being part of a family⁵ living with stroke in a long-term perspective (II) and of the long-term existential meaning of living with stroke as a couple (III).

Comprehensive understanding and reflections on the findings in the three studies revealed phenomena that stood out in these families' experiences as strongly influenced by the stroke. Families experienced a thrownness from their familiar being-in-the-world (II). Stroke survivors were thrown into transitional experiences due to bodily alterations (I). Spouses and children were similarly forced into transitions due to the sudden life-changing impact the stroke also had on their lives (II). Families' transitional path through life after stroke was no longer straightforward but had to overcome various obstacles, heading towards an unpredictable future. The phenomena that emerged and characterised these families' long-term transitions after stroke were: communication; relationships; identity (Figure 1). Most families with strong foundations cemented over time overcame these challenges and experienced positive changes leading to new values in life. This process was interpreted as self-transcendence.

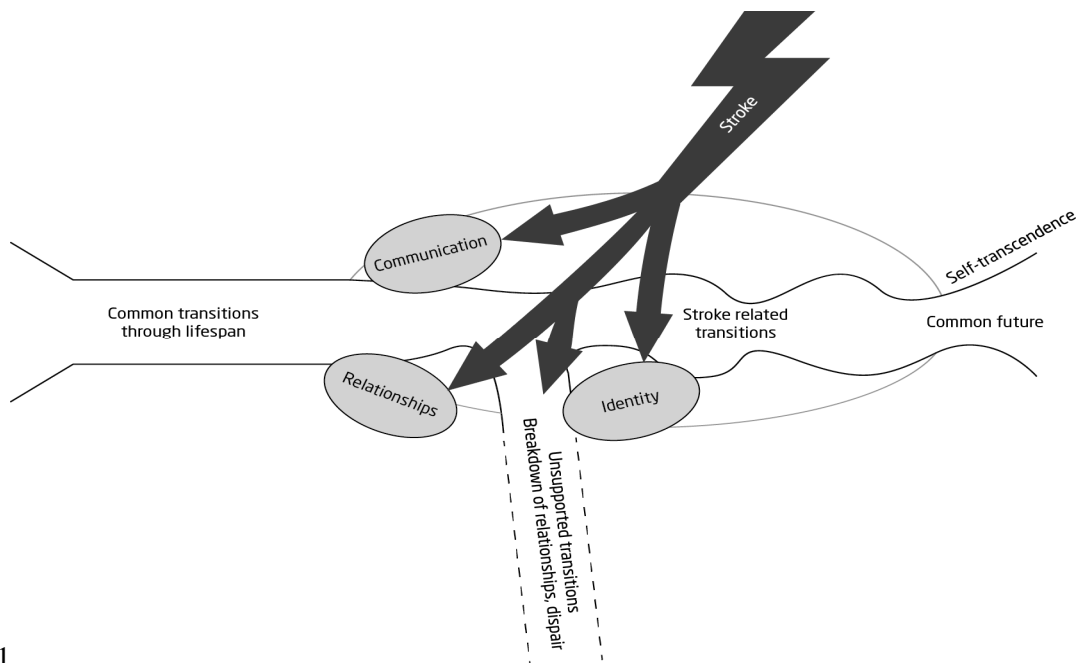


Figure 1

⁵ As the findings in the three papers mainly illuminate couples' and parent-child relationships, the 'family' is viewed mainly from these perspectives in the comprehensive understanding section.

New literature searches based on these new key words were conducted and philosophical concepts that could promote reflective awareness were sought. Extensive reading of this literature facilitated a comprehensive understanding of the meanings of these phenomena in stroke survivors' and their families' experience of their life-worlds.

7.1 Communication

The stroke event and its far-reaching consequences imposed a threat on families' ordinary and familiar everyday life by spoiling their communication processes. Communication problems arose due to the bodily alterations after stroke, e.g. aphasia and cognitive disabilities (I, II). In addition it became difficult for these families to communicate openly about their worries and fears and family members tried to hide their emotions in front of each other (II).

Overprotective actions and expectations that could not be fulfilled contributed to this gap in communication. Insufficient communication between families, their network and health care workers added even more to their burden (I, II, III). The families had been sparsely prepared for how to deal with these difficulties and mostly faced these prolonged challenges without any support from others than peers, if they joined stroke organisations.

Research findings indicate that communication is crucial for couples facing chronic illness in order to compensate for the physical interactions and the appreciated activities they lose (Acitelli & Badr, 2005). Unfortunately diminished verbal and nonverbal communication are commonly seen in stroke families (Banks & Pearson, 2004; Harlow & Murray, 2001; H. S. Thompson, 2008).

Couples with aphasic stroke survivors perceived aphasia as the worst consequence of the stroke (II). These stroke survivors could no longer vent their thoughts and feelings by means of language and their spouses experienced existential loneliness (II). It is supposed that the aphasic stroke survivors felt similar existential loneliness but they could not express their feelings. The alienating and isolating effect of aphasia is known from other stroke studies (Nyström, 2006; Parr, 2007). As aphasia often remains after stroke (Poslawsky, et al., 2010) these families have to deal with long-term challenges. Their life-world appeared to be permanently silenced by aphasia.

Telling stories about their illness, integrating these illness stories into their life narratives and applying meaning-making endeavours to understand the cause of the illness seemed to be

important for stroke survivors (III). Being hit by serious aphasia meant losing this narrative ability which could have helped them adapt to these life changes. Parr (2001) states that coping with illness, disability and disruption necessitates the use of language to adapt to a new life situation. Aphasia lessens one's control over dealing with trauma, disruption and change as all these processes are mediated through language. This may explain why stroke survivors living with aphasia often experienced depression or at least depressive thoughts (II, III). These findings correlate with other stroke studies indicating that aphasia is associated with depression (Kauhanen, et al., 2000; Thomas & Lincoln, 2006) and lower health-related quality of life (Hilari & Northcott, 2006). Spouses perceived the ill partner's depressive mood as an additional hindrance to communication (II). This had a negative influence on their own emotional well-being (II, III). McCarthy, Powers and Lyons (2011) show that stroke couples' experiences of mood changes are shared experiences and that there is a close interconnectedness of the emotional well-being of the partners in a couple.

The missed information and support from health care workers meant that spouses had to figure out by themselves how to communicate with the aphasic partner (II, III). Nätterlund (2010) states that the aphasic family member is in great need of emotional, practical and informational support and becomes extremely dependent on the family caregiver acting as a 'sounding board'. Although caregivers' needs of learning how to communicate with the aphasic stroke survivor are well documented (Bakas et al., 2006; Le Dorze & Signori, 2010; Parr, 2001, 2007; C. Pound, 2001) their long-term needs commonly remain unmet by health care workers (Denman, 1998; Hafsteinsdottir & Grypdonck, 1997; Le Dorze & Signori, 2010).

Spouses of stroke survivors with severe aphasia felt overwhelmed by the extremely demanding and time-consuming communication efforts (II). Nevertheless they tried to maintain their partner's social network as compensation for their insufficient ability to communicate. This is in accordance with Shadden's (2005) findings indicating that spouses feel responsible to bridge the communication gap and experience loss of competence themselves when facing the challenges of aphasia. Le Dorze & Signori (2010) also describe spouses' burdening experiences of their partners' persistent dependency on them to communicate, leaving them in need for respite. Compared with spouses of stroke survivors without aphasia, caregivers of aphasic stroke survivors experience more difficulties in communication and caregiving (Bakas, et al., 2006).

Conflicts arose when communication failed due to aphasia (II). Guesses that failed and misunderstandings that occurred often made communication extremely dissatisfying (II). Negative attitudes towards the stroke survivor were seen but seldom disclosed in the individual interviews (II). These findings are confirmed by the findings of Johannsen-Horbach et al. (1993) indicating that conflicts are common in couples with aphasia. Spouses of aphasic stroke survivors commonly feel guilt as the extremely difficult life situation calls forth negative thoughts and attitudes towards the aphasic spouse (Johannsen-Horbach, Crone, & Wallesch, 1999) and often leads to separation among younger couples (Johannsen-Horbach, et al., 1993). Not being able to communicate with the aphasic parent was also difficult for the children in the families (II). Sometimes they turned away from the aphasic parent without providing any support that could fill the gap, leaving the aphasic parent in despair.

Spouses' attitude of speaking for the aphasic stroke survivor was perceived negatively by the disabled spouse (II). It seemed to be difficult for spouses to cease acting as 'communication tools' when there was no longer any need for this kind of support. Overprotective behaviour is known to exaggerate stroke survivors' feelings of incompetence and lead to diminished participation in conversations (Croteau & Le Dorze, 1999, 2006; S. C. Thompson et al., 2002). This vicious circle may only be broken by open communication about helping and being helped which again turns out to be difficult with aphasia.

Participation in family communication and interaction no longer seemed to be balanced as aphasic stroke survivors tended to withdraw from settings where communication skills were necessary (II). This imbalance might have altered the marital and parent-child relationships in these families. The families' meaning-making endeavours may have been difficult due to the consequences of aphasia. Rolland (1998) states that if different belief systems cannot be communicated and openly shared, meaning-making and using shared strategies will be hindered. Changes in family members' interactions and relationships are known from other studies on aphasia after stroke (Hallé, et al., 2011; Shadden, 2005). According to S.C. Thompson & Pitts (1992) lack of equity between partners facing chronic illness has a negative impact on their perception of and satisfaction with the marital relationship; here resentment, guilt and anger are possible obstacles to communication. Turning to communication tools for their partners or being overprotective of the aphasic family member may harm the

relationship. Adjusting their marital relationship and their roles to the consequences of stroke was of great importance for couples but aphasia was a hindrance to dyadic adaptation after stroke (II, III).

Severe aphasia also deprived couples of the possibility to discuss the impact this condition had on their relationship, their present life and their future plans. It is supposed that the inability to use language to vent feelings made it difficult for the aphasic partner to seek emotional support. For the healthy partner it must have been difficult to perceive when this kind of support was needed. Nevertheless couples in long-term relationships with strong foundations developed communications strategies that were independent of words (II). They used demonstrative actions, facial expressions and gestures to communicate. Humour was used as a communication strategy that helped couples share feelings and seemed to mediate the serious consequences of the stroke (II). Walsh (2006) states that humour provides respite from stress and anxiety and helps families to reduce the negative influence of threatening situations and to ease confrontations.

Cognitive disabilities, emotional instability and changes in personality seemed to be obstacles to families' communication processes (I, II, III). Spouses perceived such changes as extremely burdening. Sometimes the ill spouse was even seen as a stranger who showed an unfamiliar behaviour and with whom it was difficult to share the same confidentiality as before (II, III). Almost all of these changes obviously had a serious impact on the communication patterns of these couples. The literature reveals that stroke survivors' memory problems and changed behaviour negatively affect caregivers' mental health and the conflicts that commonly arise in these families worsen the caregivers' condition (Bulley et al., 2010; Clark et al., 2006; Clark, et al., 2004).

Expectations that could not be fulfilled could contribute to conflicts (II). There seemed to be little communication between spouses regarding their expectations and why these expectations were not met. In the individual interviews spouses revealed their anger about things that were left undone and stroke survivors disclosed their despair about not being able to get things done. According to Evans et al. (1994) family dysfunction often derives from the gap between what the ill person can still do and what is expected of the person by his family. Effective communication about these issues may prevent conflicts. Fatigue seemed to be a problem after stroke that contributed to conflicts and was presumably also an obstacle to

stroke survivors' communication efforts (II). The literature reveals that the astheno-emotional syndrome⁶ after stroke has a negative influence on the quality of the marital relationship as it disturbs equity in decision making, joint goal-setting and maintaining purpose in life (Carlsson et al., 2004, 2007).

Paper II demonstrated overprotective care and feelings of being abandoned. It is known that couples' interaction about helping and being helped may lead to negative emotions, overprotective care or caregiver burden if couples lack efficient communication about what kind of help is expected and whether the healthy partner is willing to meet these demands (Pistrang & Barker, 2005). Even though feelings and emotions are often shared they have to be communicated instead of silenced, in order to make mutual support possible (Rolland, 1994). Coeling, Biordi, & Theis (2003) state that rules for being the caregiver and the care receiver must be negotiated as failure to agree about these rules cause a strain and burden on the relationship. After having lived with stroke for several years, couples in long-term devoted relationships seemed to have learned how to deal with the communicational challenges. Couples experienced that their relationship was strengthened when they were able to communicate openly (II).

The interview texts revealed that spouses hid their true emotions in the presence of the ill partner and withheld controversial issues that they thought might offend the stroke survivor (II, III). Only in the individual interviews were such issues addressed openly. A tremendous unmet need of having someone to talk to resulted in unfathomable existential loneliness (II, III). Trying to protect other family members by hiding one's own feelings is seen in families dealing with illness and is perceived as an obstacle to communication by creating a distance between family members that causes loneliness and isolation (Denman, 1998; Fontana, 2006; Shadden, 2005). Pierce (2001) shows that suppressed or avoided family conflicts result in anger. Suppressed feelings often lead to emotional outbursts that hurt the partner more than open communication would have (Rolland, 1994). Rolland states that unrevealed thoughts and shameful emotions over time hinder communication and if personal needs and goals are held back and conflicts are avoided for fear of worsening the ill partner's condition, this may lead to mutual resentment and guilt. According to McPherson et al. (2010) stroke survivors also try

⁶ This syndrome includes increased mental fatiguability, concentration and memory difficulties, irritability, emotional instability, impaired stress intolerance and sound and light sensitivity (Carlsson, Möller, & Blomstrand, 2004)

to shield their family by not discussing their feelings. Stroke survivors' greatest worries seem to be about how the illness will affect their family members (Figueiredo, Fries, & Ingram, 2004). Failing to verbalise such concerns is associated with poor social support and low emotional well-being. Couples' disclosed fears might have increased their emotional shielding (III). Fear seemed to be contagious as the partner's perceived fear seemed to exaggerate the spouse's own fears. Couples did not relate that they communicated verbally about their fears; instead they seemed to react on sensing the partners' fears rather than sharing their own fears (III).

There seemed to be little communication about the stroke event and its consequences between parents and children (II). Parents thought they sensed their children's reluctance to talk and kept silent. Children also felt parents' reluctance and therefore did not ask although they felt a tremendous need to talk, as revealed in one of the children's interview texts. When reaching adolescence they no longer wanted to talk and rather tried to gain distance by leaving their homes. Lewandowski in Romer et al. (2002) states that if illness and its consequences are not discussed with the child, the parents' behaviour will serve as a model for dealing with emotional distress. Being left alone with fears and fantasies is harmful for the child while open communication opens for positive adaptations. Children who are emotionally supported by their parents seem to cope better (Korneluk & Lee, 1998).

The psychosomatic complaints of children reported by their parents indicate that children internalised their fears and worries (II). Insufficient communication and lack of professional support presumably contributed to these complaints. Children commonly hide their distress from parents to spare them from worries (Steck in Metzging & Schnepf, 2007). They also feel ashamed of being different from their peers and believe that others will not understand their experiences (Metzging-Blau & Schnepf, 2008). As serious parental illness is associated with emotional stress, maladjustment, fears and depressive traits in children (Romer, et al., 2002; Sieh et al., 2010), open communication between parents and children is vital. Without open dialogue family members may even be hindered in their development processes (Pedersen & Revenson, 2005).

Health care providers' and others' communication or lack of communication was another influential factor in stroke survivors' and their families' lives (I, II, III). As Parr (2001) states aphasia is not experienced by individuals in isolation but in their social context with others.

Negative communication patterns e.g. overlooking the stroke survivor, treating him or her without respect or neglecting family members' needs hindered the families' ability to deal with the changes (III). Communication with health care providers often dashed families' hopes when they were confronted with a premature prognosis that later on turned out to be wrong. These findings support the results in Anderson & Marlett's (2004) study that point to the negative discourses of health care workers which shatter stroke survivors' hopes for their possibilities in life after stroke by trying to provide 'realistic' expectations of recovery. According to these authors there is an urgent need to improve health care workers' communication to support both stroke survivors' and their families' renegotiations of identity and to help them reframe their life narratives to include the consequences of stroke. Disempowering medical discourses seem to compartmentalise stroke survivors according to a notion of individual pathology by underlining their incompetence and dependency instead of treating them as equals (Mackay, 2003). Health care workers should be aware of the healing function of communication through sensation expressed by bodily presence, attentive listening and touch (Frank, 1995; Mundle, 2011; Sundin, Jansson, & Norberg, 2000).

Exploring the phenomenological and hermeneutical concepts of open and genuine dialogues may further illuminate the significance of communication in human relations. In Buber's (1983) ontology of the interhuman, human relationship and dialogue are seen as the starting point of being. The 'I' becomes the 'I' only through genuine meetings with the 'Thou'. According to Buber (1998) man did not exist before having a fellow being whom he could address through language. The 'being with the other' comes forth in the space of the 'in between' which they live together (Buber & Friedman, 1998, p. 65). The 'interhuman' can only blossom genuinely if men confide themselves to each other as what they really are, not what they would like to be (p.67, 71). Through genuine dialogues the other is made present as a whole and unique being - a becoming self (p.75). In order to influence the unfolding of the other he must be accepted and confirmed as a dialogue partner (p.59). Although the other cannot always be approved, one has to abstain from imposing oneself on the other. As shown in the interview texts, when health professionals failed to enter into genuine dialogues mutual respect and understanding was threatened and stroke survivors and spouses were left in despair or anger (II, III). Buber (1998, p.61) states that mutual growth is accomplished in a confirming relationship where one makes others present and is made present by others (p.61).

Through communication men can raise their thoughts into the mode of existence that Buber (1998) calls 'betweenness' – the dynamics between persons defining themselves as we (p.97). In this communication men face each other with equal rights; they do not observe each other or objectify each other but act in a genuine mode of the 'we' (p.98). Nevertheless interhuman existence presupposes honesty, acceptance of 'otherness' and courage to share what one has to say (p.59, 61). In our study, family members' communication strategies seemed to fail for a variety of reasons. The main reasons seemed to be that they could not share their experiences due to aphasia or that they did not dare to reveal themselves due to their well- intended wishes to protect each other (II). These obstacles complicated the 'in between' of their lived togetherness.

Gadamer (1995) states that communication and mutual understanding are fundamental processes of the life-world. Only through openness towards the dialogue partner's otherness and through listening to what the other has to say is the other genuinely 'experienced' (Gadamer,1960/1990 p.367). Understanding the other cannot be forced or scientifically explored but springs forth in authentic dialogues (Gadamer & Maliks, 1999). In such conversations the dialogue partners risk being altered permanently as their horizons fuse like melting snow (p.9). Buber's (1983; 1998) and Gadamer's (1960/1990) concepts underline that our life-world depends on genuine dialogues and that authentic communication is indispensable to nurture stroke survivors' and their families' incentive to go on with life and enable them to do so. Otherwise the silence of their life-world may impose an insuperable hindrance on making use of their future possibilities.

7.2 Relationships

Caring relationships within the family

The stroke survivors' life-world seemed to be shaken by their bodily alterations that influenced negatively on their self-concept (I, II, III). Therefore they were in need of long-term emotional and practical support in trustworthy relationships. Stroke families with minors were completely dependent on their relations with members of the extended family to care for their children during the first, often critical, period when both parents had to stay in hospital (II). Stroke survivors perceived their family relationships as a prerequisite for keeping up their life spirit and hope and for continuing with demanding rehabilitation tasks (II). Based on their review on social support after stroke, Glass and Maddox (1992) conclude that social support is an important predictor of rehabilitation outcomes after stroke. In another review on the

influence of the family on recovery from stroke, Evans et al. (1992) illuminate the family's buffering effect on stroke survivors' psychosocial dysfunction. Although caring family togetherness has a positive effect on families' identity and stability (Pierce, 2001), not all families act supportively as caring depends on healthy family relations (Visser-Meily et al., 2006). This underlines the need for family-centred professional support during stroke rehabilitation.

A loving and caring attitude from spouses, children or members of the extended family helped stroke survivors to overcome severe depressions (II). It has been stated that caring family relationships are crucial for stroke survivors' incentive to go on with their life by being comforted, encouraged and made to feel secure (Pilkington, 1999) and also have a positive impact on stroke survivors' quality of life and their potential to use their remaining abilities (Clarke & Black, 2005; MacKenzie & Chang, 2002). Living in a marital relationship and having a wide social network also predicts stroke survivors' possibility to return to their home instead of being institutionalised (Meijer, et al., 2004). In Study II several stroke survivors confirmed that their spouses saved them from living in a nursing home. Buffering stress and meeting the survivor's need for attention, affection and practical support are seen as reasons why married stroke survivors show better rehabilitation outcomes (Baker, 1993).

Couples' caring relationships

Although stroke survivors doubted that they would have survived without their loving spouses, enduring love claimed its price (II, III). They feared not being able to fill former roles and they felt uneasy about letting their healthy spouses down. Sometimes they were anxious about their spouses' health due to the burden of caregiving and their complete dependence on their spouses' well-meant help (II). In general, empathic care and support seemed to be of tremendous significance for stroke survivors' motivation to carry on with life. Drawing on their review on social support, Ryan & Solky (1996) conclude that in order to be perceived as supportive the provided care should nurture the psychological needs for relatedness, competence and autonomy and encourage the self of the care receiver by strengthening feelings of being valued and cared for. Sharing appreciated activities with family members was a means to enhance the experience of being valued and appreciated (II, III). Sharing is perceived as a crucial feature of supportive intimate relationships with family and friends (Cruice, Worrall, & Hickson, 2006) and is expressed in living with someone, socialising, sharing tasks and taking care of children and grandchildren.

When stroke survivors' and their spouses' lived experiences revealed a lack of caring support from their extended family or friends, couples' positive re-interpretations of life were hindered and they experienced despair and loneliness (I, II, III). Losing connections with significant others meant feeling lost or neglected. Disrespectful treatment by health care workers could even lead to a deterioration of health (I, III). These findings are in accordance with Parr's results (2007) which show that social exclusion is a huge problem after stroke where the severity of the impact for the ill person is determined by the response and behaviour of family members and significant others, but also by voluntary services, institutions and communities.

Although most spouses aimed at being caring and supportive some of them tried to control their ill partner by being overprotective (II). Spouses who acted very protectively in their care hindered stroke survivors' autonomy and deprived them of appreciated activities. Sometimes overprotective care seemed to be the price for being loved and worried about. Spouses' concern for the disabled partner's health and life made them extremely alert and limited their own and their partner's freedom (III). Hallé (2011) et al. state that protective behaviours may make stroke survivors continue to act dependently to avoid rejecting the family carer, which thereby confirms the helper's conception of their fragility and dependence. Feelings of being controlled may arise if overprotective actions get out of hand; according to Ryan and Solky (1996) such feelings may foster alienation and detachment.

Undoubtedly stroke survivors needed their families' huge practical and emotional support as many of their bodily functions were weakened or lost. It is obvious that the 'what' of support sometimes was less important than the 'how' it was given. Being insufficiently prepared for how to give practical support in a manner that did not offend stroke survivors' autonomy was challenging for spouses, especially when faced with the different kinds of cognitive decline, alterations in personality and mood changes in their disabled partners (II, III). Spouses in long-term and well-founded relationships were seemingly better prepared to succeed in this endeavour as they knew their partner well (II). Probably it was easier for these spouses to perceive what kind of support the partner needed and how it should be given. This is in accordance with the findings of Robinson-Smith & Mahoney (1995) who state that seeking and finding balance in marriage and adapting to the changes caused by chronic illness is easier in long-term relationships. Not only the length but also the harmony in the marital

relationship and the amount of support spouses receive from their network influence their ability to provide care (Visser-Meily, et al., 2006). The developmental stage of the family also seems to affect the quality of spouses' caring abilities as older adults living in long-term marital relationships experience higher marital satisfaction than younger adults. Older couples share aims, goals and decision making and experience high intimacy (Lauer et al. in Berg & Uppchurch, 2007).

The meaning of love and care brought forth hope and motivation to carry on with life (II, III). According to Bays (2001) family connectedness is an important factor in hope-related patterns after stroke. Drawing on their review on hope, Bright et al. (2011) state that hope is a key element in the recovery process and that the support of friends and family is crucial for gaining and maintaining hope after stroke.

For most of the spouses life became burdened by the responsibilities of their caring relationship and their concern for their own and the ill partner's future (II). They struggled to keep their own supportive network as they had to give up appreciated activities due to their caregiving obligations (II). These findings are in accordance with studies indicating that spouses' caring duties may hinder them in maintaining their social relationships and sometimes force them into loneliness (C. S. Anderson, Linto, & Stewart-Wynne, 1995; Nätterlund, 2010). Facing the ill partners' cognitive changes or aphasia increased spouses' need for informational and emotional support when grieving the loss of the former person they had loved (II). These findings are in accordance with Le Dorze & Signori's (2010) results pointing to the considerable need for support of stroke survivors' spouses. Furthermore, Brereton and Nolan (2000) state that it is useful to seek information and knowledge and be guided when trying different strategies in adapting to the caregiver role. Spouses' worries about the future, e.g. falling ill themselves and no longer being able to care for the ill partner, added to their burdens and the practical and emotional support from adult children or other family members were crucial when dealing with the changes (II, III).

In most cases, family was the only source of help as support from professionals was missing during the long-term stroke trajectory. Lack of professional support is commonly reflected in stroke research (Bulley, et al., 2010; Denman, 1998; Le Dorze & Signori, 2010; Nätterlund, 2010; Rodgers, Bond, & Curless, 2001) although the interrelatedness of professional support and spouses' well-being has been documented.

Caregivers' need for social support has been underlined in several stroke studies. McGurk, Kneebone and Pit ten Cate (2011) found that family caregivers' mood was influenced significantly by whether or not they could anticipate social support from others if future help was needed. Spouses' psychosocial functioning and well-being suffer if they miss social support (Grant et al., 2006; Nätterlund, 2010; Robinson-Smith & Mahoney, 1995; Visser-Meily, et al., 2008). By contrast social support seems to enhance family caregivers' adjustment and those who receive social support show better health and well-being and feel less depressed than those who lack such support (Grant, et al., 2006).

Although spouses were in need of support due to the burden of caregiving, most of them experienced positive consequences of caring (II, III). These spouses felt that the protracted but shared struggles had brought them closer in their relationship to their partner and made them realise what really mattered in life. A greater level of shared time, closeness and devotion is reported in other stroke studies (Gillen, 2005; Lawrence, 2010; McCarthy, et al., 2011). Based on their review of studies of stroke survivors' primary caregivers, Greenwood et al. (2009) found that caring resulted in feelings of satisfaction and fulfilment along with a greater closeness to the survivor and the family as a whole. Nearly all family caregivers in a study by Haley et al. (2009) reported increased appreciation of life and the authors conclude that caregivers' reported benefits should be seen as an important psychological resource and meaning-making endeavour. Another positive consequence of caring is family strength emerging from managing caregiving tasks together, aiming at the best for the stroke survivor and trusting in the family's ability to overcome difficulties (Niyomathai et al., 2010).

The lived experience of couples emerged as a shared experience that gave rise to both similar and different reactions that strengthened the mutual caring relationship of most couples (II, III). These findings are supported by McCarthy, Powers, & Lyons' (2011) statement that stroke couples' experiences should be understood as dyadic experiences within the context of their committed relationships and the interconnectedness of their emotional well-being. The interrelatedness between stroke survivors and their significant others is also seen in Wyller & Kirkevold's (1999) study that views stroke survivors' quality of life as strongly influenced by the interpretations of their significant others.

Most of the stroke survivors seemed to be well aware of the stroke's burdening consequences for their spouses (II). Worrying about their spouses' health and well-being, they tried to relieve and support them by restraining their own needs and wishes. These findings are confirmed by the results of McPherson et al. (2010) pointing to stroke survivors' awareness of the increased responsibilities of their spouses. These stroke survivors' own perceptions of burdening the spouse were especially strong if they felt they were over-benefiting in the couple relationship. Nevertheless becoming more sensitive to the partners' moods, needs and wants may also strengthen the relationship of couples living with chronic illness according to Corbin and Strauss (1984). These couples are more willing to compromise and work collaboratively and they develop a sort of mutuality in giving and receiving that ties them more closely together. The importance of mutual support and dyadic problem solving is known from studies exploring the influence of chronic illness on couple relationships (Acitelli & Badr, 2005; Rolland, 1994). The acceptance of the demands of the illness, the desire to do things for the partner and being appreciative instead of claiming one's rights seem to be crucial for the collaborative work of couples (Corbin & Strauss, 1984).

Supportive relationships with peers

Peer support in stroke organisations was another source of caring and being-with (I, II, III). As most participants had been recruited by leaders of local branches of stroke organisations, they were or had been members of these organisations. Many of the couples emphasised that this membership still was or had been of great help for them. Sharing their illness narratives and gaining new networks had become important (II). Joining these organisations resulted in long-lasting friendships and taking on duties there helped stroke survivors strengthen their self-concept (I). Peers are able to understand in a way that family and friends cannot and they teach each other how to deal with and normalise their post-stroke life (Ch'ng, French, & McLean, 2008; Murray & Harrison, 2004). Peer support mitigates the disruptive impact of the illness and provides knowledge of how to deal with its consequences (Faircloth et al., 2004). Such support promotes personal growth and social belonging (Legg et al., 2007; Shadden & Agan, 2004). Receiving confirmation and support to accomplish goals and being able to help others have a positive influence on identity renegotiation and transformation processes after stroke (Kessler, et al., 2009; Legg, et al., 2007; Shadden & Agan, 2004). Web-based peer support has been shown to be beneficial for sharing experiences and providing information and encouragement (Pierce, Steiner, & Smelser, 2009; Stone, 2007). For family caregivers peer support means better knowledge and resources when dealing with the changes after

stroke (Stewart et al., 1998). Through sharing, positive feedback and closeness, these caregivers gained in confidence and self-esteem.

When stroke survivors and spouses joined peer associations they were seeking information and support (I, II). The reason for many of them to continue their membership in the associations was their wish to support other stroke survivors and their spouses (III). There emerged a greater focus on their valued social relationships and more concern for others coupled with a greater sensitivity for their struggles. These changes may be interpreted as a reorientation from an individualistic to a more altruistic life view. This shift probably came forth alongside other changes in values and priorities and may be seen as a result of couples' ongoing transitions and transcendence. Similar shifts have been found in other stroke studies (Ch'ng, et al., 2008; Gillen, 2005). Ch'ng reported increased empathy for other stroke survivors and increased ability to express love as a result of positive reinterpretations of life. Studies on chronic illness show similar results of increased empathy and sensitivity for others' suffering as a positive outcome of the illness (Katz et al., 2001; Röding, et al., 2003; Sodergren & Hyland, 2000).

Stroke survivors' and spouses' empathy with other stroke couples was vividly revealed in the interview texts (III). They were more aware of the struggles of their fellow men and often put themselves in their place and felt compassion. They considered themselves lucky after all when observing or imagining other stroke couples' suffering. Comparing seemed to be of great help to see their own possibilities in the midst of losses and called forth gratitude and a strengthened appreciation of life. When stroke survivors became aware of their peers' achievements, comparisons provided hope and something to aim at. Comparisons seemed to have been used to master uncertainty and they helped stroke couples to understand the impact of stroke on their own lives (II). Comparisons facilitate meaning-making and adaptation after stroke, inspiring humility and gratitude and facilitating an optimistic and hopeful life attitude (Bays, 2001; Buschenfeld, et al., 2009; Faircloth, et al., 2004; Kessler, et al., 2009; Röding, et al., 2003). Faircloth et al. (2004) view comparison as a step in the adaptation process of survivors towards familiarity with being a stroke survivor.

Caring and non-caring relationships with health care workers

Caring and supportive relationships with health care workers played a crucial role in strengthening stroke survivors' hope and motivation to continue with rehabilitation tasks (I,

III). The importance of health care workers' caring relationships for the well-being of stroke survivors and spouses has been well documented (Kitzmüller, 2007; MacDuff, 1998; P. Pound et al., 1995; Sundin, Norberg, & Jansson, 2001).

Unfortunately stroke survivors' and spouses' lived experience of being neglected or treated without empathy and respect in health and social care settings overshadowed the positive relationships with health care workers. Children in stroke families received no support from health care workers and parents too missed professional guidance for their parent-child relationships. Non-caring relationships that could not be avoided had a detrimental effect on stroke survivors' self-image and well-being and weakened spouses' ability to maintain an optimistic life view (I, II). These findings highlight the fact that negative discourses on illness and disability exist even in health and social care settings. These negative discourses can be an underlying source of non-caring or neglectful attitudes towards stroke families. Such attitudes, coming on top of the families' loss of social networks, may have devastating effects on the vulnerability of stroke families. By contrast, empathic and encouraging actions are known to hold an empowering influence on stroke survivors' motivation, hope and coping strategies (Kitzmüller, 2007) and may have a positive effect on stroke families' ability to use their possibilities in life.

Supportive and caring relations with family and peers may be further illuminated by philosophical concepts on care. For Heidegger (1953/2001, p. 73) concern ('Sorge') is a substantial existential of being in the world. Being means to be concerned for the objects of the world, to be concerned for oneself and to be concerned for others with whom we share our being-in-the world (p.191-200). Being always means being with others and this kind of being may show itself in indifferent modes or as caring. Caring ('Fürsorge') for other beings is different than being concerned by the objects ('Zeug') of the world as caring relates to another being (p.121). According to Heidegger care may be given in a way that prepares the ground for the other person's being in a deliberating way or alternatively carried out in a dominating manner by depriving the other person of the possibilities of his own being (p.122). These different modes of caring and their consequences were clearly revealed in stroke survivors' perceptions of caring and uncaring actions performed by health care providers (II) and sometimes in spouses' overprotective care (II, III). As Heidegger (p.125) states: '*being as being-with*' prepares the ground for 'Einfühlung', meaning to put oneself into the position of the other. Being able to do so, stroke survivors could compare themselves with others who

had experienced stroke either to learn that their own condition was not so bad after all or to be inspired by peers' achievements (I, III). The lived experience of peers made it easy to put themselves in the position of new peers and prepared the ground for their empathic support.

Heidegger's (1953/2001) existential concept of concern constituting being has been further developed by Benner and Wrubel (1989) and Benner (1994) and it remains an important concept in the work of nursing practitioners and researchers. Benner and Wrubel (1989) refer to the primacy of caring which means to provide conditions for concern and relatedness that enable other beings to deal with difficult situations. The atmosphere created in peer organisations and the positive encounters with health professionals may be seen as reflections of this primacy of caring (I, II, III).

Eriksson (1992, p. 209) defines caring as an ontology, a way of living that represents truly being there for the other within a caring communion. Tolerance, respect and frankness typify this communion where the quality of sharing and the spirit in which caring is performed are the most important aspects. Trust as a fundamental force in human relationships comes forth in Løgstrup's (1956/1999) ethical demand of caring. Løgstrup states that our lives are intertwined as we always hold parts of others' lives in our hands. Other persons are at the mercy of our care, trusting that their appeal for assistance will be answered without any promise of repayment (p.37, 39 & 138). Reciprocal trust and confidence and the good spirit in which caring was performed shone through in couples' stable long-term relationships in Studies II and III. In spite of their burdensome experiences spouses endured caring for their ill partner without claiming anything in return. Stroke survivors in return were aware of their spouses' burdens and showed their concern through trying to relieve their spouses as best they could (II).

According to van Manen (2002) the desire to care for the beloved other stems from worrying for the loved one's well-being. The fear for the endangered or suffering person will increase the desire to care and the carer may be hurt even more by the pain, despair and anxiety of the sufferer. This was obvious in the interview texts of spouses who feared for their ill partners' life and well-being (II, III). Their fears and worries were both an incentive to care and a burdensome consequence of their caring relationship.

7.3 Identity

The meaning of bodily alterations after stroke came forth as living an unfamiliar and vulnerable body (I). The shattered bodily foundation of the self revealed a shaken identity that had to be carefully rebuilt and strengthened. A prolonged journey through unknown territory followed. Grieving, relearning and compensating for lost relationships, roles and activities was the stroke survivors' path, which led to new meanings and values in life that strengthened the self. This process can be understood as a long-term identity⁷ transformative process where disruption, unfamiliarity and objectification of the body gradually lead to adaptation, reintegration and reunion.

In Paper I Zahavi's (2005) concept of subjectivity and selfhood mainly guided the understanding of the bodily roots of identity and the interrelatedness of self, others and world. Changes in self-concept were understood as consequences of alienation and self-fragmentation due to the bodily alterations after stroke (I). Zahavi emphasises the interrelatedness between self, embodiment, inter-subjectivity and world. He claims that these concepts have to be understood interdependently as none of them can exist alone. Our body opens for perceptions and experiences and we 'are' our bodies. Thus we are our embodied selves. The embodiment of our selves opens up to inter-subjectivity. By understanding my own body I get access to others by recognising their perceptions, actions and experiences. In addition our shared community in a common world prepares the ground for inter-subjectivity in mutual understanding. As seen in Papers I and III the stroke survivors' body opened up to intersubjectivity and mutual understanding if their bodily struggles were recognised and met in a positive manner, e.g. by family members, peers or empathic health care workers. However stroke survivors' shaken bodies also became extremely vulnerable to intersubjectivity in an opposite manner through others' negative body language or stigmatising actions. The 'negative gaze' of others had an adverse effect on self.

How illness and bodily alterations give rise to identity transformation may be illuminated by Gadow's (1982) phenomenological concepts. Gadow (p.90) states that the body is experienced as the concrete otherness of the self when its incapacity is experienced by the self. This otherness of the body perceived as the object body initiates a struggle to master the

⁷ The author's understanding of selfhood and identity is grounded in the phenomenological and hermeneutical concepts of selfhood and identity described in Chapter 5. Identity, selfhood and self-concept are used as synonyms in this thesis.

incapacities and to re-establish harmony between body and self. The achieved self-body unity then clears the ground for the emerging subject body. The subject body comes forth as a new manifestation of self in illness and ageing that claims awareness and consideration and conveys meaning to human existence.

Findings in the three papers contribute to the illumination of chronic illness experiences as identity transformation processes as shown by Carpenter, Brockopp, & Andrykowski (1999) , Neill (2002) and Paterson et al. (1999). Asbring's (2001) participants describe identity transformation as 'another' self outside the familiar self, where coming to terms with the new identity brought forth reconciliation, re-evaluation and a different meaning of life. Identity transformation is described by Paterson et al. (1999) as a process where the differentiation of body and self helps participants to separate the self from the illness and allows them to take control. Participants in their study were able to transcend the limitations of the body by focusing on future life goals, thus viewing their possible selves. The concept of 'possible self' or 'potential self' encompasses representations of the self in the future. These perspectives motivate present or future actions and illuminate the importance of maintaining hope and avoiding threats in order to be able to achieve possible selves (Heller et al., 2006; Markus & Nurius, 1986).

Presumably stroke survivors who held strong hopes were able to imagine their possible selves as walking, working or regaining other functions crucial to their self-concept (III). This was clearly revealed when they persistently refused to use wheelchairs but continued trying to improve their gait function. Nevertheless stroke survivors' images of possible selves were sometimes threatened by the premature prognosis of health care workers. The lived experience of stroke survivors and spouses revealed that unfounded negative prognoses meant losing hope and being deprived of aiming towards their possible selves after stroke (III). A self-concept that permits 'possible selves' is more dynamic and includes potentials for growth and change, opening for situational and temporal malleability of the self-concept (Heller, et al., 2006; Markus & Nurius, 1986). It is thus quite clear that stroke survivors' efforts to aim at possible selves should be supported by health care professionals.

Aphasia had a devastating impact on stroke survivors' life-world as the sufferers perceived themselves as incompetent (I) and withdrew from their social network (II). Stroke survivors living with serious aphasia were no longer able to convey their illness stories and share how

these stories were understood within the frame of their life story. Thus important parts of their narrative identity could no longer be shared without the help of others. Shadden (2005) states that identity and language cannot be separated, since language is a tool in identity definition, validation and reframing. Renegotiation of self as a necessity after stroke is most difficult when language has been destroyed by aphasia. Shadden & Hagstrom (2007) underline that the reframing of life stories to maintain continuity in narrative identity forms the very core of life participation and therefore health care workers should view their interactions with stroke families as narrative processes towards a successful framing of the self. According to Nyström (2009) health care workers who have faith in the aphasic patients' capabilities and try to understand their existential doubts are able to support patients' identity, while absence of professional support contributes to feelings of loneliness and frustration.

Life participation and communication through language are crucial for the self-concept as we get to know, adapt and define our selves in social interaction with others (Shadden, 2005; Shadden & Hagstrom, 2007). According to Taylor (Shadden, 2005) a person's identity is powerfully influenced by close relationships as identity requires recognition from others. Stroke survivors experienced that others' gazes and negative reactions confirmed their fears of not being normal and weakened their self-concept further (I, II). Decreased participation due to withdrawal and rejection from others presumably inflicted further fragility on these stroke survivors' self-concept. Lack of social power due to language loss in aphasia may have contributed to an identity of incompetence (cf. Mackay, 2003).

Paper I explored the lived experience of stroke survivors' shaken body and self, but the findings in Papers II and III indicated that spouses' and children's identity was also threatened. Shadden (2005) and Anderson & Marlett (2004) state that changes in self-concept and identity in one member of the nuclear family are likely to influence all other family members in varying degrees. The family's influence on individuals' identity and vice versa involves the concept of social identity. Social identity is defined as *'that part of an individual's self concept which derives from his knowledge of his membership of a social group together with the value and emotional significance attached to this membership'* (Turner in Bennett & Sani, 2004, p.9). The first and most influential social category to which individuals normally belong is the family setting. According to Marcia (Mullis, Brailsford, & Mullis, 2005) the family is likely to be the most powerful social system in which adolescents go through their process of identity formation.

Considering the consequences of a stroke for a child's identity development, parents are known to play an important role by helping their offspring become more or less individuated in their relationships with others (Grotevant & Cooper in Mullis, et al., 2005, p.283). In families with high levels of individuation adolescents can remain close to their parents without perceiving this closeness as a threat to their own identity (Mullis, et al., 2005). Findings in Paper II showed that stroke survivors' children left their family home and moved to a different part of the country during adolescence and early adulthood. These actions may point to a need for these children to avoid both spatial and emotional closeness to help them develop their own identity but also to free their selves from burdening caring duties and responsibilities, as explained by one of the participating children (II). The strained relationship between this child and her parents improved greatly with distance in space and time. She appeared to need this distance to develop her own identity apart from her family and the tasks imposed upon her.

Pederson and Revenson (2005) refer to studies showing that children and adolescents with parents living with chronic illness show lower self-esteem than children and adolescents of healthy parents. Children react negatively when facing the devastating consequences of the stroke on their parent (Fraser, 1997; Harlow & Murray, 2001). As they do not want to differ from their peers they try to cover up their parents' cognitive changes, altered appearance and behaviour (Harlow & Murray, 2001). These changes in children's life-world and their consequences may influence children's self-concept and social identity. Paper II showed that some stroke survivors were aware that their children, no longer perceiving them as normal, were turning away from them. A similar fear of stigmatisation that made survivors retract from social settings may have led to children's withdrawal from their disabled parents.

Spouses experienced a life turned upside down by the stroke and faced similar losses to the ill partner, except from the bodily alterations (II, III). Yet in fact spouses' own bodies were also negatively influenced by their own depressive reactions and by a health decline due to the emotional and caregiving burdens. Spouses too experienced a shift from a familiar to an unfamiliar self as the crisis they were thrown into made them feel they were standing outside their body looking at their selves (III). They had lost appreciated activities and social relationships and sometimes even their work (II). For many spouses caregiving became the foremost endeavour of their life-world. One example in Study III shows how a stroke survivor's cognitive decline influenced the self-perception of his young, previously healthy

and optimistic spouse who now viewed herself as exhausted and old in the aftermath of her husband's stroke.

Jongbloed (1994, p.1006) states that stroke cannot be understood as an individual phenomenon as it interrupts the life course of both members of a couple. Changes in one of the spouses' identities may force the other spouse to adapt to these changes, thus challenging his or her own identity (S. Anderson & Marlett, 2004; Buschenfeld, et al., 2009; Reid et al., 2006). The couple's mutual identity was seen in both couple and individual interviews (III). There emerged strong expressions of shared experiences, emotions and perceptions pointing to their 'we-ness'. Couples have to manage their illness within the context of both their individuality and mutuality in order to become sensitive to each other's emotions, moods and needs and to adjust themselves to these (Corbin & Strauss, 1984). They use dyadic strategies where appraisal and coping efforts stand in relation to each other when dealing with chronic illness (Berg & Uppchurch, 2007) and they develop a mutual identity, also called 'couple identity' (Badr, Acitelli, & Taylor, 2007; Fergus & Reid, 2001; Reid, et al., 2006; Rink & Ellemers, 2007; Skerrett, 2003, 2010).

Through helping and being helped, the couple's life threads seemed to be woven together. Although still struggling with the consequences of stroke, most couples experienced that their relationships were strengthened in the long run (II). According to Fergus & Reid (2001) a couple's mutual identity arises out of their mutual belonging and sense of we-ness grounded in the give and take of the relationship. Broader self-concepts where couple identity is integrated into individuals' self-concepts mediate the burden of caregiving (Badr, et al., 2007). It is known that the mutual identity in couples living with stroke is strengthened by the interdependency of their activities of daily living when they must act as one body with two minds (van Nes, et al., 2009).

Based on a review of family function after stroke, Palmer and Glass (2003) consider stroke rehabilitation to be a collaborative process where rebuilding the foundations of identities, roles and relationships in the family is just as important as the recovery of mobility. Several interview texts revealed powerful descriptions of how families pulled together and supported each other but also how the ill parent's condition strongly influenced the children (II). This can be seen as experience of being part of a family identity that had to be both fought for and preserved. Steinglass et al. (1987, p.58) define 'family identity' as: '*... an underlying*

cognitive structure, a set of fundamental beliefs, attitudes and attributions the family shares about itself.... These shared beliefs provide a template for coherence and shared meaning-making (Walsh, 2006). McLain and Weigert (1979, p.173) speak about 'family consciousness' that constitutes a unique family attitude. The 'family world' is perceived as meaningful and always at hand and holds unique kinds of interaction and communication (Hansen & Johnson in McLain & Weigert, 1979, p.173). Underlying family themes form families' patterns of feelings, motives, fantasies and understandings (Steinglass, et al., 1987, p.58). McLain and Weigert (1979, p.173) claim that the familial 'we' and the 'enfamilied self' are a central source of identity permanence throughout life. Family members are not always consciously aware of their family identity but in times of transitions and major crises family identity is made explicit as a starting point for the actions the family has to take (Steinglass, et al., 1987). Most of the participating families seemed to have had a favourable starting point based on their strongly founded family identity which had been developed over many years and which was further strengthened by the crisis (II, III).

Family structure and identity are established early in the life cycle of a family and are seen as a critical developmental issue in families (Steinglass, et al., 1987). Family bonds are stronger in the middle phase of the developmental life cycle of a family, which is characterised by more commitment and stability than the early establishment phase. Families who had not established strong family identity seemed to fall apart (Table 2), whilst strong family bonds were seen in families who managed to adapt well to the challenges of a stroke (II, III). These families underlined the significance of their long-lasting and loving relationships for being able to face the challenges. One may assume that these families had developed a strong family identity that helped them to find a path to deal with illness and crisis.

A family's identity cannot develop without being negotiated within its social and cultural environment. Harré (1998, p.177) states that our selves are manifested in the conversations in which we engage with others as they will read our selves in our speech and actions. As the gazes and negative reactions of others reinforced stroke survivors' feelings of being altered and being 'other' than before (I) it is likely that these stroke families' perceptions of their identity were vulnerable to others' reactions and the stories being told about them. References to family members as disabled, on welfare, handicapped, needy or powerless may have had a negative impact on the self-concept of all family members.

Family members often told parts of the family's life history along with their illness experiences and these experiences were viewed in the context of their earlier family life (III). Stories about their past, present and their envisioned future were seen as an important meaning-making endeavour that illuminated the place of the illness in the family's life-course. The severe illness experiences contributed to these families' narrative identity. It is known that couples reflect their mutual identity and strengthen their relationship and compassion through telling their illness stories (Skerrett, 2003, 2010). Langellier & Peterson (2006) state that the family's stories form the basis of the family's narrative identity over time. As mentioned earlier in this thesis, individuals create and negotiate their narrative identity by telling their life stories and by integrating other's stories about themselves into their narrative identity (Ricoeur, et al., 2002). As illness represents a threat to identity and continuity of life there is a need for integrating changes into life narratives (Hydén, 1997). Ill people try to bridge disruption and discontinuity through the illness narratives they create (Ellis-Hill, Payne, & Ward, 2008; Frank, 1995, 2002; Kleinman, 1988; Murphy, 1990; Rimmon-Kenan, 2002) and the differing content of illness narratives prepares the ground for change and enlightenment (Frank, 1995).

Kleinman (1988) underlines the meaning-making and healing function of narratives not only for ill persons themselves but also for their family members. The families in this study seemed to have formed a common narrative identity where illness experiences had been integrated (III). With few exceptions the stories they shared were common stories indicating strengthened family closeness and solidarity.

7.4 Transitions and self-transcendence

The findings in Papers I, II and III demonstrated how the lived experience of a major stroke incident altered stroke survivors' life-world from being healthy and independent into a situation of illness, disability and dependency and feelings of being unfamiliar with their bodies and lives. These changes required long-term transitions in order to allow adaptation to extensive bodily changes, alterations of roles and relationships, changes in working conditions and a decrease in appreciated activities (I, II, III). Altered perceptions of life-world (III) and self (I) were revealed. Spouses had to face the transitional experience of becoming a caregiver and adapting to increased responsibilities and various losses caused by the stroke (II & III). Sometimes they even experienced health-illness transitions themselves due to emotional strain and burden (II & III). The lived experience of children in stroke families revealed situational

transitions interpreted as the absent presence of their parents triggered by hospitalisation and the healthy parent's caregiving burden and emotional distress (II). Sometimes the child had to take on the role of caregiving and was introduced to responsibilities beyond capacity.

Presumably taking on heavy responsibility too early forced these children into premature developmental transitions and led them to leave home earlier than the norm.

Transition theory may provide tools for illuminating the transitional changes in the life-worlds of these families, as this theory explains the significance and course of changes in human life (Schumacher & Meleis, 1994). Transitions are defined as passages from one state, condition or place to another (Chick & Meleis in Schumacher & Meleis, 1994) and they are marked by the direction and process of changes in fundamental life patterns (Schumacher & Meleis, 1994). As stated in Meleis et al. (2000, p.19) '*Transitions are both the result of change and result in change*'. Goodman et al. (2006) state that life changes can only be characterised as transitions by the individual who experiences the change because they have varying implications for individuals. Transitional experiences involve changes in internal processes related to e.g. change in identity, roles, relationships, abilities and behaviour (Schumacher & Meleis, 1994). Findings in the three papers showed that these kinds of changes occurred in couples' lives as they moved through the illness trajectory. In-depth explorations of the transitional concept applied to stroke were not found in the research literature. Nevertheless the term 'transition' or similar terms indicating transitions have been used in research on stroke survivors (Eilertsen, et al., 2010; Ellis-Hill, et al., 2008; Glass & Maddox, 1992; Hilton, 2002), spouses (Bäckström, Asplund, & Sundin, 2010; Pierce & Wiklinson, 1999) and children in stroke families (Fraser, 1999).

Meleis et al. (2000) state that premises for transitions are awareness of the ongoing process and engagement in the changing experiences. Stroke survivors' early endeavours of searching for the meaning of what had happened and what had caused the stroke (III) can be seen as efforts to gain insight into, describe and integrate the life-changing effects of stroke. Spouses also seemed to enter transitions early by trying to make meaning out of the chaos the stroke had induced in their own and their ill partner's life. Research on stroke confirms that understanding the cause of the illness is of great importance for how to focus on future life (Bendz, 2003; van Veenendaal, Grinspun, & Adriaanse, 1996).

In accordance with Secrest's (2000) findings, stroke survivors and spouses experienced both similar and different changes. Stroke survivors became changed from within by the consequences of the illness on their body (I, III), whilst the spouses' lives were altered from without due to the life-changing consequences of their partner's illness (II, III). For all members of the stroke family entering transitions meant facing the ending of something (cf. Bridges, 2004). For the stroke survivor, the healthy and familiar body had ceased to function (I & II), while for the spouses their familiar and predictable family life had ended (II & III) and for the children the formerly active presence of their parents had now become an absent presence (II). The couple as an entity was grieving over the broken foundations of their relationship (II). The transitional experience of stroke meant that the couples were thrown into an unfamiliar being where they experienced their whole life-world as twisted (II, III). Stroke survivors' renegotiation of their identity and spouses' adaptation to changes were seen to be either enhanced or hindered depending on positive or negative encounters with their surroundings (I, II). Being supported by others was crucial for progressing in their transitional process. Lacking information or being deprived of hope was a hindrance (II). According to Meleis et al. (2000) feeling connected and confident and being able to reformulate one's identity has a positive influence on transitions. Through communication and cooperation couples develop and change meaning perspectives and actions in response to transitions (Kessler, et al., 2009).

Couples needed professional support that in turn could facilitate this transitional process but they were left inadequately prepared (II, III). Stroke survivors and spouses appeared to need different kinds of professional support. It seemed to be essential for the stroke survivors to comprehend the cause of the stroke, in order to integrate its devastating consequences into their life narratives - narratives that included a dysfunctional and unfamiliar body. On the other hand, spouses needed support for understanding the impact of the stroke on their own life; this would have facilitated integration of its consequences into their present and future circumstances (III). Research into transitional life experiences reveals that in addition to spousal and network support the emotional support given by professionals has an important influence on transitions (Brammer, 1991; Glass & Maddox, 1992; Goodman, et al., 2006; Schumacher & Meleis, 1994). On the other hand lack of professional support (M. A. Johnson, Morton, & Knox, 1992) and stigmatising discourses on illness and disability in society (Meleis, et al., 2000) hinder successful transitions.

According to Bridges (2004) transitions are filled with chaos and strangeness but nevertheless a reorientation takes place and a shift is made to a different life stage. Transitions usually involve emotional distress, such as anxiety, insecurity, self-criticism and feelings of being overwhelmed (Schumacher & Meleis, 1994). Although loss and grief may dominate, a readiness to explore new possibilities arises and steps are made towards a renewed identity (Bridges, 2004). For couples in Paper III transitions meant facing multiple worries and fears and experiences of wavering time. Past, present and future had to be restructured in order to reshape continuity in their lives. These findings are similar to those of Hjelmblink and Holmstrom (2006) indicating that the constant fear of another stroke and the prospect of an uncertain future turn knowledge of being mortal into a deeper understanding of temporality and vulnerability. The process of restructuring life for caregiving that pervades spouses' life-world is described as a period of waiting, rearranging and stabilising where the caregiver has to come to terms with the unfamiliar and demanding role of caring for the ill partner (Silva-Smith, 2007). Findings in Study II revealed these processes as demanding and prolonged.

Transitions are often marked by periods of withdrawal, where loneliness and emptiness are natural feelings that may help to prepare for adaptation (Bridges, 2004). Both stroke survivors and spouses conveyed such feelings; these were often interpreted by themselves and others within the paradigm of natural sciences as e.g. depression, fatigue and social retraction (II, III). Within the transitional framework these reactions are viewed more positively as states of waiting in limbo where energy must be regained and a reorientation towards a new mode of being-in-the-world takes place (Bridges, 2004). Although spouses' transitional experiences were typified by a sense of loss, the positive consequences of caregiving came forth in personal growth and greater closeness to the partner. This is in accordance with Seltzer and Li's (2000) findings which reveal caregiving as a possible source of social involvement and personal growth.

Hope seemed to provide considerable guidance on stroke survivors' and spouses' transitional journeys (III). Strengthened by their hopes couples engaged in actions such as searching for new activities and new social relationships that provided options for a better future. Hope is a source of strength, harmony and life spirit in addition to its motivational effect on rehabilitation efforts (Burton, 2000; Cross & Schneider, 2010; Duggleby, et al., 2010; Popovich, Fox, & Burns, 2003). A review on the significance of hope after stroke shows that hope supports adjustment, coping and thinking of the future and nurtures positive

consequences of transitions (Bright, et al., 2011). Hope enables people in transitions to use positive strategies to deal with their experiences (Bloch & Richmond in Goodman, et al., 2006).

Transitional processes involve new beginnings, characterised by actions to reengage in former activities, relationships and projects or engage in new activities that are compatible with the changed life situation (Bridges, 2004; Rancour, 2008). This was seen when stroke survivors gradually started to integrate the residual impairment into their self-concept (I). Together couples performed actions to rearrange their lives and adjust to the changes, e.g. by engaging in new activities and relationships (II). Participants' transitions were interpreted as long-term processes wavering back and forth between grieving the losses, reengaging in former activities, striving to regain familiarity and acquiring a new meaningful purpose in life (III).

Early in their transition processes couples clung to the past and compared their former life with their present life shattered by the stroke and its consequences. As time went by they adopted a renewed orientation towards the future. Couples' previous experiences with transitions were seen to have an important influence on the new transition caused by the stroke (I, II, III). Knowing that they had mastered earlier changes and life crises and were in possession of suitable strategies and resources gave them strength. Perceptions of their past and future were integrated in a way that improved the quality of their recent life (cf. Coward & Reed, 1996). These findings are confirmed by those of Goodman et al. (2006), emphasising the positive consequences of earlier transitional experiences in preparing for new transitions.

Couples' transitions may be understood as a movement directed towards new possibilities and new values in life (II, III). They had lived several years with the post-stroke challenges and most of them had arrived at a new kind of meaning-making as a result of their transitional experiences (III). Their lived transitions had opened up for a reinterpretation of life. Their former values changed and most couples arrived at new values. Facing vulnerability and being confronted with life as limited seemed to have called forth a transition into a process that provided a new, more conscious and appreciative mode of being-in-the-world.

Couples' existential experiences can be viewed within the phenomenon of self-transcendence as a prolongation of their lived transitions. Self-transcendence is seen as a way to overcome the limitations of the body and to enjoy life in a deeper sense than before even when facing

severe disability and death (Corbin & Strauss, 1987; Lindsey, 1996). The findings in Paper III mentioned above pointing to positive reinterpretations of life are supported by P.G. Reed's (1996) theory⁸ of self-transcendence. Self-transcendence holds the power to release developmental progress toward a renewed sense of identity that connects person and self (P.G. Reed, 2008) and leads to increased self-awareness and introspection (Coward & Reed, 1996). Through these transcendental processes the self becomes more closely connected to the environment and to communion with others and more is invested in appreciated relationships. Receiving help from others and helping others are seen as important features of self-transcendence (Runquist & Reed, 2007). The interview texts revealed that close relationships with family and friends became more precious than before (III). Engagement with peers seemed to help promote growth and move the focus beyond the couple's own problems (I, II, III). In self-transcendence, according to P.G. Reed (2009), individual values go hand in hand with an increased awareness of dimensions greater than self. Neill (2002) describes self-transcendence as a way of expanding one's consciousness and transcending one's self-boundaries by focusing positively on life despite illness. Lindsey (1996) describes it as feeling healthy within illness. The interview texts revealed that although still struggling with disability, stroke survivors' conceived themselves as lucky or viewed some of their disabilities as bagatelles (III). Paterson et al. (1999) state that transitional experiences hold the power to alter illness responses, as perceptions of being healthy within the illness arise and mediate its impact.

In accordance with the research findings above, couples' lived experiences of changed values and priorities, deeper appreciation of life and movement towards a greater concern for others can be interpreted as self-transcendence. These changes seemed to be induced by their confrontations with critical illness, possible death and multiple losses (III). Papathanassoglou & Patiraki (2003) state that the transforming force of living through critical illness contributes to development of the self and inspires personal growth and spirituality.

⁸ P.G.Reed's theory (1996; 2008) draws on life span developmental theory and on several nursing theories and includes three major interrelated concepts; self-transcendence, well-being and vulnerability. This theory postulates that life events such as illness, ageing and life crises may increase vulnerability that mediates self-transcendence and improved well-being. Well-being is determined by the person's own perceptions of health and wellness and vulnerability is defined as awareness of personal mortality (P.G. Reed, 2008, p.108). Little is known about which factors may facilitate self-transcendence but personal and contextual factors are supposed to influence the relationship between vulnerability, self-transcendence and well-being (P.G. Reed, 2008).

Most couples who had lived in devoted, long-lasting or strongly founded relationships may be seen as having experienced self-transcendence (II, III) but the time that had passed since stroke onset was also an influential factor. Couples who had lived with stroke for a very long time (Table 2) seemed to have experienced more of these changes. Their experiences of a diminished focus on material goods in favour of appreciated relationships with others and their orientation towards the gift of life versus one's own mortality as shown in Paper III can be interpreted as existential growth in the meaning of exceeding one's boundaries towards a more authentic mode of being. They may also be interpreted as a means to impart meaning to the consequences of illness and to regain familiarity and congruence in one's life. The severe illness experiences which this thesis reveals as possible sources of existential growth and exceeded boundaries in both stroke survivors and spouses are in accordance with the results of previous studies and reviews on stroke (Ch'ng, et al., 2008; Eilertsen, et al., 2010; Gillen, 2005; Haley, et al., 2009; Kessler, et al., 2009; Lawrence, 2010; Palmer & Glass, 2003; Stone, 2007; Subgranon & Lund, 2000)

The existential changes in couples' life-worlds have been interpreted from the viewpoint of Heidegger's (1953/2001) concepts of being-to-death and authentic versus unauthentic being in Paper III. Participants' search for meaning and their transitional and transcendental experiences evoked by the stroke may be further illuminated by the ideas of Frankl (1973) and Jaspers (1973). According to Frankl (1973) man's desire for meaning is one of the most central features of being human. Although man is determined by biological, psychological and sociological boundaries it is possible for him or her to take a stance facing boundaries that cannot be exceeded. Human existence although confronted with suffering, guilt and death can never be meaningless. Transcendence comes forth in the attitude by which man faces destiny. Self-transcendence is seen as the 'essence of existence' defined as intentionality towards something or someone beyond oneself, either the loving encounter with others or meanings waiting to be fulfilled (p.75). Seeking for meaning and values beyond the self transforms the self and brings progress and growth into being. Being human is to show responsibility towards these choices and strive to achieve values within the limits of mortality. Frankl's (1973) concepts may explain the meaning-seeking actions of the couples illuminated in Study III. The path to self-transcendence began when couples tried to understand the meaning of the illness experience in their life course. Further meaning emanated from the caring relationships within families and peer organisations and from their expanded boundaries in life.

According to Jaspers (1973) man cannot escape from the limit situations (*'Grenzsituationen'*) of human being as they are our boundaries of history, origin, gender, age and social conditions (p.209). Encountering these limit situations means losing one's foothold and groundedness and being exposed to suffering, struggle, guilt and death (p.203, p.249). How man meets the limit situations decides if he remains in 'simply being' or enters into real existence. To enter real existence means to face the limit situation with one's eyes wide open without denial or flight through an inner process of solitude. Only then will man reach the meaning and core of existence and be transformed into someone else than before (p.204-206). As illness and suffering are inescapable parts of the human condition one has to accept them consciously as features that may release a transcendental force (p.230-232). To realise and accept these conditions provides the possibility to experience real fulfilments that only spring forth in the shadow of suffering (p.232). Jaspers' concept of real existence may be compared with Heidegger's (1953/2001, p.260) term of 'authentic being' referred to in Paper III. Both concepts may explain the participants' changes in beliefs and values in life. The existential challenges forced couples to realise and face limit situations, sometimes even the experience of impending death (III). Living with these experiences and realising and accepting human vulnerability may explain their experiences of existential growth, expanded boundaries and heightened consciousness of enjoying life while possible.

8.0 Concluding remarks with implications for practice and research

The aim of this thesis was to illuminate the long-term lived experience of stroke within a family context and to answer the research question: What is the meaning of the phenomena revealed in the long-term lived experience of stroke survivors and their families? An in-depth exploration of the original articles revealed certain phenomena which stood out in these families' experiences. These phenomena marked the families' transitions generated by the stroke and its consequences. The phenomena were: communication; relationships; identity. They all seemed to have had a significant meaning in the participating families' lives since stroke onset and were still marking these families' life-worlds.

Communication was perceived as a considerable challenge in these families. Buber's (1983; 1998) and Gadamer's (1960/1990) understanding of genuine dialogues illuminated how our life-world is grounded in communication through language. Role changes, altered relationships, loss of appreciated activities and dependency challenged families' communication patterns. Mutual understanding between family members was threatened as they experienced considerable obstacles to communication with aphasia being the worst. A literature review updated in 2012 revealed few stroke studies that focus on communication in stroke families. This thesis may contribute to increased awareness of family communication during a stroke trajectory.

Caring and supportive relationships provide an incentive to go on with life. The significance of caring relations in the human life-world was illuminated by Heidegger's (1953/2001) concepts of being concerned and being-with. The family was perceived as a lifebuoy and all family members were strongly dependent on their family relationships. Supportive relationships with peers in stroke and aphasia support groups contributed to couples' knowledge about the illness and facilitated adaptation to the consequences of stroke. Being supported themselves and later being able to help peers strengthened stroke survivors' perception of self. Generally caring relationships supported families during transitions. Families who remained without sufficient support had to face existential loneliness and short-term couple relationships with weak foundations fell apart. The participants, especially spouses and children, missed informational and emotional support from health care workers. The study's findings regarding relationships agreed with the results of earlier stroke studies that indicate the importance of family support. What this thesis added was a deeper

exploration of both family and peer support strengthening couples' options to enter successful transitions.

For the stroke survivor the meaning of the bodily changes after stroke was interpreted as living an unfamiliar body and experiencing altered perceptions of self. Negative judgements from others came on top of lost activities, positions and roles and threatened the self. Zahavi's (2000, 2005) understanding of self and Gadow's (1982) concept of the subject body offered insight into the self as an embodied self that is dependent on others' perceptions. This thesis added knowledge about spouses and children being exposed to identity threats when the family experiences a major stroke event and the whole family's identity is challenged. The findings further indicated that the male and female stroke survivors in this sample experienced similar threats to their self-concept.

Stroke families' transitional experiences came forth in their long-term struggles to adapt to an altered life situation. For stroke survivors these changes were induced by their bodily alterations. Spouses were thrown into transitions by facing a twisted life-world where altered roles and relationships in addition to loss and caregiving burden threatened well-being. Nevertheless positive consequences of caregiving were seen in this study, e.g. personal growth and a closer relationship with the partner. Children had to face situational and developmental transitions when experiencing their parents' absent presence. Maintaining hope and applying meaning-seeking strategies seemed to be important for couples dealing with transitional experiences. Health care workers' actions could support or shatter couples' hopes for a better future.

A heightened awareness of being mortal came forth during couples' transitions and both stroke survivors and spouses experienced similar existential threats. While most weakly founded couple relationships fell apart, couples in stable long-term marital relationships often arrived at new values in life and this process was interpreted as self-transcendence. Philosophical concepts regarding being, such as being-to-death (Heidegger, 1953/2001), limit situations and real existence (Jaspers, 1973) and the human search for meaning and self-transcendence (Frankl, 1973) shed light on participants' transitional and transcendental experiences. Various terms indicating transitional experiences in stroke survivors' lives have been used in stroke research. This thesis contributed to this area with a deeper exploration of these processes in the lives of both stroke survivors and their spouses. The phenomena that

appeared in these stroke families' lives were long-term phenomena that called for prolonged supportive actions, not only from family members and peers but also from health care workers.

Implications for practice

The phenomena explored in this thesis, based on the results of Studies I-III, indicate certain implications for practice. Although stroke families' path to adaptation and reconciliation has been shown to be a protracted journey, most of the support is given at the start of the stroke trajectory and mainly to the stroke survivor. Stroke survivors and their families' long-term struggles revealed the need for long-term professional guidance and support to all members of the nuclear family. To include members of the extended family also seems to be important as they may provide essential support to the nuclear family. Professional help for stroke families should consider the individual challenges faced by each stroke family in order to adapt support as well as possible. An awareness of families' interaction patterns and developmental stages at stroke onset seems to be important, especially in the case of vulnerable families. The need for continuity of relationships between health care workers and stroke families is obvious. When entering into genuine dialogue with stroke families, continuity is needed to explore the specific challenges in each family's life-world. Attentive listening to family members' illness narratives and the meaning they attach to them will provide insight into their existential challenges and may point to convenient pathways of support. In addition this endeavour may guide health care workers in how to help families arrive at shared understandings.

As communication is involved in all phases of the stroke trajectory, health care workers should focus strongly on communication strategies. All three papers clearly reveal the need for more and better information to support families' search for meaning and reorientation in life, thus underlining the importance of well-adapted communication strategies. Skill and experience are needed to prepare stroke families for their future challenges without shattering their hope. Maintaining hope is crucial to keeping up their life spirit and to persevering with their rehabilitation efforts. Preparing for family togetherness throughout the stroke trajectory and guiding family members in communicating their thoughts and emotions openly may help families to avoid emotional shielding, isolation and negative feelings. This may also enhance collaborative problem solving in stroke families. A greater focus on children in stroke

families is needed to assist parents in communicating with their children and being aware of behaviour patterns that call for professional attention.

Aphasia was perceived as the worst disability after stroke due to its devastating influence on social relationships, self-concept and the marital relationship. Therefore health care workers should focus more on mediating the serious consequences of aphasia. Families' unsatisfied needs may require health care workers to improve their knowledge and skills regarding aphasia. Teaching family members and friends how to communicate with the aphasic stroke survivor and how to maintain networks ought to be important tasks. It may also be beneficial for health care workers to inform friends and extended family about the stroke and its consequences in order to preserve supportive relationships. Cognitive disabilities and changes in personality are shown to have a negative influence on family relationships. Therefore families facing these challenges have a huge need to be informed and prepared for how to provide family care in spite of their mixed emotions for the ill family member. These families are obviously in particular need of regular respite.

As the consequences of stroke seem to leave their mark on the identity of stroke survivors, spouses and the whole family, helping these families to renegotiate identity would seem to be of utmost importance. Both the family's and the individuals' life cycles should be considered when providing support to families. To support identity renegotiation health care workers should explore the core identity issues for stroke survivors and spouses and help them to maintain or re-establish important roles, activities and relationships or to engage in new life tasks and relationships to strengthen identity. Allowing stroke survivors to view their possible selves may encourage them to continue with their rehabilitation efforts aiming at new goals. Since the contribution of peers was perceived as strengthening identity, joining peer organisations should be strongly encouraged by health care workers. Spouses' self-concept may be supported through guidance on how to care for their ill partner with a view to increasing independence and avoiding overprotection. Information about available health care services and the implementation of any services required may help spouses to keep the energy to maintain relationships and activities and could be a source of long-term emotional support for stroke families. The establishment of more rehabilitation centres, known in Norway as "learning and mastery centres", which include the whole family may provide essential guidance on how to adapt to life changes in the aftermath of stroke.

Health care workers' perception of stroke as an event that leads to transitions and possible self-transcendence may expand their pre-understandings of stroke into an understanding that the illness strikes the life-world of both stroke survivors and their families. This knowledge may increase readiness to support all members of the nuclear family to adapt to these transitions. Fatigue, depressive thoughts, grief and fear should be viewed as reactions occurring within transitions and should be accepted and adapted to rather than viewed as illness symptoms to be fought with medication. Although such inward-looking reactions seem a natural part of the process of regaining familiarity with the alterations of body and self, long-term withdrawal calls for guidance and support to avoid loss of networks.

Hope-related strategies were seen to hold an important place during transitions and health care workers should explore and support these strategies. If meaning-making endeavours and self-transcendental forces are enhanced by both health care workers and peers, stroke families may more easily attain the positive consequences of the illness.

As self-perception is strongly influenced by the attitudes and reactions of others, health care workers should focus on the positive aspects of stroke discourses. If stroke survivors and their families are perceived competent to take actions in their lives in spite of their need of guidance this will strengthen their self-concept. Being treated with respect and empathy will strongly influence these families' motivation to make the best of their possibilities in life.

Implications for research

The results of this thesis may point to directions for further research on this topic. The influence of stroke on family caregivers' concept of self should be further explored with a view to improving support for these people and preventing poor health and well-being. More experiences of children after a parent's stroke should be revealed in order to improve support and guidance through childhood and adolescence. Parenting after stroke still is an unexplored field. Little is known about suitable interventions by health care workers to help stroke families through their transitional and transcendental experiences; further research on this topic is therefore needed. Knowledge about stroke families' needs for long-term support should be an incentive to explore the possibilities for future long-term care for these families.

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Cover picture: Mathilde Løkke Velvin, Tromsø

Paper I

Paper II

Paper III

Appendices

Appendices

1: Ethical approval granted by the North Norwegian Regional Research Ethics Committee

2: Approval granted by the Norwegian Social Science Data Services

3: Information to local leaders of stroke organizations and home care nursing

4: Informed consent

5: Interview guide, stroke survivors

6: Interview guide, spouses

7: Interview guide, adult children

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**P REK NORD 55/2008 – "Å LEVE MED UTFALL ETTER HJERNESLAG" – PROSJEKTET
GODKJENNES**

Prosjektet ble lagt fram for Regional komité for medisinsk og helsefaglig forskningsetikk, Nord-Norge (REK NORD) i møtet 10.04.2008. I referatet heter det:

Et hjerneslag medfører ofte store omveltninger i livet, for den som rammes og for nære familiemedlemmer. De fleste som rammes av slag får ulike funksjonshemninger som kan vedvare resten av livet. Den overordnede målsettingen med studien er å vinne ny kunnskap om hvordan det er å leve med følgene etter hjerneslag, både for den som rammes og for nære pårørende og hvilke oppfølgingstiltak pasient og pårørende anser som viktige. Studien planlegges gjennomført som en kvalitativ studie med en hermeneutisk fenomenologisk tilnærming hvor datainnsamlingen skjer ved hjelp av narrative intervju og fokusgruppe-intervju. Den skal resultere i tre vitenskapelige artikler som publiseres i internasjonale tidsskrifter. Artiklene vil henholdsvis presentere resultatene fra intervjuene med pasienter, ektefeller/samboere og barn over 18 år som har vokst opp sammen med en far eller mor som levde med følgene av hjerneslag. Utvalget rekrutteres via interesseforeninger og hjemmesykepleie.

Komiteen klassifiserer prosjektet som ikke-terapeutisk annen helsefaglig forskning på friske og syke voksne. Doktorgradsprosjekt for Gabriele Kitzmüller.

Komiteen har ingen merknader til prosjektet, som virker godt gjennomarbeidet.

Vedtak:

Prosjektet godkjennes

Vennlig hilsen



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Vår dato: 29.05.2008

Vår ref: 18954 / 2 / JE

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TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 03.04.2008. Meldingen gjelder prosjektet:

18954

*A leve med utfall etter hjerneslag - en studie som setter søkelys på erfaringer og behov for
helsehjelp til mennesker som lever med ulike funksjonsbemninger etter hjerneslag, og
hvordan nære pårørende påvirkes av slike forandringer*
Universitetet i Tromsø, ved institusjonens øverste leder
Gabriele Kitzmüller

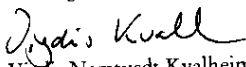
Behandlingsansvarlig
Daglig ansvarlig

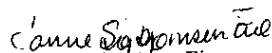
Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema,
http://www.nsd.uib.no/personvern/forsk_stud/skjema.html.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig. Prosjektet kan settes i gang.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Janne Sigbjørnsen Eie

Kontaktperson: Janne Sigbjørnsen Eie tlf: 55 58 31 52
Vedlegg: Prosjektvurdering

Informasjon vedrørende Doktorgradsprosjektet: "Å leve med utfallene etter hjerneslag" til ledere i Afasiforbundets lokallag, Norsk forening for slagrammedes lokallag og ledere i hjemmesykepleien

Takk for telefonsamtalen og for at du har sagt deg villig til å hjelpe meg med å få tak i mulige informanter til mitt forskningsprosjekt. Prosjektet er godkjent av Regional Komité for Medisinsk og Helsefaglig Forskningsetikk Nord-Norge og av Norsk Samfunnsvitenskaplige Datatjeneste. I slike prosjekter kreves det at man bruker en formidlende instans for å få ta kontakt med mulige informanter. Derfor trenger jeg din hjelp.

Vær vennlig og les informasjonsbrevet til informantene først. Det er viktig for meg å få kontakt med personer som har levd med funksjonshemninger etter hjerneslag i minst tre år, og en av deres nærmeste pårørende. Personene som har hatt hjerneslag bør ha god språkforståelse og kunne kommunisere i tilstrekkelig grad slik at man unngår misforståelser så langt som mulig. Jeg er forberedt på at samtalene kan være tidkrevende. Du kan informere aktuelle deltakere om at jeg i tillegg til lang yrkespraksis også har erfaring med intervju av afasipasienter gjennom tidligere studier.

Utvalgskriteriene er:

Deltakere som lever med følger etter hjerneslag:

Deltakerne i prosjektet må være over 18 år, bo hjemme og skal ha levd med sine funksjonshemninger i minst tre år etter at sykdommen oppstod. Deltakerne må ha god språkforståelse og kunne meddele seg. Helsetilstanden må være så god at de er i stand til å vurdere sin deltakelse selv.

Deltakerne som er pårørende:

Deltakerne må være over 18 år og bo eller ha bodd sammen med et nært familiemedlem som har vært rammet av funksjonshemninger etter slag i en tidsperiode som strekker seg over minst tre år. Slektsforholdet til den

slagrammede kan være ektefelle, samboer, datter eller sønn. Pårørendes egen helsetilstand må være så god at de er i stand til å vurdere sin deltakelse selv.

Både den som har funksjonshemninger og nære pårørende i samme familie kan delta.

Det jeg nå ber deg om å gjøre så snart som mulig, er å videresende forespørselsbrevet med samtykkeerklæringen til personer som fyller utvalgsriteriene. Jeg vil også be deg om å notere ned hvor mange du gir dette brevet til, og om disse er slagrammede eller pårørende.

De som ønsker å delta skal sende et eksemplar av samtykkeerklæringen med underskrift til meg i de frankerte konvoluttene som du finner vedlagt, det andre eksemplaret skal de beholde selv. Deretter vil jeg ta kontakt med de interesserte over telefon.

Tusen takk for hjelpen!

Vennlig hilsen

Gabriele Kitzmüller

Høgskolelektor/Stipendiat ved Høgskolen i Narvik,
Institutt for Helse- og Sykepleievitenskap

Priv. adresse:

Tiurvn. 29,

8516 Narvik

tlf 91155475 eller 76966168 (jobb)

e-postadresse er: gk@hin.no

Forespørsel om deltakelse i et forskningsprosjekt som setter søkelyset på hvordan det er å leve med ulike funksjonshemninger etter hjerneslag, både for den som rammes og nære pårørende

Undertegnede som skal gjennomføre studien, er sykepleier og klinisk spesialist med videreutdanning i eldresykepleie, og høgskolelektor og stipendiat ved Høgskolen i Narvik. Jeg er doktorgradsstudent ved Universitetet i Tromsø, Medisinsk fakultet, Avdeling for Sykepleie- og Helsevitenskap. Mine veiledere er professor Kenneth Asplund og 1.amanuensis Terttu Häggström, og førstnevnte står formelt ansvarlig som prosjektleder for studien.

Studiens målsetting:

Målsettingen med mitt doktorgradsprosjekt er å vinne ny kunnskap om hvordan det er å leve med følgene etter hjerneslag både for den som er rammet og for nære pårørende. Studien skal også gi ny kunnskap om hvorvidt pasienter og pårørende er tilfreds med hjelpeapparatet og om det finnes udekkede behov for tjenester som ikke finnes i dag. Funnene i denne studien vil bli analysert og tolket og vil bli offentliggjort i internasjonale vitenskapelige tidsskrifter og norske fagtidsskrifter og media.

Hvem som kan delta:

Deltakere som lever med følger etter hjerneslag:

Deltakerne i prosjektet skal være over 18 år, bo hjemme og skal ha levd med sine funksjonshemninger i minst tre år etter at sykdommen oppstod. Deltakerne må ha god språkforståelse og kunne meddele seg. Helsetilstanden må være så god at de er i stand til å vurdere sin deltakelse selv.

Deltakerne som er pårørende:

Deltakerne må være over 18 år og bo eller ha bodd sammen med et nært familiemedlem som har vært rammet av funksjonshemninger etter slag i en tidsperiode som strekker seg over minst tre år. Slektsforholdet til den slagrammede kan være ektefelle, samboer, datter eller sønn. Pårørendes egen helsetilstand må være så god at de er i stand til å vurdere sin deltakelse.

Både den som har funksjonshemninger og nære pårørende i samme familie kan delta.

Hvordan skal informasjonen innhentes:

I løpet av en til to individuelle samtaler med informanten ønsker jeg å ta del i de erfaringer som den slagrammede eller pårørende har om hvordan det er å leve med funksjonshemninger etter slag, og hvordan de opplever helsetilbudet. Når informanten har avsluttet sine fortellinger ønsker jeg å stille noen spørsmål. Hver samtale vil vare cirka en til to timer, avhengig av informantens ønsker. Noen av informantene vil bli forespurt om de er villig til å delta i en til to gruppesamtaler med andre informanter. Her vil også en forskningsassistent være til stede som observatør. Alle intervju vil bli tatt opp på bånd og utskrevet og anonymisert i ettertid. Mens utskrivning pågår (2008-2009) vil båndene og utskriftene bli oppbevart i låste skap. Båndene vil bli slettet når arbeidet er avsluttet i januar 2012.

Hvilke rettigheter har den som deltar:

Deltakelsen i alle intervju er frivillig, og informanten kan trekke seg når som helst i forløpet. Alle opplysninger blir behandlet konfidensielt og vil bare bli gjengitt anonymisert på en slik måte at informantene ikke kan gjenkjennes. Dette gjelder også opplysninger innenfor samme familie. Informanten bestemmer selv når de vil avslutte intervjuet og når de ønsker pauser i intervjuet. Informanten kan få tilsendt et eksemplar av doktorgradsavhandlingen når denne foreligger. Det å trekke seg fra studien har ingen konsekvenser for deltakerne, og heller ingen innvirkning på deltakernes forhold til de instanser som har formidlet informasjonen (Interesseforeninger eller hjemmesykepleien).

Hvilke ulemper kan deltakelsen medføre:

Mange vil oppleve det positivt å kunne dele sine erfaringer med en interessert forsker eller andre informanter som har liknende erfaringer. For noen kan slike fortellinger utløse minner og følelser som kan oppleves vanskelig. Forskeren vil gi tilbud om en oppfølgende samtale hvis dette er ønskelig og vil kunne tilby informasjon om hvilke hjelpeinstanser som kan kontaktes.

Denne forespørselen sendes via Interesseforeninger eller hjemmesykepleien, og forskeren har ingen opplysninger om hvem som mottar dette brevet. Formidlende instanser får heller ingen opplysninger fra meg om hvem som har sagt seg villig til å delta.

Ønsker man å delta, sendes et signert eksemplar i den frankerte og adresserte konvolutten som finnes vedlagt, det andre eksemplaret beholdes av deltakeren. De som har sagt seg villig til å delta, vil bli kontaktet så snart samtykkeerklæringen er mottatt.

Ønsker man kontakt for å få mer informasjon om prosjektet før man sender samtykkeerklæring, kan undertegnede kontaktes: tlf. arbeid: 76966168, mob.tlf. 911 55 475 eller e-post: gk@hin.no

Med dette tillater jeg meg å rette en forespørsel om deltakelse i denne studien.

Med vennlig hilsen

Gabriele Kitzmüller

Klipp her og send inn delen nedenfor _____

Samtykkeerklæring

Jeg har fått muntlig og skriftlig informasjon om forskningsprosjektet og samtykker ut fra dette i å delta i prosjektet.

Dette innebærer at

- Jeg samtykker i at intervjuene tas opp på lydbånd
- Jeg samtykker i at jeg kan få en forespørsel om å delta i gruppeintervju etter at de individuelle intervjuene er foretatt (gjelder bare pårørende)

Jeg ønsker å bli kontaktet via tlf :.....

Jeg ønsker å bli kontaktet via e-post :.....

Adresse: _____ Dato: _____ Underskrift: _____

Navn i trykkbokstaver: _____

Intervjuguide – informanter som lever med følgende etter hjerneslag:

I den innledende fase vil jeg legge vekt på at informanten og jeg skal bli kjent og trygg på hverandre. Jeg vil fortelle litt om meg selv og gjenta punktene i informert samtykke. Deretter kommer jeg til å innlede med spørsmål, som det er lett for informantene å svare på, og som samtidig utgjør bakgrunnsinformasjon. De vil få spørsmål om alder, familiesituasjon før slaget og nåværende familiesituasjon og hvor lenge det er siden slagtilfellet.

Deretter skal intervjuet ta utgangspunkt i informantens fortellinger om sitt liv med ulike funksjonshemninger og sin vurdering av helsetilbudene. Jeg vil legge vekt på å forstyrre disse fortellingene minst mulig, og heller gjøre notater om det jeg må få utdypet etterpå. Derfor vil innledningsspørsmålene være spesielt viktig, slik at fortellingene kan belyse problemstillingen.

1) Fortell hvordan ditt liv var før du fikk slag?

2) Beskriv funksjonshemningene du hadde, eller fortsatt har.

3) Beskriv hvordan disse funksjonshemninger har påvirket/påvirker livet ditt - både når det gjelder praktiske gjøremål, yrkes- og fritidsaktiviteter, familieliv og ditt sosiale nettverk?

4) Fortell noe om hvilke hjelpetilbud du og din familie har fått av offentlige instanser (helse- trygde- sosialetat) etter ditt slagtilfelle, og hvordan du vurderer disse tilbud? Ser du behov for andre tilbud du ikke fikk?

Er det andre ting du synes er viktig å fortelle om?

Intervjuguide – pårørende

I den innledende fase vil jeg legge vekt på at informanten og jeg skal bli kjent og trygg på hverandre. Jeg vil fortelle litt om meg selv og gjenta punktene i informert samtykke. Deretter kommer jeg til å innlede med spørsmål, som det er lett for informantene å svare på, og som samtidig utgjør bakgrunnsinformasjon. De vil få spørsmål om sin egen og partnerens/farens/morens alder, familiesituasjon før slaget og nåværende familiesituasjon og hvor lenge det er siden slagtilfellet inntraff.

Deretter kommer intervjuet til å ta utgangspunkt i informantenes fortellinger om sitt liv sammen med sin ektefelle/samboer/far eller mor som har ulike funksjonshemninger etter slag og hans/hennes vurdering av helsetilbudene familien fikk/får. Jeg vil legge vekt på å forstyrre disse fortellingene minst mulig, og heller notere hva som må utdypes etterpå. Derfor vil innledningsspørsmålene være spesielt viktig, slik at fortellingene kan belyse problemstillingen best mulig.

1) Fortell hvordan ditt liv og deres familieliv var før din partner/far/mor fikk slag.

2) Beskriv funksjonshemningene din partner/far/ mor hadde eller fortsatt har.

3) Beskriv hvordan disse funksjonshemninger påvirket/påvirker livet ditt, både når det gjelder praktiske gjøremål, yrkes- og fritidsaktiviteter, familieliv og ditt sosiale nettverk?

4) Fortell om hvilke hjelpetilbud din partner/far/ mor og du eller andre i nærmeste familie har fått av offentlige instanser (helse- trygde- sosialetat), og hvordan du vurderer disse tilbudene? Ser du behov for andre tilbud enn det han/hun eller dere fikk?

Er det noe annet du synes er viktig å fortelle om?

Intervjuguide – unge voksne som ser tilbake på sin oppvekst med en far/mor som hadde funksjonshemninger etter slag

I den innledende fase vil jeg legge vekt på at informanten og jeg skal bli kjent og trygg på hverandre. Jeg vil fortelle litt om meg selv og gjenta punktene i informert samtykke. Deretter kommer jeg til å innlede med spørsmål, som det er lett for informantene å svare på, og som samtidig utgjør bakgrunnsinformasjon. De vil få spørsmål om sin egen og farens/morens alder da slaget inntraff, deres familiesituasjon før slaget og nåværende familiesituasjon og hvor lenge det er siden slagtilfellet inntraff.

Deretter kommer intervjuet til å ta utgangspunkt i informantenes fortellinger om sin oppvekst sammen med en far eller mor som hadde ulike funksjonshemninger etter slag og hans/hennes vurdering av helsetilbudene familien fikk/får. Jeg vil legge vekt på å forstyrre disse fortellingene minst mulig, og heller notere hva som må utdypes etterpå. Derfor vil innledningsspørsmålene være spesielt viktige, slik at fortellingene kan belyse problemstillingen best mulig.

- 1) Fortell hvordan ditt liv og deres familieliv var før din /far/mor fikk slag.**
- 2) (Hvis informanten kan huske dette) Fortell om hvordan du opplevde det da din mor/far fikk slag.**
- 3) Beskriv funksjonshemningene din far/ mor hadde under oppveksten din.**
- 4) Beskriv hvordan disse funksjonshemninger påvirket livet ditt, både når det gjaldt praktiske gjøremål, skole- og fritidsaktiviteter, og evt. yrkesaktiviteter, familielivet og ditt sosiale nettverk?**
- 5) Fortell om hvilke hjelpe-/støttetilbud din far/ mor og du eller andre i nærmeste familie har fått av offentlige instanser (helse- trygde- sosialetat), og hvordan du vurderer disse tilbudene? Ser du behov for andre tilbud enn det han/hun eller dere fikk?**

Er det noe annet du synes er viktig å fortelle om?



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