

Work-aged stroke survivors' psychosocial challenges and follow- up needs

A qualitative, exploratory study

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List of original articles

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- III. Martinsen, R., Kirkevold, M. and Sveen, U. Younger stroke survivors' experiences of family life in a long-term perspective. A narrative hermeneutic phenomenological study. *Nursing Research and Practice*. Volume 2012, article ID 948791.
- IV. Martinsen, R., Kirkevold, M. and Sveen, U. Young and midlife stroke survivors' experiences with health services and their long-term follow-up needs. *Journal of Neuroscience Nursing*. Accepted for publication 17.10.2013.

Abstract

Background

Suffering a stroke in the age span between 18-67 years means being threatened by a serious illness during a productive phase of life. During this phase, people usually focus on education, launching a career and/or establishing a family, and the role commitments are many and demanding. Suffering a stroke during this phase of life might give rise to different psychosocial challenges and problems compared to suffering a stroke later in life.

A number of psychosocial challenges have been identified following a stroke. Research has suggested that younger stroke survivors are dissatisfied with their life as a whole. However, little knowledge is available concerning how a stroke influences life for younger stroke survivors. The lack of research concerning this topic made it necessary to investigate more in depth how a stroke impacts the lives of younger patients both from a short-term and long-term perspective.

Aim

The overall aim of this study was to explore work-aged stroke survivors' psychosocial challenges and psychosocial follow-up needs.

Design and method

This doctoral thesis grew out of a larger study that aimed to develop a dialogue-based psychosocial nursing intervention to promote psychosocial well-being following a stroke. The specific focus in this study is the psychosocial challenges of younger, work-aged stroke survivors.

The thesis consists of four sub-studies exploring experiences with the consequences of stroke in two different groups of work-aged stroke survivors. The first two studies focus on experiences among participants in the dialogue-based nursing intervention post-stroke. The last two studies focus on work-aged stroke survivors' experiences of living with a stroke over a longer perspective, particularly highlighting their encounters with the healthcare services and their experienced psychosocial follow-up needs.

Twenty-five stroke survivors aged 33-89 years participated in study I. The specific aim of this study was to evaluate the content, structure and process as well as the experienced usefulness

of participating in the intervention from the patients' point of view using a qualitative content analysis method.

Fourteen of the participants from study I, aged 33-66 years, were included in study II. The aim of this study was to illuminate the psychosocial challenges the work-aged participants thematised during and after participating in the dialogue-based intervention. The study had a hermeneutic phenomenological approach.

To expand the knowledge concerning the specific challenges and psychosocial follow up needs among younger stroke survivors in a longer perspective, a group of work-aged stroke survivors who had not participated in the intervention were included in study III. This study focused on how a stroke impacts family life from the stroke survivors' view, six months or more after the stroke. Twenty-two stroke survivors aged 20-61 years participated in this study which had a hermeneutic phenomenological approach.

In study IV, eight participants included in study II and eight participants included in study III participated in follow-up interviews one year after they were interviewed in the initial studies. The aim of study IV was to explore the work-aged stroke survivors' experiences with health services and their experienced long-term follow-up needs. The sixteen participants participating in this hermeneutic phenomenological study were aged 21-67 years.

Main findings

The participants experienced the content, structure and process of the dialogue-based nursing intervention as relevant and participation as an important support the first six months after stroke onset. The evaluation of the intervention gave valuable insights into aspects that require further consideration and development of the intervention before launching a randomised controlled trial (study I).

Life as a work-aged stroke survivor was experienced as challenging and created a risk of becoming marginalised in family life and work life the first year following the stroke (study II).

Living with the consequences from the stroke was found to pose significant and multifaceted challenges to family life even many years after the stroke. However, the challenges varied with time, from an initial struggle to suffice in and balance the relationships and roles within

the family early after the stroke, towards a more resigned attitude later on in the stroke trajectory (study III).

Non-established stroke survivors living alone seemed to be particularly vulnerable as they are often isolated in their homes. In addition, stroke survivors in parental roles were also found to be vulnerable in their attempt to fulfil their roles as mothers and fathers (study III).

The study participants struggled to gain access to follow-up services which were described as coincidental and untailored to the younger stroke survivors' specific needs. The younger stroke survivors thus appeared vulnerable to falling outside the follow-up system (study IV).

Conclusion

Understanding and managing life following a stroke is demanding and the daily demands are substantial among people aged 18-67 years. This calls for individual support and follow-up adjusted to the stroke survivors' phase in life and specific situation. The psychosocial challenges generate a need to narrate their experiences and a need for tailored follow-up support in order to meet the demands of family life and work life. Being provided opportunities to narrate their experiences outside the home context might be helpful to prevent psychosocial problems.

To be experienced as supportive, the follow-up program must be knowledge-based and address both the short-term and long-term needs. Furthermore, it must be carried out in close collaboration with the stroke survivor.

Sammendrag

Bakgrunn

Å rammes av hjerneslag når man er i alderen 18-67 år, innebærer å bli truet av en alvorlig lidelse i en produktiv fase av livet. Denne fasen har vanligvis fokus på utdanning, karriere og/eller etablering av familie, og rolleforpliktelsene er mange og krevende. Det er naturlig å tro at man møter andre utfordringer ved å leve med konsekvensene av hjerneslag i denne perioden sammenliknet med i en senere fase av livet.

Studier har pekt på at unge pasienter med hjerneslag er misfornøyde med livet i sin helhet. Likevel er det forsket lite på forskjellen mellom yngre og eldre personer med hjerneslag, og på de spesifikke utfordringene som unge personer med hjerneslag står overfor. Mangelen på forskning knyttet til dette temaet gjør det nødvendig å utforske hvordan det er å leve med konsekvensene etter hjerneslag for personer i denne produktive fasen av livet, på kort og på lang sikt.

Hensikt

Den overordnede hensikten var å utforske de psykososiale utfordringene og psykososiale oppfølgingsbehov hos personer som har gjennomgått hjerneslag og som er i arbeidsfør alder.

Design og metode

Denne avhandlingen hadde utgangspunkt i en større studie der det ble utviklet en dialogbasert psykososial sykepleieintervensjon for å fremme psykososialt velvære. Intervensjonen besto av åtte samtaler over en periode på seks måneder.

Studien i avhandlingen består av fire delstudier. De to første studiene var relatert til en første utprøving av den dialogbaserte sykepleieintervensjonen, mens de to siste studiene fokuserte på erfaringer med å leve med hjerneslag og behovet for psykososial oppfølging i et lengre perspektiv.

I studie I, som hadde et eksplorativt (feasibility) design, deltok 25 personer med hjerneslag i alderen 33-89 år. Hensikten med denne studien var å evaluere intervensjonens innhold, struktur og prosess i tillegg til opplevd nytte av å delta i intervensjonen fra deltakernes perspektiv. Data ble analysert med kvalitativ innholdsanalyse.

Fjorten av deltakerne fra studie I i alderen 33-66 år ble inkludert i studie II. Hensikten i denne studien var å belyse de psykososiale utfordringene som deltakerne tematiserte i løpet av og etter deltakelse i den dialogbaserte sykepleieintervensjonen. Analysen hadde en hermeneutisk fenomenologisk tilnærming.

For å få ytterligere kunnskap om utfordringene til yngre slagrammede, ble en gruppe personer med hjerneslag som ikke hadde deltatt i intervensjonen inkludert for å utvide kunnskap om erfaringer og psykososiale oppfølgingsbehov også i et lengre perspektiv.

Hensikten med studie III var å få en dypere forståelse for hvordan et hjerneslag virker inn på familielivet seks måneder eller mer etter hjerneslaget, sett fra den slagrammedes perspektiv. 22 personer med hjerneslag i alderen 20-61 år deltok i denne studien som hadde en hermeneutisk fenomenologisk tilnærming.

I studie IV ble åtte deltakere fra studie II og åtte deltakere fra studie III intervjuet ett år etter at det første intervjuet fant sted. Hensikten med denne oppfølgingsstudien, som også hadde en hermeneutisk fenomenologisk tilnærming, var å utforske gruppens erfaringer med helsetjenestene og å identifisere potensielle behov for oppfølging i et langtidsperspektiv.

Hovedfunn

Deltakerne opplevde innholdet, strukturen og prosessen med å delta i intervensjonen som en støtte i den tidlige fasen etter hjerneslaget. Deltakernes erfaringer ga i tillegg viktige innspill for en justering av intervensjonen før utprøving i en senere randomisert studie (studie I).

Livet som slagrammet i arbeidsfør alder opplevdes som utfordrende og medførte en risiko for å komme i en marginalisert posisjon i familie- og arbeidsliv det første året etter sykdomsdebut (studie II).

Å leve med konsekvensene av hjerneslag ga betydelige utfordringer med mange fasetter selv mange år etter hjerneslaget. Utfordringene varierte over tid, fra strev med å strekke til for å ivareta relasjoner og roller i familien i tidlig fase etter hjerneslaget til at det etter hvert utviklet seg en mer tilbaketrukket deltakelse i familielivet senere i slagforløpet. Uetablerte personer som lever alene og gjennomgår et hjerneslag, syntes å være spesielt sårbare ettersom de ofte isolerer seg hjemme. I tillegg ble deltakere som var i foreldreroller, funnet å være spesielt sårbare når det gjaldt å oppfylle rollene som mødre og fedre (studie III).

Deltakerne i studien strevde med å få tilgang til oppfølgingstjenesten som ble beskrevet som tilfeldig og lite tilpasset den yngre gruppens spesifikke behov. Studien viser at de unge som hadde gjennomgått hjerneslag, var utsatt for å falle utenfor oppfølgingssystemet (studie IV).

Konklusjon

Avhandlingen viser at å fortolke og mestre situasjonen etter hjerneslag krever individuell støtte og et oppfølgingssystem tilpasset de enkeltes spesifikke livsløp. De daglige krav gjør at unge personer som gjennomgår et hjerneslag, har behov for et oppfølgingssystem hvor de kan snakke om forpliktelser i familieliv og arbeidsliv. Å ha mulighet til å snakke om erfaringene med noen utenfor den hjemlige kontekst, vil ha betydning for å kunne forebygge psykososiale problemer.

Oppfølgingsprogrammet for unge som lever med konsekvensene av hjerneslag, må være i tråd med behovene på kort og lang sikt, og ta spesielle utfordringer på alvor i nært samarbeid med den enkelte. Oppfølgingen må dermed være individuell og kunnskapsbasert for å kunne være støttende, oppmuntrende og motiverende.

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1 Introduction

Stroke occurs in approximately 15 000 Norwegians annually (Fjærtøft & Indredavik, 2007), and 55 000 Norwegians are estimated to be affected by stroke at any time (Ellekjær & Selmer, 2007). Stroke is known to be a considerable cause of death and disability (Ellekjær & Selmer, 2007; Feigin et al., 2013; Mathers & Loncar, 2006). A significant number of those who survive a stroke must live with the after-effects for years or the remainder of their lives (Indredavik, Salvesen, Næss, & Thorsvik, 2010; Thommessen & Wyller, 2007; Vanhook, 2009).

It is generally assumed that strokes mainly occur in old age (Banks & Pearson, 2004); indeed, the mean age of stroke onset in Norway is approximately 76 years (Ellekjær, Holmen, Indredavik, & Terent, 1997). However, it is estimated that approximately 25% of the stroke population is below the age of 65 years, and 5% is below the age of 45 years (Johansen, Wielgosz, Nguyen, & Fry, 2006; Naess, Tatlisumak, & Kõrv, 2011). An increasing burden of stroke worldwide and decreasing mortality rates in high-income countries may indicate that there are more individuals living with stroke for an extended time. Although the trends are unclear, the global increase in the rates of obesity and diabetes among young people might influence the prevalence of stroke in the future (Ellekjær & Selmer, 2007; Feigin et al., 2013).

A number of psychosocial challenges have been identified following a stroke. Anxiety, depression, fatigue and struggles with social participation are frequently observed among the young stroke population (Daniel, Wolfe, Busch, & McKeivitt, 2009; Lerdal et al., 2009; Naess, Nyland, Thomassen, Aarseth, & Myhr, 2005b; Teasell, McRae, & Finestone, 2000; Varona, 2011). Furthermore, a significant number of stroke survivors fail to return to work (Daniel et al., 2009; Hofgren, Esbjornsson, & Sunnerhagen, 2010; Wilz & Soellner, 2009).

Suffering a stroke before retirement age means being threatened by a serious illness during an active phase of life when serious disease is not typically anticipated (Banks & Pearson, 2004 ; Stone, 2005b). Traditionally, lifespan tasks related to education, launching a career and/or establishing family life are predominant during this phase of life (McGoldrick, Carter, & Garcia-Preto, 2013). Suffering a stroke during this “productive” period of life, when the role commitments are numerous and demanding, may give rise to different challenges compared with older stroke survivors (Burton, 2000; Carlsson, Möller, & Blomstrand, 2009; Murray &

Harrison, 2004; O'Connell et al., 2001; Röding, Lindström, Malm, & Öhman, 2003; Wood, Connelly, & Maly, 2010).

Several research studies have suggested that younger stroke survivors are dissatisfied with their life as a whole (Achten, Visser-Meily, Post, & Schepers, 2012; Carlsson, Forsberg-Wärleby, Möller, & Blomstrand, 2007; Nilsson, Aniansson, & Grimby, 2000; Röding, Glader, Malm, & Lindström, 2010). However, there is significant disparity in the research involving the challenges of younger and older stroke survivors; little knowledge is available concerning how a stroke influences life for younger survivors. Thus, it is necessary to investigate in greater depth how suffering a stroke impacts the lives of younger patients from both a short-term and long-term perspective. A greater understanding of how a stroke influences life across different phases is necessary to understand the specific challenges following a stroke for persons of different ages. Such knowledge will help health professionals to provide the relevant assistance and support during rehabilitation as a contribution to subjective well-being.

This doctoral thesis grew out of a larger study that aimed to develop a dialogue-based psychosocial nursing intervention to promote psychosocial well-being following a stroke (Kirkevold, Bronken, Martinsen, & Kvigne, 2012). The specific focus of this dissertation is the psychosocial challenges of younger, work-aged stroke survivors. This thesis consists of four sub-studies exploring experiences with the consequences of stroke in two different groups of work-aged stroke survivors. The first two studies focus on experiences among participants participating in a dialogue-based nursing intervention post-stroke. The last two studies focus on work-aged stroke survivors' experiences of living with a stroke over a longer perspective, particularly highlighting their encounters with the healthcare services and their experienced psychosocial follow-up needs.

2 Background

This background chapter presents a brief overview of the pathological and epidemiological aspects of stroke in the young, defined in this dissertation as work-aged stroke survivors aged 18-67. Furthermore, this chapter presents relevant research concerning the younger stroke survivors' experiences of living with stroke¹ and psychosocial interventions aimed at promoting psychosocial well-being.

The literature search was conducted in the electronic databases Cinahl, Eric, Medline, PsychInfo and Web of Science, focusing on articles published from 1990 onward, which was the time at which the number of articles about stroke rehabilitation began to increase (Lanska, 2009).

The main keywords included in the electronic searches were as follows: stroke, experience, young, middle-aged, family, work, life-span, life-course, life-cycle, psychosocial, well-being, intervention and qualitative. The Mesh terms and Cinahl headings were supplied to expand the searches. The keywords were used in different combinations using the Boolean operators AND and OR. Searches were also refined by ages. However, as this approach provided few results, all ages were included in the searches.

The Library database Bibsys Ask, databases including systematic reviews (Cochrane Library, BMJ Best Practice and Clinical Evidence) and Google Scholar have also been used as sources to identify literature of relevance.

The literature search was conducted in a stepwise fashion. The first searches were conducted before the commencement of the study in 2008 but were updated several times to incorporate new studies including different topics during the study period (2008-2013).

¹ Some of the literature does not differentiate between the young and older cohorts of stroke survivors. Gaining an overview of the body of literature concerning aspects of the young stroke survivors' experiences therefore made it necessary to review literature concerning both young and older stroke survivors' experiences.

2.1 Stroke in the young

According to the World Health Organization (2013), stroke, an acquired brain injury, is a cerebrovascular disease “caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue”.

The collective term “stroke” largely refers to the three specific diagnoses ischemic stroke, intra-cerebral haemorrhage and subarachnoid haemorrhage (Bennett et al., 2012). In general, approximately 85% of stroke victims suffer an ischemic stroke, whereas 15% are diagnosed with an intra-cerebral haemorrhage or subarachnoid haemorrhage (Bennett et al., 2012). Ischemic stroke is the most frequent diagnosis among the young group of stroke sufferers (Cotter, Belham, & Martin, 2010). However, haemorrhage and prothrombotic states, including genetic predispositions, malignant disease, oral contraception or pregnancy, are more frequent causes among those younger than forty years of age (Naess, Nyland, Thomassen, Aarseth, & Myhr, 2004a). The aetiology of stroke is unknown in approximately one third of the young stroke survivors (Cotter et al., 2010).

The symptoms following a stroke vary depending on stroke severity and localisation. The most common symptoms are one-sided weakness of the arm, leg, and/or face, confusion, speech-related problems, and/or loss of balance and coordination (Bennett et al., 2012; World Health Organization, 2013). The consequences of a stroke may be classified as mild, moderate or severe (Bennett et al., 2012).

Improved diagnostic work-up and treatment are factors contributing to better outcomes for stroke survivors in recent years (Stroke Unit Trialists' Collaboration, 2013). The young stroke survivors have a more favourable prognosis compared with their older counterparts, i.e., lower short-term and long-term mortality rates, lower recurrence rates, and better long-term functional outcomes (Varona, 2011). Naess, Nyland, Thomassen, Aarseth, and Myhr (2004b) reported a mortality rate of almost 10% in a follow-up after 6 years among Norwegian stroke survivors aged 15-49 years. Mortality rates have been found to be significantly decreased in female stroke survivors (Olsen, Dehlendorff, & Andersen, 2009).

Several studies have reported that females are more likely to suffer a stroke under the age of thirty years, whereas male prevalence is dominant above the age of thirty (Cotter et al., 2010; Naess et al., 2002; Putaala et al., 2009). However, an Italian study including 324 stroke

sufferers below 44 years did not observe a significantly higher prevalence of females under the age of 29 (Tancredi et al., 2013).

The lack of awareness of the fact that young people may suffer a stroke, both among the stroke survivors themselves, the general public, and health personnel, has been highlighted as an obstacle to taking the symptoms seriously and to early diagnosis (Stone, 2005b). Studies have revealed that young stroke survivors have been sent home without a proper diagnostic workup, causing a delay in diagnosing the stroke (Banks & Pearson, 2004 ; Carlsson et al., 2009; Stone, 2007). Furthermore, one study found that rather than being diagnosed with a stroke, women were initially given a psychosomatic diagnosis, a drug overdose diagnosis or diagnosed with problems related to pregnancy (Stone, 2007).

Although strokes occur at any age, the knowledge of the consequences of stroke in younger stroke survivors' lives is limited. Consequently, there is a need to further our knowledge of how a stroke influences the lives of work-aged survivors.

2.1.1 Psychosocial well-being among work-aged stroke survivors

The psychosocial domain is related to subjective experiences of quality of life (Cummins 2004). However, the term quality of life is complex and ambiguous (Eriksson & Lindström, 2007; Næss, 2001b). Within the social sciences, quality of life is frequently operationalised as subjective quality of life or subjective well-being and represents in general a positive state of mind and a satisfaction with life (Cummins, Lau, & Stokes, 2004; Eriksson & Lindström, 2007).

Suffering from stroke at a younger age is expressed as an overwhelming, catastrophic, and traumatic event eliciting fear of suffering a new stroke, insecurity about the future and fear of being a burden to the family (Alasewski, Alasewski, & Potter, 2004; Banks & Pearson, 2004 ; Bendz, 2003; Burton, 2000; Carlsson et al., 2009). Although physical, emotional and social recovery are found to vary greatly; stroke survivors seem surprisingly uniform in describing themselves as losing control of their bodies and experiencing their bodies as disrupted, fatigued, changed and strange (Bendz, 2003; Burton, 2000; Morris, 2011; Murray & Harrison, 2004; Röding et al., 2003). Even mild or minor strokes may lead to non-visible, cognitive problems, such as emotional problems, anxiety, depression, fatigue, concentration problems

and reduced memory (Murray & Harrison, 2004; Röding et al., 2003; Stone, 2005b; Teasell et al., 2000; Varona, 2011).

A Norwegian study including participants aged 15-49 years found the incidence of post-stroke depression to be 28.6% (Naess et al., 2005b). The depression was in this study assessed as milder compared with depression in older counterparts. In this population of 196 stroke survivors, nobody was found to have a severe post-stroke depression, 25% were found to exhibit a mild depression, and 3.6% suffered moderate depression (Naess et al., 2005b). The same research group also found that the quality of life decreased among those who were functionally dependent, depressed, unmarried or unemployed six years following a first-ever stroke (Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006).

Fatigue, defined as "... an overwhelming feeling of exhaustion, which leads to inability to sustain even routine activities and which is commonly expressed as a loss of drive" (Staub & Bogousslavsky, 2001, p. 76), is found to be one of the most prevalent struggles influencing life among stroke survivors both during the acute phase and over the long-term (Lerdal et al., 2009). Naess, Nyland, Thomassen, Aarseth, and Myhr (2005a) found fatigue to more frequent in young stroke survivors compared with the general population and older stroke survivors.

Suffering from the invisible symptoms has been described as particularly challenging for younger stroke survivors, making them frustrated and feeling "outside" of society (Murray & Harrison, 2004; Röding et al., 2003; Stone, 2005b). Explaining the invisible symptoms to persons who have not suffered a stroke may be challenging (Carlsson et al., 2009; Green & King, 2010). Many stroke survivors have experienced negative reactions from others to their invisible symptoms, leading to the avoidance of situations where they may be exposed to such reactions (Bendz, 2003; Murray & Harrison, 2004; Stone, 2005b).

The symptoms and changes following a stroke have been described as leading to a dependence on others, losing confidence and trust in themselves, and grief (Alasewski et al., 2004; Bendz, 2003; Burton, 2000; Carlsson et al., 2009; Jones, Mandy, & Partridge, 2008; Lutz, Young, Cox, Martz, & Creasy, 2011). Stone (2005a) highlighted that stroke survivors often have to relinquish more or less busy lives, instead letting go of worries, appreciating life in a new manner, and focusing on developing a new sense of self.

Challenges related to leisure, i.e., being able to participate in recreational and social activities, are confirmed in several studies (Daniel et al., 2009; Johansson, Högberg, & Bernspång, 2007; Kersten, Low, Ashburn, George, & McLellan, 2002; O'Connell et al., 2001; Röding et al., 2010). Not being able to participate in meaningful activities taken for granted prior to the stroke onset or not being autonomous in resuming or replacing activities is found to be frustrating. Furthermore, struggling to regain a sense of self-confidence and competence and having reduced personal influence may lead to incongruence between pre-and post-stroke identity (Bourland, Neville, & Pickens, 2011).

Some research exists about the impact of stroke on family relationships and return to work, two significant lifespan issues in the work-aged stroke population. These issues are reviewed below.

2.1.2 The impact of stroke on family relationships

Suffering from stroke impacts social participation, relationships and communication with family and friends (Banks & Pearson, 2004 ; Carlsson et al., 2009; Daniel et al., 2009; Kersten et al., 2002; Low, Kersen, Ashburn, George, & McLellan, 2003; Teasell et al., 2000). In particular, couples in newly established or conflicting relationships have been found to be more likely to terminate their relationships following a stroke (Kitzmüller, Asplund, & Häggström, 2012; Teasell et al., 2000).

Fulfilling marital and parental roles has been described as challenging (Daniel et al., 2009; Green & King, 2009; Kitzmüller et al., 2012; Röding et al., 2003; Teasell et al., 2000; Thompson & Ryan, 2009; Wood et al., 2010). Although few details were provided, Röding et al.'s (2003) qualitative study reported that women expressed frustration of not being able to fulfil their roles as mothers and housewives. Similar findings were reported by Kitzmüller et al. (2012). Men expressed concerns of the family economy (Röding et al., 2003). In a follow-up quantitative study, Röding et al. (2010) found that women were more concerned about work and financial issues than men.

2.1.3 Work challenges following a stroke

The reported numbers of stroke survivors returning to work differ substantially across different studies. This discrepancy may be explained by differences in the populations

included, different definitions of return to work, and differences in the research designs (Treger, Shames, Giaquinto, & Ring, 2007). A systematic review including 78 studies identified a mean of 44% returning to work (Daniel et al., 2009). Treger et al. (2007), in their systematic review including data from thirteen countries, reported that the numbers of stroke survivors returning to work varies between 19% and 73%. A Scandinavian study including 72 participants, of whom 48 suffered from stroke, found that only 18% returned to work after one year (Hofgren et al., 2010). Wilz et al (2009) found that 26.7% of the participants were able to go back to work.

Different factors contribute to work challenges following a stroke. Residual symptoms following the stroke may affect the work capacity (O'Brien & Wolf, 2010; Vestling, Tufvesson, & Iwarsson, 2003), leading to changes in work responsibilities, and voluntary or involuntary downsizing to part-time or quitting work all together (Alasewski, Alasewski, Potter, & Penhale, 2007; Medin, Barajas, & Ekberg, 2006; O'Brien & Wolf, 2010; Vestling et al., 2003).

Even a minor or moderate stroke may have a negative impact on return to work. Nevertheless, stroke survivors suffering a comprehensive stroke have succeeded in resuming work (Hofgren et al., 2010; O'Brien & Wolf, 2010). However, a recent review concluded that a comprehensive stroke, leading to extensive physical and cognitive deficits, was negatively associated with resuming work (Treger et al., 2007). This is in line with several studies that highlight that a positive physical condition is a significant factor influencing return to work (Lindström, Röding, & Sundelin, 2009; Medin et al., 2006; Wilz & Soellner, 2009).

Highly educated and self-employed stroke survivors are more likely to return to work than others (Alasewski et al., 2007; Lindström et al., 2009). Blue collar workers have been found to return to work quickly compared with white collar workers. However, the white collar workers tend to remain in their work permanently after return to work, whereas the blue collar workers more often downsize or quit working even if they return to work closer to the stroke onset (Morris, 2011).

Younger patients are more likely to return to work than older patients (Hofgren et al., 2010). However, stress, fatigue, tiredness, and cognitive impairments, including aphasia, are barriers affecting the possibility of return to work (Alasewski et al., 2007; Culler, Wang, Byers, & Trierweiler, 2011; Gilworth, Phil, Cert, Sansam, & Kent, 2009; Koch, Egbert, Coeling, &

Ayers, 2005; Morris, 2011; van Velzen, van Bennekom, van Dormolen, Sluiter, & Frings-Dresen, 2011).

External support from employers, colleagues, social workers and family are decisive factors related to the return to work (Alasewski et al., 2007; Hofgren et al., 2010; Lindström et al., 2009; van Velzen et al., 2011). Although a supportive employer is found to be the most pertinent external factor for the return to work (Culler et al., 2011), spouses are of most importance within the family, in addition to children and parents (Alasewski et al., 2007). However, lack of knowledge about stroke among colleagues or lack of interest in and understanding of the stroke survivor's struggles may negatively influence return to work (Medin et al., 2006).

A positive attitude and an intrinsic will to re-enter into the work force might be decisive for succeeding in returning to work (Lindström et al., 2009). This is consistent with the findings of a phenomenological study highlighting that stroke survivors close to the stroke onset exhibit positive attitudes and take for granted that they will be able to return to work. However, the rehabilitation services are found to focus primarily on bodily restoration and activities of daily living, neglecting to address issues related to return to work. Consequently, the services are not adjusted to the individual stroke survivors' ages and needs. Information from and interactions with different rehabilitation professionals, discussing both intrinsic and external expectations, are decisive in returning to work (Medin et al., 2006).

2.2 Rehabilitation following stroke

The serious consequences of stroke require rapid admission to medical emergency treatment to reduce neurological consequences (i.e., the after-effects) and improve recovery following the stroke (Indredavik et al., 2010).

Receiving organised inpatient care in established stroke units, i.e., specialised hospital units dedicated to stroke patients' medical treatment and rehabilitation conducted by a multidisciplinary team, are found to improve outcomes with respect to death, functional outcomes, and independence both in a short-term and long-term perspective (Indredavik, 2007; Stroke Unit Trialists' Collaboration, 2013). However, a combined model including early supported discharge, i.e., early discharge from the hospital with more rehabilitation follow-up in the homes, is further documented to improve functional outcomes and reduce length of stay

in hospitals compared with care in traditional stroke units (Indredavik, Fjærtøft, Ekeberg, Løge, & Mørch, 2000; Langhorne, Holmqvist, & Trialists, 2007). A national goal is to hospitalise individuals with stroke in stroke units, either organised in ordinary medical wards or in specialised stroke units (Indredavik et al., 2010).

Those patients in need of comprehensive rehabilitation might be discharged to specialised rehabilitation units. However, most patients are discharged to home beyond the acute phase of stroke (Adams et al., 2007; Tancredi et al., 2013). After discharge from the hospital, the communities are responsible for providing rehabilitation services. Consistent with the international guidelines (Adams et al., 2007), the Norwegian guidelines for treatment and rehabilitation of stroke (Indredavik et al., 2010) emphasise an early, flexible, person-centred rehabilitation to gain physical, psychological, social and occupational independence. An interdisciplinary collaboration between the professionals within the communities is thus required. Within this system, the general practitioner (GP) is the main individual responsible for the follow-up, i.e., a final check-up one to three months following stroke onset as well as assessments of the secondary prevention medication (Indredavik, Salvesen, Næss, & Thorsvik, 2010). The Norwegian guidelines for the treatment and rehabilitation of stroke (Indredavik et al., 2010) do not specifically address the needs of psychosocial rehabilitation but recommend the provision of information and supportive conversations.

The heterogeneity in the consequences following a stroke make it necessary to deliver treatment and rehabilitation tailored to the stroke survivors' individual needs (Indredavik et al., 2010). In Norway, inhabitants in need of long-term complex follow-up services have a statutory right to have an "Individual Plan", this is a personal drawn up by a designated coordinator to secure a follow-up based on the specific needs of the individuals. This statutory right was established in 2001 and further strengthened through the "Coordination Reform" (Ministry of Health and Care Services, 2009) in 2012, aiming to outline individual objectives, resources and required health services.

The physical and psychosocial adjustment process following stroke is known to be lengthy (Kirkevold, 2002; Kouwenhoven, Kirkevold, Engedal, Biong, & Kim, 2011; Salter, Hellings, Foley, & Teasell, 2008). Kirkevold (2002) has described the rehabilitation process during the first year following stroke as a gradually adjusting unfolding process consisting of four phases. Because a stroke occurs abruptly, the first phase following the stroke is characterised by surprise and suspense. The second phase, the initial rehabilitation phase, is characterised

by focusing on hard physical work. During the third phase, following the discharge from the hospital (which varies individually in time) the stroke survivors are found to attend their focus to psychosocial and practical adjustment. During approximately the second half-year following the stroke (the fourth phase, called the semi-stable phase) life is settled more down. The focus changes from the stroke itself and the treatment of the stroke towards focusing on familiar aspects of daily life (Kirkevold, 2002).

Although the rehabilitation within the communities is a multi-professional collaboration, nurses are expected to address psychosocial support and needs as well as provide support and guidance to improve adjustment to living the life with stroke (Kirkevold, 2010).

2.2.1 Interactions with professionals

Interactions with professionals following a stroke have been expressed in negative terms (Stone, 2007). Studies have concluded that healthcare professionals tend to give one-sided attention to biomedical factors, whereas stroke survivors themselves request attention to both the biomedical, social and psychological factors (Bendz, 2000, 2003; Burton, 2000; Peoples, Satink, & Steultjens, 2011; Röding et al., 2003). Being compared to older stroke survivors, placed in wards together with older people (Banks & Pearson, 2004 ; O'Connell et al., 2001) and not being involved in identifying their own goals post-stroke have been identified as additional negative factors during hospitalisation (Burton, 2000; Jones et al., 2008). The possibility of discussing their situation and being offered information is often neglected in the care of younger stroke victims (Banks & Pearson, 2004 ; Röding et al., 2003; Stone, 2007).

Returning home following a stroke is described as a relief (Banks & Pearson, 2004), although the homecoming does not necessarily comply with the stroke survivors' expectations. Rather, the consequences of living with the stroke became more real after facing the challenges at home (Banks & Pearson, 2004 ; Burton, 2000).

Dissatisfaction with life following a stroke has been highlighted (Achten et al., 2012; Carlsson et al., 2007; Nilsson et al., 2000; Röding et al., 2010). Röding et al. (2010) reported that male informants living alone are more dissatisfied with life, whereas Nilsson et al. (2000) reported that single people are more dissatisfied irrespective of gender and age.

2.2.2 Psychosocial interventions following stroke

A greater number of different stroke-specific pharmacological and non-pharmacological psychosocial interventions have been developed and tested without convincing results (Campbell Burton et al., 2011; Ellis, Mant, Langhorne, Dennis, & Winner, 2010; Graven, Brock, Hill, & Joubert, 2011; Hackett, Anderson, House, & Halteh, 2009; Hackett, Anderson, House, & Xia, 2008; McGeough et al., 2009; Salter, Foley, & Teasell, 2010).

Pharmacological treatment is found to be more positive in the treatment of depression than to prevent such problems (Hackett et al., 2009; Hackett et al., 2008). The knowledge of how to treat anxiety following a stroke is insufficient (Campbell Burton et al., 2011). In their review including three interventions, Campbell Burton et al. (2011) concluded that pharmacological treatment may have some positive effects in reducing anxiety symptoms in stroke patients with co-morbid anxiety and depression.

Because few studies have provided adequate theoretical foundations, knowledge about the active ingredients that contribute to the positive outcomes remain unclear (Ellis et al., 2010; Forster et al., 2012; Redfern, McKevitt, & Wolfe, 2006). However, information, emotional support, practical advice and motivational support are identified as positive factors to reduce and prevent psychosocial problems (Burton & Gibbon, 2005; Ellis et al., 2010; Forster et al., 2012; Redfern et al., 2006; Watkins et al., 2007; Watkins et al., 2011).

Watkins and colleagues delivered four weekly sessions of motivational interviewing (MI), i.e., a patient-centred counselling technique, with a trained therapist with background in nursing and psychology during the acute phase. In this randomised controlled trial (RCT) study including 411 patients aged 61-77 (median 70), the authors observed significant improvement in the patients' mood at the three-month follow-up (Watkins et al., 2007). A significant improvement in the patients' mood was also observed at the twelve-month follow-up, in addition to a decreased mortality among the study participants (Watkins et al., 2011). These studies concluded that MI improves mood 3 and 12 months post-stroke (Watkins et al., 2007; Watkins et al., 2011) and reduces mortality one year following a stroke (Watkins et al., 2011). This study is one of few nursing-led psychosocial interventions that have been found effective. However, the study did not address the needs of younger/work-aged stroke survivors in particular.

Burton and Gibbon (2005) investigated the effect of outreach education and support delivered by a specialist nurse after discharge from hospital in a pragmatic RCT study. Eighty-seven patients (mean age 75.8) were included in the intervention, and 89 patients (mean age 74.7) were included in the control group. This intervention consisted of a follow-up of a stroke nurse at the place of discharge within two days after discharge from hospital. The stroke nurse guided the planning for future follow-up and assessment of both physical and emotional aspects of living with a stroke. As the follow-up was flexible, the participants in the subsequent follow-ups were invited to contact the stroke nurse by telephone. Each stroke survivor contacted the stroke nurse three times over a period of two months on average. The intervention was assessed to improve general health, particularly negative emotional reactions and perceived social isolation, measured 12 months post-stroke. This intervention was also assessed as having a positive effect on carer strain and physical dependence (Burton & Gibbon, 2005). Again, this study did not particularly address the challenges of younger stroke survivors.

A review including 16 trials addressing multi-disciplinary rehabilitation in adults 16-65 years following acquired brain injury (including stroke) reported strong evidence that information and advice were essential for recovery in those suffering mild strokes. Among those who suffered a moderate or severe brain injury, more intensive rehabilitation programs were needed to sustain gains. The authors concluded that although more research is needed, access to an out-patient or community-based follow-up is decisive to address individual needs and different problems (Turner-Stokes, Disler, Nair, & Wade, 2005).

A multidisciplinary rehabilitation program targeting physical, cognitive and linguistics disabilities among younger stroke survivors' included 50 patients aged 18-65 in an intervention consisting of two to three hours individualised daily therapy and group activities. The stroke survivors were transferred to a rehabilitation unit after discharge from a hospital. The intervention improved the participants' physical and cognitive abilities, and quality of life measured at discharge from the rehabilitation unit. However, it is impossible to draw firm conclusions about the effect of this intervention because of the small sample size and absence of a control group (O'Connor, Cassidy, & Delargy, 2005).

Based on the lack of psychosocial nursing interventions with clear theoretical and empirical underpinnings, Kirkevold et al. (2012) developed a complex intervention with the overall aim to promote psychosocial well-being. The development was consistent with the Medical

Research Council's (MRC) (Craig et al., 2008) guidance for developing and evaluating complex interventions and was systematically based on qualitative studies of stroke recovery, theories of psychosocial well-being, coping, life skills, narrative theory and guided self-determination. The intervention focused on fostering understanding and (re)creation of meaning through narrative dialogues as well as supporting coping efforts and the development of new skills for managing life after a stroke. The intervention was designed to consist of eight dialogues between stroke survivors and a trained healthcare worker. A guiding topical outline and worksheets (reflection sheets) were developed to support the dialogues. The MRC framework was in this study found to support the development of the intervention. However, a further development of the intervention and an exploration of the impact and effects of the intervention was found to be necessary (Kirkevold et al., 2012).

2.3 Summary and rationale of the study

This background chapter has highlighted that a lack of focus concerning the experiences and needs of the younger cohort of stroke survivors persists and that stroke rehabilitation in general does not specifically address the needs of stroke patients at different ages. However, the existing literature indicates that suffering from stroke before retirement age impacts life substantially and influences well-being negatively.

Experiencing a stroke below retirement is an event that hits unexpectedly, disrupting and challenging psychosocial well-being. Knowledge about how to assist and support work-aged stroke survivors in addressing their particular psychosocial challenges and needs during the rehabilitation period is scarce. The knowledge gaps in this research area actualise a need to investigate the experiences following a stroke during the younger period of life and explore ways of supporting the younger cohort of stroke survivors.

The effects of psychosocial interventions developed to support stroke survivors remain to a large extent unclear, and clinical nursing interventions are underdeveloped. This necessitates a further development of psychosocial nursing interventions based on explicit theoretical assumptions and empirical evidence. The testing of the dialogue-based nursing intervention developed by Kirkevold et al. (2012) was thus the point of departure of this thesis.

3 Aims

The overall aim of this study was to explore work-aged stroke survivors' psychosocial challenges and psychosocial follow-up needs.

The study was conducted in three main phases. The first phase consisted of a feasibility study of the dialogue-based nursing intervention addressing psychosocial well-being. The two first studies were related to this phase. During the second phase, a group of work-aged stroke survivors who had not participated in the intervention was included to further explore younger stroke survivors' experiences over time. During the last phase, a cohort from each of the earlier phases was interviewed in a follow-up interview to investigate their follow-up needs.

The specific aim of **study I** was to evaluate the content, structure and process of a dialogue-based nursing intervention and the experienced usefulness of participating in the intervention from the participants' point of view.

The aim of **study II** was to illuminate the psychosocial challenges that work-aged participants (included in study I) thematised during and after participating in the dialogue-based intervention.

As a part of a further development of the complex intervention, we found it necessary to expand the knowledge to tailor the intervention to the work-aged stroke survivors' specific needs over time. During these interviews, concerns of the stroke survivors' relationships with their family lives became very more prominent. The stroke survivors' experiences related to their family life was thus investigated more in depth.

The aim of **study III** was to gain a deeper understanding of how a stroke impacts family life from the stroke survivors' point of view, six months or more after the stroke.

The aim of **study IV** was to explore work-aged stroke survivors' experiences with the health services and to identify potential long-term follow-up needs.

4 Theoretical perspectives

This chapter presents the theoretical perspectives underpinning the study.

4.1 Phenomenological nursing

The basic premise of phenomenological nursing is that caring for individuals in need of nursing must be founded on an understanding of the individual patient's lived experiences (Benner, Tanner, & Chesla, 2009). This thesis takes a phenomenological nursing perspective as its starting point and basic premise with respect to caring for individuals in need of support and help following a stroke.

The philosophy and methodology of phenomenology was developed to understand humans' life worlds from an inner perspective (Spiegelberg, 1982). Phenomenology takes into account that the mind and body are inseparable and strives to achieve an understanding of the person in a holistic perspective. The theory underscores the need to understand the existential aspects of importance to the patients to provide adequate support and help (Dahlberg, Todres, & Galvin, 2009).

Experiencing a disease such as stroke is a lived experience interrupting life, leading to stressful situations. Stress disrupts meanings, understanding, and smooth functioning so that harm, loss, or challenge is experienced, and sorrow, interpretation or acquisition of new skills are required (Benner et al., 2009; Benner & Wrubel, 1989).

Coping is the individual's management of the experienced stressful situations (Folkman & Nathan, 2011; Lazarus & Folkman, 1984). The inherent capacity to cope with stress is individual and influenced by temporality, i.e., how the person interprets the present in light of the past and the future (Benner & Wrubel, 1989). This means that individuals' experiences of illness, i.e., the human experience of suffering the consequences of a disease, will make individuals enter situations in different ways (Benner et al., 2009; Benner & Wrubel, 1989).

Phenomenological nursing is concerned with caring for the individual who is experiencing illness. Thus, phenomenological nursing is concerned with how to help the patient live through the illness by managing stress in the best possible way. The intervention is directed towards protecting the individuals' vulnerability, supporting growth and health, or supporting a good and peaceful death when necessary. It is therefore necessary to understand the

concerns of the individual, to respond to the individual situation, and to participate in the individuals' experience of illness (Benner, 1984; Benner et al., 2009; Benner & Wrubel, 1989).

Phenomenological nursing philosophy does not provide specific practical guidance. Rather, the philosophy points to underlying principles for how to encounter the other's need for care. A basic principle is to approach the suffering individual based on a caring comportsment that aspires to an understanding of the other while acknowledging that such an understanding will never be completely possible. This premise goes beyond a technological approach, meaning that phenomenological nursing implies a non-instrumental approach to the other (Benner et al., 2009; Benner & Wrubel, 1989; Galvin & Todres, 2009; Todres, Galvin, & Dahlberg, 2007).

Nevertheless, to practice nursing from a phenomenological perspective, this study assumes that developing specific nursing approaches based on the phenomenological perspective is necessary to implement this approach in a healthcare service mainly guided by a biomedical approach to health and illness.

4.1.1 Subjective well-being

Consistent with the theoretical assumption of the dialogue-based intervention developed by Kirkevold et al (2012), the understanding of psychosocial wellbeing in this thesis draws on the description of Næss (2001b). Psychosocial well-being is defined as "high if the cognitive and affective experience is positive and low if the cognitive and affective experience is negative" (Næss 2001b, p. 1940, own translation). The cognitive component of the definition refers to thoughts and assessments, whereas the affective component refers to the emotional conditions (Næss, 2001b).

Næss (2001b) identified four dimensions of psychosocial well-being: (1) a basic mood of contentment and the absence of pervasive feelings of sadness and emptiness, (2) participation and engagement in meaningful activities beyond oneself, (3) good social and mutual relations, and (4) a self-concept characterised by self-esteem, self-acceptance, usefulness and belief in one' own abilities (Kirkevold et al., 2012; Næss, 2001a).

This study's understanding of subjective wellbeing is also influenced by the sense of coherence framework developed by Antonovsky (1979). This framework is a salutogenic,

dynamic and flexible approach incorporating health and well-being that was originally formulated to guide the discipline of health promotion. The global orientation within this framework reflects how individuals view their lives in general. The focus is directed towards the ability and capacity to manage stressful situations, i.e., taking individual resources and capacities into account rather than the traditional pathogenic (biomedical) view, which focuses on barriers and deficits. Health is viewed as a movement on a continuum between the two poles of ill-health (dis-ease) and health (ease) and is built upon accessible general resistance resources (i.e., internal and external resources). The general resistant resources facilitate viewing the world as making sense, referring to physiological resources and cognitive and emotional resources (knowledge, intelligence and self-identity) as well as the cultural context, interpersonal relationships, and the social and economic situation (Antonovsky, 1979, 1987, 1996; Lindström & Eriksson, 2005).

Subjective well-being is thus influenced by the individual's experience of a sense of coherence (SOC), which depends on the possibility of experiencing situations as comprehensible, manageable, and meaningful. Comprehensibility is the cognitive component of SOC and relates to the individuals' ability to perceive stimuli as predictable or at least to perceive the stimuli as possible to order and explain. Manageability is the instrumental/behavioural component of SOC and refers to an individual's ability to respond to the inherent demands and/or demands initiated by the environment. Meaningfulness is the motivational component and refers to how individuals emotionally sense life as worthy of energy investments when life becomes challenging and demanding (Antonovsky, 1979, 1987, 1996; Lindström & Eriksson, 2005). SOC was in the intervention assumed to be an essential intermediate goal for promoting psychosocial wellbeing (Kirkevold et al 2012).

4.1.2 The significance of narratives in nursing

Storied lives and experiences are inherently meaningful (Bamberg, 2007). Through stories, humans seek to negotiate a position within a given social context that gives meaning, direction, identity, belonging and value in life (Kraus, 2007; Taylor, 2007). Narratives have thus implications for human existence and constructions of meaning in life (Polkinghorne, 1988). Narratives are subjective and give voice to personal experiences (Mattingly, 1998). By telling stories, humans connect the present to the past and the future (Polkinghorne, 1988).

A narrative refers to any real or imaginative, spoken or written presentation, either as the cognitive process of making a story or the result of the process, and is consistent with the terms story, tale or history (Polkinghorne, 1988). Narratives thus render and order partial sequential events into a meaningful whole that creates meaning (Mattingly, 1994). The schematic whole of the significant events of a story is the narrative plot (Polkinghorne, 1988).

Research suggests that telling one's story is a fundamental need following a traumatic event and that this may actually promote health in and of itself. Being encouraged and supported to tell one's story, receiving responses from others and experiencing that stories are shared are found to be positive in stimulating reflection and adjustment, affirming and strengthening identity, self-understanding and self-esteem (Frank, 1995, 1998; Mattingly, 1998). Hjelmblink and Holmstrom (2006) found narration to be a positive influence in giving vent to a fear of the future following stroke. To reveal emotions by narrating was also found to have a significant reduction in developing posttraumatic stress disorder among refugees in a randomised controlled trial (Hensel-Dittmann et al., 2011).

Ill people need to tell their own stories to work through their present situations. To tell their story of an estranged body gives the body a voice. Storytelling might contribute to repairing the damage of suffering an illness (Faircloth, Boylstein, Rittman, & Gubrium, 2005; Frank, 1995, 1998). To tell stories is an interplay between a teller and a listener, a contribution of making the personal and invisible visible, making the implicit explicit or make the muddy more clear in a human's life, and thus represents a recuperative event (Atkinson, 2001; Frank, 2000).

Professional workers attend to illness stories to derive information to offer support and treatment in their clinical work (Charon, 2007; Frank, 1995; Mattingly, 1994). From a nursing perspective, it is imperative to understand the interruptions that occur in life when suffering a disease such as stroke. Understanding the patients' experiences of illness and the needs for care is necessary to ease the experience of stress and helps the patient to recreate meaning in life with illness (Benner et al., 2009; Benner & Wrubel, 1989).

To share stories might thus have a positive influence in clarifying experiences, enhancing self-esteem, being confirmed, and releasing negative thoughts and feelings. Furthermore, storytelling might influence and clarify future goals (Atkinson, 2001). The storied narratives are contextual and might differ depending on the situation and the receiver (Taylor, 2007).

Knowing that interplay in constructing stories contributes positively (Atkinson, 2001; Frank, 2000), nurses' contributions in listening to and co-constructing (i.e., create the story in cooperation with the patient) stories are of importance in eliciting experiences. Understanding and being aware of the meaning of interpreting narratives to develop a common understanding is thus a fundamental and necessary activity within nursing (Benner et al., 2009).

4.2 Guided self-determination

Guided self-determination (GSD) is a person-centred communication and reflection model based on empowerment philosophy (Zoffmann, 2004). The overarching idea is that the interactions and communication between nurses or other healthcare professionals' and patients must be conducted in a way that elicits the patient's experiences, perspectives and needs. This is essential to support the patients in making decisions that they feel address their personal needs and fits with their life situation (Zoffmann, 2004; Zoffmann, Harder, & Kirkevold, 2008).

According to this model, the interactions between patients and professionals is based on a reciprocal exchange of information about the challenges of living with the illness, shared decision-making and/or guided self-determination in terms of how to deal with these challenges (Zoffmann, 2004). The person-specific knowledge created during the dialogues is based on a dialogical co-construction between the patient and the professional by bringing difficulties to the surface and developing further self-insight in terms of adjusting to the illness. The dialogues based on this reciprocal situational reflection and communication are supported by semi-structured reflection sheets, called worksheets (Zoffmann et al., 2008; Zoffmann & Kirkevold, 2012; Zoffmann & Lauritzen, 2006).

The GSD model was initially developed as a problem-solving process aimed at developing life skills in patients with diabetes (Zoffmann, 2004). The intervention was tested in patients with poorly controlled diabetes type 1 aged 18-49 years and was found to be helpful in improving life skills in overcoming barriers or pitfalls to control this chronic illness over a period of one year (Zoffmann & Lauritzen, 2006). The patients improved their life skills in identifying, expressing and sharing difficulties in their living with diabetes (Zoffmann & Kirkevold, 2012) and even improved their long-term blood sugar (Zoffmann & Lauritzen,

2006). This approach has also been used in other populations, such as in persons with schizophrenia (Jørgensen, Hansson, & Zoffmann, 2012), stoma surgery patients (Olsen, 2011) and patient with cardiology challenges (Gum & Danielsen, 2010) with promising results. However, the GSD model has not been tested in relation to individuals suffering from stroke. This present study is thus a contribution to strengthen the knowledge of how GSD might work in clinical situations among stroke survivors and their helpers.

4.3 Psychosocial challenges across the adult life span

A basic assumption in this study is that suffering from a stroke might be experienced differently and have a different impact on life when an individual is work-aged compared with being retired or in old age. Such differences do not necessarily lie inherent in the chronological age but are rather assumed to be determined by the different life situations of people of different ages. To be able to understand how a stroke influences life when being work-aged and be able to connect individuals' present situations to the past as well as the future, it is necessary to be aware of the psychosocial challenges prone to influence the life worlds of work-aged stroke survivors. The further text describes the factors normally expected to influence individuals during their work-aged period of life.

Psychosocial development follows similar patterns across individuals, with a gradual introduction to different social roles across the life span (subsequently becoming a pupil, student, worker, son/daughter, wife/husband and so on with increasing age). During life-long development, different lifespan tasks, i.e., successive tasks in different contexts, are involved (Baltes, Reese, & Lipsitt, 1980). Although there are substantial variations, there is an expected common pattern that individuals follow as they grow up, mature and grow old.

Individuals are generally born into and grow up in families, and most individuals will establish their own family during their life course. Families also move through a series of phases, and this development impacts on the individual members (Carter & McGoldrick, 1999; Day, 2010).

The initial adult phase involves single young adults separating from the origin family by leaving home and developing intimate peer relationships. Younger adults focus on independence and emancipation. Developing one's own personal goals, establishing identity

and emotional and financial responsibility, studying, working, and committing to a career path are dominating developmental tasks during young adulthood. Turning to parents or other family members for advice during this period of life might be difficult, as achieving independence from parents is a major goal of maturity in this phase of life (Carter & McGoldrick, 1999; McGoldrick et al., 2013).

In the mid phase of adult life, central psychosocial challenges focus on establishing partnership/ marriage and, for many, on parenthood. Central life span tasks, such as raising children, household tasks, launching a career, and financial commitments, are comprehensive and long-lasting. During this phase, individuals have to deal with new members entering the family, flexibility in accepting children's independence and the frailty of grandparents (Carter & McGoldrick, 1999; McGoldrick et al., 2013). According to Carter and McGoldrick (1989), the negotiation of different roles during this mid-phase of adult life is traditionally viewed as one of the most challenging transitions.

In the long run, families develop adult relationships with grown-up children, in-laws and grandchildren, eventually moving forward to deal with the disabilities and death of aging parents. During the empty-nest period, the absence of children in the home requires fewer parenting commitments and, to most, creates a more favourable economic situation. To some, this phase is viewed as a time for exploring new arenas and new roles. Others view the phase in negative terms (Carter & McGoldrick, 1999; McGoldrick et al., 2013).

Family relationships involve multiple developing individuals, including not only the children but also the parents and other individuals involved in the family system (Baltes et al., 1980; Chibucos, Leite, & Weis, 2005; Daly, 2003). The family frames identity and development, consists of irreplaceable relationships often viewed as more valuable than roles and functions. The relationships are not able to be realigned by others. Furthermore, the relationships represent psychological bonding and influence the social balance (Carter & McGoldrick, 1999).

Family processes are non-linear and non-age specific, influenced by genetic heritage and behaviour, including attitudes, taboos, expectations as well as developmental life cycle transitions, unpredictable factors and historical events (Carter & McGoldrick, 1999). Carter and McGoldrick (1999) underline families as complex, multifaceted and flexible; individuals are going through different family phases at different ages and are furthermore living in

different relationships. Earlier life events and hereditary factors are assumed to influence future development. Life events can alter expectations, perceptions, and emotional ties to others (Baltes et al., 1980; Daly, 2003).

The social role of working outside home is important to psychological health (Blustein, 2008), in this sense contributing to independence, autonomy and personal development in addition to having a positive economic impact, allowing interactions with work mates and having meaning to others (Alasewski et al., 2007; Koch et al., 2005; Lindström et al., 2009; O'Connell et al., 2001).

Adulthood comprises multiple life transitions, i.e., the movement and adaptation to change of expected as well as unexpected life events. Some of these transitions are normative and expected; others are not expected and are caused by non-predictable events. The transitions can be both positive and negative to the individual and may emerge “on time” (e.g., at the expected time) or “off time” (too early or too late) according to the normative expectations within society. Transition events change familiar situations and may be challenging and lead to disruptions in life. Transitions related to illness are considered to be more challenging than on-time transitions (Elder & Giele, 2009; Kralik & van Loon, 2010; Kralik, Visentin, & van Loon, 2006; Marks & Lambert, 2005; McGoldrick et al., 2013; Parsons, 1991).

As highlighted above, a basic assumption in the present study is that the life span phase in which the individuals find themselves will influence the lived experiences following a stroke. In this study, we explore the work-aged stroke survivors’ challenges, taken into account challenges across the life span.

5 Methods

The overall design of the study was explorative and qualitative. The study was performed in three phases. The first phase, which included the first two sub-studies (study I and study II), had a feasibility design (Craig et al., 2008). The two other sub-studies (study III and study IV) had an interpretive, phenomenological design (Polit & Beck, 2012).

An overview of the studies is presented in table 1.

Table 1: Overview over the studies

	Study	Aim	Design	Data	Period	Analysis
Phase I	I	To evaluate the content, structure and process of a dialogue-based nursing intervention and the experienced usefulness of participating in the intervention	Feasibility design	Log notes and worksheets during the intervention; in-depth interviews two weeks after conclusion of the intervention	May 2007- Oct 2008	Qualitative content analysis
	II	To illuminate the psychosocial challenges that work-aged participants thematised during and after participating in the dialogue-based intervention	Feasibility design	Log notes during the intervention; in-depth interviews two weeks after conclusion of the intervention	May 2007- Oct 2008	Hermeneutic phenomenological analysis
Phase II	III	To gain a deeper understanding of how a stroke impacts family life from the stroke survivors' point of view, six months or more after the stroke	Interpretive, phenomenological design	In-depth interviews	Jan 2009- Apr 2010	Hermeneutic phenomenological analysis
Phase III	IV	To explore work-aged stroke survivors' experiences with the health services and to identify potential long-term follow-up needs	Interpretive, phenomenological design	Follow-up, in-depth interviews one year after conclusion of the intervention (study II) and one year after the in-depth interviews of non-intervention participants (study III)	Dec 2008- Apr 2011	Hermeneutic phenomenological analysis

This chapter describes the methodological assumptions of conducting feasibility studies as highlighted by the Medical Research Council (MRC) framework (Craig et al., 2008) followed by a description of investigating lived experiences. Furthermore, the chapter provides a

presentation of the three phases (consisting of four sub-studies) and the ethical considerations of the study.

5.1 Feasibility assessment

The intervention was developed in line with the MRC framework for developing and evaluating complex interventions (Craig et al., 2008). The MRC framework emphasises the importance of conducting a feasibility assessment of interventions before launching a large-scale evaluation study (such as a randomised controlled trial).

The MRC framework (Craig et al., 2008) was developed to assist researchers in developing interventions systematically to make interventions appropriate to improve health and facilitate implementation in practice. The framework is dynamic and cyclical and consists of four major phases. The first phase, the development phase, consists of identifying the evidence base, identifying or developing appropriate theories, and modelling the intervention. The second phase, the feasibility/piloting phase, consists of testing of intervention procedures, recruitment, and sampling. The third phase, the evaluation phase, consists of assessing the effectiveness, understanding change processes, and assessing the cost-effectiveness. The last phase, the implementation phase, consists of dissemination, monitoring and long term follow-up of the intervention (Craig et al., 2008). The development of the psychosocial intervention tested in this study was completed when the study included in this thesis commenced. The outset of this study was thus the feasibility/piloting phase, which implies conducting the intervention followed by a process evaluation to understand the changing processes, possible outcomes and exploring the active ingredients of the intervention.

Evidence from a variety of sources is known to be useful in identifying limitations and obstacles that address the uncertainties in conducting complex interventions. A mixture of quantitative and qualitative methods is recommended to provide insight into the effective components as well as to understand barriers and obstacles in delivering of the intervention (Craig et al., 2008). To understand how the intervention works, i.e., the practical effectiveness and uncertainties, and how the intervention can be fine-tuned to be optimised and useful in promoting stroke survivors' psychosocial well-being, the feasibility testing of the intervention is in this study focused on a qualitative evaluation, i.e., the stroke survivors' experiences of participating in the intervention.

Although presented in subsequent phases, the framework highlights flexibility and allows different forms and interactions between the four phases (Craig et al., 2008). A qualitative evaluation of the feasibility of the dialogue-based intervention focusing the participants' experienced usefulness of the intervention is thus assumed to maximise the possibility of identifying the active ingredients and securing further development of the intervention.

5.2 Investigating lived experience

As highlighted in the previous chapter, phenomenology is concerned with the lived experiences of the human life world as it is subjectively experienced and intuitively taken for granted (Lindseth & Norberg, 2004; van Manen, 1997). However, meanings do not necessarily come directly to humans but may need to be created through a hermeneutic interpretation. Thus, it is useful to connect hermeneutics, initially founded to facilitate interpretation of sacred texts, and phenomenological descriptions (Flood, 2010; Lindseth & Norberg, 2004). To arrive at the meaning of lived experiences thus requires an interconnection of hermeneutics and phenomenology (Ricoeur, 1976, 1999). Based on these assumptions, a hermeneutical phenomenological approach is assumed to be appropriate for investigating lived experience (Lindseth & Norberg, 2004; Ricoeur, 1976).

To investigate human meaning, it is necessary to elicit the humans' experiences by listening to their stories (Lindseth & Norberg, 2004). In-depth interviewing represents an appropriate data collection method within qualitative research that provides access to individuals' thoughts, feelings, and experiences of the everyday world and provides a better understanding of the phenomenon under investigation (Kvale & Brinkmann, 2009; Patton, 2002).

During narrative research interviews, stories are centred on the study participants' more or less spontaneous stories in cooperation between the interviewee and the researcher (Kvale & Brinkmann, 2009; Vandermause & Fleming, 2011). To gain access to the participants' lived experiences by eliciting textually rich, in-depth data focusing on the research topic, it is useful to organise the interview sessions by using a thematic interview guide. However, to seek open-ended responses, the interviewer is challenged to ask open-ended questions to encourage the interviewee to make "free" or non-directed narrations of everyday experiences. To secure depth, probing and follow-up questions are methods used to elicit descriptions (Kvale, 2007; Kvale & Brinkmann, 2009).

To come to an understanding of the implicit meaning of lived experience is a critical dialectic action between explanation and understanding the essential meaning (Ricœur, 1976, 1999). This understanding is rendered possible by following the texts in the movement from “sense to reference” (Ricœur, 1976, p. 87-88), i.e., from what the texts says to obtain an understanding of the nature of the texts. This approach helps reveal the essential meaning of the phenomenon described in the text (Lindseth & Norberg, 2004; Ricœur, 1976). To interpret the meaning of texts, it is, for research purposes, necessary to transfer the oral narratives to text to be able to examine the meaning of the text in depth (Kvale & Brinkmann, 2009; Lindseth & Norberg, 2004).

Following the transcription of the oral narrations, the texts are autonomous and open to multiple interpretations (Ricœur, 2008). To understand the meaning of texts requires the researcher to be involved with the transcribed texts (Kvale & Brinkmann, 2009; Thorne, 2008). The analytic approach is a non-linear activity and an on-going process wherein themes and subthemes are compared and contrasted by a continuous alteration between the parts and the whole of the text to be able to render a comprehensive understanding of the phenomenon under investigation (Kvale & Brinkmann, 2009; Ricœur, 1976; Tan, Wilson, & Olver, 2009).

Hermeneutics emphasise the researcher’s awareness of his/her own knowledge and pre-understandings as necessary elements during the investigating processes. My working experiences as a nurse in a medical ward in a hospital, in the home services and in a nursing home, as well as the literature research during the period of working with this study, have probably influenced both the way I met the participants participating in this study, my ability to create a positive atmosphere and the manner in which the interviews were conducted. It is also important to be aware that the experiences may have influenced the analysis work, as well as the results of the study. On the other hand, this study was conducted within a larger research group, and all aspects of the research process were discussed among the members of the research group. This approach compensated for the more limited pre-knowledge of each individual researcher by bringing diverse experiences into the interpretive processes.

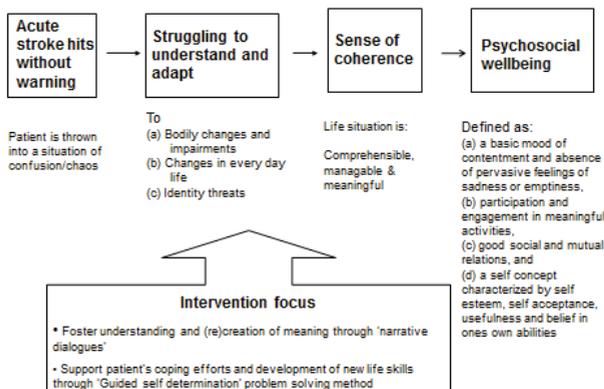
5.3 Phase I

This section describes the first phase of the study, consisting of the feasibility studies (study I and study II). These two studies are described following an initial presentation of the intervention.

5.3.1 Presentation of the intervention

The intervention aimed to promote psychosocial well-being. The development of the intervention was developed based on earlier qualitative studies, systematic reviews of psychosocial intervention studies, and theories addressing psychosocial well-being (Kirkevold et al., 2012)². The theoretical structure of the intervention is illustrated in figure 1.

Figure 1: The theoretical approach of the intervention



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The intervention was designed to consist of eight one-hour dialogue-based encounters between a stroke survivor and a skilled health professional (mostly nurses) over a period of six months. Each encounter had a guiding topical outline that addressed significant issues described in the research literature, including bodily changes, personal relationships, daily life issues, meaningful activities, existential issues, important values, and other dimensions of

² As the development phase was not part of this dissertation, the details of the development process are not described here.

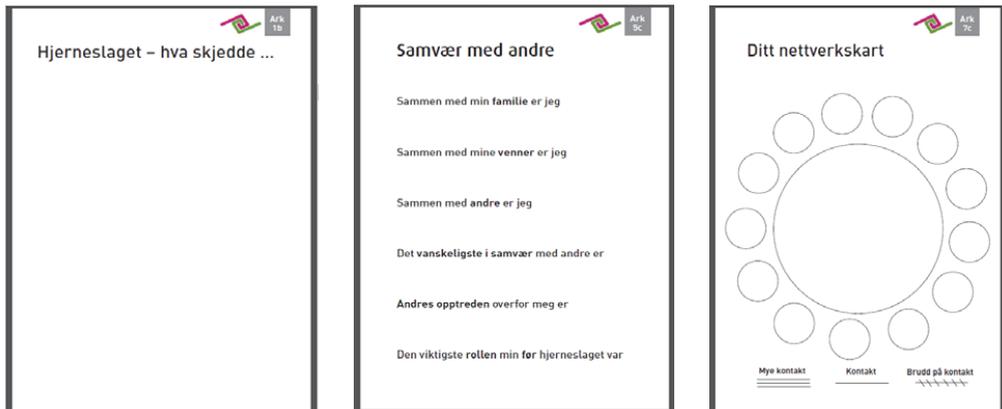
psychosocial well-being (Kirkevold et al., 2012). An overview of the topical outline of the encounters is described in table 2.

Table 2: Topical outline of the intervention (guiding structure)

Encounter number	Aim	Worksheet
One	To establish a relationship for collaboration in an early phase after the stroke.	1a: Invitation to collaboration 1b: The stroke - what happened?
Two	To gather knowledge about personal values, interests and goals as a common platform for further collaboration (Who are you (identity), which life is interrupted by the stroke?). To prepare for further collaboration after home coming.	2a: Life line – Personal background, values and interests 2b: Metaphor –”Your grate trial of strength”
Three	To support the participant in their process of adjusting to a changed situation (from healthy to stroke survivor in everyday life). To support the participant in clarifying setting goals (short terms) and opportunities.	3a: Personal metaphor of your life as a stroke survivor 3b: Mood in everyday life (unfulfilled sentences)
Four	Invitation to narrate about bodily experiences and changes. Support in making sense of the new experiences, and mobilise available recourses. Renegotiate new roles and identity adjustment.	4a: Me and my life (unfulfilled sentences) 4b: My body (graphical illustration of a woman/man)
Five	Identify goals to focus and sort out what has to be done by whom to reach the goals. Support to identify personal resources and significant resources in their network.	5a: Problem-solving process 5b: Daily activities in everyday life (unfulfilled sentences) 5c: Relationship with others (unfulfilled sentences)
Six	Help to integrate illness and life in a way that appear manageable for the participant. Support to promote health and build up resistance resources (i.e. sleep, social relationships, meaningful activities, food, physical activity). Support to develop new life skills that are necessary to live well with changes caused by the stroke.	6a: Illness and life 6b: Choice of aims to focus 6c: Balance in everyday life 2b: Metaphor (What kind of support do you need)
Seven	Talk about experiences and support the coping process. Assistance to be conscious about personal recourses and recourses in their network/environment.	7a: Coping in everyday life 7b: Habits I need to change/should change 7c: Network
Eight	Negotiating perspectives and goals for the further recovery process. Summarising the collaboration process.	2b: Metaphor (past – present – future)

The dialogues were pedagogically and methodologically supported by worksheets consisting of drawings, figures, unfinished sentences and keywords pointing to the highlighted issues. The design of the worksheets was adjusted to take into account the possible language challenges due to aphasia (Kirkevold et al., 2012). Figure 2 provides some examples of worksheets.

Figure 2: Examples of work sheets



The number of eight encounters was based in part on previous studies and in part of pragmatic grounds (as few encounters as possible but enough to provide adequate support). The suggested times for each encounter were designed to coincide with significant transition points and times of increased vulnerability in the recovery process as revealed by previous research (Kirkevold et al., 2012).

The intervention was delivered by health workers who were trained in a 16-hour training course prior to the intervention. Members of the research team also participated in conducting the intervention to evaluate how it worked in practice and to be able to develop it further. For this reason, I conducted the intervention with two individual participants. One of these participants was work-aged, and the other was retired.

The worksheets were compiled into a workbook and were handed to the participants during the first encounter, which gave the participants an opportunity to read, reflect on and/or fill in the worksheets prior to and after participating in the dialogue encounters (Kirkevold et al., 2012).

Although the dialogue encounters were developed to have a topical outline to facilitate problem solving, the dialogues were also intended to be flexible and “open” as a means of inviting the participants to discuss the issues and challenges that were important to them at the present and thus to attend to their individual challenges following the stroke (Kirkevold et al., 2012).

The health workers delivering the intervention were trained to adjust the intervention and select the worksheets during the encounters according to the participants’ individual needs. Consequently, the successions of the worksheets supporting the specific encounter were changed as necessary, and not all work sheets were used with all participants. The participants were thus in charge of the topics to be discussed during each encounter. This approach secured a flexible design suited to the individual’s needs.

The intervention was tested both in an individual intervention format (n=20) and as a group intervention (n=5). The participants participating in the group intervention were initially offered two individual encounters followed by six group dialogues with four fellow stroke survivors. Offering the two individual encounters before entering the group intervention was seen as necessary in order to establish working relationship between the health worker and the participant, grounded on the stroke survivors’ individual situation (Kirkevold et al., 2012). The group intervention was facilitated by two health professionals.

The individual encounters were delivered in hospital/rehabilitation units or nursing homes as long as the participants were hospitalised and in the participants’ homes upon discharge. The six group encounters were delivered in a patient education centre (“Learning and mastery centre”). The content and structure of the dialogues were identical in both of the intervention formats. However, the group meetings lasted two hours to allow sufficient time for the dialogues. All participants were encouraged to participate and voice issues and concerns, but the individual flexibility was, by necessity, more limited. On the other hand, the group participants were encouraged to share experiences, thoughts and ways of coping.

5.3.2 Study I

The aim of study I was to evaluate the content, structure and process of a dialogue-based nursing intervention and the experienced usefulness of participating in the intervention.

Sample

The inclusion criteria for the intervention study were people suffering from a stroke within the last eight weeks, aged above 18 years-old, medically stable, speaking Norwegian and interested in participation. Participants were evaluated by the stroke team or their physician to be able to benefit from the intervention. Stroke survivors with language problems were eligible to be included after an assessment and the specification of their language problems by their speech therapist. The exclusion criteria included stroke survivors suffering from dementia or being judged too ill to benefit from participation in the intervention program.

The participants were mainly recruited when hospitalised in the acute phase of their stroke, although some were recruited after being discharged from the hospital while transitioning to the community health services. Local nurses were responsible for recruiting the patients.

Twenty-nine stroke survivors were recruited to the intervention study. Four patients dropped out because of deteriorating health (2), new serious illness (1) or unwillingness to discuss problems (1). Consequently, a total of 25 stroke survivors (17 men and 8 women) aged 33-89 (median 64) completed the study. The participants comprised three subsamples; 13 participants without language problems received an individual intervention, 7 with moderate to severe language problems received an individual intervention, and 5 participants without language problems received the group format of the intervention.

The participants were initially diagnosed with occlusion or haemorrhage of an artery in the left or right hemisphere. The consequences from the strokes varied from mild (few or no observable symptoms) to severe (wheelchair-bound and/or dependent on assistance of daily living) and included upper and lower limb weakness or paresis, spasticity, and cognitive impairments such as lapse of memory, concentration problems, neglect, and aphasia. Some suffered from fatigue and vision or hearing deficiencies. In addition, some of the participants were diagnosed with epilepsy following the stroke.

All of the participants participating in the intervention study lived at home prior to the stroke onset, and all but two lived at home at the conclusion of the intervention.

Data collection

Data were collected immediately before the intervention (T1), during the intervention (T2) and two weeks after the end of the intervention (T3). At T1, demographic data (age, gender, education, job, family relations and living conditions) and medical information (time and type of stroke, functional data, treatment, other medical diagnoses and treatments) were collected. At T1 and T3, standardised instruments, measuring health-related quality of life, emotional wellbeing, life satisfaction and anxiety and depressive symptoms, were collected. During the intervention (T2), log notes and worksheets were used to describe the intervention process. Two weeks after the intervention (T3), individual qualitative interviews were conducted.

The standardised instruments were included to evaluate their appropriateness for a future larger, controlled trial. The sample size was too limited to conduct statistical analyses. Furthermore, many of the standardised instrument forms were incomplete and were thus not able to be analysed. The standard instruments are not described further here because this thesis focuses on the qualitative feasibility evaluation of the intervention.

The qualitative data, including the worksheets, the log notes and the narrative in-depth interviews, were thus the data sources in this study and are further described in the text below.

The worksheets that supported the dialogues were used differently during the encounters. Some of the participants or the health personnel wrote on most of the worksheets, whereas others did not use them actively. When used during the encounters, the worksheets provided valuable information about the participants' experiences and thoughts.

The health personnel who performed the intervention documented the encounters in log notes following each encounter. The log notes were structured to secure a minimum of documentation of the intervention sessions. The health personnel documented the length of the intervention sessions, the themes addressed in the encounters, and the specific worksheets used. In addition, the health personnel also documented specific observed reactions during the encounters (if any), whether other participants (i.e., next of kin) were present, and their own reflections of the intervention situations, e.g., their own roles, interruptions, difficulties, and theoretical reflections in the log notes.

Most of the log notes consisted of one page from each intervention encounter. However, some intervention encounters were interrupted because of the stroke survivors' conditions and were

resumed later. These situations increased the number of log notes. The log notes also differed with respect to the descriptions and reflections.

Study I involved an evaluation of the content, structure and process of the intervention. The qualitative interviews therefore combined open ended questions concerning the stroke survivors' present situations with structured questions related to the intervention program.

The first thematic question concerned thoughts and feeling regarding the present life situation, the psychosocial needs and well-being, thoughts about the future, formulated as follows: "Can you describe how you experience your life at present?" The next question concerned the experiences and opinions with regard to participating in the intervention. The participants were also asked about their opinion of whether participating in the intervention made a difference or not in relation to their well-being. At the end, the participants were asked whether they had other comments or suggestions related to participating in the intervention. Family members could participate in the interviews if this was approved by the stroke survivors.

The interviews lasted between 50 and 120 minutes and were conducted in a patient education centre, in the stroke survivors' homes, nursing homes, and a conference room in a hospital according to the participants' preferences. The stroke survivors were interviewed by members of the research team who had not delivered the intervention. This approach was of importance to encourage the participants to openly voice criticism and concerns regarding participating in the intervention. However, some of the participants with moderate to severe aphasia (n=7) were interviewed by the same member of the research team who conducted the intervention because of the substantial communication problems. This member of the research team had been trained in communication techniques for persons with aphasia and was supervised by a speech therapist. These interviews were video-recorded as a supplement to better capture both verbal and non-verbal expressions of the stroke survivors.

Analysis

To evaluate the content, structure and process of the complex dialogue-based intervention and the usefulness of participating in the intervention from the patients' perspective, a qualitative content analysis method was chosen. Content analysis was originally a method appropriate for quantitative methods (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon,

2005; Kvale & Brinkmann, 2009). In recent years, however, the method has been developed to be a more flexible method appropriate for providing a condensed and broad description of qualitative data and is therefore referred to as qualitative content analysis (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

During the analysis, themes and categories are discovered through interactions with the data, derived directly from the transcribed texts. Meaning units, i.e., words, sentences or paragraphs, relating to the same meanings are derived from the texts, shortened, condensed and abstracted. Codes, i.e., labels that refer to meaning units, are identified and grouped in categories that highlight commonalities among the content. The descriptive categories, which can also include sub-categories, can then be organised into themes. Within this latter process, the researchers are searching for the underlying meanings, also described as the latent content (Graneheim & Lundman, 2004).

In study I, the analysis was directed by the following questions: How is the intervention judged with regard to the content, structure and process of the intervention? What does the text tell us about the participants' experiences (positive and negative) of participating in the intervention?

At first, each case was analysed separately by individual members of the research team. The initial analysis began with reading the interviews. The log notes and worksheets (when available) supplemented the analysis and thus added a richer picture of all of the participants with regard to their experiences of living with the stroke as well as their experiences of participating in the intervention.

The content of the data sources was categorised in light of the research questions highlighted above. At the end, similarities and differences were identified across cases and between the different subgroups, such as participants receiving the individual versus the group format, participants with and without aphasia, younger participants versus older participants and participants with different degrees of emotional and/or physical challenges. The analysis process continued until mutual agreement about questions and unclear issues were reached among the members of the research group.

5.3.3 Study II

In study II, a subset of the 25 cases in study I were separately analysed in-depth to strengthen the knowledge of the work-aged stroke survivors' specific challenges of living a life with a stroke.

The aim of study II was thus to illuminate the psychosocial challenges that work-aged participants thematised during and after participating in the dialogue-based intervention.

Sample

Fourteen of the stroke survivors participating in the intervention met the inclusion criteria of being aged between 18 and 67 years. These fourteen participants aged 33-66 years (mean 54.6) were therefore included as a subset in study II.

Seven of the work-aged participants were married, two were cohabitants, three were divorced and two were single. Five had children living in their homes. Six of the participants had adult children who had moved out of the home, and the remaining three participants were childless. Eleven were employed part-time or full-time prior to the stroke onset, whereas the remaining three were unemployed or on social security benefits. Five of the participants had returned to 13%-70% part-time work at the conclusion of the intervention.

Analysis

In this study, we applied a hermeneutic phenomenological approach to obtain a more in-depth understanding of the participants' experiences. The hermeneutic phenomenological analysis approach was conducted through three main analytic steps (Lindseth & Norberg, 2004; Ricœur, 1976).

The point of departure of the analysis process requires a careful reading, typically several times, of the recorded and transcribed interviews as a whole to obtain an initial and holistic impression of the participants' experiences. This initial reading provides a preliminary understanding of the texts, also referred to as a naïve reading, or an intuitive grasping of what the texts talk about (Kvale & Brinkmann, 2009; Lindseth & Norberg, 2004; Ricœur, 1976).

The next analytic step consists of a structural thematic analysis of the narrative texts. The preliminary understanding written during the first analytic step guides the structural analysis.

During the structural analysis, the interpretations are expanded by dividing the text into meaning units, condensed further into detailed subthemes and themes. The structural analysis seeks to validate or invalidate the naïve reading (Lindseth & Norberg, 2004; Ricœur, 1976).

At last, the subthemes are summarised and reflected on to develop a deeper understanding (Tan et al., 2009). The structural analysis is reformulated to a summary of the meaning of the text (Ricœur, 1976). To develop a comprehensive understanding of the lived experience, the original texts are reread as a whole and reflected on critically in light of the naïve reading, theory, the research question(s) and the research literature. This rereading provides further interpretations, which may result in the reformulation of the initial impressions (Lindseth & Norberg, 2004). The process continues until no new insights or interpretations are found within the texts (Kvale & Brinkmann, 2009).

The analysis process in study II began with a careful reading of the transcribed interview texts as a whole to obtain an initial and holistic impression of the work-aged participants' experiences during and after participating in the dialogue-based intervention. This naïve reading resulted in a narrative summary of each of the participants. The log notes and researchers' notes were then explored and added to the fourteen cases and read carefully as a whole to obtain an initial and holistic impression of the experiences and psychosocial challenges and needs of the participants. During this naïve reading, we developed an initial understanding suggesting that the work-aged stroke survivors described their lives as difficult and changed with respect to performing the roles and responsibilities related to family and work. We interpreted this result as an indication of a position of being in a marginalised situation. The naïve impression was further reflected upon by formulating the following research questions: What are the specific experiences and psychosocial needs of work-aged stroke survivors? Is the initial interpretive working hypothesis of possible marginalisation confirmed or rejected upon the further analysis?

During the structural analysis, we divided the narratives into meaning units and condensed the meaning units into detailed subthemes related to family and work to further explore the meaning of the text and to validate or invalidate the initial impression. Finally, we summarised and reflected on the subthemes to develop a comprehensive understanding and reformulated the initial impression. Finally, the narratives were reread as a whole and reflected on in light of the theory of marginalisation and the broader research literature on

psychosocial aspects of stroke. Each step during the analysis was discussed within the research group until a consensus was reached.

5.4 Phase II

Phase II includes study III as described below.

5.4.1 Study III

Based on the findings in study II, we found it necessary to expand the knowledge to tailor the intervention to the work-aged stroke survivors' specific needs over time. During the second phase of the study, a group of work-aged stroke survivors who did not participate in the intervention was recruited and interviewed in-depth.

The aim of study III was to gain a deeper understanding of how a stroke impacts life six months or more after the stroke (see table 1).

Sample

Norwegian-speaking adults aged 18-67 suffering from stroke were invited to participate. The population of adult stroke survivors younger than 67 is less likely to be followed-up in the health service system; thus, this population is more difficult to identify from a long-term perspective after being discharged from hospitals and rehabilitation services. Therefore, the main strategy for recruitment in this study was to place a notice on the website of the Norwegian Stroke Foundation. Twenty stroke survivors responded to the invitation. An additional three stroke survivors who met the inclusion criteria were identified by the local newspaper or identified by colleagues who knew stroke survivors meeting the inclusion criteria. Consequently, 23 stroke survivors aged 20-64 years were recruited to this study. However, the oldest stroke survivor, aged 64 years, did not sign the informed consent form and was excluded after two reminders. Twenty-two participants (fifteen men and seven women) aged 20-61 years (mean age 44.8) gave their consent to take part in the study.

The time since stroke onset ranged between six months and nine years, and all of the participants lived in their own homes.

The participants were initially diagnosed with occlusion or haemorrhage of an artery in the left or right hemisphere. One of the participants was diagnosed with a subarachnoid haemorrhage. The consequences of the strokes varied from mild to severe.

Seven of the participants were single, one was separated, three were divorced, one was cohabitating and ten were married.

Nine of the participants had minor children, i.e., under the age of 18, and two of the participants had adult children, i.e., older than eighteen years, still living at home.

Four of the participants worked full-time, one worked part-time and one was studying when the interview took place. Two participants were on sick leave, and fourteen were on social security benefits.

Data collection

The interviews with the non-intervention participants were open-ended but had a thematic guide that focused the stroke survivors' experiences of living their life with stroke. The interview started with the question of what happened at the onset of stroke. The first thematic question was formulated as follows: "Can you please talk about what happened when you were hit by the stroke"? Next, the participants were asked about their experiences of the present situation, including their thoughts about their everyday lives and relationships to family, friends, neighbours, colleagues (if any) and peers. If necessary to gain in-depth accounts, the participants were also asked to describe their activities at home as well as outside home, their need for help and their general contentment. At last, the participants were asked about the future (goals, wishes, and plans).

The study participants chose the place where the interviews were conducted. The majority of the interviews were performed in the stroke survivor's homes and in a "Learning and mastery centre", whereas the rest of the interviews took place in other official buildings, such as the participants' workplaces, a café or a hotel, for practical reasons.

The interviews lasted between 48 and 120 minutes and were conducted by me.

Analysis

The hermeneutic phenomenological analysis approach in study III followed the same major steps as described under study II. However, in this study, the first impression of the naïve reading was related to the stroke survivors' struggle to participate in family life. The first reading gave us an impression that struggling in family life differed with respect to the

relationships and roles as well as the social situation in which the subjects found themselves at the present time. These impressions were further reflected on during the structural analysis. The transcribed texts were divided into meaning units, revised and formulated as subthemes and themes. For example, the initial struggle to re-establish family life was formulated as the subtheme “facing the shortcomings”, whereas the struggle to manage the participation in family life leading to a retreat from participating in family activities was formulated as the subtheme “the need for self-protection”. These two subthemes were formulated in a theme named “struggling to re-enter the family”.

At last, the subthemes and themes were further challenged and reflected on critically in light of family theory to create a comprehensive understanding of the experiences of family life of work-aged stroke survivors and were verified by returning to the original narratives to confirm that the interpretation was adequate.

5.5 Phase III

Phase III includes study IV as described below.

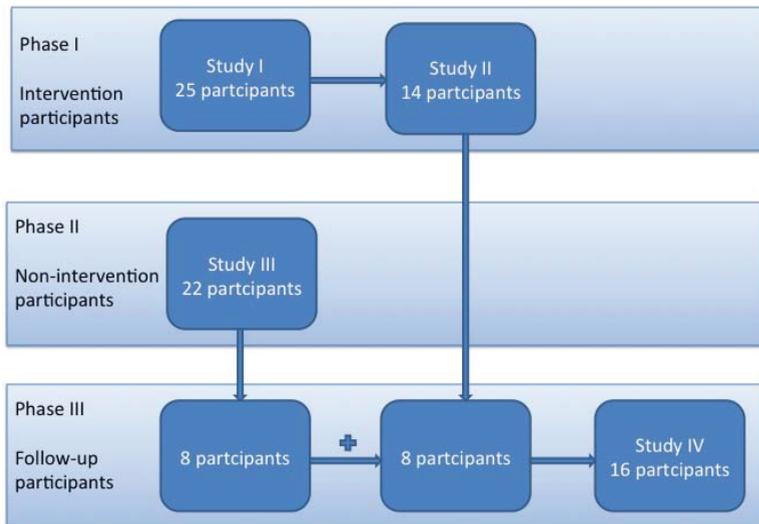
5.5.1 Study IV

The follow-up study (IV) aimed to explore the long-term follow-up needs experienced by the two cohorts included in study II and III.

Sample

Cohorts from each of the two first phases were interviewed during this third phase of the study. Thus, sixteen of the participants were interviewed twice. An overview of the study participants in the study is presented in figure 3.

Figure 3: Overview of the study participants



All participants were asked of their willingness to be contacted one year later to participate in an additional interview at the time of the preceding interview. When the sixteen participants included in study II and III were contacted by phone one year later, all consented to participate in the follow-up study.

A purposive, maximum variation sampling procedure was used to include study participants with a variation in age, gender, and time since stroke onset. All of the study participants were judged to provide rich insights about their experienced follow-up needs over time after the stroke. The rationale for including patients who had participated in the intervention study was the expectation that they would provide insights into the follow-up needs up to one and a half years post-stroke. The patients who did not participate in the intervention were expected to highlight the specific follow-up needs over a time-span of two to ten years post-stroke. Due to their varied and long-term experiences, the participants were considered experts on how the challenges of living with stroke had been addressed by the health services. Thus, the participants were in a unique position to provide input regarding actions that may be necessary to address stroke survivors' long-term needs. Additionally, the data from these two diverse groups was assessed to enable a qualitative comparison of whether participation in a

dialogue-based intervention shortly after stroke onset could promote psychosocial well-being during the follow-up period and reduce the need for long-term follow-up³.

The sixteen participants included eleven men and five women aged between 21 and 67 years (mean 48). The time since stroke onset ranged from one and a half to ten years. Eleven of the participants were married, two were divorced and three were single. Eight of the participants had children under the age of 18 years. All eight participants with one exception were living together with their own children. All but one participant lived in his or her home. The remaining patient was living in a sheltered accommodation. Five participants were employed full-time or part-time, one had recommenced studies, one was unemployed, six were on security benefits, and three were retired.

Data collection

The first thematic question in the follow-up interviews (study IV) encouraged the participants to provide an open narration of their experiences of living with stroke during the preceding year. The further thematic questions were adjusted individually based on the utterances in the first interview and thus differed between the participants. The phenomena narrated during the open interviews could be related to for example the social network (family, friends, boyfriends or girlfriends), exercise, activities (training and hobbies), recovery progress, work, education, and their thoughts about the future.

The eight participants who had participated in the intervention one year before were also asked about their opinions regarding participating in the intervention at this follow-up interview.

The interviews lasted between approximately 35 and 85 minutes. Most of the interviews took place in a patient education centre or in the participants' homes. One interview took place in a participant's workplace and one in a sheltered accommodation. All of the interviews in study IV were conducted by me.

³ The participants included from study II suffering from severe aphasia were excluded. Their experiences were isolated in another subset of the intervention study and reported elsewhere (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Bronken, Kirkevold, Martinsen, Wyller, & Kvigne, 2012)

Analysis

This study also used a hermeneutic phenomenological analysis approach, following three main steps: naïve understanding, structural analysis and comprehensive understanding.

Our previous analysis had revealed that the intervention had supported the stroke survivors through a difficult period and provided support during their attempts to cope with the situation, which suggested that we would find a difference in how the two cohorts summarised their follow-up experiences and needs following the stroke. By investigating this hypothesis during the initial analysis process, we observed some differences in how the participants described their subjective well-being at the time of the second interview. A number of the participants who had participated in the intervention described their well-being one year following the termination of the intervention in positive terms compared with the participants who received “usual care”. Nevertheless, in general, the descriptions of their relationships with and follow-up from the health services did not differ substantially. Rather, the participants’ descriptions were found to be very similar. During the structural analysis, the two cohorts were therefore merged and analysed as one sample.

The specific experiences revealed through the analysis were divided into meaning units, subthemes that resulted in two main themes “difficulties in assessing health services” and “lack of tailored follow-up services”. The themes were reflected on in light of the literature and the original narratives, which led to a comprehensive understanding of the stroke survivors’ long-term needs, which highlighted that younger stroke survivors are in need of a long-term follow-up tailored to their specific challenges related to work and family life. The analysis process continued until consensus within the research team was achieved.

5.6 Ethical considerations

The researcher is responsible for protecting vulnerable persons involved in research (Northern Nurses' Federation, 2003). In line with the Helsinki Declaration (World Medical Association, 2008) and the Ethical Guidelines for Nursing Research in the Nordic countries (Northern Nurses' Federation, 2003), the universal principles of autonomy, beneficence (doing good), non-maleficence (not causing harm) and justice were applied to the study participants included in the study. These principles include information, consent, confidentiality and safety (Northern Nurses' Federation, 2003) and guided the whole research process.

The study participants were given oral and written information by designated nurses when hospitalised (study I and II). The participants were informed about the aim of the intervention study and the study progress. To underline the voluntary nature of the study, no contact between the participants and the researcher was made before the participants had signed the consent form and returned it to the researcher by the designated nurses. The participants were then contacted, and an appointment was made.

In study III, the initial information was provided on the website, and the participants' self-recruitment was not seen as threatening the study participants' autonomy. To the three study participants who were recruited by colleagues, the first contact was made by a colleague not involved in the interview process. In this study, the participants received an informed consent form by mail. The appointments of the interviews were made after the participants had signed and returned the informed consent form.

When the study participants were contacted for the follow-up interview (study IV), the information was repeated consistent with the ethical guidelines described above. The contact had already taken place one year earlier, and when the participants were phoned to ask them to participate in the follow-up interviews, all participants were initially willing and eager to participate in the follow-up interviews. Repeated written consent forms were obtained. The participants' confidentiality was ensured, and the participants were informed that they could withdraw from the study at any time without consequences.

Research ethics extend beyond approval from the ethics committee and knowledge of the code of ethics. The situated ethics is similarly important when conducting interview research (Guillemin & Heggen, 2012). The researcher's awareness of his or her own impact on the situation when conducting the interviews and the responsibility for ensuring that the situations are not causing harm is of high importance (Hem, Heggen, & Ruyter, 2007). To the participants in the intervention study, verbal consent was therefore repeated during the intervention period (Usher & Arthur, 1998).

Cooperation with the informant to understand the experiences in the phenomenological interviews provides the researcher with the possibility of gaining access to the informant's descriptions of the phenomenon (Kvigne, Gjengedal, & Kirkevold, 2002). To achieve descriptions during the interviews require openness of both the informant and the researcher. The ability to reach the goal of an open dialogue during the interviewing is influenced by the physical and psychological health of the informant. Throughout the dialogue, the researcher's theoretical insight and ability to communicate as well as the relationship between the

informant and the researcher will influence the climate, tone and mood of the interview session (Kvigne et al., 2002). Being aware that this interactive process in the interviews may cause emotional stress (Kvale & Brinkmann, 2009), it was important to be sensitive during all interview sessions, acknowledging all participants as unique. It was further important to be aware of the asymmetry between the researcher and the interviewee (Kvale & Brinkmann, 2009).

Some dialogues were interrupted because the participants became affected and cried when they described their life living with stroke. In all of these cases, the dialogues were paused. The voice recorder was turned off, and the participants were asked whether they wanted to cease the interview or whether they wanted to continue. The patients were reminded of the possibility of withdrawing from the interview (Northern Nurses' Federation, 2003). However, no participants decided to withdraw, and all continued the interview sessions.

It is important to reduce the risk for complications after the interview (DiCicco-Bloom & Crabtree, 2006). Before closing the interviews, it was therefore confirmed that the participants had been given the opportunity to express what they wanted and considered to be important and that they felt safe in closing the dialogues.

There were some situations where I could feel some unrest about leaving the participants, although the participants stated that it was okay to leave them. In these cases, the participants were encouraged to make contact, contact their GP or their contacts within the health service system if necessary. None of the participants contacted me at a later date.

Nevertheless, most of the participants expressed relief about the possibility of telling their stories to a person able to listen. This reaction supports the idea that most people are willing to tell their stories to help others (Iphofen, 2005) and that participating in interview studies can be a positive contribution to ill patients (Kvale & Brinkmann, 2009).

The project was approved by the Regional Committee for Medical Research Ethics in the Eastern Health Region in Norway (Project number: 2.2007.37) and the Social Science Data Service in Norway (Project number: 16369).

6 Findings

This chapter presents a synopsis of the main findings of the four sub-studies presented in the original articles.

6.1 Study I: Promoting psychosocial wellbeing following stroke using narratives and guided self-determination: a feasibility study

The aim of this study was to evaluate the content, structure and process of the complex dialogue-based intervention and the experienced usefulness of participating in the intervention from the patients' point of view.

Assessment of the intervention content, structure and process

Most of the participants judged the topics addressed in the intervention to be relevant to the experiences, challenges, needs and problems they encountered during the recovery and adaptation processes. The participants highlighted the importance of addressing the psychosocial aspects of stroke recovery, stating that other rehabilitation professionals had not specifically addressed these issues. However, the youngest participants suggested additional topics that the intervention did not bring up explicitly, including jobs, economic security, challenges and worries of returning to work. Information and the support needs of their families were also suggested to be more explicitly included, in particular, individualised information about stroke treatments and follow-up that could help the young participants and their families understand their own condition.

Most of the participants did not have their worksheets completed at the start of each encounter as intended. Although the topics of the worksheets were relevant, some participants found them difficult to understand and use on their own. Some participants had trouble reading the worksheets, difficulties in concentrating, or were afraid of providing "incorrect answers". Some did not complete the worksheets because of fatigue or an inability to write. Some found the worksheets abstract and complex, whereas a number of the youngest participants found them interesting and helpful in focusing, reflecting or thinking through their situations and issues of relevance. Some of the work-aged participants had thus looked at the worksheets

without writing anything down. However, the youngest participant, aged 33, found it helpful to review the worksheets between the encounters and was actively reading and writing on the worksheets to prepare for the encounters.

The opinions about the number of encounters and their timing differed. None of the participants thought that the intervention had too many encounters, but some felt that the number of encounters was adequate. The participants with aphasia felt that the intervention was stopped too early and suggested that the follow-up time ought to be at least one year. Eight encounters were judged to be inadequate, and it was suggested that the meetings should be held weekly, at least in the beginning. In this group of participants, the time and the topics planned for each encounter could not be covered as planned. Consequently, the number of meetings had to be increased up to approximately 10-12 months.

The majority of the individual encounters were completed in approximately an hour. Among the participants with aphasia, the time for encounters varied between 40 minutes and two hours because the participants tired easily. The group encounters lasted two hours.

The participants receiving individual encounters highlighted the importance of their relationship with the healthcare professional. The participants stressed the importance of having the same person lead the intervention. The participants appreciated the supporting dialogues with “a committed professional who understood what they were going through” and the opportunity to discuss issues of personal significance to them.

The participants participating in the group format of the intervention highlighted the value of sharing common experiences and the exchange of ideas about how to address the different issues. However, the youngest participant participating in the group, aged 43, expressed that he felt that the group format was somewhat restrictive because the dialogues were concentrated on topics that were common between the participants and less on individual issues. This participant felt he had more questions than were highlighted during the intervention encounters.

The experienced usefulness of the intervention

The experienced usefulness of the intervention highlighted by participants was classified into three overall themes as described below.

Being supported through a difficult time

Many participants considered the intervention to be a highly positive experience and appreciated the access to a series of supportive meetings that they did not have to request. This support was described as an experience of *not being left alone* in a situation described as difficult, insecure and frightening. The work-aged participants participating in the intervention described a knowledgeable professional “working alongside [them]” as feeling cared for and providing security. This positive experience was contrasted with experiences of feeling deserted by the traditional health services. Several participants also expressed the importance of healthcare professionals holding up a “vicarious hope” or “vision for the future” that inspired them to keep struggling through the difficult times, facilitating the “recovery work” when they felt tempted to give up.

Provided a chance to tell and (re)create their story

The participants valued the opportunity to tell their stories and talk through their experiences in their own words. This narrative aspect contributed to increasing their understanding, helped them see possibilities and created opportunities for formulating realistic goals. The participants became more conscious of the different aspects concerning their situations. The dialogues helped them to clarify the issues at stake in their lives and assisted them in reflecting about the possibilities and difficulties. Sharing their stories initiated reflection processes in which they would not have engaged on their own, (re)negotiating their understanding, values, and goals. The work-aged participants highlighted specifically narratives related to interactions with children and family life as well as work and economic issues.

Being supported in their attempts to cope with the situation

The participants struggled to cope with their new and unknown situations, which varied widely from performing daily activities and solving practical problems to understanding and coming to terms with their own emotional reactions and those of their family, friends and colleagues. Facing different social situations within and beyond their family entailed many challenges, especially to those having minor children at home.

The intervention helped the participants cope with their struggles. Participants in both the individual intervention and the group intervention emphasised that the dialogues were helpful in clarifying what their coping challenges entailed, illuminated their coping options, and

supported them as they tried different coping strategies. The intervention also aided in analysing unexpected situations. Some participants emphasised the importance of being supported in their own initiatives rather than being told how to manage the situation. This led to an experience of being in charge of their lives. The participants in the group-based intervention (who all were work-aged) also reported that they learned new ways to approach different situations by listening to other stroke survivors, although the youngest participant, aged 43, underlined that he was at a different phase of life and had different questions than his fellows.

6.2 Study II: Work-aged stroke survivors' psychosocial challenges narrated during and after participating in a dialogue-based psychosocial intervention: a feasibility study

The aim of this study was to illuminate the psychosocial challenges and needs described by stroke survivors aged 18-67 during and after participation in the complex dialogue-based intervention. The study participants in this study represent a sub-group of the participants included in study I. This study thus explores the work-aged stroke survivors' specific psychosocial challenges thematised during and after participating in the intervention more in depth, further exploring the needs specific to work-aged stroke survivors throughout their life span.

The findings from this study revealed that the stroke had a substantial impact with respect to family life and work life in the first six to twelve months following a stroke, as summarised in two main themes.

The threat of becoming marginalised in family life

The theme described challenges in terms of meeting expectations in family life following the stroke and was related to both the immediate and extended family as well as friends. This theme was further expressed in the following subthemes: "unable to perform the caring role as before" and "falling out of extended family activities".

Unable to perform the caring role as before highlighted the stroke survivors' concerns of impairments in their abilities to collaborate with their partner in caring for their children, to

talk with their children about how symptoms influence everyday life and to support their children's activities as well as worries about their children's inability to concentrate on their schoolwork. The participants reported a need for greater emotional and social involvement in family life than what they currently felt was the case. Cognitive difficulties, emotional distress and a lack of stamina affected their level of participation in daily activities and prevented them from meeting their own expectations and/or those of the immediate family.

The challenges could lead to family conflicts. Some families did not communicate about their life situation.

The participants highlighted the importance of information and support to understand the consequences of stroke, and they emphasised that this support and communication was a means of helping both the participant and the family move on with life in the best possible way as well as a means of overcoming the frustration.

Falling out of extended family activities highlighted how the cognitive challenges, including a lack of stamina, concentration problems and tiredness or exhaustion, affected ordinary leisure activities and made it difficult for the participants to pursue interests and attend leisure gatherings. The situation resulted in activity avoidance to prevent unbearable situations. However, not participating in social gatherings made the stroke survivors afraid of losing friends.

The inability to drive a car also contributed to the experience of social isolation and being dependent on others, which further complicated their ability to participate and contribute socially on equal terms. Remaining at home or in a nursing home strained life and isolated most of these stroke survivors from an ordinary social life. Their new life evolved, in many ways, at the margins of the active and busy lives of their family and friends.

The threat of becoming marginalised in work life

This theme reveals how stroke influenced work life and how the participants experienced this as employees, captured by the following two subthemes: "being forced to leave work" and "struggling to meet work expectations".

Being forced to leave work emphasised that the consequences of stroke forced some of the participants to leave work. One female who was suffering from aphasia was dismissed from

her job. Another woman close to retirement experienced that the healthcare professionals decided that she should retire. These situations were experiences that were difficult to accept and disrupted the patients' self-confidence and identity, as well as making them feel marginalised and disempowered.

Participants with children at home who in this study were men only, were preoccupied with their roles as breadwinners and highlighted the importance of returning to work. The informants spoke about *when* they would go back to work, their hopes of managing work life after the stroke, the struggle to imagine what would happen if they were unable to return to work and the threat of becoming impoverished in the future.

Struggling to meet work expectations emphasised that the consequences of stroke complicated returning to work. Some participants struggled with how they could cope with the working situation and meet work expectations while others described uncomfortable experiences of being questioned regarding their abilities to return to work, or being assessed not to manage their work responsibilities .

The experiences of being marginalised in terms of performing their usual work roles left some participants in a challenging financial position and caused emotional distress. They contemplated whether it would ever be possible to resume regular work. The participants' goal was to continue being the primary wage earner to avoid impoverishing the family.

6.3 Study III: Younger stroke survivors' experiences of family life in a long-term perspective: a narrative hermeneutic phenomenological study

The aim of this study was to gain an understanding of how stroke impacts family life six months or more after the stroke from the stroke survivors' perspectives.

The participants revealed in general that their challenges varied with time, from an initial struggle for normalcy and balance in the relationships within the family early after stroke towards a more resigned attitude later on in the stroke trajectory. The findings are revealed in the two main themes, "struggling to re-enter the family" and "screaming for acceptance", further described in the text below.

The “struggling to re-enter the family” began with the difficulties for the participants in realising that they were less able to care for others, to devote attention to others or to sufficiently engage in or perform normal life tasks, highlighted in the subtheme “*facing the shortcomings*”. Facing these shortcomings influenced their identity and made them dependent on support from their partners, children and/or parents.

The inability to participate sufficiently in family life demands revealed the stroke survivors’ needs to protect themselves. The situation necessitated an ability to retreat to overcome their new life of living with stroke, highlighted in the subtheme “*the need for self-protection*”. Withdrawing seemed the best way to survive and avoid questions when living alone. The single participants talked generally about their choices with respect to staying alone, being able to avoid questions from others and being able to protect themselves from situations that negatively influenced their self-esteem.

The theme “screaming for acceptance” reflected the stroke survivors’ experiences when recovery was delayed or after a change in interest or support from others. Interest and support became increasingly diminished and influenced life in a negative manner. The stroke survivors progressed from being treated with “silk gloves” and being the “commander” close to stroke onset to a more secluded situation. The support offered by others that gradually decreased and changed was expressed in the subtheme “*the silent cry for acceptance*”. The stroke survivors thought about their lives following their strokes and the slow recuperation process despite being “young”, thinking that a stroke was an illness that only affected the elderly and retired. The participants expressed a decreasing engagement with others as a barrier from discussing their situations. The narratives expressed a sense of discouragement about the lack of understanding from friends, even though the relationships were close. The longing for sympathy experienced at stroke onset was also highlighted, and the suspicion from others of exaggerating the challenges that some of the stroke survivors expressed was difficult to overcome. The survivors wanted the others to understand their present situations and their inability to participate in activities and gatherings the way they had before their stroke. Nevertheless, some of the informants expressed the dialogues with spouses, children, parents and adult siblings as positive.

The struggle to fulfil family roles and obligations and the struggle to balance protection and participation continued over time, reflected in the subtheme “*living on charity*”. The participants struggled with telling others and expressed a kind of resignation about telling

their partners, children, friends, parents, and grandparents what living with stroke was like. The participants “put a lid on” their situation continuing to suffer from the illness. To some participants, this led to a state of defenselessness. If the stroke survivors believed that they could manage more participation, they strived to communicate that they could be more responsible in their roles.

Being in the lower socioeconomic strata prevented some of the stroke survivors from participating in social events.

Regardless of the disabilities incurred following a stroke, none of the stroke survivors gave up, and they continued to hope they would be able to fulfil their roles and participate in meaningful activities, become financially independent, find a partner or complete their education.

Because the struggles varied among the participants’ different social situations, we found it helpful to divide the participants aged 20-61 into three social groups to highlight the specific challenges across the work-aged life span. The groups were divided as follows: (1) young, non-established participants; (2) participants living together with family, i.e., minor children, with or without a partner; and (3) participants without children at home, with or without a partner.

The specific challenges related to each of these groups are described in the text below.

Young, non-established participants

Being single and independent resulted in fewer commitments to fulfil family roles or student roles. Accordingly, these participants were able to isolate themselves from having to give reasons for not participating.

The single non-working or non-studying participants stayed in their homes more than desirable and described their days as boring. They missed their friends and ruminated about their absence while simultaneously expressing an understanding that their friends and associates were occupied with their own activities. However, one of the participants was satisfied with the decision to prioritise focusing on his work during the weekdays and being with his girlfriend during the weekends.

Some of the participants in this group expressed difficulty telling their parents about their illness, as they preferred to remain independent and protect their parents from worrying about them and thus avoiding being overprotected.

Some of the single stroke survivors expressed a desire to establish contact with new friends and to develop intimate relationships.

Participants living together with minor children, with or without a partner

Parenting children or becoming parents close to the time of stroke onset brought even more challenges to the parenting role. Situations that are normally considered manageable were described as difficult to overcome both among new and long-term stroke survivors. The established patterns of actions and activities in the family continued. Some participants described it as challenging to be supported by the teenagers in the family. The single-parent families' vulnerability was apparent, as there was no other adult to share the parenting responsibilities. The involuntary role as a home-worker was expressed as frustrating and uncomfortable, although some had reconciled themselves to their new life and found that being the principal home-worker also had positive aspects compared with being the traditional breadwinner.

The stroke survivors expressed that their day-to-day challenges at home in a parenting role demanded their presence. They viewed their lack of extended social relationships as temporary because their current tasks demanded that they care for their children. The participants expressed less ability to choose a self-protecting lifestyle because of their own and their families' expectations that they participate and engage actively in family life. The participants described their lives as busy, unlike those stroke survivors not living in an immediate family. Although they felt shame as they struggled for personal "self-protective time", the participants continued to try to schedule their own activities.

Some participants expressed a fear of being rejected by the family and left alone, ruminating about a future in which the family would become annoyed with the stroke survivor's dependence and failure to fulfil their expected role. These participants also envisioned how the family would move on once the children had grown up and moved outside the home. Following this negative thinking, the strategy was to not complain and hope that the family could persevere with a non-functioning family member.

As a consequence of a challenging economic situation, some of the participants in this group expressed that they prioritised staying at home to save money and pay for their children's leisure activities.

Participants without children at home, with or without a partner

The participants with adult children also discussed the opportunity to withdraw from participating in extended family activities. These participants felt vulnerable and frustrated because of their struggle to participate in situations as desired. Not being able to fulfil the role of a grandparent was experienced as a sorrow and a loss. However, being together with grandchildren was perceived as a meaningful experience when nonbinding and sociable.

6.4 Study IV: Young and midlife stroke survivors' experiences with health services and their long-term follow-up needs

The aim of this study was to explore young and midlife stroke survivors' experiences with health services and to identify long-term follow-up needs revealed by two different cohorts (i.e., participants in the dialogue-based intervention and participants receiving "usual care").

The experiences by these two cohorts were assessed to be valuable to uncover long-term follow-up needs and to determine the actions necessary to address stroke survivors' long-term needs. The data from these two diverse groups was also assumed to provide knowledge of whether participation in a dialogue-based intervention shortly after stroke onset could reduce the long-term follow-up.

When exploring the two different cohorts, the results revealed that four of the study participants from the intervention study described their lives as satisfactory, whereas the other four stated that they were less satisfied with their lives at one year after the intervention had ended. Three of the eight participants who did not participate in the intervention study but who had received "usual care" following stroke stated that their lives were satisfactory during the two to ten years after the stroke. The remaining five participants who received "usual care" stated that their lives were better than one year ago but that they remained unsatisfied.

The stroke survivors struggled to understand their own life and situation even though they had lived with the effects of stroke for periods ranging from one and a half years to ten years. The findings are described in the two main themes in the text below: “*difficulties accessing health services*” and “*lack of tailored follow-up services*”.

Difficulties accessing health services

The participants struggled to find methods to contact the health service system to obtain support to better manage their lives after a stroke. Delayed access led to experiences of “being left in the lurch” in their struggles.

Some participants stated that they waited for a follow-up call from health services but that the call never came. The participants wanted a check-up due to worries and uncertainty regarding their condition. Some participants had obtained medical information from the Internet and had the impression that their bodies should be checked by a brain scan or assessed by a neuropsychologist, a physiotherapist, an occupational therapist or a general practitioner.

One of the male participants who was upset and frustrated that receiving sufficient information and managing the situation was up to himself, was offered the opportunity to attend a peer group at two and a half years following the stroke. He was surprised to receive this offer so long after the stroke but wanted to attend the group and obtain ideas from others about how to manage life with stroke as a busy father and employee with others.

Some questioned the quality of the follow-up services when the follow-up services were scarce or coincidental. A follow-up would ensure that they did not feel left alone. Follow-up that addressed the participants’ physical condition but not their psychological well-being resulted in despair.

The informants expressed frustration with respect to the lack of contact with the social security system, the lack of a designated coordinator and the lack of understanding of the challenges following a stroke among health professionals. They questioned the competence of the health service practitioners and also their willingness and ability to offer relevant support to address the patients’ specific concerns.

Lack of tailored follow-up services

Although Norwegian legislation stipulates that all citizens in need of long-term complex follow-up health services receive coordinated service guided by a designated coordinator, only one of the study participants had an Individual Plan (i.e. a personal document drawn up to outline individual objectives, resources and required health services to those in need of long-term coordinated health services). Some participants were aware of this tool and noted that a systematic follow-up service was lacking.

The only single participant who was offered an Individual Plan and a personal coordinator at one year after her stroke expressed disappointments in the system because her regular meetings did not occur or failed to address personal questions.

Several worried that their lives would “come to nothing”. The participants reported that they had experienced that the consequences of the stroke threatened their return to a normal social life and work life. Their inner thoughts on these intangible topics were described as difficult to manage and influenced their motivation. The participants wished to contact professionals interested in helping them adjusting their lives living with a stroke.

Some participants questioned the willingness and ability of the professionals to offer relevant support and were unsure what to expect from the health services, although they expressed a need for assistance to provide direction in their lives when unable to find solutions by themselves. The participants questioned why they should continue with rehabilitation when recovery did not occur. They lacked information on why it was necessary to continue and stated that they were unable to contact someone who could motivate them.

The participants highlighted their experiences with a follow-up system that was not tailored to their specific needs as young and midlife stroke survivors. They highlighted that their age and specific life situation should be taken into account when offering a rehabilitation service. The youngest study participants spoke of the challenges of attending rehabilitation together with older individuals because of their differences in interests and daily-life concerns. The participants noted that the follow-up system had to be flexible and adjusted to their total life situation. Some of the participants with minors at home stated that the changing needs and activities of their children were difficult to reconcile with a strict and inflexible rehabilitation service. Others were students and had to meet study obligations. It was therefore critical that the follow-up was adjusted to their daily life to enable them to meet their obligations to family

life, student life, and work life. A lack of follow-up service was experienced as frustrating and demotivating.

7 Discussion

The overall aim of this study was to explore the psychosocial challenges (both short-term and long-term) faced by younger, work-aged stroke survivors and to identify their psychosocial follow-up needs.

The discussion of the findings is divided into the following three main sections. “The psychosocial challenges” addresses the first overall aim of the study and mainly discusses the findings of studies II and III, highlighting the challenges of suffering a stroke when being work-aged. “The experienced psychosocial follow-up needs” addresses the second overall aim of the study and mainly discusses the findings of studies I and IV, highlighting the psychosocial follow-up needs of work-aged stroke survivors. At the end of the discussion section, the methodological issues associated with the study are discussed, highlighting the strengths and limitations of the study.

7.1 The psychosocial challenges

The main findings of this study underscored that the stroke survivors experienced a threat of becoming marginalised in their lives following the stroke and that the challenges following the stroke were experienced differently across the work-aged life span.

7.1.1 The threat of becoming marginalised

The participants experienced that the stroke contributed to dependency and inability to fulfil social roles. This put the stroke survivors at high risk of social exclusion which we interpreted as a threat of becoming marginalised (II). Marginalisation is defined as an involuntary situation inflicted by others (Ecks & Sax, 2005). It entails being on the periphery of the central majority (Hall, 1999). Social isolation, i.e., a lack of social contact or alterations in social relationships, is a far better known concept within research into stroke survivors compared with the concept of marginalisation, and social isolation is highlighted as a social consequence of stroke in general (Burton, 2000; Daniel et al., 2009; Mukherjee, Levin, & Heller, 2006). Social isolation is established as one aspect of marginalisation (Ware, 1999). However, the concept of marginalisation encompasses more than interruptions in physical and social contacts; it highlights the experiences of being overlooked, misrepresented, and

categorised as “different” or “inferior” (Galvin, 2003; Lynam & Cowley, 2007) or even being oppressed (Hall, 1999).

The participants expressed that they found it challenging to perform their caring roles as before and to participate in regular family activities. This threatened to marginalise them in family life. The participants also described themselves as challenged in fulfilling their work roles, which also made them marginalised in participation in their work life (II). Although the participants described their lives as difficult and challenging, some of them highlighted that their “new” life also had given them different perspectives on life (III). Although the number of stroke survivors who viewed their lives following the stroke in a positive manner was small, some of them were able to adjust to their present situations and to maintain psychosocial well-being despite having suffered a stroke. This finding suggests that all stroke survivors will not experience themselves as marginalised in their social lives following a stroke and illustrates that the concept of marginalisation should be used with caution. To introduce this concept to stroke survivors themselves might not necessarily be helpful. However, the concept of marginalisation might be helpful as a sensitising tool for health care professionals in terms of understanding the experiences of work-aged stroke survivors and point to ways of supporting them during their demanding adjustment process. The concept of marginalisation has been argued to be an effective lens through which to view the nursing of individuals living with chronic illness generally (Giddings & Roy, 2013; Hall, 2004), but has not, to my knowledge, been studied in the group of younger, work-aged stroke survivors. In my view, marginalisation provides a useful theoretical angle for examining the experience of life after stroke among work-aged individuals under the age of 67, because it highlights aspects that is not usually associated with social isolation,

7.1.2 Difficulties across life span

Dividing the work-aged stroke survivors by social group was found to be helpful in study III for differentiating the specific challenges occurring across the work-aged life span. The challenges related to the different groups are discussed further below.

Difficulties associated with being non-established

In study III, we discovered that the psychosocial challenges that the participants described depended on their age, social situation and phase across the life span. The non-established participants, i.e. those who did not live with a partner or their family of origin, lived alone and struggled alone with the consequences of their stroke. This situation left this group in a distinctly vulnerable situation. The findings underlined the needs and difficulties of these youngest work-aged stroke survivors in living an independent life despite suffering from an illness. These participants described substantial challenges in re-entering a regular life concerning education and work, re-establishing contact with friends, developing new friendships, and developing intimate relationships. The lack of contact with other students, colleagues, friends, and family members made these stroke survivors prone to being isolated in their homes and living a life described as “boring”. The normal focus on emancipation from family and ongoing socialising with friends during this phase of life (Carter & McGoldrick, 1999) left this group vulnerable to being marginalised and to developing poor psychosocial health. Situations normally acknowledged at this phase during the adult life span might be at stake and might negatively influence the start of their adult lives. The difficulties they experienced in maintaining participation and engagement in meaningful activities and social relationships might threaten their well-being (Næss, 2001a, 2001b).

Research concerning non-established stroke survivors is lacking in the literature. Some qualitative studies have noted the struggles of young individuals suffering from stroke (Banks & Pearson, 2004 ; Röding et al., 2003; Stone, 2005b, 2007). However, they have not focused on the challenges and vulnerability associated with being non-established and living alone. Although a small group within the larger stroke population, this is a particularly important minority who is less likely to receive attention and follow-up from the health care services (IV), live a long time with the consequences of stroke and suffer from a disease that is usually associated with an older age group. This makes it necessary to explore the challenges of this specific vulnerable group further.

Difficulties in performing the family roles

The parent role

The expectation of participating in the busy lives of their families as parents, and the impossibility of withdrawing from their parental obligations while recovering, challenged the

daily functioning of the participants in parent roles (III). The challenge of adapting to life after stroke, in parallel with their children's regular transitions during childhood and adolescence, placed this group of stroke survivors in repeatedly challenging situations during their recovery. These participants described how the parent role repeatedly pushed them to their limits during a period of life when they were expected (and also expected from themselves) to support and care for their children. The lack of self-protection caused by the daily demands of family life also influenced their relationships with their children. Feeling obligated to participate in their children's various activities, but unable to be completely involved, frequently left the participants in a situation of powerlessness and inability to hide their struggles. They found themselves in situations where they felt forced to expose their shortcomings. Finally, their struggles with telling their children about the consequences of the stroke sometimes challenged the relationships between the stroke survivors and their children (II, III). The lack of communication could lead to a changed relationship between the stroke survivor and their child, leaving both individuals in a difficult situation.

The findings underscored both the mothers' and fathers' struggles in caring for their children. This finding is consistent with recent studies highlighting both women's concerns about their role as mothers (Kitzmüller et al., 2012; Röding et al., 2003) and men's concerns about their role as family protectors and breadwinners (Kvigne, Kirkevold, Martinsen, & Bronken, 2013; Röding et al., 2003). These findings reflect that, at least in a Western context, both men and women assume major responsibilities within their families. Consequently, the challenges they face in managing their roles as parents and partners must receive more attention during rehabilitation following a stroke.

Some of the participants reported a lack of support and trust from their partners, who discouraged them from caring for their children (III). To some, these situations resulted in a secluded parent role and a retreat from discussions with their partners concerning how they could manage their roles as partner and parent. The worries caused by such situations influenced the stroke survivors' well-being. Knowledge about relational aspects within the families from the stroke survivors' own view is limited. Banks and Pearson (2004), who conducted a longitudinal study of 38 stroke survivors aged 20-49 years and their partners, found that although both the survivors and their partners worried about common issues, they found it difficult to communicate about their altered roles, their changed relationships, and the additional responsibility placed on the partner. Thus, there is scarce data concerning family

relationships seen from the viewpoint of stroke survivors, and parent roles have been examined to an even lesser extent. Although Kitzmüller et al. (2012) investigated the experience of family life, their study took a broader approach by including stroke survivors, spouses, and children in the study sample.

The study conducted by Kitzmüller et al. (2012) found that the family was viewed, positively, as a “lifebuoy”. However, they also found some distinctions in how stroke survivors viewed their close family depending on whether the interviews were conducted in collaboration with their partners or not. A similar finding was documented by Thompson and Ryan (2009), who found marital relationships after stroke to be dominated by unilateral care rather than by a reciprocal marital relationship. Thompson and Ryan (2009) also found spousal empathy lacking, although the home was viewed as a safe and comfortable place. This family struggle, seen from stroke survivors’ point of view, highlights the need to conduct dialogues with stroke survivors to clarify the specific challenges in their family life. On the other side, these findings also underline the need for families to communicate about the challenges following a stroke to explain their experiences and challenges to all family members.

The grandparent role

Both participants with adult children at home and participants whose children had left home expressed sorrow for their inability to care for their adult children and grandchildren as before. The inability to care for their children and grandchildren influenced their social contact with their closest family (III). Stroke survivors living in empty nests were particularly prone to being isolated in their homes. Being able to engage in their grandchildren’s lives might make a positive contribution to the well-being of stroke survivors living in empty nests, allowing them to be engaged in meaningful activities (Næss, 2001a). Previous studies have found that older women are troubled by not being able to support children and grandchildren (Eilertsen, Kirkevold, & Bjørk, 2010). Eilertsen et al. (2010) underlined contact with adult children and grandchildren as existentially meaningful situations. The negative impact of a stroke on social life and leisure activities is also documented elsewhere (Daniel et al., 2009; O’Connell et al., 2001; Røding et al., 2003). The positive influence of grandchildren on their grandparents should be highlighted during dialogues with stroke survivors and their family, at the same time addressing issues about how to accomplish the grandparent role in a way that is congruent with the new life situation of the stroke survivor.

Difficulties in fulfilling work roles

Of the fourteen work-aged participants in the intervention (II), five had returned to part-time work at the conclusion of the intervention. Four of the 22 participants in study III had returned to full-time work, and one had returned to full-time studies six months to nine years post-stroke. Additionally, one participant had returned to part-time work, whereas the remaining sixteen participants in study III were not employed. This finding means that approximately $\frac{3}{4}$ of the participants were unemployed over the long term. The low numbers of people returning to work in this study are in line with recent studies (Daniel et al., 2009; Hofgren et al., 2010; Treger et al., 2007; Wilz & Soellner, 2009) and underline the challenges of returning to work following a stroke.

The findings underscored that the participants experienced significant struggles in terms of fulfilling work expectations. Both newly graduated participants in the early phase of their careers and participants close to retirement experienced significant difficulties (II). The inability to realise the goal of returning to work, which is generally taken for granted (Medin et al., 2006), might contribute to the experience of being marginalised, even for those nearing retirement age (II). Not resuming work might be a negative factor influencing the meaning of life and subjective well-being. Although the stroke survivors took it for granted that they would manage to re-enter the work force, many of them did not succeed in returning to work over the long term (III). Lindström et al. (2009) found that having an intrinsic will and a positive attitude was highly valuable for succeeding in returning to work, and Hofgren et al. (2010) found that younger stroke survivors were more likely to return to work than their older counterparts. However, returning to work following a stroke is a multifaceted challenge related to factors such as the individual consequences of the stroke, professional status or employment, economic situation and support received from colleagues, employers, and health and social professionals (Gilworth et al., 2009; Koch et al., 2005; Morris, 2011; O'Brien & Wolf, 2010; van Velzen et al., 2011; Vestling et al., 2003). The importance of fulfilling the essential requirements of work assignments has been highlighted from the employer's point of view (Culler et al., 2011), which might make it difficult to return to work or apply for new work following a stroke. In addition, an intensive rehabilitation programme, the employer's flexibility and a supportive social network have been found to be necessary factors for success in returning to work (Hofgren et al., 2010).

Some of the participants experienced being forced to leave work, and that the decision to leave work was made by others (II). The findings also indicate that an involuntary role as a homemaker i.e., being excluded from work life outside the home, was experienced as frustrating and threatening to the participants' self-esteem and identity (III). To be forced to leave work, voluntarily or involuntarily, might negatively influence well-being irrespective of age and proximity to retirement age. Being unable to return to work may require support, even for those who are close to retirement age, to be able to adjust to a "new" life without working outside the home. This finding highlights that work is of high value and a contributor to well-being across the work-aged life span (Alasewski et al., 2007; Blustein, 2008; Côté & Coutu, 2010). Although men have been found to have ambivalent experiences of retirement soon after a stroke (Lobeck, Thompson, & Shankland, 2005), knowledge about the process of retirement appears to be scarce.

7.2 The experienced psychosocial follow-up needs

This section mainly discusses the findings of study I and study IV, which are highlighted through the themes "the need for professional support" and "the need for being supported through narrative co-construction and guided self-determination".

7.2.1 The need for professional support

The stroke survivors in this study found it difficult to access health services on the one hand; on the other hand, they found that health services lacked any tailored follow-up programmes that were considered beneficial. Those who succeeded in accessing regular rehabilitation services assessed the follow-up as incidental (I,IV). These experiences were independent of the time since stroke onset.

Half of the participants in study IV belonged to a follow-up group from study II (n=8). Although they found the psychosocial intervention useful and evaluated their lives as satisfactory when terminating the intervention, many nevertheless expressed disappointment in their follow-up one year after terminating the intervention (I). One aspect of this disappointment might indicate an experienced vacuum after leaving the intervention. Opportunities to share stories and receive responses from others have been found to be important factors following a traumatic event (Frank, 1995, 1998; Mattingly, 1998). The

health personnel who conducted the intervention provided responses and follow-up to the participants, who found these interactions helpful for their adjustment to life following the stroke. However, when the intervention was terminated, these interactions were also terminated. These aspects, in addition lack of opportunities to continue with storytelling after leaving the intervention, might have contributed to an experience of being left alone and the view of the follow-up as lacking.

This study confirms that although there is progressive adjustment to the consequences of stroke, the need for follow-up is prolonged by several years when the consequences of stroke are chronic (i.e., lasting for more than six months), as was the situation for most of the participants. This finding highlights that recovering from stroke is a protracted struggle (Kirkevold, 2002; Kouwenhoven et al., 2011; Salter et al., 2008) and that the consequences of stroke become fully apparent after the stroke survivor is discharged from rehabilitation (Kirkevold, 2010).

Most of the participants were aware of their statutory right to have an individual plan designed (IV). However, the “Individual Plan” system (Ministry of Health and Care Services, 2009) apparently did not ensure a tailored and flexible follow-up plan that would be experienced as helpful in the adjustment to life following the stroke. Challenges with the individual plan system have also been discussed in other studies conducted in Norway (Alve et al., 2012; Nilsen & Jensen, 2012; Slettebø et al., 2012). Holum (2012) found individual plans to be supportive for improving user participation and empowerment among young individuals aged 17-37 years who were in need of mental health care services. Holum’s study underlined that a well-functioning process for drafting individual plans required mutual cooperation among the patient, a knowledgeable and competent coordinator, and other health professionals (Holum, 2012).

The lack of a system for systematic follow-up led the stroke survivors in our studies to question the professionals’ understanding of how the consequences of stroke interfere with the lives of young stroke survivors and of the importance of offering individually tailored support (IV). The competence of coordinators was also questioned by participants in an investigation of individual plans for providing care to children with special needs (Nilsen & Jensen, 2012). The question of whether individual plans function more as an organisational procedure than as support for patients in need of community-based psychological health care services has also been highlighted by Hansen (2007). This concern raises the question of

whether the legislation requiring an individual plan to be created is merely an organisational element that does not ensure tailored follow-up addressing individuals' needs. Recent research has documented fragmented follow-up and discrepancies in the evaluation of follow-up needs between professionals and young stroke survivors (Bendz, 2000, 2003).

The stroke survivor's next of kin and friends might play a prominent role in the psychosocial follow-up process. However, the findings underlined that the communication among family members often was described as difficult and/or insufficient (II,III). Furthermore, the participants experienced that the social support provided close to the stroke onset declined over time, leading to an experience of decreased interest and support and resulting in a lack of communication about the individual's struggles (III). These findings indicate that leaving the follow-up responsibility *only* to family members might result in a threat to the stroke survivor's well-being. In other studies, family members have also been found to struggle with their support of younger family members suffering from strokes (Banks & Pearson, 2004 ; Buschenfeld, Morris, & Lockwood, 2009; Lawrence & Kinn, 2013). This finding necessitates securing systematic follow-up outside the home context. The design of follow-up plans tailored to individual needs should recognise that some stroke survivors will need less support, whereas others will be in need of extended support to maintain psychosocial well-being. From a health-promoting perspective, therefore, it appears necessary to prepare for follow-up to be extended over time *if* and *when* necessary. This is in line with a study by Burton and Gibbon (2005), who underlined the need for extended follow-up while emphasising an individual, flexible approach. The follow-up should be secured and systematised regardless of who the stroke survivor is and should be independent of social situation, occupation, dwelling place and economic status. Not considering the stroke survivor's social situation when delivering health service support might thus have a counterproductive effect and lead to an experience of being "left in the lurch", i.e., not experiencing the health service system as supportive (IV).

Despite better treatment outcomes in recent years (Stroke Unit Trialists' Collaboration, 2013), it should be questioned why the same positive results appear to be lacking in the rehabilitation services (Daniel et al., 2009; Giaquinto & Ring, 2007; Johansson et al., 2007). The experienced ignorance of follow-up needs revealed by the findings of this study (IV) highlight the need for a stronger focus on rehabilitation following stroke and stroke survivors' self-care abilities during their daily lives (Guidetti, Andersson, Andersson, Tham, & Koch, 2010;

Guidetti & Ytterberg, 2011). A stronger focus on rehabilitation is in line with governmental goals (Ministry of Health and Care Services, 2009). However, achieving such goals depends on enhanced knowledge of effective supportive interventions. The Norwegian guidelines for the treatment and rehabilitation of stroke survivors (Indredavik et al., 2010) emphasise that rehabilitation should occur early and continue for a limited time but still be broad, flexible, and patient-centred to promote physical, psychological, social and occupational independence. However, the guidelines do not highlight the specific needs of young, midlife and elderly stroke survivors or the need for dedicated, tailored psychosocial rehabilitation. This lack may contribute to the inattentiveness to younger, work-aged stroke survivors' specific needs and their experienced lack of follow-up. The guidelines should thus be evaluated and revised, taking these aspects into account.

7.2.2 The need for being supported through narrative co-construction and guided self-determination

The significance of telling one's story and recreating meaning

In this study, the need to narrate was found to be essential, and the opportunity to have a dialogue partner was highlighted by most of the participants as positive and helpful for continuing with life (I-IV). Participating in the intervention provided them with a chance to tell their stories during their adjustment process. Having the opportunity to tell about their own situation appeared to contribute to strengthening their sense of coherence (Antonovsky, 1987) by recreating meaning and supporting them in their attempts to cope with their new situations (I). This finding supports the importance of being provided the chance to tell one's story following a serious life event, such as a stroke (Frank, 1995, 1998; Hensel-Dittmann et al., 2011; Hjelmblick & Holmstrom, 2006; Mattingly, 1998).

The lack of specific, individual information about their own situation and information addressed to family members was highlighted by the participants. Providing information has been found to be essential to facilitating an understanding of stroke and its implications (Ellis et al., 2010; Forster et al., 2012; Redfern et al., 2006; Turner-Stokes et al., 2005). We assumed that the participants had received information about the consequences of the stroke when hospitalised in the acute care hospital or in a rehabilitation unit. Consequently,

information about the stroke, as such, was not highlighted as a specific topic of the intervention.

The experienced lack of sufficient information about the stroke and its implications might have different explanations. On the one hand, the cognitive consequences of the stroke, such as lapses in memory and a reduced ability to concentrate, might challenge the patient's ability to grasp the information. On the other hand, standardised information provided in a professional language might be experienced as less relevant to the specific situation of each individual, making it difficult to adapt the information to their individual struggles and needs (Zoffmann, 2004). Adding individual information tailored to the individual's challenges and needs across the life span might therefore contribute to a better understanding and make the situation more comprehensible and coherent (Antonovsky, 1979, 1987). This issue must be considered in the further development of the intervention.

Assessment of the dialogue-based nursing intervention

The worksheets

The topics addressed in the worksheets were experienced as relevant, creating the opportunity to voice psychosocial challenges and facilitating reflections about living with stroke, which were not addressed by the usual care. The topics of family life and work life were explicitly highlighted as being of importance to the work-aged participants because these topics were not found to be highlighted by the existing health service system. However, the further development of the intervention makes it necessary to explicitly address relevant issues concerning specific roles related to family and work to ensure that the intervention content is tailored to the work-aged group of stroke survivors.

The work-aged participants found the worksheets interesting and helpful, although they used them actively by writing on them on their own to a lesser extent. This finding differs from the work of Zoffmann (2004). The discrepancy in the experiences of using of the worksheets might be related to the consequences of the stroke, which resulted in reduced cognitive capacity in some participants, making it difficult to read, write and concentrate.

We conclude that work sheets are helpful as structural elements in co-constructing stories in a dialogue-based intervention. However, the further development of the worksheets,

particularly regarding family and work issues, is necessary to facilitate reflections and dialogues with younger, work-aged participants.

The number of meetings

Most of the participants assessed the number of eight meetings as adequate. However, some considered the meetings to be too few. Watkins et al. (2007) found four meetings using motivational interviewing over a period of four weeks to be effective in improving mood, whereas a study by Burton and Gibbon (2005) found a flexible follow-up approach by a stroke nurse to be effective. In the study of Burton and Gibbon (2005), the stroke survivors contacted the nurse only three times over a period of two months, on average, but the meetings varied from zero to 28. This finding indicates there is no agreement on the adequate frequency of meetings but underlines the importance of flexibility with regards to frequency and number of meetings. Further research into this topic is needed.

Individual versus group formats

The feasibility study explored the delivery of the intervention in both a one-to-one format and a group format. On the one hand, the individual dialogues allowed a more flexible and individualised approach than the group format. On the other hand, sharing stories with peers was highlighted as being supportive in the group format, although the common topics were experienced as somewhat restrictive by the youngest participant. Although an individual format is easy to adjust and tailor to individual needs, delivering the intervention in the participants' homes might create an economic challenge within the community health services. A group format is less costly, which might make it more feasible to apply. Groups with peers are found to be attractive (Dickens, Richards, Greaves, & Campbell, 2011). However, self-help groups are found to have challenges (Chaudhary, Avis, & Munn-Giddings, 2010). Chaudhary et al. (2010) found it challenging for self-help groups to endure over time in their study of 936 self-help groups. Self-help groups had a tendency to close before becoming sufficiently established to function properly. Their continued existence over time relied on enthusiastic key members willing to assume organisational responsibility. Chaudhary et al. (2010) also concluded that self-help groups are in need of professional assistance. Groups developed on a clear theoretical basis were found to last longer (Chaudhary et al., 2010; Dickens et al., 2011).

Based on the above discussion, a mixture of individual and group sessions could be a possible format for psychosocial support within the community health service system. However, it is necessary to adapt support groups to stroke survivors' social situations to be able to explicitly tailor the intervention to individuals. Living with the consequences of a stroke when being work-aged is a complex situation, which suggests that psychosocial support groups should be led by professionals, at least initially. However, after becoming well established, self-help groups could be positive in the long term.

It is not possible to firmly conclude on individual versus group formats for delivering the dialogue-based intervention for work-aged stroke survivors based on the available evidence. More research is needed to reach a conclusion on this issue.

The experienced usefulness of the intervention

The guided self-determination communication method used in the intervention was found to be supportive. Being aware of individual challenges across the life span requires individual and dynamic follow-up services and legitimises the need for dialogue-based interventions based on reciprocal guidance and shared decision-making (Zoffmann et al., 2008; Zoffmann & Lauritzen, 2006). Based on the qualitative evaluation of the intervention conducted in this study, it is impossible to reach conclusions on the effectiveness of the intervention; however, our findings suggest that positive benefits were experienced by the participants. It is necessary to assess the effects of the intervention in a larger, controlled trial.

In summary, co-constructing stories through narratives and being supported in the effort to cope with the situation by using the method of guided self-determination seems to promote a sense of being cared for and followed up through a difficult period of adjustment. A tailored follow-up, more specific than that experienced by the participants in this study, might be a positive contributor to promote subjective well-being (Næss, 2001a, 2001b). Focusing on stroke survivors' experiences, developing life skills and co-constructing meaning and continuity in line with lifeworld-led care (Galvin & Todres, 2009; Todres et al., 2007) might make a positive contribution to the rehabilitation of work-aged stroke survivors. The expressed experiences revealed in the sub-studies in this study will enable the further development of the dialogue-based nursing intervention tailored to the work-aged group of stroke survivors.

7.3 Methodological issues

The strengths and limitations of this study related to the research team, the study design, the analysis and the findings were assessed using the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007).

Research team and reflexivity

The research team consisted of five female individuals with different clinical experiences. Four were nurses, and one was an occupational therapist. All were trained as qualitative researchers. One was a professor, two were senior researchers, and two were doctoral students. Four had conducted previous qualitative studies of experiences following stroke, with one specifically focusing on individuals with language disorders.

Three members were responsible for the development of the intervention. All the members of the research team were involved in the data collection and the analysis process at different phases.

Four of the researchers were actively involved in conducting both the intervention and the data collection. However, we sought to prevent the individual who conducted the intervention with a particular participant from conducting the follow-up interview with the same participant. Nevertheless, due to practical constraints, one of the intervention participants was both followed up and interviewed during the follow-up interview by me one year after the intervention was terminated. This situation might have influenced this participant's ability to speak openly and might represent a limitation of the study.

Study design

The study consisted of sub-studies with different designs. Traditionally, a feasibility design (I,II) and a hermeneutic phenomenological design (III,IV) would be considered to adhere to two different paradigms (Graneheim & Lundman, 2004; van Manen, 1997) and therefore be incompatible. However, in recent years, the combination of qualitative and quantitative methods has been advanced to off-set the limitations of each. In this study, we considered them to be complementary. Furthermore, the main study is guided by a phenomenological hermeneutic stance which emphasises that persons confronted with serious illness experience breakdown of meaning and therefore need to be supported in recreating meaning and

coherence in life. The intervention sought to facilitate the (re)creation of meaning through a dialogue-based, narrative approach. This philosophical stance underpinned all sub-studies, including the feasibility study.

Participant selection

The participants in the intervention study were recruited using purposeful sampling methods (Patton, 2002; Polit & Beck, 2012). The ages of the included participants ranged from 33-89 years (in study I), thus including both work-aged and older participants. By considering the participants' age in the analysis process, the interpretation of the interviews indicated (in addition to the experienced daily challenges, which overlap among younger and older stroke survivors) that younger stroke survivors had different challenges, which we were able to isolate during the evaluation of the intervention. This challenged us to further isolate the specific challenges of this group to gain further knowledge of the group under study. However, including only work-aged stroke survivors in the intervention study might have created even more depth in the data.

The population of adult stroke survivors younger than 67 is less likely to be followed up in the health service system and is more challenging to recruit. This led us to choose a convenience sampling method (in study III and IV), which identified stroke survivors who were willing to participate in the study. Although this sampling method might generate a biased sample, we succeeded in securing a sample with diverse background characteristics in terms of gender, age, social situation, and experienced time living with the stroke. These variations in the participants' experiences facilitated our investigation of their experiences of living life after stroke over time.

Data collection

Different data sources were included in the feasibility studies (I,II) in accordance with recommendations for developing and evaluating complex interventions (Craig et al., 2008). The triangulation of qualitative data consisting of log notes, work sheets (I,II), researchers' notes (II), and qualitative interviews (I-IV) enabled the development of rich descriptions, which are emphasised in qualitative research (Graneheim & Lundman, 2004; Patton, 2002). The variety of data sources, combined with repeated interviews with sixteen of the

participants (IV), produced data with both depth and breadth over time, allowing us to explore the complexity of the phenomenon of living with stroke at a younger age.

Analysis and findings

The transcribed interviews were analysed separately by the research members. The preliminary results of the coding process were contrasted and compared within the team to ensure consistency and transparency. The researcher triangulation ensured a transparent process, encouraging each member to further reflect on and adjust the analysis in light of discussions within the research group. The continual and open discussions continued until consensus was achieved, leading to a shared understanding of the phenomenon under study (Tong et al., 2007).

Transparency was also ensured by describing all the steps within the research process.

A qualitative content analysis (I) and a hermeneutic-phenomenological analysis (II-IV) were chosen for the data analysis process. Both qualitative content analyses and hermeneutic-phenomenological analyses are appropriate analytic methods for identifying themes and patterns within a qualitative text (Polit & Beck, 2012). The fact that the questions and analytic process for the evaluation of the content, structure and process of the dialogue-based intervention (I) were specified prior to the study made a qualitative content analysis method useful for analysing the data from study I. However, a hermeneutic-phenomenological analysis was found to be appropriate for inductively investigating the experiences of living with the consequences of a stroke in studies II, III, and IV.

The quotations presented provided representative examples to allow readers to access the expressions of the participants and to facilitate the transparency of the interpretations (Graneheim & Lundman, 2004; Patton, 2002; Sandelowski, 1994; Tong et al., 2007).

The study data were derived from both women and men. However, gender aspects were not investigated in depth in this study. This might thus represent a limitation of the study.

Stroke survivors are a heterogeneous group. However, only Norwegians were included in the sample, which makes it impossible to transfer the findings to other ethnic groups.

The variations in gender, age and time since stroke onset produced a broad range of experiences within the study group. The consistency between our findings and those of other

studies supports and strengthens the findings. Comparing this study with recent international studies also provides an opportunity to evaluate the relevance of our findings to other contexts. Acknowledging that the situations never can be fully understood (Lindseth & Norberg, 2004), there is every reason to be careful. Nevertheless, we believe that it is possible to transfer the insights from our study to other comparable contexts, bearing the above limitations and considerations in mind.

8 Conclusions

This study aimed to broaden the understanding of younger stroke survivors' psychosocial experiences of living life after stroke, to identify their psychosocial follow-up needs during rehabilitation and evaluating a dialogue-based intervention to address their psychosocial well-being. The conclusions were drawn with regard to the study aims presented in chapter 3.

Life as a work-aged stroke survivor was experienced as challenging and associated with a risk of becoming marginalised in family and work life during the first year following the stroke.

Living with the consequences of the stroke was found to pose significant and multifaceted challenges to family life, even many years after the stroke. However, the challenges varied over time, from an initial struggle to function in and balance the relationships and roles within the family early after the stroke, towards a more resigned attitude.

Non-established stroke survivors appeared to be particularly vulnerable because they were often isolated in their homes. In addition, stroke survivors in parental roles were also found to be vulnerable in their attempts to fulfil their roles as mothers and fathers.

The study participants struggled to gain access to follow-up health services, which were described as coincidental and untailored to the younger stroke survivors' specific needs. The younger stroke survivors thus appeared vulnerable to not being followed-up.

To interpret and manage a life that includes the consequences of a stroke requires individual support and follow-up adjusted to the stroke survivors' specific needs across the life span. Stroke survivors may benefit from narrating their experiences and receive tailored follow-up support with regard to handling the daily demands of both family life and work life. Being provided with opportunities to narrate their experiences outside the home context might be helpful for preventing psychosocial problems.

To be considered supportive, follow-up programmes must address both short-term and long-term needs and must consider the particular challenges of younger stroke survivors in close collaboration with the stroke survivors themselves.

Health personnel should consider younger stroke survivors' own experiences and perspectives and should support their motivation to continue with life by providing individualised, flexible, and knowledge-based support and encouragement.

The intervention that was feasibility tested in this study was found to be useful in promoting psychosocial health and well-being following stroke. The intervention appeared to provide initial support in adjusting to life after stroke. The study provides valuable insights into aspects that require further consideration and development before launching a randomised controlled trial.

9 Implications for nursing practice

Because rehabilitation services represent a multi-professional cooperation involving different health and social workers, the findings of this study have ramifications for a number of professionals. However, because this study was contextualised within the area of nursing, the emphasis on its implications will concentrate first and foremost on nursing practice, i.e., how nursing should be performed at the individual level and organised at the organisational level.

To map out challenges and resources

Living an independent life is not equivalent to living a satisfactory life. Although obvious bodily and functional symptoms may be absent following a stroke, it is important to recognise how invisible symptoms influence and challenge life following a stroke. To support stroke survivors on their “journey towards recovery” after discharge, it is necessary to evaluate their resources and struggles related to the present situation. Not bringing invisible topics to the surface might lead to threats to well-being and the development of psychosocial problems.

To be aware of specific vulnerable groups

Although most stroke survivors might be in need of some support, it is imperative for nurses to be aware of those who are especially vulnerable. One group identified in this study as vulnerable comprised non-established stroke survivors living alone. By not living close to their close or extended network, this group might be at risk of becoming socially isolated. Another group identified as vulnerable comprised established stroke survivors in parental roles. Their daily demands in caring for young children or adolescents made them vulnerable in terms of over-stretching themselves and/or getting into conflicts regarding the parent role. Consequently, daily life with a sense of inability to fulfil their caring roles and their working roles might threaten their well-being. This implicates a need of support for non-established stroke survivors and stroke survivors in parental roles.

To focus on individual needs

Nurses have specific roles within the area of nursing rehabilitation (Kirkevold, 1997, 2010). To be able to support stroke survivors in early and late rehabilitation requires care to be

provided throughout the period encompassing both the stroke and the consequences experienced by the survivor.

Identifying resources and struggles in close collaboration with stroke survivors is critical for being able to care for, assist and support stroke survivors during their rehabilitation, independent of their bodily and functional status. The biographical adjustment and transformation is an important concern for nurses. Offering lifeworld-led care in accordance with phenomenological nursing requires focusing on the experience of illness and individual concerns. A consciousness and attention towards existential issues might contribute to opening up, sustaining and assisting stroke survivors in their efforts to continue with life.

Awareness of individual concerns is fundamental in phenomenological nursing. Assisting tools that could contribute to revealing existential issues and promote well-being would be helpful for the implementation of dialogic interventions. Developing supportive methods for dialogic nursing is thus critical. The implementation of the method of guided self-determination, known as a problem-solving method for enhancing life skills (Zoffmann et al., 2008; Zoffmann & Lauritzen, 2006), could also be helpful in the dialogic interactions between younger stroke survivors and nurses to secure the inclusion of all the psychosocial aspects of living life after a stroke.

The findings revealed that the stroke survivors sensed a lack of knowledge and understanding within the health personnel groups. Consequently, they questioned the competence and even the willingness of the health personnel to offer relevant support. Offering support and information requires nurses with updated knowledge related to the specific group. This is a premise to be able to offer meaningful support.

To secure a follow-up system

The stroke survivors' frustration with not knowing how and where to seek help tended to paint a somewhat dismal picture and was expressed as a sense of being left alone or "left in the lurch" in this study. This finding has implications for the role of the health care organisational system in nursing. The findings of this study lead to two specific implications for the health care system.

First, the transitions between the acute phase, rehabilitation care and home care should be strengthened. Developing a seamless system might ensure that stroke survivors in need of

follow-up will be included in a follow-up system. The transitions between the health service levels should therefore be secured.

Second, nurses should be actively involved in the management of nursing. Nurses' holistic view provides a unique opportunity to offer individual support in line with stroke survivors' life span challenges. Acknowledging nurses as having important roles in stroke rehabilitation (Kirkevold, 1997, 2010) and acknowledging their roles as coordinators and managers of individual support might strengthen the sense of being offered a coordinated, coherent system. This places nurses in the unique situation of being responsible for information and teaching of stroke survivors and their families. As revealed in this study, information should be offered to families.

10 Recommendations for further research

This study contributes to the knowledge of younger stroke survivors' experiences and follow-up needs. However, we still lack sufficient knowledge regarding this sub-population of stroke survivors.

Although this study focused on roles and relationships, more research regarding life-span challenges is needed. Although this study revealed challenges in fulfilling parental roles, more research is needed concerning this specific area. Focusing on the specific roles of mothers, fathers and grandparents will also produce more knowledge of stroke survivors' experiences and needs across the life span. Children's experiences of living with a parent suffering from stroke should be further investigated as well.

In addition to stroke survivors in parental roles, non-established stroke survivors were revealed to be a vulnerable group and thus deserve further investigation. A longitudinal study following the youngest stroke survivors during their education and career "journey" on their way to an established life would give valuable new insights.

The feasibility study, which provided individual support, was promising. Despite the promising qualitative evaluation, there is a need for further development and testing of the intervention in a larger, controlled trial. The rapid transition from discharge to community health services makes it pertinent to conduct a randomised controlled trial within the community health care context. The findings of the present study will contribute to a further accommodation of the process, content and structure of the intervention.

We need further knowledge of one-to-one interventions and interventions delivered in group formats, as well as the ways these two formats could be combined to be cost-effective while still being experienced as supportive. The balance between delivering an ideal intervention and a realistic one is challenging and requires the fine-tuning of quantitative and qualitative aspects of the intervention process and content prior to the implementation phase. Including a control group will give further insight into the intervention's effect on psychosocial well-being.

Including other national contexts in parallel studies would be helpful for the further development of international rehabilitation guidelines.

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RESEARCH ARTICLE

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Promoting psychosocial wellbeing following stroke using narratives and guided self-determination: a feasibility study

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Abstract

Background: Extensive studies have documented the complex and comprehensive psychosocial consequences of stroke. Psychosocial difficulties significantly affect long-term functioning and quality of life. Many studies have explored psychosocial interventions to prevent or treat psychosocial problems, but most have found modest effects. This study evaluated, from the perspective of adult stroke survivors, (1) the content, structure and process and (2) experienced usefulness of a dialogue-based psychosocial nursing intervention in primary care aimed at promoting psychosocial health and wellbeing.

Methods: This was part of a feasibility study guided by the UK MRC complex interventions framework. It consisted of dialogue-based encounters with trained health professionals during approximately the first year poststroke. It was tested in two formats; individual or group encounters. Inclusion criteria were: Acute stroke, above 18 y.o., sufficient physical and cognitive functioning to participate. Data were collected immediately before, during and 14 days after the completion of the intervention. Pre- and post-data included medical and demographic data, quality of life, emotional wellbeing, life satisfaction, anxiety and depression. Qualitative interviews focusing on participant experiences were conducted two weeks following the intervention. Log notes taken by the health professionals conducting the intervention and work sheets filled in by participants also comprised data. Data analysis was case-oriented. The structured instruments were analysed regarding completeness of data and indication of changes in outcome variables. The qualitative interviews, log notes and work sheets were analysed using thematic content analysis.

Results: Twenty-five stroke survivors (17 men, 8 women), median age 64 (range 33–89), participated. Physical limitations varied from mild to severe. Seven participants had moderate to severe expressive aphasia. The participants found the content and process of the intervention relevant. Both the individual and group formats were found useful. Patients with aphasia reported that there were too few encounters (eight encounters were originally planned). The participants underscored the benefits of being supported through a difficult time, having a chance to tell and (re)create their story and being supported in their attempts to cope with the situation.

Conclusions: This study provides initial support for the usefulness of the psychosocial intervention and highlights areas requiring further consideration and development.

Trial registration number: ClinicalTrials.gov Identifier: NCT01912014

Keywords: Complex intervention, Nursing intervention development, Psychosocial wellbeing, Stroke, Feasibility study, Multiple case study, Narrative, Quality of life, Patient-centred, Goal-setting

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Background

Psychosocial wellbeing may be threatened following a stroke (Donnellan et al. 2006; Knapp et al. 2000). Depressive symptoms, anxiety, general psychological distress and social isolation are prevalent the first months and years (Knapp et al. 2000; Barker-Collo 2007; Ferro et al. 2009; Hackett et al. 2008a, 2008b). Psychosocial difficulties may significantly impact long-term functioning and quality of life (Ferro et al. 2009; Teoh et al. 2009), reduce the effects of rehabilitation services and lead to higher mortality rates (Ferro et al. 2009; Hackett et al. 2008a, 2008b).

The causes and risk factors of psychosocial problems are ambiguous. Some researchers theorise that poststroke depression may be a direct effect of ischemic brain lesions damaging the nervous circuits regulating mood (Whyte and Mulsant 2002). However, this theory is controversial (Bhagal et al. 2004; Kouwenhoven et al. 2011). Other researchers assume that poststroke depression is a response to overwhelming stress, affective overload and inability to cope with the extensive losses following a stroke (Whyte and Mulsant 2002; Kouwenhoven et al. 2011). Our work builds on the latter theory and aims to reduce the stress associated with adjusting to the consequences of the stroke by providing psychosocial support and facilitating the stroke survivor's own coping efforts.

A large number of studies have explored possible interventions for preventing and/or treating psychosocial problems (Knapp et al. 2000; Hackett et al. 2008a, 2008b; Forster et al. 2012; Redfern et al. 2006), but the results have been modest. Pharmacological treatment is effective in treating poststroke depression, but not in preventing it (Hackett et al. 2008a, 2008b). Psychosocial interventions have had modest effects but indicate that information, emotional support, practical advice and motivational support are important (Forster et al. 2012; Redfern et al. 2006; Ellis et al. 2010). It remains unclear how the different elements of the interventions contribute to positive outcomes and which elements work best at the different stages and among different subgroups (Forster et al. 2012; Redfern et al. 2006; Ellis et al. 2010). Few studies have provided adequate theoretical accounts of the mechanisms assumed to contribute to positive outcomes (Forster et al. 2012; Redfern et al. 2006; Ellis et al. 2010).

In Norway, the context of this study, the municipalities are responsible for providing rehabilitation services beyond the acute phase. However, the municipalities often lack the resources and specialised personnel that are available in hospital-based stroke units. Nurses outnumber specialised rehabilitation therapists in the community care setting, and are therefore more accessible to stroke survivors following discharge from acute treatment and rehabilitation. They are expected to address emotional and psychosocial needs and provide support and guidance to improve coping (Kirkevold 2010). Nevertheless, few nursing interventions

have been developed to address the psychosocial wellbeing of stroke survivors (Burton and Gibbon 2005; Forbes 2009; Watkins et al. 2007). Consequently, our goal was to develop a program that can realistically be delivered in the community. In this paper, we report on findings from a feasibility study (Craig et al. 2008) of a psychosocial intervention developed to promote psychosocial adjustment and wellbeing. Specifically, the aims of this study were to evaluate the content, structure and process of the intervention and its usefulness from the perspective of stroke survivors.

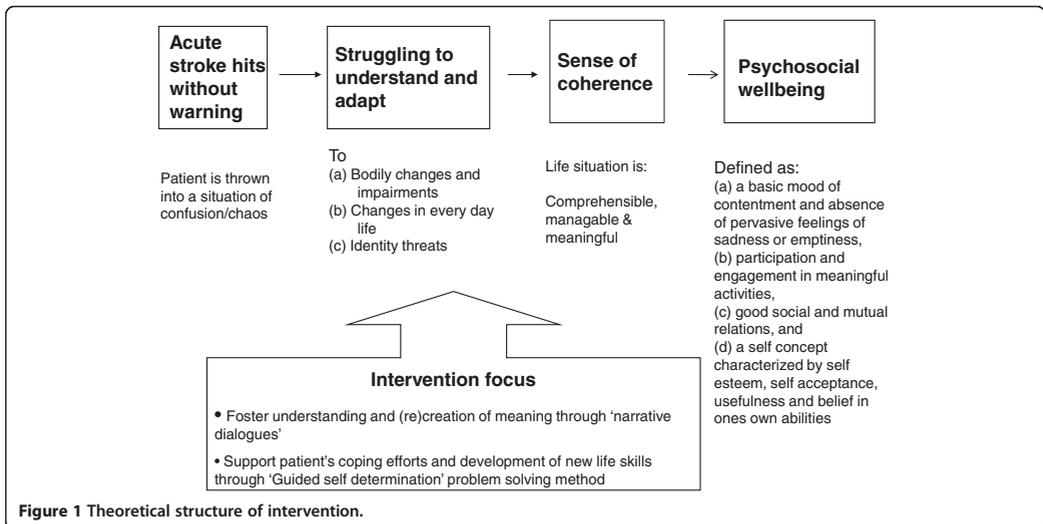
The intervention

The intervention was developed based on earlier qualitative studies, systematic reviews of psychosocial intervention studies and theories addressing psychosocial wellbeing and coping (for a detailed account, see (Kirkevold et al. 2012)). The theoretical assumptions, guiding the development of the intervention, are summarised in Figure 1.

The overall goal was to promote psychosocial wellbeing, defined as (a) a basic mood of contentment and the absence of pervasive feelings of sadness or emptiness, (b) participation and engagement in meaningful activities, (c) good social and mutual relations, and (d) a self-concept characterised by self-esteem, self-acceptance, usefulness and belief in one's own abilities (Næss 2001). These overarching goals were operationalised in terms of self-assessed satisfaction with each of the domains.

Experiences of chaos and a lack of control are major threats to wellbeing following a stroke (Donnellan et al. 2006; Knapp et al. 2000; Barker-Collo 2007; Ferro et al. 2009; Hackett et al. 2008a, 2008b). These experiences are related to difficulties in understanding what is happening in the body, what to expect in the future and how to address the new symptoms, difficulties and a changing life situation. Experiences of chaos and lack of control may threaten the stroke survivors' sense of coherence (Antonovsky 1987). According to Antonovsky's theory (Antonovsky 1987), wellbeing is related to a sense of coherence in life (SOC). SOC is promoted by experiencing life events as comprehensible (cognitive), manageable (instrumental/behavioural) and meaningful (motivational) (Antonovsky 1987; Eriksson and Lindström 2005, 2006). SOC was assumed to be an essential intermediate goal for promoting psychosocial wellbeing (Figure 1).

To promote SOC, we drew on narrative theory (McAdams 2009; Polkinghorne 1988), which emphasises that human beings create meaning, direction, identity and value in their lives through the stories they tell (Taylor 2007; Kraus 2007). Research suggests that telling one's story is a fundamental need following a traumatic event and may promote health (Frank 1995, 1998). We assumed that being supported to tell one's story would stimulate reflection and adjustment and would strengthen the identity, self-understanding and



self-esteem that are otherwise challenged following a stroke.

People suffering from aphasia are restricted in their natural abilities to tell their stories (Parr 2004; Shadden and Hagstrom 2007). The method "Supported Conversation for Adults with Aphasia" (Kagan et al. 1996) assigns more responsibility to the person who does not have communication difficulties to facilitate social interactions and provides a number of techniques that may enhance communication and understanding in dialogues with aphasia patients.

To promote coping and the development of new life skills, we applied ideas from guided self determination (GSD) (Zoffmann 2004), an approach founded on empowerment philosophy. GSD highlights the importance of being in control of one's own adjustment process. In this approach, the role of the health care professional is conceptualised as being a "supporter" or "coach" rather than a "care-giver" or "therapist".

We planned an intervention consisting of dialogue-based encounters between the stroke survivors and specially prepared health care professionals (mostly community care nurses). Dialogue-based was defined as individual or group encounters between equal partners, where the topics and issues of discussion were agreed upon by those involved, based on the needs expressed by the stroke survivor(s). The dialogues were, in principle, open or "unstructured", inviting participants to voice issues of particular salience at the time of each encounter. However, each encounter had a guiding topical outline that addressed significant issues that are highlighted in the stroke literature as particularly relevant to the stroke trajectory (e.g., bodily changes, personal relations, daily life

issues, meaningful activities) (Kirkevold et al. 2012). Each encounter included work sheets developed to support the dialogues. The work sheets consisted of drawings, figures, unfinished sentences and key words pointing to the topic to be addressed (see (Kirkevold et al. 2012; Bronken et al. 2012a, 2012b) for examples).

Methods

Design

We applied the framework for developing and evaluating complex interventions proposed by the UK Medical Research Council (MRC) (Craig et al. 2008). The MRC framework describes the development and testing of complex health interventions in terms of four major processes; (1) Development of the intervention based on relevant theories and empirical studies, (2) Feasibility testing to evaluate the potential usefulness and methodological issues (3) Evaluation to assess the effectiveness and cost-effectiveness, and (4) Implementation. In our study, we have completed the development and feasibility work. The results from the development work are presented in detail elsewhere (Kirkevold et al. 2012) and are therefore not presented here. However, the reader should keep in mind that the previously published developmental work represents the foundation for the work presented in this paper. In this paper, we present findings from the second phase (the feasibility testing of the intervention), focusing on the stroke survivors' evaluation and experiences of the intervention. We used a multiple case study approach, wherein each individual participant was studied in detail, drawing on different data sources (Stake 2006). This paper supplements previous feasibility reports from the study,

focusing on the aphasia subgroup (Bronken et al. 2012a, 2012b) and young persons with stroke (Martinsen et al. 2013).

Conducting the intervention

The intervention was tested in two formats, as individual dialogues or as a group intervention, with two initial individual encounters followed by six group dialogues with fellow stroke survivors and two group facilitators. Allocation to either individual or group intervention depended on geographical location. At one of the three participating locations, only the group format was offered. At the other two participating locations, the individual format was offered. Twenty stroke survivors received the individual intervention and five the group intervention. The content and work sheets were identical in the two formats. The two individual one-hour encounters that were offered to the group participants were aimed at becoming familiar with the participants' individual situations, establish a working relationship with each participant and addressing early needs before they entered the group sessions. The individual encounters were delivered in a private room in the hospital/rehabilitation unit as long as the participant was hospitalised and in the participant's home (or nursing home) upon discharge. The group sessions were delivered at a patient education centre associated with a university hospital.

The work sheets were handed out prior to each encounter in order for the participants to be able to review the topics and identify which issues they wanted to discuss at the next encounter. If a participant initially introduced a topic that differed from the topic suggested for the particular meeting, the health care professional was advised to change the planned order of topics, e.g., by using work sheets from other planned meetings. For example, if a participant were very concerned about returning to work or resuming family obligations in one of the first encounters, these topics would be rearranged from later encounters, even if bodily changes had been the planned topic of the day. In this way, the intervention was adapted to meet the individual participant's needs.

The facilitators delivering the intervention were trained prior to the intervention (16-hour training course) and were supervised throughout the intervention via individual and group supervision sessions. The training consisted of an introduction to the theoretical background and scientific basis for the intervention, the goals and content of the encounters and practical exercises for conducting the dialogues.

The participants suffering from aphasia received individual encounters. A person with in-depth knowledge and specific training in supported communication for persons with aphasia facilitated these individual encounters. The

facilitator was supervised by a speech therapist throughout the intervention.

The individual encounters lasted about one hour, while the group meetings lasted 2 hours to allow enough time for all participants to join in the dialogues. For the group format, individual flexibility was more limited. However, the goal was to address issues of common interest among the participants and to allow for discussions of individual needs.

The first meeting occurred as soon as possible after the stroke, usually within 4–8 weeks, and the last occurred approximately 6 months after the stroke (except for the aphasia group, in which the intervention had to be prolonged, see later). The intervention was administered during the period when the adjustment process was assumed to be most challenging (Burton and Gibbon 2005; Watkins et al. 2007; Kirkevold et al. 2012). The meetings were placed at times of increased vulnerability based on known transition points (e.g., at discharge, when physical improvement slows down, assumptions of new challenging roles or activities) (Burton and Gibbon 2005; Watkins et al. 2007; Kirkevold et al. 2012). We developed a guiding timeline suggesting that the first two meetings be carried out prior and immediately after discharge and then every two weeks for about two months and every four weeks the last two months. The timeline was adjusted to meet the needs of the participants in the individual intervention format, but this was not possible in the group intervention due to conflicting needs among the participants. The number of meetings was set at eight in an attempt to balance the ideal with the realistic (i.e. as few encounters as possible but enough to provide adequate support).

Sampling and recruitment

We chose a purposeful sampling approach. The target group was adult stroke survivors. Inclusion criteria were age 18 and older, having suffered a stroke in the past eight weeks, medically stable, judged by their physician/stroke team to possibly benefit from the intervention, interested in participating, adequate cognitive functioning to participate (judged by stroke team) and speaking Norwegian. Patients suffering from aphasia were included after their language was assessed and specified by a speech therapist. Excluded were persons with dementia and severely ill persons, as judged by their physician/stroke team, for whom the intervention would be of little benefit.

Setting

Participants were recruited from three different regions in Norway, including two larger cities with large university hospitals and a rural area with two local hospitals and several small counties. The regions were selected to include participants who lived in a variety of urban and rural areas and who received treatment and care from

different regional and local jurisdictions. Local recruiters in the hospital or home care service approached potential participants; the recruiters judged whether the patients met the inclusion criteria, provided written and oral information about the study and collected informed consent.

Data collection

Data were collected immediately before the intervention (T1), during the intervention (T2) and two weeks after the end of the intervention (T3). At T1 demographic data (age, gender, education, job, family relations and living conditions) and medical information (time and type of stroke, functional data, treatment, other medical diagnoses and treatments) were collected. In addition, standardized instruments, measuring health-related quality of life, emotional wellbeing, life satisfaction and anxiety and depressive symptoms were collected (see Table 1). The latter instruments were included to evaluate their appropriateness for a future controlled trial, as the sample size in this study was too limited to conduct sound statistical analyses.

During the intervention (T2), log notes and work sheets were used to describe the intervention process. In the log notes from each encounter, the health care professionals conducting the intervention described their experiences and reflections from each encounter and the reactions and comments from the participating stroke survivors. The log notes were structured to ensure consistency in reporting and focused on the experiences with the content, structure and process of each encounter. The work sheets contained information about the thoughts, feelings, experiences, worries, needs, values and goals that the participants expressed in preparation for and/or during the dialogues.

Two weeks after the intervention (T3), individual in-depth qualitative interviews were conducted, based on a thematic interview guide (see Table 2). In addition, each participant was interviewed using the standardized instruments from T1. The qualitative data represent the data for this paper.

The qualitative interview combined open-ended questions with more specific topical questions. The participants

were encouraged to describe their experiences in their own words. Some of the persons with aphasia were accompanied by a family member once or several times during the dialogues. In such cases, the family members were also invited to participate in the interview, subject to approval by the participant. Members of the research team, who had not delivered the intervention and whom the participants did not know, interviewed the participants without language problems, allowing them to more openly voice criticism and concerns regarding the intervention. For participants with aphasia, the same person conducted both the intervention and the interviews. Their substantial communication difficulties required continuity in the relationship and familiarity with the intervention process to elicit the participants' experiences and thoughts. For patients with aphasia, the interviews were video-recorded to preserve as much non-verbal data as possible and supplement their more limited verbal expressions.

Data analysis

The standardised instruments were analysed qualitatively in terms of degree of completeness of the data and any changes in scores from T1 to T3. A substantial portion of the forms were incomplete and could therefore not be used. For the complete cases, we reviewed the scores in each case in relation to the qualitative analysis to look for consistencies or inconsistencies in terms of expressed experiences. Generally, we found the instruments useful. However, particularly the SAQoL 39 was difficult for some participants to complete, especially at T1, as they expressed that they had not yet experienced many of the activities/situations described.

The qualitative interviews were transcribed verbatim, and the transcripts and log notes analysed with qualitative content analysis (Graneheim and Lundman 2004). We also analysed work sheet notes when these were available (some participants wanted to keep them). The interviews for each case were analysed first. The log notes and work sheets were subsequently analysed using the same approach. The three data sources supplemented each other and gave

Table 1 Standardized instruments

Name of the instrument	Type	Concept and dimensions	Scores
Stroke and aphasia quality of life SAQOOL-39 (Hilari et al. 2003, 2009)	Health related quality of life (disease specific)	Total score and four sub scores; physical function, communication ability, psychosocial life and energy level.	39 statements where informants rate the extent to which they struggle with the different functions with scores ranging from "can do it" (5) to "cannot do it" (1).
Faces Scale (Andrews and Robinson, 1991)	Global evaluation	Emotional wellbeing	Seven visual faces expressing different degrees of happiness/sadness, with scores ranging from "very happy" (7) to "very sad" (1).
Cantril's Ladder Scale (Cantril 1965)	Global evaluation	Life satisfaction	Visual ladder with ten steps. Step ten at the top of the ladder depicts the highest level of satisfaction (10), and step one depicts the lowest (1).
Hopkins symptom check list - 8 items (Tambis, 2004)	Symptom specific	Psychological distress/mental health	Eight statements related to common symptoms of anxiety and depression with scores ranging from "not bothered" (4) to "very bothered" (1).

Table 2 Thematic interview guide - qualitative interviews

Themes	Main questions	Subtopics
Theme 1	Can you tell about how you experience your life at present?	<ol style="list-style-type: none">1. Thoughts and feelings regarding present life situation2. Psychosocial needs and well-being3. Thoughts about the future
Theme 2	Can you tell about your experiences/opinions with regard to participating in the intervention?	<ol style="list-style-type: none">1. Number of meetings (too few/too many/appropriate timing of the meetings)?2. Length of intervention (appropriate, too short, too long)?3. Topics/focus in the meetings (were the topics addressed relevant/were any important topics missing? Was the ordering logical/helpful?)4. The worksheets (how did you like using worksheets? What about the content, number, layout, usefulness of the work sheets?)5. Inclusion of family/relatives (too little involved, too much involved or appropriate?)6. Any advice regarding changes in the content, structure or process of the intervention?
Theme 3	Can you tell whether participating in the intervention has made a difference or not in relation to your well-being?	<ol style="list-style-type: none">1. Experiences related to changes in emotional state?2. Experiences related to changes in activities?3. Experiences related to changes in social relations?4. Experiences related to changes self-esteem/identity?
Theme 4	Any other comments/suggestions based on your participation in the intervention?	

a richer picture of the participants' experiences and the nature of the intervention in each case.

The content analysis addressed the following two main questions: 1. How is the intervention judged with regard to the content, structure and process of the intervention? 2. What does the text tell us about the participants' experiences (positive and negative) of participating in the intervention? The researchers categorized the content of the interviews, log notes and worksheets into subthemes and themes in relation to each of the questions above. At the end, similarities and differences were identified across cases, looking at different subgroups, such as participants receiving the individual versus the group format, participants without language problems versus persons with aphasia, younger participants versus older participants and participants with different degrees of emotional and/or physical challenges. Questions, lack of agreement and unclear issues led to new rounds of analyses until mutual agreement was reached.

Ethics

The project was reviewed and approved by the Regional Committee for Medical Ethics and the Norwegian Social Science Data Service. Participants provided written, informed consent to a person outside the research group before being included. The consent was adjusted to the needs of persons with aphasia, and they were supported by a speech therapist when necessary. All participants

were assured anonymity, confidentiality and the right to withdraw at any time.

Trustworthiness

Our study confirm to the COREQ criteria (Consolidated criteria for reporting qualitative research) (Tong et al. 2007), which emphasize attention to three domains; the research team, study design and analysis. The last two domains have already been accounted for in the previous sections. With regard to the research team, all researchers conducting this study had a nursing background, were women and were trained as qualitative researchers within nursing science. They had different clinical experiences. Three of the researchers had conducted previous qualitative studies of experiences following a stroke, one specifically focusing on persons with aphasia.

A reference group of multi-professional expert clinicians, researchers in different relevant fields and previous stroke survivors and family members critically reviewed the study protocol and the initial findings, providing significant input.

Results

Participants

Of the 29 stroke survivors recruited to the study, 25 completed the study (17 men and 8 women). Four dropped out because of deteriorating health (2), new serious illness (1) or unwillingness to discuss problems (1). The median age of the participants was 64 years (range 33–89). The participants comprised three subsamples; those without

language problems receiving individual intervention (13), those without language problems receiving group intervention (5) and persons with aphasia receiving individual intervention (7). The participants' physical limitations varied from mild (few or no observable mobility limitations) to severe (wheelchair-bound and dependent on assistance for many daily living activities), but most were moderately affected (some muscle weakness and mobility challenges). Several suffered from fatigue, vision or hearing deficiencies, reduced memory and concentration difficulties. Participants with aphasia had moderate to severe aphasia. Twenty-two lived at home, three were discharged to a nursing home following the stroke. By the end of the intervention, one of these had returned home.

In the following, the findings are structured according to the main goals of assessment in this study: (1) assessment of the intervention content, structure and process and (2) assessment of the usefulness as experienced by the stroke survivors. We did not find systematic differences in the experiences recounted between patients with different physical and/or psychological challenges or between participants in the individual and group formats, except from those specified below.

Assessment of the content, structure and process of the intervention

Topics addressed

With one exception (a man with very few limitations following the stroke), the participants judged the topics introduced to be relevant to the experiences, challenges, needs and problems they encountered during the recovery and adaptation processes. Several participants highlighted the importance of addressing the psychosocial aspects of stroke recovery, stating that other rehabilitation professionals taking care of them had not specifically addressed these issues. Some suggested additional topics. The younger participants were concerned about their jobs and economic security, and they talked extensively about their challenges and worries in terms of returning to work. The intervention did not bring up this topic explicitly. Several participants also emphasised the information and support needs of their families and suggested that families be more explicitly included. Many of the participants requested more individualised factual information about stroke treatment and follow-up to help them and their family understand their condition. The following quotations represent the sentiment among the participants:

I (interviewer): What do you think about the content?

P (participant): I think it was fabulous

I: Was anything irrelevant?

P: No! The way it (was)... keep going! (Man 73 y.o., severe aphasia/ individual intervention).

I: Did the topics cover your situation?

P: They did, but there were certain things I missed, like involvement of the family. They have many unanswered questions in a situation like this, but they fall outside, so at least one information meeting for the family was important ... And then there are different issues [from patient to patient]. I do not know how clogged my blood vessel was at the time of the stroke, only how it is now. I'd like to know the change, if it is positive or negative, to try to avoid getting it once more. And the medications - what do they actually do and not? (Man, 54 y.o./ group intervention).

Work sheets

According to the planned intervention, the participants were expected to review the work sheets prior to each encounter to facilitate individualised dialogues. However, the majority had not done so. Consequently, this part of the intervention did not work as intended. Although they agreed that the topics of the work sheets were relevant, some found the work sheets difficult to understand and use on their own. Some had trouble reading them due to poor eyesight. Others had difficulties concentrating or were afraid that they would provide "incorrect answers". Some said they just could not make themselves complete the work sheets because of fatigue or simply because they could not write. Others reported that the work sheets were abstract and complex. The following quotations illustrate the participants' experiences with the work sheets:

P: The work sheets were ok to understand, but ... difficult to read and write.... The main themes were very good. It was very good that we talked about what had happened and about the future. (Man 43 y.o., aphasia/individual intervention).

P: I don't think I got that much out of the workbook. I got more out of the conversations with the others. But, then again, I am not a very theoretical person, I am not that good at expressing myself in writing. (Woman, 66 y.o./group intervention).

Those that found the work sheets helpful, explained that the work sheets helped them focus, assisted reflection and led to meaningful dialogues with the health care professionals. Even if they were not able to complete the work sheets themselves, simply examining them helped the participants think through the issues and their relevance. The following quotations illustrate this perspective:

P: [The work sheets] were good. They helped me put things into words. The illustration of the rehabilitation process as a "The Great Trial of Strength" [strenuous bicycle race of 500 km] was useful. I have brought this way of thinking about rehabilitation with me. The great trial of

strength was quite illustrative. I have travelled from Oslo to Ulven [a very short distance]. The journey has been hard, mainly uphill! (Man, 49 y.o./individual intervention).

P: The content, I think that was very good ... to think through the situation that one finds oneself in – I liked that very much.

I: Did you use the work book between the meetings?

P: Yes, I did write to prepare for the meetings ... it sort of started my thoughts. (Woman, 33 y.o., aphasia/individual intervention).

Number and timing of the dialogues

The participants differed in their opinions about the number of encounters and their timing. None thought that the intervention had too many encounters. Some felt that the timing and number of encounters was adequate and that completing the intervention after eight meetings and six months was reasonable:

P: I think ... [the intervention] lasted long enough... (Woman, 66 y.o./group intervention).

P: For me, the number of meetings was just about right. (Man 61 y.o./individual intervention).

Others, particularly the participants with aphasia, felt that the intervention was stopped too early and suggested that the follow-up time ought to be at least one year:

P: [The intervention should last] at least a year, probably two. (Man, 43 y.o., aphasia /individual intervention).

Some felt that although the timing of the meetings was alright, there were too few encounters. They suggested that the meetings should be weekly, at least in the beginning. Particularly among the participants suffering from aphasia, eight encounters were judged to be inadequate. For participants with speech difficulties, the dialogues took much longer and the topics planned for each encounter could not be covered as planned. Consequently, the number of meetings had to be increased, and the intervention prolonged. In the aphasia group, the interventions lasted approximately 10–12 months. The following quotation represents the sentiments among this group of participants:

P: The way I feel, I would have liked more time.

I: Do you mean more encounters?

P: Yes

I: How often would have been ideal for you?

P: Once a week would have been enough, I think.

I: Once a week?

P: Yes, to really master it. (Man, 53 y.o., aphasia/individual intervention).

Each individual encounter was planned to last one hour and the group encounters two hours. The majority of the individual meetings, particularly for participants without speech problems, were completed in about an hour. However, among the participants with aphasia, the time varied widely. Particularly in the early phases after the stroke, the participants tired easily due to their immense struggle in trying to express themselves. The meetings were adjusted individually depending on their stamina and ability to concentrate. The meetings with the persons with aphasia lasted between 40 minutes and 2 hours (one and a half hours on average). The group encounters lasted two hours, as planned.

Individual versus group format

The participants were generally positive about the intervention format they participated in, although they differed somewhat in what they emphasised as positive aspects. The participants receiving individual encounters highlighted the importance of their relationship with the health care professional. They stressed the importance of having the same person lead the intervention. Furthermore, they appreciated the supporting dialogues with “a committed professional knowing what they were going through” and the opportunity to discuss issues of personal significance to them:

P: To me, the program [intervention] was luck in an unlucky situation. ... That a person has listened to you and kept you under her wings, so to speak, that is good when you are trying to get back into life. (Woman, 82 y.o./individual intervention).

The participants in the group format highlighted the value of sharing experiences and exchange ideas about how to address different issues. However, at the same time, some participants felt that the group format was somewhat restrictive because the dialogues were concentrated on topics that were common between them and less on issues that were individually important:

P: I think it has been interesting, but ... the range in age was high, from those that were retired ... Whereas I am at a completely different phase of life and had a different stroke (hemorrhage). So even if the treatment is the same, I feel that I have a lot more questions. And I don't feel that I got answers to them through the project. (Man, 43 y.o./group intervention).

P: I found it very difficult in the beginning because you had to expose yourself. You had to be honest... But when this “teenager” [young participant] was able to do it ... well, it got easier for the rest of us, right? ... I think that if I hadn't had this course

[intervention], I would have felt terribly alone.
(Woman, 66 y.o./group intervention).

Experienced usefulness of the intervention

The experienced usefulness of the intervention highlighted by participants may be classified into three overall themes, as detailed below.

Being supported through a difficult time

Many participants considered the intervention to be a highly positive experience and appreciated the access to a series of supportive encounters that they did not have to request. This unconditional offer of support was described as an experience of *not being left alone* in a situation that they experienced as difficult, insecure and scary. They experienced this “going alongside” by a knowledgeable professional as an expression of someone caring for them and providing security:

P: Of course it has helped me along, just knowing you were there and that I could ... just move on. ... Things are progressing more slowly when you are not here.

I: Do you think it would be helpful with this kind of program for others in a similar situation?

P: Yes, if they get the same [program]. Exactly the same ... [getting help to understand] how the stroke affects you ... because it is quite strange, being knocked out on one side ... and then the way we have talked very well! (Man, 53 y.o., aphasia/individual intervention).

Some of the participants contrasted this positive experience of social support with experiences of feeling deserted by the traditional health services:

P: I didn't spend many days at the hospital. One day, they came and told me that I was going home. I said no, I can't go home, we need to talk about rehabilitation somewhere. They gave in that day, but the next day I was “kicked out”, and they left the responsibility for finding a rehabilitation place to the municipality. And then my GP had to help me apply ... and I had to call repeatedly to get in. ... What I liked with this program was that you followed me up and I didn't have to do a lot of work to get help”.
(Woman, 71 y.o. individual intervention).

Several participants also emphasized the importance of the health care professionals holding up a “vicarious hope” or “vision for the future”, which inspired them to keep on struggling through the difficult times. This facilitated the ‘recovery work’, when they felt tempted to give up.

Provided a chance to tell and (re)create their story

The participants valued the opportunity to tell their stories and talk through their experiences in their own words, supported by the health care provider and the structure that the work sheets provided. Some participants noted that this narrative aspect of the intervention contributed to increasing their understanding of their situation, helped them see possibilities and created opportunities for formulating realistic goals. By talking through their situation, they became more conscious of the different aspects of it. The dialogues helped clarify the issues at stake in their lives and assisted them in reflecting about the possibilities and difficulties. The invitation to tell their stories initiated reflection processes about questions and issues that they had not thought of on their own. Telling their stories also supported their efforts to integrate their experiences and move towards acceptance of the new situation, which happened when the expression of thoughts and dialogue led to reflection and the (re)negotiation of understanding, values and goals. The following quotations encapsulate these experiences:

P: Well, it forced me to think things through ... On the one hand, it was good that I had to take a stand. On the other hand – well, it wasn't exactly exhausting, but it forced me to think things through. And I have had a lot of things to think through – all along... (Man, 49 y.o./individual intervention).

Being supported in their attempts to cope with the situation

The participants struggled to cope with their new and unknown situations after the stroke. The issues they struggled with varied widely, from performing daily activities and solving practical problems to understanding and coming to terms with their own emotional reactions and those of their family, friends and colleagues. Facing different social situations within and beyond their family entailed many challenges.

The participants reported that the intervention helped them cope with their struggles. Participants in both the individual and group-based interventions emphasised that the dialogues helped them cope by clarifying what their coping challenges entailed, illuminating their coping options, supporting them as they tried different coping strategies and supporting them as they analysed unexpected situations. Some participants emphasised the importance of being supported in their own initiatives rather than being told how to manage the situation. This led to an experience of being in charge of their lives. The following quotations illustrate these experiences:

P: It has been very good to have someone push me a little – I think it has speeded me up. And then being

supported in structuring the days through the work sheet she gave me ... (Woman, 71 y.o./individual intervention).

The participants in the group-based intervention also reported that by listening to how other stroke survivors managed their situation, they learned new ways to approach different situations:

P: I always left [the meetings] a little inspired! I think it is important when a serious thing like a stroke happens, that one may exchange experiences with others who have been in the same situation.... That is what has been most important for me – to be together with people in the same situation. The strength of being in a group is that you get to share others' experiences ... I had never realised that you could get psychological problems after stroke unless I had seen one of the other participants ... I found that very enriching. (Woman, 66y.o./group intervention).

Discussion

The major findings in this study was that the participants found the content, structure and process of the psychosocial intervention relevant to their situation and that it contributed with helpful psychosocial support through the initial adjustment process. There were no systematic differences in the experiences and opinions between survivors with different physical and/or emotional challenges or participating in the individual vs. group format of the intervention. In the following we discuss the findings in more detail, relating them to existing knowledge in the field.

Evaluation of the content, structure and process of the intervention

Our findings confirm that the intervention addresses relevant, concerning issues for stroke survivors. Many of the participants specifically highlighted the importance of addressing psychosocial issues, as they experienced that the existing services did not explicitly address these. Issues of particular salience for many of the participants, particularly the younger ones, were return to work and family obligations and relationships. These are significant issues that may threaten psychosocial wellbeing and should thus receive attention during the adjustment phase following a stroke. Previous studies have found that information, emotional support, practical advice and motivational support are important components for treating stroke victims (Forster et al. 2012; Redfern et al. 2006; Ellis et al. 2010). Compared to these recommendations, our intervention primarily provided emotional support, motivational support and, to a certain degree, practical advice in coping and life skills. The intervention

did not include general information about stroke, treatment and follow-up services because we assumed that this information was available through the existing stroke services. However, several of the participants missed individualised information about their stroke to facilitate understanding of their particular situation. This is consistent with other studies on guided self determination (Zoffmann 2004).

The majority of the participants without language problems thought that the number of meetings and the length of the intervention were appropriate. However, the participants with aphasia were unable to complete the intervention within the default time frame. Instead, they required approximately 40% more time to complete the intervention. Determining the number and frequency of encounters was difficult because there is no agreement in the literature. Previous studies of effective psychosocial interventions vary widely on this issue (Burton and Gibbon 2005; Watkins et al. 2007). Based on our findings, it seems important to differentiate between persons with and without language problems when choosing the structure and process of psychosocial interventions, even if the same content is relevant to both groups. Furthermore, our findings suggest that flexibility is needed in terms of the frequency and number of encounters. Because the majority of our participants without language problems found the number of encounters to be sufficient, while some did not, we believe that the intervention should span eight meetings during the first six months as a default. However, for persons still struggling to adjust at the end of six months, additional encounters should be offered. This suggestion is in agreement with Burton and Gibbon's (Burton and Gibbon 2005) flexible approach. More research is needed to address this issue.

Regarding the use of work sheets to facilitate reflection and dialogue, the findings were inconsistent. Some found the work sheets very helpful, others found them difficult or of little use. This finding is inconsistent with previous studies in diabetes care, which found the use of tailored work sheets useful and efficient in facilitating adjustment and coping (Zoffmann 2004). There are several possible explanations for this finding. First, a stroke entails brain damage, which may affect reading, writing, concentrating and seeing. Although we had considered these consequences when designing the work sheets, emphasizing simplicity and readability, several of the participants found the work sheets difficult. Furthermore, the majority of our participants were elderly, in contrast with the younger participants in the diabetes care study. Older participants may find less benefit and more difficulty in filling in work sheets, and several of our participants expressed worries that they might fill in the sheets incorrectly, although they were repeatedly assured that there were no right or wrong answers. The participants agreed that the encounters were

helpful and that the topics introduced by the work sheets were relevant, although they missed some topics (work, family). We conclude that the work sheets have their place in the intervention as an important structuring element but that different participants might utilise them to different degrees.

Testing the intervention in individual and group formats was useful, in that the two forms generated somewhat different experiences and highlighted different challenges. The feasibility study showed that the individual format could be easily adjusted and tailored to individual needs and challenges occurring in the illness trajectory. Because of its flexibility, most participants completed the intervention, and very few missed any of the encounters. However, this is a rather costly intervention with its one-on-one encounters conducted mostly in the participants' homes. The group format is less costly and provides ample opportunities for sharing experiences with other stroke survivors. However, it is not possible to address individual needs to the same degree as in individual encounters, and the timing could not be as flexible as in the individual intervention. Therefore, participation was not as consistent, and many participants missed one or more of the meetings. These findings are in line with the conclusions drawn in recent reviews (Forster et al. 2012; Redfern et al. 2006; Ellis et al. 2010) and must be considered in the further refinement of the intervention.

Evaluation of the effective components of the intervention

The major goal of the psychosocial intervention was to promote psychosocial wellbeing by fostering understanding and the (re)creation of meaning, supporting the patient's own coping efforts and facilitating the development of new life skills. Although the feasibility design did not allow us to evaluate the effect of the intervention on psychosocial wellbeing, the findings suggest that the stroke survivors found the intervention useful. The participants reported that the intervention supported their coping efforts and that this help was needed. They struggled to cope during the first six months and did not experience dedicated assistance with psychosocial issues through the ordinary stroke follow-up services. The participants emphasised the importance of being allowed to tell their story and reflect on their experiences with a knowledgeable dialogue partner. They considered this element of the intervention to be helpful in a situation characterised by insecurity and confusion. In addition to these elements, which we assumed to be effective components (Kirkevold et al. 2012; Antonovsky 1987; Eriksson and Lindström 2005, 2006; McAdams 2009; Polkinghorne 1988; Taylor 2007; Kraus 2007; Frank 1995, 1998; Parr 2004; Shadden and Hagstrom 2007; Kagan et al. 1996; Zoffmann 2004), the participants also emphasised that being followed up and supported through their own adjustment efforts

helped maintain focus and hope as they struggled to reach their goals and resume meaningful activities.

Stroke survivor support in the community

In Norway, the municipalities are responsible for providing rehabilitation services beyond the acute phase. However, they lack the resources and specialised personnel that are available in hospital-based stroke units. Our intention was to explore whether it would be feasible to conduct an effective stroke support service from the community by giving community care personnel specific, albeit limited, training in the developed methodology. Most of the facilitators in this feasibility study were nurses, who are primary care providers in community care. Based on this study, community-based nurses may integrate this type of follow-up support as part of their responsibility. However, more research is needed to evaluate the effectiveness of this approach.

Limitations

This feasibility study had several limitations. The sample was limited, particularly in the group intervention part of the study, which may have reduced the variation of experiences and responses. However, because the inclusion criteria were wide, the sample represents a diverse group of stroke survivors in terms of age, gender, level of disability and family and work situations. The participants, including those with aphasia, provided rich descriptions of their experiences through the application of multiple methods and data triangulation. The design did not include a control group; thus preventing us from comparing the experiences of the participants to stroke survivors who did not receive the intervention. Despite these limitations, the case-oriented design and detailed qualitative data from different data sources provided detailed information about the different experiences and viewpoints of the participants.

Conclusions

This feasibility study provided initial support for the usefulness of the main elements of the psychosocial intervention and provided valuable insights into aspects that require further consideration and development.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

MK, BAB and KK were responsible for the development of the intervention. All authors participated in the data collection and data analysis. MK secured the financial support and wrote the initial draft. All authors reviewed the manuscript and contributed to the final version of the manuscript.

Authors' information

All authors are nurses with a clinical interest in stroke rehabilitation.

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Article II

RESEARCH ARTICLE

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Work-aged stroke survivors' psychosocial challenges narrated during and after participating in a dialogue-based psychosocial intervention: a feasibility study

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Abstract

Background: Studies point to the lack of psychosocial support and rehabilitation services that are adjusted to the work-aged stroke survivors' specific needs in order to promote psychosocial well-being. The aim of the study was to illuminate the psychosocial challenges work-aged participants (i.e. aged 18–67 years) thematised during and after participating a dialogue-based psychosocial intervention during the first year following a stroke.

Methods: The study was a feasibility study guided by the UK Medical Research Council Framework for developing and evaluating complex interventions. Qualitative data from in-depth interviews with fourteen stroke-survivors aged 33–66 years, researcher field notes and log notes written during the intervention were analysed applying a hermeneutic-phenomenological approach.

Results: The stroke and its consequences had a substantial impact on family and work life. Their experiences were summarised in the two themes *The threat of becoming marginalised in family life* and *The threat of becoming marginalised in work life*.

Conclusion: Life as a work-aged stroke survivor was experienced as challenging and created a threat of becoming marginalised in family and work life. The study highlights the need to understand the specific psychosocial challenges and needs facing work-aged stroke survivors' in order to promote their psychosocial well-being. More research is needed concerning specific life-span challenges amongst work-aged stroke survivors in order to further develop appropriate interventions that helps address this issue.

Keywords: Stroke, Work-aged stroke survivors, Marginalisation, Feasibility study, Complex intervention, Qualitative method, Hermeneutic-phenomenological, Rehabilitation

Background

The mean age of persons suffering from stroke in Norway is 76 years [1]. However, stroke may appear at any age [2]. It is estimated that approximately 25 percent of the stroke population is work-aged, i.e. below 65 years [3,4]. The seriousness and consequences of a stroke vary widely and may affect both physical functioning and psychosocial well-being [5]. Many stroke survivors experience emotional

difficulties, such as anxiety and depression, both early on and later in the rehabilitation process [6-8]. Cognitive challenges, fatigue, social isolation and loss of self-confidence and control are frequent [5,9-11].

Although the challenges that older and younger stroke survivors experience overlap considerably, some studies suggest specific challenges to the work-aged stroke survivors, particularly with regard to relationships within and external to the family, marriage and parental roles and financial challenges [12-15]. Amongst work-aged stroke survivors, the psychosocial factors appear to have at least as great an impact on life after stroke as the physical consequences [13,16].

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Work positively influences identity, self-esteem and psychosocial well-being. However, a limited number of stroke survivors return to work, indicating that residual stroke symptoms influence their ability to continue work as well as the ability to find new employment [17-21]. A successful return to work might have a positive impact on psychosocial well-being [19,22].

Studies point to the lack of psychosocial support, lack of information and rehabilitation services that are adjusted to the work-aged stroke survivors' specific needs [5,13,23-25]. Because of the documented need for psychosocial support after stroke, our research group conducted a feasibility study to explore the usefulness of a dialogue-based psychosocial intervention. In this paper, we focus on the experiences of the work-aged participants who were included in the intervention. The aim was to illuminate the psychosocial challenges work-aged participants thematised during and after participating a dialogue-based psychosocial intervention during the first year following a stroke. Work-aged participants are defined as stroke survivors between the ages of 18 and 67 years.

Methods

Design

This study, conducted in Norway between May 2007 and October 2008, explored the usefulness of a complex nursing intervention. It was conducted according to the principles suggested by the UK Medical Research Council Framework [26]. As part of assessing the feasibility of the intervention, we examined the work aged participants' experiences of psychosocial challenges and needs in order to refine the protocol before entering a full-scale randomised controlled trial (RCT).

The overall aim of the intervention was to promote psychosocial well-being. The intervention was planned to consist of eight one to two hour dialogue-based encounters over a six months period. The encounters focused on the psychosocial consequences of the stroke. Each meeting had a preplanned guiding topical outline, based on existing knowledge of psychosocial needs during the rehabilitation trajectory. The participants were invited to tell about the issues that were most important to them at the time and the guiding topical outline was adjusted based on the participants' individual needs. Family members were invited to take part in one or more of the intervention encounters, subject to approval by the participants. The intervention is described in detail elsewhere [27].

Recruitment

Norwegian speaking stroke survivors aged above 18 years were recruited to participate in the intervention by a designated nurse during hospitalisation or by the home

care services. They were invited to participate in the intervention if they had suffered a stroke within the last eight weeks, were medically stable, were judged to have adequate cognitive functioning and to benefit from the intervention by their physician. A speech-and-language therapist assisted in recruitment of persons with moderate to severe aphasia. Oral and written information was adjusted linguistically, and consent was obtained. A speech-and-language therapist assessed language abilities according to production and understanding of oral and written language, reading, and writing prior to inclusion.

Data collection

Background information, consisting of demographic data and medical information, were collected by the recruitment personnel.

During the intervention, the health workers who carried out the intervention wrote log notes after each encounter noting the themes addressed in the encounters, specific reactions during the encounters (if any), whether other participants (i.e. next of kin) were present and the health workers' own reflections.

Two to four weeks after conclusion of the intervention, three members of the research team interviewed the participants in-depth. All members of the research team were nurses; one was a senior lecturer and two were doctoral students. All had previous experience conducting qualitative interviews. Two had conducted qualitative interviews with stroke survivors previously, one was specially trained to conduct interviews with stroke survivors' suffering from aphasia. The principal investigator was a professor who supervised the research team during the interview processes. A speech-and-language therapist supervised the researcher interviewing the participants with aphasia.

The interviews had a guiding thematic outline, which focused on the experiences of the participants, including their present lives, their thoughts and reflections concerning their lives and psychosocial needs following the stroke. The interviews had open-ended questions as a point of departure, like "Please tell about your life at the present". Probing was used to encourage the participants to expand their descriptions related to their psychosocial well-being after participating in the intervention, for instance: "Can you tell me whether participating in the intervention has made a difference or not in relation to your well-being?" The interviews with the participants with aphasia were carefully prepared and carried out by a specially trained nurse, using the approach Supported conversations for adults with aphasia [28].

The interviews were audiotaped and the researchers wrote reflection notes after the interviews. In addition, the interviews with the participants suffering from

aphasia were video-recorded to better capture both their verbal and non-verbal expressions.

Five participants were interviewed individually in a city-based Learning and Mastery Centre, two in a conference room at a hospital, five in their homes and two in a nursing home, according to their preferences. No family members took part in the in-depth interviews.

Participants

Fourteen of the twenty-five stroke survivors who participated the feasibility study, met the inclusion criteria of being work-aged (i.e. aged 18–67 years). Eleven men and three women, aged 33 to 66 years (mean age 54.6) were included in this subset of the study. The time range between inclusion in the study and the first intervention encounter differed for practical reasons. Consequently, the time between the stroke incident and the in-depth interviews ranged from seven to ten months. For participants suffering from aphasia the intervention period was prolonged until twelve months post stroke, as they were unable to complete the intervention within the original timeframe due to their communication challenges. In these cases, the time from stroke onset to the in-depth interviews ranged from eleven to thirteen months.

Six of the participants were diagnosed with thrombosis in the right hemisphere. Four of these had paresis of the left side, one had reduced strength in the left side, and one had no visible physical symptoms. Four of the participants were initially diagnosed with a thrombosis in the left hemisphere of whom two suffered paresis on the right side. One had a slight numbness and reduced strength in the right side, while the last one had no visible physical symptoms. Three of the participants were diagnosed with a haemorrhage in the left hemisphere. One of these had paresis on the right side, one had reduced strength on the right side, while the last one had no visible physical symptoms. One participant was diagnosed with a thrombosis and haemorrhage in the left hemisphere and had paresis on the right side.

Four of the participants suffered from visual deficits. Three of the participants had neglect, while two had concentration problems and/or laps of memory. Two of the participants were initially diagnosed with mild aphasia, while six were diagnosed with moderate to severe aphasia.

The participants lived in rural and urban areas of southern Norway. Seven of the participants were married, two were cohabitants, three were divorced, and two were single. Five of the participants had minor children living at home. All of the participants lived at home prior to the stroke, and all but two lived at home at the conclusion of the intervention. Eleven of the participants were employed part-time or full-time prior to

the stroke onset, whereas the other three were unemployed or received social security benefits. Five of the participants had returned to part-time work at the conclusion of the study.

Data analysis

The analysis was conducted applying a hermeneutic-phenomenological approach and consisted of three steps [29-31].

During the first analytical step, the recorded and transcribed interviews were read carefully as a whole to get an initial and holistic impression of the participants' experiences. This step resulted in a narrative summary of the experiences of each participant. Next, the researchers' notes and the health workers' log notes were explored and new insights about the participants' experiences added to the fourteen narratives. The compiled text for each case was then read carefully as a whole to get an initial and holistic impression of the participants' experiences of psychosocial challenges and needs. This open, inductive reading suggested a naïve understanding of work-aged stroke survivors describing their lives as difficult and changed with respect to carrying out roles and responsibilities related to their family and work. We interpreted their descriptions as indications of possibly being in a marginalised situation defined as being placed on the periphery of society [32-34], in this case in the family and with regard to work. Marginalisation is related to personal identity and impacted by personal experiences and environmental factors [32]. Using this working definition, the second analytical step consisted of an inductive structural analysis of the narratives, guided by the following overall questions: What are the specific experiences and psychosocial needs of work-aged stroke survivors? Is the initial interpretive working hypothesis of possible marginalisation confirmed or disconfirmed upon further analysis?

During the structural analysis (the second analytic step) the narratives were divided into meaning units, condensed into detailed subthemes related to family and work in order to further explore the meaning of the text and to validate or invalidate the initial impression. Finally, during the third analytic step, we summarised and reflected on the inductively derived subthemes in order to develop a comprehensive understanding of the experience of being a work-aged stroke survivor. This resulted in a reformulation of the initial impression; we found that being a work-aged stroke survivor implies a threat of becoming marginalised in relation to family life and work life. During this step, the narratives were reread as a whole and reflected on in light of theory of marginalisation and the broader research literature on psychosocial aspects of stroke.

Each step of the analysis was discussed within the research group and consensus obtained before moving to the next step. An example of the analysis is shown in Table 1.

Ethics

Ethical approval was obtained from the Regional Medical Ethics Committee and the Social Science Data Service in Norway. All participants provided written, informed consent prior to being enrolled in the intervention. A verbal consent was repeated during the intervention period [35]. All participants were assured of their confidentiality and the possibility to withdraw from the study at any time without consequences, as stated in the Helsinki Declaration [36].

Results

Stroke was experienced as having a substantial impact on family and work life. *The threat of becoming marginalised in family life* and *The threat of becoming marginalised in work life* summarised the work-aged stroke survivors' experiences during the first six months following a stroke, and is further described below.

The threat of becoming marginalised in family life

The participants described challenges in terms of meeting expectations in family life following the stroke related to both the immediate and extended family, and friends. This theme is divided into the following two subthemes: *Unable to perform the caring role as before*, and *Falling out of extended family activities*.

Unable to perform the caring role as before

The struggle to participate in family life in the same manner as before the stroke raised numerous concerns. The reduced ability to collaborate with their partner in caring

for their children made them feel like they were not part of the family. Although some expressed themselves as "restored" in a physical sense, they reported a need for greater emotional and social involvement in family life than what they currently felt were the case. Cognitive difficulties, emotional distress and lack of stamina affected their level of participation in daily home activities and prevented them from meeting their own expectations and/or those of the immediate family.

One of the male participants who lived in a nursing home, but had small children at home, expressed powerlessness as a father. The parental situation caused significant worries that dominated the first weeks of his hospital stay and continued throughout the follow-up period. The consequences of a severe stroke left him unable to care for himself and his partner was reluctant to take him home because of his extensive care needs. Although he expressed an understanding of her resistance to have yet another person to care for, he struggled with being on the periphery of his family, prevented from participating in the care for his children and supporting his partner in her caring role. The inability to fulfil his responsibility in family life led to the need for professional help to care for the children during some of the weekends in order for his partner to get some relief. This caused "terrible feelings" that worsened his situation. He realised that he had to abandon or renegotiate his previous family role. As his ability to manage and influence family life was limited; his role as a father was constricted, and he lacked the ability and opportunity to fulfil his expectations and desires:

I will not be able to participate the children's life like before. Time is gone when I was able to play together with my own children. I used to be strong like a horse. Could be together with my children for hours, and then go to work without having a rest.

Table 1 Example of structural analysis process

Meaning unit	Condensation	Sub-theme	Theme
Increased need for rest and sleep, lack of memory complicate caring for own family. His need is to resume activity, to suffice in caring for those he lives together with.	A challenge to care for the family Difficult to care for the family	<i>Unable to perform the caring role as before</i>	The threat of becoming marginalised in family life
Friends were making contact, but he was too exhausted for company. He missed the social life, but felt he had to manage organising his own life first.	To participate in social gatherings is exhausting	<i>Falling out of extended family activities</i>	
Difficult to adapt to a life without working and that others told her that she not was able to return to work.	Leave work involuntary	<i>Being forced to leave work</i>	The threat of becoming marginalised in work life
A meeting at the workplace changes her expectations. The employer tells her that she is fired and that she cannot come back to work.	Fired		
Hopes to be full-time worker within the next six months. He is unsure of how he could manage return to ordinary work. The leadership position demands a lot of travelling.	Challenging to return to ordinary work	<i>Struggling to meet work expectations</i>	

Some participants expressed that their changed mood, their inability to explain their situation and the children's and/or spouse's lack of patience could be a challenging ordeal that, for some, led to family conflicts. Some families did not communicate about how their life situation was affected when a family member had suffered from a stroke. This led to broken relationships or conflicts. One father talked a lot about an on-going conflict with his son during the intervention, which caused him a lot of worries. The father's aphasia complicated their communication, resulting in misunderstandings and frustrations:

I have problems with [...] my son. Serious problems. He has not taken part in anything. Nothing has he taken part in! [Upset]. He has been angry [...] It is like an explosion.

Most of the participants highlighted the importance of information and support in order to understand the consequences of stroke and they emphasized that this was a means of helping both the participant and the family move on with life in the best possible way. The family's lack of information concerning the impact of stroke contributed to the participants' difficulties with caring for their children:

They are looking at my shuffling walk, [and it is] not always easy to get understanding for all situations. I can't keep up, can't come along to everything or join everything. It's not a problem to me, but it's not always easy to get understanding for [the fact] that you need to rest and are not able to keep up all the time. They need information.

The participants spent much time considering their inability to talk with their children about how symptoms influenced everyday life; their inability to support their children's activities; or worries about their children's inability to concentrate on their schoolwork. One father expressed his despair of the lack of concern by the children's teachers and the school nurse:

Nobody has asked my children. The teachers haven't asked my children. They know about my stroke. [...] It's a pity. It's incredible [...] She [the daughter] was [so scared] sent me sms every second hour [just saying] Hi! [to check if I was ok].

The inability to keep up the traditional parent role was also underscored by the fact that for two of the stroke survivors, their sons had to support them in carrying out basic mathematics. This demonstrated that not only were their roles constricted, but their roles were reversed. Contrary to their expectation of the opposite, the fathers experienced

having to be cared for by their children. The fathers wanted to support their children, but were unable to manage because of cognitive difficulties. They found the situation difficult to explain to their children:

I had anxiety talking with my kids about what had happened. I need energy to be capable to talk with them. I had enough with myself, so I didn't manage, or I didn't dare. I had anxiety.

Some participants expressed how their lack of understanding influenced their motivation to meet the challenges and expressed the need to have someone to talk to in order to overcome the frustration of not being sufficiently motivated:

I had a lot of questions about my own life. Why am I so tired? [...] What is going on in my brain? [...] So, I could understand myself in terms of [...] [having suffered a stroke] and in a way get the answer of why I was changing [...] emotionally.

Falling out of extended family activities

Living in a family implies social gatherings beyond the immediate family. The extended family may include other relatives and/or close friends. The participants stated that it was challenging to participate in gatherings in the same manner that they did before the stroke. One of the participants was told by his wife:

[...] that the in-laws wondered if I was outside or if I participated. I was sitting quietly and calmly in a corner, far away from the centre of activities.

During a birthday party, the screaming children and the laughing families made him even more exhausted and tired. He participated in the gathering as a passive spectator, marginalising himself by withdrawing from the centre of activities. He preferred being at the periphery to manage the situation.

Cognitive challenges, including a lack of stamina, concentration problems and tiredness or exhaustion affected ordinary leisure activities and made it difficult for the participants to pursue interests and attend leisure gatherings. The situation resulted in activity avoidance to prevent unbearable situations of being exhausted afterwards. However, the fear of losing friends because of not participating was challenging:

[...] Now I'm mostly together with my family. Before I was probably mostly together with friends. My circle of friends has decreased. In the beginning I didn't want to [withdraw], I wanted to try to keep on just like before, but it [participating in social life] doesn't work.

The inability to drive a car also contributed to the experience of social isolation. Several participants struggled with whether they would be able to drive again, realising that the inability to drive kept them from participating in life as they had before the stroke onset. However, getting the driver's licence back did not necessarily solve the problem. Despite obtaining a renewed driver's license, a woman explained:

Somehow, when I got it [driver's license] back [...] I was afraid of driving.

The inability to drive caused stroke survivors to depend on others which further complicated their ability to participate and contribute socially on equal terms. Remaining at home or in a nursing home, involuntarily or as a voluntary safety measure, was like an environmental barrier that strained life and isolated most of these stroke survivors from an ordinary social life. Their new life evolved, in many ways, at the margins of the active and busy lives of their family and friends.

The threat of becoming marginalised in work life

The theme *The threat of becoming marginalised in work life* reveals how the stroke influenced work life and how the participants experienced this as employees. These experiences are captured by the following two subthemes: *Being forced to leave work* and *Struggling to meet work expectations*.

Being forced to leave work

Although some of the participants expected to return to work, some were forced to leave work because of the consequences of stroke. A newly graduated woman had her stroke when she was newly employed. In a planned meeting at the conclusion of the rehabilitation process, this woman, who suffered aphasia, was called to meet her employer. In her mind, the purpose of the meeting was to plan her return to work. Instead, she was dismissed from the job, which stunned and upset her, because continuing in her newly acquired job had been a major goal for her rehabilitation. She received no warning and was not prepared for being fired. Struggling to express her chock and despair, due to her language problems, the participant expressed how this event disrupted her self-confidence and identity. Throughout the intervention period, she returned to this situation and struggled to receive help in order to fight her employer and get her job back.

A female participant close to retirement age wished to return to work, but experienced that health care professionals decided that she should retire. She found the decision difficult to accept and experienced that an important part of her adult life and her day-to-day experiences had completely changed:

I liked my colleagues and everything that happened. [Now, after retirement] you, you, just get up and only [do nothing] [...].

Her social life and work life had been interrupted, and she felt marginalised and disempowered.

Participants with children at home, who in this study were men only, were preoccupied with their roles as breadwinners. The financial responsibility highlighted the importance of returning to work. The informants spoke about *when* they would go back to work, their hopes of managing work life after the stroke, the struggle to imagine what would happen if they were unable to return to work and the threat of becoming impoverished in the future.

Struggling to meet work expectations

As the previous theme underscored, the consequences of stroke complicated returning to work. However, two of the participants had employers who arranged the work environment to accommodate continued employment by protecting them from noise, allowing for flexibility and creating rest periods during the day. One of the participant's boss had suffered from a stroke himself and understood the need for facilitating a post-stroke-friendly work place. The health worker's log note illuminated the situation:

He [...] works two days a week now. [...] Is very happy about that. [...] He has to ask his doctor for a new sick leave. Hopes he can work 60% from next month. It is okay for the employer. It is going well to communicate with colleagues. Feels included and taken care of.

One of the male participants, who had been on sick leave for a long time before the stroke and had not worked full-time for three years, was planning to return to work and hoped to be a full-time worker within the next six months. However, he was unsure of how he could cope with the working situation. He said it would be challenging to return to ordinary work as a manager because of the difficulty of working without becoming exhausted. Additionally, the leadership position demanded his travelling to visit customers, which he felt would be very difficult for him. He realised that his position had to change. His cognitive and physical impairment affected his self-esteem, which left him in a marginalised position that made it difficult for him to meet his work life expectations.

Another participant who returned to half-time work during the intervention struggled with whether he could work full-time without becoming exhausted. He described some uncomfortable experiences when his employer questioned his ability to return to work:

They are asking me at work: When do you think you will start to work a hundred percent again? [...] I can't say anything about that. I can't be specific.

Further on, one of the stroke survivors experienced a situation in which his colleague, who was temporarily acting in his position as day-to-day head of the company, was collecting information concerning his workday performance in order to have him dismissed:

I can't think of it. He [the employer] wouldn't give me new clients. I don't understand that he claims that I don't manage. I'm going to convince him that I manage!

The employer's willingness to maintain income or avoid a salary reduction which was the case to two of the stroke survivors released them from economic troubles. Being marginalised in terms of performing usual work roles left some participants in a challenging financial position, and caused emotional distress. They contemplated whether it would ever be possible to resume regular work. The goal was to continue being the primary wage earner to avoid impoverishing the family.

Discussion

Overall, this study suggests that work-aged stroke survivors experience substantial threats of becoming marginalised, both in family and work life. To the best of our knowledge, work-aged stroke survivors' experiences of threats of marginalisation have been poorly explored and discussed in the literature.

Marginalisation can lead to an experience of becoming "invisible" compared to those who find themselves in the centre of events, which in turn causes negative consequences that threaten health and psychosocial well-being [32]. Throughout life, multiple sources of marginalisation may occur, influencing one's personal sense of worth [32,37]. The social course of the marginalisation process can lead to role constriction and inability to fulfil various social functions, delegitimation and a lack of validation as a person, and being relegated to the position of being "sick", impoverished and socially isolated [38]. This study confirms that role constrictions can negatively affect stroke survivors. Suffering from invisible symptoms, as many of the study participants did, might increase delegitimation and create a threat of marginalisation as family and friends have difficulties understanding or recognizing these symptoms and the problems and consequences they create [13,39].

All participants experienced a reduced ability to maintain the roles of parent, partner and breadwinner. These findings differ from and extend those of Röding et al. [13] who found that challenges related to caring for

children and housework were specific to female stroke survivors. None of the women in this study had children living at home; thus, our data cannot confirm gender differences with respect to the caring role. However, our findings suggest that the men did experience marginalisation in their roles as fathers of small children and teenagers. This outcome might be a result of recent changes in caring roles in Norway in which mothers and fathers have more equal roles in caring for children. Similar trends are seen elsewhere [40]. The men also expressed economic concerns and worried about their ability to take care of their family economically. This is consistent with the findings of Röding et al. [13].

Our findings suggest that challenges related to work life may be experienced as a threat to identity affecting psychosocial well-being. This is the case even for those who are near retirement. The two women in this study, who had full-time work prior to their stroke, were told by others that they could not continue to work. According to Ahlgren and Hammarström [41], women are more likely to have decisions made for them during rehabilitation than men. Involving the stroke survivor, irrespective of gender and age, in decisions concerning leaving work appears to be essential because both women and men strongly identify life with work, and consequently experience leaving work as disrupting [18,40]. Physical dysfunction should not affect an individual's opportunity to make decisions [11]. Being uninvolved could contribute negatively to psychosocial well-being by making life after a stroke more challenging and by threatening one's right to self-determination and empowerment.

In this study, marginalisation was not an explicit theme introduced by the intervention. However, the flexible outline of the intervention permitted discussing the participants' own needs and challenges, which resulted in dialogues about a number of issues related to marginalisation in their lives. This study revealed the importance of rehabilitation professionals being aware of the threat of marginalisation that arises when work-aged stroke survivors struggle to meet family and work life responsibilities and expectations. Such awareness may likely increase the ability of health workers to help work-aged survivors manage the psychosocial challenges after a stroke. Knowing that the consequences of stroke can be long lasting [42] and lead to marginalisation, our study suggests that an individualised, dialogue-based intervention that invites stroke survivors to talk about their family and work life could be a positive contribution to enhancing psychosocial well-being [43-45]. In contrast, the lack of opportunities to talk about experiences and challenges following a stroke may threaten psychosocial well-being. However, further research is needed to evaluate the effect of such an intervention.

The threat of becoming marginalised identified in this study does not signify that all work-aged people living with stroke will be marginalised. However, it is important that health care professionals are aware of the threat of becoming marginalised. Although it might not necessarily be helpful to stroke survivors to be introduced for the concept of marginalisation, especially early in the rehabilitation process, using the concept as a professional, sensitising tool, which points to challenges that often escape the attention of health care professionals, might be useful. The most pertinent approach, according to our findings, is to encourage and support the stroke survivors' innate ability to narrate their experiences and new situation.

This study, which was part of a feasibility and piloting stage to prepare for a randomised study, is consistent with the development of complex interventions suggested by the UK Medical Research Council [26]. This framework recommends the feasibility to be assessed before proceeding to a full trial. A feasibility evaluation will maximise the possibility of identifying effective components and securing the necessary development of the intervention before launching a RCT. The issues uncovered in this study, will assist us in the further development of the intervention in order to address the needs of work-aged survivors.

Limitations

Several standardised instruments, measuring quality of life, depression, anxiety and psychosocial well-being, were tested in the feasibility study for their appropriateness in a RCT. However, because not all participants were able to complete them, they are not included in this qualitative evaluation of the intervention study. We did not include standardised instruments for stroke severity, physical and cognitive functioning and personality, but relied on the responsible clinicians' descriptions of the participants at the time of inclusion. This is a limitation in this study and will be changed in the follow-up RCT.

The health workers' log notes differed with respect to the descriptions of the themes addressed in the encounters, specific reactions during the encounters and the health workers' own reflections. However, the triangulation of different data collection methods that were utilised assured us that we had rich descriptions of the participants' experiences.

The sample size of fourteen participants is limited and our participants do not necessarily represent the general population of work-aged stroke survivors. Nevertheless we believe that our findings are relevant for many work-aged stroke survivors, as they are consistent with and extend other qualitative studies.

Validation was promoted by having several researchers performing the analysis and by maintaining open and continuous discussions within the research group in order to reach consensus about the findings.

Conclusion

Life as a work-aged stroke survivor was experienced as challenging and created a risk of becoming marginalised in family and work life. The study highlights the need to understand the experience of becoming marginalised in order to promote work-aged stroke survivors' psychosocial well-being. More research is needed concerning specific life-span challenges amongst work-aged stroke survivors in order to further develop appropriate interventions that address this issue.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

RM, MK, BAB and KK were responsible for the study conception and design, and data analysis. RM and MK were responsible for the manuscript preparation. All authors contributed to the critical revisions of the manuscript, read and approved the final manuscript.

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Article III

Research Article

Younger Stroke Survivors' Experiences of Family Life in a Long-Term Perspective: A Narrative Hermeneutic Phenomenological Study

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The psychosocial consequences following a stroke are known to be challenging, influencing the stroke survivors' ability to participate in and carry out the taken-for-granted roles and activities in family life. This study explored how living with the consequences of stroke impacted on family life in the late recovery phase, that is, six months or more after stroke onset. Twenty-two stroke survivors aged 20–61 years were interviewed in-depth six months to nine years after stroke onset. The interviews were analyzed applying a narrative, hermeneutic phenomenological approach. The findings revealed challenges that varied with time, from an initial struggle to suffice in and balance the relationships and roles within the family early after the stroke, towards a more resigned attitude later on in the stroke trajectory. The struggles are summarized in two main themes: "struggling to reenter the family" and "screaming for acceptance." Nonestablished people living with stroke and stroke survivors in parental roles seem to be particularly vulnerable. Being provided with opportunities to narrate their experiences to interested and qualified persons outside the home context might be helpful to prevent psychosocial problems.

1. Introduction

A number of studies suggest that suffering from a stroke at a young age (i.e., younger than 67 years old) may impact significantly on family relationships and functioning [1–9]. This is related to the fact that a stroke usually leads to long-lasting consequences that influence the stroke survivor's abilities to carry out family roles and engage in family relations in the same manner as before the stroke [2, 9, 10]. Among young stroke survivors, these consequences are frequently related to psychological challenges, such as loss of control and self-efficacy, dependency, feelings of isolation, or loss of self as previously known [3, 11–14]. In addition, invisible symptoms, such as memory loss, concentration problems, fatigue, and neglect, may be particularly challenging and

frustrating, not only to the young stroke survivors, but to their families as well [1, 2, 15].

Today's families vary greatly in composition, functioning, and the roles and responsibilities they are expected to address, depending on the cultural and social context. Family processes and family roles are influenced by a number of factors, including genetic heritage, behaviours, attitudes, and expectations as well as developmental life cycle transitions, unpredictable factors, and historical events [16, 17].

Despite a great variation in family patterns, the family life cycle seems to have some universal characteristics, at least within western cultures [16, 17]. During the initial adult phase, the single young adult period, the focus is on independence and emancipation as the young adult separates from the family of origin by leaving home and developing

intimate peer relationships. Personal goals such as establishing one's identity, assuming emotional and financial responsibility, working, studying, and committing to a career path dominate the young adult's life. Thus, turning to parents or other family members for advice may be challenging [16, 18]. Nevertheless, following a stroke, the younger stroke survivors have been found to increase dependency on their parents [19].

The midphase of adult life is most often focused on forming a partnership, getting married, and becoming parents. Life tasks such as raising children, performing household tasks, launching a career, and engaging in financial commitments are comprehensive and long lasting. Individuals in this phase form new bonds, must face their own children's independence, and later address their parents' frailty [16]. The negotiating of different roles during this phase is traditionally viewed as one of the most difficult transitions [18]. Studies point to altered relationships between stroke survivors and their partners during this phase [2, 6, 9, 12, 19–21]. Even a minor stroke may negatively impact marital relationships [22] and possibly result in disrupted marriages [5, 9, 19]. However, younger marriages seem to suffer more from broken relationships than do long-lasting relationships because of the ability of those in longer-lasting marriages to rearrange and adjust to the changes brought about after a stroke [9, 19].

The parent role is psychologically bonding, influencing the social balance between work, friends, siblings, and parents [16]; thus, adapting the parental role after a stroke has been found to be challenging [1, 4, 7, 9, 19]. Being separated from children over time was found to have a negative impact, particularly for single mothers [9]. Female stroke survivors have expressed concern about their roles as mothers and housewives [1], while both women and men worry about the economic situation of the family [1, 23]. Studies have also underlined that men's quality of life was negatively influenced when they experienced shortcomings in terms of being able to protect their family [20] or when living alone [23].

Parents at midlife develop adult relationships with their grown children, in-laws and grandchildren, while also dealing with the disabilities and death of their aging parents. During this "empty nest" period, children home leaving requires fewer parenting commitments and, to most, results in a more fortunate economic situation for the parents. To some extent, this phase is a welcome and positive one, allowing the parents to explore new arenas and new roles; others, however, find this new phase of their lives to be empty and meaningless [16].

Although friendships tend to be more temporal than family ties [24], friends, neighbours, and extended family may often serve as a resource to the immediate family during both positive and troubled times [16]. Social interactions within and outside the immediate family are considered critical for those trying to reintegrate into the community [4, 5, 12]. Friendships are often affected [1, 10, 15, 21], and the loss of friends can be a traumatic experience [21], while the opportunity to establish both new intimate relationships

and new friendships has been found to be quite limited after an acquired brain injury [15, 21].

2. Aim and Research Question

Despite the existing knowledge of how the long-lasting impacts challenge the daily lives of stroke survivors under the age of 67 years [2, 10, 15, 25], in-depth research on how a stroke impacts on the family life of the stroke survivor over an extended period of time is still limited. Knowing that family life is a process that may be filled with various challenges [16–18], it is pertinent to explore how living with a stroke influences family life during the young adult phase, the mid-phase, and the "empty nest" phase, respectively, from the stroke survivors' point of view. Such knowledge will make it easier to provide adequate support and guidance following a stroke. Consequently, the aim of this study was to gain a deeper understanding of how a stroke impacts on family life six months or more after the stroke, as experienced by young stroke survivors aged between 18 and 67 years. The following research question was asked: how do stroke survivors aged between 18 and 67 years experience their roles and interactions within the family six months or more after suffering a stroke?

3. Research Methodology

The study had an exploratory design and applied a qualitative, hermeneutic phenomenological approach. The hermeneutic phenomenological method is appropriate to understand the meaning of lived experiences [26, 27] and was therefore chosen to explore younger stroke survivors' experiences of family life.

3.1. Sample. This study was carried out in Norway. Most young stroke survivors are discharged from the health services within a few weeks or months after stroke. After discharge, the stroke survivors are difficult to identify, thus it was necessary to recruit participants by using a convenience sampling method [28]. The main strategy of recruitment was to place a notice on the website of the Norwegian Stroke Foundation inviting Norwegian speaking adults between the ages of 18 and 67 years who had suffered a stroke to participate in a qualitative interview study. Additionally, some stroke survivors were asked by acquaintances if they were willing to participate in the study. Although we used a convenience sampling strategy, we aimed to recruit a wide variety of participants with respect to age, gender, social status, and time since stroke onset.

Recruitment continued until the information obtained in the interviews was determined to provide no new information. Of the 23 stroke survivors recruited for the study, three were recruited by acquaintances; the others responded to the announcement on the website. One participant did not sign the written consent form after two reminders and was therefore excluded from the study.

3.2. The Participants. Twenty two participants (15 men and 7 women) aged between 20 and 61 years (mean age 44.8 years) who lived in urban and rural areas in the southern part of Norway gave their consent to participate in the study. The time since stroke onset ranged between six months and nine years. Despite the wide range of time since stroke onset, we determined all of these stroke survivors to be of interest, allowing us to obtain more detailed knowledge about living life with the aftereffects of a stroke during the semistable phase, which is defined as more than six months after stroke [29].

All but one of the participants were initially diagnosed with occlusion or haemorrhage of an artery in the left or right hemisphere of the brain. The one exception was diagnosed with a subarachnoid haemorrhage. When interviewed, most of the participants still suffered from a variety of symptoms such as upper and lower limb weakness/paresis, spasticity, cognitive impairments such as lapse of memory, concentration impairment, neglect, and aphasia.

The participants were divided into three social groups, inspired by the Family Life Circle Framework [16] as follows: (1) young nonestablished participants, (2) participants living together with family, that is, from babies to teenagers, with or without a partner, and (3) participants without children at home, with or without a partner.

Two of the participants (aged 20 and 27) in group one were students and single and were forced to discontinue their studies after stroke onset. When the interview took place, one of them tried to follow an education course without success, while the other one had not been able to return to the university to continue studies. One of the male participants, aged 25, had a girlfriend and had recommenced studies. A single male, aged 32, who was working prior to stroke onset, was on social security benefits four years after stroke onset. All but one of participants from the first social group lived on their own: the female participant lived with her original family.

The ages of the participants in the second social group ranged from 32 to 61 years. Six were married, one was a cohabitant, one was divorced, and one was separated. The numbers of children living at home ranged from one to three, and they aged between 1 and 18 years. Among this group, three had returned to fulltime work, two were still on sick leave, and four were receiving social security benefits.

The oldest participant (aged 60) in group three (aged 48 to 60) was married and working part-time, one participant was working fulltime, and the other seven were receiving social security benefits. Three were single, two were divorced, and three were married.

Some of the participants from groups two and three had grandchildren. For further details, see Table 1.

All the participants lived in their own homes. One of the participants in group two, and one in group three, needed assistance with activities of daily living.

3.3. Data Collection Method. In-depth interviewing is an acknowledged method to explore experiences within qualitative research. The interviews gain access to participants'

narratives, opening up the meaning of their lived world [26]. Thus, interviewing was the selected strategy to obtain data.

The interviews, carried out by the main author, lasted between 48 and 120 minutes and were conducted between January 2009 and April 2010. Twelve of the interviews took place in the stroke survivors' homes, seven in a learning and mastery centre, one in the stroke survivor's place of work, one in a café, and one in a hotel (for practical reasons).

A thematic outline of open-ended questions was used to guide the interviews [27], focusing on the experiences of living a life after stroke. The experiences of what happened at the onset of stroke and experiences of the present situation were initially inquired about with thematic questions. Probing was used to encourage the participants to expand their responses related to the family context.

3.4. Data Analysis Method. The hermeneutic phenomenological analysis was guided by Ricoeur's narrative interpretative theory [30] and conducted in three main interpretative steps. During the first step, all recorded and transcribed interviews were read several times to gain a preliminary "naïve" understanding of the content. The events and actions expressed during the interviews were then summarised into 22 "thumbnail portraits" that captured the plots of the participants' narratives [31]. A first interpretation of the experiences of the stroke survivor's family life was then formulated. During the second step, that is, the structural analysis, the different aspects of the experiences of the family situations expressed in the narratives were explicated by dividing the interview texts into meaning units and developing initial subthemes and themes. This expanded the interpretation of the plot line presented in the thumbnail portraits and facilitated a more thorough comprehension [30] of the experiences of a stroke survivor living within a family context. During the third step, the interpretation was further challenged, and the meaning was examined up against family theory. Accordingly, the interpretation was adjusted several times, and the texts were discussed, written, and rewritten, taking the context of the three different social groups into account. In the third step, the critical interpretation, the researchers further challenged the analysis and verified the most significant interpretations by comparing and contrasting the themes and subthemes in order to render a more comprehensive understanding of the family experiences of living after stroke for individuals between the ages of 18 and 67. The comprehensive understanding was verified by returning to the original narratives in order to check that the interpretation adequately reflected the experiences of the participants. Direct quotes from the narratives are used to illustrate the interpretation.

3.5. Ethical Considerations. All participants were provided verbal information prior to being given written information about the study, and confidentiality was ensured. They were also informed that they could withdraw from the study at any time without consequences, as stated in the Helsinki Declaration [32]. The participants signed and returned an

TABLE 1: Selected participant characteristics.

(a) Social group 1: Young non-established participants

Sex	Age	Consequences of stroke	Time since stroke onset	Civil status	No. of children at home
Male	32	Subarachnoid hemorrhage. Concentration and memory affected.	4 years	Single	0
Male	27	Thrombosis left hemisphere. Hemiplegia right side. Aphasia. Concentration and memory affected.	3 years	Single	0
Male	25	Hemorrhage cerebellum. Slight visually impaired.	4 years	Single	0
Female	20	Thrombosis right hemisphere. Hemiplegia left side	1 year	Single	0

4 of 22 (1 woman, 3 men).

(b) Social group 2: Participants living together with family, that is, from babies to teenagers, with or without a partner

Sex	Age	Consequences of stroke	Time since stroke onset	Civil status	Age of children at home
Female	46	Emboli right hemisphere. Visually impaired. Aphasia. Concentration and memory affected.	7 months	Separated	6 and 11 years
Male	61	Hemorrhage right hemisphere. Hemiplegia left side.	4 years	Married	16 years
Female	38	Hemorrhage right hemisphere. Concentration and memory affected.	4 years	Divorced	13 and 18 years
Female	38	Thrombosis left hemisphere. Visually impaired. Apraxia. Aphasia. Concentration and memory affected.	6 years	Cohabitant	2 years
Male	32	Emboli right hemisphere and cerebellum. Concentration and memory affected.	1,5 year	Married	1 and 3 years
Male	50	Thrombosis right hemisphere. Aphasia.	3,5 years	Married	13 and 18 years
Male	43	Thrombosis right hemisphere. Hemiplegia left side. Memory affected. Epilepsy.	9 years	Married	12, 14 and 15 years
Male	38	Hemorrhage right hemisphere. Hemiplegia left side. Epilepsy	4,5 years	Married	4 years
Male	52	Thrombosis cerebellum. Numbness right hand.	6 months	Married	14 and 16 years

9 of 22 (3 women, 6 men).

(c) Social group 3: Participants without children at home, with or without a partner

Sex	Age	Consequences of stroke	Time since stroke onset	Civil status	No. of children at home
Male	49	Hemorrhage cerebellum. Reduced strength left side. Epilepsy	3 years	Married	0 ¹
Male	54	Hemorrhage right hemisphere. Concentration and memory affected.	1,5 year	Married	0 ¹
Female	55	Thrombosis left hemisphere. Concentration affected.	2,5 years	Divorced	0
Male	60	Thrombosis right hemisphere. Hemiplegia left side. Neglect. Concentration affected.	4,5 years	Married	0

(c) Continued.

Sex	Age	Consequences of stroke	Time since stroke onset	Civil status	No. of children at home
Female	48	Hemorrhage right hemisphere. Hemiplegia left side.	6 years	Single	0
Male	54	Not specified.	8 years	Single	0
Male	56	Hemorrhage right hemisphere. Concentration and memory affected.	9 years	Married	0
Female	58	Thrombosis right and left hemisphere. Neglect. Concentration affected.	1,5 year	Divorced	0
Male	49	Thrombosis right hemisphere.	3,5 year	Single	0

9 of 22 (3 women, 6 men).

¹This participant had an adult son who lived at home.

informed consent form to the researcher. After giving consent, the participants were contacted, and an appointment for the interview was scheduled.

The project was approved by the Regional Medical Ethics Committee (REK) (Project number: 2.2007.37) and the Social Science Data Service in Norway (Project number: 16369).

4. Results

The stroke survivors participating in this study experienced their present lives in light of their life prior to stroke onset and a longing for a meaningful life in the future. The plotline of the narratives highlighted that challenges within the family changed over time. From an initial struggle for normalcy and balance in the relationships within the family when returning home, the process shifted over time to a more resigned attitude. The challenges they experienced are summarised in two main themes: “struggling to reenter the family” and “screaming for acceptance.”

4.1. Struggling to Reenter the Family. This theme reflects the initial struggle to reestablish life as it was before stroke onset with respect to fulfilling family roles. It became obvious that the stroke influenced the participants’ abilities to meet family expectations, and the analysis revealed that the participants struggled to reestablish their role identities, which is highlighted in the subtheme “facing the shortcomings.” The second subtheme, “the need for self-protection,” revealed that the stroke survivors need to protect themselves when facing their inability to participate sufficiently in family life and meet family demands. The situation called for an option of retreat to “survive” their new life of living with stroke.

4.1.1. Facing the Shortcomings. It was difficult for the participants to realise that they were less able to care for others, devote attention to others, or sufficiently engage in or carry out normal life tasks within the family. Facing this shortcoming influenced their identity, as they transformed from an independent, active, and participating individual

to a person who is dependent on support from partners, children and/or parents:

Yes, he [the cohabitant] is just amazing. What he does for me [...] he is doing everything [...] so incredible, that he does such things. But you feel yourself that it's not right. You really want to repay with something. It should be others coming here and do my part of the housework, so we could have some more time to be sweethearts. [...] You get very dependent and simultaneously you don't want to be so dependent that others take your role. [...] I think he is worn out (woman 38, six years after stroke).

Parenting children or becoming parents close to the time of stroke onset brought even more challenges to the parenting role. Becoming parents is usually a positive life transition. However, parenting is a comprehensive activity that requires one to be able to fulfil myriad parental tasks that can be interrupted when one is unable to meet the expectations. A male aged 32 had his second child during the acute phase of the stroke. He expressed his struggle with this situation one and a half years after stroke:

You are supposed to say that it was great [to have a new child] and it is. But others have told me that, “Now that you are at home, you can use your time to be together with your new son”. I couldn't do it. I've been at home for one year, but I've been absent-minded. [...] So I didn't experience it [the birth of the new child] as something great at all. [...] I would prefer another situation. I've stayed home for one year, but I haven't managed being there. [...] It has cost her [my wife] something too, having a new-born and a two-year-old, that she has to practically care for alone.

Emotional and cognitive changes such as being short-tempered, suffering memory loss, or experiencing slow thinking were expressed as challenges in parenting and the partner role. Situations that are normally considered manageable were described as difficult to overcome both among new and long-term stroke survivors. One of the fathers, aged

43, expressed the impact of a stroke on vulnerability nine years after stroke:

At the beginning, with the kids, it was a problem that I was short-tempered. [...] I got angry for nothing. I grew better [at managing it]. However, when this was under control, the teenage period started and new challenges arose. Then I was suddenly "too slow" and "I don't hear and I don't understand" [laughing]. [...] I don't think I'm thinking fast enough. [...] If I don't hear at once, forget it! [...] It's difficult to differentiate how it would have been if I was healthy [...] I've been talking to other parents of teenagers that say that it is just like that for them as well. So, on this point I'm not sure. We stroke sufferers are probably especially sensitive to these things.

The established "behavioural standards" (i.e., the way things were generally carried out in the family) within the families continued, despite the fact that one of the family members is suffering from a stroke. The expectations of teenagers' participation in the household tasks did not seem to alter, although they were required to assist their parents with stroke. The single-parent families' vulnerability was apparent, as there was no other adult to share in the parenting responsibilities. Thus, the responsibility to care for children could result in a guilty conscience or in the sacrificing of the stroke survivor's personal needs:

Well, it becomes a little too much sometimes. [...] Now after she [the daughter aged 18] got pregnant and had a baby I feel that I don't manage to follow up the thirteen-year-old [daughter]. [...] She [oldest daughter] is so young and [...] needs help [...] but I'm becoming exhausted [...]. And then there are so many thoughts that wear me out (woman 38, four years after stroke).

However, the established family roles could change as a result of the stroke survivor's inability to continue the former "executive roles" (i.e., carrying out the activities and responsibilities to solve designated tasks in the family). The involuntary role as a home worker was expressed as frustrating and uncomfortable for both women and men. In the narratives, the informants expressed that others were talking about how they just stayed at home and were not participating in society as expected. These worries were especially apparent among those stroke survivors struggling with invisible symptoms.

Some of the participants had reconciled themselves to their new life following the stroke. They described their roles in staying at homes during the daytime as satisfactory. The contact and dialogues with family and friends contributed to making the situation tolerable. The years spent at home raising the children and being the principal home worker also had positive factors compared to being the traditional breadwinner. A nonbusy life offered the stroke survivor the opportunity to make new choices that placed greater emphasis on family life and home care combined with the

possibility to take better care of the children. One father whose children were aged two to five years at stroke onset stated the following:

[To be at home] has been positive. [...] Not all fathers have that opportunity. I've had the opportunity to be there for my kids, pick them up at school and make dinner. [...] That's somehow the great, positive part of this (male 43, nine years after stroke).

4.1.2. The Need for Self-Protection. Although a busy family life still demanded participation, fulfilling the expected roles was hard to manage and called for a retreat from participating in activities inside and outside the family. The suffering associated with not being able to fulfil the family role was expressed as a bodily pain:

A lot has happened to you. [...] Emotionally, if I get into situations where I discuss or if there is a quarrel or discussion or something like that, I often don't manage to talk at all. [...] I burst into tears, and that can happen both when I'm sad and happy. [...] It's not a normal cry, [...] but it is like something cracks inside you. And you lose much of your self-control. [...] It is difficult. [...] Because when she [wife] is irritated, she feels that I utilize the crying and the emotions as a means for sympathy. [...] She says my behaviour is different. That I'm slower, that I don't perceive [or] hear as well as before. I'm not present like before. [...] [It is hard] because I don't wish to defend myself, I don't wish to have changed. I wish to be the one I was. I wish to be myself. And that she experiences this, is sad (man, 50, three and a half years after stroke).

Withdrawing seemed the best way to "survive" and avoid the questions when living alone. The single participants talked about their choices with respect to staying alone, being able to avoid questions from others, and being able to protect themselves from situations that may negatively influence their self-esteem. Being single and independent resulted in fewer commitments to fulfil family roles or student roles. Accordingly, these participants were able to isolate themselves from having to give reasons for not participating. One male participant stated: "You get some warning to not immerse yourself, correct? I think of that sometimes, that I'm there. That I'm not out on something. So [...] I've something to do there" (man, 49, three and a half year after stroke).

The participants with adult children also discussed the opportunity to withdraw from participating in extended family activities. Being forced into a self-protective role was experienced as doubly cumbersome. On the one hand, the survivors felt vulnerable in situations where they could not fully participate as desired, while, on the other hand, they were frustrated because they struggled to participate. Not being able to fulfil the role of grandparent was expressed as a sorrow and a loss. Accordingly, the struggle of not

being able to properly relieve their grandchildren's parents was expressed as a shame:

I don't think I've been lucky. I have two grandchildren aged five and three. I'd imagined having the grandchildren here. [...] But after two hours, I'm completely exhausted because [the oldest] talks all the time. [...] So I am not able to be what I wished to be, a real grandma. That is terrible. [...] And you would like to be a mum, you should not be a suffering patient either. [...] I have at least tried to explain without too much complaining that I don't manage being a babysitter the way I wished, and I can't be grandma the way I wish. But, as they say, [...] you are the grandma you can be, and that's enough [crying] (woman, 55, two and a half years after stroke).

However, being together with grandchildren was perceived as a meaningful experience when nonbinding and sociable.

The single nonworking or nonstudying participants stayed in their homes more than desirable and described their days as boring. They missed their friends and ruminated about their absence, while simultaneously expressing an understanding that their friends and associates were occupied with their own day-to-day-activities. However, one of the single participants, who had recently found a girlfriend some months prior, viewed his situation as satisfying. He explained that while his social contacts had changed, it was a conscious choice. He had made a decision to prioritise focusing on his work during the week-days and being with his girlfriend during the week-ends in the period before his girlfriend moved in with him.

The stroke survivors in parenting roles expressed that their day-to-day challenges at home demanded their presence. They viewed their lack of extended social relationships as temporary because their current tasks demanded that they care for their children. They expressed less ability to choose a self-protecting life style because of their own and their families' expectations that they participate and engage actively in family life. Accordingly, they felt they were unable to find the leisure time necessary to recover. They described their lives as busy, which is opposite to that of those stroke survivors not living in an immediate family. The family expected attention following a situation filled with challenges and commitments. Although they felt shame as they struggled for personal "self-protective time," they still tried to schedule their own activities such as sports activities, walking the dog, or hunting:

It has to do with recovering, to make sure to go out and do things that give me positive energy. I find that important. And to be good at thinking "this is my need, this is for me" (woman, 46, seven months after stroke).

4.2. Screaming for Acceptance. When recovery was delayed, the interest and support from others changed, becoming more silent and influencing life in a more negative manner.

The stroke survivors progressed from being treated with "silk gloves" and being the "commander" close to stroke onset to a more secluded situation. The support offered from others gradually decreased and changed, as expressed in the subtheme, "the silent cry for acceptance." Close to stroke onset, the dialogues focused on the stroke survivor's feelings of living with stroke, and, later on, the communication altered to be more oriented on practical tasks to fulfil daily family roles. The attention from others decreased, though the suffering from the illness still remained a day-to-day challenge. The second subtheme in this section, "living on charity," reflects the stroke survivor's insecurity about how to "survive" as a family-member when living a life that is marked by chronic consequences as the result of a stroke.

4.2.1. The Silent Cry for Acceptance. The stroke survivors thought about life following their strokes and the slow recuperation process despite being "young", thinking that a stroke was an illness that only affected the elderly and retired. Involvement from the immediate and extended family increasingly decreased as time passed. The stroke survivors expressed a decreasing engagement from others as a barrier from discussing their situations. They presumed that others did not understand, and, therefore, they avoided bothering others:

[...] She [wife] works in an institution. I'm not sure which, but the patients there have different [problems], are both old and young, and she has folks there who had have the same injury as me, and are suffering worse. I could have run the risk of being in an institution myself. So [my current problems] are really nothing. [...] We only talk about the epilepsy, the other things are not a theme any longer. Talking about it [the stroke] is finished (man, 38, four and a half years post-stroke).

The participants expressed frustration about being misunderstood by people around them. They suspected that others noticed their disabilities, but they never inquired about their conditions. Because of this lack of attention from others, they tried to live life as normally as possible.

The narratives expressed a sense of discouragement about the lack of understanding from friends, even though the relationships were close. The stroke survivors wanted others to understand their present situation and their inability to participate in activities and gatherings the way they had before their stroke:

I don't join them on a night out [...] I [am not able] to dance [...], I am not active the same way they are, [it would] not be very social, so it is no point (woman, 20, one year post-stroke).

Some of the nonestablished stroke survivors expressed difficulty telling their parents about their illness, as they preferred to remain independent and protect their parents from worrying about them, thus avoiding being overprotected:

I don't want to reel off all my health problems to everyone [...] I feel it's my problems. [...] I don't

want to trouble the family. [...] So I probably try to protect them [from getting worried]. [...] They [the parents] don't know more than others. And I think that's okay. I didn't mention when I went on sick leave or when I was on vocational rehabilitation. My mother would have been scared and start to nag at me, call me every day and ask for my condition [...] I don't manage that nagging. [...] I've a mother that worries a lot [...]. So it's better to [not tell them] [...]. But I don't know how she's thinking about it (man, 32, four years post-stroke).

The longing for sympathy experienced at stroke onset was also highlighted, and the suspicion from others of exaggerating the challenges that some of the stroke survivors expressed was difficult to overcome. Nevertheless, some of the informants expressed the dialogue as positive. The stroke had resulted in paying more attention and becoming closer to spouses, children, parents, and adult siblings:

I'm feeling good [...] I want to be together with my family, relax and do things I neglected when I was working "twenty-four hours a day". [...] Me and my wife [...] were forced to talk about it [the stroke]. [...] The siblings are thinking of me. [We are] touching things we didn't before. [...] After all, the relations are stronger (male, 49, three years post-stroke).

4.2.2. Living on Charity. As life continued, the stroke survivors continued to struggle with fulfilling family roles and obligations, struggled with balancing protection and participation, and struggled with telling others to gain an understanding of what it meant to live with stroke. Life after stroke was compared to living in a box or in a shell, struggling to be released and to become more independent. The participants expressed a kind of resignation about telling their partners, children, friends, parents, and grandparents what living with stroke was like. They put a lid on the situation, continuing to suffer from illness. This led to a state of defencelessness. One of the participants aged 52 was nevertheless attentive to how his stroke influenced his wife six months after stroke onset. He tried to ask her specific questions and encouraged her to tell him her struggle to maintain the open dialogue that was important to the family. Even if the stroke survivors were judging that they could manage more participation, they strived to communicate that they possibly could be more responsible in their roles:

The problem is that I don't have sensibility in one of my hands. That is difficult, when I'm going to change nappies, dress [the child] and such. Sometimes I can hurt [the child]. It has happened that I have pinched. It's difficult. [...] I think she [the wife] has done too much. [...] It looks like she wants to, but I still think, it's a kind of naturally, that the mother becomes the main [parent] the first years. [...] I think I can do more, but [...]

it has to be good for the kid (male, 38, four and a half year post-stroke).

Some of the stroke survivors expressed a fear of being rejected by the family and left alone. They ruminated about a prospective scene where the family would become fed up with the stroke survivor's dependence and failure to fulfil their expected role and envisioned how the family would go on once the children had grown up and moved outside the home. Following this negative thinking, the strategy of the stroke survivor was to not complain and hope the family could persevere with a nonfunctioning family member:

The worst thing to think about is if they [my family] become fed up with me and throw me out. [...] Therefore, I have to try to remain as cheerful as possible. [...] Even worse is if someone finds out that they don't want to have anything to do with me. [...] Sometimes this thinking comes to me on [difficult] days [...] (man, 61, four years post-stroke).

Two of the single stroke survivors expressed regret that their intimate relationships came to an end shortly after stroke onset. They expressed the desire to establish contact with new friends and develop intimate relationships. Although they did not understand why some friends were not visiting at all, they interpreted their lack of presence as a difficulty in being around ill people. They understood the fact that their friends gave up on the relationship to focus on their personal life projects, and the stroke survivors had to realise that their own lives were progressing in a different way:

I've lost a lot of friends. Many friends think of me, but they don't get in touch. I always have to call them first, sure because of the injuries. [...]. When I contacted them the first time, I also have to contact them the second time [...]. When they come back [to hometown] with their kids and families [...] they have almost forgotten me. [...] We chat on the phone, but if I visit them, it becomes only that time. [...] I miss school. [...] If I start at a new school, I'll make some more friends. [...], establish a new social network and get a job afterwards (man, 27, three years post-stroke).

Stroke survivors who were in the lower socioeconomic strata encountered increased challenges with respect to participating in family activities. Living on disability benefits prevented some of the participants from participating in social events. Other participants explained that they prioritised staying at home to save money and pay for their children's leisure activities. Some of the nonestablished stroke survivors wanted to become financially independent so they could live by themselves and be not dependent on family support.

Regardless of the disabilities incurred following a stroke, none of the stroke survivors gave up, and they continued to hope they would be able to fulfil their roles and participate in

meaningful activities. Additionally, hoping to find a partner, one's complete education or establishing a family were also important to some of the stroke survivors.

5. Discussion

This study highlighted that maintaining roles and interactions within the family as a working-age stroke survivor was challenging, as summarised in the two main themes "struggling to reenter the family" close to stroke onset and "screaming for acceptance" later on in the stroke trajectory. Although the participants' experiences as stroke survivors ranged from six months to nine years, their descriptions regarding life since stroke onset confirmed some common experiences. As time passed, even though it was expected that life would become normalised, it remained difficult for stroke survivors to fulfil certain roles and to interact within and outside the family many years after stroke onset.

All but one of the nonestablished participants in this study were dissatisfied with their current lives. From being left by their partners or significant others to being forced to discontinue their studies or their work and finding it difficult to maintain friendships changed the lives of the participants and isolated them from living a normalised life. The participant who found life different, but was still satisfied, had established an intimate relationship, and succeeded in being independent and emancipated by resuming studies and work was perceived to be of high value to young adults [16]. The need for emancipation was also expressed by their desire to live with minimal intervention from their families. This differs from what was found by Teasell et al. [19] who found that younger stroke survivors had a tendency to increase their dependency on their parents. The struggle to maintain relationships and intimate relationships is also evident elsewhere [1, 2, 21].

Stroke survivors in parental roles did not express the same opportunities to isolate themselves from activities as did the nonestablished group. In fact, they expressed the opposite, as their lives were busier because of parenthood commitments and demands within the family. The inherent responsibilities of being a parent [16] could result in a conflict between managing time for parental tasks while simultaneously finding time to focus on recovering from their stroke. The expressed struggle with raising children aged one to eighteen years emphasised the fact that the upbringing of children is comprehensive [16, 18], making the situation even more challenging for stroke survivors when the flexibility that is necessary to interact with children [16] may be interrupted by psychological challenges following the stroke. While mothering is found to be challenging when suffering from illness [1, 9], as this study confirmed, the fathers also worried about their inability to fulfil their parental roles. The fathers' expressed emotional shortcomings in their parental roles go beyond their need to protect their families both physically and economically, as noted by others [1, 12, 20].

It is important to underline that although participants in parental roles struggled to fulfil that role, some fathers

expressed that they could have contributed to the family life more than they did. However, because of poor communication regarding how to participate, some felt that they were forced to withdraw from fulfilling their parent roles as expected. Other fathers, however, found a new role as the principal parent who stayed at home. This highlights the need for health services to be aware of the general vulnerability of stroke survivors in parental roles, and to be particularly aware of the fathers' struggles to fulfil their roles.

The participants without children and those with children that had moved out of the home also perceived their lives as challenging because of the remaining psychological symptoms. Their family challenges were more specifically related to their role as grandparents, a point not highlighted in previous studies, and to a struggle to maintain contact with friends. Furthermore, couples in long-lasting marriages have greater opportunities to create a new marriage path, even after the partner has suffered a stroke [9, 11].

The different life situations indicate that living with stroke is not easy for any of the social groups analysed here. The expressions of life with respect to facing struggles of not being able to fulfil role expectations resulted in negative mental activities. Although the support from family is important [9], nonestablished stroke survivors as well as stroke survivors living with children seem to be particularly vulnerable because of the stroke's impact on life at a time when one is expected to be emancipated from the family of origin. These findings confirm adults with families and children as vulnerable after stroke and in need of support in later phases of recovery [33]. In addition, access to practical childcare would be helpful for those stroke survivors with young children.

5.1. Strengths and Limitations. The participants in this study were recruited using a convenience sampling method, due to the difficulties getting access to this subpopulation of stroke survivors. Although this is a less preferred method for qualitative research than maximum variation sampling [28], the applied sampling strategy generated a wide variety of participants with respect to age, gender, social status, and time since stroke onset and therefore the participants represent a broad range of experiences. Furthermore, they provided rich and detailed descriptions of their experiences and concerns. Accordingly, we maintain that the findings provide in-depth knowledge regarding family life challenges during the recovery phase ranging from six months to nine years.

Despite the participants' variations in time since stroke onset, the narratives expressed significant commonalities across age and social situation. These findings, together with the differences across the family cycle, underscore the challenges faced by long-term stroke survivors and the need for better followup. However, maximum variation sampling would have strengthened the transferability [28] of the findings.

Validation of the findings was sought through the research group's continuing and open discussions during the analysis process until consensus about the findings was attained.

6. Conclusion

Being a stroke survivor between the ages of 18 and 67 poses significant and multifaceted challenges to family life many years after stroke. To interpret and manage the family situation calls for support across the life span, suggesting that individual followup by health services would be helpful. Nonestablished people living with stroke seem to be particularly vulnerable, as they are often isolated in their homes. It is also important to be aware of the vulnerability of stroke survivors as they attempt to fulfil their parental roles as both mothers and fathers. The daily demands and their struggles to attend to family life leave them in need of tailored followup with regard to how to arrange their daily demands of childcare and marital relations. Being provided opportunities to narrate their experiences outside the home context might be helpful to prevent psychosocial problems.

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Errata

Errata

Page V, line 8-9: “Younger Stroke Survivors’ Experiences of Family Life in a Long-Term Perspective” corrected to “Younger stroke survivors’ experiences of family life in a long-term perspective”.

Page VII: The heading «Aims» corrected to «Aim»

Page VIII, line 11: “Twenty-three stroke survivors aged 20-64 years...” corrected to “twenty-two stroke survivors aged 20-61 years...”.

Page XII, line 10: “23 personer med hjerneslag i alderen 20-64 år...” corrected to «22 personer med hjerneslag i alderen 20-61 år...».

Page 19, line 5: “...events of the a story...” corrected to “...events of a story...”

Page 27, line 4: (Ricoeur, 1976, p. 87) corrected to (Ricoeur, 1976, p. 87-88).

Page 28, Figure 1 The theoretical approach of the intervention: Added: “The figure is reprinted with permission. Copyright International Journal of Nursing Studies 49(2012), p. 391”.

Page 28, last line: “... and dimensions of...” corrected to “... and other dimensions of...”.

Page 43, line 4-5: “Thirteen of the participants were married, three were divorced and two were single” corrected to “Eleven of the participants were married, two were divorced and three were single”.

Page 54, line 12: “Because the struggles varied among the participants’ in different social situations” corrected to “Because the struggles varied among the participants’ different social situations”.

Page 77, line 2: The word “and” is replaced with a comma.

Article IV:

Page 7, line 12: “... the stroke survivors’ long-term needs” corrected to “... the stroke survivors’ long-term experiences and needs”.

Page 20, line 15: The word “Authors” is deleted.

