Exploring life after stroke

experiences of stroke survivors, their family caregivers and experts in an Iranian context

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Stockholm 2011
To my beloved family:
Farideh
Niusha, Mandana and Mohammad Mahdi
ABSTRACT

The global burden of stroke is immense; stroke is the second most common cause of death and the seventh leading cause of disability-adjusted life years. Furthermore stroke burden is greater in low-income countries than in high-income countries as in Iran. Despite the high incidence of stroke, little research has been done on the post stroke recovery process. The overall aim of this research project was to explore life after stroke based on experiences of stroke survivors (I,II), their family care givers (I-III) and expert in field of rehabilitation (IV) in an Iranian context.

Data were analyzed by the basic tenets of the grounded theory approach according to Strauss & Corbin, specifically the constant comparison analysis within data collection and simultaneous analysis of interviews and focus group discussions (II-III-IV) and qualitative content analysis qualitative (I). Data for the studies were gathered from knowledgeable participants and followed to figure out the themes by purposeful selection and then by theoretical sampling with. In Study (I) The results were categorized into the two main themes that were identified as; (1) challenged by changes in life situations with sub-themes: to straggle with physical dysfunctions, to have no daily plan for spending times, changes in mood, to be faced with economical problems and to worry about changing roles and (2) striving to cope with new conditions with sub-themes: to try to preserve self-worth, to search from spirituality, to learn and re-learn and to regain independency. Study (II) identified “functional disturbances” as core concept in physical, psychological, social domain. Functional disturbances were encompassed by the lack of appropriate strategies in managing and supporting, such as lack of adequate social support by social insurance and access to the few existing rehabilitation centers. This caused many other problems for survivors and their family caregivers. In study (III) the core concept identified was “continuity of rehabilitative care”. Seven related main categories were extracted: Three of them related to the problems family caregivers faced, including inadequate knowledge and skills, inappropriate accessibility to rehabilitative services, and inadequate social insurances. Four categories were about the strategies that family caregivers used to deal with the major concerns; modifying home environment, managing coexisting medical conditions, improving nurses’ roles and, relying on family unity. In study (IV) “non-integrated rehabilitation service” emerged as core concept of the study. The explored concepts were ‘deficiently allocated budget’, ‘inadequate social insurance’, ‘lack of availability of rehabilitative care’, ‘negative public opinions’, ‘lack of
consistency of care’, ‘split services and professional separation’. Potential areas for improvements were ‘need for changing policymakers’ attitudes’, ‘needs for refining rehabilitation in health care system’, ‘needs for establishing a registration system’, ‘needs for providing information and skills’ and ‘needs for seeing the family as a whole’.

In conclusion, the core concept for life after stroke was “functional disturbances”. The participants perceived that Iranian stroke survivors lacked availability to rehabilitation services, lacked knowledge and skills and had suffered from inadequate social support and social insurances. Non-integrated rehabilitation services within health care system and lack of continuity of rehabilitation care caused stroke survivors and their family caregivers to experience ranges of dysfunctions in terms of physical, emotional, psychological and social aspects. Change of policy makers’ attitude appears to be important in order to allocate adequate budget in this regards. Stroke survivors and their family caregivers experienced everyday life in terms of being challenged by changes in life situation and striving to cope with new conditions. The study results indicate that focusing on multidisciplinary approach and establishing registration system for follow-up of survivor’s rehabilitation are to be recommended. Nurses should be oriented regarding the effect of stroke on physical, cognitive, emotional, psychological, social and spiritual domains for managing survivors and their family caregivers by participating in stroke rehabilitation programs.

**Key words**: stroke event, life after stroke, stroke survivor, family care giver, rehabilitation expert, home rehabilitation care, community rehabilitation services, experiences, everyday life, constant comparison method and grounded theory approach.
LIST OF PUBLICATIONS

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

I Dalvandi, A., Khankeh, H.R., Ekman, S-L., Maddah, S. S. B., Heikkilä, K. Everyday life situation as experienced by stroke survivors and their family caregivers in an Iranian context. (Manuscript)


IV Dalvandi, A., Ekman, S-L., Khankeh, H.R., Maddah, S. S. B., Heikkilä, K. Experts’ experiences of community rehabilitation services for stroke in Iran. (Submitted)
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<th>Full Form</th>
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<tr>
<td>AD</td>
<td>The Author</td>
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<tr>
<td>ADL</td>
<td>Activity of daily living</td>
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<td>CCM</td>
<td>Constant comparative method</td>
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<td>CVA</td>
<td>Cerebral vascular accident</td>
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<td>DALYs</td>
<td>Disability-Adjusted Life Years</td>
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<tr>
<td>DPT</td>
<td>Diphtheria, pertussis (whooping cough), and tetanus</td>
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<td>EMRO</td>
<td>Regional Office for the Eastern Mediterranean data</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>GT</td>
<td>Grounded Theory</td>
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<td>ICH</td>
<td>Intracerebral hemorrhage</td>
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<td>ISF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>MOHME</td>
<td>Ministry of Health and Medical Education</td>
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<tr>
<td>NGOs</td>
<td>Non Government Organizations</td>
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<tr>
<td>SAH</td>
<td>Subarachnoid hemorrhage</td>
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<tr>
<td>SCI</td>
<td>Statistical center of Iran</td>
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<tr>
<td>USWR</td>
<td>University of Social Welfare and Rehabilitation Sciences</td>
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<td>WHO</td>
<td>World Health organization</td>
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1 INTRODUCTION

“We know more than we can tell” (Polanyi).

“If there were only one truth, you couldn’t paint a hundred canvases on the same theme” (Pablo Picasso).

During two last decades, my previous personal and professional career within the health care profession and especially my experiences in the fields of rehabilitation and education sectors in Iran, it is my impression that brain stroke is one of the major health issues in Iran and stroke survivors have many problems in their home. That is why I was eager to know how these people live after stroke and what challenges they are faced with.

My motivation to do this research by illuminating the phenomena of life after stroke was to open up a new potential area for education and detailed research and also to shed light on how to better help stroke survivors and their family caregivers.

My research project is based on a personal and professional interest in expanding understanding of how stroke survivors and their family caregivers experience their life after stroke and what challenges they have, and which adaptive strategies they use and recommend. This interest motivated me to pay attention to the phenomena on three levels: individual, family and community.

I was motivated to start the “process” of life after stroke to investigate the experiences of stroke survivors, their family caregivers, and rehabilitation experts in order to describe the process of recovery and rehabilitation which stroke survivors and their families were involved in.

My ambition is that the results of this project can be beneficial for health care policymakers and healthcare providers to re-define post hospital care for stroke survivors in the health care system of Iran.
2 BACKGROUND

2.1 EPIDEMIOLOGY OF STROKE

Stroke is the second most common cause of death and disability worldwide. It requires the involvement of patients, caregivers and experts for achieving optimized recovery, reducing long-term burden and successful improvement in patients’ quality of life (Varma, 2005). Since the older population would increase in the next 20 years, the burden of stroke will increase greatly, particularly in the developing countries (Duncan et al, 2005). According to Ostwald (2008), fifteen million people globally are affected by stroke and sixty percent of them either die shortly after the stroke or are permanently disabled as a result of stroke. It is projected that the global stroke burden would increase from 38 million of disability-adjusted life years in 1990 to 61 million in 2020 (Ostwald & Duggleby, 2004).

Stroke is a complicated disease with physical, psychological, emotional and behavioral problems differing among survivors. Even those with similar types of impairment may experience differences in range of severity, pathways of recovery, and social and financial resources (Ostwald, 2008). Moreover, according to Bonita et al (2004), demographic changes, inadequate control and increased exposure to major stroke risk factors would increase the stroke burden in the future.

Two-thirds of strokes occur in low-income and middle-income countries where the average age of patients with stroke is 15 years below that of high-income countries. Bonita et al (2004) also claim that despite the huge and increasing burden of stroke, particularly in people of working age, the disease does not receive the awareness it deserves and requires for prevention and management in terms of research funds.

According to the National Stroke Association (2009): 10% of stroke survivors recover almost totally, 25% get better with minor impairments, 40% experience moderate to severe impairments that require special care, 10% require care in a nursing home or other long-term facilities, 15% die shortly after the stroke and approximately 14% of stroke survivors experience a second stroke in the first year following a stroke.
After the age of 55, the incidence of stroke doubles with each lived decade in developing countries (Ahmadi Ahangar et al, 2005). According to Salamati et al (2008), compared with developed countries, far fewer epidemiologic studies of stroke have been conducted in Asian countries, except for Japan (2008). The incidence of stroke per 100,000 per year in Western countries is between 100-300 while in Asian populations average annual stroke attacked rates are 85-638 per 100,000 (Taqui & Kamal, 2007). Despite numerous epidemiologic studies of stroke, there is still scant population-based information in developing countries. Therefore, such studies do not provide comparable data on stroke incidence (Azarpazhooh et al, 2010). However, stroke incidence rates and mortality rates vary, even within Western countries (Feigin et al, 2009). Globally, the mean age of onset was 69.8 in males and 74.8 in females (Valery et al, 2003).

There are large geographic variations in stroke incidence and mortality around the world, and differences in the types of stroke occurring, distribution of stroke, and the mechanism of stroke between Western and Asian populations (Azarpazhooh et al, 2010).

According to Ahmadi Ahangar et al (2005), in developed countries, stroke occurrence is higher in men than in women and stroke happens in males 40% more frequently than in females in the north of Iran. Delbari et al (2010), in contrast, reported that Iranian women have higher stroke mortality than men, and that sex was not statistically associated with death after stroke in Iran.

2.1.1 Stroke pathophysiology

Stroke is a common cause of mortality and morbidity. The first aim of public health policy-makers is prevention of rheumatic cardiac diseases and hypertension as the two main underlying factors of stroke (Salamati et al, 2008).

According to Rosamond et al (2007) stroke can have serious complications for survivors. There are two major types of stroke including: ischemic and hemorrhagic. Ischemic type (ICH, includes thrombotic and embolic stroke, with incidence of 87%, where arterial embolus from atrial fibrillation, hypo-perfusion, hypertension, or a dislodged arterial plaque causes reduced blood supply to the brain. Hemorrhagic type includes subarachnoid hemorrhage (SAH) and intracerebral hemorrhage (ICH) with incidence of 13%. It is
caused by a rupture of a blood vessel which causes blood to leak into brain tissue. The most common cause of ICH is hypertension and the most common cause of SAH is rupture of an aneurysm or arteriovenous malformation (Urden et al, 2006).

According to Adams et al (2007) stroke occurs under intervention of modifiable risk factors and non-modifiable risk factors. The first factors include hypertension, high cholesterol level, diabetes mellitus, smoking, excessive alcohol intake, sedentary lifestyle, obesity and increased abdominal fat and atrial fibrillation. The second factors include age, gender (more women than men) and family history of stroke.

2.1.2 Impact of Stroke

Stroke is an unexpected major life incident that suddenly disrupts life’s course and which has severe effects on bodily and mental functions, although the effects vary depending on where the stroke hits. Stroke may affect all functions such as autonomic nervous system, balance, ambulation, speech, perception, cognition, mood motor dysfunction (Sonde et al, 2000). According to WHO (2004), the quality of life after stroke depends on many situations and conditions that stroke survivors face individually. Moreover, the effect of stroke is significant on physical functioning and can lead to changes in lifestyle and inability to manage self care, work or leisure (Duncan et al, 2005).

According to the National Stroke Association (2009) “Stroke has individual effects on those who are stricken with stroke. It can cause hemiparesis or hemiplegia, a weakness or paralysis, on one side of the body. This can affect both one side or only an arm or leg. Hemiparesis or hemiplegia may lead to spasticity, muscle spasms, stiffness, balance and coordination problems, aphasia (difficulty understanding and using speech or writing), and dysarthria (knowing the right words but having trouble saying them clearly)”. It can also cause bodily neglect or inattention, pain, numbness or odd sensations. Furthermore, stroke can cause problems with memory, thinking, attention and learning. Other symptoms may be troubles with swallowing (dysphagia), or problems with bowel or bladder control. Mentally, stroke can lead to fatigue, difficulties in controlling emotions and to depression. All these may lead to difficulties in conducting daily tasks (USA Agency for HealthCare Research and Quality, 1995).
2.1.3 Medical complications of stroke

Medical complications are common among individuals who have had a stroke. The complications increase the length of hospitalisation as well as the costs of care. Besides, these complications are a major cause of death in the acute and sub-acute stroke phases (Kumar et al, 2010). Pre-existing medical conditions, pre-stroke and disability advanced age, can affect an individual's risk for developing stroke (Langhorne et al 2000). Patients with severe, disabling strokes are particularly vulnerable. Medical complications can hinder functional recovery and are associated with poorer functional outcome after adjusting for stroke severity and age. The explanation for this association is unclear but stroke probably interferes with rehabilitative therapies. Furthermore, fever, hyperglycaemia, systemic inflammatory response, hypoxia, or medications that are used to treat some of these complications can have a directly damaging physiological effect on the injured brain or can hinder its capability for plastic change (Kumar et al 2010).

Most medical complications develop within the first few weeks after a stroke event (Indredavik et al, 2008). Some events, such as cardiac abnormalities, dysphasia, and pneumonia, are often apparent early after stroke onset whereas others, such as bed sores, venous thrombosis, and falls, can occur after several days. Many complications are preventable. When not preventable, early recognition and treatment can be effective in ameliorating these events early in their course. Treatment of a systemic complication can pose a harmful effect on the stroke-injured brain, thus requiring appropriate tailoring of strategies of different treatment approaches (Kumar et al, 2010).

According to Perry et al (2006) many of those stroke patients who are discharged from hospital have experienced some range of persistent impairments, such as weakness, balance difficulty, cognitive impairment, immobility and dependence in activities of daily living. McKevitt et al (2004) show in their literature review that low functional ability is often described not only in terms of loss of functional activities, but also of emotional and social loss, and a change in identity.

Survivors have also developed their own strategies to deal with disabilities, including dealing with tasks more slowly and initiating learning and exercise, developing strategies to keep or re-building a sense of continuity after the stroke, and they use strategies to
foster hope during the process of adjusting to life after stroke, drawing even on spiritual practices (Pound and Gompertz, 1998).

### 2.1.4 Rehabilitation and care after stroke

The acute phase varies from a couple of days to a couple of weeks. Thereafter an obvious improvement in neurological and neuropsychological deficits can be accessed from the acute stage up to 3-12 months (Kotila et al, 1984).

Bruno-Petrina (2009) defined stroke rehabilitation as “an integrated and coordinated utilization of medical, social, educational, and vocational plans and procedures for retraining stroke survivors in order to optimize physical, psychological, social, and vocational potential, involvement with physiologic and environmental restrictions” (P1). It is an active process beginning in acute hospitalization care and has a goal of returning to the community and aims at assisting the clients to recapture their functional independence (Hochstenbach & Mulder, 1999) and to return to an active and productive lifestyle (Gresham et al, 1997).

According to Duncan et al (2005), stroke rehabilitation care starts as soon as the diagnosis of stroke is recognized and the life-threatening problems are stabilised, that is, during the acute hospitalization. The main priority during this early phase is to prevent a recurrent stroke or complications, ensure appropriate management of general health functions, mobilize the patient, encourage self-care activities, and provide emotional support to the survivors and family. After the discharge from the hospital, the stroke survivors either go to long-term care in the community or begin rehabilitation either at home or at a rehabilitation facility (Pecotić-Jeričević et al, 2008).

According to Woo et al (2008) the main goal of an inpatient rehabilitation setting is to help patients to cope with their disabilities and dependence using different assessments and interventions. Thereafter, care and rehabilitation is provided at the survivors’ home and the focus of care turns to assessment and recovery of any residual physical and cognitive deficits, as well as compensation for residual impairment. There are different professionals involved in stroke rehabilitation care: physical medicine, occupational therapy, physiotherapy, speech therapy, nursing and varying therapeutics and treatment settings (Duncan et al, 2005).
Paolucci et al (2003) reported that delivering of rehabilitation services within 20 days for stroke patients gave six times higher chance of recovery than delayed rehabilitation. A similar finding by Duncan et al (2005) confirmed that the effectiveness of rehabilitation results in cost effectiveness due to shorter stays in the hospital. Teasell and Lalit (2005) in a Cochrane stroke group review indicated that therapy-based rehabilitation services improve the functional level for community-dwelling persons one year post stroke, similar to the conclusions drawn by Turner-Stokes et al (2005) in their review of 21 trials.

2.1.5 Nurses’ role in stroke rehabilitation
According to Hawkey & Williams (2007), nurses are involved in eight major roles in rehabilitation care: fundamental nursing skills, education, therapeutic practice, co-coordination, advocacy and empowerment, clinical governance, counselling, advice and political knowledge. This means that the nurses are a coordinators and informants. They have a principal planning responsibility for each patient. This responsibility involves providing information to stroke survivors and their families and relatives and get in touch with different aspects in the patient care, in acute care, rehabilitation clinics, primary care, and municipalities (Swedish National Board of Health and Welfare, 2000). Kirkevold (1997) and O'Connor et al (2001) asserted that nurses’ role in rehabilitation care for stroke survivors is to coordinate the performance of other professionals or to replace other team members in their absence, rather than to provide common interventions. In this, rehabilitation nurses play a role in promoting the quality of life of stroke survivors (Hawkey & Williams, 2007).

Kirkevold (1997) suggested that more studies are needed to develop nursing interventions in term of the integrating of various functions and also exploring to what extent systematic nursing programs may actually impact on stroke survivors’ and families’ outcomes and improve their ability to return to a life worth living.
2.2 STROKE IN IRANIAN CONTEXT

2.2.1 General facts about Iran

Iran is a large country situated in south-western Asia. Iran covers an area of 1.648.000 square kilometers and has different landscapes and climates. Over half of the area is covered by mountains; a quarter is desert, and less than one quarter can be used for growing crops. The great mountain ranges of Alborz are in the North and Zagross in the West and the South. The country's various climates determine the socio-economic and cultural state of the people. The extremes of the variations are the flourishing, productive green fields and forests of the humid North; and the unfriendly desert sands of the centre and parts of the South (Mohit, 2000).

The population of the country is roughly 73,200,000 of whom 60.4 per cent live in urban and 39.6 per cent in rural areas. More than two-thirds of the population is under the age of 30. The average size of the family is just less than five persons. In recent years, however, Iran's birth rate has dropped significantly. Today's Iranian family is a family in transition from an extended structure to a nuclear arrangement, therefore prone to many stresses. Overall literacy rate is 80 per cent, representing 85 per cent of the population in urban and 74 per cent in rural areas (Statistical centre of Iran, 2008).

Iran is ethnically and linguistically diverse, with some cities, such as Tehran, bringing various ethnic groups together. Tehran is the capital and largest city of Iran, and the administrative center of Tehran Province, with a population of 7.7 million (Statistical center of Iran, 2008). Tehran is home to around 11% of Iran's population. It is the hub of the country's communication and transport network (World Bank, 2009).
2.2.2 Family structure and relationships in Iranian culture

There is little research on the Iranian family structure and functions apart from general information about Iranian life situations, and only related to a small part of the population or a specific social class (Jalali & Rah, 2001). According to Nassehi-Behnam (1985) the Iranian family has preserved many of its traditional functional aspects, the most important being its function as a support system. Most adult Iranians (83%) are married and have strong socioeconomic relations with their kinship network. Moreover, Mohit (2000) stated that the best picture for the Iranian family of today is a family in transition from an extended structure to nuclear form, and is therefore faced with many stressors.

According to Gable (1959), in Iranian culture and society, the family is the most important element that dominates an individual's whole life. The significance of the family as a social unit for Iranians dates to Zoroastrian time (pre-Islam period), when raising children, and duties of children toward their parents were considered sanctified.

Lagerström et al (2010) stated that Iranian norms and values and also the meaning of the family in traditional Iranian society are varying compared with western cultures. The family in Iranian society is an important source of belonging to each other, for achieving
influence, power, position, support and security. It is usual to communicate with extended family members who have responsibilities and obligations toward each other.

2.2.3 Health status and stroke incidence in Iran

According to Salamati et al (2008) injuries, cardiovascular diseases, depression, substance abuse and cerebrovascular diseases are the most important health issues in Iran. It seems that chronic and non-communicable diseases are becoming a threat to the Iranian population in spite of improvements in communicable disease controls, vaccinations and mother and child health care.

According to different local studies in Iran the mean age of stroke onset is between 61 and 65 years, and the incidence of stroke varies in these studies between 33-372 per 100,000 people (Salamati et al, 2009; Salamati et al, 2008; Ahmadi Ahangar et al, 2005; Azarpazhooh et al, 2010; Salman Roghani et al, 2006). Although, Hosseini et al’s, study (2010) shows that an incidence of ischemic stroke in all age ranges in Iran is 43.12 in 100, 000 population, meanwhile the incidence and prevalence of stroke is predicted to increase about 40% from 2000-2020 in Iran (Duncan, 2005).

Therefore, Hosseini et al (2010) claim that for improving healthcare planning programs in Iran, well-designed and comprehensive population-based inquiries are needed to update and fulfill the published excellence criterion, by using public training and understanding of these disabling conditions in this part of the globe.

2.2.4 Health care system and stroke rehabilitation in Iran

There are four major health insurance organizations in Iran, which cover 90% of the population. However, most health care spending is still paid out-of-pocket, thus many services are not available for those who lack property (Mehrdad, 2009).

According to Payne et al (2002), the health care budget in Iran is inadequate to meet the rising rate of stroke, with its attendant future demands for stroke services.

The public sectors in Iran provide primary health care, treatment and rehabilitation and the Iranian government puts emphasis on primary health care (Mehrdad, 2009). The Welfare Organization, an independent department of the Iranian Ministry of Health and
Medical Education (MOHME), is responsible for tertiary care which provides rehabilitation services to disabled people, such as those having stroke, cancer, asthma and other chronic, neurological disorders. The Welfare Organization is also used to deliver services to these people. The services include: rehabilitation, medicine, vocational, social, educational and professional services to the disabled people in different centers of physiotherapy, occupational therapy, audiometric, speech therapy, optometry and technical orthopedics. (Nahvinejad, 2003).

In Iran the private sectors play a significant role in provision of rehabilitation care. Their major services are focused in urban areas. Besides, such non-governmental organizations (NGOs) are essentially active in special fields, like in care of children with cancer, diabetes and neurological disorders (Nahvinejad, 2003).

Momensaraie & Pourreza (2002) claim that there are gaps between the Iranian public and private sectors in terms of rehabilitation services as insurance coverage for rehabilitation services on both sides are limited. Because the private sectors deliver these services broadly and holistically, people have to receive these services from both public and private sectors, including home care services and professional care based on survivors’ needs. However, they are very expensive. According to Al Mahdy (2002) the rehabilitation services are not integrated and lack a multidisciplinary approach and teamwork in their delivery. The social expectation is that survivors should be cared for by their families and relatives because of inappropriate accessibility and affordability from public services.

Stroke survivors, after discharge from hospital, are usually referred to public or private sectors or cared for at home. They are cared for in their homes, without appropriate discharge planning programs (Alaei, 2003). This may result in many challenges and long-term difficulties for stroke survivors and their family members who are usually the main caregivers within the Iranian cultural context (Mohammadi and Kaldi, 2006). However, there is a little knowledge available on the life situation or service use of individuals following a stroke (Eftekhar et al, 2010).
3 THE RATIONALE FOR THE STUDY

The impact of stroke is complex and diverse, depending on the injury and the essential functions which are affected, such as cognition, communication and physical abilities (Kumlien 2005). According to Palmer & Glass (2003), stroke also changes the individual’s capability for social task functioning and can make a vulnerable self-concept in the sense of self-government, and effects on quality of life.

Yogeve-Seligmann et al (2008) claim that the patients’ whole situation should be taken into account, not only loco-motor inefficiency, but also emotional disturbances, cognitive deficits, and restrictions in performing one’s social functions (Geyh et al, 2004).

Moreover, there is a need to incorporate the individuals’ views and experiences of living with a stroke in rehabilitation interventions, by deriving evidence from available qualitative research studies (Eriksson et al, 2010). It is essential to shape the content and aim of stroke rehabilitation programs so they suit an individual’s expectations and needs. Therefore, it is important to provide better understanding of the stroke recovery period and facilitate formulation and delivery of rehabilitation following stroke from the individuals’ perspective (Jones, 2006).

However, there is still a lack of knowledge of the key points of experiences, especially in life after stroke and how the survivors and their family caregivers deal with the stroke consequences in home and community. The question is, how can health care providers reduce stroke survivors’ problems without any clear picture of their life after stroke?

Exploring life after stroke, based on experiences of stroke survivors, their family caregivers and experts are essential in planning for successful recovery. As Eftekhar et al (2010) point out, the future knowledge and resources that are considered necessary to meet the increasing health service is needed, caused by a growing number of patients with stroke.
A new line of relevant research, focusing on the experiences of stroke patients related to rehabilitation processes following a stroke can provide significant new insights in order to refine, and extend rehabilitation care (Kirkevold, 2010).

Knowing more about basic social psychological processes, barriers and facilitators through life after stroke in Iranian community may be useful for the health system. Hopefully, this thesis can enhance healthcare providers, rehabilitation professionals and specialty nurses’ competencies by increasing their understanding of the stroke patients’ life situation and how they deal with this situation.
4 RESEARCH AIM

The overall aim of this research project was to explore life after stroke based on experiences and perceptions of stroke survivors, their family care givers, formal care givers and experts in the field of rehabilitation in the Iranian context.

The specific aims were to:

Describe the everyday life situations as experienced by stroke survivors and their family caregivers, 3-6 month after stroke (study I).

Illuminate life experiences and perceptions after stroke among stroke survivors (study II).

Explore the Iranian family caregivers’ experience of providing rehabilitation care at home (study III).

Explore the experiences of Iranian rehabilitation experts concerning community rehabilitation services for stroke survivors and their opinions on how to further develop and improve these services (study IV).
OVERALL STUDY DESIGN

Due to the lack of knowledge about experiences of having a stroke in the Iranian context, and the need to obtain deeper knowledge of this phenomena the study has been qualitative in nature. To explore the experiences of life after stroke, qualitative research methods using qualitative content analysis (I) based on Graneheim & Lundman (2004) and grounded theory approach according to Strauss & Corbin (1998) paradigm model has been conducted with three sub studies (II-IV). The data is based on individual in-depth interviews (I-IV) and focus group discussions (IV) with stroke survivors (I-II), their family caregivers (II-III) and rehabilitation experts (IV).
6 RESEARCH METHODS

6.1 QUALITATIVE STUDY DESIGN

Qualitative research is naturalistic inquiry, because the data collection strategies used are interactive to discover the natural flow of the events and processes. This qualitative research deals with people's individual and collective social actions, beliefs, thoughts, and perceptions about life after stroke (Patton, 1990). This is an inductive study based on qualitative content analysis and Grounded Theory approach (GT). According to Streubert & Carpenter (2003) qualitative research methods in general provide a basis for exploring and understanding multifaceted human experiences. Qualitative research methods involve the systematic collection, organization and interpretation of textual material derived from talk or observation (Malterud, 2001). Qualitative research is used to gain insight into people’s attitudes, behaviors, value systems, concerns, motivations, aspirations, culture or lifestyles (Bryman & Bell, 2003). According to Mack et al (2005) and Green & Thorogood (2004) the strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue and can help us to interpret and better understand the complex reality of a given situation. Lincoln & Guba (1985) and Kvale (1996) state that qualitative methods are used in the exploration of meanings of social phenomena as experienced by individuals themselves, in their natural context. Therefore, to explore how life after stroke is experienced, qualitative research methods were used in this thesis.

6.2 GROUNDED THEORY APPROACH (GT)

According to Strauss and Corbin (1998) the grounded theory (GT) approach seeks to determine how the actors respond to changing conditions and to the consequences of their actions in relationship to a common problem.

Grounded theory is created to generate policy and practice-orientated findings, and is popular in health and social research for this reason (Green & Thorogood, 2004).
In GT the data collection and analysis processes are simultaneous and the data is sampled theoretically (Strauss and Corbin, 1990). In GT, a sample becomes "saturated" when no new categories or properties emerge from the data (Curry, 2003).

The analysis begins with an open coding phase that requires a brainstorming approach to analysis because it is important to open up the data to all potentialities and possibilities contained within them (Corbin & Strauss, 2008). After the open coding phase, axial coding level is used to examine and collapse codes into categories or higher level concepts. The goal of this phase is generation of a set of categories and their properties which fit the data and are relevant for integrating into a theory (Schreiber & Stern, 2001). Thereafter, in selective coding, the categories that have been developed from the initial theoretical framework are integrated. Here, the core variable is identified (Strauss and Corbin, 1990).

In grounded theory, probing questions derived from previous data analysis are also addressed. If the answers are not found in the data, further data collection is indicated. The consistent return to the data at each stage of development validates the theory. The theory is regarded as mature as data elements are integrated into the whole and the grounded network of relationships is established (Corbin & Strauss, 1990).

Constant comparison is the process of constantly comparing instances of data that are labeled as a particular category with other instances of data, to see if these categories fit and are workable. If they do, then we have what Strauss (1987) and Glaser (1992) call ‘theoretical saturation’.

### 6.3 QUALITATIVE CONTENT ANALYSIS

According to Graneheim & Lundman (2004) “qualitative content analysis” is a research method for “the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p 106).

As Graneheim & Lundman (2004) noted that qualitative content analysis can be a valuable method for students when attending a research class for the first time due to the opportunity to perform the analysis at various degrees of difficulty. Researchers wanted to understand which areas of life after stroke are important for participants by using
qualitative content analysis. This analysis method focuses on the subject and context, and emphasizes differences between and similarities within codes and categories (Graneheim & Lundman, 2004).

In study (I) data from the interviews with the survivors and the family caregivers were analyzed using the inductive qualitative content analysis (Graneheim & Lundman, 2004). After the transcription of interviews, the researcher engaged with the data by reading through the interviews several times. Thereafter, words, phrases or sentences that shared common characteristics or related meanings were identified as meaning units.

The condensation of meaning units was done by a process of reducing the text while still preserving the core. These units were then subsequently coded according to the content of data. After the coding process, all codes were categorized, and then underlying meanings in categories were interpreted. This resulted in two central themes.

The researcher found that there is information missing about everyday life and he wanted to write about the everyday life situation after stroke. Moreover, the researcher chooses content analysis that was existing material that even included rich material of experiences of everyday life.

According to Hallberg (2006) in the constant comparative method, every part of the data, i.e. emerging codes, categories, properties, and dimensions as well as different parts of the data, are constantly compared with all other parts of the data to explore variations, similarities and differences in data. Making comparisons assists the researcher in guarding against bias. Such comparisons also help to achieve greater precision and consistency (Corbin & Strauss, 1990).

Hallberg (2006) quotes Glaser (2002) who claims that via constant comparisons of different data, categories will emerge, or in Glaser’s own words (2002); “the theory will be a transcending abstraction although each informant has his or her own perspective when telling his or her story”. The researcher raises the informant’s perspective to an
abstract level of conceptualization and strives to see the underlying or latent pattern in the participants’ collective words, in a new perspective.
7 STUDIES (I-IV)

7.1 SAMPLES AND SETTING
Ten stroke survivors (I, II) twelve family caregivers (I, III); and fourteen rehabilitation experts (IV) were recruited for this research project. For study (II, III & IV) purposeful sampling followed by theoretical sampling has been implemented and for study (I) the same sampling was used. Purposeful sampling aimed to include people who were experienced and knowledgeable about the phenomenon under study. The further sample is chosen in order to fulfill the experienced gaps in emerging categories and relations between them. Further persons to the sample were recruited in order to find persons who can fulfill the knowledge gaps. At the starting point of this project it was decided to include stroke survivors and family caregivers in the study. Later on, rehabilitation experts have been included in the process of rehabilitation, as key persons.

7.1.1 Stroke survivors (I, II)
Ten stroke survivors were selected for the study. They were selected purposefully from public sectors where general populations receive services. The inclusion criteria for the stroke survivors was that they had been discharged from hospital since February 2007 through to July 2007, had suffered a stroke within the past 3–6 months, lived with their family member, resided in an urban area in Tehran and were able to communicate in Persian. The recruiting of informants started in three hospitals and two rehabilitation clinics. Permission to undertake the study was asked formally from the deputy of research of Tehran Medical University. After the permission was granted, more than 400 case documents were read. Based on inclusion criteria, 59 patients were contacted by telephone. A person who was well experienced, literate, and easily accessible and willing to share his/her experiences was chosen as the first informant. After the analysis of the first interview, the results were presented for supervisors and interview questions were revised. Then the second participant was chosen based on the gaps in knowledge. This process has continued and after interviews with 10 eligible people, the data was saturated (Strauss & Corbin, 1998).
7.1.2 Family caregivers (I - III)
Based on the researcher’s (AD) experience in interviews with stroke survivors the first family caregivers who were well experienced, and willing to share their experience were selected as proposed sampling and then followed by theoretical sampling.

Family caregivers for those stroke survivors who were recruited to the study (I and III), were asked to participate in the study. The inclusion criteria were that they were taking responsibility of the stroke survivor’s care, such as spouses and offspring. Twelve persons who fulfilled the inclusion criteria agreed to participate.

7.1.3 Rehabilitation Experts (IV)
Fourteen rehabilitation experts, who were professionals in the field of stroke rehabilitation and had been working in one of the universities and its Neuro-rehabilitation clinics, were selected by purposeful sampling. The sample included two neurologists, two occupational therapists, one speech therapist, one physiotherapist, two nurses and two social workers, two psychiatrists and two psychologists. The inclusion criteria were: minimum of two years experience of working with stroke survivors in clinics and in community. After the first FGD for developing data, the second FGD was held and for achieving data saturation four individual interviews have been done.

7.2 DATA GENERATION
In studies (I-III), the potential participants were contacted and the research objectives were explained. If the participant agreed to take part in the research, an interview was scheduled. Interviews were conducted at the stroke survivors’ homes or at Neuro-rehabilitation day clinics, based on the participants’ wishes, and lasted 45–60 minutes depending on the tolerance and interest of the participants in explaining their own experiences. In five cases, a second interview was conducted after some ambiguities were identified during the first interview. In the interview guide the researcher followed the content domains that were initially developed with help from expert peers.

In Studies (II-IV), data collection included in-depth interviews. Based on interview guidelines, interviews began with general questions. Some general questions were posed
for the stroke survivors such as in study (II), “How is your life now after the stroke?”,
“What problems have you experienced after stroke?”

Then, step by step, the interviews progressed to more specific and directed questions. Questions were based on what each respondent wanted to share with the interviewer and aimed to cover themes around their experiences of life after stroke.

More specific questions were posed differently for each group of interviewees. The theoretical sampling process followed by focusing on analysis from different interviews to fill the knowledge gap in life after stroke.

Probing was performed according to the reflections offered by each respondent, but sought to cover themes such as their experiences of post-stroke life and the role of family caregivers in this process.

Study IV: Two focus group discussions (FGDs) were conducted with 10 persons. Each (FGD) included five experts. Because of extended discussions and as the group members requested to continue the exploration of the phenomena of interest the FGDs were repeated to achieve the aim. At the beginning of the FGDs, the participants were asked general questions about their concept of stroke rehabilitation, and how they experience community rehabilitation services for stroke survivors. Then the discussion continued with more detailed questions about their own experiences and perceptions. They were also asked about their suggestions as to how to develop care for stroke survivors and their family caregivers within the community. FGDs were based on an interview guide which was initially developed with help from expert peers.

During the FGDs, notes were made about non-verbal cues and the topics that were raised by the participants. These topics were explored later if participants had not already spontaneously discussed them. The researcher acted as moderator, having one note-taker for registration. Each session took between 1 to 1.5 hours. For completing information regarding rehabilitation services in community, individual interviews were made with four experts who could not participate in the FGD, based on theoretical sampling. For this, two psychiatrists and two psychologists were selected purposefully based on inclusion criteria. Every individual interview took between 60 to 90 minutes and the same
interview domains were discussed as in FGDs. In study (IV), after the first FGD, the final transcripts for analysis were based on the transcribed audiotapes and written notes. These data were analyzed using a grounded theory approach. Then, a second FGD followed, based on the first draft of data analysis and theoretical sampling.

All interviews and FGDs (I-IV) were carried out in Persian, which was the mother tongue of both the interviewer and interviewees. All interviews were tape-recorded. Then, these records were transcribed verbatim and analyzed consecutively. In order to be confident, those participants, who agreed to it, checked their transcripts (member check) and a few minor revisions were made.

Figure 2: Area of study and Source of information

<table>
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<tr>
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<th>Source of information</th>
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Study I
- Everyday life situation
- Life after stroke

Study II
- Stroke survivors’ Interview
- Family caregivers’ Interview

Study III
- Family caregivers’ Interview

Study IV
- Focus group Discussions
- Individual in-depth Interviews
7.3 DATA ANALYSIS

7.3.1 Grounded theory analysis

Data collection and data analysis for studies II-IV took place simultaneously by using the process of constant comparative analysis. Every interview was analyzed directly after the interview in order to identify ideas, which guided the next interview. During the phase of open coding, all interviews were read several times word by word, and incidents, facts, key words or phrases in the text were selected as in-vivo codes.

After that, the codes were compared to the contents in order to find points of similarities and differences as a base for those categories and sub-categories that were developed. These codes outlined properties and dimensions of each category and subcategory. In the next phase, axial coding was conducted. Axial coding means to put data back together in new ways by making connections between categories and subcategories, and developing main categories and their sub-categories.

After axial coding, at the end of the process, a selective coding was conducted in order to integrate the categories that had been developed to form the initial theoretical framework. In this process all categories were unified around a core concept.

7.3.2 Qualitative content analysis

In study (I) data from the interviews with the survivors and the family caregivers were analyzed using the inductive qualitative content analysis (Graneheim & Lundman, 2004). After the transcription of interviews, the researcher engaged in data by reading through the interviews several times. Thereafter, words, phrases or sentences that shared common characteristics or related meanings were identified as meaning units.

The condensation of meaning units was done by a process of reducing the text while still preserving the core. These units were then subsequently coded according to the content of data. After the coding process, all codes were categorized, and then underlying meanings in categories were interpreted. This resulted in two central themes.
8 ETHICAL CONSIDERATIONS

The studies were approved by the National Ethical Committee of the Ministry of Health and Education of Iran (MOHME: P/391, 310705) and also the Ethical Committee of USWRs (801.4.84.1292/120805).

All participants were informed of the purpose and design of the study and the voluntary nature of their participation. Participants gave their signed informed consent prior to the interviews.

The ethical proposal was written both in English and Persian. Other ethical issues in the study involved providing participants with assurance of confidentiality and anonymity.

The interviewees were also told that they could withdraw from the actual sessions at any time and that this applies to the digital recording of the interview as well.

A formal permit from the University of Social Welfare and Rehabilitation Sciences’ Dean and Vice Chancellors of USWRs and head of medical schools and hospitals was received before the start of the research project.

All records and forms were finalized without using any personal information on the subject; and such information was kept in secure files. Data collection was carried out solely in Iran. Therefore ethical permission was not sought from Sweden, but the Swedish guidelines were followed.
9 RESULTS

Stroke survivors and their family caregivers (I-IV) expressed similar experiences from their own perspective. Life after stroke was often very difficult for stroke survivors and their family due to the functional disturbances that stroke survivors had acquired through the stroke. Functional disturbances caused changes in the survivors’ and their family caregivers’ everyday life situation (I) and activity limitations for mobility and other self-managed activities such as ADL (I-II). Lack of continuity of rehabilitation care at home and community (III) and non-integrated rehabilitation services within the health care system (IV) caused the stroke survivors to experience a range of dysfunctions in terms of physical, emotional, psychological and social aspects (I-III).

This thesis showed that the struggle with physical dysfunctions, inappropriate daily plans for leisure activities, changes in mood, facing with economical problems and being worried about changing roles, were experienced as major problems in life after stroke. Participants tried to cope with this new condition by trying to preserve self-worth, seeking support from spirituality, learning, re-learning and thereby regaining independence (I).

Stroke survivors and their family caregivers perceived inability to move the body was the most important problem that was caused by the stroke (I). They often faced limitations for playing roles in the family and society as well as losing their jobs, which resulted in their social limitations and isolation (II).

Inadequate social and financial support, lack of an educational plan, lack of access to rehabilitation services, and physical and psychological problems were found in the study (II) to lead survivors to functional disturbances, poor socio-economical situations and life disintegration. Stroke survivors were dependant on their family members, which caused them to feel useless.
Study (III) showed that lack of continuity of rehabilitation care was connected to certain problems, such as inadequate knowledge and skills for survivors and their family caregivers, inappropriate access to rehabilitative services and inadequate social insurances.

Family caregivers tried to solve the problems by modifying the home environment and managing co-existing medical conditions with help from the extended family and friends. The extended family and friends were also an important element to preserve the unity of family. Family engagement was needed to compensate for the lack of continuity of care at their homes (III).

The rehabilitation experts in study (IV) experienced that the survivors faced with a lack of integrity in the rehabilitation service, due to a shortage of public resources, inadequate social insurance, lack of availability of rehabilitation care, negative public opinion, lack of consistency in care and of separated services and professional division. According to experts’ recommendations, rehabilitation care could be modified by reforming rehabilitation care and devising a registration system as well as providing information and skills for survivors and their family caregivers.

9.1 Problems mentioned by all participants

Inadequate rehabilitation services and lack of them
Survivors (I-II), their family caregivers (II-III) and rehabilitation experts (IV) experienced that they could not use the existing services and the rehabilitation services in the community because of long travel times to the centers and inappropriate transportation and public facilities. Participants perceived that rehabilitation services were mainly offered in public rehabilitation centers (I-IV) that usually relied on students as the work force, which means that students can only deliver services to their clients according to the school calendar. Lack of availability of these rehabilitation centers is difficult for stroke survivors and their families (II-III-IV). Experts perceived that the private sector plays a significant role in health care provision (IV) and accessing these services was regarded to be expensive and not easy to afford in the survivors’ home (I-IV). Main causes for this were identified as undefined rules and rehabilitation services expenses and
also lack of a discharge plan (III-IV). Therefore, stroke survivors and their family caregivers have suffered from not receiving suitable rehabilitation services (I, IV).

Survivors (I-II), family caregivers (II-III), and the rehabilitation experts (IV) recommended that good accessibility to rehabilitation services would be effective for survivors. Therefore, they recommended that rehabilitation centers should be extended by government and non-government organizations within the cities and country in order to ease the access to them. Besides, these services should be covered by governmental and private insurance (II, IV). Caring services were also wished to be available and be covered by insurance companies, so that even home care services would be covered by these insurances (II). Loss of energy and increased family burden caused delays in recovery (II).

**Lack of knowledge and skills**

All groups of participants experienced lack of knowledge and skills; it meant that survivors and their families did not know how to deal with the new situation and how to provide care for the survivors (I, III, IV). They perceived that without receiving appropriate information and education, problems such as transferring, lifting, feeding, and drug taking, occurred. This lack of knowledge resulted in loss of energy and increased family burden and delays in recovery (II-IV). Thus, the participants recommended that appropriate rehabilitation programs should be designed, and that the survivors and their family caregivers were to be provided with information regarding stroke recovery by information programs in mass media and that the stroke survivors and their family caregivers should receive medical and rehabilitation recommendations from formal caregivers and experts (II, IV).

**Financial problems due to inadequate social insurances**

One major problem that was experienced by the different participating groups was the inadequate social insurances for stroke survivors and their family caregivers (I-IV), as they were perceived not to support the rehabilitation services sufficiently. Therefore, most of the survivors and their families paid these expenses from their own pockets, if they could afford it. For those who were unable to afford the costs, neither the public nor the private rehabilitation facilities in their homes or in the community could be accessed.
**Strategies and recommendations**

The appropriate strategies that stroke survivors and their family caregivers used to deal with the new life situation and improving functional performances including; sustaining the integrity of the family, searching from spirituality, acquiring knowledge and skills regarding post stroke life and recovery, following medical recommendation with experts, using coping strategies and, covering services by social insurances and using nursing care at home (II-III-IV).

9.2 The process of life after stroke in an Iranian context

According to Wack (2009), “the Storyline Method is based on the theory that knowledge is complex and many layered, that learning is guided by one’s prior knowledge and experience, and that learners construct their own meaning through action and experience. Storyline provides the context for learning that actively engages the student, building on the student’s own experiences, and developing knowledge based on a student’s self determined needs. The goal of the storyline is to bring many elements of the curriculum into a collective interactive environment; an environment created by the student” (, p. 153).

The storyline of this project (Figure 3) has shown, how the concepts from studies (I-IV) were related to each other regarding life after stroke and providing rehabilitation care among survivors in an Iranian context. Some variables’ effects on this process, were contextual conditions, including non-integrated rehabilitation services (IV), lack of discharge plan, daily plan for leisure activities and negative public opinions (I-II-IV), family integrity and family networking (I-III). These factors influence situations such as barriers for accessing survivors to appropriate rehabilitation care in their homes or community (I-IV). The functional disturbances occurred for stroke survivors, were by causal conditions. Also intervening concepts, like lack of continuity of rehabilitation care (III) and negative public opinions (IV), caused survivors to face a range of functional limitations (II). For instance gender aspects, such as female patients preferred to take services by female professionals, and female professionals felt insecure going into survivors’ homes, interfered with the rehabilitation care provision. Even male professionals were uneasy and unmotivated about going into survivors’ homes (IV).
Moreover, due to lack of a socio-economic support system (II-IV) the stroke survivors experienced no appropriate stability in life because they were inadequately supported by social insurance, or had not enough financial support and social services (I-IV).

Stroke survivors were usually referred to public or private care centres or were cared for at home (I-IV). Rehabilitation is offered mainly in the public rehabilitation clinics that usually rely on students as a work force (IV), while in the private sector; the services are broad including home care services and professional care based on clients’ needs. However, the private services are very expensive for the survivors and their families (II-III-IV).

As parts of Iranian cultural values and Islamic religious beliefs, preserving family unity and maintaining family structure and emotional support during the rehabilitation period (I-II-III), were the strategies that the families used. Participants valued appropriate knowledge and skills regarding the adaptive strategies for stroke survivors and their family caregivers as essential in performing activities of daily living. Participation in social activities for improving their life situation emphasised (I-IV). Social supports from family, from community and from a close personal relationship were each regarded to have a beneficial effect on stroke patients. The stroke survivors and their families who regarded their friends or family as a source of encouragement sought social supportive resources. Families sought to use new information on how to deal with stroke and the available services and tried to make use of the health care providers’ recommendations as resources (I-III).

Despite of the existence of problems for stroke survivors and their family caregivers, they tried to accept reality and they actually believe in God and God’s consent for achieving a higher level of ability and mastery of their situation (I-III) to learn how to deal with and adapt to their new situation (I-II-III). However, stroke survivors and their family caregivers adopt different strategies to master the situation (I-III).

As a consequence of lack of continuity of rehabilitation care (III-IV) and non-integrated rehabilitation services (IV), survivors and their families experienced physical dysfunction, which caused limitations in physical activity and in ADL (I-IV). Due to the lack of a functioning social network and supportive systems, public care and educational systems, stroke survivors were faced with high dependency on others (I-II), especially
on family members (I-IV). Therefore, the stroke survivors often faced limitations in playing a role in their family and in society due to their physical impairment (I-II). Stroke forced some to leave their jobs, which resulted in social limitations and isolation (II). They also suffered a lack of success in handling and controlling the new situation (I-III). The survivors experienced decreased motivation, which affected their quality of life. They felt that they were a burden to others, and their lives were disintegrated (I-II).

They also suffered from having no access to the few existing rehabilitation centres and suffered from low incomes, which made it impossible for them to get such services at their homes (I-IV). They felt that the government should help them in providing these services as they would then enjoy a better quality of life and escape the physical, emotional and social limitations (II-IV).

Therefore, the rehabilitation services seem to need refinement (II-IV), with teamwork and cooperation between the different agencies and professionals and to organise a functioning registration system (II-IV). There was also a need to see the whole family’s needs in order to provide successful rehabilitation (IV) and to inform the stroke survivors and their families about stroke and stroke rehabilitation (I-IV). Family caregivers believed that an effective nurse's role is important in the recovery of these patients (III). They also emphasised that the lay caregivers could help them during the first few months (II-III). As the non-integration in many parts depended on policymakers’ decisions, it was also important to change policymaker’s attitudes, and persuade them to understand the benefits of community rehabilitation (I-IV). Then the services could be better integrated (II-IV). Continuity of delivery services and adequate family consulting should be considered during home care to facilitate and improve family and survivor’s functions (III-IV).

Rehabilitation services should be involved within the health care system in order to facilitate the referral system, follow ups and the continuum of care and recovery process of survivors to achieve their maximum functions (II-IV). Appropriate distribution of, and accessibility to these services, were considered by participants as important (II-IV). Educational, practical and financial support are perceived as needed by the stroke survivors and their family caregivers in order to enhance better coping in the difficult life situation and increasing continuity in rehabilitation care (I-IV).

Social and emotional support should also be provided to minimize the family members’ burden and help them manage the consequences of stroke. Family caregivers regarded
nurses to be in a unique position to facilitate and increase understanding of what has happened and the consequences of it (I-III).

Therapist, specialist, survivors and their family care givers are concerned with the home environment medications to prevent survivors' limitations from immobility and to motivate survivors to mobility, physical activity and functional roles (I-III).

Provision of survivors’ rehabilitation care by social supports when they have lost their job and training them to participate in new jobs based on their capacities, encourages survivors and their families to healthy living (II-IV) and would help them learn how to organize their own family and prevent their burden (II-III). Physical activity and encouragement of further mobility, including social activities such as going to parties, travelling and pilgrimages could be beneficial for stroke survivors (II-IV).

Stroke survivors and their family care givers perceived that an appropriate program, some information regarding stroke, use of a special program in mass media and also taking medical and rehabilitation recommendation from formal caregivers and experts, are very useful for them (I-IV).

Participants experienced that there is a need to establish a holistic registration system for rehabilitation services from hospitals to homes for following the stroke survivor situation (III-IV). It would help the experts, the survivors and their family caregivers to be informed about new information and recommendations (I-IV).

The role of the family was regarded as crucial in every aspect of health care (I-IV). Experts suggested that professionals should work with both the stroke survivors and their family members in order to gain better functions. Researchers explored the reasoning that survivors needed to be supported by insurance companies for assessment of functional status by standardized tools and taking suitable rehabilitative care in their homes (II-IV).

Experts also considered that continued physical activity and rehabilitation services could help improve the stroke survivor's quality of life, encourage independence and lower the risk of a future stroke (I-IV). All participants wanted services that facilitate greater consistency, including shared journals of patients and their families and multidisciplinary and discharge planning meetings (I-IV).

Therefore, rehabilitation services at home by teamwork, can improve stroke survivors and family’s functions (I-III).
10 DISCUSSION

10.1 Methodological considerations

When this research project was designed, there was no information regarding life after stroke in the Iranian context. Only a few papers had been published about epidemiology of stroke in some local parts of Iran. Therefore, qualitative research methods were chosen to explore this relatively new area. The project commenced by studying the process of life after stroke with a GT approach (II-IV), and then the everyday life situation was explored by qualitative content analysis (I) to indicate good material from which the researcher could answer the questions through content analysis. It means the researcher followed the process of life after stroke (II-IV) as well as looked at the everyday life (I) to understand what has occurred and how survivors and their family dealt with the consequences of stroke and met the everyday life situations. This was to clarify the aspects that then resulted in the process. Also when the researcher wanted to see the whole picture of life after stroke, he selected experts who were professionals in the rehabilitation field to help to clarify this story (II-IV).

One of the challenges during this research project was the mistrust among the participants and researcher, especially regarding letting him enter the participants’ home. Trust was achieved by being sensible and by giving clear information.

Despit, using of five panels of expert for analysing of study (I) it seems more interpretation is needs to achieve high quality of the analysis as reminded weakness in this paper.

According to Lincoln and Guba (1985) trustworthiness is achieved by the satisfactory attainment of four constructs that relate to credibility, dependability, confirmability and transferability which together establish applicability, consistency and neutrality.

For trustworthiness of the data in this research project the researcher used five main strategies. For confirmability and credibility of the data the researcher has given participants the opportunity of revision of their interviews (member check). He also prolonged in-depth engagement with the data and the emerging codes and categorizations as well as conducted seminars with PhD students. For dependability and
confirmability of the data, co-authors’ reflections of the reasonability of the analysis was used (peer check). Revisions were made by faculty members, who were experts in the field of rehabilitation care, and who checked summaries of half the transcripts and all coding procedures (expert check).

By using different data generation strategies, such as an individual in-depth interview and FGDs, the researcher has tried to achieve more credible results.

The experts to study (IV) were chosen with a similar process by holding two small FGDs (each group of five persons). Although they belonged to one university they were experts in stroke rehabilitation both in the public and private sectors.

Data was collected from a small group of stroke survivors (I-II), their family caregivers (II-III), and rehabilitation experts (IV) in the capital of Iran, Tehran. Due to the small sample of this study project, the findings cannot be generalized to other contexts, but might be transferable to other urban as well as rural conditions in developing countries.

In order to explore the phenomenon of “life after stroke”, a greater variety of the participants in terms of age, gender, socio-economic background, education, severity of stroke, level of recovery process and their support services would have given a broader picture. However, as the research field is new in Iran, the relatively uniform urban group made it possible to go deeper into the analysis, and develop a tentative model, which can be used in future projects with broader perspectives.

The interviews and analysis process (I-IV) was conducted in Persian language; two of the supervisors were Persian speaking. The analyses were mainly conducted under the supervision of the Iranian supervisors and the Swedish supervisors participated in discussions and helped by providing critical comments and questions to refine the emerging analysis.

In paper (II-IV) the method used is described as grounded theory, as the ideas of GT directed the process of data collection and analysis. According to Backman & Kyngäs (1999) Strauss & Corbin’s (1998) GT approach is a good tool for a novice because of the
well-defined concepts which make it easier to maintain the logic of the study. Heath & Cowley (2004) recommended the novice researchers adhere to the principle of constant comparison. This seemed a suitable method for analyzing the data. However, the analysis did not manage to follow the demands of the abstraction needed for grounding a theory, and can be seen as a weakness of the study. Therefore our data analysis was presented in a descriptive level which can be developed in future.

Moreover, as the data triangulation outlined several common problem areas, mentioned by all the different participant groups, it thereby strengthens the trustworthiness of these findings.

10.2 Discussion of the results

Due to lack of continuity of rehabilitation care (III) and non-integrated rehabilitation services (IV) the stroke survivors and their family caregivers were not able to perform their roles and activities in terms of physical, psychological, emotional, social and spiritual dimensions. Therefore, all participants recommended some strategies (I-II-IV). All groups of informants in this research project mentioned as problems the availability and affordability of rehabilitation services. Moreover, the survivors and their family caregivers have been faced with lack of knowledge and skills. Also inadequate social insurances were seen as problem for covering rehabilitation services at home as well as in community settings. These problems were perceived to delay recovery process and contribute to the families’ burden.

Physical dysfunction

Physical dysfunction caused stroke survivors’ activity limitations for mobility and other self-management tasks such as ADL (I-II). Family caregivers experienced that they have been faced with problems in moving and transferring their survivors (III). Therefore, education of stroke survivors and their family caregivers, by nurses and other rehabilitation team members, could improve the survivors’ physical activities allowing them to perform their individual and social roles.
In this line Alguren et al (2010) found that problems in body functions at 6 weeks, after stroke, as well as at 3 months were identified as significant in International Classification of Functioning, Disability and Health (ICF) categories of body functions.

**Availability of rehabilitation services**

Availability of rehabilitation care was regarded by the participants as a large problem for the survivors and their families, particularly for those with low incomes (II-IV). The stroke survivors and their families had problems accessing the services, as the rehabilitation centers were often located far from the stroke survivors’ homes (II-IV). Therefore, these problems caused delay in the recovery process and were experienced by stroke survivors to contribute to the families’ burden. This research shows that stroke survivors suffered from having limited access to the few existing rehabilitation centers and that they suffered from low incomes, which made it impossible for them to get such services at their homes. They felt that the government should help them in providing these services as they would then enjoy a better quality of life and escape from physical, emotional and social limitations. Therefore, the family caregivers recommended that all families should have access to nurses’ help in the rehabilitative care after stroke.

Similarly, Kirkevold (2010) mentions that because such services are not available, this may be a critical time when stroke survivors and/or their families may need intensified support, emotional encouragement, and help to interpret future possibilities and limitations. According to Kirkevold (2010), the transition period frequently leads to frustration, sadness, desolation, and grief as new limitations are discovered. At the same time, many stroke survivors no longer receive nursing care or other regular follow-up from healthcare services, either because such services are not available or, in countries without a national health plan, because they are not reimbursed by the patient's health insurance plan.

**Family roles**

The families tried to preserve family structure, functioning and emotional feelings by receiving help given by members of the extended family and friends according to the Iranian cultural values and Islamic religious beliefs (III). Based on this study result, because of inadequate social insurance, the families in middle class and low income
categories could not receive rehabilitation services at their homes (I-III-IV). That is why the family engagement was needed to compensate for the lack of continuity of care in their homes (III).

Some family caregivers advised that their family had moved from small cities and villages to Tehran and had lost the resources of extended family and therefore they could not use their support, and therefore both the family's functions and relations were lacking after stroke.

In these cases, it is the government’s and NGO’s responsibility to preserve family integrity and consider family support in terms of social and economical situations so as to pay attention to the needs of the patient's family (I-IV).

In this regard, Lagerström et al (2010) point out that the family in Iranian society is an important source of support. Moreover, McKeivit et al (2004) noted that caregiving often takes place within a context of family relationships. Family caregivers have a positive benefit, because caregivers develop their own strategies to increase their competence, creating their own solutions for patient’s functional loss, constructing their own sense of what recovery means, and using their own spiritual beliefs and practices.

**Social insurance**

The main difference in findings of this research compared with other studies, especially from the Western countries, was the inadequate social insurances in Iran, which was expressed by all participants. Participants perceived that covering of rehabilitative services by social insurances can help survivors and their family caregivers get better rehabilitation facilities and improve functional performance. The social insurances can also reduce stress in the survivors’ situation by providing relief to lay caregivers for helping those family members. So in these cases to improve the survivors and their families’ social functions, covering sick leave and cost of rehabilitation services by social insurances help them to be independent financially (I-IV).

Previous studies have examined the effect of different types of social support on functional recovery after stroke (McKinney et al, 2002 and Friedland& McColl, 1992). They have shown that social support of family and close personal relationships have a beneficial effect on stroke patients. As Shah (2006) and Weimar et al, (2002) claim, the
post stroke family support, financial status, and community resources should be evaluated to optimize a successful return to the community. Accordingly, Smith & Midanik (1980) also noted that favorable recovery was associated with socially supportive primary groups, in terms of lay help and consultation, and a wider range of kin and non kin sources tended to enhance outcomes.

**Knowledge and skills**

The participants expressed the need of education and skills related to stroke care and the recovery process should be provided and transferred from hospital to home in order to improve the quality of the survivor’s daily life and how they should deal with problems related to stroke. They also believed that there was a relationship between stroke survivors’ needs and the educational abilities of caregivers (I-IV).

This study also indicates that there is a need to train rehabilitation workers about the role of planning and practice by each member of the teams (IV).

Bakas et al’s study (2004) show that family caregivers have concerns about managing the symptoms and deficits of the stroke survivor. Lui et al (2005) indicate that teaching family caregivers how to cope with these problems and to relieve their stress is essential. There is also some evidence that the caregivers’ well-being affects even the health and recovery of stroke patients (ibid). The findings of this research can be compared to the Iranian context, and even Sahebalzamani et al (2009) who emphasize that self-care education of stroke survivors can improve a patient's performance, and change them from a dependent to an independent person. Therefore, government should provide some rules and facilities within the community via educational programs for stroke survivors, their family caregivers and health care providers.

**Nurses’ roles**

The participants experienced that the nurses’ role and functions were helpful to promote healthy lifestyle, advocate available recourses and give the survivors and the family caregivers' guidance and recommendation and advice on prevention of stroke relapse. According to this study’s results, the nurses helped the survivors and their care givers to improve their situation at home regarding education regarding medical recommendations and how to manage co-morbidities. Therefore, nurses can bridge the gap between the
family and health care providers in order to get continuity of rehabilitation care in their homes and community settings.

According to Kirkevold (2010), stroke nurses can ensure that the nursing care contributes to the therapeutic goals set for the individual patient. Kirkevold’s (ibid.) findings are important in that they point out how nurses can contribute to the adjustment and rehabilitation process of stroke patients if contextual, organizational, and educational measures are put in place to support this level of functioning. The stroke nurse can review the situation and provide support to the stroke survivor and/or caregiver with regard to the physical functioning and ADL, knowledge about the consequences and implications of the stroke, the ability to cope emotionally, the potential support of the home environment, medication management, transfer of care arrangements, and health promotion issues.

**Challenges with changes and coping with a new situation**

When the stroke survivors and their family have found a steady state and a new orientation a few months after stroke, they are usually resigned to what has happened in their lives and their new conditions. Those who manage to regain their autonomy and independency also point to more positive feelings about what happened to them and have a more positive view of the future according to preserving of self-worth, and searching for strength from spirituality to achieve better functional performance. Stroke survivors and their family caregivers suggest to a greater extent what they are capable of and how they try to find solutions and adapt to cope with the new conditions (I-IV).

The results show that stroke survivors and their families suffered from stroke consequences; it means their lives have changed. It was something that suddenly happened to them that they were not prepared for it. It can be seen as a loss of their former lives. According to Meleis (1986), they have begun a transition involving their health and disease. The results of the study show that there is a problem for the stroke affected in not knowing about what happens when such a change occurs that is beyond their control and they do not know what the future will bring. This can, as Meleis et al (2000) claim, lead to negative feelings about the transition.

**Stroke as a transitional process**
Based on these study results, it seems the life after stroke like the transitional process is one from dependency to greater independency after rehabilitation. Stroke survivors and their family care givers are trying to cope with the new situations through an independent approach and try to help them recover their autonomy (I-IV). Meleis (1986) argues that in order to enter into a transition, the individual must be aware of the changes that have occurred and will occur, otherwise, the individual will not be able to start this process. Barriers to this may be the denial of the consequences of the event from which the individual does not yet understand that a change has occurred.

According to Kralik et al (2006), transition is not only a passage or movement but also a time of inner re-orientation and/or transformation. The experience of transition is a process that involves disruptions in close relationships and daily living. This means that individuals seek to regain control following the disruptive event, and reconstruct their self-identity.

The author of this study believes that rehabilitation care needs to be supported by social insurances for people who undergo this transition to enable them to cope with the process and reach a new stable state. Rehabilitation care needs to be offered and it means that ways should be made available to those who suffer from disabilities after a stroke to rebuild their lives and gain a new form of independence. They need the support of experts to deal with different parts of the complexities that make up a human being and which concern them. The nurse plays an important role in responding to survivors’ needs and then ensures that there is good cooperation with other professionals to meet the needs.
11 CONCLUSIONS

According to the experiences of the majority of stroke survivors, their family caregivers, and rehabilitation experts, non-integrated rehabilitation services within health care system, lack of continuity of rehabilitation care and inappropriate daily plans for leisure activities cause stroke survivors’ functional disturbances in terms of physical, emotional, psychological and social aspects of life. Lack of availability of rehabilitation services, lack of knowledge and skills and inadequate social insurances were the main problems in post-stroke life among Iranian stroke survivors and their family caregivers.

As daily rehabilitation plans for continuity of recovery and leisure time for spending stroke survivors’ days would ease facilities for survivors and their family caregivers, this is why training the stroke survivors and the family’s how to deal with the consequences of stroke and improving self-governing skills of patients, family assistance in how to deal with the new situation at home, is needed.

The participants recommended changing policy makers’ attitudes in order to allocate an adequate budget and a focus on a multidisciplinary approach as well as to establish a registration system for following stroke survivors’ rehabilitation process.

There is also a need for keeping family integrity, acquiring knowledge and skills regarding post stroke life and its recovery, controlling co-morbidities, following medical recommendation with experts, using mass media, covering the services by social insurances and expanding nursing roles.

In recent years an understanding of nursing roles in stroke rehabilitation, and an increasing interest in caring for stroke patients and in defining nurses’ role in rehabilitation, is evident. Therefore, based on this study, there are reasons to recommend the expansion of nurses’ roles in programs for rehabilitation after stroke.
IMPLICATIONS FOR NURSING CARE

This project has some recommendations for survivors, their family caregivers and experts for understanding survivors’ needs and expectations:

More information is needed to prepare patients for what awaits them after they come home after the hospital visit so that it does not come as a surprise to them; that is, to what extent this will affect their lives. It is necessary to develop daily recovery plans and easily accessible information for patients and relatives, and training of health professionals on what to expect of patients after discharge.

Rehabilitation services should be redefined and involved as part of the health care system in Iran. Community oriented rehabilitation services and team work should be considered.

All rehabilitation care and services should be covered by social insurances.
A comprehensive rehabilitation plan is necessary for survivors and their families.
A focus should be on a family centered approach to providing rehabilitation care.

Public education through mass media and schools should be made available to attract community participation in dealing with the stroke issue.
Generated concepts from this research could be used as a guide for stroke survivors within the family and community.

As an educational plan is the pivotal key in the nurse’s roles, nurses could design and prepare an applicable education plan based on survivors and their family care givers’ needs and the expectations from hospital to community.

Some stroke rehabilitation programs should be designed and broadcast by nurses for survivors and their family care givers from radio and television at a public level.

Nurses should be oriented regarding the effect of stroke on physical, cognitive, emotional, psychological, social and spiritual domains for managing survivors and their family caregivers by participating in stroke rehabilitation programs in nursing...
departments. Nurses should be activated in rehabilitation, especially in the field of Neuro-rehabilitation by becoming involved with other professional rehabilitation services.

Nurses should be encouraged to follow the results of this research to extract concepts and themes and then apply them in context.

Working with an expert team could improve the knowledge and skills of nurses for carrying out procedures individually or providing group work related to survivors and their family care givers.

To be competent and excellent, nurses should be involved in a special field, such as stroke rehabilitation at three levels; hospital, family and community. Research suggests that the health policy makers need to look at results of this research to give opportunities to nurses to enable them to fill these roles by following its rules and related laws for delivering rehabilitation services within homes and community.
13 FUTURE PERSPECTIVE

Based on this study’s results, it will be useful if a further study could be conducted by the Inductive deductive approach between Meleis’s transition nursing theory and the conceptual map of this study, to look at this phenomenon more deeply.

This study is focused on the experiences of stroke survivors, their family care givers, and experts regarding life after stroke in a large populated city in Tehran, and based on the results, the researcher recommends that it would be useful if researchers carry out a future study in a small (Iranian) city or the countryside.

This study recommends that a larger population based research project to confirm these finding and their applicability, even in rural areas of Iran is needed.

The Researcher recommends that for achieving a full picture of life after stroke, the policymakers’ points of view will take into account any future study to light some of these covered areas of post stroke rehabilitation care and rehabilitation management.
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15 REFERENCES


Figure 3- Exploring life after stroke in an Iranian context

Life after stroke

Causal Conditions (I & II)
- A few rehabilitation clinics
- Distance from day clinics to survivors’ home
- Deficiently allocated budget
- Inappropriate social insurances
- Poor knowledge & skills
- Incompatible home and social environments
- Physical-psychological disturbances

Context (I, III & IV)
- Non-integrated rehabilitation System
- Lack of discharged plan
- Inappropriate daily plan for leisure activities

Core concepts
- Functional Disturbances

Intervening (I-IV)
- Negative public views
- Low socio-economical situation
- Participants’ education and experiences
- Lack of continuity of care

Strategies (II & IV)
- Using of public & private sectors
- Family integrity
- Helping from extended family & friends
- Following financial support
- Emotional support
- Self care & preserve self-worth
- Searching strength from spirituality
- Adaptive strategies
- Using of experts’ recommendations

Consequences (I, III & IV)
- Physical limitation
- Emotional disturbance
- Family burden
- Loss of energy & frustration
- Dependency
- Role functions Limited
- Inadequate care & rehabilitation services
- Social isolation
- Loss of job & low socio-economic situation
- Life disintegrated
GENERAL INFORMATION

Today’s Date: 
Place: 
Time: 
Interviewer Name: 

Subject’s Full Name: 
Sex: 
Birth date: 
Age: 
Birth place: 
Born in 
………………………………………………. Till …….big, medium, little city, rural

Marital status: 
Married ☐ single ☐ divorced ☐ other ☐

Education level: 

Occupation: 

Children:

<table>
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<tr>
<th>No</th>
<th>Name of children</th>
<th>Sex</th>
<th>age</th>
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**Interview with the patient**

**Experience of Stroke:**

1. Tell me about when you got stroke? When did it happen? How, what happened?
2. Tell me about your feelings and reactions?
3. Tell me about the feelings and reactions of your near one’s?
4. Tell me about your experience of being hospitalized, staying there, and being discharging?
5. How do you feel about your rehabilitation in the hospital?
6. How do you feel about your rehabilitation at home?
7. How is your life after stroke?
8. What do you think your life is like today (after stroke)?
9. How are your relation with your families, relatives and friends after getting stroke? Have they changed?
10. Do you think that any changes occurred in your family roles after stroke?
11. What changes are made in your life satisfaction?
12. How was your life before stroke?
13. What do you think about the role of nurses in rehabilitation process?
14. What were your experiences with the rehabilitation care at the hospital?
15. How your experiences with the rehabilitation are care at home?
16. What do you think your life will be like one year after today?

**Needs:**

1. What are your needs due to physical, social economical effects of stroke?
2. What are your rehabilitation needs?
3. What do you need to improve the quality of your life?
4. With the care you get today, is there anything that could be done better? In that case what is it?
Experience of Stroke:

- Tell me about your family life? What kind of person was he/she before stroke?
- Tell me about when the member of your family got stroke? When and how did it happen? What happened?
- Tell me about your feelings and reactions, when this happened?
- Tell me about the feeling and reactions of the patient?
- How did you find his/her rehabilitation?
- How do you find his/her rehabilitation process at home?
- What do you think about his/her most important barriers for receiving rehabilitation care were?
- How did you find the nurses’ roles in rehabilitation process?
- What do you think regarding the rehabilitation process for stroke patients?
- What should be done to make your family/patient’s situation better?
- How is your life after stroke?
- What do you think your life is like after stroke?
- How is your relation with your family members, relatives and friends after getting stroke?

Needs:

What do you need due to having a stroke patient?
What are your patient’s rehabilitation needs?
What do you need to improve your patient’s quality of life?
Some more questions for more clarification?

<table>
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<tr>
<th>Question</th>
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<tr>
<td>Do you know what they do?</td>
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<td>Can you give me an example?</td>
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<td>Please speak more about it?</td>
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Guideline for focus group discussions

General questions

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<td>1-</td>
<td>What are the most important challenges of the survivor’s life?</td>
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<td>2-</td>
<td>How do you find delivering of the rehabilitation services to the survivors?</td>
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<tr>
<td>3-</td>
<td>Which strategies do you recommend for improving their life situation?</td>
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Specific and probe questions:

- What are your viewpoints about the patients and their family after stroke?
- How do you experience post stroke situation?
- How do you experience the rehabilitation services?
- What are the most important problems of the survivors’ families and how did you experience them?
- What are the barriers to deliver rehabilitation services to survivors at home and community?
- How you did experience them?
- What are your viewpoints regarding how to improve these services?
- Which strategies do you recommend for improving these services?