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EVERYDAY LIFE EXPERIENCES OF POST-STROKE PATIENTS:
A QUALITATIVE STUDY ON THE IMPORTANCE OF ADJUSTMENT STRATEGIES OF POST-STROKE PATIENTS

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Abstract

This study is an attempt to describe the everyday life experiences of post-stroke patients and their adjustment strategies. It examines the coping strategies of post-stroke patients and analyzes how these strategies have influenced stroke survivors in post-stroke life. A stroke is an unexpected life event leading an individual with various physical, psychological, and social consequences. Stroke survivors may have to deal with immense pain, psychological disturbance, and other cognitive problems such as memory loss, communication deficit, etc., and interruption of social and professional life. Stroke survivors try to cope with their stroke to return to their normal/pre-stroke life. Coping strategies play a significant role as it paves hope and enhances post-stroke patients' quality of life.

The study uses the social cognitive transition model post-stroke patients (SCoTS) to see post-stroke patients' coping strategies. This qualitative research is based on the subjective experiences of post-stroke patients. A semi-structured qualitative interview is conducted with six Norwegian stroke survivors to collect the primary data. The findings of the study illustrate that participants experienced that their post-stroke life has been changed markedly. Bodily change, disruption in working life, and losing pre-stroke self are some of the participants' everyday life experiences. They adopted different types of coping strategies to deal with the stroke. Positivity, support from various sources, exercise and training, and engagement in other activities are some of the strategy participants applied to their everyday lives.

In a nutshell, this study is relevant for post-stroke patients and health professionals to gain a better understanding of the everyday experiences of post-stroke patients and their coping strategies to achieve a normal life. This research also highlights some of the common post-stroke experiences and coping strategies with specific subjective experiences.

Acknowledgment

First of all, I would like to thank the participants who participated in this study and shared their valuable thoughts and stroke experiences. This study would not have been possible without their trust in me and without their support and involvement.

Secondly, I would like to thank my supervisor Dag Jenssen for believing in me and helping me explore my abilities. This research would not have shaped its journey without the guidance and motivation of my supervisor. I couldn’t stay thanking the Norwegian Institute of Public health for providing the best possible resources and opportunities in facilitating this thesis work. I would like to thank Storbyuniversitet (OsloMet) for allowing me to study in Oslo, Norway. I am ever grateful to my family and friends who made Norway my second home. Thank you for being there for me.

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1. Introduction:

1.1 Epidemiology:

Cerebrovascular accident (CVA), stroke, or "brain attack" is one of the leading causes of death and acquired disability in adults in the world today. Stroke is a global health problem and ranked as the second most common cause of death (Lozano et al. 2012) and a third most common cause disability-adjusted life years (DALYs) worldwide (Murray et al. 2012) according to the estimate from the global burden of diseases, injuries and risk factor studies (GBD 2010). Different factors are related to the increase in stroke survivors and people affected by the stroke of which improved stroke care, aging, and growth of the population combined with the increased prevalence of many modifiable stroke risk factors play an important role (Feigin et al. 2016).

In high-income countries, stroke incidence has been decreased by 42% in the last four decades (O'Donnell et al. 2010). There is no apparent reason for the differences between high and low low-income countries. Still, it is supposed that low and middle-income countries lack the same advancements in acute stroke care and secondary stroke prevention measures as seen in high-income countries in recent decades (Ovbiagele and Nguyen-Huynh 2011).

Despite the progress in private mention and treatment of stroke in the European nations, the number of strokes is set to rise due to the increase in Europeans' proportion over 70. The global burden of stroke in Europe predicts that between 2015 and 2035, there will be a 34% increase in the total number of stroke events in the EU union from 613,148 in 2015 to 819,771 in 2035 (Stevens et al. 2017). It is also expected that stranding coronary artery disease together will be the leading cause of lost healthy life years by 2020 (WHO 2000).

1.1.1 Stroke in Norwegian Context:

Norway is a comparatively wealthy country with a high life expectancy (81.9 years as of 2015) and a universal public health care system. It has a population of over 5 million with an increase from 4.86M to 5.17M (6.4%) and the number of individuals aged 60 and above increases from 0.96M to 1.06M (10.4%) between 2010 and 2015 (Rand et al. 2019). As in other high-income countries, there is a decreasing trend in the mortality from stroke in Norway in recent decades (Indredavik, Ellekjær, and Selmer 2008). Incidence rates for strokes have also declined in Norway over the last couple of decades, from estimates approximately 400 per 100,000 people at risk (PY) before 2000 (Ellekjær et al. 1997) to around 200 per 100,000 PY based on reports by the National Institute of Public Health (NIPH) in 2015 (Rand et al. 2019). Between 2010 and 2015, 53,431 unique individuals were admitted to Norwegian hospitals with a primary stroke diagnosis and 6315 additional individuals were registered as dead due to stroke, for a total of 59,746 unique individuals (Rand et al. 2019). According to Rand et al (2019), there has been a substantial decrease in the incidence of an ischemic stroke while hemorrhagic stroke incidence remained relatively unchanged. If this trend continues, there will be a continued decline in Norway's overall stroke incidence over the next decades. It is also expected that the incidence of stroke will decline markedly in Norway in the coming years due to the increase in the elderly population (Russell, Dahl, and Lund 2007).

Stroke is still one of the leading causes of death and disabilities in Norway. Approximately 15000 people are affected with stroke, functional loss in the forms of various motor, cognitive, and emotional difficulties are common (Buseth 2013). The mean age for the first stroke in Norway is 75 years for men and 78 years for a woman (Engstad et al. 2012). Lifestyle factors like smoking, physical inactivity, obesity, unhealthy diet contribute to the relatively high incidence of stroke in Norway (Russell, Dahl, and Lund 2007). According to Wekre (2004), approximately 50-60,000 Norwegians live with the consequences of stroke of which 2/3 cases of multiple handicaps like paresis (75-85%), aphasia (20-25%), and cognitive or behavior disorders (10-50%).

1.1.2 Pathophysiology:

According to the WHO criteria, stroke is defined as the rapidly developing clinical signs of focal (at times global) disturbance of cerebral function lasting more than 24 hours leading to death with no apparent cause other than that of vascular origin (Aho et al. 1980). There are two major types of stroke, ischemic and hemorrhagic. Eighty-five percent of strokes are ischemic and result from occlusion of a cerebral vessel with subsequent brain ischemia and infarction, which may be caused by emboli or atherosclerotic thrombi (Toole, Murros, and Veltkamp 1999). Fifteen percent of all strokes are hemorrhagic. Two-thirds of hemorrhagic strokes are caused by intracerebral bleeding, the remaining one-third may be attributed to aneurysmal rupture and subarachnoid hemorrhage (Felberg and Naidech 2003). The underlying pathogenic mechanism for cerebrovascular accidents is the interruption of blood flow and the delivery of essential oxygen and glucose to the brain tissue. The brain does not store glycogen and requires 60-70 mL of perfusion per 100 g of tissue per minute for normal function (Felberg and Naidech 2003). A drop in the blood flow to 25 mL/100 g/min leads to neuronal ischemia, energy failure, and neurologic symptoms, followed by irreversible tissue damage within minutes (Toole, Murros, and Veltkamp 1999).

The INTERSTROKE study of risk factors for stroke found five risk factors accounted for more than 80% of the global risk of all stroke (ischemic and intracerebral hemorrhagic). Hypertension, current smoking, abdominal obesity, diet, and physical activity were the prominent ones. Besides, diabetes mellitus, alcohol intake, and other psychosocial factors were also responsible for stroke onset (O'Donnell et al. 2010). Cardiovascular disease like coronary artery disease, valvular pathology, arterial fibrillation increases the risk of stroke to a greater extent (Engstad et al. 2012).

1.1.3 Impact of stroke:

Stroke is a sudden and often traumatic major life event that usually occurs with minimal warning and, for many, results in life-changing consequences with which affected people must cope (The Lancet 2005). It is an unexpected life event leaving an individual with various degrees of mental and bodily consequences. Life after stroke is certainly tough for all who experienced it. Stroke survival may have to deal with immense pain, memory loss, and other cognitive problems such as communication problems and personality changes. Many studies show that post-stroke effects have a major impact on return to work, social participation, coping with everyday activities, participation in recreational activities, and quality of life. After the stroke, there may be a major disruption to adapt to a new life with altered functional ability. The loss of functional abilities after stroke can lead to self-concept changes, with stroke sufferers describing a sense of no longer being normal and loss of one’s real self. (Becker 1993).

1.1.4 Medical Complication after stroke:

Stroke is often complicated by medical problems that require recognition and specific treatment. Medical complications can occur early or late after stroke and the types of problems that develop vary over time where some of these are preventable with good medical care, whereas others are unavoidable (Stein 2004). Medical complications are common among individuals who have had a stroke, increasing the length of hospitalization and the cost of care (Kumar, Selim, and Caplan 2010). The severity of stroke is the main factor associated with different complications because patients with severe stroke had more complications than those with mild to moderately severe stroke (Dromerick and Reding 1994). Medical complications can hinder functional recovery and are associated with poor functional outcomes after adjusting for stroke severity and age (Johnston et al. 1998).

Most medical complications develop within the first few weeks after the stroke event (Johnston et al. 1998). Some events such as cardiac abnormalities, dysphagia, and pneumonia are early after stroke onset, whereas venous thrombosis, pressure sores, and falls can occur after several days. Many medical complications are preventable; when it is not possible early recognition and treatment can be effective in ameliorating these events early in their course (Kumar, Selim, and Caplan 2010).

The structural changes in muscle tissues start as early as four hour after the brain damage and within the first week after the stroke, muscle weakness develops not only in the affected limb but also on the contralateral limb (Scherbakov et al. 2013). Neurological consequences such as limb paresis or immobility could also predispose the stroke survivors to falls and fractures.

1.1.5 Stroke care and rehabilitation:

More than one-third of patients are functionally dependent or dead at three months after stroke, and up to 90% of stroke survivors are left with functional deficits despite recent improvement in acute stroke treatment (Bettger et al. 2017). A multidisciplinary rehabilitation program remains the mainstay of treatment to improve functional recovery beyond 3 months of stroke onset (Winstein et al. 2016)

The purpose of rehabilitation is to limit the impact of stroke-related brain damage on daily life using a mixture of therapeutic and problem-solving approaches (Smith 2010). Rehabilitation is relevant to both initial stroke recovery and later recovery. Early rehabilitation (first few weeks) uses techniques that seek to influence the potential for neuroplastic change, and later rehabilitation encourages adaptive responses and coping strategies based on educational and psychological theory (Jørgensen et al. 1995).

According to Duncan et al. (2005), stroke rehabilitation begins as soon as the diagnosis of stroke is done and life-threatening problems are alleviated during the acute hospitalization phase. During this phase, the major priority is to prevent recurrent attacks and complications, ensure proper management of general health function, mobilize the patient, encourage resumption of self-care activities, and provide emotional support to the patient and family. Stroke rehabilitation is a multidisciplinary approach and there is the involvement of different professionals like physical medicine, occupational therapy, physiotherapy, speech therapy, nursing, and varying therapeutics (Duncan et al. 2005). The stroke survivors either go too long-term care in the community or begin rehabilitation either at home or at a rehabilitation center (Pecotić-Jeričević et al. 2008).

1.1.6 Stroke and coping:

Stroke causes a variety of physical and psychological challenges and manifestations. Stroke patients might see the changes in the capacity for social functioning, social relations, and self-concept. These stroke experiences have been described in three phases: (1) acute phase (2) improvement/rehabilitation phase and (3) stable post-rehabilitation phase (Kaufman 1988). In the first stage, stroke patients struggle with dysfunction and discontinuity. The second stage is the stage of transition where stroke patients may return home. The third stage is improvement and rehabilitation where stroke patients try to apply different strategies to cope with the stroke. Lazarus and Folkman (1984) have defined coping as the sum of cognitive, emotional and behavioral efforts that aim to handle particular stressors in various situations, whether the situation is demanding or frustrating is decided by the individual. Coping plays an important role in stroke survivors' lives as it gives hope and positively influences the quality of life. Coping after stroke might depend on different cognitive systems and life situations where other influencing factors include individual personality traits and the choice of coping style (Persson et al. 2017). In one of the review articles on coping strategies and health-related quality of life (HRQoL) after stroke, well-being was related to using active coping strategies (Lo Buono et al. 2017). Helpful strategies during recovery seemed to be information seeking, participation in rehabilitation, problem-solving, and engagement in activities (Ch'Ng, French, and McLean 2008).

1.2 Significance of the study:

As already mentioned, stroke can have a major impact on anybody´s life. Stroke may lead to various physical and psychological disabilities. A lot of academic research has been done on how to prevent and treat stroke. Still, comparatively, little study has been done on post-stroke patients' everyday life experiences and their response to stroke and coping with everyday life. Post-stroke patients' everyday life experiences include cognitive, communicative, physical, social, and psychological deficits, which they struggle within the post-stroke phase. Geyh et al. (2004) write that post-stroke patients' whole situation should be taken into account such as emotional, cognitive, and social, as that gives a detailed picture to cope with stroke.

This study attempts at how post-stroke patients identify their challenges and how they deal with that particular challenge. Exploring post-stroke patients' everyday life experiences and their coping strategies is essential in planning for successful recovery (Eftekhar et al. 2010). As he further points out, future knowledge and resources that are considered necessary to meet the helpful coping strategies are always needed. Kirkevold (2010) claims that a new line of relevant research focusing on post-stroke patients' experiences and their coping strategies can provide new insights into effective coping strategies and to an extent rehabilitation care. Post-stroke patients' everyday life experiences and their applied adjustment strategies may be useful for other post-stroke patients to cope with the stroke.

This study aims to explore the everyday life experiences of post-stroke patients and their adjustment strategies to stroke. The present study will focus on the adjustment strategies of stroke patients facing physical, emotional, psychological, and cognitive challenges. Adjustment strategies have a significant role in stroke patients as it gives both positive and negative transition. Throughout their post-stroke life, many choose to collaborate closely with their doctors and physiotherapists and become better informed about their situation and treatment; many people change their diet, believing that this would prevent a recurrence. These adjustment strategies can bring a positive transition in post-stroke patients' life where they learn to adapt themselves to the disease.

On the other hand, many stroke patients suffer from the clinical manifestation of relationship and sexual difficulties, pain, a psychological manifestation of anxiety, depression, and loss of self-image and self-worth, leading to negative transitions like suicidal attempts. This thesis's overall purpose is to explore the everyday experiences of stroke survivors and identify adjustment strategies used by them during their recovery and to enhance understanding of these strategies to manage stroke. The specific aims of the study are to:

1. Describe the everyday life experience of the post-stroke patients,
2. What coping strategies do they use to cope and how has it affected them in the post-stroke phase?

2 Literature Review:

This review evaluates the literature on coping strategies following stroke as well as social cognitive theory. Empirical research is reviewed and critiqued in terms of methodology, findings, and limitations regarding the research question of this thesis:

1.To describe the everyday life experience of post-stroke patients.

2.What coping strategies do they use to cope, and how it has affected them in the post-stroke phase?

Theoretical models for coping strategies to stroke are drawn upon to illuminate the findings. Systematic searches were completed using various databases (Ebscohost, PubMed, Oria, Google scholars). Fourteen papers were identified and categorized according to two research questions.

2.1 Stroke experience, and it is varying over time:

A stroke is an interruption of blood supply to the brain, which stops oxygen supply and nutrients, resulting in brain tissue damage (WHO 2015). Stroke is one of the leading causes of death and disabilities in Norway. Every year approximately 15000 people are affected with stroke; functional loss in the forms of various motor, cognitive, and emotional difficulties are common (Buseth 2013).

The advanced medical intervention in the current era has significantly helped people survive a stroke, which means people live with the consequences of stroke. The most common stroke consequences are physical (paralysis and weakness, difficulties with mobility, pain, n, and fatigue). Sensory impairment, such as eye movement problems, visual loss, and communication deficits, is common in stroke patients. Besides physical difficulties, cognitive impairment and psychological complications make the life of stroke survivors more complicated.

Eight studies were identified out of fourteen that have used the qualitative method to explore the stroke experience and its varying over time. Six of the studies and an interview (Carlsson 2018), (Kirkevold et al. 2012), (Williams and Murray 2013), (Carlsson, Möller, and Blomstrand 2009), (Kuluski et al. 2014), (Moorley 2015). One of the studies used a series of the focus group (Ch'Ng, French, and McLean 2008), and direct content analysis method was used in one of the studies (Kuluski et al. 2014).

These studies frequently described the experience of stroke in individual life. The findings of these studies can be grouped into two major themes: psychological experience and physical experience. Growth of depressive symptoms over time for post-stroke patients (Kouwenhoven et al. 2011), the experiences of sensory impairments in the upper limb of stroke survivors (Carlsson 2018), the experience of fatigue by the stroke patients (Kirkevold et al. 2012), lived experiences of occupational adaptation of stroke patients (Shoshannah Williams 2013), the physical, psychological challenges of stroke suffers during recovery (Ch'Ng, French, and McLean 2008), the co-occurrence of positive and negative feelings of stroke survivals (Carlsson, Möller, and Blomstrand 2009), the experiences of stroke as a disabling life situation among young people (Kuluski et al. 2014), the lived experiences on life after stroke among a group of African Caribbean women (Moorley 2015) are some of the major psychological and physical experiences of stroke survivors presented in these studies.

2.2 Stroke as a Physical Experience:

The physical experience of stroke patients has been described by Ch'Ng, French, and McLean (2008), Kirkevold et al. (2012), Kuluski et al. (2014), where stroke survivors struggled to maintain a normal life in response to the physical difficulties. Major physical symptoms in the stroke survivors included paralysis, loss of mobility, difficulty with vision, cognition, and communication difficulties(Ch'Ng, French, and McLean 2008). Both mental and physical fatigue was another disabling factor in the post-stroke phase. The factor most consistently related to post-stroke tiredness was poor functional status (Kirkevold et al. 2012). The impact of different disabilities and poor functional status on the day-to-day tasks realized by stroke survivors is an attempt to resume their previous life.

The lost abilities made them realize that their life had changed completely after the onset of stroke, and they were struggling to adapt themselves to the new life which was full of difficulties (Ch'Ng, French, and McLean 2008). The impact of physical disabilities on the day to day tasks was a major experience of stroke; many stroke survivors reported a gradual realization of the extent of change they faced as they attempted to resume their previous lifestyle. The experiences of stroke are varying while adapting to the new life which is the life after stroke, and many participants of this study have experienced the lost abilities, and life changed during their recovery process.

Kirkevold et al. (2012) describe fatigue in their study as a physical experience and how they vary over time. Fatigue could be experienced as physical or mental or both physical and mental, but I will include fatigue only to the physical aspect. Their study shows that feeling fatigue is an aspect of post-stroke life, and post-stroke patients might have to deal with many obstacles to maintain balanced actions and reactions. These experiences could change over time, and it seemed to have a less negative impact on life as time passed. Their study which followed the stroke survivors over two years found that 59%, 44%, 38%, and 40% of the stroke survivors experienced fatigue respectively at 10 days, 3 months, 12 months, and 2 years of post-strokes but after that, the level stayed constant. The factor most consistently co-related to post-stroke fatigue was poor functional status.

Kuluski et al. (2014) write about the experience of stroke as a disabling life situation among young people. The participants expressed that to be affected by a life-challenging disease at a young age was shocking in many ways. They further mentioned that stroke leads to psychological consequences for them and their young kids because they continued to experience impairments and disruption in their personal and work lives. Stroke survivors identified fatigue, speech and memory impairment, mobility restrictions, pain, and muscle spasticity more devastating. These challenges made them realize that they were back in their childhood with a sudden loss of their former selves. Carrying out everyday activities and socializing with family, friends were also described as severely affected after stroke. Many participants discussed the struggle in maintaining a relationship with their spouses. Loss of employment at a young age was shocking for many participants as they were the family's bread earner.

2.3 Stroke as a psychological experience.

The psychological experience of the stroke patients has been discussed in the study of Ch'Ng, French, and McLean (2008) (Kouwenhoven et al. 2011) Carlsson et al. (2009) (Williams and Murray 2013). Ch´Ng French and McLean (2008) and Kouwenhoven et al. (2011) write about the post-stroke depression and diagnosis, rehabilitation, and recovery process of stroke patients. Both of these studies significantly address the psychological consequences of post-stroke patients.

Ch'Ng, French, and McLean (2008) mentioned psychological challenges such as anxiety, depression, and decreased self-esteem in their study. Most of the participants in their study described a sense of confusion even after the diagnosis because they could not accept the loss they were facing due to stroke. Anxiety and depression was a critical challenge because they were uncertain about their recovery. Distress was connected with the hobbies and activities of stroke patients. Hobbies and activities were directly connected to distress as those were major sources of happiness and pleasure. Life was not normal after stroke for many participants which resulted in frustration, anger, and despair. DA decrease in self-esteem was also noticed in the participants because they couldn't perform all the activities which they could easily before the onset of the stroke.

Kouwenhoven et al. (2011) also describe the similar psychological consequences of post-stroke patients in their study. This study found that post-stroke depression could lead to poorer outcomes in stroke survivors in the process of recovery and rehabilitation. The non-depressed stroke survivors accepted the stroke-related disability, whereas the depressed survivors referred to themselves as useless and could not accept it. Depressive symptoms such as fatigue and tiredness, sleeplessness, lack of energy and emotions of sadness and frustration, and helplessness feelings were common in the stroke survivors. Episodes of anger, anxiety, frustration were some of the common experiences described by the participants. They also mentioned that crying was frequent after the outset of the stroke. This study further discovered that unpleasant feelings such as sadness, loss of pleasure, self-criticism, loss of energy, suicidal thoughts were also connected to stroke survivors.

Carlsson et al. (2009) also mentioned persistent cognitive and emotional dysfunction in his study. The participants expressed fear of a new stroke and were uncertain in every aspect of life because they could not manage difficult life situations. Negative thoughts and views about life were also discussed in the study. Participants blamed themselves for being misfortune because of the stroke. Feeling of uncertainty, worry, distress, and confusion were also discussed by the participants.

The participants have expressed similar types of experience in the study by Williams and Murray (2013). For many having a stroke was an extreme shock because it brought unexpected changes in their lives. Being trapped inside the house with limited occupational choices leads to a feeling of hopelessness and a decrease in occupational engagement motivation. The feeling of frustration and confinement was noted in participants due to the reduced social contact and the limited number of available occupations. They could no longer perform occupations like weeding, gardening to the previous standard. It was also observed that the participants were in fear and apprehension due to limited mobility and compromised balance.

2.4 Coping strategies:

This study includes several pieces of literature as a secondary source of data collection. These literature works have been thoroughly reviewed and try to find out whether they have some coping/adjustment strategies or not, if yes, what kind of coping strategies and how coping strategies enable stroke patients in their recovery process.

2.4.1 Individual and group coping strategies

Several coping strategies are used by stroke patients to cope with the everyday difficulties. These strategies can be divided into individual coping strategies and group coping strategies (Moorley, Cahill, and Corcoran 2016). Individual coping strategies refer to the personal approaches applied by the stroke patients; for example, it could be self-motivation, strength, determination, religious belief in god, etc. Group coping strategies refer to support from family, friends, support groups, or medical professionals. Different types of coping mechanisms are used by the stroke patients in different qualitative and quantitative studies, either individual or group based.

In a study by Carlsson (2018), it has been found that the participants used several personal coping strategies that were used to ease everyday activities like personal care, household, and leisure activities. The participants accepted that the affected limb would not recover, so they avoided using limb for everyday activities. Placing the keys in the pocket of functioning hand, using clothes without button, elastic shoelace helped the participants to manage their lives more efficiently. Participants expressed that too much force in the affected limb would be harmful to their recovery, so lifting was minimized.

Participants with long-term pain after stroke also used similar coping strategies to cope with central post-stroke pain, nociceptive pain, and tension-type headache. Participants with nociceptive pain avoided rapid should movements and were comfortable using the unaffected arm for carrying out everyday tasks. Changing the body's position, massage, aquatic, and other physical training like stretching was noted to be effective in dealing with pain and discomfort. Reading books or solving the puzzles would trigger the tension-type headache, so participants avoided activities that required too much concentration (Widar, Ek, and Ahlström 2004).

2.4.2 Positivity as a coping strategy

Kuluski et al. (2014) concluded that participants with stroke at a young age had a positive reflection towards a life where they felt happy and thankful for being given a second chance to live. They reflected on the story of others who were more devasted than they, which motivated them to move forward in life. Participants also expressed that they were trying to restore the sense of self by engaging in the important activities before the stroke. For example, arts, music, public speaking, or it could also be household activities like taking kids to school and preparing meals.

In similar literature on managing an everyday life of uncertainty, the author has found that participants were motivated to change their lifestyle by bringing change in their eating habits, working habits, and the exercising pattern. It was also noted that both positive and negative emotions were filled in their coping process, where participants believed that self-affirmation and seeking affirmation from others played a vital role in their coping. Participants also expressed faith and hope to be a strong coping factor (Carlsson, Möller, and Blomstrand 2009).

Kirkevold et al. (2012), in their study on “Fatigue after stroke” mentions the participants' motivation to cope. They concluded that participants were physically active, mentally dynamic, and searched for new ways to regain energy to compensate for the fatigue. Going shopping, exercising self, cycling eating healthy stuff made them more positive towards life. Rest, taking nap, not using too much energy on difficult things for them were the changes participants expressed after the onset of fatigue.

The other study “Pain Management Strategies among persons with long-term shoulder pain after stroke: A qualitative study” by Lindgren, Brogårdh and Gard (2019) explores the strategies that a person with persistent shoulder pain after stroke to manage pain in daily life. The participants used various practical and cognitive coping strategies like a practical modification to solve daily life problems. To reduce the shoulder pain, participants used different individual strategies like moving household utensils from higher to lower shelves, using aids when cooking, reducing heavy goods when shopping, and using costumed adopted bicycles or cars with automatic transmission. Participants also expressed that they learned to move the affected arm in a non-painful way or limit the painful movements and activities. Walking, swimming and meditation helped distract pain, whereas leisure activities like gardening, playing golf, or tennis became difficult. The participants also talked about optimism, self-perceived high pain tolerance, and comparing the discomfort to others with a worse situation which gave them the strength to move forward.

The lived experience of older adult's occupational adaptation following stroke is a study to explain older people's occupational adaption after the onset of stroke (Shoshannah Williams 2013). The author concluded that humor, touch, expressing anger, and having a sense of being fortunate when comparing them with other people in misery were useful to the participants when trying to move forward. The use of assistive devices, engagement in problem-solving strategies, and the use of trial and error were also considered to be an important source of coping (Shoshannah Williams 2013).

2.4.3 Support from family and society as coping strategies

The literature on the coping mechanism among African Caribbean women concluded that the church, medical professionals, and faith in religion were the positive aspect of coping. The participants in the study had strong trust for the doctors, physiotherapists, and occupational therapists, where they followed rules of healthy behaviors as instructed by them. Taking medicine on time and training was important for all of them. It was also found that the participants were motivated, strong and had increased self-esteem which helped them to tackle the illness. Attending church, praying, listening to religious media, and maintaining a positive spiritual life helped get peace, forgiveness, and solace (Moorley 2015).

The role of family, friends, and society has been discussed in almost all the literature. In different findings by Kuluski (2014), Widar (2004) and, William (2013) role of families, relatives, friends played an important role in coping. Participants expressed that they had been an important source of support and encouragement in times of need and when they felt very low. Having good social relationships was considered a major part of coping. Carlsson (2018) and Moorley (2015) mentioned the importance of rehabilitation centers for stroke survivors. The opportunity to share experiences with other patients and seek help from professionals helped the participants in their recovery process.

In another study on the association between coping and quality of life, the author discovered a gradual reduction in the physical, emotional, and cognitive ability of a person after stroke. (Lo Buono et al., 2017). Active coping strategies like social support received and the acceptance of life change improved the life of quality after stroke. Support from the family members became an important source in disease management and was also related to a decrease in depressive symptoms. It was also noted that individual personality traits such as positivism and extroversion also positively influenced the health-related quality of life.

2.4.4 Adaptive and maladaptive coping strategies

In different quantitative studies, it has been found that the stroke patients used multiple coping strategies which included adaptive coping strategies and maladaptive coping strategies. In a study on coping during inpatient stroke rehabilitation, it was concluded that adaptive coping strategies like planning, seeking emotional support, and acceptance were used often than maladaptive strategies which included denial and self-blame. Stroke survivors with depression used maladaptive strategies quite often whereas participants with many comorbidities used adaptive coping strategies (Gillen 2006).

A similar quantitative study was based on a coping questionnaire where main strategies were classified into magical thinking, distancing, self-controlling, seeking social support, escape avoidance, positive reappraisal, and problem-solving. It was found that the most used adaptive strategies were problem-solving and magical thinking and the least used was escape avoidance (Anne Rochette 2002). In both, the above study women used more adaptive coping strategies than men as they were less depressed.

Association between executive function and coping aspects is discussed in one of the studies (Kegel, Dux, and Macko 2014). The executive function of the body is related to the cognitive control of the behavior and it also leads to the utilization of adaptive coping strategies. Primary features of executive function include reasoning, planning, decision making, working memory, and judgment. The author of the study concluded that executive function was negatively correlated with escape avoidance which is an avoidant coping. Males were found to be using higher levels of escape avoidance strategies than females. Another finding was that as executive function performance decreased, the use of maladaptive coping strategies increased.

2.5 Adjustment model as a theoretical framework:

The theoretical framework provides structured while interpreting behavior, shows how it interacts with the environment, and predicts interventions' methods. Defining practice based on “a theoretical research” (Boynton De Sepulveda 1994) can result in the use of interventions designed from potentially coincidental relationships that may not be verified with replication. Coping has been defined as the process of managing external or internal demands that are perceived as taxing or exceeding a person’s resources (Lazarus and Folkman 1984). It is also a process of managing a series of transactions between the individual and the environment (Lambert and Lazarus 1970). Coping is a process of learning, development, and accommodation of changes rather than a series of changes that one needs to adjust with.

A study on physical and psychological functioning in recovering stroke patients has primarily focused on post-stroke depression. Post-stroke depression affects one-third of all stroke survivors, it raises mortality risk and hampers functional recovery (Taylor, Todman, and Broomfield 2011b). In comparison, there has been a relative lack of study modeling the post-stroke adjustment process.

2.5.1 Social cognitive theories

Social cognitive theory emerged largely from the writings of Albert Bandura. According to social cognitive theory, social cognitive process such as feelings and behaviors contribute to the development of aggression (Bandura 1986). People can acquire new behavior by adjusting their actions and observing a model accordingly (Bandura 1986). This is to say that learning occurs through observation within a social context. People observe the behaviors of others and use those reflections to construct their own behaviors. Modeling, outcome expectations, self-efficacy, goal setting, and self-regulation are some of the theoretical components of social cognitive theory.

Social cognitive theory looks at wider personal and social changes required in the context of the traumatic events. According to social cognitive theory, a person does not only cope with the event but also draws a conclusion or makes assumptions from the event, some of which could be the sources of psychological distress. Studies show that the conclusion drawn from a traumatic event can act as positive psychological and interpersonal change (Grubaugh and Resick 2007).

2.5.2Social-Cognitive Transition (SCT) model of adjustment

This study will keep on Social Cognitive Model of Adjustment (SCT) to cancer proposed by James Brennan (2001). According to Taylor et al. this model provides a sound theoretical basis upon which to build an understanding of post-stroke adjustment, as they have applied this method in their "Post-stroke emotional adjustment: A modified social cognitive transition model" (Taylor, Todman, and Broomfield 2011b).

According to Brennan (2001), social-cognitive theorist regards cognitive and social transition as being the more critical issues, unlike coping theorist, who focus on how people respond to the crisis, social cognitive theorist is more interested in the broader social cognitive changes required of an individual and their social network in such circumstances. Patients, and their social attachments, are not only responding to and coping with a crisis in their lives, but they are also drawing conclusions from that crisis. Some of these conclusions may be the source of psychological distress and subsequent disorder, but also the source of what has been termed post-traumatic growth.

SCT model is a psychological framework that tries to explain both positive and negative adjustment experiences among cancer patients. It is a psychological model that emphasizes the social context of an individual's experiences and incorporates coping and traumatic stress theories as applied to illness. According to this model, we have a cognitive map or representation of the world, reflecting our social and cultural context and accumulating our life experience. This highly complex assumptive world is biologically adaptive in that it allows us to anticipate and plan for the future (Taylor, Todman, and Broomfield 2011).

This strategy model enables the making of predictions based on assumptions, which are either confirmed or disconfirmed by subsequent experience. The assumption tends to strengthen by confirmation, and disconfirmation leads to disorientation. This model can support an understanding of both positive and negative adjustments as part of the process of adjustment to illness, and the cyclical nature of the recovery process.

2.5.3 Social Cognitive transition model in post/stroke patients (SCoTS)

This model developed by Taylor et. al. (2011b) describes a general framework within which individual differences in post-stroke adjustment can be understood.

This model suggests a dynamic process that may lead to a variety of outcomes for post-stroke patients. It also suggests that adjustment involves a cynical process until the eventful adjustment of assumption is achieved. Taylor et al. (2011b) say that although the study can observe that some patients emerge from this process with better functioning than others, there is no right or wrong way to adjust and there is no time scale proposed for how long adjustment may take.

In the case of typical stroke patients, their assumptive world will almost always be challenged or discomfort by the experience of stroke and its immediate consequences. This often leads to acute emotional difficulties, such as confusion, loss, sadness, and anger. This model foresees that patients who modify their assumptive world to accommodate stroke are unlikely to suffer ongoing mental health problems and maybe observed to have adjusted well. Those patients who do not readily accept or adjust to what has happened, or those who carry negative belief such as “I am worthless,” “others see me as weak,” are prone to emotional distress.

The SCoTS propose that several cognitive abilities are fundamental to stroke patients’ ability to adjust. A cognitive deficit affecting insights or self-awareness may reduce an individual’s capacity to understand their stroke experience and engage in behaviors that would facilitate the adjustment. Similarly, deficits of attention, language, memory, or executive functioning, which are common after stroke, may influence patients’ ability to process and remember the outcome of their post-stroke coping responses. This might prevent the formation of new beliefs and assumptions during rehabilitation, resulting in repeated disconfirmation of the pre-stroke assumptive world and potentially to further emotional difficulties.

The SCoTS describe individuals’ disconfirmation in terms of intra-personal and inter-personal responses. Intra-personal responses represent patients varied cognitive and emotional reactions towards disconfirmation, such as perception about the self, chronic illness, denial, acceptance, anger, and grief. These will impact upon adjustment. Inter-personal responses represent the impact of the stroke experiences on fundamental behavioral and social factors, such as attachment and sexual relationships, social interaction, and health care experiences that have significant meaning for almost all patients. These intra and inter-personal responses propose that post-stroke cognitive, emotional, and behavioral and social coping responses are dynamically and reciprocally linked. These responses occur within a particular social context, which will influence coping strategies and subsequent adjustment. In combination with a patient’s cognitive deficit, this aspect of the model can explain various factors that may serve to maintain or worsen adjustment related distress.

Stroke patients and their families often observe a clear schism between their pre and post-stroke selves (Taylor, Todman, and Broomfield 2011a). In this process, the possibility of disconfirmed assumption increases, which may revolve around body image, self-esteem, independence and control, life goals, and previously valued roles (Taylor, Todman, and Broomfield 2011a). If stroke patients value their work and productivity over other aspects of life, it is believed that they may also be prone to negative coping responses (Taylor, Todman, and Broomfield 2011a). Maladaptive intra-personal coping responses resulting from belief disconfirmation may include negative self-perceptions, low mood, and anxiety, and catastrophic thoughts about recovery. In contrast, negative inter-personal may include attempts to hold on to former roles, social withdrawal, and reduces activity levels (Taylor, Todman, and Broomfield 2011a).

Stroke Patients' interpretations of their stroke experiences are dependent upon their previous perceptions and beliefs about illness and disability. Assumptions about the meaning of having a stroke may be confirmed or disconfirmed by post-stroke experiences (Taylor, Todman, and Broomfield 2011a). Stroke patients who had a healthy lifestyle are likely to have their assumptions about illness challenged and may find it hard to understand why they got a stroke, which is likely slowing the adjustment process. Stroke patients often express frustration with the lengthy timescale in the post-stroke recovery. In such cases, previous assumptions about the recovery time or personal efficacy may have been disconfirmed, leading to a range of intra- and inter-personal responses.

Brennan (2001) writes about the impact of stroke on attachment relationships. Stroke may create profoundly distressing changes in assumptions and interpersonal roles. Assumptions about changed sexual relationship and familial roles appear particularly important to many stroke patients¨ adjustments. Beliefs about social roles and gender identity may also increase patients’ anxiety about judgments others make about their disability. In these cases, patients often adopt behavioral avoidance strategies, further isolating themselves and affecting their emotional well-being (Brennan 2001).

3. Methodology:

3.1 Methodological consideration

I became interested in carrying research on this particular topic because I am a health worker who has worked with post-stroke patients both in the rehabilitation center and hospital in Nepal. This allowed me to look at post-stroke patients' lives very closely and understand the pain and struggle they had undergone due to this unexpected and life-taking disease.

The stroke survivors in Nepal had many problems, including physical, emotional, social, and psychological. The cost to treat this big disease is very expensive in a low-income country like Nepal, where people with low income cannot afford to take treatment in the hospital. One of the reasons where stroke patients lose their life is due to the lack of immediate treatment. Even though they survive the stroke, the consequences after that become very tough. Many of them cannot afford to stay in the rehabilitation center for the required period for the necessary rehabilitation. Those who come to the rehabilitation center are also affected emotionally and psychologically in one way or the other. Some of them are worried about their family, where some of them are worried about the future that holds for them. Learning about all these difficulties in stroke patients in my country, I thought of looking at the situations, and the experiences stroke patients have gone through in a highly developed country like Norway. There is no doubt that people in Norway also have greater experience of this life-taking disease. But the difference is that people get treatment in time, and the government takes responsibility for all the costs in the hospital and the rehabilitation center. This study aims to look at the experiences of stroke survivors in Norway and different types of coping strategies they use to overcome the pain and difficulties due to stroke.

I chose to explore the everyday life experiences of stroke survivors and the role of coping strategies in living a better life after stroke in Norwegian society. It was certainly not easy to come across the stroke survivors and discover their life activities in a community where I am not very familiar. Getting access to the respondents was the biggest problem for me because I was not a health worker in Norway, neither I could speak the language fluently.

In this chapter, I present the methodology I used to collect the data for conducting this research. The present study is an empirical qualitative research gained by collecting data based on semi-structured interviews, data collection, and data analysis. Denzin and Lincoln (2011) define qualitative research as:

> Qualitative Research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.

According to Taylor, Bogdan and DeVault (2015) “Qualitative research refers in the broadest sense to research that produces descriptive data- people´s own written or spoken words and observable behavior”. This means that qualitative researchers study things in detail about people´s experiences. “Qualitative Research is inductive in nature, and the researcher generally explores meanings and insights in a given situation” (JulietCorbin and AnselmStrauss 2008). Qualitative Research enables the researcher to go in-depth from greater involvement in the actual experiences (Creswel 2009). It also helps us to know people personally and learn about what they experience in their daily struggles in the society they live. It further helps the researcher learn about pain, faith, suffering, frustration, and love. The person's inner life, including struggles, successes, and failures in securing destiny with his hopes and ideals, is also learned through the qualitative study (Taylor, Bogdan, and DeVault 2015).

As already mentioned, this study attempts to look from a broader perspective on how post-stroke patients identify their challenges and how they deal with that particular challenge. Qualitative research is best suited to explore these patients' everyday lives because it focuses on words rather than numbers, and it also helps in interpreting the situations to understand the meaning that they make from day-to-day life (Walia 2015). Furthermore, qualitative research helps understand the experiences, feelings, and people’s thought in day to day life as it describes the social phenomena that occur naturally (Mohajan 2018).

3.1.1Methods of Data collection

As my study is based on stroke patients' subjective experience, semi-structured qualitative interviews were used to collect the primary data. According to Kvale (1996), “the qualitative interview attempts to understand the world from the subjects' point of view to unfold the meaning of people's experiences, to uncover their lived world before scientific explanations”. I decided to employ this method in my study because it suits the explanation of the respondents' perception and opinions (stroke survivors) regarding their experience after the onset of stroke. With the help of the interview guide, semi-structured interview also helps to get a similar result from each participant when they express their views, emotions, and experiences. Interviews can also tell us how individual handles the situation and what they feel and think about it. So qualitative interview helps to understand the depth of an individual’s way of lives where the interviewer has a greater say in focusing the conversation on issues that he or she seems important concerning the research project (Leavy 2014).

3.1.3 Researcher participant relationship

The relationship that the researcher and participant maintain during the interview process plays a vital role in gaining the required information from the participants. The participants' openness in disclosing the kinds of information depends in part on the nature and quality of their relationship with the researcher (Given 2008). The distance between the participant and the interviewer should be maintained so that the participant does not feel uncomfortable in disclosing their aspects of life. To make the participant feel comfortable, I started by sharing some of my backgrounds. When I shared my own experience as a physiotherapist, it became easier to build a bond with the participants. I have a history of working with post-stroke patients in rehabilitating them. When I shared my own experience in this field, the participants identified me to a certain extent and were more flexible. This helped in building a rapport with the participants and was essential in avoiding the power relations in my study.

3.1.4 Recruitment issues

When designing my project, I decided to recruit 10 participants who have had a stroke in the last ten years. Thinking this is mind, I became interested in researching with the younger post-stroke patients. I wanted to recruit younger stroke survivors between ages 30 to 50 because stroke at a younger age can leave an individual with disabling impact that may affect their personal, professional, and emotional life. I do not mean that older people do not experience disabling life situations, but when compared to younger ones who are strongly active in all aspects will struggle more and find different ways of coping. Even though I wanted to recruit younger participants in my study, things did not become as easy as I expected. Being an international student in Norway, the first difficulty I encountered was contacting the post-stroke patients in the country. With my supervisor's help, I wrote to different organizations and rehabilitation centers that are working for the rehabilitation of post-stroke patients. I got disappointing results from most of the organizations. But luckily, one organization in Oslo was ready to help me to come in contact with post-stroke patients. They invited me to give a short presentation about my project. I made a short presentation describing my project's main objective and presented it in front of the stroke survivors. The organization also helped me in forwarding my project description to every member through emails. I got a response from 8 post-stroke patients who became interested in my study. I sent personal emails to all eight of them, introducing myself, and describing my study and the research topic. Two of them were not so positive about the interview, and they did not want to be a part of it. But I got a very positive response from six of them where they expressed their time available for the interview. Even though I wanted to recruit younger patients, not all of them fell into my age criteria. So, I decided to include all 6 of them in the age group 40 to 75 with stroke onset in the last ten years. Stroke is a devastating disease and leaves an individual with physical, psychological, cognitive, emotional, and social changes. These changes can persist throughout the life of stroke survivors. Early rehabilitation helps stroke survivors regain physical ability back, but the emotional and psychological pain that stroke gives can persist throughout the lifetime. So, I thought including the participants from the past ten years would not make any difference in my study.

Eventually, I conducted six interviews with every participant. Three of the interviewees were male, and the remaining three were female. Five participants had a history of a single stroke attack, whereas one participant had three attacks. I included the participants who have had mild to moderate stroke and did not have any means of communicative difficulties. The participants who were able to express themselves and were functional were included in the study.

3.1.5 Overview of the interview situations

Before conducting the interviews, every participant was given a consent form to read. Before the interview, I assured them that their names would be changed, and I also explained to them about the confidentiality of the tape recording. All of the participants were positive and allowed me to tape-record the interview. The interview was chosen according to the participant's will because I had to make sure that they feel comfortable in any way. Four participants wanted to be interviewed at my school (OsloMet), where I reserved a group study room to conduct the interviews, whereas two participants preferred their home. It was only the participant and me during the entire interview, as all the participants were self-capable of expressing without being dependent on others. All six of them were inhabitants of Oslo and had been living in the city for many years. Norwegian was the mother tongue of all the participants, but all of them could speak English fluently. Since I was not very much acquainted with the Norwegian language, all the interviews took place in English.

Interviews were proposed to be approximately 60 minutes for each participant, but some lasted around 45- 50 minutes and some 70-75 minutes. Before starting the interview, I gave a short overview of myself, and I asked every participant to do the same to make them feel comfortable. The conversation was further guided by open-ended questions to address the research questions. I focused on the challenges, adjustments, and coping strategies of the participants during their post-stroke phase. In addition to the recording, I took notes during the interview process to remind myself of the useful points. The interview guide, which I had prepared, worked as an important source, even though there were many additional questions during the interviews.

At the end of each interview, all the recordings were transferred to my laptop. It was only me who could access the collected data. The process of transcription began with the transferring of data to my computer. The process of transcribing each interview was long because I spent almost a day transcribing one single interview. I tried to transcribe each interview right after I had the interview with each participant so that I would not miss any important details of the participants. Overall, the process of the interview was a new and fruitful experience for me.

3.2 Ethical consideration

One of the important aspects of any research is that the researcher needs to take into consideration the fact that his/her project is morally and socially justifiable or not. As with every research, ethical considerations are crucial in this research as well. As my project focused on the participants' everyday activities, I was more concerned about two aspects. The project would not cause any mental, physical, and emotional harm to any of the participants and acquire informed consent from each participant before the interview.

Before commencing the project, it was important for me to get approval from NSD (Norwegian center for Research data), a national archive and center for research data. Therefore, I started with the process of getting ethical approval from NSD. The main purpose of getting approval from NSD was to ensure that the Norwegian Research Committee ethically approves my project. After the approval by NSD, the project was conducted following their ethical guidelines and regulations.

An invitation letter and the consent form were given to all the participants where I explained the main purpose of my research. Participants were reassured that the participation was voluntary. They had the right to withdraw at any time where they feel discomfort able or become unsure about their engagement in the study. All the participants were provided with contact details of my supervisor, who could be contacted directly during the study. Each participant was given enough time to go through the written consent form developed in English. In the consent form, I stated that it was completely voluntary to be a part of the project and not based on any pressure. I also made sure that the participants could withdraw at any time or withhold from answering any question they did not want to answer. In the consent form, I also mentioned that recording the interview was completely voluntary and their choice would be fully respected. According to Bryman (2012), "the advantage of such forms is that they allow respondents to be fully informed of the nature of the research and the implication of their participation".

It was also very important for me to protect participants' privacy and not to cause any means of harm to them. Being very confidential with the data was the way to safeguard the privacy of participants. The participants' names were only mentioned in the consent form where pseudo names were used during the transcription process. Thus, the collected data were processed without using the name of the participants. The transcribed data were kept in encrypted files and the original recording was deleted. I made sure that nobody except me could access the processed data.

I also made sure to respect and understand the participant's situation if they experience any emotional difficulties during the interview process. If the participant encounters any emotional difficulty and would not want to continue with that particular story, their views would be respected, and they could also withhold from answering. Above all, this study will never attempt to represent participant views and ideas as something other than what it is.

3.3 Reliability and Validity

Reliability and validity are two important components when evaluating any kind of research. "Reliability pertains to the consistency and trustworthiness of research findings. It is related to the issues of whether a finding is reproducible at other times by researchers" (Kvale and Brinkmann 2009). For example, if any researcher carries out the same project again following the same protocol, they should arrive at the same findings as made in this study. So the researcher must spell out his or her procedure; otherwise, replication is impossible (Bryman 2012). But Goetz and LeCompte (1982) claim that no studies can be replicated exactly because human behavior is not static and keeps changing. Thus, it is certainly very difficult to repeat any studies in all aspects. However, I have tried to describe all the procedures throughout the methodology chapter, which can be important in enhancing the reliability and the transparency of my study. I have tried my best to describe all the procedures in detail and justify how the procedure was carried out and findings were produced. The detailed description of the procedures in this study helps the other investigator to follow the same protocol, which, to a certain extent, can be repeated accurately.

Validity in research is concerned with scientific findings' accuracy and truthfulness (LeCompte and Goetz 1982). Validity also refers to the truth, correctness, and the strength of the statement and in social science, it has pertained to whether a method investigates what it purports to investigate (Kvale and Brinkmann 2009). The issue of validity arises in each step of the research. It rests on the quality of researchers' craftsmanship in the investigation process, on continually checking, questioning, and theoretically interpreting the findings (Kvale and Brinkmann 2009). Different writers have suggested different approaches to evaluate qualitative research. For example, Lincoln and Guba (1985) proposed trustworthiness as the major criteria for assessing qualitative research. Trustworthines further has four criteria: credibility, transferability, dependability and confirmability (Bryman 2012). When we focus on the study's trustworthiness, we aim to validate the social world where reality is constructed by each individual's discourses, actions and experiences rather than giving importance to identifying the absolute truth (Mishler 1990). In my study, I tried to maintain transparency throughout the process. This study is based on the individual's personal experience, but these experiences and views did not influence the interviews, analysis, and findings. It was important for me to build trust- relationships with the participants to not prevent me from obtaining important information. Participants were allowed to express their views freely and I repeated their answers at the end of the interview so that I would not miss anything. The participants would confirm their views again and give relevant feedback. All the interviews were transcribed right after they were conducted, and important points were jotted down so that I would not forget any important aspects during the analytic process. I was also concerned about maintaining a level of interaction between subjectivity and objectivity throughout my study because the researcher's subjectivity can dominate the interpretation and analysis of the data where research findings are often questioned (Brink 1993).

Table 1: Profile of the participants

Participant	**Sex and age**	**Lesion type and side**	**Living situation**	**Functional disability**	**Profession**

1	F/62	Infarction	Alone	Limited function on left lower extremity	Associate professor (100%)
2	F/54	Infarction	With daughter	none	Nurse (60%)
3	M/49	Infarction	Alone	Limited function on left lower extremity	Self-employed
4	M/71	Infarction	With wife	None	Pension
5	F/53	Infarction	With husband	None	Employed (100%)
6	M/75	Infarction	Alone	Limited function on left upper and lower extremity	Pension

4. Analysis of empirical data: a framework for the following chapter

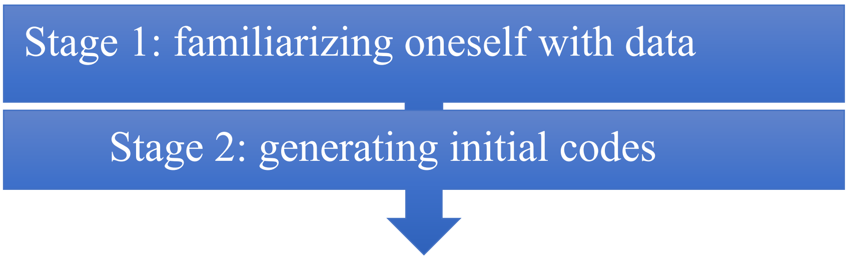
In this section of the study, I will explain the process and method I have used to analyze empirical data. Thematic analysis (TA) is a widely used qualitative analytical method that identifies, analyzes, organizes, and describes data set in rich detail (Boyatzis 1998). Thematic analysis can be both a realist and a constructionist method. It can report participants' experiences, meanings, and reality, or it can examine how realities, meanings, and experiences operate in society. So, TA can be a method to reflect reality and loosen the surface of reality (Braun and Clarke 2006).

4.1. Thematic analysis

Since thematic analysis is based on developing themes, it is essential to know what research theme refers to. A theme is described as something important about the data concerning the research question and represents some level of patterned response or meaning within the data set (Braun and Clarke 2006). There is no hard and fast rule on the correct theme or how many themes should be included in the research. It is not that many data items are given high priority than a sentence or two to be considered a theme. So, it depends upon the researcher's own ability to judge and determine what a theme is. It is determined whether it captures something important concerning the research questions (Braun and Clarke 2006).

4.2 Analytical process

Carrying out a thematic analysis is not a single process but a step-by-step process. Braun and Clarke (2006) have given six different stages in thematic analysis.



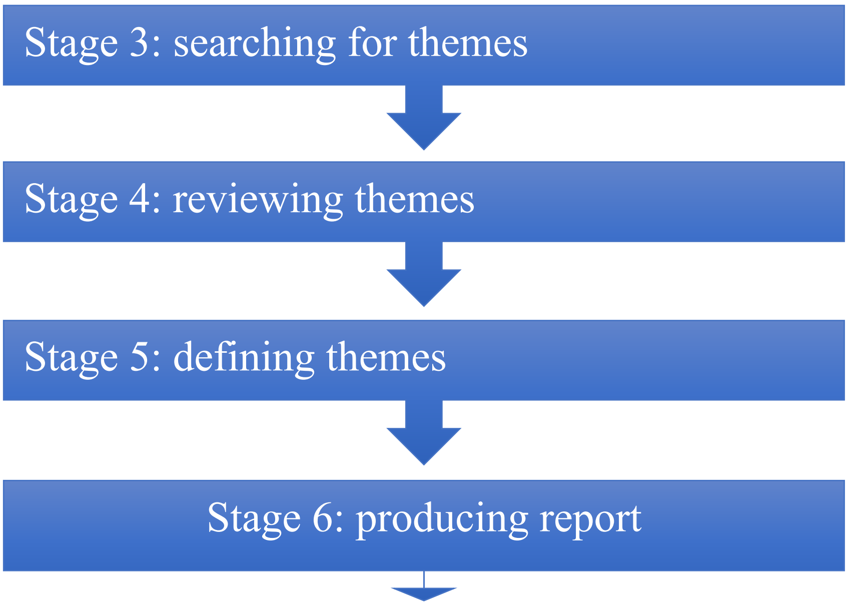


Fig: Analytical process

After completing the transcription process, I went through the data several times to become well acquainted with the content. Reading and re-reading several times made me familiar with the transcribed data, which further helped me produce the initial codes. After generating the codes, it was easier to combine different codes in identifying themes. According to Bryman (2012), themes and subthemes are the product of thorough reading and re-reading of the transcripts or field notes that make up the data. Looking for the commonalities and differences in each text's content helped me generate final major themes. Then I moved into the final stage of analysis.

4.3Analysis

My research aims to explore the everyday life experience of post-stroke patients and the coping strategies they have used in their post-stroke phase. In the following chapters, I present my empirical data findings in the form of different themes. I will analyze my data about the Research question that I have considered to answer, which are to:

1. Describe the everyday life experience of post-stroke patients
2. What coping strategies do they use to cope, and how it has affected them in the post-stroke phase?

Two core themes *changed life,* and *coping with the change* emerged from similarities and differences in participants' experiences. The core theme *changed life* was further structured into the following subthemes:

1. Bodily changes
2. Disruption in working life
3. Loosing pre-stroke me

Similarly, another core theme *coping with the change* was further structured into the following subthemes:

1. Exercise and training
2. Positivity
3. Engagement in other activities
4. Support from various sources

4.3.1. Changed life:

Post-stroke life had changed considerably for stroke survivors. For some, the changed life was something they had never thought of as it brought uncertainty and fear for another stroke. Others struggled in getting adapted to the changed body and the new self. Their stories also revealed how concern they were for their professional life and what could be done to live a good and healthy life in the future. Participants described their everyday life in the form of short phrases like “tiring,” “stressful,” “how long,” “not happy,” “it really hurts,” "I can overcome it," "I am positive," "I want to move on.” Participant's stories also disclosed how sad they were for not being able to live on expected life and carry out the things they could easily pre-stroke. However, the participants accepted that post-stroke days were not catastrophic. It was a combination of both good and bad days. Some of them also expressed that they had a worse experience before the stroke, so stroke could be a reason for those experiences.

Bodily change:

Bodily change after stroke can be understood as an altered perception of self where stroke survivors perceive their body as fragile, unfamiliar, and unreliable (Kitzmüller, Häggström, and Asplund 2013). This means that the stroke survivors experience pain and discomfort with their changed body, preventing them from living a normal life as before. Almost all the participants in my study experienced changes in their body in one way or the other. Some of the participants experienced functional difficulty, whereas others had difficulty with memory and concentration. For some, changes were not so devastating, but for others, life changed drastically after stroke. Functional changes were significant in some of them, where they accepted body-based restrictions due to limited function in the muscles and joints. These restrictions further led to other problems like mental and physical fatigue. Some of them described that they would get physically tired in a short time, while for others, they would have to stop at the point where they are due to mental tiredness. Few participants also described both physical and mental tiredness. One of the participants said:

*I get tired easily. I have to leave things undone or incomplete and need to lie down. The ability to do things is very less than before due to less strength, and I do not have control over my own body (*respondent 1)

She had to use more energy than before for doing the same task and could not keep up with the workload, despite loving to work. She described that her body was not in her control and expressed the fear that working too much would result in another stroke attack. Participants also reported that walking on the same phase as before was great challenging. Being left out alone for not being able to walk fast was something participants experienced to be the worst part. Some of they also encountered episodes of frequent falls. One of the participants said with great frustration:

Due to weakness on my left side, I have fallen so many times in public transport. Once I fell and broke my shoulder. You already have paralysis and above that a broken shoulder. Life was so much better before the stroke, but now I do not know how long can I manage on my own (respondent 6).

He expressed great frustration for not being able to walk like others and for his body being unreliable. He was in a dilemma about whether to trust his body or not because his ability to walk was getting worse every day. The great fear was that he would have to go to the elderly home soon. Even easy and the little task became complicated for some of them due to disheartening changes in the body. Some of the participants fought hard to hear clearly what other people were saying. Some of them meant that being unable to hear properly would spoil so many things, while others expressed sadly that they could not take part in the conversation and express themselves verbally. Not being able to get connected was expressed as great dissatisfaction. One of the participants described his situation as:

When people look at me from the outside, I look fine, but it is different from the inside. I lost hearing in one ear after the stroke. When you go to the bar or cafeteria with lots of noise, it becomes difficult to hear because when you have two ears functioning, it is easier to filter out background noise and be focused. But you cannot do it with a single ear (respondent 3).

Decreased function and strength in muscles and joints resulted in pain in different parts of the body. This pain further led to functional difficulties. One of my respondents shared that pain in her back, which started six months after stroke, is more disabling than her left foot's weakness. She said:

I have a poor balance on my left foot, I can accept that, but the pain in my back is a great challenge for me. It really stresses me. I have done a lot to treat it, but nothing has helped (respondent 1).

Stroke survivors acknowledged discouraging changes in their muscles with limitations to a controlled movement that further led to poor coordination and balance. Participants expressed that their physical body was experienced something different and not in connection with the mind. Confidence and control to do certain things were also restricted due to the changes in the physical body. One of the participants described how muscle weakness had affected his ability to write and type:

You know I have lost one of the big skills (with a smile). I was a very good typist on the computer. I could type very fast without looking at the keyboard. But now I cannot do that. It's the same with my handwriting. I do write, but it is not that good and satisfactory (respondent 3).

Similarly, another participant's story revealed that he could not be as spontaneous as he was pre-stroke. He would have to manage extra time and use extra energy to complete a small task, which he could easily pre-stroke. He thus said with great frustration:

It takes a lot of time to do one small thing. Especially during the winter with snow, it is extra difficult for me to walk. I need to manage the time accordingly because I cannot always be late at the expected places (respondent 6).

None of the participants expressed that they were suffering from depression; neither had the thought of suicide. They were worrying about how tomorrow would be like and, this was one of the reasons for anxiety and stress in some of them. Questions of uncertainty and difficulty replaced motivations and energy. One of the participants expressed exhaustion and stress and were not certain whether to give up or keep pushing to get back.

I cannot still accept that I had a stroke. I would very much indeed not have it. I am living myself, but it is not as good as it should be. I am physically ok, but my head is not working. I can do things physically but not mentally. If I knew I would be alright, it would be easier to keep going, you know (fighting with tears). But that's not the issue. The question is whether to give up or not. It's very tiring, frustrating, exhausting and I am not happy about it (respondent 2).

Mood swings were prominent in almost all the participants. Controversies and conflicts within the mind and body would make some days worse than the other. Emotional outbursts of frustration, anger, happiness, sadness would appear in the form of tears. Most of the participants admitted that they had been emotionally very weak post-stroke. As one of them said:

I do not need a special reason to cry. When watching any movies, I sit a little far from the TV and start to cry. Little things make me feel happy and little things bring tears to my eyes (respondent 4). He further continued:

I don't know if this is the reflection of stroke or not, but last week, we met a group of people to discuss some special issues. I do not know what happened to me, I started crying suddenly, and I was told that I am very afraid, and something is wrong.

Another participant said:

I was a strong man before, and tears would hardly fall, but now I am much more emotional, and tears fall very easily. If I read something sad, I start crying. Sometimes I realize that I am crying without any reason (respondent 6)

On the other hand, participants also reported that they had difficulty with memory and concentration. The ability to concentrate on particular things was greatly decreased after the onset of stroke. Participants expressed that they were dependent on the mobile telephone, which would work as a helping aid for memory. They would make a note of the things to be done on the telephone that helped them in not missing the important tasks. Some of them described that lack of memory and concentration made them feel insecure in their works. Others admitted that reading a single novel would be difficult, as the mind would deviate somewhere else. One of the participants said:

I keep trying to read but it's not giving me so much pleasure as before. You know, I cannot concentrate, it takes a lot of brain capacity to concentrate so I get tired very easily. Above that, there is always a zzzz sound on my head; when I try to concentrate, this sound gets higher which I cannot tolerate. (respondent 2)

Not everyone blamed that memory problem was only the result of a stroke but also felt that the growing age was responsible for forgetting things quite often. Participants also described changes in their sleeping patterns. Even though they would feel asleep, the pattern of sleeping was not as before. Horrible dreams would make some participants wake up in the middle of the night while others expressed that they would have slept a little more. One of the participants reported that she would struggle to fall asleep and wake up several times in the night.

I take low-dose tablets for my sleeping disorders, but still, I can hardly sleep 4- 5 hours. I wake up very often in the middle of the night. I would say that I do not get as good sleep as before. (respondent, 2).

Disruption in working life:

Almost all the participants showed great motivation and love for their work even though they were struggling with some degree of impairment. A strong will to work and remain engaged was the highest priority for them. All six participants were full-time workers before they had a stroke. It means working 37.5- 40 hours per week. Almost all the participants had been working for many years, but stroke led to significant changes in their working life. Participants expressed that they always admired their work and were happy with their works. Not being able to work as before was a great loss for some of the participants. Workload, stress, and problem with memory and concentration were a great obstacle for participants to get back to work.

As one of the participants who had returned to sixty percent work said with a very sad tone:

I work only sixty percent, and I am very afraid of losing this also due to my insufficiency. I am afraid of making mistakes and doing things wrong even though I do simpler tasks than before. If I do not carry out my work properly, I cannot stay there. That's one thing that stresses me. (respondent 2)

She accepted that she could not work efficiently as before due to mental tiredness, and the level of confidence to complete the tasks was not as before. She had the feeling that her body was being uncooperative with her. The feeling of insecurity and uncertainty was something she was struggling with at the workplace. She further said:

I don't think I can get back to the same position as before. I am not who I was yesterday. I feel isolated at my workplace because I cannot participate like I used to. They are not very happy to have me because it's a very big ward and they want young nurses who can do things easily at any time. It's complicated for them to have people like me, but they are bound to the agreement. (respondent 2)

Another participant mentioned that something he missed after the stroke was his work. Being on sick leave for more than half a year and not being able to work according to his will was something he was not satisfied with. As like he said:

The most dramatic thing that ever happened to me was being on sick leave for seven months. It had huge consequences for my work because being present was very important in my workplace. I had to quit the job because my employer said, "you have been away for like a year and I think you will be better by finding something else to do." Maybe you find it strange, but it's not unusual for people working in the private sector here (with a smile). (respondent 3)

Even though he had great pain inside for not continuing with the same work, he was determined to find something better soon. He further said:

Now I am self-employed. I am paid quite handsomely until sometime but not always. I need to find something else after that. I hope everything becomes easier in the coming days. (respondent 3)

Participants expressed that work was something, which would give them an identity and an opportunity to serve society. Some of them mentioned that being engaged would help them overcome sadness, anxiety, and stress. Others mentioned that being not as competent as before would make them feel a little apprehensive. Two of the participants had to go on a pension after some time off sick leave even though they had the same motivation and energy to work. Like one of the participants said:

I have been working all my life. I have worked in many different organizations. I had a stroke when I was 66. It was a year left for me to go to a pension. I wanted to work that last year, but I was recommended by the doctor to take my pension a year before I retire. I stayed on sick leave for a year and went on a pension. (respondent 4)

On the other hand, participants also expressed how happy they were to return to work early and resume the same work they had done before. They were also happy to have supportive colleagues who became extra helpful after the stroke. Like one of the participants said happily:

I feel so lucky because I was not left behind. I got my work back, which was the most important thing for me. I have to sit and deliver the lectures because I get tired very easily, but I do my best to make my students happy and satisfied. (respondent 1)

I am very fond of working. I have always been keeping myself busy. I am also part of the editorial team for the scientific journal. Getting back the same position after the stroke was something very important for me because writing has always been my field of interest. (respondent 1)

Another participant said:

I feel very lucky that I did not have to lose my job because of a stroke. Now I am further motivated to keep working because it's a healthy thing that you get going, and you also feel that you are needed in society. I enjoy my work to the fullest. (respondent 5)

Loosing pre-stroke me:

Almost all the participants experienced that they have become a different person in one way or the other. Some of them believed that stroke brought some good changes in their lives while for others, stroke forced them to lead a different life, which they did not enjoy. Participants described that they lost their pre-stroke identity and self and struggled to be familiar with those changes. Their stories also disclosed that losing pre-stroke self-resulted in different personal and social consequences. For example, not carrying out the most appreciated things in life left them with a lifetime of sorrow. There were also thoughts about the impact of not being in society. Most of the participant's stories also revealed that not being able to contribute to society was a great loss for them. However, participants also admitted that even though they were losing their pre-stroke self, they still had reasons to smile and be happy. Some of them were thankful to God for allowing a second chance to survive and were further determined to live a good life in the future. The overall impression was that participants had lost their pre-stroke identity and had become someone different.

One of the participants expressed how things changed suddenly after stroke. She admitted that she was someone who valued her own life and was a happy and satisfied person pre-stroke, but Stroke led to uncertainty, disappointments, and helplessness. She said with great sadness:

I was a happy person. I completed my master's degree in May and thought about a Ph.D. degree but (tears rolling down). In October, I had a stroke, which changed my life completely. I was part of the leading team in my working ward and was responsible for teaching other nurses what they were supposed to do. I am no more with that responsibility, and I don't think I will get back there. So, my goals are completely different. (respondent 2)

On the other hand, she was being left out by her husband after the stroke was very much disappointing and shocking. The fact that she would have to sell the house after the divorce and all the paperwork related to it made her health even worse. She admitted that being alone was stressful in this long journey of life, where she would have to tackle all the ups and downs alone. She further said:

Life would have been much easier if I did not have this extra problem. The health system has helped me; I get help whenever needed, but in the end, I am left alone with an economic burden. This has made things more complicated and difficult. I wake up 4-5 times at night and have to take tablets for my sleeping problem, which I never had pre-stroke (respondent 2).

Participants expressed how they missed doing things that they appreciated the most pre-stroke. Some of them were quite disheartened for not being able to go skiing where others felt bad for not being able to drive the car, which they had done for many years. Participants also expressed that change in their eating and drinking habits post-stroke made them little social compared to pre-stroke life. Even though they had friends and family to hang out with, life was not as beautiful as before because they had restrictions on many things. One of the participants said:

I miss going to the shopping center and enjoying different offers. I need to order everything online. That is so annoying, and I do not like this at all. If you can go and select things yourself, that makes you happy. (respondent 6)

He continued further:

I was a happy going person pre-stroke, I had such a good voice, and I would always sing in the church as I am catholic, but after I got the stroke, my vocal is not as good as before, I cannot sing anymore and that makes me feel very bad. (respondent 6

Participants also described how active they were in various social gatherings pre-stroke and expressed great sadness for not being able to do the same now. Some of the participants mentioned that instead of taking part in different activities, they would prefer to hear and watch others doing. Like one of the participants said:

Little strange was, I was in a gathering, people talked, I could follow them but could not take part in the conversation. (respondent 4)

He further said:

Now I like listening to what people say because I have realized that I do not speak at the same pace as others do. (respondent 4)

In the same way, another participant said with a desperate tone:

I was always in good humor and liked talking to folk but now this has changed completely. Instead of talking, I am very satisfied to hear people talking. I must say I have become a good listener. (respondent 6)

Participants' stories also revealed that they would not anticipate doing things that they liked doing. Some of the participants explained how they were pre-stroke and how they have become now. As one of the participants expressed:

I do whatever I can, not waiting for tomorrow because nobody knows what is going to happen the next day. I have started doing things that give me pleasure and happiness because I do not know if I will be the same person tomorrow. (respondent 5)

On the other hand, one of the participants shared how stroke suddenly brought a positive change in her feelings. Her story revealed that she was happy to forget her past, which had brought great negativity in her life. As like she said happily:

*You know what? I was guilt for my sister's death though it was not my fault. I was suffering from this guilt since my childhood. But the feeling of guilt suddenly disappeared after I had a stroke. I now realize that I have become a different person and somewhere I feel good about it. (responden*t 1)

Concluding remarks:

Stroke survivors experienced various degrees of changes in their bodies. The participants markedly noticed changes in emotions, cognition, and physical body where they struggled to adapt to the changed body and the new self. Life was not as easy as before due to inabilities and uncertainties.

Stroke led to a significant change in the working life of many stroke survivors. Participants had the same desire, motivation, and love towards their work despite inabilities. Not being able to work, as before, was expressed as a great loss by several of the participants, and the factors influencing their working life were memory, concentration, stress, and the workload.

Stroke survivors experienced a change in their self -identity post-stroke. Losing pre-stroke self resulted in various social and personal consequences where they struggled to preserve their identities. It has also been found that the changes in their self -identity prevented them from doing the most appreciated things in life.

4.3.2 Coping with the change:

Participants experienced that their life had changed markedly after the stroke, and they needed to find a way to deal with it. It was thus different types of coping strategies were adopted by the participants to deal with their everyday life. Coping was related to their life situations. Coping with the change was not an easy task initially, but they concluded that it was the only way to move ahead. Participants described that they avoided the situations or context they felt uncomfortable or difficult to cope with. Described below are examples of the coping strategies used by the participants in their day-to-day life.

Positivity

Positivity was found to be an important source of coping in most of the participants. Participants' stories revealed that an optimistic approach to life could help them in getting adapted to the new self-identity. They also expressed how lucky they were for being given a second chance to survive, even though they had some degree of impairment.

I feel lucky when looking at others in distress. I can walk on my own, turn around in the bed and do things on my own. I feel progress on my left foot. I will definitely be better tomorrow with new programs and technology, and I look for a nice future ahead. (respondent 1)

I know that I am not walking straight, I have lost hearing in one ear but for a person waking up from a coma, this is excellent, I must say. (respondent 3)

Some of them expressed that there were times when negative and disabling thoughts would block their way, but still they did not give up strengthening the positive thoughts. A positive approach to life helped them build new trust and acceptance of bodily changes. Participants also believed that positivity would help them to lead a meaningful life. One of the participants reported that his life story before the stroke was much distressing and he had been treated for post-traumatic stress disorder.

I am a fighter, has always been a fighter. My past experiences are much worse than stroke, so I watch inspiring stories to move forward in life. (respondent 3)

None of the participants talked about being a burden to the family due to several impairments but instead expressed gratitude for being back home and not in the nursing home. Participant's stories also revealed that they were thankful to god for not being handicapped and dependent on others. Being able to carry out everyday activities (ADL) self was described as a great achievement by all of them.

I knew that time would heal everything. For the first few months I had sort of good and bad days, uncertainty, different thoughts but now life is changing, and I thank god for making me independent again. (respondent 5)

Motivation, determination, hope, and enthusiasm for the future were also found in participants' stories. Participants did not look at themselves as different from others but expressed that they had to take a different approach to their lives. Most participants accepted that stroke was not only the cause for their changed self; they somehow related it with other factors.

I am a little afraid of being dement as I forget things easily. But I don't think it is the result of a stroke. For my age this should be normal, I feel so. (respondent 4)

Sometimes I feel a little isolated when people leave my company, but I don't think it's due to stroke. Maybe it's because of my hearing. I take it positively (with a big smile). (respondent1)

Support from various sources

Participants expressed that they had received various degrees of support from different sources in their post-stroke phase. Participants expressed gratitude for being able to start the rehabilitation as early as possible. They described that they were given all the help and support in terms of rehabilitation from the very beginning, even though there was a delay in diagnosing and starting the treatment. Participant's stories revealed that they were very happy to get all the care and assistance from the health care professionals who always encouraged them to regain confidence and motivation. They also learned the importance of physical activity through them.

I was completely paralyzed on my left side both upper and lower limb but within a few days of rehabilitation, I started working on my PC, can you imagine. I am so thankful for the rehabilitating unit because they started training both my upper and lower limb simultaneously the other day. It was important for me to regain function on my upper limb because wheelchairs can be used for foot but nothing for arm, isn't it? (Respondent 1)

After I was discharged from the hospital, I was in a day training. They would pick me up in the morning; take me to the hospital where they would train my affected parts. After a month I got a place in the rehabilitating center, I was very happy to be there because the trainers were amazing, they trained me very well and everyone was very helpful. (respondent 6)

Almost all the participants reported that they were able to carry out their ADL (activities of daily living) after returning home weather from the hospital or the rehabilitation centers. The level of strength was not as before, they would struggle both mentally and physically but did not completely rely on others for little things. None of the participants were dependent on a wheelchair when they came back home.

My right side was paralyzed. I started walking with the help of a walker when I was in the rehabilitating center. By the time I came home, I was not dependent on anyone. I could do my things alone. (respondent2)

I started living alone after I was discharged from the rehabilitation center. I could manage my things, not a hundred percent but somehow ok for me. I never wanted to be dependent and go to a nursing home. (respondent 2)

Life was difficult but I managed to cook, go to the toilet and do my things self. I was not so much dependent on others. (respondent 6)

Participants expressed family members as their strongest pillar in their hard times. Receiving help from their family members helps them cope with the stroke and inspired them to keep moving. Some of them described how cooperative their partners were in their hard times while others appreciated the love and care shown by their children. For example, one of the participants appreciated how her husband listened to her patiently whenever she was talking for hours and hours. Another participant described how stroke personally influenced his wife. As like he said:

I received wonderful support from my two sons during my hard time but my stroke influenced my wife very much. We are very close to each other and I was the person she could trust. She is already a cancer patient and when she knew about my stroke, she was very much afraid that I could have died.

In the same way alone living participants expressed that their children who lived in the same building helped them with the things they could not manage:

My son does not live with me. He lives on the second floor and helps me in many ways, for example, cutting grasses in the lawn during summer and removing snow in the winter. He is also very good at computers and helps me with computer-related problems. (respondent 6)

My granddaughter uses to help me with things like cleaning my apartment, vacuuming once a week, but now I have changed the floor, and I manage to do it on my own (respondent 1)

Several of them reported that they had some good friends who were always willing to help them. They expressed that sharing the pain with their friends would help them to heal it to some extent. Participants also expressed how grateful they were for having such friends in their hard times.

Some of them also described the support from technical sources. Using mobile telephones and computers helped them to cope with the situation to a greater extent. Participants described that computer and telephone served as a memory aid and helped them have a proper grasp of their timetable.

I use my phone to note down the things I am supposed to do. It has served as an important tool to keep myself updated with my timetable. Luckily, we have this helping device; otherwise, things would be complicated, and I would have to depend on others. For example, I have my *bank account on my computer, but I do not remember the password, but I have made a note of my phone password. (respondent, 4).*

Exercise and training

Participants described the importance of physical training and exercise for their recovery in post-stroke life. Their stories revealed that being physically active was an important way to cope with their changed self. Some participants reported that they needed increased assistance from health care professionals initially, whereas others started to train themselves after arriving home. Some of them had physiotherapy sessions once or twice a week, while others reported that they did not find it very useful in the longer term. None of the participants were reluctant to carry out the training, but were highly motivated and had a proper training schedule. They had the motivation that training their body would help them feel better in many ways. Desire to come back to the pre-stroke stage motivated participants to make an effort to do the exercise and training. Participants also believed that proper exercise and training to the body would reduce the chance of another stroke.

Two of the participants reported that they had bought a stationary bicycle to train themselves at home in addition to other exercises. Walking was also reported to be the most used form of training by some of them. As one of the participants said:

I start my day with some stretches and yoga. Then I bicycle at home for like 10minutes. In the evening, my wife and I go out on a walk. We walk like 5- 6 km every day. Being active is important for my health and me. (respondent 4)

The same participant added that:

After the stroke, I was a member of one of the training centers. I used to go there for 3-4 times a week. I did different trainings for like 50 minutes, including swimming. But now I am concerned about exercising at home because my wife had breast cancer, and she is under chemotherapy. (respondent 4)

Another participant reported that she would like either bicycle to work or walk to work. When she is unable to bicycle to work, she would use the stationary bicycle as a training tool. She also reported that she visited physiotherapy once a week and brain training at the other learning center|(respondent 2). Participants emphasized performing the exercises in the same manner as taught by the health care professionals. They also reported that they could perform those exercises without any assistance from other family members. Stretching and strengthening, including balance and coordination exercises, was the central ones performed by all the participants at home. Most of them had a feeling that their muscles were not cooperating with them, and it was important to train them.

I wake up at 6, and the first thing I do is exercise. I do different exercises, which I have been learned to do. Mostly I focus on balance and coordination, as you know, I am not walking the way I am supposed to. I also do some stretching and strengthening exercises. (respondent 3)

I have a training routine home, which I follow every day. It takes 30 minutes to do some balance, stretching, and strengthening exercises. I do it alone, but now I have noticed that it is not going as good as before because I have become much weaker than before. I also go to the physiotherapist two times a week. (respondent 6)

The participant above (respondent 6) has had two small strokes after he had the first one. These strokes further resulted in the worsening of his left half of the body. But still, he had faith in exercises that he could be better and would be able to live on his own for a few more years. Three participants reported that meditation was equally important for them as other forms of physical exercise and training. One participant was reluctant because she could not concentrate even though she wished to meditate. Two of them expressed that they were not so fascinated by meditation.

I do meditation twice a day, every morning, and every afternoon. I used to meditate once a day before stroke, but now I do it twice. Meditation helps me to think positively and relax my body. Most importantly, it helps me to overcome my stress. I cannot manage my day without meditation. (respondent 1)

I know the importance of meditation. It is extra important for people like us. I do meditate, and I know how to do it. (respondent 5)

Engagement in other activities

Participants expressed that getting engaged in activities they admired would give them pleasure, even though they lacked the self-confidence. They felt that being able to continue with the enjoyable activities would help them forget the displeasure life had given them. Participant's stories also revealed that activities would help them regain their pre-stroke abilities. Some of the participants embraced the opportunities, which they still had post-stroke, while others were disheartened for not being able to grab the opportunities. Some of their stories were full of sorrows for not being able to represent the same person with the same level of energy and enthusiasm. Some of them also reported that they had to abandon the activities they appreciated the most in life.

Engagement in different activities created a sense of satisfaction for most of them. They also described that activities helped them the most when they were feeling low or discouraged. Participants reported that they were involved in different post-stroke support groups and organizations, which helped them build confidence, hope, and positivity.

I have different organizations to go and talk to when I feel low. They hold sessions or talks to people who have had a stroke. Meeting other people with the same problem and sharing each other's experiences gives so much motivation. (respondent 5)

She further added:

Organizations have become so much helpful and cooperative; they have helped me a lot. If I have any questions or queries, I can just call them or go to them. I must say they have become great support in my post-stroke life. (respondent 5)

Several of them expressed that they would be happy to attend gatherings and remain social. Family gatherings and meeting with grandchildren was expressed as the most pleasing thing for a few participants, while others expressed that being able to connect with friends was important for them. Few participants reported that they did not like to be social because they would get easily tired when surrounded by people around them.

Most of them reported that they were involved in different organizations for a weekly or monthly meeting. They expressed that it would give them very much satisfaction and pleasure.

I cannot stay idle, as I have worked all my life. Now I work as a chairman in an organization for people who are above 60; we have meetings 4, 5 a year. (respondent 4)

I am a member of some organizations, and we have meetings once or twice a month. I feel very happy to go to the meetings even though I cannot contribute much to it. I like being engaged in whatever ways I can. (respondent 6)

I make sure that I fix social appointments at least once or twice a week. If you keep yourself busy, you do not feel low. (respondent 3)

Two female participants reported that they would engage themselves in activities like sewing and knitting to keep them busy. Among them, one was very fond of knitting and was happy that she started to knit early after the stroke. Some of them believed that trying to solve Sudoku, puzzles, and crosswords would help them train their brain, while others expressed reading useful books and watching inspiring stories as an important means to relax their mind. Few of them highlighted the importance of prayers and church in keeping them alive. They acknowledged that they would go to the church frequently. One of the participants liked going to the concert while another participant missed going to the concert due to his inability. One of the participants talked about starting group training at the training center for stroke patients. As like she said happily:

I am starting a group at the training center for stroke patients because I believe that it can be useful for different groups of people who have had a stroke. I also feel that it is an effective way to help people like me. (respondent 1)

Concluding remarks:

Stroke survivors had a positive approach toward their life. Positivity helped them in coping with their changed life and getting adapted to the new self -identity. Positivity also helped them to build new trust and acceptance of bodily changes.

Various degrees of support from different sources helped stroke survivors to cope in their post-stroke phase. Assistance and support from health care professionals helped most of them to lead an independent life after stroke. It has also been found that family acted as the strong pillar of support in their hard times, and assistance from technical sources like mobile phones helped them solve different problems independently.

Exercise and training helped the stroke survivors to speed up their recovery and cope with their changed self. Participants were highly motivated and determined to carry out the training and exercise regularly. They also believed that training their body would help them get back to their pre-stroke stage.

Stroke survivors engaged themselves in different activities that they admired doing. Involvement in these activities gave them pleasure and a sense of satisfaction even though they lacked the same confidence level as before. Activities also helped them to train their mind and body and to cope with their lost self.

5 Discussions and professional implications:

This study presented the everyday life experiences of post-stroke patients and their coping strategies to reconstruct their current life. In this part of the study, I will discuss the research's significant findings and how these findings could be constructive for other post-stroke survivors in the coming days.

The critical issue that emerged from the current study is the changed life after the stroke, which led to the change in the body, disruption in the working experience, loss of the pre-stroke self, and how the stroke survivors managed to cope these post-stroke changes. I also tried to discuss the significant findings of this research based on theoretical perspectives.

SCoTS model foresees that patient who modifies their assumptive world to accommodate stroke are unlikely to suffer ongoing mental health problems than those who do not readily accept what has happened or those who carry negative beliefs. In the present research, it is found that participants have applied different adjustment strategies to accommodate stroke. These adjustments can be categorized in terms of (1) emotional focused strategies, (2) problem-focused strategy, (3) avoidant coping, (4) benefit finding coping.

In the present research, several participants reported that seeking emotional support from family and friends would help them heal their pain to some extent. This can be categorized under emotional focused strategies to accommodate stroke. Emotional support from family and friends has been discussed in many other research articles. The findings of the other researches also show that good social relationships as a significant part of coping as family and friends were the only people whom participants relied on and would seek emotional support (Kuluski et al. 2014) (Widar, Ek, and Ahlström 2004) (Williams and Murray 2013).

Participants in this research employed several exercise and training as well as rehabilitative therapy to accommodate stroke. This is a problem-solving strategy. In their research, Carlsson

(2018) Moorley (2015), mentioned the importance of rehabilitative therapy for stroke survivors. Stroke survivors and rehabilitation found the opportunity to share their experiences with other stroke patients that further helped them in their recovery process. Some of the participants in the present research described how beneficial mobile phone and computer was to cope with stroke as it enabled them to remember their daily routine and timetables. The use of assistive device and engagement as a problem-focused coping strategy is also one of the significant findings in Shoshannah Williams (2013) research.

Similarly, few participants in the present research tried to avoid social gatherings because they would easily get tired when surrounded by people around them. At the same time, some of them had to abandon the most appreciated activities in life due to a lack of energy and enthusiasm. This can be analyzed as avoidant forms of coping as participants tried to modify their assumptive world to accommodate stroke. Avoidant forms of coping have been discussed significantly by Folkman & Lazarus (1980).

Participants in the present study tried to cope with stroke with more positivity. This optimistic approach not only helped them to cope with illness but also enabled them to regain the new self-identity. This new self-identity made their life more accessible to some extent, even though they had some degree of impairment. This is also what we called benefit-finding coping. Similar findings have been reported in the study of Gillen (2005) where it was documented that through benefit finding, coping post-stroke patients were able to identify positive consequences of stroke which included improved social relationship, increased health awareness, good eating, and sleeping habit, change in religious life, personal growth and altruism.

According to social cognitive theory, post-stroke patients cope with the changed circumstances and conclude or draw assumptions from these events. Some of these conclusions or assumptions may be the source of psychological distress or subsequent disorder, whereas others could be the source of post-traumatic growth.

In the present research, it has been found that all the participants drew conclusions in the post-stroke period. These assumptions/conclusions are the primary sources of their post-traumatic growth. The central assumptions were their concerns about the future life. They were worried about how tomorrow would be like but were self-motivated and determined to make the best of it. One of the participants (3), although not been able to continue his previous job, was self-determined to find something better soon; his determination can be described as the source of post-traumatic growth. Participants (1, 5) aware of how important it is to keep themselves engaged in post-traumatic growth that would help them overcome stress, anxiety, and sadness.

All the participants had difficulty with memory and concentration, but not everybody blamed stroke for their inability to concentrate. Their perception of stroke was quite helpful that they didn't only blame but also accepted that their growing age was responsible for forgetting things quite often. This acceptance can be described as post-traumatic growth, which helped them reduce their distress.

The post-stroke phase of the life of every participant had been different in one way or another. Some of them believed that the consequences of stroke threw them in a situation where they could not enjoy life as they did pre-stroke, whereas some thought that post-stroke life also had something to cheer up. For example, the participant (2, and 6,) were nostalgic about their pre-stroke self and lamented most of the time in their life as they described that stroke led them to uncertainty, disappointment, and helplessness. They were also pretty much concerned about their present social life which was completely different from the earlier one with lots of restrictions even though they had friends and family. This concern is another source of psychological distress. Similar findings on concern for social life have been reported in the previous research that feeling of unattractive and self-consciousness about visible disabilities after stroke and restriction of social life (Ch'Ng, French, and McLean 2008).

Other participants (4, 5, 1) although had different life after stroke, they accepted the stroke and tried to find out the positivity within it. For example, the participant (4,6) thought that they had been really good listeners after stroke, they liked listening to what people say. Participant (1) also believed that stroke brought not only negative feelings in her but also some positiveness, as she had been able to forget her past which was the feeling of guilt. This perspective of seeing their post-stroke self with positivity is a source of post-traumatic growth, and this maturity helped them cheer up their present life.

The SCoTS model describes individuals` disconfirmation to stroke in terms of intra-and inter-personal responses. These responses occur within a particular context, which influences their coping strategies and subsequent adjustment. It is found that participants' disconfirmation to stroke in terms of intra and interpersonal responses of participants resulting in the psychological distress or subsequent disorder didn't impact their coping strategies. All the participants seemed extremely motivated and tried to accommodate their stroke with positivity, support from family and friends, and exercise and training. Similar findings have been reported in the study from Carlsson, Möller, and Blomstrand (2009). They write that seeking affirmation from self and others played a vital role in participants and their coping strategies. Their psychological distress did not significantly affect their motive of coping with stroke. Almost all the participants were highly educated; one probable reason might be that their inner awareness of stroke helped them to cope with the illness. As awareness of the participants has been discussed in many studies, understanding stroke and its deadly impact itself is a motivation to cope with it.

Some of the participants in the present research reported that they needed increased assistance from health care professionals at the beginning of their stroke. All the participants were highly motivated in carrying out the training with proper schedule and they emphasized on performing the exercises in the same manner as taught by the health care professionals. Moorley's (2015) research on *Mechanism among African Caribbean Women to cope with stroke* also draws similar conclusions. This study reported that the role of a medical professional and healthy behaviors helped participants to get motivated and helped them to enhance their self-esteem which helped them to tackle the stroke.

The present study has described how the stroke has been a traumatic event for the participants, which affected their psychological, physical, and social life and troubled their professional and personal life to a more considerable extent. Therefore, it is crucial to consider and assess every aspect of individuals' consequence for planning care. The implications of the stroke were prominent for the participants of the study significantly “bodily changes,” “disruption in working life,” and “losing pre-stroke self.” As we have seen that family members and friends have been huge source of support for the stroke patients in reducing depression and reconstructing their post-stokes lives, it is also important to consider the significance of family members and friends while dealing with stroke patients.

This study also discussed how the participants applied various coping strategies to reconstruct their lives. For example, coping strategies “exercise and training”, “positivity”, “engagement in other activities” and, “support from various sources” are the practical way of reconstructing their traumatic lives or getting themselves back to everyday life. The study participants applied an optimistic approach to life that eased them to adapt to stroke with the new self-identity and helped them recover from stroke and its traumatic experiences. They consider a positive outlook as assets in the recovery process. Therefore, the significance of coping strategies should always be a big part of professional implications.

It is also essential that information should be appropriately explained to the stroke patients so that they can comprehend the reason. For example, such as hearing and memory problems of the present study might not be because of the stroke. It is evident that growing age might reduce the memory and capacity to hear a person. If things like these have been explained better to stroke survivors, it could minimize disappointment and adapt to the new self-identity.

6. Appendix

6.1 References:

Aho, Komi, P Harmsen, Seiko Hatano, J Marquardsen, Vadim E Smirnov, and Tom Strasser. 1980. "Cerebrovascular disease in the community: results of a WHO collaborative study." *Bulletin of the World Health Organization* 58 (1):113.

Anne Rochette, Desrosiers, J 2002. "Coping with the consequences of a stroke." *International Journal of Rehabilitation Research* 25:7.

Bandura, Albert. 1986. *Social foundations of thought and action : a social cognitive theory, Prentice hall series in social learning theory*. Englewood Cliffs, N.J: Prentice-Hall.

Becker, G. 1993. "Continuity after stroke: Implications of life-course disruption in old age." *The Gerontologist* 33:10.

Bettger, Janet Prvu, Laine Thomas, Li Liang, Ying Xian, Cheryl D Bushnell, Jeffrey L Saver, Gregg C Fonarow, and Eric D Peterson. 2017. "Hospital variation in functional recovery after stroke." *Circulation: Cardiovascular Quality and Outcomes* 10 (1):e002391.

Boyatzis, Richard E. 1998. *Transforming qualitative information: Thematic analysis and code development*: sage.

Boynton De Sepulveda, L. Chang B. . 1994

. "Effective coping with stroke disability in a community setting: The development of a casual model." *Journal of Neuroscience Nursing* 26:10.

Braun, Virginia, and Victoria Clarke. 2006. "Using thematic analysis in psychology." *Qualitative research in psychology* 3 (2):77-101.

Brennan, J. 2001. "Adjustment to cancer - coping or personal transition?" *Psycho-oncology* 10 (1):1. doi: 10.1002/1099-1611(200101/02)10:13.0.CO

2-T.

Brink, Hill IL. 1993. "Validity and reliability in qualitative research." *Curationis* 16 (2):35-38.

Bryman, Alan. 2012. *Social research methods*: Oxford university press.

Buseth, Monica Risvik. 2013. "Waiting, but Still Hoping: A Qualitative Study of Every Day Life after a Stroke." *Ergoterapeuten* 04:8.

Carlsson, Gunnel E., Anders Möller, and Christian Blomstrand. 2009. "Managing an everyday life of uncertainty – A qualitative study of coping in persons with mild stroke." *Disability and Rehabilitation* 31 (10):773-782. doi: 10.1080/09638280802638857.

Carlsson, Håkan. 2018. "Upper-limb Sensory Impairments After Stroke: Self-reported Experiences of Daily Life and Rehabilitation." *Journal of Rehabilitation Medicine* 50 (1):45-51. doi: 10.2340/16501977-2282.

Ch'Ng, Amanda M., Davina French, and Neil McLean. 2008. "Coping with the Challenges of Recovery from Stroke." *Journal of Health Psychology* 13 (8):1136-1146. doi: 10.1177/1359105308095967.

Creswel, John W. 2009. "Research design: Qualitative, quantitative, and mixed methods approaches." *Los angeles: University of Nebraska–Lincoln*.

Denzin, Norman K, and Yvonna S Lincoln. 2011. *The Sage handbook of qualitative research*: Sage.

Dromerick, Alexander, and Michael Reding. 1994. "Medical and neurological complications during inpatient stroke rehabilitation." *Stroke* 25 (2):358-361.

Duncan, Pamela W, Richard Zorowitz, Barbara Bates, John Y Choi, Jonathan J Glasberg, Glenn D Graham, Richard C Katz, Kerri Lamberty, and Dean Reker. 2005.

"Management of adult stroke rehabilitation care: a clinical practice guideline." *Stroke* 36 (9):e100-e143.

Eftekhar, P, D Cameron, K Yoshida, MD Landry, and D Brooks. 2010. "Clients' and Health Care Professionals' Perspectives on Post Stroke Rehabilitation Services in Tehran, Iran." *Middle East Journal in Age and Ageing* 7 (1):33-40.

Ellekjær, Hanne, Jostein Holmen, Bent Indredavik, and Andreas Terent. 1997. "Epidemiology of stroke in Innherred, Norway, 1994 to 1996: incidence and 30-day case-fatality rate." *Stroke* 28 (11):2180-2184.

Engstad, Torgeir, Tora Torgersen Engstad, Matti Viitanen, and Hanne Ellekjær. 2012. "Epidemiology of stroke in the elderly in the Nordic countries
incidence, survival, prevalence and risk factors." *Norsk epidemiologi* 22 (2):121-126.

Feigin, Valery L, Gregory A Roth, Mohsen Naghavi, Priya Parmar, Rita Krishnamurthi, Sumeet Chugh, George A Mensah, Bo Norrving, Ivy Shiue, and Marie Ng. 2016. "Global burden of stroke and risk factors in 188 countries, during 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013." *The Lancet Neurology* 15 (9):913-924.

Felberg, Robert A, and Andrew M Naidech. 2003. "The 5 Ps of acute ischemic stroke treatment: parenchyma, pipes, perfusion, penumbra, and prevention of complications.(Featured CME Topic: Stroke)." *Southern medical journal* 96 (4):336-343.

Geyh, Szilvia, Alarcos Cieza, Jan Schouten, Hugh Dickson, Peter Frommelt, Zaliha Omar, Nenad Kostanjsek, Haim Ring, and Gerold Stucki. 2004. "ICF Core Sets for stroke." *Journal of rehabilitation medicine* 36 (0):135-141.

Gillen, Glen. 2005. "Positive consequences of surviving a stroke." *American Journal of Occupational Therapy* 59 (3):346-350.

Gillen, Glen. 2006. "Coping during inpatient stroke rehabilitation: an exploratory study." *The American journal of occupational therapy : official publication of the American Occupational Therapy Association* 60 (2):136. doi: 10.5014/ajot.60.2.136.

Given, Lisa. 2008. *The SAGE Encyclopedia of Qualitative Research Methods*. 0 vols. Thousand Oaks, California.

Grubaugh, Anouk L., and Patricia A. Resick. 2007. "Posttraumatic Growth in Treatment-seeking Female Assault Victims." *Psychiatric Quarterly* 78 (2):145-155. doi: 10.1007/s11126-006-9034-7.

Indredavik, Bent, Hanne Ellekjær, and Randi Selmer. 2008. "Stroke in Norway." *International journal of stroke : official journal of the International Stroke Society* 3:205-6. doi: 10.1111/j.1747-4949.2008.00201.x.

Johnston, Karen C, Jiang Y Li, Patrick D Lyden, Sandra K Hanson, Thomas E Feasby, Robert J Adams, R Edward Faught Jr, and E Clarke Haley Jr. 1998. "Medical and neurological complications of ischemic stroke: experience from the RANTTAS trial." *Stroke* 29 (2):447-453.

Jørgensen, Henrik S, Hirofumi Nakayama, Hans O Raaschou, Jørgen Vive-Larsen, Mogens Støier, and Tom S Olsen. 1995. "Outcome and time course of recovery in stroke. Part I: Outcome. The Copenhagen Stroke Study." *Archives of physical medicine and rehabilitation* 76 (5):399-405.

JulietCorbin, and AnselmStrauss. 2008. *Basics of Qualitative Research (3rd ed.): Techniques and Procedures for Developing Grounded Theory*, *Basics of qualitative research (3rd* *ed.): Techniques and procedures for developing grounded theory*. Thousand Oaks: United States, California, Thousand Oaks: SAGE Publications, Inc.

Kaufman, Sharon. 1988. "Illness, biography, and the interpretation of self following a stroke." *Journal of Aging Studies* 2 (3):217-227. doi: 10.1016/0890-4065(88)90002-3.

Kegel, Jessica, Moira Dux, and Richard Macko. 2014. "Executive function and coping in stroke survivors." *NeuroRehabilitation* 34 (1):55-63.

Kirkevold, Marit. 2010. "The role of nursing in the rehabilitation of stroke survivors: an extended theoretical account." *Advances in Nursing Science* 33 (1):E27-E40.

Kirkevold, Marit, Doris Christensen, Grethe Andersen, Søren Paaske Johansen, and Ingegerd Harder. 2012. "Fatigue after stroke: manifestations and strategies." *Disability and Rehabilitation* 34 (8):665-670. doi: 10.3109/09638288.2011.615373.

Kitzmüller, Gabriele, Terttu Häggström, and Kenneth Asplund. 2013. "Living an unfamiliar body: the significance of the long-term influence of bodily changes on the perception of self after stroke." *Medicine, Health Care and Philosophy* 16 (1):19-29.

Kouwenhoven, Siren E., Marit Kirkevold, Knut Engedal, Stian Biong, and Hesook S. Kim. 2011. "The lived experience of stroke survivors with early depressive symptoms: A longitudinal perspective." *International Journal of Qualitative Studies on Health & Well-Being* 6 (4):1-13. doi: 10.3402/qhw.v6i4.8491.

Kuluski, Kerry, Clare Dow, Louise Locock, Renee F. Lyons, and Daniel Lasserson. 2014. "Life interrupted and life regained? Coping with stroke at a young age." *International Journal of Qualitative Studies on Health and Well-being* 9 (1). doi: 10.3402/qhw.v9.22252.

Kumar, Sandeep, Magdy H. Selim, and Louis R. Caplan. 2010. "Medical complications after stroke." *The Lancet Neurology* 9 (1):105-118. doi: https://doi.org/10.1016/S1474-4422(09)70266-2.

Kvale, Steinar. 1996. *Interviews : an introduction to qualitative research interviewing*. Thousand Oaks, Calif: Sage.

Kvale, Steinar, and Svend Brinkmann. 2009. "Learning the craft of qualitative research interviewing." *Thousands Oaks: Sage Publications*.

Lambert, William W., and Richard S. Lazarus. 1970. Psychological Stress and the Coping Process.

Lazarus, Richard S., and Susan Folkman. 1984. *Stress, appraisal, and coping*. New York: Springer.

Leavy, Patricia. 2014. *Oxford Handbook of Qualitative Research : Oxford Handbook of Qualitative Research*. Cary, UNITED STATES: Oxford University Press, Incorporated.

LeCompte, Margaret D, and Judith Preissle Goetz. 1982. "Problems of reliability and validity in ethnographic research." *Review of educational research* 52 (1):31-60.

Lindgren, Ingrid, Christina Brogårdh, and Gunvor Gard. 2019. "Pain management strategies among persons with long-term shoulder pain after stroke–a qualitative study." *Clinical rehabilitation* 33 (2):357-364.

Lo Buono, Viviana, Francesco Corallo, Placido Bramanti, and Silvia Marino. 2017. "Coping strategies and health-related quality of life after stroke." *Journal of health psychology* 22 (1):16-28.

Lozano, Rafael, Mohsen Naghavi, Kyle Foreman, Stephen Lim, Kenji Shibuya, Victor Aboyans, Jerry Abraham, Timothy Adair, Rakesh Aggarwal, and Stephanie Y Ahn. 2012. "Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010:

a systematic analysis for the Global Burden of Disease Study 2010." *The lancet* 380 (9859):2095-2128.

Mishler, Elliot. 1990. "Validation in inquiry-guided research: The role of exemplars in narrative studies." *Harvard educational review* 60 (4):415-443.

Mohajan, Haradhan Kumar. 2018. "Qualitative research methodology in social sciences and related subjects." *Journal of Economic Development, Environment and People* 7 (1):23-48.

Moorley, C. R. 2015. "Life after stroke: Coping mechanism among African Caribbean women." *Int. J. Stroke* 10:24-24.

Moorley, Calvin R, Sharon Cahill, and Nova T Corcoran. 2016. "Life after stroke: Coping mechanisms among african caribbean women." *Health & social care in the community* 24 (6):769-778.

Murray, Christopher JL, Theo Vos, Rafael Lozano, Mohsen Naghavi, Abraham D Flaxman, Catherine Michaud, Majid Ezzati, Kenji Shibuya, Joshua A Salomon, and Safa Abdalla. 2012. "Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010." *The lancet* 380 (9859):2197-2223.

O'Donnell, Martin J., Denis Xavier, Lisheng Liu, Hongye Zhang, Siu Lim Chin, Purnima Rao-Melacini, Sumathy Rangarajan, Shofiqul Islam, Prem Pais, Matthew J. McQueen, Charles Mondo, Albertino Damasceno, Patricio Lopez-Jaramillo, Graeme J. Hankey, Antonio L. Dans, Khalid Yusoff, Thomas Truelsen, Hans-Christoph Diener, Ralph L. Sacco, Danuta Ryglewicz, Anna Czlonkowska, Christian Weimar, Xingyu Wang, and Salim Yusuf. 2010. "Risk factors for ischaemic and intracerebral haemorrhagic stroke in 22 countries (the INTERSTROKE study): a case-control study." *The Lancet* 376 (9735):112-123. doi: https://doi.org/10.1016/S0140-6736(10)60834-3.

Ovbiagele, Bruce, and Mai N. Nguyen-Huynh. 2011. "Stroke epidemiology: advancing our understanding of disease mechanism and therapy." *Neurotherapeutics : the journal of the American Society for Experimental NeuroTherapeutics* 8 (3):319-329. doi: 10.1007/s13311-011-0053-1.

Pecotić-Jeričević, S, T Vlak, A Rota-Čeprnja, M Visković, N Franulović-Golja, and K Reuben Eldar. 2008. "Rehabilitation Hospital in Royal College of Nursing Clinical governance: how nurses can get involved." *Croatian Medical Journal* 49 (3):291-294.

Persson, Hanna C, Karin Törnbom, Katharina S Sunnerhagen, and Marie Törnbom. 2017. "Consequences and coping strategies six years after a subarachnoid hemorrhage–A qualitative study." *PLoS One* 12 (8):e0181006.

Rand, Kim, Fredrik Andreas Dahl, Joe Viana, Ole Morten Rønning, Kashif Waqar Faiz, and Mathias Barra. 2019. "Fewer ischemic strokes, despite an ageing population: stroke models from observed incidence in Norway 2010–2015." *BMC health services research* 19 (1):705.

Russell, D, A Dahl, and C Lund. 2007. "Stroke--primary prophylaxis." *Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, ny raekke* 127 (6):754.

Scherbakov, Nadja, Stephan Von Haehling, Stefan D Anker, Ulrich Dirnagl, and Wolfram Doehner. 2013. "Stroke induced Sarcopenia: muscle wasting and disability after stroke." *International journal of cardiology* 170 (2):89-94.

Shoshannah Williams, Carolyn Murray 2013. "The lived experience of older adults' occupational adaptation following a stroke.(Report)." *Australian Occupational Therapy Journal* 60 (1):39.

Smith, L. 2010. *Management of patients with stroke: Rehabilitation, prevention and management of complications, and discharge planning: A national clinical guideline*. Vol. 118: SIGN.

Stein, Joel. 2004. "What Is a Stroke?" In *Stroke and the Family*, 3-11. Harvard University Press.

Stevens, Eleanor, Eva Emmett, Yanzhong Wang, Christopher McKevitt, and Charles Wolfe. 2017. *The Burden of Stroke in Europe*: Stroke Alliance for Europe. Commissioned report.

Taylor, Gavin H., Jonathan Todman, and Niall M. Broomfield. 2011a. "Post-stroke emotional adjustment: A modified social cognitive transition model." *Neuropsychol Rehabil* 21 (6):808-824. doi: 10.1080/09602011.2011.598403.

Taylor, Gavin H., Jonathan Todman, and Niall M. Broomfield. 2011b. "Post-stroke emotional adjustment: A modified social cognitive transition model." *Neuropsychological Rehabilitation* 21 (6):808-824. doi: 10.1080/09602011.2011.598403.

Taylor, Steven J., Robert Bogdan, and Marjorie DeVault. 2015. *Introduction to Qualitative Research Methods : A Guidebook and Resource*. Hoboken, UNITED STATES: John Wiley & Sons, Incorporated.

The Lancet, Neurology. 2005. "Tackling the global burden of stroke." *The Lancet Neurology* 4 (11):689. doi: 10.1016/S1474-4422(05)70202-7.

Toole, James F, Kari Murros, and Roland Veltkamp. 1999. *Cerebrovascular disorders*: Lippincott Williams & Wilkins.

Walia, R. 2015. "A Saga of Qualitative Research." *Social Crimonol* 5 (2):124.

Wekre, Lena Lande. 2004. *Lærebok i rehabilitering: når livet blir annerledes*: Fagbokforlaget Vigmostad & Bjørke.

WHO. 2015. "Stroke, Cerebrovascular accident ". https://www.who.int/topics/cerebrovascular_accident/en/.

WHO, I. 2000. The world health report 2000. Health systems: improving performance. World Health Organization Geneva.

Widar, Marita, Anna-Christina Ek, and Gerd Ahlström. 2004. "Coping with long-term pain after a stroke." *Journal of Pain and Symptom Management* 27 (3):215-225. doi: 10.1016/j.jpainsymman.2003.07.006.

Williams, Shoshannah, and Carolyn Murray. 2013. "The lived experience of older adults' occupational adaptation following a stroke." *Australian Occupational Therapy Journal* 60 (1):39-47. doi: 10.1111/1440-1630.12004.

Winstein, Carolee J, Joel Stein, Ross Arena, Barbara Bates, Leora R Cherney, Steven C Cramer, Frank Deruyter, Janice J Eng, Beth Fisher, and Richard L Harvey. 2016. "Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association." *Stroke* 47 (6):e98-e169.

6.2 Information letter to the participant:

Are you interested in taking part in the following research project?

Everyday Life Experience of Post-Stroke Patients: A study on the Importance of Adjustment Strategies

Purpose of the project

The main purpose of this study is to look at the everyday experience of post stroke patients, kinds of coping strategies ang the role of these strategies in the process of recovery. The research questions are: How the stroke patients perceive their stroke experiences and how these experiences change over time. What kind of negative and positive adjustment strategies do they adopt? How this adjustment affects them in post stroke phase?

Who is responsible for the research project?

OsloMet- Oslo Metropolitan University is the institution responsible for the project.

Supervisor of the project: Dag Jenssen, OsloMet.

Why are you being asked to participate?

"Mild to moderate stroke affected patients" is the main criteria for inclusion in the study. The study does not have a single age group but includes candidates from 30 to 70 years. I contacted different organisations which are involved in stroke rehabilitation. These organisations shared my preliminary research presentation to their members. Then I received numbers of emails from the members who were interested and who wanted to be a part of my project.

What does participation involve for you?

The method of this study is semi-structured interview. The aim of the interview is to collect reliable first-hand information on stroke experiences and coping strategies. All the interviews will be recorded electronically (sound recording).

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made anonymous. There will be no negative consequences for you if you chose not to participate or later decide to withdraw.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose(s) specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

- As a researcher, I am the only one who is responsible for this project, and the only one to access the personal data.
- I will replace the original name with some imaginary names and I am not going to use the contact details. However, I will be using the real age and the occupation of the participants. The imaginary names will be stored separately from rest of the collected data so that it will not be possible to identify the real participants.

What will happen to your personal data at the end of the research project?

The project is scheduled to end on December 2019. The collected data will be anonymised at the end of the project.

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?

We will process your personal data based on your consent.

Based on an agreement with OsloMet – Oslo Metropolitan University, NSD – The Norwegian Centre for Research Data AS has assessed that the processing of personal data in this project is in accordance with data protection legislation.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- *OsloMet – Oslo Metrpolitan University* via Dag Jenssen*,* *dag.jenssen@oslomet.no, tlf:+47 908 54 805*
- NSD – The Norwegian Centre for Research Data AS, by email: personverntjenester@nsd.no, or by telephone: +47 55 58 21 17.

Yours sincerely,

Project Leader Student (Researcher/supervisor)

Consent form

I have received and understood information about the project *Everyday Life Experience of Post-Stroke Patients: A study on the Importance of Adjustment Strategies,* and have been given the opportunity to ask questions. I give consent:

☐ to participate in interview
☐ for my personal data to be stored after the end of the project in anonymised form for later study purposes.

I give consent for my personal data to be processed until the end date of the project, approx. December 2019.

(Signed by participant, date)

6.3 Consent form

Everyday Life Experiences of Post-Stroke Patients: A case Study on Importance of Adjustment Strategies of Post Stroke Patients

The purpose of this study is to understand the everyday life of post-stroke patient and their adjustment strategies. Adjustment strategies have a significant role to stroke patients for it gives both positive and negative transition. It is expected that the finding of this research will help in the adjustment tactics of the post stroke patients in the future to moderate the adjustment manoeuvres for the quality of life.

If participant wants more information about the project or have any question about the project, can contact researcher (Pratikshya Khanal Sharma) at pratikshya824@gmail.com. This project has been approved to conduct interview by the Research NSD Data Official for Research. The supervisor of this project is Associate professor Dag Jenssen (dagjen@oslomet.no), Department of Social work and Social Policy, Oslo Metropolitan University.

Consent form

Thank you for reading the information sheet about the interview. If you are willing to participate then please complete and sign the form below.

I confirm that I have read and understood the information sheet dated (20.02.2019) and have had the opportunity to ask question. I fully understand that the participation for this interview is voluntary and I am free to withdraw at any time without giving any reason. I have full rights not to answer any particular question or questions, I am free to decline.

I understand that my interview will be kept strictly confidential. I understand that my name and address will not be linked with research materials and will not be identified or identifiable in the research.

I agree this interview to be tape recorded. I understand that the audio recording made of this interview will be used only for analysis purpose. The extract from the interview will be used confidentially and I will not be personally identified. I understand that no other use will be made of the recording without my written permission, and no one outside the research team will be allowed access to the original recording.

I agree to take part in this interview.

______________________	______________	____________________
Name of the participant	Date	Signature

6.4 Interview guide for the participants

I part

Tell me about yourself.
Tell me your stroke experience/ what does it mean to you?
What has living with stroke been like for you? (could you share me an incident)
(response of family, dependent and independent, struggle, did you get proper sleep at night, vision for future)
What is a typical day like for you (post stroke phase)?
Do you have sound sleep?
How often do you drink?
Do you avoid activities that affects your health in one way or other? (drinking, smoking, eating habits, stress,)
Since you had stroke, could you please share me how these experiences have been changing with the time.
Do these emotions and feeling remain constants or remain changes?
If you could change anything about that experience, what would it be?

II part
What are the challenges you have been facing in your life after stroke and how do you manage to cope with?
What have been helpful in dealing with these tough situations? (family, god, exercise, medication, yoga, social relation, positive thinking).
What have not been helpful in this situation/ what kind of thing do you think is not helpful?
What are the changes you notice within you before and after stroke? (physical, psychological, social, emotional changes)
What are the things that make you feel positive? (for eg, exercise, meditation, prayers)
The things that make you feel negative… negative thoughts, tiredness, fatigue,

III part

During your difficulties how supportive were your family, friends, and neighbours and in what ways?
How do you describe yourself? Are you a social person?
What kind of social activities do you prefer?
How often you involve yourself in any form of community work?
What was your goal in the life before stroke?
Do you still have the same goal in life after stroke?
What about motivation and energy? How stroke has affected in your motivation?
How do you see yourself in the future?
Did you find any situation where you find yourself isolated?
What else would you like to share about living with stroke?
Do you have any suggestion for someone who is having stroke?

PROBES and conversation continuers

- Can you give me an example of what you mean?
- Please tell me more about that.
- Tell me more about that experience (or that time)?
- How do you see that (or yourself) in the future?

-