

CHAPTER 2

REVIEW OF LITERATURE

The review of literature for the study about the lived experience of stroke survivors at home in Bandung, Indonesia was based on reviewing the theoretical and empirical literature in the following topics:

- 1 Stroke patients
 - 1.1 Definition of stroke
 - 1.2 Incidence of stroke
 - 1.3 Manifestations and impacts of stroke
 - 1.4 Management and rehabilitation programs for stroke patients in Indonesian.
- 2 Lived experience of stroke survivors
- 3 Hermeneutic phenomenology.

1. Stroke Patients

1.1 Definition of Stroke

“Cerebrovascular accident” (CVA: Stroke) is a broad term used to describe a condition in which blood flow to the brain is interrupted, with a consequent temporary or permanent dysfunction of the patient’s motor, sensory, perceptual, emotional, or cognitive abilities. Symptoms vary depending on the part of the brain affected. A cerebrovascular accident, often referred to as a brain attack or stroke, is a condition in which neurological deficits occur as a result of decreased blood flow to a focal

(localized) area of brain tissue. In addition, stroke can be an interruption of blood flow to the brain because of an occlusive disease of the cerebral arteries and/or vessels (Monahan & Neighbors, 1998). The resulting neurological deficits are caused by ischemia, cerebral thrombosis, cerebral embolism, or cerebral hemorrhage (LeMone & Burke, 2000).

1.2 Incidence of Stroke

Stroke or cerebrovascular accident can occur at any age, however the incidence rate increases as people get older, and for each decade of life after age 55, the chance of having a stroke more than doubles (www.frankfordhospitals.org). The incidence of stroke and risk factors peaks in subjects over 75 years of age (Barnett, 2002). In Indonesia, the incidence of stroke is roughly 200 per 100,000 people per year (FHS, 1995), and about 19% higher in males than in females. Stroke is an increasing cause of morbidity and mortality in Indonesia, and in one study recurrent stroke was found in nearly 20% of patients (Misbach, 2001). The same study found that of 2,065 acute stroke patients admitted to 28 hospitals all over Indonesia, the mean age was 58.8 years (range: 18-95 years). 12.9% were younger than 45 years, 51.3% were between 45 and 65 years, and 35.8% were older than 65 years. There were more male stroke victims than female.

1.3 Manifestations and Impact of Stroke

The manifestation of stroke varies according to the cerebral artery involved and the area of the brain affected (LeMone & Burke, 2000). The typical manifestations include motor deficits, elimination disorders, sensory-perceptual disorder, language disorder, and cognitive and behavioral changes. These manifestations may be transient or permanent, depending on the degree of ischemia

and necrosis. Because of the neurological deficits, the stroke victim may have manifestations involving many different body systems (LeMone & Burke, 2000).

Strokes most commonly occur as a result of lesions of the middle cerebral arteries, which supply the lateral cerebral hemispheres and subcortical areas of the basal ganglia and internal capsules, producing homonymous hemianopsia and collateral hemiplegia and sensory disturbances. Right-hemisphere strokes can result also in lack of impulse control and insight, spatial and perceptual deficits, and possibly apraxias. Communication is generally affected with left-hemisphere strokes, producing fluent, nonfluent, or global aphasia, along with alexia and agraphia. Left-hemisphere lesions may also produce problems with right-to-left discrimination and organizational abilities when performing tasks (Leahy, 1991).

Motor deficits depend on the area of the brain involved. Stroke may cause weakness, paralysis, and/or spasticity. According to LeMone & Burke (2000), the deficits can include: hemiplegia, paralysis of the left or right half of the body (hemiparesis), weakness of the left or the right half of the body (flaccidity), absence of the muscle tone (hypotonia), spasticity (increased resistance to stretching of the extremities with resistance increasing as the extremity is stretched), and rigidity (increased resistance to stretching of the extremity that is uniform throughout the stretching). These conditions lead to the physical limitations of stroke survivors in conducting the activities of daily living.

Elimination disorders consist of disorders of the bladder and bowel elimination, which are common in the stroke victim. Stroke may cause partial loss of the sensations that trigger bladder elimination, resulting in urinary frequency, urgency, or incontinence (LeMone & Burke, 2000). Changes in bowel elimination are

common and are the result of changes in the level of consciousness, immobility, and dehydration (Hickey, 1997 cited in LeMone & Burke, 2000).

Sensory-perceptual disorders, according to LeMone & Burke (2000), include:

1) hemianopia: the loss of half of the visual field of one or both eyes; when the same half is missing in each eye, the condition is called homonymous hemianopia; 2) agnosia: the inability to recognize one or more subjects that were previously familiar; agnosia may be visual, tactile, or auditory; or 3) apraxia: the inability to carry out some motor pattern (e.g., drawing a figure, getting dressed), even when strength and coordination are adequate.

Language disorders, especially communication problems, are usually the result of the stroke affecting the dominant hemisphere. The left hemisphere is dominant in about 95% of right-handed people and 70% of left-handed people (Porth, 1998). According to LeMone & Burke (2000), language involves oral and written expression and auditory and reading comprehension. Among these disorders are 1) aphasia: the inability to use or understand language; aphasia may be expressive, receptive, or mixed (global); 2) expressive aphasia: a motor speech problem in which one can understand what is being said but can respond verbally only in short phrases; also called Broca's aphasia; 3) receptive aphasia: a sensory speech problem in which one cannot understand the spoken (and often written) word. Speech may be fluent but with inappropriate content: also called Wernicke's aphasia; 4) mixed or global aphasia: language dysfunction in both understanding and expression; or 5) dysarthria: any disturbance in the muscular control of speech (LeMone & Burke, 2000).

Cognitive and behavioral changes due to stroke include emotional lability (in which the client may laugh or cry inappropriately), loss of self-control (manifested by

behavior such as swearing or refusing to wear clothing), and decreased tolerance for stress (resulting in anger or depression). The stroke victim may also show intellectual changes such as memory loss, decreased attention span, poor judgement, or an inability to think abstractly (LeMone & Burke, 2000).

Psychologically, during the initial evolution of the stroke, the stroke victims usually experience extreme shock and fear when they feel their arm(s) and leg(s) becoming increasingly weak. The suddenness of the stroke, the loss of body control associated with evolving weakness and the uncertainty set the scene for a rendered immobile by shock, and the dismantling of their known world (Doolittle, 1992). A study conducted by Desmond, Remein, Moroney, Stern, Sano, and Williams (2003) on ischemic stroke and depression found that depression was associated with more severe strokes, particularly centered in vascular territories that supply limbic structure; dementia; and in females. The reported prevalence of depression after stroke varies widely, from 18% to 61% (House, 1987). Astrom, Adolfson, and Asplund (1993), studied major depression in stroke patients and found that the prevalence was 25% at the acute stage and approximately the same at 3 month (31%), decreased to 16% at 12 months, was 19% at 2 years, and increased to 29% at 3 years.

Socially, the impact of stroke reaches beyond the patient's physical and psychological being, as it also involves their social existence and lifestyle. During hospitalization following stroke, the patient is dependent on others and has to rely on health care personnel for their basic needs. In the Framingham study, Gresham, Fitzpartict, Wolf, McNamara, Kannel, and Dawber (1975) studied residual disability in survivors of stroke and found that of the 119 stroke patients evaluated, 84% were living at home, 80% were independent in mobility and 69% were independent in

ADL. However, only 29% were engaged in gainful employment, and 62% showed a decrease in social activity. One study found social dysfunction to be significantly related to depression only at 6 months (Parikh, Lipsey, Robinson, & Price, 1987).

There are spiritual effects from a stroke as well. The word spirituality derives from the Latin word *spiritus*, which refers to breath or wind. A person's health depends on a balance of physical, psychological, sociological, cultural, developmental, and spiritual factors. Spirituality is often identified as an important factor in helping to achieve the balance needed to maintain health and well-being and to cope with illness (Potter & Ferry, 2001). Spirituality is described as the sense of a presence higher than humans, a divine intelligence that creates, sustains, and organizes the universe and an awareness of our inner connection with this higher reality (Calabria & Macrae, 1994 cited in Potter & Ferry, 2001).

The relationship between spirituality and healing is not completely understood. It is the individual's intrinsic spirit that seems to be a factor in healing. Research is indicating a definite link between spirit, mind, and body, and an individual's beliefs and expectations can and do have effects on a person's physical well-being (Coe, 1997). In addition, spirituality also gives support and strength for coping and offering hope for stroke survivors. Bays (2001) studied older adults' descriptions of hope after a stroke and found that factors associated with hope patterning were family connectedness, spiritual connectedness, and goal achievement.

Spiritual practices can also assist stroke survivors in finding meaning and wholeness through the confidence they offer (Robinson & Smith, 2002). And finally, the effect of spiritual practice contributes to well being, and individuals who regularly participate in spiritual worship services or related activities and who felt strongly that

spirituality or the presence of a higher being or power are sources of strength and comfort were healthier than those without such faith (Undermann, 2000).

1.4 Management and Rehabilitation Programs for Stroke Survivors in Indonesian.

Normally, management and rehabilitation programs for stroke patients are in the community hospital. If the degree of disease is severe, the patient will be referred to a bigger hospital, which is commonly located in a bigger city. In that hospital the patient will receive health treatment until their hemodynamic condition is stable. Treatment includes an examination to decide if surgical treatment is required or not; if so, the patient will be transferred to an operating room and then the intensive care unit. If an operation is not required, they will be hospitalized in a neurological ward, and finally treated with medicine followed by physiotherapy and speech therapy (Hasan Sadikin Hospital Profile, 2000).

Duration of hospital stay depends on the degree of stroke. For example, with a moderate stroke the normal stay is 1 to 2 weeks before the patient can be discharged to home. For severe stroke the necessary stay can be up to one month or more before discharge to home. Before returning home the patients participate in their discharge planning, which includes health education on rehabilitation for stroke patients. After discharge the patient visits the hospital for a check up and to receive their drugs approximately once a month. Health services for stroke survivors can be provided by a community or general hospital (Hasan Sadikin Hospital Profile, 2000). Complementary therapies for stroke patients can also be performed, according to the needs or wishes of the victim, such as herbal therapy or traditional medicine (Department of health, 2000).

In Indonesia, the cost of health care fee is either paid by the individual, or by health insurance. There are four types of health care insurance policies in Indonesia. The first is National Health Insurance, usually for government employees or others who join privately. Second is private insurance, but not many people have this, as it is quite expensive. Third is employee insurance, offered by certain factories or businesses, and fourth is government-sponsored insurance for poor citizens, who can access health services free of charge as long as they have an official letter (Department of Health, 2000).

In terms of management, a person's religion or beliefs can influence their pattern of seeking for help and coping with problems. The majority of Indonesians are Muslim, and the Muslim faith tells people to connect an illness with previous sins, and to ask God for help through performing some special acts of atonement such as prayer, fasting, giving to charity, or doing other good

2. The Lived Experience of Stroke Survivors

Experiencing a stroke and its aftermath can be devastating for patients and their families. It may be associated with severe physical, social, psychological and spiritual consequences for patients. A decline in physical function following stroke is generally related to the initial severity of the stroke and to the pre-existing comorbidity (Alexander, 1994). The patients' emotional state also to be linked both physical recovery and social adjustment (Morris, 1992). These problems lead a stroke survivor to face and use some strategies to cope the aftermath of stroke (Rochette & Desroiseirs, 2002).

The lived experience of the stroke survivors, especially during the first three months following their stroke, was important, because it is this time they have the new experiences and many problems due to the impact of stroke, as recorded in many studies (Tanne, Goldbourt, Zion, Reicher-Reis, Kaplinsky and Behar, 1993). Another study found that at 1 week and 1 month after a stroke event there were major mental changes in mood, judgement, memory, and personality (Seisson, 1998). Berg, Lehtihalmes, and Lonnqvist (2002) identified post stroke depression and found depressive symptoms associated with older age during the first 2 months after a stroke. Another problem is a financial support. The degree of economic support also influences the recovery of stroke survivors, who require drugs to maintain their health, and the money available determines the medicines they can afford. Strokes can impose a significant cost burden on some victims (Youman, Wilson, Harraf, & Lalit, 2003) and not only the victim, but also their families, who often become responsible for the cost of treatment. And if the stroke victim was the main income provider for the family, the family income may be significantly reduced as well, and changes in how the future income will be obtained may add to the stress and problems of the family.

The problems due to the impact of stroke influenced the feelings of being stroke survivors. The feeling of the stroke survivors' experience of living with stroke and their future expectations were explored by Haggstrom, Axelsson, and Norberg (1994). The stroke survivors identified four themes: uncertainty; sadness and mourning; gratefulness, hope, and satisfaction; and isolation. The study demonstrated the importance of ensuring the integrity of an individual's life history after stroke, as extensive reinterpretation may be required for successful adaptation to the sequelae.

The stroke survivors faced the impacts of stroke. These impacts involve all aspects of their life including physical, psychological, social and spiritual (Bronstein, 1991; Hafsteinsdottir & Grypdonck, 1997; Robinson & Smith, 2002). The impacts of stroke often happened on the patients and spouse as a study conducted by Mumma (1986) found that patient and spouses perceived of losses following stroke. By using a combination of structured scales and open-ended questions, Mumma (1986) yielded three major categories of loss: activities, abilities, and independence. The loss most often described by patients was mobility and traveling was most frequently described by spouses. In all phases after the stroke onset, independence was identified as a prominently mentioned loss for most groups. The study found that the loss of activities, abilities, and independence were the most commonly noted losses following the stroke.

Recovery from stroke is complex and multidimensional. While physical, psychological and social facets of recovery are interlinked. The exact relationship between these factors is poorly understood. Many factors contribute to the stroke survivor's ability to live and to cope with the aftermath of the stroke. These factors included physical adaptation, psychosocial adjustments, social support, and spiritual adaptation.

One strategy is physical adaptation. The stroke survivors do exercise regularly in order to maintain their body as much as possible (Teixeira, Salmela, Olney, Nadeau, & Brouwer, 1999). Some stroke survivors use a complementary therapy with their medicine such as herbal therapy, massage therapy, acupuncture, or moxibustion (Moon, Whang, Park, Ko, Kim, Bae, & Cho, 2003). Other activities for coping include dietary regulations, in which the stroke survivors lesson the risk of a

secondary stroke by being careful with their diet (Sauvaget, Nagano, Allen, Grant, & Beral, 2003). Such activities are important for stroke victims in helping to maintain their health and survive after their stroke.

Psychosocial adjustments usually occur as an effect of the physical problems brought on by the stroke. Adequate psychosocial adjustment is crucial for a positive long-term outcome as part of rehabilitation from the stroke. For example, many stroke survivors have depression or mood disorders due to their new disability, and psychosocial adjustment is necessary to counteract these problems after the stroke (Thomson, Sobolew, Graham, & Janigian, 1989; Swartzman, Gibson, Armstrong, 1998; Trigg, Wood, & Hewer, 1999).

Social support from spouse or family members can also have a significant influence on the stroke survivor (Langhorne, 2001). The spouse or family members play a central role in caring for the stroke survivor, as most such survivors are quite dependent and require assistance from someone, most often the spouse. In addition, stroke survivors also have a need to express their emotions to someone, which is beneficial in releasing stress or tension.

Another contributory factor is spiritual adaptation. The degree of spirituality of the individual can influence recovery after a stroke. Robinson and Smith (2002) studied prayer after a stroke, looking at the relationship of such prayer to the quality of life of the stroke victim, and found that prayer was a way of coping after a stroke. They also found that some who had not been especially spiritual prior to their stroke became more spiritual following the stroke, as a coping mechanism.

Stroke survivors perceive the lived experience both as a problem and as a part of their life. That perception depends on the problems that emerge, and on how much

they are able to use their coping mechanisms to deal with the problems (Rochette & Desroiseirs, 2002). For example, many stroke survivors must deal with a severe disability due to the stroke, and may have serious problems such as difficulty moving, communicating, eating or working (O'Connell, Barbara, Wendy, Martin, & Phil, 2001; Wolfe, 2000). However, some stroke survivors have relatively mild disabilities and they still can perform activities with only some limitations. Stroke survivors who have positive coping mechanisms find it easier to live with or accept such disabilities.

Previous study revealed the lived experience of stroke survivors, as a study conducted by Hilton (2002) studied about the meaning of stroke in elderly women, and the lived experience and meanings following the stroke. The participants were five elderly women who had experienced a stroke more than one year previously. Five themes were identified: deterioration and decline, loss and helplessness, regret, uncertainty and anxiety about the future, and resiliency - all negative experiences. In this study revealed information that knowing meanings of individual stroke experience may enable nurses to understand elderly women patients more completely, supporting acute and rehabilitation care that embraces humanistic perspectives. Another study had revealed the stroke survivor experience during rehabilitation using grounded theory (Folden 1994). The process described by the participants ensured forward progress, which included accepting that life would be forever different, maintaining hope, preserving energy and increasing personal control over recovery. The study explored the ability of the stroke survivors to deal with the stroke. In addition, recovery experiences following a lacunar stroke revealed that seven themes identified: stroke as a bodily experience, stroke in evolution, meaning of

hospitalization, living with uncertainty, differing medical and personal views, facing the night, and discharge home (Doolittle, 1992).

In addition, as early as three months after the stroke, and extending to two years, the survivors begin to improve, and become more settled than in the previous months (<http://www.Irishhearth.ie/patientqueries/stroke3.htm>). This is the period during which the functions of the body organs begin to recover, particularly damaged neural and functional systems (<http://strokecenter.com/poststroke.html>), and the victims begin to feel there is an improvement in their quality of life as well, 3-12 months after the stroke (Jonkman, deWeerd, & Vrijens, 1998). It is during this period the survivors begin to cope better; prior to this time, the settling-in period, the stroke survivors are mainly concerned with describing the event, and telling their lived experience after the crucial event.

The stroke survivors revealed the need during their recovery, as a study done by Lui & Mackenzie (1999), which identified elderly Chinese patients' perceptions of their rehabilitation needs following a stroke, and found that five major categories of need: informational need, physical need, psychological need, social need, and spiritual need. Informational need was covered all data concerning the illness, its treatment and recovery. Physical need was concerned with the physical care and carrying out daily activities. Psychological need referred to the need for psychological support and comfort. Social need was related to the need to maintain normal social life and social activities. Spiritual need was regarded as the need for religious support and carrying out usual rituals within physical limitations during rehabilitation.

3. Hermeneutic Phenomenology

The lived experiences of the world of everyday life are the central focus of phenomenological inquiry (Streubert & Carpenter, 1999). In addition, Schutz (1970 cited in Streubert & Carpenter, 1999) described the world of everyday life as the total sphere of experiences of an individual which is circumscribed by the objects, persons, and events encountered in the pursuit of the pragmatic objectives of living. In other words, it is the lived experience that represents to the individual what is true or real in his or her life. Furthermore, it is this lived experience that gives meaning to each individual's perception of a particular phenomenon and is influenced by everything internal and external to the individual. The goal of phenomenology is to describe the lived experience (Streubert & Carpenter, 1999).

The term hermeneutics has historically been associated with the theory and practice of interpretation. Hermeneutics is known as a contemporary philosophy that emphasizes the human experiences of understanding and interpretation (Moody, 1990). Hermeneutic or interpretive frameworks within phenomenology are used to search out the relationships and meanings that knowledge and context has for each other (Lincoln & Guba, 1985).

The term phenomenology derives from the Greek *phainomenon*, whose root words are *phainein*: appear; and *logia*: science or study, therefore together they become the study of appearances (Hoad, 1986/1996). Developed as a philosophy by Edmund Husserl (1859-1938), phenomenology is a "reasoned inquiry into the world of appearances, that is, anything of which one is conscious" (Stewart & Mickunas, 1990). There are three dominant key concepts of Husserlian phenomenology:

intentionality, essences and phenomenological reduction ('bracketing') (Spielberg, 1960 cited in Koch, 1995).

Martin Heidegger (1889-1976), Husserl's student, introduced hermeneutics into the study of phenomena, since he believed that pure description was limited in its ability to reveal meaning (Osborne, 1994). The word "hermeneutics" has its origins in the Greek *hermeneuein*: to interpret (Hoad, 1986/1996), and derives from the Greek god Hermes, the messenger of the gods, who made the unknowable knowable through the invention of language and writing (Thompson, 1990). Originally, the term "hermeneutics" referred to the study and interpretation of biblical texts, but as a result of the contributions of various philosophers, including Heidegger and Gadamer, the term is now defined as "the theory and practice of interpretation and understanding (*Verstehen*) in different kinds of human contexts" (Odman, 1988 cited in Wilcke, 2002).

Hermeneutics is recognized as a philosophy that supports an interpretive approach to people through research methods that focus on meaning and understanding in context (Mischler, 1979 cited in Wilcke, 2002). Hermeneutics has emerged as a broadly based philosophy that focuses on the experience of understanding and the act of interpretation as general features of human life (Howard, 1982 cited in Wilcke, 2002).

The goal of hermeneutic phenomenology is to "reveal a totality of meaning in all its relations" (Gadamer, 1997 cited in Wilcke, 2002), through a process of interpretation which involves making manifest that which is hidden by going "beyond what is directly given" (Spiegelberg, 1982 cited in Wilcke, 2002), reading between the lines and paying attention to what has been omitted, to the silences and the

assumptions, to that which has been so taken for granted that it has not been questioned. Hermeneutic phenomenology thus seeks a deeper understanding of human experience by rediscovering it and opening it up (Bergum 1997 cited in Wilcke, 2002).

Many of the elements that shape our being-in-the-world are hidden and require interpretation for existence to be understood; therefore Heidegger's concern was to uncover these hidden phenomena of our lives as well as their meanings (Spiegelberg, 1982 cited in Wilcke, 2002). Rather than the phenomenal reduction and "bracketing," Heidegger emphasized the importance of our preconceptions. He posited that we experience and understand the world by means of projection and that "an interpretation is never a pre-supposition less apprehending of something presented us". Our interpretation consists of structures of pre-understanding, that is, a "framework of already interpreted relations" (Odman, 1988 cited in Wilcke, 2002), which anticipates the future and encompasses the person's past and current situations. Understanding and experience are thus inextricably linked.

Hermeneutic phenomenology therefore differs from descriptive phenomenology in significant ways. Descriptive phenomenology emphasizes knowledge of the world through the study of consciousness; it assumes that phenomena have an essential essence, which can be intuited through the process of "bracketing" that allows the phenomena to be studied objectively. Findings are offered through explicit descriptions. Hermeneutic phenomenology seeks to go beyond description in order to discover meanings that are not immediately apparent (Merleau-Ponty, 1996 cited in Wilcke, 2002). Rather than bracketing our assumptions, Heidegger (1889-1976) maintains that our preconceptions are an integral

part of the process of understanding and that each individual's experience is unique, although generalizations about the human condition are possible.

Heidegger has two essential notions, i.e. historicity of understanding, and the hermeneutic circle; the two notions are inextricably intertwined. Several of Heidegger's related ideas require explanation in order to grasp the importance of the historicity of understanding and the hermeneutic circle – for instance, Koch (1995) notes the ideas of background, pre-understandings, co-constitution and interpretation.

The notion of background is an inescapable part of the hermeneutic circle. Benner and Wrubel (1989) state that a person's history or background is what culture gives a person from birth. Background is handed down and presents a way of understanding the world. This understanding determines what counts as 'real' for the person. Heidegger's position assumes that background meanings, skill and practice cannot be made completely explicit.

Heidegger uses the term 'pre-understanding' ('fore-conception') to describe the meaning and organization of a culture (including language and practices) that are already in the world before we arrive. Human beings always come to any situation with a story or pre-understanding. These stories are already within our common background understanding and are brought into focus in order to be understood. Pre-understanding is a structure of our 'being-in-the-world' it is not something we can eliminate, or bracket, it is already with us in the world.

Another way to understand this process is to see the person and their world as "co-constituting" each other (Heidegger, 1962 cited in Koch, 1995). Co-constitutionality refers to the philosophical assumption of indissoluble unity ("person world"). This means being constructed by the 'world' in which we live and at the

same time constructing this world from our own experience and background. In other words, one of the most important Heideggerian assumptions stresses the indissoluble unity between the person and the world. That is to say, the person is at home in the world (Weinsheimer, 1985 cited in Koch, 1995). The world is already there before analysis, and from the beginning the person is in the world. A person participates in this *a priori* world in cultural, historical and social contexts. Human existence and the world are co-constitution each other.

Heidegger (1962 cited in Koch, 1995) declares nothing can be encountered without reference to the person's background understanding, and every encounter entails an interpretation based on the person's background, in its 'historicality'. The framework of interpretation is the fore-conception in which we grasp something in advance. Heidegger (1962) claims that we cannot have a world, and have life at a cultural level, except through acts of interpretation. Understanding occurs because we are born into the world. We are what we take ourselves to be and how we interpret ourselves in our practices, in other words we are self-interpreting beings (Dreyfus & Dreyfus, 1987). Even in *Being and Time* (Heidegger, 1962) the real question is not what way 'being' can be understood but in what way understanding is 'being'. For Heidegger, understanding is no longer conceived of as a way of knowing but as a mode of being, as a fundamental characteristic of our 'being' in the world.

Gadamer (1997), Heidegger's student, further develops his own approach to the process of understanding. He uses, the term "hermeneutic circle of understanding", which refers to a circular movement, an ever expanding circle of understanding and interpretation (Gadamer, 1997 cited in Wilcke, 2002). He states we approach a topic with some pre-conceptions, or a projection, and this projection is

then examined and revised in the face of what “the things themselves” reveal to us, and we return to a further exploration in the light of this new understanding. In addition, the topic is understood by viewing “the whole in terms of the detail and the detail in terms of the whole”. This dynamic movement of understanding from projection to topic to new projection, and from whole to part to whole, constitutes the hermeneutic circle of understanding and interpretation.

The fusion of horizons refers to a facet of the process of understanding (Gadamer, 1997). Every person’s horizon consists of “a range of vision that includes everything that can be seen from a particular vantage point”, and can be understood to refer to our frame of reference, based on our experiences and current situation, with which we orient ourselves in the world. The limits of anyone’s particular horizon are not fixed but expand as our range of vision expands, as we deepen our understanding.

The term “fusion of horizons” refers to the encounter between the researcher and the topic of inquiry, in which two standpoints come together, and “we genuinely let the standpoint of another speak to us, and in such a way that we are willing to be influenced by the perspective of another” (Thompson, 1990). In other words, Gadamer describes understanding as the fusion of these standpoints, as the intersection, coming together, or merging of different vantage points. The term “fusion” implies that one does not eliminate one’s own horizon, or ever leave it entirely behind (Moody, 1990).

Stroke survivors have many problems, not only the visible physical problems, also less visible but nonetheless real and important psychological, social, and spiritual problems. If not properly addressed, such psychological and social problems can lead to a worsening of the condition of the stroke survivors. Thus the hermeneutic

phenomenology is important as it can help to unveil such less-visible phenomena of stroke survivors, and also to gain understanding of the stroke survivors within their lived experience.

3.1 Issues of Trustworthiness

Both quantitative and qualitative researchers are concerned with establishing validity and reliability during their data collection. However, the meanings of terms differ for qualitative and quantitative research because the selection of the sample, the data collection, and data analysis are carried out differently (Dempsey & Dempsey, 2000). In the qualitative study the researcher serves as a means to transfer the collected data from the participant's life world, as related to his experience, to the reader. The researcher is eager to have his findings reflect the true state of the phenomena she/he is examining. To establish trustworthiness in this current study the researcher used the criteria of Lincoln and Guba (1985), which is based on maintaining credibility, transferability, dependability, and confirmability.

3.1.1 Credibility

Careful qualitative researchers take steps to improve and evaluate data credibility, which refers to confidence in the truth of data (Polit & Hungler, 1999). It might be said that credibility (in qualitative studies) is equal to validity (in quantitative studies). Lincoln and Guba (1985) note that the credibility of an inquiry involves two aspects: first, carrying out the investigation in a way that believability is enhanced, and second, taking steps to demonstrate credibility.

Lincoln and Guba (1985) recommend activities that increase the likelihood of producing credible data and interpretations. A first and very important step is prolonged engagement - the investment of sufficient time in data collection activities

to have an in-depth understanding of the culture, language, or views of the group under study and to test for misinformation. Prolonged engagement is also essential for building trust and rapport with informants (Polit & Hungler, 1999). The second important step is persistent observation, which refers to the researcher's focus on the aspects of a situation that are relevant to the phenomena being studied. As Lincoln and Guba (1985) note, "If prolonged engagement provides scope, persistent observation provides depth." A third important step is "member checks". Member checks refer to providing feedback to study participants regarding the preliminary findings and interpretations and securing the participants' reactions. Member checking can be carried out both informally in an ongoing way as data are being collected and more formally after data have been collected and analyzed. Lincoln and Guba (1995) consider member checking the most important technique for establishing the credibility of qualitative data. Another aspect of the credibility of the research as noted by Patton (1990) is researcher credibility, the faith that can be put in the researcher. In qualitative studies, the researcher is the primary data collecting instrument as well as the creator of the analytic process and, therefore, the researcher's training, qualifications and experience are important in establishing confidence in the data.

3.1.2 Transferability

In Lincoln and Guba's framework, transferability refers to the extent to which the findings from the data can be transferred to other settings or groups and is thus similar to the concept of generalizability. As Lincoln and Guba (1985) note, however, a researcher's responsibility is to provide sufficient descriptive data in the research report for readers to evaluate the applicability of the data to the other contexts:

“...thus the naturalist cannot specify the external validity of an inquiry, he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility...”. “Thick” description refers to a rich, thorough description of the research setting, and the transactions and processes observe during the inquiry. Thus, if there is to be transferability, the burden of proof rests with the researchers to provide sufficient information to permit judgments about contextual similarity.

3.1.3 Dependability

The dependability of qualitative data refers to data stability over time and over conditions (Polit & Hungler, 1999). It might be said that dependability in qualitative studies is comparable to reliability in quantitative studies. Like the reliability-validity relationship in quantitative research, there can be no credibility in the absence of dependability. One approach to assessing data dependability is to undertake a stepwise replication. This approach, which is conceptually similar to a split-half technique, involves having several researchers who can be divided into two teams. These teams deal with data sources separately and conduct, essentially, two independent inquiries through which data and conclusions can be compared. Another technique relating to dependability is the inquiry audit. An inquiry audit involves a scrutiny of the data and relevant supporting document by an external reviewer, an approach that also has a bearing on data confirmability.

3.1.4 Confirmability

Confirmability refers to the objectivity or neutrality of the data, such that two or more independent people would agree about the data’s relevance or meaning. In qualitative studies, the issue of confirmability does not focus on the characteristics of

the researcher (is he or she objective and unbiased?) but rather on the characteristics of the data (i.e., are the data confirmable?) (Polit & Hungler, 1999).

Inquiry audits can be used to establish both the dependability and confirmability of the data. In an inquiry audit, the investigator develops an audit trail, which is a systematic collection of documentation that allows an independent auditor to come to conclusions about the data (Polit & Hungler, 1999). Six classes of records are important in creating an adequate audit trail: (1) raw data (e.g., field notes, interview transcripts); (2) data reduction and analysis product (e.g., theoretical notes, documentation on working hypotheses); (3) process notes, (e.g., methodological notes, notes from member check sessions); (4) material relating to intentions and dispositions (e.g., personal notes on intentions); (5) instrument development information (e.g., pilot forms); and (6) data reconstruction products (e.g., drafts of the final report). After the audit trail materials are assembled, the inquiry auditor proceeds to audit, in a fashion analogous to a financial audit, the trustworthiness of the data and the meanings attached to them. Although the auditing task is complex, it is an invaluable tool for persuading others that qualitative data are worthy of confidence.