1998

The lived experiences of patients who have experienced a stroke

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Recommended Citation

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DOI: https://doi.org/10.31979/etd.2ub6-zwxd
https://scholarworks.sjsu.edu/etd_theses/1706

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THE LIVED EXPERIENCES OF PATIENTS WHO HAVE EXPERIENCED A STROKE

A Thesis
Presented to
The Faculty of the School of Nursing
San Jose State University

In Partial Fulfillment
Of the Requirements for the Degree
Master of Science

By
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August 1998

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ABSTRACT

THE LIVED EXPERIENCES OF PATIENTS WHO HAVE EXPERIENCED A STROKE

by Jeannine Lipka-Blachly

The purpose of this qualitative study was to examine the lived experiences of individuals who had experienced a stroke. A phenomenological approach was utilized in order to understand and capture the individual experiences. The interviews were examined for common themes. The six themes developed from the data were: activity becomes a conscious effort; learning to move and walk again; rethinking performance of activities of daily living; dealing with being housebound; marking progress towards recovery; and looking towards the future.

The findings revealed that the lives of these individuals had completely changed. The automatic response of functioning was lost and they were constantly redefining themselves. Their continued existence required relearning, pre-planning, and seeking assistance from others. The implication for health professionals working with stroke patients is that they should look beyond neurophysiological recovery to view the person.

ACKNOWLEDGEMENTS

I want to thank the individuals who were brave enough to share their lived stories that made this study possible. Hopefully, others can gain insight from their struggles.

I would also like to thank my husband, Brad, because without his knowledge of computers, early assistance, and constant patience I would have never been able to start the graduate program or been able to reach this level of independence with computers. Thank you for the unconditional love and support.

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Chapter 1

INTRODUCTION

Cerebrovascular accidents (CVA), referred to as strokes, are the third leading cause of death in the United States (U.S. Department of Health and Human Services [USDHHS], 1995). One half million individuals are afflicted by stroke each year. Although there is no known cure for strokes at this time, intense rehabilitation has become the accepted treatment for survivors.

The treatment approach to stroke rehabilitation is currently in a state of flux due to changing needs and demands of the health care industry and the public. These needs and demands are driven in part by the financial constraints set by the third party payers. There are also current societal standards that place greater value on returning home post stroke rather than going to a skilled nursing facility to live out one's life in a dependent state. Therefore, rehabilitation professionals are looking for ways to provide cost effective, quality care (Vanetzian & Corrigan, 1995). Many professionals are looking towards research to find the answers.

A large portion of the stroke rehabilitation process is based on medicine's biophysiological disease approach, even though the stroke survivor is a complex entity who consists of more than just a body of tissue and cells. In order to better understand and serve the stroke victim's needs, the rehabilitation process should include an approach that examines the impact of stroke on the whole person. According to Benner (1985), the phenomenological perspective is concerned with just this issue. Phenomenology provides a way of examining medicine through the human experience. This study investigated the experiences of a sample of stroke patients who participated in a rehabilitation program.

Statement of the Problem

Each year, 500,000 to 600,000 people will have a stroke and one third of these people will die within one month (National Stroke Association [NSA], 1992). The remaining two thirds of these victims will have permanent degrees of disabilities varying from mild to severe. Currently in the United States, three million people live with the permanent and disabling effects of a stroke (USDHHS, 1995). A large percentage of the survivors undergo some form of rehabilitation as a means of facilitating their recovery. Many of the people are inpatients in a comprehensive rehabilitation program.

The financial impact of stroke costs Americans an estimated 30 billion dollars per year (NSA, 1994). The figures include direct costs (hospitals, physicians, and equipment) and indirect costs which are the result of a loss of productivity and earnings by the stroke victim. The statistics have attracted the attention of the Agency for Health Care Policy and Research which recently published post-stroke rehabilitation guidelines for clinicians and consumers (USDHHS, 1995). The guidelines serve to educate the stroke patient/family about rehabilitation recommendations. In addition, these guidelines are intended for use by clinicians in practice in order to improve quality of care and increase the cost effectiveness of stroke rehabilitation.

Although these guidelines provide a rehabilitation plan for professionals to follow, they were developed from research that is mainly quantitative in nature. The emphasis of this research is on the medicalization of stroke care and biophysical problems. As rehabilitation professionals work toward establishing programs of excellence, one aspect of the entire process must not be forgotten, that is the stroke patient's experience. It is this experience that must be explore if rehabilitation programs that address the whole person are to be developed. Innovative research approaches need to be utilized in order to understand this phenomenon's impact upon the total of the human experience. One such approach is qualitative research. This approach to the study of rehabilitation can lead to more effective and useful clinical practice (Spencer, 1993).

Purpose and Significance of Study

The purpose of this study was to describe the experiences of stroke survivors who participated as inpatients in a rehabilitation program. The subjects were drawn from Dominican Rehabilitation Center (DRC) in northern California. This researcher examined data for commonalities and differences among stroke victims' experiences with rehabilitation. This study explored the subjects' experiences through their rehabilitation process and their return to home. Though limited, these findings raise issues and suggest implications pertinent to stroke victims' recovery process and rehabilitation. This study was based on the following assumptions:

1. The experience of having a stroke is unique. This experience is not comparable to any other neurological disorder.
2. Receiving stroke rehabilitation is a specific process and is different from any other type of process or life experience.
3. Understanding the stroke victim's experience will have implications for nursing care of these individuals.
4. The qualitative research method is the most appropriate method to explore stroke victims' experiences.

This study is significant for rehabilitation nursing because few studies have been conducted that focus on the human experiences of disability and rehabilitation among this population. "The human, lived responses of the individual to the stroke experience are not addressed" (Doolittle, 1988, p. 170). The lack of nursing literature on the human experience of stroke survivors has been documented by Adkins (1993), Mumma (1986), Doolittle (1988, 1991), Davidson and Young (1985), and Folden (1994) in the areas of quality of life, perceived losses following stroke, the stroke recovery experience, post-discharge problems encountered, and managing the effects of a stroke. Other professionals in the areas of rehabilitation (Spencer, 1993) have also expressed a need for rehabilitation research literature that investigates the real world of disabled people. Kaufman (1988b) argues that to truly study the meaning of illness is to see it through the patient's perspective.

Question

The question addressed in this study is: What are the lived experiences of patients who have experienced a stroke?

Objective

The objective of this study is to describe the experiences of a sample of stroke patients for commonalities and differences in their post stroke experiences which include being an inpatient prior to their return to home.

Definitions

Lived experience: is defined as a person's essence or being in this world (Merleau-Ponty, 1962). Subjects describe their experiences through their verbal and non-verbal statements. This term is also referred to as life world or real world in other literature. The words, lived experience and perspective, are terms used in phenomenological writings only to describe subjects' lives. The term "experience" rather than "lived experiences" will be utilized in this thesis.

Stroke: refers to a cerebrovascular accident which is a condition that affects blood flow to the brain. Strokes can cause death to portions of the brain, ultimately leading to physical and cognitive deficits. The type of physical and cognitive deficits demonstrated by stroke victims depend upon the areas of the brain that are affected. A stroke may leave a victim paralyzed on one side of the body or both sides; it can cause severe cognitive losses in the areas of speech, memory, communication, vision, perception, space, and problem solving. Strokes are classified as thrombotic, embolic, or hemorrhagic depending upon their causes (Foley & Pizer, 1990).

Stroke patient: is defined as a person who has had a cerebrovascular accident and as a consequence has been hospitalized for acute treatment and rehabilitation care.

Stroke rehabilitation: is a restorative learning process which seeks to hasten and maximize recovery from stroke by treating the disabilities caused by the stroke, and to prepare the stroke survivor to reintegrate as fully as possible into community life. It encompasses a broad array of biomedical, social, educational, and vocational interventions which are provided by an interdisciplinary team of nurses, therapists, case managers, physicians, and dieticians (USDHHS, 1995).

Summary

Stroke is a devastating and disabling condition that affects one half million Americans every year. The incidence of stroke costs this country billions of dollars annually. The ultimate health related goal is to prevent strokes and their effects from happening. Until advances in medical technology make this possible, the United States needs ways of managing this overwhelming problem. Presently, rehabilitation treatment programs have been established to assist the stroke victim's recovery process. Rehabilitation for the most part is based on the biophysiological aspects of the patient's condition and perceived needs. "People do not die or survive strictly according to our best biochemical and physiological accounts" (Benner, 1985, p. 2). The challenge is to view the stroke victims' experience from their own perspective in order to provide new thoughts and understanding to this overwhelming problem. This could lead to new directions for stroke care. Currently, the nursing and rehabilitation literature is limited in the number of qualitative studies that investigate stroke victims from their perspective.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

"Health and illness are lived experiences and are accessed through perceptions, beliefs, skills, practices, and expectations" (Benner, 1985, p.1). These lived experiences of every human being are accessed through the human body which contains the soul, spirit and knowledge. According to Merleau-Ponty (1962) the mystery lies in the relationship of the body and soul (self) and how they are experienced, interpreted, and perceived. Descriptions of how stroke victims perceive and experience life are deficient in current research studies. A systematic account of survivors' experiences as they undergo rehabilitation is important to nursing knowledge. Information derived using a phenomenological approach has the potential to contribute to nursing knowledge because it offers a new understanding of old problems and may provide a new perspective on solving the problems that plague these individuals.

This chapter is divided into two parts. The first section is the conceptual framework and the second is the review of the literature.

Conceptual Framework

This discussion on conceptual framework contains three sections. The first section explores and describes phenomenology. Section two provides rationales for utilizing phenomenology as a method for studying stroke. The last section describes the conceptual framework utilized in this study.

Phenomenology defined

A person does not experience this world with either merely his or her mind or body. According to Merleau-Ponty (1962), we are able to experience this world through our body which stores the mind. "Health and illness cannot be understood by studying a mind that possesses a list of talents, traits, and attributes, nor can they be understood by strictly studying biophysiological states" (Benner, 1985, p. 2). The phenomenological approach is a method in which the researcher attempts to look through the subject's eyes in order to describe his or her experience's of life through health and illness. This thesis was developed utilizing a phenomenological framework in order to look at stroke victims' experiences.

There are several schools of thought within phenomenological philosophy. The following is a description of phenomenology which takes it origin from Edmund Husserl (1962) whose philosophy contained Cartesian concepts. It was later redefined by Martin Heidegger (1962), a student of Husserl's, who took the opposite view of his teacher in the concepts of being and time. Maurice Merleau-Ponty (1964) further explored the philosophy by investigating perception. This description has been included in order to provide the reader with a clearer understanding of the phenomenology philosophy which is the basis for the phenomenological method. According to Powers and Knapp (1990), phenomenology is a way of thinking about life experiences and what they are like for individuals. Research that is of a phenomenological nature always asks about the meaning of the human experience or what it is like.

Merleau-Ponty (1962) describes phenomenology as a science in which one strives to find the definitions of essences. A philosophy that projects that the world is always "already there" and the idea is to reflect on this world as it truly exists. It offers an account of space, time, and the world we live in as we live in it. The phenomenological method (Paterson & Zderad, 1988) cultivates knowing from within an experience rather than looking at the experience from the outside.

Phenomenology offers a different view from Cartesianism which holds that the mind and body are separate and are distinguished by objective and subjective symptoms or data. The mind/body (Benner & Wrubel, 1989) is not a simple split of dual realities "mind over matter" or "body over mind". Phenomenology offers a way to approach the synergistic and mutual relationship between the mind and body.

Merleau-Ponty (1964) considers the body to be the vantage point of perception. The nature of perception is to return to the phenomenon; the phenomenon that is apparent is the body. "The body is the medium through which conceptions of self are formed" (Corbin & Strauss, 1988, p. 53). Therefore, the mind and body must be studied as a joint organism, but each must also be studied as having separate qualities that are dependent on each other.

The basis of Merleau-Ponty's view of phenomenology is on perception. He believed that perception is paradoxical. "The perceived thing itself is paradoxical; it exists only in so far as someone can perceive it" (Merleau-Ponty, 1964, p. 16). As a conceptual framework, phenomenology provided a focus on perception which guided this researcher through the data. The following summarizes this guide to perception.

> If I consider my perceptions as simple sensations, they are private; they are mine alone. If I treat them as acts of the intellect, if perception is an inspection of the mind, and the perceived object an idea, then you and I are talking about the same world, and we have the right to communicate among ourselves because the world has become an ideal existence and is the same for all of us (Merleau-Ponty, 1964, p. 17).

Phenomenology as a Method of Studying Stroke

Most research on stroke is quantitative in nature and is focused on the current problems of rehabilitation. Many of the current solutions to the problems of stroke rehabilitation are being determined by familiar measures and approaches. Utilizing familiar measures derived through quantitative research approaches may not be enough to understand the many complex issues that arise during the rehabilitation process. "We all recognize that {the quantifiable} is not all there is in rehabilitation, and that counting or measuring is not sufficient as a way of understanding the resilience of our patients or what inspires either their despair or their joy" (Spencer, 1993, p. 119).

Studying the meaning of illness through the patient's perspectives and experiences can be illustrated by Kaufman (1988a) who cites three primary goals of qualitative research. The following is a summation of her arguments.

The social, psychological, and moral aspects of illness can be thoroughly identified by capturing the ill person's subjective responses. This response includes how the person views the significance of their illness, how it affects their status and relationship to others, their life situations and the present environment, and how they view the treatment or care of their condition. The second goal of this type of study is to explore the problem behaviorally instead of through objective data which offers a narrow understanding of a disease and treatment. This is especially important because decisions that individuals make about their treatment reflects more on their personal priorities, imperatives of daily life, and their lifelong response to crisis and disruption, rather than to medical advice. Finally, the third goal is to expand any provider's understanding of the patient's perspective of the illness so that realistic plans of care can be designed and implemented. An effective treatment plan should be based not only on the provider's knowledge, but also on the patient's perspective. Kaufman and Becker (1991) utilized the phenomenology method to explore ways in which some primary care physicians draw boundaries of medicine as they respond to chronic illness in their geriatric stroke clients. In the article "Toward the Phenomenology of Boundaries in Medicine", the use of the phenomenological perspective was explored. Kaufman (1988a) utilized this approach because it allowed the subject of medical boundaries to be explored with respect to how it limited and compromised the illness of stroke and how other factors influenced the experience. "Phenomenological examination of stroke articulates particular transformations of the body, social world, time, and notions of limitation and possibility" (Kaufman, 1988a, p. 341). Becker and Kaufman (1995) continue to utilize phenomenology as an accurate method to study the many aspects of stroke as seen in "Managing an uncertain illness trajectory in old age:

patients and physicians views of stroke."

In reviewing the nursing literature, very few studies have been published utilizing phenomenology as a conceptual framework. On the other hand, Paterson and Zderad (1988), who developed the "humanistic" nursing theory based on phenomenology, believed that nursing appreciates and values the meaning of experiences to man (patients) and that nursing needs to know how to study this phenomenon. Thus, their theory's existence arose from their philosophical and applied nursing experiences. According to Dittmar (1989), more descriptive studies are needed because they reveal independent variables that may influence the rehabilitation process and outcome. Phenomenological studies are becoming more prevalent in many areas of nursing. The reason for this movement toward the qualitative method (Habermann-Little, 1991) is due to the recognition that these approaches are capable of making contributions to nursing science. There has also been an acknowledgement of these approaches as congruent with the values and concerns of nursing. The phenomenological approach (Munhall & Oiler, 1986) is needed because the concepts and theories produced from these studies would possess a greater relevance for utilization throughout nursing.

Conceptual Framework Guide

The specific concepts used for the conceptual framework of this study are from Patricia Benner's and Judith Wrubel's book, The Primacy of Caring (1989). The concepts were developed based on Heideggerian phenomenology. These concepts include embodied intelligence, background meaning, concern, and the situation. Together they describe the phenomenological view of a person as a self-interpreting being.

A person is a self-interpreting being. The person does not come into the world defined, but becomes defined through their course of living in the world. Human beings are able to interpret their cultural background through skills and practices (Leonard, 1989). The individual utilizes many aspects to be this self-interpreting being. The following is a guide to these aspects of self.

The phenomenological view of embodiment is that rather than having a body, individuals are embodied. Merleau-Ponty (1964) refers to this as bodily intelligence. The body responds to situations in various rapid, non-explicit, nonreflective, and unconscious ways. Embodied intelligence helps the individual to grasp lower level activities and higher, more complex functioning. This means that human beings have a mind-body unity and have the capacity to be in a situation in a meaningful way. This embodied intelligence allows an individual to live in the world and to understand it in relation to him/her self.

Meaning is utilized in terms of subjective and objective. The subjective meanings of things are private and accessed by only the individual. Once subjective meaning is reflected upon or examined, it can be made explicit or made into objective meaning. Background meaning (Heidegger, 1962) is what determines what counts as real for that person. It is what a culture gives an individual at birth. Background meaning is the public understanding of what "is" for the individual. It allows for the perception of the factual world. This background meaning provides the content for what is to be understood by the individual in this world.

When things matter to individuals they become involved in the world. This is called concern. The term concern accounts for why the person is in the world in the manner in which he or she is. The individual's concerns may be used to define that individual. It is what motivates the individual (Benner & Wrubel, 1989); it may be the person's own internal drive, needs, structural traits, external prodding or environmental rewards.

Sometimes this unconscious functioning does not work well or it may breakdown. The real world content of an individual can change especially with death, divorce, marriage, childbirth, career promotion or demotion, and environmental changes. The individual's embodied intelligence, background meaning, and concern, which allow him to function smoothly in the world, become useless in many of these situations. These events place the individual in a situation in which the old self-understandings are no longer relevant (Benner & Wrubel, 1989). An example of one of these situations is stroke, whereby, many taken-for-granted aspects of an individual's being no longer work.

This conceptual framework will be used as a general guide for the entire study and more specifically, it will be utilized throughout the methodological approach. The various concepts of the framework will be used as points of reference when looking for the key themes during the exploration and the interpretation of the data. Finally, the conceptual framework will be used to derive conclusions and recommendations.

Review of Literature

The literature on stroke and stroke rehabilitation is overwhelmingly vast. The literature which is published by the thousands each year is based on many facets of stroke and the incurred problems surrounding its phenomena. The following literature review explores a few aspects of stroke rehabilitation.

Financial Costs of Stroke

Stroke remains the third leading cause of death in the United States (USDHHS, 1995). One half million people are afflicted by a stroke each year and one third of those afflicted die. The two thirds that survive are left with some form of disability which may vary from a mild impairment to a severe disability (Doolittle, 1990). Stroke has become one of the major causes of disability today and contributes to the increase of individuals institutionalized in long term care facilities (Baum & Manton, 1987). It is also one of the most expensive medical problems in the United States, with estimated costs at 30 billion dollars annually (NSA, 1994). Stroke costs are consuming large portions of the gross product in many developed countries.

Health care delivery is being forced to change because of the financial stress placed on the system. The ability to contain the rising costs, now and in the future, seems to be diminishing (Smurawska, Alexandrov, Bladin, & Norris, 1994). Current research is focused on the use and costs of inpatient stroke rehabilitation compared to outpatient day use and home care for stroke patients (Gladman, Whynes, & Lincoln, 1994;Young & Forester, 1992). Currently, researchers are looking at the present health care delivery system and outcomes of stroke care are being challenged by the justification of costs. According to the post stroke guidelines (USDHHS, 1995) there are few quality studies examining cost effectiveness of stroke rehabilitation. Does the end justify the means and how does patient experience relate to the costs?

The Effectiveness of Stroke Rehabilitation

The cost for an individual to receive rehabilitation from a stroke unit is higher than from a skilled nursing unit, but the issue is whether inpatient stroke rehabilitation produces greater outcomes and decreases length of stay. According to recent studies (Kalra, 1994; Kalra, Dale, & Crome, 1993; Indredavik, Bakke, Solberg, Rokseth, Haaheim, & Holme, 1991; Ottenbacher & Jannell, 1993), shorter lengths of stay and faster return of functional recovery were facilitated by the use of stroke inpatient rehabilitation. According to the post stroke guidelines, there is very little scientific research supporting that stroke rehabilitation is beneficial. The stroke guideline panel sees this as an open opportunity to stimulate more research in order to develop more comprehensive stroke rehabilitation programs.

Rehabilitation Methods

One study conducted on outcomes of two different therapy methods utilized in stroke rehabilitation found that there was no conclusive difference in therapy approaches correlating to individuals' recovery (Eakin, 1991). According to Larkin

(1991), there is agreement in the medical community that stroke rehabilitation is beneficial, but the consensus about the benefits does not mean consensus about methods. There continues to be copious amounts of data drawn from studies that are looking at new methods. Each study examines a very specific area of stroke rehabilitation. A search of rehabilitation literature found such studies as: the use of biofeedback in improving footdrop (Intiso, Santilli, Grasso, Rossi, & Caruso, 1994), overcoming nonuse of motor ability (Taub, Crago, Burgio, Groomes, Cook, Deluca, & Miller, 1994), continuous passive range of motion on upper extremity edema (Dirette & Hinojosa, 1994), and dysphagia therapy (Depippo, Holas, Reding, Mandel, & Lesser, 1994). Although several of these studies were limited by sample size and non-randomized grouping, they each debated the current methods of treatment to combat the problem investigated in their study.

In addition to medicine and professional therapy, nursing has been concerned with its role in adopting an effective method to stroke rehabilitation (Passarella & Lewis, 1987). Dittmar (1989) compiled a comprehensive guide to nursing process and application in rehabilitation. Hoeman (1996) has updated the documentation about the nurse's role in rehabilitation. Both Dittmar and Hoeman documented that evaluation, prediction, and methods in rehabilitation are not consistent. Perhaps it may not be the specific method utilized by therapists or nurses within a given rehabilitation facility, but the dedication of staff, coordination of services, and education emphasis on patient and family in that setting which contributes to better recovery outcomes (USDHHS, 1995). Examining a patient's experiences in stroke rehabilitation may increase understanding on validation of methods and care.

Assessing and Evaluating Stroke in Activities of Daily Living

Another facet of stroke care is based on how an individual is assessed for progress and discharge within a program. Many rehabilitation facilities are beginning to utilize an assessment tool that documents the stroke patient's level of function in activities of daily living (ADL) at admission, through each week, and at discharge in order to establish outcomes. An assessment tool called the FIM (functional independent measure) is currently being used because studies found it accurately reflects the patient's functional status, is practical to use, and contributes to the scientific basis of rehabilitation medicine (Granger, Cotter, Hamilton, & Fiedler, 1993; Hamilton & Granger, 1994; Segal & Schall, 1994)). Although the FIM enhances the summary of an individuals's ability to function, it only allows for objective data which is determined on a subjective level and there can be no interrater reliability by rehabilitation team members. In addition, the problem with the FIM is that it may fail to detect improvements, not be sensitive to changes in patients with high levels of disabilities, and summation of scores can be misleading because areas not associated are added together (USDHHS, 1995).

Other assessment tools have been developed to assess the stroke patient's level of consciousness, response to treatment, functional ability, and neurological impairment. Several assessment tools have been explored for validity throughout all disciplines of rehabilitation (Depippo, Holas, & Reding, 1994; Le, Venti, & Levin, 1994; Mate-Kole, Major, Lenzer, & Connolly, 1994; Sanford, Moreland, Swanson, Stratford, & Gowland, 1993; Toedter, Schall, Reese, Hyland, Berk, & Dunn, 1995). Currently, the assessment practices in the field of rehabilitation are numerous, and unfortunately very few have been validated (USDHHS, 1995). The stroke patients' experience may provide a direction for utilization of more accurate tools.

Predicting Disability

Predicting disability for stroke survivors has become important because of changes in reimbursement which influence admission criteria. Third party payers are looking more closely at weekly and discharge outcomes not only to justify costs, but to check standard criteria utilized to determine services provided for appropriate patients. Duncan (1994) proposes that a conceptual model on disability (impairments, disabilities, and functional limitations) used by physical therapists would ensure more accurate targeting of individuals who would more likely benefit from stroke rehabilitation. On the other hand, a study performed by occupational therapists (Brodie, Holm, & Tomlin, 1994) proposed that rehabilitation be focused on the level of impairment versus the level of disability.

The severity of a stroke and pre-morbid disability are considered strong predictors of outcomes (Alexander, 1994; Anderson, 1994). In addition, incontinence, regardless of other demographic variables, was a powerful predictor of disability (Anderson, 1994; Taub, Wolf, Richardson, & Burney, 1994). The literature search revealed that there are many studies on reliability and validity of new scales that predict disability. The most common scale utilized is the Rankin scale which predicts overall disability (USDHHS, 1995). According to Bonita and Beaglehole (1988), the two major drawbacks to this tool are that it can be insensitive to changes in status and only fully assesses ambulation to determine disability.

All of the research and tools developed to predict disability seem to leave out the humanistic side and the stroke victim's view of his disability. Even though functional deficits may largely contribute to disability, where does the person's attitude, will, internal strength, hope, and coping fit into the scheme of disability? Looking at the stroke victim's experience may offer some new meaning on predicting disability.

Functional Mobility

Much of the current neurological research in stroke rehabilitation continues to focus on return of physical functioning as the real impact of rehabilitation (Adkins, 1993; Davidson & Young, 1985; Doolittle, 1988, 1991; Folden, 1994). The return of physical functioning is quite often seen in rehabilitation as the only measure of functional independence or recovery.

The major areas of focus include the ability to ambulate or weight bear, use the upper extremities, and to swallow. Even cognition is measured as a physical function. Functional independence is measured by some physical indicator and is documented as the completion of a specific task (Doolittle, 1990). The return of physical functioning, most often equated with ambulation, is considered a large part of the stroke rehabilitation process (Hesse, Jahnke, Bertelt, Schreiner, Lucke, & Mauritz, 1994). The status of ambulation is used by many rehabilitation teams to measure progress. Jorgensen and associates (1995) found that walking is the most common goal set by patients for themselves. However, these researchers utilized quantitative methods and focused primarily on the biophysical aspect of the patient's recovery. According to one current study on measures, "there is much to be learned from the stroke survivors themselves, especially in the assessment of their own attitudes, moods, and struggles to reassert meaning and to cope with major alterations in health, abilities, and life roles" (Toedter et al, 1995, p. 719).

Strokes in the Elderly

The largest percentage of strokes affect the elderly, ages 55 and older. Stroke is the major cause of physical and mental disability in the elderly (Ferrini & Ferrini, 1993). Studies are now investigating the effect of stroke rehabilitation units on the elderly patient. One study found that a well managed inpatient stay on a stroke unit was associated with a better outcome (Kaste, Palomaki, & Sarna, 1995). Harper (1995) states that stroke treatment in older patients is the rule rather than the exception and state of the art stroke treatment (stroke unit) is reducing mortality and disability. On the other hand, two studies found that increasing age of a stroke patient was associated with a poorer or less beneficial stay in a rehabilitation unit (Falconer, Naughton, Strasser, & Sinacore, 1994; Kalra, 1994). Their conclusions noted that sufficient evidence was present to warrant further investigation into strategies for older adult stroke victims. Many factors such as age, social support, medical complications, and pre-morbid health problems were examined in these gerontological studies.

Becker (1993) performed one of the few phenomenological studies on an elderly population. This qualitative study explored the disruption in the lives of elderly persons who had experienced a stroke. The study provides insight into the elderly person's experience with stroke. More studies that examine the experiences of elderly stroke patients could lead to practical strategy development for returning continuity in their lives.

Depression in Stroke

Depression is a common factor after stroke and it can be manifested as an effect of the brain damage or as an emotional reaction to the illness. According to Bolla-Wilson and colleagues (1989) depression can affect a patient's participation in rehabilitation, their long term outcome, and exacerbate any cognitive dysfunction they may have. However, diagnosis and early intervention of depression in stroke victims may enhance the rehabilitation potential (Ramasubbu & Kennedy, 1994). The effect of depression on physical functioning is currently being debated in the medical literature (Kelly-Hayes & Paige, 1995). One such study (Zalewski, Keller, Bowers & Miske, 1994) examined the relationship between depressive symptomology and level of functioning. The conclusion was that while the depressed group may have required a longer length of stay, they had higher initial and discharge levels of functioning than the non-depressed group. Overall, researchers have found that depression in stroke is associated with a higher rate of discharge to long term institutions (Cushman, 1988), a greater rate of disability of ADL functioning (Parikh, Robinson, Lipsey, Starkstein, Federoff, & Price, 1990), and higher ten year mortality rates (Morris, Robinson, Andrzejewski, Samuels, & Price, 1993).

Depression in stroke and its relationship to hemispheric damage is also being examined. In comparing three studies published about depression, the findings were varied. In the first study, it was concluded that there was no significant difference in depression between right hemisphere and left hemisphere damage (Agrell & Dehlin, 1994). The second study concluded that left hemisphere strokes were initially more affected by depression, but over six months time the right hemisphere damage groups tended to exhibit more signs of depression (Nelson, Cicchetti, Satz, Sowa & Mitrushina, 1994). Finally, the third study concluded that incidence of depression was higher in patients with right hemispheric damage, but the number of variables affecting these results were numerous and the need for future research into each variable was needed (Whitney, Burns, Frederic & Lowery, 1994).

The state of depression is primarily diagnosed from objective data, but regardless of diagnostic techniques, it can have devastating effects upon the individual and family if not treated. In rehabilitation, depression is seen as a physical problem, but depression is a personal experience. How does the stroke patient's experience with depression get evaluated and what part does it play in the treatment?

Nurses Managing Stroke

There exists a small amount of literature about nursing's contribution and knowledge in the rehabilitation of stroke patients (Kirkevold, 1992). Part of the problem may be that most nursing education programs do not emphasize rehabilitation issues regarding stroke recovery and neurological retraining (Galarneau, 1993). Gibbon and Little (1995) concluded that nurses have a vital role to play in stroke rehabilitation and it could be enhanced by greater knowledge. On the other hand, one British study found that nurses do not play a major role in stroke rehabilitation (Gibbon, 1994). These finding were based on care in the community (home care) where nurses were involved after the patient had reached a level of inability to meet self care demands.

There are some significant nursing studies that examine the methods or approaches utilized by nurses in stroke rehabilitation. These researchers and clinicians have explored areas of stroke rehabilitation concerned with bowel retraining (Munchiando & Kendall, 1993; Venn, Taft, Carpentier, & Applebaugh, 1992), catheterization techniques (Quigley & Riggin, 1993), bladder incontinence (Owen, Getz, & Bulla, 1995), and supportive-educative intervention (Folden, 1993). However, these areas have traditionally been deemed a concern for nursing staff, usually by the other rehabilitation team members. In the past, nurse researchers have encouraged rehabilitation nurses to look past traditional care modes and adopt new therapeutic methods that encompass all aspects of stroke care, not just bowel and bladder care

(Borgman & Passarella, 1991; Passarella & Lewis, 1987).

Health care providers have different perspectives on the meaning of recovery (Doolittle, 1990). Traditionally nurses have seen themselves as the advocate for their patients capable of providing understanding for humanistic issues caused by health problems. More research into the stroke victim's experience may provide a realistic perspective for nurses to investigate new methods or validate current methods.

Family and Spouse Involvement

Stroke affects long term quality of life and the well being of the family and spouse. The confines of today's medical treatment and insurance stances dictate that inpatient stroke rehabilitation be limited to a matter of a few weeks. Support by family members is critical to achieving successful outcomes with stroke patients (USDHHS, 1995). The crux of rehabilitation education and retraining begins in the inpatient program and is continued at home. This continuum is made possible by the individual's support system (family and friends). Rehabilitation is a family issue because ultimately it becomes responsible for insuring and providing the services and care that determines each patient's quality of life (Evans, Connis, Bishop, Hendricks, & Haselkorn, 1994; Evans, Griffith, Haselkorn, Hendricks, Baldwin, & Bishop, 1992). Family involvement has also been found to be positively related to functional improvement among stroke patients (Brandstater & Basmajian, 1987). Unfortunately, the family/spouse is at risk for deleterious effects of caregiving for a stroke victim. This information on caregiving stress and burden has been well documented in the literature, but rarely are the studies qualitative in nature and focus on the caregivers' total experience. An exception to this is Unending Work and Care, by Corbin and Strauss (1988). Their work investigated the effect of chronic illness on the patients' and the caregivers' lives.

Pierce (1994) found that fear is a large component of the experience of stroke for not only the patient, but more often for the spouse or caregiver. A recent study found that the staff's perceptions of wives' needs were significantly different than what the wives viewed as their actual needs (Rosenthal, Pituch, Greninger, & Metress, 1993). The researchers found that emotional issues or those having to do with feelings were ranked lower on the priority level of needs than those regarding physical care. Vanetzian and Corrigan (1995) found that caregivers rated their own well-being as a low priority in comparison to assisting the disabled adult and learning about health and human resources, even though many of the participants rated their health as poor. Losses are not only experienced by the patient, but usually reported by the spouse. The same losses due to stroke (lack of independence and social withdrawal) have been reported simultaneously by spouses (Mumma, 1986). The spouse has been found to be instrumental in contributing to the adaption process in stroke victims (Baker, 1993). However, a small study performed by Enterlante and Kern (1995) found that wives reported a significant increase in unhappiness after the spouse's stroke and dissatisfaction with the increased responsibility for the household and spouse's well-being.

Individuals Managing Stroke Recovery

There has been little research done on the quality of life following stroke by any rehabilitation professionals (Adkins, 1993). Quality of life is a broad issue, but most research has focused on the physical aspects of stroke recovery and little on the emotional issues, social factors, or virtual experience. An early study explored problems post discharge of stroke patients (Davidson & Young, 1985), but the findings were focused toward more environmental and community reentry issues. Boynton De Sepulveda and Chang (1994) investigated individual's coping with stroke from the angle of social support and resources, but the study's findings were limited by the quantitative nature of the study. How individuals manage their deficits and treatments over time has not been explored (Folden, 1994).

There is a need for rehabilitation professionals to understand the post stroke individual's recovery goals. These goals are how each individual measures self progress and plans for management of recovery. Little research has been conducted on the recovery experiences and the impact of stroke on individuals' lives (Doolittle, 1988, 1990, 1991; Folden, 1994). Rehabilitation can lead to independence for individuals and can give them a sense of reclaiming purpose in their lives. Rehabilitation professionals who set the criteria and propose the standards have done little to understand the stroke victim's perspective. The rehabilitation professional's perspective of recovery and progress is often divergent from those of the stroke patient (Kaufman, 1988b). How does the stroke victim's perspective of management of disabilities differ from that of the rehabilitation team's perspective?

Viewing Stroke Illness and Recovery in Medicine

Two social scientists (Kaufman & Becker, 1986, 1991) utilized a phenomenological approach to understand medicine's view of stroke rehabilitation. Two conflicting frameworks were revealed from the study, holism and medicalization. Consistent with holism, the physician should always consider the patient's psychological, behavioral, and sociocultural composite as relevant in the medical care. Whereas, the medicalization framework refers to all these components as part of the disease or medical problems.

Early in medical history, stroke victims were seen as occupying a sick role (Gold, 1983). According to current rehabilitation standards, stroke patients are immediately seen as individuals in recovery trying to obtain independence. It is a two fold problem in that acute medicine and rehabilitation medicine view stroke care differently. Within the rehabilitation process, the professionals and the stroke patients have considerably different thoughts about the recovery process and proposed activities. According to Kaufman and Becker (1986), the health care system devalued rehabilitation because it differed from acute care, and poor understanding on the part of physicians meant little advocacy for programs. Unfortunately, the health care system continues to devalue rehabilitation by refusing to pay for services. It pre-sets outcomes of rehabilitation effectiveness by either by-passing inpatient stays completely or allotting extremely limited time to any type of rehabilitation services.

Summary

Phenomenology is defined as a method to know the essence of a being. It is given that the world exists, but it is the researcher's job to reflect upon a human beings as they exist in this world or in their world. Phenomenology as a conceptual framework offers the researcher a way of presenting the individual's perspective as if telling the story in the individual's own words. The concept of self-interpreting being is composed of embodied intelligence, background meaning, concern, and the situation. These components are the guide to understanding each individual as a human being and describing their experiences.

The literature is vast on stroke and rehabilitation. The literature is comprehensive in the fact that many issues surrounding stroke have been studied. Volumes of stroke rehabilitation literature are published annually; articles range from cost effectiveness of services, determination of outcomes, prediction of disability, validation of reliability of measures, new assessment techniques, enhancement of functional mobility, geriatric issues, and management of disability. Very little of this literature has focused on the experiences of the stroke patient.

While nursing literature in rehabilitation may have focused on more psychosocial aspects of stroke, rehabilitation medicine has addressed more physical functioning issues regarding stroke recovery. The medical research most frequently identifies the biophysiological perspective of the stroke recovery, not the holistic or biopsychosocial perspective (Benner, 1985; Doolittle, 1988). The biophysiological perspective views disease as the biochemical and neurophysiological dysfunction at the cellular, tissue and/or organ level. In contrast, the biopsychosocial approach (Engel, 1977) views the course of illness through the patient's behavioral, interpersonal, and psychological attributes.

The human story of the stroke experience is important because it describes the impact of living with this devastation and it's impact on the individual's course through life. Agnes De Mille (1981) was compelled to write about her experiences in life following a major stroke. Her memoirs called Reprieve, eloquently describe her story of devastation and recovery through her own words. The literature review led this researcher to the conclusion that there is a paucity of described human experiences in the area of stroke. There is not only a need for further research in the area of stroke, but an increased need for the utilization of the phenomenological approach to describe these lived experiences. The phenomenological approach offers a method to obtain rich data about an illness/disease experience where other scientific studies may view the situation in a narrower way. So many of the experiences in rehabilitation may not be recognized when utilizing quantitative measures. On the other hand, much of the data obtained in a phenomenological approach can bring this data into the arena and may generate information for new studies while offering solutions to some of the same problems.

Chapter 3

METHODOLOGY

This chapter is a discussion of the methodology utilized. The sections that are discussed include: research design, subjects and setting, data collection, and analysis.

Research Design

The design utilized in this study is a non-experimental type. According to Brink and Wood (1988), this design is exploratory and descriptive in nature. The study was guided by a phenomenological approach. The data were collected through open-ended interviews, a demographic data form, and field notes. The interviews were taped and the data were transcribed to narrative form for analysis.

Subjects and Setting

A non-probability sampling or convenience sampling method was utilized to recruit subjects for this study. The following criteria were devised to organize the recruitment of subjects. Each subject had to have experienced a stroke within six months of being recruited. All of the subjects were able to verbally communicate in English (voice and words are clear and distinguishable) and were able to participate actively in a conversation. All of the subjects were over the age of 55 when they experienced the stroke. Those subjects that met the criteria were interviewed in their own residence three months post discharge from the rehabilitation facility. The sample consists of six human subjects over the age of 60. The youngest subject is 61 years old and the oldest subject is 82 years old. The mean age of the study's population is

69 years old. Three males and three females make up the sample. This convenient sample produced three subjects with right brain strokes (left hemiplegia) and three subjects with left brain strokes (right hemiplegia). All of the subjects are of a European background and are considered Caucasian. The socioeconomic status of the sample varies from low income to high income. The subjects had been patients in the rehabilitation facility for a minimum of at least 2 weeks with the mean length of stay being approximately 3 weeks, and the longest length of stay being 4 weeks. All of the subjects were discharged directly to the home in which they had resided before the stroke experience. Five of the subjects returned to residential dwellings and one subject returned to an assisted living environment. Four of the subjects are relying on their spouse's assistance for ADL and two of the subjects are relying on assistance from hired non-licensed personnel.

The hospital-based general rehabilitation facility offers a comprehensive inpatient rehabilitation program. This facility is a small rehabilitation unit with a 12 bed capacity. Each subject had been directly admitted to the facility after discharge from an acute hospital facility. Upon discharge from the facility, all of the subjects received therapy through home health services. Two of the subjects were able to continue with out-patient therapy after their home health services were discontinued. The home health services varied in regards to occupational therapy, nursing, and speech therapy, but all subject's received physical therapy. The outpatient services varied, except no nursing care was provided.

Data Collection

The data were collected from the subjects through several methods. The first method was an interview using open-ended questions. All of the subjects were interviewed three months post discharge from the DRC facility. Each interview was taped and the information was transcribed immediately following each interview with all identifying information removed by erasing the tapes. In addition, a personal tape was made immediately following each interview by this researcher in order to record subjective and objective impressions. This information assisted in enhancing recollection of any details or information during the analysis of the data. Data were also collected by field notes taken by this researcher during each interview. They included observations of physical aspects and non-verbal communication. Personal and biographical data were collected for each subject utilizing a demographic instrument. These data were collected via the medical chart and any missing data from the chart was obtained from direct questioning of the subject.

Data Analysis

Each interview was analyzed utilizing theme analysis as described in the chapter on open coding by Strauss and Corbin, Basics of Qualitative Research, (1990). Open coding allows the data to be accurately processed and analyzed. The interviews were first read and analyzed line by line or by sentence. They were then re-analyzed by reviewing the entire document. Finally, each interview was analyzed for common or recurring themes.

After intensive review of the data, the major themes were identified and labeled from each subject's interview. The data were further analyzed by comparing each subject's responses to the same question. Finally, the themes were chosen by comparing each subject's responses and extrapolating the common threads. Since much of the data overlapped, the descriptions under each theme bear the greatest relevance, not just exclusive emphasis. Finally, the data were grouped into six main themes.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

A stroke leaves a person with a "damaged body", one that no longer automatically functions as it used to. These six subjects did not lose all functional ability, but what they lost was enough to alter their lives significantly and leave them living in what may be conceptualized as the "focused present." This period is marked by an ongoing struggle to regain sufficient functional ability in order to be able to act independently and to carry out some of the activities that they once found meaningful in the past. They've lived through the crisis of the stroke, fought depression, and went through a difficult process of rehabilitation. Now they are at home working at overcoming disability while relying on others to do for them what they cannot. Each day is a process of defining the present (where they are now in terms of ability) in light of the "before stroke past" and "the immediate past." Keeping them going is an eye towards the "hoped-for future." The following quotation summarizes the major findings of this study.

> It's (the body) got a long way to go. My mind is still fairly sharp, my body is not. It needs a lot of healing. I can tell it what to do, it just doesn't get there. Eventually I guess it will. They say it gets rechanneled. All I can do is hope.

Living life in the "focused present" can be described in terms of the following six themes. These are: (a) activity becomes a conscious effort; (b) learning to move and walk again; (c) rethinking performance of activities of daily living (ADL); (d) dealing with being homebound; (e) marking progress towards recovery; and

(f) looking towards the future.

Activity Becomes a Conscious Effort

Each participant cited that movement had to be a conscious effort. Movement was no longer an automatic process. Movement of the leg or arm or both had to be thought out. The mind and body connection was always apparent in the fact that the subjects had to tell themselves to move or tell themselves that they could not move. One participant stated, "Things that I used to do automatically, I have to stop and think about how to do them." The process of being aware was continuous and never ending for each participant. This process had the effect of constantly reminding each individual about their deficits. This constant reminder was making each subject realize and recognize their abilities and inabilities.

For these individuals, embodiment (movement and their response to that movement) is no longer automatic, unconscious, rapid, or explicit. The meaning of movement has changed for each of these individuals. What was previously understood, the physical mechanics, the automatic thinking, and the cerebral experience, is not longer applicable. The meaning and the motion have changed significantly. Safety was now a major concern for each person, and the actual movement (steps) each individual performs is more significant. Therefore, the departure, the journey, and the arrival in movement, from point A to point B, has a new significant meaning to these individuals.

Through pre-planning and thinking about each movement, each individual compensated for the loss of the automatic movement. Also, the subjects used a lot more time to complete the physical tasks required to move. Four of the subjects discussed how their life was spent scheduling and performing physical movements essential to meet their daily needs. One of the participants stated, "Every time I want to do something, I have to think twice. I have to figure it out in my head first. It takes all day to get things done."

Learning to Walk and Move Again

Each participant talked about the difficulties encountered in performing any kind of movement. They could no longer depend on their hemiparetic (affected) leg or arm for assistance in normal movement. This not only affected their sense of balance causing extreme instability in their locomotion powers, it also caused general weakness. This weakness was seen by the individuals as the inability to generate normal movement as they did previous to the stroke.

One subject compared herself to being as weak as a paper bag. The following quote was a description of how one subject learned to walk again, the process he followed for every step. "In the process of walking I take a big step then a little step. Walking is new to me. It drains my energy; I get very tired when I'm walking.....So it's a change since the stroke."

Each participant discussed two concepts surrounding the phenomenon of coming back or getting movement back. Three of the participants discussed the coming back of their leg or hand/arm or waiting for the comeback. They were experiencing their arm or leg beginning to move and they were hopeful about the continued recovery of movement. Two of the participants described the experience of feeling the way their post stroke body moved for the first time. Learned activities like picking up a coffee cup and walking became new experiences. "Sometimes I think I don't know how to walk, but I do." This statement made by one participant explained that as a person with a stroke one had to learn how to walk, even though one knew how to walk before the stroke.

Because of their lack of mobility and other deficits the subjects found that they had to rely on others. Three of the participants needed someone present when they walked or transferred. Most often this meant the subject had to depend on the spouse's assistance or hired help. More importantly this meant the subject had to arrange his or her schedule around waiting for assistance with getting to the bathroom, getting from room to room. going outside to a patio or yard, and going to eating areas. They were not free to move spontaneously because movement of the affected side had become an obstacle. The participants talked about pre-planning each physical step of activities in order to get to where they wanted. Another participant quoted as saying "I often think I can....I get the urge to just get up and walk to the sink and then I realize I can't do that, I have to stay where I am." The participant who had fallen, who then was so safety conscious, was also now completely movement conscious. She was quoted as saying "I'd have to see where my feet were, see where the wheels were on my chair before I ever got up. I'd have to know where they were, and after I stood up."

This meant that all movement had to be safety based. This was another phenomenon related to movement that was discussed by the subjects. Each participant stated that each step or movement had to be made slowly and be well planned. The participant that stated she had fallen once said it was extremely scary. She then described meticulously how she had to watch every step she needed to make in order to complete a simple movement. The following statement from one participant simply explains how the concepts of safety and movement have changed in his life.

> Before, if I wanted to go upstairs I just trotted on up two at a time and now I have to take them one at a time, go slowly. Every time I come across a hole I have to be careful and step. And the rug here, I have trouble getting over the rug.

Several of the participants stated they knew that the movement or their afflicted extremities would comeback. They were always hopeful even when describing not being able to perform a specific task. These individuals were always anticipating getting better or coming back as a strategy for dealing with waiting for the comeback or experiencing different movement.

Every subject discussed the need to follow their exercises prescribed by their rehabilitation therapists. Any therapeutic stride toward recovery was viewed as a positive strategy. Each subject spoke about listening to their therapist and following the exercises as being utmost important to regaining mobility. They believe if they follow the program/exercise regime that comeback will be eventual.

Rethinking Performance of ADL

Each participant talked about how performing ADL had changed in his or her life. Many of the tasks took much longer than before and some experienced new problems in attempting to finish these tasks; for example, fatigue and endurance were major variables. Several of the participants spent most of their day performing their ADL or they were no longer capable of performing these duties. Therefore, many of the participants needed partial assistance or needed their spouse/caregiver to perform these activities.

Each subject spoke of his or her specific changes and ability to perform particular ADL. Two of the subjects discussed problems with eating because of deficits in both hands. They both were able to eat independently, but required special equipment and techniques to perform this life sustaining activity. The following is a description by one of those two subjects.

> "I have to put my plate over a little bit and still turn my head because if I watch my plate here I can't see it over there. Because I'll always have food on the edge of my plate almost off before I realize it so I have to check it pretty often."

Dressing was an issue for each subject and each needed some level of assistance from set-up to actual hands-on. The difficulty of putting on shoes and socks was the problem mentioned most often by the subjects. Not only did the task of putting on shoes and socks require fine motor control associated with the return of normal movement, but it also signified a state of returning to normality for each subject. In general, dressing was identified as a daily task once taken for granted. After the stroke it had become a major chore which consumed a major portion of each subject's day. One of the subjects described how the act of dressing had changed. "It takes me all day to get dressed and undressed."

The three female subjects described their experiences with not being able to cook and keep house like they did before the stroke. Only the female subjects identified this as a deficit. They had identified themselves as the caregiver of the home and family. Cleaning or cooking was most likely one of their main daily tasks.

Finally, each of the subjects described fatigue, weakness, and poor tolerance as being factors in accomplishing any of the ADL on a daily basis. Throughout the interviews, each person described some changes or loss of physical strength and endurance which affected his or her ability to perform their ADL. All of the subjects had comorbidity problems in addition to the stroke experience and each medical problem was diagnosed previous to the stroke. Therefore, it can be concluded that the stroke caused the changes in performance and mobility since each reported being capable previous to this event.

Dealing with being Housebound

Three participants could move around independently, but only in their own home. Therefore, most of the time they were housebound. Being housebound meant they remained inside the walls of their home, not able to go outside to patios, yards, driveways, or lawns. One participant stated, "I was always very active in my garden.

I would have so many flowers. People came up to watch them. I was always up and down the hill and I don't dare go to some of this area now." These individuals were dependent on others to get out to appointments, purchase items for everyday living at stores, or to get out socially.

All the participants described loss of independence because they were housebound. That loss of independence was equated with the inability to drive. All participants discussed how the inability to drive had completely impacted their independence. Each subject was homebound and dependent on others to take them to appointments and more importantly they were dependent on others to take them out of their homes for any type of necessity, social event, or recreational enjoyment. Normalcy and having "everything" was equated with driving by each subject. A comparison of their current status was described as not being able to do anything because they could not drive.

In our society, individuals are dependent on services and products long distances from their homes. Even places within walking distances are inaccessible for individuals who are not able to walk well or propel a wheelchair without fatigue. The inability to drive is a major change factor for stroke patients to experience. This leaves them either dependent on others or homebound. The following is a statement from one of the subjects that helps to summarize this theme.

> I have to sit at home which I don't really want to be. I have been not really housebound, but pretty close to it and before I would jump in my car and go wherever I wanted. And if I wanted to stop someplace, I

> would. And I used to do about what I wanted, no problem. I love to go places I used to go all the time - but now, like I say, I can drive all right, but I have to get this leg better - but right now I can't. You don't know, you've never been housebound for as long as I have, but it's terrible.

Marking Progress Towards Recovery

All of the subjects made comparisons between their current abilities to function and their pre-stroke functional status. All of the participant's own perceptions of what they were like before the stroke were used as a measuring tool to compare their daily activities, abilities, and quality of life to their current status. They defined getting better or recovering, as becoming like they were before the stroke. Becoming normal again was emphasized throughout all the interviews. Therefore, their perceived physical and mental conditions that might be the best or most adapted state they were ever going to achieve was not acceptable or considered normal by them. Each participant described and compared actions or events, to their old self (previous to the stroke). The following are a few descriptions by the subjects experiencing this marking of their progress against their old self. One subject described himself as better by being mobile and getting around without help. "I want to get back to normal. I don't know how close I'll come to it, but I want to get back." Another subject's statements were simply "doing what I did before and I'm going to get well." This subject made references to not being able to use his hand and foot like he used them before to work, travel, and play leisure sports. "I just want to be a whole person already," was one subject's statement about his future goals. He wanted to get to a normal physical state and not have the stroke restrict him. The stroke kept him from doing natural things such as picking up things on the floor, dressing, shopping, and driving a car.

Many of the participants talked about coming back. The coming back referred to the return of functioning and the ability to do things that they did before in all aspects of their lives. One subject stated that she could not do the things she did before and that everything was a job. but that her hand and leg were coming back slowly. She stated that she was getting better and better, and would soon be able to do things by herself.

Not only did subjects mark their new self against their old self, they marked themselves against others. especially when they were in the rehabilitation facility. One of the participants described her experience of modeling herself after another woman who was in the rehabilitation unit with her. She was impressed by this women and in comparison, felt if this woman was able to do this program so could she. In the same breath this participant damned others, accusing them of being hopeless because they were either too lazy or did not have the same characteristics as she did. Another subject compared herself to others and felt fortunate to possess her current level of functioning.

> "I can't always think of the name, but he (God) left me with my mind. I can talk and I could walk and use one leg and arm and I can help myself to a certain extent, better than some of the people I've seen, so I am fortunate."

Another subject found making the comparison frightening. He sat across from a gentleman in the dining room at the rehabilitation facility who was globally aphasic and apraxic. This quote summarizes his feelings.

> He would get his utensils and eat with his hands. I think I saw him pour orange juice in his coffee once which really got to me. I couldn't handle that. Just everything he did, I thought, well this is not for me I've got to get away from here.

He felt that he could have been affected by the stroke much worse than he had been and that was frightening. The fear of what could have happened was one comparison each subject made when comparing themself to others. There was also a feeling of encouragement produced by a belief that if others could do rehabilitation so could they. Finally, there were several experiences by those that had built relationships with other stroke patients while in the rehabilitation facility. Many cited times where they attempted to help others and encourage them through their progress.

Looking Towards the Future

The participants were asked what advice they would seek from someone who had been living with the effects of a stroke. Four of the six participants wanted to know how to live with this problem. They were interested in knowing how to cope with the changes they were now experiencing. Two of the subjects would ask what exercises they needed to do to get well. They felt that maybe there was a secret they could uncover or a magical exercise that they had not tried. One subject wanted to know how to cope with the isolation and loneliness. One male and one female participant stated that they would not want to seek any advice. They did not elaborate on the issue, but they may have felt that there were no answers or magical cures. It could be fear of finding out what they may experience in the future. This point is clarified by a statement made by one of these two subjects. "Nothing, because they think probably it's too late to get well."

When asked the question about advice, all of the participants expressed a desire to have a clearer picture of their future. They were acting as if they were in a holding period and the future was going to hold a success recovery story. One participant was quoted as saying:

> What is he doing to cope with it? What do you get for somebody who has to go through the same thing? That's all I can think of, of course I don't know how it is to go through long term effects because I don't expect to.

The circumstance of stroke was placing these individuals into a world where the old self understandings were not appropriate. Four of the subjects wanted to know how to deal with the changes because they recognized they had no skills or background meaning in order to effectively approach the problem.

Additional Findings

Since all of these subjects had participated in a rehabilitation program, at the end of the interview they were questioned about what they viewed as benefits or failures of the process. Each participant stated that the rehabilitation facility and the process enabled them to return to home and helped them to make gains in the physical aspects of their recovery. All of the participants discussed special compensation techniques they had learned during rehabilitation. The techniques were individualized in order to assist the subject in managing his or her changed locomotion pattern. All of the compensation techniques were based on physical needs. Overall the subjects thought the rehabilitation process helped them make gains.

On the other hand, not all of them found their stay in the rehabilitation facility to be completely positive. Several of the subjects had conflicts with the facility staff, while others found that their stay in the rehabilitation facility was a depressing and fearful experience. One participant stated he felt frightened. "In the rehab, I had a confused state of mind. It was a very dark area of my life." Another subject felt the time in the rehabilitation facility was filled with a lot of unknowns and she did not look forward to rest periods because she had time to think about what was going to happen. "A lot of times when I got to lay down I was so tired that I'd just go right to sleep and other times I'd lie there and think about my life. I was too depressed in the hospital." Two of the participants made strong statements concerning their conflicts with the staff. One subject believed his hemiplegic shoulder was injured because a staff member had sneaked into his room at night and placed a restraint on him. The other subject felt the staff should have had "a little more understanding and feeling." Other negative comments concerned gender issues. Two of the female subjects noted some difficulty performing personal hygiene with male staff members and felt that some physical exercises were provocative in nature. Neither woman ever refused any treatment, and both agreed the facility provided an environment that fostered recovery.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This study explored the lived experiences of a sample of stroke patients who were post discharge from a rehabilitation facility. The subjects had experiences which were similar and different, but they all found that having a stroke had completely changed their lives. They all had to redefine their self, sometimes based on past knowledge, but mostly by pure reaction to what was currently happening to their mind and body. The ways they viewed the world or lived in the world, their embodied intelligence, were different. In very few instances did they have the background meaning, the understanding, necessary to live with this new experience of stroke. There were several similarities among subjects regarding their embodied intelligence and objective meaning.

Summary of Findings

Six main themes were developed from the analysis of data. The following is a summary on each theme. All the activity these individuals perform now has to be on a "conscious level". The automaticity of response is gone and the day to day ADL requires extensive pre-planning and increased time to complete. All subjects stated they had to learn to walk and move again. This also became a conscious effort, but it involved several other phenomenon as well. Movement required the learning of new information. Subjects had to become efficient with the use of this new information in order to guide their body through any movement. Safety awareness was another major factor these subjects had developed when moving. They also became dependent on others such as spouses or hired care givers in order to meet their needs. The subjects talked about their experiences of comeback. Comeback was described as the moment when they felt their post stroke body move for the first time. They also discussed comeback as a future event to be looked forward to. Now they are focused on the present, waiting for an extremity to comeback to normal functioning. Fatigue and time complicated functioning and they have to rethink their performance of ADL. Activities that were simple and had been taken for granted are now a chore and at times difficult to complete. The inability to drive was synonymous with loss of independence for each of these subjects. Some of the subjects are able to move independently, but all are restricted to their own home and are dependent on others to go outside. The subjects marked their comeback progress by measuring present ability against their pre-stroke self. Their perception was that their present abilities are unacceptable because they do not consider themselves to be normal (like they were before the stroke). They also compared themselves to others in the rehabilitation facility. For many subjects this comparison was a catalyst to continue to achieve and work toward recovery. At times the observation of others was frightening, but a realistic look at themselves.

Finally, several of the subjects turned to looking towards the future as a coping strategy. Some were looking for a specific exercise or method that would get them back to where they were previously in terms of functioning. Others were looking for ways to cope with their deficits. Several hoped their body deficits would be temporary while others thought their bodies were as good as they were going to become.

Implications for Practice

These individuals found that they had to relearn to live in their world. According to the first three themes, these subjects had to learn how to move again and they had to learn how to rethink through the process of movement. Theme one identified how the normal process of movement and day to day functioning is not automatic. Therefore, it is important to understand that these individuals have to develop a new language for themselves to cue themselves in how to move, a language which is not always clear or responsive. It's as if they are learning to speak a foreign language, but everyone else is expecting them to speak in their native tongue. To apply this to practice is to invite professionals working with stroke patients to see these individuals as if they are going through a metamorphosis. This change is a constant struggle. It is also important to understand that this metamorphosis (rebirth) may not be accepted by these individuals. This change begins immediately after the stroke has occurred, but they may not acknowledge the changes until much later. An excellent time to work with these individuals on understanding their new body is during rehabilitation. This is the time for developing the body language cuing they need to adapt. As a rehabilitation professional, steps need to be taken to have the individual realize the need for this language and how to begin using it. For the rehabilitation professional, this will require leaving pure neurophysiological recovery behind. For many this will be difficult because the current scope of practice is based on scientific physiological methods. Rehabilitation practitioners will need to incorporate the stroke patient, their personal metamorphosis, and this new language they need to speak into their care plan.

Another significant finding from the data was the lack of preparation the subjects had in order to live or cope with their stroke. It is apparent that they did not have the necessary tools or knowledge. The question is where do they receive these tools after having a stroke? Even after an inpatient rehabilitation stay, this sample of stroke patients did not feel completely adequate to deal with the complications from this condition. Some of the subjects were in the midst of continuing their rehabilitation through home health and outpatient services. They wanted to know how to improve the physical functioning of their body, but they also wanted to know how to psychologically cope with their current physical status. They wanted to know how to learn to live with this new self. According to current practice recommendations (USDHHS, 1995), a portion of rehabilitation should include compensation mechanisms to offset and adapt to residual disabilities, and to help the person maintain function over the long term. In post stroke rehabilitation, professionals attempt to teach the patient and family to mange all health patterns associated with physical and mental well-being. However, the outcomes of rehabilitation are measured, for the most part, on physical results. According to the USDHHS post stroke guidelines (1995), quality of life is an outcome that can be measured. The USDHHS defines quality of life as the ability to engage in life's activities, the satisfaction derived from them, and overall perceptions of health status and well-being. Rehabilitation professionals are trained to provide the physical compensation techniques and to explain the physiology behind the neurological deficit. Teaching is an integral part of any health care rendering, but in rehabilitation of stroke patients it becomes essential for all members of the team providing care (Dittmar, 1989; Hoeman, 1996).

The question is how do rehabilitation professionals teach stroke patients to adapt to this new self and instill the concept that quality of life is possible? The subjects wanted to know how to live with this condition. They were looking for ways to cope in order to provide meaning for their changed lives. Given that this study is based on individual's lived experiences, it would seem that other individuals that have experienced the same situations (stroke) could provide honest answers. Peer groups or one to one sessions could provide stroke survivors with a level of therapeutic counseling. Granted, this may not provide any one answer or create any solutions, but it would provide honest dialogue concerning experiences. Such a dialogue could be a cathartic experience for some individuals. According to the subjects' experiences, starting this process in the rehabilitation facility could be beneficial, but it could be too soon. The subjects in this study were three months post stroke and many were not receiving any more post stroke rehabilitation. They were at a point of looking at where they had been and where they need to go. Peer encouragement and camaraderie could be essential to continued recovery. They need to be able to find meaning in their life and feel hopeful in order to go forward.

Unfortunately, access to peer counseling would be limited because these individuals are homebound and dependent on family or friends for transportation. Initiating peer counseling in the inpatient setting may be the only appropriate time and place this process could be facilitated. Some solutions to this problem could be using the internet to connect homebound individuals. Given the age of these subjects and their assumed lack of computer skills or access to a computer, this could be difficult. According to the Roper Starch Survey done for the American Association of Retired Persons in 1997 (Kong, 1998), at age 65 and up, only 1% of individuals used the internet. On the other hand, strokes are effecting younger populations and according to those individuals surveyed 8% of those aged 50 to 64, used the internet. Currently, Stanford University is piloting a project for seniors to access the internet for all types of information. The project is being conducted in a senior housing complex and the individuals are using the television with remote control as their equipment (Kong, 1998).

Other implications deciphered from the data concern the practice and training of rehabilitation professionals. In teaching adaption and compensation techniques, the professionals need to approach the patient with understanding and empathy. These individuals need to be given the time and the understanding because those responses (physical and mental) are no longer rapid, ordinary, or automatic. In addition, these individuals are responding to a new self and they have no background meaning (understanding) about how to respond. Rehabilitation professionals need to remember they cannot live the experience for the patient, but they can attempt to empathize. Working with one stroke patient may be vastly different than working with the next because of the differing perceptions, even though the physical techniques utilized may be the same. Training and orientation to rehabilitation should always include thoughts, stories, and perspectives told by actual patients. Possible role playing and exploring case studies would be appropriate for an in-house training program.

The experiences revealed by the subjects contain many common processes and situations that were integral to their recovery. Unfortunately, one factor that was missing from their stories was the role of the rehabilitation nurse as a force in their recovery. Several participants mentioned how nice the nursing staff had been to them when they were inpatients in the rehabilitation facility, but no one discussed the rehabilitation nurse as being a significant contributing factor to their recovery. On the other hand, many of the participants noted the role of the therapist. As exercises were significant to their recovery so were the therapists who helped them learn and practice these regimes. The words therapy and therapists were significant throughout the interviews. According to their stories, the therapist was identified as the person having the most interaction with the patient. Because the physical therapist worked with the patient's on ambulating and transferring exercises they were identified most frequently.

The lack of identification of the rehabilitation nurse is significant because the fundamental role of the rehabilitation nurse is "to act as the primary educator within the rehabilitation team" (Rehabilitation Nursing Foundation [RNF], 1993). Why did these subjects not discuss any specific experiences with the rehabilitation nurse? According to the RNF's rehabilitation nurse core curriculum (1993), the nurse should be an effective communicator to other team members about the client's needs and desires and shares the client's successes and struggles. In addition, the nurse encourages clients to use their remaining abilities, helps them prepare for a return to successful functioning, and helps them meet complex current and future needs. The rehabilitation nurse works with the patient on a 24 hour basis to provide continuity of care.

One factor that may have contributed to this finding was that all the subjects were from one facility within a six month period. The nursing staff at this facility represents a very small sample of rehabilitation nurses. Many conditions, such as skill level, experience, staffing, or program set up could have contributed to the extent of the nurses' role at the facility. Since rehabilitation nurses function as coordinators of care, their overall role may not have been specific enough to be noted by the subjects. The continuity of care was not seen as being generated by nurses. The current inpatient rehabilitation model is collaborative, but most disciplines see the patient by scheduling one-to-one treatment time. Rehabilitation nurses are not able to practice this concept regularly. The nurses practice under the conditions of hospital staffing and budget. The nursing system is set up to care for all the patients on the unit at the same time. This makes it difficult to spend uninterrupted time with one patient.

Rehabilitation nurses must teach as they are doing their care which may be in 5 to 10 minute periods. Therefore, the instruction may seem disjointed or lack a cohesive flow.

The role of the rehabilitation nurse may not have been defined thoroughly in this facility. The nurses may not have been recognized as significant team members. The team roles are recognized most often at patient care conferences. The nurses at this facility may have been unable to attend these important meetings due to staffing or scheduling constraints. More importantly, the nurses may not have attended patient and family conferences. During these conferences the patient and the family are able to identify members of the team and the significance of their individual roles on the patient's recovery. It also reinforces what the other team members see as each other's role. Patients, families, and other team members may see rehabilitation nurses in a more traditional role. According to Benson and Ducanis (1995), non-nurse personnel in rehabilitation settings are, to some extent, unaware of the expectations that nurses hold for themselves. The problem may be that if the nurses' role is not defined well enough for those working within a team dynamic, it may be difficult to convey that role to the patient and family.

Though the sample was limited, both non-nurse and nurse professionals agreed the rehabilitation nurse had little autonomy. Having little autonomy is a conflict of interest. According to the RNF (1995), the characteristics required for the role of rehabilitation nurse are caregiver, coordinator, educator, advocate, case manager, leader, collaborator, facilitator, liaison, consultant, discharge planner, and researcher. It is impossible to have limited autonomy and perform any of these roles. The facility may not have enabled the nurses to perform as rehabilitation specialists, but the nurses need to actively advocate as professionals for the correct training and tools required to perform these roles.

What can the nurse do to prepare the stroke patient for day to day living and coping with a stroke? The nurse should incorporate what the stroke patient has learned in the rehabilitation setting into a context that can be utilized everyday. For example, the physical therapist may teach the patient how to transfer to the bedside commode, but the nurse teaches the patient and the caregiver how and when to use the commode. The nurse is the individual who thinks about the basics of survival. The example of the commode can illustrate this point. The patient can transfer to the commode, but how does the patient get their pants up and down in order to use the commode? The nurse provides the answers to the questions about how the patient and the caregiver perform the toilet hygiene and how the caregiver provides safety and privacy during toileting. The nurse thinks of these types of questions when planning care for the individual and caregiver. Teaching the patient and caregiver to view adapted methods and strategies in performing ADL as "normal" will help them cope with stroke. The nurse must help the patient and caregiver apply what they have learned so they can live in "the real world" and not just in a rehabilitation environment.

Incorporating consistent teaching strategies among the nurses would create a stronger connection with individual patients while they are in the rehabilitation setting. In general, nurses are good at using any opportunity to teach, but not successful at using documentation to support their efforts. A strategy that would enhance the verbal instructions and reinforce the patient learning is simple written handouts. The material could be tailored to fit specific instructional approaches and the nurses could develop written material based on specific problems and diagnosis within the unit. Many vendors and educational resource companies also provide excellent written information that is appropriate for patients and families.

Another strategy is to utilize alternate times to instruct patients. Nurses have the ability to be with the patient 24 hours a day whereas the therapists are limited to the daytime hours. The nursing staff needs to capitalize on this opportunity during evenings and weekends. Another alternative that may enhance the nurse's approach is to schedule teaching sessions along with other disciplines. This is commonly referred to as co-treatment. In the rehabilitation environment, patient problems are viewed as multifaceted and each member of the team offers a portion of the solution to each problem. The nurse could also schedule a specific time with the patient and caregiver designated as family training. This would help identify the nurse as a member of the rehabilitation team, not just as the 24 hour caregiver.

As nurses provide continuity of care they should also identify themselves as experts in specific areas within rehabilitation. Historically, rehabilitation nurses have been responsible for the care and treatment in the areas of bowel, bladder, skin, and medications. Patients usually consider these to be sensitive areas because they involve dignity and privacy issues. These areas can also be the most challenging and problematic for individuals. Perhaps the sensitivity of these issues caused the subjects to refrain from discussing those aspects of their life. Therefore, any discussion about nurse involvement in their recovery was excluded. Rehabilitation nurses should continue to identify themselves as experts in these areas. By doing so, they can develop a professional, intimate, and trusting relationship with the patients. Assisting a patient to solve a significant problem or adapt to an overwhelming deficit can create a memorable bond.

A final intervention would be to continue the caring relationship with each patient post discharge. The real impact of living with a stroke is experienced upon return to home. The rehabilitation nurse can help the patient make the connection to the community by being available for advice and encouragement. Making home visits could be beneficial, but reimbursement for these visits could be difficult to obtain. An alternative to home visits could be to make follow-up phone calls to discharged patients. Patients could be followed for days, weeks, months, and even years post discharge from the facility. Research could be gathered via mailers or phone calls by the nurses on a variety of topics. Such follow-up might not only be rewarding for the nurses, but helpful for the patients. The patients would be able to speak with the nurse as they experience the recovery process. The rehabilitation nurse would be able to support the patient through the process as each problem or event occurs. It would provide the nurses with an opportunity to reinforce the teaching that had been provided when the individual was in the rehabilitation facility.

An additional finding worth discussing is that the subjects often found the rehabilitation facility to be a frightening and overwhelming place. As the subjects looked back, they noted the overall positive outcome gained from their stay, but each had negative perspectives to discuss. All of their negative perspectives could be summarized as a loss of control. This loss of control was manifested by frustration with the program. The subjects made comments about the program concerning slow progression and altercations with the staff. Each subject spoke about the overall value of the facility and program. Rehabilitation was beneficial and they would not have recovered to their present form without it. On the other hand, many times the negative experiences overshadowed the positive aspects. The valuable lesson to be learned from these stories is that each member of the team needs to stop and think about where they are in relation to the patient. Team members are able to get into their cars, drive home, and live their lives. The stroke patients with whom they work (the subjects) can not. Their lives are changed forever. The professional team member working with stroke patients has a significant impact on their lives, no matter whether it involves offering a simple good morning or providing privacy when toileting. Everyone needs to remember how frightening the stroke experience can be and that a simple gesture or quiet understanding may make the difference.

Scope and Limitations

The scope of this study was limited by the selection of subjects, their performance in the interviews, and the accuracy of interpreting the data. The subjects were obtained by convenience sampling. According to Haber (1990), convenience sampling may be the easiest for researchers to utilize, but it is also at the most risk for having bias related problems. Another limitation is the problem of social desirability, not knowing if the respondent is telling the truth or responding in a socially desirable way. With multiple interviews, recurring patterns (Benner, 1985; Leonard, 1989) begin to emerge and distinguish any idiosyncratic episode. According to Grey (1990), all methods that involve verbal reports have a problem with accuracy. The community of scientific research values rigor in the research process and often this type of study is not viewed as disciplined.

An obvious limitation of this study is the small sample size. On the other hand, qualitative studies, which generally have small sample sizes, refer to applicability of findings rather then their generalizability. The subjects were selected from only one facility and one geographic area. The use of one facility also limited the information received about inpatient rehabilitation since all the subjects experienced the process from the same rehabilitation team. Another limitation could be this researcher's own biases toward the patients, their culture, and their extent of recovery. Sandelowski's framework (1986) includes a discussion of neutrality in qualitative research that was a helpful guideline in conducting this study.

Future research

Recommendations for further research include qualitative studies with more cognitively impaired individuals who suffer from severe forms of aphasia and apraxia caused by stroke. The interest would be in learning what their experiences with stroke have been and the challenge would be in attempting to retrieve the information from them.

Another recommendation for research would be to use a larger sample to extract information specific to the rehabilitation process. These studies could be focused on specific approaches utilized at inpatient facilities, home health, or outpatient settings. In light of the findings from this study, conducting research focused on the stroke patients' perspectives of the role of rehabilitation nurses in their recovery would be beneficial.

A challenging study would be to examine the experiences of stroke patients through the complete recovery process. The study might be conducted by interviewing patients at the onset of stroke, at three months post stroke, and at six months post stroke. The interview process would eventually continue to one year post stroke. The subjects would then be interviewed once a year for up to 3 year period. Another interesting study would be to follow the caregiver for the same period of time to compare and contrast their experiences of surviving and living with stroke.

An emerging issue is the incidence of stroke in younger people. The incident of stroke is not confined to the elderly. The impact of what happens to these individuals is important to society. There are financial and social considerations. The impact on the current work force is significant. How do we care for individuals, those aged 30 to 60, afflicted with stroke? The stories of these individuals are significant because until there is a cure for stroke they will be the new aging population with disabilities.

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Appendix A

Consent Letter

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

College of Applied Sciences and Arts • *School of Nursing* • *Graduate Program*
One Washington Square • San José, California 95192-0057 • 408/924-1321

Consent to Act as a Subject in a Research Project

I hereby authorize Jeannine Lipka-Blachly R.N. B.S.N. to conduct the following study on me. I understand this study will explore and describe my perceptions and feelings about having a stroke. I understand that I have been asked to participate because I have had a stroke and have been an inpatient in The Dominican Rehabilitation Center.

I understand that if I consent, I will be asked to answer brief demographic questions and personal questions about my stroke experiences. I will be interviewed by Mrs. Blachly at a mutually agreed upon time in my current home environment. I also agree to provide a quiet and private place at my home for the interview. The interview will not exceed more than two hours and will be recorded on tape while Mrs. Blachly takes brief notes.

I understand that there are no risks or discomforts in the study unless I find it uncomfortable to express my feelings, opinions, or perceptions to Mrs. Blachly. The benefit of this study is to have the opportunity to express personal feelings and to provide insight for rehabilitation healthcare providers and other stroke victims.

I understand that my identity will not be disclosed in connection with the study and that when the study results are published my perceptions and comments will not be identifiable to me personally. I also give Mrs. Blachly the right to contact me by phone if any further questions or data needs to be collected. Another interview may need to be scheduled.

I understand that I have the right to refuse to participate and to withdraw from this study at any time.

I understand that Mrs. Blachly can be reached at (408)684-0782 and will answer any questions I may have at any time concerning the study. If the study or use of information is changed after the date of interview, I will be notified and my consent reobtained. If I have any major concerns or complaints I can direct them to Dr. Bobbye Gorenberg, Department Chair of the School of Nursing at San Jose State University at (408) 924-3134. I also understand that if I have any questions or complaints about research, subjects' rights, or research related injury they may be directed to Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research, at (408) 924-2480.

Subjects Signature____________________________________

Witness____

Date______________________

Appendix B

Interview Questions and Biographical Data

INTERVIEW QUESTIONS/BIO DATA

What has your life been like since the stroke?

What were your experiences at the rehabilitation facility?

What influence has the rehabilitation process had on your life?

How would you compare your life now to before the stroke?

If you were to give advice to a person who just had a stroke, what would you say?

What advice would you seek from a person that has been living with the effects of a stroke for many years?

What are your plans for the future?

DEMOGRAPHIC DATA

Age____________

Gender_______________

Ethnicity________________________

Occupation____________________________________

Economic status/Income_______________________________

Marital Status____________________

Family Status____

____

Type of CVA____

Other Diagnosed Illnesses____

____

Present Residence____

Discharge Date from Rehab_______________________________

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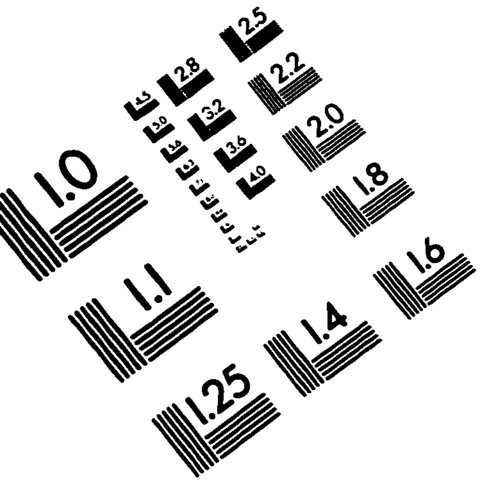

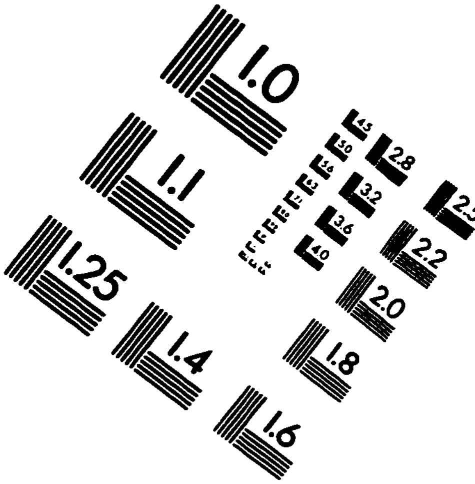

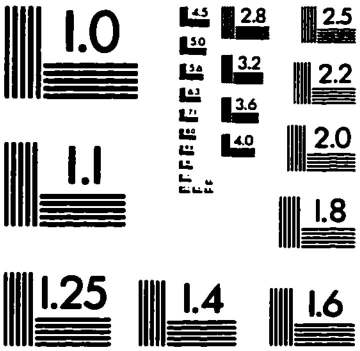

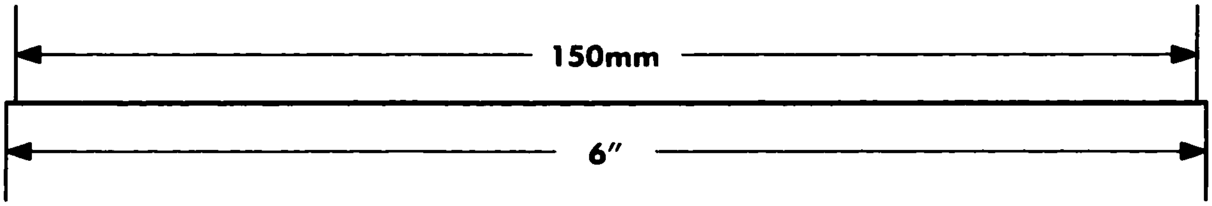

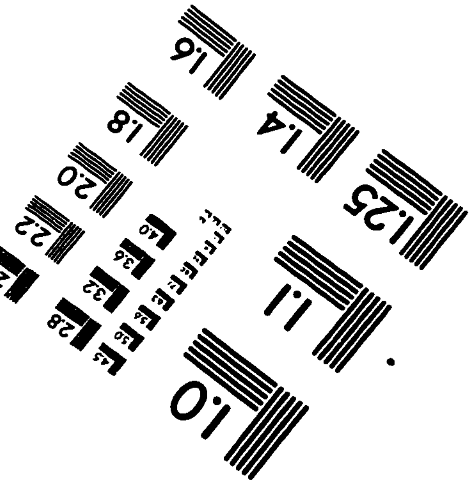

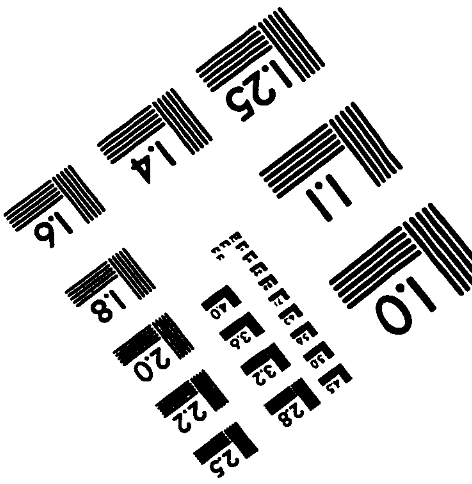

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