Coping with Stroke: Psychological and Social Dimensions in U.S. Patients

by

Judith M. Popovich, D.N.Sc., F.N.P, C.R.R.N. Associate Professor, Northern Illinois University, School of Nursing, 1240 Normal Road, DeKalb, IL 60115, USA
Office (815) 753-6559. FAX (815) 753-0814 E-mail jpopo22@aol.com

Patricia G. Fox, PhD, FAAN Associate Professor, Northern Illinois University, School of Nursing, 1240 Normal Road, DeKalb, Illinois 60115, USA

Ram Bandagi, M.B.B.S. Graduate School, Northern Illinois University
DeKalb, IL 60115, USA

Abstract

Stroke is the third-leading cause of death in the world, affecting 3 million women and 2.5 million men annually. The success of rehabilitation efforts for stroke patients is often measured in terms of physical functioning. However, the literature suggests that the effects of stroke and subsequent adaptation include psychological and social dimensions as well. The purpose of this study was to investigate how patients in the United States perceived their stroke experiences by examining their coping strategies and hopes for recovery. In addition, factors that inspired hope during recovery were identified. Sixty participants with a diagnosis of embolic or ischemic stroke were interviewed during their initial hospitalization. Tape-recorded interviews were coded and categories of data identified. Findings suggested that stroke patients experience a range of physical symptoms and emotions surrounding their stroke experience, and that stroke often interfered with daily functioning. Coping strategies included maintaining a positive attitude and asserting independence, as much as possible, during the acute stroke experience. Many patients expressed general hopes for recovery while some admitted fear of getting worse. Hopefulness was often inspired by interaction with family and spiritual beliefs and practices. The findings will hopefully enhance nurses' understanding of patients' perceptions of the stroke experience and increase their ability to provide interventions that will aid in promoting effective coping strategies.

Introduction

Stroke is the third-leading cause of mortality world-wide, affecting 3 million women and 2.5 million men each year (WHO, 2004). Compared with other causes of death globally, mortality from stroke is higher than for malaria, diarrhea, and tuberculosis combined (WHO, 2004). While the incidence of stroke is declining in developed countries, the absolute number of strokes is rising due to an aging population. Globally, of those people who survive stroke, 5 million are left with residual disabilities.

In the U.S., stroke is a leading cause of serious, long-term disability (Center for Disease Control and Prevention, 2001). While a stroke can occur at any age, the prevalence increases with age, resulting in a rate of 43% of silent cerebral infarcts in persons over 85 years old (Thom, Haase, Rosamond et al., 2006). The number of stroke survivors is increasing, with 15-30% of stroke survivors being permanently disabled and 20% requiring institutional care within 3 months of the stroke (National Institute of Health, 2001).

The success of rehabilitation efforts for stroke patients is often measured in terms of physical functioning. However, the effects of stroke and subsequent adaptation involve psychological and social dimensions as well. While a stroke can leave an individual with physical changes, several psychosocial difficulties after brain injury have been identified including depression, anxiety, and difficulties with social relationships. These stroke-related problems have been found to affect functional independence and social functioning (Feibel & Springer, 1982; Robinson et al., 1985, Kelley-Hayes et al., 2003), as well as coping ability during recovery (Armstrong, 1991).

Literature Review:

This study was concerned with how individuals in the U.S. perceived the effects of a stroke, and their hopes and coping strategies used during stroke recovery. Coping, defined as cognitive and behavioral efforts to manage demands that may tax or exceed one's resources (Lazarus & Folkman, 1984), consists of thoughts, emotions and behaviors. Coping strategies are elicited by unusual and extreme stressors such as a stroke.

Coping with illness and disability has been investigated in acute and chronically-ill populations (Felton, Revenson & Hinrichsen, 1984), and during illness requiring short and long-term recovery periods (Hamburg, Hamburg & DeGoza, 1953; Visotsky, Hamburg, Goss & Lebovits, 1961). Few researchers have investigated coping strategies of stroke patients (Bronstein, 1986; Mahoney, 1985). Furthermore, studies of stroke patients have given limited consideration to psychological variables. An example of such studies are those that explore depression (Robinson,, Kubos, Starr, Rao & Price, 1984; Sinyor, Jacques, Kaloupek, Becker, Goldenberg & Coopersmith, 1986; Kauhanen, Korpelainen, Hiltunen et al., 1999; and Aen, Denollet, Lousberg et al., 2002)..

Researchers have investigated types of coping strategies to determine if certain strategies are more optimal than others. Coping dispositions investigated in preoperative stress and recovery of surgical patients revealed that avoidant copers did better after surgery than vigilant copers (Cohen & Lazarus, 1973). Bronstein (1986) found that in stroke patients problem-oriented coping behaviors were positively correlated to total adaptation scores and that affective coping behaviors were positively correlated to depression. Other studies suggest a direct relationship between depression and avoidant coping styles (Foster & Gallagher, 1986). Previous research suggests that the use of certain types and combinations of coping strategies may be more effective than others.

Hope has been defined as having an inner readiness (Fromme, 1968) which is based on faith and strengthened by disappointments; achieving a future goal and a necessary condition for action (Stotland, 1969); and, knowing there are solutions to these difficulties (Lynch, 1965). Based on these definitions and the work of others, hope has been characterized as global or specific (Dufault and Martocchio, 1985) and involving four attributes: rational thinking, relationships with others, spiritual beliefs, and hope evolving out of trial or suffering (Farran, 1985).

The rational elements of hope provide one with a specific expectation of the future that affect attitudes, beliefs and actions during treatment (Orne, 1968); hope motivates the person to achieve goals (Stotland, 1968), to engage in problem-solving (Van Dyke, 1961). In the affiliative aspects of hope, one expresses hope for others, relies on others for assistance, and is receptive to their help in hoping (Dufault & Martocchio, 1985). Examples of how family, friends, and professionals might influence one's hope include: affirmation, loving support, encouragement, listening, sharing hopes, and associated thoughts and feelings (Dufault & Martocchio, 1985). Others who inspire hope in patients are nurses and other health care professionals (Miller, 1983).

Through the spiritual dimension of hope, one trusts in a higher being; and becomes disengaged from oneself and open to new possibilities (Marcel, 1967). This enables one to transcend the present moment (Lynch, 1965). Hope that evolves from trial, captivity or suffering generates action (Marcel, 1967), and gives the individual the fundamental knowledge and feeling that transcends the moment. For example, hope was a factor enabling persons to survive in concentration camps (Nardini, 1952) as it enabled people to focus on the future and overlook the present.

Hope is therapeutic in maintaining health in the well-elderly (Farran, 1985), and in those recovering from chronic illness and cancer (Schinale & Iker, 1966, Raleigh, 1980). Loss of hope has been linked to suicide (Minkoff, Bergman, Beck & Beck, 1973).

Maintaining hope is a strategy that may help one to manage the effects of stroke. In rehabilitation, hope may be a resource that helps motivate persons, thereby empowering them to actively engage in rigorous physical and psychological work. If one is hopeful, one may have the tenacity to deal with unavoidable failures when trying new things in the rehabilitation setting, and may help one deal with uncertainties by anticipating the future.

Purpose:

The purpose of this study was to explore patients' perception of their stroke experience, and identify hopes and coping strategies used during recovery. The specific aims of this study were to develop an understanding of: 1) how patients' perceived their stroke experience; 2) what strategies they used to manage the experience; 3) the hopes patients had, and 4) what inspired hopefulness. This study was part of a larger longitudinal study of stroke patients during which both quantitative and qualitative data were collected (Popovich, Fox & Burns, 2002 and 2003).

Methods – Participants:

In the larger study, patients age 50 or older with a diagnosis of embolic or ischemic stroke, were recruited from three sites in the Chicago metropolitan area of the U.S. Participants were screened for cognitive and speech deficits by trained research assistants. Screening instruments included the Blessed Mental Status Examination (BMSE) (Blessed, Tomlinson & Roth, 1968), and the Commands and the Responsive Naming sections of the Boston Diagnostic Aphasia Examination (BDAE) (Abeles, 1984). Patients with scores of 2-8 errors (adjusted for age) on the BMSE, and with scores on the BDAE subscales of 10 or above and 16 or above respectively, were assumed capable of giving reliable and valid responses. Patients meeting these criteria were invited to participate in the study.

Participants (n = 60) ranged in age from 51 to 89 years (M = 68 years, SD = 9.24). The majority of patients were black (68%) with 32% white; while 53% of the total sample was male and 47% female. Level of formal education ranged from a 4th grade education to graduate and professional degrees (M = 11 years, SD = 3.9). Most participants were retired (55%), while 30% were employed, and 15% were unemployed at the time of their stroke. Patients were interviewed during the first two weeks after their stroke (M = 7.3 days, SD = 4.5).

Location of stroke lesion was diagnosed in 61.9% of patients, and included the following areas: basal ganglia (21.7%), parietal lobe (10%), brain stem (6.7%), and occipital lobe and cerebellar strokes (5%) each. The remaining subjects (13.5%) had a stroke in one of the following areas: frontal, temporal, internal capsul, thalamus, frontal-temporal, parietal-occipital and internal capsul-basal ganglia.

Data Collection:

Stroke patients participated in a 45-minute interview that took place in the hospital. Data were collected by the researchers who asked patients to answer several questionnaires and to take part in a structured interview. A total of sixty interviews were tape-recorded. Four open-ended interview questions provided further qualitative data: 1) What difficulties have you had since your stroke? 2) How have you managed these difficulties? 3) What hopes do you have since your stroke? and, 4) What keeps you going or gives you hope?

Data Analysis:

Responses to interview questions were transcribed verbatim and coded using apriori codes previously identified in a pilot study of stroke patients (n= 36) (Popovich, 1987). Data were coded by trained research assistants. A coding manual was developed to ensure that coders consistently applied definitive coding categories. The coding manual included category and subcategory codes with definitions and examples for each code. The manual was used to code all transcripts, and each interview was independently coded twice by different coders. Interrater reliability for each category was examined using a percent agreement procedure (Krippendorf, 1980). Overall agreement was 83% among four coders. Discrepancies in coding were evaluated by the investigators who made the final decision regarding which code best fit the data.

Findings and Discussion:

Patient responses could be grouped into the following categories: emotions, physical symptoms, and physical and psychosocial functioning (insert Table 1). Data falling into the category of emotions, included a response or feeling the patient expressed when asked about "difficulties since stroke". Stroke patients related a range of emotions including fear/anxiety, a sense of doom, disbelief, anger, shock, dependency, stigma, confinement, depression and other emotions. Patients expressed fears of falling, of having another stroke, losing more function, and fear of leaving the hospital (lest they couldn't take care of themselves). Other categories of emotions included feeling depressed, angry, and of not wanting to be dependent on family for help. The category of 'other' included infrequent responses that were not included in existing categories. For example, two respondents said they were disgusted at themselves for their inability to do simple things (ie. pick up a fork, comb hair).

Physical symptoms were characterized by any altered sensations or body functions the person described since their stroke. Participants identified several symptoms ranging from slight sensory changes to significant motor and sensory losses. The degree to which patients were bothered by their symptoms varied greatly and did not seem related to severity of symptoms experienced (as measured by ADL scores)*.

Major identified impairment themes were changes in mentation, sensation, motor function and altered activity/rest. Changes in mentation included slurred and slow speech, difficulty telling time, and difficulty concentrating. The above findings are consistent with previous studies of commonly reported losses after stroke of altered communication (Mumma, 1986), weakness and sensory impairments (Mahoney, 1985.

Altered sensations noted after stroke included numbness of limbs, strange sensations (tingling, paresthesias), visual problems, and pain. Altered mobility was the most common deficit reported after stroke and included decreased coordination and balance, facial droop, trouble swallowing, spasms, unilateral weakness, and difficulty walking. Reports of altered activity and rest included fatigue, shortness of breath, and changes in sleep patterns.

Physical and psychosocial functioning was defined as any changes patients noted in daily activities related to personal care, activities of daily living, and changes noted in relationships with others. Three major themes developed: activities of daily living (ADL's), home and outside activities, and changes in family relationships. Patients often noted difficulties with ADL's including transferring in/out of the bathtub, difficulty picking up utensils, adjusting to dietary changes, and taking longer to dress self.

Difficulties participating in home and outside activities included: inability to work, drive, go to church, pursue hobbies and carry out household chores. Identified difficulties in personal relationships were: trouble interacting with grandchildren, communicating with spouse, and loss of family roles (ie. caregiver of another family member, caretaker of the home). These findings are supported by other studies and personal accounts of the effects of stroke (O'Kelly, 2005; Staub & Carota, 2005). Other studies suggest that negative mood states accompanying stroke are risk factors for stroke-related mortality (Carney, & Freedland, 2002).

Previous literature has categorized coping strategies as cognitive and behavioral. However, responses in this study indicate other additional dimensions. Thus, responses were coded as "self" if strategies stemmed from resources within the individual, and as "other" if the strategies involved other people or resources in the person's environment. Responses were then coded into a total of 10 subcategories identified between each of the two major categories (insert Table 2).

For responses in the "self" category, six themes of coping were identified: being independent, awareness of recovery, having a positive attitude, reminiscing, avoidance, and implementing health behaviors. The goal of being independent was expressed by phrases such as "I manage as long as I can do for myself" or "I don't depend on anyone".

Seeing or needing to see improvement in physical symptoms was viewed as a way of coping and was reflected in phrases such as "its a blessing my speech has improved" or the strength in my arm is coming back". Having a positive attitude was considered a very potent way of coping and was reflected in such responses as "I don't give up", and "the mind is powerful- I believe I'll be healthy". For some reminiscing about "the wonderful things in their lives" or "how tough life has been", gave them the strength to get through the stroke experience.

Implementing health behaviors was also useful and included such activities as following diet, exercises and medication regimes, slowing down, changing drinking/smoking behaviors, or incorporating strategies learned from health care providers in rehabilitation. Finally, avoidance was named as another coping strategy and included "not wanting to think about the stroke" and "distracting oneself and keeping busy". Of these themes, the most common resource used in patients' coping strategies were having a positive attitude, implementing health behaviors, and maintaining independence.

For responses in the "other" category, four themes of coping were identified: support of family/friends, interaction with staff, spiritual beliefs/practices, and material resources. The subcategory of spiritual beliefs/practices was placed under "other" because of the emphasis participants placed on the control of their situation by a higher power and the frequent mention of church-related activities. The subcategory of support of family/friends encompassed reference to thoughts about individual family members, desires to live to see accomplishments of specific individuals, and specific interventions initiated by family/friends such as visits, talking, providing encouragement, and not letting the patient over extend themselves.

Helpful interactions with hospital staff included getting therapy, having interactions with nurses that engendered strength and confidence, receiving encouragement, and learning how to use adaptive devices to compensate for their deficits. Spiritual beliefs or practices were frequently identified and included responses such as "I leave it in the hands of the Lord," and "I go to church". Material resources named as ways of coping included having needed community services (ie. transportation to the doctor) and "having the ability to pay for what I need" The most common ways of coping in the category of "other" were support of family/friends, spiritual beliefs/practices, and interactions with hospital staff.

Responses to the question of "hopes" following stroke were grouped into two major coding categories: general and specific hopes. Responses were coded as "general" if respondents spoke of generalized, more global hopes and "specific" hopes if they mentioned particular entities that they hoped for in relation to the stroke. Responses were further coded into a total of 7 subcategories identified between each of the two major categories (insert Table 3).

For responses in the general category, three themes emerged: general hope for recovery, hope that one's condition does not worsen, and hope to accomplish a future goal. Examples of general hopes in each of the respective three subcategories are "I hope I'll overcome this", I hope to live to 90," and "I don't want to have another stroke". In this category, the most frequent response was hope for recovery followed by desire to accomplish a future goal.

For responses in the specific hopes category, four subcategories of hopes emerged: hopes for independence, that specific stroke deficits would resolve, to return to pre-stroke activities, and hopes related to family and friends. Patient's hopes to return to pre-stroke activities included the hope to return to work, hobbies and to be able to participate in church and community activities. Hopes for family and friends included hopes that relationships would not be impaired by the stroke, and hopes to continue fulfilling certain roles in the family. Specific hopes that persons with stroke most often identified were returning to pre-stroke activities followed by hoping for stroke deficits to resolve and specific hopes for family relationships.

Patient responses to what "keeps you going or gives you hope," were grouped into six categories: family/friends, spiritual beliefs/practices, independence, awareness of recovery, attitude, and interaction with staff (insert Table 4). Family and friends inspired hope in patients by urging them not to give up, giving encouragement, visiting while in the hospital, and taking care of matters at home.

Patients' hope was also inspired by spiritual activities/beliefs such as reading the bible, going to church, and by finding courage and willpower in their belief in a higher being. Hope was also inspired when patients could do things for themselves and not relying on others for help. Seeing improvement inspired hope by regaining lost functions and "when the pains went away".

Patients' attitudes that inspired hope were having willpower, not giving up, and pretending they didn't have a stroke. Interactions with hospital staff that inspired hopefulness included staff recognizing their accomplishments, and their providing education on how to compensate for deficits. Hope was most often inspired in patients by their families, followed by patients' own spiritual beliefs/practices. No patient said they had lost or diminished hope during this time.

Implications for Practice and Research:

The data related to hope and coping are an important subset of variables in a larger study of stroke patients that have relevance to nursing practice in the U.S. For example, patients use a variety of strategies after stroke including maintaining a positive attitude, implementing health behaviors, accepting support from family/friends, and affirming their spiritual beliefs/practices.

Nurses can support patient and family coping by assessing how the person perceives the stroke event, their repertoire of coping strategies, and the quality of their support systems. Assessed findings can then be used to support strategies that patients find useful, to determine other coping resources and assist the patient and family to mobilize constructive ways to cope. Further research is needed to test the impact of nursing interventions on patients' recovery process and hopefulness.

Some coping strategies may be more useful to patients than others in preventing depression and facilitating positive adjustment to stroke. Nurses have the opportunity to observe the effects of patient and family coping and provide direction if signs of emotional distress develop. Patients' experience many emotions as a result of their stroke including: fear, anger, dependency, depression, shock, and feeling confined. Nursing interventions to facilitate emotional adjustment to stroke should include: listening, discouraging self-blame, encouraging the patient to verbalize feelings, promoting independence, helping patients reappraise their situation, and demonstrating acceptance and recognition of the patient's progress. It is important that early signs of ineffective coping be detected so that patients at risk for depression may be assessed and treated.

For some patients, the stroke prompted re-evaluation of their health care behaviors and provided motivation to implement new health behaviors such as changes in diet, medication practices and exercise. This represented a form of coping during which nurses had an opportunity to educate patients about their individualized health needs. Examples of information relevant to patient needs included, signs and symptoms of another stroke, knowing the side effects of their medications and the importance of medication compliance. Additional education on the sodium, cholesterol and calorie content of foods, the appropriate amounts of exercise, and the importance of keeping follow-up appointments were also recognized as supportive.

Stroke patients believe that hope is important to their recovery. This belief is supported by the observation that hope may have positive effects on rehabilitation outcomes by stimulating active patient involvement, resulting in physiologic responses that foster recovery from brain damage (Bach-Y-Rita & Bach-Y-Rita, 1990). In this study, patients viewed hope as providing inner strength and endurance to cope, and the ability to play an active role in their recovery.

Patients' hopes focused on becoming medically stable, recovering, regaining independence, and returning to pre-stroke activities. Patients derived hopes from: family/friends, spiritual beliefs/practices, positive attitudes, seeing recovery, being independent and from interactions with staff. The goals of rehabilitation encompassed the patients' sources of hope by promoting independence and soliciting family involvement through comprehensive interaction with professionals. The compatibility of rehabilitation goals with patients' needs, further underscores the importance and therapeutic effects of rehabilitation for stroke patients.

It is imperative that nurses acknowledge and understand how important their interactions are with patients and families. Nurses can create a hopeful environment by assessing and supporting patients' sources of hope, fostering reality-based hope, and actively engaging patients in learning to be as independent as possible.

Specific hope-generating activities in rehabilitation nursing practice include: continuous assessing of patient and family needs, helping the patient mobilize their resources and support systems, mutual goal setting, and educating patient and caregivers in all aspects of care (information-giving and supervised opportunities to practice care). These activities will help build self-confidence in the patient and family, enabling them to see gains in recovery thereby creating a hopeful climate.

Findings from this study cannot be generalized to stroke patients outside the U.S. since our study was limited to patients in the U.S., and did not consider the context of the illness experience in other cultures. Because of the subjective nature of the illness experience, the cultural context is likely to play a major role in shaping patient and family response. The cultural context of stroke studies may include variables such as hope and coping during rehabilitation, the impact of cognitive and perceptual deficits and the effectiveness of current nursing interventions. Studies may also be enriched by combining methodological approaches such as collection of qualitative and quantitative data which utilize assessment measures that consider the special needs of the stroke patient population.

Since we know at least 5 million people world-wide are left with residual disabilities following stroke each year, more nursing research is needed in assessing social and psychological factors that may predict improved stroke outcomes. Improved psychological and emotional outcomes following stroke would hopefully increase the quality of life for many people globally. In turn, better quality of life would perhaps help provide the motivation for individuals to continue making valuable contributions in their relationships, families and communities.

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Table 1. Difficulties Since Stroke (n=60)

Emotional Reactions	N	% Responding
Confinement	11	18
Fear/anxiety	6	10
Dependency	5	8
Depression	4	7
Shock	4	7
Sense of doom	3	5
Stigma	3	5
Disbelief	2	3
Anger	2	3
Other	2	3

Physical Symptoms

Altered mobility	51	85
Sensory changes	24	40
Altered mentation	21	35
Altered activity/rest	6	10

Physical and Psychosocial Functioning

Home and outside activities	11	18
Activities of daily living	7	12
Family relationships	3	5

Note: n=60 patients. Percentages total> 100 due to multiple responses of each participant.

Table 2. Major Coping Strategies Identified by Stroke Patients (n=60)

Self	N	% Responding
Positive attitude	34	57
Implement health behaviors	19	32
Being independent	15	25
Seeing recovery	10	17
Reminiscing	4	7
Avoidance	4	7

Others

Family/ friends	27	45
Spiritual beliefs/practices	20	33
Interaction with staff	19	32
Material resources	1	2

Table 3. Hopes during Recovery from Stroke (n=60)

General	N	% Responding
To recover	35	58
To accomplish a future goal	17	28
That condition does not worsen	10	17

Specific		
Return to prestroke activities	32	53
That stroke deficits resolve	19	32
Hopes for family and friends	13	22
To be independent	9	15

Table 4. What Inspires Hope in Patients (n=60)

	N	Responding
Family/friends/pets	50	83
Spiritual beliefs/practices	49	82
Personal attitude	23	38
Seeing own recovery	14	23
Being independent	11	18
Interaction with staff	9	15