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PREDICTORS OF PERCEIVED LEVELS OF PREPAREDNESS AMONG CAREGIVERS OF STROKE SURVIVORS

By

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ABSTRACT

PREDICTORS OF PERCEIVED LEVELS OF PREPAREDNESS AMONG CAREGIVERS OF STROKE SURVIVORS

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This descriptive study was based on secondary data analysis from the study "Caregiver Responses to Managing Elderly Patients at Home". A sample of 61 caregivers of stroke survivors were recruited to examine the perceived level of caregiver preparedness. These caregivers provided care for individuals who were dependent in most of their activities of daily living and instrumental activities of daily living. Preparedness was evaluated through use of a self-report questionnaire with data collected 6-7 weeks after discharge from the hospital. Proposed predictors of preparedness consisted of caregiver and care-recipient characteristics. The findings indicated that the majority of caregivers felt well prepared to care for an individual who has had a stroke. Factors found to influence perceptions of preparedness were unpleasant patient behavior and relationship status. Recommendations for future research and implications for the advanced practice nurse are discussed.

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INTRODUCTION

Stroke is the third leading cause of death in the United States, killing almost 150,000 people every year (US Department of Health and Human Services [DHHS], 1995). Nearly 4 million Americans are currently living with varying degrees of neurological impairment following a stroke, making it the leading cause of disability among adults (National Stroke Association [NSA], 1994). A stroke is a life-threatening event in which the brain's oxygen and nutrient supply is suddenly cut-off. The specific deficits resulting from stroke depend on the portion of the brain affected. The most common disabilities caused by stroke include hemiparesis or hemiplegia, problems with balance and coordination, aphasia and dysarthria, dysphagia, visual field and perception problems, loss of emotional control and changes in personality and mood, cognitive changes (memory, judgment, problem-solving), and problems with bowel or bladder control (DHHS, 1995; Harvard Health Letter, 1996; Hickey, 1997, chap. 27). Stroke leaves 25 to 50 percent of survivors with persistent disabilities that require help with one or more activities of daily living (ADL) such as bathing, dressing, feeding, and mobility (DHHS, 1995; Hickey, 1997, chap. 27). The total cost of caring for stroke survivors is estimated at $30 billion annually in the United

States (NSA, 1994). It is easy to see that the consequent burdens in human and economic terms are enormous.

Stroke risk increases dramatically with advancing age. For each decade after age 55 the risk doubles (DHHS, 1995). Nearly two thirds of strokes occur in people over age 65, with men experiencing strokes more frequently than women, and African Americans more frequently than whites (DHHS, 1995; NSA, 1994). With the aging American population expected to rise dramatically over the next decade, proportionately more people will be at higher risk for developing stroke. It is estimated that four out of five American families will be affected by stroke over the course of a lifetime (NSA, 1994).

It is estimated that 69% of stroke survivors perform self-care activities independently, 80% are independently mobile, and 70% have significant life-changing losses related to vocational and social functioning (Johnson, Pearson, & McDivitt, 1997). Stroke survivor outcome and rehabilitation needs are influenced by location and amount of brain injury. Discharge disposition of stroke patients to home, nursing home, or rehabilitation center is strongly associated with stroke severity and functional status (Jorgensen et al., 1995; Silliman, Wagner, & Fletcher, 1986). Recovery is limited by the inability of the brain to replace of regenerate nerve cells. However, different parts of the brain can either spontaneously or through

rehabilitation be trained to take over functions the destroyed cells can no longer perform. Frequently, recovery from a mild stroke is spontaneous and complete (NSA, 1994). Most stroke survivors, however, experience serious disabilities in the acute stages, followed by a recovery period of significant, but not total, improvement from many of these deficits (Harvard Health Letter, 1996). The brain has many specialized functions and whether a stroke occurs on the left or right side can make a difference in outcome and interventions planned. A left-sided stroke damages the left hemisphere, resulting in: weakness or paralysis on the right side of the body; speech and language deficits; difficulty listening, understanding, gesturing, reading, or writing; emotional liability; and a slow cautious behavior style (Hahn, 1987; Hayn & Fisher, 1997). In contrast, a right-sided stroke damages the right hemisphere, resulting in: weakness or paralysis on the left side of the body; spatial and perceptual deficits; memory deficits and difficulty learning; inability to recognize visual, tactile, or auditory stimuli; vague emotional responses; and a quick and impulsive behavioral style (Hahn, 1987; Hayn & Fisher, 1997).

The current emphasis on health care cost containment and the impact of diagnosis related groups (DRGS) have contributed to shortened hospital stays. As a result, the responsibility of providing care to a stroke survivor often

rests with family members who provide informal care in the home (Davis & Grant, 1994). Most family members assuming the role of primary caregivers of the dependent elderly are women, either wives or adult daughters (Cantor, 1983; Stone, Cafferata, & Sangl, 1987). Frequently, the responsibility for caregiving is undertaken by individuals with no previous experience in caring for someone who has a chronic disability such as stroke (Braithwaite & McGown, 1993).

Families can play a vital role in a stroke survivor's rehabilitation outcome. Home care is usually the preferred alternative to nursing home placement and family caregivers frequently approach their new role with a strong commitment to performing it well (Boland & Sims, 1996). The role of caregiver produces a variety of stressors as the physical, mental, emotional, and spiritual demands and responsibilities can be overwhelming (Ruppert, 1996). The degree to which a caregiver is able to adapt can dramatically affect whether a stroke survivor remains in the home or is institutionalized. Preparing a family member to take on the caregiver role should begin while the patient is hospitalized. However, shortened hospital stays have compressed the amount of time available for hospital nurses, therapists, and discharge planners to address caregiver preparedness for all aspects of care. Caregiver preparedness refers to caregivers' perceptions of how ready they are for performing the tasks of caregiving (Schumacher, Stewart, &

Archbold, 1998). A lack of preparedness in managing a patient's day-to-day care may result in the caregiver experiencing undue stress and interfere with the ability to provide necessary care to the care-recipient.

Though the primary focus of health care providers is on the patient, family caregivers, whose lives are heavily affected by the demands of a new role, need just as much support and attention. Some prospective caregivers feel overwhelmed and ill-prepared by the demands placed upon them, they are at heightened risk for depression and physical illness. Therefore, appraisal of caregivers' perceptions of how well-prepared they are for providing home care is necessary in order to plan family-oriented interventions (Rusinak & Murphy, 1995; Smith, 1994). The purpose of this study is to explore the level and distribution of caregiver preparedness and to determine whether or not specific caregiver and care-recipient characteristics predict variations in caregiver perceived levels of preparedness. The ability to identify caregivers who feel ill-prepared and overwhelmed for their new role will assist the advanced practice nurse (APN) is suggesting specific resources, educational programs, or health promotion strategies.

Research Questions

Specifically, this research will examine the following three questions:

1. How well-prepared do family caregivers feel in performing physical care, managing emotional and behavioral problems, accessing formal services, and managing financial needs related to home care of stroke survivors?

2. What caregiver characteristics (age, gender, relationship to patient, educational level, and employment) predict variations in perceived levels or preparedness?

3. Do care recipient characteristics (age, gender) and functional limitations in activities of daily living (ADL's) (bathing, dressing, toileting, walking) instrumental activities of daily living (IADL's) (cooking, housework, transportation, shopping, money management), health care activities (HCA's) (oral medications, injections, incontinent of urine and/or stool, exercises/physical therapy), and cognitive deficits (problems expressing thoughts, confused, forgetful, uncooperative, depressed/tearful) predict variations in caregivers' perceived level of preparedness?

CONCEPTUAL FRAMEWORK

An adaptation of the ABCX model (see Figure 1) is proposed to describe the association of caregiver and care recipient characteristics with caregiver perceived levels of preparedness to care for an individual who has had a stroke. The ABCX model was originally developed by Reuben Hill to describe the impact of a stressor on family systems and focuses on stressors, resources, and perceptions to explain

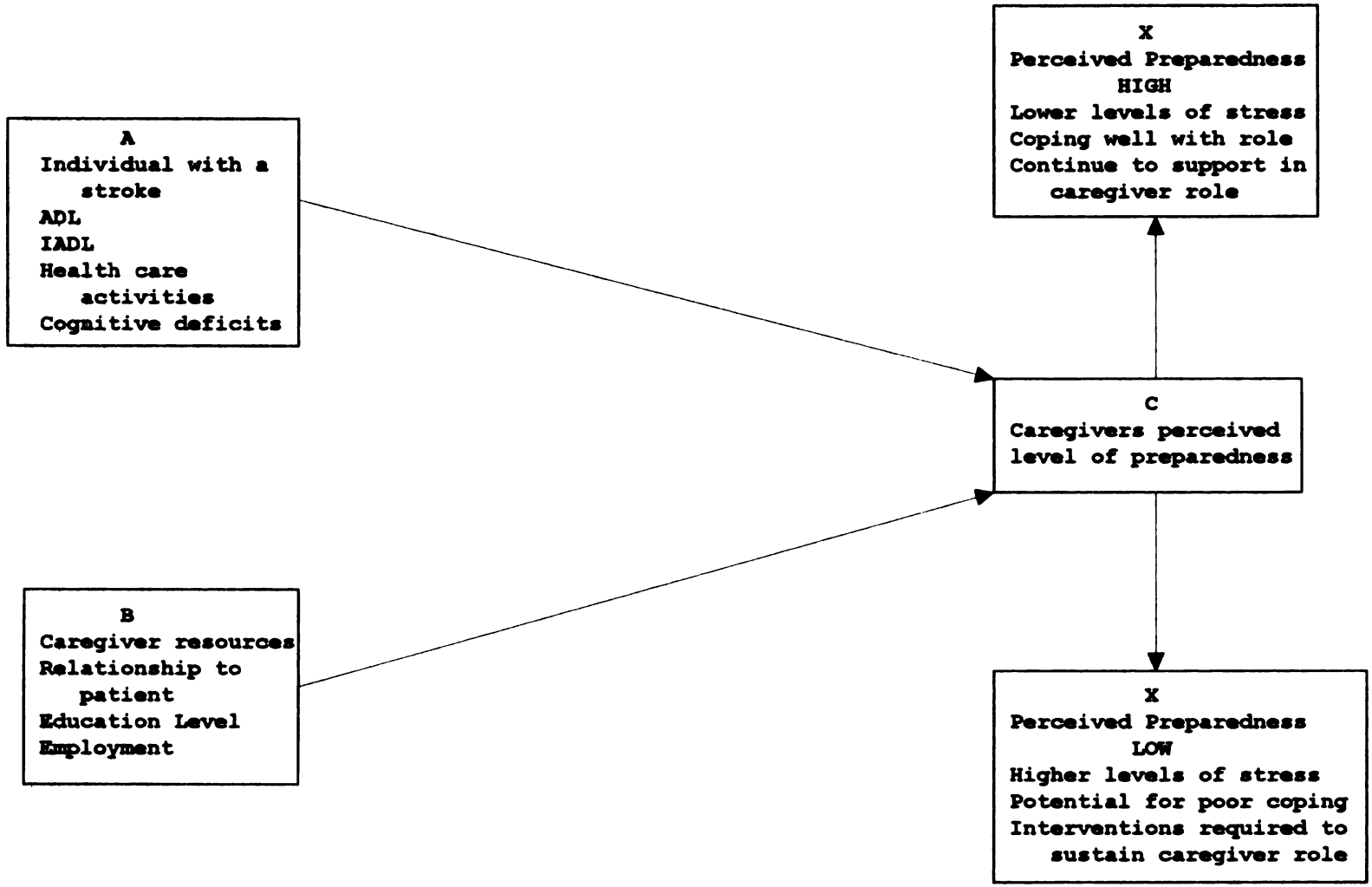

Figure 1. Conceptual model of the caregiving process, indicating relationship of caregiver-care recipient characteristics to perceived level of preparedness.

the amount of family disruption due to a stressful event. An assumption of this model is that lack of experience with a stressor event leads to increased perceptions of stressfulness (Harmon-Hanson & Boyd, 1996). This model has four primary concepts: an external event that acts as an initial stressor (A), resources the caregiver brings to the situation, (B), perception of the caregiving situation (C), and the potential crisis (X) that results (Biegel, Sales & Schulz, 1992, chap. 2). Stressors (A) are events that disrupt the family system and result in associated hardships. Examples of stressors include: health of patient, cognitive functioning, ADL status, and patient symptomatology. Resources (B) are characteristics the caregiver can draw upon in times of stress to cope effectively. This may include: physical, psychological, material, social, spiritual, informational, and financial resources. Perceptions © refer to the caregiver's subjective interpretation of the stressful event. This can be assessed in terms of burden, guilt, role strain, or sense of mastery. These three factors: stressors (A), resources (B), and perceptions © combine to create a potential mental/physical health crisis (X) which can result in varying degrees of disruptiveness or incapacity within the family system. In this model, interventions target A, B, or C variables and can be measured using self-report instruments or diagnostic assessments.

The stressor (A) in this study occurs when an individual has suffered a stroke and is dependent in one or more ADL, IADL, HCA, or cognitive functioning. This event initiates the caregiver-care recipient dyad and requires the caregiver to rely on personal resources (B) in order to cope with stroke related disabilities in home care of the patient. The caregiver's perception of the situation © can be assessed in terms of the level of preparedness for caregiving. The caregiver reaction and proneness for a crisis situation (X) is influenced by the degree to which a caregiver feels prepared. The current conceptual model equates high or low levels of preparedness with role stress and ability to cope. If a caregivers preparedness if high, there is less stress and lower potential for a mental/physical health crisis for the caregiver. In contrast, if preparedness is low the potential is greater that the caregiver may experience increased levels of stress which could result in crisis and negatively affect the caregiving situation. This study will concentrate on the relationship between B (resources the caregiver brings to the situation), and C (the perception of the caregiving situation), both of which are influenced by A, B, and C. The APN can target interventions directed at C to enhance family resources or help the caregiver modify their subjective perception of the situation.

REVIEW OF LITERATURE

Research studies over the past decade using samples of caregivers have shown that families play a substantial role in providing care for relatives at home. Although researchers have recognized positive aspects of caregiving, most studies report that caregivers experience negative effects on their emotional and physical health, personal and social life, and financial resources (Biegel et al, 1991, chap. 1; Boland & Sims, 1996; Silliman, Fletcher, Earp, & Wagner, 1986; Wright, Clipp & George, 1992). A large body of literature exists about caregivers of persons with Alzheimer's disease and cancer. This literature has become the model for caregiver studies in other population groups. In recent years, more studies have been published that address caregiving in relation to individuals who have had a stroke (Bishop & Evans, 1995; Braithwaite & McGown, 1993; Davis & Grant, 1994; Grant, 1996; McLean, Roper-Hall, Mayer, & Main, 1991; Tyman, 1994; Williams, 1994). As the American population ages and the number of individuals who survive a stroke increases, there is a need to study specific caregiving issues associated with stroke. Little research has been done to describe the caregiving experience in relation to caregiver preparedness. Even less information exists on caregiver and care recipient characteristics that help to identify variation in level of preparedness. The following sections review pertinent literature found on

family caregivers, caregiver preparedness, and stroke survivors functional limitations.

Family Caregivers

Family caregivers have always played an important role in providing care for family members discharged from the hospital. Barnes and Oglesby (1992) estimated that 80% of health care for the elderly is being provided by family members. Stone, Cafferata and Sangl (1987) developed a comprehensive national profile of caregivers of the frail elderly. Major caregiver characteristics were identified in this classic study that compiled data from the 1982 National Long-Term Care Survey (LTC) and Informal Caregivers Survey (ICS). The majority (72%) of caregivers were women, adult daughters comprised 29% and wives 23% of all caregivers in the population studied. Male caregivers accounted for 28% of the population in this study, with husbands comprising 13% and sons only 8%. Although the average caregiver age was 57.3 years, roughly one-third were over age 65. Further analysis indicated that three-quarters of the caregivers and care recipients shared living arrangements. Another important finding indicated that spouse caregivers tended to provide care alone or received assistance from unpaid helpers. Only 10% of caregivers received assistance from paid formal care helpers and this was reserved for the most severely impaired elderly. More than half of caregivers reported lowered incomes due to the caregiver-care recipient

dyad. The study identified competing familial obligations and work conflict as two important areas of caregiver strain. With respect to employment, 20% of all caregivers reported having to alter their work schedules in order to fulfill caregiver obligations. Wives and daughters were more likely to rearrange their schedules to accommodate caregiver demands than husbands or sons. Another important finding was the observation that the most frequent type of caregiver assistance entailed shopping and household tasks (80.6%) and transportation (86.2%). Assistance with personal hygiene, indoor mobility, medication administration, and help with financial matters were reported by one-half of the caregivers.

Family Caregivers of Stroke Survivors

Research studies on caregivers of stroke survivors are limited. Some investigators have addressed the physical impact stroke caregivers experience in their new role. Other investigators have examined caregivers' psychological and emotional well-being and coping abilities. There are a few studies that have focused on caregivers' perceived educational wants and needs for home care. However, no studies were found that specifically address caregivers' perceived level of preparedness in caring for a person who has had a stroke.

Grant (1996) conducted a qualitative study to explore home care problems experienced by stroke survivors and their

family caregivers. A total of ten caregiver-stroke survivor dyads were recruited for this study. Selection criteria included first time stroke patients who were no more than four months post-stroke. Caregivers and stroke survivors were recruited from an acute care hospital immediately before discharge, from a rehabilitation setting or from an outpatient clinic. Nine out of ten of these family caregivers were female from 32 to 68 years old. Four major problems were identified from the data: loss of the stroke survivor's familiar identity, managing ADL's, seeking and mobilizing tangible services, and obtaining emotional/social support. The most common home care problems related to the stroke survivors are functional and cognitive losses. Caregivers cite problems with bathing, dressing, transferring, walking, and feeding. Family caregivers also cite frustration with the emotional losses associated with the stroke. One caregiver stated, "She does nothing but sit in that chair . . . She is lost" (p. 896). Caregivers cite problems with obtaining equipment, supplies, and financial assistance. "The doctor said for me to have a walking stick, but my insurance ran out" (p. 897), was reported by one caregiver. Another caregiver reported, "the insurance company doesn't pay for outpatient speech . . . So that is something I have to think about - his expenses" (p. 897). The central theme that emerged from this study is that caregivers experience a variety of problems in the

transition from acute care to home care. Development of early intervention strategies to assist the family caregiver in mobilizing resources may increase their subjective feeling of preparedness in dealing with the multiple stressors that they are confronted with once they are in the caregiver role.

A pilot study by McLean, Roper-Hall, Mayer, and Main (1991) examined the service needs of stroke survivors and their family caregivers. The sample for this study consisted of 20 stroke survivors and their caregivers who were interviewed using the Clifton Assessment Procedure for the Elderly. This tool was used to assess the physical disability level of the stroke survivor. The Hospital Anxiety and Depression Scale was used to assess anxiety and depression. The reliability and validity of these tools were not reported. The stroke survivors in this study consisted of 16 females and 4 males with mean ages of 78 and 69 respectively. The majority of caregivers were female (15) with remainder males (5), their mean ages were 59 and 52 respectively. Although the subjects consisted of both first time stroke and established stroke patients, it was not stated as to how long after the stroke the interviews were conducted. None of the caregivers worked full-time, three were employed part-time and two had reduced their hours in order to devote more time to their caregiving role. McLean et al. (1991) found that caregivers identified several areas

of unmet needs. Seventy-five percent (15) of all caregivers felt they needed some assistance with physical care needs. However, only 20% received the help they required and most were unaware of the availability of social services or different aids available. Well over half the caregivers in this study showed a high need for personal-emotional advice in dealing with the stroke survivors disabilities and dependencies produced. Despite the seriousness of the disease, most caregivers felt poorly informed about the nature of the disease, recovery and treatment. All caregivers felt more preparation was needed with respect to information and for the acquisition of skills to perform certain care tasks before taking on the caregiver role.

Vanetzian and Corrigan (1995) studied the educational wants of family caregivers of stroke survivors. The study compared responses of current and future caregivers. Future caregivers consisted of individuals who anticipated delivering home care to a family member who was currently hospitalized. Current caregivers had been providing care for one to six months. The investigators sought to compare four categories of educational wants: assisting disabled adults, maintaining caregiver well-being, maintaining family well-being, and understanding health and human resources. The convenience sample of 59 consisted of 27 current and 32 future family caregivers. Data were gathered by having participants self-administer the Questionnaire of

Educational Wants (Cronbach's alpha .86 to .98). Educational wants were examined in relation to caregiver status group and gender. There was a significant interaction between caregiver status (current vs. future) and gender (male vs. female) in the category of assisting disabled adults. Current male caregivers and future female caregivers assigned greatest importance to educational needs in this category. Women who were planning to be caregivers in the future rated all categories of educational wants as equally important, whereas, current female caregivers assigned highest importance to learning more about health and human resources. Actual experience in caring for a disabled adult allowed current caregivers to focus on educational wants as their applicability became more apparent in their particular situation. The investigators felt the findings indicated that people will not truly know their learning needs until they are actually in the caregiving situation, experience serves as the foundation for future learning.

Current literature cited in this section reveals some of the effects caregivers of stroke survivors may experience. The psychological, physical, and financial effects can have a profound impact on the caregiver-care recipient dyad. Many of the studies addressed the caregivers perceived wants and needs in helping them to deliver home care more effectively. The ability to recognize caregivers at greatest risk for feeling overwhelmed from a perceived

lack of preparedness for taking on the caregiver role will aid the APN in developing specific intervention strategies that will help caregivers understand and manage their caregiving experience. The following section reviews several articles specific to caregiver preparedness.

Caregiver Preparedness

Families are increasingly involved in providing care to disabled family members in the home following hospitalization. The ability of caregivers to do their job well is vitally important to the well-being of care receiver and provider. Preparing caregivers for their new role frequently begins while the patient is hospitalized. Caregiver preparedness, as defined by Archbold et al. (1990), refers to the caregiver's perception of how ready they are to provide care. It does not assess the adequacy of how well the care is provided. In this context, preparedness should be measured prospectively. Perceived preparedness has an anticipatory connotation because caregivers are assessing their readiness before actually taking on the new role. This definition of preparedness would indicate that, clinically, what is most important for the care-recipient is the ability of the caregiver to possess the necessary knowledge and skills to provide care. However, the fact that caregivers are responding before they have actual experience in the role, may reflect a measurement of general confidence level as opposed to perceived preparedness. Individuals who are

highly confident about dealing with life's problems in general may report high levels of preparedness regardless of the severity of a care-recipients disability or lack of experience in providing care. Once the caregiving role is undertaken and caregivers are confronted with the tasks and stresses they did not anticipate, preparedness may become more of an issue. In contrast, individuals who report low levels of preparedness prior to taking on caregiving may actually do very well in their new role as time goes on and they gain experience in dealing with specific problems that arise and as a result increase their confidence level. In this context, a retrospective measurement of preparedness may actually be measuring caregiver mastery or a general feeling of competence in the caregiving role. The instrument used in the current study was derived from a preparedness measure developed by Archbold et al. (1990) which focuses on domain-specific preparedness as opposed to task-specific preparedness. Measurement difficulties may result from the fact that one measure alone doesn't capture the full dimensionality of preparedness. Caregiver perceptions may need to be combined with observational studies to validate the concept of preparedness.

Limited research exist specific to level of preparedness and no articles were found specific to stroke survivors. Following is a review of several articles

pertaining to caregiver preparedness and caregiver's educational needs.

Rusinak and Murphy (1995) investigated knowledge of cancer care, perceptions of preparedness, and coping strategies in elderly spousal caregivers. The sample consisted of 30 spousal caregivers over age 65 who were caring for a spouse over age 65 who was recently diagnosed with cancer. Exact length of time since the caregiver role had been taken on was not reported. Eighty-three percent of the caregivers in this sample were female. A high school education or higher was reported by 64% of caregivers and 29% reported a monthly income greater than $1,000. The Quayhagen and Quayhagen Coping Strategies Inventory (alpha coefficients of .57 to .79), a measure of perceived level of Preparedness Scale (alpha .72), and a scale developed by the researcher to measure Knowledge and Skills in Cancer Care (extensive face validity reported) were used to measure the variables within this study. The investigators reported a moderate level of preparedness and a high level of knowledge and skills concerning cancer care. Predominant coping strategies included "existential-growth" (controlling the meaning of the situation), "helping-seeking", and "problem-solving" as used most often. Caregivers who were more educated had higher levels of knowledge and skills but perceived themselves as less prepared to assume the caregiver role. Findings indicated that caregivers who

reported high levels of preparedness also reported that their spouses had a chronic disease which required caregiving assistance prior to the diagnosis of cancer. Experience with caregiving in the past may have resulted in high levels of confidence in dealing the anticipated changes associated with a new diagnosis.

Weeks (1995) investigated the educational wants of 83 prospective family caregivers of newly disabled adults who were currently receiving inpatient care. The caregivers in this study were mostly female (63%), wives comprised 34% and daughters 22%. In contrast, husbands accounted for 13% of caregivers and sons only 6%. The majority had a high school education or above and incomes greater than $20,000 per year. Caregivers were asked to complete the Educational Wants of Family Caregivers of Disabled Adults questionnaire (Cronbach's alpha .86 to .98). Analysis of results revealed the number one educational want of prospective caregivers was to learn about assisting the disabled adult and learning about health and human resources. Caregivers were especially interested in learning ways to normalize the daily routine for the disabled adult. Maintaining caregiver and family well-being was only moderately important to the caregivers in this study. It may be that the immediacy of the role to be undertaken intensified the need to learn about resources available to assist the caregiver.

In a similar study, Matthis (1996) examined if there was a difference in how future, current and noncaregivers rate importance of learning about caregiving tasks. Each participant identified their caregiving involvement based on the following categories: current caregiver (currently providing assistance to a disabled adult), future caregiver (expects to provide assistance in the near future to a family), and noncaregiver (neither a current or future caregiver). The length of time current caregivers had been providing assistance or how long before future caregivers would take on the role was not reported. Data for the study was provided by 86 current caregivers (19.5%), 161 future caregivers (36.5%) and 194 noncaregivers (43.9%). All participants in this study were women. The researcher developed a questionnaire derived from common caregiver tasks identified in previous studies to measure caregiver educational wants. Reliability of the questionnaire had Cronbach's alphas of .86 to .98 for various categories. It was reported that future caregivers affirmed that it was very important for them to prepare and plan for family caregiving tasks. Both current and future caregivers attached greater importance to learning about caregiving tasks than did noncaregivers. No significant difference was found between future and current caregivers' learning interests. The findings in this study would indicate that caregiver preparedness occurs largely as a response to the

current caregiving needs in a family and only takes on significance when individuals are confronted with actually taking on the caregiver role.

Archbold, Stewart, Greenlick, and Harvath (1990) studied whether preparedness for caregiving was related to lower levels of caregiver role strain. Role strain was defined as the caregivers' perceived difficulty in performing their role. The sample consisted of 78 caregiver-care recipient dyads who participated in 6-week and 9-month interviews after hospital discharge. The dominant diagnosis of care recipients was not reported. Care recipients required assistance in one or more of the following areas: medications or injections; bathing or dressing; walking, shopping, or errands; or household chores. Most caregivers were female (62%), wives (19%) and daughters (21%), husbands comprised 26% of the population and sons 6%. A quarter (23%) had completed high school and 39% had attended college. Median income was between $15,000 and $24,000. Care recipients' average age was 78 and most (70%) were female. Two structured interviews were conducted utilizing The Family Caregiver Inventory. Measures of seven predictor variables and nine measures of caregiver role strain are included in the inventory. The reliability and validity for this tool was not reported. This study did find that higher levels of preparedness for caregiving were associated with lower levels of caregiver role strain related to strain from

direct care, increased tension, and global strain. However, caregiver strain related to economic burden was not reduced by preparedness. At 6-weeks, caregiver preparedness was a significant predictor of lower role strain for seven of nine role strain measures as compared to only four of nine measures at the 9-month analysis. This may indicate that preparedness reflects caregiver competence and is a stronger predictor of role strain during periods of transition than during periods of greater stability in the caregiver role. Interventions aimed at caregiver preparedness would need to be applied during the early transition period in order to be beneficial over time. As caregivers gain experience in their role they also increase their confidence level in dealing with problems.

A number of researchers have explored the needs and wants of family caregivers in learning more about caregiving tasks, but only a few studies specifically examined caregiver preparedness. In addition, the studies reviewed in this section have not dealt with caregivers of stroke survivors. This population of caregivers needs to be addressed separately in order to determine if the perceived impact of caregiving is the same or different from other groups. The following section will review literature pertinent to the functional limitations of stroke survivors in order to clarify the degree of disability and how it may impact preparedness in caregivers.

Functional Limitations of Stroke Survivors

Functional outcome following a stroke is important because it impacts the quality of the patients' life and influences discharge disposition to home or institutionalization. The majority of research on stroke-related disability have focused on functional level, psychosocial functioning, burden on spouses, and rehabilitation outcome. Most studies have followed patients at 1-month, 6-months, and 1 year post-stroke. The literature reports that 69% of stroke survivors perform ADL independently and 80% are independently mobile, 70% have significant losses related to their vocational and social functioning (Johnson, Pearson & McDivitt, 1997). The literature identifies the following patient characteristics as adverse prognostic indicators of functional outcome: prior history of stroke, older age, urinary and bowel incontinence, and visuo-spatial deficits (Jongbloed, 1986).

Jorgenson et al. (1995) conducted a study that examined outcome and time course of recovery in stroke. The sample consisted of 1,197 patients who were enrolled in the Copenhagen Stroke Study. Female stroke survivors comprised 54% of the sample and males 46%. Weekly examinations of neurological deficits and ADL function were performed from admission to end of rehabilitation, and at 6-months post-stroke using the Scandinavian Neurological Stroke Scale (SSS) and the Barthel Index (BI). The SSS evaluates level of

consciousness; eye movement; power in arm, hand and leg; orientation; aphasia; facial paresis; and gait. The Barthel Index (BI) evaluates 10 different functional abilities (feeding, orientation/transfer, grooming, toileting, bathing, walking, stair walking, dressing, bowel continence, and bladder continence). The reliability and validity of these tools were not reported. Discharge to home was strongly linked to initial stroke severity, 93% had mild strokes compared to 14% with very severe strokes. In patients with mild stroke, 68% had no disability in ADL function and 25% had only mild disability. Stroke survivors who had severe disability initially did remarkably well, 84% improved in ADL function after rehabilitation with 17% reaching full function and 48% remaining only mildly disabled. The greatest improvement in ADL functions occurred in feeding, transfer/orientation, toilet use, staircase walking, dressing, and bowel continence. Results of the time course of recovery for stroke showed that the best neurological outcome was achieved within 4.5 weeks in 80% of the patients and within 11 weeks in 95% if patients. Best ADL function was achieved within 6 weeks by 80% of patients. Among all patients in this study, recovery from stroke was mainly achieved within the first five months from onset. The implications of this study in regard to caregiver preparedness would indicate that preparedness may only be an

issue for caregivers of stroke survivors during the early phase of the disability before improvements are achieved.

Silliman, Wagner, and Fletcher (1987) investigated the social and functional consequences of stroke in elderly patients. The sample consisted of 147 stroke patients, 83 (56%) male and 64 (44%) female. Their average age was 75 years. The majority suffered strokes which involved the left (53%) or right (42%) cerebral hemisphere. This was a first time stroke in 79% of the sample. At time of hospital discharge 119 (82%) of the patients returned home while 27 (18%) were institutionalized. The investigators found functional status to be the most powerful predictor of discharge disposition following an acute hospital stay. Discharge to home was strongly associated with functional independence in ADL. At time of discharge, 52 (98%) of patients independent in ADL returned home. The majority of patients who were dependent in ADL 67 (70%) also returned home as opposed to 26 (30%) who entered nursing homes. The family caregiver interview covered six areas: attributes of the caregiver and caregiving setting, services, quantity and quality of social supports, health and psychosocial impact of the experience on caregivers, and perceptions about the caregiving process. Among stroke survivors remaining in the home at time of follow-up, while only 36% were able to walk independently, 74% could follow directions and 64% had no speech deficits. In contrast, those patients residing in

nursing homes functioned poorly and frequently had speech impairments. This research has shown that most elderly patients return home after an acute stroke and remain there. Persisting functional dependence in this population indicates that attention should be focused on ways to minimize the affects of stroke related disability on the patient and caregiver.

Kotila, Waltimo, Niemi, Laaksonen, and Lempinen (1984) developed a profile of neurological and neuropsychological deficits among stroke survivors. The sample for this study consisted of 154 patients, 70 (45%) women and 84 (55%) men, who were alive one year after the stroke. There mean age was 61 years. The location of stroke was left hemisphere in 40% and right hemisphere in 39%. Evaluations done at time of hospital admission showed that 112 (73%) of patients experienced hemiparesis, 132 (86%) coordination disturbances, 55 (36%) dysphasia, 88 (57%) dysarthria, 20 (13%) dysphagia, and 45 (29%) incontinence of urine and/or feces. Participants were evaluated at the time of hospital admission, at 3-months and 12-months post-stroke. Neuropsychological testing methods included the Wechsler Adult Intelligence Scale, the Wechsler Memory Scale, and the Benton Visual Retention Test. Emotional reactions were assessed through use of Gainotti's Systematic Observation and Beck's Depression Inventory. ADL's included evaluation of ambulation, self feeding, dressing, and personal hygiene.

The disability grading system range was: fully independent, needs some help, needs much help, or totally disabled. The reliability and validity of these tools were not reported. The profile of neurological findings included: hemiparesis, coordination disturbances, dysphasia, dysarthia, dysphagia, and incontinence of urine and/or feces. There was no difference found in patient outcomes between right and left hemispheric lesion. All neurological deficits showed improvement between acute stage and 3-months and this improvement continued up to 12-months but to a lesser degree. The profile of neuropsychological deficits included: visuoperceptual; speech/language and aphasia; dyslexia, dysgrafia, dyscalculia; impairment of intelligence; impairment of memory; and depression. The frequencies of neuropsychological deficits also showed improvement over time. During the acute stage of stroke only 32% (50) of patients were independent in ADL. At 3-months independence increased to 62% (95) and at 12-months 68% (105) of patients were fully independent in ADL's. The profile of recovery found that 69% (107) patients were living at home 3-months after the stroke and 78% (120) were home after 12-months. Hemiparesis, visuoperceptual deficits and impairment of intelligence had the most significant influence on patient outcomes. Patients without these deficits were more likely to be independent in ADL's and residing at home. Patients who were depressed in the acute stage showed greater

dependence in ADL but after 3-months the depression decreased and showed continued improvement at 12-month follow-up. The initial depression may be associated with the emotional crisis or grief reaction to a serious illness. The implications from this study for caregiver preparedness may suggest that it is during the acute stage of stroke and when certain deficits are present that caregivers will need the most support. Level of preparedness may only be an issue early in the disease process.

In summary, the literature provides evidence of the varying degrees of disability following stroke. Functional outcome and discharge disposition appear to be influenced by stroke severity. The majority of stroke survivors discharged to home were classified as having suffered a mild stroke with minimal or no alteration in ability to perform ADL. The transition to home may be more difficult for patients and their caregivers when certain disabilities are present. Studies indicate that certain patient characteristics such as: visuoperceptual deficits, urinary and bowel incontinence, depression, impairment of intelligence and memory appear to impede functional recovery and is associated with poorer outcome. The greatest degree of functional recovery appears to occur within the first five to 6-months after which no significant improvement seems to occur. Depressive disorders among stroke patients receive less attention than physical disabilities but can

significantly impact quality of life for the patient. Level of preparedness among caregivers may be a multidimensional concept given the fact that there is such a variety of functional disabilities associated with stroke that are influenced by area of brain affected.

METHODS

To assess levels of preparedness two outcome variables representing different dimensions of preparedness were employed. Independent variables will include caregiver characteristics: age, gender, relationship to patient, educational level, and employment; and care-recipient characteristics (age, gender) and functional limitations: ADL's (bathing, dressing, eating, toileting, walking), IADL's (cooking, housework, transportation, shopping, money management), HCA's (oral medication, injections, incontinent of urine and/or stool, exercises/physical therapy), and cognitive deficits (problems expressing thoughts, confused, forgetful, uncooperative, depressed/tearful). Following is a description of the design of the study and how these variables will be measured.

Research Design

This study relies on secondary analysis of data from a three wave panel study. The original study design was a panel study which followed caregivers and patients discharged from the hospital with new care demands. The

focus of this study was on the beginning or onset of the caregiving role.

Sample and Data Collection

The sample for this study was derived from the sample utilized in the study "Caregiver Responses to Managing Elderly Patients at Home", funded by the National Institute on Aging (Grant #2, R01 AG06584-04), Charles W. Given, principal investigator, Michigan State University.

A total of 73 stroke patients were identified but data on preparedness was available on only 61 caregivers who responded to the questionnaire. Only Wave I data was utilized in the current study which was collected 6-7 weeks after discharge from the hospital. Information on preparedness was collected from caregivers through self-report questionnaires. Telephone interviews were conducted to collect data on caregiver reports of patients ADL's, IADL's, HCA's, and cognitive deficits.

The original study is based on a convenience sample of 628 patients recruited from 27 acute care hospitals in Michigan. Recruitment of participants was done by nurses, discharge planners, and medical students. Eligibility criteria of the original study included: 1) patients 55 years of age or older; 2) patients required assistance with at least one new ADL, IADL, or medical care task following hospital discharge; 3) had identified a primary caregiver. Within two weeks following hospital discharge, care-

recipients and caregivers were contacted and screened for eligibility. All eligible participants were then scheduled for one intake interview (Wave I) to occur approximately ten days later. Data was collected by trained telephone interviewers, using a written script and from a self-administered questionnaire. In addition to the eligibility criteria of the original study, the current study employed the following additional criterion: the care-recipient had to be classified as having had a stroke. Identification of stroke patients was based on caregiver reports. A stroke is defined as the disabilities that result from an injury to a blood vessel(s) in the brain. The injury to a blood vessel can occur as the result of partial or complete occlusion or hemorrhage in the brain. An ischemic stroke can be due to a thrombus or embolism, whereas, a hemorrhagic stroke can occur from arteriovenous malformation (AVM) or an aneurysm (subarachnoid hemorrhage), (Hickey, 1997). In this study, patients were classified as having a stroke based upon the hospital discharge diagnosis and confirmed through the caregiver interview. The generic classification of stroke fails to recognize the varying degrees of stroke. Therefore, a range of functional limitation measures of the patient will be utilized to help describe the severity of stroke.

Protection of Human Rights

All methods to protect human rights that were utilized in the original study are maintained. Anonymity is

maintained due to lack of access to any identifiers linking study participants with data. All subjects will have their anonymity safeguarded through the assignment of an identification (ID) number. Signed consents were obtained by the original investigators of the study. There were no identified risks to the patient-caregiver dyad in the original study, which remains true for this secondary analysis. Approval for this study has been received from the University Committee on Research Involving Human Subjects at Michigan State University (see Appendix C).

Operational Definition of Variables

Preparedness

The caregiver preparedness scale assesses the feelings of how ready caregivers believe they are to take on the tasks of caregiving. Archbold et al. (1990) developed the original scale which consisted of five items to assess perceived level of preparedness. Response options were based on a 5-point Likert scale (0=not at all prepared to 4=very well prepared). Given and Given (1994) utilized a variation of the instrument for their study of "Caregiver Responses to Managing Elderly Patients at Home". In this version, each item employed a 4-point Likert-type scale, ranging from not at all prepared to very well prepared (1=not at all prepared, 2=not too well prepared, 3=pretty well prepared, and 4=very well prepared). This same questionnaire was employed in two other studies to address preparedness issues

for cancer caregivers. Cronbach's alpha for the total preparedness scale in the community-based cancer study (Given & Given, 1991) was .92 (N=154) and in the rural cancer study (Given & Given, 1992) it was .93 (N=141). It should be emphasized that caregiver preparedness in caring for stroke survivors recently discharged from an acute care hospital may differ from preparedness issues facing cancer caregivers. In the current study, to assess levels of preparedness a previously developed 9-item scale that represented different dimensions of preparedness was used to collect data from caregivers in the original study. Reliability analysis was performed to explore if all preparedness items formed a unidirectional scale. The first reliability analysis included all 9-items on the preparedness scale (PREP1=physical needs, PREP2=emotional needs, PREP3=formal service needs, PREP4=medical-nursing treatments, PREP5=managing finances, PREP6=planning for activities, PREP7=managing behavior problems, PREP8=managing equipment, and PREP9=how well prepared overall), this resulted in a Cronbach's alpha of .93. Preparedness subscale PREP5 (managing finances) was the only item that did not correlate highly with the other subscales. Removing item PREP5 and treating it as a separate dimension of preparedness resulted in a Cronbach's alpha of .94. Based on the reliability analysis it was decided to explore a model of preparedness with two separate dimensions: Preparedness

Scale PREPARE2 (without PREP5) and PREP5 (managing finances). Predictor variables were selected, based on literature review, that included caregiver and care-recipient characteristics thought to influence preparedness.

Family Caregiver

A family caregiver is defined based on the relationship to the patient. In the current study, these categories are based on self reports during the interview and defined as spouse vs. nonspouse. Family relationship was coded as "0"=other and "1"=spouse.

Functional Limitations

Care-recipients' functional limitations will be based on the caregivers' interview responses which indicate whether or not patients need assistance with ADL's, IADL's, and medical care tasks. The measures of functional limitations are counts of dependencies in: ADL's (bathing, dressing, eating, toileting, and walking); IADL's (cooking, housework, transportation, shopping, and money management); HCA's (oral medications, injections, incontinent of urine and/or stool, exercises/physical therapy). In addition, cognitive deficits (as reported by the caregiver) provide additional assessments of care-recipients' functioning. Items include: problems expressing thoughts, confused, forgetful, uncooperative, and depressed/tearful. Caregiver response options for the cognitive deficit scale were based on how often certain behaviors were displayed and ranged

from 1=not at all to 4=always. Cronbach's alpha for this scale was .84.

Age and Gender

Caregiver and care-recipient age will be based on the caregiver interview responses which indicate the age of both persons in years. Gender is also based on a simple interview response of "male" or "female". Caregiver gender was coded as "0"=male and "1"=female.

Educational Status

Educational level of caregiver is defined as: attended grade school, attended high school, graduated high school, attended college, graduated college, some graduate or professional school. The education variable was converted into an interval-level variable by recoding the categories into approximate years of schooling ("6"= attended grade school, "10"=attended high school, "12"= graduated high school, "14"=attended college, "16"= graduated college, and "18"=some graduate or professional).

Employment Status

Employment status will be defined as full time, part time or no employment outside the home. Caregiver current employment status was coded as "0"=not employed and "1"=employed.

Data Analysis

The dependent variables in this study are the two dimensions of caregiver preparedness. The independent

variables are caregiver and care-recipient characteristics. Data analysis has been performed through use of SPSS 8.0 for desktop computers. Frequency, means and percentages will be employed to describe sample characteristics and to provide information about the distribution of research variables in the study.

To answer Question 1 regarding caregiver preparedness, frequency distributions and summary statistics for the preparedness items and scales are shown. To answer Questions 2 and 3 regarding caregiver and care-recipient characteristics that may predict variation in perceived level of preparedness, multiple regression analysis was performed with all independent variables coded as either continuous or dichotomous variables.

RESULTS

Description of the Sample

Table 1 describes the caregivers in this sample. The majority of caregivers were female (n=55, 90.2%) and Caucasian/White (n=50, 82%). The caregiver mean age was 57.4 years, with a range of 21 to 84 years. The majority of caregivers (n=44, 72.1%) were not currently employed. The remaining caregivers were either employed full or part-time, laid off, in between jobs, or not employed for pay. One caregiver took a leave of absence and one had to quit work in order to provide care. The median income for caregivers was $30,749.64 with a range of $3,000 to $62,500. The

Table 1

Frequencies and Percentages of Sample Caregiver Demographics (n=61)

Variable	Frequency n	Percent %
Gender		
Male	6	9.8
Female	55	90.2
Age		
39 or <	5	8.2
40-49	11	18.0
50-59	14	23.0
60-69	21	34.4
70-79	8	13.1
80 or >	2	3.3
Race		
Caucasian/White	50	82.0
Other	11	18.0
Employment Status		
Employed	17	27.9
Not employed	44	72.1
Income		
$9,999 or <	6	9.8
$10,000-$19,999	10	16.4
$20,000-$29,999	15	24.6
$30,000-$39,999	8	13.1
$40,000-$49,999	7	11.5
$50,000 or >	10	16.4
Missing	5	8.2
Education		
Grade school or less	4	6.6
Some high school	19	31.1
Graduated high school	17	27.9
Some college	12	19.7
Graduated college	8	13.1
Some graduate/professional	1	1.6

majority of caregivers (n=38, 62.3%) had a high school education or higher. Spouses comprised the majority (n=35, 57.4%) of caregivers with daughter, daughter in law, and granddaughter accounting for the remainder. The majority of caregivers were married (n=51, 83.6%) and the remaining were either single, divorced, or widowed.

Table 2 contains the patient demographic characteristics in regard to gender, age and living arrangement. The majority of patients in this sample were male (n=34, 55.7%) and lived with the caregiver (n=56, 91.8%). The mean age of the patients is 71.4 years, with a range of 55 to 91 years.

Table 2.

Frequencies and Percentages of Sample Patient Demographics (n=61)

Variable	Frequency n	Percent %
Gender		
Male	34	55.7
Female	27	44.3
Age		
50-59	7	11.5
60-69	20	32.8
70-79	22	36.1
80 or >	12	19.7
Living Arrangement		
Together	56	91.8
Apart	5	8.2

Table 3 offers information on the functional status of the patient as reported by the caregiver. Functional status was determined by dependencies in ADL's, IADL's, HCA's, and cognitive functioning. The average number of dependencies in ADL's was 3.7 out of 6, in IADL's it was 5.6 out of 6, and HCA's 3.2 out of 8. The majority of patients experienced none or only occasional problems with confusion (n=43, 70.5%) or displayed unpleasant behavior (n=50, 82%).

Research Questions

The primary purpose of this study was to examine factors that may influence a caregivers perceived level of preparedness. The first step is to describe the distribution of preparedness scores in the sample. The next step is to examine the relationship of various predictor variables to preparedness through multiple regression analysis.

To answer research Question 1, how well prepared caregivers feel in performing domain specific tasks, responses were taken from the original questionnaire and frequencies and percent were obtained. Table 4 displays the caregiver responses for each item. Table 5 shows the summary measures for the preparedness scale PREPARE2 (Cronbach's alpha .94) and the separate item PREP5 (managing finances). It is evident from all these individual items that well over half of all caregivers in this study reported feeling "pretty well prepared" to "very well prepared".

Table 3

Patient Dependencies in Number of ADL's, IADL's, Health Care Activities (HCA's), and Cognitive Deficits by Frequencies as Rated by Caregiver (n=61)

Variable	Mean x	Frequency n	Percent %
# of Dependencies in ADL's	3.7		
0		9	14.8
1		9	14.8
2		4	6.6
3		3	4.9
4		4	6.6
5		9	14.8
6		23	37.7
# of Dependencies in IADL's	5.6		
0		0	0.0
1		1	1.6
2		1	1.6
3		2	3.3
4		1	1.6
5		7	11.5
6		49	80.3
# of Dependencies in HCA's	3.2		
0		1	1.6
1		7	11.5
2		18	29.5
3		14	23.0
4		7	11.5
5		8	13.1
6		3	4.9
7		2	3.3
8		1	1.6
Cognitive Deficits			
Confusion	1.7		
1.00-1.99		43	70.5
2.00-2.99		14	23.0
3.00-3.99		3	4.9
4.00		1	1.6
Unpleasantness	1.6		
1.00-1.99		50	82.0
2.00-2.99		11	18.0

Table 4

Frequencies and Percentages of Sample Caregivers Perceived Level of Preparedness for all Items on the Preparedness Scale (n=61)

Items	Not at all Prepared freq./%	Not too well Prepared freq./%	Pretty well Prepared freq./%	Very well Prepared freq./%	Mean x
PREP1 physical needs	8(13.1)	5(8.2)	23(37.7)	25(41.0)	3.07
PREP2 emotional needs	11(18.0)	11(18.0)	29(47.5)	10(16.4)	2.62
PREP3 formal service needs (missing 1)	9(14.8)	13(21.3)	19(31.1)	19(31.1)	2.80
PREP4 med-nurs needs (missing 1)	9(14.8)	4(6.6)	22(36.1)	25(41.0)	3.05
PREP5 managing finances	3(4.9)	4(6.6)	27(44.3)	27(44.3)	3.28
PREP6 plan for activities (missing 2)	6(9.8)	5(8.2)	29(47.5)	19(31.1)	3.03
PREP7 managing behavior problems (missing 3)	8(13.1)	15(24.6)	22(36.1)	13(21.3)	2.69
PREP8 manage equipment (missing 1)	7(11.5)	7(11.5)	25(41.0)	21(34.3)	3.00
PREP9 how well prepared overall	2(3.3)	8(13.1)	28(45.9)	23(37.7)	3.18

Table 5

Summary Measures for the Preparedness Scale PREPARE2(without PREP5) and PREP5(managing finances) (n=61)

Scale	Mean x	Median	Standard Deviation	Minimum Value	Maximum Value
PREPARED2	2.9	3.0	.82	1	4
PREP5 (managing finances)	3.3	3.0	.80	1	4

To answer research Questions 2 and 3, multiple regression analyses were carried out to examine the combined effects of various predictor variables on the two measures of preparedness. Two regression analyses were run. The first with Preparedness Scale PREPARE2 (without PREP5) as the dependent variable and the second with PREP5 (managing finances) as the dependent variable. The set of independent variables were the same in each case and included: caregiver age, gender, relationship status, education, employment; patient ADL'S, IADL'S, HCA'S, patient mental confusion, and patient unpleasant/bothersome behavior. Table 6 describes the regression analysis with Preparedness Scale PREPARE2 as the dependent variable and Table 7 the analysis of PREP5 (managing finances) with resulting scores for b, beta, t, and the overall significance level of the F-test.

Table 6

Multiple Regression to Determine Influence of Predictor Variables on Caregivers Perceived Level of Preparedness (n=61)

Predictor Variable	b	Beta	t	Sig.
Caregiver Age	-.0099	-.158	-1.081	.285
Caregiver Gender 0=male 1=female	.6000	.221	1.654	.104
Relationship Status 0=other 1=spouse	-.1500	-.092	-0.683	.497
Education	.0197	.065	0.504	.616
Employment 0=not employed 1=employed	-.0231	-.013	-0.099	.921
Patient ADL's	-.0112	-.033	-0.199	.843
Patient IADL's	.1360	.168	1.161	.251
Patient HCA's	.0842	.177	1.169	.248
Patient Confused	.1180	.098	0.737	.464
Patient Unpleasant*	-.9600	-.456	-3.412	.001

*Overall significance level of F-test: .032

Table 7

Multiple Regression to Determine Influence of Predictor Variables on Caregivers Perceived Level of Preparedness in Managing Finances (n=61)

Predictor Variable	b	Beta	t	Sig.
Caregiver Age	-.0149	-.248	-1.543	.129
Caregiver Gender 0=male 1=female	.0732	.028	0.210	.834
Relationship Status* 0=other 1=spouse	-.5140	-.321	-2.442	.018
Education	.0384	.129	0.923	.360
Employment 0=not employed 1=employed	-.0561	-.032	-0.251	.802
Patient ADL's	-.0158	-.047	-0.264	.793
Patient IADL's	.0461	.058	0.369	.713
Patient HCA's	-.0727	-.156	-0.949	.347
Patient Confused	-.1660	-.142	-0.981	.331
Patient Unpleasant	.0216	.010	0.072	.943

*Overall significance level of F-test: .090

Regression analysis of PREPARE2 showed no statistically significant ($p>.05$) relationship of any predictor variables with overall level of preparedness, except for one: patient unpleasant/bothersome behavior which resulted in a significance level of $p=.001$ ($\beta=-.456$, $t=-3.412$). Caregivers felt less prepared as patients displayed more unpleasant/bothersome behaviors.

PREP5 (managing finances) showed no statistically significant ($p>.05$) relationship to the predictor variables except for family relationship which had a significance level of $p=.018$ ($\beta=-.321$, $t=-2.442$). Preparedness to deal with financial matters was lower for spouse than nonspouse caregivers.

DISCUSSION

In this study, a total of 61 caregiver interviews were reviewed to determine reports of caregiver preparedness in home care of stroke survivors. As reported in the literature (NSA, 1994; DHHS, 1995; Stone, Cafferata, and Sangl, 1987; and Weeks, 1995), caregivers were primarily spouses and female, and stroke patients were predominantly male and over the age of 70.

Although patients tended to have high levels of dependencies, the majority of caregivers in this study reported feeling "pretty well prepared" to "very well prepared" on all 9-items of the preparedness scale. This may be attributed to several factors. First, these caregivers

were interviewed within 6-7 weeks following hospital discharge. It may be that this group of caregivers had not yet had time to fully experience all aspects of the caregiver role. Novice caregivers may be overly optimistic in dealing with a new caregiving role. Second, in the early stages of the caregiver role various support persons (family, friends, or home care workers) may be more readily available and willing to provide assistance to the caregivers and this may result in greater feelings of preparedness. Third, the majority of caregivers were elderly women for whom the caregiving role was typically part of their socialization. Fourth, it was not known whether this was a first time caregiver experience and previous experience could account for feelings of greater preparedness.

Most of the predictor variables seemed to have no effect on the perceived levels of preparedness. Principally, there are four possible explanations: (1) these variables do, indeed, have no effect on levels of preparedness; (2) the sample size was too small to show significant effects; (3) the outcome variables (measures of preparedness) were highly skewed, i.e., they showed very little variation to begin with; and (4) the measures lack validity for assessing relevant preparedness dimensions. Still, two predictor variables do seem to affect caregivers perceived levels of

preparedness: unpleasant patient behavior and relationship status.

The preparedness scale used in this study measured different types of domain specific activities yet the majority of caregivers reported doing all care activities well. Few caregivers reported dealing well with patients physical care needs yet having problems with emotional care needs or obtaining formal services. Only 61 caregivers out of the 73 stroke patients identified completed the preparedness questionnaire, it is possible that the 12 caregivers who choose not to reply were feeling too overwhelmed to deal with the issues confronting them. It may be more appropriate to develop a knowledge/skill scale and than validate the caregivers perceptions through a observational study. This may give a more accurate assessment of preparedness than self-report questionnaires and phone interviews.

As reported in previous studies (Jorgenson et al, 1995; Kotial et al, 1984; and Silliman, Wagner, & Fletcher, 1987), most individuals, who have had a stroke, experience more physical disabilities than cognitive deficits. The ability of most patients in this study to comprehend and communicate, either verbally or nonverbally, may result in a caregiver feeling more prepared to handle their new role. Although a patients' unpleasant or bothersome behavior proved significant in caregiver preparedness, the small

convenience sample in this study does not allow findings to be generalized. It would, however, make sense that as a patients behavior becomes more unpleasant or difficult to deal with, a caregiver would feel less prepared in their ability to carry out their role.

The finding that preparedness to deal with financial matters was lower for spouse than nonspouse caregivers cannot be generalized due to sample size and possible confounding with gender. As stated previously, 90.2% of the caregiver sample were female with a mean age of 57.4 years and lack of preparedness to deal with financial matters could be attributed to the socialization of this generation of caregivers.

In utilizing an adaptation of the ABCX model to look at the outcomes or findings of this study in relation to perceived levels of preparedness, one can see that a number of variables could potentially impact preparedness. The high level of preparedness reported by the caregivers in this study demonstrates that caregivers were coping with their new role. However, the selected predictor variables did not appear to account for this finding. The results of this study are unable to support the proposed conceptual model that the predictor variables selected for analysis influence a caregivers perceived level of preparedness. Because this relationship was not statistically significant, the Null

hypothesis which states that there is no actual relationship between variables cannot be rejected.

Limitations

A number of limitations are acknowledged in this study. The findings in this study should be viewed as representative of this group of caregivers and should not be generalized because of the small sample size and the nature of the sample as convenience sample. The rate of preparedness among this group of caregivers may be explained in part by sample characteristics. For example, a majority were elderly, female and Caucasian. Further, the findings describe a particular population at a particular point in time. Caregivers may feel different at 6-7 weeks post-discharge from hospital versus 6-months later and this may result in a different concept of preparedness. A further limitation of this study is that stroke is defined in generic terms based on functional limitation. A right-sided vs. left-sided stroke can have very different clinical presentations and resulting deficits requiring different approaches to care delivery and this may affect caregiver preparedness. Also, it is not known if the patients or caregivers had participated in any type of rehabilitation program prior to interview and this could potentially affect how well a caregiver feels about taking on the caregiving role. Two predictor variables, caregiver income and social assistance, were not included in this study and could very

likely influence preparedness. Managing finances obviously depends on one's income and how much help a caregiver expects to receive or is actually receiving may influence preparedness.

The adaptation of the ABCX model used as the conceptual framework for this study had advantages and disadvantages. The model allowed for a clear depiction of the events which may produce a caregiving situation. From this line of events one can see how various factors can influence preparedness. However, the proposed model does not fully explain preparedness as a multidimensional situation influenced by factors such as formal and informal support systems, coping skills, living arrangement, household size, financial status, patient comorbid conditions, caregiver mental and physical health, competing role obligations, and other life stressors that may influence the caregiving situation.

There is also a need for methodological improvement in both the conceptualization and measurement of preparedness. The predominant focus of caregiver literature has been on burden. Preparedness is a relatively new concept with limited literature available on the subject. As stated previously, preparedness has an anticipatory connotation and should really be assessed before a caregiver takes on the caregiving role. The concept of preparedness is a question of whether preparedness precedes or follows involvement. For example, a caregiver may be taught how to assist a patient

with walking but still report they don't feel prepared to do it. However, once the caregiver is in the home and confronted with the situation, new ways to assist with walking emerge by trial and error and with each act caregiver performance increases. Central to the issue of preparedness is how good the care is that is being delivered to the care-recipient. If a caregiver reports high levels of preparedness but delivers poor care the outcome for the care-recipient will be negatively affected. Once an individual has actually moved into the caregiving role, such as in the current study, we may in effect be testing caregiving mastery rather than preparedness. A caregiver's perception of how well they are performing (mastery), may reflect a general feeling of competence in the role.

Assessing preparedness may require a different approach. Phone interviews and self-report questionnaires may not be the best way to evaluate preparedness. This approach permits only one viewpoint, that of the caregiver, and does not allow for validation of responses. Caregiver rating of a patients cognitive status is very subjective and problematic in terms of accuracy. Instead, presenting a caregiver with a specific caregiving situation and asking how they would handle it may yield more useful information on ways to describe and assess preparedness. Another way to enhance evaluation of preparedness is to develop measures in which items refer to specific caregiving tasks and problems

rather than to global domains of caregiving. This type of instrument may allow for more sensitivity to change and allow researchers to describe, identify, and test different models of preparedness. Development of a knowledge or skill scale and measurement of objective care-recipient outcomes could yield useful information about preparedness. This would allow an interesting analysis of whether confidence or judgment correlates with knowledge and how prepared caregivers report they feel.

The concept of preparedness is important to understand as part of the multidimensional concept of family caregiving. Although the concept of preparedness, as currently defined, takes on meaning before the caregiving role has been taken on, there may be times when the advanced practice nurse can utilize the concept to assist caregivers in their role. For example, Robinson and Price (1982) found that there is an early and late stage of depression among stroke patients, the caregiver could be prepared for this possibility through anticipatory guidance which could result in earlier recognition and treatment for the patient and thus enhance and maintain the caregiver role.

Implications for Future Research

The literature review, as delineated previously, revealed little research on caregiver preparedness in the stroke population. Determining predictors of perceived levels of preparedness among stroke caregivers is difficult

with such a small sample size (n=61). However, this study does produce several possible directions for future research.

Future studies should incorporate a knowledge/skill scale and objective patient outcome measures to assess preparedness. This would allow for not only assessment of knowledge and skills required by the caregiver, but also the evaluation of how well the care is being given. Missing in current caregiver literature is an assessment of the care recipients opinion of the adequacy of care given, this would fit nicely in a study of caregiver preparedness.

Additional studies should examine formal and informal support systems, income level, gender, and prior caregiver experience for their possible effects on preparedness. As mentioned previously, the sample in this study was composed of novice caregivers at the beginning of the caregiver role. Utilizing a larger sample of caregivers, who are dealing with a new caregiving situation, to see if similar results are produced would allow for more generalizability of findings. Studying these variables will help develop a better picture of the caregiver who is well prepared versus one who feels ill-prepared to take on this role, allowing researchers to recommend which caregivers may require interventions in order to sustain the caregiver role.

This study focused on caregivers at a particular point in time. Longitudinal studies are needed to examine the

changes that occur in preparedness over time and in relation to illness stages. Better instruments are also needed to evaluate preparedness, measures that frame items based on specific caregiving tasks or problems rather than global domains of caregiving would enhance sensitivity to change. In addition, future research should incorporate more than one measure to capture dimensions of preparedness which would add to a better understanding of what preparedness really means.

In the current study, only 61 out of 73 stroke caregivers completed and returned the questionnaire on caregiver preparedness. Future studies should compare those who remain in a study with those who drop out to detect reasons for attrition. The twelve caregivers who did not complete the preparedness questionnaire may have been too overwhelmed and experiencing too much stress to continue to participate. This may be the group of caregivers where the APN would need to target interventions.

A qualitative research design that is exploratory and investigative in nature may also be of benefit in discovering what stroke caregivers felt least prepared to handle once the caregiving role has begun. The studies reviewed that examined caregiver needs and wants provide important insight into what preparation may be needed prior to the caregiver role being enacted. Unstructured qualitative approaches will assist the investigator in

understanding environmental influences on caregiving and decision-making processes.

It is clear that further research is needed to identify and confirm the importance of predictors of caregiver preparedness, to establish their generalizability, and to determine their implications for advanced practice nurses.

Implications for Advanced Practice Nurses

Implications for advanced practice nurses (APN) in primary care can be derived from the findings in this study. There are a number of strategies the APN can utilize in the clinical practice setting. Implementing these strategies requires the APN to draw upon his/her unique role characteristics. Implications for the roles of assessor, planner, clinician, educator, advocate, leader, and researcher will be discussed.

Stroke is a leading cause of disability in the United States. Its incidence increases steadily with age and tends to affect men more frequently than women. With the aging American population it can be expected that more people will be at higher risk for developing stroke. Health care services previously provided within the acute care setting are increasingly being shifted to home and family care. Societal expectations demand that families provide the majority of care to its disabled members. Individuals who assume the role of primary caregiver may find themselves ill prepared and uninformed about what to do in their new role.

The potential for caregivers to become overwhelmed and develop stress-induced illnesses could result in detrimental effects for both caregiver and care-receiver.

Family caregivers of stroke survivors tend to be elderly female spouses. Many of these women may be facing health problems of their own. As an assessor, the APN is responsible for performing a comprehensive assessment by identification of data, subjective and objective, that may influence a caregivers health status. In collecting data the APN needs to assess a caregiver's knowledge, expectations, and perceived needs on issues related to stroke, home care and social factors. Specific questions may focus on: to whom and for how long has this individual been providing care; what is the quality of relationship with care receiver; how does she perceive the situation and its effects on her health; how much and what type of care is required; does she receive assistance from family or friends; what has she done to prepare for the role; how has she handled crises in the past. Objectively, the APN needs to assess for possible physical and/or psychological effects of caregiving which may include hypertension, fatigue, depression, anxiety, or back strain.

Appraisal of the caregiving situation needs to be ongoing. Periodic health screening appraisals will allow the APN to detect changes in the physical and/or mental health status of either caregiver or care receiver. An appraisal

may include such issues as: patients' cognitive/social behaviors, quality of patient-caregiver relationship, ability of caregiver to find time for rest and relaxation. Early interventions may require suggestion or acquisition of specific services as the need arises, as well as offering anticipatory guidance and teaching coping strategies. Catching problems before they become full blown health concerns can save the family unnecessary grief and suffering. An assessment of the caregivers social support is also essential at this stage.

Caregiver planning is critical to all forms of caregiving. Once a thorough assessment has been made, the APN can develop a goal directed plan of care to support caregivers in their roles. The APN must develop individualized interventions that are planned with the family caregiver. The outcome of this should be maintenance of the caregiver role, promotion of optimal health status of the caregiver, and to decrease the potential for crisis situations to arise that would negatively impact caregiver and care receiver. The individualized plan needs to take into consideration the caregivers economic resources, social support systems, education level, employment status, competing roles, and patients functional disabilities.

The APN as a planner of care may independently develop or offer consultation on programs that support caregivers in their role. Given that family caregivers spend time

assessing and evaluating a care-receivers symptoms, as well as functioning as the primary home care problem solver, programs that help caregivers develop, refine, and expand problem-solving skills would be beneficial. This is an ideal way to provide anticipatory guidance to caregivers and when done within a small group setting can draw upon the experiences of other caregivers. Planning and implementation of a stroke support group would be another way to assist caregivers in their roles.

The APN as planner and coordinator of care must be familiar with community resources. Because of the high dependency needs seen in the patients in this study, there may come a time when the caregiver would require additional assistance. Caregivers who have little family support may benefit from such programs as meals on wheels, chore services, respite care, and transportation assistance. Many of these services are free or charge only minimal fees which can be beneficial if financial resources are a concern for caregivers. Arranging referrals when appropriate and acceptable to the caregiver can relieve some of the stress associated with caregiving. As a clinician, the APN can use alternative interventions such as relaxation techniques, diary/journal writings, humor therapy, or music therapy within the office setting to aid the caregiver in their ability to cope with a stressful situation.

The role of advocate for the caregiver and the implementation of advocacy as an intervention are integral to the practice of an APN in primary care. Developing a sustained partnership with caregivers can assist the APN to facilitate the clients ability to identify their rights and abilities as a caregiver. Resources can than be identified that can assist the family caregiver in his/her role. These resources may include community support groups, local or national associations for caregivers, and respite programs.

The educator role is one of the most commonly utilized components of the APN role. Through the role of educator the APN is in a pivotal position to influence client, family, and health care team member behaviors. As an educator the APN can assist family caregivers of stroke patients in learning new skills that may be required for caregiving as well as educating in regards to available resources. The specific skills required by caregivers were not addressed in this study, however, the dependencies in ADL's and IADL's among care-recipients indicate that caregivers may be required to perform tasks that are usually performed by health care professionals. The variety and complexity of these tasks may influence the caregivers perceived preparedness due to a lack of knowledge or familiarity regarding necessary skills or resources available to assist them in their role. Counseling the caregiver in such stress management strategies as pacing obligations, learning to ask

for help, and obtaining resources may prevent unnecessary stress.

The APN, by assessing the care-recipients unique physical condition, emotional state, or other particular need is able to develop and individualize the content of educational programs that address specific tasks of caregiving. Content of these programs could range from techniques for lifting, transferring, bathing and dressing, to teaching caregivers how to manage time, balance a check book, pay bills, or do minor home repairs. Programs such as these could be conducted at local stroke support group meetings, in rehabilitation centers, or local hospitals prior to patient discharge. The caregivers need anticipatory guidance regarding the changes that caregiving will bring into their lives, as well as how to manage the patients' physical and emotional needs. It would make sense that education and preparedness are linked in that exposure to an unfamiliar task would increase that caregivers subjective feeling of being prepared to deal with it again in the future. Further research that examines the effect of educational programs on preparedness need to be conducted to substantiate this assumption.

In addition to caregiver education, the APN can participate in the education of professional colleagues, primary and acute care providers, and policy makers. Increasing awareness of the issues impacting caregivers can

lead to community and legislative agendas that support quality care in the home care setting. Support services (support groups, respite care, and home care services) are essential to helping caregivers carry out their role and to maintain care-recipients in the home setting. Community leaders need to be made aware of this important service for caregivers in order to help provide services that are free of charge or reimbursable through third party payer. Acute care providers can be made aware of the importance of education for caregivers prior to hospital discharge and how this impacts preparedness and the care that care-recipients receive.

There are several implications for the APN as researcher. The APN, whether novice or experienced clinician, should be a consumer of research that focuses on family caregivers. Remaining current on caregiver literature will allow the APN to evaluate what interventions are effective in assisting caregivers in their role. As the APN becomes more of an expert clinician, he/she may become more involved as initiator or collaborator of research in order to advance a scientific basis for nursing knowledge and practice in order to improve quality care. Specifically, future research by the APN may focus on development of a knowledge or skill scale and measurement of objective patient outcomes to assess caregiver preparedness.

Summary

This study focused on caregivers of stroke survivors in an attempt to identify factors that may influence caregiver preparedness. Although most predictor variables had no effect on perceived preparedness, two variables that proved to be significant were unpleasant patient behavior and relationship status. Caregivers reported high levels of preparedness in caring for stroke survivors who experienced high dependencies in ADL'S and IADL'S. A unique feature of this study was that caregivers were dealing with a new caregiving situation, in essence they were novice caregivers. The preparedness scale utilized in this study lacked validity for assessing relevant preparedness dimensions. Further research is needed that uses more than one measure to capture the multidimensionality of preparedness. Advanced practice nurses and other health care professionals must assume a lead role in continued efforts to address issues of caregiver preparedness.

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APPENDIX A

ID _ _ _
CARD 0 1 9

The following questions ask you to consider how well prepared you feel for a number of caregiving activities for your relative/friend. For each item please indicate the following:

Overall, how well prepared do you feel you are to.....
Would you say: (CIRCLE ONE RESPONSE)

1 = Not At All Prepared
2 = Not Too Well Prepared
3 = Pretty Well Prepared
4 = Very Well Prepared

How well prepared do you feel you are to	(CIRCLE ONE RESPONSE)				
5. To care for (____'s) physical needs (e.g. Dressing, Toileting, Bathing, etc.)?	1	2	3	4	25
6. To take care of (____'s) emotional needs?	1	2	3	4	26
7. To find out about and set up formal services for (___'s) care?	1	2	3	4	27
8. To care for (___'s) medical/nursing treatments (e.g. giving medicines, changing dressing, skin care, exercises, etc)?	1	2	3	4	28
9. To manage finances, bills, and insurance forms related to (___'s) care needs?	1	2	3	4	29
10. To plan for activities such as rest, meals, recreation, or things for (____) to do	1	2	3	4	30
11. To manage (___'s) behavior problems, such as moodiness, irritability and confusion?	1	2	3	4	31
12. To manage equipment and techniques necessary to care for (___)?	1	2	3	4	32
13. Overall, how well prepared do you think you are for the role of caregiving?	1	2	3	4	33

APPENDIX B

PATIENT COGNITIVE/SOCIAL BEHAVIORS

In the following questions, we would like to know how frequently (_____) displays the following behaviors. The answers you may choose from are: NOT AT ALL, SOMETIMES, MOST OF THE TIME, and ALWAYS. (CHECK ONE FOR EACH)

1. How often does your friend/relative ...	NOT AT ALL	SOMETIMES	MOST OF THE TIME	ALWAYS
a. have problems expressing thoughts?				
b. get the present mixed up with the past?				
c. forget where he/she is?				
d. see or hear things that are not there?				
e. forget important or recent events?				
f. forget your name?				
g. have difficulty recognizing familiar people?				
h. seem confused?				
i. forget what day it is?				
j. repeat himself/herself or ask same question over and over?				
k. say sentences which make no sense?				

2. Nowadays, how often does it strike you that (_____'s) behavior is characterized by any of the following ... (CHECK ONE FOR EACH) Again, your choices are: NOT AT ALL, SOMETIMES, MOST OF THE TIME, or ALWAYS.

How often is _____'s behavior ...	NOT AT ALL	SOMETIMES	MOST OF THE TIME	ALWAYS
a. unpleasant and uncooperative?				
b. depressed and/or tearful?				
c. withdrawn or lethargic?				
d. fearful, anxious, or extremely tense?				
e. full of unrealistic physical complaints?				
f. suspicious (more than reasonable)?				
g. bizarre or inappropriate in thought or action?				
h. excessively talkative or overly cheerful or elated?				

/jf
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ACTIVITIES OF HEALTH CARE

The next set of questions includes health care activities or treatments that (_____) may or may not require. First, I will ask if (_____) requires this kind of help, and then I will have additional questions about how you and others help.

INTERVIEWER: The following questions have four sections: A,B, C, & D.
Ask section A -- each item for all caregivers.

If answer in section A is NO -- go to next item.
If answer in section A is YES -- go to section B.
If answer in section B is NEVER or 0 -- go to section D.
If answer in section B is 1, 2, 3, or 4 -- go to section C then section D.
If answer in section D is 1, 2, 3, or 4 - go to section E

(MARK THE APPROPRIATE ANSWERS FOR EACH)

A. Does your relative have or require help with...	YES NO (CIRCLE ONE)	B. If YES, how frequently do you help your relative with _____? 0 = NEVER 1 = ONCE A WEEK OR LESS 2 = SEVERAL TIMES A WEEK (2-6) 3 = ONCE A DAY 4 = SEVERAL TIMES A DAY (CIRCLE ONE)	C. If answer 1-4 to part B, how competent do you feel in helping your relative/friend with _____? 3 = EXTREMELY COMPETENT 2 = SOMEWHAT COMPETENT 1 = NOT VERY COMPETENT 0 = NOT AT ALL COMPETENT (CIRCLE ONE)	D. If YES to A, how frequently do OTHERS help your friend/ relative with _____? 0 = NEVER 1 = ONCE A WEEK OR LESS 2 = SEVERAL TIMES A WEEK (2-6) 3 = ONCE A DAY 4 = SEVERAL TIMES A DAY	E. If others help, are they family or friends or health professionals or both. CHECK ALL THAT APPLY
	1 2	0 Go to Sec. D / 1 2 3 4 Go to Sec. C	3 2 1 0 Go to Section D	0 1 2 3 4	Family or Friends / Health Prof.
13. Urinary catheter/ catheter care.	1 2	0 / 1 2 3 4	3 2 1 0	0 1 2 3 4	_____ _____
14. Oxygen administration.	1 2	0 / 1 2 3 4	3 2 1 0	0 1 2 3 4	_____ _____
15. IV, Hickman or Broviac, catheter care/dressing.	1 2	0 / 1 2 3 4	3 2 1 0	0 1 2 3 4	_____ _____
16. IV medications/ fluids/feedings	1 2	0 / 1 2 3 4	3 2 1 0	0 1 2 3 4	_____ _____
17. Tube feedings or IV feedings.	1 2	0 / 1 2 3 4	3 2 1 0	0 1 2 3 4	_____ _____

A. Does your relative have or require help with...	YES NO (CIRCLE ONE)	B. If YES, how frequently do you help your relative with _____? 0 = NEVER 1 = ONCE A WEEK OR LESS 2 = SEVERAL TIMES A WEEK (2-6) 3 = ONCE A DAY 4 = SEVERAL TIMES A DAY (CIRCLE ONE)	C. If answer 1-4 to part B, how competent do you feel in helping your relative/friend with _____? 3 = EXTREMELY COMPETENT 2 = SOMEWHAT COMPETENT 1 = NOT VERY COMPETENT 0 = NOT AT ALL COMPETENT (CIRCLE ONE)	D. If YES to A, how frequently do OTHERS help your friend/ relative with _____? 0 = NEVER 1 = ONCE A WEEK OR LESS 2 = SEVERAL TIMES A WEEK (2-6) 3 = ONCE A DAY 4 = SEVERAL TIMES A DAY	E. If others help, are they family or friends or health professionals or both. CHECK ALL THAT APPLY	
	1 2	0 Go to Sec. D 1 2 3 4 Go to Sec. C	3 2 1 0 Go to Section D	0 1 2 3 4	Family or Friends	Health Prof.
18. Injections (ex., pain meds/insulin).	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
19. Special exercises/phys. therapy.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
20. Care of ulcers/ bedsores.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
21. Skin care (special cleansing/ lotions).	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
22. Colostomy/ colostomy care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
23. Care of Post Op. incision/ wound	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
24. Oral medications.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
25. Nasograstric tube and care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
26. Incontinence of urine.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
27. Incontinence of stool.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
28. Tracheostomy/ tracheostomy care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
29. Respirator/care of respirator.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____
30. Suctioning.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	_____	_____

CG II, Wave 1
Regular Telephone
Involvement
Page 1

INVOLVEMENT

The next set of questions addresses the PRESENT level of performance for the person you care for on a number of activities and the way YOU AND OTHER PEOPLE help him/her. For each item, please choose the response that most closely describes the patient's PRESENT condition and how you assist him or her.

> INTERVIEWER: OTHER PEOPLE category may include assistance from agencies, paid helpers, and family and friends. The purpose of these questions is to assess current involvement. CLARIFICATION -- "Generally speaking over the past month ..."

1. DRESSING

[INTERVIEWER: CATEGORY DEFINITIONS ARE MEANT FOR PURPOSES OF CLARIFICATION]

This category includes the entire process of dressing or being clothed, including change from bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES NOT include management of clothing during toileting. If your relative always wears bed clothing during the day, answer "NEVER DRESSED." Select the category that best describes your relative's level of functioning for DRESSING.

1a. With regard to dressing, would you say (_____) ... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity) (GO TO ITEM #2). (1)

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2) (Go to 1b)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

___ IS NEVER DRESSED (5)

(The next set of questions is about how frequently you and other people help your relative/friend with dressing.)

1b. How frequently do YOU help the patient with dressing? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: "Help" includes any combination of supervision, some physical help, and total physical help.

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

1c. How often do OTHER PEOPLE help the patient with dressing? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

2. EATING

This category includes all types of food and liquid taken by mouth.

> INTERVIEWER: Includes all types of presentation used -- tray, finger foods, etc.; client does not need to use utensils.) Does not include selection or preparation of food.

2a. With regard to eating, would you say (_____) .... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity) (GO TO ITEM #3). (1)

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

___ NOT APPLICABLE (needs tube feedings, IV's ONLY - Go to item #3)

(The next set of questions is about how frequently you and other people help your relative with eating.)

2b. How frequently do YOU help the patient with eating? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

> INTERVIEWER: "Help includes any combination of supervision, some physical help, and total physical help.

> INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

2c. How often do OTHER PEOPLE help the patient with eating? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

3. BATHING

This category includes all activities of bathing, whether tub or shower or bed bath: entry into tub or shower, wetting, soaping, rinsing, exit, drying body. Does not include washing of head or drying hair. Does not include dressing or undressing. Select the response that best describes your relative's level of functioning for bathing.

3a. With regard to bathing, would you say (_____) ... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #4).

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.

(The next set of questions is about how frequently you and other people help your relative with bathing.)

3b. How frequently do YOU help the patient with bathing? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C, OF QUESTION (others help).

3c. How often do OTHER PEOPLE help the patient with bathing? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

4. WALKING INSIDE THE HOUSE

This category includes all upright movement on foot over the floor inside the house. MUST MOVE AT LEAST FIVE FEET. May use cane, walker, crutches, or handrail. Select the response that best describes your relative's level of functioning for walking.

4a. With regard to walking inside the house, would you say (_____) ... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #5).

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.

___ UNABLE TO WALK -- (will not bear weight.)

INTERVIEWER: If relative is <u>UNABLE TO WALK</u>, go to item #5.

(The next set of questions is about how frequently you and other people help your relative with walking.)

4b. How frequently do YOU help the patient with walking? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", <u>GO TO PART C. OF QUESTION</u> (others help).

4c. How often do OTHER PEOPLE help the patient with walking? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

5. TOILETING

This category includes all those behaviors associated with bowel/bladder emptying: getting to and from toilet (or use of toileting equipment such as bedpan), removal/adjustment of clothing, positioning on toilet, cleaning of body parts, replacement of clothing. Select the response that best describes your relative's level of functioning for toileting.

5a. With regard to toileting, would you say (_____) ... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #6).

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.

___ NOT APPLICABLE (has catheter, colostomy - Go to item #6)

(The next set of questions is about how frequently you and other people help your relative with toileting.)

5b. How frequently do YOU help the patient with toileting? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

5c. How often do OTHER PEOPLE help the patient with toileting? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

6. TRANSFERRING -- IN/OUT OF BED

This category includes movement to and from bed, to chair or wheelchair, or set on toilet or commode. Devices, bars, and other mechanical aids may be used. Select the response that best describes the relative's level of independence.

6a. With regard to transferring, in/out of bed, would you say (_____)... (CHECK ONE)

___ IS INDEPENDENT -- (does not need help of another person in any part of this activity.) (GO TO ITEM #7).

___ NEEDS SUPERVISION ONLY -- (requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.)

___ NEEDS SOME PHYSICAL HELP -- (requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES.

___ NEEDS TOTAL PHYSICAL HELP -- (needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE.

___ REMAINS BEDFAST

INTERVIEWER: If relative <u>REMAINS BEDFAST</u>, go to item #7.

(The next set of questions is about how frequently you and other people help your relative with transferring.)

6b. How frequently do YOU help the patient with transferring? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", <u>GO TO PART C. OF QUESTION</u> (others help).

6c. How often do OTHER PEOPLE help the patient with transferring? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

The next list includes additional activities with which your relative may require assistance. For each activity, please tell me how much help your relative needs and how frequently you and other help with this activity.

7. COOKING/PREPARING MEALS

7a. How much help does (_____) presently need with cooking? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #8)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has done in the past.)

___ TOTAL HELP? (Patient does not participate in this activity and never has. Not family role.)

___ NOT APPLICABLE (patient has tube feedings, IV's ONLY - Go to item #8)

7b. How frequently do YOU help the patient with cooking or cook for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

7c. How frequently do OTHERS help the patient with cooking or cook for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

8. HOUSEWORK -- (PICKING UP, DUSTING, LIGHT CLEANING, VACUUMING, DOING DISHES)

8a. How much help does (_____) presently need with housework? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #9)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has done in past.)

___ TOTAL HELP? (Patient does not participate in this activity and never has done. Not family role.)

8b. How frequently do YOU help the patient with housework or do housework for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

8c. How frequently do OTHERS help the patient with housework or do housework for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

9. SHOPPING (Includes all types of purchases.)

9a. How much help does (_____) presently need with shopping? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #10)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has in the past.)

___ TOTAL HELP? (Patient does not participate in this activity and never has. Not family role.)

9b. How frequently do YOU help the patient with shopping or shop for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

9c. How frequently do OTHERS help the patient with shopping or shop for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

10. LAUNDRY

10a. How much help does (_____) presently need with laundry? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #11)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has done in the past.)

___ TOTAL HELP? (Patient does not participate in this activity and has never done. Not family role.)

10b. How frequently do YOU help the patient with laundry or do laundry for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

10c. How frequently do OTHERS help the patient with laundry or do laundry for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

11. TRANSPORTATION

11a. How much help does (_____) presently need with transportation? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #12)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has done in the past.)

___ TOTAL HELP? (Patient does not participate in this activity and has never done.)

11b. How frequently do YOU help the patient with transportation? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

11c. How frequently do OTHERS help the patient with transportation? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

12. MONEY MANAGEMENT -- (PAYING BILLS, MAINTAINING ACCOUNTS)

12a. How much help does (_____) presently need with money management? Does he/she need: (CHECK ONE)

___ NO HELP? (Patient is independent.) (Go to item #13)

___ SOME HELP? (Patient requires some assistance; relative participates in this activity.)

___ TOTAL HELP? (Patient does not participate in this activity but has in the past.)

___ TOTAL HELP? (Patient does not participate in this activity and never has.)

12b. How frequently do YOU help the patient with money management or do money management for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER:	Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

12c. How frequently do OTHERS help the patient with money management or do money management for them? (CIRCLE ONE)

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

/jf
10/11/89
3/6

APPENDIX C

(caregiver)

MSU FAMILY CARE STUDY
CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an elderly family member affects the person providing the care.

Over the next 18 months, 650 caregivers will be interviewed five (5) times over the telephone by a member of the MSU Family Caregiver Study research staff. Each telephone interview will take approximately 20-40 minutes to complete. In addition, you may be asked to complete mailed questionnaires, which should also take about 20-30 minutes, and return them in the self-addressed stamped envelope. The telephone interviews and mailed questionnaires will be completed at your convenience.

If you are willing to participate in this study please read and sign the following statement.

1. I have freely consented to take part in a study of family caregivers conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve, and to remain in the study I must continue to meet the criteria for entry.

3. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care.

4. I understand that I may withdraw from participation at any time without penalty to me by calling 1-800-654-8219.

5. I understand that the results of this study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.

6. I understand that I will not be placed at any increased risk by participating in this study. Participation does not involve any physical activity. Interviews will be administered by thoroughly trained and closely monitored graduate students in a private and confidential manner.

7. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and my influence future family care.

8. I understand that I have the right to seek further information about this study, and my right relating to it, by calling the research office (517) 355-1851 or toll free, 1-800-654-8219.

I, _____, state that I understand what is required of me as a participant and agree to take part in this study.

Signed_____Date_____

8/15/89
100:3

(patient)

MSU FAMILY CARE STUDY
CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an elderly family member affects the person providing the care.

Over the next 18 months, 650 caregivers will be interviewed five (5) times over the telephone by a member of the MSU Family Caregiver Study research staff. They will be asked questions regarding changes in your health and issues related to caregiving. Your participation will involve providing information on your insurance coverage and your health status. If you are willing to participate in this study please read and sign the following statement.

1. I have freely consented to take part in a study of family caregivers conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve.

3. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care.

4. I understand that I may withdraw from participation at any time without penalty to me by calling 1-800-654-8219.

5. I understand that the results of this study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.

6. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and may influence future family care.

7. I understand that I have the right to seek further information about this study, and my rights relating to it, by calling the research office: (517) 355-1851 or toll free, 1-800-654-8219.

8. I understand that a member of the research staff may need to review part of my current medical record to obtain a list of my current medical diagnoses/problems. I consent to allow access to the hospital discharge planning documents for information about my home care needs and services, and understand that this information will remain strictly confidential.

9. I understand that a member of the research staff may wish to inquire about my group health insurance policy benefits to understand what benefits are available to me and compare these to what I am presently using. I give my consent for the hospital discharge coordinator to provide my group insurance(s) policy numbers so the research staff may identify what insurance benefits I have, with the understanding that they will remain strictly confidential

I, _____, state that I understand what is required of me as a participant and agree to take part in this study.

Patient Signature_____Date_____
OR
Guardian/Family Member_____Witness_____

8/15/89
100:3

MICHIGAN STATE
UNIVERSITY

June 22, 1998

TO: Manfred Stommel
A-103 Life Sciences Building

RE: IRB#: 98-385
TITLE: PREDICTORS OF PERCEIVED LEVELS OF PREPAREDNESS AMONG CAREGIVERS OF STROKE SURVIVORS

REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 06/19/98

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Roxanne M. Meo

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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