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WHO HAS HAD A STROKE?

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WHAT IS THE PERCEIVED IMPACT OF CAREGIVING ON CAREGIVERS OF AN INDIVIDUAL WHO HAS HAD A STROKE?

By

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ABSTRACT

WHAT IS THE PERCEIVED IMPACT OF CAREGIVING ON CAREGIVERS OF AN INDIVIDUAL WHO HAS HAD A STROKE?

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This descriptive study, based on secondary analysis, utilized a sample of 42 caregivers of an individual who has had a stroke to examine the perceived psychosocial and physical impact of caregiving. Subscales from the Caregiver Reaction Assessment were utilized to measure the perceived impact of caregiving. Data was collected three months after discharge from the hospital. Findings revealed caregivers perceive an impact on their psychosocial health. This impact is perceived as a positive reaction on their esteem and a negative reaction on their schedule. The findings also indicated caregivers who live with the care recipient and who care for an individual who is dependent in three or more ADLS and IADLS experience a higher impact on their schedule. The caregivers in this study did not perceive an impact on their physical health. Limitations of the study, recommendations for future research, and implications for the advanced practice nurse are discussed.

To my Family, who, through their
love and support
I was able to reach my goal

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INTRODUCTION

Over the past decade the concept of caregiver burden has been the basis of numerous articles and studies (Berry, Zarit & Rabatin, 1991; Covensky et al., 1994; Barush & Spaid, 1989; Given, King, Collins & Given, 1988; Pruchno & Resch, 1989). Many of these studies have specifically examined the impact or effects of caregiver burden on caregivers of Alzheimers and Cancer patients, while others have utilized mixed samples. Few studies have looked specifically at caregiver burden in relation to caring for an individual suffering from the effects of a stroke (Draper, Poulos, Cole, Poulos & Ehrlich, 1992; Wade, Legh-Smith & Hewer, 1986; Schulz, Tompkins & Rau, 1988; Davis & Grant, 1994). This study identifies the perceived impact on the family caregiver for an individual who has suffered a stroke.

Family caregiving has increased over the past decade due to an increase in the age of the population associated with the risk of chronic illness (Abraham & Berry, 1992; Malonebeach & Zarit, 1991). Family caregivers can be male, female, spouses, adult children, sisters or brothers. Spouses provide the majority of homecare followed by adult children (Given & Given, 1991; Malonbeach & Zarit, 1991; Abraham & Berry, 1992). Family caregivers are subject to demands on their physical health, social life and financial resources (Evans, Bishop & Ousley, 1992; Gaynor, 1990; Abraham & Berry, 1992; Wright, Clipp & George, 1993).

Due to an increase in survival rates for individuals who have had a stroke (Noll-Roth, 1994) and shortened hospital stays (Davis & Grant, 1994) more family caregivers are providing home care for these individuals. Stroke is the third leading cause of death and disability in the United States (Schulz et al., 1988; Davis & Grant, 1994), and is the most common cause of chronic neurological disability in the adult population (Hickey, 1992). Approximately one million individuals survive a stroke with disability each year (Hickey, 1992). A stroke occurs suddenly and produces long lasting effects, resulting sequelae may be physical, cognitive and/or emotional (Tompkins, Schulz & Rau, 1988). Disabilities, caused by a stroke, can include hemiplegia, aphasia, sensory/perceptual deficits and behavioral problems (Stroker, 1983). Sillman, Wagner and Fletcher (1987), reported one-fourth to one-third of all individuals who have had a stroke experience persistent dependency in one or more activities of daily living (ADL) six months post stroke, and one-half of elderly stroke patients suffer permanent loss of function. Statistics show 40% of patients who survive six months post stroke will require help with one or more ADL's such as bathing, dressing, feeding and mobility (Wade, 1992).

An individual who has had a stroke can remain at home for months or years, causing financial stress and loss of social life for the caregiver (Wade et al., 1986). Homecare produces physical stressors on the caregiver from such activities as lifting and transferring, as well as mental stressors caused by sudden changes in life style (Braithwaite & McGown, 1993). Negative aspects of caregiving for stroke survivors reported by Silliman et al. (1987), stemmed from changes that caregiving had made in the caregivers lifestyle. These changes occurred as a result of changes in the patients' personality, behavior and cognitive functioning and physical limitations. Evans, Leith-Matlock, Bishop, Stranahan & Pederson (1988) reported that family dysfunction can result directly or indirectly from stroke related problems with disruption occurring in usual coping mechanisms, communication patterns and social roles. Because of these disruptions, emotional disorders characterized by anxiety, depression and fatigue are common among caregivers of stroke and dementia patients (Draper et al., 1992).

As previously stated, there are approximately one million individuals who survive a stroke with a disability each year (Hickey, 1992). Many of these individuals will remain in their homes or reside with a family member, requiring the family member to assume all or part of their care needs. By studying the impact of perceived burden, in relation to caregivers of an individual who has had a stroke, nursing interventions can be developed that decrease the amount of burden perceived and experienced. The advanced practice nurse (APN) as well as other health care providers need to know what effects a stroke has on the primary caregiver, in order for appropriate interventions to be developed. The purpose of this study is to describe the psychosocial, and physical impact of caring for an individual who has had a stroke on the family caregiver.

Research Question

What is the perceived impact of caregiving (psychosocial and physical) experienced by family caregivers of individuals who have had a stroke?

CONCEPTUAL FRAMEWORK

An adaptation of the basic stress coping framework (XYZ Model) is utilized to describe the effects of caring for an individual who has had a stroke, as perceived by the caregiver. This model has three primary elements, potential activator(s) (X), a reaction (Y), and the consequences or responses to the reactions (Z) (Beigel, Sales & Schulz, 1991). Potential activators are events that change an individual's current state or lifestyle. Reactions are considered responses to the activator and may be intense enough to produce consequences. Reactions are usually biological or psychosocial. Consequences are considered to be the cumulative effects from the reaction (Biegel et al., 1991).

The potential activator (x) in this study occurs when an individual has a stroke, and requires homecare. This occurrence produces a reaction, that of taking on the

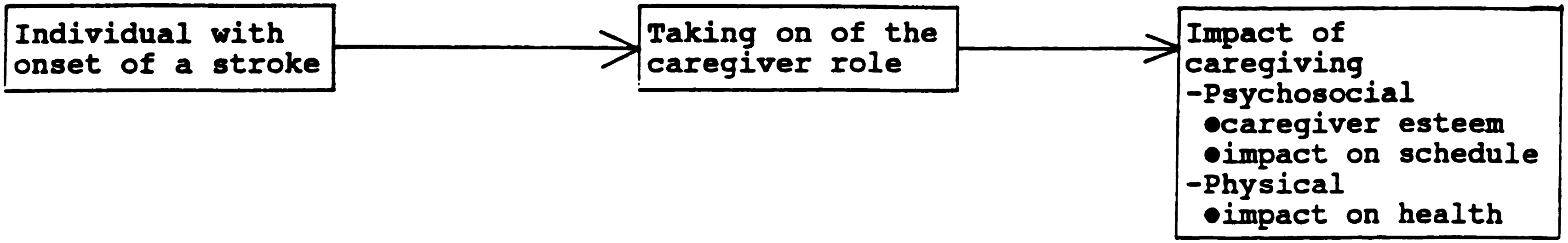

Figure 1: Conceptual model of the caregiving process, indicating the effects that are produced when taking on the caregiver role for an individual with a stroke.

caregiver role (Y). The effects of this reaction are seen in the consequences (Z). Consequences are the perceived effects that the caregiver role has on the caregivers' physical and psychosocial health.

CONCEPTUAL DEFINITION OF VARIABLES

Caregiver Burden

The term caregiver burden has been used in many studies to describe the effects of caregiving on the care provider. Dillehay and Sandys (1990) defined burden as a psychological state. The combination of physical work, emotional pressure, social constraints, and financial demands resulting from caregiving requirements produces the psychological state of burden. Beigel, Sales, and Schultz (1991) describe burden as a subjective state reflecting the perceptions of individual caregivers.

Montgomery, Gonyea, & Hooyman (1985) distinguish between objective and subjective burden this way - objective burden reflects disruptions or changes in the caregivers' life, while subjective burden reflects the caregivers' attitudes and/or emotional reactions toward the caregiving experience. Objective burden is reflected in changes to personal freedom, amount of privacy and time caregivers had for themselves.

Given & Given (1991), defined burden as a biopsychosocial reaction that results from an imbalance of demands, relative to available resources. Given, et al. (1988) earlier defined burden as reactions to caregiving.

These reactions are the individuals perceptions of caring for an individual, including the impact on their schedule, finances and health that result from an imbalance of demands on available resources. Given & Given (1995) further refined their definition of caregiver burden to state that caregiver burden "is a multidimensional biopsychosocial reaction resulting from an imbalance of care demands and requirements relative to physical, social, emotional, and financial resources available to the individual providing care and support to a family member" (p. 7).

For the purpose of this study, caregiver burden is defined as an individuals perception of the psychosocial and physical impact that caregiving has produced. The aspects of psychosocial and physical will be further defined in the following sections.

Psychosocial Impact

The psychosocial impact of caregiving can be seen as caregivers' decrease personal time, social activities and hours at work in response to the caregiving role. Some caregivers may resign from their jobs due to the demands of caregiving. Psychosocial effects can also be seen as caregivers expressed feelings of frustration, guilt and/or anger which develop in relation to their caregiving role.

Grafstrom, Norberg and Hagberg (1993) cited that limitations on social and personal activities are frequently reported when an individual assumes care for a frail elderly relative. Yaffe (1988), Stoller (1983), George and Gwyther

(1986) and Killeen (1990) have reported caregivers suffer a negative impact on their social life as a result of caregiving.

Impacts on employment status have also been reported. Barnes, Given and Given (1995) reported employed daughters have conflict with their roles, and approximately 12-21% of daughters will terminate employment, and approximately 11% of all caregivers will quit work in order to provide care for an elder (Stone, Cafferta & Sargl, 1987). Feelings of frustration, guilt, anger, resentment and family strain have been reported as a result of the competing demands of family, job and caregiving (Pett, Caserta, Hutton & Lund, 1988).

As cited above, one can see how caregiving can have varying psychosocial effects on the caregiver. The effects can be seen as changes in employment status, personal time, and amount of time spent with others. The dimensions of psychosocial impact, for the purpose of this study is defined as the perceived impact on the caregivers' social life, employment status, daily schedule and on their self esteem.

Physical Impact

The physical impact of caregiving on caregivers has been reported in several studies (Given et al., 1988; Gaynor, 1990; Killeen, 1990; Young & Kahana, 1989). Killeen (1990) reported that the most frequently mentioned physical problems associated with caregiving by caregivers were hypertension and an increase in frequency of illnesses. Other physical problems mentioned were intestinal irritability, weight loss or gain, an increase in cigarette use and arthritis. Gaynor (1990) and Given et al. (1988) mentioned complaints of arthritis and hypertension in relation to caregiving. Young and Kahana (1989) reported fatigue and health deterioration as physical effects of caregiving.

The physical impact of caregiving is perceived by many caregivers, as evidenced by complaints of physical illnesses, such as, arthritis and hypertension or as complaints of fatigue or the increase in frequency of illnesses. For the purpose of this study it is this perceived physical effect that will be addressed. The physical impact of caregiving is defined as the individuals perception of the impact caregiving has had on their physical health.

REVIEW OF LITERATURE

Studies over the past decade conducted on family caregivers have shown that caregivers experience effects on their personal and social life, physical and mental health, and financial resources (Sayles-Cross, 1993; Ballie, Norbeck & Barnes, 1988; Gaynor, 1990; & Covinsky et al., 1994). However, none of these studies have looked specifically at caregivers of an individual who has had a stroke. As the incidence of individuals who survive a stroke increases, there develops a need to study the effect caregiving has on caregivers of this population. Recently, a few studies have been published that address caregiving in relation to individuals who have had a stroke (Brandriet, Lyons & Bently, 1994; Davis & Grant, 1994; Stroker, 1983; Draper et al., 1992; Schulz, Tompkins & Rau, 1988). The following sections review pertinent literature found on family caregivers and caregivers of stroke patients in relation to caregiver burden. The studies reviewed address both the psychosocial and physical impact of caregiving.

Family Caregivers

Clipp & George (1990) investigated the needs of caregivers in relation to patterns of social support. In a Duke University Family Support Program 510 family caregivers were surveyed in two phases, one year apart, using a questionnaire which addressed social support, predictors of social support, economic resources, physical and mental health, social and recreational activities and characteristics of the caregiving context. Reliability and validity of the tool was not reported. Findings in this study indicated caregivers who provide full time care have the greatest need for support. In addition, caregivers with the least amount of support, the oldest in the sample, came from larger households and were supported by the lowest incomes. These caregivers admitted to more symptoms of stress and received the least amount of assistance as compared to others caregivers in the sample. However, these caregivers perceived their financial security as good.

Ballie et al. (1988) looked at the effects of perceived caregiver stress and social support on the psychological distress of family caregivers. The sample for this study consisted of 87 family caregivers who provided care in their own home or in the elders home without pay. The investigators found the variables of mental condition, levels of functioning, hours of care needed and total years of caregiving contributed to the caregivers perceived stress. The perceived stress of caregiving was measured by a sixteen item, Likert type questionnaire developed for their study. The standardized alpha test for internal consistency reliability for the study sample was .90. Caregivers who had low social support and had been providing care for an extended time period were at higher risk for psychological distress and/or depression.

Sayles-Cross (1993) looked into perceptions of family caregivers and found that the more caregivers held back from what they wanted to do most, the more disgusted and angry they felt. Caregivers perceived caregiving as a threat to their self esteem, health and well-being, and coped with their caregiver role by decreasing the amount of time spent on personal activities. Sayles-Cross (1993) utilized five self-reported instruments in collecting data, the Age Social distance Scale (alpha .83), the What's at Stake Scale (alpha .80 - .82), the Emotions Scale (alpha .85 - .86), the Cost of Care index (alpha .92) and a research designed demographic inventory. The sample consisted of 139 non-paid familial caregivers in which the majority where adult child and spouse caregivers.

Abraham and Berry (1992) investigated the needs of family caregivers. The sample consisted of 40 family caregivers who were interviewed in their home using a questionnaire developed for the study. The reliability and validity for this tool was not reported. In this study 44% of the caregivers gave an extra three hours or more daily, beyond their daily routines, in delivering care to a relative. This extra time restricted their personal freedom and impacted on their daily schedule requiring them to rearrange their schedule in order to meet the needs of the care recipient.

Similar to the studies by Sayles-Cross (1993) and Abraham and Berry (1992), Killeen (1990) found caregivers felt anger and resentment toward their caregiving role. The more the caregivers personal or free time decreased, the more the amount of perceived stress increased. In addition, Killeen's (1990) study of 126 family caregivers who provided care in the home for a frail elder 65 years of age or older revealed younger caregivers were more likely to experience more stress in their roles than older caregivers. The perceived Stress Scale (Cronbach's alpha .84), the Jalowiec Coping Scale (Cronbach's alpha .72) and the Current Health Scale (Cronbach's alpha .92) were used to measure the variables within this study. In relation to the impact on physical health, Killeen (1990) reported caregivers tended to perceive their own health as less positive. The most frequently identified physical problems were high blood pressure and an increase in frequency of illnesses. Other problems identified were cancer, intestinal irritability, arthritis, weight loss or gain, and an increase in cigarettes smoked.

Gaynor (1990) found the most common illness mentioned by caregivers to be arthritis and hypertension. Gaynor (1990) studied the patterns of illness symptoms in elderly female caregivers and the relationship of those symptoms to age and caregiving role. A convenience sample of elderly women who were either long-term, short-term or noncaregivers was utilized. Long-term caregivers cared for husbands with disabling neurological illness e.g. Parkinsons, Multiple Sclerosis, etc. Short-term caregivers had husbands who had a transurethral prostectatomy for a nonmalignant condition within the past 12 months prior to the study. The Zarit Burden Scale, to assess the subjective feelings of health, psychological well being, financial and social status and the nature of the relationship between the caregiver and the care recipient, and also the Structural Model of Self-Reported Physical Health scale was used to measure the subjective ratings of the caregivers own health. Gaynor (1990) found no difference between the three groups of caregivers in relation to the amount of medication taken, ill days and caregiver hospitalized days. This study did find women younger than 54 years of age experienced higher feelings of burden, however, this group of women had performed in their role as caregiver for a longer period of time.

Baumgarten, Battista, Infante-Rivard, Hanley, Becker and Gauthier (1992) studied 125 demented patient caregiver dyads compared with 115 cataract patients (non caregivers) to determine whether there is an excess of psychological and physical health problems among family caregivers of elderly persons with dementia. Tools utilized by these investigators were the Center of Epidemiologic Studies Depression (CESD) scale, the Aday and Andersen's checklist used to quantify physical symptoms, a checklist from the Older Americans Research and Services questionnaire, Olson and colleagues inventory of family coping strategies, Cutrona and Russel's Social Provisions Scale and the Louisville Older Person Events Scale. Results indicated that the caregivers had lower levels of well-being on all measures of psychological and physical health status. The most common physical symptoms reported by caregivers were persistent cough, persistent fatigue, chest pain, headache and morning fatigue. Caregivers who reported the highest levels of depression and physical symptoms cared for individuals who had greater degrees of functional impairment and behavioral disturbances.

The financial impact of caregiving was the basis of a study by Covinsky et al. (1994). The purpose of this study was to examine the impact of illness on the families of seriously ill adults and to determine the correlates of adverse economic impact. The sample consisted of 2661 seriously ill patients who survived their initial hospitalization and were discharged home. The family was interviewed about the impact of the patients illness on the family members. Questions about both the financial impact of the illness and the caregiving burden for family members were administered at two and six months following hospital discharge. Covinsky et al. (1994) found families needed to make major life changes and were unable to function normally because of the stress of the care recipients illness. Thirty-one percent of the families reported losing most of their savings, while 29% reported losing their major source of income. The costs of the illness required 17% of the families to change their personal plans.

Differences in burden experienced by spousal caregivers and adult child caregivers have been reported. Given et al. (1988) using the Caregiver Reaction Assessment (alpha coefficients .66-.89), studied 87 family caregivers who were providing care for persons over the age of 60. Findings indicated that adult child caregivers expressed less positive reactions and perceived a greater impact on their health then spouse caregivers. The most common reported health problems were heart disease, hypertension and arthritis. Caregivers in this study reported they devoted an average of fifteen hours per day toward caregiving activities and that they performed these activities with little assistance.

Young and Kahana (1988) compared spouse and non-spousal caregivers, using an instrument that was constructed from several validated measures. These were the Symptom Checklist (Cronbachs alpha .94), Multilevel Assessment Inventory (Cronbachs alpha .93 and .74), Burden Inventory (Cronbachs alpha .94), and the Social Support Index (Cronbachs alpha .84 and .61). Findings indicated daughters perceived a significantly greater negative impact and were more likely to report they had experienced a deterioration in their health as a result of providing care. Daughters reported higher burden scores and higher scores representing a decline in physical health than did the wives and husbands. The sample for this study was comprised from 183 older patient-caregiver dyads, 63% were spouses and 52% of the non-spouse caregivers were children.

The effects that caregiving has on a family caregivers psychosocial and physical health, as well as finances, is evident in current literature. The literature indicates caregivers report an increase in physical illness (i.e. hypertension) and/or a decline in their perceived physical health. It is also known that caregivers feel an impact on their schedules causing them to decrease their personal time and/or decrease their hours at work in order to meet the demands of caregiving. What is not known is whether caregivers of stroke patients experience and perceive the impact of burden the same as caregivers of groups with other illnesses and disabilities. In summary the studies reviewed have failed to address the population of caregivers for an individual who has had a stroke. This population needs to be addressed separately in order to determine if the effects are the same or different from caregivers of individuals with alzheimers and/or cancer. In the following section the literature reviewed is specific to stroke caregivers.

Family Caregivers of an Individual who has had a Stroke

Caregiver studies on caregivers of an individual who has had a stroke are very limited. Some investigators have examined the effects on the caregiver of a stroke survivor in relation to the termination of home care services (Brandriet, Lyons & Bentley, 1994; Mclean, Roper-Hall, Mayer & Main, 1991). Few researchers have addressed the impact of caregiving on caregivers of an individual who has had a stroke (Stroker, 1983; Wade, Legh Smith, Langton-Hewer, 1986; Draper et al., 1992; Davis & Grant, 1994). These researchers address the psychosocial and physical impact on the caregiver, however, none of them attempt to address the caregivers perception of the effects caregiving has had on their lives.

A pilot study by McLean, Roper-Hall, Mayer, and Main (1991) looked at the service needs of post stroke care recipients and their family caregivers. The sample for this study consisted of 20 post stroke care recipient/caregiver dyads who were assessed using the Clifton Assessment

Procedure for the Elderly. This tool was used as an objective measurement of the disability of the stroke care recipient. Anxiety and depression was measured using the Hospital Anxiety and Depression Scale. Mclean et al. (1991) found that the caregivers needs resulted from their inability to meet the basic care needs of the care recipient. This was due to the caregivers lack of information or ability to perform certain care tasks. Mclean et al. (1991) also found caregivers perceived that their physical health was adversely affected. Sleep was often interrupted by caring needs resulting in fatigue. Other physical complaints made by caregivers were backache and weight loss. All caregivers reported weeping at times and the feeling of being tied down was reported by seven of the caregivers.

Brandiet et al. (1994) studied the unmet needs, biopsychosocial problems and strategies for coping as perceived by elders following the termination of skilled home care services. A convenience sample of 20 subjects who had been diagnosed with a stroke were utilized. A semistructured interview using questions developed by the investigators was used to gather data. Many of the caregivers became overwhelmed with the skill, time and intensity needed for the provision of care. They identified unmet needs in relation to household tasks, lack of finances, nutrition and safety. Frustration was reported by both caregivers and stroke care recipients. This frustration resulted from physical and cognitive deficits in mobility, speech, memory, reading, thinking and decision making skills.

Evans, Bishop, and Haselkorn (1991) in their study of 135 stroke patients and their families found four variables that when combined helped to predict satisfactory homecare for the stroke patient. The variables are, 1) caregiver perception of family function; 2) level of caregiver depression immediately following the stroke; 3) marital status; and 4) caregiver knowledge of stroke care principles. All of these variables contributed to a successful homecare experience. Families who had satisfactory home care experiences, one year post stroke, were less likely to have been depressed initially, were more knowledgeable about stroke at time of discharge from the hospital, reported healthy family function and were the patients spouse. The investigators utilized several different tools in their study: depression was measured by the Center for Epidemiologic Studies - Depression scale; patient cognition was measured with the Cognitive Capacity Screening Exam; outcomes were measured by the ESCROW profile; caregiver knowledge of stroke care was measured with the Stroke Care Information Test; and the Family Assessment Device measured family functioning. The reliability and validity for these tools were not reported.

Using a qualitative analysis approach grounded in social construction theory, Davis and Grant (1994), explored the management strategies of eight family caregivers use to solve home care problems. Caregivers in this study cited problems with care activities such as lifting, transferring and bathing, due to the patients functional losses that resulted from the stroke. Caregivers also cited frustrations with the patients cognitive and emotional losses associated with the stroke. One caregiver stated "Her thinking is slower...She doesn't remember a lot of things...She has to write things down now..." (p. 70). Caregivers also cited problems with access to services and/or costs of care. "You see, I need some nurses for 12 hours a day...I need someone part of the night and early in the morning...I can't lift him..." (p. 70), was reported by one caregiver. Another caregiver reported "The doctor recommended rehab, but without insurance we couldn't afford it...." (p. 70). Even though this study did not set out to describe the impact caregiving has on the caregiver, it does demonstrate some of the physical and financial impacts that can occur while caring for a stroke survivor.

Wade et al. (1986) found 25% of caregivers showed signs of depression one year post stroke. The patients' disability, caregivers' perception of recovery, patients' level of depression and their level of activities of daily living were factors which contributed to the caregivers' level of depression one year post stroke. At two year post stroke the investigators could not relate depression to any measure in the study, however the investigators did not cite if the level of depression experienced by the caregiver changed from one to two years after taking on the caregiver role. Wade et al. hypothesized, that caregiver depression was related more to the occurrence of the stroke rather than due to the physical stress of caregiving. Depression in caregivers was measured by the Wakefield Self Assessment Depression Inventory, and by asking direct questions about mood changes in relation to their state before the stroke.

In a study comparing 99 caregivers of stroke and dementia victims the General Health Questionnaire, Relatives Stress Scale, Behavior and Mood Disturbance Questionnaire, Barthel Index for Physical Disability, Quality of Life Questionnaire, Life Satisfaction Questionnaire and Caregiver Health Scale were used (Draper et al., 1992). Draper et al. (1992) found caregivers of both types of patients experienced similar degrees of burden and psychological morbidity. The majority (80%) of the caregivers in this study perceived their caregiver role positively and were satisfied with their current life. The stroke patients in this study demonstrated a higher level of physical disability then the dementia patients, while the dementia patients demonstrated higher levels of psychiatric disturbances. It should be noted that the investigators excluded subjects who had a stroke with resulting physical disability and dementia.

The studies cited in this section have revealed some of the effects caregivers of stroke patients may experience.

The psychosocial effect of depression, the physical effects of fatigue and weight loss, and the financial effects seen in the inability to pay for necessary rehabilitation services have been expressed by caregivers of post stroke care recipients. Many of the studies have not addressed the caregivers perceived effects of their role on their psychosocial and physical health status. These perceived effects need to be addressed in order for appropriate interventions to be utilized or developed that specifically reduce the amount of burden experienced by these caregivers.

METHOD

Design

This is a descriptive study which looks at the relationship of a known variable (caregiver burden) with an unknown population (stroke patients) (Brink & Wood, 1988). The question for this research study was addressed using secondary analysis of data from the study Caregiver Responses to Managing Elderly Patients at Home, funded by the National Institute on Aging (Grant #2, R01 AG06584-06), conducted by principal investigator Charles W. Given, Michigan State University.

Sample and Data Collection

The sample for this study was derived from the sample utilized in the study of caregivers responses to managing elderly patients at home. The original study used a convenience sample, in which 1,238 cases were contacted, and 839 met eligibility. Forty-two of the eligible sample met criteria for this study. Eligibility criteria are: 1) the individual had to have been classified as having a stroke; 2) have a designated family caregiver assisting them at home; and 3) meet the eligibility criteria of the original study (Appendix A). The sample was recruited from 27 hospitals around the state of Michigan, including one in the Upper Peninsula. Recruitment was done by discharge planners employed by the hospitals and graduate medical students from Michigan State University (Pohl, Given & Given, 1991). Patients and caregivers were screened within two weeks of discharge, and one intake interview of the primary caregiver was administered ten days later. A second caregiver interview was conducted 3 months following the intake interview. Data was collected by trained telephone interviewers and from a self administered booklet (SAB) (see Appendix B) (Darin, Pohl & Given, 1993).

Instrumentation

The Caregiver Reaction Assessment (CRA) assesses the reactions of family members caring for elderly persons with physical impairments (Given, Given, Stommel, Collins, King & Franklin, 1992). This instrument consists of five subscales, each addressing a specific area of perceived effects or reactions produced by caregiving. Caregivers esteem, impact on schedule, impact on health, impact on finances and lack of family support are the areas addressed by the CRA. Three subscales are used for this study: caregiver esteem; impact on schedule; and impact on health.

The lack of family support subscale was excluded for it was felt by the investigator that it measured an external rather than internal component of burden. Impact on finances subscale was not utilized for this study due to the lack of available data. Each subscale is utilizes a five point Likert-type response, ranging from strongly agree to strongly disagree (1=strongly disagree, 2=disagree, 3=neither agree or disagree, 4=agree, & 5=strongly agree).

Caregiver esteem and impact on schedule is used to measure the psychosocial impact of caregiving. Impact on schedule (Cronbachs alpha .82) has five questions which address employment, changes in schedule and impact on changes in visiting with family and friends, and measures the extent to which caregiving causes interruptions in or elimination of activities and interferes with relaxation time (Given et al., 1992). Caregiver esteem (Cronbachs alpha .90) includes seven items that address the individuals feelings regarding the care situation and measures how much caregiving imparts individual self-esteem (Given et al., 1992).

The impact on health subscale (Cronbachs alpha .80) is utilized to measure the physical impact of caregiving. This subscale consists of four items which are used to address the individuals' perceptions of how their physical strength and health have been effected by taking on the caregiving role. This subscale measures the physical capabilities of the caregiver and his/her strength to provide care (Given et al., 1992).

Operational Definition of Variables

Caregiver Burden:

Caregiver burden is defined as an individuals perception of the psychosocial and physical impact of caregiving. The aspects of psychosocial and physical impact will be measured by using questions from the caregiver reaction assessment (see Table 1 for break down of questions by subscale). Data for impact on schedule, caregiver esteem and impact on health will be taken from data collected during wave 1 of the original study. Scoring will be done by comparison of means for each subscale.

Stroke:

A stroke is defined as events that follow the blockage or occlusion of a major vessel(s) in the brain or feeding the brain. Events can result from partial or complete obstruction to a major intracranial vessel, an intracerebral hemorrhage including bleeds that occur from an arteriovenous malformation (AVM) or an aneurysm (subarachnoid hemorrhage), (Marshall, Marshall, Vos & Chestnut, 1990). All patients who were self classified and/or classified by the original investigators as having a stroke will be utilized. In the original study diagnoses were classified using the International Classification of Diseases categories.

Table 1: Breakdown of Questions by Subscale

1. Impact on schedule
    - a. I have to stop in the middle of my work or activities to provide care.
    - b. I have eliminated things from my schedule since caring for_________.
    - c. My activities are centered around care for ______.
    - d. I visit family and friends less since I have been caring for __________.
    - e. The constant interruptions make it difficult to find time for relaxation.
2. Caregiver Esteem
    - a. I feel privileged to care for ___________.
    - b. I really want to care for ____________.
    - c. I enjoy caring for ______________.
    - d. Caring for ___________ makes me feel good.
    - e. I will never be able to do enough caregiving to repay __________________.
    - f. Caring for _______________ is very important to me.
3. Impact on Health
    - a. It takes all my physical strength to care for ___________.
    - b. I am healthy enough to care for ____________.
    - c. My health has gotten worse since I've been caring for _______________.
    - d. Since caring for ______________, it seems like I'm tired all of the time.

Family Caregiver

A family caregiver is defined as the individual who assumes the caregiving role for a relative who has had mental and/or physical disabilities resulting from a stroke.

Data Analysis

Data analysis was done by using SPSS/PC+. Descriptive statistics, i.e. frequency, means and percentages were utilized to determine the individuals perceived effects of caregiving. Descriptive statistics were used to answer questions regarding impact on psychosocial health and physical health. Demographic statistics were utilized to determine caregiver characteristics at the onset of the caregiving experience. Characteristics such as age, gender, relationship to the individual who has had the stroke, employment, marital status, income and number of hours used in providing care were utilized. Patient characteristics that were addressed using demographic data were age, marital status and the functional ability or physical health of the individual.

Protection of Human Rights

All methods to protect human rights that were utilized in the original study were maintained. Anonymity was maintained due to lack of access to all identifiers. All subjects had their confidentiality safeguarded through the assignment of an identification (ID) code number. The responses of all study participants remained confidential.

Signed consents were obtained by the original investigators (See Appendix C for consents and approval letters).

RESULTS

Demographic Variables

Table 2 describes the caregivers in this study by sex and relationship to patient. The majority of the caregivers in this sample were female (n = 36, 85.7%). Spouses comprised the majority (n = 29, 69%) in regards to family relationship to the patient.

Table 3 describes the caregiver by age and marital status. The caregiver mean age was 59.9 years, with a minimum age of 34 years and a maximum age of 84 years. The majority of the caregivers were married (n=36, 85.7%) the remaining caregivers were either single, never married, divorced or widowed.

Table 4 describes the caregivers in this study according to employment status and income. The majority of the caregivers in this sample (n=17, 40.5%) were retired. The remaining caregivers were either employed full or part-time, layed off, in between jobs or not employed for pay. One caregiver, in this sample, had to quit work in order to provide care. The average income for the caregivers was $27,236, with a range of $3,000 to $62,500.

Table 2: Frequency and percent of caregivers described by sex and relationship to patient (n=42).

Variable	Number	Percent
Sex		
Male	6	14.3
Female	36	85.7
Relationship To Patient		
Spouse	29	69.0
Daughter	12	28.6
Granddaughter	1	2.4

Table 3: Frequency and percent of caregivers by age and marital status (n=42)

Variable	Number	Percent
Age		
39 or <	2	4.8
40 - 49	6	14.3
50 - 59	9	21.5
60 - 69	18	42.8
70 - 79	6	14.3
80 or >	1	2.4
Marital Status		
Single, Never Married	2	4.8
Married/Remarried	36	85.7
Divorced	2	4.8
Widowed	2	4.8

Table 4: Frequency and percent of caregivers by employment status and income (n=42)

Variable	Number	Percent
Employment Status		
Fulltime	8	19.0
Parttime	2	4.8
Retired	17	40.5
Layed Off/betw jobs	6	14.3
Not employed for pay	8	19.0
Quit work to care	1	2.1
Income		
$9,999 or <	5	14.7
$10,000 - $19,999	14	41.2
$20,000 - $29,999	5	14.7
$30,000 - $39,999	4	11.8
$40,000 - $49,999	3	8.8
$50,000 or >	3	8.8
Missing	4	9.5

Table 5 describes the total hours of care provided per day by the caregiver. Caregivers provided 14.3 mean hours of care per day, with a range of .00 to 24 hours of care.

Table 6 describes the patient demographic data, age, sex and marital status. The mean age of the patients is 70, with a range of 55 to 89. The majority of the patients were married (n=31), the rest were either widowed, divorced or separated.

Table 7 describes the functional status of the patient. Functional status was determined by dependencies in Activities of Daily Living (ADLS) and Instrumental Activities of Daily Living (IADLS). ADLS consisted of items such as dressing, bathing, feeding, and toileting. IADLS

Table 5: Hours of care provided by the caregiver by number and percentage of caregivers.

Variable	Number	Percent
Hours of Care		
0 - 3	6	14.3
4 - 6	6	14.3
7 - 9	3	7.2
10 - 12	3	7.2
13 - 15	0	0.0
16 - 18	7	16.7
19 - 21	5	11.9
22 - 24	12	28.6

Table 6: Selected patient demographics by number and percentage (n=42)

Variable	Number	Percent
Age		
50 - 59	6	14.4
60 - 69	17	40.6
70 - 79	13	31.1
80 - 89	6	14.4
Sex		
Male	25	59.5
Female	17	40.5
Marital Status		
Married/Remarried	31	73.8
Divorced	1	2.4
Widowed	9	21.4
Separated	1	2.4

Table 7: Dependency in number of ADLS and IADLS by number and percentage of patients and caregiver rating of the patients health status.

Variable	Number	Percent
# of Dependencies in ADLS		
0	7	16.7
1	3	7.1
2	3	7.1
3	3	7.1
4	3	7.1
5	8	19.0
6	15	35.7
# of Dependencies in IADLS		
0	0	0.0
1	1	2.4
2	0	0.0
3	2	4.8
4	1	2.4
5	6	14.3
6	32	76.2
Rating of Patients Health Status		
Good	13	31.0
Fair	14	33.3
Poor	14	33.3
Missing	1	2.4

consisted of such items as, cooking, housework, shopping and laundry. The average number of dependencies in ADLS was 3.8 out of 6 and in IADLS was 5.5 out of 6. The majority of the caregivers rated the patients health as fair or poor.

Research Question

The purpose of this study was to describe the perceived impact of burden (psychosocial and physical) on caregivers of an individual who has had a stroke. Three sub-categories of the CRA were utilized. Caregiver esteem and impact on schedule were used to measure impact on psychosocial health. The impact on health subscale was used to measure the physical impact of caregiving.

Table 8 describes the range of mean scores obtained for each subscale of the CRA, caregiver esteem, impact on schedule and impact on health. The CRA utilized a five point likert type scale in which 1=strongly disagree, 2=disagree, 3=neither agree or disagree, 4=agree and 5=strongly agree. Two of the questions under the impact on health subscale were reversely scored, it takes all my physical strength to care and I am healthy enough to care. Overall the caregivers had a mean score of 3.8 (sd = .94) in the area of impact on schedule, 4.0 (sd = .62) for esteem and 2.4 (sd = .79) for impact on health.

Incidental Findings

In addition to looking at the caregiver group as a whole, the investigator also compared the mean scores for each of the CRA subcategories for spouse and nonspouse caregivers, employed and non-employed caregivers, male and female caregivers, living arrangements between the caregiver and the patient and patient functional ability to see if there was any difference in the perceived impact of caregiving between either of these groups (see Table 9).

Overall the mean scores for each of these groups were consistent with the average scores for all of the caregivers

Table 8: Number and percentage of caregivers according to scores on CRA subscales: Caregiver Esteem, Impact on Schedule and Impact on Health (n=42)

Variable	Number	Percent
Esteem		
1.00 - 1.99	0	0.0
2.00 - 2.99	0	0.0
3.00 - 3.99	23	54.7
4.00 - 4.99	15	35.8
5.00	4	9.5
Schedule		
1.00 - 1.99	1	2.4
2.00 - 2.99	6	14.4
3.00 - 3.99	13	31.1
4.00 - 4.99	16	38.1
5.00	6	14.3
Health		
1.00 - 1.99	10	23.9
2.00 - 2.99	24	57.1
3.00 - 3.99	7	16.6
4.00 - 4.99	1	2.4
5.00	0	0.0

Table 9: Comparison of type of caregiver by mean score for subcategories of CRA.

Caregiver	Esteem	Schedule	Health
Spouse (n=29)	3.9 (sd .59)	3.8 (sd .84)	2.4 (sd .85)
Daughters (n=12)	4.1 (sd .65)	3.8 (sd 1.19)	2.2 (sd .64)
Employed (n=10)	3.8 (sd .48)	3.8 (sd .99)	2.4 (sd .83)
Non-Employed (n=32)	4.0 (sd .66)	3.9 (sd .94)	2.4 (sd .79)
Male (n=6)	4.6 (sd .50)	4.0 (sd 1.10)	2.2 (sd .95)
Female (n=36)	3.9 (sd .58)	3.8 (sd .93)	2.4 (sd .77)
Live Together (n=38)	4.0 (sd .63)	3.9* (sd .90)	2.4 (sd .87)
Live Apart (n=4)	3.9 (sd . 63)	3.2* (sd 1.18)	2.2 (sd .55)
Dependent in 3 or less ADLs (n=16)	3.8 (sd .62)	3.1* (sd 1.00)	2.2 (sd .76)
Dependent in > 3 ADLS (n=26)	4.1 (sd .61)	4.3* (sd .54)	2.4 (sd .82)
Dependent in 3 or less IADLS (n=3)	3.6 (sd . 32)	2.7* (sd .61)	2.3 (sd .43)
Dependent in > 3 IADLS (n=39)	4.0 (sd .63)	4.0* (sd .90)	2.4 (sd .82)

(* Chi Square = $p < .05$)

as a whole. The largest difference within these groups was found in the area of impact on schedule between caregivers of patients who were dependent in greater than three IADLS, and caregivers of patients who were dependent in less than three IADLS. Other areas in which a difference in mean scores is seen is in relation to the living arrangements, and dependency in ADLS when looking at the impact on schedule subscale. Difference were also seen in the area of caregiver esteem between spouses and daughters and male and female caregivers.

A Chi-square was performed on each of the areas in which a difference was seen in mean scores in order to determine if there was any significance between the variables. In relation to impact on schedule a statistical significance was found between living arrangements, dependency in ADLS and dependency in IADLS ($p < .05$). There was no statistical significance found in relation to caregiver sex or relationship to patient and caregiver esteem ($p > .05$)

DISCUSSION

From the findings in this study a profile of a caregiver for an individual who has had a stroke can be developed. This profile is one of a female spouse, over the age of 55, who is unemployed or retired with a income less than $30,000 per year. This caregiver provides sixteen or more hours of care per day for an individual who is dependent in most or all of their ADL's and IADL's.

Some of the characteristics of this caregiver is consistent with caregivers from other groups found in the literature. The majority of the caregivers in this study were female, this is consistent with sample findings in other studies that look at caregiver burden (Given et al., 1988; Baumgarten et al., 1992). Also consistent with other studies included in the caregiver literature (Abraham & Berry, 1992; Covinsky et al., 1994) spouses and/or adult children comprised the largest percentage of the sample. The majority of the caregivers (57.2%) provided sixteen or more hours of care per day, indicating that this group of patients required a high level of care. This is also indicated in the finding that 90.5% of the patients were dependent in five to six IADLS and 54.7% of the patients were dependent in five to six ADLS.

In utilizing the XYZ model to look at the outcomes or findings of this study in relation to the perceived psychosocial and physical impact on health, one can see that the taking on of the caregiver role does produce a impact on the caregivers' psychosocial health. The caregiver esteem mean score of 4.0 (sd = .62) demonstrated that caregivers had positive feelings or reactions to their caregiver role. This subscale measured how the extent in which caregiving influenced or imparted esteem on the caregiver.

The caregivers identified a more negative reaction toward the impact on their schedule (m = 3.8, sd = .94). This subscale measured how much the caregiver felt caregiving influenced their personal time and ability to perform usual activities. A significant relationships was found between impact on schedule and dependency in ADLS and IADLS ($p < .05$). Caregivers who cared for an individual who was dependent in more than three ADLS and IADLS demonstrated the greatest impact. These patients probably required more care which resulted in a greater time requirement from the caregiver.

Significance was also found in the relationship between caregiver and patient living arrangement and impact on schedule ($p < .05$). Caregivers who resided with the patient reported the highest levels of impact in this area. Once again, this is probably related to the patients' health status and time required in caregiving. Patients who resided with the caregiver most likely required more caregiving activities than those who were able to live apart from the caregiver.

Impact on the caregivers physical health was not perceived as negative or positive ($m = 2.4$, $sd = .79$). The majority of the caregivers (81.0%) disagreed that their physical health had been affected by their caregiving role. The remaining caregivers (16.6%) did experience or agreed that their physical health had been impacted. This finding can possibly be attributed to the newness of the caregiving role. The data for this study were collected within three months from discharge from the hospital. In addition most individuals who have had a stroke experience more physical deficits than cognitive deficits. The ability for most of these patients to comprehend and communicate, either verbally or nonverbally, is still intact, this may decrease the negative effects of caregiving.

Limitations and Assumptions

This study is limited by the fact that it is secondary analysis of data. The small sample size prevents its generalization to all family caregivers of stroke patients. Another limitation includes the fact that this study did not take into consideration the effects that the patients' characteristics, caregivers' characteristics and prior relationship of the caregiver and patient had on the perceived effects of caregiving on the family caregiver. A final limitation is that the patient classification of stroke was one that was self-reported by the caregiver.

The XYZ model used as the conceptual framework for this study had advantages and disadvantages. The model which is linear in nature, allowed for a clear depiction of the events which produce a caregiving situation. From this line of events one can see how an impact on the caregivers physical and psychosocial health can develop.

However, due to the linear style of this model, influencing factors such as, living arrangements, financial status, social support systems, and caregiver/care receiver relationship are difficult to measure. Caregiving, actually is a multidimensional situation. In order to assess how each dimension influences and/or contributes to the caregivers reactions, a framework which takes a more multidimensional approach should be utilized. Possible frameworks which could have been utilized are: 1) the caregiving framework developed by Given, Collins & Given, 1988, or 2) a model based on the utilization of Family Systems Theory.

The following conclusions or assumptions can be made from this study: 1) family caregivers of an individual who has had a stroke do perceive effects on their psychosocial health; 2) these perceived effects are greater on the caregivers of patients who are dependent in three or more IADLS and three or more ADLS and on caregivers who reside with the patient; 3) family caregivers of an individual perceive a positive effect on their esteem versus a negative effect their schedule; and 4) family caregivers perceive neither a positive or negative effect on their health status.

Implications for Future Research

Due to the limited literature on caregiver burden in this population, this study was descriptive, however, this study does produce several possible directions for future research. Since this study did not take into consideration any specific patient and/or caregiver characteristics, and or the nature of the relationship between the caregiver and the patient prior to the caregiving relationship, additional studies may want to address the influence these factors have on the caregivers perceived impact of burden.

The focus of this study was on the beginning or onset of the caregiving role. Unlike patients with Cancer or Alzheimers, whose conditions deteriorate over time, individuals who have had a stroke may see no changes in their conditions or they may improve over time. It is important to look at how this can effect the perceived impact of caregiving. An assumption can be made that with improvements in the patients condition one would see a less negative effect on the caregivers schedule over time.

If the stroke patient's condition did not change over time would there be an improvement to the impact of the caregivers schedule, possibly attributed to the development of time management skills, or would there be an increase in the effect perceived on the caregivers health and esteem? Without longitudinal studies these assumptions and/or questions can not be answered. Longitudinal studies are needed to see how the perceived effects of caregiving are changed over time.

In addition, it is important to see how caregivers of an individual who has had a stroke compare with caregivers of other types of individuals. In comparing other groups, such as cancer patients and alzheimers patients, it is important to assess if the overall impact of caregiving varies and how. An assumption could be made that caregivers of individuals who have had a stroke and caregivers of an individual who has alzheimers both experience similar overall levels of burden. However, the influencing factors that produce the burden may vary, and the amount of impact on specific areas, i.e., schedule, physical health, and esteem may also vary. Only one study by Draper et al. (1992) has attempted to compare stroke caregivers with another population. Until more studies are done of this nature a true understanding of how the caregiving experience varies between groups of caregivers cannot be achieved.

Future research by also want to address if there is a difference between types of stroke patients. Some stroke patients suffer from more of a psychological effect, i.e., dementia versus a physical effect, i.e., hemiplegia. Many stroke patients develop aphasias, or difficulty with communicating. Some aphasia patients have an inability to understand or comprehend communication as well as an inability to communicate. Other aphasia patients may just have difficulty with speech but are able to comprehend. How does this effect the caregivers perception of burden. Does the age of the patient and/or the age of the caregiver at the onset of the stroke have an influence on the perceived burden and how much does socioeconomic status, education, support systems influence the amount of burden experienced. These questions need to be addressed through future research projects.

Another focus for future research is to utilize a larger sample size to see if similar results are produced. Sources that could be utilized to find individuals to participate in future studies could be 1) stroke caregiver support groups, 2) hospital rehabilitation units or rehabilitation centers, and/or 3) hospital stroke units - many hospitals recently have developed stroke units or specific stroke programs that specialize in the treatment of stroke patients.

Studies of this type and others mentioned above should help to generate nursing interventions for this population of caregivers. These interventions such as the development of 1) support groups, 2) respite services, 3) educational programs, and 4) legislation, should focus on decreasing the amount to burden experienced by the caregiver of an individual who has had a stroke.

Implications for Advanced Nursing Practice

Implications for the advanced practice nurse (APN) in primary care can be derived from the findings in this study. In addressing these implications the APN needs to utilize his/her different role characteristics. Implications for the roles of assessor, advocate, educator, planner, leader, clinician and researcher will be discussed. These implications can also be applied to other health care professionals who provide services to family caregivers as well.

The findings from this study suggests that family caregivers of an individual who has had a stroke tend to be female spouses over the age of 60. As an assessor the APN is responsible for the identification of data, subjective and objective, that may influence the patients health status. In collecting subjective data from this group of individuals, especially older female clients, the APN needs to include in the assessment specific home and social factors. Specific questions the APN may want to address are: is this individual a caregiver and to whom; what is the caregiving situation like; how does she perceive the situation and its effects on her health; does she have assistance; and how much and what type of care is required? Objectively the APN needs to assess the caregiver for possible physical and/or psychological effects of caregiving i.e. hypertension, fatigue, depression and/or anxiety.

The APN also needs to be aware of the impact on the caregivers schedule that is produced by the caregiving situation. This study found caregivers care for very dependent individuals and that this dependency negatively influenced the caregivers schedule. This impact may prevent the caregivers ability to seek health care for themselves, and may make it difficult for them to bring the care receiver in for necessary health care visits. Gaynor (1990) suggest that home assessments and checkups done by nurse practitioners may ease some of the burden. Abraham and Berry (1992) also recognize the importance of in home monitoring of the caregivers health when they are unable to make a regular appointment.

In home monitoring does not only allow for the meeting of specific health care needs, it also allows the APN to better assess the home environment and to see how the caregiver deals with some of the specific demands of caregiving. This assessment can allow the health care professional to have a better understanding of that caregivers specific situation and allow for the development of specific and individualized interventions.

The APN in primary care needs to do a continuous assessment of the caregiving situation. This continual assessment is needed in order to pick up changes in the caregiving situation that may occur over time and have an impact on the caregivers health status. This assessment may need to occur when the caregiver brings the care recipient in to be seen due to the amount of time required in caring for this individual and the impact that is felt by the caregiver on his/her schedule. An assessment of the caregivers social support system is also essential.

Once the assessment is made the APN as a planner, can collaborate with the family caregiver to develop a goal directed plan of care. The overall goal for this plan should be the maintenance and/or achievement of outcomes that promote the health status of the individual, and decrease the negative effects caregiving has on the caregiver. The plan needs to take into consideration the caregivers socioeconomic status, support systems and hours needed in the provision of care. Findings from this study indicate that caregivers for an individual who has had a stroke come from lower income households and provide many hours of care to very dependent individuals.

The APN as a planner may also assist in or independently develop programs to assist the caregiver. Based on the findings from this study programs focused on the teaching of time management skills and also the development of programs for the purpose of respite care would be important. Both of these programs hopefully would help to decrease the amount of impact on the caregivers schedule. Also by teaching and/or providing these services the caregiver over time would continue to have positive effects on their esteem and effects on their physical health would be minimized. Other programs could be developed that focus on caregiver support, education of other health care providers, and education of caregivers.

This plan of care may require the APN to utilize the role of advocate. The role of advocate is based upon a relationship that promotes mutuality and empowers the client. Through this relationship, the APN can assist the individual in identifying their rights and abilities as a caregiver. Resources can then be identified that can assist the family caregiver in his/her role. These resources can include community support groups, local or national associations for caregivers, and respite programs.

Through the role of educator the APN can assist the family caregivers of stroke and nonstroke patients, in learning skills that may be required for caregiving as well as educating in regards to available resources. The specific skills required by family caregivers were not addressed by this study, however, many of the family caregivers in this study, as well as caregivers for other individuals, may be required to perform tasks that are usually performed by health care professionals. These tasks may influence the caregivers perceived impact of burden, due to a lack of knowledge regarding necessary skills or tasks they may be asked to provide. Also as an educator the APN can increase the caregivers knowledge and awareness to the effects of a stroke and how this may impact the care they provide.

The APN could develop educational programs that address specific tasks of caregiving, i.e., lifting, transferring, bathing and dressing as well as teaching the caregivers how to manage time, balance a check book, pay bills and/or do minor home repairs. Many of the caregivers in this study are older women caring for their husbands. Many of whom never had to worry about paying the bills or fix a leaky faucet. This lack of knowledge can attribute to the amount of burden perceived by the caregiver. Programs specifically focused on these areas can provide knowledge needed by caregivers and also provide a form of support through the development of relationships with other caregivers. These individuals do not need to feel like they are alone.

In addition to educating the caregiver, the education of primary care providers, acute care providers and policy makers needs to also occur. The education of primary care providers can help to improve their awareness of the issues impacting caregivers. Acute care providers need to be made aware of the impact caregiving has on family caregivers in order to increase their awareness of how education of the caregiver and referral to support groups prior to discharge can help to possibly decrease the negative impact of caregiving.

The education of policymakers needs to occur in order to increase their awareness of how much care is provided in the home and how this affects the caregivers. With this increased awareness the needs of caregivers and the need for support services and respite services can be considered in health care reform legislation.

Support services for caregivers are essential for their psychological well being. These services can be in the form of organized caregiver support groups or as individual counseling services. Abraham and Berry (1992) state peer counseling from individuals or support groups can help the caregiver maintain a health perspective. Legislators 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 payers.

Respite services are also essential for the caregivers well being. Respite care can allow the caregiver time away from the care receiver. This time can be for the purpose of attending support groups, educational programs or for leisure time which allows the caregiver to have a rest.

Many respite services require an out of pocket expense from the caregiver. It is important for APN's to educate policymakers about the importance of respite services and the financial restraints placed on family caregivers for the purpose of legislation that would assist in third party reimbursement for respite services and/or for the allowance of programs which could be supplemented by the government for the provision of respite care.

The APN as a leader needs to assist policymakers and others that are involved in healthcare reform process. The APN in this role needs to assist with the development of legislation that will provide support for and assist family caregivers.

There are several implications for the APN as a researcher. One is for the APN as a consumer of research, specifically research that has focused on family caregivers. The APN needs to be aware of what the literature shows as far as the effects on family caregivers, as well as what interventions are effective in assisting to decrease the effects of caregiving. The APN, as a researcher, also may want to further study the effects of caregiver burden, as mentioned earlier, this study has several implications for future research, these implications could easily be addressed by the APN.

Summary

This study has looked descriptively at caregivers of an individual who has had a stroke in an attempt to begin to describe the impact of burden experienced by this groups of caregivers. Caregivers of an individual who has had a stroke do experience a impact on their psychosocial health. This impact is positive, in relation to their esteem, and negative, in relation to the impact on their daily schedules. The data did not reflect that this group of caregivers perceived an impact on their physical health. This study, as discussed earlier has many implications for future research and for the APN in primary care. And only through the continued efforts of APNs and other healthcare professionals willing to address the issue of caregiver burden in this population, as well as other populations, can an impact be made on the negative affects caregiving has on the caregivers psychosocial and physical health status.

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APPENDICES

APPENDIX A

Sample Criteria
"Caregiver Responses to Managing Elderly Patients at Home"

1. 55 years of age or older
2. Had a designated person to assist the patient at home
3. Had experienced new losses in functioning following discharge from the hospital

Source: Darin et al., 1989 - 1993

APPENDIX B

ID		1-3
CARD	0 1 8	4-6
DATE	_ _/_ _/_ _	7-12
INT		13-14
INTCODE	1	15
STUDY	5	16

CAREGIVING INVENTORY

We are trying to understand how providing care for your family member has affected you, your relationships with others, and your social activities and daily routines.

In the questions that follow, please circle the response that most represents <u>how you feel</u> about each statement. <u>**The blank line in some statements represents the name of the elderly person for whom you provide care**</u>. It may be helpful (but is not necessary) for you to place the initials of the person on the blank line. Answer all the questions in response to caring for your relative. Please circle one number for <u>each</u> statement using the code below:

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

---

1. My activities are centered around care for _____.	5 4 3 2 1	17
2. I am healthy enough to care for _____.	5 4 3 2 1	18
3. My family works together at caring for _____.	5 4 3 2 1	19
4. Caring for _____ is important to me.	5 4 3 2 1	20
5. Since caring for _____ I have enough time for myself.	5 4 3 2 1	21

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

6. I feel overwhelmed by the problems I have caring for _____.	5 4 3 2 1	22
7. It takes all my physical strength to care for _____.	5 4 3 2 1	23
8. I enjoy caring for _____.	5 4 3 2 1	24
9. I wish the family depended less on me to care for _____.	5 4 3 2 1	25
10. I have to stop in the middle of my work or activities to provide care.	5 4 3 2 1	26

ID
CARD 0 1 8

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER
FOR EACH)

11. My health has gotten worse since I've been caring for _____. 5 4 3 2 1 ___ 27
12. Since caring for _____, I feel my family has abandoned me. 5 4 3 2 1 ___ 28
13. Caring for _____ makes me feel good. 5 4 3 2 1 ___ 29
14. I have enough time for leisure and recreational activities since caring for _____. 5 4 3 2 1 ___ 30
15. It is very difficult to get help from my family in taking care of _____. 5 4 3 2 1 ___ 31
16. Being a caregiver prevents me from taking care of my own health. 5 4 3 2 1 ___ 32
17. I feel privileged to care for _____. 5 4 3 2 1 ___ 33

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER
FOR EACH)

33

18. Other have dumped caring for _____ onto me. 5 4 3 2 1 ___ 34
19. I have eliminated things from my schedule since caring for _____. 5 4 3 2 1 ___ 35
20. I believe it is my responsibility to care for _____. 5 4 3 2 1 ___ 36
21. I get very discouraged caring for _____. 5 4 3 2 1 ___ 37
22. I have enough physical strength to care for _____. 5 4 3 2 1 ___ 38
23. The constant interruptions make it difficult to find time for relaxation. 5 4 3 2 1 ___ 39
24. My family (brothers, sisters, children) left me alone to care for _____. 5 4 3 2 1 ___ 40

ID
CARD 0 1 8

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

25. Since caring for _____, it seems like I'm tired all of the time.	5	4	3	2	1	41
26. I really want to care for _____.	5	4	3	2	1	42
27. Since caring for _____, sometimes I hate the way my life has turned out.	5	4	3	2	1	43
28. I visit family and friends less since I have been caring for _____.	5	4	3	2	1	44
29. Taking care of _____ has <u>not</u> affected my physical health.	5	4	3	2	1	45
30. I feel I was forced into caring for _____.	5	4	3	2	1	46
31. I have enough time to do my own work and chores since caring for _____.	5	4	3	2	1	47

5 = STRONGLY AGREE
4 = AGREE
3 = NEITHER AGREE OR DISAGREE
2 = DISAGREE
1 = STRONGLY DISAGREE

(CIRCLE ONE NUMBER FOR EACH)

32. I will never be able to do enough caregiving to repay _____.	5	4	3	2	1	48
33. I feel trapped by my caregiving role.	5	4	3	2	1	49
34. Since I began taking care of my relative, I take better care of <u>my</u> health.	5	4	3	2	1	50
35. I sleep just as much since caring for _____.	5	4	3	2	1	51
36. At this time in my life, I don't think I should have to be caring for _____.	5	4	3	2	1	52
37. I am sick more often since I began caring for my relative.	5	4	3	2	1	53
38. I could not live with myself if I just quit caring for _____.	5	4	3	2	1	54
39. Just when I thought times were going to be easier for me, I have to be a caregiver.	5	4	3	2	1	55

ID
CARD 0 1 8

Please remember we are trying to understand how providing care for your family member has affected you. Please circle one number for <u>each</u> statement using the code below:

4 = A GREAT DEAL
3 = QUITE A BIT
2 = SOME WHAT
1 = VERY LITTLE

(CIRCLE ONE NUMBER FOR EACH)

To what extent ...

40.	do you get frustrated with your situation?	4	3	2	1	56
41.	are you so frustrated that you have to leave the room?	4	3	2	1	57
42.	did you get angry with the person for whom you were providing care?	4	3	2	1	58
43.	do you feel that you are manipulated by the person for whom you were providing care?	4	3	2	1	59

4 = A GREAT DEAL
3 = QUITE A BIT
2 = SOME WHAT
1 = VERY LITTLE

(CIRCLE ONE NUMBER FOR EACH)

44.	did you resent the fact that others didn't help provide care?	4	3	2	1	60
45.	do you believe your relationship with your relative is strained?	4	3	2	1	61
46.	did you become irritated with the person for whom you provided care?	4	3	2	1	62
47.	did you resent the way your life has turned out?	4	3	2	1	63
48.	did you get so angry you have to stop what you are doing?	4	3	2	1	64
49.	do you get so upset that it interferes with caring?	4	3	2	1	65

APPENDIX C

MICHIGAN STATE
UNIVERSITY

April 10, 1995

TO: Denise Soltow

RE: IRB#: 95-149
TITLE: WHAT IS THE PERCEIVED IMPACT OF BURDEN EXPERIENCED BY CAREGIVERS OF AN INDIVIDUAL WHO HAS HAD A STROKE?
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 04/10/95

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 including any revision 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)336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Barbara A. Given

OFFICE OF
**RESEARCH
AND
GRADUATE
STUDIES**

**University Committee on
Research Involving
Human Subjects
(UCRIHS)**

Michigan State University
237 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX 517/432-1171

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

April 20, 1992

Charles W. Given
B108 Clinical Center

RE: CAREGIVER RESPONSES TO ELDERLY PATIENTS AT HOME, IRB #89-175

Dear Dr. Given:

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise you that since reviewer comments have been satisfactorily addressed, the conditional approval given by the Committee at its March 2, 1992 meeting has now been changed to full approval.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to March 2, 1993.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

David E. Wright, Ph.D
Chairman
University Committee on Research
Involving Human Subjects

DEW/pjm

(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.

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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