Perceived life changes and feelings of depression in caregivers of persons with stroke

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Medical College of Ohio

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Perceived Life Changes and Feelings of Depression in Caregivers of Persons with Stroke

Submitted by

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In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

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Perceived Life Changes and Feelings of Depression in Caregivers of Persons with Stroke

Michele Jorstad

Medical College of Ohio

2004
DEDICATION

This thesis is dedicated to my husband, Rodney. I am grateful for his loving support, understanding, and patience during this research process.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dedication</td>
<td></td>
<td>ii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td></td>
<td>iii</td>
</tr>
<tr>
<td>Table of Contents</td>
<td></td>
<td>iv</td>
</tr>
<tr>
<td>List of Figures and Tables</td>
<td></td>
<td>vii</td>
</tr>
<tr>
<td>Chapter I</td>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Statement of the Problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Theoretical Framework</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Statement of the Purpose</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Research Question</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Hypothesis</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Definition of Terms</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Significance</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Assumptions</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Limitations</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>10</td>
</tr>
<tr>
<td>Chapter II</td>
<td>Review of Literature</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Theoretical Framework</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Literature Review</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>31</td>
</tr>
</tbody>
</table>
Chapter III Method ............................................................................................................32
  Design ....................................................................................................................32
  Materials ................................................................................................................32
  Data Collection ......................................................................................................35
  Data Analysis .........................................................................................................38
  Summary ................................................................................................................40
Chapter IV Results .............................................................................................................41
  Sample ....................................................................................................................41
  Findings ..................................................................................................................43
  Summary ................................................................................................................48
Chapter V Discussion ........................................................................................................50
  Findings ..................................................................................................................50
  Limitations .............................................................................................................52
  Implications ............................................................................................................52
  Recommendations for Further Research ...............................................................54
  Summary ................................................................................................................55
References ..........................................................................................................................56
Appendices
  Appendix A Bakas Caregiving Outcomes Scale (BCOS) ....................................60
  Appendix B Bakas Caregiving Outcomes Scale (BCOS) .....................................62
  Appendix C Letter of Correspondence .................................................................64
Appendix D  Center for Epidemiologic Studies Depression Scale (CES-D) ....................65

Appendix E  Demographic Information Sheet.................................................................67

Appendix F  IRB Approval Letter ..................................................................................68

Appendix G Letter of Agency Approval .......................................................................70

Appendix H Letter of Invitation to Participate ..............................................................71

Abstract..............................................................................................................................72
LIST OF FIGURES AND TABLES

Figure 1 Conceptual Model ...................................................................................................12
Table 1 Demographic Characteristics of the Caregivers of Persons with Stroke ..........42
Table 2 Demographic Characteristics of Persons with Stroke.........................................43
Table 3 Means of each item on the BCOS........................................................................45
Table 4 Means of each item on the CES-D........................................................................47
Table 5 Pearson $r$ Correlation of BCOS and CES-D......................................................48
CHAPTER I

Introduction

A statement of the problem, an introduction of the theoretical framework, statement of the purpose, and research question are included in this chapter. Within the research question, the dependent and independent variables are conceptually and operationally defined. The focus of this study is to examine the relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. In addition, the significance, assumptions, and limitations are included in this chapter. A summary of the contents concludes this chapter.

Statement of the Problem

Approximately 700,000 Americans will experience a stroke (American Stroke Association, 2004). Once discharged from the hospital or rehabilitation center, many persons with stroke require assistance in their activities of daily living. Most of the assistance in the activities of daily living is provided by family members (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Bakas & Burgener, 2002; Periard & Ames, 1993; Weaver-Moore, Maiocco, Schmidt, Guo, & Estes, 2002). The stroke affects more than the person. The stroke affects the family members as well (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Forsberg-Warleby, Moller, & Blomstrand, 2001; Hartke & King, 2002). Not only do persons with stroke have to modify their lives, but family members may have to modify their own lives as well because of the caregiving needs of the person with stroke. Due to the caregivers’ perceived life changes related to caring
and feelings of depression, support groups and interventions have been developed to assist caregivers in their caregiving role. Mitchell (1996) identified that the primary purpose of support groups is to provide support for the caregiver.

Family members are usually placed suddenly in the caregiver role due to the stroke disease process. This new role may have the caregivers feeling unprepared and overwhelmed. Besides feeling unprepared, a lack of information about the disease and the disease process can interfere with effective coping for the family caregivers. Caregivers of persons with stroke experience difficult problems such as lack of emotional support, lack of social involvement, and difficulty in receiving home health services (Grant, 1996; Hartke & King, 2002). The caregiving demands can have emotional and physical outcomes which could have implications in continuing the caregiving role. Depressive symptoms in caregivers of persons with stroke as a result of providing care were identified in studies by Anderson, Linto, and Stewart-Wynne (1995) and Dennis et al. (1998). The lives of caregivers of persons with stroke may change just as the lives of the persons with stroke have changed. Some of the perceived life changes of caregivers may be positive, negative, or even unchanged (Johnson, 1998; Periard & Ames, 1993; Thompson, Bundek, & Sobolew-Shubin, 1990).

Theoretical Framework

Orem’s (2001) self-care deficit nursing theory served as the theoretical framework for this study. The self-care deficit nursing theory is described as a relationship between action capabilities of individuals and the self-care demands of the individual or the care demands of another individual such as a child or an adult dependent (Orem). The theory
of self-care, theory of self-care deficit, and theory of nursing system are the three theories within the general theory.

The central idea of the theory of self-care requires an individual to deliberately perform operations for themselves (self-care) to maintain life, development, health, and well-being (Orem, 2001). Self-care is a human regulatory function which differs from other regulatory functions because it must be learned and performed continuously. Self-care agency is the individual’s acquired capability to deliberately perform self-care requisites. Self-care requisites are the necessary goals of self-care in regulating an individual’s function to maintain life, development, health, and well-being. Orem discussed three kinds of self-care requisites: universal self-care requisites, developmental self-care requisites, and health-deviation self-care requisites for the theory of self-care. Self-care agency varies with the individual’s health state, ability to learn, and life experiences which affect learning. Perceived life changes related to caring and feelings of depression may impact the caregivers’ ability to maintain acts of self-care.

The central idea of the theory of self-care deficit is that individuals benefit from nursing because of limitations in providing self-care. The relationship between the self-care agency and the therapeutic self-care demand articulates the theory of self-care deficit. Therapeutic self-care demand is a structured course of action which must be performed to produce action processes, using the means chosen to meet the regulatory goals of both known existent and emerging self-care requisites of the individual (Orem, 2001).
The central idea of the theory of nursing system involves the formation of the nursing system designed for an individual by nurses. The individual is influenced through nursing in several ways according to Orem (2001). Supportive-educative system is for situations in which an individual has the ability or capability to perform the required therapeutic self-care measures with supportive-educative nursing interventions (Orem). For example, nursing interventions are utilized when an actual or potential self-care deficit exists on behalf of the caregiver. Specific to this study on the perceived life changes related to caring and feelings of depression in the caregivers of persons with stroke; nursing provides psychological support as well as a supportive environment, including teaching and guiding the individual.

Statement of the Purpose

The purpose of this study was to examine the relationship between perceived life changes related to caring and feelings of depression in a population of caregivers of persons with stroke who are receiving ongoing support.

Research Question

Is there a relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support?

Hypothesis

There is a relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support.
Definition of Terms

Caregivers of Persons with Stroke who are Receiving Ongoing Support

Conceptual definition. In Mosby’s Medical, Nursing, & Allied Health Dictionary (2002), a caregiver is defined as a person who contributes the benefits of medical, social, economic, or environmental resources to either a dependent or partially dependent individual. A person with stroke was conceptually defined as an individual who experienced a type of cardiovascular disease (American Stroke Association, 2004). A stroke can occur when a blood vessel which carries oxygen and nutrients to the brain is either blocked by a clot or the blood vessel bursts, as defined by the American Stroke Association. When either occurs, a part of the brain cannot receive the required oxygen and nutrients and, thus, the brain starts to die (American Stroke Association). The conceptual definition of support as defined in Mosby’s Medical, Nursing, & Allied Health Dictionary is maintaining a desired condition such as emotionally supporting an individual under stress.

Operational definition. The operational definition for a caregiver was an individual, such as a family member, who provided care to a person with stroke (Bakas, et al., 2002). Caregivers may receive services in meeting their own needs, such as in a support group as discussed by Mitchell (1996). The person with stroke was operationally defined in this study as an individual who experienced a stroke and required assistance in care or activities of daily living from an individual providing care and assistance in activities of daily living (not institutionalized care), according to Anderson et al. (1995). The operational definition of support was defined in the context of support groups. A
primary objective of caregiver support groups is to support and meet the needs of the caregivers rather than the persons with stroke as mentioned by Mitchell. The support groups may be generic, which are open to all types of caregivers, or specific to a medical condition. Providing social activities and companionship, and sharing problems and feelings are some services that may be provided in a support group for the caregivers (Mitchell).

Perceived Life Changes Related to Caring

Conceptual definition. Perception was defined in Mosby’s Medical, Nursing, & Allied Health Dictionary (2002) as a conscious recognition of an individual’s sensory stimuli in which the perception serves as a basis for understanding and learning. Life was defined as the energy that allows a person or organism to grow (Mosby’s Medical, Nursing, & Allied Health Dictionary). Change was defined as “the conversion of something to a different form” (Miller-Keane Encyclopedia & Dictionary of Nursing & Allied Health, 1997, p. 304). Caring was defined by Miller-Keane Encyclopedia & Dictionary of Nursing & Allied Health as being an interpersonal process involving the person who is being cared for and the person who is providing care.

Operational definition. This research study measured perceived life changes reported from the caregivers by utilizing the Bakas Caregiving Outcomes Scale (BCOS), which was developed by Bakas and Champion (1999). The BCOS was designed to measure the degree to which the caregivers of persons with stroke perceived life changes as a result of providing care to the person with stroke. Each item is rated numerically as
-3, -2, -1, changed for the worst, +1, +2, +3, changed for the best, or as 0, did not change (Bakas & Champion).

Feelings of Depression

*Conceptual definition.* Depression was conceptually defined as a mood disturbance. Depression is characterized by feelings of sadness, despair, and discouragement which may result from a personal loss or tragedy (Miller-Keane Encyclopedia & Dictionary of Nursing & Allied Health, 1997).

*Operational definition.* This research study measured depression utilizing the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D contains 20 items rated on a Likert scale. A higher score indicates greater depressive symptoms (Radloff).

Significance

The advancement in medical technology has allowed people to have a longer life expectancy. Since people are living longer, there is a greater chance for health problems to occur. Once these health problems occur, assistance is needed to continue the activities of daily living. Due to the disease process of those persons who have experienced a stroke, the caregivers assume new roles and responsibilities. An increasingly more common occurrence is the number of caregivers providing care to persons with stroke in the home setting. A study by Johnson (1998) reported that caregivers stated that their role with the person with stroke had changed in a positive manner. No changes and positive changes in the relationship between the caregivers of persons with stroke and the care recipient were identified from a study by Thompson et
al. (1990). Weaver-Moore et al. (2002) elaborated on how caregivers were often unprepared in assuming the caregiving role for persons with stroke. Emotional health consequences (anxiety, depression, and frustration) were examined in the studies by Anderson et al. (1995) and Dennis et al. (1998). Teel, Duncan, and Min Lai (2001) discussed how caregiving demands could result in negative emotional and physical consequences for the caregiver. The need and role of support groups and interventions are receiving more attention because caregivers can become vulnerable and stressed due to the caregiving demands. Mitchell (1996) identified the primary purpose of support groups is that of providing support for the caregiver. Kaasalainen, Craig, and Wells (2000) examined the relationship between caregiver stress and social support and their effects on the morale of the caregiver.

The current study focused on the relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. This study is significant to nursing to help develop interventions that can be implemented for the caregivers of persons with stroke. During the difficult time of adjustment for the family unit to the stroke disease process, nurses provide support in many aspects of care. Nurses have a responsibility to provide stroke education and supply information regarding coping strategies to caregivers of persons with stroke, according to Williams (1994). A nurse practicing from a holistic framework recognizes and intervenes in self-care deficits for all members of the family unit.
Assumptions

The following assumptions were made about this study: 1) the perceived life changes related to caring and feelings of depression varies with each caregiver who is receiving ongoing support, 2) caregivers require continuous input to themselves and their surroundings through the use of support groups to maintain caregiving roles, and 3) individuals have the capabilities of maintaining their own life, development, health, and well-being according to Orem’s (2001) self-care deficit nursing theory. The caregiver of a person with stroke desires to engage in activities which maintain their life, development, health, and well-being, thus promoting positive perceived life changes. Nurses can identify the caregiver who is unable to engage in these activities, and can implement a supportive-educative nursing system. The goal of the supportive-educative nursing system is for an individual to accomplish their own self-care and the development of their self-care agency (Orem).

Limitations

Orem (2001) discussed nursing as a human and helping service. The human service is concerned with the health and well-being of individuals whereas the helping service is concerned with assisting individuals to achieve their goals. The relationship between nurse-patient is a complementary relationship in which the nurses provide the care and patients participate in the care. The nurse-patient relationship involves a person-to-person relationship in order for the nurse to know and help the patient (Orem). Limitations of this study included Orem’s basic conditioning factors such as age, health status, environment, and resources. Age and health status affected the learned behaviors
of the caregivers to maintain their own life, development, health and well-being required for the theory of self-care.

Summary

The incidence of stroke is increasing and, thus, there is a need for nursing services, rehabilitation, and long term care assistance. While the assistance could be provided for many people, this study narrowed the focus to those caregivers of persons with stroke who are receiving ongoing support. The primary focus of many healthcare professionals involves the needs of the person with stroke. However, a less obvious but just as important aspect, involves the needs of the caregiver responsible for providing care to the person with stroke. As the life of the person with stroke changes, so does the life of the caregiver of a person with stroke. When the caregiving demands exceed the capabilities of the caregiver, then both the person with stroke and caregiver experience deficits. Nurses can provide Orem’s (2001) supportive-educative nursing system by assessing the self-care operations of the caregiver. As nurses gain a better understanding of the perceived life changes related to caring and feelings of depression, they can provide therapeutic interventions.
CHAPTER II

Review of Literature

This chapter is divided into two sections beginning with a discussion of Orem’s (2001) theoretical framework relating to caregivers’ roles. A schematic drawing of the theoretical framework follows the theoretical framework discussion. The second section contains a review of research concerning the caregivers. A summary of the contents concludes this chapter.

Theoretical Framework

Orem’s (2001) self-care deficit nursing theory was utilized as the theoretical framework for this research. The self-care deficit nursing theory is explanatory of the relationship between an individual’s action capabilities and the self-care demands. Orem discussed that deficit should be interpreted as a relationship rather than a human disorder. Deficit is symbolized as a relationship between the action an individual should take and the action capabilities of the individual for self-care. The self-care deficit nursing theory serves as a framework for studying perceived life changes related to caring and feelings of depression as a result of providing care to the persons with stroke, which is illustrated in Figure 1.

The theory of self-care postulates that self-care is the action individuals deliberately initiate or perform on their behalf to maintaining life, development, health, and well-being (Orem, 2001). Self-care agency is the individual’s acquired capability to deliberately perform self-care and varies with the individual’s health state, ability to learn, and life experiences which affect learning. The self-care agent is identified as the
Figure 1. Conceptual Model: Orem’s (2001) self-care deficit nursing theory and study variables of perceived life changes related to caring and feelings of depression in caregivers of persons with stroke.

provider of self-care. Most individuals, such as adults, are capable of self-care. Self-care requisites are the necessary goals of self-care in regulating an individual’s ability to
maintain life, development, health, and well-being. Universal self-care requisites, developmental-self-care requisites, and health-deviation self-care requisites are the three kinds of self-care requisites. Universal self-care requisites are universally required goals which are to be met through self-care as discussed by Orem. The maintenance of sufficient intake of air, sufficient intake of water, sufficient intake of food, the maintenance of balance between activity and rest, and the promotion of human functioning and desire to be normal (normalcy) are some of Orem’s eight self-care requisites. Normalcy is described as essentially human and is in concurrence with the inherited and constitutional characteristics of an individual. Meeting the universal self-care requisites contributes to the promotion of maintaining life, development, health, and well-being of an individual. The promotion of normalcy prevents the development of conditions which may develop hazards to an individual’s life, development, health, and well-being (Orem).

The theory of self-care deficit articulates the relationship of self-care agency and therapeutic self-care demand (Orem, 2001). A self-care deficit occurs when therapeutic-self care demand exceeds self-care agency; therefore, developing the reason an individual requires nursing. An individual may benefit from nursing due to limitations in providing self-care. Orem identified the self-care deficit as being either permanent or transitory. Self-care agency is referred to as powers of an individual and is the individual’s acquired capability to deliberately perform self-care requisites. Orem discussed therapeutic self-care demand as being an entity which is separate and apart from an individual’s engagement in self-care. An individual requires nursing when the known self-care
demands are greater than the care abilities. When an individual is unable to meet their own needs, then a self-care deficit exists.

According to Orem (2001), the theory of nursing system establishes the relationship of nursing agency with therapeutic self-care demand. Orem defined nursing agency as a set of developed capabilities that nurses may exercise in providing nursing care to an individual. The nursing system is established by the utilization of nursing powers to an individual requiring the nursing agency. Nursing is a deliberate action performed by nurses and the goals of the nursing system are to develop the existing self-care agency and assist an individual in meeting therapeutic self-care demands. The supportive-educative nursing system is for situations in which an individual has the ability or capability to perform the required therapeutic self-care measures with supportive-educative nursing interventions. Supportive-educative system techniques may include support, guidance, and teaching (Orem).

Therapeutic self-care demands must be met, such as the perceived life changes related to caring and feelings of depression experienced by the caregivers, to have a desired effect on the caregivers’ development. Nursing interventions become a vital role in overcoming the self-care deficits because the caregivers of persons with stroke are likely to benefit from assistance during this stage (Orem, 2001). The supportive-educative nursing system by Orem can be implemented with the caregivers of persons with stroke. The supportive-educative nursing system is selected when the caregivers are able to perform self-care. The basic nursing system of the supportive-educative system
recognizes that individuals will accomplish the self-care and regulate the exercise and development of the self-care agency, according to Orem.

The purpose of nursing is to implement intervention(s) once the self-care deficit is recognized in the individuals’ self-care limitations (Orem, 2001). For this study, exploring the perceived life changes related to caring and feelings of depression of caregivers who are receiving ongoing support provided insight to the nurse regarding the caregivers’ perceived life changes. This study assisted the nurse in identifying the perceived life changes related to caring and feelings of depression as reported by caregivers so that appropriate interventions can be implemented.

Literature Review

The literature review is focused on studies of caregivers and their experiences in providing care to a family member. This portion of the literature review is divided into sections regarding emotional distress, life changes which are positive or negative experiences, and social support.

Emotional Distress

Identifying the predictors of caregivers’ emotional distress, general health, and caregiver outcomes was the purpose of a study by Bakas and Burgener (2002). The participants consisted of 28 male and 76 female caregivers of persons with stroke. The caregivers were middle-aged (mean = 62.15) husbands and wives with a high school education. On average, the caregivers had been caring for the person with stroke for a little over 2 years. The Cognitive Status Scale (CSS) was utilized to measure the caregivers’ perceptions of the cognitive function of the person with stroke. The Profile of
Mood States Short Form (POMS) measured caregivers’ emotional distress such as depression, anger, fatigue, and anxiety for a total emotional distress score. The Self-Esteem Scale (SES), Appraisal of Caregiving Scale (ACS), and SF-36 Health Survey subscale (SF-36 GH) measured the caregivers’ self-esteem, emotional and physical health, and perception of their own health, respectively. Bakas and Burgener reported that good cognitive function of the person with stroke was identified from the caregivers. The results of the study found that low caregiver self-esteem, high task difficulty, and a high threat appraisal were predictors of emotional distress. Not living with the person with stroke, low income, and a high threat appraisal were predictors of poorer health, even though the caregivers rated their health as being good. Emotional distress, high task difficulty, and low benefit appraisal were identified as predictors of poor caregiver outcomes (Bakas & Burgener). These findings suggest potential areas to focus interventions for the caregivers.

A correlational study by Thompson et al., (1990) was conducted between depression in caregivers of persons with stroke and four classes of variables (level of functioning of the persons with stroke, caregivers’ perception of increased work and burden, quality of the caregiving relationship among the caregivers of persons with stroke and the care recipients, and caregivers’ interpretation of the caregiving situation). The study was conducted with 40 caregivers of persons with stroke and their care recipients in the home setting. The caregivers were primarily female (67%), spouses (80%), with ages ranging from 21-81 years (mean = 56.0). The Geriatric Depression Scale (GDS) which measures psychological adjustment, and the Physical Limitations subscale of the
Questionnaire on Resources and Stress (QRS) which measures the quality of the relationship between the caregiver and the person with stroke as well as level of functioning of the persons with stroke, were administered to the caregivers and persons with stroke. Five other subscales from the QRS measured the caregivers’ perception of increased work and burden, and quality of the caregiving relationship. Open-ended questions were asked about the caregivers’ interpretation of the caregiving situation. Results showed a significant relationship between depression in caregivers of persons with stroke and caregivers’ perception of increased work and burden (Thompson et al.). The researchers concluded the person with stroke reported more often than the caregiver that the stroke strengthened the relationship.

Examining the stress and rewards in the roles of being a mother, wife, and employee in combination with stress in the parent care role that affected women’s psychological well-being (depression and life satisfaction) was the purpose and primary objective of the study by Parris Stephens and Townsend (1997). The sample size consisted of 296 women who were caregivers to a parent or parent-in-law who was ill or disabled. Scales were utilized to measure role stress, role rewards, and psychological well-being. For role stress, 87% of the caregivers reported the most frequent stressor was the parent care role which involved dealing with a parent’s emotional problem or mood. Role rewards were reported in roles of being a mother, wife, and employee, but not in the caregiver role. The Center for Epidemiologic Studies Depression Scale (CES-D) was utilized to measure depressive symptoms, with a higher score indicating greater symptomatology. The CES-D scores ranged from 0-54 with the average score being
12.5. The life satisfaction scores ranged from 6-25 with the average score being 15.9. The dispositional optimism scores ranged from 14-40 with the average score being 29.2 (the higher score indicates greater optimism). Parris Stephens and Townsend reported a statistically significant relationship between parent care stress and depression, but not between parent care stress and life satisfaction among the caregivers. The results from this study suggested the caregivers’ psychological well-being is not only related to the stress of providing care, but also related to the negative and positive experiences in the caregivers’ other roles. The caregivers who experienced higher level of rewards in the role of mother, wife, and employee also experienced more life satisfaction.

The purpose of the Lee, Brennan, and Daly (2001) study was to examine the relationship between empathy and caregiving appraisal and outcomes in older adult caregivers. The sample size consisted of 140 caregivers. Eligibility to participate in the study required the older adult caregivers to be 60 years of age or older and provide care to an older adult requiring assistance in activities of daily living. Scales measuring empathy, appraisal, depression, life satisfaction, and perceived physical health were utilized in this study. Lee et al. reported a positive relationship existed between emotional empathy and stress appraisal. The caregivers with a higher cognitive empathy reported the caregiving situation as being less stressful and less threatening, as well as experienced less depression and higher life satisfaction. The total household income and the caregivers’ educational level were positive influences on the caregiving outcomes. The positive influences on the caregiving outcomes resulted in decreased levels of caregiver depression and higher levels of life satisfaction and physical health (Lee et al.).
Examining the emotional distress of caregivers of persons with stroke after 1 year of providing care was studied by Anderson et al. (1995). Emotional distress was examined by measuring the caregivers’ depressive symptoms and levels of anxiety. Of the 84 participants in this study, 15 were male and 69 were female caregivers with ages ranging from 30-80 years (mean = 58.0). The Hospital Anxiety and Depression Scale (HADS) and General Health Questionnaire (GHQ) assessed depressive symptoms and levels of anxiety of the caregivers. The results from the study showed levels of anxiety (58%), depression (50%), frustration (32%), and resentment (29%) in the caregivers. The social consequence for the caregivers was not being able to leave the home to visit other family members or friends due to fears of leaving the person with stroke at home alone (Anderson et al.). More than half of the caregivers reported increased levels of anxiety when the persons with stroke were home alone due to fears of experiencing another stroke or potential falls.

Similar to Anderson et al.’s (1995) study, Dennis et al. (1998) studied emotional distress by measuring the depressive symptoms and levels of anxiety in caregivers of persons with stroke. The GHQ and HADS measuring caregivers’ depressive symptoms and levels of anxiety were administered to 102 participants. The GHQ results indicated that the caregivers had significantly worse depressive symptoms and levels of anxiety as a result of providing care to the person with stroke. The HADS results revealed that 55% of the caregivers indicated depressive symptoms and levels of anxiety often. Dennis et al. reported that female caregivers scored worse on levels of anxiety, and therefore reported higher levels of anxiety than male caregivers. This finding of higher levels of
anxiety may be due to differences between the sexes in the frequency of the reported
levels of anxiety (Dennis et al.). Depressive symptoms were more likely in the caregivers
of severely dependent persons with stroke, although levels of anxiety were less likely in
the caregivers of severely dependent persons with stroke.

Wright, Hickey, Buckwalter, Hendrix, and Kelechi, (1999) did a comparison
study exploring the emotional and physical health of caregivers of a person with stroke
and caregivers of a person with Alzheimer’s disease (AD) at 1 month, 6 months, and 1
year time intervals. The time intervals were chosen in order to study any changes the
caregivers experienced regarding their emotional and physical health. A comparison
study was performed because caregiving responsibilities were different even though
behavioral disturbances in persons with stroke and AD were similar. There were 14
participants in both the stroke and AD groups. For emotional health, depression was
measured by utilizing the Short Zung Interviewer Assisted Depression Scale. Results
showed depression for the caregivers of a person with AD was higher than the caregivers
of a person with stroke during the three time intervals as reported by Wright et al.
Physical health was measured by utilizing the Multilevel Assessment Inventory (MAI).
No change in physical health during the three time intervals was reported by either group
in this study (Wright et al).

Jacob (1991) discussed the caregiver role with regards to stress, assessment for
intervention, and education. Jacob identified the caregiver as being a family member,
usually a female, with no formal training in the caregiving role. Jacob mentioned a
variety of daily stresses such as isolation, loss of privacy and personal time, and family
distress. Providing appropriate community resources to the caregiver is an essential role of the health care provider. Assessment for intervention includes identifying the caregiver’s physical and emotional distress. Jacob reported that relief from the emotional distress the caregiver may be experiencing could prevent elder abuse. Mental support can also be provided by allowing the caregiver to express their feelings about the caregiving role. Health care providers should promote a healthy adaptation to the stress caregivers may be experiencing by educating the caregiver about behavioral problems of the person with an illness. Jacob concluded that the needs of the caregiver are just as important as the needs of the person with an illness.

Life Changes

Positive experiences. Investigating the lived experience of rural caregivers of persons with stroke was the purpose of a study by Johnson (1998). A convenient sample of 10 participants, who have been in the caregiver role for at least 6 months, were asked seven open ended questions in this qualitative study. Some of the caregivers felt their caregiver role with the person with stroke had changed in a positive manner and 90% of caregivers reported positive family and social support. Five themes associated with life changes were identified by Johnson: 1) a sense of loyalty, 2) a sense of acceptance, 3) a sense of “feeling good” about what the caregivers were doing, 4) satisfaction in association with helping people, and 5) burden. Johnson mentioned the caregivers reported several positive aspects of caregiving (the caregiver role being satisfying) as well as some negative aspects of caregiving (being the sole decision maker).
Burman (2001) explored the caregivers’ expectations and management strategies of the stroke trajectory. The participants consisted of 5 males and 8 female caregivers, with ages ranging from 28 to 85 years. Interviews with the participants lasted from 30 minutes to 2 hours. The findings revealed a theme in which caregivers reported having “no idea” in regards to the care of the persons with stroke. The difficulties the caregivers had in making projections regarding the recovery process were discussed. A primary strategy of the caregivers was to promote a positive recovery for the persons with stroke by accepting new life changes. Other management strategies reported by the caregivers were living life day to day and decreasing social contact with friends (Burman).

Positive experiences of caregivers of persons with stroke also were identified in the correlational study by Thompson et al. (1990). Results showed significant relationships between depression and three other classes of variables (level of functioning of the persons with stroke, quality of the caregiving relationship between the caregivers of persons with stroke and the care recipients, and caregivers’ interpretation of the caregiving situation). No change in the relationship was reported by 40% of the caregivers, a positive change in the relationship was reported by 35% of the caregivers, while a negative change in the relationship was reported by 25% of the caregivers (Thompson et al.). The caregivers’ age, sex, and length of time caring for the person with stroke were not related to the caregivers’ depression (Thompson et al.).

Negative experiences. Identifying the needs and concerns of caregivers of persons with stroke within the first 6 months of a family member’s stroke was the purpose of a study by Bakas et al. (2002). The first 6 months after a stroke were
identified to be the period of rapid transition from the role of being a family member to a caregiver of a person with stroke. The study included 14 Caucasian and African American female caregivers providing care in the home setting. The caregivers were asked five open-ended questions during taped interviews. As a result, five themes were identified in which the caregivers reported needs or concerns. The themes included the need for additional information about the disease process of a stroke, managing finances, managing the physical care in the activities of daily living, managing the behavioral problems of the person with stroke, and managing their own health and well-being (Bakas et al.).

The purpose of the Casas (1989) study was to determine if a positive correlation existed between the caregivers’ coping ability and the quality or quantity of information given to the caregiver prior to discharge of the person with stroke. Eighty six caregivers participated in the study in which a questionnaire, “Experience in Coping with Stroke,” was mailed to their homes. Casas reported more than 75% of the caregivers were Caucasian, primarily females over the age of 60 years, and had at least a high school education. The results failed to show a positive correlation between the caregivers’ ability to cope and the quality or quantity of information given to the caregiver prior to discharge. Casas reported the estimated correlation between the variables was -.076, but could not conclude that there is no relationship between the two variables (p>.05). The researcher mentioned education level, age, race, and other socio-demographic variables were not taken into account in this study and may have contributed to the low estimated correlation. Casas concluded that the underlying issue was the perception of the
caregivers’ well-being (the ability to cope) and not the quality or quantity of information given. Even though the null hypothesis could not be rejected, the caregivers reported wanting more information about stroke, stating the information would have helped in coping better.

Weaver-Moore et al. (2002) conducted a qualitative study with 8 (3 male and 5 female) caregivers of persons with stroke to identify their needs and concerns. These caregivers perceived their caregiving role both as a benefit and a drawback as a result of providing care to the person with stroke. The role was overwhelming for the caregivers when their own chronic illness was coupled with caregiving. Results showed that the caregivers reported: (a) a need for assistance with activities of daily living, and (b) concerns about deterioration in health (their health and the person’s with stroke health).

A study, utilizing a qualitative and quantitative method of analysis, was conducted by Hartke and King (2002) to examine the types of problems caregivers experienced when caring for persons with stroke. Criteria for participation were spousal caregivers over 60 years of age, living with the person with stroke, and primary caregiver for at least a month. A variety of scales were utilized for the quantitative analysis to measure depressive symptoms, caregiver burden, and loneliness in the caregiver. The qualitative analysis consisted of a telephone interview. The results were reported according to the frequency and difficulty of the problem. The caregivers reported problems such as lack of social involvement and financial concerns. Noncompliance of the person with stroke was the least frequent, but the most difficult problem experienced by the caregivers (Hartke & King).
Similar to Hartke and King’s (2002) study, Grant (1996) examined the problems experienced by caregivers of persons with stroke. Grant identified that the first 4 months was the time in which major functional recovery occurred for the person with stroke. The sample size consisted of 10 caregivers of persons with stroke and their care recipients. Of these 10 caregivers, 9 were female and 1 was male providing care in the home setting. An initial interview with the caregivers was conducted in either the home or the outpatient clinic. A follow up telephone call with the caregivers, 1 week after the interviews, was done to validate the problems discussed in the initial interview. The problems experienced by caregivers were difficulty in seeking and receiving home health services, assistance in housekeeping, and lack of emotional and social support for the caregivers (Grant).

Studying the well-being of spouse caregivers and identifying factors which may influence their well-being was the purpose of a study by Forsberg-Warleby et al. (2001). The Swedish study evaluated spouses of first time persons with stroke. The caregivers’ psychological well-being was measured using the Psychological General Well-Being Index (PGWB) 10 days after the person’s stroke. Forsberg-Warleby et al. identified that most of the spouse caregivers experienced a decrease in their psychological sense of well-being. The uncertainty about the stroke disease process and the impact on activities of daily living were the factors which may have influenced the well-being of the caregivers. The caregivers’ view of the future correlated with the level of disability of the persons with stroke (Forsberg-Warleby et al.).
Williams (1994) conducted a study to explore the caregiver experience when providing care to the person with stroke. The sample size consisted of 8 male and 21 female caregivers with ages ranging from 26 to 80 years (mean = 56.41). The Brain Impairment Behavioral Inventory (BIBI) and the companion Brain Impairment Behavior Bother Scale (BIBBS) were given to the caregivers to identify and rate how the behaviors of the persons with stroke were bothersome to them. Williams reported that caregivers listed the person with stroke demonstrating irritable behaviors and dependence on the caregiver as most bothersome. The three most common causes of stress for the caregivers were dependence of the person with stroke which resulted in the caregivers’ confinement, irritability of the person with stroke, and immature behaviors (Williams).

Bakas, Lewis, and Parsons (2001) compared caregivers’ perceptions regarding caregiving tasks between spouse caregivers and adult children caregivers of lung cancer patients. The sample size consisted of 62 spouses and 16 adult children caregivers of lung cancer patients. The caregiving tasks were categorized into the time and difficulty of the tasks. Both spouse and adult children caregivers perceived that the most time consuming tasks as a result of providing care to the lung cancer patient were providing emotional support, transportation, and monitoring of symptoms. The most difficult tasks for both spouse and adult children caregivers were providing emotional support, managing behavioral issues of the lung cancer patient, and performing household tasks. The perception of the spouse and adult child caregivers concerning the time and difficulty of tasks did not differ significantly (Bakas et al.).
A comparison study of the role changes of spousal caregivers was explored by DeLaune and Brown (2001). The participants in the study were 8 husband and 9 wife caregivers. The Buxbaum’s Marital Roles Questionnaire was utilized to assess the marital role responsibilities. The spousal caregivers were asked to rank the degree of marital happiness, enjoyment of the caregiver role, role responsibilities, and frequency of attending social functions or family gatherings. Both caregiver groups experienced an increase in marital unhappiness, an increase in the role responsibilities with a disliking of the role responsibility, a decrease in attending social functions or family gatherings, and a dislike for assuming the care recipient’s traditional role responsibilities as a result of providing care to the person with stroke (DeLaune & Brown).

Examining caregivers’ perceptions of life changes and coping patterns as a result of providing care to persons with stroke was the purpose of the study by Periard and Ames (1993). Criteria for participation were a family member with a first stroke, 55 years of age or older, and ability to respond reliably. Two male and 18 female caregivers participated in the study. Finances, activities of daily living, personal care, relationships with friends, family relationships, community activities, leisure activities, physical activities, and nutrition comprised the life changes categories. Results showed that 19 caregivers reported a negative perception of life changes in at least one of the categories previously mentioned. One caregiver did not perceive any life changes. Caregivers of persons with stroke coped with their caregiving role by praying, reading, and watching television (Periard & Ames).
The purpose of the Teel et al. (2001) study was to examine the caregivers’ experiences at 1, 3, and 6 month intervals after a family member’s stroke. These time periods were essential for this study because changes during the first 6 months of caregiving were being examined, similar to Bakas et al. (2002). Of the 83 caregivers who participated in this study, 71.1% were female with a mean age of 57, 82.9% were white, and 89.2% had at least a high school education. As a result of providing care, the caregivers reported experiencing fatigue, stress, feelings of being depressed, and difficulties in managing finances at the 1, 3, and 6 month intervals (Teel et al.).

**Social Support**

The need for and role of support groups and interventions are receiving more attention because caregivers can become vulnerable and stressed due to the caregiving role. Mitchell (1996) reported on the beneficial effects of support groups. The relationship and effects of social support are discussed in the studies by Kaasalainen et al. (2000) and Schwarz and Roberts (2000).

Mitchell (1996) discussed how support groups are a service aimed at providing for the needs of caregivers. The study sample consisted of 18 participants who were asked a number of questions pertaining to the importance of support groups. Questions being asked in this study were: Why did the caregivers join a support group? What did the support group offer? What was the impact on self image from the support group? Mitchell reported the caregivers originally joined the support groups to obtain information about the services available as well as information regarding a family member’s illness. Other findings from this study included how the caregivers valued
mutual support offered by other caregivers. The caregivers reported that attending the support groups impacted their self image in a positive manner. Being able to help other caregivers was one reason why some caregivers continued attending the support groups. The caregivers concluded that the support groups were not only beneficial for social outlets but also for the professional services provided by the health care providers. Support groups can provide a variety of services such as social activities and companionship. The caregivers reported a high level of satisfaction received from other caregivers and health care professionals as discussed by Mitchell.

Kaasalainen et al. (2000) examined the relationship between caregiver morale, social support, and information about the caregiving role in an intervention and a comparison group of caregivers. The intervention group consisted of 23 female caregivers who attended a caregiver support program, Caring for Aging Relatives Group (CARG). The comparison group consisted of 23 female caregivers who had not attended the CARG program. The Profile of Mood States (POMS) measured the morale of the caregivers while the Personal Resource Questionnaire (PRQ) measured social support. Both groups received a pretest and posttest of the two instruments. The caregivers in the intervention group received an additional instrument, the Visual Analog Scale (VAS), which measured the social support the caregivers received from the CARG program and was administered as a posttest. Kaasalainen et al. reported a positive relationship between morale and social support for both groups of caregivers. A positive relationship existed between morale and information about the caregiving role for the comparison groups’ pretest and posttest scores. There was no significant correlation between the
VAS and PRQ which measured the social support for the intervention group. The caregivers in the intervention group reported the CARG program provided social support for the caregivers even though no significant differences resulted between the pretest and posttest scores for morale and social support (Kaasalainen et al.).

A correlational study was conducted by Schwarz and Roberts (2000) in that examined the effects of social support and strain in caregivers of functionally impaired older adults during a 3 month period. The sample size consisted of 100 caregivers living with an older adult over 65 years of age. Social support was measured by the Modified Inventory of Socially Supportive Behaviors (MISSB), the effects of strain were measured by utilizing the Caregiver Strain Questionnaire (CSQ), depressive symptoms in caregivers were measured by utilizing the Center for Epidemiologic Studies Depression Scale (CES-D), caregiving appraisal was measured by the Philadelphia Geriatric Center Caregiving Appraisal Scale, and coping was measured by the Revised Ways of Coping Checklist. Schwarz and Roberts conducted a multiple regression analysis to examine whether caregiving appraisal, coping, and social support had a positive effect on strain and depressive symptoms in the caregivers. Schwarz and Roberts reported the only significant variable in explaining less strain and depressive symptoms in the caregivers was a more positive caregiving appraisal. The interaction effects of social support and strain were not significant. Schwarz and Roberts concluded that social support did not moderate or lessen the effects of strain on depressive symptoms in the caregivers.

Summary
Orem’s (2001) self-care deficit nursing theory was discussed as the theoretical framework for this research. The self-care agent was identified to be the caregiver of a person with stroke and the purpose of nursing interventions were discussed.

Emotional distress such as depression, anger, and levels of anxiety were examined by several studies (Anderson et al., 1995; Bakas & Burgener, 2002; Dennis et al., 1998; Lee et al., 2001). Life changes which are positive experiences in caregiving were reported in the studies by Burman (2001) and Johnson (1998). Positive family and social support were reported in 90% of the caregivers in the study by Johnson. Life changes which are negative experiences in caregiving such as a decrease in attending social functions or family gatherings, difficulty in seeking and receiving home health services, and lack of social involvement were identified (DeLaune & Brown, 2001; Grant, 1996; Hartke & King, 2002). Mitchell (1996) discussed how support groups are a service aimed at providing for the needs of caregivers. Social support was discussed in studies by Kaasalainen et al. (2000) and Schwarz and Roberts (2000).
CHAPTER III

Method

The purpose of this study was to examine the relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. A description of the research design, participants and setting, questionnaires utilized, data collection procedures, protection of human subjects, and the method of data analysis are included in this chapter.

Design

The design of this study was descriptive correlational.

Materials

To examine the relationship between perceived life changes related to caring and feelings of depression, the Bakas Caregiving Outcomes Scale (BCOS) developed by Bakas and Champion (1999) and the Center for Epidemiologic Studies Depression Scale (CES-D) developed by Radloff (1977) were utilized in this study. Demographic data also were collected. The questionnaires and a demographic sheet were assembled into packets for this study and are discussed in the order given.

Developing and testing the Bakas Caregiving Outcomes Scale (BCOS) in measuring perceived life changes of the caregiver was the purpose of the study by Bakas and Champion (1999). Being able to measure perceived life changes could identify the caregivers who are in need of intervention (Bakas & Champion). The BCOS was examined with other instruments such as the Burden Interview (BI), Objective Burden Scale (OBS), Caregiver Burden Scale (CBS), and Appraisal of Caregiving Scale (ACS)
to determine relevance in measuring the perceived life changes of the caregivers. The LIFE-3 is a 2 item instrument which measures global well-being by asking one question, “How do you feel about your life as a whole?”, twice during the interview. Evidence of reliability and validity of the BI, OBS, CBS, ACS, and LIFE-3 instruments has been established from previous studies, according to Bakas and Champion. A hierarchical multiple regression was utilized to test the model relationship of the instruments in both sample groups. The findings from this study showed that the criterion related validity of the BCOS was supported by two sample groups with significant correlation ($r = .56, p < .01$ for group 1 and $r = .54, p < .01$ for group 2) with the LIFE-3. The criterion related validity was further supported by the significant BCOS correlation ($p < .05$) with the Medical Outcomes Trust SF-36 Health Survey subscales (SF-36 GH) in group 2. The SF-36 GH measured physical functioning, general health, social functioning, and bodily pain in the stroke caregiver. Appendix A is the BCOS that was read to the caregivers over the telephone. Appendix B is the BCOS that was read by the caregivers. The questions remained the same in Appendix A and B of the BCOS questionnaire, only the directions for the caregivers were different.

A letter of correspondence dated September 2002, was given to this researcher from Dr. Bakas regarding a revised BCOS (Appendix C). Two items, “My ability to pay bills” and “My ability to buy necessities” were deleted because of the psychometric findings from Bakas and Champion (1999). Five items: “My level of energy, my roles in life, my financial well-being, my physical functioning, and my general health” were added to comprise the 15 item BCOS questionnaire. The items on the BCOS address
perceived life changes in social functioning, subjective well-being, and somatic health (Bakas & Burgener, 2002). Each item is rated as -3, -2, or -1, changed for the worst, +1, +2, or +3, changed for the best, or 0, did not change (Bakas & Burgener). To reflect positive numbers for the data analysis of the BCOS, each item was recoded. The score of -3, “Changed for the Worst” was recoded to 1. The score of +3, “Changed for the Best” was recoded to 7. All scores in between also were recoded. The recoded positive item responses are then added for a total caregiving score. Scores can range from 15 (changed for the worst) to 105 (changed for the best) with a score of 60 on the scale indicating no change (Bakas & Burgener). The Cronbach Alpha reported for the BCOS was .77, which indicates good internal consistency (Bakas & Burgener).

The 20 item CES-D questionnaire (Appendix D) is a self report scale designed to measure depressive symptoms in the general population (Radloff, 1977). Depressed moods, feelings of helplessness and hopelessness, and sleep disturbance are some of the components of the CES-D. Questions on the CES-D reflect how the caregivers felt during the past week, with responses on a Likert scale ranging from depressive symptoms less than 1 day to depressive symptoms for 5-7 days. The range of scores is 20 to 80; lower scores on the CES-D are indications of higher emotional health. A cut off score of 32 is indicative of a risk for clinical depression. The items on the CES-D have previously been validated with longer depression scales (Radloff). Validity was established by correlating the CES-D with other self-report measures and with clinical ratings of depression. The coefficient alpha and the Spearman-Brown indicate high internal consistency (.90) for this measure (Radloff).
The collection of demographic data (Appendix E) included information regarding the caregiver’s age, gender, ethnic background, educational background, employment status and occupation, health status, and relationship to the person with stroke. In addition, whether he/she lives within the greater Toledo area (within 1 hour) and length of time caring also were recorded. Demographic data for the care recipient (person with stroke) included age, gender, and whether he/she lives in a home setting.

Data Collection

Sample

A convenience sample of caregivers of persons with stroke using education and support groups was recruited from a larger, ongoing research study at the Medical College of Ohio (recruitment site 1) (Steiner & Pierce, 2002) and a local stroke caregiver support group from the Toledo area (recruitment site 2). To decrease the probability of a Type I error (rejecting the null hypothesis when it is considered true) the level of significance was determined to be .05 prior to this study. A sample size of 29 achieves 80% power to detect a difference of .5 between the null hypothesis correlation of 0.00 and the alternative hypothesis correlation of .5 using a two-sided hypothesis test with a significance level of .05.

Inclusion criteria for subjects to participate in this study were: 1) caregivers of persons with stroke who have provided care for greater than 1 month, 2) 18 years of age or older, 3) living in a metropolitan area in Toledo (within 1 hour), and 4) able to read, write, and comprehend the English language. A telephone connection was an additional
inclusion criterion for the subjects at recruitment site 1. Exclusion criteria were subjects under the age of 18 and not caring for the person with stroke in a home setting.

Protection of Human Rights

Approval for this study was obtained from the Institutional Review Board for Protection of Human Subjects at the Medical College of Ohio (Appendix F) prior to data collection. The potential subjects were fully informed that participation was voluntary and that they could withdraw from the study at any time. Subjects also could refuse to answer any questions at any time during the study. Participants from recruitment site 1 were provided with an opportunity to ask the trained interviewers any questions they may have had. Participants from recruitment site 2 were encouraged to contact the researcher with any questions or concerns. If the potential subjects decided not to participate, there was no penalty, loss of benefits, or any effects on current or future relations with the Medical College of Ohio or the local caregiver support group. Minimal risks were anticipated for study participation and this was verbalized to the subjects. The minimal risks were loss of confidentiality and anonymity. Confidentiality and anonymity were protected by assuring the subjects’ name or signature would not appear on any of the questionnaires. The researcher minimized the risk of loss of confidentiality by keeping all data secure. All data were stored in a locked, fire resistant safe in a personal home office and will be properly destroyed (shredded) in 6 years. All subjects were informed that the results of this study might be shared with a professional journal and its readers; however, all subjects would remain anonymous.
Recruitment Site 1

During a regularly scheduled telephone interview, participants were asked if they would be willing to answer a few more questions about life changes related to caring. These participants had at least 1 month experience in caring for a person with stroke. They had given written consent to participate in a larger, ongoing research study at the Medical College of Ohio about the caregiving experience. These participants also verbally consented to this study prior to completing the questionnaire. Only the BCOS was administered for this study. Data collection for these participants already included the CES-D and demographic data because of the larger, ongoing research study and was combined with the data from the BCOS. Only the first names of the participants were used by the interviewers. Completed questionnaires were given to the project coordinator of the larger study. The coordinator removed the names from the questionnaires and placed a previously assigned identification number on them. These identification numbers also were used to match demographic data from the database for these participants. All data given to this researcher only contained identification numbers.

Recruitment Site 2

Written permission was given to the researcher from the American Heart Association/American Stroke Association Health Initiatives Manager to attend the local caregiver support group meeting (Appendix G). The researcher attended two monthly support group meetings and read a letter of explanation, in the form of a cover letter, prior to inviting attendees to participate in this study (Appendix H). Consent to participate in this study was implied by written response to the BCOS and CES-D.
questionnaires and demographic data. The instruments and demographic data were assembled into packets and distributed to the participants at the local caregiver support group meeting by this researcher. The participants had the opportunity to return the completed questionnaires and demographic data at the end of the caregiver group meeting in a box or by mail in a self addressed and stamped envelope which was provided in the packets. The researcher requested the surveys to be returned within 1 week of the meeting. The telephone number of this researcher was provided and the participants who had questions or concerns were encouraged to call.

Assumption

The following assumption was made for this study: that caregiver subjects answered the questionnaires honestly and to the best of their abilities.

Limitations

Limitations of this study included: 1) use of a convenience sample of caregivers instead of a random sample, 2) homogeneity of the sample, and 3) all subjects sought formal support and education in a support group setting.

Data Analysis

Research Question: Is there a relationship between perceived life change related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support?

Data were set up by defining the variables and the variable values which represented the contents of a variable. After defining the variables, the data were systematically organized and entered into a software analysis program by the researcher.
Data were analyzed utilizing the Statistical Package for the Social Sciences (SPSS) 11.5 computer software (Chicago, Il., 2002). A careful review of each field was completed to clean the data.

The recoding of the BCOS data consisted of recoding the variables and modifying the variables that had already been entered. The transformed variable replaced the value of the current variable by adding 4 to each item of the BCOS. Each item of the 15 item BCOS was recoded to reflect positive numbers for the data analysis and was recoded one at a time by the researcher. The items then were summed for a total caregiving score.

For the 20 item CES-D, each of the items was scored on a scale from 1 to 4 based on the frequency of occurrence of depressive symptoms during the past week. The directions for the CES-D read “How you have felt during the past week” to reflect current symptoms. The items were summed for a total score indicating levels of depressive symptoms. Descriptive statistics included frequencies and percentages of the demographic variables along with the means and standard deviations of the study variables.

The statistical method used for this study was the Pearson’s Product-Moment Correlation Coefficient ($r$). The significance test for $r$ evaluated whether a linear relationship exists between perceived life changes related to caring and feelings of depression in the caregivers. The summed total caregiving score of the BCOS and the summed total score indicating depressive symptoms of the CES-D were correlated to assess the degree of linear relationship. Upon completion of the data entry and analysis, the data were downloaded onto a floppy disk and stored in a locked file by the researcher.
Summary

This research study examined the relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. The results of this study may assist health care professionals in developing interventions to help caregivers cope.

After gaining approval from the Institutional Review Board at the Medical College of Ohio, data collection occurred. The study design was descriptive correlational. Two questionnaires were utilized in this study, the BCOS by Bakas and Champion (1999), and the CES-D by Radloff (1977). The questionnaires were administered to caregivers of persons with stroke who were receiving ongoing support at two recruitment sites. Recruitment site 1 consisted of caregivers from a larger, ongoing research study of web-based education and support, and recruitment site 2 consisted of caregivers from a local support group meeting. For the protection of human rights, the participants were fully informed that participation in this study was voluntary. Information related to controls for internal and external validity threats, assumptions and limitations, as well as the process of data collection and analysis were discussed in this chapter.
CHAPTER IV

Results

The results obtained from this study are presented in this chapter. Demographic data of the sample are given. Data which answer the research question are discussed in a narrative form prior to presentation of a table. A summary concludes this chapter.

Sample

A convenience sample of caregivers of persons with stroke receiving ongoing support in a group setting in the Toledo area composed the sample. All participants met the inclusion criteria for this study of living within 1 hour of the greater Toledo area and of the persons with stroke living in a home setting. Forty-two questionnaires were made available and 29 questionnaires (69%) were completed.

The subjects in the sample (n = 29) were primarily white, middle-aged (range = 32-77 years) husbands and wives with a high school education (range = 9-21 years). On average, the subjects had been caring for the person with stroke for a little over a year and more than half (58.6%) of the caregivers also were employed outside of the home. The sample in this study is representative of the population of caregivers of persons with stroke as described by other studies (Bakas et al., 2002; Bakas & Burgener, 2002; Casas, 1989; Grant, 1996; Teel et al., 2001; Thompson et al., 1990; Williams, 1994). Descriptive statistics to summarize the demographic data for the caregivers are shown in Table 1.
Table 1. Demographic Characteristics of the Caregivers of Persons with Stroke (n = 29).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
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<tbody>
<tr>
<td><strong>Age:</strong></td>
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<td>30-39</td>
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<tr>
<td>9-12 (high school)</td>
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<td>13-16 (college)</td>
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<td>44.8</td>
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<tr>
<td>17→ (post-graduate)</td>
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</tr>
<tr>
<td>Other relative</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Months caring:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-12 (1 year)</td>
<td>15</td>
<td>51.4</td>
</tr>
<tr>
<td>13-24 (2 years)</td>
<td>9</td>
<td>30.8</td>
</tr>
<tr>
<td>25-36 (3 years)</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td>37-48 (4 years)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>49→ (over 4 years)</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>3.4</td>
</tr>
</tbody>
</table>
The care recipients were older than the caregivers (ages ranged from 33-85 years) and the majority of them were female. Table 2 has the demographic data for the persons with stroke.

Table 2. Demographic Characteristics of Persons with Stroke (n = 29).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>2</td>
<td>6.8</td>
</tr>
<tr>
<td>40-49</td>
<td>7</td>
<td>24.0</td>
</tr>
<tr>
<td>50-59</td>
<td>4</td>
<td>13.6</td>
</tr>
<tr>
<td>60-69</td>
<td>4</td>
<td>13.6</td>
</tr>
<tr>
<td>70-79</td>
<td>8</td>
<td>27.3</td>
</tr>
<tr>
<td>80→</td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>55.2</td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>44.8</td>
</tr>
</tbody>
</table>

Findings

Data to test the hypothesis that there is a relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support were analyzed utilizing the Statistical Package for the Social Sciences (SPSS) 11.5 computer software (Chicago, Il., 2002).

Two of the subjects did not entirely complete the CES-D questionnaires. One questionnaire was missing one item response and the other questionnaire was missing four item responses. Therefore, per consultation with a statistician, this researcher evaluated the items on the questionnaires and the missing items were assigned the average value given by the other caregivers for that item.
Each item of the Bakas Caregiving Outcomes Scale (BCOS) was summed for a total caregiving score and each item of the Center for Epidemiologic Studies Depression Scale (CES-D) was summed for a total score of depressive symptoms for each caregiver.

**BCOS Findings**

The BCOS total caregiving score for each caregiver ranged from 20-77 (mean = 55.79, SD = 12.23). The BCOS total caregiving score may range from 15 (changed for the worst) to 105 (changed for the best). A BCOS total caregiving score of 60 indicates no change. For this study, the mean was 55.79, resulting in an overall change for the worst due to caring for a person with stroke. In addition to the BCOS total caregiving score for each caregiver, the mean of each BCOS item was calculated. Item means close to 1 are reported as changed for the worst, item means close to 4 are reported as no change, and item means close to 7 are reported as changed for the best. The means of each BCOS item is ranked from worst to best (Table 3). The item addressing time for social activities with friends resulted in the lowest mean score of 2.62, indicating a change for the worst. The item addressing the relationship with the person with stroke resulted in the highest mean score of 4.79, indicating a slight change for the best.

**CES-D Findings**

The CES-D total score of depressive symptoms for each caregiver ranged from 20-61 (mean = 33.86, SD = 10.56). The CES-D total score of depressive symptoms may range from 20 to 80; lower scores on the CES-D are indications of higher emotional health. A cut off score of 32 is indicative of a risk for clinical depression (Radloff, 1977). For this study, the mean was 33.86, indicating these caregivers are at risk for clinical
Table 3. Means of Each Item on the BCOS (n = 29).

<table>
<thead>
<tr>
<th>BCOS Item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social activities w/friends</td>
<td>2.62</td>
<td>1.37</td>
</tr>
<tr>
<td>Roles in life</td>
<td>3.27</td>
<td>1.36</td>
</tr>
<tr>
<td>Level of energy</td>
<td>3.27</td>
<td>1.38</td>
</tr>
<tr>
<td>Family activities</td>
<td>3.27</td>
<td>1.50</td>
</tr>
<tr>
<td>Financial well-being</td>
<td>3.41</td>
<td>1.26</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>3.55</td>
<td>1.02</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>3.55</td>
<td>1.29</td>
</tr>
<tr>
<td>Physical health</td>
<td>3.58</td>
<td>1.11</td>
</tr>
<tr>
<td>Cope w/stress</td>
<td>3.75</td>
<td>1.61</td>
</tr>
<tr>
<td>General health</td>
<td>3.79</td>
<td>1.11</td>
</tr>
<tr>
<td>Future outlook</td>
<td>3.86</td>
<td>1.50</td>
</tr>
<tr>
<td>Relationship w/friends</td>
<td>3.96</td>
<td>1.26</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>4.37</td>
<td>1.01</td>
</tr>
<tr>
<td>Relationship w/family</td>
<td>4.68</td>
<td>1.41</td>
</tr>
<tr>
<td>Relationship to person w/stroke</td>
<td>4.79</td>
<td>1.67</td>
</tr>
</tbody>
</table>

depression. In addition to the CES-D total score of depressive symptoms for each
caregiver, the mean of each CES-D item was calculated. Items were reported as
depressive symptoms less than 1 day, depressive symptoms for 1-2 days, depressive
symptoms for 3-4 days, or depressive symptoms for 5-7 days. The item addressing how caregivers’ felt about people disliking them resulted in the lowest mean score of 1.13, indicating they felt this way less than 1 day during the past week. The item addressing how caregivers’ sleep was restless resulted in the highest mean score of 2.37, indicating they felt this way for 1-2 days during the past week. The means of each CES-D item are displayed in Table 4.

The Cronbach Alpha, a type of reliability, is an index of internal consistency used to measure the degree in which all of the items from the questionnaire are measuring the same element. The Cronbach Alpha summarizes the correlation between all the items and the total. Since the Cronbach Alpha is a type of reliability, a higher alpha results in higher internal consistency of the measure. The Cronbach Alpha for the BCOS was .87 for this study and was compared with the Bakas and Burgener (2002) study which indicated a Cronbach Alpha of .77; supporting Bakas and Burgener’s report of good internal consistency. The Cronbach Alpha for the CES-D was .89 for this study and was compared with the Radloff (1977) study which indicated a Cronbach Alpha of .90; supporting Radloff’s report of a high internal consistency.

A Pearson $r$ statistic was calculated to obtain the correlation coefficient indicating the strength of the relationship and significance between the specified variables. The Pearson $r$ correlation for the total scores of the BCOS and CES-D was -.65 showing a moderate linear relationship. The results of the correlational analysis presented in Table 5 show that the relationship between perceived life changes related to caring and feelings
### Table 4. Means of Each Item on the CES-D (n = 29).

<table>
<thead>
<tr>
<th>CES-D Items</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>People dislike me</td>
<td>1.13</td>
<td>.44</td>
</tr>
<tr>
<td>Life had been a failure</td>
<td>1.17</td>
<td>.46</td>
</tr>
<tr>
<td>People were unfriendly</td>
<td>1.24</td>
<td>.63</td>
</tr>
<tr>
<td>Appetite poor</td>
<td>1.34</td>
<td>.72</td>
</tr>
<tr>
<td>Crying spells</td>
<td>1.37</td>
<td>.67</td>
</tr>
<tr>
<td>Felt fearful</td>
<td>1.48</td>
<td>.78</td>
</tr>
<tr>
<td>Could not shake the blues</td>
<td>1.51</td>
<td>.87</td>
</tr>
<tr>
<td>Talked less than usual</td>
<td>1.51</td>
<td>.87</td>
</tr>
<tr>
<td>Felt I am as good as other people</td>
<td>1.51</td>
<td>1.02</td>
</tr>
<tr>
<td>Felt depressed</td>
<td>1.75</td>
<td>.95</td>
</tr>
<tr>
<td>Felt lonely</td>
<td>1.75</td>
<td>1.02</td>
</tr>
<tr>
<td>Trouble in keeping mind of task</td>
<td>1.82</td>
<td>.88</td>
</tr>
<tr>
<td>Felt sad</td>
<td>1.86</td>
<td>.83</td>
</tr>
<tr>
<td>I enjoyed life</td>
<td>1.93</td>
<td>.99</td>
</tr>
<tr>
<td>Bothered by things</td>
<td>1.93</td>
<td>1.06</td>
</tr>
<tr>
<td>Everything was an effort</td>
<td>2.00</td>
<td>.88</td>
</tr>
<tr>
<td>I was happy</td>
<td>2.00</td>
<td>1.10</td>
</tr>
<tr>
<td>Hopeful about future</td>
<td>2.03</td>
<td>1.11</td>
</tr>
<tr>
<td>Could not get “going”</td>
<td>2.06</td>
<td>1.06</td>
</tr>
<tr>
<td>Sleep was restless</td>
<td>2.37</td>
<td>1.32</td>
</tr>
</tbody>
</table>
Table 5. Pearson $r$ Correlation of Bakas Caregiving Outcomes Scale (BCOS) and Center for Epidemiologic Studies Depression Scale (CES-D).

<table>
<thead>
<tr>
<th></th>
<th>BCOS</th>
<th>CES-D</th>
</tr>
</thead>
<tbody>
<tr>
<td>BCOS</td>
<td>1.0</td>
<td>-.654**</td>
</tr>
<tr>
<td>CES-D</td>
<td>-.654**</td>
<td>1.0</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).**

of depression was statistically significant at the 0.01 level (2-tailed).

The data analysis in this study showed a negative or an inverse relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. In general, the results suggest that as the perceived life changes related to caring increased (changed for the best), the feelings of depression decreased.

Summary

This chapter described the demographic data and results obtained. Descriptive statistics to summarize the demographic data for the caregivers and the persons with stroke were shown in tables. Data to test the hypothesis were analyzed utilizing the SPSS 11.5 computer software (Chicago, Il., 2002). A discussion of the findings included the BCOS total caregiving score for each caregiver and the mean of each BCOS item, and the CES-D total score of depressive symptoms for each caregiver and the mean of each CES-D item. The Cronbach Alpha of the BCOS and CES-D also were discussed. A Pearson $r$
statistic was calculated to obtain the correlation coefficient indicating the strength of the relationship and significance between the BCOS and CES-D. There was a statistically significant relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support.
CHAPTER V

Discussion

A discussion of the findings from this study is included in this chapter. This chapter includes a discussion of Orem’s (2001) theoretical framework related to caregivers’ roles, a conclusion of the data analysis, and limitations of this study. Implications for nursing practice, education, and theory are discussed. Recommendations for further research and a summary conclude this chapter.

Findings

The hypothesis that there is a relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support was tested in this study. The correlational analysis resulted in a statistically significant relationship at the 0.01 level (2-tailed). As perceived life changes related to caring increased (changed for the best), feeling of depression decreased.

Previous studies focused on caregivers’ emotional distress (Anderson et al., 1995; Bakas & Burgener, 2002; Dennis et al., 1998; Lee et al., 2001; Parris Stephens & Townsend, 1997). Depression in caregivers of persons with stroke was studied by Thompson et al. (1990) in which the researchers reported that the caregivers’ age, sex, and length of time caring were not related to the caregivers’ depression. Several studies discussed life changes which are positive or negative experiences. Some of the caregivers felt their caregiver role with the person with stroke had changed in a positive manner as reported by Johnson (1998). Negative experiences in life changes such as a
decrease in attending social functions or family gatherings, difficulty in seeking and receiving home health services, and lack of social involvement were identified (DeLaune & Brown, 2001; Grant, 1996; Hartke & King, 2002). Caregivers reported support groups as being beneficial for social outlets as well as impacting self image in a positive manner (Mitchell, 1996). No studies were identified in examining the relationship between perceived life changes related to caring and feelings of depression.

Orem’s (2001) self-care deficit nursing theory guided this study for nursing practice and research. Caregivers need to possess the abilities (self-care agency) and requirements for action (therapeutic self-care demand) to have a desired effect on their development. The caregiver may benefit from the implementation of nursing interventions (supportive-educative nursing system) in which the caregiver is able to perform self-care actions. The findings of this study showed an inverse relationship between perceived life changes related to caring and feelings of depression \( (r = -.65, p < .01) \); as the perceived life changes related to caring increased (changed for the best), the feelings of depression decreased. The perceived life changes related to caring and feelings of depression in caregivers who are receiving ongoing support impacted the caregivers’ ability to maintain acts of self-care. The findings suggest that a supportive-educative nursing system could focus on interventions targeting either actual or potential self-care deficits in caregivers of persons with stroke.

For this study, the BCOS total caregiving score for each caregiver ranged from 20-77 (mean = 55.79, SD = 12.23). On average, the caregivers reported a change for the worst in perceived life changes related to caring for persons with stroke. Each BCOS
item then was ranked from worst to best according to the means. The findings suggest that each BCOS item with a mean of less than 4 (changed for the worst) would be the focus for nursing interventions.

Limitations

Limitations for generalization of the results of this study were as follows: 1) the use of a convenience sample of caregivers instead of a random sample; 2) homogeneity of the sample; 3) all subjects sought formal support and education in a support group setting; and 4) while the sample size achieved adequate power for this study, this sample size may have been too small to achieve true heterogeneity of demographic characteristics.

Implications

The purpose of this study was to examine the relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke who are receiving ongoing support. The self-care deficit nursing theory, as discussed by Orem (2001, p. 136), is “a general theory of what nursing is and what nursing should be as it is produced in concrete nursing practice situations.” Orem’s self-care deficit nursing theory suggests that actual or potential self-care deficits may exist in individuals and nursing interventions may be utilized. The supportive-educative nursing system is implemented when nurses provide interventions related to the caregivers’ development of self-care agency (abilities).

Assessing and screening for depressive symptoms in caregivers of persons with stroke should be included in the initial assessment process. The caregiving demands may
have negative implications for continuing the caregiver role for persons with stroke. Implications for nursing practice should include a holistic framework to include family members and friends who may fulfill the role as caregiver. Nurses should assess the resources of the caregivers’ community and their social support, the caregiving demands that are perceived as life changes related to caring, and feelings of depression to determine the impact of being a caregiver. Assessments may be made through the use of questionnaires, through the nurse-patient relationship, or through the nurse-family member relationship. Assessments assist nurses in implementing appropriate interventions.

Nursing interventions may be implemented when an actual or potential deficit occurs in caregivers of persons with stroke. Social activities with friends was reported as a change for the worst in caregivers of persons with stroke, therefore, nursing interventions should include psychological or environmental support. Roles in life, level of energy, and family activities also were perceived as a change for the worst by the caregivers. Interventions for these perceived life changes may include educational literature about the disease process of stroke and the acquisition of new roles, energy conservation techniques, and collaboration with other disciplines in improving/maintaining the caregivers’ own health and well-being. Financial well-being was reported in the top five items as being a change for the worst. Assessing financial well-being may include a discussion of any financial concerns about daily expenses, medical supplies/equipments, or medication therapy. Interventions may include a referral
to financial counseling and education about medical equipment or pharmaceutical programs to assist with costs.

Implications for nursing education should focus on increasing the knowledge and awareness of the nursing profession about the importance of the caregivers’ needs and concerns. Perceived life changes related to caring may be a potential self-care deficit for the caregivers. Therefore, nursing education is essential to teaching caregivers of persons with stroke to cope effectively and implementing interventions to help them. Nursing administration may utilize evidence based research in developing or continuing the funding of educational programs and nursing staff. Nursing administration may collaborate with the advanced nurse practitioner(s) in identifying niches which may further educate nurses about providing a holistic approach to caregivers, therefore, empowering the caregivers to manage the care of themselves and the persons with stroke. The advance nurse practitioner(s) may implement regularly scheduled meetings with nursing professionals or caregivers to follow up on any future needs, concerns, or issues about the caregiving role.

Recommendations for Further Research

Recommendations for further research include replicating this research utilizing a random sample and a sample of caregivers who are not seeking formal support and education in a support group setting. Another recommendation includes a study examining the difference in feelings of depression and the length of time providing care. These recommendations may provide better generalization of the findings to a larger population of caregivers.
Summary

The discussion of the findings related to caregivers of persons with stroke who are receiving ongoing support was presented in this chapter. The findings of this study were discussed in relation to previous research studies and the theoretical framework. Several studies focused on emotional distress, life change either positive or negative experiences, and social support (Anderson et al., 1995; Bakas & Burgener, 2002; Grant, 1996; Hartke & King, 2002; Johnson 1998; Mitchell, 1996). No studies were identified that examined the relationship between perceived life changes related to caring and feelings of depression. Orem’s (2001) self-care deficit nursing theory guided this study for nursing practice and research. Limitations for generalization of the results were specified. Implications for nursing practice, education, and theory were discussed. Recommendations for further research also were discussed and included replication of this research study utilizing a random sample and caregivers not currently seeking formal support and education in a support group setting.
REFERENCES


APPENDIX A

Bakas Caregiving Outcomes Scale (BCOS)

IRB # 104524
Life Changes Questionnaire 1

Interview Week ______________ ID # ____________________

I am going to read a sentence to you and I want you to tell me about the possible changes in your life from providing care. For each possible change listed, tell me a number indicating the degree of change. The numbers indicating the degree of change range from -3 “Changed for the Worst” to +3 “Changed for the Best.” The number 0 means “Did Not Change.” Please be open and honest in your response.

(CIRCLE THE APPROPRIATE NUMBER)

<table>
<thead>
<tr>
<th>Changed for the Worst</th>
<th>Did Not Change</th>
<th>Changed for the Best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>0</td>
<td>+1</td>
<td>+2</td>
</tr>
<tr>
<td>+3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As a result of providing care for the person with stroke:

1. My self esteem          O  O  O  O  O  O  O  O
2. My physical health      O  O  O  O  O  O  O  O
3. My time for family activities O  O  O  O  O  O  O  O
4. My ability to cope with stress O  O  O  O  O  O  O  O
5. My relationship with friends O  O  O  O  O  O  O  O
6. My future outlook       O  O  O  O  O  O  O  O
7. My level of energy      O  O  O  O  O  O  O  O
8. My emotional well-being O  O  O  O  O  O  O  O
As a result of providing care for the person with stroke:

<table>
<thead>
<tr>
<th></th>
<th>Changed for the Worst</th>
<th>Did Not Change</th>
<th>Changed for the Best</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>-3  -2  -1  0  +1  +2  +3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. My roles in life
   O O O O O O O O

10. My time for social activities with friends
    O O O O O O O O

11. My relationship with my family
    O O O O O O O O

12. My financial well-being
    O O O O O O O O

13. My relationship with the stroke survivor
    O O O O O O O O

14. My physical functioning
    O O O O O O O O

15. My general health
    O O O O O O O O

[STUDENT USE ONLY  Total _________]
First, think about how providing care has changed your life. For each possible change listed, circle one number indicating the degree of change. The numbers indicating the degree of change range from -3 “Changed for the Worst” to +3 “Changed for the Best.” The number 0 means “Did Not Change.” Please be open and honest in your response.

### (CIRCLE THE APPROPRIATE NUMBER)

<table>
<thead>
<tr>
<th>Changed for the Worst</th>
<th>Did Not Change</th>
<th>Changed for the Best</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td>+2</td>
<td>+3</td>
</tr>
</tbody>
</table>

As a result of providing care for the person with stroke:

1. My self esteem
   -3 -2 -1 0 +1 +2 +3
2. My physical health
   -3 -2 -1 0 +1 +2 +3
3. My time for family activities
   -3 -2 -1 0 +1 +2 +3
4. My ability to cope with stress
   -3 -2 -1 0 +1 +2 +3
5. My relationship with friends
   -3 -2 -1 0 +1 +2 +3
6. My future outlook
   -3 -2 -1 0 +1 +2 +3
7. My level of energy
   -3 -2 -1 0 +1 +2 +3
8. My emotional well-being
   -3 -2 -1 0 +1 +2 +3
<table>
<thead>
<tr>
<th>Changed for the Worst</th>
<th>Did Not Change</th>
<th>Changed for the Best</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changed for the Worst</td>
<td>Did Not Change</td>
<td>Changed for the Best</td>
</tr>
</tbody>
</table>

As a result of providing care for the person with stroke:

9. My roles in life
   -3 -2 -1 0 +1 +2 +3

10. My time for social activities with friends
   -3 -2 -1 0 +1 +2 +3

11. My relationship with my family
   -3 -2 -1 0 +1 +2 +3

12. My financial well-being
   -3 -2 -1 0 +1 +2 +3

13. My relationship with the stroke survivor
   -3 -2 -1 0 +1 +2 +3

14. My physical functioning
   -3 -2 -1 0 +1 +2 +3

15. My general health
   -3 -2 -1 0 +1 +2 +3

[STUDENT USE ONLY  Total _________]
APPENDIX C

Letter of Correspondence

September 26, 2002

Thank you very much for your interest in the Bakas Caregiving Outcomes Scale. The scale was developed and tested using two separate samples of stroke caregivers as published in the Bakas and Champion (1999) article in Nursing Research 48(5), 250-259.

Attached is the latest version of the scale. I have deleted the two items, “My ability to pay bills” and “My ability to buy necessities” due to the psychometric findings mentioned in the Bakas and Champion (1999) article.

I have added the following items to improve the scale:
“My level of energy”
“My roles in life”
“My financial well-being”
“My physical functioning”
“My general health”

The last item, “In general, how has your life changed as a result of taking care of the stroke survivor?” is included to check for scale validity.

In scoring the scale, you will need to recode the (-3 = “Changed for the Worst” to +3 = “Changed for the Best”) to (1 = “Changed for the Worst” to 7 = “Changed for the Best”) so that positive numbers are obtained for analysis. Add the recoded item responses for a total caregiving outcomes score.

I have tested this newer version of the 15 item Bakas Caregiving Outcomes Scale in a sample of 91 family caregivers of lung cancer patients, and in a small sample of 32 family caregivers of stroke survivors. I have attached presentation abstracts for these two studies.

If you decide to use the Bakas Caregiving Outcomes Scale in research or practice, you should use the latest version that I have attached. If your results become published, please cite the Bakas and Champion (1999) article when referring to the scale and the findings. You may also cite the enclosed presentations.

I hope that you find the Bakas Caregiving Outcomes Scale helpful, and if you have any questions or comments, please don’t hesitate to contact me. Thank you again for your interest in the Bakas Caregiving Outcomes Scale.

Sincerely,
Tamilyn (Tami) Bakas, RN, DNS, FAHA
Associate Professor
Indiana University School of Nursing
1111 Middle Drive, NU 417
Indianapolis, IN 46250 USA
Office: (317) 274-4695
Fax: (317) 278-1856
Email: tbakas@iupui.edu
APPENDIX D

Center for Epidemiologic Studies Depression Scale (CES-D)

IRB # 104524
Past Week Questionnaire 1

Next, think about how you have been feeling lately. For each phrase, please circle a response as to how you have felt during the past week, if you have felt this way for less than one day, one to two days, three to four days, or five to seven days.

<table>
<thead>
<tr>
<th></th>
<th>Less than 1 Day</th>
<th>1 – 2 Days</th>
<th>3 – 4 Days</th>
<th>5 – 7 Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I was bothered by things that usually don’t bother me</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>b. I didn’t feel like eating; my appetite was poor</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>c. I felt that I could not shake off the blues even with the help from my family or friends</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>d. I felt that I was just as good as other people</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>e. I had trouble keeping my mind on what I was doing</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>f. I felt depressed</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>g. I felt that everything I did was an effort</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>h. I felt hopeful about the future</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>i. I thought my life had been a failure</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>j. I felt fearful</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>k. My sleep was restless</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>l. I was happy</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Question</td>
<td>Less than 1 Day</td>
<td>1 – 2 Days</td>
<td>3 – 4 Days</td>
<td>5 – 7 Days</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>------------</td>
<td>------------</td>
<td>------------</td>
</tr>
<tr>
<td>m. I felt lonely</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>n. People were unfriendly</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>o. I enjoyed life</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>p. I had crying spells</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>q. I felt sad</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>r. I felt that people dislike me</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>s. I could not get “going”</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
APPENDIX E

Demographic Information Sheet

Finally, please tell us a little about yourself and the person you care for. IRB# 104524

1. What is your age? ___________                                12. Do you live within the greater Toledo area (within one hour)?
   ____ 1) Male                                                                         ____ Yes
   ____ 2) Female                                                                 ____ No

2. What is your gender?                                                        _____ Yes
3. What is your ethnic background?                               _____ No
   ____ 1) American Indian or Alaska Native                          _____ Yes
   ____ 2) Asian or Pacific islander                                          _____ No
   ____ 3) Black, not of Hispanic Origin                                  ____ 5) White, not of Hispanic Origin
   ____ 4) Hispanic Origin                                              _____ 6) Unknown
   ____ 5) White, not of Hispanic Origin
   ____ 6) Unknown

4. How many years of school have you completed? _________________

5. Are you currently employed?                                                
   ____ 1) Yes, full time 
   ____ 2) Yes, part time 
   ____ 3) No

6. What is/was your occupation? ____________________________________________

7. What is your health status?                                                
   ____ 1) Poor
   ____ 2) Fair
   ____ 3) Good
   ____ 4) Very good
   ____ 5) Excellent

8. What is the age of the person you are caring for? __________

9. What is the gender of the person you are caring for?                     
   ____ 1) Male
   ____ 2) Female

10. What is your relationship to the person with stroke? That is you are his/her…..
    ____ 1) Wife                                                                 
    ____ 2) Husband                                                           
    ____ 3) Daughter                                                          
    ____ 4) Son                                                               
    ____ 5) Other relative (specify) __________________________________________
    ____ 6) Friend

11. How many months have you been caring for the person with stroke?       

   ______________________
APPENDIX F

Medical College of Ohio
INSTITUTIONAL REVIEW BOARD

MEMORANDUM

TO: Linda Pierce, Ph.D., R.N.
Department of School of Nursing
MCO

FROM: Daniel Cipriani, Ph.D., P.T.
Vice-Chair, Institutional Review Board
Research and Grants Administration

DATE: October 15, 2003

SUBJECT: IRB #104524- Examining the Relationship Between Perceived Life Changes and Feelings of Depression in Caregivers of Persons with Stroke

The above project was reviewed and approved by the Chairman of the Institutional Review Board as an expedited review (category #7). This review and approval includes the Life Changes questionnaires and the cover letter submitted with the IRB application. The requirement to obtain a signed consent/authorization for use and disclosure of protected health information form has been waived as this research is determined to be minimal risk and a signed consent/authorization document would be the only record linking the subject to the data. It was determined that this waiver for signed consent/authorization for use and disclosure of protected health information form will not adversely affect the rights and welfare of the participants. The Principal Investigator must provide a copy of the cover letter to all participants that are recruited from the support group prior to participation. The full board will review it at its meeting on 11/20/2003.

NOTE: THE ATTACHED COVER LETTER WITH THE IRB APPROVAL STAMP IS THE ONLY VALID VERSION AND SUPERCEDES ALL PREVIOUSLY APPROVED VERSIONS. THIS FORM MUST BE COPIED AND USED FOR ALL STUDY PARTICIPANTS BEING RECRUITED FOR THIS RESEARCH. STUDY PARTICIPANTS FROM THE SUPPORT GROUP MUST BE GIVEN A COPY OF THIS FORM PRIOR TO CHOOSING TO PARTICIPATE IN THIS RESEARCH.

APPROVAL DATE: 10/15/2003
EXPIRATION DATE: 10/14/2004

It is the Principal Investigator’s (P.I.’s) responsibility to:
1. Abide by all federal, state, and local laws and regulations; the MCO federal assurance and institutional policies for human subject research and protection of individually identifiable health information and be sure that all members of your research team have completed the required education in these areas.
2. Ensure that all subjects, or their legally authorized representatives, are provided a copy of the Cover Letter prior to choosing to participate in this research.
3. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule Privacy Rule (45 CFR 164) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information.
4. Promptly notify the IRB at (419) 383-4251 of any untoward incidents or unanticipated adverse reactions that develop in the course of your research on human subjects. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MCO IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).
5. Report promptly to the MCO IRB any deviations, violations, participant non-compliance from the IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject's initials and study I.D. number, date of the event, a brief description of the occurrence and a description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.
6. Obtain **prior IRB review and approval** for changes in procedures, inclusion/exclusion criteria, study personnel, source of participants, new or additional advertising materials, modifications to subject payments, and for any and all changes to the cover letter and survey tool.

7. Report promptly new information affecting the risk/benefit ratio and obtain **prior IRB approval** for any changes in the study documents that may be required by the new information.

8. Obtain **prior IRB review and approval** for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and/or the institution. These incentives may be in the form of money or other items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

9. Approval by the MCO Institutional Review Board does not take the place of any other approval required by the Medical College of Ohio, non-MCO performance sites, the government and/or the study sponsor.

To request review and approval for changes to IRB approved research, please complete and submit RGA Form 314 (http://www.mco.edu/research/rga_frms/rga314.doc) with a copy of all materials relevant to the requested change (including the cover letter and survey tool if applicable) with the changes underlined. If you are requesting review and approval of a cover letter or survey tool, please attach a clean copy of the revised forms for the IRB to stamp.

IRB protocols must be reviewed and re-approved **not less than once per year**. Research and Grants Administration will try to remind you when re-approval is due. **However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date.**

**When you decide to stop this research, you must complete and submit a final report (RGA Form 320) to the IRB for review.**

Enclosures: Stamped Cover Letter and Survey Tool
APPENDIX G

Letter of Agency Approval

October 17, 2003

Michele Jorstad
1844 Peacock Lane
Holland, OH 43528

Dear Ms. Jorstad,

I have read the attached materials and consent to allow you recruitment opportunities at the Toledo Metro Stroke Survivor and Caregiver Support Group. I understand that the participants are not under obligation to complete the surveys and that all information received will be held in the strictest of confidence. I look forward to meeting you at the November meeting date. It will be most appropriate as November is National Caregiver Month.

Sincerely,

[Signature]

Kris Pupos
Health Initiatives Manager
APPENDIX H

Letter of Invitation to Participate

My name is Michele Jorstad. I am a Registered Nurse and a graduate student at the Medical College of Ohio School of Nursing. My academic professor is Dr. Linda Pierce. I would like to study your feelings and how you think your life may have changed since caring for a person with stroke. This study may assist health care professionals in developing ways to help caregivers cope. I invite you to take part in my study.

The surveys are on the following pages. Taking part in this study is voluntary and you may refuse or withdraw from the study at any time. You can choose to not answer any portion of the survey at any time during this study. If you decide not to take part, it will be not effect your current or future relations with the Medical College of Ohio.

If you choose to complete the surveys, the risks are small. There is a slight chance that other individuals may find out personal information about you, although the researcher will make every effort to maintain confidentiality. Please complete and return the surveys within 1 week to Michele Jorstad by mail in the stamped and addressed envelope provided. Your consent to take part in this study is implied by your written response to the surveys. Please do not place your name or other identifying information on the survey materials. All the information collected from you is confidential to the extent permitted by applicable laws and regulations, which means your name will not appear on any papers on which this information is noted. The results of this survey may be shared with a professional journal and its readers as well as your support group, however all information will remain anonymous. If you have questions or concerns, please contact Michele Jorstad at (419) 867-7902. Please do not leave a voice mail message that identifies you, if you do not want your name and number known. Thank you for you helping me with this study.

Michele Jorstad, BSN, RN           Linda Pierce, PhD, RN

IRB # 104524
ABSTRACT

The relationship between perceived life changes related to caring and feelings of depression in caregivers of persons with stroke was examined. A convenience sample of caregivers (n = 29) who were receiving ongoing support completed two questionnaires: Bakas Caregiving Outcomes Scale (BCOS) and Center for Epidemiologic Studies Depression Scale (CES-D). Subjects were primarily white, middle-aged spouses who had been caring for the person with stroke for about a year. The mean score on the BCOS was 55.79, indicating an overall change for the worst due to the caregiving role. The item addressing time for social activities with friends resulted in the lowest score. The mean score on the CES-D was 33.86, indicating a risk for clinical depression. Correlational analysis found that as perceived life changes decreased (changed for the worst), feelings of depression increased. Interventions aimed at decreasing the negative perceived life changes related to caring need further exploration.