A DESCRIPTION OF A PROJECT ON THE USE OF MINDFULNESS FOR STROKE SURVIVOR CAREGIVERS

by

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DEDICATION

This is dedicated to my family. To my husband Russell, who supported me through the tears, laughter, and success I experienced in my DNP journey, to my mother and father, Anita and Maurice Kirby who gave me the courage to achieve even what seemed to be unattainable, and to my son, Rhys, who is my inspiration to push forward even when the challenges faced seem insurmountable. I love you all, and you each inspire me every day.

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ABSTRACT

Some stroke survivor caregivers experience caregiver burden and depression after their family member experiences a life-altering cerebrovascular accident. Stroke survivor caregivers may face negative mental and physical health impacts when providing stroke survivors' care within their home, which can lead to the stroke survivor encountering negative health outcomes. Educating stroke survivor caregivers on mindfulness cognitive behavioral therapy provides them with a tool that can allow them to better cope with caregiver burden and depression that can be experienced when providing care. Therefore, the purpose of this project was to provide stroke survivor caregivers with education about the use of mindfulness to improve mental health. Data collection consisted of the Caregiver Burden Scale and Patient Health Questionnaire at baseline, at time of stroke survivors' discharge and two weeks after discharge to home. Largely related to the onset of the COVID-19 pandemic, this project had limited recruitment (n=2) and retention (n=0). Given the mounting evidence on the benefits of mindfulness practices, this project could be implemented in the future when social interactions, such as in-person support groups, resume post COVID-19 era.

CHAPTER ONE

INTRODUCTION

Background and Significance

In today's healthcare, patients who, in the past, may have had longer stays within the hospital are now discharged into the community with significant others or immediate family members as their primary caregivers. As technology and medical treatments advance, many patients who experience a cerebrovascular accident (CVA) survive but are functionally impacted enough that they require assistance for their day-to-day care once they are discharged home. Once home, the day-to-day care is often provided by a significant other or immediate family member, and their health and mental well-being can be negatively impacted due to the stress of caregiving (Greenwood, Mackenzie, Wilson, & Cloud, 2009). Because of the nature of strokes occurring suddenly, greater than 50% of stroke survivors are unable to live independently after one year, and they remain functionally impaired after five years (Zhu & Jiang, 2018). In addition to being functionally impaired, between 7% and 41% of patients who survive a stroke will develop dementia (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011).

Depression is a major health issue that is affected by stroke survivor caregiver stress. Between 30% and 68% of stroke survivor caregivers experience depression from the initial time of the family members' stroke to up to three years after the event (Woodford, Farrand, Watkins, Richards, & Llewellyn, 2014). Maintaining and supporting the mental health of stroke survivor caregivers is crucial as depression has been negatively associated with the outcomes of stroke survivors (Jani, Simpson, Lawrence, Simpson, & Mercer, 2018). How well the stroke survivor

caregiver manages the changes to their emotional well-being can be a predictor for their stroke survivor family member's future hospitalizations, length of hospitalizations, and mortality rates (Railka de Souza Oliveira et al., 2013). Interventions that teach new cognitive behavioral skills to stroke survivor caregivers can positively impact their physical and emotional quality of life, and in return impacts stroke survivors' quality of life (Wilz & Barskova, 2007).

Mindfulness is a method of cognitive behavioral therapy that can be used to manage stress levels. Mindfulness cognitive behavioral therapy teaches a generalized method of stress management that can apply to many different stressful situations (Brown, Coogle, & Wegelin, 2016). Mindfulness teaches the user to pay attention to their body and mind in the current moment and to be non-judgmental towards themselves (Cullen, 2011). Teaching mindfulness to stroke survivor caregivers allows them to manage their response to stressors less impulsively while at the same time it helps them to focus more reflectively on their stressors (Whitebird et al., 2013). Stroke survivor caregivers are often faced with coping with sudden life-changing stressors. Providing a tool for them at the beginning of their care journey can help them to better cope with the day-to-day stressors they face and to reduce the risk of developing depression. Educating stroke survivor caregivers while their family member is in the acute care environment allows them to practice their new skills and receive guidance when they are challenged with what they have learned.

Problem and Rationale for Project

Stroke survivor caregivers in the community experience significant levels of burden that have the potential to create mental health issues such as depression. Further, stroke survivor caregivers often feel inadequately prepared for the challenges associated with the mental,

physical, and cognitive demands related to stroke survivor care (Brasier et al., 2016). Nearly 24.6% of stroke survivor caregivers report high burden levels at two months after stroke survivor discharge from hospital, and after one year, 22.7% continue to report high burden levels (Kruithof et al., 2016). Ineffective caregiver coping with new stressors can negatively affect the personal relationship between the stroke survivor and the carer while placing the survivor at high risk for adverse outcomes which may result in future hospitalizations and worsening health for the stroke survivor (Kruithof et al., 2016). Stroke survivor caregivers are at high risk for depression as well as for physiological disease such as cardiovascular disease (Zhu & Jiang, 2018). Once the caregiver's health is negatively impacted, the possibility that the caregiver can no longer care for the stroke survivor at home increases, and the stroke survivor may need to leave their home for assisted living care.

Purpose

The goal of this project was to help maintain the mental well-being of stroke survivor caregivers by developing an educational process for stroke survivor caregivers that could be used by nursing staff to introduce and teach basic mindfulness cognitive behavior techniques while a stroke survivor family member is in the acute care environment of the hospital. By teaching stroke survivor caregivers mindfulness cognitive behavioral therapy, stroke survivor caregivers have the potential of being better able to cope with the emotional, physical, and cognitive changes experienced by their family member, as well as the role changes that they experience once the stroke survivor is discharged to the community. The benefit of providing education on mindfulness is that stroke survivor caregivers have a greater chance at successfully managing any potential depression (Brasier et al., 2016). Providing mindfulness skills education while the

stroke survivor is admitted to a rehabilitation unit provides the stroke survivor caregivers with a tool that can assist them in coping with the stressors and life changes that they will face once the stroke survivor is discharged into the community and under their direct care.

Implementing mindfulness education was a feasible project for the rehabilitation unit that this project was implemented on, as it focused on addressing the needs of caregivers with family members who were patients on the rehabilitation unit. An important part of the requirements for patient and family care on the rehabilitation unit includes providing family and patients with mental health support and education during the challenges stroke survivors face while recovering from a stroke. Delivering education and support for mental health well-being to family members (i.e., stroke survivor caregivers) of patients is a priority for the rehabilitation unit.

Significance to Nursing Practice

Stroke affects 800,000 Americans a year, and stroke mortality has continued to decrease, leaving more stroke survivors to be discharged home with informal caregivers (Koton et al., 2014). Stroke survivor caregivers are often the primary caregivers of stroke survivors with significant physical, mental, and psychological impairment, resulting in 30% to 68% of caregivers experiencing depression from the time of the initial stroke to three years after the stroke (Woodford et al., 2014). While not all stroke survivor caregivers experience depression, based on research, a significant percentage of them do. Stroke survivor caregivers experience instantaneous changing of their life, the loss of personal time, and feelings of loneliness and isolation due to their family member's stroke (Pereira & Rebelo Botelho, 2011). It is beneficial for caregivers to receive interventions aimed at managing any depressive symptoms during the time in which the stroke survivor is hospitalized, and nurses can provide cognitive behavioral

therapy skills that can help stroke survivor caregivers manage negative psychological reactions (Guo & Liu, 2015). Mindfulness encourages focusing on the now and accepting feelings and emotions without judgement (Edenfield & Saeed, 2012). In addition, stroke survivors who are discharged into the community with their informal caregivers have better outcomes when their caregiver can cope effectively with their new care responsibilities (Kruithof et al., 2016). Stroke survivor caregivers are particularly vulnerable to depression during the first nine months after discharge from hospital, and how well they cope with their new life changes can impact whether a stroke survivor is re-hospitalized (Pucciarelli et al., 2018). Stroke survivors and their caregivers need to receive the support and tools to maintain mental well-being during the rehabilitation phase of stroke survivor recovery (Peyrovi, Mohammad-Saeid, Farahani-Nia, & Hoseini, 2012).

CHAPTER TWO

REVIEW OF LITERATURE AND THEORETICAL FRAMEWORK

This chapter focuses on the summary of literature on stroke survivor caregivers, the effect of stroke on caregivers, stroke survivor caregivers and depression, the effect of caregiver well-being on stroke survivors, the role of healthcare providers in stroke survivor well-being, the definition of mindfulness cognitive behavioral therapy, and the effects of mindfulness cognitive behavioral therapy on stroke survivor caregivers. The search terms “CVA caregiver,” “stroke survivor carer,” “mindfulness and caregivers,” “stroke survivors in the community,” “stroke survivor caregivers,” “cognitive behavior and caregivers,” “cognitive behavior therapy,” “caregiver burden,” “caregiver depression,” “stress reduction for caregivers,” “mindfulness and caregiver depression,” “mindfulness and healthcare”, “and effect of mindfulness on stroke survivor caregivers” were used to identify literature. The electronic databases that were searched were CINAHL, Cochrane, Ovid, Medline, PSYCArticles, and Pubmed and included literature from 1999 to 2019. The review of the literature is organized below by themes that were identified from the relevant literature. Following the review of literature is a description of the theoretical framework that was used to guide this project.

Relationship between Caregiving and Stress

While caregivers can achieve a feeling of well-being and personal achievement from caring for their family member, caregivers experience stress from adapting their personal and professional lives to the role of caregiver (Cormac & Tihanyi, 2006). In 2009, there were approximately 42.1 million caregivers who provided care to family members within the home,

and the family members suffered from disease processes such as Alzheimer's disease, chronic health problems, Parkinson's disease, cancer, and dementia, leaving family caregivers with significant feelings of caregiver burden (Stjernsward & Hansson, 2018). Family caregivers can experience negative feelings that can impact their mental health, and in turn, their stress affects how they are able to care for their family member (Stjernsward & Hansson, 2018). Caregivers may experience feelings of inability to take time for themselves, and they have decreased time for a social life due to the amount of time required for caring for their family member (Moral-Fernandez, Frias-Osuna, Moreno-Camara, Palomino-Moral, & Del-Pino-Casado, 2018).

Stroke Survivor Caregivers

Due to the improvements in acute stroke care and the utilization of thrombolytics, many more people are surviving stroke events that may leave them with significant disabilities (Okoye et al., 2019). While the stroke survivor's new disabilities can negatively impact their ability to perform their own activities of daily living independently, many are provided with therapies to help relearn how to care for themselves. After receiving therapies in specialized rehabilitation units, the goal for stroke survivors is to be discharged back into their community. While the stroke survivor may be recovering from their stroke, they may still have functional limitations, and they often are discharged home under the care of an informal caregiver such as a spouse or family member who is instrumental in how successful the stroke survivor is in staying within their community (Atteih et al., 2015).

Once a stroke survivor is discharged from a hospital into the community, the stroke survivor caregiver faces significant stress in caring for the stroke survivor, and they often report feeling unprepared for the challenges they face in their day-to-day care of the stroke survivor

(Cecil, Thompson, Parahoo, & McCaughan, 2013). Stroke Survivor caregivers may have little to no experience in providing the day-to-day care necessary for their stroke survivor family member, and this can be overwhelming for the caregiver. Stroke survivor caregivers are faced with trying to obtain as much education as they can on caring for the stroke survivor while they are in hospital, and often they feel that they are not given enough information about how to care for the stroke survivor (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). Faced with the many facets of change that directly impacts their way of life and relationship with the stroke survivor, often stroke survivor caregivers experience an impairment of their own emotional health (Forsberg-Warleby, Moller, & Blomstrand, 2004).

Effect of Stroke on Caregivers

Medicare stroke survivors are discharged to home 45% of the time, and because of the suddenness of strokes, caregivers are frequently unprepared for the care and burden that will be involved (Jessup, Bakas, McLennon, & Weaver, 2015). The nature of a stroke causes an immediate change in the role dynamics between a stroke survivor and their family member, and the changes place new emotional, physical, and cognitive demands on both the stroke survivor and the caregiver (Brasier et al., 2016). How the stroke survivor caregiver manages their life changes and their impact can cause a negative effect on the well-being of the caregiver (Okoye et al., 2019). Once the stroke survivor is discharged back into their community, the stroke survivor caregiver is often the main provider for stroke survivor care, and strokes can affect the communication, mobility, and self-care abilities of the stroke survivor, leading to an increased feeling of burden experienced by the stroke survivor caregiver (Eldred & Sykes, 2008).

Approximately 35% of people who survive a stroke will experience significant changes in their ability to care for themselves, and 30% of them will experience cognitive impairment as well as depression (Savini et al., 2015). The stroke survivor caregiver is left to manage a balance between the needs of the stroke survivor and their own needs, both of which experience significant changes because of the stroke (Gbiri, Olawale, & Isaac, 2015). Once in the community, stroke survivor caregivers are faced with higher rates of financial, societal, personal, and physiological problems that place them at high risk for impaired psychological well-being (Balhara, Verma, Sharma, & Mathur, 2012). Three months after discharge of the stroke survivor into the community, 46% of caregivers experience mental and physical strain, and at six months, the number only decreases to 43% (Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014).

The mental well-being of stroke survivor caregivers is a determining factor in their quality of life, and often supportive services within their community are increasingly specialized and unavailable to them (Tebb, Berg-Weger, & Rubio, 2013). Stroke survivor caregivers frequently face an overabundance of burdens within a short time frame that can negatively impact their well-being if they are not emotionally prepared and do not have the interventions in place to effectively cope with life changes after their family member returns home after a stroke (Zhu & Jiang, 2018). Stroke survivor caregivers are also often unaware of the emotional and behavioral changes of the stroke survivor, and this can cause significant stressful feelings and a change in the relationship between the stroke survivor and stroke survivor caregiver (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). While the stroke survivor caregiver experiences high levels of stress and burdens, they may not feel able to ask for help, leaving them to suffer while caring for their stroke survivor (Bakas et al., 2002).

Stroke Survivor Caregivers and Depression

Depression in stroke survivor caregivers is three times greater than the general population, and these caregivers face a decrease in quality of life (Pucciarelli et al., 2018). Spouses, who are often the stroke survivor's primary caregiver when discharged into the community, experience symptoms of depression at a rate of 68% after the initial stroke and at 50% three years after the initial stroke (Smith, Egbert, Dellman-Jenkins, Nanna, & Palmieri, 2012). One year after the initial stroke diagnosis and discharge into the community, stroke survivor caregivers continue to score higher in measures of ineffective stressor coping which can affect levels of depression (Eldred & Sykes, 2008). When stroke survivor caregivers have difficulty managing depressive symptoms, they are at risk for cognitive and physical decline which negatively impacts their ability to care for their stroke survivor (Zhu & Jiang, 2018). Stroke survivor caregivers who experience high levels of depression and anxiety have greater difficulty managing their caregiver role and this affects how they cope with the stress of caring for the stroke survivor (Chow, Wong, & Poon, 2007). Faced with the demands of caring for their stroke survivor places stroke survivor caregivers at a high risk for burnout, and they may not have the ability or tools to effectively cope with their life changes (Pereira & Rebelo Botelho, 2011). The negative impact on the mental and physical well-being of stroke survivor caregivers caused by caregiving burden can impact the caregiver's general quality of life, and caregivers are particularly vulnerable during the first month after discharge to home because of the overwhelming burden of care they are facing (Guo & Liu, 2015).

Oftentimes, the stroke survivor caregiver is elderly and has functional limitations of their own. Stroke survivor caregivers who are older, less self-reliant, have less social support, and

have their stroke survivor discharged to a rehabilitation environment have a 34.1% increase in levels of depression two months following the initial stroke (Kruithof et al., 2016). Stroke survivor caregivers are more likely to not ask for help with managing depressive symptoms that they experience due to the negative connotation associated with depression, and depressed caregivers are at a higher risk for harming themselves, others, and their stroke survivor family member (Kamel, Bond, & Froelicher, 2012).

Effect of Caregiver Well-Being on Stroke Survivors

Whenever a member of a family experiences a disease that severely impacts their physical and mental well-being, the stroke survivor and their entire family are impacted by this critical event (Chow, Wong, & Poon, 2007). While the family member survived the initial stroke event, they are frequently left with neurological and physical impairments that will necessitate long term care and support once they are discharged into their community (Chow et al., 2007). Commonly, caregivers of family members with significant mental and physical limitations fail to manage their own health and mental well-being as they use all their energy to focus on caring for their loved one, placing them at a high risk for physical and mental disease (Li, Yuan, & Zhang, 2016). Stroke survivor caregivers have a 63% higher mortality rate than non-stroke survivor caregivers, placing stroke survivors at risk for institutionalization (Peyrovi, Mohammad-Saeid, Farahani-Nia, & Hoseini, 2012).

The relationship between caregiver and stroke survivor extends to their emotional well-being, and caregiver depression is associated with stroke survivor depression (Malhotra et al., 2016). Without management of depression and support of caregiver well-being, maintaining stroke survivors within their community becomes challenging, and without supporting stroke

survivor caregivers' coping skills and decreasing their levels of burden, the likelihood of the stroke survivor's remaining in their community is jeopardized (Brasier et al., 2016). How well the stroke survivor caregiver manages their psychological burdens directly affects how well the stroke survivor reintegrates into their community and has a positive quality of life (Okoye et al., 2019).

Role of Healthcare Providers in Stroke Survivor Well-Being

Healthcare providers are the initial contact for providing education such as self-care, and they play a role in assisting caregivers in maintaining a healthy quality of life (Low, Payne, & Roderick, 1999). Nurses can provide the support necessary for stroke survivor caregivers to maintain their own well-being to provide optimal care for the stroke survivor once they are discharged back into their community (Chow et al., 2007). Often, caregivers express feeling that they are not given enough preparation for their stroke survivor's discharge back into the community, and this leaves them feeling stressed and anxious about how they will cope once they are home (Cecil et al., 2013). One tool that nurses can provide stroke survivor caregivers with to manage their stress is cognitive behavioral therapy. Cognitive behavioral therapy that is self-directed is an effective treatment in the management of mild to moderate depression that helps the user to maintain interpersonal relationships, preserve a sense of self-worth, and focus on the reality of their life situation (Woodford et al., 2014; Hesamzadeh, Dalvandi, Maddah, Khoshknab, & Ahmadi, 2015).

The Definition of Mindfulness

A frequently used cognitive behavioral therapy tool for educating caregivers in the management of stress is mindfulness meditation. Mindfulness meditation has been practiced for more than 5,000 years and is the basis of the technique known as mindfulness-based stress reduction that was developed by Jon Kabat-Zinn in 1979 at the University of Massachusetts Medical Center (Li et al., 2016). Mindfulness based stress reduction is a stress management technique that assists the user in meditation techniques, body mindfulness, and stress reduction (Jani et al., 2018).

Practitioners of mindfulness learn to focus their thoughts and feelings on the present rather than the past or future and facilitates the user's ability to look at their feelings and experiences in a nonjudgmental manner that allows for personal acceptance of those feelings and experiences (Cullen, 2011). Mindfulness uses meditation that trains the user to clear their minds to achieve inner calmness, and it is an effective, low-cost stress management tool that is easily accessible for the average person to use when it is convenient for them (Li et al., 2016). Mindfulness meditation has been well studied in its efficacy coping with disease processes such as chronic pain, anxiety, depression, and life stressors, and it is an effective tool in managing stress through self-observation (Grossman, Neimann, Schmidt, & Walach, 2004).

The Effects of Mindfulness Cognitive Behavioral Therapy on Stroke Survivor Caregivers

The cognitive behavioral therapy skill of mindfulness provides a tool for caregivers to manage their daily stress and emotional challenges that they experience as they care for the stroke survivor (Whitebird et al., 2013). Mindfulness techniques have been used as effective

tools to manage stress and depression and has been used with a variety of health issues with beneficial results (Li et al., 2016). Practicing mindfulness allows the user to respond to stressors in a more reflective manner and improves the user's psychological and physical well-being (Whitebird et al., 2013). Research has shown that mindfulness meditation affects the brain's functioning and structure and is noted to impact the areas of the brain that control attention, emotion, and self-awareness (Berk, Warmenhoven, Van Os, & Van Boxtel, 2018). By learning to accept their caregiving situation as stressful but manageable, caregivers can experience a better quality of life (Liu, Chen, & Sun, 2017).

Instructing stroke survivor caregivers on stress coping techniques can improve caregivers' level of depression, and it is important to provide psychoeducation while the patient and caregiver are within the acute healthcare environment (Brasier et al., 2016). Cognitive behavioral therapy can be provided to patients via written format for them to use the information as a self-help tool (Woodford et al., 2014). Providing stroke survivor caregivers with the self-help tools in a written and video format allows them to study the information provided to them on their own time, and when given the information during the stroke survivor's hospital stay, it allows the caregiver to ask questions and receive support on mindfulness therapy. Once discharged into the community, stroke survivor caregivers can continue to use the printed mindfulness tool when it is convenient for them since often a barrier to receiving support is the demands of caring for the stroke survivor (Woodford et al., 2014).

Theoretical Framework

Nursing theory is a conceptualization that "is articulated for the purpose of describing, explaining, predicting, or prescribing nursing care" (Masters, 2015, p. 7) and is fundamental to

providing the basic framework for nursing research. Because of its framework of promoting well-being during difficult experiences, the Self-Transcendence Theory was chosen to guide this project (Masters, 2015). Central to this scholarly project is the concept that promoting caregivers' well-being through a specific intervention can assist them in effectively coping with the stressors experienced during a challenging experience of caring for a stroke survivor in the community.

Self-Transcendence Theory

For the foundation and guidance of this project, the Self-Transcendence Theory by Pamela G. Reed was used as it focuses on encompassing one's behaviors and views that are spiritual and psychological in nature (Reed, 2009). The Self-Transcendence Theory also focuses on individuals' experiences of vulnerability from personal or shared sickness and loss, both of which are experienced by stroke survivors and stroke survivor caregivers (Reed, 2009). By understanding how stroke survivor caregivers can look past their personal and emotional boundaries by accepting that the stroke has happened to their stroke survivor, one can better address their need to live in the present which is the hallmark of mindfulness meditation (Reed, 2009).

The Self-Transcendence Theory's creator identified self-transcendence as a concept that applied to mental health and well-being (Ellerman & Reed, 2001). In particular, the theory applies to those who are experiencing difficult situations in their life, and by using self-transcendence, the individual is able to manage challenging health events that they are a part of and gain new perspectives of the events to create a sense of well-being (Smith & Liehr, 2014). The concept of self-transcendence involves one's ability to take the self-boundaries that one has

within themselves and with others and to expand them, allowing them to see how they connect with the world and beyond (Masters, 2015). By looking beyond their self-boundaries, one develops a greater appreciation for the world around them, a respect for things they cannot see, and a greater understanding of their inner self (Masters, 2015). The concept of self-transcendence, i.e., gaining a new perspective during difficult times, informed the development of the mindfulness curriculum used in this project.

The concept of well-being is another important aspect of the Self-Transcendence Theory. Well-being is defined as "a sense of feeling whole and healthy, in accord with one's own criteria for wholeness and health" (Smith & Liehr, 2014, p. 112). Well-being is therefore defined as how the individual perceives their quality of life and health. Finally, the concept of vulnerability is noted in the Self-Transcendence Theory. Vulnerability involves the individual understanding their own mortality and with it, the inevitability of experiencing life events that are difficult (Masters, 2015). By being self-transcendent, the individual can transform experiences within their life that are difficult into experiences that can be healing (Smith & Liehr, 2014).

Rationale

The Self-Transcendence Theory involves a relationship between the individual, their environment, their health/well-being, and the nurse (Masters, 2015). For this scholarly project, presenting education on mindfulness to stroke survivor caregivers in the acute rehabilitation environment allows for stroke survivor caregivers to look at their difficult situation in a new light. This perspective may offer acceptance of their new life and increase feelings of well-being. All individuals, regardless of age or background, have the potential to heal themselves and grow from their experiences (Parker & Smith, 2010). The experience of becoming a stroke survivor

caregiver creates a sense of vulnerability in stroke survivor caregivers, and with self-transcendence, they can transform a negative experience into a positive one. Since individuals determine for themselves what creates a sense of well-being, providing tools that can promote well-being may assist the individual in achieving life satisfaction within themselves (Parker & Smith, 2010).

CHAPTER THREE

METHODS

Ethical Issues and Human Rights

For the purposes of this project, potential participants were identified by this student (a Doctor of Nursing Practice [DNP] student) and rehabilitation nurse specialists. Stroke survivors who experienced an ischemic stroke were evaluated to determine if they had caregivers who would assist them once they were discharged into the community and would be appropriate for the proposed mindfulness intervention. For project recruitment, data examined from admission records included patient demographics, age, and contact information. No patient or caregiver identifying information, such as name, date, or gender were linked to the patient or the caregiver for this project. There were no limitations on age for project participation. To ensure HIPAA compliance, all data with personal identification information were destroyed by confidential shredding. Education for the staff about the project was provided by this student to staff, and to ensure uniformity in the education, all staff were provided with the same written and verbal information.

The hospital selected for project implementation does not have a Human Subjects Review Board or an Institutional Review Board Committee; however, there was an assigned organizational development member who reviewed this project, its feasibility, and its potential impact on patients, families, staff, and the organization (J. Leishman-Donahue, personal communication, November 8, 2019). This member determined that the project was acceptable to implement. In addition, the project was reviewed and approved by the Montana State University

Institutional Review Board. Informed consent was obtained both in verbal and written format prior to the collection of data.

Population

The population selected for this project was adult caregivers of ischemic stroke survivors who were admitted to an inpatient rehabilitation unit in a medical center in northcentral Montana. There were no limitations on the age of participants, and both genders were included.

Setting

The hospital used for this project is a 516-bed system that is divided into two separate campuses. The rehabilitation unit is located on the West Campus and is comprised of 20 acute rehabilitation beds. Patient care is provided by registered nurses, licensed practical nurses, physical therapists and assistants, occupational therapists and assistants, speech therapists, and certified nurse's assistants. Medical, psychiatric, and physiatrist care are provided by physicians and a licensed clinical social worker. The rehabilitation unit includes patients greater than or equal to 14 years old, with the majority of the patients consisting of older adults. The rehabilitation unit utilizes a rehabilitation unit nurse specialist and a critical care nurse specialist who evaluate all patients upon arrival. The rehabilitation unit is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), and meets requirements including providing information, resources, and services that enhance the lives of the patient, their families, support groups, and communities (CARF International [CARF], 2019). Part of the goals for the rehabilitation unit is to increase the overall psychosocial care of patients and their families, and the need for providing stroke survivor caregivers with tools to better manage their

psychological health was determined to be an important concern that warranted further exploration (A. Trainor, personal communication, 2019).

Intervention

In discussions with a psychologist employed on the rehabilitation unit, it was determined that there was a significant need for increasing education for self-care and improving well-being for stroke survivor caregivers. Typically, stroke survivor caregivers do not understand the impact caring for their stroke survivor will have on their mental health and well-being and attending a social support group could be beneficial (S. Burcusa, personal communication, October 22, 2019).

This project was approved for implementation shortly before the onset of the coronavirus-19 (COVID-19) pandemic. The impact of the pandemic resulted in revisions to implementation (discussed in detail in chapter four). While the initial project was meant to include in-person weekly support groups with mindfulness curriculum delivered via video and printed material, the consequences of the pandemic required that the curriculum be provided to for this project entailed rehabilitation unit nurse specialists being actively involved with identifying stroke survivor caregivers and providing them with details regarding this project. However, the COVID-19 pandemic required unit staff, including rehabilitation unit nurse specialists, to be used in other areas of the hospital. The details with respect to how the methods shifted in response to the pandemic are discussed in chapter four.

Data Collection

The Caregiver Burden Scale (CBS) was used for data collection to determine the overall burden experienced by the stroke survivor caregiver. The CBS is a self-administered tool that consists of 22 questions that focus on caregiver well-being, environment, physical workload, social environment, and family relations (Bergstrom, Eriksson, Von Koch, & Tham, 2011). The CBS has been used in studies with stroke survivor caregivers, and evidence shows that it demonstrates stability related to test-retest reliability, as well as good construct validity (Bergstrom et al., 2011). In addition to the CBS, the Patient Health Questionnaire (PHQ-9) was used to determine depression severity levels in stroke survivor caregivers. The PHQ-9 is a frequently used test that assists clinicians in determining level of depressive symptoms, and questions relate to suicidal ideation, fatigue, anhedonia, restlessness, appetite changes, guilt, worthlessness, mood, and sleep impairment (Galenkamp, Stronks, Snijder, & Derks, 2017). Psychometric analyses show that the PHQ-9 is a well-established reliable and valid tool as a measure of depression severity (Williams, 2014).

Project Procedures

Once stroke survivor caregivers were identified and agreed to participate in the project, an Internet accessible PowerPoint presentation was emailed to them, as well as a Survey Monkey link with the CBS and PHQ-9 questionnaires. Further, a link was embedded in the email that directed participants to a video containing mindfulness education. The video consisted of an introduction to mindfulness, a PowerPoint presentation on how to access a short, five-part mindfulness video, how to complete the CBS and PHQ-9 questionnaires using Survey Monkey,

and how to practice mindfulness meditation. Instructions included six mindfulness exercises that stroke survivor caregivers could use independently, which consisted of mindful breathing, mindful observation, mindful awareness, mindful listening, mindful immersion, and mindful appreciation. Stroke survivor caregivers were instructed to watch the videos as often as they needed, but they were asked to complete the five mindfulness sections to decide which exercise they would use daily.

At the stroke survivors' discharge, participating stroke survivor caregivers were contacted via telephone by this student to instruct participants to complete the PHQ-9 questionnaire (Appendix B) and CBS questionnaire using the Survey Monkey link that was emailed to them (Appendix C). Two weeks after the stroke survivor was discharged, the participants were contacted again by this student to remind them to complete the CBS and PHQ-9 questionnaires. Participants were also asked, "How has mindfulness helped or not helped you?", "How have you used mindfulness?", and "How will you use mindfulness in the future?"

CHAPTER FOUR

RESULTS

Many obstacles and challenges were faced during the implementation of this project with the main challenge being the onset of the COVID-19 pandemic. On January 21, 2020, the first confirmed case of COVID-19 in the United States was documented (The American Journal of Managed Care [AJMC], 2021) and the unprecedented event of the pandemic negatively impacted the implementation of this scholarly project. Initially, mindfulness education for stroke survivor caregivers was to be provided in a support group environment; however, in February 2020, the Centers for Disease Control and Prevention recommended cancelling gatherings of people due to the potential for increasing the spread of the virus from person to person and then into the community (Centers for Disease Control and Prevention [CDC], 2020). By March 13, 2020, the federal government declared a national emergency, which led government officials of Montana to issue a statewide lockdown (AJMC, 2021). The hospital that this project was implemented at began visitor restrictions and a hospital wide lockdown plan in March 2020, which is the month that this project was scheduled to begin. As a result, all meetings and visitations were halted, leading to the inability of providing mindfulness education to stroke survivor caregivers in person. Therefore, the decision was made to postpone project initiation until May 2020 to determine if the delivery of mindfulness education to stroke survivor caregivers could occur as originally planned.

In May 2020, there was no official date for the discontinuation of hospital visitor restrictions, and the decision was made to change the delivery of mindfulness education to an Internet-based curriculum. This student developed a video that was sent to Montana State

University Institutional Review Board and the hospital's education department for approval. By mid May 2020, approval was granted from both entities, and participant recruitment efforts began with the assistance of rehabilitation unit nurse specialists. However, other issues, which are described below, created challenges for the project to be successfully implemented.

Because of the numbers of COVID-19 cases reported in other states, the hospital began the process of preparing for the possible deluge of COVID-19 infected individuals that would likely cause an incredible strain on available resources. A shift of nursing duties occurred, and nurses who were in other roles, including rehabilitation unit nurse specialists, were tasked with providing bedside care for medical and rehabilitation patients on the rehabilitation unit. At the hospital, a nursing shortage existed prior to the start of the COVID-19 pandemic, and management of the rehabilitation unit made the decision to cease allowing rehabilitation unit nurse specialists to participate in project recruitment, as they prepared to care for overflow patients to help with the increase in patient admissions at the main campus. The influx of COVID-19 patients, along with a shortage of nurses, created an increased workload on the rehabilitation unit. In turn, staff nurses were unable to assist with recruitment for this project.

Another challenge of this project was a decrease in the number of stroke patients who received care on the rehabilitation unit. Of the 94 ischemic strokes admitted to the hospital for acute care from May 2020 to December 2020, only 34 of them were admitted to the rehabilitation unit. The decrease in admissions to the unit could have been due to changes in stroke care noted during the COVID-19 pandemic. During the pandemic, fewer patients presented to the hospital, possibly due to the fear of becoming infected or exposed to patients

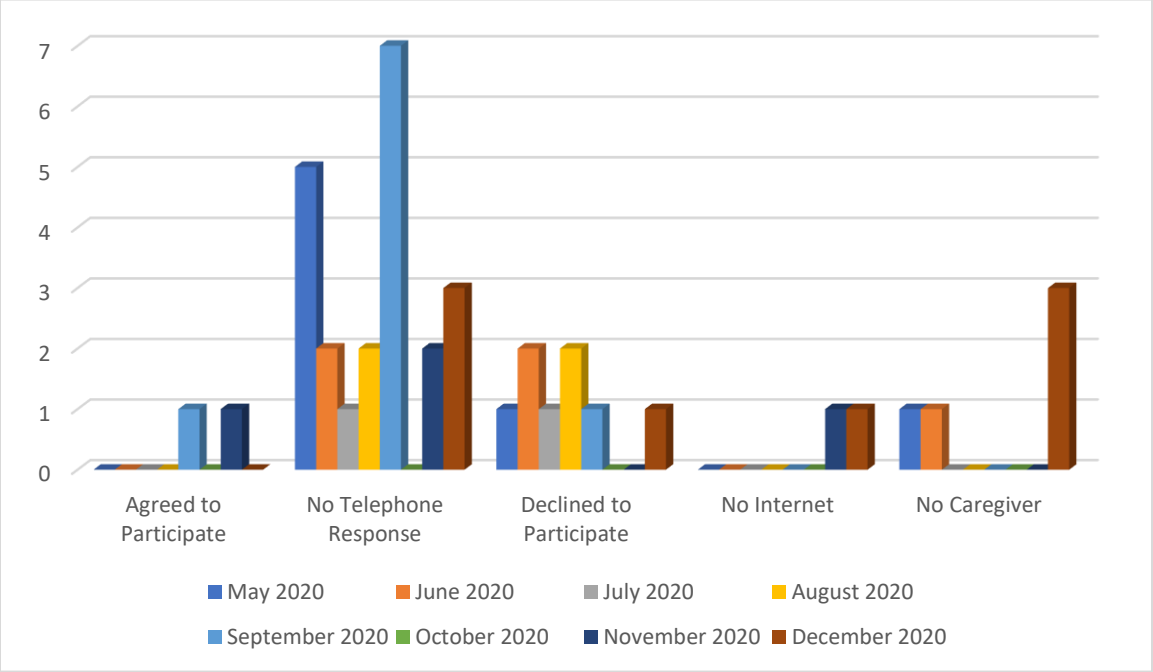
with COVID-19 (Reddy et al., 2021). Overall, in the United States, there were 29% fewer stroke admissions into acute care facilities (Reddy et al., 2021).

While family members were allowed to visit the hospital after a change in visitation policy took place during the summer of 2020, many family members continued to stay home due to the fear of becoming ill from the coronavirus. In June 2020, the hospital allowed two patient visitors to visit the rehabilitation unit; however, despite the change, many patients had no visitors at all making it difficult to recruit stroke survivor caregivers for this project. The lack of face-to-face discussion regarding the project and mindfulness education with potential participants resulted in interactions with potential participants to occur via telephone. The challenge for completing telephone interactions became obvious when this student had incorrect phone numbers due to inaccurate admission information and no return calls from potential participants.

Finally, the challenge of the lack of Internet access for some potential participants meant they could not participate in the project. Some rural areas do not have consistent, high-speed access to digital connections that are necessary for Internet use, and the hospital that this project was implemented at is the closest hospital for rural areas in northcentral Montana (Salemink et al., 2017). In rural areas in the United States, 14.5 million people do not have access to broadband Internet; however, the Federal Communications Commission has been following the Telecommunications Act of 1996 which provides funds to states in order to expand the availability of internet for low income and rural areas (Federal Communications Commission [FCC], n.d.). However, broadband Internet has been slow to come to rural Montana, and many individuals do not have the connectivity to watch videos, such as the one presented in this project.

Thirty-four stroke survivor caregivers were called by this student to participate in this project. Of these, two stroke survivor caregivers agreed to participate, 20 potential participants did not respond to telephone calls, five declined to participate, two did not have internet access, and five stroke survivors did not have a caregiver (Figure 1).

Figure 1. Participants versus Reasons for No Participation



Project Participants

Both participants who consented to participate in this project were Caucasian females. One participant was 75 years old and the other was 49 years old. Both participants completed baseline assessments but did not view the PowerPoint presentation or mindfulness education video. One participant had a baseline PHQ-9 score of 20 indicating severe level of depression, and a baseline CBS score of 38, suggesting mild to moderate burden (Kroenke & Spitzer, 2002;

Dementia Pathways, n.d.). Further, the other participant had a baseline PHQ-9 score of nine, indicating mild level of depression and a baseline CBS score of 26 indicating mild to moderate burden (see Table 1; Kroenke & Spitzer, 2002 Dementia Pathways, n.d.). The second participant's stroke survivor contracted COVID-19 and subsequently died related to COVID-19 complications, and she did not complete the project. The other participant was considered lost to follow up after baseline assessments were obtained.

Table 1. *Participant Characteristics*

	Gender	**Race**	**Age** (in years)	**PHQ-9 Score**	**CBS Score**
Participant One	Female	Caucasian	75	20*	38±
Participant Two	Female	Caucasian	49	9**	26±

PHQ-9 = Patient Health Questionnaire; CBS = Caregiver Burden Scale. * score indicates severe depression; ** score indicates mild depression; ± score indicates mild to moderate burden

It is important to note that the stroke survivor for one of the participants was closer to discharge when the PHQ-9 and CBS questionnaires were completed, which could potentially explain higher scores on both of the scales. The stroke survivor for the other participants had been in the rehabilitation unit for four days when she completed the questionnaires, which may explain why her scores were lower than the scores of the first participant.

CHAPTER FIVE

DISCUSSION

The purpose of this project was to understand if mindfulness meditation improves stroke survivor caregiver well-being, such as caregiver burden and depression. However, the lack of participation in the project, likely related to the COVID-19 pandemic, meant that no meaningful results were obtained. What was found was that, at baseline, the two participants who completed the PHQ-9 and CBS were noted to have mild to severe depressive symptoms, as well as mild to moderate levels of caregiver burden. These findings suggest that mild to severe depression was present prior to becoming a stroke survivor caregiver, which may represent underlying depressive disorder. In contrast, the shock of a family member experiencing a stroke may have influenced baseline PHQ-9 and CBS scores. Because neither participant completed the Internet-based mindfulness education, it is difficult to determine whether they would have benefited from the intervention. Based on the review of the literature completed prior to implementation of this project, it would be reasonable to believe that stroke survivor caregivers would have an improvement with feelings of caregiver burden and depression.

Limitations

For this project, limitations were noted. One limitation was that this student was employed by the hospital that this project took place at. This student served in a nursing supervisory role and had limited patient care on the rehabilitation unit, which resulted in the lack of established interpersonal relationships with stroke survivor caregivers. This lack of personal connection may have limited the ability to recruit more participants. Another limitation was the

small sample size for the project. Only two stroke survivor caregivers participated in the initial portion of the project but did not complete the project. The limitations of small sample and attrition did not provide adequate data for analysis. Also, as another limitation, while mindfulness is well researched as an effective tool to manage well-being, ensuring stroke survivor caregivers practice meditation daily could be challenging. While the mindfulness curriculum instructed stroke survivor caregivers to practice mindfulness daily for as little or as long as they wanted, there was no evaluation tool in this project that monitored for actual mindfulness use or duration of use. Finally, Internet-based mindfulness curriculum was a limitation due to not all stroke survivors having access to adequate Internet services or having difficulty accessing the mindfulness education curriculum related to Internet services.

Recommendations

While there were several challenges faced during the implementation phase of this project, there are recommendations to consider. For example, monitoring how much time stroke survivor caregivers spend daily on practicing mindfulness meditation would be an important data collection point. This would be helpful to determine if the length of time stroke survivor caregivers used mindfulness meditation is related to reducing depression and caregiver burden. Stroke survivor caregivers could use a provided timesheet to document the amount of time spent on using mindfulness, and project personnel could collect this information weekly by telephone or in person. Moreover, considering that the current project faced Internet-access concerns, future projects may consider the implementation of detailed written instructions that are provided in a stroke education binder. Also, offering in-person training on how to access the Internet-based curriculum is a recommendation to improve understanding of how to use the curriculum.

In the current project, retention was a concern, with neither participant completing the project. In order to improve future mindfulness project retention, text messaging, support phone calls, email reminders, and voucher incentives, which have all been shown to improve retention (Teague et al., 2018) could be employed.

With respect to model selection for a future project, the plan-do-study-act (PDSA) strategy might be beneficial for evaluating the effectiveness of providing mindfulness education to stroke survivor caregivers. The use of the PDSA model would allow for challenges faced during the implementation of mindfulness education curriculum, as it focuses on a process of continuous improvement while adapting to any challenges experienced (Lies & Shojania, 2017). Finally, in future projects, a larger sample size is recommended to allow for a better representation of the population of stroke survivor caregivers.

Feasibility and Sustainability

Mindfulness education is a viable component of providing mental health support for stroke survivor caregivers as it is an easy to learn, easy to use form of mental health care support. This student performed a review of published research that showed the benefits of managing stroke survivor caregiver burden and depression through the use of mindfulness. Based on the evidence obtained from this review, it is feasible to consider that nurse educators in hospital settings could incorporate teaching the benefits on the use of mindfulness so nurses can share them with patients and family members. Materials on mindfulness education could be provided in stroke information binders, which are received at the time of admission to acute care hospitals to open a discussion between stroke survivor caregivers and staff nurses about the need to

manage their mental health. Inclusion of mindfulness education in a binder could easily be completed, and printed information, as well as Internet-based links could be presented. In addition to printed education material, presenting mindfulness education in a video format is a low-cost intervention that can reach many stroke survivor caregivers. Many hospitals provide patient and family education through videos that can be watched in patient rooms, and it is a simple way for stroke survivor caregivers to receive mindfulness education.

While sustainability was not achieved in this project, future implementation could occur at hospitals. The PDSA strategy would be helpful in maintaining the sustainability of mindfulness education, as this strategy involves assessing the problem, implementing a solution, and monitoring to determine if the mindfulness education helped stroke survivor caregivers' mental well-being (Sayma et al., 2018) Nurses, education nurses, and advanced practice nurses can determine which educational format works best at their hospital and begin the process of implementing mindfulness education. This would require monitoring through stroke survivor caregiver surveys to determine whether the mindfulness education format was used, and adjustments to the mindfulness education format would need to be performed to improve the utilization of mindfulness techniques.

Lessons Learned

During the implementation and completion of this project, valuable lessons were learned. Educating physicians about the effects of mindfulness on stroke survivor caregivers may have improved participant recruitment, as physicians may have provided support for the project. The creation of a project committee may have also been useful, particularly relevant to supporting the rehabilitation unit staff. The project committee may have helped with staff education on

mindfulness benefits, leading to more individuals offering education to stroke survivor caregivers and potentially improved stroke survivor caregiver recruitment. Moreover, seeking input from stakeholders prior to implementing a project might have helped facilitate sustainable project methods. This includes ensuring that a sample includes enough participants to generate data is recruited by flushing out eligibility criteria before implementation.

Finally, this student learned that communicating with stroke survivor caregivers face to face at the time of the stroke survivor's admission to a rehabilitation unit may be a preferred approach over contacting stroke survivor caregivers by phone. It can be difficult to express compassion via telephone, and had this student been able to carry out the project as originally intended, a therapeutic alliance may have been developed between stroke survivor caregivers and this student, which may have led to increased recruitment. The dynamic relationship between nurses, advanced practice nurses, patients, and family members is a core component of the discipline nursing, and without this relationship, future attempts at evaluating mindfulness education for stroke survivor caregivers will remain challenging. By creating a therapeutic alliance with stroke survivor caregivers, the nursing professional can assist stroke survivor caregivers with understanding that, as posited in the Self-Transcendence Theory (used to guide this project), self-transcendence can allow stroke survivor caregivers to see beyond the stroke survivors' illness to examine life patterns, personal identity, and higher level of consciousness (Good, 2018).

The lessons learned during this project will be used in this student's future practice as an advanced practice nurse. As part of the DNP program and through the experience of carrying out this scholarly project, this student learned about the importance of using a team to help address a

clinical concern. While an advanced practice nurse is in a position to provide leadership, the utilization of teamwork helps facilitate successful project implementation. Further, the use of a change model (e.g., PDSA model) may have the potential to help guide advanced practice nurses to effectively implement evidence-based practice, evaluate progress, and allow for adjustments as needed to improve patient outcomes.

Doctor of Nursing Practice Competencies

As a graduate of a DNP program, an advanced practice nurse is equipped with the knowledge and skills to integrate nursing theory, research, and practice to manage healthcare needs of individuals and populations, influence health care outcomes for patients, and provide leadership skills in healthcare policy implementation (AACN, 2006). While all eight DNP Essentials were involved in this project, two DNP essentials were focused on.

Part of DNP Essential II states that graduates of DNP programs must focus on and include the needs of a specific population while effectively working with the organization that is involved with the population (AACN, 2006). This student was able to assess the mental health needs for the population of stroke survivor caregivers and develop a plan to maintain their mental well-being. Working with hospital leadership, rehabilitation unit leaders, and nurses, a new education program was developed. While the goal was to improve the mental health outcome of stroke survivor caregivers, due to unique circumstances related to the COVID-19 pandemic, mindfulness education was not successfully implemented. However, in the future, support and increased buy in from nurses and staff on a rehabilitation unit, including individuals in leadership positions, may improve implementing mindfulness education.

DNP Essential IV focuses on the use of technology to improve patient care, and during this project, technology was an integral piece of mindfulness education delivery (AACN, 2006). Due to the need to change the format for mindfulness education, this student developed and delivered a mindfulness education that could be accessed through computers, tablets, and smartphones, making mindfulness education easy to access when Internet connections were available. Internet-based learning has the potential to improve the health and care of patients and their families, and as technology becomes more available and easier to use, it will continue to be an important tool to use to provide knowledge and support for a variety of populations. DNP programs may consider including courses to improve knowledge and skills to effectively use technology, including Internet based healthcare, to improve patient health outcomes, as well as communication with patients (Rutledge et al., 2017).

Conclusion

In conclusion, the mental health needs of stroke survivor caregivers must be addressed to ensure that stroke survivor caregivers can maintain their overall well-being. This project sought to provide stroke survivor caregivers mindfulness education to support them following the life changing event of a family member suffering a stroke. Challenges related to the COVID-19 pandemic resulted in revisions to how mindfulness education was delivered for this project. While the COVID-19 pandemic has required healthcare professionals to utilize new ways to implement interventions, lessons learned from this project demonstrated that mindfulness education may be better delivered in person.

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APPENDICES

APPENDIX A

MINDFULNESS FOR STROKE SURVIVOR CAREGIVERS: CARING FOR YOURSELVES, CARING FOR YOUR OWN

Double click the picture to listen to the presentation.

Mindfulness For Stroke Survivor Caregivers: Caring For Yourselves, Caring For Your Own

Valerie Kirby-Johnson RN, BSN, PMHNP Student, Montana State University

APPENDIX B

PHQ-9 QUESTIONNAIRE

Over the last 2 weeks, how often have you been bothered by any of the following problems?	**Not at all**	**Several Days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3

Total Score: 1-4 Minimal depression; 5-9 Mild depression; 10-14 Moderate depression; 15-19 Moderately severe depression; 20-27 Severe depression

APPENDIX C

CBS QUESTIONNAIRE

Circle the response that best describes how you feel.

	Never	*Rarely*	*Sometimes*	*Quite frequently*	*Nearly always*
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.