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Social Support, Psychological Distress, and Behavioral Outcomes Among Palliative Care Caregivers

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Abstract

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MA, Argosy University, 2010

BS, Clayton State College and University, 2004

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Public Health

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Abstract

Social support and acute care facility providers need information about how to help improve the practices and knowledge of caregivers related to the stages of palliative care. The purpose of this study was to examine whether there was a significant association between social support and psychological distress and behavioral outcomes among palliative care caregivers, and to determine to what extent social support buffered psychological distress and behavioral outcomes. The quality-of-life model guided the study. The study used a quantitative cross-sectional research design with secondary data analyses. The sample included 320 adult family caregivers who were part of a telephone survey on caregiver burden collected in 2000 representing the U.S. population. The independent variable was social support (caregivers' awareness of resources and receipt of direct support) and the dependent variables were psychological distress (anxiety, stress, and depression) and behavioral outcomes (sleep deprivation and patient abuse). Caregivers' receipt of direct social support significantly predicted reduction of psychological distress: anxiety ($OR = .434$, $p < .001$), stress ($OR = .603$, $p < .041$), and depression ($OR = .464$, $p < .013$). Social support was not a predictor of behavioral outcomes. The positive social change implications of this study include use of findings by healthcare providers and social service agents to formulate services to aid caregivers in reducing the burden of negative behavioral outcomes and improve quality of life of caregivers and their families.

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Dedication

God is my light in all darkness; He carried me through when I thought I could not take another step. God's grace, mercy, and favor is upon me even when I know the enemy is before me. I am strong, not weak because I know my God is able. I could see the finish line before it approached (Hebrews 11:1-3). In admiration, I dedicate this study to my mother Kathleen (Kathy) Smith-Aguirre, who was diagnosed with Chronic Myeloid Leukemia (CML) on July 15, 2010. At the time of her diagnosis, she was given only six weeks to live, and instead of giving up or giving in, she is still fighting the strong fight of cancer. As her only child and sole support, I commend her daily for her strength, endurance, and positive lifestyle. Not having a guide in understanding how to help her, I applaud her for helping me to know how to become better support for her, how to be more sensitive and attentive during both her good and difficult days. I pray this study makes her proud. To my father, Gary Aguirre and step-mother Louise Aguirre (Momma Lou), I thank you for all your encouraging words and uplifting talks, and for cheering me up when my tears flowed. To my three sweet loving grandmothers (Marie Aguirre, Charlene Jones McAllister and Clarice "Peaches" Aguirre), all of whom have gone into the heavens above, I walk in the shoes I have because you all set precedents for me to be strong, courageous, and dedicated. You all have taught me to reach beyond the stars to the galaxy no matter what my circumstances. I love each of you for molding me into the woman and scholar I am today and believing in me to be the best I could ever be as I continue to strive always for more.

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Section 1: Foundation of the Study and Literature Review

Introduction

Multiple life changes affect palliative care caregivers while taking on the care of loved ones. As informal caregivers, substantial roles involve providing care for loved ones. Caregivers experience distress, depression, anxiety, and reduced quality of life (Ugalde, Krishnasamy, & Schofield, 2014). Taking care of the concerns of palliative care patients can cause physical suffering, psychosocial concerns, spiritual suffering, and emotional discomfort (Lo, Quill, & Tulsky, 1999). Social support is an affirmative answer to improving the quality of life of caregivers. The association between psychological distress, social support, and behavioral outcomes among those who provide palliative care as caregivers raises concerns about their physical, mental, and emotional care. Few studies address the needs of caregivers, and there is a lack of tools available to assess family caregivers' situations. There is a need for more attention by social services, community support centers, and healthcare agents, addressing challenges and mental health of palliative care caregivers.

Caregivers who are family members are referred to as informal caregivers. Informal caregivers provide a range of tasks over time, including but not limited to cooking, cleaning, paying bills, running errands, buying groceries, and activities of daily living such as dressing, bathing, feeding, and providing emotional encouragement (Centers for Disease Control and Prevention [CDC], 2015). These responsibilities can take a toll on the caregiver. It is essential for caregivers to know that there is value in caring for themselves as well; they must meet the physical, emotional, and spiritual demands of caregiving (Beach & White, 2015). Family caregivers assist with daily activities that manage complex care, navigate the health system, and communicate with healthcare professionals about the availability of support services (Beach & White, 2015).

Problem Statement

Palliative care is a method that provides comfort care for those who have a short time left to live (National Caregivers Library, 2015). Currently, there is a dearth of professional caregivers available for chronic and end-stage illnesses; therefore, patients who receive palliative care are more likely to have a family member involved as a caregiver. In 2012, over 22,000 residential care communities were in place. Of these 22,000 communities, approximately 7,260 provided in-home care (Harris-Kojetin, Sengupta, Park-Lee, Valverde, 2013). About 2,396 of those with family involvement in care have caregiver burdens that involve psychological effects, financial strains, and family tension. These results of caregiving often are the main reason families are in distress, and there are few resources to support healthy psychological dispositions among caregivers.

Caregivers face burdens that become detrimental to their health and psychological status, leading to adverse behavioral outcomes such as sleep deprivation and patient abuse (O'Dwyer, Moyle, & van Wyk, 2013). Mosher et al. (2013) noted that one-third of spousal caregivers of cancer patients experience clinically elevated anxiety or depressive symptoms caused by psychological distress. There is minimal support to identify and prevent behavioral outcomes among family caregivers during end-of-life care. Future studies of behavioral interventions to help support positive behavioral outcomes may help to develop tools for assessing family caregivers’ needs. There are specific mental health and social service tools needed to address effective measures of family responses in supportive ways, as well as analyze cost-effective ways to alleviate burdens and efficiently present intervention methods.

The psychological distress of caregivers who provide palliative care affects families as well as the caregivers themselves. Psychological distress and behavioral outcomes need further investigation to help caregivers and families have a better quality of life. According to Chi et al. (2016), caregiving can have a negative impact on a caregiver's health because of physical demands, emotional distress, and expected loss of their loved one. Caregiving is negatively associated with caregivers' health. According to Chi et al. (2016), the most detrimental consequence of being a caregiver is reflected in their physical health and emotional distress. The CDC (2015) noted that caregivers develop stress, which can cause aches, pains, and sleep problems as well as changes in appetite.

Behavioral outcomes generated from the distress of caregiving, such as high anxiety or depression, are not reasonable in healthy or even unhealthy persons and can result in caregiver suicide. Illness is associated with sadness, insomnia, and hopelessness for those who provide care to the chronically and severely ill (Fegg, Brandstätter, Kögler, Hauke, Rechenberg-Winter, Fensterer, Borasio, 2013). The responsibility of caring for the ill in palliative care services often brings forth ailments; however, the caregiver receives less attention andcare, which leadsd to an overall decrease in quality of life. Caregivers need availability of round the clock support, and they need respite breaks allowing for short periods of relief from providing ongoing care. Respite care is an area in need of improvement, because it is lacking within acute care hospitals and at home

(Ling, 2012). Palliative care and the psychological distress that caregivers endure is the primary focus of this quantitative study. I reviewed the multiple burdens that caregivers endured and explored psychological distress, which impacts quality of life for caregivers, leading to adverse behavioral outcomes (sleep deprivation, patient abuse).

Purpose of the Study

The purpose of this quantitative study was to examine the association between social support, psychological distress, and behavioral outcomes among caregivers. This study is distinctive because it reports on an underresearched area regarding caregiver burdens and behavioral outcomes. Social support can buffer caregiver burdens and improve quality of life. The findings from this study may assist in helping both healthcare providers and social service agents formulate services to aid caregivers. Acknowledging the burdens of caregivers is necessary to understand how stressors such as depression, anxiety, or financial difficulties can take a toll on caregivers and their families (Ugalde et al., 2014). Recognizing the importance of social and professional support can assist caregivers in formulating a goal to prevent psychological distress. Self-efficacy may help minimize psychological burden and avoid psychological distress, thus enabling caregivers to maintain a healthy quality of life during every stage of care (Ugalde et al., 2014).

Providing social and professional assistance to assist in the gap of palliative care caregivers through community and healthcare facilities would be a step towards preventing the overwhelming hardships that caregivers endure (CDC, 2013). According to Chi (2016), there is a need to fill this gap in the healthcare system, that would assist in the social service area to help caregivers of palliative care patients. Preventing adverse behavioral outcomes may help minimize caregiver ailments caused by the psychological distresses incurred.

Research Questions and Hypotheses

The research questions examined the association between social support and psychological distress and social support and behavioral outcomes among palliative care caregivers.

Research Question. Is there an association between overall awareness of resources and overall direct social support and psychological distress (anxiety, stress, and depression) among palliative care caregivers?

H_o1_a: There is no association between overall awareness of resources and overall direct social support and anxiety among palliative care caregivers.

H_A1_a: There is an association between overall awareness of resources and receipt of overall direct social support and anxiety among palliative care caregivers.

H_o1_b: There is no association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

H_A1_b: There is an association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

H_o1_c: There is no association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

H_A1_c: There is an association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

Research Question 2. Is there an association between social support (awareness of services and direct social support) and behavioral outcomes (sleep deprivation, patient abuse) among palliative care caregivers?

H_o2_a: There is no association between overall awareness of social support and overall direct social support and sleep deprivation among palliative care caregivers.

H_{Aa}:There is an association between overall awareness of social support and overall direct social support and sleep deprivation among palliative care caregivers.

H_o2_b: There is no association between overall awareness of social support and overall direct social support and patient abuse among palliative care caregivers.

H_A2_b: There is an association between overall awareness of services and overall direct social support and patient abuse among palliative care caregivers.

Theoretical Foundation of the Study

Social support theory is a theory that focuses on interventions, social support, and behavioral change. This theory helps to identify behavioral change and pinpoint the resources needed for effective responses. The theory focuses on support received from others, such as family, friends, neighbors, and often colleagues (Reblin & Uchino, 2008). Social support is communication that establishes reassurance. Three types of social support are emphasized: The first is anchored in stress and uses social support such as group meetings to help normalize and control it. The second kind of social support is oriented toward the health of an individual, which may be helped with one-on-one counseling and contributes to the positive boost in self-esteem that occurs when someone receives help from another person (Reblin & Uchino, 2008). The third kind of social support, which can be family counseling; the theory is relationships and how they play a role in a person’s mental and physical health. Relationships are a form of social support which enables a better health condition overall by allowing for intimate conversations about personal feelings of support, and with all three perspectives, the caregivers’ goal is for a better outcome of healthier livin and caregiver well-being.

Nature of the Study

The nature of the study was a quantitative cross-sectional design with an applied research method of inquiry. The approach to this quantitative cross-sectional design was secondary data analysis. The Chronic Illness and Caregiving survey collected in 2000 interviewed multiple individuals, including the general public, chronically ill persons, and informal caregivers. The gap in the literature that this research sought to fill was that there is a gap in social support, which contributes to the development of psychological distress and behavioral outcomes. The hypotheses were tested used multiple logistic regression analysis. The key study predictor for RQ1 was social support. The dependent variable for RQ1 was psychological distress logistically measured as anxiety, stress, and depression. The dependent variable for RQ2 was behavioral outcomes measured as sleep deprivation and patient abuse.

Literature Review

Literature Search Strategy

I began the literature search by using standard search engines to explore written materials available on the Internet. These initial findings pointed toward peer-reviewed journal articles and empirical studies relevant to the doctoral study’s objective and research questions. Search engines included Walden University’s library health science search engines, CINAHL & MEDLINE, ProQuest Nursing & Allied Health Source, ProQuest Health & Medical Collection, PubMed, and PsycINFO. I also used published articles from local hospital facilities and the CDC, as well as Google Scholar.

The key search terms used were: *palliative care, caregivers, distress of caregivers, caregiver burdens, daily stressors of palliative care caregivers, social support for caregivers*, and *psychological outcomes of caregivers*. Throughout the search, there was a range of results; however, not all pertained to caregivers' dispositions of care. I reviewed over 60 articles that referred to caregivers. Support for and psychological outcomes of caregivers were not as well reported as I would have hoped for or expected. Studies were selected for use if they met the following criteria: They (a) focused on family caregivers, (b) explored caregiver burdens, (c) explored interventional strategies, and (d) included information about behavioral outcomes of caregivers. As this is a secondary study, the studies used were random selection, treatment or control groups, cross-sectional, and some quasiexperimental designs.

Psychological Distress, Social Support, and Behavioral Outcomes

Palliative care is the care provided to individuals diagnosed with advanced and incurable diseases; it assists by focusing on relieving suffering during the disease process. Palliative care patients need psychosocial support and closure assistance near the end of life. Closure assistance, will help family members to deal with the lost of their loved one, by expressing feelings, doing art work, journaling and other techniques which can help. Palliative care caregiving can be a family-centered process, involving patients and their family members; this level of caregiving is at the core of how a family functions (Hudson & Aranda, 2013). In the United States, there are approximately 30 to 38 million family caregivers who provide care for about 90% of dependent ill individuals who have acute and chronic health issues (Beach & White, 2015). According to Redinbaugh, Baum, Tarbell, and Arnold (2003), there was a ninefold increase between 1988 and 1997 in the number of family caregivers that use Medicare's home hospice benefits. With such an increase, it is evident that family caregivers are used in higher numbers. The increase also suggests that there is a change in the quality of life for family members who take on the role of caregiving. Family caregivers of palliative care patients experience psychological distress, which leads to the need for social support and assistance with behavioral outcomes. The families' perspectives of supportive actions allow for a focus on stress and coping skills, thereby allowing provision for supportive behaviors and proper coping skills as an outcome (Lakey & Cohen, 2000).

The World Health Organization (WHO) advocates for healthcare services that focus on improving family members' quality of life during the time of caregiving as well as bereavement (Hudson & Aranda, 2013). Family members who take on the responsibility of being a caregiver also incur psychological morbidity, which includes distress, depression, anxiety, and reduced quality of life (Ugalde, Krishnasamy, & Schofield, 2014), all of which need more attention to ensure better outcomes. To understand the outcomes of caregiver reactions, family members experiencing the stages of caregiving is essential. Caregiver stages begin during the time of diagnosis and progress with hospitalization, ongoing treatments, transitions to home and home care, post-treatment, and end-of-life care (Beach & White, 2015). Throughout the different stages, palliative care caregivers can experience a multitude of changes that impede their quality of life and quality and strength of physical health. Family caregiving requires psychomotor, cognitive, and psychological skills; those who become informal family caregivers need knowledge, skills, and social support (Beach & White, 2015). Caregivers are faced with significant stressors, such as finances, home safety issues, caregiving scheduling, once they take on the needs of a patient (Redinbaugh et al., 2003), which alters the quality of life for the caregiver by adding additional financial responsibilities, changing schedules that were in place, and perhaps rearranging their home for proper accomodations of the patient.

Prevalence of Social Support

There is a demand for social support for caregivers, that progressively increases in the arears of home safety, proper scheduling, bathing assistance and more (Chi, Demiris, Lewis, Walker, & Langer, 2016). Disease processes may be different, but the need for social support in palliative care remains. However, family caregivers are not always aware of available support, they often have limited prior exposure to death and dying, and care planning is inadequate (Hudson & Aranda, 2013). There is a challenge with providing psychosocial support to family members, as medical professionals, Case Managers, Social Workers, may not have the proper resources that are required to help, and caregivers therefore are not equipped with proper support services. Providing resources such as telephone-based support groups for family caregivers would help to improve social support and psychosocial intervention (Dichter, Albers,Wermke, Trutschel, Seismann-Petersen, & Halek, 2017), thereby assisting in a need to help relax and axiety attach, or help during depression and increasing quality of life for a caregiver. Social integration, being a part of different networks that are familia with caregiving difficulties, and participating in communities socially are important for caregivers because it forms a family of support that caregivers do not feel alone in the process.

Purposeful components such as emotional support (Reblin & Uchino, 2009), also allow caregivers to have a better quality of life, by being able to express feelings, share concerns and release fears. With the lack of caregiver support, caregivers are prone to physical and psychological morbidity as well as financial disadvantage, and often can become socially isolated (Hudson & Aranda, 2013). To help avoid outcomes such as isolation, obstacles in the way of attending support groups and participating in activities outside of the home should be removed. Also, social support via online networks, chat forums, videophone, or telephone is an effective way to positively intervene and reduce negative outcomes (Berwig et al., 2017) as these forms of communication can be quick and life saving for suicide, as it is an instant connection.

Support services are essential for caregivers. Support services can include having the option to speak with hospital staff members about how they feel and how they are coping with the illness. Attending support groups with other family members can also be helpful (Mosher et al., 2013) as it will allow for all members to discuss their feelings about the care and the caregiving of their loved one.

The American Association of Retired Persons (AARP) provides valuable information for caregivers that will help with financial planning, caregiver's assistance, hospice acknowledgement on its website that is directed toward caregivers. Tools offered for caregivers on the AARP's site include a list of questions and answers, state-by-state information, and care provider information. This organization is assisting the community of caregivers with resource help. The AARP is aware of the needs faced by caregivers, and it has addressed them with support in several areas of care as mentioned above.

Assistance from other public organizations is needed, and any help to support palliative care caregivers is warranted. Caregiver support centers should be equipped with techniques to educate, empower, and provide vitality to caregivers (Scott, 2014). Support services also must align themselves with mental health services for caregivers as well as attend to those who are stressed, experience anxiety and depression.

Mosher et al. (2013) noted that complementary and alternative medicine (CAM) use is a support service that can help caregivers. CAM services include yoga, meditation, massage, psychotherapy and medication (Mosher et al., 2013). Approximately 43.5 million American adults are serving as family caregivers (Chi et al., 2016). Without support available for family caregivers, negative impacts such as stress, depression, and anxiety, on caregivers' health are expected due to the physical demands of lack of sleep, (Chi et al., 2016). Better quality adherence to caregivers could present better outcomes for families.

The Effects of Caregiver Distress

Family caregivers experience an array of burdens that are associated with taking care of their loved ones. Primary caregivers are subject to stressors, poor health, negative social interaction, low life satisfaction, and depression (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). According to the CDC (2015), caregivers experience physical, emotional, and financial problems that lead to sleep deprivation, poor eating habits, and problems with anxiety, frustration, anger, and guilt. Any of these areas of distress can be detrimental; for example, sleep deprivation or poor eating habits can invite fatigue, colds and flu, and longer-term chronic illness. If the caregiver has health issues, the situation can become critical for the patient's well-being and health outcomes (Brummett et al., 2006). Lack of sleep can affect medication intake, glucose monitoring, and proper turning in the bed for a patient. Finances are also a distress factor. Caregivers can incur immediate and long-term problems, often having to reduce work hours to fulfill their caregiving responsibilities.

According to former First Lady Rosalynn Carter, “there are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers” (Fowler, 2014). Family members who provide informal care often find themselves in what is considered to be the sandwich generation. They are generally between the ages of 45 and 65 and perhaps still caring for their children while taking on the responsibility of providing care for a parent (Fowler, 2014), thereby they are caregivers. They are faced with new life changes and distress that come with the position.

Distress levels of caregivers have been described as discouraging and demoralizing, associated with a feeling of a loss of freedom (Stern, 2015). The role of caregiver has been associated with an increased risk of physical, emotional, and financial strains. Quality of life is altered for caregivers, adaptation to illnesses is acquired, and coping skills are challenged. The burdens of caregiving can result in an imbalance, eventually causing caregivers to feel helpless (Carona, Silva, Crespo, & Canavarro, 2014). Carona et al. (2014) noted that caregivers who are parents of children with chronic conditions endured a higher risk of increased stress and decreased quality of life as well as more psychological problems.

Furthermore, caregivers are faced with the need to learn different coping, communication, and quality of life skills. In Figure 1, the quality of life model is displayed for both the patient and the family caregiver.

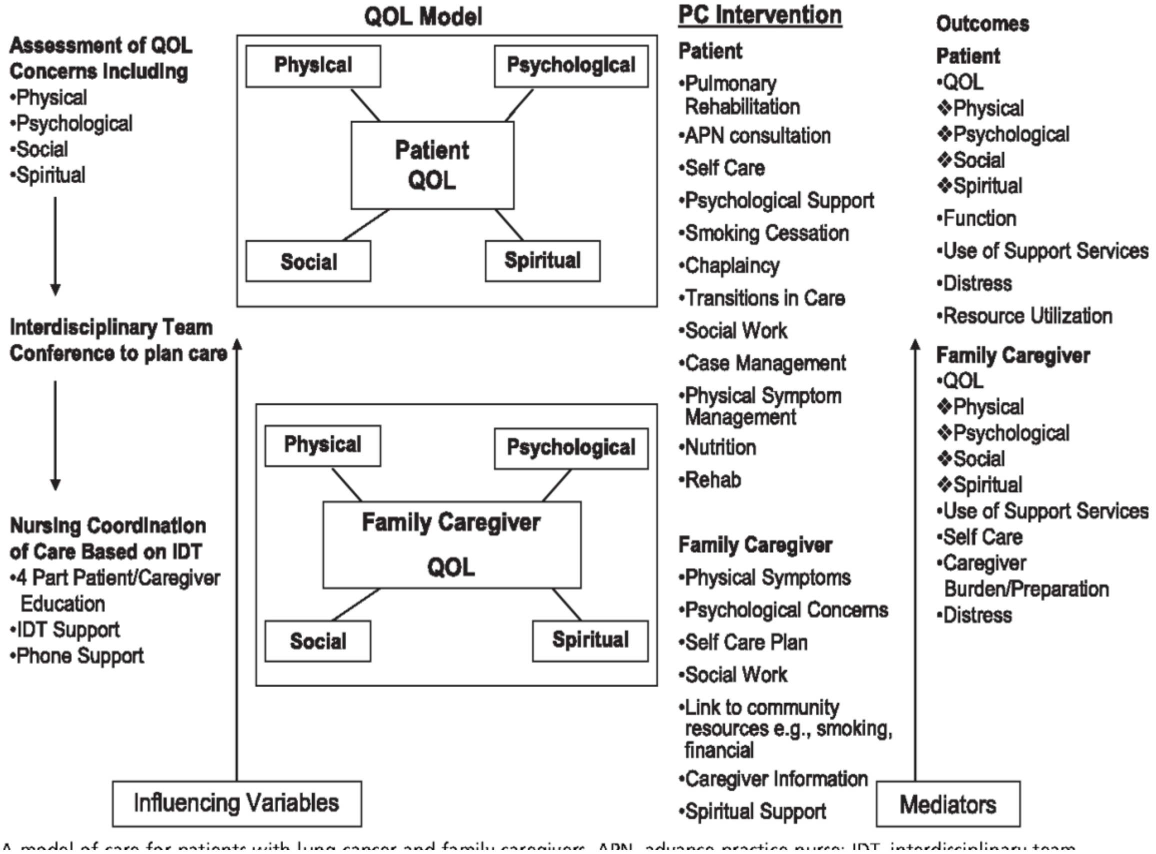

Figure 1. Quality of life outcomes among palliative care caregivers. (*Ferrell, B., Koczywas, M.N., Grannis, F., & Harrington, A.R. (2011))*

Depression Among Caregivers

Depression occurs at unspecified higher rates among caregivers of palliative care patients. In addition, there is an increased risk of developing mental and physical health problems (Haley et al., 2003) such as depression, or manic depression as well as sleep deprivation. Multiple chronic illnesses affect palliative care patients such as lung cancer, dementia, and acute coronary syndrome. Acute coronary syndrome palliative care patients' partners who experience depressive symptoms are more likely to be women who have trouble coping with the stressors (Vilchinsky, Dekel, Revenson, Liberman, & Mosseri, 2015). For patients with acute coronary syndrome, a great deal of caregiving falls onto a partner, and as Vilchinsky et al. (2015) noted, caregivers are prone to emotional and physical health, social, and financial burdens.

Caregivers experience symptoms associated with depression that are common and overlooked as being a part of depression. Symptoms such as restless sleep, poor appetite, and loneliness are known to impede the quality of life of caregivers and can shorten lifespan (Haley et al., 2003). Restless sleep quality was measured by Brummett et al. (2006) using the Pittsburgh Sleep Quality Index, which is an instrument used to measure the quality and patterns of sleep; the scale used consisted of 19 items that assessed various aspects of sleep over a one-month period. The results of the test, showed high scores of negative effects such as failure to stay awake during work hours, poorer perceived social support, and more unfortunate sleep quality overall. Without social support addressing sleep quality, negative outcomes for caregivers are likely to continue and increase.

Vilchinsky et al.'s Brief Symptom Inventory depression subscale measures the rate and degree of depression by examining six specific symptoms. The scale ranged from 1 (not at all) to 4 (very much); of the 6-month assessments, the baseline for coefficients was a range of 75 and 84 respectively (Vilchinsky et al., 2015). The percentage of patients above the normal range for depression was 6.6%. Caregivers have a higher risk of becoming depressed if they appraised their tasks as stressful, indicated feelings of low self-efficacy, and reported feeling less satisfaction due to being a caregiver (Haley et al., 2003). When social networks are provided to support caregivers, there is a perceived satisfaction and increase in participation in social activities, which helps their quality of life. Increasing quality of life for caregivers leads to a less stressful environment and greater life satisfaction with lower depression (Haley et al., 2003).

According to Lakey and Cohen (2000), the social support theory focuses on social psychology to assist in the evaluation of social support and the quality of influence it has for caregivers. The theory was created to assist the caregiver regarding both psychological and social support aspects such as emotional, informatinal, tangiable aid and service and empathy, love trust and caring. Social support theory is fundamentally associated with psychcological outcomes involving morbidity, mortality, recovery from illness, and caregiver’s capacity to withstand stressors. Incorporating the social support theory into this dissertation helps to show the beneficial effects social support has for cognitive learning and behavioral analytical and expressive styles. According to Sarason and Sarason (2009), individuals who experience high levels of stress will display relatively low levels of psychological difficulty and physical problems if they have excellent support.

Anxiety Among Caregivers

Anxiety is associated with distress. Emotional outcomes of patients such as sadness or anger due to pain or the disease prognosis tend to leave caregivers with anxiety and distress (Raivio, Laakkonen, & Pitkala, 2014). Caregivers of Alzheimer’s patients, for example, exhibited poorer wellbeing according to the Psychological Well-being Scale (Raivio et al., 2014), which measures six aspects of wellbeing and happiness including but not limited to environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptace. This scale evaluates distress and anxiety according to caregiver age, gender, education, personal coping mechanisms, competence and sense of coherence; it also evaluates recipients' care. The severity of Alzheimer's, psychiatric symptoms, and functional limitations were also arears that impacted caregivers' burdens (Raivio et al., 2014).

In patients with frontotemporal dementia (an uncommon disorder that affects the frontal and temporal lobes of the the brain), family caregivers experienced anxiety and depression, along with an unspecified high rate of physical health and psychological stress (Caceres et al., 2015). Being a caregiver for a patient with frontotemporal dementia too often creates a higher concern because patients are effected generally with personality, behavior and language problems and for caregivers' the ability to fulfill the caregiving role is challenging. When palliative care cargivers are faced with challenging duties, and cannot understand, and accept the end-life process, Caceres (2015) said that the caregiver role consequently applies limits to the success of patient and family-centered care initiatives.

Distress Among Caregivers

Family caregivers also are for those who may have experienced traumatic ordeals. Although parents who have taken care of children who have experienced sexual abuse, are not palliative caregivers, the care is parallel. For parents of children who have been sexually abused, it is noted that caregivers may at times experience intense emotional distress following acknowledgment of their child's sexual abuse (Stewart, 2010). Some areas of distress that can manifest include somatic symptoms, anxiety, and post-traumatic stress, along with self-blame, feelings of denial and disbelief (Stewart, 2010). Caregivers of palliative care patients endure the same or similar emotional states. Parental caregivers have been subject to moderate to severe depressive states, and support groups are needed to assist both the parents and child in dealing with reactions to the abuse, just as the support care is needed for palliative care caregivers.

The effect of depression, which parents often experience, leads to a parent being less able to provide support for the abused victim. The maternal support for adolescent children creates terrible dynamics for a family environment and the mental health of a parent (Stewart, 2010). Parents who are palliative care caregivers are faced with challenges of avoidant emotion-focused coping, involving wishful thinking and denial, which are all related to psychological maladjustment (Carona et al., 2014). A caregiver's support differs from those who care for patients with Alzheimer's. Raggi et al. (2015) note that emotion-focused factors may be associated with higher levels of distress while an active and problem-focused approach to stressful conditions may act as protective factors for caregivers. Every patient and caregiver situation are different, as are the strategies and mechanisms of coping. The psychological distress can manifest in multiple ways as can the ability to cope with the behavioral outcomes.

Caregivers’ Behavioral Outcomes and Coping Skills

There are a host of behavioral outcomes and coping skills that emerge for caregivers during the process of taking care of a loved one. Caregivers' behavioral outcomes relate to the distresses that a caregiver incurs. Results, on the other hand, refer to how a caregiver manages personally and professionally, and how well he or she can maintain being a caregiver. According to Stern (2015), one study showed that there were cognitive and emotional changes found in caregivers, showing an increase in impatience, anger, mood swings, sexually inappropriate behaviors and some substance abuse. The changes in behavior are of course different for each person per the disease process of the patient.

These behavioral changes affected the quality of life for patients, while at the same time increasing caregiver's burdens (Stern, 2015). Coping skills that address behavioral changes are tools created or adapted to by a caregiver. Some coping skills can be social, environmental, family and emotional. According to Raggi (2015), coping is a part of conscious efforts to resolve a personal and interpersonal problem to tolerate the stress. Coping skills are learned to assist in reducing the stress levels and help solve the problem. Caregivers need strategies to deal with the changes in lifestyle. According to Stern (2015), there are two heavily researched coping strategies. These include problem-focused coping and emotion-focused coping. A study of acquired brain injury patients and their caregivers demonstrated that problem-focused coping skills work directly to address the problem that caused the distress. The same study showed that the emotion-focused coping skills decreased the negative emotions associated with the issues faced by the caregiver (Stern, 2015).

The behavioral outcomes are the reflection of the burdens that caregivers incur. Carona et al. (2014) shared a study from the Portuguese version of the Revised Burden Measure in which caregivers responded to a caregiver burden scale with three subscales: relationship burden, objective burden, and subjective burden. Measures used with a 5-point Likert scale were the relationship burden scale (5 items), the objective burden scale (6 items), and the subjective burden scale (5 items) with higher scores representing greater caregiving burdens. The behavioral disengagement coping skills, on a subscale, included two items measuring the extent to which parents reduce efforts to deal with stressful events (i.e., "I give up the attempt to get what I want"; "I just give up trying to reach my goal"). These statements were answered on a 4-point Likert scale, that noted higher scores indicating greater use of the copying strategy (Carona et al., 2015).

Caregivers experienced some form of distress, and there must be a form of coping skills to help them adjust to the stressor of being caregivers regardless of the disease process of the patient. Raggi (2015) notes that caregivers are advised to partake in self-help groups, family meetings, educational seminars, and telephone counseling, all of which will assist in the psycho-educational approach of coping. When caregivers use coping skills effectively, it helps them maintain a better quality of life (Stern, 2015). Having strategic coping strategies that will focus on the distresses of caregivers allows for an increased positive outcome effect on caregivers.

Definition of Terms

Caregiver Burden: An experience of overload that results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness (Carona et al., 2014).

Caregiver Psychological Distress: Theoretically defined as symptoms of anxiety, depression, and anger that emerge because of a stressor (Stack, 2012).

Coping: Continuously changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the individual (Stack, 2012).

Distress: Meeting the clinical cutoff for significant anxiety or depressive symptoms on a standardized and widely used self-report measure (Mosher et al., 2012).

Family Caregivers: Provide the bulk of support to patients receiving palliative care; without this assistance, patients' well-being and capacity to remain at home would be compromised (Hudson et al., 2015).

Palliative Care: To provide medical care, symptoms management, emotional and spiritual support, and improve the quality of life (QOL) for terminally ill patients and their families (Chi et al., 2015).

Social Support: The function and quality of social relationships (Stack, 2012).

Assumptions

The assumption is that the participants suffered behavioral outcomes because of the minimal social support provided for caregivers. With continued minimal social support for family caregivers, the chances of an increase in distressed behavior rates will continue to grow. Thamer (2000) said that the willing participants of this study were truthful in their responses about caregiver burdens and accurately described their experiences. Less distress was found in caregivers who have more extensive social networks, higher perceived satisfaction with support and increased participation in social activities (Haley et al., 2003). It was assumed that the participants, chosen decisively, were an advantageous source of information, allowing for an understanding of the topic and resulting in greater insight into the outcome of behaviors shown in association with psychological distress, sleep deprivation, and abuse.

Scope and Delimitations

There are several chronic illnesses which can lead a person to need palliative care caregiving. Family caregivers can range from parents of children to children of parents, even siblings, all of whom need social support services. The health conditions, which lead individuals to family caregivers, place those caregivers at risk for developing behavioral outcomes that have mental and physical health effects. For example, the rate of depression is increased, the immune system is challenged, and there is an increased rate of infectious illness (Haley et al., 2003). For caregivers, the burdens develop by having a sparse support network (Ravio, Laakko, & Pitkala, 2014); having limited resources available tends to bring forth negative outcomes. Of the total weighted base of 286 surveyed participants who responded to the need of more support, there were 32% who felt they should have had more support based on the Harris Interactive Inc. survey, 2000. The survey was delimited by not providing specific types of social support and explaining specifically how they can help family caregivers. The examples of support given were local churches or other religious organizations, community support groups, and social service providers, of which no comprehensive essential services such as group support, one on one counseling or peer-related assistance were provided.

Reviewing the lack of assistance provided in this quantitative cross-sectional study, I delimited the study by assessing there were no control groups nor interventions to compare for sequential evaluation. As a secondary data analysis, there was no opportunity for primary data collection; therefore, the data analyzed was of the available variables within the dataset selected. Furthermore, the exclusion of available data collection tools allowed further delimitation based on the sample size used for the national study and information provided by the data collectors.

Significance, Summary, and Conclusions

This study is significant because family members are increasingly taking on the responsibility of caring for loved ones. Taking on the role of caregiver can become a health concern in multiple ways, namely mentally, physically, emotionally and financially. Palliative care caregivers have a high rate of mortality due to the lack of self-care. Behavioral problems develop, and psychological distresses often become a norm.

It is essential for caregivers to have social support in their life to enhance their quality of life, which will in turn help reduce incidents of depression, anxiety, stress, sleep deprivation and patient abuse. Maintaining positive feelings and avoiding negative ones, such as bitterness, isolation or distress, are key attributes for caregivers to live stable and healthy lives (Ravio, Laakkonen, & Pitkala, 2015).

This research regarding palliative care caregivers and the association between psychological distress, social support, and behavioral outcomes provides an essential understanding about the lack of needed social support for caregivers as well as the associated results of taking on the role as a caregiver. The perspectives of the caregivers lead to greater awareness of the processes and actions of healthcare facilities (i.e., acute hospitals, long-term care facilities, and skilled nursing facilities) as well as at-home palliative care. These perspectives have also allowed for better strategies of social support within communities, allowing caregivers to improve personal health outcomes.

Social support provides proficient ways to improve assistance for caregivers that will impact stress levels, abuse, sleep deprivation and anxiety. Through social support, coping skills are learned and used by caregivers for both problem-focused solving and emotion-focused solving, which can help caregivers improve quality of life skills, impacting the level of distress and negative outcomes.

Providing awareness about the lack of social support for family members who care for palliative patients can ultimately enhance the behavioral and health outcomes for caregivers. It can have a positive impact on the systematic disadvantages of at-home family caregiving and can reduce the social isolation so often reported. In addition, I highlighted the needs of family caregivers, in-turn advocating for family members' quality of life during caregiving and bereavement (Hudson & Aranda, 2013). New insights into social support bring forth social change implications, such as better mental health and behaviors of caregivers. The acknowledgment that improvement is needed will have a long-term positive impact on families; it can also lead to new theories and informed insights for the processes of family caregiving and quality of life.

Section 2 focused on the research design and methodology for this study. In this section, the data was described in detail, including the population of the survey used, measures to operationalize the hypotheses constructs, and statistical plan.

Section 2: Research Design and Data Collection

Introduction

The purpose of the study was to examine the association between social support and psychological distress and social support and behavioral outcomes among palliative caregivers. This study was a quantitative cross-sectional design comprised of secondary data from a larger United States on Chronically Ill and Caregivers Survey of 1,663 caregivers and chronically ill adults 18 years of age and older. The data are archived at the University of Michigan Inter-university Consortium for Political & Social Research, In this section, the study design, sample, setting, data collection procedures, and data analysis are discussed.

Research Design and Rationale

In this study, I used a quantitative cross-sectional approach with secondary data analysis. The data included a sample size of 320 adults who were 18 years and older and caregivers. This survey was suitable for the study in that it provided a cross-section of U.S. caregivers and its emphasis on chronic illness provides the variables needed to examine whether social support affects psychological distress and behavioral outcomes among palliative caregivers. The key predictor was social support with demographic characteristics as covariates. The dependent variables were psychological distress (anxiety, stress, and depression) along with behavioral outcomes (sleep deprivation and patient abuse). The statistical plan includes descriptive analysis to characterize the participants and multiple logistic regression to test the hypotheses.

Methodology

Population

The population pool of this survey began with a larger sample size of a national cross section of chronically ill caregivers in the United States based on the Current Population Survey from the U.S. Census Bureau, which is a monthly survey of about 60,000 U.S. households for the Bureau of Labor Statistics. The population surveyed for this study consisted of both males and females between the ages of 18 and 65. The survey was administered through telephone interviews. The income range for participants was between $15,000 and $65,000 annually and levels of education ranged from high school graduates to postgrad. The Robert Wood Johnson Foundation funded the survey.

Sampling and Sampling Procedures

The total population consisted of 1,663 adults who are 18 years of age and older. There were no historical or legal documents used in the collection of data for this study. This study included a national cross section of 1,490 adults, with an additional oversample of those with chronic illnesses and adults who provided familiar caregiving services (N = 173). Based on the study criteria of caregivers, 80% of the 1,663 participants in the survey were excluded; 680 (40.9%) were excluded because they were neither chronically ill nor caregivers, and 663 (39.9%) were excluded because they were chronically ill but not caregivers. The remaining 320 met the inclusion criteria. Of these, at least half experienced at least one form of psychological distress.

Justification for the Effect Size, Alpha, and Power Level

To calculate power, I used the medium effect size 0.15, which allowed for greatest external validity. The alpha [α] level of 0.05 was used to reduce Type 1 error while the power level of 80 reduces Type 2 error with a confidence interval (CI) of 95%. The minimum sample size with the calculation by using G*Power, a statistical program that measures power analysis was 43%. The G*Power analysis tool is a tool available on the Internet. The sample size for this secondary analysis study was 320 palliative care caregivers. Type I error is the rejection of a true null hypothesis, whereas the Type II error is the false negative, failing to reject a false null hypothesis. According to Beins (2017), the alpha level Type I error is the norm for researchers to accept between groups or a correlation as statistically significance. If the result or a more extreme result occurs that is less than 5% yield no effect. However, researchers can conduct studies with erroneous Type II error rates resulting in conclusions that have no significant differences between groups and no significant relationship between the variables.

Instrumentation and Operationalization of Constructs

The instrument used in the survey of caregivers included data on sociodemographic characteristics such as gender, ethnicity, education, and income. The key independent variable was social support and consisted of nine items to measure caregiver's awareness of support services and direct social support. As shown in Table 1, the overall social support variable was calculated by adding the yes codes and could range from 0 to 9. Social support was measured by using nine items to determine direct social support received, including relatives, friends, doctors, local churches or other religious organizations, local volunteer groups, social services, therapists/counselors, government, and other sources. The dependent variables were psychological distress and behavioral outcomes.

Table 1

Operational Description of Variables

Variable Name	Short Description	Response Categories	Variable Type
Awareness of Social Support			
Spiritual organizations	Aware of local spiritual organization-churches/other (e.g., Faith in Action)	1=Yes 0=No	Binominal
Volunteer groups	Aware of help from volunteer group in the local area	1=Yes 0=No	Binomial
Social services	Aware of providers of Social Services	1=Yes 0=No	Binominal
Other support services	Aware of other support services	1=Yes 0=No	Binomial
Overall Social Support Awareness	Number of support resources aware of	0=None 1=One 2=Two 3=Three 4=Four	Ordinal
Direct Social Support			
Family Support	Did you have family support?	1=Yes 0=No	Binominal
Provider Support	Are Providers Supportive	1=Yes 0=No	Binominal
Religious Support	Are Religious Organization Supportive?	1=Yes 0=No	Binominal
Local Volunteer Support	Are Local Volunteer Organizations Supportive	1=Yes 0=No	Binominal
Social Services Support	Are Social Service Organizations Supportive?	1=Yes 0=No	Binominal

(table continues)

Overall Direct Social Support	Number of direct social support entities	0=None 1=One 2=Two 3=Three 4=Four 5=Five	Ordinal
Psychological Distress			
Anxiety	Caregivers who experience anxiety and other mental health disorders	1=Yes 0=No	Binominal
Stress	Caregivers who experience anxiety and other mental health disorders	1=Yes 0=No	Binominal
Depression	Caregivers who experience anxiety and other mental health disorders	1=Yes 0=No	Binominal
Behavioral Outcomes			
Abuses Patient	Have you ever abused the person you provided support for?	0=Never 1=Hardly Ever 2=Sometimes 3=Often	Ordinal
Sleep Deprivation	Have you experienced insomnia or any other sleep problem?	1=Yes 0=No	Binominal
Socio-demographic			
Gender	Gender of participant	1=Male 2=Female	Nominal
Race	Origin of race	1=White 2=Black/African American 3=Other	Nominal
Education	Years of school completed	1=HS Grad/GED 2=Some College 3=AS/BA Degree 4=MA/PhD/Prof. 5=Other	Ordinal
Income	Annual income by category	1=< \$25,000 2= ≥ \$25,000	Ordinal

Dependent variables. The dependent variables were psychological distress and behavioral outcomes. Psychological distress was the dependent variable for research question 1 and behavioral outcomes for research question 2. Psychological distress included three types of distress: anxiety, stress, and depression. Behavioral outcomes referred to negative behaviors (patient abuse, sleep problems) that caregivers developed as a result of lack of social support and increased psychological distress.

Independent variables. Social support was the key independent variable. Social support consisted of 9 items ranging from awareness of support services the caregiver could reach out to (spiritual organizations, volunteer groups, social services, other support services), to direct support (family support, provider support, religious support, local volunteer support, social service support). Both overall social support awareness and direct social support were summed up and calculated with a range from 0 to 9.

Data Analysis

The Statistical Package for Social Science (SPSS) version 24 was used in the analysis of this secondary dataset. The data were acquired from one file available from ICPSR. The data were reviewed and analyzed by using descriptive and inferential techniques. Univariate statistics were used to describe the frequency distribution for each categorical variable and means and standard deviation for ordinal and continuous variables (sociodemographic, social support, psychological distress, and behavioral outcomes). The hypotheses of the study were tested using the logistic regression technique and Spearman correlation. The research questions examined the association between social support and psychological distress and social support and behavioral outcomes among palliative care caregivers. The first research question has the concept of psychological distress with three hypotheses for each symptom (anxiety, stress, depression). The second research question explores behavioral outcomes and has two hypotheses to test sleep deprivation and patient abuse.

Research Questions and Hypotheses

The research questions examined the association between social support and psychological distress and social support and behavioral outcomes among palliative care caregivers.

Research Question 1. Is there an association between social support and psychological distress (anxiety, stress, and depression) among palliative care caregivers?

Ho_{1a}: There is no association between overall awareness of resources and overall direct social support and anxiety among palliative care caregivers.

H_{A1a}: There is an association between overall awareness of resources and receipt of overall direct social support and anxiety among palliative care caregivers.

Statistical Plan: The predictor variables were overall awreness of social support (index of 4 yes/no items) and overall direct social support (index of 5 yes/no items), and the dependent variable was anxiety measured with a binominal variable coded 1=anxiety and 0=no anxiety. The hypotheses were tested using logistic regression. The null hypotheses were rejected if $p < .05$.

Ho_{1b}: There is no association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

H_{A1b}: There is an association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

Statistical Plan: The predictor variables were overall awreness of social support (index of 4 yes/no items) and overall direct social support (index of 5 yes/no items), and the dependent variable was stress measured with a binominal variable coded 1=stress and 0=no stress. The hypotheses were tested using logistic regression. The null hypotheses were rejected if p < .05.

Ho_{1c}: There is no association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

H_{A1c}: There is an association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

Statistical Plan: The predictor variables were overall awreness of social support (index of 4 yes/no items) and overall direct social support (index of 5 yes/no items), and the dependent variable was depression measured with a binominal variable coded 1=depression and 0=no depression. The hypotheses were tested using logistic regression. The null hypotheses were rejected if p < .05.

Research Question 2. Is there an association between social support (awareness of services and direct social support) and behavioral outcomes (sleep deprivation, patient abuse) among palliative care caregivers?

Ho_{1a}: There is no association between overall awareness of social support and overall direct social support and sleep deprivation among palliative care caregivers.

H_{A1a}: There is an association between overall awareness of social support and overall direct social support and sleep deprivation among palliative care caregivers.

Statistical Plan: The predictor variables were overall awreness of social support (index of 4 yes/no items) and overall direct social support (index of 5 yes/no items), and the dependent variable was sleep deprivation measured with a binominal variable coded 1=sleep deprivation and 0=no sleep deprivation. The hypotheses were tested using logistic regression. The null hypotheses were rejected if $p < .05$.

Ho_{2b}: There is no association between overall awareness of social support and overall direct social support and patient abuse among palliative care caregivers.

H_{A2b}: There is an association between overall awareness of services and overall direct social support and patient abuse among palliative care caregivers.

Statistical Plan: The predictor variables were overall awreness of social support (index of 4 yes/no items) and overall direct social support (index of 5 yes/no items), and the dependent variable was patient abuse measured with an ordinal variable coded 0=never, 1=hardly ever, and 2=sometimes. The hypotheses were tested using Spearman correlation. The null hypotheses were rejected if $p < .05$.

Threats to Validity

Validity explores whether the investigator's conclusion is correct. It examines the changes in the independent variable to observe the variation in the dependent variable. And it also looks at the relationship between the dependent variable and other possible causes. The current study has several limitations and threats to validity. The study population and response rate in the secondary data source is low. To receive a higher validation and caregiver response, surveys should have a broader range when conducted throughout the United States. A way to increase the validation and response rate would be to include several facilities such as acute hospitals, hospice facilities, and skilled nursing facilities, to include all family caregiver responses.

With the data, it cannot be determined that all caregivers are being provided the appropriate social support, nor can the research provide an adequate account of available social support services to caregivers. Another threat to the validity of this study is having an increased population of family caregivers with at home patients respond. We cannot assume or conclude that the surveyed population for this study satisfies the needs of caregivers nor the psychological distresses caused by being a caregiver is represented.

A further limitation for the population sampled is the homogeneity of race in caregivers presented with 77.5% of caregivers being Caucasian, 11.6% being Black and 10.9% being of other races. This study can become more heterogeneous if the study is expanded to include the different facilities with a stronger focus on caregivers.

Ethical Procedures

Permission to use the de-identified data from the Chronic Illness and Caregiver survey was obtained from the ICPSR. Although ICPSR makes the survey data available for public use over the Internet, a registration by users is required. The participants of the Chronic Illness and Caregivers were informed of the purpose of the study via telephone, and their consent was obtained before the interview began. The investigators of the data source ensured that participants provided voluntary consent, and both patients and caregivers were presented with a written report of the questions and answers provided.

The documentation on the caregiver survey along with the doctoral study proposal was submitted to Walden University Institutional Review Board for approval of secondary analysis as indicated in this proposal (IRB approval number 10-19-17-0392471). I understood that the data received from ICPSR was to be solely used as secondary data for the current study and in the manner approved. No identifying information was released or sought after the secondary analysis for further information unless required by law.

Summary

In Section 2 of this study, the research design expounded upon the cross-sectional quantitative approach, rationale, and methodology of the study. The population was described along with an understanding that the sample consisted of 320 caregivers who reported their psychological distress, behavioral outcomes, and social support services awareness as well as direct social support received.

Palliative care caregiving is a position that family members take on as informal caretakers. Assessing the threats is vital to increasing the social support and minimizing the psychological distress. The research explored whether there is an association between social support and psychological distress, and behavioral outcomes among palliative care caregivers. The positive social change implications of this study may allow awareness for palliative care caregivers about their risk of distress and negative behavioral outcomes. Also, findings from this study may identify the extent alterations in social support may be protective of negative behavioral patterns of caregivers. Section 3 of this study will proceed with descriptive analysis of the characteristics of the caregivers in the study, distribution of key variables by social support, and multivariable analyses for hypothese-testing.

Section 3: Presentation of the Results and Findings

Introduction

The purpose of this quantitative study was to examine the association between social support and psychological distress and social support and behavioral outcomes among palliative care caregivers. Two research questions were examined to determine whether there was an association between social support and psychological distress and social support and behavioral outcomes among palliative care caregivers. I hypothesized that higher social support buffers psychological distress and negative behavioral outcomes. The results and findings in Section 3 include the data collection process, a review of the sampling methods, and differences noted within the existing data. Section 3 also includes the assessment of descriptive statistics, including frequencies, percentages, and inferential statistical analysis for hypotheses testing.

Data Collection of Secondary Data Set

The archival ICPSR 3402 database was a survey conducted between March 17 and November 22, 2000. The survey was collected from a centralized telephone research center in Youngstown, Ohio and Binghamton, New York. Participants were not asked to appear in person; therefore, all questions were posed verbally and coded into the survey responses. The sample was drawn to represent the population of the United States. The total sample size of the secondary data set was 1,663, and this number was reported in Section 2 as the proposed sample size (see Table 2). However, after obtaining basic frequencies for each variable and examining missing values, only 19.2% of the sample was classified as caregivers (N = 320). While the power to detect differences was below the calculated 80%, the sample of 320 caregivers are believed to represent a national sample, and thus the sample has good external validity.

Table 2

Distribution of Participants by Caregiver and Chronically Ill Categories

Survey Participant Classification	**Frequency**	**Percent**
Caregiver	320	19.2
Chronically Ill	663	39.9
Not Chronically Ill/Not a Caregiver	680	40.9
Total Sample	1663	100.0

Results

In the results section, I first describe the characteristics of the sample of caregivers by gender. Second, I describe the univariate frequencies for the key independent variable (social support) and two dependent variable categories (psychological distress and behavioral outcomes). I then summarize and compare the caregiver's overall awareness of social support and overall direct social support. The univariate frequencies for each key variable and demographics are described and displayed in tables.

Demographic Characteristics of Caregivers

The demographic characteristics of the caregivers are presented in Table 3. About two-thirds (62% of the caregivers were female and 38% were male. Race, marital status, education, and income were analyzed by gender. There were statistically significant differences by gender for marital status (*p* = .000) and income (*p* = .006). Male caregivers were more likely to be married or living with a partner (69.4%) compared to female caregivers (45.7%). Female caregivers were more likely to report being divorced or separated (17.6%) compared to male caregivers (5.8%). Income differences by gender were also statistically significant where 77.7% of males and 68.4% of females were more likely to have incomes equal to and above $25,000.

Table 3

Demographic Characteristics of Palliative Care Givers (N = 320)

Characteristic	Males 38% (121)	Females 62% (199)	p-value
Race/Ethnicity			.886
White	76.0	78.4	
Black/African American	12.4	11.1	
Other	11.6	10.6	
Marital Status			.000
Married/Living with Partner	69.4	45.7	
Single	22.3	21.6	
Divorced/Separated	5.8	17.6	
Other	2.5	15.1	
Education			
HS graduate/GED	25.6	24.1	.901
Some college	24.8	29.6	
Associate’s or bachelor’s degree	25.6	25.1	
Master’s, doctorate, or professional	11.6	9.5	
Other	12.4	11.6	
Income			
Less than $25,000	22.3	31.6	.006
>= $25, 000	77.7	68.4	

Note: Significance value based on Chi-square test

Awareness of Resources and Receipt of Direct Social Support

The distribution of awareness of resources and receipt of direct social support reported by palliative care givers is shown in Table 4. Each category of social support was answered either yes or no. An overall score for each of the two types of social support was calculated by adding each of the affirmative responses to each question. Almost 92.8% of caregivers were aware of some type of social support service with 55.6% reporting awareness of volunteer groups and 22.5% awareness of spiritual organizations and 23.8% social services. However, 66.6% of the caregivers reported that they were aware of other support services not identified in the survey. In terms of direct support services, 60.0% of caregivers reported receipt of at least one direct support service. The caregivers did not report receiving direct support from other sources (i.e., churches, neighborhood assistance) thus, while caregivers were aware of support resources, they did not receive direct support except from family members.

Table 4

Awareness of Resources and Receipt of Direct Social Support

Self-Reported Social Support	***N* = 320**	**%**
Awareness of Social Support		
Spiritual organizations	72	22.5
Volunteer groups	178	55.6
Social services	76	23.8
Other support services	213	66.6
Overall Social Support Awareness	297	92.8
Receipt of Direct Social Support		
Family support	189	59.1
Provider support	0	0.0
Religious support	0	0.0
Local volunteer support	0	0.0
Social services support	10	3.1
Overall Direct Social Support	192	60.0

Note: Categories are not mutually exclusive

Social Support by Psychological Distress and Behavioral Outcomes

In Section 2, the univariate distribution of social support was presented. In this section, the prevalence of psychological distress and behavioral outcomes are described, as well as the association between social support and these self-reported symptoms and behaviors. As shown in Table 5, the prevalence of different types of psychological distress ranged from 30.0% to 35.9%, with anxiety reported more often, followed by depression and stress. Behavioral outcomes were less likely to be reported than psychological distresses where 23.8% of caregivers reported sleep deprivation, and 7.5% reported patient abuse.

Caregivers were more likely to report awareness of resources across psychological distresses compared to receiving direct social support. Caregivers reporting anxiety were more likely (34.0%) to be aware of resources compared to stress (29.0%) and depression (27.0%). There were less differences in reported direct social support among the three types of psychological distress reported by the caregivers with anxiety and stress both at 28.0% and depression at 24.0%. On the other hand, caregivers with sleep deprivation were more likely to report receiving direct support (28.0%) compared to 21.0% reporting being aware of resources. Either type of social support (7% and 8%) was reported with the same low frequency as reporting patient abuse (7.5%).

Table 5

Social Support by Psychological Distress and Behavioral Outcomes

	Psychological Distress			**Behavioral Outcomes**	
	Anxiety (N=115)	Depression (N=102)	Stress (N=96)	Patient Abuse (N=76)	Sleep Deprivation (N=24)
Prevalence	35.9%	31.9%	30.0%	7.5%	23.8%
Awareness of Resources (N=213)	34.0%	27.0%	29.0%	7.0%	21.0%
Direct Social Support (N=189)	28.0%	24.0%	28.0%	8.0%	28.0%

Note: Categories are not mutually exclusive

In Figure 2, I present a bar graph showing the distribution of the variable patient abuse. The category of “never” indicates that over three-fourths (76.2%) of the caregivers reported never abusing a patient. The prevalence of patient abuse reflected those caregivers who stated they often, sometimes, or hardly ever abuse patients. While very few caregivers declined to answer the question, several stated that they were not sure if they had abused a patient.

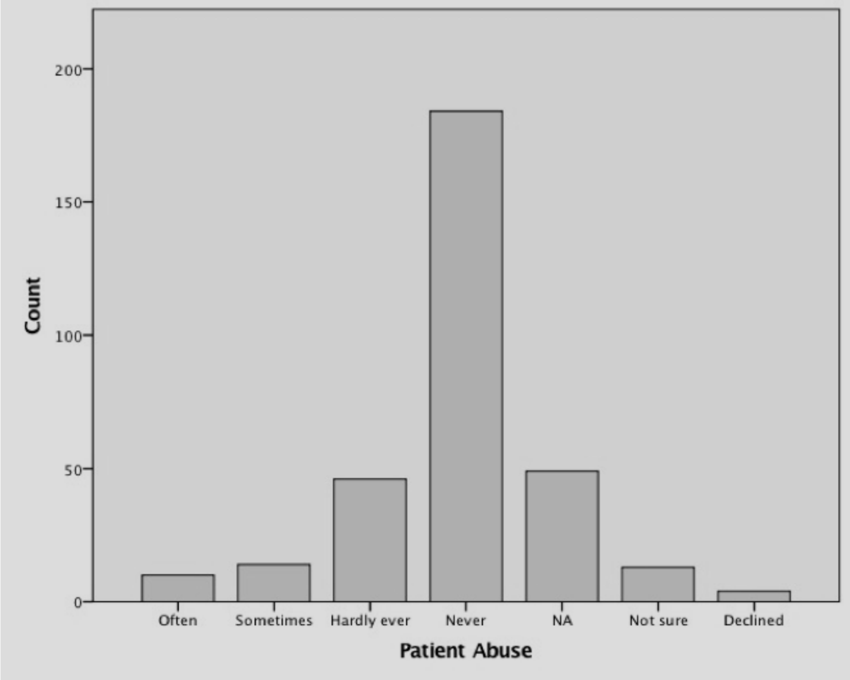

Figure 2. Distribution of caregivers’ self-report of patient abuse.

Multivariable Statistical Analyses

Research Question 1. Is there an association between social support (awareness of services and direct social support) and psychological distress (anxiety, depression, and stress) among palliative care caregivers?

Logistic regression analysis was performed to test the hypothesis, whether awareness of services and direct social support were predictors of psychological distress outcomes (anxiety, stress, depression). Social support consisted of two measures, overall awareness of social support index (ranging from 0 to 4) and overall direct social support index (ranging from 0 to 5). The dependent variables were anxiety, depression, and stress and were measured with a binominal distribution where reporting the condition was coded 1 and not reporting it coded as 0. Logistic regression models are presented in tables and include beta coefficients with standard errors, weighted p-values, adjusted (POR) odds ratios, and 95% confidence intervals.

Ho_{1a}*:* There is no association between overall awareness of resources and overall direct social support and anxiety among palliative care caregivers.

H_{A1a}*:* There is an association between awareness of resources and receipt of direct social support and anxiety among palliative care caregivers.

The association between the overall awareness of social support index and the overall direct social support index as predictors of anxiety was tested using logistic regression. The logistic model (Table 6) indicates that overall awareness of social support did not predict anxiety ($X^2(4)$ = 3.34, p = .503).

Table 6

Overall Awareness of Social Support as a Predictor of Odds of Anxiety

Variable	β(*SE*)	*W(p)*	Adjusted *POR*	95% CI
Constant	-.087 (.417)	.043 (*p* = .835)	.917	
Overall Social Support Awareness		1.562 (*p* = .816)	--	--
Overall Social Support Awareness (Spiritual Organization)	-.480(.464)	1.070 (*p* = .301)	.619	[.249, 1.537]
Overall Social Support Awareness (Volunteer Group)	-.564(.453)	1.552 (*p* = .213)	.569	[.234, 1.382]
Overall Social Support Awareness (Social Services)	-.447(.517)	.747 (*p* = .387)	.639	[.232, 1.762]
Overall Social Support Awareness (Other Support Services)	21.116(28420.722)	.000 (*p* = .999)	.000	[.000, .]

Note: Logistic Regression model predicting *odds of* anxiety ($X^2(4)$ = 3.34, *p* = .503

The logistic model for overall direct social support (Table 7) indicates that direct support from family significantly ($X^2(3)$ = 20.59, *p* < .001) predicted anxiety reducing the odds to .416 (95% CI [.259, .670]) compared to those that did not receive direct social support. The null hypothesis for overall awareness of social support and anxiety was not rejected while the null hypothesis for overall direct social support and anxiety was rejected. There is an association between direct social support from family and anxiety among palliative care caregivers

Table 7

Overall Direct Social Support as a Predictor of Odds of Anxiety

Variable	β(*SE*)	*W(p)*	Adjusted *POR*	95% CI
Constant	-.048 (.179)	.072 (*p* = .788)	.953	--
Overall Direct Social Support	--	13.167 (*p* = .004)	--	--
Overall Direct Social Support (Family Support)	-.876 (.243)	13.031 (*p* = .001)	.416	[.259, .670]
Overall Direct Social Support (Provider Support)	-21.155 (14210.361)	.000 (*p* = .999)	.000	[.000, -]
Overall Direct Social Support (Religious Support)	.048 (1.425)	.000 (*p* = .973)	1.049	[0.64, 17.149]
Overall Direct Social Support (Local Volunteer Support)	--	--	--	--

Note: Logistic Regression model predicting odds of anxiety ($X^2(3)$ = 20.59, *p* < .001)

Ho_{1b}: There is no association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

H_{A2b}: There is an association between overall awareness of resources and overall direct social support and stress among palliative care caregivers.

The association between the overall awareness of social support index as predictor of stress was tested using logistic regression. The logistic model (see Table 8) indicates that overall awareness of social support did not predict stress ($X^2(3)$ = 1.59, *p* = .207).

Table 8

Overall Awareness of Social Support as a Predictor of Odds of Stress

Variable	β*(SE)*	*W(p)*	Adjusted *POR*	95% CI
Constant	-.450 (.267)	.2.839 (*p* = .092)	.637	[--,--]
Overall Social Support Awareness	-.183 (.146)	1.583 (*p* = .208)	.832	[.62, 1.108]

Note: Logistic regression model predicting odds of stress ($X^2(3)$ = 1.59, *p* = .207).

The association between the overall direct social support index as predictors of stress was tested using logistic regression. The logistic model (see Table 9) indicates that overall awareness of social support did not predict stress ($X^2(3)$ = 4.56, *p* = .207). However, for direct family support, the odds of experiencing stress were significantly lower than if there was no direct social support (*OR* = 0.603, *p* < .041, 95% CI: [.371, .980]). The null hypothesis was not rejected for the association between overall awarenes of social support resources and stress but was rejected for direct social support and stress.

Table 9

Overall Direct Social Support as a Predictor of Odds of Stress

Variable	β*(SE)*	*W(p)*	Adjusted *POR*	95% CI
Constant	-.473 (.184)	6.604 (*p* < .010)	.623	--
Overall Direct Social Support	--	4.550 (*p* = .208)	--	--
Overall Direct Social Support (Family Support)	-.506 (.248)	4.170 (*p* < .041)	.603	[.371, .980]
Overall Direct Social Support (Provider Support)	-.038 (.753)	.003 (*p* = .960)	.963	[.220, 4.212]
Overall Direct Social Support (Religious Support)	.473 (.184)	.110 ((*p* = .740)	1.604	[.098, 26.252]
Overall Direct Social Support (Local Volunteer Support)	--	--	--	

Note: Logistic regression model predicting odds of stress ($X^2(3)$ = 4.56, *p* = .207).

Ho_{1c}: There is no association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

H_{A1c}: There is an association between overall awareness of social support and overall direct social support and depression among palliative care caregivers.

The association between the overall awareness of social support index as predictor of depression was tested using logistic regression. The logistic model (Table 10) indicates that overall awareness of social support did not predict depression ($X^2(1)$ = 1,572, *p* = .210).

Table 10

Overall Awareness of Social Support as a Predictor of Odds of Depression

Variable	β(*SE*)	*W*(*p*)	Adjusted *POR*	95% CI
Constant	-.532 (.271)	3.851 (*p* = .050)	.588	[--,--]
Overall Social Support Awareness	-.185 (.148)	1.562 (*p* = .211)	.831	[.62, 1.11]

Note: Logistic regression predicting odds of depression ($X^2(1)$ = 1,572, *p* = .210).

The association between the overall direct social support index as predictor of depression was tested using logistic regression. The logistic model (Table 11) indicates that overall direct social support predicted odds of depression ($X^2(3)$ = 10.857, *p* < .013). Specifically, for only one type of direct social support (family), the odds of experiencing depression were significantly lower than if there was no direct social support (*OR* = .464, *p* < .002, 95% CI: (.28, .76)). The null hypothesis was not rejected for the association between overall direct social support and odds of depression. There is an association between overall direct social support and depression among palliative care caregivers.

Table 11

Overall Direct Social Support as a Predictor of Odds of Depression

Variable	β*(SE)*	*W(p)*	Adjusted *POR*	95% CI
Constant	-.405 (.183)	4.93 (p < .026)	.667	--
Overall Direct Social Support	--	9.368 (p = .025)	--	--
Overall Direct Social Support (Family Support)	-.768 (.837)	9.243 (p < .002)	.464	[.283, .761]
Overall Direct Social Support (Provider Support)	-.693 (.837)	.686 (p = .407)	.500	[.097, 2.577]
Overall Direct Social Support (Religious Support)	-20.797 (.284)	.000 ((p = .999)	0.00	[.000, --]

Note: Logistic regression model predicting odds of depression ($X^2(3)$ = 10.857, p < .013).

Research Question 2. Is there an association between social support (awareness of services and direct social support) and behavioral outcomes (sleep deprivation, patient abuse) among palliative care caregivers?

Logistic regression analysis was performed to test the hypotheses, whether overall awareness of services and overall direct social support were predictors of sleep deprivation, and Spearman correlation to test the hypothesis of patient abuse. Social support consisted of two measures, overall awareness of social support index (ranging from 0 to 4) and overall direct social support index (ranging from 0 to 5). The dependent variables were sleep deprivation and patient abuse and sleep deprivation was measured with a binominal distribution where reporting the condition was coded 1 and not reporting it coded as 0. Patient abuse was measured as an ordinal variable with “never,” “hardly ever,” and “sometimes.” Logistic regression models are presented in tables and include beta coefficients with standard errors, weighted p-values, adjusted (POR) odds ratios, and 95% confidence intervals.

Ho_{1a}: There is no association between overall awareness of services and overall direct social support and sleep deprivation among palliative care caregivers.

H_{A1a}: There is an association between overall awareness of services and overall direct social support and sleep deprivation among palliative care caregivers.

The association between the overall awareness of social support index as predictor of sleep deprivation was tested using logistic regression. The logistic model (Table 12) indicates that overall awareness of social support did not predict the odds of sleep deprivation ($X^2(1)$ = .084, p = .772). The null hypothesis was rejected for the association between overall awareness of social support and odds of sleep deprivation.

Table 12

Overall Awareness of Social Support as a Predictor of Odds of Sleep Deprivation

Variable	β(*SE*)	*W*(*p*)	Adjusted *POR*	95% CI
Constant	1.543 (.605)	6.501 (p < .011)	4.679	[--,--]
Overall Social Support Awareness	-.084 (.291)	.084 (p = .772)	.919	[.52, 1.62]

Note: Logistic regression model ($X^2(1)$ = .084, p = .772)

The association between the overall direct social support index as predictor of sleep deprivation was tested using logistic regression. The logistic model (Table 13) indicates that overall direct social support did not predict the odds of sleep deprivation ($X^2(3)$ = 5.078, p =.166). The null hypothesis was not rejected for the association between overall direct social support and odds of sleep deprivation.

Table 13

Overall Direct Social Support as a Predictor of Odds of Sleep Deprivation

Variable	β*(SE)*	*W(p)*	Adjusted *POR*	95% CI
Constant	1.344 (.458)	8.592 (*p* < .003)	3.833	--
Overall Direct Social Support	--	4.172 (*p* = .243)	--	--
Overall Direct Social Support (Family Support)	-.246 (.575)	.182 (*p* = .669)	1.278	[.41, 3.95]
Overall Direct Social Support (Provider Support)	-1.749 (1.022)	2.932 (*p* = .087)	.174	[.023, 1.288]
Overall Direct Social Support (Religious Support)	19.859 (28429.721)	.000 ((*p* = .999)	421428220	[.000, --]

Note: Logistic regression model ($X^2(3)$ = 5.078, *p* =.166).

H_{o2b}: There is no association between overall awareness of services and overall direct social support and patient abuse among palliative care caregivers.

H_{A2b}: There is an association between overall awareness of services and overall direct social support and patient abuse among palliative care caregivers.

The hypothesis was tested using Spearman correlation coefficients. As shown in Table 14 the correlation coefficient between the overall awareness index and patient abuse was ρ = .024 and not significant (*p* = .702) and between the overall direct social support index and patient abuse was ρ = .096 and also not significant (*p* = .129). The null hypothesis for the correlation between overall awareness of services and overall direct social support and patient abuse among palliative care caregivers was not rejected.

Table 14

Correlation Between Overall Awareness and Direct Social Support with Patient Abuse

Patient Abuse	Patient Abuse	Overall Awareness of Social Support	Overall Direct Social Support
Correlation Coefficient	1.000	.024	.096
p-value	---	.702	.129
N	254	320	319

Note: Spearman correlation test. Patient abuse excludes responses of “n/a,” “not sure,” and “declined”

Summary of findings. I proposed to examine the association between two types of social support and psychological distress and behavioral outcomes among palliative care caregivers. Only overall direct social support was a statistically significant predictor of psychological distress. The logistic regression models for overall direct social support were statistically significant only for anxiety and depression. All three psychological distresses, anxiety, stress, and depression were predicted by direct social support; however, this was due to receiving family social support and not the other types of direct support. The summary of the odds rations and p-values are presented in Table 15. Caregivers who received overall direct social support had less psychological distress as they were 58% less likely to report anxiety (OR = .434), 37% less likely (OR = .603) to report stress, and 54% less likely (OR = .464) to report depression. Social support (direct or awareness) was not a predictor of behavioral outcomes.

Table 15

Direct Social Support as Predictor of Psychological Distress and Behavioral Outcomes

Variables in the Model	Overall Model	p-value	Odds Ratio	95% CI
Psychological Distress				
Awareness of Services	n.s.			
Direct Social Support				
Anxiety (family)	.004	.001	.416	.259, .670
Stress (family)	n.s.	.041	.603	.371, .980
Depression (family)	.025	.002	.464	.283, .761
Behavioral Outcomes				
Sleep Deprivation	n.s.	.215	1.007	0.984, 1,031
Patient Abuse	n.s.	.129	---	---

Summary and Transition

In Section 3, I presented the results of the secondary analysis of the ICPSR 2000 survey, which was comprised of 320 palliative care caregivers. The purpose of this study was to examine how social support among caregivers would associate with psychological distress and behavioral outcomes within the palliative care community. Two research questions were proposed to examine whether there was an association between social support as a predictor of psychological distress (anxiety, stress, depression) and behavioral outcomes (sleep deprivation, patient abuse). Social support consisted of two measures, overall awareness of social support index and overall direct social support index.

There was support for the association between direct social support as a significant predictor of psychological distress for anxiety, stress, and depression. Logistic regression analysis indicated the null hypothesis was rejected for an association between direct social support and anxiety ($p < .001$) between direct social support and stress (p <

.041) and between direct social support and depression ($p < .013$). However, there was no support for the association between social support and behavioral outcomes (sleep deprivation, patient abuse).

In Section 4 of this study, I summarize and interpret key findings and corroborate the interpretations using findings from other studies. I describe recommendations for further research grounded in the strengths and limitations of the current study as well as the literature reviewed in Section 1. I also describe the limitations to generalizability, validity, and reliability that arose with the secondary data set. Recommendations for professional practice are included as well as implications for social change.

Section 4: Application to Professional Practice & Implications for Social Change

Introduction

The purpose of this study was to examine the association between social support and psychological distress and behavioral outcomes. Two research questions were proposed to examine whether there was an association between social support as a predictor of psychological distress (anxiety, stress, depression) and behavioral outcomes (sleep deprivation, patient abuse). There was support for the association between direct social support as a significant predictor of psychological distress for anxiety, stress, and depression. However, there was no support for the association between social support and behavioral outcomes (sleep deprivation, patient abuse). In this section, I present the interpretation of the findings, limitations of the study, recommendations for professional practice, implications for social change, and conclusion.

Interpretation of the Findings

Social Support

It is important to review the construction of the social support measures to understand the interpretation of the hypothesis testing findings. Social support scale consisted of nine items that participants answered yes/no. Four items asked about caregiver awareness of resources for social support (spiritual organizations, volunteer groups, social services, and awareness of other services) and five items asked whether caregivers received direct support from family members, providers, religious groups, local volunteer groups, social services, and other support. An overall index score for each of the two types of social support was calculated by adding each of the affirmative responses to each question. Almost all caregivers were aware of some type of social support service with almost two-thirds (56.6%) reporting awareness of volunteer groups, and over a fourth (22.5%) reporting awareness aware of spiritual organizations and social services. Two-thirds (66.6%) of caregivers reported that they were aware of other support services not identified in the survey. In terms of receiving direct social support services, almost two-thirds (60.0%) of caregivers reported receipt of at least one direct support service, reflecting great majority of support from family and er from social services. Thus, while caregivers were aware of support resources, they did not receive direct support except from family members.

Almost 92% of caregivers reported being aware of at least one social support service. The high number of other responses indicates a lost opportunity to learn types of services that can be promoted to caregivers. The lack of service specificity in the survey is a limitation in terms of ability for palliative care caregivers to be more descriptive of social support awareness of services and interpretation of what awareness of other services may mean as social support for the caregivers. In terms of the response items for direct social support, the support received was basically from family members.

Summary of Research Questions

The first research question was proposed to examine whether social support was a predictor of psychological distress (anxiety, stress, depression). The second research question examined whether there was an association between social support and behavioral outcomes (sleep deprivation, patient abuse). Social support consisted of two measures, overall awareness of social support index and overall direct social support index.

There was support for direct social support as a significant predictor of psychological distress for anxiety, stress, and depression. Based on logistic regression analysis, the null hypothesis was rejected for an association between direct social support and anxiety ($p < .001$), stress ($p < .041$), and depression ($p < .013$). However, there was no support for the association between social support and behavioral outcomes (sleep deprivation, patient abuse). The odds ratios below 1.00 indicates that direct social support was protective of anxiety (*OR* =.434), stress (*OR* = .603), and depression (*OR* =. 464).

Psychological Distress

The palliative care caregiving community is somewhat removed and unaware of social support such as community services that may help to relieve stress, anxiety, and depression and improve quality of life. The high number of other services the caregivers were aware of supports this view. The findings regarding the association between direct social support and caregiver distress are consistent with previous studies that report that social support is a buffer to psychological distress. Raggi et al. (2015) found that severity of caregiver distress was negatively correlated with caregiver coping skills such as seeking social support. Conversely, those needing more family and social support were more likely to have higher levels of distress (Raggi et al., 2015). Therefore, seeking support may be an indicator of higher burden expressed as anxiety, stress, and depression.

Broadly, social support is viewed as a compartmentalized functionality, in that the defense mechanism is of mental discomfort, cognitive dissonance and anxiety caused by having conflicting values, emotions and beliefs. The caregivers in my study reported a very high level of awareness of social support services, but there was very low use of social services and a heavy reliance on family for direct social support. According to

Reblin and Uchino (2009), there is a discrepancy between perceived support and received support. Brandon (2013) noted that 87% of caregivers felt they needed more information and understanding about topics related to caregiving, yet there was not enough support given, hence the lack of knowledge for social support available. According to Brandon (2013), while a caregiver may be positively affected through education about being a caregiver, social support in the form of peer support was not effective.

According to Hudson and Aranda (2013), adequate social support is limited; caregivers are often not aware of the available support. In addition, caregivers may be reluctant to find health professionals as a resource, or it may be that health professionals do not have the appropriate skills to provide the support that a family may need (Hudson & Aranda, 2013). I found that caregivers did not indicate receiving direct social support from providers. Reblin and Uchino (2009) indicated that social support could have a greater positive effect on improving lower quantity or quality of social relationships. The findings from my study only indicated the distribution of social support services they used but not the reasons for lack of use among the 40% who did not use any. Brandon (2013) said that caregivers who have a passive coping style, seem anxious or depressed, or lack family support may be at higher risk of psychological distress.

Behavioral Outcomes

According to the National Center on Elder Abuse Administration on Aging, 1 in 10 older adults has reported abuse or mistreatment. According to the Acierno, Hernandez, Amstadter, and Resnick (2010), 20% of elder abuse cases involve neglect, which is defined as “refusal or failure by those responsible to provide food, shelter, healthcare or protection for a vulnerable elder” (p. 293). Exactly 24 caregivers (7.2%) answered “often,” “sometimes,” or “hardly ever” to the survey question regarding patient abuse as a behavioral outcome, but the extent of abuse to the patients is not known. Out of the 320 palliative care caregivers, 76% did not participate in any patient abuse. These instances of abuse may count as self-neglect and passive neglect. Self-neglect and passive neglect may also count as types of elder abuse. Passive neglect is failure to meet older adults’ needs, is not necessarily deliberate, and results from caregivers’ lack of knowledge or ill-health (National Council on Child Abuse & Family Violence, n.d.). While caregivers may be charged with neglect, they are likely to be sleep deprived and lack social and financial support (Acierno et al., 2010).

Theoretical Implications

This study was guided by the social support theory and quality of life model that includes four domains that impact caregivers: physical, psychological, social, and spiritual. Among the expected outcomes according to this theory are use of support services and reduced distress. Findings from my study were that while caregivers were aware of support resources, they did not receive direct support except from family members.

The caregivers were almost unanimous in being aware of at least one social support resource. However, a high number of caregivers were aware of “other” resources not listed in the survey. This finding represents a disconnect in being able to associate awareness of specific resources and psychological and behavioral outcomes. It also indicates a lost opportunity to learn additional types of services that can be promoted to caregivers during education classes or discussions with providers. In terms of the response items for direct social support, the support the caregivers received was basically from family members. This limited use of direct social support is also a disconnect that social services and health providers can tap to improve quality of life of caregivers.

The research questions proposed examined two of the four domains in the quality of life model (see Figure 1). Social support was associated with psychological distress and behavioral outcomes which are thought to occur during high psychological distress and low social support. A third domain, spirituality, was tapped as one of the resources that caregivers reported or could have received direct support from. The physical domain was not included in this study. The findings indicate that use of direct social support services was associated with decreased psychological distress. The odds ratios indicate that direct social support was protective of anxiety (*OR* = .434), stress (*OR* = .603), and depression (*OR* = .464).

Limitations of the Study

The limitations of the study revolve around the research design which was cross-sectional and use of a secondary data set collected by telephone in 2000. Examination of social support and outcomes does not allow for a temporal relationship. The survey measured social support based on yes/no responses and not a Lickert-type scale that would provide more robust analysis. More depth of awareness and receipt of social support could have been obtained if the survey included open-ended questions. The sample size of the study may have placed limitations on the study outcomes as after confirmation of the sample of caregivers, the calculated power was only 43%. However, statistical significance was reached for three of the psychological distress measures, but none of the behavioral outcomes.

Recommendations

Future studies should address a module of social support available to palliative care caregivers that caters to the social support available to assist with psychological distress and behavioral outcomes. A longitudinal research design where caregivers log their symptoms, resources they are aware of, and actual direct social support, days and times available, can contribute more accurate quality of life experiences. Furthermore, palliative care caregivers should become more informed through hospital social services, organizations, and physicians about what to expect, and what forms of support are available in their area. I feel that it would be in the best interest of future researchers to focus on examining specific age groups, the status of family caregivers, the differences in financial sustainability, and retired versus employed caregivers, to obtain the psychological distress and behavioral outcome in association with social support.

Other factors that constrained the study deserves additional research within this population. Factors such as the surveying of palliative care caregivers regarding their healthcare and ability to maintain a quality of life while being a caregiver would be insightful. As established in the study by Raivio (2015), feelings related to caregiving or their situations rarely are discussed or evaluated, and the services provided do not always meet caregivers' needs sufficiently thereby a strain is placed upon the quality of life.

The lack of communication, feelings, and burden strain limits the accuracy of social support that can be given to caregivers. Raivio (2015) noted that previous studies had not explored psychological well-being and feelings, and a realistic outcome may not be achieved if the caregiver's well-being is not explored. Raivio’s study included an open-ended section that captured caregivers’ feelings. My study has shown two sides of palliative care caregiving, how direct family caregiving was most essential to the participants who answered, and showed the lack of awareness of social support could indeed hinder the care for both the palliative care caregiver and the patient.

Another factor that may have constrained the study is the lack of explanation of social support and how it can assist palliative care caregivers. Although the findings indicated that some participants were not interested in social support when offered, the study did not define what social support was available in their best interest. The areas of social support evaluated included, churches, friends, and other family support; however, the type of support within those areas was not explored well enough during this survey to convey whether the outcome would be different.

Further research is recommended to explore qualitative interviews that can uncover the services that caregivers have become aware of, whether they used them or not, and which ones help to buffer psychological distress and behavioral outcomes. It is essential to conduct further research for a more extensive evaluation of how the increase in awareness of social support and the usage of direct social support can benefit the health of palliative care caregivers. Hudson et al. (2015), notes that future studies should be conducted to include more extensive samples and focus on strategies to reduce psychological distress.

An essential component of palliative care caregiver assessments would be the frequency of psychological distresses and behavioral outcomes tracked well enough to document specific outcomes. The ICPSR survey utilized a group of palliative care caregivers who were surveyed over the telephone, but not approached in person or by a therapist who may be able to provide a better assessment. By utilizing the social support theory based on improving quality of life, other personalized and mental health assessments could have been performed to acquire a more substantial outcome that would assist in evaluating caregivers in a more meaningful approach.

Implications for Professional Practice and Social Change

I found that direct social support provided by family was more frequent than any other type of direct social support in association with psychological distress or behavioral outcomes. My findings also indicate that there is moderate prevalence of psychological distress (anxiety, stress, depression) and behavioral outcomes (sleep deprivation, patient abuse). However, the implications are that with or without social support, palliative care caregivers will endure psychological distress and behavioral outcomes.

The level of awareness of social support services reported is very high but does not align with the level of direct social support received, and although caregivers are aware of several resources they rely mostly on family to get by. It would be important for practitioners to make direct referrals and suggestions to caregivers to ask for direct social support. Pamphlets, advertisements, and education classes need to include the importance of seeking direct social support. While some caregiver interventions have been evaluated for effectiveness, there are mixed results (Brandon, 2013). Not all interventions may work for all caregivers. The majority of the studies support that education alone has a positive effect, but peer support was not found to be effective. Counseling appears to be the most effective intervention for high levels of caregiver burden (Brandon, 2013). Raggi et al. (2015) recommend multi-component interventions for caregivers such as self-help groups, family meetings, educational seminars, and telephone counseling.

The social change implications for this study may include focus on the improvement of quality of life for palliative care caregivers and the availability of social support from communities, medical facilities, and other organizations. Thereby, social support may allow for a decrease in both psychological distress and adverse behavioral outcomes amongst caregivers. Other factors to consider for improvement of social change is decreasing the anxiety, stress, and depression levels of caregivers. The psychological effects of caregivers affect others in daily encounters, thereby with services and support offered to caregivers the support will provide healthier well-being and may improve social relationships. To build relationships and educate caregivers on social support and coping skills public health providers should focus on reaching palliative care caregivers during the early stages of a patient's disease process when caregiving is needed.

Conclusion

The strengths of this study include bringing attention to the hidden patient -- the palliative care caregiver and the undiscovered problem of psychological distress and behavioral outcomes associated with lack of social support. Through this study I examined the association between social support and psychological distress and behavioral outcomes among palliative care caregivers. I examined two types of social support including awareness of social support services and receipt of direct social support.

Broadly, social support is viewed as a compartmentalized functionality. The caregivers in my study reported a very high level of awareness of social support services but a very low use of social services and a heavy reliance on family for direct social support. The palliative care caregiving community is somewhat removed and unaware of social support, such as community services that may help to relieve stress, anxiety, and depression. The fact that caregivers in my study reported such a high number of “other” services supports this view and represents a lost opportunity to have collected the information in an open-ended fashion.

Two research questions were proposed to examine whether there was an association between social support as a predictor of psychological distress (anxiety, stress, depression) and behavioral outcomes (sleep deprivation, patient abuse). There was support for the association between direct social support as a significant predictor of psychological distress for anxiety, stress, and depression. Direct social support was protective of anxiety (OR = .434), stress (OR = .603), and depression (OR = .464) among caregivers. However, there was no support for the association between social support and behavioral outcomes (sleep deprivation, patient abuse).

Psychological distress among caregivers in this study was substantial, with 36% caregivers reporting suffering from anxiety, 30% from stress, and 32% from depression. Patient abuse was reported by 7.5% of caregivers and 24% reported sleep deprivation. Demographic characteristics indicated the 2:1 ratio common in female to male caregivers. Men are more likely to have support at home as caregiver men were more likely to be married or living with a partner compared to women. The sample was majority of European American descent, high school to college educated, and had incomes above $25,000. There were significant gender differences by marital status and income.

This study is distinctive because it reports on an under-researched area of caregiver burdens and behavioral outcomes. Social support can buffer the caregiver burden and improve the quality of life. The findings from this study may assist in helping both healthcare providers and social service agents formulate services to aid caregivers. Acknowledging the burdens of caregivers is necessary to understand how stressors, such as depression, anxiety, or financial difficulties, can take a toll on caregivers and their families.

According to former First Lady, Rosalynn Carter, “there are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers” (Fowler, 2014). These circumstances while in the role of caregiving bring on a certain amount of distress. Family members who provide informal care often find themselves in what is considered the sandwich generation. They are generally between the ages of 45 and 65 and perhaps still caring for their children while taking on the responsibility of providing care for a parent (Fowler, 2014). They are faced with new life changes and distresses that come with the position. The critical element of family caregiving is taking on the role of being the essential functioning person(s) for the ill family member

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