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Coping Methods of Caregivers Dealing with Patients Suffering from Geriatric Dementia

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This is to certify that the doctoral dissertation by

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Abstract

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M.S., University of Phoenix, 2009

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Dissertation Submitted in Partial Fulfilment
of the Requirements for the Degree of
Doctor of Philosophy
Health Psychology

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Abstract

Dementia is a neurological disorder primarily diagnosed in the geriatric population. A problem for paid caregivers of patients diagnosed with stage-4 dementia is that they may experience caregiving stress while rendering care. However, there was no research that described the lived experiences of paid caregivers. Caregiving stress can be accompanied by behaviors or comorbid conditions and specific symptoms of stress can have a differential wellness impact. This phenomenological study explored the lived experiences of paid caregivers of patients with dementia through Vroom's expectancy theory. Data were gathered through interpretative interviews from a sample of 10 to 15 purposefully selected nursing home paid caregivers. Research questions on the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients were explored. Responses to the open-ended questions were recorded and themes emerging from the interview questions were developed. Findings indicated that caregivers cope with their stress in part by coping with challenging patients through empathizing and being ready for anything. Results further showed that caregivers cope with stress by briefly withdrawing from the stress trigger, either physically or mentally. Caregiver stress can be reduced, and health maintained by other caregivers who learn from the coping methods of caregivers involved within this study.

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Dedication

I dedicate this research to my late father, Chief Brownson Needam Deemua, who was the first one to reiterate that I was brilliant and should study to achieve a Ph.D. because he believed I could. To my late mother, Mrs. Matilda Leborloo Deemua who was impressed by all my academic achievements and made sure I never lacked for anything. To my brothers, Fresh and Jerry and my sisters, Charity, Zor, Happy and Victoria who called me "Joseph" and were always proud of me, and most importantly to my children, Kayete and Mene, who supported me in all, and were my computer technicians and listeners when I often lost my saved papers and got frustrated. It was always the three of us versus the world. Thank you so much and I love you always. I could not have done it without you all.

Rest in peace, Mama ne Deede!

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Karen Lynne Mathews, thanks for the encouragement. I did it. Rest in peace.

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Chapter 1: Introduction to the Study

Introduction

Healthcare professionals include an array of interdisciplinary backgrounds. The current study was to explore the shared experience of coping strategies used to reduce or prevent burnout of paid caregivers of individuals diagnosed with stage-4 dementia. Campbell, Rowe, and Marsiske (2011) pointed to the magnitude of stress experienced not just by diagnosed individuals but also their caregivers in attending to the behavioral challenges posed by individuals with dementia. For instance, it was found that caregivers of persons with dementia experience stress, depression, and burnout in dealing with challenging behaviors of patients (de Rooij, Luijk, Declercq, Emmerink, & Schols, 2012; Kim, Chang, Rose, & Kim, 2012; Llanque, Savage, Rosenburg, & Caserta, 2016; Tolhurst, Bhattacharyya, & Kingston, 2016). However, Greenberg, Tanev, Marin, and Pitman (2014) posited that the relationship between stress and dementia could be viewed from different standpoints, including intensity, duration, novelty and type. Additionally, Greenberg et al. (2014) stated that researchers within future studies might consider studying the individual experiencing stress as well as the relationship to the stressor. When an understanding of each unique entity can be understood in isolation, a more comprehensive explanation of an individual’s response to stress can be ascertained (Greenberg et al., 2014). Stress is the body’s inability to respond to demand or change (Selye, 1976). According to Blumberg et al. (2013), stress is a set of complex neurodevelopmental disorders that hinder, mildly or severely, a person’s social interaction and ability to communicate with others. Moreover, stress can equally impact the health of caregivers, hindering these individuals from caring with full capabilities (Crumpei & Dafinoiu, 2012). Although stress can be subjective and controversial, personal reactions to stressors or triggers, such as emotional upsets, extreme temperatures, life experiences, debilitating diseases, pain, physical and emotional challenges, and loss can facilitate hormonal imbalances and cause stress (Contrada & Baum, 2011).

The term stress can be used in different ways and easier to control if care is rendered by paid caregivers (Stalder et al., 2014). However, the behaviors that are exhibited by stage-4 dementia patients can trigger intense stress reactions and burnout in caregivers attempting to facilitate activities of daily living for patients (From et al., 2013; Kontos & Martin, 2013). Stress experienced by individuals caring for someone with stage-4 dementia is a problem because stress can impact a caregiver’s potential and affect the quality of care rendered to the diagnosed individual who exhibits challenging behaviors related to dementia (National Institute of Health [NIH], 2015). Therefore, stress can impact the caregiver as well as the receiver, the dementia-diagnosed stage-4 patient. In this chapter, I discuss the background of the study, problem statement, purpose of the study, research questions, theoretical background, nature of the study, definitions of terms, assumptions, scope and delimitations, limitations, and significance.

Background

Dementia is a set of symptoms caused by several diseases or the aging process (Mayo Clinic, 2015). There are five stages of the disease, and per the Clinical Dementia Rating (CDR), stage-4 dementia is influenced by moderate impairment, disorientation, and complete reliance on others or caregivers for hygiene maintenance or activities of daily living (Alzheimer’s Association, 2014; McKhann et al., 2011). Some stage-4 symptoms include disorientation, mood changes, recent memory loss, loss of initiatives, confusion, poor judgment, misplacing things, personality changes, problems with abstract thinking, problems with communication, and difficulty completing familiar tasks (Prince et al., 2013).

The challenging behaviors exhibited by stage-4 dementia patients are significantly correlated with caregiver stress (Venturato, Moyle, & Steel, 2013). These challenging behaviors can cause stress for caregivers and impact the quality of care rendered by caregivers and received by persons diagnosed with dementia (Crumpei & Dafinoiu, 2012). Despite these challenges, using different and individualized coping styles, caregivers can often distract patients or divert behavior and maintain the dementia-diagnosed person’s dignity through a person-centered approach where the individual is the focus of attention in that instant (Johnson & Hipwell, 2013). In general, it was found that sharing one’s own lived experiences can enhance social change and can be a coping strategy for caregivers (Judge, Menne, & Whitlatch, 2010). The active strategies shared through lived experiences can also enhance the quality of care given to those diagnosed with stage-4 dementia.

Knowledge of lived experiences of caregivers is imperative to devise a course of action and suggestions to reduce stress and improve the quality of care rendered to individuals with geriatric dementia. A disorder such as insomnia is a challenge and stressor for caregivers (Campbell et al., 2011). Moreover, Kaufmann and Engel (2014) explained that wellbeing of the caregiver is increasingly becoming a determinant of the quality of care rendered to patients with dementia.

Crumpei, and Dafinoiu (2012) said that, if not able to discern that manifested behavior is influenced by the diagnosed individual’s impaired cognition, caregivers may not show empathy. If such were the case, there may be negative outcomes where the caregiver may compromise care or abandon responsibilities that could enhance the quality of care. Mayo Clinic (2015) defined geriatric dementia as a chronic and progressive disorder that can be marked by personality changes, impaired cognition or reasoning, memory disorders, or persistent disorders of mental processes that can be caused by brain diseases.

Bandura (2011) said that the ability of individuals to have control of the quality and nature of the person's life is a reason for being human. Individuals are proactive and self-organizing people who are shaped by the environmental factors that are influenced by intrinsic thoughts or attitudes (Bandura, 2011).

Problem Statement

A problem for paid caregivers of patients diagnosed with stage-4 dementia is that they might experience challenges caused by problematic behavior exhibitions from patients while rendering care. These disruptive behaviors include disrobing in public, noncompliance with mealtimes and medication regimen, difficulty with grooming and poor hygiene, sleeplessness, wandering, and verbal or physical aggression. There is no research that described the lived experiences of paid caregivers of individuals diagnosed with stage-4 dementia. There is a gap in the literature concerning coping methods of caregivers of patients with stage-4 dementia. This gap will be filled because caregivers, through shared experiences, will be aware of strategies that will allow them to render care without being stressed. In addition, filling this gap through current research is relevant because caregiving stress can be accompanied by behaviors or comorbid conditions such as depression, physical aggression, and paranoid delusions. These medical conditions can further trigger stress if interventions are not put in place. Shared experiences provide information about these needed coping strategies. Also, it is possible that specific symptoms of stress can have a differential impact on respective individuals, such as burnout on caregivers (Ornstein et al., 2013). These symptoms, in turn, can affect care rendered to persons diagnosed with dementia and ultimately impact wellness for them and caregivers (Nogales-González et al., 2015). Furthermore, identifying challenges that lead to burnout, such as persistent caregiving demands or work with no rest and poor coping skills, may assist organizations in developing strategies that would enhance coping and reduce burnout in paid caregivers of patients diagnosed with stage-4 dementia. This approach can enhance staff stability and become cost-effective as staff turnaround will be reduced. The phenomenological approach that was chosen for this study involved the sharing of experiences by caregivers who render care to individuals diagnosed with dementia.

Purpose of the Study

The purpose of this phenomenological study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. The phenomenological approach was emphasized to decrease caregiving stress by describing lived experience through data collection for all individuals. Through interviews regarding shared experiences of caregivers, the study examined the lived experiences involving caregivers' coping methods and the impact of stress on the quality of care rendered to geriatric dementia patients.

Research Questions

The following research questions were relevant to this phenomenological research:

RQ1: What are the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients?

RQ2: What are the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients?

Theoretical Framework

The theoretical framework for this phenomenological study is Vroom's expectancy theory. This theory addressed caregiver burnout, as Vroom implements a method that is focused on individual understanding of burnout. Additionally, this theory was congruent with the constructs in this phenomenological research study as both Vroom's expectancy theory and phenomenological research engrosses on the individual experience.

Expectancy Theory

The concept of the expectancy or valence-instrumentality-expectancy (VIE) theory is that, as future predictions are made, future expectations are equally made (Vroom, 1964). This theory allows individuals to be motivated based on assumptions that can make differences within the future, especially assumptions that may facilitate positive outcomes (Lunenburg, 2011). Inherent motivation as part of the expectancy theory is comprised of three key factors: valence, instrumentality, and expectancy (Vroom, 1964). Valence, within this context, refers to the value an individual place on achieving an expected outcome, while instrumentality refers to the expectation that a reward is gained by completing a task (Vroom, 1964). Expectancy, the last component of expectation theory, refers to the belief that, if a task is completed, it will garner a desired goal (Vroom, 1964).

Valence and expectancy are vital to this study as these factors aid in the explanation of motivation in task completion. Vroom believed that, if certain actions are completed, an outcome will be achieved. Expectancy is the perception that completion of an action is possible. This theory, therefore, supported the lived experiences of caregivers because their own verbalization of shared outcomes enhanced caregiving coping strategies based on personal experiences involving caring for dementia-diagnosed persons. Motivating caregivers through awareness of other caregivers' struggles as it relates to challenging behaviors of dementia-diagnosed persons could reduce stress experienced by caregivers when caring for individuals diagnosed with dementia and facilitate rendering of quality care (NIH, 2014).

Nature of the Study

The nature of this study was a qualitative method with a phenomenological approach. This approach is consistent with understanding how stress is expressed and knowing how stress is relieved. The phenomena of stress exhibition and relief will culminate in shared coping strategies in care rendering of individuals diagnosed with dementia. This phenomenological study involved descriptions of lived experiences according to participants through personal response to interviews. Because the study included participants who have experienced a phenomenon (stress), the phenomenological method was the best approach for answering the research questions. This reasoning is supported by the purpose of the phenomenological approach, which is to decrease a caregiver’s experience of a phenomenon by describing lived experiences through data collection and interviews.

Definitions

Dementia: An array of conditions, or diseases, common in older persons, which is characterized by the impairment of at least two brain functions including memory loss, recall and judgement. Often dementia interferes with daily tasks and social interaction (Mayo Clinic, 2015).

Expectancy*:* Expectancy is the belief that increased effort will maximize performance and outcomes (De Simone, 2015). For example, if I study harder, I will have excellent grades. This perception is enhanced by having the appropriate tools, such as books, time, and money, commitment, family, faculty, and peer support.

Instrumentality**:** Instrumentality is the belief that a favorable outcome will be experienced from accomplishing a function (Bonner et al., 2016). An example is the belief of a caregiver that, if care is consistent and trust is established between patient and caregiver, aggressive behavior by the patient will be minimized and the caregiver will render care without being stressed. This perception is influenced by trust and understanding of the link between outcome and performance and discerning who will benefit from the outcome.

Personhood: Personhood is a sense of self or identity that has different connotations and characteristics that are associated with being human (Buron, 2008). Being a person is important in determining a relationship with others. In the context of dementia, understanding and relating to others contributes to the development and maintenance of personhood (Dewing, 2008). This sense of self or identity (recognizing one's self) is what is usually lost in most patients diagnosed with stage-4 dementia (Statewide Clinical Outreach Program for the Elderly, 2014).

Stress: A state of emotional or mental tension resulting from distressing or uncomfortable situation or circumstance (Stalder et al., 2014).

Valence, Instrumentality, Expectancy (VIE) theory: Vroom's expectancy theory separates outcomes, performance, and effort brought about by motivation. Although Vroom's theory is based on perception and assumes that an exhibited behavior is deliberate and motivated by the desire to decrease pain and increase satisfaction, the three key terms of Vroom's theory that enhance this concept are valence, instrumentality, and expectancy (VIE).

Valence: Valence is motivated by the importance that individuals place on desired outcomes, and there must be a preference in order to complete of the task (Bonner, Baumann, & Netchaeva, 2016). For example, caregivers must desire a stress-free work environment and work towards a trusting patient-caregiver relationship to achieve care rendering without stress.

Assumptions

I had the following assumptions regarding this study. I assumed that all responses by participants were sincere and truthful to the best of their knowledge. Moreover, I considered guided questions for the interviews that I developed and was able to collect necessary information which addressed the research questions. Also, I assumed that these questions were constructed in a way that participants would understand. Finally, I assumed and believed that the findings of the current study would lead to positive social change and address ongoing concerns regarding coping strategies for stress among caregivers.

Scope and Delimitations

The scope of this qualitative phenomenological study was limited to caregivers' lived experiences of stress. I envisaged interviewing between 10 and 15 caregivers. The number did not exceed 15 because the 13th participant met saturation. By limiting the participants of this study to a specific geographical location, the results of this study were not generalizable to other populations.

Limitations

The primary limitation of the current study was participants' honesty in articulating their lived experiences and perceptions regarding stress. Moreover, while participants were chosen from a nursing home in New Jersey, the criteria for selecting participants was another limitation of the study. Participants were limited by the requirement that they were all paid caregivers of geriatric residents diagnosed with dementia in a nursing home in New Jersey. Generalizability was another concern. Since this qualitative study used 10 to 15 nursing assistants in a nursing home. The sample size was therefore not representative of the whole population. However, the data collected produced in-depth findings involving coping strategies regarding burnout and stress experienced by nursing assistants. Nursing assistants were paid caregivers of individuals diagnosed with dementia marked by cognitive impairment, inability to recall or maintain an identity (personhood), and lack of functional capability to take care of themselves (Cohen et al., 1983; Twigg, 2013).

Significance

Thematic findings from the interviews regarding caregivers' lived experiences were used to address the steps caregivers use daily to relieve stress and ultimately provide effective care to patients. Currently, there is no reported cure for dementia, and per the Centers for Disease Control and Prevention (CDC, 2016), it is estimated that nearly 500,000 new cases are diagnosed each year. In 2013, it was reported that five million Americans were living with dementia, and the number is projected to rise to about 14 million by 2050, with a new diagnosis every 66 seconds in America (CDC, 2016; Statewide Clinical Outreach Program for the Elderly, 2014). In addition to gaining awareness through shared information regarding how to manage challenging behaviors, wellness can be maintained through understanding coping skills and stress reduction methods for caregivers. This body of knowledge would enhance delivery of quality care to dementia-diagnosed individuals and enable caregivers to care without compromising their health. Being informed would mean knowing how to render care without stress on a continuous basis and effect positive social change.

Summary

The purpose of this phenomenological study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. Chapter 1 presented a detailed explanation of the problem statement and how it is aligned with the research questions. Chapter 1 included the problem statement, purpose of the study, background of the study, research questions, theoretical background, nature of the study, definitions of terms, assumptions, scope and delimitations, limitations, and significance. Chapter 2 provides a full discussion of the literature regarding the central phenomenon under study, and Chapter 3 offers detailed information regarding the research methodology. Chapter 4 presents the findings of the study, while Chapter 5 concludes this study by discussing the implications of the findings and recommendations for further study.

Chapter 2: Literature Review

Introduction

Knowledge of shared lived experiences of caregivers of individuals suffering from dementia can help lead to coping strategies to reduce caregiving stress and improve the quality of care rendered to care recipients. Campbell et al., (2011) have pointed to the magnitude of stress experienced not just by diagnosed individuals but also their caregivers in attending to the behavioral challenges posed by those individuals with dementia. Judge et al. (2010) also pointed out how the overall wellbeing of patients diagnosed with dementia is an important determinant of care related to dementia. Negative influences involving caregiving stress affect the care environment as it is often reflected in evasion of coping strategies, caregiver denial of stress, and severe depression (Gilhooly et al., 2016). In empathizing with care recipients, it is essential for caregivers to recognize that such challenging behavioral symptoms exhibited by patients diagnosed with dementia result from their impaired cognitive functions (Crumpei & Dafinoiu, 2012).

Caregiving stress looms as a challenge that not only affects the health of the caregiver, but also makes it difficult for caregivers to render quality care and maintain the personhood of individuals with dementia (Cowdell, 2006; Crumpei & Dafinoiu, 2012). Such debilitating effects may be considered collateral damage in terms of dealing with patients diagnosed with dementia and preventing caregivers from delivering their optimal level of care, as a result, both caregivers and patients suffer. There is a gap in the literature regarding coping mechanisms that caregivers can adopt to produce better health implications for themselves and patients diagnosed with dementia. The primary purpose of this research was to discover, through the shared lived experiences of caregivers, coping mechanisms that could be used to deal with the challenges of caring for people diagnosed with geriatric dementia.

Caregivers of patients diagnosed with dementia experience stress, depression, and burnout in dealing with the challenging behaviors of patients (de Rooij et al., 2012; Kim et al., 2012; Llanque et al., 2016; Tolhurst et al., 2016). In fact, behavioral and psychological symptoms of dementia (BPSD) and impairment of functions associated with daily living of dementia patients have been identified as predictors of caregiver stress (Kim et al., 2012). Caregiving stress has a negative impact on caregivers' physical health (NIH, 2015). The care environment has a considerable impact on the lives of the patients diagnosed with dementia (Tschanz et al., 2014) and caregiver stress affects the quality of care rendered to dementia patients because stress influences emotional lability and leads to cognitive impairment (Campbell et al., 2011).

Caregivers can use coping mechanisms that can improve stress management and the quality of care rendered to patients (Chen, Huang, Yeh, Huang, & Chen, 2015; Tschanz et al., 2014). Lived experiences of caregivers attending to dementia patients can provide valuable insight into care recipients' behavioral problems and identify the needs of caregivers to help them cope with the negative implications of caregiving stress (Tuomola et al., 2016). This study investigated how caregivers rendered quality care that led to positive outcomes for patients diagnosed with dementia and reduced their health risks associated with stress and depression.

To have a better understanding of the challenges associated with caregiving stress, this chapter discusses the theoretical framework and trends that emerged from the literature search. After the discussion on the theoretical framework that was used for this study, the main body of the chapter is divided into the following sections and subsections: challenges of working with patients diagnosed with dementia, definition, causes, and symptoms of dementia, caregiving stress, definition of stress, and health-related issues. The necessity of learning to cope with the challenges of working with patients diagnosed with dementia includes awareness of the needs of patients diagnosed with dementia and a person-centered approach to care for the patient. Additionally, caregivers must understand the importance of sharing lived experiences of caregivers in informing the process of stress alleviation, and implications of the study for social change within the nursing field. The conclusion of this chapter reiterates the importance of the study given the lack of relevant research and need for educating caregivers.

Literature Search Strategy

A literature review was primarily conducted by using several search engines and educational databases, including Google Scholar, ERIC, ResearchGate, PsycArticles, and EBSCOHost. The search terms and phrases used were *caregivers for dementia*, *personhood in dementia*, *Alzheimer's disease*, *Stage-4 dementia*, *caring for dementia patients*, *stress in caregivers for dementia*, *coping strategies for caregivers of dementia patients*, *behavioral challenges of dementia patients*, *qualitative research design*, *expectancy theory*, *lived experiences of dementia patient caregivers*, *predictors of stress in caregivers of dementia patients*, *person-centered approach to dementia care*, *quality of care for dementia patients*, and *education for caregivers of dementia patients*.

To find literature germane to the topic of this study, search terms were used in different combinations. While the review of the literature identified research regarding lived experiences of dementia patient caregivers, very few of the studies focused on the lived experiences of paid caregivers. The sources used were from peer-reviewed journals; 85% of them were published from 2012 onwards. These sources revealed the nature of the risks that caregivers face and gaps that exist in terms of addressing the needs of caregivers.

Theoretical Framework

Victor Vroom's expectancy theory, also called the VIE theory, is implemented for this research to understand how caregivers might be motivated to ensure positive results for the patients as well as themselves. The rationale for using this theory is that it provides a perspective for understanding how caregivers might feel motivated to put forth their best efforts if they believe that their performances will yield positive results. The theory proposed that future predictions and future expectations are made concurrently.

Vroom's expectancy theory was not only used to predict why people choose the professions that they are in, but also what motivated them to excel and what offered them satisfaction at their jobs. Based on what is known as VIE, Vroom explored how people are motivated to improve performance to achieve desired goals.

Valence refers to the desire or emotion that people have for achieving specific rewards or benefits (Vroom, 1964). Instrumentality refers to the belief that reward or results will be commensurate with the effort and that the reward will have a positive value (Vroom, 1964). Expectancy refers to individuals' belief that better effort will yield better rewards (Vroom, 1964).

Furthermore, Vroom (1964) proposed that, with increased effort, there is an increase in performance that, in turn, leads to desired outcomes which fulfill a specific requirement of the individual. The concepts of expectancy and valence are particularly significant for the current study. While expectancy will highlight caregivers' belief that effort will yield satisfactory performance, valence will underscore caregivers’ belief that rewards will be desirable and positive. These concepts steer the attention of the caregiver towards feeling that it is possible to achieve a goal by putting in effort, and that effort will be rewarded with a positive outcome.

While analyzing Vroom’s expectancy theory, Lunenburg (2011) drew attention to the cognitive processes that lead to motivation like ideas, perceptions, practical probability conjectures, and beliefs. According to Lunenburg (2011), expectancy theory is considerably different from need-based theories that focus on internal urges or satisfaction of demands. Rational choices made by individuals can be used for improving performance in a work environment because employees perceive that increased efforts lead to better performance, which consequently produces better rewards (Lunenburg, 2011).

Chu (2016) conducted a study to examine how motivation mediated the association between positive mood and job performance and postulated that employees who experience emotions such as compassion and kindness at work perform better and demonstrate what he called organizational citizenship behavior. The results revealed that compassion could increase job performance and, motivation plays a significant role in promoting positive mood in employees. Further, the author noted that people with a positive disposition tend to consider the results of their efforts as more desirable and valuable (Chu, 2016). The author proposed that people who have positive dispositions are more willing to believe that exerting greater effort will lead to better performance and desirable rewards (Chu, 2016). This study provided a valuable framework for understanding how motivation can play a role in improving the overall performance of the caregivers, which in turn will lead to desirable rewards for the caregivers and the patients with dementia.

Review of Relevant Literature

Researchers, including Peacock, Duggleby, and Koop (2014), and Tuomola et al. (2016), indicated that sharing of the lived experiences of working with patients diagnosed with dementia could provide the knowledge about caregiver stress and the impact it has on the quality of care rendered to people who have dementia. Researchers have found that caregiver stress and burden increased with the progressive degeneration of behavioral symptoms and physical functioning in patients with dementia (Kamiya, Sakurai, Ogama, Maki, & Toba, 2014). However, to get a better understanding of the challenges faced by caregivers and how they develop coping mechanisms to reduce stress, it is imperative to take a closer look at what is entailed in the term caregiver stress, what are some of the issues associated with caregiving stress, what caregivers experience when working with patients diagnosed with dementia and the influence caregiver stress has on patient outcome.

Caregiver Stress and Burden

Caregiving stress is rated very high by almost two-thirds of Alzheimer patients' caregivers (Hall et al., 2014). Branger, Burton, O'Connell, Stewart and Morgan (2016), the NIH (2015), and Stalder et al. (2014) highlighted how caregivers of patients with dementia exhibit psychological stress, which puts them at risk for psychiatric diseases as well as deteriorating health conditions. Stalder et al. (2014) remarked on the difficulty of narrowing down on a specific definition of stress because of its broad scope and multidisciplinary applications. They emphasized how the term "stress" can be used in different ways (Stalder et al., 2014). Cannons (1932) defined stress as "a desperate response to deal with an imminent threat" (as cited in Llanque et al., 2016, p. 3). The NIH (2015) highlighted that stress not only manifests in different ways, but the severity and the coping mechanisms also vary from person to person. The NIH (2015) emphasized the serious physical and mental health repercussions of chronic stress and warned against ignoring stress-related signs.

Analyses of the causes of stress revealed multiple factors at work, including behavioral symptoms of patients diagnosed with dementia, impairment of physical and cognitive functions of patients diagnosed with dementia, severity of illness in patients and lack of support network (From, Nordström, Wilde-Larsson, & Johansson, 2013; Kim et al., 2012; Kontos & Martin, 2013; Llanque et al., 2016; Ornstein et al., 2013). Researchers such as From et al. (2013) and Kotos and Martin (2013) indicated that stress reactions in caregivers can be triggered by behaviors that are exhibited by dementia patients. Research have shown how physical, biological and psychological factors play a role in the etiology of stress (Kim et al., 2012; Llanque et al., 2016). Llanque et al. (2016) identified several factors that influence caregivers' stress and physical wellbeing, for instance, the severity of the care recipient's illness, the degree of impairment of the care recipient's physical and cognitive functioning, lack of support and confines of the caregiver's social life. Also, caregivers' perception of stress plays a significant role in increasing caregiver stress (Llanque et al., 2016).

Ornstein et al. (2013) argued that the manifestation and the influence of specific stress symptoms can produce a differential impact on caregivers. Ornstein et al. (2013) utilized a longitudinal study on Alzheimer's and other dementia patients to analyze the effects of behavioral and psychological symptoms of dementia on caregivers' health. They suggested that caregiving stress can be ascribed to the wide range of behavioral and psychological symptoms of dementia, like aggression, depression, and hallucinations. The results revealed that patient depressive symptoms were related to depression in caregivers (Ornstein et al., 2013). These results became apparent through caregivers' reports on how the symptoms affected the patients and how they perceived the symptoms as liabilities for them (Ornstein et al., 2013). The results support the need for the current study, which investigates the lived experiences of caregivers of dementia patients, as they show how caregivers' perceptions about the disease symptoms affect their health.

Crumpei and Dafinoiu (2012), as well as Smebye and Kirkevold (2013) provided evidence that caregivers are at risk of developing stress symptoms by being exposed to patients suffering from dementia and showed that positive patient-caregiver relationships can have positive implications for patients. Crumpei and Dafinoiu (2012) indicated that the medical workers and caregivers are significantly more at risk of developing secondary traumatic stress because of their exposure to patients suffering from traumatic stress. The researchers specifically investigated the presence of secondary traumatic stress in healthcare professionals working with individuals who experienced traumatic events and the nature of the relationship between secondary traumatic stress to empathy and sympathy (Crumpei & Dafinoiu, 2012). A comparative analysis of the scores between the experimental group consisting of medical workers and the control group composed of pharmacists indicated that the medical workers, such as assistants, nurses, and physicians, were significantly exposed to the risks of developing secondary traumatic stress (Crumpei & Dafinoiu, 2012). The study also revealed that, while sympathetic medical workers had more satisfaction, they were also more prone to trauma symptoms compared to unsympathetic medical workers (Crumpei & Dafinoiu, 2012). However, clinical empathy was not significantly related to trauma symptoms (Crumpei & Dafinoiu, 2012). The study has significant implications for this research as it shows that, while empathizing with patients can improve patient outcome and job satisfaction for healthcare professionals, evading emotional involvement can reduce the risks of developing stress symptoms. This perception is also supported by the research conducted by Smebye and Kirkevold (2013), who found that professional relationships between caregivers and patients diagnosed with dementia fostered personhood in the patients diagnosed with dementia.

Similar to the difficulty of defining stress or burn-out, researchers have commented on the complexity of conceptualizing the term caregiver burden and lack of clarity about what constitutes as caregiver burden (Bastawrous, 2013; Hall et al., 2013). Bastawrous (2013) pointed to the utilization of role theory and stress theory in arriving at a better understanding of caregiver burden. The author illustrated that, while role theory elucidated the issues associated with role overload, stress theory provided an understanding of the objective and subjective aspects of caregiver burden (Bastawrous, 2013). According to the author’s analysis, caregiver burden can be analyzed from primary and secondary stressors perspective or objective and subjective aspects (Bastawrous, 2013). She emphasized how these elements interact with each other and influence caregiver health and patient outcomes (Bastawrous, 2013). In general, objective aspects are related to primary stressors like caring for the patients diagnosed with dementia, helping with activities of daily living of the patients, and the caregiving environment. Subjective aspects are related to secondary stressors which consist of psychological factors like loss of self-confidence or mastery perspectives (Bastawrous, 2013). The author reiterated that caregivers’ physical, mental, and emotional health is also affected by the caregiving role (Bastawrous, 2013). Although this study primarily focused on unpaid family caregivers, the findings are relevant to professional caregivers because similar objective and subjective stressors act as severe impediments to achieving positive outcomes for patients and provision of proper care.

Hall et al. (2014), like Bastawrous (2013), identified the role of stressors in the caregivers' burden. They defined caregiver burden as the stress related to caring for people with chronic conditions, like dementia. The researchers investigated the relationship between severity of dementia symptoms and caregiver stress to identify the factors that contributed to maximum caregiver stress (Hall et al., 2014). The results revealed that several dementia-related factors were correlated with caregiving stress, of which, the degree of severity of dementia, inability to perform daily tasks and behavioral symptoms affected caregiving stress level (Hall et al., 2014). Other researchers have also found that dementia-related symptoms of patients affect caregiver burden and stress (Kim, Oh, & Richards, 2014). While investigating dementia symptoms in older people such as sleep disruptions, wandering, comorbidity, nighttime agitations and caregivers' attitudes and beliefs about those symptoms, researchers have found that caregivers' perceptions about care recipients' sleep patterns influenced caregiver burden (Kim et al., 2014). In addition, impairment of cognitive functions and physical abilities are also significantly related to caregiver burden (Kim et al., 2014).

Researchers analyzed the factors that can predict depression in caregivers (Bastawrous, 2013; Piercy et al., 2013). Piercy et al. (2013) investigated five contextual aspects that predicted depression in dementia caregivers. Those factors encompassed sociocultural contexts, like caregiver gender and education; situational context like care recipients' progressive degeneration of cognitive and behavioral functions; interpersonal context comprising support systems; temporal context; and personal context comprising of caregiver qualities (Piercy et al., 2013). Results indicated that more qualified and educated caregivers exhibited lower levels of depression (Piercy et al., 2013). Also, caregivers who were healthy and more practical, utilized support networks, and used problem-based coping strategies, were less prone to depression-related symptoms (Piercy et al., 2013).

Studies have consistently shown that lack of time and care recipients' level of dependence on caregivers for cognitive and day-to-day instrumental functions are huge contributors to caregiver stress and burden (Bass et al., 2012; Bastawrous, 2013; Hughes et al., 2014). Hughes et al. (2014) focused on the unfulfilled needs of family caregivers and found that a lack of time to accomplish tasks associated with taking care of patients diagnosed with dementia, culminated in caregiver stress and burden. Like Bastawrous (2013), Hughes et al. (2013) showed how objective burden related to care recipients' functional dependence and subjective burden related to care recipients' behavioral issues resulted in caregiver burden. Bass et al. (2012) also identified impairment of cognitive functions, challenging behavior, dependence on day-to-day instrumental functions, and severity of dementia as factors that predicted caregiver stress and burden. According to the authors, these factors contributed to negative effects for caregivers like the feeling of isolation, depression, and sense of unsatisfied needs (Bass et al., 2012). Thus, the authors underscored the importance of targeting the negative caregiving effects to help caregivers reduce the repercussions of those effects on their health and the quality of care they provide (Bass et al., 2012).

Along similar paths and underlining the critical nature of burnout in caregivers of persons with dementia, researchers have considered individual attachment issues (Kokkonen, Cheston, Dallos, & Smart, 2014). Advocates of attachment theory would predict that the level of attachment between the care recipient and the caregiver has bearing not only on the quality of care delivered but also on the caregiver burnout

(Kokkonen et al., 2014). Consequently, practitioners and caregivers can utilize such information to make decisions about caregiver stress coping mechanisms, and interaction between the persons with dementia and their caregivers' burnout (Kokkonen et al., 2014). The results of their study suggested that insecure attachment, more optimistic attitudes and lower levels of self-efficacy were positively related to caregiver burnout (Kokkonen et al., 2014). The authors recommended staff education on the role of attachment in dementia care, even as more research is required to investigate the role of mediating factors between adult attachment styles and caregiver burnout (Kokkonen et al., 2014).

Interestingly, other researchers have pointed to the role played by caregivers' psychological aspects in causing distress related to behavioral and psychological symptoms of dementia rather than distress originating from the actual presence of behavioral and psychological symptoms of dementia in the patients (Feast, Orrell, Russell, Charlesworth, & Moniz-Cook, 2017). This study focused on caregivers' psychosocial factors including quality of the relationship and health-related issues (Feast et al., 2017). The study revealed that caregivers' level of competence, guilt, and reaction to patients' challenging behaviors explained most behavioral and psychological symptoms of dementia-related distress (Feast et al., 2017). Consequently, the authors suggested customized interventions to better manage behavior issues in family caregiver settings that could eventually alleviate behavioral and psychological symptoms of dementia-related distress in both patients and families (Feast et al., 2017). Thus, although behavioral and psychological symptoms of dementia have a significant impact on caregivers' mental and physical health, caregivers' attributes and psychological factors also play a critical role in putting them at risk for stress and poor health (Feast et al., 2017).

Challenges of Working with Patients Diagnosed with Dementia

Various researchers indicated that caregiver stress is significantly correlated with the challenging behaviors exhibited by the stage-4 dementia patients (Mayo Clinic, 2015; Ornstein & Gaugler, 2012; Tschanz et al., 2013; Venturato et al., 2013; Wong & Wallhagen, 2014). Ornstein and Gaugler (2012) pointed to how behavioral and psychological symptoms related to dementia are known to be predictive of caregivers' stress and burden. Consequently, research has also shown how caregiving stress affects patient outcomes (Tschanz et al., 2013). The Mayo Clinic (2015) highlighted how physical and emotional stressors associated with Alzheimer's disease and dementia associated symptoms affect the quality of care and affect patient outcomes, as well as the wellbeing of the caregivers. Before delving deeper into the challenges of working with people with dementia, it is necessary to understand the nature of dementia and factors that influence it.

Definition of dementia, causes, and symptoms of dementia. The NIH (2014) identified dementia as a set of symptoms that affect the normal functioning of the brain rather than a particular disease. The Alzheimer's Association (2014) described dementia to be a degenerative manifestation of debilitating symptoms that produce disorientation, mood changes, memory loss, and lack of motivation. Dementia can be caused by various diseases like Alzheimer's or a stroke (NIH, 2014). The Mayo Clinic (2015) defined dementia as a set of symptoms caused by several conditions, which is often involved in the general process of aging. McKhann et al. (2011) modified the clinical criteria for dementia to include behavioral and cognitive symptoms that impede daily activities, interfere and deter performance, and lead to impairment of thinking skills, memory, and language functions. The revision aimed to develop criteria that had a more global application, making it more accessible for general healthcare providers and workers without having to resort to specialized tools or instruments (McKhann et al., 2011).

Although it is hard to identify the exact causes of dementia, researchers have found that a combination of physical, psychological, and environmental factors contribute to its development (Campbell et al., 2011; Judge et al., 2010; Kontos & Martin; 2013; Llanque et al., 2016). Kontos and Martin (2013) indicated that dementia is a product of the complex interrelationship between the body and sociopolitical processes, where the broader social context must be considered to understand how dementia is represented in the social environment and how it is experienced by the patients.

Judge et al. (2010), in their stress process model, highlighted multiple dimensions that contribute to the illness experience of patients diagnosed with dementia, some of which are discussed below. One of the dimensions of the stress and wellbeing of the individuals with dementia that Judge et al. (2010) analyzed was related to background and context, which highlighted the life circumstances of the individuals. Judge et al. (2010) also identified objective and subjective primary stressors, which relate to the type and degree of the severity of the disease and the ensuing distress associated with that stressor. Another factor that the authors identified related to secondary strains stemming from the primary stressors, like the effect on roles played by the person with dementia in the family, at work or society (Judge et al., 2010). The authors also categorized internal mediators comprising innate characteristics like personality and resilience that account for coping mechanisms or the lack of such mechanisms. External mediators include external resources that provide support to the individual like family, caregivers, and therapists (Judge et al., 2010). Finally, Judge et al. (2010) pointed to outcomes relating to wellbeing and how the factors mentioned above affect the results, preventive measures, and treatment options that can be adopted to produce positive outcomes. The researchers suggested that it was important for caregivers to understand the stressors associated with the different stages of dementia so that treatment and care could be geared towards those specific challenges (Judge et al., 2010).

Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007; Judge et al., 2010; Kaufmann & Engel, 2014; Tolhurst et al. 2012 have found that quality of life, in general, deteriorates with the severity of dementia. Tolhurst et al. (2012), in addition to the dimensions identified by Judge at al. (2010), argued that age-based factors also influence stress, the concept of the personhood of the patients diagnosed with dementia, and their lived experience of the disease. While evaluating the effectiveness of a quality of life instrument (QUALIDEM), Ettema et al. (2007) found that progression in dementia resulted in lower quality of life scores, thus, providing evidence on how the progression of dementia could affect certain aspects of the quality of life for the people who have dementia.

Dementia is a huge impediment in the way of leading a healthy and meaningful life (Bassal, Czellar, Kaiser, & Dan-Glauser, 2016; Stewart et al., 2016). Not only does it affect the regular day-to-day living of the patients suffering from dementia, but it also thwarts an individual’s sense of self or personhood. Furthermore, it has a profound impact on paid caregivers or family members who act as caregivers (Bassal et al., 2016; Stewart et al., 2016). It is a two-fold challenge for caregivers to provide a high quality of care to meet the needs of the patients diagnosed with dementia while reducing the effects of stress that they experience in rending care.

Effects of caregiving stress on quality of care, the personhood of patients diagnosed with dementia, and caregiver health. Researchers, such as Judge et al.

(2010) and Tschanz et al. (2014), have shown that caregiving stress negatively affects the provision of quality of care, maintenance of personhood in patients diagnosed with dementia, and the overall health of caregivers. Tschanz et al. (2014) identified caregiving stress as a most significant influence on the lives of patients who have dementia. They recognized several factors that can deter the progression of dementia including medications and nutritional supplements. However, these factors often have side effects that pose health risks. Under these circumstances, caregiving strategies can play a critical role in curtailing or increasing the behavioral challenges associated with dementia (Tschanz et al., 2014). The authors indicated that caregiving qualities could even lead to the institutionalization of the patients suffering from dementia (Tschanz et al., 2014).

Campbell et al. (2011) have also emphasized the relationship between caregiver stress and the behavioral symptoms of dementia patients. Campbell et al. (2011), in their analysis of the relationship between caregivers' stress and behavioral symptoms of dementia, revealed that when caregivers' stress levels were higher, the behavioral symptoms of dementia increased in severity. In general, the study showed that perceived stress appeared to have a greater influence on behavioral symptoms of dementia than emotional-behavioral responses (Campbell et al., 2011). Caregivers also exhibited higher levels of perceived stress, which often verged on depression. Overall, the study showed that caregivers' stress is a predictor for an increase in behavioral symptoms of dementia and caregivers' negative attitude towards the care recipients, affected the quality of care and resulted in worsening of symptoms for patients diagnosed with dementia (Campbell et al., 2011). Smebye and Kirkevold (2013) indicated that reluctance towards patient needs and mechanical task-oriented care negatively affects personhood in patients diagnosed with dementia.

Additionally, Yan (2014) found that elderly patients suffering from dementia can be subject to abuse by the family caregivers (Yan, 2014). Yan (2014), in his study on a Chinese population of dementia patients residing in Hong Kong, explored the relationship between the agitation demonstrated by care recipients and the caregivers' burnout. The data revealed that caregivers' burnout often resulted in lack of empathy and abuse of the patients who have dementia (Yan, 2014). Professional caregivers might benefit from being aware of how vulnerable patients diagnosed with dementia are to verbal and other types of abuses that they might be subjected to and that this may influence their behavioral symptoms (Yan, 2014).

Nogales-Gonzalez et al. (2015) also emphasized how stress symptoms bear a negative influence on the quality of care and the wellbeing of the patients diagnosed with dementia. They showed caregivers with high self-efficacy revealed lower distress, while caregivers with low self-efficacy revealed higher levels of distress in dealing with higher occurrences of aggressive, depressive and disruptive behaviors (Nogales-Gonzalez et al., 2015). Llanque et al. (2016), in their analysis of the concept of stress, highlighted the physical and emotional stress ensuing from the inherent inequality in the relationship between the caregiver and the care recipient, where the caregiver is often viewed as providing more assistance. Although the above study was conducted on unpaid caregivers, it sheds light on how the relationships between caregivers and patients diagnosed with dementia contribute to caregiving stress. The authors underscored the importance of identifying the antecedents to caregiving stress and taking necessary steps to preempt and reduce the negative consequences (Llanque et al., 2016).

While Nogales-Gonzalez et al. (2015) and Llanque et al. (2016) have established the relationship between caregivers' stress and the behavioral symptoms of patients diagnosed with dementia, other researchers have shown how the points of views vary when care recipients’ perspectives are taken into consideration (Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016). Moon et al. (2016) focused on the quality of life and considered the predictors of discrepancy between self-reports of the caregivers and the care recipients, who exhibited mild-to-moderate dementia. Data analysis revealed, contrary to expectations, that caregivers rated the care recipients’ quality of life much worse than care recipients themselves (Moon et al., 2016). Results also revealed discrepancies between care recipients’ perception of care and decision-making involvement (Moon et al., 2016). Thus, it is imperative for practitioners and researchers alike to pay adequate attention to caregivers’ perspective in conjunction with care recipients’ opinions, especially concerning care recipients’ quality of life (Moon et al., 2016).

Gilhooly et al. (2016), in their meta-review study on stress, coping, and dementia interventions, argued that most of the studies provided general coping strategies instead of specific ones. Thus, despite the plethora of studies, information is lacking in finding targeted solutions. Overall, they found that problem-oriented coping and social and emotional support networks for dealing with dementia were beneficial both for the caregiver and the care recipient (Gilhooly et al., 2016). The intervention programs they focused on were mostly geared towards one of the three categories, psychological wellbeing, knowledge on coping strategies, and delaying the process of institutionalization of the dementia patients (Gilhooly et al., 2016). The analysis of the intervention approaches showed that social and educational interventions had positive implications for both the caregivers and the care recipients. The analysis revealed that caregivers of patients diagnosed with dementia are at risk of stress and poor health (Gilhooly et al., 2016). The review reiterated the relationship between negative outcomes and avoidance of coping strategies and support networks. Based on their analysis, they recommended future studies to provide more individualized coping strategies that target specific dementia-related problems (Gilhooly et al., 2016).

Despite Gilhooly et al.'s (2016) emphasis on taking actions to reduce the health risk factors for caregivers, there are insufficient studies that target the actions or strategies that caregivers can utilize for improving quality of care. The few studies that exist fail to establish specific coping strategies that can be tailored to meet the needs of the patients. Thus, this study employed Vroom's expectancy theory to discover the underlying motivations that might yield better efforts and positive outcomes for both caregivers and patients diagnosed with dementia.

Personhood of people suffering from dementia and person-centered care. Research studies, such as those by Hydén, Lindemann and Brockmeier (2014), Smebye and Kirkevold (2013), and Twiggs and Buse, (2013), have shown that longevity in life, pressures of modern-day world and technological advancement have resulted in people living by themselves away from home, families, and friends for more extended periods of time. As such, there is an increased reliance on caregivers and person-centered care (Twiggs & Buse, 2013). It is imperative for caregivers to understand the need for providing individualized care to the patients diagnosed with dementia to improve the patients' quality of life by addressing their physical and psychological needs as well as promoting their personhood. However, Smebye and Kirkevold (2013) have indicated that caregiver stress has a negative impact on the personhood of patients diagnosed with dementia. The following paragraphs focus on understanding the meaning of personhood and its relationship with person-centered care and how caregiving stress is related to personhood in patients diagnosed with dementia.

The theoretical and practical applications of person-centered care are deeply rooted in the concept of personhood (Buron, 2008; Dewing, 2008). The term personhood has a wide variety of connotations. According to Buron (2008), personhood refers to those characteristics and qualities that are identified with being human in the society. In his personhood model of dementia care (PMDC), Buron (2008) proposed a person-centered approach for taking care of people suffering from dementia. He emphasized the significance of personhood and how it is threatened in people suffering from dementia, who experience impairment of the proper functioning of memory, communication, and cognition skills (Buron, 2008). The author discussed the challenges, benefits, and implications of utilizing the person-centered care approach (Buron, 2008). He suggested that the PDMC would provide a framework for implementing and assessing person-centered approaches in a nursing home environment, organize and consolidate person-centered care interventions, and provide a knowledge base and direction for future person-centered interventions (Buron, 2008).

Dewing (2008) supported Buron's (2008) assertion that personhood has significant implications for the welfare of the patients diagnosed with dementia. He postulated that, through the course of its evolution, the term personhood has come to mean the essential attributes and characteristics of a person (Dewing, 2008). The evolving practices and research on person-centered care are based on the premise of personhood. He criticized how the interpretations of the concept of being a person in the Western world reveals a bias towards cognitive attributes, which fail to consider social, emotional, and psychological aspects (Dewing, 2008). The author, who based his interpretation on Kitwood’s work, emphasized that personhood incorporates qualities like sociability and agency (Dewing, 2008). He highlighted that the underlying principles of Kitwood’s personhood theory were concern and respect for ‘others’ (Dewing, 2008). According to Dewing (2008), the loss of identity often makes the people who have dementia feel vulnerable and weak. This results in other individuals (such as caregivers) to treat patients diagnosed with dementia as individuals with inferior abilities, who depend on them for survival (Dewing, 2008). Kitwood emphasized that the people suffering from dementia have an even greater need for love and respect (Dewing, 2008). Following Kitwood’s theory of personhood, the author pointed out the need for a ‘moral concern’ towards people with dementia, who have lost their sense of identity and are often at the mercy of their caregivers to help maintain their dignity (Dewing, 2008).

Love and Femia (2015) emphasized the importance of person-centered care in improving the psychological wellbeing of the person suffering from dementia. The basic tenets of person-centered care reveal that quality of life is dependent on how others value it, how purposefully involved and engaged one is in life activities, how much respect and dignity is ascribed to quality of life, and how much importance one assigned to the capacity to choose (Love & Femia, 2015). They postulated that these tenets are integral to living as humans (Love & Femia, 2015). Above all, they argued, it is important in person-centered care to recognize that individuals with dementia also lead full, meaningful lives (Love & Femia, 2015). They also underlined the social stigma associated with dementia to choose, which undermines the rights of people suffering from dementia and denies them the opportunity to lead meaningful lives (Love & Femia, 2015).

Hydén et al. (2014) shared similar perspectives as they emphasized the importance of treating people who have dementia as active agents in their own lives rather than as target subjects for treatment. They focused on the predicament of the loss of identity and personhood that dementia patients must face and the ensuing sense of helplessness. They also claimed that, when people suffering from dementia experience loss of memory and linguistic functions, a lot more is at stake because they lose their sense of personhood (Hydén et al., 2014). Thus, they argued that it is imperative for caregivers to understand how people suffering from dementia find ways of adjusting themselves to the progression of dementia (Hydén et al., 2014).

Hydén et al. (2014) argued that when individuals lose their thinking and linguistic capabilities, they lose a great deal more than that because they lose their sense of self. Smebye and Kirkvold (2013) believed that, in dementia, personhood is increasingly concealed rather than lost. This perspective lends a new lens for viewing personhood, which stresses that the sense of personhood is continually evolving through relationships with others, in spite of the debilitating influences of dementia. They discovered that relationships that nourished personhood were mainly close attachments between patients diagnosed with dementia and family caregivers and professional rapport between patients diagnosed with dementia and trained caregivers (Smebye & Kirkvold, 2013). They also discovered a reluctance to help and a task-oriented approach to care between patients diagnosed with dementia and family caregivers and that unprofessional attitudes of the professional caregivers had a negative impact on the personhood of people suffering from dementia (Smebye & Kirkvold, 2013). Following Kitwood’s (as cited in Smebye & Kirkvold, 2013, p. 2) notion of personhood, Smebye and Kirkvold (2013) recommended ways of approaching person-centered care: believe that personhood pervades the entire entity of the patient, appreciate the points of view of the patients with dementia, believe in the agency of the individuals to be able to contribute to decision-making, and offer individualized care.

The previous viewpoints are supported by Kaufmann and Engel (2014), who analyzed the psychological needs of patients diagnosed with dementia as identified in Kitwood's model of needs. According to the model, the primary psychological needs of the patients diagnosed with dementia include comfort, attachment, inclusion, occupation, and identity (Kaufmann & Engel, 2014). The study provided support for the empirical relevance of Kitwood's model, and the results revealed that the individuals with mild to moderate dementia could provide valuable information on their wellbeing (Kaufmann & Engel, 2014). This empirical relevance supports Dewing (2008) and Hydén et al.'s (2014) assertion that patients diagnosed with dementia can be active agents in their lives and contribute to their wellbeing. As such, the researchers emphasized the importance of a person-centered approach in catering to the needs of patients diagnosed with dementia, to be able to maintain their personhood and improve the quality of their lives.

Cowdell (2006) also studied the prevalent practices of taking care of patients diagnosed with dementia as well as how research often ignore patients' right to choose. In his analysis of the extant literature of dementia, he found very few studies that attempted to engage people with dementia in the actual research. Rather, most researchers showed a tendency to just conduct experimentation 'on' them by treating them as mere subjects of their studies. His research showed the common practice of misrepresentation of person-centered care (Cowdell, 2006). He emphasized the importance of respecting and acknowledging personhood in people suffering from dementia (Cowdell, 2006).

While most researchers have emphasized the loss of personhood in dementia, Wallace et al. (2013) have shown how personhood can be used to revitalize the sense of agency in patients diagnosed with dementia and empower them to take control of their lives. In their study on a couple in which the husband took care of his wife living with dementia, the researchers saw how active participation in designing and technology-related activities helped the couple reminisce and recollect memories to foster agency in Gillian, the wife. Thus, they not only recognized the personhood of the patient diagnosed with dementia but also underlined the role it could play in improving the patient's quality of life (Wallace et al., 2013).

Researchers, such as Tuomola et al. (2016), Venturato et al. (2013), and Vohs and Baumeister (2013), also revealed how—in addition to physical and psychological factors—contextual factors play critical roles in influencing provision and quality of care. Vohs and Baumeister (2013) emphasized the role played by culture in shaping our responses, choices, and beliefs about self-regulation. Tuomola et al.'s (2016) study on Chinese spousal caregivers showed that cultural factors affected caregivers' beliefs and caregiving practices. Thus, caregivers' stress management and care related practices were guided by their cultural milieu.

Venturato et al. (2013) emphasized the discrepancy in the conceptualization of the philosophy of person-centered care for people with dementia and the actual implementation of it. They studied the guiding documents on dementia care from a long-term care facility in Australia to identify significant consistencies and incongruities within the documents that might reveal a disconnection with the philosophy of person-centered care. They conjectured that inconsistencies in the guiding documentation might diffuse and misdirect the proper translation of philosophy into actual practice (Venturato et al., 2013). The researchers utilized principles from hermeneutics and institutional ethnography, whereby they analyzed the discords and tensions in the language used. Results indicated that the documents revealed ambiguity in the conceptualization of dementia care and a lack of connection between the care philosophy and the documents guiding care for people with dementia (Venturato et al., 2013).

In another study, Twiggs and Buse (2013) emphasized the importance of external appearance, dress, and clothing in reflecting and maintaining personhood of the people suffering from dementia. They suggested how caregivers can help maintain the external appearance of the patients to uphold their sense of identity. To groom the care recipients in ways similar to how they usually dressed helps keep a sense of continuity for family members and relatives. As degeneration of cognitive functions occurs with the progression of dementia, care recipients become increasingly more dependent on the caregivers for maintaining clothes and dressing skills (Twiggs & Buse, 2013). The authors cautioned caregivers from considering these chores as degrading or futile as it often leads them to depersonalize care and to distance themselves from the care recipient (Twiggs & Buse, 2013). Thus, the researchers underscored the importance of clothes as a way of externally manifesting one's identity.

The ramifications of caregiving stress on the personhood of patients diagnosed with dementia are multifaceted and affect the lives of the patients in many ways. The above review of the literature shows the importance of maintaining personhood in people with dementia. It shows that with the onset and progressive degeneration of dementia, individuals experience impairment of cognitive, sensory, linguistic, and physical functions that are critical for day-to-day living. Researchers have underlined the importance of not only taking care of patients suffering from dementia but also their caregivers' wellbeing (Piercy et al., 2013). Unfortunately, despite the presence of existing or contemporary literature on the association between challenges of working with patients diagnosed with dementia and caregiving stress, it is relatively rare to find studies that address the need of the caregivers. The following section will discuss the importance of coping strategies for mitigating the negative effects of caregiving stress and the importance of relevant training and resources in helping caregivers learn about those strategies.

The necessity of learning to cope with the challenges of working with patients diagnosed with dementia. Both Chen et al. (2015) and the Mayo Clinic (2015) have shown that, despite problems using different and individualized interventions and coping style, caregivers can often divert behavior and maintain the dementia-diagnosed person's dignity through a person-centered approach. The Mayo Clinic (2015) warned caregivers to be wary of stress symptoms and to take necessary measures to prevent worsening of symptoms and behaviors. While investigating coping strategies as means of improving the efficacy of interventions, Chen et al. (2015) analyzed four coping strategies, which were: problem-solving, knowledge about dementia, emotional support, social support, and resources. Results showed that the group of caregivers who were exposed to the interventions demonstrated higher scores on problem-solving skills and utilizing social support than their control group counterparts. Consequently, the intervention group also showed lower caregiver stress and burden (Chen et al., 2015).

Tschanz et al.'s (2014) research was based on data from the Cache County study on memory in aging, which was a longitudinal study on people with dementia, to assess the influence of biological and environmental factors on the degeneration of cognitive, functional, and behavioral skills. The results indicated that problem-based coping strategies significantly lowered the decline of cognitive and physical functions. According to the authors, the problem-based approach involves proper identification of the issue, finding potential solutions, and planning and implementing the solution to yield the desired effect (Tschanz et al., 2014). The positive patient outcomes associated with this approach provide the confidence to caregivers to continue to use those strategies for improving quality of care (Tschanz et al., 2014). This process contributes to caregivers' personal development and a greater sense of job satisfaction. In previous studies, Tschanz et al. (2014) also found that superior bonding between dementia patients and their spousal caregivers reduced the rapid degeneration of mental and physical abilities. This study also provided support for the current research, which considered how environmental factors like caregiver stress influences outcomes for dementia patients and seek coping strategies that can alleviate caregiver stress symptoms and yield positive patient outcomes.

While most researchers focus on caregiver characteristics, contextual factors, and patients' dementia behavioral problems to evaluate caregiver health factors, Snyder et al. (2015), in a unique manner, investigated coping strategies to trace the implications of stress on caregiver health. Snyder et al.'s (2015) study revealed that caregiver coping strategies play a mediating role in caregiving stress and caregivers' health and overall wellbeing. According to the authors, how caregivers cope with stress may affect their physical and mental health. The researchers assessed how caregiver characteristics and exposure to behavioral symptoms are associated with coping strategies (Snyder et al., 2015). The results indicated that caregivers identified caregiving for the patients to be a source of stress. The results also indicated that wishful thinking or blaming yourself play significant roles in anxiety amongst caregivers (Snyder et al., 2015). The authors identified two types of coping strategies, namely, problem-focused and emotion-focused coping. While problem-focused coping deals with targeting actions to bring positive change in a caring environment, emotion-based coping refers to changing attitudes to reduce emotional distress. Overall, the study provided evidence that coping strategies were associated with caregivers' age, gender, stressors related to dementia symptoms, anxiety, and health (Snyder et al., 2015).

Wong and Wallhagen (2014) proposed that caregivers' attitude and problem-oriented approach of coping are positively related to caregiver wellbeing. In their study, aimed at identifying strategies for family caregivers to cope with the caregiving challenges of dementia patients, Wong and Wallhagen (2014) found that emotion-focused strategies for coping were significantly related to caregivers' mental health, with the use of strategies related to improved psychological health. Thus, the researchers indicated that emotion-based coping strategies might prove valuable in managing caregiver stress.

Researchers, such as Judge et al. (2010) and Kamiya et al. (2014), have pointed to the importance of caregivers to understand the stressors associated with the different stages of dementia so that treatment and care could be geared towards those specific challenges. Understanding the patients' life circumstances, the probable sources of stress, innate qualities and external agencies that influence individual patient's behavior, will provide a more tailored approach to meet the physical and emotional needs of the patient. Kamiya et al. (2014) found that, with the progression of dementia through multiple stages, the caregiver burden also increased in proportion. Specifically, the results indicated that caregiver stress was dependent on the deteriorating symptoms of dementia as it progressed through the stages (Kamiya et al., 2014). Caregiving stress affected several factors such as behavioral and psychological symptoms, inability to complete day-to-day life functions, impairment of memory functions, age-related weakening of motor functions, and other geriatric conditions (Kamiya et al., 2014).

Interestingly, Glidewell, Johnston, and Thomas (2012) emphasized that people with dementia can provide insight into their conditions and that it is critical for caregivers to understand the state and current status of dementia to determine the care options. The study utilized the common sense-self regulation model (CS-SRM) illness representations (IRs) to ascertain individuals' beliefs and thoughts about their illness. The results revealed some discrepancies in viewpoints and thoughts regarding the illness in the participants (Glidewell et al., 2012). The study has important implications as it shows that caregivers can communicate better if they understand how the care recipients feel and think about their condition (Glidewell et al., 2012).

For example, individuals with stage-4 dementia can wander into other patients' rooms and misperceive that the place is theirs with no recollection that the room belongs to another individual. Explanations will yield no effect because the patients have no understanding of the extent of their disease due to impaired memory or cognitive deficits. The caregiver attempts to explain the reality of the situation; however, the patients refuse to budge. Realizing the shortcomings of the patient, the caregiver will not argue because the situation can manifest a possible verbal or physical aggression toward the caregiver or a patient-to-caregiver altercation.

While understanding the nature of dementia and that the challenges that it poses for caregivers are critical, research indicated that caregivers' personal traits and qualities of human agency, self-regulation, self-efficacy, and resilience are crucial for offsetting stress and other health risk factors for caregivers and delivering better quality of life for the patients diagnosed with dementia (Dias et al., 2016; MacKenzie

& Baumeister, 2015; Tschanz et al., 2013). Broughton et al. (2011), Franzmann, Haberstroh, and Pantel (2016), as well as Takizawa, Takahashi, Takai, Ikeda, and Miyaoka (2017) also provided evidence that education and training play a significant role in equipping caregivers with the coping mechanisms they need to prevent and reduce stress.

Bandura (2011) postulated that human agency, which he described as the capability to modify the course of events through personal actions, is influenced by social and cognitive processes. He proposed that, by virtue of human agency, individuals become active contributors to their life events rather than being mere products (Bandura, 2011). This theoretical perspective is an important component of this study since it demonstrates (a) how individuals suffering from dementia learn to cope with the debilitating effects of the disease and strive to maintain their personhood; and (b) how caregivers' self-development occurs through adaptation and change to reduce stress and cope with the demands of the job. While the former argument has been discussed in detail earlier in this chapter, the latter evidence warrants a closer look. In support of Bandura's theory, Jennings et al. (2015) found evidence that lower levels of self-efficacy were predictive of stress symptoms in caregivers working with patients diagnosed with dementia. Additionally, the researchers found that the degree of depressive symptoms was dependent on the severity of the patient's dementia.

MacKenzie and Baumeister (2015), McAuliffe, Kinsella, Ong, and Nay (2013), and Toms, Quinn, Anderson, and Clare (2015) emphasized the role played by self-regulation and self-management strength, both of which influences behavioral outcomes. McAuliffe et al. (2013) explored the relationship between personal mastery and perceived stress. According to the authors, mastery refers to own beliefs about the ability to control the course of events or future actions. The results indicated that low mastery skills were correlated with higher levels of depression, anxiety and caregiver burden. Toms et al. (2015) also emphasized the importance of self-management in both the patients with dementia and their caregivers to yield positive outcomes.

Infurna, Gerstorf, and Zarit (2013) studied the complementary construct of global mastery concepts that is influenced by the placement of patients diagnosed with dementia in nursing facilities. The results revealed that caregivers exhibited lower mastery perceptions before the placement of the patients diagnosed with dementia in the nursing homes, which was, interestingly, followed by a surge in the mastery of perceptions within one year of placement (Infurna et al., 2013). This enhancement in perception shows that the context or environment, within which the patient is attended, influence caregivers' perceptions of mastery. Caregivers, who believed that they had depression-related symptoms, demonstrated higher mastery perceptions when care recipients were placed in nursing homes (Infurna et al., 2013).

This belief was especially applicable for caregivers of those patients who were dependent on the caregivers for their activities of daily living. The caregivers feel stressed from 'role overload,' which refers to being overwhelmed with responsibilities before the placement. However, once the patients are placed in nursing homes, they feel that the responsibilities have been relatively reduced and that they are more in control of the circumstances (Infurna et al., 2013). The study by Infurna et al. (2013) revealed how caregivers' sense of mastery and control could change with the level of stress, an overwhelming sense of responsibilities or role overload, and the environmental factors, such as whether the care recipient is at home or at a nursing home.

Adding to the research of the aforementioned studies, Baumeister and Vohs (2007) analyzed how motivation helps trigger and engage self-regulation as well as how motivation is restrained by self-regulation. According to the authors, self-regulation is the ability to transform behaviors and actions to adapt to social challenges (Baumeister & Vohs, 2007). The advantages of efficient self-regulation are that it influences performance, mental and physical health, and social skills. They also underlined how motivation counteracts the negative effects of self-depletion and encourages people to work toward goals. In other words, motivation plays a role in making self-regulation successful and self-regulation, in turn, regulates or controls motivation. In the process, they evolve as more socially responsible individuals (Baumeister & Vohs, 2007). This study could be utilized in understanding how proper motivation can curtail the negative effects of stress in caregivers as well as inspire them to provide quality care. The NIH (2014) provided recommendations on how to exert control over frustration and suggested some strategies like calming down, deep-breathing and eradicating negative thoughts and fostering positive ones. Also, it highlighted the need for self-care to prevent stress and suggested how support groups could help caregivers relate to other caregivers in similar situations to release pain.

In addition to self-regulation and self-management skills, Dias et al. (2016) proposed that caregivers' resilience can be a mediating factor in improving caregivers' quality of life and reducing depression symptoms. While caregivers' gender did not mediate resilience, gender was related to caregiver's quality of life and negatively related to risk for depression (Dias et al., 2016). When faced with stress, a successful adaptation is possible if the caregiver is resilient. A caregiver's gender does not determine the ability to bounce-back when faced with challenges, rather, the individual's coping skills and positive outlook can influence stress-free outcomes and curb depression. The researchers recommended support groups to focus on strengthening resilience factors in caregivers (Dias et al., 2016).

While attributes such as self-efficacy and resiliency provide a perspective of understanding caregivers’ coping strengths, other researchers have pointed out the importance of education and training that caregivers can resort to in developing coping strategies (Broughton et al., 2011; Franzmann, Haberstroh & Pantel, 2016; Takizawa et al., 2017). Takizawa et al. (2017) underlined the importance of training for professional caregivers in acquiring effective stress management skills and coping strategies. Specifically, the authors studied the effectiveness of training programs for equipping caregivers with coping strategies for working with patients diagnosed with dementia. The after-training scores revealed an increase in coping measures and decrease in stress reactions. The results indicated differences in male and female participants, where female participants’ stress reaction scores were associated with assistance from superiors, male participants’ stress reaction scores were associated with changes in consultation and problem-solving (Takizawa et al., 2017). These results indicate that gender might be a mediating factor in caregiver stress reactions and coping mechanisms (Takizawa et al., 2017). Future studies focusing on gender aspects might provide valuable insights into the process of caregiving stress reactions and coping mechanisms.

The results of a study conducted by Broughton et al. (2011) on a DVD based caregiver training program indicated that the caregivers who received the training had a significant enhancement in their knowledge about strategies for supporting memory and communication functions in people with dementia in comparison to their control group counterparts. Further, qualified nurses demonstrated higher levels of satisfaction in the three-month follow-up assessment (Broughton et al., 2011). In another training program, Franzmann et al. (2016), found that improvement in dementia-related communication helped reduce caregiver stress. Caregivers, who received training registered improvements in communication skills compared to their control group counterparts who did not receive education and training. Also, the intervention group caregivers showed more enduring effects related to stress reduction (Franzmann et al., 2016).

In addition to effective communication skills, Sarabia-Cobo (2015) showed that beliefs, thoughts, and emotions can be altered to foster positive thought processes that have better implications for the overall health of individuals. In the study on stress management through heart coherence techniques, Sarabia-Cobo (2015) showed how heart coherence is correlated to a reduction in stress and improvement in performance and wellbeing. The study was conducted by applying heart coherence techniques on the participants. Results indicated that development of proper heart coherence techniques had a positive effect on stress management for caregivers of the patients diagnosed with dementia (Sarabia-Cobo, 2015). The results of the study have significant implications for this research as it shows that adoption of heart coherence techniques can improve stress management and specific negative thought processes can be modified to embrace more positive ones, which contribute to better health for caregivers (Sarabia-Cobo, 2015).

While researchers like Graham and Philips (2016) and Jennings et al. (2015) have expounded on the implications of relevant education and training on improving the quality of care, some researchers have expressed concerns about the lack of resources and even proper utilization of resources by caregivers. Graham and Phillips (2016) tried to investigate how interventions and resources are accessed and utilized by different racial and ethnic groups. They found that caregivers from Black, Hispanic and White origins showed no significant difference as far as exposure to the content of the interventions or resources were concerned. However, Black caregivers attended relatively fewer sessions of the resources for enhancing Alzheimer's caregiver health (REACH II) intervention than their White and Hispanic counterparts (Graham & Phillips, 2016). The results indicated that there might be demographic differences about who attended the interventions, which in turn, will affect the quality of care.

Jennings et al. (2015) emphasized that the lack of proper support from providers often leave caregivers without adequate knowledge to cope with the challenges of dealing with patients diagnosed with dementia. Jensen and Inker (2013) also discovered, through caregiver interviews, that caregivers did not always receive information on the availability of resources. The researchers recommended having better communications and partnerships amongst patients, caregivers, and doctors. They also pointed out the necessity of providing training resources for caregivers and doctors and educating people in general about dementia (Jensen & Inker, 2013).

Malak et al. (2016) pointed to the importance of caregivers recognizing the unique experiences of the patients diagnosed with dementia in dealing with their symptoms. Malak et al. (2016) argued that even though people with dementia display similar symptoms, they experience symptoms like loss of memory, language, delusions, or functional dependence, that are unique to them. The researchers stressed the importance of taking into consideration all these aspects by the caregivers to improve the quality of care rendered to the patients (Malak et al., 2016). They aimed at assessing the professional caregivers' opinion about the benefit of the UnderstAID, a platform that helps informal caregivers to understand and aid their demented relatives (Malak et al., 2016). The study participants, comprised of professional caregivers, were required to complete questions regarding the pros and cons of the

UnderstAID application. Results indicated that caregivers found the platform very useful for providing support to caregivers. The results also indicated that older professional caregivers provided a higher number of positive opinions about the platform's effectiveness (Malak et al., 2016).

Ervin and Reid (2015), Jennings et al. (2015), and Jensen and Inker (2013) have shown how lack of resources and relevant information creates impediments in the provision of care. Tschanz et al. (2014) also indicated how caregivers' stress and lack of coping strategies often result in the institutionalization of the dementia patients. Also, the extant literature shows that under-utilization of resources by caregivers makes them more vulnerable to stress and depression-related symptoms (Ervin & Reid, 2015). Ervin and Reid (2015) explored the effects of under-utilization of community resources by informal caregivers who attended to dementia patients. Data revealed that very few of the caregivers utilized the available community resources (Ervin & Reid, 2015). The researchers emphasized the need for using community resources since they may provide information on coping strategies for dealing with the behavioral challenges of people suffering from dementia (Ervin & Reid, 2015).

Ervin and Reid (2015), and Stevens (2012) commented on the lack of studies on caregiving stress that address the needs of the caregivers regarding strategies, resources, or recommended interventions that would help reduce caregiving stress while still being able to provide quality care, which is imperative for maintaining the patient's personhood . Jennings et al. (2015), and Stevens (2012) pointed to the need for relevant public policy, proper allocation of funds and resources, and education and training to address the tremendous proliferation of dementia around the world. It is imperative for people to educate themselves about the debilitating influences of dementia to be able to help them.

Hurd, Martorell, Delavande, Mullen, and Langa (2013) pointed to the monetary burden that dementia poses to society. According to their research, in 2010, the yearly cost for everyone varied from $41,689 to $56,362, which was dependent on the method of evaluation. This data was based on the out-of-pocket expenses and nursing home expenditures that the patients incurred. Informal or unpaid caregivers' charges were calculated based on the formal care rates (Hurd et al., 2013). The study utilized data about individuals from across the nation who were part of a longitudinal study called the health and retirement study (HRS) (Hurd et al., 2013). Hurd and colleagues (2013) categorized the individuals who were at risk of developing dementia based on data available about the existing cognitive and functional conditions of individuals involved in the HRS study. Thus, the authors recommended changes in public health policies for meeting the growing demands of care and treatment for the patients diagnosed with dementia (Hurd et al., 2013).

Importance of sharing experiences of caregivers in informing the process of stress alleviation. Very few studies have utilized the lived experiences of caregivers to gain knowledge about the challenges of working with PPD and the coping strategies caregivers use to reduce their stress and health risks while improving the quality of care of the patients. The few studies that have utilized caregivers' lived experiences are based on family caregivers' knowledge and practice. By utilizing the shared lived experiences of the paid caregivers, I propose to gain an understanding of multiple aspects associated with the phenomenon of taking care of people suffering from dementia. The phenomenological approach to this research provides a framework for utilizing interviews to gain knowledge about the lived experiences of individuals who have experienced an event or phenomenon (Creswell, 2013a). The assemblage of the experiences of multiple individuals, who experienced the same phenomenon, helps discern the essence and nature of the phenomenon (Creswell, 2013b). A closer look at the lived experiences of the caregivers who work with patients diagnosed with dementia might shed light on the coping strategies for counterbalancing the adverse effects of caregiving stress and pave the way for improving quality of care and maintaining personhood in people with dementia.

The role of culture in influencing the lived experiences of caregivers is evident in the study conducted by Tuomola et al. (2016). The researchers delved into the lived experiences of caregivers working with dementia patients and the effect of caring on the caregivers' sense of self. The main concepts identified were the impact of caregiving, acceptance of destiny, taking control, and view or sense of self (Tuomolo et al., 2016). The results indicated that Confucian beliefs permeated in the wives' views on their roles as wives, mothers, and caregivers (Tuomolo et al., 2016). There was an inherent sense of guilt and resignation to fate. Interestingly, the caregivers' view of self-revealed a certain sense of empowerment at being able to play all the roles (Tuomolo et al., 2016). Although the study was conducted on spousal caregivers, who had limited exposure to formal training, the finding is relevant for the professional caregivers of this study as it provided details on how caregiving influences sense of control and view of self. However, the researchers found that the family caregivers were willing to utilize resources and seek community and professional help to meet the challenges of dealing with the individuals with dementia (Tuomolo et al., 2016).

The lived experiences of caregivers often demonstrate the development of negative thinking and beliefs that have harmful repercussions on their health as well the individuals suffering from dementia (Ali & Bokharey, 2015; Navab, Negarandeh, & Peyrovi, 2012). Navab et al.'s (2012) study emphasized how caregivers' constant fear of having to deal with degenerative symptoms of dementia results in severe stress. They conducted a qualitative study to investigate the lived experiences of Iranian family caregivers while caring for their loved ones with Alzheimer's (Navab et al., 2012). The data revealed a common underlying theme of reminiscing about the patients' past, concerns about the present state of health, and fear and uncertainty of what will happen in the future. Specifically, the family caregivers repeatedly compared the patients' past abilities with their current deterioration in condition and subsequent worsening of the same (Navab et al., 2012). Consequently, the findings of the study suggest that the only solution to such degenerative state of health is providing unqualified and consistent education and support to family caregivers so that they could, in turn, care for their loved ones suffering from Alzheimer's. The experiences the family caregivers acquired while living and taking care of the patients, may identify some of the concerns of that professional caregivers might experience while working with patients diagnosed with dementia.

Ali and Bokharey (2015) explored the experience of Pakistani family caregivers during their interaction with dementia patients. Akin to research by Navab et al. (2012), the results of the analysis revealed several instances of maladaptive thinking that caregivers develop while taking care of the patients diagnosed with dementia (Ali & Bokharey, 2015). Maladaptive thinking has negative implications for caregivers' mental and physical health. Examples of maladaptive thinking include catastrophizing, which refers to the overwhelming sense of anxiety about future events; overgeneralizing, which refers to a pervading sense of negativity about different aspects in life; and blaming, which refers to blaming others responsible for certain actions or events (Ali & Bokharey, 2015). The authors believed that these maladaptive thinking processes were a result of the inability of the caregivers to cope with the stressors and their inability to maintain an equilibrium between the multiple roles that they must play (Ali & Bokharey, 2015). Given that help, support, and education in this regard are scarce in the Pakistani sociocultural context, the authors argued the importance of developing an indigenous and robust therapeutic intervention to aid the family caregivers of dementia patients (Ali & Bokharey, 2015). Although the above study was conducted on family caregivers, the findings are relevant for the current research as it shows how lack of resources, health issues, and lack of a personal sense of balance can contribute to stress and fatigue.

In addition to maladaptive thinking, researchers such as Ali and Bokharey (2015), Kim et al. (2014), and Simpson and Carter (2013) have also pointed to caregivers' frequent and consistent concerns about physical problems related to sleep deprivation. Given that sleep deprivation is one of the primary concerns of caregivers of dementia patients, Simpson and Carter (2013) conducted a study to investigate specifically, (a) causes of lack of sleep; (b) how caregivers manage their sleep, and (c) caregivers' perception on improving sleep quality. Three underlying themes that emerged from the study were: the quality of sleep was a function of the patients with dementia; the need for monitoring the dementia patients at night, and concern about current and future events, leading to contemplation (Simpson & Carter, 2013). While caregivers realized the importance of education and positive steps to alleviate this situation, they nonetheless cited lack of time, resources and additional costs associated with caring for the patients as reasons for their inability to participate in health promotion activities. The authors concluded that the study reveals several exemplars of caregivers' beliefs, attitudes, preferences, and thoughts about sleep experiences even as they cared for their patients with dementia (Simpson & Carter, 2013). Kim et al. (2014) also found how care recipients' sleep patterns and agitation at night and caregivers' perceptions of these sleep disorders result in caregivers' stress, which consequently, affect the health of the caregivers.

Peacock et al. (2014) focused on end-of-life caregiving experiences by family caregivers to terminally ill dementia patients. The two themes that evolved from the study were the importance of being with and being there for the patients. Future studies can also consider if and how such perception varies with the gender and relationship to the care receiver (Peacock et al., 2014).

Kim et al. (2014), Peacock et al. (2014), and Simpson and Carter (2013) found that caregivers are often subject to extreme stressors that affect their physical and psychological health resulting in sleep deprivation, fatigue, maladaptive thoughts, anxiety, vulnerability and fear, and depression. The patterns also revealed that lack of resources and proper training makes it harder for caregivers to develop coping mechanisms that might help them counterbalance or even evade health risks. Further, they also show the importance of cultural context in shaping the experiences and coping mechanisms that caregivers might draw from to deal with challenges related to working with patients diagnosed with dementia. These studies, however, were mostly conducted on family caregivers, thus, making it hard to generalize the results for professional caregivers. Nonetheless, the studies provide insights into the lives of the caregivers and what is entailed in caring for the patients diagnosed with dementia. Additionally, the lived experiences of other caregivers in similar situations might help to discover alternate methods of coping with caregiver stress and improving patient outcomes, which are often very expensive (Hurd et al., 2013). The current study fill the gap and extend existing research by incorporating the lived experiences of the paid professional caregivers and by identifying coping patterns that emerge from analyses of those experiences.

Conclusion

The CDC (2017) estimated that in 2013, more than five million Americans had Alzheimer’s disease (the most common form of dementia). Despite the advancements made in the study of dementia, there is insufficient awareness of the condition, leading to lack of proper allocation and usage of resources (Prince et al., 2013). Stevens (2012) pointed to the rapid proliferation of dementia across the globe and the lack of proper policies to address the needs of the people suffering from the disease. While there is a plethora of research on the debilitating effects of caregiving stress on the caregivers and the patients diagnosed with dementia, there is surprisingly little research on ways to offset those negative outcomes. This study attempted to fill the gap by analyzing the shared lived experiences of the caregivers to identify coping methods used by them to reduce the effects of stress that they encounter while taking care of people suffering from dementia.

Considering the above, it is imperative to delve deeper into challenges of working with people with dementia to find ways to reduce caregiving stress and its effects on the overall health of the caregivers to pave the way for more person-centered care that sustains the personhood of the people suffering from dementia. Social implications of this study are twofold, taking into consideration the health of the dementia patients and the health of the caregivers. The findings of the study might be used by caregivers to alleviate stress symptoms associated with caring for patients diagnosed with dementia. The CDC (2017) said that, at present, there is no known cure for dementia. However, the findings of this study add to the knowledge base about ways to improve patient outcomes. The study helps caregivers identify and empathize with the problems that patients suffering from dementia encounter, find strategies for providing person-centered care to sustain personhood in patients diagnosed with dementia, and reduce or even prevent health risks associated with caregiving stress. Chapter 3 elaborates on the research strategies and results of the study.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. Knowledge of shared experiences and strategies used to cope when rendering care creates awareness that allows other caregivers to treat patients without being stressed. There exists a gap in knowledge relating to coping strategies that individuals caring for geriatric individuals use to reduce stress. Through sharing of lived experiences by paid caregivers, individual coping strategies to assist others in avoiding stress can be understood. The methodology I used for this study was the phenomenological approach. What I intended to do was interview caregivers who would share personal coping strategies and interventions that allowed them to render care without experiencing burnout. The phenomenological design was optimal for the problem because caregivers shared their experiences on how they coped and rendered care under the difficult circumstances resulting from the care recipient's symptoms of dementia. In this chapter, I provide the research design and rationale for the study, my role as the researcher, as well as the methodology, instrumentation, data analysis plan, and a discussion regarding researcher trustworthiness and ethical procedures.

Research Design and Rationale

The purpose of this qualitative study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. The use of a qualitative phenomenological research design enabled me to explore themes that would better describe lived experiences of caregivers and their coping mechanisms. Furthermore, with the phenomenological approach, it is understood that variables are difficult to identify (Creswell, 2013b). Based on the expectancy theory, the following research questions were relevant to the phenomenological research regarding coping methods of caregivers dealing with patients suffering from geriatric dementia:

RQ1: What are the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients?

RQ2: What are the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients?

For this study, the modified Van Kaam method by Moustakas was used. This method enables the conduct of semi structured interviews that are audiotaped, and later transcribed (Moustakas, 1994). According to Leedy and Ormond (2001), the goal of a qualitative phenomenological study is to explore beyond what seems to be the obvious case and dig deeper into reality and reveal ordinary life experiences. Moreover, this approach allowed me to view the phenomenon through a fresh perspective that led to an in-depth exploration of the event. This study was further organized around the expectancy or VIE theory to understand the different stressors associated with being a caregiver for patients with dementia.

Role of Researcher

For this phenomenological study, my role was to serve as the primary tool for data collection and analysis. I gathered, organized, analyzed, and interpreted the data. I used necessary tools such as pens and paper, as well as a recording device for data gathering information. The participants’ responses to my open-ended research questions (see Appendix B) were the source of my data collection. Moreover, it was essential for me to consider allocating appropriate space to conduct the interviews.

Creswell (2013b) stated that the researcher should, if possible, seek out neutral and noise-free environments to reduce distractions and undue stress. In interpreting data, my focus was to understand how caregivers rendered care to stage-4 diagnosed patients on a regular basis without being stressed. Such coping mechanisms or strategies are worth understanding and sharing with caregivers in similar or other caregiving capacities.

Also, it was necessary that ethical standards be considered, and I am not related to any of the participants to avoid researcher bias. Participants were selected from one nursing home in which I have not previously worked. Finally, participants were facility-employed and paid caregivers, and I assured that the participants could exit from the interview at any time if they wanted to do so for any reason.

Methodology

The purpose of this phenomenological study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. This qualitative inquiry was done through interviews, and data were collected using semi structured open-ended questions. Through interpretative interviews, data were gathered from a sample of 15 purposefully selected participants, with up to five participants from each shift: 7:00-3:00 p.m., 3:00-11:00 p.m., and 11:00-7:00 a.m. The target population were caregivers of geriatric residents diagnosed with dementia in a nursing home population at a facility of 120 beds in central New Jersey. These caregivers were 15 paid staff nursing assistants who were currently employed at the nursing home. Data were collected until saturation was met at participant number 13. Data saturation allowed sampling data to be stopped and analysis to be completed. It ensured that quality and adequate data that supported the study were used.

The justification for the choice of 15 purposefully selected participants representative of all three shifts was to allow for an in-depth understanding of the phenomena through ensuring that saturation was reached. Saturation occurs when no new themes emerge regardless of addition of novel data. Letters and consent forms were sent to the public affairs officer of the nursing home. A request for flyers to be posted at locations inside the facility was made. Flyers requested that volunteer Certified Nursing Assistants (CNAs) participate in the study without compensation. Participants were recruited based on their responses to flyers (see Appendix C). When approved by facility administrators, initial contacts were made with participants of the study by appointment for approximately one hour individually on each shift.

Instrumentation

I developed an interview guideline before data collection to solicit answers for the open-ended type of questions. This interview guide was essential for the open-ended questions and allowed responses that are "unconstrained by any of my perspective or past findings" (Creswell, 2005, p. 214). For this study on the coping methods of caregivers dealing with patients suffering from geriatric dementia, the participants responded to semi-structured, open-ended questions about their lived experiences and perceptions about their stress in taking care of patients with dementia. Before conducting the interview, I reconfirmed that participants were participating willingly and gave them opportunities to opt out if they wanted to. Because of the population interviewed, I did not ask them to answer a short demographic questionnaire. The interviews were audiotaped and transcribed solely by the researcher. With these open-ended questions, I anticipated potential feedback and allowed unexpected responses. Some participants expanded on their responses; others were brief but content with their answers.

This phenomenological study explored what the nursing assistants perceived to be the issues concerning their line of work and the coping methods they used to avoid stress. Also, this research method allowed the participants to explain their experiences deeply in a way that helped me fully understand their thoughts on stress. Since some of the nursing assistants elaborated on their interviews, the study may have revealed insights that are yet to be discovered. Because of the nature of the job description and challenges experienced by some paid caregivers when rendering care, the human component can be forgotten in a task-oriented environment, however, this research allowed me to realize that the caregivers understood the disease process, did not take the challenging behaviors personal, envisioned that some of the patients could be their parents, and expressed the fond and trusting side of the patient / caregiver relationship. Some of the participants' positive attitudes as shared by them are additional coping strategies that they use to render care without being stressed.

Data Analysis Plan

In this qualitative phenomenological study, research questions were based on a theoretical framework called expectancy theory. To analyze data, an open coding (NVivo) was used. Transcripts were characterized to acquire a general feel about the statements, questions asked, and similarities were compared. The specific statements, phrases, and descriptions regarding the phenomenon being researched were then extracted. Similar shared experiences were categorized. Responses were recorded via audio and journal notations to confirm accuracy. The quotes, phrases, and notes were encoded in a Word document. Coding was done using NVivo. Transcriptions were done using digital audio by Verbal Inc. (confidentiality agreement from the company was disclosed to the Institutional Review Board (IRB) and permission was granted).

The data analysis plan involved the typical data preparation activities related to qualitative data. Initially, transcripts were prepared from the audio-recorded interviews collected from the nursing assistants. Once the transcripts were obtained, they were read several times for identification of the main themes that emerged from the data. Also, the data were analyzed using a similar procedure. Additionally, when the main themes were decided, these themes were compared to the concepts of the expectancy model to determine the consistencies and differences. Essentially, I ensured that the research truly expressed the interpretations of the data in a manner that closely represented the intended meaning. More so, the experiences of the nursing assistants were reflected clearly and without bias as proposed by Bernard and Bernard (2012).

To further allow the discovery and development of the common themes, a coding process for the current study was utilized. The open coding that was used for this type of study allowed for division of data into segments and scrutinized for commonalities to determine themes. The coding process was characterized by reading all the transcripts to acquire a general feel about the statements, asking questions and comparing similarities. The specific statements, phrases, and descriptions regarding the phenomenon being researched were then extracted. Similar shared experiences were categorized. I also recorded the responses in a journal and the quotes, phrases, and notes were encoded in a Word document for coding. The participants' exact words were additionally written in quotes.

In addition, the eight-step modified Van Kaam method by Moustakas (Moustakas, 1994) allowed for interview conduction, audiotaping and to transcription. This method involved (a) recording statements of relevance to shared experience, (b) getting rid of duplicates and vague comments, (c) listing what remained or invariant horizons, (d) grouping these statements into theme categories, (e) organizing the themes with their statements to create a story of the caregiver's individual experience or textural description, (f) constructing a structural description of interpretation, (g) constructing a textual-structural description that blended steps five and six, and (h) constructing the textual-structural description which is the synthesis of the experiences of the textual-structural description (step seven) of all the interviewees' experiences.

Based on the work of Matthews, Smith, MacMillan, and Gilbert (2012) that enabled me to reveal the lived experiences and perceptions of nursing assistants of patients with dementia, three steps were taken: (a) a close reading of the interviews, (b) an organized breaking down of the data from the text into smaller units of meaning to reveal discrete meaning units, and (c) an investigation of those meaning units to isolate and find invariant constituents of experience. Accordingly, the units of relevant meaning were examined to eliminate redundancies. I then organized the emerging themes by the interview questions. In accordance to the work of Marsh and White (2006), I allocated numbers to codes and phrases that were most stated to indicate the importance of concern. After data collection ended, the Moustakas' (1994) modified Van Kaam method of phenomenological research was used for analysis.

To summarize, first transcripts were re-read after the recorded semantics were developed after, emergent themes were developed, and connections of emergent themes were created using codes (open coding). Beginning data were noted. Data were further checked through audio recording and data analysis. Once data was checked through analysis, connections across themes and knowledge of theoretical application were determined. Subsequently, patterns across cases were reviewed and a table of themes was created. Finally, coding was done using NVivo. Transcription was done using digital audio by Verbal Inc.

Issues of Trustworthiness

Creswell (2013b) posited that, in a qualitative study, the term validation is used to reference trustworthiness. Lincoln and Guba (1985) used terms such as "credibility, authenticity, transferability, and dependability" (p. 300). According to Creswell (2013b), there are four types of validation: triangulation, construct validation, face validation and catalytic validation. For this qualitative research, trustworthiness was achieved through my honesty in conducting the study. It is accounted that researcher bias was prevented. Furthermore, trustworthiness was achieved by not considering any data that may be deemed unusable. In the case of unusable data, it is important that the reason why data were deemed to be unusable was presented. The research data is shown in Chapter 4, and in-depth descriptions are provided, using the participants' own words.

Ethical Procedures

Participants in this study were all volunteers with no compensation. Before beginning data collection for this research, approval (approval number 08-03-18-0228405) was obtained from Walden University's IRB. Participation in this research study was purely voluntary. To meet criteria, participants were asked to self-identify and their ages ranged from ages 20 to 55 years old. Upfront, I provided the participants with an informed consent document, which outlined any benefits or consequences associated with the study. The informed consent document provided the reason for conducting the research as well as providing a clear insight into any foreseeable ethical issues related to confidentiality. Also, the collected data in this study is stored on a password-protected flash drive, while all the printed materials are placed in a secured location. Additionally, no real names were used to identify the participants. Furthermore, no person other than I has access to this data. After five years, the data collected will be deleted. Copies of flyers, and demographic forms are included in Appendix C.

Summary

In this chapter, I explained that the purpose of this phenomenological study was to discover the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. This qualitative inquiry was done through interview data that was collected using semi structured open-ended questions. In Chapter 3, I presented a detailed explanation of the significance of the proposed research. The presentation of the research methodology included: (a) role of the researcher, (b) instrumentation, (c) methodology, (d) data analysis plan, (e) issues of trustworthiness, and (f) ethical procedures. Chapter 4 provides detailed findings of the research.

Chapter 4: Results

Introduction

The purpose of this phenomenological study was to explore the shared experiences of caregivers regarding coping mechanisms used when caring for people diagnosed with geriatric dementia. Two research questions that I used to guide this study were:

RQ1: What are the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients?

RQ2: What are the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients?

Chapter 4 includes a description of the setting of data collection, followed by a description of the relevant demographic characteristics of the study participants. Next, the chapter contains information involving implementation of the data collection and data analysis procedures described in Chapter 3. The focus of this chapter then shifts to provide evidence of the trustworthiness of the study's results, followed by a presentation of the results, which are organized by the research question. Chapter 4 concludes with a summary.

Setting

Interviews were conducted in person in a local library. A secluded area in the local library was used as the interview location to ensure privacy and protect confidentiality. Interviews were conducted at a time of the participant's choosing, such as during a break from duties so that participants would be able to give full and rich responses to interview questions without feeling pressured to attend to other obligations. No other known personal or organizational conditions influenced participants or their experiences at the time of study that may affect interpretation of the study results.

Demographics

Participants were 13 paid staff nursing assistants who were employed as caregivers of geriatric residents diagnosed with dementia in a nursing home facility of 120 beds in central New Jersey. To ensure confidentiality, demographic information was not collected for individual participants. The sample size of 13 was used because data saturation was achieved with 13 participants. Data saturation is reached when additional data collection and data analysis yields no new themes or insights (Creswell, 2013a). In the present study, analysis of the interview data from the 12th and 13th participants yielded no new themes, ideas, or insights, data saturation had been achieved, and data collection was concluded.

Data Collection

The IRB at Walden University approved my data collection process in August 2018 with approval number 08-03-18-0228405. Semi structured interview data were collected from 13 participants. Each participant was interviewed once in a secluded area in the local public library where privacy was possible. The average duration of the interviews was approximately 30 minutes to one hour. All interviews were audio-recorded with participants' consent using a digital recording device. There were no variations from the data collection plan described in Chapter 3, and no unusual circumstances were encountered during data collection.

Data Analysis

Recorded interviews were transcribed verbatim into Microsoft Word documents by Verbal Inc. Interview transcripts were uploaded into NVivo 12 software for analysis. Data were analyzed thematically. During the first step of the thematic analysis, I read and reread transcripts to become familiar with their content and identify points of potential analytical interest. During the second step, I conducted open coding. Open coding consisted of identifying meaning units in the transcripts and grouping similar units into NVivo nodes, which were labeled with descriptive words or phrases. These nodes represented codes. Meaning units were phrases or groups of phrases from the data that expressed a perception, experience, or theme. During the third step of the analysis, the content of the nodes that had been created in NVivo during open coding were reviewed. Similar nodes were grouped in NVivo and were labeled with descriptive phrases. The parent nodes represented themes. During the fourth step of the analysis, I reviewed and refined the themes. If, upon review of the data, I determined that a meaning unit should be moved to a different theme, or a theme or code's label should be revised to reflect better the data it included, these changes were made at this time. During the fifth step of the analysis, I conducted a final refinement of the themes while determining their significance to the research questions. During the sixth and last step of the analysis, I presented results which appear in the results section of this chapter. Discrepant cases are discussed in the results section in relation to the themes from which they were discrepant. Table 1 shows the themes that emerged during data analysis and the number of meaning units included in them (i.e., theme frequency).

Table 1

Data Analysis Themes

Theme	*N* of meaning units included in theme	*%* of meaning units included in theme
Theme 1: The caregiving role is perceived as important and rewarding	51	41%
Theme 2: Challenges associated with caregiving can feel overwhelming	37	30%
Theme 3: Coping with the patient by empathizing and being ready for anything	20	16%
Theme 4: Coping by stepping back	16	13%

Note. A total of 124 meaning units were identified during open coding.

Evidence of Trustworthiness

The trustworthiness of a study's results is enhanced by strengthening the four elements of trustworthiness: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Each of these elements and the procedures used to strengthen them are described in the following subsections.

Credibility

The findings in a study are credible if they accurately represent the reality they are intended to describe (Lincoln & Guba, 1985). To enhance the credibility of the study's results, I assured participants that their identities would remain confidential to encourage their honesty. Processes regarding data collection interviews were explained to participants and in return, explanations were requested from participants to confirm their understanding of the steps of the interview process. Participants were also notified that, if warranted, they were not required to continue with the study and could stop at any time. This enhanced credibility and reduced any pressure they may have felt in continuing with the study. Additionally, I checked interview transcripts and preliminary interpretations.

Transferability

The findings from a study are transferable to the extent that they would hold true in a different research context (Lincoln & Guba, 1985). Transferability must be assessed by future researchers because the present researcher is unaware of the specific circumstances in which future researchers might attempt to transfer results (Lincoln & Guba, 1985). To allow future researchers to assess transferability, I have provided detailed descriptions of the study population and research context so readers may evaluate whether these results are likely to hold true for other populations or in other settings. I also provided detailed descriptions of the data collection methods.

Dependability

The findings in a study are dependable to the extent that they can be reproduced in the same research context at a different time (Lincoln & Guba, 1985). I enhanced the dependability of the study's results by providing detailed descriptions of the data collection and data analysis procedures I employed. I also reviewed and compared other published and peer-reviewed resources from researchers who were versed in the psychological influences of rendering care to individuals diagnosed with chronic diseases such as dementia.

Confirmability

Confirmability is the extent to which a study's results are determined by the experiences and perceptions of the participants, rather than characteristics of the researcher (Lincoln & Guba, 1985). To enhance the confirmability of this study's results, I provided in-depth methodological descriptions of the research design to allow the integrity of the procedures to be assessed. Additionally, I made use of a personal journal to reflect thoughts and avoid personal bias towards participants' coping methods when rendering care to persons diagnosed with stage-4 dementia.

Results

This presentation of the results of the data analysis is organized by the research question, and within the research question by theme. Results associated with RQ1 indicated the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients. For RQ2, results indicated the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients. Discussion of the themes includes discussion of the open codes that were grouped into them, as well as evidence in the form of quotations from the data.

RQ1

RQ1: What are the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients? Two themes emerged to answer the research question. Theme frequencies are indicated in Table 1.

Theme 1: The caregiving role is perceived as valuable and rewarding. Participants indicated that, even when they were experiencing stress in working with stage-4 dementia patients, they encountered and regarded their caregiving role as important and rewarding. Three open codes were grouped to form this theme. Table 2 indicates the codes that were grouped to form this theme, as well as the number of participants who contributed to them. The following discussion includes an explanation of and evidence for each code.

Table 2

Theme 1 - Contributing Codes

Open code (from step 2 of data analysis)	Number of participants contributing data to code (*n*=13)
Relationships with patients are perceived as rewarding	13
Meeting patient needs is perceived as rewarding	12
The caregiving role is perceived as important	12

Relationships with patients are perceived as rewarding. Thirteen out of 13 participants indicated that, even when they were experiencing stress related to caring for patients with stage-4 dementia, they perceived the caregiving role as rewarding in part because their relationships with the patients were experienced as rewarding. No participants were discrepant cases who indicated that relationships with patients were not rewarding. Participants tended to characterize their relationships with patients as family-like. Participant 5 stated, “I treat [my patients] as my own family members because most of them, they are like my grandparents, my grand mom, so I treat them like family, family members, yeah, and I'm always happy working with them.” Participant 8 said, “I feel happy [when working with patients]. I like to go and take care of my father and my family, and my father suffer the same dementia. I feel happy together.” Participant 4 said, “I care for [my patients] like my own parents.”

Participants indicated that these close relationships with patients were part of what made the caregiving role rewarding, even when it was stressful. Participant 6 said caregiving was rewarding because “My relationship [with patients] is excellent. I don’t just love my patients, but I love what I do, and that the point that I can make a difference at the end of the day makes me happy.” Participant 11 said that having close relationships with patients was rewarding because, “Well, you see these people. They need some help, and at the end of the day, when you see that you helped someone, you feel fulfilled that that person that needs you, you accommodate what they needed.” Asked to characterize her experience of her relationship with patients, Participant 11 repeated the word, “Fulfilling.” Participant 7 said that working with patients was rewarding because “You become attached to [patients] and make [caregiving] personal.” Participant 12 described the rewarding outcome of a relationship with a patient:

> I have to say when this patient, she couldn't say words good, and one day, I walk into work, and she took my hand and said my name. She said that she loved me, and she told me how much she appreciate me and that I take good care of her, and she never said nothing to me after that.

Meeting patient needs is perceived as rewarding. Twelve out of 13 participants indicated that when they were experiencing stress related to caring for patients with stage-4 dementia, they perceived the caregiving role as rewarding, in part because meeting patient needs was experienced as rewarding. No participants were discrepant cases who indicated that meeting patient needs was not rewarding. Participant 11 stated that caregiving was rewarding because, “at the end of the day, you feel happy to make a difference.” Participant 3 alluded to the identification of patients with the caregiver’s own family members in stating that caregiving was rewarding in part because it entailed, “Knowing that you are caring for someone and know one day it can be you or your family later in life.” Participant 6 felt fulfilled in caregiving in part because, “At the end of my shift, I feel as though I made a difference, and I gave my time to care for someone that was in need of me.”

For Participant 13, the most rewarding aspect of the job was seeing the difference that caregiving made in the capabilities of the patient:

> I believe the most rewarding aspect is the outcome of the care that is given, the moments when a patient tries to do something independently. That shows you that you're doing your job, making them comfortable in their own situation.

Five participants reported that they felt they had made a difference when they received expressions of gratitude from patients. Participant 7 felt rewarded for making a difference, "By [patients] saying, 'Thank you,' for helping them." Participant 8 reported that she felt rewarded for making a difference, "When [patients] call me by name, [and] I think that they remember me, what I do to care [for] them." Participant 8 reported that this acknowledgment from patients made her feel, "Happy," despite the stresses of caregiving.

The caregiving role is perceived as important. Closely related to participants' sense that their caregiving made a difference in their patients' lives was their perception that their caregiving role was important. No participants were discrepant cases who reported that they did not perceive their caregiving role as important. Participant 11 stated, "I would say my role is very important," while Participant 8 said, "My role is very important for [patients] and for me." Participant 13 expressed a perception that not everyone was capable of effective caregiving: "My role is very special to do. Not all people can take on this role. I believe you have to have a heart for it and the patients, so most people aren't built to be a caregiver."

For Participant 10, the perception that the caregiving role was important was associated with the perception of its importance to patients: "most of our patients, they need our help in order to perform their act of daily living, so we try the best that we can." Participant 2 associated the importance of the caregiving role with the physical consequences that would affect patients if the role were neglected: “My role is important. I have to wash [patients] to avoid redness and a skin ulcer.” Participant 5 described some necessary services with which the caregiving role was associated:

> I know my role is providing direct care and making sure that all of [the patients’] needs are accomplished. That is my role because I give direct care to the patient, so I make sure that everything that he need at end of the day, if they want to use the bathroom, if they want to eat, anything that they want to do, I make sure by the end of my shift, I do it for them, and I make sure that they feel comfortable with the outcome.

Participant 6 spoke in similar terms but added “being there for” patients to the list of important services provided by caregivers: “My role is to make sure [patients’] daily activities are met: bathing, feeding and being compassionate, and just being there for them.”

Theme 2: Challenges associated with caregiving can feel overwhelming. Participants indicated that they experienced significant challenges when providing care to stage-4 dementia patients and that these challenges could cause stress that felt overwhelming at times. Two open codes were grouped to form this theme. Table 3 indicates the codes that were grouped together to create this theme, as well as the number of participants who contributed to them. The following discussion includes an explanation of and evidence for each code.

Table 3

Theme 2 - Contributing Codes

Open code (from step 2 of data analysis)	Number of participants contributing data to code (*n*=13)
Caregiving involves significant challenges	13
Stress from challenges can feel overwhelming	13 (including one discrepant case)

Caregiving involves significant challenges. Thirteen out of 13 participants reported that they experienced significant challenges when providing care for stage-4 dementia patients. No participants were discrepant cases who reported that they did not encounter significant challenges as caregivers. Participants reported that the most significant challenges they had experienced in their caregiving role were patients' violence and aggression, and patients' passive resistance to receiving help. Six out of 13 participants reported that patients' aggressive and violent behaviors were the greatest challenge they experienced. Participant 4 said of the challenges of caregiving, "The most challenging is being punched or hit." Participant 6 offered a similar response, saying, "the most challenging is when [patients are] violent. That's a very most challenging besides everything else, the violence, yes." Participant 7 said, "The most challenging is being able to deal with a person that's combative: the spitting, the anger." Participant 13 acknowledged that stage-4 dementia patients had little control over their aggressive behaviors, saying, "A patient that has dementia tends to behave in ways they have no control of, like they can be combative sometimes."

Seven out of 13 participants reported that the most significant challenge associated with caregiving was patients' passive resistance to being helped. Participant 12 said the greatest challenge of the caregiving role was, "Sometimes [patients] don’t want you to touch them. They resist you because they look at you as a stranger or somebody trying to hurt them.” Participant 5 described a common scenario in which a patient’s resistance to help was perceived as stressful and a challenge:

> It's very challenging, the most challenging aspect of it 'cause when you trying to help somebody, you know that they are wet. Their diaper needs to be changed, but they said, “No,” and you feel bad that you’re leaving them. You’re leaving them wet, but they are the one. If they say, “No,” you can’t force them. So, if that happens, you have to go and come back and see whether they would change their mind.

Participant 1 noted that patients’ passive resistance to help sometimes seemed completely involuntary, as if the patient had lost the ability to cooperate: “The most challenging part is when [patients] lose their ability to follow instructions.”

Stress from challenges can feel overwhelming. Twelve out of 13 participants reported that stress associated with the challenges of caring for stage-4 dementia patients could sometimes feel overwhelming. One participant was a discrepant case who claimed not to experience stress, saying, “I do this every day, so I don’t take it personal. I don’t experience a stress” (Participant 2). Notable in Participant 2’s response was the implication that stress associated with caregiving challenges was a result of “taking personally” the resistant or violent behaviors of patients; however, other participants who reported that they experienced stress indicated a full understanding that stage-4 dementia patients had limited rational behavioral control, suggesting that they did not take patient resistance or violence personally, either. Participant 7 was a partially discrepant case who said during the interview, “I really don’t get stress because I pray. That what’s keeping me from being stressed.” At a different point during the interview, however, she said, “It’s overwhelming.”

Participant 8 reported experiencing headaches because of stress associated with caregiving, stating, “I had stress. I had a [recurring] headache that go for a few minutes, [then I] sit down, and [it goes] away for a few minutes.” Participant 13 said of the overall experience of caregiving, “Overall, I felt overwhelmed sometimes and tired mentally.” Participant 1 said of the experience of caregiving, “I am usually stressed out . . . Honestly I think it started affecting my mood.” Participant 10 described the stress of caregiving as inevitable and perpetual but expressed determination to overcome it: “There are always going to be stressful situations, but you just got to manage it.” Participant 4 said of caring for stage-4 dementia patients, “It's very stressful,” and then laughed, apparently to relieve the strong feelings the response evoked.

RQ2

RQ2: What are the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients? Two themes emerged during data analysis to answer the research question. Theme frequencies are indicated in Table 1.

Theme 3: Coping with the patient by empathizing and being ready for anything. Participants indicated that they coped with the stress of caring for stage-4 dementia patients in part by coping with the patient and that coping with the patient involved empathizing and being ready for anything. Two open codes were grouped together to form this theme. Table 4 indicates the codes that were grouped together to form this theme, as well as the number of participants who contributed to them.

Table 4

Theme 3 - Contributing Codes

Open code (from step 2 of data analysis)	Number of participants contributing data to code (*n*=13)
Coping with the patient by empathizing	7
Coping with the patient by being ready for anything	6

Coping with the patient by empathizing. Seven out of 13 participants reported that they coped with their own stress in part by coping with the patient and that they coped with the patient by empathizing with the patient. Empathizing with the patient served two purposes for the participants: it allowed participants to alleviate their own stress by gaining the cooperation of challenging patients, and it allowed participants to relieve their personal stress by grounding them in a perspective of nurturance when patients were aggressive or resistant. Participant 5 said that an important skill for gaining patients' cooperation was to understand the patient's needs: "have patience and understand what the patient needs, because sometimes they just don't want to be where they are now, so you just have to calm down, know how to talk to them, and always give them privacy." Participant 3 also spoke of understanding patients in terms of knowing their needs in order to calm them down, saying an important coping skill was, "knowing what the patient needs to calm him or her down."

Three participants spoke of empathizing with the patient as a way to bring out their own capacity for providing nurturance, such that their own stress was alleviated not by any improvement in the patient's behavior, but by their own feeling of care for the patient. Participant 4 said that when experiencing stress due to patients' behaviors, "I put myself [in the patient's place], so I cope with them like myself. You would never know what will happen to you in future." Participant 5 used empathy to become more patient:

> If I am understanding and being patient with the people on stage-4 dementia, you have to understand them, and you have to know that they are grown-up people, and they are not happy where they are, so when you're working with them, you need to understand them, and you have to have patient with them when dealing with them. While Participant 6 said, "I cope with compassion . . . Sometimes I do question myself, like if I was in this position, would anyone be here for me to get me through this the way I'm here for others?"

Coping with the patient by being ready for anything. Six out of 13 participants reported that they coped with their own stress in part by coping with patients, and that they coped with patients by being ready for anything. Participant 10 stated, "You never know what to expect, so you always have to be ready for anything. . . . You always have to be alert." Participant 7 stated that it was necessary to be ready for anything because, "I have a lot of experience, [but] everything is different [from day to day]. Nothing's the same." For Participant 11, being ready for anything meant, "To be calm and follow what [the patients] need," because patient needs changed from moment to moment. Participant 13 indicated that being ready for anything also meant being ready to cope when there was no way to gain the patient's cooperation or make him or her comfortable, stating, "I try my best to help, but sometimes when there's no solution, there's not much I can do, but trying my best is the only thing that keeps me comfortable with my patient. I try to make them as comfortable as I can."

Theme 4: Coping by stepping back. Participants indicated that they coped with the stress of caring for stage-4 dementia patients in part by stepping back from stressful situations, such as by taking a short break, praying, or calling on a friend to vent. Two open codes were grouped together to form this theme. Table 5 indicates the codes that were grouped together to form this theme, as well as the number of participants who contributed to them.

Table 5

Theme 4 - Contributing Codes

Open code (from step 2 of data analysis)	Number of participants contributing data to code (*n*=13)
Coping by "taking a breather", or physical withdrawal	11
Coping through mental withdrawal	5

Coping by physical withdrawal. Eleven out of 13 participants reported that they coped with the stress of caring for stage-4 dementia patients in part by taking a breather or a short break when they began to feel overwhelmed. Taking a breather always involved the caregivers physically removing him or herself from the vicinity of the stress trigger. Participant 1, for example, said, "I would just leave [patients] alone if they become violent, and go back afterwards." For Participant 11, taking a breather meant, "Walk away, maybe drink some water, and then come back." Participant 5 also mentioned getting a drink of water, saying that when caregiving became too stressful, "I take a break, go over to the break room, get water to drink, sit down for a little minute, and go back later. . . Just drink a glass of water or maybe eat something just to take my mind from that." Notable in Participant 5's response was the sense that physically removing oneself from the vicinity of the stress trigger and engaging in an unrelated self-care activity allowed the caregiver to reset and gain perspective on the stressful situation. Participant 7, instead of getting a drink of water, sought privacy and then engaged in prayer: “I go off to myself for a minute, take a break, and I pray.”

Coping through mental withdrawal. Five out of 13 participants reported that they coped with the stress of caring for stage-4 dementia patients in part by briefly, mentally withdrawing from the immediate cause of stress. This coping strategy was different from taking a breather because it involved physically remaining with the stress trigger; the withdrawal was solely mental and could consist of praying or thinking about something other than the stress trigger. Participant 9 said that to cope with stress, “I close my eyes and say to myself, “Relax”.” Participant 4 thought of something other than the stress trigger: “I'm thinking [of something else] in my mind so that I won’t pay no attention to what [the patients] are doing.” Participant 7 said, “I have to pray for strength,” and Participant 12 also spoke of preparing for stressful situations by praying: “I always pray before tending to them because for God for helping them ‘cause it’s challenging.”

Chapter 5: Conclusion

Introduction

The purpose of this study was to examine the stress experienced by caregivers of patients diagnosed with stage-4 dementia. A caregiver who provides comfort to people diagnosed with geriatric dementia is more susceptible to experiencing stress in their daily lives. As such, appropriate coping and management mechanisms are needed to reduce stress and improve patient care.

This study specifically focused on the lived experiences and perceptions of caregivers when dealing with stress related to their care of stage-4 dementia patients. Additionally, this study sought to determine which coping methods were used by caregivers and whether they were effective in working with stage-4 dementia patients. Caregiver stress is a significant issue in that it not only affects the personal health of caregivers, but also makes it difficult for caregivers to provide quality care for persons with stage-4 dementia. Stress in caregivers may have long-lasting effects in that they will have to deal with issues such as caregiver burnout that may prevent patients from receiving optimal care.

Caregivers who relied on coping mechanisms improved their stress management and the quality of care that they provided to their patients. It is likely that the coping strategies used by caregivers were able to provide mental benefits that helped them manage their stress levels. Self-care plays a significant role in caregiver health because often a caregiver does not have time to devote to themselves based on work-related demands and the functional ability of the dementia patient. If a dementia patient solely relies on their caregiver for basic daily living functions or activities of dialing living, the caregiver will have increased stress and burden. This increased stress and burden are often compounded when the caregiver no longer has time to do small tasks such as take a short break or read the newspaper. The lack of caregiver self-care activities meant to refresh the caregiver implies that the building or pent up stress never has a chance for release. This will trigger health decompensation.

This inability to take advantage of self-care activities and refresh can lead to burnout among caregivers of persons with dementia. Another reason that burnout can occur in caregivers involves the level of attachment that a care recipient and caregiver may have with each other. Unreasonable attachments between the care recipient and the caregiver influences burnout because the care recipient becomes so reliant on the caregiver that the caregiver may not be able to have respite breaks for clarity or to refresh their mental and psychological abilities.

The ability of patients to complete daily living tasks can predict caregiver stress. The more reliant a patient is on caregivers for daily living activities, the more this will not only affect the caregiver's emotional and mental health but can also affect physical health. Caregiver stress is interwoven with the challenging behaviors that a stage-4 dementia patient may exhibit. The best way for caregivers to manage the stress of caring for dementia patients is to implement interventions that will deal with behavioral issues and possibly eliminate the stress associated with these issues.

Researchers also determined that caregivers attain intrinsic value in sharing experiences regarding stressors in caregiving with other caregivers to identify processes used to eliminate or alleviate stress. The knowledge that caregivers shared with others regarding coping mechanisms to reduce stress and maintain their health while caring for stage-4 dementia patients was regarded as meaningful. The interactions with others provided caregivers with insights and mechanisms that may be implemented for their situation. It was common for caregivers to feel resentment or guilt about their circumstances. The community process of sharing experiences with others helped them find comfort and solutions to meeting some of the challenges involving caring for stage-4 dementia patients. The sharing of experiences provided an outlet for caregivers to understand that others were going through similar situations and they were not alone.

The key findings from this study were that the social implications of caregiving for stage-4 dementia patients were twofold. First, adverse effects existed for patients in terms of the quality of care when caregivers were stressed or overburdened. Adverse effects may include delayed response times from caregivers to patients, caregiver malfeasance and reduced bedside manner. Secondly, patients' care often deteriorated because of the unaccommodating behaviors that caregivers sometimes displayed. When patients' health deteriorated due to dementia progression and the caregivers were stressed, overall patient care was negatively impacted.

The lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients showed that these patients can be challenging. The most identified challenging behavior of patients was physical combativeness. There was a theme amongst participants that dealing with patients who were prone to hitting or kicking could make their work more challenging because more time is spent on maintaining a safe work environment. Another common theme amongst participants was that patients could become verbally combative when they did not want to be touched or want the caregiver in their personal space. When these events occurred, participants had different ways of dealing with the problem. For instance, some of the participants would give the patients time to themselves, while others would try to engage patients and talk to them. It was particularly challenging because the caregivers also had to guarantee patients' safety.

The coping methods used by caregivers when experiencing stress working with stage-4 dementia patients are to take a break, take deep breaths, mentally distract, and pray. Each of the coping methods reported by the participants had a commonality in that each of them required caregivers to focus their thinking on something else when the stress began to appear. Through taking a break, mental distractions, deep breaths, or praying, caregivers were forced to focus on something other than the patient to reframe their thinking and manage stress.

Summary

Two research questions were used to guide this study. The first research question was: What are the lived experiences and perceptions of caregivers when experiencing stress working with stage-4 dementia patients? Findings indicated that caregivers perceive the caregiving role as rewarding and important even when they are experiencing stress related to it, but that the stress associated with the challenges of caregiving (for example, patients' violent or passive resistance) could sometimes feel overwhelming. The second research question was: What are the coping methods used by caregivers when experiencing stress working with stage-4 dementia patients? Findings indicated that caregivers cope with their own stress in part by coping with challenging patients, through empathizing and being ready for anything. Results further showed that caregivers cope with stress in part by briefly withdrawing from the stress trigger, either physically or mentally.

Interpretation of the Findings

The findings confirm that caring for stage-4 dementia patients is stressful. Each of the participants reported multiple situations in which they became stressed while performing their caregiving activities. Caregivers of stage-4 dementia patients are often required to deal with verbal and physical abuse. Some of the participants reported that, once they became familiar with their patient, they were better able to anticipate when the stressful behavior would occur and place interventions in their routine to minimize challenging behavior. However, there was also a theme amongst participants that some days for patients were better than others and that was just a fact of life.

While confirming the challenges of caregiving for stage-4 dementia patients, the participants also revealed that it was necessary to have coping strategies in place to deal with challenging behaviors. The participants discussed that incidents occurred with the dementia patients that could regularly test their patience or stress levels. As the participants reiterated, in these moments, it was important to be able to take a step back and reframe the situation.

In examining this problem through the expectancy theory, the issue of caregiver stress and burden arose. Research showed that caregivers of stage-4 dementia patients exhibited an increased level of psychological stress, which made them more susceptible to psychiatric diseases and other deteriorating health concerns. This finding emphasized the need for caregivers to have coping mechanisms and other strategies available to them to stave off the negative side effects often attributed to caregivers of dementia patients.

Limitations of the Study

Limitations in the study were related to the fact that many of the participants were paid caregivers. While the literature review demonstrated that most caregivers dealt with stress when providing care to stage-4 dementia patients, the research did not have many discussions on the stress experienced by familial caregivers. Although individual income and educational levels may play a role in coping outcomes, it is possible that the stress experienced by familial caregivers may differ from that of paid caregivers. Additionally, it is possible that familial caregivers may undertake different coping mechanisms for stress management associated with their caregiving.

Recommendations

The study revealed that many of the interviewed caregivers felt fulfillment in the care that they were providing to their stage-4 dementia patients. Further research could focus on whether the sense of fulfillment influenced a caregiver’s ability to manage stress. This study revealed that many paid caregivers were able to separate the actions of stage-4 dementia patients and their meaning because of their understanding of the patient’s illness. In other words, the caregivers interviewed for this study were not personally harmed by the reactions of the patients because they knew that it was something that the patient could not control. However, it is unclear if this would be a similar finding in a study that focused on familial caregivers. In those cases, it is more likely that the caregiver may take the actions of the stage-4 dementia patients as a personal affront based on their extended relationship with the patient.

Implications

Positive Social Change

There is a potential impact for positive social change at the individual, family and organizational level. On the individual level, the positive change that can be accomplished is that caregivers will have a better understanding of how their stress management affects the quality of care provided to patients. Once caregivers understand the connection between their ability to effectively manage stress and the care provided to the patient, it is likely that caregivers will put more emphasis on self-care and coping strategies. At the family level, this research has potential impact for positive social change because the family of caregivers will have higher satisfactory levels or respite if their loved one is receiving optimal care. At an organizational level, this study provides insight into the stress levels that caregivers experience when caring for stage-4 dementia patients. This insight is useful because it can spur communities and other organizations to create support systems and activities for caregivers of stage-4 dementia patients. Also, by having coping strategies in place to manage stress, organizations may be better placed to reduce staff turn-over due to employee resignations as a result of challenging behaviors that affect caregivers. This could make economic sense for the management teams of organizations.

The implications for social change are that caregivers can anticipate increased stress levels and proactively try to mitigate them. Past research focused on the health of the patients and the effects that a patient may experience depending on their caregiver. This was a strong focus and observation. However, this research prompted many questions about caregiver health and identified the ways that a caregiver's stress levels, and health may affect the patient. With this understanding, it is obvious that there should be more emphasis on caregiver health to ensure optimal outcomes for the patient and to make sure that the caregiver is living a healthy lifestyle.

Recommendations for practice include making sure that the caregiver understands that stress is common for individuals that provide care to stage-4 dementia patients. Caregivers of stage-4 dementia patients may feel alone in the stress and burden that they are experiencing. For this reason, it will be important that a community for caregivers is cultivated to ensure that they have a way to talk about their perceptions and experiences and not feel isolated. Another recommendation is to make sure that the caregiver has an outlet for stress to ensure that the caregiver has appropriate coping mechanisms. This research proved that coping strategies are needed for caregivers of stage-4 dementia patients. During the caregiving, it seemed customary that stressful situations arose and the primary way that caregivers were able to rise above the stress levels and maintain clarity was to utilize their coping mechanisms.

Conclusion

Caregiver stress can and does impact the care of the stage-4 dementia patient. It is important that caregivers have mechanisms or interventions in place to help them manage stress associated with the care provided to these patients. The challenges manifested by patients suffering from dementia is individualized and based on the stage of the disease, the utilized coping strategies of each caregiver is also specific and failure to have coping strategies in place will result in declined care being delivered to the stage-4 dementia patient at a time when the highest level of care is needed. A caregiver should be informed and aware of the individual triggers that can cause stressors or stressful reactions and attempt to avoid those when possible. Additionally, it is important that caregivers reach out to their caregiving community and share their experiences with others. Not only can the shared perspective afford others knowledge of interventions to use when rendering care without being stressed, this outlet can provide a meaningful focus of comfort to the caregiver.

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Appendix A: Letter to Public Affairs Officer

Date: 10/24/2017

Name of PAO
Address

Dear (Name),

My name is xxxx, and I am a doctoral candidate at Walden University. I am conducting dissertation research on the coping methods of caregivers dealing with patients suffering from geriatric dementia. There are several studies on burn-out and individual coping strategies that detail effective and ineffective interventions by paid caregivers. What is not known, however, are the magnitude of stress that is experienced by caregivers while rendering care due to challenging behaviors exhibited by the patient diagnosed with dementia. This research through caregivers' shared experience will provide insight into lived experiences of caregivers and the strategies each utilizes to render care without experiencing burn-out.

Your assistance is needed in conducting this important research. If you are willing, I will request that you identify caregivers that experience stress that causes burn-out while care is being given to patients diagnosed with dementia, and unable to independently manage their activities of daily living. Identification of caregivers will allow an opportunity to contact and inform them of this study. Once identified, I would appreciate meeting them to discuss the nature of this study. The participants of this study must be paid caregivers of patients diagnosed with stage-4 dementia and reside in the nursing home. Information provided by the participants will be kept strictly confidential. The participants are free to choose to participate in the study and can discontinue participation at will, anytime.

I would welcome a telephone call from you to discuss any questions you may have concerning this study and your role in identifying research participants. I can be reached at xxx or emailed at xxx.

Sincerely,
Xxxx
Doctoral Candidate
Walden University

Letter to Participant

Date: 10/24/2017

Name of Participant
Address

Dear (Name),

My name is xxxx, and I am a doctoral candidate at Walden University. I am conducting dissertation research on the coping methods of caregivers dealing with patients suffering from geriatric dementia. There are several studies on burn-out due to stress and individual coping strategies that detail effective and ineffective interventions by paid caregivers. What is not known, however, are the magnitude of stress that is experienced by caregivers while rendering care due to challenging behaviors exhibited by the patient diagnosed with dementia. This research, through caregivers' shared experience, will provide insight into lived experiences of caregivers and the strategies each utilizes to render care without experiencing burn-out.

I am aware that your time is essential and appreciative your willingness to commit time to participating in this study. To get acclimated to the requirements of the study, and to understand your experience, we need to meet once for approximately one hour, to fully understand your experience. The meeting can be held at a location of your choice, and you are not required to do or adhere to anything you are not comfortable with. The meetings are designed to learn from your experiences as the paid caregiver of geriatric individuals diagnosed with stage-4 dementia and to get to know you. Your shared information will be kept confidential

Please contact me at your earliest convenience to schedule a date and time that we can meet. My telephone number is xxxx. You can also email me at xxx. I look forward to hearing from you.

Xxxx
Doctoral Candidate
Walden University

Appendix B: Interview Protocol

Interview Protocol

Date: ____________________________

Location: _________________________

Name of Interviewer:

____

Name of Interviewee:

____

Interview Number: One

- How do you cope with the challenging behaviors exhibited by stage-4 dementia diagnosed patient?
- What are your lived experiences working with Stage-4 dementia patients?
- How do you perceive your experience of stress when caring for a patient with stage-4 dementia?
- What coping methods did you use while experiencing stress working with Stage-4 dementia patients?
- How would you describe your experiences while working with Stage-4 dementia patients?
- Please tell me how you felt working with Stage-4 dementia patients.
- What is the most challenging aspect of rendering care to stage-4 dementia diagnosed patient?
- What is the most rewarding aspect of your role as the paid caregiver to stage-4 dementia diagnosed patient?
- How would you describe your role as a paid caregiver in caring for an individual that relies on you for all activities of daily living?
- How would you describe your relationship with your Stage-4 dementia patients?

Appendix C:

Flyer

A QUALITATIVE RESEARCH STUDY

ON

THE COPING METHODS OF CAREGIVERS DEALING WITH PATIENTS SUFFERING FROM GERIATRIC DEMENTIA

VOLUNTEER CNAs NEEDED

IF YOU ARE INTERESTED IN SHARING HOW TO COPE WHEN YOU DEAL WITH DEMENTIA DIAGNOSED PATIENTS, CONTACT ME.

COMPENSATION: NONE

DURATION: ONE HOUR

DATE: VARIED

TIME: VARIED

CONTACT: Xxxx

Xxxx

Xxxx

Demographics:

- Gender
- Birth Date / Age
- Race / Ethnicity: Black/African American
- Marital Status
- Household Size
- Income
- Number of years worked
- Email
- Phone Number (landline)
- Cellphone Number
- Address