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A Story to Tell among Minority Alzheimer's Patient Caregivers: A Phenomenological Study

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2017

Abstract

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MS, TUI University, 2011

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Abstract

The level of burden experienced by caregivers of patients diagnosed with Alzheimer's disease is high. Studies that examine this burden by taking into account cultural and spiritual differences are limited, particularly with regard to minority populations. The purpose of this study was to investigate the burden and challenges faced by minority caregivers providing in-home care to Alzheimer's patients. Guided by social support theory, a phenomenological study design was used with semi-structured interviews of 12 caregivers to examine their perspectives on the burden and challenges they face, including their lived experiences, cultural and spiritual values, and interaction with health professionals. Thematic analysis in an inductive way was used to analyze the collected qualitative data. The results of the analyses of the collected data showed that cultural and spiritual values are important in making decisions, as caregivers in minority populations face daily challenges in terms of limited social support and resources. The findings of this study suggest that public health interventions aimed at alleviating the burden on Alzheimer's caregivers need to take into account differences in cultural and spiritual values. Findings also show that there is a need for social support programs that reduce the burden on caregivers in general and on the minority population in particular. The findings of this study may drive positive social change by helping public health workers design and implement programs that consider differences in the cultural and spiritual values of minority populations while garnering the resources to provide the needed social support and alleviate the burden faced by the family member caregivers.

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Dedication

I dedicate this dissertation to my grandmother, Ada ‘Madea’ Walker, and my mother Earnestine ‘Cookie’ Gardner. I would like to dedicate my work to the Walker sisters, Bobbie Jean Campbell, Willie Mae Walker, and Fannie Mae Allen. Milagro Gardner this is very much your study as it is mine. Michelle Gousha thank you very much for the love and support. And to my angel in heaven Maria Gousha-Walker I miss and love you very much. Shirley Ann Mourning, Charles Duhon, and Kenneth Thomas thank you very much for the support. I would also like to dedicate my work to those compassionate caregivers for taking the time to provide care with the least amount of support. To all those who participated in this research study, you provided an enormous impact on social change that will benefit the overall diverse community of caregivers and their loved ones. This study in itself became the voice of the minority caregiver seeking to provide a positive outlook on cultural specific awareness for your needs. There is an inspiring dedication and commitment that is instilled in those caring for loved ones no matter the cultural background or influences. Being strong and remain committed to family will always be a part of our cultural values that we hold dear.

Acknowledgments

First and foremost, I would like to give praise and thanks to our Father in heaven. None of this would have been possible without the highest of power. Dr. Gudeta Fufaa, thank you for being you. Your assistance was greatly appreciated. Dr. Joseph Robare, thank you for being the first in accepting to be the chairperson for this study. Dr. Patrick Tschida thank you for being a part of this study and the insight provided. I do not believe it would have been possible without all the members of this dissertation committee. Finally, I would like very much to acknowledge the entire staff of Walden University for making the selection of their school the greatest decision of my life in pursuit of my PhD.

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Chapter 1: Introduction to the Study

Alzheimer's disease places a tremendous economic and social burden on families and society. Providing care for Alzheimer’s patients becomes more overwhelming in the home than in institutional care settings (Cho, 2007). In this study, I describe the unique lived experiences of the minority Alzheimer’s caregiver community and effects of Alzheimer’s patient dependency from a cultural perspective. By employing a qualitative research design with a phenomenological approach, the parameters of the study are to explore the influences of culture within the minority caregiver community. The findings from this study may add meaning to these influences and its impact regarding cultural sensitivity, the burden of caregiving, and minority social support programs. In Chapter 1, I explain the background, the problem and purpose of the study, the research questions, and the conceptual framework, as well as the nature, assumptions, scope, limitations, delimitations, and significance of the study. In the summary of Chapter 1, I provide a transition to the Chapter 2 literature review identifying gaps in research, study focus, and the conceptual framework.

The specifications detailed in each chapter includes revealing the gaps created from the minimal existing research involving the impact of culture influences on minority Alzheimer's caregivers. As such, the objective is to clarify cultural meanings from the perspective of minority caregivers. The expected result is that caregivers will benefit from community-based programs tailored to their needs based on findings from this study.

Background

In 2012, the ethnic minority population in the United States was 37% (116.2 million; U.S. Census Bureau, 2014). By 2060, the ethnic minority population could reach 57% (241.3 million), including an increase in the geriatric ethnic minority population diagnosed with Alzheimer's disease (U.S. Census Bureau, 2014). According to Gurland et al. (1999), health problems, economic issues, and limited access to quality education are reasons for the differences in the risk of developing Alzheimer's disease among various racial groups. Gurland et al. explained that the prevalence of Alzheimer’s cases is considerably higher among African Americans (11%) and Hispanics (12%) than among the geriatric Caucasian population. Because of the minority representation increase, the overall general populace will also be impacted by the economic and social burden of Alzheimer cases (Manly & Mayeux, 2004, 2004). The risk of developing Alzheimer's disease is one of the pressing public health problems at both the national and local levels (Manly & Mayeux, 2004).

The slow progression of Alzheimer's disease impacts an individual's ability to complete simple daily tasks, requiring patients to have around-the-clock caregiver assistance (Elliott, Burgio, & DeCoster, 2010; Fiandaca, Mapstone, Cheema, & Federoff, 2014; Ryan et al., 2010). For many geriatric minority Alzheimer patients of lower socioeconomic status, there is a delay in transitioning to institutional healthcare from home healthcare (Gilligan, Malone, Warholak, & Armstrong, 2012). The culture among diverse communities influences not only the decision to provide community healthcare, but also adversely impacts the physical, mental, and emotional well-being of the caregiver. Regardless of gender, caregivers’ burden of responsibility influenced by the culture is rapidly becoming a critical issue in the long-term care of Alzheimer patients. Furthermore, the increase in ethnic and cultural diversity, in addition to the increase in Alzheimer’s cases among geriatric minority populations demands changes for meeting the cultural needs of the minority caregiver (Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014).

The influences of values and culture reflect the family-patient relationship, making acceptance of confidence in care stress-free, yet, an overwhelming responsibility (Payne, 2015). Therefore, cultural sensitivity and targeted social support program literature addressing the requirement for public health and healthcare professionals will help identify the needs of the minority Alzheimer’s caregiver (Alzheimer's Association, 2015; Alzheimer's Association, 2016). In the coming years, the risk for developing Alzheimer's disease among minorities will increase considerably (Manly & Mayeux, 2004), in addition to the expenses sustained by society; thus, healthcare professionals must understand these identified needs to provide adequate support for the development and implementation of cultural-based community support programs for minorities (Family Caregiver Alliance, 2009). In this study, the intent is to fill the gaps in the literature regarding healthcare professionals’ awareness of the minority caregiver phenomenon of home care for Alzheimer’s patients. I expected that healthcare and public health professionals could use this study to support the needs of minority caregivers, consequently alleviating the challenges and barriers incurred.

Many minority caregivers of Alzheimer's patients deal with various uncertainties because of a lack of preparation and support. Researchers have focused on the possibility of understanding the cultural sensitivity and information awareness which were important in the development of caregiver intervention programs (Brand, O'Connell, & Gallagher, 2015; Holm et al., 2015). While specific research addressing caregivers of Alzheimer’s patients exists, there is a gap in understanding the cultural influences of minority caregivers. The understanding of the minority community from a cultural perspective is vague. Additionally, it is important to know and understand the minority caregivers' views on strategies for preparation and knowledge from a cultural viewpoint. Even though there is ample literature on caregiving and support for the caregiver, more research on cultural influences among the minority caregiving community would provide public health professionals the understanding to develop community-based social support programs tailored to minorities. To be specific, understanding the diverse culture of the minority community and the lived experiences of caregivers will allow public health professionals to better understand the influences of culture that are vital for the minority caregiver.

Problem Statement

Compared to the general caregiver population, minority caregivers face unique challenges often influenced by cultural and spiritual beliefs (Corcoran, 2011). Because of the cultural influences, minority caregivers are confronted with a heavier burden of care and stress, ultimately impacting their overall health and the care of the recipient (García-Alberca, Lara, & Berthier, 2011; Mitnick, Leffler, & Hood, 2010). The challenges minority caregivers face and the costs to society will continue to increase as the expected incidence rate of Alzheimer's disease among geriatric minorities grows by 2060 (U.S. Census Bureau, 2014). Inadequate community social support programs and plans will create greater costs to society unless solutions are realized sooner rather than later.

While the research on the general caregiver population is abundant, the research is minimal on the cultural aspect of the minority caregiver. Cho, Ory, and Stevens (2015) concluded that society should act by supporting minority communities with community-based programs and public health policy initiatives. Without social action, they contended, the overwhelming financial hardships will continue to increase. While the research on the caregiver role has secondary literature, there were minimal research findings available about the cultural lived experience of minority caregivers. The minority caregiver voice can help provide effective intervention methods by public health advocates. The findings from this study could be the voice of the minority caregiver to help public health workers develop and implement effective community-based social support programs, possibly even for the general caregiver population.

Purpose of the Study

The purpose of this study was to explore the shared lived experiences and cultural beliefs of minority caregivers who provide care for Alzheimer's patients. Healthcare resources in formal settings are not a significant support option for minority caregivers, hence the need for enhancing culture-specific community-based programs. In this study, I explored the themes surrounding the shared and lived experiences of the sample population in order to provide a cultural perspective that could improve the caregiving process for minorities.

Research Questions

The results of this study relied on the responses to the following research questions:

RQ1: What are the lived experiences of family members of minority Alzheimer's patients as caregivers?

RQ2: What cultural beliefs or spiritual beliefs have influenced the experiences of minority caregivers?

RQ3: How does knowledge, socioeconomic status, or perception justify the disparity in the minority caregiver's willingness to obtain healthcare for caregiver burden?

Conceptual Framework

For this study, a conceptual framework provided the continuance for further exploration of the shared and lived experiences of minority caregivers for Alzheimer patients. Social support is an important motivational tool linking empirical data from shared and lived experiences that increases coping mechanisms and supportive behaviors (Barling et al., 1988). Barling, MacEwen, and Pratt (1988) research based on the social support theory incorporated behavioral health changes significantly the incorporation in health promotion intervention which utilized one of four forms of support: emotional, informational, instrumental, and appraisal.

Emotional support a form of support is an informal representation of nurturance and empathy caregiver receive from loved ones or close friends. Informational support is also informal social support from the minority caregiver’s close social network. Instrumental support signifies tangible assistance such respite care or financial services, allowing the caregiver time away from personal care. Appraisal support is continuous information for ongoing support in stressful situations. These four concepts of the social support theory act as buffers with the intent of generalized interaction and sharing of coping strategies for a common stressful phenomenon (Barling et al., 1988). The vision for using the social support model is to help illustrate supportive connections between minority caregivers and efficient community-based social support programs.

Nature of the Study

A qualitative method using a phenomenological design was appropriate for studying the lived experiences and capturing the voices of the minority caregivers from a cultural perspective. Given the nature of this research study the findings focused on cultural awareness and understanding of minority caregivers caring for Alzheimer care recipients living in the home. The completed findings from this study will be shared with public health professionals and the community.

In this study, I focused on the general cultural lived experiences and understanding from a minority perspective about caregiving for patients diagnosed with Alzheimer's disease. The information I gathered is valuable for understanding the role of differences in cultural values and providing social support intervention for Alzheimer's disease patients by minority family caregivers, for example, how cultural values hinder or enhance caregiving for the caregiver and the recipient. The study also included findings and understanding of the various cultural values and attitudes of the minority caregiver toward the lack of formal and informal social support enabling prolonged community care versus institutional care (Cho, 2007).

Definition of Terms

The following definitions provide a clear interpretation of the main words and concepts used throughout the development of this qualitative phenomenological study:

Alzheimer's disease: A common form of dementia, a progressively slow terminal illness in which the healthy brain cells become slowly damaged as the disease progresses, eventually impairing the functions of memory, recognition, speech, the ability to complete daily tasks ultimately ending in death (Fiandaca et al., 2014; Ganguli et al., 2011). As an official cause of disability and ill health, Alzheimer’s disease is also the leader in morbidity cases among minorities age 65 and older (Barnes et al., 2011). While the primary goal of this study is to address the needs of the minority caregiver based on the lived cultural experience, it is also important to provide an understanding of Alzheimer's disease.

Caregiver burden: The effects of caring for an individual with a terminal illness or disability can equally impact the caregiver and the recipient of their care. Because of the influences of ethnicity and culture, it is important to understand the impact of the tremendous burden of care in the role of minority caregiving (Aranda & Knight, 1997).

Cultural sensitivity: The heightened awareness and response of public health professionals' to the minority caregiver's ethnic background through observation and questions about the importance of caregiving. This awareness substantiates the health professional's ability to understand and respond to verbal and nonverbal cultural indications. Even though the research was considerable to support the variances of ethnicity, race, and culture, there were existing gaps regarding appropriate psychosocial interventions culturally suitable for those diverse communities (Napoles, Chadiha, Eversley, & Moreno-John, 2010).

Minority Alzheimer's caregivers: Cultural norm for adult minority females and males accepting caregiving responsibility of loved ones diagnosed with Alzheimer's disease. For many minority caregivers, this type of attention is a cultural experience without compensation for the daily care and assistance provided to the patient (Pharr, Dodge Francis, Terry, & Clark, 2014). Conversely, the use of formal support is less likely to happen among minorities than among the general population of caregivers (Pharr et al., 2014). There is a common link between cultures and negative health effects, which put the individual at a greater risk of becoming a second patient (Pharr et al., 2014).

Phenomenological study: The objective exploration and explanation of a lived experience of a phenomenon, which are essential to the historical data for analysis, free from bias, for the benefit of providing the reader with an accurate description and understanding of the phenomenon (Bradbury-Jones, Irvine, & Sambrook, 2010). The attempt is not to develop a theory, rather to collect data from the details of lived experiences highlighting the individual experiences (Schumacher, 2010).

Social support services: Services or programs enacted and established in support of the informal caregiver of chronically ill persons (Administration for Community Living [ACL], n.d.). There are a variety of services or programs offered in the form of community-based forums, such as skills enhancement training, respite care, stress management theory, individual counseling, and web-based social support systems (Barber, 2013).

Assumptions

The assumption fundamental to the framework of this study is essential for keeping the study on track. In an effort critical to the premise of this phenomenological study, the subjective responses are an accurate joint account of the cultural perspective of caring for Alzheimer's patients living in the community. Additionally, there is the co-existence between the caregiver and patient (Johnson, 2013). This research study is focused on the minority caregiver as both provider and secondary patient before healthcare professionals can assume this individual is capable and knowledgeable of providing competent care without causing harm to themselves or the care recipient. These findings are critical to the experience of minority caregivers as a giver of care to patients with Alzheimer's disease.

Scope, Delimitations, and Limitations

Scope

The problems addressed in this study are associated with insufficient culture-based support programs for minority caregivers of persons diagnosed with Alzheimer's disease. The reason I selected this target population group was that inadequate health maintenance for the minority caregiver poses a risk to the care of recipient. Adult minority caregivers are greatly impacted by cultural influences unbeknownst to the personal health risks and risks to the patient. For that reason, community-based social support programs tailored for culturally diverse populations has become critical. With the increase of Alzheimer's disease and delay in institutional care, society will absorb the rising healthcare costs for both the caregiver and recipient.

Delimitations

In this qualitative phenomenological study, I explored themes from the responses given by the minority caregivers. The data in their responses are specific to the culture of minority caregivers of Alzheimer patients living in Louisiana. The findings from this dissertation, therefore, do not represent the general caregiver population in Louisiana or elsewhere in the United States.

Limitations

For this study, I collected data from the northwest region of Louisiana Alzheimer's minority community database. The population of minority caregivers in Louisiana is predominately underrepresented in urban areas of the state. Furthermore, the accuracy of lived experiences of the caregiving process of family members living with Alzheimer's requires the elimination of personal bias (Walden University, 2013). Thus, the selection of the conceptual framework is sufficient for addressing the different limitations of this study.

Significance of the Study

Although diverse minority groups are becoming the majority in the United States, disparities of care still exist (U.S. Census Bureau, 2014). According to Napier et al. (2014), a majority of healthcare professionals require training and skills to comprehend the influences of culture to communicate with diverse populations effectively. Adult minority caregivers are informal caregivers from lower socioeconomic, demographic backgrounds. As a result, these individuals face the risk of greater caregiver burden and the associated disproportionate health consequences for themselves and the patient.

In this study, I sought to fill the gaps in literature based on the shared lived experiences and cultural influences of the minority caregivers. My expectation in conducting this research was that I could provide awareness to healthcare professionals about cultural sensitivity and cultural tailoring of support programs and supplementing expenses for developing programs to assist minority caregivers.

Caregiver programs tailored for minority community groups have shown minimal specific information on cultural enhancement. Some adult minority caregivers discovered the ideal community-based programs tailored for minorities were difficult to follow (Napier et al., 2014; Piraino, 2012). Given the increase in minority Alzheimer's cases by 2060, developing culturally specific community-based social support programs will become a critical necessity (U.S. Census Bureau, 2014). As the number of Alzheimer cases among minorities continues to increase (McGuire, Grant, and Park, 2012; U.S. Census Bureau, 2014), the findings of this study could bolster community-based social support programs tailored to this community.

Summary

By 2060, society will experience a decrease in the availability of minority caregivers to care for the unparalleled increase in the number and diversity of Alzheimer's patients, negatively impacting the U.S. economy (Office of the Assistant Secretary for Planning and Evaluation, 2013). The development of culturally sensitive community-based programs supporting minority caregivers with skills enhancement and respite programs could alleviate the economic impact and burden of care provided to Alzheimer patients (Office of the Assistant Secretary for Planning and Evaluation, 2013). Accurate information based on data from this qualitative research phenomenological study is essential for the effective social change to delivery these and other programs that support the minority community (Collins & Swartz, 2011).

In Chapter 1, I introduced the research topic, emphasizing the importance of cultural support for adult minority caregivers for the increasing number of Alzheimer’s patients. I also presented the background and problem of the research topic and demonstrated the need for a qualitative, phenomenological exploration of the adult minority caregiver experience. Additionally, Chapter 1 contained information about the research questions, the nature of the study, and the definition of terms. The chapter concluded with an explanation of the study’s significance, contributions from the literature, caregiver practice, and need for social change.

In Chapter 2, I will review the literature and establish the gap in the research, revealing the focus of this study and the specifics of the conceptual framework employed. I will also provide information on the cultural influences between adult minority caregivers, caregiver burden, and shared experiences derived from personal caregiving experiences. Furthermore, Chapter 2 involves reporting and interpreting the voice of adult minority caregivers.

Chapter 2: Literature Review

Introduction

The purpose of this study was to explore the unforeseen long-term caregiver demands and diverse cultures of minority caregivers. In Chapter 2, I present a review of literature related to phenomenological research on the caregiver population in general and the minority caregiver population in particular. The use of the term *minority* is slightly challenging. Therefore, I have considered the trustworthiness and accuracy of various sources, given the existence of intra-group cultural differences among minorities. The influence of culture and family obligation are stronger among the African American and Hispanic populations despite being at a lower socioeconomic status (McCann et al., 2000). I will further address the gaps in research regarding the cultural meaning of the underutilization of social support services and the reporting of caregiver burden from the minority caregiver perspective.

To understand the cultural aspect and acceptance of the minority caregiver role and to explore the possible cultural barriers impeding patient care and the health of the caregiver, I used social support theory as the conceptual framework. In the literature review, I demonstrate the gaps in knowledge about cultural characteristics that directly or indirectly impact cultural variations in the minority caregiver community (Cho, 2007; Knight & Sayegh, 2009).

In Chapter 2, I will describe the literature search methods used to identify and locate relevant literature. In addition, I will provide a concise explanation of the social support theory conceptual framework. Chapter 2 includes a review of the literature and an exploration of gaps in the research on (a) the cultural characteristics and values of minority caregivers, (b) the underutilization of formal social support services for in-home care assistance, (c) the burden on minority caregivers, (d) healthcare and public health professionals' understanding of the minority caregiver role, and (e) the needs of minority caregivers for cultural community-based support programs.

Literature Search Strategy

To find relevant literature, I used Google Scholar and the following online databases: EBSCO Host, PubMed, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINHAL), Walden University's Thoreau. I limited my search to peer reviewed scholarly sources published between 2012 and 2016. A consultation with the Walden University librarians was beneficial in the search for peer-reviewed journal articles. The following keywords and phrases were used in conducting the search: *Alzheimer's disease a form of dementia, diagnosis and stages of Alzheimer's disease, minority caregiver or family member, African Americans, Hispanics, Asian Americans, Caucasian Americans, caregiver burden, secondary patient as an informal caregiver of Alzheimer patients, informal and formal social support, cultural barriers, culture sensitivity, culture competency, health care professionals, phenomenological approach, qualitative research,* and *social support theory*.

I used comparable terms to search for peer-reviewed articles on legislative guidelines in support of minority caregivers and community-based social support programs. In brief, a description of the paradigms and validation for the research questions also required entering the following terms and phrases into each database: (a) social support theory, (b) understanding lived experience of minority caregivers and diverse culture influences of caregiving of Alzheimer patients, (c) caregiving and economic burden of minority caregivers, (d) explaining the minority caregivers needs for community support, and (e) what healthcare professionals understand and need to know to help minority caregiver.

I used peer-reviewed journal articles retrieved from the search engines, databases, and approaches described above to conduct the review of literature under the headings and subheadings indicated below.

Problem Statement

Over the next four decades, the population of diverse minority communities in the United States will increase dramatically (Broughton, 2008; Morrison, Plaut, & Ybarra, 2010). Consequently, the growing elderly minority population will increase the demand for informal caregivers in the minority community (National Alliance for Caregiving and American Association of Retired People, 2015). The increase in research studies have documented the various aspects of the general informal caregivers. Minorities of diverse ethnic groups have cultural values about family obligations and a sense of responsibility for providing care to elderly family members (Flores, Hinton, Barker, Franz, & Velasquez, 2009; Silverstein & Giarrusso, 2010). African Americans, Hispanics, and Asian Americans hold strong cultural beliefs concerning the responsibility of elderly family members, thus increasing the emotional assistance (Flores et al., 2009; Penrod, Baney, Loeb, McGhan, & Shipley, 2012).

The expectation of minority caregivers is a norm often seen as not only a cultural fulfillment, but also a good deed (Edelstein, Band-Winterstein, & Bachner, 2016). When the demands of this good deed begin to increase during the stages of disease progression, a caregiver must consider the benefits of a social support system (Brémault-Phillips et al., 2016). Because of culture and language barriers, there is limited use of such formal services by minority caregivers (Dong et al., 2010; Gelman, 2010). Documentation of evidence-based studies is important in the development and implementation of culturally sensitive community-based social support programs. For example, Hispanic American caregivers have voiced a concern for formal support services applicable to various cultures in the form of caregiver training, social support groups, case management, and respite care (Lopez Hartmann, Wens, Verhoeven, & Remmen, 2012). Similarly, African Americans have recognized the need for cultural information and referral programs for social support services (Lopez Hartmann et al., 2012).

Since the United States has a culturally diverse group of minorities as informal caregivers, these results will be beneficial for healthcare professionals working with minority caregivers (Burgio et al., 2009; Gitlin, Jacobs, & Earland, 2010). Traditionally, each generation’s response to the care of family members living with Alzheimer's disease comes from the powerful influences of culture. Narratives, the lived experiences as told by minority caregivers, depict the distinctive understanding of their world. The differences between diverse cultural narratives of minority caregivers of family members or friends living with Alzheimer's disease are apparent during times of caregiver burden

(Maslow, 2012). One such situation occurs during these times when the adult minority takes on the responsibility of caregiver for the senior family member.

Culturally diverse reliance among minority caregiver and the care recipient has become a growing public health concern (Goins, Spencer, & Byrd, 2008; Knight & Sayegh, 2010). As a result of the increased number of minority family members are becoming informal caregivers the tasks are compared to paid healthcare professionals in the same role, yet these individuals experience impacts due to the lower-socioeconomic status and cultural barriers. Because of the negative impact faced by both the caregiver and care recipient it is imperative public health call for an organized response in support of minority caregivers. The response itself can be facilitated through cultural diversity training for the proper care of Alzheimer patients and the well-being of the caregiver. Further increases in the population of culturally diverse caregivers present a significant challenge for the development of conceptual models (Goins, Spencer, & Byrd, 2008; Knight & Sayegh, 2010). This literature review presents primary gaps in the research on cultural influences among minority caregivers and recommendations for future studies.

Conceptual Framework

Social Support

The conceptual frameworks of social support have evolved into various meanings with none being definitive. Social support is defined as internal and external influences that assist with coping mechanisms useful for minority adults transitioning to the caregiver for Alzheimer patients (Caplan & Killilea, 1976; Sun, Kosberg, Kaufman, & Leeper, 2010). The direct effect model and stress-buffer model are specific alternative conceptual frameworks of social support. The direct effect model “enhances health and well-being irrespective of stress exposure,” and the stress-buffering model protects individuals “from the harmful effects of stress” during exposure to stress (Rodriguez & Cohen, 1998, p. 535). The buffer effects of social support require individual self-efficacy for the fostering of social networks (Bandura, 1988; Chiu, 2013). Social support is a dynamic phenomenon essential to the continued cultural form of survival for minority caregivers. The cultural structure of ethnic population groups, gender, socioeconomic status, and geographic regions are all relevant to the interaction changes of social support (Lai, 2012). Moreover, the constant interaction of support explains how individuals perceive, interpret, and react to social support including emotional support, informational support, tangible support, and appraisal support (Barling, MacEwen, & Pratt, 1988; Nurullah, 2012).

The suggestion of previous theoretical references details the significance of social support that influences the recipient for emotional support and feelings of being an asset to a social network (Cobb, 1976). Nonetheless, present day theories argue that various forms of social support be necessary for minority caregivers and beneficial intervention methods in which the socio-cultural contexts are considered. Aranda and Knight (1997) revision of the sociocultural stress and coping model postulates the significance of caregiver stress and coping mechanisms among culturally diverse caregiver communities. Individuals receive social support in the form of emotional support, informational support, tangible support, and appraisal or esteem support (Gottlieb & Bergen, 2010; House, 1981). As a critical entity, the availability of social support in the form of emotional support, instrumental support, informational support, and appraisal support is a likely cause of caregiver burden among minority caregivers (Gottlieb & Bergen, 2010; Ko, Wang, & Xu, 2013). For example, a minority caregiver support network provides support in the form of information awareness, obtaining formal support such as respite care, and coping with the burden of caregiving. The understanding is to explore the alternative conceptual frameworks direct effect and stress buffering effect in addition to the common paradigms of social support; emotional, instrumental, tangible, and appraisal.

Direct Effect

Cheng, Lam, Kwok, Ng, and Fung (2012) explains the direct effect model of social support as a provision of self-efficacy beneficial to individual health and well-being during stressful events. Caregivers dealing with emotional confrontation and the burden of caregiving react more positively with greater self-efficacy. Direct effect postulates the proponents of emotional distancing creating a protective barrier between the caregiver and stressful experiences (Chen et al., 2012; Tang, Jang, Lingler, Tamres, & Erlen, 2015). The direct path has been ineffective in, terms of caregiver burden and culture. However, each was resolved by the influences of emotional support, informational support, tangible support, and appraisal support.

Direct effect model benefits of having a diverse social support network system provide the caregiver stability within the community and interpersonal experiences (Ko et al., 2013). The positive social integration allows positive feedback from appraisal support through a network for the formation of self-identification and promotion of self-worth to control the lived experience (Chen et al., 2012; Ko et al., 2013). Finally, for caregivers having self-efficacy through cultural awareness of the burden for the type of care required results from the benefits of direct effect model.

Stress Buffering Effect

The stress-buffering model acts as a buffer for the protection of individuals during stressful events (Cohen & Wills, 1985; Wheaton, 1985). The cultural effects of caregiver burden are lessened through the protection of buffers by the negative consequences of caregiving. Having a supportive relationship promotes a healthy environment through emotional support, which buffers the effects of a broad range of stressors (Wheaton, 1985). Additional support may also be offered in the form of informational support that useful counseling and management of stressors. Emotional support and informational support buffers are effective in supporting the challenges of the lived caregiver experience from a cultural aspect (Cohen & Wills, 1985; Wheaton, 1985). For minority caregivers, Cohen and Wills (1985) further suggests a stress-buffer will reduce the negative health impacts of stress. Minority caregivers seeking the positive benefits of these influences must understand the objectives for the appropriate response to facilitate support for stressful events.

Paradigms of Social Support

For minority caregivers, the benefits of social support are dependent upon the various types and availability. Thoits (as cited in Whiteman, Barry, Mroczek, & MacDermid Wadsworth, 2013) explains emotional support as a direct buffer to the damaging effects of caregiver burden improving individual physical and mental health.

The awareness of emotional support to healthcare professionals requires an understanding of the process dynamics, potential outcomes for minority caregivers and their informal social networks (Kaufman, Kosberg, Leeper, & Tang, 2010). Although emotional research evidence is increasing it is suggested that the positive impact of an informal social network will satisfy the physical, mental, and emotional well-being of the minority caregiver (Harknett & Hartnett, 2011). Therefore, the availability of emotional support from caring family and friends a crucial for a positive social network (Grav et al., 2011; Harknett & Hartnett, 2011). Caregiver burden increases the instability to provide the proper care for patients with Alzheimer's disease when there is an absence of emotional support (Grave et al., 2011). The representation of emotional support includes social support networks of closeness with a varying range of kinships (Fleury, Keller, & Perez, 2009; Ko et al., 2013). These variations include levels that reflect socioeconomic differences, cultural norms, and family backgrounds (Fleury et al., 2009; Ko et al., 2013).

Instrumental support unlike emotional support benefits the caregiver through various forms of information regarding formal social support services and respite care (Fleury et al., 2009). In a broader sense of the term the adaptation of the behavioral model of health service from Anderson and Newman (as cited in Willis, Price, & Glaser, 2013) there is "the association between ethnicity and instrumental support" (p. 279). The possible impact of instrumental support highlighted in a study of cultural experiences among minority caregivers who received instrumental support or practical assistance reported less stress and burden rather than the general caregiver population who did not receive instrumental support (Willis et al., 2013). Therefore, informing minority caregivers about the potential of caregiver burden and coping techniques to manage burden protects the individual from physical, mental, and emotional health issues such as depression.

The benefits of tangible support are equally beneficial to health and well-being of individuals providing care to patients living at home with Alzheimer's disease. Being able to provide concrete assistance to the caregiver requires outside resources and information such as financial provisions or techniques on coping with the burden of informal caregiving (Fleury et al., 2009; Ko et al., 2013). Minorities are part of a lower socioeconomic bracket making it evident that the importance of financial provisions will benefit the not only the caregiver but also the patient (Fleury et al., 2009; Ko et al., 2013). Appraisal support offers another buffer against the effects of caregiver burden. Minority caregivers can have a positive effect when the development of community-based social support programs is tailored based on culture and the shared lived experiences. The support of appraisal is grounded on the factors of praise, positive views, or encouraging feedback.

Cultural Characteristics and Values of Minority Caregivers

Minority caregivers through a cultural aspect are concerned with the well-being of the care for patients living among the community with Alzheimer's disease. Because of the challenges there is confusion regarding the types of care preferences among these culturally diverse groups. The cultural influences impede the understanding and importance of care for elderly patients with chronic illnesses thereby exacerbating caregivers' burden. Lehman (2009) researched the importance of cultural intervention methods from the Margaret Blenkner Research Institute and the Benjamin Rose Institute to rectify the misperception thereby decreasing the negative impact of caregiving. The role of the healthcare and public health professionals can also improve communication and cultural understanding about diverse cultures, informal care, and a community-based social support care plan that empowers and builds competence through education.

Gupta and Pillai (2012) examined the aspects of minority caregiving who provided care to family members or friends and purpose of the caregiver role of cultural values in foreseeing the positive aspects of caregiving. There is also the cultural belief shared by minorities regarding the experience of having positive feelings toward the responsivity of caring for a loved one (Knight & Sayegh, 2009). For healthcare professionals and public health professionals to understand the minority caregiver there must be the understanding of the existence of diverse cultures and traditional values. Reverends Wintz and Cooper (2009) are advocates and creators of learning modules about cultural sensitivity and spirituality that educate healthcare professionals and social workers. In addition to the learning, modules provide information relevant to the need to empower minority caregiver population groups (Wintz & Cooper, 2009).

Formal Social Support Services

In the United States, the majority of ethnic minority population groups provide informal home care as the primary method to family members or friends without any supplemental care (Barnes & Bennett, 201 Diverse minority population groups are more likely to provide care to family or friends with Alzheimer's disease than the majority of general caregiver population (Griffith, 2010; Shanley et al., 2013; Williams et al., 2016).

Diverse minority population groups are more likely to provide care to family or friends with Alzheimer's disease than the majority of general caregiver population (Griffith, 2010; Shanley et al., 2013; Williams et al., 2016). Community-based social support programs, outreach services, healthcare cultural awareness, caregiver training suitable to caring for loved ones afflicted with Alzheimer's disease among African-Americans and minority caregivers are lacking (Gelman, 2010; Koehn & Badger, 2015) calling for a systematic investigation of the underlying cultural and socioeconomic factors limiting access to services.

The existence of cultural norms associated with caregiving in the minority community is likely to influence the decision to utilize formal social support services (Robinson, Buckwalter, & Reed, 2013). According to Bookman and Kimbrel (2011) family is an important cultural value that influences the responsibility of the caring for aging parents or loved ones. As a major determinant, the expectation is that children become the primary caregiver as a sign of respect which is a significant value of the minority cultural (Bookman & Kimbrel, 2011). Spirituality is another culture value that is important to minorities especially African Americans when family members are suffering from health issues (Chin, Negash, & Hamilton, 2011). Having the value of spirituality proves to be a difficult task in explaining the importance of the care provided by the caregiver (Chin et al., 2011). Understanding the minority cultural values and norms is significant to the effects of the decisions about formal caregiving and social support services.

Minority Caregiver Burden and Health Disparities

The reality of informal caregiving is becoming a central part of the American society. Caregiver burden is the overwhelming responsibility that increases as the condition worsens (Duthey, 2013; Xiaoyu, 2013). Some research studies concerning the general caregiver population and their families have documented the negative effects of caregiver burden (Duthey, 2013). Minority caregivers of Alzheimer's patients experience a greater risk of disease and health impairments in addition to mortality (Löckenhoff, Duberstein, Friedman, & Costa, 2011). According to the Alzheimer's Association (2011) in 2010 the state of Louisiana over 200,000 caregivers was primarily responsible for the care of an estimated 80,000 Alzheimer's patients. Furthermore, the United States the increasing healthcare costs of caregivers impacted physically and emotionally resulted in an estimated $7.9 billion (Alzheimer's Association, 2011).

While the cultural norms of family togetherness and the satisfaction of caring for loved ones brings about positive feelings, the level of stress are reportedly high when providing care (DeForge, 2013). More importantly, statistics continue to show that the burden of caring for loved ones with Alzheimer will continue to increase considerably (Beard, Knauss, & Moyer, 2009). The impacts of the burden of being a minority caregiver intensify as Alzheimer's patients near the end of life (Beard et al., 2009). Most minority caregivers begin working a 24-hour day now are left feeling with an extreme overwhelming sense of responsibility. Research on the end of life care found that 88% of minority caregivers experience a sense of relief after the family member or loved one with a chronic illness died (Garlo, O'Leary, Van Ness, & Fried, 2010).

Healthcare Professionals and the Minority Caregiver

The efforts necessary in defining distinct classifications of cultural competency is a continuing process (Pharr, Dodge Francis, Terry, & Clark, 2014; Wheeler, 2010). Cultural competency for understanding racially diverse communities is essential as it directly impacts the quality of care delivered and received (Like, 2011). Cultural competence according to Like (2011) is meeting the needs of culturally diverse minority caregivers living in underserved communities caring for family members or friends diagnosed with Alzheimer's disease. The Institute of Medicine Unequal Treatment Confronting Racial and Ethnic Disparities in Healthcare, explains the consistency of general research lacking on cultural competency a direct contributor to poor health, decrease in patient compliance, and increased health disparities despite the availability of healthcare systems (Smedley, Stith, Nelson, Institute of Medicine (U.S.), 2003; Sorkin, Ngo-Metzger, & De Alba, 2010). Services that are culturally suitable have the potential to reduce health disparities thereby improving health outcomes. Additionally, the competence of healthcare professionals stands to gain a greater satisfaction among both the caregiver and patient. The reduction in health disparities calls for government interaction in the development of culturally competent programs for healthcare professionals. Understanding the norms of diverse cultures will enable better healthcare and avoidance of misunderstandings.

During 2006, the U.S. Census reported a 19% increase in elderly minorities age 65 years and older being diagnosed with Alzheimer's disease (Mayeux et al., 2011; Thies & Bleiler, 2012). By 2050, minorities will be representing nearly 39% of the nation's elderly adult population group (Vincent & Velkof, 2010). Healthcare professionals are becoming aware of the fact that minority caregivers share common cultural characteristics handed down through generations (School of Medicine University of Indiana, 2012). Healthcare professionals are learning the importance of culture as a necessity when working with minority caregivers of Alzheimer's patients. The expectations are to be aware and understanding of diverse cultures thus, tailoring individual behavior and expectations in a respectful manner. For the quality of support to be effective healthcare professionals must also consider personal biases and cultural values with regards to cultural sensitivity. The ideology of the minority caregiving experiences varies across diverse populations. Therefore, the generalization of caregiving should be avoided to prevent inaccuracy if applied to all minority caregivers.

Minority Caregivers and Cultural Community-Based Programs

In this comprehensive literature review, the details of caregiving by adult minorities for family members with Alzheimer requires emphasis on access and equitability of programs by considering the role of cultural values and norms of the community. Exploration of the shared lived experiences of culturally diverse caregivers will focus on the burden of care, socio-cultural factors. It is likely that diverse ethnic cultures impact the acceptability of utilizing respite care and other forms of formal social support services. Previous research studies conducted discovered the cultural norms that are an expectation of adult family members to assist in the care of household members with debilitating diseases. These and additional findings suggest that seeking formal services is subjective to the cultural norms and values about family objection which might be viewed as a failure in meeting the responsibility of caregiving. Moreover, family involvement makes it challenging for the minority caregiver to pursue outside resources without the knowledge of the immediate family. Future research is necessary to understand the impact of cultural values on the minority caregiving experience. The outcome of qualitative research would be especially useful in justifying the caregiver needs thus, facilitating government intervention and culturally tailored programs for the increasingly diverse minority caregiver population.

Summary

In this chapter, a comprehensive literature review was conducted focusing on culture awareness and understanding of the minority caregiver. A general description of the conceptual framework of the study, the central thinking behind this study, minority caregivers and cultural awareness for the development of community-based programs were first provided. The specific points addressed in the literature review include: (a) background on the cultural characteristics and values of minority caregivers, (b) underutilization of formal social support services for in-home care assistance, (c) minority caregiver burden and health disparities, (d) healthcare professionals understanding of culture and the minority caregiver role, and (e) justifying the minority caregiver needs to support cultural community-based programs.

Beginning with the background on the cultural characteristics and values of minority caregivers various research articles and associations provided an exploration of the role culture play in the minority community. The underutilization of formal social support services for in-home care assistance was the next section which applies to the cultural norm or reasons why minorities feel the need to object to formal assistance. Furthermore, the section on Minority Caregiver Burden and Health Disparities was explained in detail through comparison research from various articles capturing the positives and negatives of the caregiver experience. In this section, a sense of understanding and awareness is given to the responsibility of caregiving and the role culture plays in minority communities. Caregiver community-based social support programs must meet the requirement to include cultural development for effective support for minority caregivers. The literature review conducted helped to establish the presence of a research gap regarding the cultural understanding and awareness for addressing the minority caregivers' needs from a cultural perspective. The literature review also suggested the need for change in accommodating minority caregiver's needs to address the burden of care borne by the minority caregiver population. In Chapter 3, a description of the research methodology as pertains to study design, data collection, analysis, and interpretation will be provided.

Chapter 3: Research Method

Introduction

The purpose of the proposed qualitative study was to explore the lived experiences of minority caregivers of care recipients diagnosed with Alzheimer’s disease patients residing in diverse minority communities. Culturally specific community-based programs are the plausible choice for providing care for Alzheimer’s patients when formal institutional care is not an option. The underutilization of support programs such as counseling, caregiver respite support, emotional support, and cultural educational programs prompted me to conduct this study in order to promote social change. Further comparisons of themes based on responses from the interview and survey questions from a cultural perspective promoted awareness for social change of informal care for elderly patients diagnosed with Alzheimer's disease.

The methodology section consists of criteria for participant recruitment, research instruments, the protocol for interview sessions and surveys, data collection recording instruments, and strategies for data analysis. In the final sections, I will explain the issues of trustworthiness, including ethical practices, credibility, transferability, dependability, and confirmation. Lastly, I will summarize the chapter and transition to Chapter 4.

Research Design and Rationale

The qualitative, phenomenological approach provided further understanding of the lived experience of minority caregivers through individual interpretation analysis. Phenomenology, according to Creswell (2013), is a narrative as told by research participants describing the “what” and “how” of a current experienced phenomenon. The phenomenological approach that I selected for data analysis allowed an in-depth exploration of the lived experience from the cultural perspective of minority caregivers of Alzheimer patients. The participant willingness to discuss in-depth details and appearance of the phenomenon during the interview process is a process acknowledged as Epoche bracketing (Van Manen, 2016).

In this study, I investigated the shared lived experiences of minority caregivers for Alzheimer’s patients. The specific research questions that I addressed in the research proposal were as follows:

RQ1: What are the lived experiences of family members of minority Alzheimer's patients as caregivers?

RQ2: What cultural beliefs or spiritual beliefs have influenced the experiences of minority caregivers?

RQ3: How does knowledge, socioeconomic status, or perception justify the disparity in the minority caregiver's willingness to obtain healthcare for caregiver burden?

Role of the Researcher

As a researcher for this study, I was responsible for participant recruitment, voice recording of all interview sessions, data collection for transcription and coding, data analysis, and interpretation of the findings. Throughout the study, I upheld the ethical rules described by the Walden University Institutional Review Board.

As the primary research tool during the interviews, I made myself a willing participant (Walden University, 2013). As the researcher, I needed to remain an instrument of data collection when asking probing questions, to listen carefully, to think critically, and to ask further questions to gain more in-depth insights of the lived experiences of the participants in view of the research questions.

Methodology

This study encompassed an exploration from the minority caregiver cultural perspective supported with a phenomenological approach. According to Creswell (2011), the phenomenological approach was appropriate for data captured based on the perceptions and perspectives of the minority caregiver experience caring for Alzheimer's patients in regards to social support accessibility, challenges, barriers, and related health stigma. The intent of the study was to provide an understanding of both lived and shared experiences of minority caregivers. This study not only provided the essential data, but also contributed to healthcare professionals' education on culture sensitivity and the development of community-based social support programs culturally tailored to the minority caregiver.

Participant Selection

In recent research, Han and Radel (2015) conducted an interpretative phenomenological study which focused on the experience of caregiving and social programs. The study consisted of 5 couples, which provided for sufficient data collection to effectively reach data saturation. The emergence of new themes occurred at the point of data saturation for added understanding to the study's phenomenon. According to Fusch and Ness (2015), the purpose of data saturation was the demonstration of data replication with additional information for the validity of research quality. Likewise, the transcription of large amounts of evidence would be inadequate when trying to reach the point of saturation. Therefore, the validity of data saturation from a small sample size was adequate to this qualitative research study (Fusch and Ness, 2015).

Having 12 participants for this study was sufficient in the transference of results not suitable for the general caregiver population, but for the target population. Furthermore, the sample size was adequate for the collection of data transcribed from each interview session. The following participant selection process included email and telephone contact with potential candidates from the identified recruitment process:

1. A letter of cooperation (Appendix C) was forwarded to local community churches to request assistance for potential members' willingness to contribute their lived experience from a cultural perspective as a caregiver of loved ones living at home with Alzheimer's disease either through e-mail or telephone providing daily care to loved ones. Additionally, I requested permission to place an advertisement flyer (Appendix D) in each of the following facilities announcement boards for potential candidates. Participants who provided informal care to Alzheimer patients were considered suitable candidates.
2. Contact was only be made with individuals that met the sample selection criteria and agreement for participation in the study.
3. The requested sample size of 10 to 12 minority caregivers caring for individuals with Alzheimer's disease completed a consent form in acknowledgement of participation, the refusal to respond or withdraw

throughout the study (Appendix A) and demographic form (Appendix E) prior to the start of the interview sessions.

4. With the approval of the Walden University, Institutional Review Board (received on April 12, 2017 under # 04-12-17-0402763) at this stage the recruitment process was authorized for continuation.

Instrumentation

As the principal instrument for this research study, I was solely responsible for the collection of data. The interview sessions included participants from diverse ethnic backgrounds responsible for the care of loved ones living with Alzheimer's disease. The pre-established research questions allowed guidance of responses and proper collection of data from each participant (See Appendix F). By using open-ended questions, I allowed each participant to provide responses distinctive to their personal cultural experiences as an informal caregiver to an Alzheimer patient. The interview sessions aided in the extraction of data collected from the individual responses to the research questions of the lived and shared cultural experiences among minority caregivers. Furthermore, I made an audio recording of each interview and transcribed the recordings.

Researcher-Developed Instrument

I designed and used an instrument (See Appendix E) to acquire the following demographic information for this study:

- Participant Name (coded as minority caregiver MC #1, MC #2, etc.)
- Telephone or Email Address for additional information (concealed for privacy)
- Ethnicity

· Gender (Male/Female)

· Age

· Formal diagnosis of care recipient by healthcare professional (yes/no)

· Length of time as minority caregiver (6 months or longer)

· Unpaid Hours as Caregiver per Week

· Relationship (relative, spouse, acquaintance)

The development of the research instrument tool was similar in approach to previous research-developed instruments for the acquirement of actual participant information as in-depth, descriptive details of each experience (Bastos et al., 2014; Jansen, 2010).

Procedures for Recruitment, Participation, and Data Collection

The research study procedure for data collection consisted of three questions. The first of the three guided research questions focused on the minority caregivers’ personal views and experience as a caregiver for an individual with Alzheimer's. Next, participants could express cultural and spiritual influences on the daily caregiving tasks. The final question addressed the significance of healthcare disparity among minority caregivers and caregiver burden which was extremely important to social change and future research. Additionally, the phenomenological approach was constant in the individual responses given the interview protocol I followed (Appendix F). The interview location was at the discretion of the participant. This ensured the achievement of data saturation through the data collection. After the initial interview, I deemed follow-up sessions necessary for data verification and saturation. The use of prompt questions encouraged a more in-depth conversation for response clarity during the data collection process. Each of the 12 minority caregiver discussed personal views on cultural and spiritual experience in caring for an Alzheimer patient. The 30 minutes to an hour interview session was an acceptable timeframe that was dependent upon the length of the responses. The data collection phase consisted of accurate transcription from audiotaped interview sessions which minimized the chance for bias or misinterpretation. Nonetheless, as the researcher with personal experiences, there was the possibility that the participant's responses could have been influenced. The required number of participants were recruited, with additional participants requested if previous participants willing removed themselves from this study. The creation of nine questions served as guidance for authenticated responses to be collected for data:

1. How would explain the influences your culture imposes on the responsibility of caring for a loved one?
2. Did you consider employing a formal Alzheimer's caregiver after the confirmed diagnosis?
3. Can you provide insight on then now or previously about the lived experience through a culture lens?
4. Because of the personal relationship to the care recipient, would you say there is a common bond already in place?
5. Does your diverse cultural or spiritual background have any impact on the experience of being a caregiver?

6. In your own words, please share some limitations that are hindering the care you are providing?
7. Have you ever felt discouraged because of your health literacy level concerning this disease, including your healthcare knowledge disparities with healthcare professionals?
8. Do you feel that the minority community would benefit from culturally tailored community-based social support program?
9. Aside from developing a community-based social support program, what are other areas that could be improved for the minority caregiver experience?

How Interview Questions Related to Research Questions

The development of the interview questions were in accordance to the exploration of the lived experience of the minority caregiver. As a guide for stimulated conversation revealed in-depth responses given by each participant in addition to the responses to the nine prompt questions during each interview sessions (Appendix F). The first RQ1, questions the cultural perception of social support resource availability for minority caregivers of Alzheimer patients in addition to the healthcare disparities or limitations. RQ1 correlated with the responses given to interview questions 1-3. Next, RQ2 focused on the importance of culture influences and ethnic background of the minority community. The participants addressed these issues to interview questions four and five. Lastly, RQ3 concentrated on the final interview questions about the whole person concept, personal and care recipient healthcare disparities, cultural stigma and misinterpretations made by healthcare professionals.

Themes and Descriptions of the Minority Caregiver Lived Experience

The construct of the primary phrases correlated with the nine interview questions and three research questions addressed as the central focus of this study:

1. Understanding the cultural perspective of caregiving by minorities.
2. The unavailability of formal or informal social support resources.
3. Being the voice for community-based social support programs tailored for diverse cultures.
4. Overwhelming stress and financial issues.
5. How to effectively approach healthcare disparities such as screening and diagnosis of disease, and healthcare access for both the caregiver and recipient.

I will examine data interrelation to that of the primary phases. Additional themes may be insignificant to the study. Likewise, the role of caregiving for minorities and cultural influences transpires in retrospect to the conceptual framework social support theory.

Data Analysis Plan

One of the important steps was the data to be analyzed when using the phenomenological approach as a means in the development of an evolving strategy that revealed personal lived experience of a current phenomenon (Walden University, 2013). In this research study, the current phenomenon focused on minority caregivers of Alzheimer's disease in community dwellings. Although, the personal understanding of the minority community was useful the interview sessions revealed new notes in addition to past concepts or beliefs essential to the phenomenon (Englander, 2012). According to

Moustaka (1994), an exploration of information required the utilization of each step in the phenomenological process which served as a guide during the data analysis process.

In this study, the essential meanings of the cultural experience as a minority caregiver of Alzheimer's patients was maintained since exact interview responses unique to the themes within the literature review. The examination of the transcript data was completed multiple times for generated themes. This process provided a coding list for accurate and reliable information from captured data during each session (Berg, 2009).

The researcher used ATLAS.ti software for qualitative data analysis to import the interview transcripts from each session (Humble, 2012; Saldaña, 2013). The development of an electronic codebook for 12 semi-structured interview sessions with minority caregivers included data for bracketing themes specific to the research questions (Saldaña, 2013). If coding consistency was not reached during data saturation, follow-up with participants was necessary to reach unanimity about coding. The process of axial coding linked codes and data examination for themes. Next, to re-code data transcriptions required a constant comparative method for code and memos development, tally of codes, and the comparison of major theme emergence from the organization of codes across interview transcripts by ethnicity (Saldaña, 2013). As such, the following method allowed for similar and different findings across the interview sessions. The final stages of the data analysis process commenced after completion of the first interview and at the end of the interview sessions.

The implicit meanings needed to be made explicit within the six stages of thematic analysis (Marshall & Rossman, 2016). As a critical entity, the organization process of thematic analysis followed the collection and organization of specific themes for data coding, test emergent, alternative explanation search, and the final report of the data analysis (Marshall & Rossman, 2016). The benefits of the conceptual framework social support theory were appropriate to the outcome of this research study. Social support acted as a ‘buffer' in the reduction of caregiver burden and resilience reinforcement for stressful lived experience of a current phenomenon (Zhao et al., 2011; Drageset et al., 2012; Hoban & Liamputtong, 2013). As a research methodology, phenomenology focused on the lived experience of minority caregivers. The completed analysis of data used direct content analysis method along with the computer-assisted data analysis software Atlas.ti to code interview transcripts shifting between the participant's viewpoint and the researcher's understanding. In collecting research data in general and the qualitative research data in particular trustworthiness, transferability, dependability, and confirmability are crucially important. To minimize bias and enhance the trustworthiness of collected data, triangulation, peer debriefing and support, and transcript auditing were employed in this study (Padgett, 1998).

Atlas.ti limitations of rigor made for an effective computer-assisted quality data analysis software tool with unchanging analysis, nonetheless added provisions for organizational improvement (Ryan, 2009). Additionally, the utilization of Atlas.ti increased the trustworthiness through the ability and representation of analysis and interpretation of data for theme emergent (Ryan, 2009). Moustaka's (1994) methodology for the exploration of information included the phenomenological process in addition to the computer-assisted qualitative data analysis software Atlas.ti. The following modification approach encompassed (1) data transcription, (2) reading and reading of transcripts, (3) highlighted themes, (4) open-coding, (5) arrangement and organization of themes, (6) interpretation, and (7) vivid details (Moustaka, 1994; Ryan, 2009). A phenomenological method summarized the lived experience for data analysis in which the reader could understand. According to Moustakas (1994), the data analysis model incorporated four components to separate bias when bracketing data for specific themes or concepts to seek out meanings. At this stage, the research overview of the synthesis of common data became a representation of the current phenomenon (Moustakas, 1994).

Issues of Trustworthiness

According to the influential work of Lincoln and Guba (1986), quality assurance for research "trustworthiness," is a suitable concept with the aspects of credibility, transferability, dependability, and confirmability (Fig.1) (Lincoln & Guba, 1985; Sinkovics & Alfoldi, 2012). Guba and Lincoln's model of trustworthiness for qualitative research is relevant to the qualitative rigor in this study (Elo et al., 2014; Lincoln & Guba, 1985; Sinkovics & Alfoldi, 2012). Additionally, the four aspects along with trustworthiness served as a guide rather than an accepted view acceptable in determining the quality of the evaluated qualitative inquiry. The ideology of Guba's model is the four-aspect substitution support evident to the investigation of study (Lincoln & Guba, 1986; Lincoln & Guba, 1985).

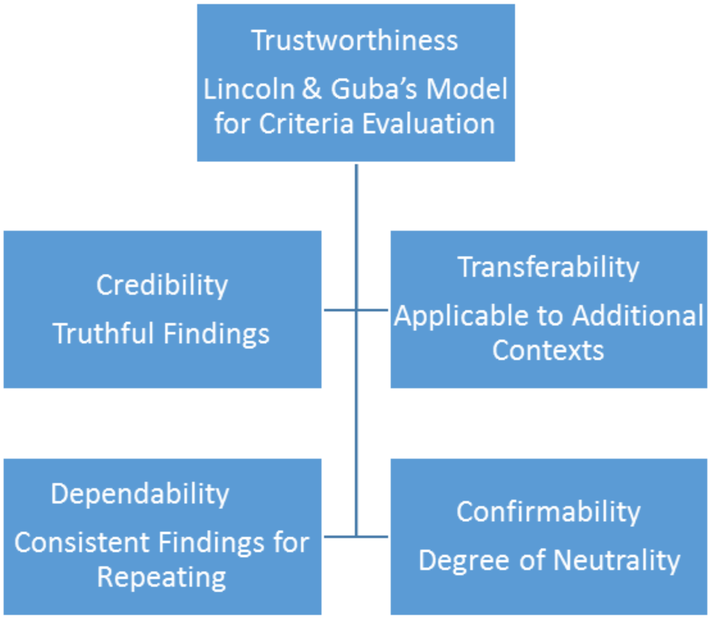

Figure 1. Model for criteria evaluation, from Lincoln, Y. S., & Guba, E. G. (1985). Reprinted from *Naturalistic Inquiry*. Retrieved March 29, 2017. Beverly Hills, CA: Sage Publications.

Credibility

The threats of internal credibility came into the question when converged on the rationalization of research findings in a phenomenological study. The characteristics and bias of the data collector were specific threats to the credibility of the internal validity. Because this was a qualitative study, the instrument tool for the collection of data was primarily the researcher. As such, this qualitative research ensured the data was authenticated by the outcome (Lincoln & Guba, 1985). Therefore, to focus on the validity of the data a detailed explanation of the limitations and issues encompassed by the minority caregiver community were specified based on data saturation. The following methods for credibility verification were triangulated and peer checked for confirmation of the lived experience as a caregiver of Alzheimer patients in community dwellings (Hanson, Balmer, & Giardino, 2011). Regarding the phenomenological standpoint, credibility was the equivalent of internal validity in a qualitative study (Elo et al., 2014; Hanson, Balmer, & Giardino, 2011).

Transferability

Transferability and generalizability are equally important elements in qualitative research that are applied to the outcome of the study (Polit & Beck, 2010). The fact remains the generalizability of varying degrees was supported by the transferability of the outcome (Polit & Beck, 2010). In the diversity setting, the participants were adult minorities responsible for the care of community-dwelling Alzheimer patients. Further investigation into the validity of the results required maintenance of external validity through research ethics (Polit & Beck, 2010). Because this research applied to a small sample size, the generalizability would be insufficient to the general caregiver population. The reliability of the researcher's detailed report on the lived experience of the minority caregiver would confirm transferability of the outcome (Giesbrecht, Crooks, Williams, & Hankivsky, 2012).

Dependability and Confirmability

Dependability provided stability of data collection in time and specific conditions in qualitative research (Bowling, 2002). Lincoln and Guba (1985) proposed the dependability of quality evaluation required for replication and audit inquiry of data due to changing conditions. In this process, analysis by an external reviewer for documentation allowed for replication of the study to produce a similar outcome (Barratt, Choi, & Li, 2011; Bowling, 2002). Although this study consisted of a small sample size there was a need to simultaneous utilize dependability and confirmability for audit trails. Chapter 4 offers further provisions concerning the details of dependability and confirmability under trustworthiness.

Ethical Procedures

The process of recruitment began after the submission and approved application received by IRB application noted by Walden University (Walden University, 2012). For an approved application, the IRB warranted the ethics of conduct towards all participants and data collection in this study. The IRB requirement for all legal documents to carry out this study have been explained fully to those voluntarily participating in this research study.

Ethical Concerns

The Walden University IRB approved consent was an important requirement prior to the recruitment process of human participants for the collection of data analysis. All participants received an explanation of the consent form for signature agreeing to participate this study. Additionally, all participants were made aware that this study was strictly voluntary and withdrawal was based on personal decisions. Furthermore, if any participant incurred additional stress or burden during the study, they could rightfully under their own recognizance have withdrawn from this study.

Treatment of Data

In keeping with research standards, all sensitive data collection for this study has been coded as anonymous for confidentiality purposes over the next five years. The safe storage of personal identification of participants will be maintained in the residence of the researcher only be accessible to the researcher.

Data Presentation

The presentation of the study results is in Chapter 4 contain personal viewpoints from responses of each research question. Chapter 4 included the identification of the information for inconsistencies, clarification of data and explanations. As a final point, similar themes or experiences were compared against the literature review primary phrases which were written in dissertation format for the topic objective of discussion.

Strengths and Limitations

The data collected from each interview sessions suggested a need for coping mechanism by the caregiver centered on the reflection of cultural ideals versus the lived experiences (Funk et al., 2010). There were inclusion methods for the collected data that could have possibly modified this limitation. Despite the limitations, this study presented several strengths which focused on individual responses. The objective of this study was the identification and summary of those primary barriers for minority caregivers in access to social support, however with insufficient evidence of satisfaction regarding ethnicity the findings were unlikely general. Because of the small sample size, the findings were also questionable for the generalization to the overall caregiver community, but could prove transferable because of the similar context (Lincoln and Guba, 1986).

Summary

Chapter 3 description of the purpose for this study restated the research questions in the research proposal. The ability of the provided details and understanding of cultural influences of the lived experience shared among minority caregivers the qualitative research method with a phenomenological approach was appropriate to understanding the current the phenomenon faced by minorities from culturally diverse lives. A phenomenological approach was suitable to the conducted study proposal which allowed for a systematically approach for the acquired relevant information from the minority caregiver perspective about this phenomenon. This study provided an exploratory description of the target population based on the selection criteria, purposive sampling approach, data collection method, methods for coding and analysis of data made evident in Chapter 3. Data trustworthiness, credibility, transferability, dependability, conformability, the interconnection between the research questions, interview questions and developing themes, and ethical guidelines were made evident in this chapter. In Chapter 4, the results of the data that has been analyzed in view of the following research questions were present with a description and framework for communicating the essence of data disclosure to be made available for future research.

Chapter 4: Results

Introduction

The central purpose of this qualitative phenomenological study was to explore the minority caregiver lived experience of family members diagnosed with Alzheimer’s disease, specifically concerning the cultural aspect of their role, personal health, and relationship with health care professionals. In this chapter, I provide the reconstruction of the care recipient lived experiences, as well as the complexity of such analyses. I used a phenomenological approach to explore in-depth shared responses from 12 participants to create meaning and understanding of lived experience influenced by culture (Creswell, 2013). I employed purposive sampling to recruit the 12 participants for this research study and interviewed each participant personally (Creswell & Plano, 2011). Additionally, this study details the existence of health disparities between the minority caregiver and care recipient that I will make available to all health professionals, including public health practitioners.

I captured the lived experience of the minority caregiver of Alzheimer’s patients based on the cultural perspective of various participants and their concerns about the characteristics of caregiving versus those of the general caregiver population (Powers & Whitlatch, 2016). The issues included the following (1) lack of disease knowledge (2) burden of care (3) medical professional relationships between the minority caregiver followed by (4) health disparities which impact on the caregiver and the received by the recipient. This chapter contains the (a) research study setting, (b) participant demographics and characteristics, (c) data collection methods, (d) qualitative data analysis, (e) evidence of trustworthiness, (f) research results, and (g) chapter summary of the findings suggested by emergent themes related to the influences and impact of culture.

Study Setting

It is important for a qualitative researcher to have a positive rapport with participants when conducting face-to-face interviews (Creswell, 2009). The atmosphere provided for any interview setting should be natural, yet private, so that the participant feels comfortable in disclosing private information (Creswell, 2009; Rudestam & Newton, 2015). For this study, the study setting took place in a natural environment either in a public coffee shop or private library conference room. I conducted 12 interviews, after obtaining participants' signatures consenting to the research study. Since each interview and follow-up sessions took place in a comfortable, natural setting, there was no adverse impact caused by the interview environment. The objective was to collect data through observation and responses to the semi-structured interview questions with prompts.

The first of four interview sessions conducted at the public library may have been a somewhat less relaxed, natural setting. However, because these meetings took place in private and semi-private areas, behind closed doors and free from distractions, each participant was more apt to disclose personal in-depth information. During the observation period, the participants were noticeably less distressed. I used volume control to mitigate problems of interference and to ensure the accuracy of data being captured during the initial interview and follow-up session.

The overall interview experience for data collection was a complex and dynamic process. Understanding the culture of several minority adults caring for family members or friends with Alzheimer’s disease is an increasingly important public health concern (Dilworth-Anderson, Pierre, & Hilliard, 2012; Robinson, Buckwalter, & Reed, 2013). While there have been debates about the appropriateness of analyzing qualitative data, I sought to obtain a comprehensive understanding of the lived cultural experience of the minority caregiver and the care recipient to obtain information pertinent to this study.

Demographic Characteristics of Participants

The primary demographic for this study were 12 minority caregivers of individuals formally diagnosed with Alzheimer's disease. Each participant lacked home healthcare training, earned no compensation, and suffered a decline in their own health. The cultural influences on the acceptance of the role and responsibility of caregiving have had significant adverse effects on the interpretation of caregiving, knowledge of Alzheimer's disease, and quality personal care among minority caregivers more than among the general caregiving population. Before the individual interview sessions, each participant was expected to complete the initial demographic questionnaire (Appendix E). Table 1 shows responses to that initial demographic questionnaire, and Table 2 shows the care recipient demographics used to interpret the research findings. The information was specific to the participants without violating any patient privacy. A confidentiality code was assigned to the participants and care recipients for the procurement of demographic information to determine caregiver and care recipient relationship status. The following variables included age, race/ethnicity, marital status, relationship to the caregiver, and length of residency in the Shreveport/Bossier surrounding area. The information collected is depicted in two tables (Table 1 & Table 2) regarding each minority caregiver and their care recipient.

Table 1

Demographic Characteristics of Participants

Caregiver Identifier	Age	Gender	Highest Level of Education	Ethnicity	Type of Work (Part-, Full-time, or Retirement)
MC #1	48	F	Associate's degree	African American	Full-Time
MC #2	52	F	High School Diploma	African American	Full-Time
MC #3	68	M	Bachelor's Degree	African American	Part-Time
MC #4	56	F	High School Equivalent Diploma	Hispanic/Latino American	Full-Time
MC #5	63	M	No High School Diploma	African American	Part-Time
MC #6	60	M	Master's Degree	Asian American	Full-Time
MC #7	47	F	Certified Nursing Assistant	Hispanic/Latino American	Full-Time
MC #8	40	F	Bachelor's Degree	African American	Full-Time
MC #9	58	M	High School Diploma	African American	Full-Time
MC #10	65	M	High School Diploma	African American	Retirement
MC #11	56	F	Bachelor's Degree	Asian American	Full-Time
MC #12	62	F	Vocational Degree	African American	Full-Time

Table 2

Care-Recipient Demographics

Care-Recipient Identifier	Gender	Age	Ethnicity	Relationship to Participant	Estimated Time of Diagnosis[a]
CR #1	M	66	African American	Father	2 Years Ago
CR #2	F	79	African American	Mother	1 Year Ago
CR #3	F	62	African American	Spouse	1 Year Ago
CR #4	F	68	Hispanic/Latino American	Sister	2 Years Ago
CR #5	F	67	African American	Spouse	1 Year Ago
CR #6	F	73	Asian American	Mother	2 Years Ago
CR #7	M	72	Hispanic/Latino American	Father	2 Years Ago
CR #8	M	61	African American	Father	3 Years Ago
CR #9	F	64	African American	Friend	1 Year Ago
CR #10	F	72	African American	Spouse	1 Year Ago
CR #11	F	77	Asian American	Mother	3 Years Ago
CR #12	M	60	African American	Spouse	2 Years Ago

[a] Estimated time of diagnosis was disclosed per the caregiver.

Minority caregiver participants were adults ranging from ages 40 to 68 who provided six or more months of care. The median age for the participants was 56.25, with 70% having a college education and the other 30% with only a high school education. The care recipients diagnosed with Alzheimer's disease were between the ages of 60 to 79 living at home with the caregivers, with the median age of 68.41. The sample included four African American females, four African American males, two Hispanic females, one Asian American female, and one Asian American male, all residents in the Shreveport/Bossier City area. The relevance of the characteristics supports the findings of previous researchers that fewer men are caregivers than women in the general caregiving community (Pharr, Dodge Francis, Terry, & Clark, 2014). Table 2 includes the characteristics and demographic information of the care recipients excluding any formal medical information from a healthcare professional other than an estimated diagnosis date as stated by the participant. For their time and participation, no caregiver was or has been compensated for taking part in this study.

Data Collection

After receiving Walden University Institutional Review Board approval, I followed the data collection process precisely as outlined in Chapter 3. Some individuals received the advertisement from various locations for participation in this research study. Several people who were eager to participate in this study met the inclusion criteria. However, the process required a review of all information for the selection of 10 to 12 participants. After careful consideration, I selected12 individuals and notified them by phone, text, or email. I recruited an additional six participants in case any of the selected participants withdrew from the study.

Purposive sampling proposed a level of control rather than being at the mercy of any selection bias inherent in pre-existing groups. The objective was met with the small sample size of this quality which did not include an overall generalization of caregivers of Alzheimer patients. Rather, this qualitative research study sought to provide an understanding from the minority caregiver's perspective based on cultural diversity and the care provided to family members or friends diagnosed with Alzheimer’s disease. The collection and analysis of data for narration were intended for clarification purposes, understanding and exploration into the small sample size, not the overall general caregiver population.

All acts of participation were strictly voluntary without compensation during this research study. The method for collecting data included scheduled interview and follow-up sessions that were semi-structured. The next step involved the scheduling of each interview and follow-up session was completed only after conferring with the participant not to impede upon their schedule. Finally, as a reminder, a confirmation message was sent by text or email should any matters of concerns arise and the sessions needed to be rescheduled.

In the role of researcher as the primary tool for collection and analysis of data, preliminary introductions between myself and the participants were important to establish rapport (Creswell, 2009). During each session, the context of the consent form was read in its entirety to explain the purpose of conducting this research study and the method used for the recruitment selection criteria before signing. Each participant acting as a volunteer was given ample time to reconsider should doubts arise before, during, and after participating in this study. Upon agreeing to participate, each signature was required in addition to a copy given to the participant, and a copy kept on file for the researcher's record per Walden University's IRB guidelines. The consent forms although signed before the study setting location did not hinder the collection of characteristic and demographic information (Appendix E). Being able to speak with each participant prior explaining the research process served to establish a positive rapport further. Next, the interview sessions began with a set of semi-structured interview questions with prompts created by myself (Appendix F) to guide the face-to-face interaction for more open-ended responses. Lastly, the minority caregiver was given the opportunity to discuss further, what their lived experience in this new role has reflected the challenges and barriers encountered.

It seemed evident within the findings of this research study that “social support and human connection” is an essential factor for effective means of support and communication between minority caregivers, Alzheimer patients, and health care professionals. “They understand me or my cultural traditions,” or they do not understand me or my cultural traditions” characterizes frequently mentioned descriptions as the reasons for effective or ineffective communication for the minority caregiver at the time of the current phenomena. Each participant seemed to transcend the technical and power barriers where culture, social support, and positive interaction are encouraged within the community.

It was imperative that all quotes selected from the interview sessions were used in support of data findings to be interpreted and not used to illustrate a biased opinion. The quotes were only used with the signed consent form of each participant per the approval of the Walden University Institutional Review Board. At the concern of the participant confidentiality and anonymity concerns still existed based on whether their identity could be recognized. The extraction of specific quotes written was to provide the reader sufficient information based on the arrived results and conclusion of this study. While there was the contradiction of participants being identified by their responses, these were minimal to non-existent as previously stated in Chapter 3, also, no unusual occurrences throughout the process.

Data Analysis

The steps developed by Moustakas (1994) were the basis for the analysis of data collected during this research process. Throughout this qualitative research study which took a phenomenological approach, I was solely responsible as the primary instrument in the collection and analysis of data. As an important entity, the separation of bias according to Moustakas (1994) was the incorporation of the four components of the data analysis model. Therefore, any inter-related or personal thoughts were maintained separately from that of the participants. As another effective approach to epoch, the collection of responses through careful listening, critical thinking and asking additional probing questions was important to the in-depth insight of the minority caregiver lived experience (Moustakas, 1994). The process of data reduction and elimination irrelevant to that of the research question for understanding, conceptual, regarding a specific theme based on the responses given to the research and impromptu questions (Moustakas, 1994). All responses made were equal to those of value to the research study (Moustakas, 1994). The completion of the analysis process included the final data bracketing for themes specific to responses during the interview sessions (Saldaña, 2013). While the coding consistency data saturation was achieved, additional follow-up sessions were only necessary to reach unanimity of data coding for specific themes.

Evidence of Trustworthiness

In this qualitative research study, a phenomenological approach was taken to explore the lived experience of minority caregivers. The evaluation of this research study according to Lincoln and Guba (1986) is where the trustworthiness is postulated. The focus for this study relied heavily upon the establishment of credibility and confirmability. Because of the small sample size, the findings could interpret a generalization for the general caregiver population thus making the transferability inapplicable (Lincoln & Guba, 1986). The phenomenological approach explored the lived experience of minority adults with six or more months of care in community dwellings to family members or friends diagnosed with Alzheimer's disease. Dependability another method of established trustworthiness in qualitative research was limited and therefore was unsuited due to the number of participants (Lincoln & Guba, 1986). To have included dependability would have required an efficient way complete a research audit during and after the collection and analysis of data that could be replicated in future studies (Cohen & Crabtree, 2006). To further strengthen the credibility and validity of the data collected, triangulation was employed to ensure the accuracy and clarification of the responses made by each participant. After the participants completed a thorough review of the interview responses, confirmability was used for the measure of trustworthiness for confirmation of study results. Furthermore, the strength of the credibility and confirmability was ensured regarding bias and personal involvement. For clarification, this included information that was documented as a part of my beliefs and bias that could have the potential to influence the data.

Study Results

The rationale for this study was to provide an established understanding of the lived experience of minority caregivers and care recipients diagnosed with Alzheimer's disease. The gaps in research identified minimal studies in the exploration of cultural perspective and backgrounds as reasons for the lack of intervention with social support or interaction among health care professionals. This study’s objective is to provide an interpretation for health care professionals and community-based social support program developers about existing cultural influences of caregiver responsibility, prolonged diagnosis of Alzheimer's disease, understanding the disease, and health disparities to both the caregiver and care recipient without proper social support systems. As noted in the literature review of Chapter 2, the following themes evolved after a consideration of the transcribed data: the cultural perspective, unavailability of social support resources, diverse community-based social support programs, emotional and financial hardship, healthcare disparities, and interaction among minority caregivers and health professionals. The primary method of exploration into the lived experience of minority caregivers of Alzheimer patients was based on the central research questions. The following issues that evolved because of the primary research questions were:

1. What is the cultural perspective or influences surrounding the shared lived experience of a minority caregiver?

2. What is comprised of the responsibility of daily living assistance that is provided to the care recipient?

3. What is important from a cultural perspective that is necessary for the development of community-based social support programs and resources?

Results by Main Themes

Theme 1: Understanding the Cultural Perspective of Caregiving by Minorities

The cultural concept of caregiving among each participant is relevant to the shared lived experience passed from generations and expected of future generations. Each member interviewed expressed shared ideas about the personal obligation of daily care provided to elderly loved ones as an embedded right without question. This perspective was a common response among minority caregivers that the responsibility is subconsciously rooted in nature rather than by deliberate decision of acceptance. There were also times during the interview sessions where the minority caregiver expressed concerns of impact to their personal life and health in addition to other responsibilities such as work and family.

Table 3 provides an in-depth illustration of the unique similarities of the cultural perspective of caregiving. The following responses were transcribed by the responses given by each participant to RQ1 and IQ 4-6. A documentation of participant's response to the current phenomenon of minority caregiving was captured and documented verbatim as noted in Table 3. In the following chart, a random selection of participant responses has recorded concerns that emerged from the first theme. Through an interpretative collection of data, there was an in-depth exploration of similar and different shared responses considering the diverse cultural influences.

Table 3

Understanding the Cultural Perspective of Caregiving by Minorities (Interview Questions 1-10)

	Individual Response	Response & Observation Analysis
MC#1	"Yes, the demands are overwhelming and burdening, but this responsibility is the forefront of our culture that has been passed from generation to generation."	Very well versed on the topic of culture.
MC#4	"It is not a matter of choice to care for a loved one with a chronic illness, respite care does sound tempting, but not at the expense of feeling guilty when leaving your loved one for personal time."	Seemed emotional when responded, but interested and committed, but with some feelings of remorse.
MC#7	"I know that need to recharge now and then, but I feel as if the pre-existing respite programs do no offer a form of strength to diverse persons."	The response gave the impression that there is disconnect between community programs and minority caregivers
MC#8	"Despite the pressure that is placed on my well-being it is not only a cultural thing, but also my savior that keeps me going."	The context of religion showed a "peace of mind" in the following response.
MC#10	"You eventually their needs above your own ignoring the fact that you are becoming a hidden patient."	Straightforward response with no emotions.
MC#12	"It is often difficult to turn to others for support when they do not fully understand Alzheimer's disease. I just choose to pray about it."	There were some feelings of aggravation when expressing the difficulties of getting others to understand the current situation.

Theme 2: The unavailability of formal or informal social support resources for minority caregivers providing care to Alzheimer patients living at home

The second theme addresses research aimed at protecting the care recipient from an ill-prepared family caregiver. Throughout times, culture has been instilled upon minority family members handed down from generation to generation. The identity of culture as explained by Baider and Surbone (2014) "is not limited to: race, ethnicity, national origin, migration background, gender identity, sexual orientation, marital or partnership status, and spiritual, religious, and political affiliation" (p. 1). For a minority family, cultural influences become relevant when loved ones require care in addition to the personal support of the caregiver during times of illness. MC#12 stated that "Often when taking on such responsibility, you do feel unprepared because it is that cultural influence that has been instilled. And as such, there is that lack of knowledge to deliver proper care".

A majority of the participants acknowledged there are differences and similarities when it comes to cultural differences, yet it would be essential to provide access to healthcare knowledge on both the macro and micro level (Schim et al., 2010).

MC#5 response was not very different from that of MC#2 where it was mentioned that being a caregiver for family members will always be considered the norm. Cultural diversity with respect to those that participated in this study believes in a higher power and the closeness of their family when it comes to caring for elderly family members. MC#7 discussed the lack of open communication between the adult minority and healthcare professionals that prevents them from gaining the knowledge on proper healthcare and personal care. Most of the participants felt this left ill-prepared when it comes to the care of the recipient and their health and well-being. Themes extracted from the data collection emphasizes the need for active engagement between minority caregivers and healthcare professionals providing healthcare education and community-based social support systems.

Theme 3: Being the voice for community-based social support programs tailored for diverse cultures

The critical responses to IQ3 were pervasive when it came to the analysis and transcription of theme 3 utilizing the following. MC#4 response to IQ#3 was "there is never enough support provided to minority caregivers." MC#4 also stated, "With all the programs available the focus is on the general population of caregivers with minimal diversity which is many minorities rely on such coping mechanisms like religion."

Both male and female minority caregivers shared similar responses on pre-existing community-based could be culturally tailored specific to minority caregivers. Minority caregivers also found that receiving information or answers promptly from a healthcare professional can be a task. There were also issues noted during the interview sessions that included the inability to discuss emotions and feeling alone while the general population of caregivers had reachable outlets. MC#1 responded to the RQ3 and IQ3 when asked about the potential for developing community-based social support programs whether telephone, community, or computer-based:

…If there are ways to help me cope because nowadays I am running on auto pilot…I have to find the means to control my anger if not I find myself near a breakdown, but for the sake of my family, any social support program would suffice.

MC#10 response to IQ3 focused on the lived experienced being physically and emotionally exhausting responsibility because this was their spouse, yet they were unable to adapt to various stages of Alzheimer's disease:

…If sleep was a thing I could tell you or remember the last year when I got a full eight hours…it was when my spouse passed away that I suddenly realized that my health was in jeopardy….I never fully understood why this even happened to my partner I just know I had to be there day and night.

MC#6 and MC#8 have similar responses to RQ1 about their feelings toward isolation from friends and family, yet they felt their decision to have any personal time made them feel guilty even for a few minutes:

MC#6…The emotional guilt I felt over giving my responsibility to another family member or a formal caregiver was a burden in itself. I kept telling myself that it would not be right and while this is a huge burden, it's mine and no one else. MC#8...Time and time again I knew the responsibility of caring for a patient with Alzheimer's disease and that is why I could not pass on my responsibility. I knew the Lord would help carry this burden.

When asked about overcoming such challenges and barriers, many of the participants stated that it is due in large part to culture, language barriers, lack of healthcare professional intervention, and social support programs. To assist the target population group would require the practicality and development of low-cost intervention programs. These intervention community-based social support programs are developed and adapted in support of the target population group.

Theme 4: Overwhelming stress and finance issues

Minority caregivers lack the "explicit attention to detail" which has caused a significant gap in health care. During an interview session with MC#4, who responded to RQ2 and IQ1 on the role of religion as a coping mechanism when dealing with the stress of caring for patients diagnosed with Alzheimer’s disease. In this study, the literature review provides documented research exposing the potential hazards of the lived experience of minority caregivers. MC#8 gave insight to each of the following questions stating how "the cultural influences and the diverse backgrounds other minorities play a significant role when it comes to the responsibility of caring for a loved one with an acute or chronic illness." MC#9 felt that not only was it a duty to fulfill but that it is almost impossible to pass on that responsibility. In most cases, as stated by MC#11, minorities do not look to the impact of the overwhelming stress and financial issues, thus failing to realize the burden of care places them at risk of becoming a secondary patient affecting their well-being and the care recipient.

For many minority caregivers, the typical lived experience is one where culture overrides the association of caregiver burden caused by the different stages of Alzheimer's disease. These stressors as defined by Pearlin, Mullan, Semple, & Skaff, (1990) are conditions that present problems or difficulties experienced by adults often placing an emotional, physical, and financial strain on their ability to adapt to this responsibility. The utilization of a modified conceptual framework model was specific in addressing this theme and the overall lived experience of minority caregivers. Despite substantiation of differences among the diversity which surrounds the lived experience of minority caregivers, the outcome would involve culturally tailored pre-existing community-based social support programs that address the unknown differences based on the extensive research provided in this study.

Theme 5: How to effectively approach healthcare disparities such as screening and diagnosis of disease, and healthcare access for both the caregiver and recipient

The following topic coincides with the unswerving and adverse disparities among minority caregivers and care recipients diagnosed with Alzheimer's disease. In the literature review, there are known gaps associated with the occurrence and prevalence rate, mortality, active clinical trial participation, treatment and care, health professional intervention, social support programs, quality of care, and knowledge of attention at home. The underlying reasons included cultural influences, diversity, socioeconomic factors, discrimination, and health care professional, cultural incompetence. The gaps in research provide information about these disparities, however, there is little known about ways to actively engage practical approaches, such as programs on cultural competence for health care professionals and the evaluation of intervention programs for the target population group.

Research questions focused on the minority caregiver found that healthcare professionals' treatment viewed as racially biased or prejudice. MC#1 explained there was a feeling of being looked down upon or being treated with less respect. In response to the interview questions, MC#5 explicitly stated, "During a visit to find out if there was a memory lapse problem with their loved one, the healthcare professional lacked empathy and made little to no contact with either of them." MC#2 felt as if there was a feeling of stereotyping where the health professional could have collaborated and communicated more breaking that barrier that was between the three of them. These problems are linked to areas that include lack of interaction, communication, and the absence of diverse community-based social support programs. The consequences of providing informal care to Alzheimer patients in a community dwelling are even more pronounced as seen when the participants were asked questions specific to the coping problems noted in Figure.2; (a) balancing personal/family needs, (b) physical health (c) mental health (d) finances (e) lack of social support systems (f) relationship with healthcare professionals (Figure.2).

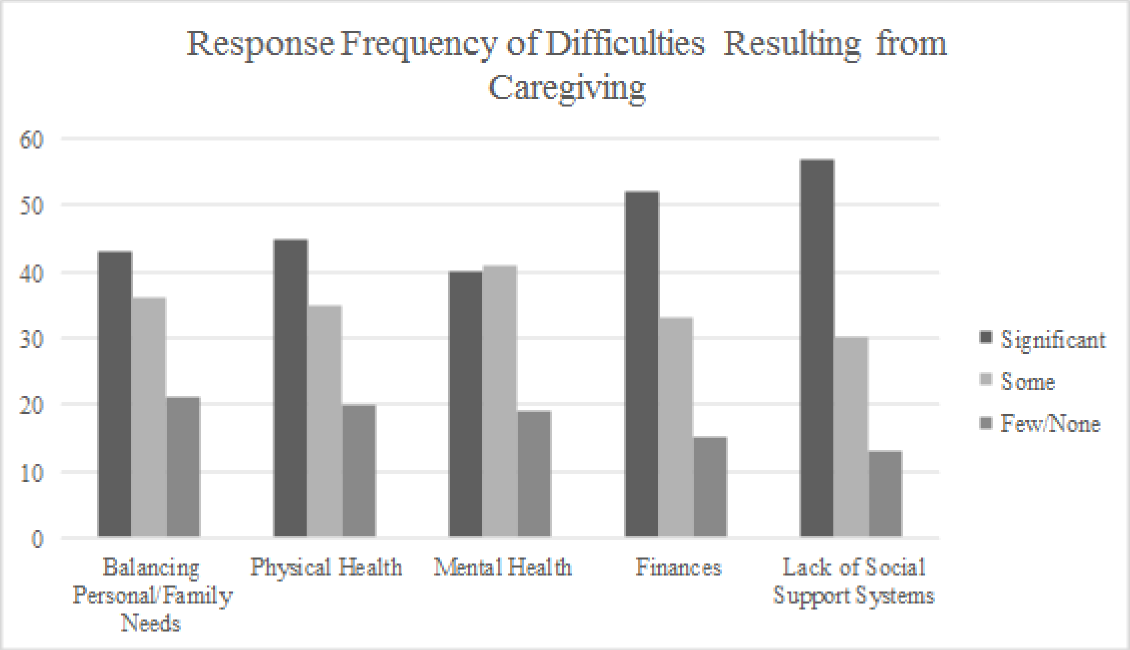

Figure.2. Frequency of caregiver responses by specific terms

Tables 1 and 2 describe the socio-demographic attributes of the 12 minority caregivers interviewed. In Table 3 there are quotes from selected responses provided by participants specific to the five themes. Each theme was independently detailed, linked to other themes, and organized collectively with similar themes. In Figure 2 groups of responses and the frequency of difficulty associated with caregiving were categorized as follows: (a) balance personal/family needs; (b) physical health; (c) mental health; (d) finances; and (e) lack of social support systems. While the role of being a minority caregiver is one of cultural responsibility many found it difficult when it came to managing their role. This also included finding ways to cope with the increased one-sidedness of being a caregiver which has led to extreme caregiver burden. Because the responsibility of care among the participants included a diverse cultural influences such as feeling of unpreparedness, lack of knowledge, and minimal to no guidance from healthcare professionals. These results suggest the importance for the healthcare professionals to understand the minority caregivers' cultural values, beliefs, and lived experiences as important determinants of health in general and the minority Alzheimer's Patient population in particular. For the majority of the study each participant understood that assistance and support was a necessity and therefore not a luxury. Based on my empirical observation in the current research it was found that the closest Alzheimer's disease chapter is located in Baton Rouge, Louisiana. This meant that the participants would have to phone in for assistance or make a four-hour trip to the nearest chapter. Many of the research participants were unaware of the existence of a support group for caregivers of Alzheimer's patients. This suggests that outreach efforts would be needed in informing the target community the availability of such resources using appropriate public health messaging and health promotion tools.

Summary

After the interview sessions, the participants were asked if there was other information they deemed necessary to decrease the burden of care. Regardless of cultural influences and the challenges faced by minority caregivers, nearly all the participants except one still had a feeling that this responsibility was rewarding in other words being able to spend that time with their loved one. Each theme generated in this research study not only emphasized the meaning and understanding of diverse culture from the perspective of minority caregivers, but also the burdensome task, lack of social support, healthcare professional relationship, and barriers to coping mechanisms. Integral to the fabric of all interviews was the constant cultural diversity, love, and care provided to the loved one. The lack of knowledge regarding what Alzheimer's disease and what to expect made an already difficult situation at times seem almost unbearable. Likewise, the inaccessibility of social support systems meant that resilience is important for the individual enabling them to sustain themselves in their new role. Lastly, the data highlighted how misunderstood minorities felt in accepting the role, often by close family members and those in the healthcare profession.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In Chapter 5, I discuss information discovered during this study exploring the lived experience as told by minority caregivers. I also present conclusions of the findings and recommendations for future research as it applies to a larger scope. Furthermore, because this is a qualitative study with a phenomenological approach, the interpretation is only significant to the twelve participants from a cultural perspective.

There are factors such as the inadequacy of understanding and awareness of the diverse cultural beliefs, roles, and responsibilities concerning the care of elderly minorities, healthcare interaction, and social support systems. Minority elders with Alzheimer's disease represent a significant portion of Americans being cared for by family members or friends in the home. However, there is minimal information involving the cultural aspects of understanding, awareness, caregiver health, healthcare interaction, and social support systems. Previous research studies were comprised mostly of the general caregiver population.

The primary objective of this study was to explore certain factors influenced by the culture of the minority caregiver perspective, disease knowledge, and sociodemographic status. Study participants included 12 adult minority caregiver residents of Shreveport/Bossier City, Louisiana between the ages of 40 and 68, attendees of selected community churches, who met the inclusion criteria and agreed to participate. Each participant completed three survey instruments: Demographic Information (Appendix E) and Interview Questions with Prompts (Appendix F).

In keeping with the research gaps noted within the literature review, significant barriers and challenges were revealed hindering the care of the recipient and placing the caregiver at risk of becoming a secondary patient. I used the following research questions to guide my exploration of the findings.

RQ 1: What are the lived experiences of family members of minority Alzheimer's patients as caregivers?

RQ 2: What cultural beliefs or spiritual beliefs have influenced the experiences of minority caregivers?

RQ 3: How does knowledge, socioeconomic status, or perception justify the disparity in the minority caregiver's willingness to obtain health care for caregiver burden?

Interpretation of Findings

Throughout the interview sessions, "culture" was the one constant mentioned by each participant. It linked together all the themes associated with this study. Culture served as a significant factor that facilitated the expectation of caregiving reinforced through traditional norms. Culture encompassed the actions of the participant and at times their emotional responses during the interview sessions. This is supported by the research of Ar and Karanci (2017) who focused on the understanding and awareness of cultural diversity among Turkish adult caregivers and their roles. As with minorities in the United States, and like Turkish caregivers, the acceptance of caring for a loved one is viewed from a cultural perspective as a sense of empowerment that is a fulfillment of purpose and meaning (Ar & Karanci, 2017). The data in Table 1 reveal the added responsibility of being employed, yet still, being involved in the care of the recipient. Table 2 provides demographic information based on responses from each participant's personal relationship involving the care of the recipient that is either a family member or friend. The population data received was critical to the cultural perspective and viewpoint of adult minorities considering their new-found role and responsibility.

In Chapter 2, much of the literature focused on the significance of caregiver burden concerning the role and accountability of caregiving from an adult minority perspective. The concept of caregiver burden emphasizes not only the required responsibility, but also the physical, mental, and emotional impacts. While the participants did not explicitly reference caregiver burden, they referenced feelings of being overwhelmed. As with the research for this study, previous researchers have acknowledged that the overall general population of caregivers provide intensive and exhausting care for a loved one diagnosed with Alzheimer's disease (Kahn, Wishart, Randolph, & Santulli, 2016). Table 3 provides a synopsis and observation of each participant's perspective on the shared lived experience as that of a positive one. During the interviews, I sometimes observed feelings of unexpressed guilt in addition to overt acknowledgment of the physical, mental, or emotional impact that can result in the caregiver's becoming a secondary patient (Adams, 2010).

The participants selected for this study were a critical of professionals in healthcare and public health. I noted this in Theme 2 where the participants were displeased with the care received by their loved one. As the primary caregiver, these participants shared similar responses concerning inadequate care and at times often questioned the quality of care. The distrust based on the responses documented during the collection of data was consistent with cultural beliefs, social impacts, and historical events that are influential in how adult minorities feel they are being viewed by healthcare professionals and other family members. According to Keefe (2010), minorities have acknowledged the existence of health disparities. Keefe (2010) also noted that healthcare professional prejudices and delays in care stem from the existence of bias and discrimination rooted within the minority community. Smedley et al., (2003) also indicated that there is evidence that health care professionals are unable to provide care due to patient bias or stereotyping. The distrust that has become a phenomenon is where minorities feel a sense of suspicion towards the healthcare professionals and the place of care (Sue & Sue, 2016). This distrust leaves many minorities more reliant on familial care and religious support as the primary care ahead of formal care (Sue & Sue, 2016).

The collection of data and qualitative analysis revealed differences between the overall caregiver population and the minority caregiver population. Minority caregivers encountered a more complicated set of barriers that involved cultural influences that are not only important for interpretation but also as the subject of further research. These individuals contend with the burden of care, acceptance of caregiving, secondary health issues, and financial concerns (Gillespie, Harrison, & Mullan, 2015). Although I deemed social support systems a necessary protective factor for minority caregivers, there is also the caveat of a negative association regarding the availability of social support systems. The role of social support systems is pivotal in providing support and feelings of worth among minority caregivers. Having a support system, whether familial or social, is essential in maintaining established relationships, coping mechanisms, and lifestyle modifications.

When any of the following are unmet or unfulfilled within the family social support system, the result tends be conflict. In understanding this interpretation of the findings, cultural diversity was acknowledged as a negative encounter which placed strain on the family social support systems. However, the lack of social support system among minority family members was more prevalent in this study. The voice of each participant was not only heard, but it was important to share because community-based social support programs that are culturally diverse require a collaborative approach (Todorova, Turner, Castaneda-Sceppa, Young, & Bonner, 2016). Although the voices of the participants are important, there is also the equitable involvement of empowering the community and ensuring a culturally relevant intervention program. The scope of these specific principles is critical to the guided approach in the development of programs that serve multicultural community residents.

Table 3 provides the frequency of variables which impact the quality of care necessary for the care recipient. It details the impact of finances that has led to significant caregiver burden. According to the Alzheimer's Association (2014), the overall general population of caregivers has experienced financial difficulties where they either had to take a leave of absence, switch from full- to part-time work, or quit altogether. There was also a decrease in spending accounts to include retirement and educational account for those with children to provide for the care recipient (Alzheimer's

Association, 2014). Additionally, the increased burden of care will impact the care for the recipient and may impact the health of the caregiver. For an effective social change, it is important to understand the resources available and beneficial programs necessary for caregivers to know during disease progression. Minority caregivers will benefit from individuals understanding their needs to balance personal/family needs, physical health, mental health, and the lack of social support systems.

Despite the cultural disparity, minority caregivers of diverse population groups often see a delay of diagnosis or inadequate treatment for family members or friends in their care. This study explored these disparities by conceptualizing the Alzheimer's disease process as a product of mainly cultural factors, but also socio-demographic factors. The known cultural factors noted during this study included various perceptions; (1) what is considered normal and not normal for the aging process, (2) inaccessibility to adequate healthcare, and (3) the lack of trust between the minority community and health professionals. Besides these perceptions, racial bias is also a complication that is inherent to the screening process. Being that I conducted this study with a small sample size, the responses only provide an understanding of this target population and would require further research with a larger diverse group.

Limitations of the Study

Numerous limitations to this study are noted within this section. The first limitation of this study was the sample size. As discussed in Chapter 3, the recruitment process for this qualitative research study consisted of 12 participants, sufficient to the transference, yet unsuitable for a general population of Alzheimer’s disease caregivers.

Having a larger sample size would have been inappropriate for this study. A further limitation was that African American caregivers made up the majority of the purposive sampling pool whereas there only four were either Hispanic or Asian Americans. Another limitation was an absence of rural minority caregivers. If rural minority caregivers had been included in this study, there would have been added cultural experiences from rural residents. Additional research is required to expand upon this qualitative study to provide for further exploration of the minority caregiver cultural phenomenon of care and loved ones diagnosed with Alzheimer's disease in Louisiana.

Recommendations

The most notable recommendations that resulted from the data gathered during the initial interviews and additional follow-up sessions during this study are (a) minority caregivers, (b) healthcare professionals, and (c) future research.

Recommendations for Minority Caregivers

Minority caregivers involved with the care of loved ones clinically diagnosed with Alzheimer's disease should consider the following:

1. Consistently reflecting on the cultural, social, and community component to determine the level of disruption between family relations and needs. There are also the challenges whether influenced by culture when accepting the responsibility that will cause disruptions and cause further estrangement between current values and actual behavior. Furthermore, intervention and social support tailored to the adult minority will increase caregiver knowledge, reduce caregiver burden, and improve the quality of health.

2. Actively seeking effective coping mechanisms from other minority caregivers of shared circumstances who have learned to balance their responsibility of care to the recipient and family. Starting points would include informal networking, community-based social support programs, and healthcare professional intervention programs.
3. Put forth the effort to establish realistic goals and expectations when making time available for each cultural value: devotion to religion, family, employment, and self;
4. Available for each cultural value: devotion to religion, family, employment, and self.

Recommendations for Healthcare Professionals

Healthcare professionals should consider:

1. Developing a systematic approach to assist health professionals in closing the gap between diverse ethnic groups within the United States is a serious situation that calls for education on attitudes, knowledge, and skills known as cultural competence. Some professional associations have endorsed cultural competency education as a valuable training tool. The evidence is clear that cultural competence is necessary for current and continuing practitioners in the healthcare field. Cultural competence itself as an education tool is a combination of various medical and nursing school programs that are not standardized or universal in content (Horvat, Horey, Romios, & Kis-Rigo, 2014).

2. Healthcare professionals will be assisted in the awareness of understanding the in-depth relevance of cultural competence. The training will encompass the issues involving diverse population groups in addition to focusing on their personal needs for education in terms of quality healthcare delivery for both the minority caregiver and Alzheimer patient. There will also be the inclusion of policymakers for the drafting of requirements and regulations that cover the quality of care and advocates for the promotion of such programs that serve the diverse communities.
3. Alternative social support from social workers can assist minority caregivers with community-based social support programs with Alzheimer's disease information and informal caregiver education to include cultural awareness. Support from social workers gives minority caregivers that added attention when being overlooked because of their cultural values. Minority caregivers will be provided the full knowledge of Alzheimer's disease, the different stages, and the type of care involving cognitive disease. These individuals will encourage supportive direction and care as the go between the caregiver and family members in areas of respite care, education, coping mechanisms, disease familiarization, based on cultural needs.

Recommendations for Future Research

For future research, it is recommended that an expansion of additional research would be necessary to provide an in-depth scope of this study. Minority caregivers have taken on a role that has been culturally instilled in their families from generation to generation. From the perspective of the participants, there needs to be more awareness of culture and how it impacts the lived and shared experience of these adult minorities.

Thereby, intervening with coping mechanisms to manage the burden of caregiving and diminish the gap between healthcare professionals. Due to the limitation of the scope of this study and selection of qualitative research as the preferred methodology, I would recommend additional information regarding the following topics to further develop and validate the outcomes of this research study:

1. A purposive sample size of 12 minority caregivers acting as the primary caregiver of their loved one clinically diagnosed with Alzheimer's disease was the central focus of this study. To generalize the future outcome studies could be completed with an equal number of minority and general caregivers to compare outcomes.
2. In this qualitative research study using a phenomenological approach, data was captured through semi-structured interview sessions and follow-up sessions as needed. The lived and shared experiences of those participants provided validation for the unknown concerning culture influences and its impact on the individual.
3. The minority caregivers that participated in this research study had a variety of demographics. Future research studies should focus on the general caregiver population group.

Social Change Implications

Given the knowledge of explored information and the gaps in the literature of this research study, minority caregivers of loved ones clinically diagnosed with Alzheimer's disease are in desperate need of support. The application for active social change support from family members and friends is important when assisting the primary caregiver in addition to social workers who can provide Alzheimer's disease and informal caregiver education. It is not only important for the primary caregiver to understand the full scope of this disease, but also their family members.

Participants in this study displayed considerable respect not only to the cultural values, but also to the support needed by family members and friends that have been diagnosed with Alzheimer’s disease. Despite their enduring care, these individuals expressed a critical need of support, cultural understanding, and awareness to remain in the life of the care recipient. There was also the importance of intervention from health care professionals to show compassion for culturally diverse population communities. As we move forward there must guidance specific to the minority community for the development of diverse community and educational-based social support programs, respite care, coping mechanisms, and self-reliance to ensure the quality of care provided.

Additionally, there needs to be more intervention and developmental programs aimed at culturally diverse caregivers of Alzheimer's patients. While the general aspect of education and public awareness is necessary intervention methods should include community groups and conferences, self-care coping mechanisms, and more occurrence of respite care. Because of the various status and financial burden, the costs of short-term respite care should be afforded as needed to minority caregivers for their loved ones.

Conclusion

The cultural aspect of caring for your loved one that has been clinically diagnosed with Alzheimer's disease presents with unique challenges that cause emotional, physical, and mental strain not mention financial burden. Despite cultural influences as a means of taking on the responsibility of caregiving adult minorities are becoming an increased risk of becoming secondary patients. This in turn hinders the care of the recipient being cared for in the home. Thereby, data captured for this research study was pertinent to this study for social change based on the exploration into the lived and shared experiences of each participant.

As the rate of elderly minorities being diagnosed with Alzheimer’s disease continue to increase so will the need to rely upon those who take on the responsibility of care. Minority caregivers who participated in this study discussed the cultural norms in addition to the burden of care and the lack of support essential to the quality of life. It was understood from a personal perspective that although culture was significant in the decision-making process, having access to a community-based social support system is. Therefore, a good support system is very important in easing the burden of care, promoting a better understanding of cultural influences, health care professional interaction, and assistance with respite care. This research study also highlighted gaps in research that encompassed the characteristics of diversity within the minority caregiver community and insufficient studies.

The social support system for positive social change allows those influenced by culture to feel some validation without overlooking their health and well-being, and sovereignty while caring for a loved one who has been clinically diagnosed with Alzheimer's disease. While there are useful tools to lessen the burden of caregiving they be must tailored to diverse population groups, personal care, and grief counseling.

Minority caregivers are outstanding individuals who become the primary caregiver of a loved one that has been clinically diagnosed with Alzheimer's disease. Unlike the overall general caregiver population, minorities experience is one of the cultural influences that involves higher levels of caregiver burden which makes them vulnerable to becoming a secondary patient. Therefore, it is essential that the following stakeholders collaborate in the development of a comprehensive plan for intervention purposes and improved quality of care for both the caregiver and care recipient. Research in this study finds that the susceptible adverse effects are identifiable and can be aimed for intervention. Again, this study was conducted from a small sample size of 12 participants that is not to be generalized for the general caregiving community.

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Appendix A: Pre-Screening Questionnaire

This pre-screening questionnaire is being conducted by a researcher named Albertina L. Walker who is a doctoral student at Walden University. Please understand that as a volunteer taking part in this research study you do not have to answer any question or questions due to personal reasons. Please note any unanswered question will exclude you from the screening process to participate in this study.

Minority Caregiver Pre-Screening Research Participant Form

Date: ________________________ Time: __________

What is your current age? _________

If you are 65 or older are you competent to complete this research study? ( ) Yes ( ) No

Do you feel competent enough to understand the reasons for this research study ( ) Yes ( ) No

Are you proficient in English? ( ) Yes ( ) No

What is your relationship to the care recipient?
( ) Husband
( ) Wife
( ) Son/Son-in-Law
( ) Daughter/Daughter-in-Law
( ) Brother
( ) Sister
( ) Other Relative, Specify: ____________
( ) Friend
( ) Neighbor

What is the current age of your loved one/neighbor/friend? __________

Have you been a caregiver to the care recipient for 6 months or more? ( ) Yes ( ) No

Does cultural influences impact recipient care, social support access, and quality of care for yourself and the care recipient? ( ) Yes ( ) No

Has your loved one/neighbor/friend been officially diagnosed by a healthcare professional with Alzheimer's disease or cognitive memory loss? ( ) Yes ( ) No

How many hours of direct care daily are provided to your loved one/neighbor/friend with Alzheimer’s disease or cognitive memory loss?

( ) < 1 hour
( ) 1 – 3 hours
( ) 4 – 6 hours
( ) 7 – 9 hours
( ) > 10 hours

Appendix B: Volunteers for Research Recruitment Advertisement

Greetings,

I am Albertina L. Walker, a Walden University doctoral student. I am accomplishing a research study involving minority caregivers of loved ones or friends diagnosed with Alzheimer's disease living in community-dwellings. The research requires pre-screening process for the selection of 8 to 12 participants with the following inclusions. Please understand that as a volunteer taking part in this research study you do not have to answer any question or questions due to personal reasons:

1) Proficient in English
2) A minimum of 6 months or more as a caregiver to an Alzheimer patient
3) Formal diagnosis of Alzheimer's by a healthcare professional
4) Alzheimer's disease Stage
5) Shared experience with other caregivers of Alzheimer patients

The interview location for participants will be at their personal discretion. All interview sessions will be between 30 minutes and one hour. The sessions will include semi-structured open-ended questions concerning the quality of care, cultural impact, cultural sensitivity, and the health of the caregiver. Information collected during the interview session is strictly voluntary therefore all participants have the right to withdraw from the study at any time and the refusal to answer any question. For the purpose of this study I would like to request permission to display the recruitment flyers for this study. Please forward all responses to the email address below. Your assistance would be greatly appreciated! If you have any questions or concerns regarding this study please contact me at the number below.

Thanks in advance.

Albertina L. Walker

(XXX) XXX-XXXX

Appendix C: Letter of Cooperation

Letter of Cooperation

Date

Dear Albertina L. Walker, PhD Student,

Based on my review of your research proposal, I give permission for you to conduct the study entitled A Story to Tell among Minority Alzheimer's Patient Caregivers: A Phenomenological Study within the ____. As part of this study, I authorize you to distribute advertisement flyers for the purpose of recruitment of participants. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: permission to recruitment participants for your research study. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the student will not be naming our organization in the doctoral project report that is published in Proquest.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

Walden University policy on electronic signatures: An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically. Electronic signatures are regulated by the Uniform Electronic Transactions Act. Electronic signatures are only valid when the signer is either (a) the sender of the email, or (b) copied on the email containing the signed document. Legally an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. Walden University staff verify any electronic signatures that do not originate from a password-protected source (i.e., an email address officially on file with Walden).

Appendix D: Advertisement Posted in Local Community Facilities

REQUESTING ADULT MINORITY CAREGIVERS FOR RESEARCH IN THE CARE OF COMMUNITY-DWELLING Alzheimer’s Patients!

The following minority caregiver of community-dwelling loved ones diagnosed with Alzheimer’s disease research is being conducted by a doctoral student enrolled at Walden University. Ten to Twelve participants will complete a 60 minute individual interview session by telephone or in person. Please note the in person interview session location will be at the discretion of the participant. Each session for the purpose of collecting data for the study will be recorded with an additional information need or verification will require a follow-up call. English is the required language for all participants. The specifics of the interview questions will focus on the cultural influences on the caregiving experience, healthcare professional cultural sensitivity training, and culturally tailored community-based social support or respite programs. Please understand that as a volunteer taking part in this research study you do not have to answer any question or questions due to personal reasons.

Please contact me by email or telephone if you are interested in participating in this study:

Email address: XXXXXXXXXXXXXX

Telephone: (XXX)-XXX-XXXX

Appendix E: Demographic Information

The following questions enquires about you the minority caregiver and family circumstances. Please select the appropriate response or fill in the blank. As a volunteer taking part in this research study you do not have to answer any question or questions due to personal reasons. Please note any unanswered questions will void your participation in this study.

1. Name: __________________________ (will be coded as MC #1, MC #2, etc.)
2. Gender: a. Male b. Female
3. Marital Status: a. Single b. Married c. Divorced d. Widowed
4. 4. Educational Level: a. Less than High School b. High school diploma or equivalent c. Some college, no degree d. Associate's degree e. Bachelor's degree f. Master's degree g. Doctorate
5. Employment Status: a. Employed b. Self-Employed c. Unemployed d. Retired
6. Overall Physical Health Status: a. Excellent b. Good c. Fair d. Poor
7. Length of time since diagnosis: ________
8. What is the current stage of Alzheimer's for the patient: ________
9. Relationship to care recipient: _______________________________
10. Race/Ethnicity: ___________________________
11. Length of time as caregiver: ________________________________
12. Do you receive any assistance from family members? a. Yes b. No
13. Are you a caregiver to anyone else? a. Yes b. No; If yes, is the individual a family member or friend? ______________________
14. Are there additional persons living in the household? a. Yes b. No; If yes, how many?

    ____

Appendix F: Interview Questions (With Prompts)

The following Prompts will be used in conjunction with the research questions to provide awareness and understanding of the cultural influences as a minority caregiver of Alzheimer patients. As a volunteer taking part in this research study, you do not have to answer any question or questions due to personal reasons. Please note any unanswered questions will void your participation in this study:

1. How does the influences of culture impact the experience of being a caregiver?
2. Can provide insight on lack of available social support resources?
3. What are some types of social support programs that you would like to see developed for the minority caregiver?
4. Is the responsibility of being family caregiver a cultural norm minority communities?
5. Do you consider yourself as an informal family caregiver to your care recipient?
6. What does your role mean to you?
7. Why is the caregiving role for minorities heavily influenced by culture?
8. Has the overall lived experience from a cultural viewpoint been more or less negative in terms of adequate care for the recipient?
9. Do you have any common interests or experiences shared with other minority caregivers?
10. Are there any unexpected barriers or challenges that limit the ability to provide adequate care to the recipient?

Appendix G: Confidentiality Agreement

CONFIDENTIALITY AGREEMENT

Name of Signer: Albertina L. Walker

During the course of my activity in collecting data for this research: "A Story to Tell among Minority Alzheimer's Patient Caregivers: A Phenomenological Study" I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:

Date: