African American Dementia Caregivers' Information Needs and Information Seeking Behaviors

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Dedication

This work is dedicated to all those living with dementia and their dedicated caregivers.

To the caregivers of persons with dementia, it goes without saying, this moment would not have been possible without each of you. The inspiration and strength I have gained through our many interactions through this journey has served as fuel for me to press forward and continue through to the end. Each of your experiences are paramount in educating our communities and developing useful resources. I sincerely thank each of you for sharing your experiences with me and praise the dedication and strength each of you have.

Acknowledgments

Growing up as a child I was taught to give thanks to God in all things. When I started this academic journey, Proverb 3:5-6 was laid upon my heart as my guidance through this program. The passage from the King James version of the bible reads "**Trust in the LORD** with all thine heart; and lean not unto thine own understanding. In all thy ways acknowledge him, and he shall direct thy paths". I thank God for directing my path through this academic journey for I know it would not have been possible without him.

To my dissertation chair Dr. Michelle Kimzey, RN you have selflessly shared your knowledge and experiences with me. I thank you for including me in the many experiences that have broaden my knowledge of dementia and the impact on caregivers. To my entire committee that includes Dr. Kathy Baker, APRN, ACNS-BC, FCNS, FAAN, Dr. Carol Howe, RN, CDCES, FAAN, and Dr. Fayrene Epps, RN, FGSA, FAAN. I thank you individually and collectively for your guidance, support, and dedication through this process.

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To the ladies of Chi Eta Phi Sorority, Incorporated, Top Ladies of Distinction, Incorporated, Alpha Kappa Alpha Sorority, Incorporated, and Links, Incorporated, thank you for being women of excellence. Your mentorship and encouragement continue to help me grow as a woman and community servant. I love each of you and look forward to our continued endeavors to make a difference in our communities.

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African American Dementia Caregivers' Information Needs and Information Seeking Behaviors

Introduction

Memory loss and a decline in cognitive functioning are common difficulties experienced by people as they grow older. However, in some cases, these declines in mental function are significant and interrupt a person's ability to continue living independently. Dementia, which is a term used to encompass general declines in mental ability that interfere with daily life, affects nearly 2% of people who are over 60 years old (Gao et al., 2019). Indeed, over 10% of Americans older than 65 are diagnosed with Alzheimer's Disease, which can cause dementia, and this prevalence is likely to grow to over 15 million people as the baby boomer generation continues to age (Samson et al., 2016). Recent statistics have indicated that older African Americans are up to two times more likely to develop dementia compared to their Caucasian counterparts (Lennon et al., 2022).

Dementia can have a devastating effect on activities of daily living (ADLs) as their ability to judge, think, plan, and organize deteriorates (CDC, 2020). In many instances, the burden of care of people with dementia falls on family members who act as caregivers and perform care services at home. Caregivers often provide care to their family member with dementia at the expense of their own physical, mental, and financial well-being (Samson et al., 2016). Carer burden is defined as the physical, emotional psychological, and financial strain associated with being a caregiver to a family member (Pinquart & Sörensen, 2005). Empirical research has shown that caregiver needs and perceptions of carer burden vary along racial and ethnic lines (Pinquart & Sörensen, 2005). For example, Fabius et al. (2020) found that African American dementia caregivers reported less access to services and more unmet needs than White caregivers while they are also more likely to delegate more time and monthly expenses to care

(Cohen et al., 2019). Having access to culturally appropriate support resources is crucial for dementia caregivers' well-being and ability to provide adequate care (Nguyen et al., 2021).

Importance of the Problem

Caring for people with dementia can be uniquely challenging due to the progressive nature of the disease and a lack of a cure and effective treatment (Engel et al., 2022). As dementia progresses, caregivers take on more responsibilities that extend to providing constant care and supervision of their family member. Scholars have described informal dementia caregivers as 'invisible second patients" due to high rates of depression, anxiety, and stress among caregivers (Schoenmakers et al., 2010). As their responsibilities increase, caregivers are often forced to give up other responsibilities and engagement in social activities, which can lead to decreased well-being (Romano et al., 2022).

Caring for persons with dementia can negatively impact caregivers' mental health, therefore caregivers become less able to perform their caregiving role well (Smith & Graves, 2021). Elderly caregivers are at a 63 percent higher risk of mortality than non-caregivers in the same age group. It is therefore important for dementia caregivers to utilize effective self-care strategies. Identifying the facilitators and barriers to such strategies is a crucial first step toward improving self-care in practice; without understanding the foundational elements, identifying strategies to promote self-care will potentially be ineffective or meaningful. Oftentimes, caregivers are unable to acquire sufficient self-care resources due to a lack of knowledge regarding self-care best practices, a lack of knowledge regarding alternative self-care strategies or techniques, the burden of the patient's behaviors, and difficulty maintaining clear and productive communications with other caregivers, including healthcare professionals and other

informal caregivers (Moore & Cook, 2011). Additionally, in some cultures, stigmas surrounding dementia may prevent caregivers from engaging in help-seeking behavior (Raphael, 2016).

Racial and ethnic minorities are expected to make up 42% of the US population by 2050, an increase that will likely be reflected in an increased dementia care burden (Rosenthal et al., 2014). African Americans living with dementia and their caregivers are more likely to live in communities that have fewer formal dementia care resources such as affordable care homes (Design et al., 2016). Research has shown that African American caregivers experience higher carer burden due to issues such as lower socioeconomic status and systemic racism that limit their access to care resources (Best et al., 2021; Design et al., 2016). Furthermore, African American dementia caregivers typically devote more resources to caregiving (Cohen et al., 2019). Given these observations, it is important to understand specifically the information and resource needs as well as the information seeking behaviors African-American caregivers use to address their concerns. Gaining this knowledge and understanding can help facilitate the strategic placement of resources deemed as important to dementia caregivers and can help providers to be more intentional regarding assessing and addressing the needs of African-American caregivers and the person with dementia.

Statement of Purpose

The purpose of this study was to explore African American dementia caregivers and examine their support, information needs and information seeking behaviors. A qualitative research design was used, interviews were carried out with African American dementia caregivers, and data was analyzed using direct content analysis. The aim was to explore the experiences of African American caregivers taking care of people living with dementia. The overall research question guiding this study was:

What are the support and information needs and the information seeking behaviors of African American dementia caregivers?

Overview of Literature & Theoretical Foundation

Before any studies represented here were conducted, a review of the literature was performed to inform and provide the theoretical foundation that guided the three studies contained in this dissertation.

Literature Review

Alzheimer's disease and related dementias along with the systemic bias experienced by African Americans raise the burden of dementia caregivers compared to caregivers of other ethnic groups (Rote et al., 2019). Informal dementia care is more common among African American families than non-Latino families according to Rote et al. (2019), and approximately 30 percent of family caregivers are African Americans. As a result of having fewer support services available to African American dementia caregivers and more unmet needs in comparison to their racial counterparts, the realities of caregiving for African Americans may be compounded. In contrast to their white counterparts, African American dementia caregivers delegate more time and income to caregiving (Cothran et al., 2021). An African American caregiving network usually consists of multiple individuals who have limited resources and spend significant amounts of time providing care (Bonds Johnson et al., 2022). African American caregivers are generally between the ages of 40 and 64 and those who are working while providing care to a loved one with dementia have been estimated to lose a combined total of $6.1 billion in wages due to hours devoted to caregiving needs (Cothran et al., 2021). African American dementia caregivers are disproportionately burdened by systemic failures and disadvantages are exacerbated by poor access to primary care and distrust of primary care

clinicians (Alexander et al., 2022). It is common among African American caregivers of persons with dementia to feel discriminated against when seeking health care services for themselves or their family members (Bonds Johnson et al., 2022).

The health of the African American caregiver cannot be overlooked. Not only are African Americans at higher risk of developing dementia, but those who are caring for people with dementia have shown to be even at a higher risk for cognitive impairment and premature death (Robinson-Lane et al., 2021). Several genetic risk factors are linked to Alzheimer's Disease and Related Dementias (ADRD) in African American family caregivers, including the presence of the APOE genotype, as well as stress-related conditions like obesity, high blood pressure, and cardiovascular disease (Robinson-Lane et al., 2021). Systemic social inequities such as discrimination and racial issues are well-established contributors to stress for this population (Cothran et al., 2021). When the responsibilities of being a caregiver are added, it can further complicate health outcomes. To reduce this risk and create comprehensive culturally responsive interventions to help caregivers, the development of informed models of care is needed that promote the strengths of family caregivers. Robinson-Lane et al. (2021) conducted a study that collected data from 30 caregivers using a survey. The goal of that study was to identify a culturally responsive model of care that can contribute to adaptive coping for African-American caregivers. The findings of the study concluded that many of the caregivers use common coping strategies such as spiritual coping, church, use of past experiences, and information gathering.

Theoretical Foundation

This study utilized The Middle- Range Theory of Caregiver Stress derived from the Roy Adaption Model as conceptualized in 1984 (Roy, 1984). This theory is a relational construct that assumes that individuals are affected by both internal and external environments known as

stimuli and that they can adapt to these stimuli. Andrews & Roy (1991) argued that the ability to adapt or cope to a given situation varies from person to person. This ability indicates an individual's capacity to positively respond to their environment and is determined by prior environmental stimuli that individual has experienced (Andrews & Roy, 1991). If the pooled effects of the stimuli are less than the individual's adaptation level, the responses are adaptive (Roy, 1976). But if the combined effects of the stimuli are greater than the individual's adaptation level, ineffective adaptation results, as is the case in the burdens and stressors that are faced by African American dementia caregivers. Figure 1 provides a visual representation of the concepts in the Roy Adaptation Model.

Figure 1

The Roy Adaptation Model
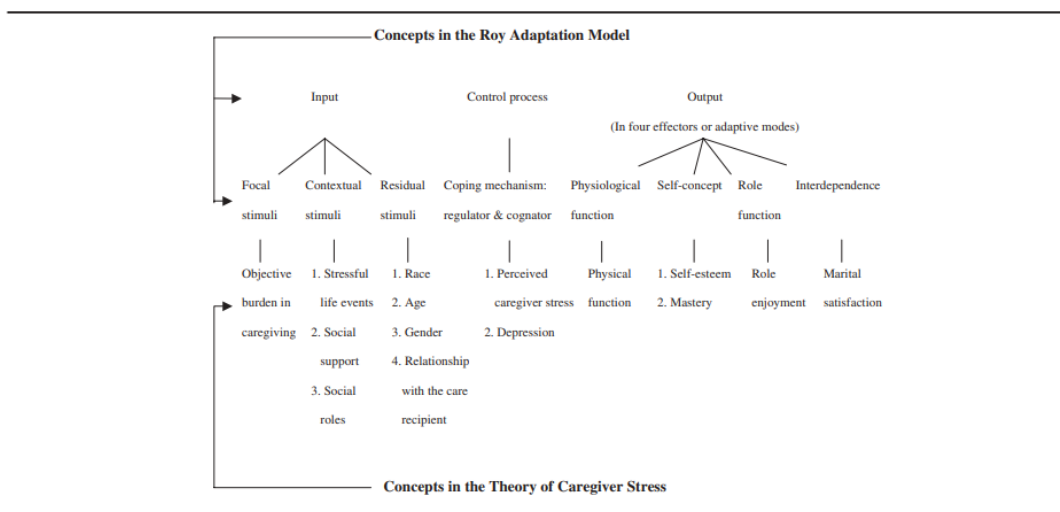
Figure 2. Major Conceptual-Theoretical Structure
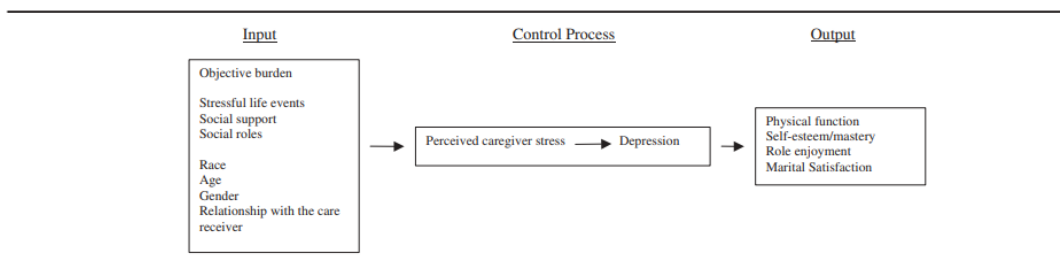
Figure 3. Theory of Caregiver Stress

Note: Adapted from Tsai, P. F. (2003). A middle-range theory of caregiver stress. *Nursing Science Quarterly, 16*(2), 137-145. https://doi.org/10.1177%2F0894318403251789

Objective burden is the African American caregivers' duties or tasks associated with providing caregiving for the loved one with dementia, such as hours of care and care arrangements, which activate the coping mechanism and prompt caregivers to seek available physical and psychological resources to cope with caregiving. Caregivers who perform more hours of work and provide more direct patient care, in the case of African American caregivers experience more stress and adverse health outcomes than their counterparts. Caregiver burden may disrupt the caregiver's life in terms of finances, other roles, and interpersonal relationships (Thompson & Doll, 1982). Figure 2 below shows a visual representation of Roy's Theoretical Model.

Figure 2

Theoretical Model and Hypothesis from Roy's Model
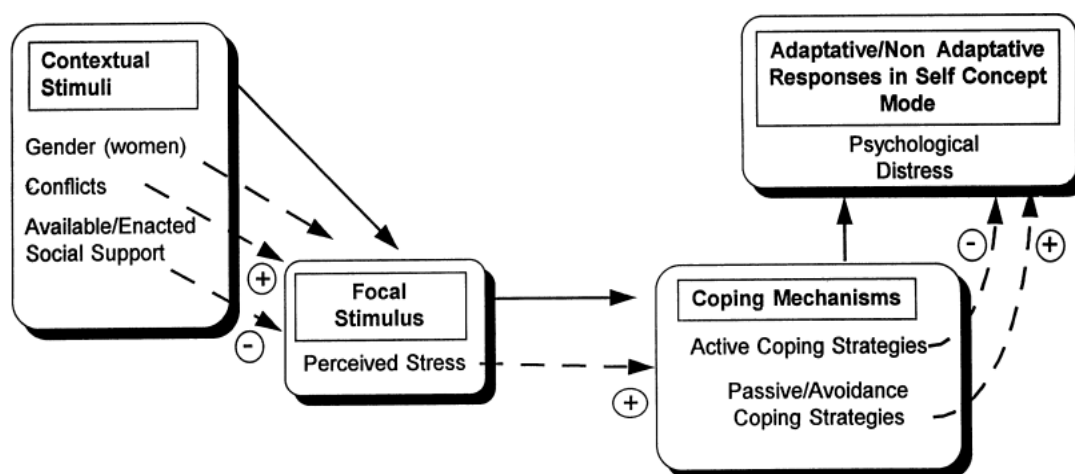
Note: Adapted from: Levesque, L., Ricard, N., Ducharme, F., Duquette, A., & Bonin, J. P. (1998). Empirical verification of a theoretical model derived from the Roy adaptation model: Findings from five studies. *Nursing Science Quarterly*, *11*(1), 31-39.

There have been numerous studies conducted using Roy's Adaptation Model and caregivers. The study by Hatami and Hojjati (2019) used this model to determine its effect on depression, anxiety, and stress in caregivers of chronic psychiatric patients. A randomized controlled trial was conducted with 46 home caregivers. The results indicated the Roy Adaptation Model-Based training reduced depression, anxiety, and stress of home caregivers of chronic psychiatric patients. The Roy Adaptation Model was also used as a theoretical framework for the study by Robinson-Lane et al. (2021). The goal of the study was to test the feasibility of recruitment and participant burden that can be used to identify culturally responsive models of care that can promote adaptive coping for African American family caregivers. The study was guided by the Roy Adaptation Model and concluded that while African Americans are well-educated, there are also underlying health concerns such as obesity, hypertension, and diabetes that are further complicated by caregiving stress. Common coping strategies that were found from the study were spiritual coping, church, use of past experiences, and information gathering.

Roy's Adaptation Model has been used in numerous studies, including dementia caregivers, and proves to be a well-supported model to understand the challenges and barriers for African American caregivers while still allowing for sociocultural values and beliefs to be considered. As stated by Dilworth-Anderson et al. (2020), cultural beliefs have a profound influence on health determinants. Roy Adaptation Model is a universally accepted model and is adaptable to these socio-cultural factors through conceptual and residual stimuli identified in the

model. Sociocultural perspectives and beliefs that contribute to the actions and barriers of African American caregivers are necessary to explore to develop strategies and resources that meet the needs of African American dementia caregivers. Table 1 below shows a visual representation of concepts of Roy's Theoretical Model adapted to variables/factors applicable to African American caregivers.

Table 1

Correlation of Roy Adaption Model concepts to Variables of African American Dementia Caregivers

Concepts from Roy Model	Variables
Input Focal Stimuli- Internal or external factor that immediately confronts the person	Objective burden and perceived stress (**Caregiving**)
Contextual Stimuli- Identifiable factors contributing to the effects of the focal stimulus	Stressful life events Social Support (**Church, Family**) Social and family roles (**Family Structure**) **Socioeconomic/Healthcare disparities** Access to resources (**Limited**)
Residual Stimuli- Factors that have unclear effects in the current situation	Age Race (**African Americans**) Gender
Control Process Coping Mechanism	Adaptive/Maladaptive coping strategies
Output	**Physiological health decline** **Psychological health decline** **Decline in self-care** **Poor health outcomes** **Relinquish caregiver role**

Note: Adapted from: Levesque, L., Ricard, N., Ducharme, F., Duquette, A., & Bonin, J. P. (1998). Empirical verification of a theoretical model derived from the Roy adaptation model: Findings from five studies. *Nursing Science Quarterly*, *11*(1), 31-39.

Cultural beliefs and attitudes have an influence on how people learn and are also determinants of health (Dilworth-Anderson et al., 2020). It is important to understand what knowledge and resources African American dementia caregivers seek in the role of a dementia caregiver to better meet their needs and ease the burden of providing care. As has been noted by Alexander et al. (2022) the social history of African Americans has contributed to the additional difficulties that are faced by African American dementia caregivers and this group has been shown to demonstrate unique stressors and vulnerabilities that are not present in other groups. Conducting this study will add valuable information to the current literature on African American caregivers by providing empirical evidence on what specifically are the information needs of these caregivers in alleviating the stressors and burdens associated with caring for a loved one with dementia. There are numerous studies that have focused on the specific stressors of African American dementia caregivers and the ways in which their environment of caregiving is different than other groups, but very little research exists on what information and resources are useful and effective in addressing their most critical concerns.

Statement of Relationship Among Manuscripts

As a result of in-depth exploration of the burden amongst dementia caregivers who provide care for a family member or friend with dementia, three separate manuscripts were produced to contribute to this study on the information needs and information seeking behaviors in African American dementia caregivers. The first manuscript was a scoping review. The purpose of this review was to understand broadly the facilitators and barriers to dementia caregivers' self-care. The scoping review also offered the foundation for future studies which can more fully explore and compare the effectiveness of different dementia caregiver self-care strategies within the complex context of caring for a dementia patient. This study was conducted

by this student, Sonia Shamlin, MBA MSN, RN with authors Dr. Kathy Baker, PhD, APRN, ACNS-BC, FCNS, FAAN, Michelle Kimzey, PhD, RN, and Ms. Alysha Sapp, TCU Librarian.

The second manuscript was a study to examine the ability of the Zarit Caregiver Burden scale to capture the burden experienced by caregivers of persons with dementia during the COVID-19 pandemic. This work offered the student (SS) the opportunity to work with codes, themes, and interpretation of original qualitative data. This student, Sonia Shamlin, served as first author for this paper along with faculty author Michelle Kimzey, PhD, RN.

The third manuscript reports on findings of a study conducted with African American caregivers who are caring for a person with dementia. The study was formulated from the foundation of knowledge developed in manuscript one, the scoping review, and with the qualitative methods learned in the qualitative data of manuscript two. This qualitative study was conducted by this student (SS), with the input and guidance of her faculty mentor, Michelle Kimzey, PhD, RN and with the support of faculty collaborators Kathy Baker PhD, APRN, ACNS-BC, FCNS, FAAN, and Carol Howe PhD, RN, CDCES, FAAN.

Definition of Terms

Dementia Caregivers: Dementia caregivers are defined as individuals who provide hands-on care to individuals with dementia with various responsibilities such as finances, personal care, and activities of daily living (Brodaty & Donkin, 2022).

Information needs: Information and resources to satisfy a conscious or unconscious need (Samus et. al, 2019).

*Information seeking behaviors***:** The act of passively or actively interacting in seeking information to adopt knowledge (Samus et. al, 2019).

Self-care: The ability of individuals, families, and communities to promote health, prevent disease, maintain health, and to cope with illness and disability in themselves with or without the support of a healthcare provider (WHO).

Self-care barriers: Factors that if present, decrease the likelihood of self-care use or expressly inhibit it (Smith & Graves, 2021).

Self-care strategies: Broad techniques used to manage the demands and stresses incurred by day-to-day life (Smith & Graves, 2021).

Self-care facilitators: Factors that contribute to the likelihood of self-care use (Smith & Graves, 2021).

Chapter 2: Manuscript 1

Barriers, Facilitators, and Strategies for Self-care in Dementia Caregivers: A Scoping Review

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Abstract

Objective: The objective of this scoping review was to identify and map the facilitators, barriers, and strategies for self-care in dementia caregivers.

Inclusion criteria: This review considered studies that included self-care for dementia caregivers. Conceptual papers and other literature reviews were excluded from the scoping review.

Methods: The scoping review strategy established by the Joanna Briggs Institute was followed. The databases searched included CINHAL, Medline Complete and Embase. Sources of unpublished studies and gray literature searched included ProQuest Dissertation & Theses Global and Epistemonikos, Studies published in English were included.

Results: After 175 articles were located, inclusion and exclusion criteria yielded nine publications to review. These articles spanned from 2011 to 2021. The main findings of this scoping review provided knowledge regarding what research was already available regarding facilitators, barriers, and self-care strategies for dementia caregivers. Facilitators to self-care that were identified included education, the ability to take breaks from caregiving duties, sharing responsibilities, demographic factors, and cultural beliefs. Barriers can be broadly classified as (a) the needs of the care recipient, (b) the demands of caregiving, (c) ineffective services, and (d) demographic factors. Finally, strategies for self-care identified included finding a sense of objective/subjective duality to help promote self-care, relying on past experiences, and leaning into one's sense of spirituality.

Key Words: Alzheimer's disease, dementia, self-care, primary caregiver, scoping review

Barriers, Facilitators, and Strategies for Self-care in Dementia Caregivers: A Scoping Review

As the developed world sees increasing life expectancy through improved medicine and lifestyles, new issues affecting the health of older adults have come to the forefront. Dementia, an intensifying neural degenerative disorder, affects nearly 2% of people who are over 60 years of age (Gao et al., 2019). Dementia is associated with a precipitous decline in numerous cognitive spheres including attention, learning, language, memory, and social cognition. Dementia can have a devastating effect on activities of daily living (ADLs) as patients' ability to judge, think, plan, and organize deteriorates (CDC, 2020). Yet, even as the condition has become prevalent and prioritized, it remains in another way elusive; to date, there is no single diagnostic "dementia test" in existence (WHO, 2020).

Diagnosing dementia requires the consideration of numerous factors, especially given the confounding effects of delirium and depression that often closely follow dementia's onset (Gao et al., 2019). Moreover, dementia is not a singular condition, but rather one with several important subtypes of different symptomology and potentially differing causes. Reported sub-types include Alzheimer's disease (AD), Lewy body dementia (LBD), vascular dementia, Parkinson's dementia, and unspecified dementia. Alzheimer's dementia is the most prevalent form of dementia affecting approximately 24 million people worldwide (CDC, 2020).

In addition to the already striking increases in longevity, the life expectancy of people over 65 is expected to increase drastically by 2030 (Gao et al., 2019). As life expectancy increases, dementia becomes a more relevant problem. Each diagnosis represents the potential impact of dementia on affected individuals for even a greater number of years. More older adults mean more cases of dementia in general. Taken together, these two circumstances

emphasize the importance of developing effective ways for the caregivers of people diagnosed with dementia to support not only those they care for, but also themselves. Research suggests that caring for people with dementia can take a significant toll on caregivers, whether those caregivers be healthcare professionals or family members (Riffin et al., 2017; Samus et al., 2019; Zahir et al., 2019).

Understanding the best way to address self-care consists of three important components. A caregiver's natural inclination toward and ability to engage in self-care depends, in particular, on facilitators and barriers to self-care. Self-care facilitators are defined as factors that contribute to the likelihood of self-care use, whereas self-care barriers are defined as factors that, if present, decrease the likelihood of self-care use or expressly inhibit it (Smith & Graves, 2021). A person's likelihood of engaging in self-care on their own can by thought of as an equation in which the facilitators are added and the barriers subtracted.

For many caregivers, the barriers are more powerful than the facilitators of self-care. In order to help those who are unable to overcome the barriers they face, self-care strategies are needed. Self-care strategies are broad techniques used to manage the demands and stresses incurred by day-to-day life (Smith & Graves, 2021). In order to determine appropriate self-care strategies and who to target with them, it is essential to understand the underlying self-care landscape through facilitators and barriers. Therefore, all three concepts are bound together conceptually. Though self-care strategies are of greatest interest, an understanding of facilitators and barriers is required as well to characterize the context in which strategies are needed, optimize potential facilitators, and minimize potential barriers. This scoping review, therefore, was undertaken to identify and map the facilitators, barriers, and strategies for self-care in dementia caregivers.

Background

Health decline has been reported in a greater number of caregivers caring for people with dementia in comparison to caregivers caring for people with other diseases (Li, 2012). The term "caregiver" refers to a person who supports a person's activities of daily living and functional needs (Abramsohn et al., 2019). Alternative terms might include primary caregiver, informal caregiver, and family caregiver. However, the responsibilities of caregivers vary depending on the person they are caring for. In the context of dementia, caregivers are responsible for helping patients carry out their ADLs as the sphere of cognition is drastically damaged (Zahir et al., 2019). This cognitive decline can be associated with a child-like behavior of the person with dementia. The burdensome responsibility of caring for a person with dementia therefore puts the caregiver at risk of developing negative health conditions such as burnout or depression (Riffin et al., 2017). Common primary caregivers exposed to these risks and stresses include spouses, siblings, or adult children. These caregivers often experience overwhelming distress caring for the person with dementia while maintaining their own personal life and health (Samus et al., 2019). For this reason, there is a crucial need to identify known facilitators and barriers to self-care maintenance for caregivers of persons with dementia in order to aid development of efficacious interventions (Verkaik et al., 2016).

As caring for persons with dementia weighs on the caregiver's mental health, caregivers become less able to perform their caregiving role well (Smith & Graves, 2021). Hence, the development of effective self-care strategies for primary caregivers is in the interests of patients and caregivers alike. Identifying the facilitators and barriers to such strategies is a crucial first step toward improving self-care in practice; without understanding the foundational elements, identifying strategies to promote self-care will potentially be ineffective or meaningful. Based on

the literature, the key problems facing dementia caregivers include a lack of knowledge

regarding self-care best practices, a lack of knowledge regarding alternative self-care strategies

or techniques, the burden of the patient's behavior, and difficulty maintaining clear and

productive communications with other caregivers, including healthcare professionals and other

informal caregivers (Moore & Cook, 2011).

Although no single strategy can alleviate all these problems, better self-care would do

much to address many of them. Self-care is a complex intervention impacted both positively and

negatively by context. Investigating contextual factors that facilitate self-care or those which act

as barriers to the effective practice of self-care is key to facilitating effective self-care. However,

the practice of self-care is not uniform (Smith & Graves, 2021). Caregivers may adopt numerous

strategies for self-care, and it would be fallacious to expect that these differing strategies would

encounter the same facilitators and barriers uniformly. Consequently, the present scoping review

comprised two stages. In the first stage, a search of the literature was used to identify the most

prevalent strategies for self-care. Within each of these key strategies, the individual facilitators

and barriers were then identified. The results serve to help understand the breadth of self-care

strategies available as well as understanding the context in which these strategies are

implemented. A better understanding of the types of self-care strategies that are available and

the circumstances in which they are used is important because it will help healthcare

professionals better support caregivers' self-care (Verkaik et al., 2016).

Method

The present scoping review sought to understand broadly the facilitators and barriers to

dementia caregivers' self-care. A scoping review was appropriate because this topic has not yet

been examined in a unified fashion, despite the wide array of research into dementia and

caregiving. The present scoping review also offers the foundation for future studies which can more fully explore and compare the effectiveness of different dementia caregiver self-care strategies within the complex context of caring for an individual living with dementia.

Review Questions

The scoping review was guided by two key review questions:

RQ1. What are the self-care strategies for dementia caregivers identified in the recent (i.e. 2011-2021) literature?

RQ2. What facilitators and barriers to self-care have been reported in the recent (i.e. 2011-2021) literature?

Eligibility Criteria

This scoping review was guided by the PRISMA framework. Consequently, careful eligibility criteria were defined for the included studies. These criteria were as follows:

Population

The population under study was primary dementia caregivers. The population was limited to caregivers who were 18 years of age or older. The population was also limited to caregivers who provided care in an at-home setting. Only primary caregivers who lived in the same residence as the individual with dementia were included. Studies including paid healthcare professionals were excluded. Studies with caregivers working in nursing homes, hospitals, or other formal healthcare provision settings were also excluded. While these caregivers also require self-care, the types of self-care needed and utilized by healthcare professionals may differ from that required by those caregivers who are not professionally trained and unpaid.

Concepts

Two key concepts were central to the review. The first concept was *primary caregivers*. Primary caregivers are an important concept because they represent the population of interest; hence, all of the studies in the review pertain to primary caregivers. As defined above, primary caregivers for persons with dementia constitute in the scope of this study those who act as the main, daily caregiver for persons with dementia. Evidence suggests a higher incidence of depression and health deterioration in primary caregivers of persons with dementia (Riffin et al., 2017). In addition, the burden of being a primary caregiver for a person with dementia often exists with other personal and professional responsibilities of the caregiver. For example, an adult child acting as primary caregiver may also be the partial or complete breadwinner for the household and have parenting responsibilities to their own children. Primary caregivers are the population of interest in this study and hence all the literature reviewed pertains to primary caregivers.

The second key concept is self-care. For this study, the definition of self-care was taken from the World Health Organization (WHO), which states that self-care is "the ability of individuals, families, and communities to promote health, prevent disease, maintain health, and to cope with illness and disability in themselves with or without the support of a healthcare provider." Using the WHO definition in this review is broad and intentional, aiming to capture the studies that discuss self-care in any way. However, not all the studies included need use the WHO definition. Instead, it is sufficient that their definition of self-care be contained within the WHO's broader definition of self-care. As a result, resulting studies may include research in which the researchers use the term *self-care* in ways that do not precisely align with one another across included studies. Studies were generally included if they worked toward a definition of

self-care that was broadly consistent with the WHO definition. Studies whose definitions

differed extensively were excluded.

Under the broad concept of self-care, the results were categorized based on three sub-

concepts that related to self-care: *self-care strategies, self-care facilitators,* and *self-care*

barriers. Table 1 displays the number and citation of the studies included in this review,

organized by which sub-concept of self-care the study focused on. Note that multiple studies

focused on more than one sub-concept; for example, some studies discussed both facilitators and

barriers to self-care. Self-care strategies are defined as broad techniques used to manage the

demands and stresses incurred by day-to-day life (Smith & Graves, 2021). Examples of general

self-care strategies include lifestyle choices such as fitness activities such as yoga, or mental

health practices such as meditation or mindfulness (Spalding-Wilson et al., 2018). Self-care

strategies as a concept represent approaches, techniques, or interventions that promote self-care.

In the context of this study, *self-care facilitators* are defined as factors that contribute to the

likelihood of self-care use (Smith & Graves, 2021). In contrast to strategies, facilitators are more

passive; they are aspects of a person's life, lifestyle, or circumstances. Finally, *self-care barriers*

are defined as factors that if present, decrease the likelihood of self-care use or expressly inhibit

it (Smith & Graves, 2021).

Conceptual Framework

The Middle- Range Theory of Caregiver Stress derived from the Roy Adaption Model as

conceptualized in 1984 (Roy, 1984) is a relational construct that assumes the individual is an

adaptive system affected by both internal and external environments known as stimuli. Roy

(Andrews & Roy, 1991) argues that each person has an adaptation level or range of ability to

cope in a situation. Adaptation level is a changing point that indicates the person's ability to

respond positively to his/her environment and it is determined by the environmental stimuli that an individual has experienced in life (Andrews & Roy, 1991). If the pooled effects of the stimuli are less than the individual's adaptation level, the responses are adaptive (Roy, 1976). But if pooled effects of the stimuli are greater than the individual's adaptation level, the resulting responses are ineffective adaptation as is the case in the burdens and stressors that are faced by African American dementia caregivers.

Methodology

Included studies addressed the topic (self-care of dementia caregivers) and included either a qualitative or quantitative methodology. Reported data could be collected directly from participants or via archival data. Excluded types of studies were conceptual papers. Because of the review's scoping nature, methodological diversity was sought rather than avoided to ensure the results of the review reflect the diversity of reported research approaches.

Language

Only articles in English or which provided a full text English translation were included as English is the authors' native language.

Sources of Information and Search Strategy

The search strategy for this study focused primarily on peer reviewed articles though high-quality grey literature was considered. The databases used in the literature search included PubMED and CINAHL Complete. The search was conducted following PRISMA guidelines. Within the identified databases, a keyword search was carried out using the following keywords: *dementia, Alzheimer's disease, Lewy body dementia (LBD), vascular dementia, Parkinson's dementia, unspecified dementia, self-care, strategies, barriers, weaknesses, facilitators, strengths, context, techniques, caregiver, primary caregiver, home caregiver, mental health,*

physical health, and *wellbeing.* Based on consultation with a librarian trained in scoping review methodology, these keywords were used primarily in AND combinations to narrow the search results and ensure the relevancy of the articles yielded by the search. The search period was also delimited to the period 2011-2021 to ensure the results were recent and relevant. The initial keyword search yielded a total of 175 articles.

Selection Process

Once the initial search strategy yielded the preliminary 175 articles, the results were refined using the Joanna Briggs Institute (JBI) data extraction technique. The initial list of results was refined by a review of article titles by the primary author. Based on titles, the potentially relevant articles (n = 175) were identified and then reviewed in abstract form. Those which remained relevant based on their abstracts (n = 27) were retrieved in full text form and reviewed individually by two reviewers. There were no disagreements on individual identification of studies which met the review criteria.

The 27 studies that met the review criteria and were included in the final review included 14 qualitative studies, 2 mixed methods studies, 3 literature reviews, and 8 quantitative studies. Data from each study were extracted into a table (see Table 2 in Appendix). Extracted data included citation, year, country, study methods and designs, sample size, and key findings (i.e., barriers and facilitators of self-care management, strategies for self-care). The results of the data analysis, presented in the following section, are divided into categories reflecting the most commonly cited self-care strategies as well as barriers and facilitators.

Figure 1

PRISMA diagram of search outcomes

Identification of studies via databases and registers		

Identification

Records identified from*:
Databases (n = 175)

→

Records removed *before screening*:
　　Duplicate records removed (n = 0)
　　Records marked as ineligible by automation tools (n = 0)
　　Records removed for other reasons (n = 0)

Screening

Records screened
(n = 175)

→

Records excluded**
(n = 119)

Reports sought for retrieval
(n = 56)

→

Reports not retrieved
(n = 10)
Not available

Reports assessed for eligibility
(n = 46)

→

Reports excluded:
　　Medical caregivers (n = 4)
　　Other reviews (n = 4)
　　Mentioned self-care but did not focus on it (n = 9)

Included

Studies included in review
(n = 29)

Results

The results presented herein report on the specific barriers, facilitators, and strategies with respect to self-care for dementia caregivers identified in the studies selected for inclusion. Study details can be found in Table 2 in the appendix. Table 1 below maps the literature to the three themes of the review.

Table 1

Linking Review Themes to the Literature

Study Focus	Number of Studies	Citation	Findings
Facilitators to self-care	11	Abramsohn et al. (2019) Alonso-Cortés et al. (2019) Alonso-Cortés et al. (2021) Balbim et al. (2019) Gottschalk et al. (2021) Grigorovich et al. (2015) Moreno- Cámara et al. (2019) Oliveira et al. (2019b) Wang et al. (2015) Wang et al. (2018) Wang et al. (2019) Waligora et al. (2019) Xiuxiang et al. (2020)	Cultural beliefs Dependency Duration of caregiving Reflecting care demands Education Female gender Financial status Active coping Dedication to self-care Positive experiences with caregiving Knowledge Boundaries Self-reflection Necessity Awareness Social support Formal support Socialization Religion Rest Adequate healthcare access
Barriers to self-care	12	Abramsohn et al. (2019) Alonso- Cortés et al. (2019) Gottschalk et al. (2021) Layek et al. (2020) Lu and Wyckle (2007) Moreno-Cámara et al. (2019) Oliveira et al. (2019b) Wang et al. (2015) Wang et al. (2018) Wang et al. (2019) Waligora et al. (2019) Webb et al. (2016) Withers et al. (2021)	Pressures Stress Worries Children Finances Comorbidity Lack of resources Poor service organization a Coordination Lack of respite breaks Lack of continuity of care Difficulty prioritizing own needs Health Relationships and feelings Inability to leave the person with dementia alone

			Care recipient's disinterest in participating in their own self-car
Strategies for self-care	12	Alonso-Cortés et al. (2021) Alperson and Fowler (2017) Balbim et al. (2019) Bull (2014) Gottschalk et al. (2021) Huis in het Veld et al. (2015) Lu and Wyckle (2007) Moreno-Cámara et al. (2019) Oliveira et al. (2019a) Robinson-Lane et al. (2021) Langman, 2012 Polenick et al. (2018) Riffin et al. (2017) Sabo & Chin (2021) Sheehan et al. (2021) Spalding-Wilson et al. (2018) Verkaik et al. (2016) Waligora et al. (2019) Wang et al. (2015) Xiuxiang et al. (2020)	Rationalization Social interactions Physical activity and leisure activities Activity engagement Humor Self-care Social support Looking for distractions Getting rest Discussing their feelings and experiences Early interventions rather than waiting until functional ability deteriorates under stress More interventions to support the needs of caregivers Culturally focused interventions

Facilitators

Self-care facilitators are defined as factors that contribute to the likelihood of self-care use (Smith & Graves, 2021). The final uncovered list of studies included a number of key facilitators to self-care. In this section, each facilitator is presented along with any relevant context. The types of facilitators that were identified included education, the ability to take breaks from caregiving duties, sharing responsibilities, demographic factors, and cultural beliefs. Overall, the categories of facilitators identities were varied across a multitude of studies. The results are divided in terms of demographic facilitators, cultural factors, and miscellaneous facilitators.

Demographic Facilitators

Several studies identified demographics as facilitators. For example, Wang et al. (2015) identified a large set of demographic factors that facilitated greater use of self-care in caregivers, namely female gender, care length of time, care patient's daily living activities and caregiver knowledge. A later study by Wang et al. (2018) reinforced the importance of these specific factors within the context of the U.S. Because their results were quantitative, there was little indication of why these demographics facilitated self-care. Demographic factors, however, were also identified as barriers (discussed in the next section), such as Waligora et al.'s (2019) identification of the factors of gender/gender roles and minority ethnicity as barriers. Demographics would appear to have a strong moderating potential, but one that is as of yet unexplored.

Geographical Context

Some studies examined the facilitators across a wide array of geographical contexts. Gottschalk et al. (2021) conducted a study in Germany and found that caregivers' self-care was facilitated by the ability to set boundaries, the use of self-reflection, and necessity. In China, Xiuxiang et al. (2020) identified that certain cultural beliefs could facilitate self-care, related in part to Asian cultural traditions such as Zen. Similarly, in Mexico, Balbim et al. (2019) identified cultural beliefs and spirituality as being important facilitators of self-care for the dementia caregiver. In Spain, Moreno-Cámara et al. (2019) identified being aware of one's own self-care need is essential; otherwise, the study participants did not know to pursue self-care. Among African-American caregivers, Abramsohn et al. (2019) identified shared caregiving responsibilities and education from a trusted source as facilitators of self-care.

Miscellaneous Factors

Alonso-Cortés et al. (2021) identified certain types of education as being facilitative of self-care. In particular, education that combines practical and theoretical knowledge of self-care is facilitative of actual self-care practice. More broadly, Waligora et al. (2019) identified that the burden of caregiving being acknowledged, either by the caregiver or by others, is facilitative of self-care practice. In another, more exploratory qualitative study conducted in the southeast United States (U.S.), Wang et al. (2019) identified a host of factors that potentially facilitate self-care, including knowledge, awareness, social support, formal support, socialization, religion, rest, and healthcare access. On the other hand, Oliveira et al. (2019b) identified that high-quality respite from caregiving duties could work as a strong facilitator in enabling caregivers to seek out self-care opportunities.

Summary

Overall, the facilitative factors were heterogeneous and varied in nature. Few studies identified the same factors even in the same contexts, much less across different contexts. In this regard, the most common facilitators were education/knowledge, spirituality/religion, and cultural factors. Although these factors were the most prevalent, they did not occur in every study, and in each case appeared alongside other factors as well. Given that the present study is a focused scoping review and these results demonstrate such heterogeneity, it is likely that the larger body of literature on self-care, regardless of population, contains additional facilitators.

Barriers

To reiterate, self-care barriers are defined as factors that if present, decrease the likelihood of self-care use or expressly inhibit it (Smith & Graves, 2021). As with facilitators, the barriers were reviewed separately and are presented in this section. Some studies included both

facilitators and barriers, in which case they will be listed separately in both sections. Barriers can be broadly classified as (a) the needs of the care recipient, (b) the demands of caregiving, (c) ineffective services, and (d) demographic factors.

Needs of the Care Recipient

One significant barrier to self-care may be disinterest on the part of the individual living with dementia. In a qualitative study of African American caregivers, Abramsohn et al. (2019) found that caregivers had difficulty accessing community resources that would ease the burden of caregiving, in part because the dementia patients for whom they acted as caregivers were unwilling to participate in their own care or take advantage of community resources for that care. This required the caregiver to invest more time in caregiving and have less time or resources for self-care. Along similar lines, Wang et al. (2015) identified weekly care hours as being a significant predictor of not using self-care. Gottschalk et al. (2021) further endorsed this theme, indicating that the needs of the care recipient were the main barrier to self-care in Germany.

Relatedly, Abramsohn et al.'s (2019) qualitative interviews revealed that many primary caregivers among the African American primary caregiver community were unwilling—or felt unable—to leave their relative alone or with others. This need for constant vigilance crowded out their ability to engage in activities they desired to for themselves and thereby significantly inhibited their self-care ability. This relates to a finding of Oliveira et al. (2019) that the individual factor of personal relationships and responsibilities could significantly inhibit caregivers' ability to practice self-care. Similarly, Lu and Wyckle's (2007) study in the U.S. identified caregiver stress and lack of functional ability by the individual with dementia as barriers and related these factors back to the demands of caregiving.

Demands of Caregiving

Wang et al. (2019) identified the demands of caregiving as a barrier to self-care and added also the demands of the caregiver's work life—since caregivers in this context are not healthcare workers, many also have another job (Wang et al., 2019). Moreno-Cámara et al. (2019) also identified the burden of caregiving as the primary barrier to self-care actualization. In India, a study by Layek et al. (2020) further supported the importance of caregiving demands, listing it as a barrier alongside workload, lack of knowledge, and time constraints.

Ineffective Services

Oliveira et al. (2019) identified another barrier to effective self-care in the form of poor or poorly organized services. Oliveira et al. identified, through a multimethod qualitative study with 46 caregivers, that many caregivers experienced that the services they were meant to rely upon to assist them did not assist in a way that meaningfully lightened their burden of care provision. Similarly, Alonso-Cortés et al. (2019) identified that poorly executed caregiver training (in that case, training regarding only theory) could function as a barrier.

Demographics

Some studies also identified demographic barriers. For example, Waligora et al.'s (2019) review in a global context identified the factors of gender/gender roles and minority ethnicity as being barriers to self-care on the part of caregivers. For example, the polarization of gender roles in the context of dementia caregiving may socially stigmatize female caregivers due to an obligation that they need to fulfill society's gendered expectations (Waligora et al., 2019). Similarly, Withers et al. (2021) identified factors such as children, finances, comorbidity, and a lack of resources as being predictive of poor self-care on the part of Latino caregivers.

Summary

Overall, the identified barriers emerging from the literature can be arranged into four main themes: (a) the needs of the care recipient, (b) the demands of caregiving, (c) ineffective services, and (d) demographic factors. This suggests that the barriers to self-care are more widely understood than are the facilitators to self-care because the barrier results coalesced into a smaller number of themes. Each of these themes regarding the barriers is also substantiated by more literature than was each facilitator.

Strategies

The final key point of this review was to address the types of strategies used to promote self-care. As defined previously self-care strategies are broad techniques used to manage the demands and stresses incurred by day-to-day life (Smith & Graves, 2021). A wide array of strategies was uncovered in the review.

Combined Education

Using combined education represents one strategy for self-care. In a comparative study of purely theoretical self-care education and a combination of theoretical and practical self-care education involving 45 participants, Alonso-Cortés et al. (2021) found that combining theoretical-practical training introduced significant benefits whereas solely receiving theoretical training offered no significant benefits. In particular, practical training strategies included relaxation, self-massage, and stretching. The combined aspect of this aligns well with the strategy of using comprehensive interventions (e.g., combining mental strategies such as relaxation with physical strategies such as exercise) to address mental and emotional self-care needs that was indicated by Moreno-Cámara et al. (2019).

Broad Self-Care Strategies

Another category of results addressed broad strategies rather than specific ones. For example, Lu and Wyckle (2007) identified the importance of introducing early interventions to promote self-care rather than waiting until functional ability (i.e., bathing, feeding, grooming) deteriorates under stress. Similarly, Waligora et al. (2019) suggested the broad strategy of fostering a sense of objective/subjective duality to help promote self-care. This strategy involves seeking to separate subjective experiences from objective needs. For example, to promote self-care, it may help to separate subjective feelings of being too busy for self-care from the objective need to practice self-care for the sake of the caregiver and their loved one alike. In another study, Bull (2014) identified four key strategies used by dementia caregivers to sustain themselves, namely (a) drawing on past life experiences, (b) nourishing the self, (c) relying on spirituality, and (d) seeking information about dementia. These strategies were identified through a mixed methods research approach that was intended to examine why some caregivers sustain fewer negative effects of caregiving.

The strategy of drawing upon spirituality was also identified in a quantitative descriptive survey of 30 African American caregivers by Robinson-Lane et al. (2021) as a strategy for self-care. This study identified that those African American caregivers used their prior experiences as a strategy for self-care, aligning with Bull's (2014) results in that regard. Gottschalk et al. (2021) supported the need for a broad class of culturally oriented self-care interventions, meaning interventions that make use of strategies that have demonstrated efficacy within a given cultural context. In this vein, Verkaik et al.'s (2016) review offered evidence for broad self-management support interventions as a strategy including looking for distractions, getting rest, and discussing their feelings and experiences.

Specific Self-Care Strategies

Another category of strategies took the opposite approach and reported on the efficacy of a specific intervention that implemented a key strategy. For example, Alperson and Fowler (2017) offered a favorable report on movement and centering training based on the principle of chi. In their review, Oliveira et al. (2019a) reported on the efficacy of seven empirical psychosocial interventions administered in the United States and Turkey and argued that more should be developed. These included a carer skill-building program, a structured, multi-component intervention, an intervention designed to improve physical activity, a brief, telephone-based exercise intervention, a web-based multi-component skill building intervention, a theory-based intervention, and a self-care healthy lifestyle intervention. In another example, Spalding-Wilson et al. (2018) found that a novel two-day intervention to reduce stress proved effective. The intervention focused on "techniques aimed at fostering self-care for caregivers and improving communication between caregivers and individuals with dementia" (p. 450). Balbim et al. (2019) identified the efficacy of the specific strategies of rationalization, social interactions, physical activity, and leisure activities through a series of qualitative interviews with caregivers. The strategies proved effective in some cases, but their degree of utility was affected significantly by the caregivers' cultural context and cultural values. Using a similar methodology, Polenick et al. (2018) identified the self-care strategies of activity engagement, humor, and social support as used by U.S. caregivers. Empirical research on the use of self-care strategies such as social support has yielded mixed results on their impacts on caregivers. For instance, Elliot et al. (2010) showed that attendance at support groups had a significant effect on caregivers' depression and decreased their burden of care. Meanwhile, Chu et al. (2011) found that support groups reduced caregivers' depression but not their burden of care among a sample

of Taiwanese dementia caregivers These mixed results suggest that more research into the use of certain strategies, such as support groups, for caregiver self-care is needed.

Summary

Like the facilitators, the strategies were diverse. Although they aligned into three broad categories, these categories were internally heterogeneous. Overall, there was no clear consensus on specific or even general strategies for promoting dementia caregivers' self-care. On the other hand, the results did provide relatively strong individual evidence supporting both broad approaches and individual strategies. Hence, the literature regarding self-care strategies is not so much weak as it is fragmented, focusing on a wide array of specific aspects of the problem and a number of potential solutions. The main weakness of the literature on strategies is that, since each specific result tended to be distinct from the others, it is difficult to build any kind of consensus or best practice recommendations.

Discussion

While the barriers to self-care were relatively well-supported across different studies, the most surprising finding of this study was that almost no studies offered the same results regarding facilitators or strategies. The facilitator results were diverse in nature, and the most promising, that of demographic factors (either as standalone facilitators or moderators of other facilitators) was not adequately explored. The results regarding facilitators were ultimately relatively weak, which is problematic in the sense that understanding the facilitators of self-care is analogous to understanding the baseline propensity toward self-care across the caregiving population. Understanding this basic landscape is essential to promoting self-care effectively in terms of identifying who needs the most help and who is most likely to already practice self-care.

The barriers identified in the review were more cohesive, but barriers represent only half of the basic landscape. Barriers and facilitators have the opposite effect on self-care, so if two people who face the same barriers to self-care have different facilitators in play, one of those people may, by virtue of the facilitators, overcome the barriers with relative ease, while the other may struggle because their facilitators, if any, are not enough to overcome the effect of barriers. For example, while minority status was identified as a barrier, some minority groups had specific cultural practices that acted as facilitators to counterweight the barrier of minority status while others did not. A fuller understanding of these distinctions is essential.

In this study, the strategies identified for self-care were also diverse. A full picture of facilitators is needed to understand the landscape of self-care. On the other hand, a comprehensive understanding of strategies would be valuable because isolated results still offer greater utility. In general, it would be useful to have multiple studies on strategies used for self-care because it would help to reinforce their utility and applicability.

Another surprising result was there were several studies that focused primarily on the keyword term 'self-care' yet did not include a specific type of self-care. More research like Spalding-Wilson et al.'s (2018) study of mindfulness was expected and would have been useful in terms of understanding the relative benefits of a specific approach to self-care. However, it was valuable that several of the studies (Balbim et al., 2019; Polenick et al., 2018; Spalding-Wilson et al., 2018) did report on the efficacy of specific self-care interventions.

Overall, the broad consensus on what constitutes a barrier to self-care and the disagreement on what constitutes a facilitator to self-care was expected. The lack of sufficient self-care is the problem motivating much of the research that fell under the purview of this review. Consequently, factors that inhibit self-care are more apparent than factors that facilitate

it. The most common facilitators were education/knowledge, spirituality/religion, and cultural factors. These factors were supported across at least two studies each, making them stronger results than any of the strategies identified. It is worthwhile to note that there were no conflicting results—that is, no studies suggested something was a barrier in one and a facilitator in another. Similarly, there was no contradictory evidence regarding the same strategies as being effective and ineffective.

Barriers were plentiful and four key themes were identified: 1) needs of the caregiver, 2) demands of caregiving, 3) ineffective services, and 4) demographic factors. Understanding these barriers is important to overcoming them, but an understanding alone is not enough to overcome them. The burden of self-care was the strongest of the four themes in terms of evidence. This is somewhat paradoxical given that these same demands are the bulk of what makes self-care necessary in the first place. Hence, the key takeaway in terms of barriers is that they are already well understood, and the focus should be more on confirming how they can be overcome.

Understanding the facilitators of self-care, the barriers to self-care, and the strategies for self-care are key in informing future research and, more importantly, future interventions to improve self-care on the part of dementia primary caregivers. In particular, facilitators appear to be the least well-understood aspect of self-care. This is problematic because facilitators proved a passive benefit and therefore are especially useful if they can be fostered. More importantly, not knowing what facilitators are present makes the actual practical implications of barriers harder to determine because of the opposing effects represented by barriers and facilitators. Knowing only the barriers is not enough to know who will struggle with self-care because some people facing those barriers will have the barriers offset or even negated by facilitators, while others will not. Hence, it is essential that research further develop our understanding of self-care facilitators for

the purposes of understanding who needs help the most and how to target interventions to those groups. Strategies, which provide a more active benefit, are more well-understood, but remain diverse. By contrast, barriers were the most clearly defined and widely agreed upon. This makes overcoming barriers a potentially strong venue by which to improve self-care immediately, as they offer clear targets.

The results of this study also offer some important differences to the self-care needs identified in other, somewhat parallel populations. For example, an integrative review by Sabo and Chin (2021) looked at self-care strategies in the context of older adult caretakers of people with chronic illness. They found that the most effective strategies for self-care in that context included self-advocacy, coping strategies, prioritizing of self, legacy building, and activism. In terms of facilitators, Sabo and Chin (2021) primarily identified the factors of physical activity, stress management, social support, and support resources, albeit in a slightly different formulation, as the resources necessary for self-care. The differences in facilitators are less surprising given that the present study saw great heterogeneity even within the studies that were reviewed.

In general, the literature regarding self-care for the caregivers of patients with chronic illnesses appears to be more robust and developed than the dementia caregiver literature reviewed herein. Even a cursory search yields a substantive body of literature (LeBlanc & Jacelon, 2018; Vellone et al., 2020). Another aspect of the chronic illness literature that was absent in this review was the concept of dyadic congruence (Bugajski et al., 2021; Vellone et al., 2018). This key point of difference reflects one of the greatest challenges of dementia caregiving compared to chronic illness caregiving in general, which is because of its neurodegenerative nature, dementia strains and even erases the relationship of patient and caregiver even as it exerts

a great burden on the caregiver. This makes self-care arguably even more essential to understand and facilitate for dementia caregivers.

Limitations

Though the present review was relatively comprehensive, it was not without limitations. The first and foremost of these limitations is that the study did not uncover the expected volume of research addressing specific forms of self-care such as meditation, yoga, or mindfulness. Including these in the keywords was considered but rejected to avoid biasing the results as defining the use of self-care in the literature was one goal of the study. Perhaps this exclusion avoided research which would have been relevant in spite of not expressly considering the broader construct of self-care and yet which should rightfully be included within the purview of that term.

Another limitation of the study was that the focus on facilitators, barriers, and strategies was not always clear when interpreting studies. It was often challenging to decipher what should be considered a strategy and what should be considered a facilitator. However, the definitions settled upon in the concepts section made this distinction possible. Nonetheless, it is possible that some determinations were made in error and thereby shifted the results for facilitators or strategies. This would be unlikely to significantly change the overall results, however.

Future Directions

Considering the findings of the study and the limitations, several future directions for research present themselves. Specifically, a future scoping review of the literature could use an expanded keyword search to determine whether or not specific self-care practices such as mindfulness, yoga, or meditation have been studied in relation to dementia caregivers without being expressly referred to as self-care. Such a review would enrich the results of this study by

expanding to include more potentially relevant results. Adopting the combined definition of self-care that was deemed most relevant in the results would suggest such research should consider both formal healthcare-related self-care practices and, moreover, informal self-care practices.

Another potentially fruitful direction for further research would be to review the literature focusing on self-care explicitly as either an outcome or a predictor. This study, because of its scoping nature, considered both uses. Broadly speaking, the use of self-care as an intervention or predictor seemed a more promising direction than considering the quality of a caregiver's self-care as part of a set of outcomes. Relatedly, Riffin et al. (2017) called for more research on interventions to support the needs of all caregivers.

Finally, future research should focus more on strategies to overcome the barriers identified in this review. The strategies and facilitators for self-care were significantly more heterogeneous and less well-supported than were the barriers. Therefore, their efficacy had considerably weaker support, typically one study for each investigate barrier. In addition, the strategies were more broadly focused on promoting self-care than on the specific need to overcome the barriers to self-care. Future research could focus on the same strategies and/or on how those strategies can be used to overcome the four categories of barriers identified in this review. Additionally, qualitative research on caregivers who identify as using some kind of self-care strategy could give deeper insights into the effectiveness of different strategies and why they work or don't work. Furthermore, such a methodological approach could broaden the understanding of what motivates caregivers to select certain self-care strategies and what perceived impacts these strategies have on their well-being.

Chapter 3: Manuscript 2

Dementia Caregivers burden of care during COVID-19 Pandemic

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Abstract

Aim (s)- The purpose of this mixed-method study is to examine the ability of the Zarit Caregiver Burden scale to capture the burden experienced by caregivers of persons with dementia during the COVID-19 pandemic.

Background-The COVID-19 pandemic increased the challenges associated with caregiving by denying caregivers many normal ways of coping. Additionally, as dementia patients are elderly in almost all cases and the elderly are at high risk from COVID-19, the pandemic created additional strain in terms of caregiving itself.

Method (s)- Data was collected from 8 dementia caregivers recruited through community organizations in Fort Worth, Texas who filled out the Zarit Caregiver Burden and participated in interviews.

Results- Several themes relating to caregivers' feelings during the pandemic arose during data analysis, including those caregivers felt strong feelings of stress, guilt, fear, worry, anger, hurt, and being overwhelmed. Data from the interviews also captured the burden of responsibilities caregivers felt during the pandemic, such as finding resources, navigating healthcare and precautions, navigating misconceptions, and dealing with feelings of isolation.

Conclusion- The results indicated that the ZCB scale is inadequate to fully capture the burden of dementia caregiving during the pandemic, and perhaps also in need of a more general update. These results have important implications for providing more resources to support dementia caregivers.

Key Words: Dementia, COVID-19, informal caregivers, Alzheimer's

Caring for patients with dementia is challenging, even for trained professionals in managed care settings (Riffin et al., 2017). Dementia is an intensifying neural degenerative disorder that affects nearly 2% of people who are over 60 years of age (Gao et al., 2019). However, in many if not most cases, the burden of dementia caregiving falls not on professional caregivers, but informal care providers (Riffin et al., 2017). These care providers are typically spouses, family members, or potentially close friends. In some cases, this is made even harder by competing caregiving demands; if the caregiver is a child of the dementia patient, he or she may have a family of their own as well (Samus, 2019). As a result, there is reason to believe that the burden of care provision on informal dementia caregivers is significant. Indeed, many researchers have sought ways of alleviating that burden (Smith & Graves, 2021; Spalding-Wilson et al., 2018; etc.).

The COVID-19 pandemic has made caregiving in general more challenging. Early in the pandemic, extensive lockdowns denied caregivers many normal ways of coping (Altieri & Santangelo, 2021; Panda et al., 2021). At the same time, as dementia patients are elderly in almost all cases and the elderly are at high risk from COVID-19, the pandemic created additional strain in terms of caregiving itself (Liu et al., 2020). The advent of the virus therefore shifted the care provision landscape for informal dementia providers in several important ways and likely intensified the already significant burdens of providing care. Assessing the burden of care to determine the nature of this shift is important. However, the shift in the caregiving landscape resulting from the pandemic may have been significant enough to require new ways of measuring the burden. To determine whether existing measurement approaches are adequate to the demands of the pandemic landscape, the purpose of this mixed-method study is to examine

the ability of the Zarit Caregiver Burden scale to capture the burden experienced by caregivers of persons with dementia during the COVID-19 pandemic.

Literature Review

Provision of care by family members is hardly a new development; indeed, it is perhaps older than most medical practices, having existed as long as human civilization. However, the development of modern medicine and a better understanding of diseases such as dementia has shifted the nature of caregiving significantly (Gao et al., 2019). Within the framework of modern medicine, although the informal caregiver remains the primary caregiver, that care is provided with the direction of a medical professional in many cases (Moore & Cook, 2011). That shift in framework has codified the responsibilities of the dementia caregiver in key ways. Although these shifts may improve care, they can also increase the burden of caregiving through, for example, the need to manage the patient's medications and medical appointments as well as day-to-day needs (Wang et al., 2015).

A substantive body of research has demonstrated the burdens of providing care to patients with dementia. Caregivers may feel they have no time to see to their own needs because their role of caregivers is so demanding (Samus, 2019). The pull of professional and familial obligations may also collaborate with caregiving responsibilities to worsen the burden of care provision through consuming all the care provider's time together even if neither responsibility individually does (Webb & Dening, 2016). The burden of caregiving is worsened by, on the part of many caregivers, a lack of self-care (Verkaik et al., 2016). This lack may stem from a lack of knowledge or a lack of perceived ability but intensifies the burden of self-care regardless.

The burden of caregiving can manifest in terms of a multitude of detrimental effects. The most common are negative mental health effects. Caregiver burden often manifests through

stress or anxiety (Adelman et al., 2014). These are not only mental health issues but can also be the drivers of physical health issues such as high blood pressure (Vara-García et al., 2019) or loss of sleep (Liu et al., 2018). Another effect of caregiver burden is depression (Cheng, 2017). Depression is problematic in itself and is also linked to a wide array of negative mental and physical consequences. The effects of caregiver burden are not limited to mental health, however. The demands of caregiving may lead to caregivers neglecting their own health, such as failing to take their own medications or skipping medical care (Li, 2012).

These effects have likely all been worsened during COVID-19. Though much of the focus has been on caring for children, research indicates that the overall burden of caregiving substantially worsened during the pandemic because of service closures (Altieri & Santangelo, 2021; Panda et al., 2021). In addition, the elderly is by far the most vulnerable age group to the virus (Liu et al., 2020), far exceeding the immunocompromised. As a result, caregivers of elderly patients such as those with dementia have had to navigate significant risks to those in their care, potentially further hampering their ability to make use of various services or other externalities that could be used to decrease the burden of caregiving. In this environment, it is of substantial importance to understand if traditional measures of caregiver burden remain sufficient or whether they miss important pandemic-induced facets of caregiver burden.

Method

Design

The present pilot study involved a mixed method research approach to evaluate the burden of caregiving for the informal caregivers of dementia patients. The mixed-methods approach combines qualitative and quantitative components to create a more comprehensive understanding of the research topic (Maxwell & Loomis, 2003). A mixed methods approach was

appropriate to this study because of the need to test the relevance of the Zarit Caregiver Burden

scale (ZCBS) to the current moment. The qualitative component of the study will help to identify

if there are any aspects of pandemic-era care that the ZCBS does not adequately capture in its

present form. In addition, the qualitative component is key because the existing research offers

limited theoretical conceptions of caregiving. This study used Raina et al.'s (2004) pediatric

caregiving model as a base, but that model is not fully appropriate for caregiving as provisioned

to adults. Hence, the qualitative study component is needed to more fully explore the new

theoretical ground that the proposed study will address in studying the burden of caregiving for

adults.

Population and Sample

The population under study was all adults providing informal care to a patient with

dementia in the state of Texas. The specific geographic location was chosen because of its

accessibility, and also because healthcare institutions and COVID-19 restrictions and closures

differed state-to-state in the United States. Texas represents a case where the restrictions were

relatively short-lived and brief compared to the rest of the country, but also a sunbelt state which

saw surges in cases, hospitalizations, and deaths as the pandemic progressed. Inclusion criteria

included that the caregiver speak English fluently, that he or she is not a licensed medical

professional, that he or she have at least a full year of experience as a dementia caregiver, and

that he or she be at least 18 years of age.

Participants for the study were recruited through community organizations in Fort Worth,

Texas that support dementia caregivers. Participants were recruited through a combination of

flyers posted physically on the organizations' premises, e-mails distributed through the

organizations' mailing lists, and snowball sampling in which participants were asked to provide

recommendations of other prospective participants. In either case, the researcher contacted

prospective participants who expressed interest and provided them with information about the

study. Those who chose to participate and confirmed they met the participation criteria were e-

mailed informed consent documentation.

Data collection involved two steps. In the first, participants were provided with a

Qualtrics link to complete the ZCBS. The scale was hosted online, and each participant was

asked to include a unique participation number in the survey to match surveys and interviews. In

the second step of data collection, each participant completed a one-time interview via Zoom

teleconferencing software. The interviews lasted roughly 45 minutes each and were audio

recorded for later transcription.

Ethical Considerations

Ethical research practices were adhered to at all stages of the research. Participation was

wholly voluntary and involved no coercion. Participants were provided with informed consent

information prior to participating and could only participate after reading and agreeing to it.

Participation in the study posed no physical risk to participants. The study addressed potentially

sensitive issues, and so care was taken to ensure participants' conform during the interviews. If

the survey or interviews stressed or otherwise upset participants, they were directed to the

services of a counselor employed through the community organizations which the study was

conducted in partnership with.

Materials

To guide the qualitative portion of the study, an interview guide was developed. The

interview guide attempts to qualitatively probe the effects of COVID-19 on the burden of

dementia caregiving. The interview guide was developed with the assistance of a panel of two

experts who helped to validate the included questions for their relevance top achieving the research purpose. The interview guide included 11 questions, though follow-up or probing questions were used in some cases. The interview guide can be found in Appendix B.

The materials used to conduct the study included the ZCBS and an interview guide. The ZCBS was developed by Zarit et al. (1980) as a way to measure the burden imposed on caregivers by provision of care in general. The scale consists of 22 items on a 5-point Likert scale (scored 0-4). These items measure burden across six subscales. The purpose of this study is to determine if the ZCBS remains an adequate measure of caregiver burden in the age of COVID-19. Permission to use the instrument in the study was secured. No modifications to the instrument were made *a priori*. The scale can be found as Appendix A.

Data Analyses

The interviews were analyzed using Clarke et al.'s (2015) six-step qualitative data analysis process was applied to the interviews. The key steps were (a) developing familiarity through repeated reviews, (b) open coding using initial and emergent codes, (c) developing preliminary themes, (d) cross-checking themes against the data, (e) ensuring uniqueness and completeness of themes, and (f) compiling and listing themes.

Data for the study were analyzed using descriptive statistics and qualitative thematic analysis, plus comparison. Descriptive statistics were used to assess the overall results of the ZCBS. Each subscale as well as the overall score was analyzed descriptively. Descriptive statistics were also applied to the sample itself, and to determine if there were any evidence patterns in the occurrence of specific ZCBS results vis-à-vis participant demographics.

Finally, a comparative analysis was conducted to determine if the results of the qualitative and quantitative portions of the study aligned. Determining this alignment was key to

determining whether or not the ZCBS was appropriate to measuring caregiver burden in the age of COVID-19. The comparison primarily involved determining if the sentiments expressed qualitatively had been accurately reflected in the quantitative results.

Results

Demographics

The final sample size for the pilot study was 8 participants. These participants included 0 men and 8 women. Each participant was a non-healthcare worker primary caregiver for a person with dementia. In most all cases, the individual was a family member of the person with dementia for whom they were acting as primary caregiver. Study participants were all female and ages ranged from 52 to 71, median age 67. All participants were White, Non-Hispanic. The types of dementia represented in the study include Alzheimer's (62.5%), Vascular (12.5%), and Lewy body (25.0%).

Qualitative Themes

Caregiver Feelings. Caregiver feelings encompassed the emotional reactions to the experience of caregiving for a patient with dementia, especially during the COVID-19 pandemic. Although the theme of feelings was relatively broad, respondents identified specific feelings, including stress, guilt, fear, worry, anger, hurt, and being overwhelmed.

Respondents described their stress and related causes, most prominently work-life balance. As one caregiver noted that stress arose from "juggling work, family, and caregiving." Similarly, cited that stress arose from the conflicting pressures of "teaching, caregiving, family;" this caregiver was a teacher. Stress could also arise from the environment, as expressed by one caregiver. COVID-19 was a serious environmental stressor for the participants of the study.

Guilt was another substantive subtheme. A source of guilt for one caregiver was the transmission of COVID-19 to the person with dementia they were caring for. Relatedly, another

caregiver felt guilt over the need to enact changes to their caregiving routines over COVID-19, which caused substantive disruption to the person with dementia they cared for. A third potential source of guilt was that the caregiving role caused the participants to have "neglected job and family," as expressed by the caregiver. Unlike the other guilt attributions, guilt over neglect did not connect directly to COVID-19.

In this study, the participants addressed mainly COVID-19-related worries. A substantive fear was, given the nature of dementia patients as vulnerable older adults, was the fear of the patients they were caring for "dying without [a] funeral and family being able to say their final goodbyes" as expressed by a caregiver in the pilot study. This was a stronger form of the more widely reported fear for the safety of their love one expressed by all of the caregivers.

Participants reported a combination of COVID-19-related worries and non-pandemic worries. Related to the pandemic were worries of not being able to see the person they were caregiving because of issues such as quarantines. Relatedly, one caregiver reported worries for "health of staff and love one," referring to the healthcare providers involved in the patient's care due to the risk of transmitting COVID during the pandemic from health care workers who. One caregiver expressed significant worry about their love one not recognizing them a as a result of a 7-month separation from COVID lockdowns. More general worries related to dementia itself. Participants in general also expressed worry for the patients' suffering.

Anger and resentment were reported amongst the caregivers. Anger was focused on the effects of the pandemic impeding the caregiver's ability to interact with and care for the patient. A more generalized anger and resentment was also reported regarding the effects of dementia more generally. Finally, participants expressed their frustration and resentment toward the

patient and society for not having done more in terms of preventative measures before dementia became as severe as it was.

The subtheme of hurt and overwhelmed did not pertain to the pandemic and instead was focused on the effects of dementia. All participants experienced dementia as hurtful, given the deteriorative effect of the condition on their loved one and the way it slowly erased their relationship with their loved one. One caregiver expressed emotional hurt when their loved one with dementia slapped them in the face for bringing up dementia while discussing their care with their physician. The feeling of being overwhelmed was difficult to analyze along pandemic and general lines because the effects of both factors were blurred together to make the overall caregiving experience painful and overwhelming as it was experienced at the time of the interviews.

Thoughts. Some caregivers perceived their role as beneficial to themselves. One caregiver noted the experience of caregiving was "intensely gratifying to me." Similarly, another caregiver expressed that it was an "honor to take care of them. I am grateful that—I mean, the pandemic has helped me appreciate every day that I get to be there." In addition, one caregiver expressed that the role of caregiving gave them a way to feel less helpless about dementia. Overall, the benefits of the role seemed to derive from a sense of satisfaction in taking care of a loved one during a time of need. Caregivers mentioned sacrifices as well. Notable examples included one caregiver described her sacrifice of friendships and relationships with other family members because of the time burden of caregiving. Another noted there was a substantive sacrifice in terms of their daily routine, especially because of the need to cook meals around the needs of the patient with dementia, which was not the case pre- COVID due to their daily routine of having dinner out at a restaurant daily. In addition, another caregiver noted a number of negative effects

from caregiving; a lack of self-care, having essentially a 24/7 job, and a weight gain of 30lbs—but also "we haven't slept in 2022."

Responsibilities felt during COVID. The final theme pertained to the specific caregiving responsibilities experienced during the pandemic. This theme also included multiple subthemes. Key subthemes were: finding resources, navigating healthcare and precautions, navigating misconceptions, and isolation effects.

Finding Resources. Caregivers experienced frustrations with finding care resources that actually supported them. Many of the resources they found had the opposite effect and increased the burden of caregiving. One caregiver experienced frustration as they sought out getting a definitive diagnosis early on in the pandemic when not much was known about COVID and with lockdowns resources began to vanish. As a caregiver going through the initial diagnosis, rescheduled appointments, and the shuttering of resources made it difficult to know where to turn for help.

Navigating Healthcare and Precautions. Navigating healthcare and precautions pertained to the extra strain of finding a healthcare provider during the pandemic. Caregivers were concerned about the length of wait under COVID-19 conditions, about whether/when to use telehealth, and who should stay with the person they were providing care for. The pandemic also created a relatively urgent need to avoid the emergency department because of COVID-19 risks. In general, the caregivers also expressed that navigating the pandemic precautions and keeping up to date on guidance represented a significant responsibility.

Navigating Misconceptions. Pandemic misconceptions were a significant responsibility. The most substantive issue in that regard, per one caregiver, was the "change in how we feel about each other depending on who chose to be vaccinated and who did not." The greater risk of

dementia patients—being older adults—for severe COVID-19 exacerbated this effect. In addition, many caregivers felt frustrated by the need to navigate the public's insensitivity with regard to the effects of the pandemic on persons with dementia.

Isolation Effects. Finally, the effects of isolation increased significant responsibilities. Several participants noted that pandemic-induced isolation resulted in the deterioration of the person they were caring for because of a loss of ways to get mental stimulation. In addition, the pandemic created responsibilities around managing physical touch for the patients and avoiding worsening risks from contact with others while in isolation.

Quantitative

All eight participants were also given the ZCB scale. The results for the ZCB scale are presented in tabular form, by item.

Question 1											
How often do you feel?	0 (Never)		1		2		3		4		Total
1	There is not enough time for yourself.	0.00%	0	0.00%	0	37.50%	3	50.00%	4	12.50%	1	8
2	Overtaxed with responsibilities.	0.00%	0	12.50%	1	12.50%	1	62.50%	5	12.50%	1	8
3	Like you've lost control over your life.	0.00%	0	25.00%	2	12.50%	1	50.00%	4	12.50%	1	8

Question 2											
In regard to the relative for whom you are caring, how often do you feel?	0 (Never)		1		2		3		4 (Nearly Always)		Total
1	Uncertain about what to do for your relative	0.00%	0	25.00%	2	62.50%	5	12.50%	1	0.00%	0	8

		0		1		2		3		4 (Nearly Always)		Total
2	Like you should do more for your relative	0.00%	0	0.00%	0	37.50%	3	37.50%	3	25.00%	2	8
3	Like you could do a better job of caring	0.00%	0	0.00%	0	12.50%	1	62.50%	5	25.00%	2	8

Question 3

	When you are with the relative for whom you are caring, how often do you feel?	0		1		2		3		4 (Nearly Always)		Total
1	A sense of strain	0.00%	0	37.50%	3	25.00%	2	25.00%	2	12.50%	1	8
2	Anger	37.50%	3	37.50%	3	0.00%	0	25.00%	2	0.00%	0	8
3	Embarrassment	37.50%	3	62.50%	5	0.00%	0	0.00%	0	0.00%	0	8
4	Uncomfortable having friends over	37.50%	3	12.50%	1	25.00%	2	12.50%	1	12.50%	1	8

Question 4

	How often do you feel that your relationship with the relative for whom you're caring negatively impacts:	0		1		2		3		4 (Nearly Always)		Total
1	Your social life	12.50%	1	25.00%	2	37.50%	3	12.50%	1	12.50%	1	8
2	Other relationships with family and friends	12.50%	1	37.50%	3	25.00%	2	12.50%	1	12.50%	1	8
3	Your health	0.00%	0	37.50%	3	37.50%	3	12.50%	1	12.50%	1	8
4	Your privacy	0.00%	0	50.00%	4	12.50%	1	12.50%	1	25.00%	2	8

Question 5

	How often do you:	0 (Never)		1		2		3		4 (Nearly Always)		Total
1	Feel you receive excessive help requests	12.50%	1	37.50%	3	37.50%	3	12.50%	1	0.00%	0	8
2	Feel all the responsibility falls on one caregiver	0.00%	0	25.00%	2	25.00%	2	0.00%	0	50.00%	4	8
3	Fear the future regarding your relative	0.00%	0	25.00%	2	0.00%	0	37.50%	3	37.50%	3	8

4	Fear not having enough money to care for your relative	25.00%	2	25.00%	2	0.00%	0	25.00%	2	25.00%	2	8
5	Fear not being able to continue caring for your relative	0.00%	0	37.50%	3	37.50%	3	25.00%	2	0.00%	0	8
6	Wish to leave the care of your relative to someone else	37.50%	3	0.00%	0	37.50%	3	12.50%	1	12.50%	1	8

Question 6

How much does your spouse/loved one depend on you as the caregiver?

Answer	%	Count
0 (Never)	0.00%	0
1	16.67%	1
2	33.33%	2
3	33.33%	2
4 (Nearly Always)	16.67%	1
Total	100%	6

Question 7

Please rate your overall level of burden in caring for your spouse/relative?

	Answer	%	Count
1	No Burden	0.00%	0
2	Mild Burden	12.50%	1
3	Moderate Burden	75.00%	6
4	Severe Burden	12.50%	1
5	Extreme Burden	0.00%	0
	Total	100%	8

Discussion

Overall, the purpose of this study was to determine if the ZCB scale (Zarit et al., 1980) is adequate to capturing caregiver burden during the pandemic. In this regard, the most prudent and relative way to understand the study results is through comparison to the items on the ZCB scale. To this end, each individual theme was addressed relative to the scale. From the analysis in this study, several gaps have been identified in the ZCB scale.

Caregivers described feelings of stress, guilt, fear, worry, anger, hurt, and being overwhelmed. ~~The~~ ZCB scale addresses stress, anger, and fear/worry. Stress is addressed through items regarding the time demands of caregiving and generalized strain (Zarit et al., 1980). This broadly aligns with the present study's results that emphasized time demands. Although the ZCB scale addresses anger, the present study yielded a more complex idea of anger ~~that is more~~ than is captured by the ZCB scale. Similarly, though the ZCB scale contains items for fear and worry, these do not adequately capture the pandemic-related feelings of fear and worry experienced by the participants of this study, such as the fear of not being able to hold a funeral for the love one the caregiver was providing care to. The ZCB scale addresses some aspects of guilt (e.g., not doing enough), but these aspects are misaligned with the guilt factors in this study. Similarly, the ZCB scale fails to capture the subthemes of hurt of and feeling overwhelmed. Therefore, in regard to the theme of caregiver feeling, the ZCB scale is only half adequate to addressing the key issues.

Caregiver thoughts had two sub-themes, benefits and sacrifices. The benefits theme is important because it is entirely absent from the ZCB scale (Zarit et al., 1980). In addition, the broader literature on dementia caregiving burden has tended to focus on the factors creating burden (Liu et al., 2018; Li, 2012; Verkaik et al., 2016). However, as expressed in this study, the

perceived benefits of caregiving are also an important factor in the sense that a sense of satisfaction or honor for the role of caregiver can ameliorate the burden of caregiving. Though hardly a novel idea in itself, this result is novel in the sense that it suggests a proper measure of caregiver burden should include benefits as a counterweight. On an instrument such as the ZCB scale, the perceived benefits of caregiving could be represented as negatively scored items subtracted from the overall burden score.

The other sub-theme for caregiver thoughts was sacrifices. The sacrifices represented a major contribution to the burden of caregiving. Within the sacrifice's subtheme, key ideas related to sacrificing time, sacrificing social relationships, and sacrificing self-care. Of these, only self-care is not adequately represented in the ZCB scale. The scale contains items directly measuring the burden of caregiving on multiple types of social relationships. It also addresses the extent to which caregivers lack time for themselves. It does not, however, address the extent to which caregivers feel that caregiving denies them the resources needed to more generally care for themselves. This lack is substantial because, even before COVID-19, the burden of caregiving on hindering self-care was acknowledged within the literature (Li, 2012; Verkaik et al., 2016). Therefore, the effect of care on self-care should be added to a fully comprehensive measure of caregiving's burden.

The final theme of COVID-19 responsibilities represents a set of issues that are almost entirely absent from the ZCB scale. The sub-themes under COVID-19 responsibilities included finding resources, navigating healthcare and precautions, navigating misconceptions, and isolation effects. In contrast, the ZCB scale contains only one item, "Overtaxed with responsibilities," for responsibilities in general. The pandemic, however, has spawned a substantive set of new responsibilities. The first of these was that it makes even seeking normal

healthcare a struggle, requiring finding new resources and making a heavy cost/benefit analysis of healthcare actions.

Navigating the actual COVID-19 restrictions and risks is also a large burden. Per the literature (Liu et al., 2020), age is by far the most important factor for determining the risk of severe COVID-19 and also the greatest predictor of pandemic mortality. In this regard, dementia patient caregivers have an essential gatekeeping role for those they care for. As expressed by the caregivers in this pilot study, public lack of adequate concern for the virus could add significant caregiving burden even if the caregivers were doing everything right. Caregiving could also make disputes regarding masking and vaccine adoption more burdensome. Those issues can also be a great strain on social connections given the strong feelings on the part of both sides (Altieri & Santangelo, 2021; Panda et al., 2021).

None of these issues were imagined or could have been predicted in drafting the ZCB scale, and therefore they represent perhaps the most egregious way in which the scale is inadequate to measuring the effect of the pandemic on caregiver burden. The current ZCB scale would weigh all of these expanded responsibilities under a single item out of 22, weighted the same as all the others. However, in the context of COVID-19, the responsibilities associated with caregiving are greatly expanded and should be treated as a much more substantive component of the burden of care.

Implications for Practice

Overall, the results of the present study demonstrate the gaps of the ZCB scale (Zarit et al., 1980) for measuring the burden of dementia caregiving in the pandemic context. Therefore, the first and most important recommendation for practice is that a new measure of caregiver burden should be developed and adopted in the context of the pandemic. Such a measure should

include the ~~many~~ omissions identified in the discussion section above, but most importantly, it should address the issues of self-care and pandemic responsibility. The importance of self-care and the ability of dementia caregiving to impede its utilization is not supported exclusively by this research, but is evinced in the larger literature (Li, 2012; Verkaik et al., 2016). Therefore, there is an especially strong case for including it. Pandemic-era responsibility, by contrast, is the primary focus of this study, and a full third of the results pertained to it, none of which is adequately reflected in the current measure of caregiver burden. Literature also supports the importance of better including the effects of the pandemic in caregiver burden (Altieri & Santangelo, 2021; Liu et al., 2020; Panda et al., 2021).

In addition to the need for better measurement of caregiver burden, the results of this study indicate a clear need for better ways of supporting caregivers in navigating the pandemic. Participants experienced that the pandemic had worsened the dementia in those they cared for while also steeply increasing their responsibilities in navigating healthcare and acting as health gatekeepers. As a result, there was a clear need for more supportive resources, especially those that actually supported the caregivers rather than creating more work for them. When even vaccinations have not caused the pandemic to fully abate, these factors should be addressed, where possible, by creating more pandemic-era resources for dementia caregivers, especially those relating to self-care and/or making healthcare utilization easier, safer, and more straightforward. Failing to do this could have significant, detrimental consequences for both dementia caregivers and the love ones they care for.

Limitations

Though the present study has important and substantive implications, it also has limitations. The first limitation of this research is that it is impossible to be certain that saturation

was achieved. Efforts were made to ensure that saturation was achieved, but the population of dementia caregivers is vast. Therefore, it is possible that the results in this study do not actually represent all the perspectives in the population. However, the results represent at least a substantive proportion of the thoughts, feelings, and responsibilities experienced by dementia caregivers during the pandemic. Nonetheless, future researchers may wish to more widely explore the population, especially in any research seeking to actually develop a new and expanded measure of caregiver burden.

A second limitation of the study was the sampling frame. The participants for this study were recruited in the specific context of Texas. Texas, a Republican-controlled state, has had a particularly laissez-faire response to the pandemic. This and other state-level factors may have substantively influenced the participants' perceptions of the pandemic-era healthcare landscape and the lack of public concern. To address this limitation, future research should explore the pandemic-era caregiver burden experiences of dementia primary caregivers in a wider array of geographic contexts.

Finally, this study was limited by the inability to fully disentangle pandemic and non-pandemic factors in some cases, such as in the subtheme of being overwhelmed. This makes it harder to determine which of the results would be important only for developing a pandemic-era expanded measure of caregiver burden and which would be appropriate for developing a more general expanded measure. To address this limitation, future researchers should reassess the relevant factors driving caregiver burden once the pandemic has fully subsided.

Conclusion

In conclusion, the purpose of this mixed-method study was to examine the ability of the Zarit Caregiver Burden scale to capture the burden experienced by caregivers of persons with

dementia during the COVID-19 pandemic. The results overall indicated that the ZCB scale is inadequate to fully capture the burden of dementia caregiving during the pandemic, and perhaps also in need of a more general update. In the process of determining this, the study also revealed the importance and necessity of doing more to support dementia caregivers throughout the remainder of the pandemic. Self-care resources and resources to improve access to safe healthcare for the patients they provide care to are especially essential.

Chapter 4: Manuscript 3

African American Dementia Caregivers' Information Needs and Information Seeking Behaviors

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Abstract

To help bridge the gap in health outcomes for African American dementia caregivers and their patients, this qualitative study explored the support and information needs and information seeking behaviors of African American dementia caregivers. African American dementia caregivers engage in more hours of intense caregiving and delegate more of their monthly income to caregiving yet report less access to services and more unmet needs than White-Americans. This was a qualitative study descriptive study using interviews with 12 African American caregivers who provide care for an individual with dementia. Caregivers highlighted the importance of the following four factors in their ability to obtain information: affordable community resources, (2) trusted guidance, and (3) cultural competency. Findings from this study can help healthcare providers better understand the complexities of caring for the African American population and offer an opportunity for providers to be more intentional regarding assessing and addressing the needs of African-American caregivers and the person with dementia.

Key Words: African American, caregivers, dementia, information needs, resources

African American Dementia Caregivers' Information Needs and Information Seeking Behaviors

African American dementia caregivers report less access to support services and more unmet needs as compared with their White counterparts (Fabius et al., 2020). African American dementia caregivers engage in more hours of intense caregiving and delegate more of their monthly income to caregiving (Cohen et al., 2019; Fabius et al., 2020; Romero-Moreno, 2012; Wells et al., 2017). In addition to spending significant hours providing care (Cohen et al., 2019; Fabius et al., 2020), African American caregiving networks usually encompass multiple individuals with limited financial resources with a center around the church as a source of spiritual support (Dilworth-Anderson et al., 2004; Young et al., 2020). Furthermore, systemic failures and disadvantages, particularly in the health care system, place a considerable burden on African American dementia caregivers (Oliver et al., 2022).

Research has found that African Americans are less likely to seek support services for care; this resistance can be a result of increased caregiving hours, stigma, different health beliefs, distrust of the healthcare system, and not enough knowledge about dementia (West et al., 2021). There is evidence in literature that African Americans are less likely to receive a diagnosis of dementia (West et al., 2021). Dementia caregivers are often isolated from family, friends, and community while living with above average rates of stress, burden, anxiety, and depression (Schulz & Sherwood, 2008). Furthermore, this social isolation while caring for a person with dementia leads to worsening mental health and well-being (Chatters et al., 2020). African American dementia caregivers experience a disproportionate burden compared with caregivers of other racial groups due to the increased prevalence of Alzheimer's disease and related dementias

and systemic bias experienced in the African American community (Alzheimer's Association, 2022).

The purpose of this study is to explore the support and information needs and information seeking behaviors of African American dementia caregivers. Understanding African American caregivers' unique experiences and challenges obtaining information and resources and how they seek out information can help bridge the gap in health outcomes for African American dementia caregivers.

Conceptual Framework

The Middle- Range Theory of Caregiver Stress derived from the Roy Adaption Model as conceptualized in 1984 (Roy, 1984) is a relational construct that assumes the individual is an adaptive system affected by both internal and external environments known as stimuli. Roy (Andrews & Roy, 1991) argues that each person has an adaptation level or range of ability to cope in a situation. Adaptation level is a changing point that indicates the person's ability to respond positively to his/her environment and it is determined by the environmental stimuli that an individual has experienced in life (Andrews & Roy, 1991). If the pooled effects of the stimuli are less than the individual's adaptation level, the responses are adaptive (Roy, 1976). But if pooled effects of the stimuli are greater than the individual's adaptation level, the resulting responses are ineffective adaptation as is the case in the burdens and stressors that are faced by African American dementia caregivers.

Method

Design

This was a descriptive qualitative study design using interviews to explore the experiences of African Americans caring for people with dementia.

Characteristics of Researchers

SS has worked in clinical research for drug development most of her nursing career. She has held multiple leadership roles and contributed to the research and development of several FDA approved drugs. The remaining authors are nurse researchers who are experienced in qualitative research in dementia.

Sample

A purposive sample of African American dementia caregivers were recruited from November to December 2022. Caregivers were recruited through flyers shared with community organizations providing support services to persons with dementia. Inclusion criteria included African Americans who self-identified as African American or Black who were currently providing informal and unpaid care to a person with dementia. Exclusion criteria included caregivers who are paid and those who are caring for someone who has resided in a long-term facility greater than 6 months. The setting for this study was virtual given public health concerns stemming from the COVID-19 pandemic.

Data Collection

Twelve semi-structured interviews were conducted virtually. An interview guide with open-ended questions about caregivers' information needs and information seeking behaviors was used to guide interviews (Table 1). The interview guide was piloted with one nurse researcher and one caregiver of a person with dementia, resulting in modifications to clarify questions. Participants completed a demographic questionnaire. Interviews lasted approximately 60 minutes and participants were provided with $25 gift card upon completion of the interview.

Table 1

Interview Guide Questions

1. Tell me about your role as a dementia caregiver?
2. As a family caregiver for your loved one with dementia, what information do you need to care for them?
3. How do you access information and use resources to care for your loved one with dementia?
4. Explain what social support information and resources are useful to meet your needs caring for your loved one with dementia?
5. How and where do you prefer to obtain trusted information on caring for a loved one with dementia?
6. What aspect of caring for your loved one with dementia and caring for yourself is more difficult?

Note. Questions used in interview

Data Analysis

Interviews were audio recorded and transcribed verbatim using an online transcription service. Analysis of the interviews began with a full read of each transcript in order to identify recurrent ideas and key themes. A series of meetings were held during which the authors created an initial codebook based on identification of key themes and emerging categories. Coding of interview data began with a second read of each transcript, using the codebook. Throughout the process, two primary coders (SS, MK) met regularly to discuss and iterate codes and resolve interpretive differences. Dedoose Version *9.0.17* (Data Analysis Software, Los Angeles, United States) and manual review was used for data coding and analysis. Trustworthiness was supported through saturation, peer debriefing, an audit trail, and memoing to acknowledge researcher assumptions (Creswell & Poth, 2018).

Plan for Protection of Human Subjects

This study was approved by the university institutional review board. Informed consent was obtained from each participant prior to their interview, explaining the risks and benefits of participation in the study and the right to opt out at any time. All data was de-identified and password protected.

<div align="center">Results</div>

Demographics

Table 1 describes the caregiving characteristics of caregivers in this study. Caregivers (N = 12) ranged in age 40–78 years with a median of 59 years. Most caregivers were women (n = 11, 92%). All caregivers were relatives of the person with dementia, but primarily were adult children or other family member (n = 11, 92%) and spouses (n = 1, 8%). Reported duration of caregiving and daily time spent caregiving varied widely (1–9 years, median 4.6 years). Most interviews were conducted in the absence of the person with dementia (n = 11, 92%).

Table 2
Caregiver Demographics (N =12)

Gender	Age	Years Caregiving	Relationship	Degree
Female	51	9	Child	College
Female	55	4	Child	Master's
Female	62	5	Child	Master's
Female	61	4	Child	Master's
Female	43	9	Child	Master's
Female	57	2	Niece	Master's
Male	61	5	Child	Doctorate
Female	54	4	Child	Doctorate
Female	76	1	Other relative	High School
Female	64	7	Child	Some College
Female	40	7	Child	Some College

Information and support needs

Caregivers unanimously expressed a strong need for community-based resources and guidance from a trusted healthcare provider. Most received limited, if any, information at the time of diagnosis. The following subthemes were identified: (1) community support resources, (2) trusted guidance, (3) and cultural competency. The following sections describe the themes in greater detail.

Information and Support Needs	Information Seeking Behaviors	Barriers
Community Resources	Word of Mouth	Technology
Trusted Guidance	Trusted family/friends with shared experiences	Financial Hardship
Cultural Competency	Internet	

Community Support Resources. Nearly all caregivers expressed the need for dementia support services within their communities. One caregiver expressed "I had no clue where to start … because I was overwhelmed." Another expressed urgency in obtaining support as "I need to get somebody in the house…, I can't do this and hold down a full-time job." Many caregivers felt discouraged about their options for support, one declared "there is nothing close in my community" and another voiced concern of "inadequate resources in African American community once again" and questioned "why are there no memory care facilities in African American neighborhoods like there are in white neighborhoods?" Others shared negative experiences with resources and one stated she "removed her loved one with dementia from a local nursing home after only a few days because 'my mother was slapped by a male resident' and 'fell and hit her head' without hospital follow-up." Furthermore, many caregivers were filled with a deep pride in caring for family and expressed that they would be filled with "guilt leaving family in the low-quality day centers" they have encountered.

Trusted Guidance. Nearly every caregiver felt they walked out of the doctor's office after their family member's initial dementia diagnosis feeling they lacked information on the next steps or guidance on how to provide care for their family member with dementia. One family member described being "overwhelmed" and the doctor was "just concerned with prescribing a medication and provided little information beyond that". Another caregiver described the provider as "unhelpful" because the provider's comment was…" it might be Alzheimer's, so come back in six months."

Caregivers expressed feeling "unheard" and that they were "looked over" when trying to gather information and understand how to proceed forward with the diagnosis and providing care to their family member. One caregiver described being "talked down to and felt the doctor could care less about their family member with dementia". Another mentioned that "family members of African American people have to advocate harder because the system isn't fair and we will get looked over as usual."

Caregivers who were exposed to a social worker had better success finding some resources most of the time. Finding resources requires caregivers to advocate, be self-driven, and intentional; as one caregiver expressed "the resources aren't going to come to you, you are going to have to find them and fight for them".

Cultural competency. Caregivers overwhelmingly felt their experiences were more challenging because of their race and socioeconomic status. Mistrust of the medical community by African Americans is rooted in the legacy of structural racism and socioeconomic disparities which have plagued their communities since slavery. Trust is a key concern as described by one caregiver, "Trusting people coming in the house and making sure that they take care of her the way I take care of her. That was the most challenging". Another caregiver expressed, "It's about

that trust factor. I want somebody, but I want somebody who looks like me… somebody that looks like your culture. We feel more comfortable with things that come from us versus another culture...". Several expressed a desire to have a provider that can relate to your culture and "at least try to have some understanding is necessary to build a trusted relationship".

Information seeking behaviors

Relying on "word of mouth" from people they felt they could trust was a common theme identified in tech to gather information to care for the person with dementia. Caregivers who were self-driven, experienced in navigating the internet, and were intentional in seeking out and locating resources were more inclined to be successful in obtaining information. One caregiver expressed,

> "If I hadn't read about it and gotten some of that information from my ex-daughter-in-law
>
> who is a social worker, I would have just been lost. The doctor just told me to go
>
> Alzheimer Association for more information. I expected a little more from him."

Another caregiver stated, "I reached out to people in my church who I knew had a family member with dementia". Several of the caregivers expressed that they use the Internet or lean on people they know who may have family or friends with dementia. One elderly caregiver expressed, "I'm not computer savvy so I ask people I know or what the doctor says".

Barriers

Caregivers were consistent in their desire to obtain information on support services and community resources that would help ease the burden of caring for their family member with dementia. While their desire was consistent, the barriers to accessing some of these resources are significant. Barriers included financial hardships and technology.

A majority of the caregivers expressed significant financial hardships in providing care for their family members and sustaining their own quality of life. One mentioned that the "burden of care is affecting my quality of life and ability to maintain all my responsibilities." The cost of care was a major concern with caregivers worried about their ability to provide for themselves if they depleted their resources caring for their family member with dementia. One caregiver expressed concern of finances, "while paying for my husband to partially stay in a group home. My personal bills aren't getting paid and my kids are trying to pay my car note so I can be able to go see my husband". Another caregiver expressed,

> "The financial side it's really overwhelming..., They want you to have no money, no vehicles, no property to qualify for government funded resources". Further, "You have little resources out there and honestly, I hate to say it, unfortunately for our African American community, we literally have to fight to get the things that we need…, that's like what we have to do. We just have to fight to get the things that we need".

Technology was identified as a barrier for elderly caregivers. Once caregiver expressed, " Rarely do I use the internet… I don't know how you go about finding resources to help with my husband". Elderly caregivers are the most vulnerable and are more likely to be in an information desert. Interestingly, another caregiver expressed, "There was a point that the church was a resource in the community to obtain support I don't think that because I don't think the younger generation … may not be going to church."

Discussion

This study using a qualitative approach highlights the information needs and information seeking behaviors of African American dementia caregivers. The findings from the study describes, from the African American caregivers' perspective, their experiences as they sought information regarding resources to ease the stress and burden of caring for their family member with dementia. Similar findings have been reported in previous studies that overall dementia caregivers, regardless of race, seek information and resources to better aid them in caring for the person with dementia (Mountain & Craig, 2012; Soong et al., 2020) Some of the information commonly sought out includes information on how to care for a person with dementia, tips for managing behavioral concerns, better coordination of care within the healthcare system, and community resources for respite care.

One notable finding and difference that resonated through the study was a sense of mistrust and fear associated with structural systems in society when attempting to navigate information and resources to care for the person with dementia. A long history of systematic racism and poor medical treatment has led to mistrust of the medical community posing unique challenges for African Americans who interact with the healthcare system (Best et al., 2021). Through the lens of these African American caregivers, the legacy of mistrust and fear is heard through their expressed experiences and further exacerbated as incidences of systematic racism continues to arise within the society they live. Through qualitative analysis of the interviews, three overarching themes were extracted to address the information needs, information seeking behaviors and barriers of African American dementia caregivers: community resources, trusted guidance, and cultural competency.

The burden of caregiving could be felt through each of their experiences as what equated to a systematic fight based in racism to achieve the best care for their family member with dementia in a system built on discrimination and roadblocks. African American caregivers felt they experienced different challenges navigating their role as the care provider for their family member in comparison to other races.

The caregivers interviewed in this study expressed that having access to services and resources was critical to the survival of their family member as well as the maintenance of their own well-being. Caregivers of older adults with dementia felt the burden and frustration of finding only low-quality nursing home options and less than appealing adult daycare centers in their communities. Prior research has revealed that African American dementia caregivers are 69% less likely to utilize care services such as respite than their White counterparts (Parker & Fabius, 2020). This tendency to not use care services is related to several factors such as resource access, education, and the healthcare system's lack of cultural understanding of African American's needs (Bonds & Lyons, 2018; Parker & Fabius, 2020). There is a growing realization, however, that access to these services is necessary to help both the caregiver and the person with dementia maintain a quality of life (Udoh et al., 2023). Affordable quality care options are even more critical to population already affected by socioeconomic disadvantages based in systematic racism. As revealed in the interviews, some African American dementia caregivers have limited financial resources to offset the cost of caring for their family member with dementia. Despite the relatively high education level of caregivers in this sample, they still expressed worry about finances. Perhaps this is due to the less transfer of intergenerational wealth for African Americans compared to Whites (Pffefer & Killewald, 2019). Caregivers in this study felt they were at a greater disadvantage because of the stigma of being lower income

and living in a lower income area, particularly taking notice of there being no dementia memory care centers or assisted living facilities around lower income communities as there are in more economically advantaged areas. These observations are consistent with prior research that has demonstrated that a lack of access to affordable formal caregiving services are barriers to service use by ethnic minority dementia caregivers (Kenning et al., 2017). Other barriers to service use reported in both the present study and other research include a lack of knowledge about dementia and the available services on offer (Kenning et al., 2017) These disparities and clear differences in resources as expressed by these caregivers based on socioeconomic and neighborhood class factors continue to perpetuate the perception of systematic racism and ongoing mistrust of the healthcare system by African Americans.

Caregivers in this study expressed the need for advocacy to navigate the challenges and paperwork to find and obtain resources for their loved one. Elderly African Americans with dementia are at a higher disadvantage if they don't have someone advocating for them (Oliver et al., 2022). Caregivers expressed their experiences trying to navigate finding appropriate resources, but either did not know where to start or received little to no guidance from their medical provider. These results align with prior studies that have demonstrated that a lack of specialist dementia knowledge, about both the disease and the available resources, from healthcare providers served as a barrier to service use by ethnic minority dementia caregivers (Neary & Mahoney, 2005; Shanley et al., 2012). Although it is not uncommon for dementia caregivers to express the same sentiments regarding the lack of medical guidance from their medical provider, it important for providers to understand these types of interactions with African American persons with dementia and their caregivers can be perceived as being racially insensitive and foster mistrust in their interactions based on the long history of systematic racism

against African Americans. Historical incidents of racism and unethical medical treatments such as the Tuskegee Syphilis Study, Birmingham, Alabama church bombing, and Martin Luther King Jr. assassination as well the ongoing incidences of racism currently seen in society through racial profiling and police brutality of African Americans still lie in the forefront of this population's mind when interacting with the same systems that has a history of racial bias against them. Caregivers feel because of these biases they are overlooked and must advocate harder to find resources for their family members with dementia.

Communities plagued with long-term and continuous health and socioeconomic disparities can find it challenging to advocate against a system believed to be set up to be biased against them. One caregiver expressed a positive experience when at dementia diagnosis the medical provider immediately connected her with the gerontology team who walked her through the process and connected her with a social worker. The social worker was sensitive to her needs and helped her understand what available resources they qualified for and how to navigate the paperwork to access in-home respite care to ease the burden while she tried to continue to work outside the home. The finding that social workers acted as a facilitator for African American dementia caregivers in using services supports the limited literature on facilitators to service use by ethnic minorities, including patient and carer education about dementia, improved diagnosis by general practitioners, and adaptation of services to population needs (Boughtwood et al., 2013; Karner & Hall, 2002; Shanley et al., 2012). Caregivers in the present study expressed a need for community advocates to help navigate and complete required paperwork for service enrollment, noting the complexity of all the paperwork would be nearly impossible for older adults to manage on their own. Understanding the caregivers needs and walking the caregiver through the process helped to build trust among the caregiver and medical and resource provider

is essential to breaking down the wall of mistrust and building stronger interactions amongst the African American community and community resources and medical providers.

Several caregivers described poor communication with their medical provider which contributed to mistrust and lack of engagement with the medical provider. Medical providers' inability to listen and embrace caregivers' concerns, combined with providers' focus on prescribing a medication and what they consider "push them along" to get to the next patient, affected how caregivers viewed their relationship with their provider. According to Mullins et al. (2016), poor communication from healthcare providers results in confusion, poor compliance, and mistrust. Several caregivers felt medical providers were dismissive and provided little guidance on what to expect, what's next, and where to go for help. Caregivers facing the challenges of caring for a family member with dementia were looking for their specific questions to be answered and became frustrated and disheartened from the struggles communicating with medical providers; they perceived these interactions as systematically and racially motivated.

With African Americans being twice as likely to develop dementia than their white counterparts and the fact that daily racism increases the risk of developing poor cognition among African American women by 2.75 times and institutional racism increases it by 2.66 times, efforts are needed to address the cultural aspects surrounding the care for this populations with an ongoing and long history covered in racism and mistreatment (Alzheimer's Association, 2023). Clark et al (2018) noted cultural competency amongst medical providers decreased disparities and increased engagement of patients and their families. Social and economic vulnerabilities directly impacted the patient-provider interaction. Providers being mindful of these vulnerabilities and engaging caregivers with understanding of their past experiences and

the systematic racism they have endured can improve interactions and decrease the perception of mistrust of the healthcare system by African Americans.

It's not uncommon for individuals to use different methodologies to obtain reliable information to answer their questions or provide guidance in making critical decisions. Study results show that although African American dementia caregivers obtained information from traditional sources such as physicians and other medical professions, they relied heavily on word of mouth from trusted family, friends, and/or church members of the same race who shared the same experiences. African American caregivers are apt to feel more comfortable obtaining information and resources from individuals who look like them and share the same cultural experiences and understanding due to their perception of ongoing systemic, racial and socioeconomic bias. Interestingly, Epps et al. (2020) noted the church as being a resource for information on dementia in the African American community. Although there were instances in this study where caregivers did rely on interactions within the church for information, a few younger caregivers expressed a movement away from the church as a source of information; because fewer younger individuals are attending church, they no longer lean on the church for information and guidance (Kinnaman & Hawkins, 2011). While the older generation rely more heavily on traditional word of mouth to obtain information, the younger generation are more technologically savvy and are better able to navigate the internet for resources and information (Marimuth et. al., 2022). The lack of these technical skills put the elderly African American population at further disadvantage. Furthermore, relying on word-of-mouth information increases the chances of miscommunication and sharing of misinformation. Historical precedence of socioeconomic and health disparities from structural racism further widens the gap in African American caregivers obtaining trusted information and guidance to support providing

care for their family members with dementia, as seen in this study. These findings also exemplify the importance of fostering the understanding of the cultural nuances and bias that have an impact on African American dementia caregivers' burden, stress, and coping process while addressing their concerns, information and resource needs.

Strengths and Limitations

The caregivers in this study willingly shared their experiences and provided rich details on their information needs and obtaining resources for their family members with dementia. The study does have some methodological limitations. Caregivers participating in the study were recruited from a small purposive convenience sample and were primarily recruited from the same metroplex area. Most of the caregiver were highly educated with at least some college and several having advanced degrees. These limitations could have an impact on the generalizability of the study.

Studying the information needs and information seeking behaviors of African American caregivers of a person with dementia offered critical insight into the caregivers themselves. The knowledge gained can support the search for and development of tools and resources that specifically address their challenges. Using the Middle- Range Theory of Caregiver Stress derived from the Roy Adaption Model, the study team was able to observe the internal and external factors that challenge the caregivers' ability to care for a family member with dementia. Knowing caregivers struggles, information and resource needs are important to develop adequate resources to reduce adverse effects of the disease as much as possible while trying to maintain their quality of life. Factors such as age, cultural experiences, and literacy affect caregivers' information seeking behaviors and ultimately should be considered when addressing their information needs.

Future Research Implications

Healthcare providers can utilize findings from this study to better understand the complexities of caring for the African American population and offer an opportunity for providers to be more intentional regarding assessing and addressing the needs of African American caregivers and the person with dementia. Further research to understand the specific informational and resource needs of African American caregivers is warranted. Studies should include a broader sample of African American caregivers who may not be in direct connection with community resources, decline connecting to resources, or choose to manage care all on their own. Collaboration between African American caregivers and African American providers in development of services may be key to addressing the resource needs and to decreasing systematic bias or the perception there of.

Chapter 5: Discussion

This dissertation ties together a scoping review, a mixed methods study on the usefulness of the Zarit Caregiver Burden scale, and a qualitative study on African American dementia caregivers' experiences and challenges with obtaining resources and information to provide deeper insights into the experiences of dementia caregivers. Specifically, this dissertation sought to fill a gap in the literature on African American dementia caregivers' experiences with obtaining information and resources they find useful to provide adequate care and ease the burden of caring for their family member with dementia.

The scoping review provided foundational information by mapping dementia caregivers' barriers, facilitators, and strategies for self-care. Demographic factors such as gender, caregiver education, and length of care time were identified as facilitators to self-care (Wang et al., 2015). Interestingly, however, demographic factors such as gender and ethnicity were also identified as barriers to self-care seeking behaviors by numerous scholars (Waligora et al., 2019; Withers et al., 2021). For example, conceptions of traditional gender roles may socially stigmatize female caregivers from seeking out self-care due to an obligation that they need to fulfill society's gendered expectations (Waligora et al., 2019). Several of the barriers to self-care identified in the scoping review were reflected in the data that emerged from the interviews conducted with African American dementia caregivers in manuscript three. For instance, many of the caregivers interviewed expressed that cost of care and financial hardships were barriers to self-care and prevented them from providing better quality care. Participants noted that financial hardships caused them to feel angry, worried, guilty, and overwhelmed. These feelings were also reported in manuscript two by caregivers who suffered additional financial hardships due to the COVID-19 pandemic. Participants in both studies two and three also reported that a lack of access to

resources increased these feelings and made it difficult to provide care to their family member and engage in self-care. Additional barriers to self-care identified in the scoping review included a lack of knowledge of dementia and how to provide adequate care (Oliveira et al., 2019b; Wang et al., 2019). Similar barriers were also reported by participants in study three, who often felt that they received little help from healthcare providers and were left in the dark about how to provide caregiving services. On the opposite side of the coin, more knowledge about dementia and what caregiving services are available acted as facilitators.

This research focused specifically on the experiences of African American dementia caregivers. This sub-group of caregivers often experience more challenges in providing adequate care due to an increased prevalence of dementia among African Americans (Alzheimer's Association, 2022), systemic inequalities in the healthcare system (Best et al., 2021) and a lack of access to resources (Bonds & Lyons, 2018). The scoping review also identified a lack of culturally appropriate resources as barriers to self-care and a factor that increases the burden of care. This finding reflects sentiments that emerged from interviews with African American dementia caregivers, who reflected that oftentimes there were no assisted living homes or other care facilities near lower income neighborhoods they lived in. Additionally, participants reported that oftentimes healthcare providers' lack of cultural competency increased feelings of mistrust on the part of caregivers. This observation aligns with prior research that emphasizes the importance of cultural competency in increasing the quality of providers' relationships with caregivers.

Conclusion

Results from all three of the studies in this dissertation highlight the need to provide more resources for dementia caregivers. This is not only important so that caregivers can provide high-

quality care to their family member with dementia; it is also important because many dementia caregivers suffer from carer burden (Pinquart & Sörensen, 2005) from the physical, emotional, mental, and financial hardships associated with caregiving. Therefore, it is important that dementia caregivers are able to engage in self-care activities, which may include broad strategies such as seeking out information and seeking out social support (Bull, 2014). Indeed, participants in study three emphasized the importance of the church both as a source of information to them about dementia resources and as a social support network. Given that African American dementia caregivers often experience a disproportionate amount of carer burden, this study focused on their experiences as they relate to self-care and having access to resources and information to ease the burden of care. Findings from this dissertation underscore the importance of increasing the availability of affordable community-based resources, increasing healthcare providers' cultural competency, and making sure that families have access to community-based advocacy support to help with navigating the challenges that come with a dementia diagnosis.

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Appendix A
Interview Guide Informal Caregiver

Script: I will be recording this interview so that we do not miss any of your insights and the audio-recording will only be used interview as explained in the study procedures sections. First, I want to start by thanking you for agreeing to participate in this important study. Your responses will help nurses and other health care professionals understand what it is like to support someone with dementia during the COVID-19 pandemic. I want to start by asking you a few questions. As a reminder, your participation in this study is voluntary - you do not have to answer any question that you do not want to answer, and you may stop the interview at any time. Are you ready to get started?

1. What kind of changes has the COVID-19 pandemic had on your role as a caregiver of a person with dementia?

2. Describe how caregiving for your loved one is different from before the start of the pandemic?

3. Describe some of the greatest challenges/burdens you have experienced in caregiving since the start of the pandemic?

4. Describe your experiences during COVID-19 with helping your loved one maintain social distancing and other practices to prevent COVID-19 exposure?

5. How were you able to navigate the healthcare system for medical appointments during the COVID-19 pandemic while caring for your loved one.

6. Describe how your support system has changed since the start of the COVID-19 pandemic?

7. How has your social life changed since the start of the COVID-19 pandemic?

8. Describe any changes in your loved one's behavior since the start of the pandemic?

9. How does your loved one's behavior affect you?

10. Describe any strategies you used to maintain a sense of normalcy during the COVID-19 pandemic.

11. Describe any negative impacts or feelings the COVID-19 pandemic has had specifically on your life as a caregiver?

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