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Improving the Experiences of Informal and Formal Alzheimer's Disease and Dementias Caregivers

Roxroy Anthony Reid
Walden University

Walden University

College of Social and Behavioral Sciences

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Roxroy Reid

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Review Committee
Dr. Linda Day, Committee Chairperson,
Public Policy and Administration Faculty

Dr. Raj Singh, Committee Member,
Public Policy and Administration Faculty

Dr. Mark DeVirgilio, University Reviewer,
Public Policy and Administration Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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Roxroy A. Reid

MSW, Arizona State University 2006

BSW, Arizona State University 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Public Policy Administration

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Abstract

Informal and formal caregivers of persons with Alzheimer's disease and related dementias (ADRD) encounter a more difficult and unique set of challenges than do caregivers of individuals with general disabilities. If adequate caregiver supports are not provided, caregivers may experience increased strain as the disease progresses, increasing the likelihood of unnecessary institutionalization of their care recipients and increasing the cost to the public. Using rational choice theory and political systems theory, the purpose of this study was to differentiate between the phenomenological experiences of formal and informal caregivers of ADRD patients. The overall research was a qualitative design that used semi-structured interviews to collect data from 5 formal and 5 informal caregivers who were recommended by the local Alzheimer's association chapter. Data were analyzed using direct content analysis of recurrent themes including how policymakers might respond to needs for respite, support, and more resources. Research findings suggested more education is needed about the disease and how best to give care for both formal and informal ADRD caregivers. Furthermore, distinctions between formal caregivers and informal family caregivers and their care recipients were identified, and these details should be noted by policymakers. Informal ADRD caregivers would benefit more from the research findings. Particular benefits would include financial supports, additional funding for caregiver respites, more education, and better care methods for ADRD care recipients. These recipients are rapidly growing in numbers and pose unique 21st century socioeconomic challenges to informal caregivers.

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Dedication

This work is dedicated to my dear mother, Dorothy Vernon, who worked formally and informally with ADRD patients as a nurse's aide for 38 years and who taught me how to have compassion for caregivers and care recipients. I love you mom! I also dedicate this dissertation to the family and formal caregivers who continue to labor for their care recipients with minimal supports, training, and respite. May the findings of this study, and others like it, lead to better support for you on your caregiving journey.

Acknowledgments

I am completing this dissertation with five "Fs": Faith, Family, Friends, and Faculty. As it relates to faith, while I acknowledge the construct of a supreme intelligence, I equally acknowledge the gifts that I have inherited to enable me to get through this process. Gifts such as perseverance in the face of many large life issues truly came from a divine source.

Family includes all those significant others who have been there on the sidelines cheering me on when I questioned, "What was I thinking?" You all know who you are if you are reading this. I especially acknowledge the love of my life who fed, nurtured, and loved me unconditionally through the latter stages of this process. And if all that love and care wasn't enough, she read and pointed out my grammatical errors in this paper. Thanks for all your partnership Jeanne Marie! You are truly a gift to me from The Creator.

Special thanks to friends and colleagues from my place of employ and the greater New Mexico ADRD community; this study would not have been possible without your contribution. Thanks to my good friend and colleague, Professor Emeritus Jordan Kosberg, who continually encouraged me to stay the course, Geriatrician Dr. Carla Herman, whose dedication to serving and caring for our seniors and their caregivers at the micro and macro levels was a constant source of inspiration. To Dr. John Robertson who was one of the initial sparks of inspiration to go for the doctorate and who gave me a perpetual push to "finish it." In addition, my MSW graduate interns who kept me on my academic toes throughout this process. Thank you all for your and unyielding support.

Most of all, I give special thanks and acknowledgement to the formal and informal caregiver participants, who told their stories and gave of their time, despite their arduous caregiving schedules. Your hearts are pure gold.

Finally, I give special acknowledgement and appreciation to the faculty at Walden University who did their jobs well. To Dr. Linda Day my chair for her dedication, advocacy, and rapid turnaround time with submittals. I appreciated you when I selected you as chair and I will appreciate you always. Thanks you! Special thanks to my committee member Dr. Raj Singh who always had a comforting and encouraging word of support and to the URR Dr. DeVirgilio for countless hours of frustrating review and for pushing me to produce my best work.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

The purpose of this study was to examine the unique experiences of formal and informal caregivers of people with Alzheimer's disease and related dementias (ADRD). I attempted to discover the experiences of caregivers who serve in the community as distinct from caregivers of other chronic and disabling diseases who may serve in institutionalized settings. The study was conducted to address a gap in the literature to gain phenomenological insight into the ADRD caregiver's experience and how that gained insight might add relevant and applicable substance to those making policies that support this caregiver group.

The findings of this study could enhance the caring and support for this burdened group of care providers (Brodaty & Donkin, 2009). ADRD caregivers constitutes 80% of the caregiving workforce and are often on the verge of health and economic decline as a result of their care provision (Bookman & Harrington, 2007; Lilly, Robinson, Holtzman, & Bottorff, 2012; Richardson, Lee, Berg-Weger, & Grossberg, 2013; Shelton, Schraeder, Dworak, Fraser, & Sager, 2001). With the demographic changes and trends of the age structure in the United States and the world, the social and economic consequences of the increasing numbers of the elderly will need to be addressed as a means of heading off socioeconomic catastrophe (Wolf & Amirkhanyan, 2010). With the implementation of the affordable care act (ACA), Medicaid coverage is expanded, and informal caregiving is made a central part of the care equation. That scenario portends an increase in the national and state cost needed to support the ADRD workforce as the burden of caregiving takes its toll, and anxious caregivers opt for institutionalization of the care recipient (Miller, 2012; Noelker & Bowdie, 2012).

As a “silver tsunami” of aging in developed countries reaches unprecedented levels over the next 3 decades, there will be an equal rise in the incidence and prevalence of ADRD (Comlossy & Walden, 2013; Hebert, Weuve, Scherr, & Evans, 2013). With a larger percentage of aged or aging people in the United States with ADRD, there is a predicted corollary drop in the number of caregivers who will be available to care for them in the community setting (Redfoot, Feinberg, & Houser, 2013). Public health policies that support and encourage this workforce of caregivers to continue at their task may help in mitigating both cost to society and burden to those who provide care to ADRD patients (Campbell, Ikegami, & Gibson, 2010; Hayashi, 2013).

In this chapter, I will address the problem, purpose, and research questions of the study; the theoretical and conceptual frameworks; and the nature, limitations, and significance of the study. The chapter will end with a summary and a transition to Chapter 2.

Background

There are currently some 8.9 million family caregivers in the United States who provide care for a person suffering from ADRD (Sansoni, Anderson, Varona, & Varela, 2013). ADRD is a neurodegenerative disorder that usually presents in patients over the age of 60 and progressively worsens with the decline of the individual’s cognitive and overall life functioning (*Diagnostic and Statistical Manual of Mental Disorders* [DSM-5], 2013). As the disease/disorder progresses, the individual requires much more assistance from a family caregiver in managing activities of daily living (ADLs). The daily task of managing the patient increases for the caregiver, and without adequate support, the burden and duress can increase to the point where caregivers lose the ability to give effective care. The loss of the ability to give effective care can result in premature institutionalization of the care recipient and additional cost to payers of long-term care services (Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Sansoni et al., 2013). The ability to give effective care depends on the degree of support the caregiver receives and is a predictor of reduced caregiver's burden and retention of the care recipient in the home or community versus institutionalization (Lilly et al., 2012).

There is little in the public administration and public health policy literature that addresses the necessity for policymakers to pay attention to the support needs of ADRD caregivers. With the increase in incidence and prevalence of ADRD cases in the next 3 decades, and a commensurate increase in public cost, policymakers need to be aware of, develop, and implement adequate supports for those who care for this population. In this study, I sought to fill the knowledge gap in the literature to give insight to policymakers about the shared and lived experiences of those who give care to ADRD patients. In conducting the study, it is hoped that policymakers will be more informed about the types of support that will mitigate future public cost of the disease, as well as adding care for those who give care.

Problem Statement

ADRD caregivers, unlike general caregivers of people with other disabilities, have a much more difficult and unique set of challenges in their caregiving (Miller, Allen, & Mor, 2009). They encounter more stress, can serve longer at their care-giving role, and face health, psychological, and economic consequences as a result of their care provision. Additionally, when unsupported by policy-driven services, they can prematurely initiate the placement of their care recipient in nursing homes and other institutional care settings, which may result in a greater cost to the public (Altshuler & Schimmel, 2010; Foster & Kleinman, 2011). These challenges and cost to society are predicted to only increase as the prevalence and incidence of the disease grows over the next several decades (Hebert et al., 2013). If the ADRD segment of the caregiving workforce is left unsupported by public policy initiatives and programs, the predicted exponential public cost burden of the condition could be soon realized (Alzheimer's Association, 2013). While there is much in the literature on general caregiving support from a public policy standpoint, little research has been conducted to give policymakers the insight needed to make supportive policies for this segment of care providers. In particular, it is not known if hearing the *voice* and experiences of caregivers will allow policymakers to better understand the public supports needed by these caregivers.

Purpose of the Study

The purpose of this qualitative, phenomenological study is to discover and describe the shared experience of formal (paid) and informal (unpaid) caregivers who provide care to people diagnosed with ADRD. Understanding and categorizing those discovered themes and meanings of those experiences will give structure to the supports needed to improve the caregiving process.

Research Questions

For this study, the following research questions were the basis for capturing the lived and shared experiences of ADRD caregivers:

RQ1: What constitutes the construct of the formal and informal caregiver?

RQ2: What are the shared and lived experiences of formal and informal ADRD caregivers?

RQ3: What situations have influenced the experiences of informal and formal ADRD caregivers?

RQ4: What can state policymakers do to better support formal and informal ADRD caregivers?

Conceptual Framework

The conceptual framework of this study provided the foundation for analyzing the shared and lived experiences of formal and informal ADRD caregivers. Additionally, the framework gives structure to how public policymakers could improve those experiences. Rational choice theory (RCT) provided one theoretical perspective for the study. RCT is also known as public choice theory, social choice theory, rational actor model, and formal and utility maximizing theories, and can be used to explain the attitudes of formal and informal ADRD caregivers towards public policy interventions.

Another competing theory that made up the conceptual framework of this study was the political systems theory (PST). The premise of PST frames the moving parts of a political system. According to Prestine (1991) and Easton (1979), PST provides a model for analyzing the internal and external forces that provides exchanges and transactions between citizens and policymakers.

RCT has several postulates that made it applicable for analysis of the concepts of this study. According to Boudon (2009), there are a few assumptions that embody RCT. First, social phenomena are the byproduct of individual decisions, attitudes, and actions. This assumes that actors in any social phenomena are autonomous. Second, actions are the results of contemplated consequences as perceived by individual actors. Such actions are developed in the actor's mind and can be comprehended. This assumes rationality of actors. Thirdly, rational actors are concerned primarily with the consequences of their actions only to the degree that it impacts them. They are also able to understand the gains and losses of different actions and to make choices and take actions that will be most beneficial to them. This assumes the actors will act in their own best interest (Boudon, 2008; Herrnstein, 1990; Lovett, 2006; Ostrom, 1998).

PST was first posited by Easton (1953) and is an adaptation of the holistic general systems theory. In its simplest form, Easton (1956) described the theory through a behavioral prism, which depicts the political system as being delimited by prescribed boundaries yet being in flux internally. For example, Easton (1953, 1956) created a descriptive theoretical model that depicts the government as an organism that responds to the demands and supports of the larger community it governs followed by a feedback of stimulus into the governing organism. Eaton (1953, 1956) illustrated the dynamic interdependence between governing systems and the governed in the following steps:

1. Changes in a sociopolitical environment, such as New Mexico Legislators and the body of caregivers they seek to support, produce a demand for some action, or input to the political system
2. Demand or input to the system produces decisions by the system of legislators to take action on behalf of caregivers' demands
3. After a decision or output is made, which includes a policy for caregivers, implementation of outputs produced interacts with the sociopolitical system to produce change or an outcome
4. New demands or inputs may be generated when a new output policy interacts within the system. This is called feedback and can produce further policy
5. The feedback from the previous step can start the process all over again in a continuous loop, which gives the process a living organic appearance.

In this case study, I used the research questions to understand the lived experiences of formal and informal ADRD caregivers and how policymakers can support them. Gathered experiential insight can then be disseminated through studies such as this to state legislators who will be able to use that feedback to create policies that will better enable and support the caregivers who provided stimulus input for new policies. The connections among the phenomenological lens, Easton's theory, RCT, and the various elements of the study will be addressed in further details in Chapter 2.

Nature of the Study

The nature of this study was inductive in style as it will expand knowledge of formal and informal caregivers' experiences by highlighting the meaning and importance of their voices (Creswell, 2009). Additionally, a qualitative phenomenological approach was the best inquiry design to capture the voice of the ADRD caregiver in a way that legislators might hear it. The key concepts and phenomenon being investigated are

1. The verbalized and overall experiences of individuals who give care to persons suffering from ADRD. I intended to discover the lived and/or shared caregiving experiences among both formal and informal caregivers. For example, what challenges or obstacles might this heterogeneous group face in their daily provision of care and what are the supportive elements, if any, that enables them to give care with minimal harm or burden to themselves?
2. It was also the intent of this study to discover what supports might be lacking that would enable caregivers to continue giving care in the community for a more protracted period and would help them keep their care recipient out of an institutional setting.
3. Additionally, data were collected from a heterogeneous group of 10 formal and informal caregivers. The participants were selected through a local caregiving support association and the criteria for their selection was

- The rendering of care to a family member with ADRD for at least 6 months

- That they are a paid or volunteer through a home health agency to give care to a person diagnosed with ADRD
- Participants were also able to speak and understand English

The method of data collection was through individually guided interviews of each of the 10 caregivers. A semistructured instrument consisting of open-ended and nonleading questions based on the research questions was used to increase the understanding of the experiences of these caregivers. The responses of these caregivers was captured and transcribed for analysis.

I used textural and structural descriptions (Creswell, 2007), as well as qualitative software (*NVivo 9 Tutorial*, 2011), to go through the interview transcriptions and highlight significant themes that emerged or that reoccurred. These emerging themes were categorized and listed for easy review.

Definitions

The following are key words and concepts used during the development of this study that may require definitional clarity and interpretation:

Alzheimer's disease and related dementia or disorders (ADRD): This concept refers to a constellation of neurodegenerative illnesses that ultimately leads to a person's demise (DSM-5, 2013). ADRD is seen as the fifth leading cause of death in people in the United States aged 65 and older (Comlossy, 2014; Comlossy & Walden, 2013). Dementia is a collective set of neuro-cognitive impairments that manifests in a loss of the person's intellectual function and is severe enough to disrupt physical daily functioning. Dementia is not a disease, but is a syndrome of attending symptoms that may accompany different diseases. While this study is about understanding the caregiver needs and policies needed to support those needs, it is equally important to understand the various diseases that are under the dementia umbrella that precipitates the needed supports. ADRD, as it related to this study, included the following neurodegenerative disorders:

1. Alzheimer's disease, which is the most common cause of dementia
2. Vascular dementia, which is a degeneration of mental capacity caused by vascular strokes
3. Parkinson's disease
4. Huntington's disease
5. Creutzfeldt-Jakob disease, which results in rapid and progressive dementia
6. Frontal-temporal dementia, which is a shrinking of the brain in the frontal and temporal lobes
7. Lewy body dementia, which is dementia associated with deposits of abnormal proteins in the brain (Alzheimer's Association, 2013).

ADLs and IADLs in the caregiver phenomenon: In the phenomenon of caregiving, two measures of functionality and independence are used. ADLs refer to tasks that a person needs to accomplish to maintain personal care on a daily basis. These tasks include, but are not limited to, walking, grooming oneself, dressing, eating, and bathing. Instrumental activities of daily living (IADLs) refer to tasks that foster independence for a person. They include activities, such as shopping for groceries, using the telephone, performing light housework, meal preparation, and managing a person's personal finances through a banking institution (Family Caregiving Alliance, 2014b).

ADRD cost to society: This idea is at times measured in other than monetary terms and often refers to the overall cost to the individuals providing this all-encompassing care. The overall cost to the providers of this care may be incalculable. Some ADRD costs can be measured by instruments, such as the cost of care index (Kosberg & Cairl, 1986).

Caregiver's burden: Researchers have attempted to understand the support needs of dementia caregivers by looking at their needs based on a measure of caregiver's burden (Akpınar, Küçükgüçlü, & Yener, 2011; Black et al., 2010; Gallagher et al., 2011; Garcés, Carretero, Ródenas, & Alemán, 2010) as opposed to the caregiver's stated need (Stirling et al., 2010). It is important for policymakers seeking understanding of caregiver support needs to focus on direct stated needs as opposed to normative measured burden. Stirling et al. (2010) conducted a mixed method study based on Bradshaw's taxonomy of needs model described by the Public Health Action Support Team (PHAST, 2010). Bradshaw's taxonomy model recognizes the undefinable and multifaceted nature of social needs and sets out to categorize social needs into four categories:

1. Normative or not absolute needs
2. Felt needs which are limited to the individual's understanding of needs
3. Expressed needs which are turned to action
4. Comparative needs which are individuals with characteristics to those already receiving help (PHAST, 2010).

Stirling et al. compared the difference between measured caregivers' burden and stated caregivers' needs of 20 community-dwelling caregivers and care recipients. The caregivers’ need for service and support was a significant indicator of their support needs, more so than measured caregivers’ burden. Stirling et al. concluded that, when assessing for the support needs of dementia caregivers, policymakers should understand that assessing for caregivers burden may not capture the actual needs of the caregiver.

The best way to assess caregiver needs is to talk directly to them to better understand their problems, strengths, and their resource and support needs (Kelly, Gibson, & Feinberg, 2013). Directly assessing and addressing the needs of informal caregivers can help in the maintenance of the caregiver’s health. Direct assessing also increases caregivers’ ability to sustain care in the community, usually in the home of the care recipient, and prevent or delay the placement of the care recipient in a skilled nursing facility (Kelly et al., 2013; Sansoni, Anderson, Varona, & Varela, 2013).

Caregiver support and services: These are programs, authorized by federal or state legislation, that provide a supportive community or private caregiver supports (Salazar, 2014). Additionally, family caregivers supports and services can include access to information, education, and training on direct care skills and in-home respite; counseling and therapy to support coping skills; family care conferences; assistive technologies; and in-person and online support groups (Kelly et al., 2013).

Informal (family) caregiver of people with ADRD: This group is the primary deliverer of care to the world’s ADRD patients and is often referred to as the invisible second patient. This type of daily caregiver often receives no more than in-kind compensation, such as food, transportation, or free rent. This is the group that bears the greater burden of care and is at high risk to their own health and well-being. The demographic of the informal family caregiver is usually a family member; spouse, child of ADRD patient; family friend, or neighbor (Brodaty & Donkin, 2009; Family Caregiving Alliance, 2014b; Navab, Negarandeh, & Peyrovi, 2012).

Formal caregiver: This group renders the same type of care to ADRD patients, but is usually compensated for their work at a market rate of $8 - $16 per hour depending on location. Additionally, they are usually trained by some home health agency or care delivery system. They may or may not be certified or licensed, and they are sometimes volunteers (Family Caregiving Alliance, 2014b).

Long-term and institutional care: This concept refers to a combination of community, medical, nursing, social, and custodial care services that support persons with ADRD and other chronic conditions. Provision of these services under a long-term care (LTC) umbrella can occur in assisted living facilities, nursing homes, the ADRD person's home, or the community at large (Family Caregiving Alliance, 2014b). Long-term support services (LTSS) are also captured under the long-term-care and institutional care umbrella (Redfoot et al., 2013).

Public health policy: Within the context of this study, this concept referred to any legislative act that seeks to address the potential national and international public health crisis that was created due to the predicted increase of ADRD prevalence around the globe. Policies to address it are looked at from several countries, including the United States (Brodaty & Cumming, 2010).

Respite: Temporary relief of caregivers from duty and responsibility of care provision. The amount of relief that is required to mitigate caregivers' burden is not fully understood in the literature (Noelker & Bowdie, 2012; O'Connell, Hawkins, Ostaszkiewicz, & Millar, 2012).

Assumptions

In this study, I assumed that the participant group of formal and informal caregivers were willing to articulate their caregiver experiences for the benefit of the policymakers and that they would be able to do so in English. This assumption was crucial to the study as it was the linchpin that held the study together. Participants' responses will be presented to legislatures to inform future supportive policymaking for New Mexico caregivers. It was, therefore, assumed that these respondents will give an accurate portrayal of their subjective and collective ADRD caregiving experiences. It is vital that this assumption be met as phenomenological studies, due to their subjective nature, are not as generalizable and practitioners and policymakers might have difficulty accepting their findings (Van Manen, 1990; Walt et al., 2008).

Another assumption was that the experience of the caregiver and the care recipient was co-occurring (Johnson, 2013). This is critical because the caregiver's experience derives from the giving of care to the care recipient. It was, therefore, necessary that the responding caregivers were actually currently engaged in giving care and not in a post caregiving status.

Scope, Delimitations, and Limitations

Scope

The research problem addressed in this study was the lack of sufficient policy-driven programs that support caregivers of people with ADRD. This particular focus was chosen because the prevalence of ADRD internationally portends a taxing, if not collapse, of the caregiving mechanism if policy-driven solutions are not brought to the forefront. With the potential cost to the public, this problem should occupy public health policymakers for the next 2 decades.

Delimitations

The study was based on the responses of the study respondents and was bound by the qualitative phenomenological approach. Data used were taken from caregivers of persons with ADRD in New Mexico. These conditions restricted the data findings to a group of subjects that may not be representative of other formal or informal ADRD caregivers in New Mexico and across the U.S. population.

Limitations

The study was limited by its qualitative and phenomenological nature. I gathered data from Albuquerque, which is an urban area. New Mexico is a predominantly rural state, and the data gathered in the urban area did not necessarily represent the ADRD caregiving needs of the whole state. Furthermore, the conceptual framework on which the study was based (i.e., RCT and PST) may not be able to completely capture the individual experiential idea that I sought to ascertain. Perhaps an ethnographic approach might have also been useful in trying to understand fully the story or voice of the ADRD caregiver. However, because my role as a researcher in this study was not to obtain a singular essence of ADRD caregiving, but to gain as complete a picture of that dynamic experience as possible, the chosen conceptual framework should suffice to address this limitation. Additionally, in my role as a researcher, I brought a certain bias to the inquiry in that I hoped respondents would have many actionable suggestions for policymakers. My bias may have led me to look for those suggestions and miss the opportunities to understand the bigger picture of the caregiver's experiences as they think it and act it (Walden University, 2013). I addressed this limitation by maintaining an awareness of my bias as I gathered, transcribed, and analyzed captured data.

Significance of Study

In this study, I addressed the information gap of supportive public policy programs and initiatives that could aid ADRD caregivers in their caregiving. Given the potential cost to society, which is predicted to be over $1.2 trillion by the year 2050, researchers believe that this problem should be the focus of local and national level legislators for upcoming decades (Johansson, Long, & Parker, 2011; Miller et al., 2009; Sano, Dahlman, Sewell, & Zhu, 2013). This study, by its design and nature, could contribute to the advancement of knowledge that could inform policymakers about supportive programs and initiatives for ADRD caregivers.

This study has an implication for positive social change as it will address the caregiving needs of a particular group of caregivers. Despite their contribution to the caregiving workforce, ADRD caregivers have been left unsupported, unpaid, and unnoticed by public policymakers. If the findings of this study could generate macro level changes that would support this segment of the caregiving workforce, then it could add to the social change goal of Walden University and the public policy administration department.

Summary

In this chapter, I introduced the study topic by highlighting the need for more formal and informal ADRD caregivers' support in light of the predicted escalating need for said support. The background of the problem was presented in order to demonstrate the need for a phenomenological look at the ADRD caregiver's experience. The research questions and the nature of the study were presented, along with definitions of concepts that needed clarity or words that could have double meanings. Finally, the significance of the study in how it could contribute to the literature, practice, and social change was discussed.

In Chapter 2, I will delve further into the literature and expound upon the main study concepts, as well as more details of the conceptual framework used to give context to the research. I will differentiate between the formal and informal ADRD caregivers, the burden and gain that they may derive from their caregiving, and the cost and market value of their services to society. Additionally, translating caregiver support needs into public policy actions and phenomenological study designs will be discussed.

Chapter 2: Literature Review

Introduction

ADRD caregivers, unlike general caregivers of people with other disabilities, face a more difficult and unique set of challenges in their caregiving (Miller et al., 2009). They often encounter more stress, can serve longer at their caregiving role, and face health, psychological, and economic consequences as a result of their care provision. Additionally, a lack of policy-driven services can prematurely initiate the placement of their care recipients in nursing homes and other institutional care settings, which may result in a greater cost to the public (Altshuler & Schimmel, 2010; Foster & Kleinman, 2011). Researchers have indicated that these challenges and costs to society are predicted to increase as the prevalence and incidence of the disease grows over the next several decades (Hebert et al., 2013). If the ADRD segment of the caregiving workforce is left unsupported by additional public policy initiatives and programs, the predicted exponential public cost of the situation could be realized sooner (Alzheimer's Association, 2013). Adding value to these care providers can result in cost savings to the public (Feinberg, Reinhard, Houser, & Choula, 2011). While there is public policy literature on general caregiving support from a public policy standpoint, little research has been conducted to give policymakers the insight needed to make supportive policies for this segment of care providers. It is unclear whether, if policymakers could hear the unique voice and experience of caregivers, it would enable policymakers to better understand the public supports needed by caregivers.

The purpose of this qualitative phenomenological study was to discover and describe the shared experiences of formal and informal caregivers who provide care to people diagnosed with ADRD. Understanding and categorizing the discovered themes and meanings of those experiences will give structure to the supports needed to improve the caregiving process. Additionally, it was my intention to present the themes of those caregivers' experiences, as revealed by the study's findings, to policymakers to allow them to hear the voices of this unique segment of the caregiving workforce and to inform their supportive policymaking for that group.

The sections of this chapter begin with a literature search strategy followed by a section describing the conceptual framework of the study. Next, the key concepts of the study of ADRD caregivers and policies needed to support them will be reviewed. The following are the main headings of the literature review:

1. Conceptual Framework with Two Contrasting Theories
2. Background for the Chosen Construct of Informal and Formal ADRD Caregiving
3. Understanding the Policymaking Process and its Application to this Study
4. Experiences of Informal and Formal Family Caregivers
5. What Policymakers Understand and Need to Know to Support ADRD Caregivers
6. Translating Caregiver Support Needs into Public Policy Action
7. Research Methods Found in the Literature

The chapter will conclude with a summary and transition to Chapter 3.

Literature Search Strategy

In a search of the literature, the following keywords were plugged into Walden University's Thoreau's advance database search engines with a date range from 2006 – 2014: *caregiver or family*, *Alzheimer's or dementia*, *health policy*, and *public policy*. Similar words were plugged into the Google Scholar search engine with an equivalent range in years to reveal peer-reviewed articles that provided information on public policy support of ADRD caregivers by policymakers. Additional literature from ProQuest, EBSCO, the Center for Disease Control and Prevention (CDC), and the Alzheimer's Association (Alz) websites and library were consulted. Finally, the following phrases and search terms were entered into the Google Scholar search engine at Walden University library to capture the constructs and give rationale for the research questions of this study:

1. Rational choice theory
2. Political systems theory
3. Understanding the policymaking process
4. What policymakers need to know about dementia caregiving
5. Experience of formal and informal caregivers
6. Cost of formal and informal dementia caregiving
7. Translating caregivers support into public policy actions

The literature that resulted from the above phrases made up the content of the seven main headings of the review. Studies on the constructs and methods of this study were also included.

Conceptual Framework

The conceptual framework for this study was provided by two theories: the RCT and PST. The RCT is based on the idea that the personal choice of individual rational actors will determine their satisfaction and the degree of gains or losses that they have because of those choices (Lovett, 2006). PST theorists demonstrate the interdependent dynamics between rational actors and the political system they choose to act within (Easton, 1979; Leslie, 1972). The two theories formed a conceptual framework to explain how formal and informal ADRD caregivers can choose to work with a political system that can provide support for their choice of continued home-based community care of their care recipients.

Rational Choice Theory

RCT is used to explain how social phenomena arise from the internal and deliberate pursuits of rational social actors (Lovett, 2006). Rational actors arrive at conclusions and choices based on cost-benefits analysis of what is in their best interest. The theory has been used to explain myriad human behavioral choices within the context of economic and sociopolitical systems. The theory ranges in application from economic behaviors where individual actors attempt to optimize their benefits based on their rational choices to racial profiling by police officers who arrest people of color at a rate disproportionate to that of other ethnicities (Green, 2002). Green (2002) referenced a rational choice model that is used to distinguish whether arrest and searching disparities are due to racial profiling or officers' desire to increase their arrest rates (p. 32). I used this theory to explain how formal and informal ADRD caregivers come to the conclusion to perform, and continue in the performance of, the tasks associated with giving care to their care recipients.

ADRD caregivers choose their roles based on the rational choice of how it benefits them cost-wise. Formal and informal caregivers are rational actors who assess the total emotional, physical, and financial costs and benefits of their caregiving when deciding to care for their care recipients at home in the community versus institutionalizing them. For example, an informal family caregiver might choose or not choose to keep their care recipient (CR) at home based on the emotional value of altruism or love for their CR (Basu & Rosenman, 2013). Formal caregivers, on the other hand, may choose to continue in the profession of caregiving contingent on pay and other material benefits that they may receive. Formal caregivers who are paid by an agency to provide care to the CR in their home within the community have a high turnover rate and usually choose not to continue their caregiving as the ADRD condition and required level of care increases (Draper, Low, Withall, Vickland, & Ward, 2009).

The choice to keep their CR at home can change to that of long-term institutionalization as ADRD progresses and increases the emotional, physical, and financial burden on both the formal and informal caregiver (Black et al., 2010; Exel, Graaf, & Brouwer, 2007; Richardson et al., 2013). Policymakers are a part of the formal and informal caregiver support system and must take an active role in bridging the support gap between informal and formal caregivers. This would be an apt strategy for translating theory into practice and reducing public cost (Draper et al., 2009; Levine, Halper, Peist, & Gould, 2010; Weimer & Sager, 2009). The fear of increased public cost is what also keeps policymakers from investing in supports for caregivers. It is a fear that may cost more in caregivers' burnout and premature institutionalization of the care recipient. It could prove to be fiscally irresponsible for government officials to not act on enhancing caregivers' support and services (Levine et al., 2010; Weimer & Sager, 2009). This dynamic of changing actors within the caregiver support system is what RCT, in concert with PST, addressed in this study to determine how rational actors should behave, but does not predict how they do behave when circumstances shift away from their favor (Herrnstein, 1990).

Studies Employing Rational Choice Theory

Many of the features and assumptions of RCT are found in social exchange theory (SET). While not a theory used in the conceptual framework of this study, proponents of SET demonstrate the social exchange that can occur between rational actors who act according to the altruistic norms of society and rational agents who act out of self-interests. For example, Caputo (2002) sought to discover if adult daughters giving care to their aging parents as rational actors did so based on the potential gain to themselves or if they acted rationally as agents based on adherence to the social norm of altruistic filial responsibility. The adult daughter caregivers acted with self-interest in that factors of potential financial inheritance added to the likelihood of them providing care. Choices to give parental care were rationalized and made by caregivers who weighed the financial benefits to themselves more so than for the altruistic notion of love for the parents. Caputo further concluded that the study was important for giving policymakers insight into the type of incentives that are needed to increase the ranks of informal caregivers.

Russell (2013) illustrated the application of RCT. Russell conducted a phenomenological study to discover and analyze citizens' perceived cost and benefits towards the use of electronic government information technology. Russell used RCT and the technology acceptance model (TAM) as a conceptual framework to determine how computer cost, access to Internet services, technological skills of users, users' familiarity with computers, and cultural views of government e-users influenced the citizens' use of electronic government service. Russell demonstrated the universal applicability of RCT to a variety of human behavioral and sociopolitical constructs, such as the ones in this study. The principles of RCT, which addresses individuals making choices based on their perception of whether those choices will be beneficial and in their best interest, are the foundation on which ADRD caregivers make the choice to give care to and to keep their CR in the community or not.

Political Systems Theory

Because the PST is one of the undergirding theories of this study's conceptual framework, this literature review will consist of data gathered from a variety of disciplines, as well as the public policy and administration literature. The nature of a systems approach relates to the stage's heuristics or policy cycle. According to the policy cycle, various disciplines struggle to define issues that should be on a policy agenda, formulate policy based on best policy alternatives, implement those selected policies, and provide evaluation of the policies. The PST requires multiple stakeholders, such as psychologists, social workers, public health workers, and others (Walt et al., 2008). The PST is an abstract or conceptual model founded by Easton (1979). The model falls under one of the network frameworks of theory and depicts government as an organism responding to demands and supports from the community of the governed and then creating outputs that are fed back into the organism as stimulus and input (Easton, 1979; Walt et al., 2008). Refer to Figure 1 below for a visual of the PST construct.

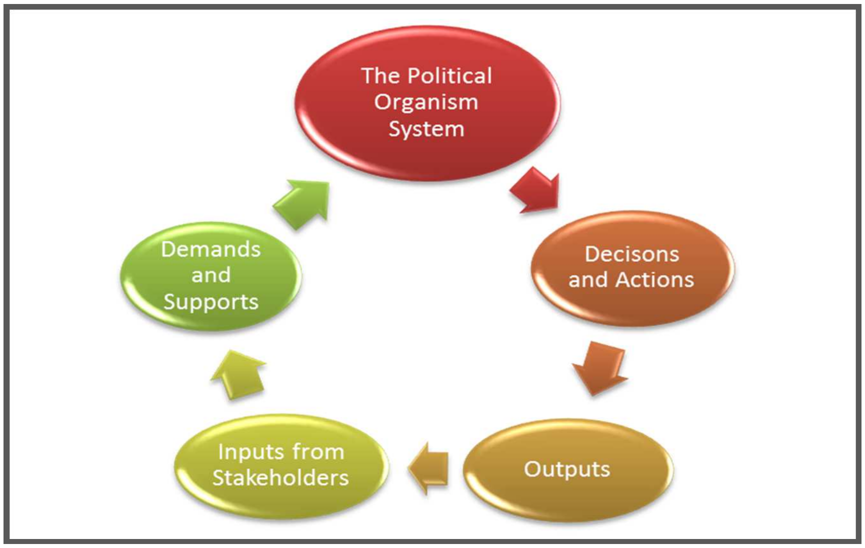

Figure 1. An understanding of how Easton's PST works: Information is gathered from the Stakeholders (Caregivers) and translated into Demands that are passed on to legislators in the Political Organism System. Decisions and Actions about supportive policies are given as Outputs to benefit caregiving stakeholders. This image is not copyrighted. (Easton, 1965).

Figure 1. Dynamics of political systems theory

Easton's (1979) theory can be used to capture the dynamic and interdependent nature of public policies that move between government and the governed. For example, The National Alzheimer's Project Act (NAPA) was proposed and signed into law by the President in 2012 (NAPA, 2011). NAPA mandated the department of Health and Human Services (HHS), the CDC, and other federal agencies to address ADRD via the escalating public cost associated with the care of the disease.

The ACA requires that health care costs be decreased and family caregivers be placed at the center of the care team for individuals requiring a higher level of care in the community (Miller, 2012; Patient Protection and Affordable Care Act, 2010). Because the unintended cost of the informal caregivers' burden is projected to increase over time commensurate with the increasing incidence of ADRD (Lilly et al., 2012), public policymakers need to consider caregiver training interventions as prescribed by the ACA, NAPA, and state ADRD plans when making decisions to support family or informal caregivers (Patient Protection and Affordable Care Act, 2010; State of New Mexico, 2013).

The CDC and the Alzheimer's Association conduct annual monitoring of the risk factors associated with caregiving to ADRD patients through the behavioral risk factor surveillance system (BRFSS). The BRFSS suggested that informal caregivers of ADRD patients are prone to give care longer, may need interventions to reduce health risks related to caregiving, and that more research is needed at the state level to assess the needs and differences among ADRD caregivers (Alzheimer's Association, 2013, "CDC - Healthy Brain Initiative," n.d.; Richardson et al., 2013).

Subsequent to the federal acts and national monitoring of caregivers' risk, state governments were stimulated to form task forces and create legislation to support, and if necessary, fund individual state plans to address ADRD in their jurisdictions. The 29 of the 50 states that have adopted an ADRD state plan agree that care training for professional and informal caregivers should be implemented. Support for the demand for care training stems from the fact that the state plans all derive from task forces that are comprised of formal and informal caregivers, as well as government officials (State Government Alzheimer's Disease Plans, 2013; State of New Mexico, 2013).

The federal government demanded that the escalating care cost of ADRD be addressed, signaling an initiating action in the process of PST. The output of federal acts, such as NAPA and the ACA, are examples of how environmental stimulus creates demand. State responses to ADRD caregivers is fed back to the federal organism to generate more supportive legislation that further addresses the ADRD caregivers' problem. The policy cycle of agenda setting, formulation, implementation, and evaluation is represented as the policies are rolled out in a way that depicts the PST approach.

Studies Employing Political Systems Theory

Prestine (1991) used the lens of the PST to explain the Teacher Education Reform that occurred in the 1980s. Prestine looked at the conflict that was occurring between a state university (University of Wisconsin-Madison) and the Department of Public Instruction to gather an understanding of emerging themes. Themes that stood out were internal institutional variables, such as pluralistic membership of the school of education and environmental forces, which indicates the lack of general and public stakeholder support. Furthermore, the formation of interest groups coalitions, the role of the school superintendent, the policy process, and the variable conditions that cause stress to the system were also themes that emerged (Prestine, 1991). Emergent themes were analyzed to determine how the conflict arose and how a systems theory analysis could assist in sorting out the main concerns and give direction for the resolution of conflicts. The PST provided a framework for analysis and structure to the different environmental variables of the systems on both sides of the conflict and how those variables interrelate functionally or with dysfunction (Prestine, 1991, p. 4). Prestine addressed conflict within an educational system, and while it is not related to the caregivers' and policymakers' constructs in this study, the process of analysis using Easton's (1979) theory can be replicated to examine themes that emerge when data from informal and formal caregivers are analyzed to see how one part of the total caregiving system interacts with the other.

Fisher (1989) used the PST to discover a correlation between the perception citizens have of the power and influence that an interest group possesses in state government and the trust that citizens have of the government. Fisher used secondary survey data from Alabama citizens by a Capstone poll and analyzed it for emergent themes using Eaton's theory and Rawls's theory of fairness as a framework. Fisher hypothesized that citizens would give more support to the state if they felt that the distribution of public benefits would be equal. If policy output favored interest groups, citizens would think of the government as unfair and would diminish citizens' stakeholder trust in government (Fisher, 1989). Easton's theory was used to examine the different components of the political system needed to make policies that affected the whole system. Fisher used two competing theories to form the conceptual framework. Fisher supported the need to create a trusting relationship between formal and informal caregivers and the legislators who serve them.

Phenomenology

The phenomenological approach was used in this study to ascertain the lived and shared experiences of the ADRD caregivers. The function of phenomenology was used to capture the phenomenon of ADRD caregiving through the experience of the caregiver (Creswell, 2007; Patton, 2002; Penner & McClement, 2008; Walden University, 2013). Using Easton's political systems theory, I presented the caregivers' experiences and views to the legislators. This interplay in the public policymaking and service delivery process is what Bovaird (2007) referred to as a needed departure from the top-down process of policy formulation and implementation. Bovaird suggested a more negotiation-oriented process that fosters interaction among different stakeholders in the policy system. Different communities need different policy changes and producers of policy. Both makers and users of policy collaborate to produce the needed policy changes (Bovaird, 2007). While coproduction is an up-to-date approach, it is a reach back to Easton's political systems theory (Easton, 1979; Leslie, 1972).

Informal and Formal Alzheimer's Disease and Dementia Caregivers

Formal and Informal Caregiver Constructs

The experiences of informal caregivers, who are usually family members, and formal caregivers, who are often professional certified nursing assistants (CNA), are the two constructs observed in this study. The majority of individuals needing ADRD care, approximately 66 %, live in the community and receive their care from family members at a rate of 2 out of every 3 (Feinberg et al., 2011). While informal family care is usually the first wave of caregiving, it is often replaced with professional (paid) formal care as the need for assistance with hands-on ADL and IADL supportive assistance increases (Davis & Curtin, 2011).

Informal caregiving is provided by family, friends and neighbors of CR, while formal caregiving is typically administered by home health agencies, nursing homes, respite care agencies, and other service organizations (Perdue, 2012, p. 20). The formal caregivers who provide care in the care recipient's home in the community are already working in an institutionalized context because they are usually trained and paid by an agency for services rendered. The informal family caregiver, on the other hand, is typically untrained, unsupported, and not paid in wages or monetarily remunerated for care rendered.

The primary instance of an informal caregiver being paid is when a family member is compensated through one of the federal and state run Medicaid waiver programs that allow family members who are already caring for an ADRD CR to receive an hourly wage for the allotted hours they give care to their family care recipient. According to the office of the Assistant Secretary for Planning and Evaluation (ASPE), Medicaid waiver programs can be referred to as personal care service options, waiver programs, personal care options, and home- and community-based service (HCBS) programs (ASPE, 1993). New Mexico, where this study was conducted, is one of the states where a family member can be compensated for some of the care they provide for an ADRD CR. It is referred to as the personal care option (PCO). The CR qualifies for the PCO program by meeting a means test and by having a need for assistance with two or more of their ADLs, such as bathing, toileting, or meal preparation. The state Medicaid program contracts with a company to assess needs for ADL assistance in terms of hours per day. If, for example, a CR is determined to need 4 hours per day of assistance with ADLs, the family member providing the care can be compensated at the market rate for those allotted hours. The current market rate for New Mexican home care providers is $8.91 per hour with a state average from $8.27 to $9.87 per hour (New Mexico Department of Workforce Solutions [NMDWFS], 2013).

The average national payment to formal ADRD caregivers is $9.67 or $20,100 per year (NMDWFS, 2013). For New Mexico ADRD caregivers, the annual income at the above rate of $8.91 per hour would be equivalent to an annual salary of $18,532 using the standard 2,080 hours per work year rate. A formal paid New Mexico family caregiver is making $6,862 above the federal poverty level (FPL) when they choose or commit to giving care to a CR. Informal caregivers, on the other hand, are usually not paid except with in-kind benefits, such as housing, food, and transportation when they live in the same home as the CR. Some informal caregivers pay the expenses of the care recipient out of their own resources (Schulz & Martire, 2004).

As the RCT construct of this study is considered in light of personal cost to caregivers, it becomes evident that family members who might consider leaving their jobs to provide care to an ADRD family member will weigh the benefits and costs of leaving their job versus receiving the allotted Medicaid compensation. When the CR is determined to be ineligible for full Medicaid and subsequent PCO, they have often chosen not to leave their employment to dedicate more time to care recipient as it would not benefit them. At this juncture, the need for more hands-on, intensive caregiving is met with a lack of financial support from the larger caregiving system. There is inadequate compensation from Medicaid PCO programs, which may cause the caregiver to consider institutionalization of their CR. This piece of the informal caregiver phenomenon is supported by the construct of RCT (Langa et al., 2001; Lovett, 2006; Miller et al., 2009).

Job Duties of Formal and Informal Caregivers

The caregiving roles for both formal and informal caregivers ranges from care providers to care managers (Brodaty & Donkin, 2009; Feinberg et al., 2011). The care provider is conducting more hands-on assistance with ADLs and IADLs, managing medication, coordinating services and supports, communicating with health professionals, and transporting their CR to appointments. On the other hand, the care manager's role is one of managing administrative aspects of care. For example, a care manager may be engaged as a long distance caregiver; one who by definition gives care at a minimum of a 1 hour distance from the care recipient (Family Caregiving Alliance, 2014a). This managing care provider would manage the financial issues of the CR, help with insurance claims, hire and coordinate home health services, and participate in interdisciplinary care team planning (Feinberg et al., 2011).

The formal and informal caregivers represented in this study were similar in that they both provided care in the community (Davis & Curtin, 2011; Perdue, 2012).While informal caregivers are seeking to delay the institutionalization of their CRs, formal caregivers, even while providing care in the CR's home, are already a part of the institutional system (Perdue, 2012).

Bookman and Harrington (2007) looked at the multifaceted work that informal family caregivers provide to the greater system of health care and how this unpaid, undertrained, and unseen group is important to the long-term care community. Bookman and Harrington believed that informal caregivers keep the fragmented geriatric health care system together, as they take the care recipients back and forth to hospitals, rehab facilities, primary care appointments, and other services within the community.

Bookman and Harrington (2007) took a different approach to studying informal caregiving by shifting the paradigm. For example, conventional research, policy development, and practice has historically been done with the formal caregiver being viewed as an individual who is paid and trained to provide care, such as attending to ADLs and IADLs, in an institutional setting. On the other hand, the informal caregiver is unpaid, untrained, and does care provision in home settings (Bookman & Harrington, 2007, p. 5). Bookman and Harrington posited that, regardless of the lack of pay and training, the informal caregiver is an essential part of the caregiver workforce and should be looked at as such when setting policy agenda, implementation, program development, and evaluation. It would be strategic policymaking to connect informal and formal caregivers with nonprofit and for-profit service providers, along with policymakers and all stakeholders in a joint analysis of the needed policy supports (Bookman & Harrington, 2007, p. 6). In so doing, the full extent and the complexity of the informal caregiver's role are represented to the policymaker with the potential of the production of more appropriate support programs. Caregivers in the study often reported a lack of coordination among different health care delivery institutions both while in them or transitioning to them (Bookman & Harrington, 2007, p.10). Other discovered needs included the need for information on home care, information on anticipating the need of care recipient, and information on how to deal with automated phone services (Bookman & Harrington, 2007, pp. 16-18). However, the lack of interagency and interservice coordination is the key to what policymakers need to address if adequate supportive caregiver services are to be enacted.

Miller et al. (2009) explored the barriers to care for a CR and informal caregivers needing long-term care. Miller et al. identified the challenges of limited funding resources and the isolation felt by millions of informal caregivers. Furthermore, Miller et al. recognized the need for an expansion of the caregiving network. The current system is overburdened and cannot tolerate an expansion of HCBS care options without a commensurate shoring up of that system by public policy actions. Buttressing the current caregiver system needs to be done, especially in light of the government's push towards community-based and in-home care as an alternative to institutional care (Miller et al., 2009).

Impacts of Alzheimer's Disease and Dementia on Caregivers

Family caregivers are the different family members, partners, and close friends who make up an informal and uncompensated care system. They are a piece of the ADRD care system (Redfoot et al., 2013). Researchers are concerned about the decline in this system of family caregivers, and they use a construct of the "caregivers support ratio" to illustrate the gravity of this decline in the face of an increasingly aging population. This ratio includes the number of caregivers to patients needing care. For example, as ADRD patients reach the risk years of age 80 and over, there needs to be a reasonable amount of caregivers in the 46-64 age range who are able to provide long-term support services (LTSS). This rate is projected to decline from a possible seven caregivers to each ADRD patient, or 7:1 in 2010 to 4:1 by 2030 and less than 3:1 by the year 2050 (Redfoot et al., 2013; World Health Organization, 2012). As the need for coordination of LTSS by the family caregiver increases and the number of available caregivers decreases, the commensurate increase in personal caregivers burden is projected (Redfoot et al., 2013). This decline in the support ratio will not only impact the informal family caregiver's system, but also stretch the resources and capacity of the professional care network. In New Mexico where this study was conducted, the caregiver to care recipient ratio was estimated at 3.8 :1 (State of New Mexico, 2013).

Risks and Positive Aspects of Caregiving

The risks and burdens of caregiving are understated in the literature. There is, however, a growing body of evidence on the magnitude and severity of this risk. Shagam (2013) described the risk as life threatening at worst and stressful at best. In between those two points on the continuum of risk are feelings of exhaustion, anxiety, depression, sadness, and anger. It is not uncommon to have caregivers feel hostility towards their CR, which can lead to elder abuse (Kosberg & Reid, 2014). Additionally, the stress hormones released as a result of caregiving to this group can lead to increased blood pressure, compromised immune system, diabetes, and other health challenging conditions. Because most of the family caregivers for ADRD (in any ethnic group) are usually older themselves (45 to 65 years and older), their lifespans are at a higher risk of being curtailed by becoming chronically ill with an attending increased cost to the public (Cooper et al., 2010; Schulz & Martire, 2004; Shagam, 2013). There is also the loss of hope, feelings of anger, and a sense of feeling cheated of plans with a spouse or a loved one, which all plays into the overall risk of diminished health and well-being of the caregiver (Morris & Morris, 2010; Putnam, Pickard, Rodriguez, & Shear, 2010).

In comparing the difference in risk factors for the formal and informal caregiver, the risk factors are mitigated for the formal caregiver and exacerbated for the informal family caregiver. For example, most informal caregivers carry a 24/7 surveillance role in the caregiving process and are subject to more of the behavioral disturbances and consequences of increased ADRD severity (Levine et al., 2010; Perdue, 2012; Schwarzkopf et al., 2011; Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Wimo, von Strauss, Nordberg, Sassi, and Johansson (2002) indicated that informal ADRD caregivers spent as much as 8.5 times more measured hours caring for their care recipient than did the formal caregivers.

While caregiving is often characterized as being costly from an economic, physical, and mental health point of view, there are benefits and gains to caregivers (Peacock et al., 2010). There will be an increasing need for family caregivers that will be commensurate with the increased prevalence and incidence of the disease/syndrome. With the increases, there is a tendency to study the link between family caregiving and results for caregivers, while neglecting to inquire into any positive gains that may derive from the caregiving and caregiver relationship (Carbonneau, Caron, & Desrosiers, 2010). There is a need for more research on the positive aspects of caregiving for ADRD. A strength perspective model (Peacock et al., 2010; Saleebey, 2002) should be used to find a person's strength, regardless of the environmental stressors and burdens, that can be harnessed to mitigate caregivers' burden and improve their outcome secondary to giving care. Strengths in this case would include (a) caregivers viewing their role as an opportunity to give back, (b) the realization of personal strengths as opposed to deficits, and (c) growing closer to the CR (Peacock et al., 2010). This perspective could work to produce positive outcomes for both informal and formal caregivers.

Kosberg, Kaufman, Burgio, Leeper, and Sun (2007) used strength-based perspectives in their study to analyze the differences between rural Black and White family caregivers. Kosberg et al. discovered that White caregivers had a higher likelihood of being married and older, and they were able to use acceptance and humor as a coping mechanism. Additionally, they had fewer financial difficulties. On the other hand, Black caregivers gave more hours of care, used denial and religion as coping skills, and were less burdened (Kosberg et al., 2007). In describing the results for both cohorts in the study, Kosberg et al. placed the emphasis on the positive aspects of the racial differences and similarities. There is a need for more research on the positive and rewarding aspects and gains of giving care to people with ADRD. Such gains could be applicable to both the formal and informal caregiver. Policymakers can benefit from this positive approach and findings in the types of legislative supports they develop for both groups of ADRD caregivers.

The Economics of Caregiving: The Societal Current and Future Cost

While ADRD is devastating for the victim, it is equally devastating to those family members who render care. Individuals suffering from the disease and their family members would prefer home care to institutional care (Sano et al., 2013). This desire of the CR and caregiver is a cost saving benefit to society as a whole when factors such as delayed institutionalization are considered (Sansoni et al., 2013b). With the current prevalence of over 5 million persons with ADRD, the public U.S. cost is around $203 billion (up from $172 billion in 2011) per year (Alzheimer's Association, 2013; Hurd et al., 2013). The state of New Mexico where this study was conducted is a majority-minority state, which means it has a large cultural minority population with all the accompanying negative socioeconomic statistics. The current ADRD prevalence in the state of New Mexico is estimated at 31,000, which is a 15% change from the year 2000. For the number of uncompensated caregiving hours needed to care for the 31,000 CRs, the state estimated the cost to be $1.38 billion (New Mexico Public Health Data, n.d.; State of New Mexico, 2013). Furthermore, the New Mexico state plan to address ADRD predicted that informal caregivers will incur $58 million in higher health care costs, as a result of them rendering care (State of New Mexico, 2013). The disease prevalence is predicted to be 43,000 by the year 2050 for New Mexico, and commensurate cost increases are expected (State of New Mexico, 2013).

The breakdown of the national $203 billion annual cost for caring for CRs is as follows: $142 billion for Medicare and Medicaid, which includes treatment and long-term care; $34 billion cost (e.g., coinsurance and copays) to the member's family; and $27 billion for other related costs. These costs do not take into consideration the cost of uncompensated informal caregiving rendered by family members and friends who account for 80% of the ADRD care workforce (Alzheimer's Association, 2013).

Informal Family Caregiver Costs

Government and private organizations that track the cost of unpaid caregiving estimate that 15.4 million informal caregivers (family and friends) provide 17.5 million hours of care at an estimated value of $216 billion (Alzheimer's Association, 2013;

CDC, 2013, Redfoot et al., 2013). These figures do not take into account the cost of care index (Kosberg & Cairl, 1986). This cost is due to job loss, early retirement of caregivers, and other economic costs incurred by the caregiver because of giving care. Policymakers should keep these figures in mind when understanding the experience of the informal caregivers.

Formal Caregiver Pay and Benefits

The formal paid caregivers enjoy some advantages over the informal unpaid family caregivers. Formal caregivers are compensated for their service at a national average market rate of $9.67 or $20,100 per year. They also spend less time with a CR than the informal caregiver, which mitigates their exposure to the burdens exacerbating caregiver risk factors. Additionally, formal caregivers already work in an institutionalized context because they are usually trained and paid by an agency for services rendered. With these benefits, the formal caregiver demonstrates a model that, if applied to the informal caregiver, could mitigate informal caregiver burdens and reduce societal cost. If informal caregivers could spend less time with their CR, get adequate respite, receive training, and be compensated similar to the personal care programs, they too may experience fewer burdens and delay institutionalization of the CR. Furthermore, formal caregivers could work in concert with informal caregivers to give the necessary relief. The caregiver's capacity to keep their CR at home within the community longer would be extended. This too could reduce public cost. More money should be spent to discover how the formal caregiver model could be adopted to fit the informal caregiver.

Money Dedicated to Other Diseases

According to the Alzheimer’s Association (2011) and the Alzheimer’s Disease Facts and Figures (2013), ADRD is one of the least funded diseases leading to death. As of 2011, cancer was funded at $6 billion, which is12 times that of ADRD; heart disease was funded at $4.1 billion; and HIV was funded at $3.1billion, which was 23 times that of ADRD and has an incidence of 5 times less than ADRD. ADRD was only funded at $480 million (Alzheimer’s Association, 2011). The majority of funding CR care went to pharmacological and disease research and little was given to caregiver research. With the increased funding of HIV and cancer, there has been a corollary reduction in the incidence for both of those funded diseases. As with cancer, heart disease, or HIV, when the government funds research for ADRD, some of those funding dollars are used to fund ADRD caregiving commensurately (CDC, 2013; Cotelli, Manenti, Zanetti, & Miniussi, 2012; Fuller, Johnson-Turbes, Hall, & Osuji, 2012).

ADRD is projected to cost over $1 trillion by the year 2050. Calculated in that figure is the cost of diminished physical, emotional, and economic health and burden of caregivers. This underfunding may cost society much more in the future if investments in treatments for both CRs and caregivers are not made. The following two graphs constitutes data from the Alzheimer’s Association and CDC (2013) facts and figures report and provides a picture of potential cost and how little is being done to address ADRD relative to other diseases:

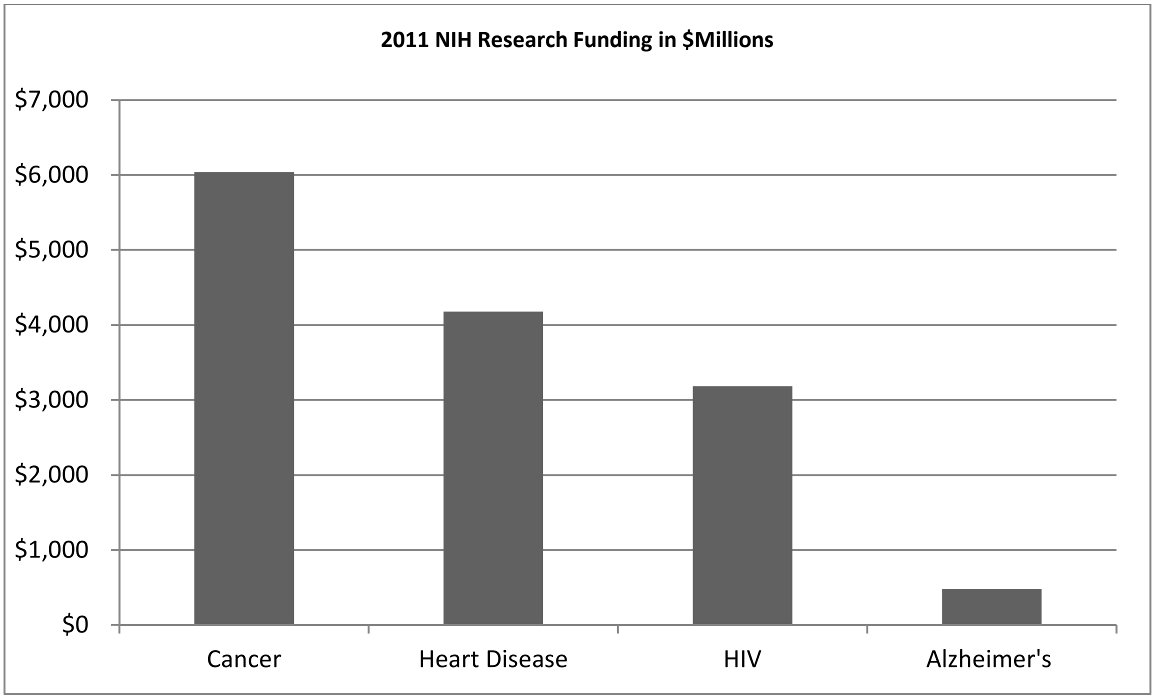

Figure 2. 2011 NIH funding in $millions. Modified and reprinted with permission.

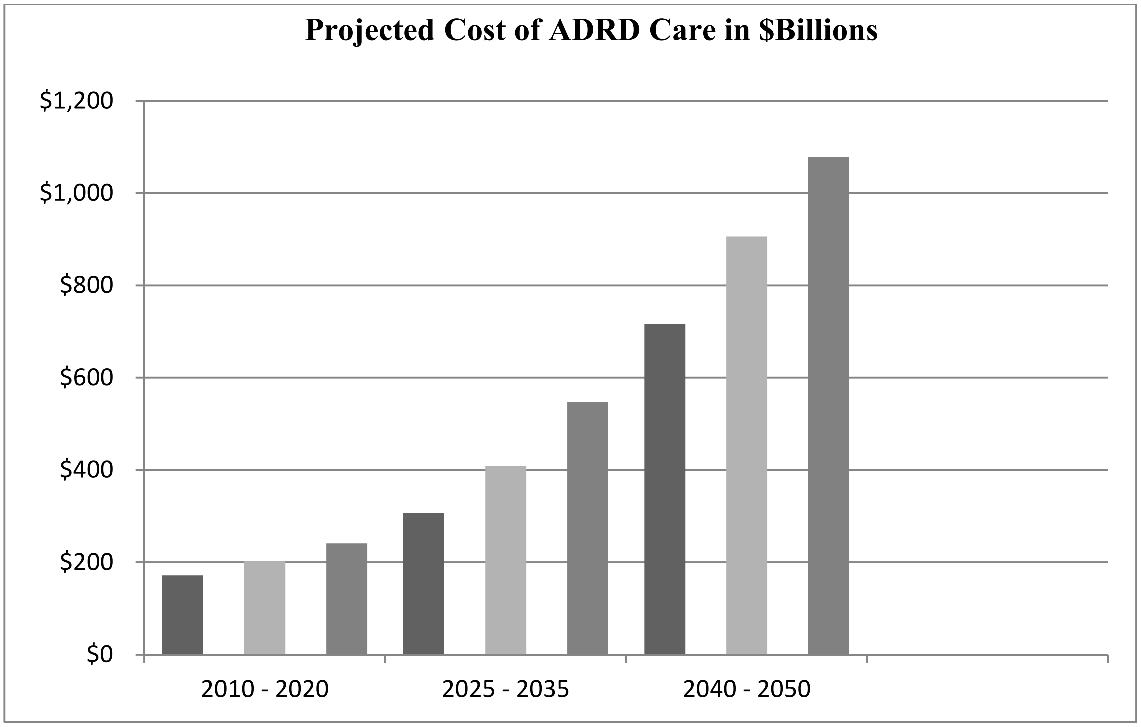

Figure 3. The projected cost of ADRD in $millions. Modified and reprinted with permission.

Federal and State Government Response to Alzheimer's Disease and Dementia

The two theories of this study's conceptual framework, PST and RCT, were used to explain why the government needed to responded to the ADRD situation. There is a need for citizens and caregivers to be relieved from the socioeconomic burden of care that accompanies ADRD by their local, state, and federal policymakers. Over the past 2 decades, the scientific community has produced and disseminated literature on the need for ADRD policy intervention at a variety of levels. RCT and PST are in play in this process in that citizens begin to make rational choices of placement in the more expensive institutions when their care burden increased. Increased institutionalization of ADRD care recipients triggers increased public cost, which captures the attention of public policymakers. The dynamics of these events served as a stimulus from the sociopolitical environment that will further trigger governmental response to the ADRD situation.

Policymakers must take steps in the federal and state government levels to mitigate both cost and burden of ADRD. Toward that end, President Obama signed into law NAPA on January 4, 2011 (NAPA, 2011). NAPA seeks to create an integrated national plan to overcome ADRD pharmacologically and with supportive services for patients and caregivers. Based on the plan, each state is directed to come up with their own individual state plan to address AD within their borders (National Plan to Address Alzheimer's Disease, n.d.).

New Mexico is one of 29 states that has convened taskforces and has implemented state plans to address ADRD needs within the state (State Government Alzheimer's Disease Plans, 2013). The New Mexico Alzheimer's disease task force is a diverse group of 60 individuals consisting of professionals and caregivers of ADRD care, an individual diagnosed with early or younger onset dementia, and representatives from the local New Mexico chapter of the Alzheimer's Association. The task force divided into five work groups (subcommittees) and addressed health care system capacity, public awareness, research, quality of care, and caregivers' needs. From these work groups came several recommendations and goals that would guide the state in addressing its own emerging and escalating ADRD problem (State of New Mexico, 2013). From the State Plan taskforce came an additional taskforce that convened in April of 2014 to address caregivers' needs (Salazar, 2014).

Besides NAPA and other state plans, the government is increasing funding to NIA, NIH, CDC, and other agencies to increase research dollars up to par with other diseases, such as cancer, HIV, and heart disease (National Institute of Health [NIH], 2013). Increased funding may produce solutions to combat ADRD and help caregivers. The 2013 healthy brain initiative is an example of such increased funding. This project is a Public Health Road Map to foster state and national partnerships for the years 2013 through 2018. The initiative encourages local and state agencies to combine their efforts to address cognitive impairment and promote cognitive functioning for community dwellers of ADRD, while meeting the care needs of the caregivers. Fuller et al. (2012) evaluated the healthy brain initiative intervention, which consisted of partnerships between states and local community partners to increase awareness, knowledge, and engagement in protective health behaviors among. Fuller et al. concluded that such interventions can increase knowledge and awareness of brain health and motivate individuals towards healthier brain health behaviors. That study is generalizable to other ethnic cohorts as well.

Understanding the Policymaking Process and its Application

The public policymaking process includes the following four parts:

- The conceptualization of the public or social need requiring a policy agenda setting
- The formulation of a policy that meets the identified social need
- The implementation of the formulated policy

- The evaluation of the implemented policy to measure effectiveness (Sabatier, 2007).

This process, as described by Sabatier (2007), appears simple; however, most public policy theorists and scholars agree that it is a complex and nuanced process that requires the collective engagement of all actors (Cameron & Gignac, 2008; DeGroff & Cargo, 2009; Hankivsky & Cormier, 2011; Hudson & Lowe, 2009; Pemberton, 2008). The interplay of social and political actors in this study includes both RCT and PST. While RCT is used to address the actions of the individual formal and informal caregivers, PST is used to address how those actors might act as an environmental stimulus to affect positive caregiver support outcomes from policymakers. The two theories that formed the conceptual frame of the study were not much competing, as they were acting in concert with the social community and political actors for the benefit and best interest of both groups.

A one-size-fits-all approach will not be adequate when trying to set an agenda, formulate, implement, and evaluate an ADRD caregiver support policy for a locale (Hankivsky & Cormier, 2011). In the case of New Mexico where my study took place, Hankivsky and Cormier (2011) suggested that policymakers understand and include the concept of social intersection (intersectionality) in their policy process. Unlike traditional policy formation approaches, which often falsely classify stakeholders into one homogeneous social grouping, intersectionality considers the individual lived reality, the experiences of constituents, and how their reality and experiences intersect socially. For example, where a conventional policy process may see all affirmative action recipients as

African Americans, and all ADRD caregivers in northern New Mexico as being Native American, an intersectionality approach would be mindful of within-group diversity of New Mexico ADRD caregivers and how that diversity intersects socially (Hankivsky & Cormier, 2011). The policy process can work for the group of caregivers. Policymakers need to be aware of the changing experiences and needs of the caregiver (Cameron & Gignac, 2008). Cameron and Gignac, (2008) highlighted the need for policymakers to recognize the changing needs of caregivers and their CRs over the care continuum and to produce policies that are in sync with those changes.

Experience of Informal and Formal Family Caregivers

Informal Caregiver Experience

Perdue (2012) conducted an ethnographic exploratory study to capture the experience of the informal "invisible" family ADRD caregiver workforce and to determine how the 1999 Supreme Court's Olmstead ruling for supporting them was being upheld. The Olmstead ruling, as it relates to this subject, mandated the care of ADRD individuals to the community and gave legal authority for support of the family members who cared for them (*Olmstead v. L. C.*, 1999). Perdue's case study approach included four cases to capture the experience of formal health care professionals, informal family caregivers, and policymakers from their own ethnographic point of view. Perdue found that caregivers were committed to continuing to care for a CR in the community despite the social, financial, emotional, and physical burdens that giving such care exerted on them (Perdue, 2012). Perdue made policy recommendations for respite care, which could bridge the gap between formal and informal care rendered in the community.

When informal family caregivers are connected to formal respite care services in the community, a link between the informal caregiver to formal community care services is made. Perdue (2012) maintained that such linkage could serve to strengthen the private-public relationship that connects informal family care recipients to formalized community services (p. 173). Other policy recommendations were to provide home consultation, expand home care programs, and create a Massachusetts office of ADRD support to give government oversight to the coordination of supportive services at the state level (Perdue, 2012, pp. 174–177). It was the intention of this study not to replicate the Perdue study, but to build upon its findings and recommendations, therefore adding to the literature of how policymakers use the experience of ADRD caregivers to provide more supportive policy.

Formal Caregivers

Miyamoto, Tachimori, and Ito (2010) addressed the experiences of the formal caregivers in contrast to the informal. Miyamoto et al. designed their study to capture how the behavioral and psychological symptoms of dementia (BPSD) influenced caregivers in formal settings. BPSD was characterized and measured as behaviors, such as wandering, noisy outbursts, physical or verbal aggression, and restlessness. The point of the study was to determine the degree that BPSD negatively influenced the experience of formal ADRD caregivers in the form of increased caregiver burden. Miyamoto et al. found that BPSD had similar burden exacerbating effects on formal institutional caregivers as it did on informal family and community caregivers. Because the Miyamoto et al, study was conducted in Japan and in formal institutions of ADRD care, the generalizability of the findings is limited. However, formal and informal caregivers have a common experience of increased burden due to increased behavioral symptoms of ADRD.

Another common experience of formal and informal ADRD caregivers is the lack of information available to them prior to and after the diagnosis. Both the source of information and the methods by which information gets to them can be limited in some jurisdictions. For example, Robinson et al. (2009) revealed dismissive and prejudicial attitudes from the system of care towards caregivers seeking information about early diagnosis of their CR. The lack of available information led to delays in necessary support services and added burden to the caregivers. Robinson et al. concluded that policymakers and other professionals needed to take a posture of value and empathy when listening to the needs of formal and informal caregivers. There is an immediate need for improved and accessible services to dementia caregivers (Robinson et al., 2009). Access to useful information and caregiver support services is needed in the United States (Thompson et al., 2007). This was one of the recommendations of the task force that developed the state's plan to address ADRD (State of New Mexico, 2013).

The majority of caregivers are women. Few researchers have addressed the male caregiver to those with ADRD. Robinson, Bottorff, Pesut, Oliffe, and Tomlinson (2014) looked at the ratio of family male caregivers to dementia care recipients. The experience of the male caregiver was captured and reviewed in the following three thematic groupings: outcomes of caregiving, men's experiences of caregiving, and factors of relationships (Robinson et al., 2014). The findings of the reviewed studies of male caregivers were consistent with findings on female caregivers of ADRD care recipients. For example, male caregivers experienced burden, stress, limitations to access to caregivers supports, and issues relating to a CR. Strategies to maintain male caregivers' health and well-being should be presented to policymakers via the narrowing of the life expectancy gender gap and increasing the number of males who will be providing care to dementia care recipients (Robinson et al., 2014). The inclusion of the male caregiver experience should be taken into account when trying to convey overall ADRD caregivers' experiences to government officials for policy decisions.

What Policymakers Need to Know to Support Caregivers

Policymakers not only need to know the experience of the caregivers, but they must also become well-informed regarding the needs of those caregivers. As the collective support needs of formal and informal caregivers increase with incidence and prevalence of ADRD, policymakers will need to make the shift in paradigm from caregivers being informal family members and friends who are not a part of the formal paid caregiving workforce to them being critical and valuable partners of care. Levine et al. (2010) highlighted a gap between the informal family caregiver and the paid professionals as being equally important and contributing members of the caregiving workforce. Levine et al. explained why family caregivers have not been a central part of the policy discussions and some policy recommendations that would make them more inclusive.

The long-term-care system, 80% of which is made up of informal family caregivers, is complex, unstable, and rife with the constant change of providers. Often the informal family caregiver is the only provider of care who experiences the entire trajectory of the CR’s decline with any consistency. This reality should add weight to the need for increased support for this segment of the caregiver workforce (Levine et al., 2010). The primary reason that the informal family caregiver has been neglected by policymakers is the understanding that their services are not only free, but are personal and moral obligations, and therefore, not a compensable part of the caregiving workforce. Policymakers often avoid paying for something they are used to getting for free (Levine et al., 2010). Efforts on the part of the government to support the informal family caregiver is based on the shortage of formal paid caregivers and the concern that informal caregivers will burn out and institutionalize their care recipient sooner. This could lead to increased public costs, which is what gives government officials the most concern.

Levine et al. (2010) recommended four main areas that should be the focus of policymakers seeking to support informal family caregivers and stem the tide of escalating public costs. First, information that is more comprehensive must be gathered about the caregivers and their needs. This information should not only capture the nuances of ADLs-IADLs and psychosocial issues, but must also encompass the lived experience of the caregivers as they interact with the various care support systems and services. Second, it is suggested that policy drive training of all individuals in the LTC continuum to develop relationships with informal and direct family caregivers. Formal and professional caregivers should be instructed to train the informal caregivers and to make them essential partners in the dispensing of care to the CR. Third, policymakers should support program development that addresses the needs of the family caregiver, particularly as those needs relate to care transitions from hospitals and other institutional care to HCBS. Adequate training of staff and funding should be a part of any program development considerations. Lastly, financing of caregiver services on a pay-for-performance protocol with appropriate performance measures should be considered. Policymakers must look at ways to use existing government caregivers' support funding authorizations and expand pay-for-performance compensation to those neediest family caregivers (Levine et al., 2010). These four areas of support can be realized if the government can recognize informal caregivers as a valued component of the caregiver system and not just family members serving out of obligatory duty and familial love.

Johansson et al. (2011) conducted a study that represents the beginning of an analysis of policy reform aimed at addressing family caregiving. The lawmakers in Sweden took steps legislatively to incorporate support for caregivers into the universal health care delivery system. In spite of these actions, there have been challenges to the kind of support that the informal caregiver needs. Due to cutbacks in Sweden's universal system, there has been a reduction of support to the informal family caregivers' system. Sweden's public policy solution is to shift the locus of funded caregivers' support from the greater universal source to the municipalities. This action was based on an amendment of Sweden's Social Service Act (1982), which made funding caregiving support more tailored and manageable, while meeting the local needs of the informal caregiver. The inclusion of the municipalities in the cost sharing was the policy paradigm analyzed in the study (Johansson et al., 2011).

The development of the policy that supports caregivers in the Johansson et al.'s (2011) study came about by a similar collaborative and coordinated process as described in the Bookman and Harrington (2011) study. In studying the effect of the policy and its development over a 3 decade period, Johansson et al. demonstrated lessons to support U.S. policymakers as they embark upon similar policies to help U.S. ADRD caregivers. The burden of costs on local municipalities, such as the state of New Mexico in the case of my study, can be overwhelming. Such a burden can also be unbearable without provision for volunteerism and commitment of family members to continue caring for their loved ones informally without monetary compensation during periods of tighter budget restraints.

Translating Caregiver Support Needs into Public Policy Actions

In translating ADRD caregiver support needs into public policy, there should first to be a translation of dementia research into practice. Draper et al. (2009) reviewed the concept of knowledge translation (KT) to determine how dementia knowledge was obtained and disseminated. Draper et al. posited that KT involves the management, use, and dissemination of knowledge among stakeholders. KT requires stakeholders, such as educators, policymakers, formal and informal caregivers, and other multifaceted service providers to operate within and between groups to communicate with each other and spur on the process of translating dementia research data into actionable results (Draper et al., 2009). Effective KT is based on the notion that much of the information found in dementia research is not efficiently translated to policy and practice outcomes that help caregivers and care recipients.

Draper et al. (2009) discovered that it is important to have appropriate interventions for the ADRD caregivers. Such interventions include education about the disease progression and treatment, how to access local Alzheimer's Association resources, and how to access other services within the community. It is equally important to engage the public policymaker in the KT process. Policymakers have held a role in the delivery of services that impact the health of various populations in need of health services (Draper et al., 2009). An example of how dementia research data can be used to guide government in the creation of useful caregiver supports was demonstrated by Brodaty, Green, and Koschera (2003). Brodaty et al. examined 30 studies (of 34 different interventions) consisting of informal unpaid caregivers of persons with dementia. Interventions for informal caregivers involving both caregivers and care recipients, which were modified to the caregivers needs, were found beneficial and produced better results. While the Brodaty et al. study was originally intended to inform clinicians, it has been used to inform Australian policymakers on how they can best contribute to that country's health policy for dementia caregivers. The findings of this study could likewise give impetus and support policymakers in translating research data into actionable policies.

The most up-to-date and effective translation of an informal ADRD caregiver support program into public policy action is demonstrated by the implementation of the Resource for Enhancing Alzheimer's Caregivers Health Veterans Administration program (REACH/VA). Nichols et al. (2011) conducted a randomized controlled study that ran for 2 years, to track the outcomes of the REACH II program being translated into policy action for the Veterans Administration (VA). The design of the study involved the delivery of REACH interventions that included risk assessment, targeted education, social support, skills training, assistance with problem behavior, depression screening and treatment, and overall health assessments. The interventions were delivered by clinical staff from 24 VA Home-Based Primary Care Programs (HBPCP) in 15 states. The content of the interventions consisted of 12 in-home and telephone sessions to distressed individual caregivers along with five telephone support group sessions. Staff members collected data on caregivers' frustration, social supports, burdens associated with caregiving, time spent in care provision, impact of depression on caregivers, and dementia-related behaviors. Nichols et al. indicated that the in-home and telephonic sessions reduced overall caregivers' distress over a 6-month period. Furthermore, 96% of the caregivers in the study recommended the program be delivered to all VA caregivers of ADRD care recipients (Nichols et al., 2011). Such a recommendation that the program be delivered to all VA caregivers seems to indicate that it would be equally beneficial to the formal providers of ADRD care. The success of the REACH/VA study, which was a translation with similar significant results from the REACH II study, is an example of the policy translation process needed to assist policymakers in bridging the gap between caregiver support needs and policy actions (Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014; Nichols et al., 2011). The model can also serve and assist in the evaluation phase of the policy process.

Research Methods Found in the Literature

The methodologies used in the formal and informal caregiver studies for this literature review were primarily quantitative and qualitative. While neither of these methods dominated the literature on the topic, the research questions of each study dictated the method used to answer them. For example, Perdue (2012) used an exploratory qualitative case study approach to answer the question of how informal family caregivers and their attending complex needs are invisible to policymakers. Russell (2013) addressed the use of e-government tools by citizens to access government services. While the group and topic studied did not relate to this study, the application of the qualitative phenomenological approach provided structure to this study’s use of RCT and PST as a conceptual framework. Additionally, O’Connell et al. (2012) evaluated the need and use of respite services for dementia caregivers. O’Connell et al. used a quantitative approach to answer their questions of whether respite programs and services could mitigate the burden of dementia caregivers. O’Connell et al. addressed the costs and benefits of dementia respite care and gave some hint of the RTC premise of how and why rational actors make decisions. Implications for policymakers to strengthen dementia respite care policies were made because of that study approach. Bookman et al. (2007) conducted observational fieldwork consisting of in-depth interviews with a self-selected sample of 50 family caregivers and to observe how they traversed the fragmented healthcare system. The study was qualitative in nature, but it could be used as one phase of a mixed-method if the data gathered in the field were later analyzed quantitatively (Creswell, 2009).

Most of the qualitative studies used semistructured, open-ended questions to guide participants’ responses to the experiences that were being elicited (Bookman & Harrington, 2007; Perdue, 2012; Russell, 2013). The quantitative studies, on the other hand, included surveys and self-report questionnaires to gather their data and make their analyses (O’Connell et al., 2012; Robinson et al., 2009; Willis, Chan, Murray, Matthews, & Banerjee, 2009).

Many articles consulted were informational and did not reveal the particular methodology used to gather the information (Feinberg et al., 2011; Miller et al., 2009; Noelker & Bowdie, 2012). Based on the methodology used in the majority of the studies consulted for this literature review, I affirmed my choice of a qualitative phenomenological approach. Unlike the other four qualitative approaches, grounded theory, case study, narrative research, and ethnographic research, the phenomenological approach was the best approach to extract the meaningful lived and shared experiences of the informal and formal ADRD caregivers (Creswell, 2007). As with most of the studies mentioned, my aim was to understand the individual and shared experiences of the formal and informal caregivers to later convey that information to policymakers so that they are informed about needed caregiver support policies.

Summary

This chapter began with a literature search strategy followed by a section on the theoretical and conceptual frames of the study. Next, the key concepts of the study, ADRD caregivers and policies needed to support them, were reviewed in the literature under the following main headings: (a) Background for the Chosen Construct of Formal and Informal ADRD Caregiving, (b) Experiences of Informal and Formal Family Caregivers, (c) What Policymakers Understand and Needed to Know to Support ADRD

Caregivers, (d) Translating Caregiver Support Needs into Public Policy Actions. and (e) Research Methods Found in the Literature.

The Background for the Chosen Construct of Formal and Informal ADRD Caregiving was discussed citing various authors and organizations who made a case for what the construct resembled. The next section was about Understanding the Policymaking Process and its application to this study. In that section, the process of policymaking was discussed in concert with the two complementing theories that made up the conceptual framework of this study. Another section on the Experiences of Informal and Formal Family Caregiver*s* was expounded on using literature from various authors who have done studies to capture the experience of that group of caregivers.

A section was written to describe What Policymakers Understand and Needed to Know to Support ADRD Caregivers. That section gave a sense of what individual states and developed countries have done to enact ADRD caregiver support policies. Another section included a discussion on Translating Caregiver Support Needs into Public Policy Actions*.* Caregiver support policies that become actual policies must first make the transition from mere knowledge to effective practice with good outcomes for caregivers. The notion of KT was discussed in support of that premise. Finally, Research Methods Found in the Literature was discussed to give a basis for the methods used in this study.

In the review of the pertinent literature for this study, I intended to address the information gap of specifically designed policies and interventions that address the rising need for ADRD caregivers supported by public policies. While the review is not exhaustive, it provides an adequate picture of what some needed policies could look like.

In the upcoming Chapter 3, the method of obtaining and analyzing data will be discussed in more detail.

Chapter 3: Research Method

Introduction

The purpose of this qualitative study was to learn the lived experience of formal and informal ADRD caregivers using the phenomenological approach to data collection. The gained experience will be presented in the analysis and discussion section of this paper with the intent of informing policymakers in the policy process. Additionally, my role as a researcher will be discussed in-depth to provide disclosure of my relationship with the topic, the subjects of the research, or any ethical or conflict considerations that may arise. A methodology section will include participant selection, researcher-developed instruments, interview protocol, audio recording instruments for data collection, recruitment procedure, and data analysis plans. In the methodology section, I provide sufficient details for other researchers to replicate this study. In the last two sections of this chapter, I will discuss issues of trustworthiness, such as credibility, transferability, dependability, confirmability/reflexivity, and ethical procedures. The chapter will conclude with a summary and transition to Chapter 4.

Research Design and Rationale

The research questions for this study were a composite of similar questions asked in the literature to capture the lived and shared experiences of ADRD caregivers. Once the experiences of the caregivers were captured and analyzed, the results were presented and discussed in the latter chapters of this paper for further dissemination to legislators to inform any policy that may add support to ADRD caregivers. The following are the research questions:

RQ1: What constitutes the construct of the formal and informal caregiver?

RQ2: What are the shared and lived experiences of formal and informal ADRD caregivers?

RQ3: What situations have influenced the experiences of formal and informal ADRD caregivers?

RQ4: What can state policymakers do to better support formal and informal ADRD caregivers?

The main concept addressed in this study was the phenomenon of care delivery to individuals with ADRD. Caregiving to ADRD patients is distinct from general caregiving to persons with chronic disabilities. This cohort of caregivers experience a much greater level of burden and duress because of the difficult caregiving demands placed on them when the CR progresses to the latter stages of the disease. Furthermore, the increase in the numbers of ADRD patients that will accompany the aging population will require more of these informal and formal caregivers in the ADRD caregiving workforce. The level and quality of support that these caregivers receive through adequate public policies is related to a reduction in public cost (Klug, Halaas, & Peterson, 2014; Klug, Muus, Volkov, & Halaas, 2012). In order for public policymakers and administrators to make informed and applicable policy decisions, they will need to hear the voice of these caregivers as collected and analyzed in this qualitative, phenomenological study.

The qualitative, phenomenological research tradition is suited for capturing and describing the lived experiences of individuals who provide health care (Creswell, 2007, 2009; Patton, 2002; Prorok, Horgan, & Seitz, 2013). The United Kingdom's health policy requires the detection and management of dementia early. Based on that requirement, Willis et al. (2009) evaluated the satisfaction of family caregivers and CRs with the government-sponsored memory service model (CMSM). Willis et al. used a phenomenological approach, which incorporated purposive sampling that included 15 caregivers and 16 CRs and structured interviews to gain an understanding of the caregivers' and CRs' experience with a policy-driven service. The qualitative data from that phenomenological study yielded seven quality enhancing measures that the program could then use to adjust its service delivery to caregivers and CRs. The six thematic findings were (a) the initial experience of dementia, (b) service experience, (c) helpful interventions, (d) normalizing the catastrophic, (e) clear communication, and (f) gaps in service.

Lee and Smith (2012) explored the attitudes of Korean dementia caregivers towards caregiving. In that study, eight female caregivers who consisted of four adult children and four older spouses were interviewed to determine the major themes that represented their caregiving experience to dementia patients. Lee and Smith produced five themes that highlighted the experience of that cohort. One of the emergent themes from the data was that those caregivers had a negative image of nursing homes as a care modality for their relatives suffering from ADRD. The data had an impact on how and where they chose to care for their loved ones. Phenomenological findings like this could have social and public policy implications (Lee & Smith, 2012).

Role of the Researcher

As a researcher for this study, I recruited participants, conducted digitally recorded interviews, transcribed and coded the collected data, analyzed the data, and presented the result in Chapters 4 and 5. Walt et al. (2008) suggested that the positionality of the researcher as an insider or outsider has much to do with the part that researchers play in health policy data collection and analysis. To the degree that I conducted the interviews aimed at gathering information about the lived experiences of these particular ADRD caregivers, I became a part of the research. The act of interviewing can itself be a phenomenon (Walden University, 2013). Being a part of the phenomenon placed me in the role of participant-researcher.

The next concern was whether I was an insider or outsider participant researcher. Insiders are those who have current or existing access to the policymaking process and, therefore, could be influential on the research subject both in the data collection and analysis phases. Outsiders, on the other hand, may be less constrained to ask tough questions of participants seeing that they have little or no á priori knowledge of the policy process (Walt et al., 2008, p. 314). To mitigate bias on my part, I positioned myself as an outsider to the caregivers.

As a matter of disclosure, I worked with ADRD patients and caregivers in my daily work for the past 8 years. I also served on the New Mexico taskforce to develop a state plan to address ADRD for the state and am currently in a workgroup on the state caregiver taskforce to address caring for caregivers. In addition to these professional positions, I am a long distance caregiver for my 77-year-old mother who is experiencing cognitive decline that could lead to ADRD. These situations made me prone to bias as I collected data from the group of 10 formal and informal ADRD caregivers. It is equally conceivable that I could have had bias when I analyzed and reported the study results.

I am living the literature from both a caregiver's and CR's point of view on a daily basis and my tendency as I approach the data collection and analysis phase may be to think I already know what the caregivers are experiencing. To mitigate this bias, I suspended my experiences and placed myself in the position of an outsider. One way to accomplish this was to avoid asking leading questions and to speak as little as possible and allow the respondents to do the majority of the responding during the interviews.

One of my personal concerns in the caregiver policy arena is the financial cost that informal caregivers incur and the limited support they receive from government programs. I was predisposed to expecting a response from the informal caregiver side of the interviewees. This expectation could have led me to not assess the formal caregivers to see if they shared similar thoughts and opinions about cost and support. Other than my personal caregiver policy concerns, I did not foresee any other ethical concerns, such as power differentials, justification for use of incentives, or work place conflicts that warranted disclosure.

Methodology

This study was viewed through a phenomenological lens. Unlike positivist approaches that are used to establish cause and effect relationships, phenomenology is a qualitative research approach used to identify the essence of human experience as described by participants of the study (Creswell, 2009; Penner & McClement, 2008; Van

Manen, 1990). In the case of this study, the phenomenon of caregiving to ADRD patients was the essence of the study. I wished to ascertain the lived and shared experiences of formal and informal caregivers of ADRD patients and to present those collected experiences to policymakers who can then use the gained insight to develop supportive policies for caregivers.

Participant Selection Logic

The sampling strategy used to select participants for this study was purposive**.** Participants were a heterogeneous group of five informal members who were not fully compensated and five formal caregivers who worked for a home health care delivery agency. These individuals were (a) taking care of a person who was diagnosed with Alzheimer's disease, (b) caring for an individual with one of the related dementias, (c) was engaged in daily hands-on caregiving requiring assistance with ADLs, and (d) had been in contact with at least one other person who is or has given care to a person with ADRD. The rationale for this inclusion criterion was based on the study's premise of ascertaining the lived and shared experiences of caregivers who care for ADRD individuals. Participants were known to meet the study's inclusion criteria when they answered in the affirmative to the above four conditions on the consent to participate form or so indicated when they respond to the recruitment flyer (Appendix C).

The study consisted of 10 participants, as this is the typical number of sample participants that are best suited for a qualitative phenomenological study (Penner & McClement, 2008; Walden University, 2013). Johnson (2013) conducted a phenomenological study that addressed the experience of adult children who gave care to dependent parents. The sample size for that study was 10 members, and it proved effective for gathering authentic accounts of the caregiving experience, as well as for reaching saturation. The notion of saturation occurs when new data collected are no longer adding new insights to the phenomenon under study. Saturation is often achieved when a balance is struck between a sample size that is large enough to capture the perceptions of the members, yet not so large that it causes a redundancy of data (Mason, 2010).

In addition, a sample of 10 participants was reasonable, as I was more concerned with transferability of results and not generalizability. Because qualitative data have an inherent point of diminishing returns, larger samples do not produce more meaning or insight into the described phenomenon or experience because one occurrence of the collected data is as good as many in conveying the sought after meaning (Mason, 2010). Additionally, the data from transcribed interviews were voluminous and less manageable, which would have made a larger sample impractical. Procedure for identifying, contacting, and recruiting respondents was as follows:

1. The New Mexico Alzheimer's Association is a nonprofit agency that works directly with formal and informal caregivers to train and connect them to community supports. I contacted this agency with a letter (Appendix B) and requested that they support me by providing access to caregivers with contact information, phone, and e-mail who provided care to people with ADRD and whom they identified as being potentially interested in participating in the study. Additionally, I had flyers posted

electronically and physically (Appendix C) to other agencies, such as special care Alzheimer’s facilities and the general community that may have access to caregivers of ADRD clients and whom I thought were appropriate candidates for the study. Participants were deemed appropriate for the study if both the formal and informal caregivers were providing care to one CR who was at the moderate or advanced stages of ADRD.

2. Upon identification of the required sample, I contacted the individuals and determined if they would be interested in participating.
3. After gaining the full sample of eight to 10 potential ADRD formal and informal caregivers, I provided them the consent to participate form (Appendix A) and the demographic form (Appendix D) for them to complete before interviews began.
4. This process only commenced after Walden University Institutional Review Board (IRB) approved the proposal and gave me permission to proceed.

Instrumentation

I was the primary instrument of data collection for this research. I conducted individual interviews with formal and informal caregivers who were engaged in providing care to people with ADRD. These caregivers were recruited through the New Mexico Alzheimer’s Association and through me. The interview questions used to guide participant responses was predicated on the study’s research questions and the data collection protocol (See Appendix E). The questions were open-ended and were used to guide the respondents in relaying their authentic and unique experience as care providers to ADRD relatives or clients. These facilitated interviews helped in answering the research questions of the lived and shared experiences of the ADRD caregiver. Additionally, two digital audio recording devices were used to capture the interview data for future transcribing, coding, and analysis.

Researcher-Developed Instrument

The only researcher-developed instrument was an instrument for capturing demographic information. Such an instrument (See Appendix D) was used to collect the following information:

- Name (coded as caregiver CG #1, CG #2, etc.)
- Contact information for follow up (was de-identified for confidentiality)
- Gender (Male/Female)
- Age
- Diagnosis of ADRD (yes/no)
- Time as an ADRD caregiver (6 months or longer)
- Formal or informal caregiver (working with family member from home/working for or assigned by an agency to a private residence)
- Relationship to CR (spouse, child, friend)

Researchers of similarly designed studies have used demographic tools to capture information about participants that added to the richness of the descriptive experience (Johnson, 2013; Lee & Smith, 2012; Willis et al., 2009).

Procedures for Recruitment, Participation and Data Collection

The data collection protocol was a set of six questions. Two questions addressed the interviewee's perception and experience of ADRD caregiving in general, two inquired about the influences and barriers to good caregiving that they experienced, and two solicited examples of what policymakers might consider doing to support informal family and formal caregivers. In being consistent with the conceptual framework of phenomenological studies, the participants gave their subjective responses to the questions from the interview protocol (Appendix E). The data collection interview process occurred at a place that was convenient for both the respondent and me. Frequency of data collection was contingent on what was needed to achieve saturation. A few follow-up telephone interviews were conducted after the initial face-to-face interviews reach the point of data saturation. I conducted the interviews using the set of questions prepared for the data collection protocol to each of the eight to 10 participants who were authentic and clear in their accounts of the ADRD caregiving experience.

Each interview was estimated to last between 45 minutes to an hour per person, but could vary between 12 minutes and 46 minutes depending on the ADRD caregiver's need to respond. Each interview was recorded on two digital devices with distinct audio files for each participant for future analysis. The proper number of participants were recruited for the study, and further follow-up with the NM Alzheimer's Association and other agencies that have access to informal and formal caregivers was not necessary. The following are the eight questions that were posed to guide the data collection:

1. Do you consider yourself as an informal family caregiver to your care recipient and what does your role mean to you?
2. Do you see yourself as a formal ADRD caregiver, and if so why?
3. What is, or has been, your general experience of giving care to a person with Alzheimer’s disease or related dementia?
4. In interacting with other ADRD caregivers, what experiences do you feel you share in common with them?
5. What are the main situations that influence your experience as an ADRD caregiver?
6. What are some barriers that limit your ability to give good care to your care recipient?
7. What public services do you believe would be helpful to you as an ADRD caregiver?
8. What are some specific things that you think the state could do to improve your experience as an ADRD caregiver?

Upon completion of the interviews, participants were debriefed by being reminded of the purpose of the study, the confidentiality of their identity, and the possibility of a follow-up phone call or meeting to clarify their responses for quality purposes.

How Interview Questions Related to Research Questions

The questions that were used in the interview were related to the four research questions. Eight interview questions were used to prompt a response from the selected study participants (See Appendix E). RQ1 asks what the construct of the formal and informal caregiver is, as perceived by the caregiver. The first two interview questions related to the first RQ. RQ2 is concerned with the lived and shared experiences of the informal and formal caregiver. Interview Questions 3 and 4 addressed this RQ. RQ3 enquired about situations that influence the caregiving experience. Situations could be important, rewarding, difficult, or burdensome. This question, with its attending situations, was answered by Interview Questions 5 and 6. Finally, RQ4 was used to capture what formal and informal caregivers think, believe, or hope state policymakers can and should do to better support them in their caregiving. This may be how state policy can reduce their caregiving burdens and help them keep their CR at home longer. The answers to this RQ were captured by Interview Questions 7 and 8.

Potential Themes from Conceptual Framework

The research and interview questions are related to the five key phrases that were used to construct the main concepts of the study. They are

1. Understanding the policymaking process
2. What policymakers need to know about dementia caregiving
3. Experience of formal and informal caregivers related to cost of formal and informal dementia caregiving
4. Translating caregivers support into public policy actions. Themes emerged from interviews that related to the key phrases. Themes that were not considered in the key phrases and research questions also emerged. Furthermore, the concept of cost and benefit of caring for CR in the home

> and the community versus placing them in an institution emerged in concert with the RCT aspect of this study's conceptual framework. PST was seen as respondents shared their views of what policymakers could do to improve their situation and support them.

Data Analysis Plan

In phenomenological research, data analysis can only be comprised of the participants' thoughts and words about the phenomenon, in this case, caregiving to ADRD individuals (Walden University, 2013). The researcher must then live and work in the rich descriptive data to code it, categorize it, and glean meaningful understandings from the phenomena being studied (Van Manen, 1990). The *noema* represented what the caregiver experienced externally about caregiving, and *noesis* depicted the way in which the caregiver experienced the phenomenon internally. Noema and noesis were the phenomenological concepts under study in this study (Moustakas, 1994). Therefore, to arrive at these deeper meanings of the ADRD caregiver experience, the interviews were transcribed verbatim, and a directed content analysis method (DCA) was used to analyze the data for emergent themes that derived from the conceptual framework of the resulting text data (Hsieh & Shannon, 2005). Hsieh and Shannon (2005) posited that a DCA approach is best suited for studies that apply a conceptual framework, such as RCT and PST. Open coding, which is a way of reducing the collected data into smaller sets of themes that describe the studied phenomena, was used to categorize the major themes and set them into clusters with similar meaning for counting (Van Manen, 1990; Walden University, 2013; Willis et al., 2009).

The DCA approach was used to capture all possible occurrences of the formal and informal ADRD caregiver experience phenomenon. This was done without coding, but by highlighting all identified text that coincided with the theoretical constructs so as to increase trustworthiness (Creswell, 2009; Hsieh & Shannon, 2005). Because the DCA approach is concerned with linking the study to theories in the conceptual framework, the researcher is prone to bias, such as finding more evidence that supports a theory than not (Hsieh & Shannon, 2005, p. 1283). The use of qualitative data analysis (QDA) software such as NVivo 10 (QSR International, n.d.) made the management and analysis of qualitative data much more efficient than in times past and can add rigor to qualitative research (Leech & Onwuegbuzie, 2011). Additionally, computer-assisted quality data analysis software (CAQDAS) can help the researcher in extracting underlying and emerging themes of meaning, assist in the coding process, and aid in the analysis of the coded and clustered findings.

In amplifying the data review process, I followed the Creswell (2009) modified plan for analysis in conjunction with the NVivo10 QDA software package. Creswell posited the following six-step plan for data analysis:

1. Organize and prepare the data for analysis. This includes transcribing the interviews and visually scanning and sorting it for further analysis.
2. Reading through the data to gain a general sense and overall meaning of the collected information.

3. Beginning of detailed analysis using the coding process. This is an extensive process of organizing the material into meaningful data segments and categories.
4. Generate descriptions of themes, settings, and categories for analysis.
5. Describe how identified themes were represented in the discussion narrative.
6. Making interpretation of the meaning of the data.

In describing the steps of data analysis for phenomenological research, Creswell (2009) referred to Moustakas' essence of description. Moustakas posited that the expressed perception of the person is the primary source of understanding of the phenomenon being studied. The task of phenomenological data analysis is to capture that lived and expressed understanding. There are four elements that depict the data analysis model namely, epoche (bracketing), phenomenological reduction, imaginative variation, and synthesizing of meanings and essences (Moustakas, 1994). Bracketing requires the researcher to isolate his or her biases or prejudgments about the studied phenomenon from the study participants. Bracketing is a self-reflection process that allows the researcher to lay down any á priori knowledge or feelings of the phenomenon to gather unbiased data from the respondents. The idea of phenomenological reduction means reducing the phenomenon down to the pure concepts being solicited by the research questions. It also requires a process of bracketing. Phenomenological reduction also includes a process called *horizontalization,* which sets out to list, group, and treat the collected data with equity (Moustakas, 1994). Phenomenological reduction is also a quest to find meanings that stand out, themes that are nonrepetitive, individual textural descriptions of each respondent, and composite textural descriptions of all themes of respondents (Moustakas, 1994, p. 92). It is at this stage that discrepant themes are addressed. Imaginative variation is a mechanism in the analysis process that amplifies the meanings and perspectives from different angles. The researcher can deduce from the textural description a structural description of how the studied phenomenon came about. In the synthesizing of meaning and essence stage, the researcher uses reflective intuition to integrate the aggregate textural and structural descriptions into a synthesis of meaning and essence that represents the experienced phenomenon (Moustakas, 1994).

Issues of Trustworthiness

Onwuegbuzie and Leech (2007) addressed the question of whether or not validity and qualitative research is an oxymoronic paradigm. Onwuegbuzie and Leech answered the question in the negative by describing their qualitative legitimation model (p. 234). This model is used to integrate the many types of qualitative research validity and to explain (24) methods for assessing the truth-value component of qualitative research (Onwuegbuzie & Leech, 2007). To add value to the trustworthiness of the current study, issues of credibility, transferability, dependability, and confirmability are all addressed here as they relate to this qualitative phenomenological study.

Credibility

There are many threats to internal credibility. Some examples are a lack of ironic rhizomatic and embodied legitimation, descriptive validity, and structural corroboration. Descriptive validity is the factual accuracy of respondents' account as recorded by the researcher (Onwuegbuzie & Leech, 2007, p. 236). This aspect of internal reliability was the one most likely to be violated in this study. To address it, I made provisions for as many follow-up interviews with the respondents as necessary to achieve saturation for the required data. This process, which includes checking back in with study participants to verify their account of the phenomenon, is known as member checking and is considered the best method of establishing credibility (Onwuegbuzie & Leech, 2007, p. 241).

Transferability

Transferability is the qualitative equivalence of external validity that includes the generalizability of study findings and conclusions (Trochim, 2006). The members in this study consisted of both formal and informal caregivers, and they were demographically diverse. Therefore, there should be some transferability of the findings and conclusions. To accomplish this, I ensured thick and rich textural descriptions of the participants' responses. Additionally, investigation validity that refers to the researcher's own ethicalness was used to maintain external validity (Onwuegbuzie & Leech, 2007, p. 238). This study is not sufficient for generalizability due to the lack of a representative and sizable sample. Rich textural descriptions and the integrity of the researcher are the ingredients that can make the findings transferrable.

Dependability

Dependability in qualitative studies is related to reliability in the quantitative realm (Trochim, 2006). Onwuegbuzie and Leech (2007) suggested that there is no research design that can guarantee complete validity and trustworthiness (dependability) of data. At best there can be an assessment of the process used to obtain the data being analyzed and disseminated. Due to the size of this study, issues of confirmability or objectivity were not necessary. However, they will be addressed in Chapter 4 in the section on trustworthiness.

Ethical Procedures

The Walden University IRB requires an application to the board for permission to commence with recruitment of participants and collection and analysis of data gathered from them (Walden University, 2012). The IRB application and its approval to conduct the study is a step in the dissertation and proposal process to ensure the ethical treatment of members and the data they may yield to the study. Documents required by the IRB to gain access to participants are included in the various appendices aforementioned.

Ethical Concerns

In keeping with IRB and Walden University standards, the participant recruitment, data collection, and data analysis portion of this study did not begin until IRB approval was gained. The ADRD participant caregivers all read and signed a consent to participate form (Appendix C) before they were able to take part in the study. They were all given the opportunity to have me explain any part of the informed consent form where clarity was needed. They were also informed that they had the right to opt out of the study at any given time for any or no given reason.

In the course of data collection, the study participants may become disturbed emotionally in the retelling of their experience and may not want to continue or completely withdraw from participation in the interviewing process. In the event of such occurrences, individuals were reminded that they could withdraw from the study promptly and without any coercion to continue. As a clinical social worker, I am able to evaluate such adverse reactions to the retelling of experiences and was available to help members if they choose to continue or to remove themselves from the study. The plan was to stop the study and refer them to local counselors or therapists in their medical provider network who may be able to help them. With that intervention in place, those who volunteered willingly to participate were unlikely to have such adverse reactions while sharing their caregiving experiences. There were no incidents of adverse reactions throughout the 10 interviews.

Treatment of Data

The raw data collected for this study will be treated as anonymous and confidential for 5 years after they were collected. Identity of subjects in the data will be removed, archived, and stored in a locked safe in my home where only I will have access.

Data Presentation

The study results will be presented in Chapter 4 in the form of direct quotations and excerpts from the interviews. Data interpretations and descriptions, along with any discrepancies found in the various individual transcripts, will be identified. Finally, emergent common themes will be compared to the key phrases and constructs of the literature review and presented in discussion form.

Summary

In this chapter, I presented an introduction to the study methodology by restating the purpose of the study as represented by the research questions. The study was a qualitative, phenomenological study used to discover and describe the lived and shared experiences of formal and informal ADRD caregivers. Participants' selection logic was also presented. Instrumentation and procedures for recruitment, participation, and data collection were also discussed with explanations of, from, and by whom data were collected and recorded; the duration of the data collection process; and follow-up plan to ensure data saturation. A method to analyze the data and to connect them to the research question was discussed, along with the DCA phenomenological analysis process and CAQDA software that helped in the analysis process. I also discussed issues of trustworthiness to include credibility, transferability, dependability, and confirmability and how these aspects of trustworthiness can enhance the quality of the study. A section describing how the research questions interrelated to the interview questions and the themes that emerged from the collected data was discussed. Finally, ethical considerations as they related to treatment of participants and treatment of collected data were discussed. In Chapter 4 will, I discuss the results of the gathered and analyzed data.

Chapter 4: Results

Introduction

This study was qualitative and phenomenological in nature. The purpose of the study was to ascertain the lived and shared experiences of formal and informal ADRD caregivers and to gain an understanding of what they think policymakers can do to support them in their roles as caregivers. By design, I sought to answer four primary research questions. The four primary research questions provided the foundation for eight semistructured interview questions that were used to guide participants' responses. The primary research questions were as follows:

1. What constitutes the construct of the formal and informal ADRD caregiver?
2. What are the shared and lived experiences of formal and informal ADRD caregivers?
3. What situations have influenced the experiences of the formal and informal ADRD caregiver?
4. What can state policymakers do to better support formal and informal ADRD caregivers?

This chapter is comprised of the following sections: (a) the overall study setting, (b) a description of the study participants, (c) the data collection process, (d) data analysis, (e) evidence of trustworthiness, (f) results, and (g) summary of the chapter.

Study Setting

Qualitative research does not typically require the researcher to bring the subjects or respondents to a laboratory, but rather to meet them in their natural setting or environment where real time, face-to-face interaction can occur over a prescribed time period (Creswell, 2009). This was the case in this study as all of the participants were interviewed in person or face-to-face. Six of respondents were interviewed in their homes, three in my office during nonworking hours, and one in a coffee shop. The participant who was interviewed in the coffee shop was the only one of the 10 who might have been impacted by the setting. The impact might have been based on the awareness or sensitivity, by both the participant and I, of others in the coffee shop. This awareness might have resulted in a lowering of the voice in response to the interview questions. This was mitigated by the volume control of the digital recording device being increased to fully capture what was being said for transcription purposes.

Additionally, the participants who were interviewed in my office may have found the setting less comfortable than if it were done in their home. Any such discomfort may have been mitigated by the fact that, in all three cases, we were in an office where the door could be closed and any distractions from others in the building could be isolated. I did not observe or measure any more discomfort from the office participants than with those who interviewed in their homes. Finally, one participant's CR was on the verge of passing away and did just that a week or so after the interview. The potential trauma from a pending death of the CR might have impacted the response of this particular family caregiver differently than those caregivers who were not experiencing the pending passing of their CR.

Participants' Demographics

The participants in this study consisted of formal and informal caregivers who were caring for people diagnosed with Alzheimer's disease or a related dementia. Informal caregivers were those who took care of a family member with ADRD in the home or who continued to care for the CR on some level if they were placed in an institution. The informal caregivers were not paid by an agency for the work that they performed. Furthermore, the informal caregivers usually received less training on how to do their job as the formal caregivers (Bookman & Harrington, 2007). Formal caregivers, on the other hand, were those who cared for ADRD CRS, but who had no familial connection. Additionally, the formal caregivers worked for an agency and were paid for the care that they rendered. Formal caregivers of ADRD individuals generally received more training on how to do their job than did the informal caregivers.

Other attributes of the study participants included gender and age. There were nine females and one male respondent. There was one couple participant unit (male and female), but the male deferred to the female for the responses and would only corroborate what the female partner said. Of the five informal family caregivers, four of them were females ranging in age from 34 to 77. The formal agency-provided caregivers were all females and ranged in age from 27 to 75. The CRs of the formal caregivers were either male or female and could alternate with changed assignments. These attributes are relevant to the study because they support the literature in Chapter 2 that suggests most formal and informal ADRD caregivers are women in their 40s and 50s and that few men are in the caregiving role for the study population (Bookman & Harrington, 2007). See Table 1 for visual clarity of the study's demographics.

Table 1
Demographics

Caregiver	Age	Gender of Caregiver	Gender of Care Recipient	Formal/Informal
CG#1	46	Female	Male	Informal
CG#2	77	Female	Male	Informal
CG#3	62	Male	Female	Informal
CG#4	34	Female	Female	Informal
CG#5	57	Female	Male	Informal
CG#6	35	Female	Male and Female	Formal
CG#7	32	Female	Male and Female	Formal
CG#8	32	Female	Male and Female	Formal
CG#9	27	Female	Male and Female	Formal
CG#10	75	Female	Male and Female	Formal

Data Collection

This study's data collection process commenced with approval from Walden University's IRB. The New Mexico chapter of the National Alzheimer's Association was the source for recruitment. The Albuquerque Regional Manager for the association had signed a letter of cooperation agreeing to allow recruitment of study respondents through that agency. After IRB approval to proceed was obtained, the regional manager invited me to present the study to a group of formal and informal caregivers gathered for educational support and to ask if any of them wished to participate in the study. A flyer was also given to some participants to disseminate to other potential caregiving participants. The regional manager also took a flyer and placed it at his agency. Additionally, the manager gave me the contact information for the association's affiliate home health care units to request additional participants if needed. All study participants came through the New Mexico Alzheimer's Association as per IRB-approved recruitment protocol. Potential participants from the agency who expressed an interest in participating were given a flyer and a consent form (Appendix A) to fully inform them of the study selection criteria, what the study was about, and a section for their consent. Some participants decided to participate in the study immediately after hearing me describe it, and others called me later to enquire of the next steps for them to participate. In either case, participants were given consent forms to review again and to sign it if they were committed to participating. Some consent forms were signed before an appointed place and time for an interview was decided upon, and others were signed immediately before the interview commenced. Participants were also asked again, before the study started, if they believed they met the selection criteria as outlined in the consent form and the recruitment flyer. The recruitment process ended when I obtained five informal family caregivers and five formal caregivers who agreed and committed to participate in the study. When signed consent forms were obtained, the respondents were given a copy for their records.

The study included 10 participants who were interviewed between December 2, 2014 and December 30, 2014. Before questions began, participants were informed that they would be asked eight guiding questions to understand their experiences as a formal or informal ADRD caregiver and what they thought the state or government could do to support them in their caregiver role. They were also informed that they could stop the interview process at any time if they were experiencing any discomfort from the questions.

Furthermore, respondents were told that they could refuse to answer any question, and no explanation would be required of them. Additionally, they were asked, before questions started, if they had any other questions or concerns. All respondents were willing to get started and none discontinued the interviews or refused to answer any of the questions. All 10 participants were asked variations of the same eight semistructured guiding questions with prompts (See Appendix E). The way the questions were asked was varied to ensure that each participant understood what was being asked so he or she could adequately address the main research questions. Respondents were told, and often reminded, during the interview that there was no right or wrong answers to their responses. An example of a varied or prompted question is the following: Given your experience as an informal caregiver of a patient with ADRD, can you tell me more about what the state or government can do to better support you?

Additionally, I took field notes that captured my observation of nonverbal cues and responses that stood out to me. For example, CG#4 stood out in that the digital recorder bothered her. Even though she consented to being recorded, she admitted at the end of the interview that knowing the recorder was running made her nervous. The longest interview lasted 46 minutes, and the shortest one was 11 minutes. There was minimal need for additional postinterview member checking as I did much clarifying with the respondents during the interviews. I did ask permission of each respondent to contact him or her if I found the need for additional clarity of their response during the transcription and data analysis process. All participants gave me permission to contact them by phone if needed. Only CG#9 was contacted to give me her age because it was missed on the demographic form that I completed for each participant before the interviews began. The data collection phase presented no deviation from the plan as described in Chapter 3. The only unusual circumstance was that CG#2 lost her CR to death within 2 weeks of the interview. I became aware of the information from an indirect source and struggled with whether I should contact her, given the new circumstances. This caregiver was happy to share her experience to benefit others. Because of her enthusiasm, I was interested in knowing how she was doing after the passing of her CR. I did call her and left a message of condolence encouraging her to call me back if I could be of any assistance. She did not return my call. While it did not impact the data collection process, as she had already given her responses to the research questions, it did make it necessary to do a member check to assess and address any psychosocial issues that may have resulted and to give her referrals to grief counseling if she desired. This outreach was an act of giving back to the caregiver, as suggested by (Creswell, 2007).

Data Analysis

The data analyzed for the study were the 10 recorded and transcribed responses to the interview guide questions. Collected data yielded 218 minutes of recorded data and 1,937 lines of transcribed data. DCA and NVivo 10 QDA software was used to capture the emergent themes that derived from the data and the RCT and PST conceptual frameworks that were used in the study. Open manual coding was used to reduce the collected data into smaller manageable sets of themes that were descriptive of the formal and informal ADRD caregiver phenomena. All identified text that coincided with the four main research questions and the eight semistructured guide questions were highlighted and categorized for further analysis. Additionally, Creswell's (2009) six-step plan for data analysis, as described in Chapter 3, was used to assist in the data analysis process. In the process, the interview data were analyzed using the following modification of Creswell's six-step step plan:

1. Data were organized and transcribed verbatim so I could visually scan and sort the text for deeper analysis
2. Data were read and listened to over and over to gain a general sense and overall meaning of the material
3. Detailed analysis occurred by organization of material into meaningful data segments and categories
4. Descriptions of themes, settings, and categories were generated for analysis
5. Identified themes were stored in the data management software for further management and discussion in the study narrative
6. Interpretation of the meaning of the data was made for write up in Chapter 5

Adherence to this process allowed me to gain intimate experience with the data. It also provided for a more efficient means of data analysis.

Codes, Categories, and Discovery of Emergent Themes

In phenomenological data analysis, while QDA software can be helpful in the storage and management of recorded and transcribed data, it is still the responsibility of the researcher to discover, code, categorize, and interpret the themes (Creswell, 2009). To initiate the coding, categorizing, and theme finding process, I had to unbracket myself as the researcher. Bracketing, as discussed in Chapter 3, means that the researcher suspends his or her preconceived notions, biases, and expertise about the study topic and is as objective as possible while collecting the data (Creswell, 2009). Bracketing allows the researcher to be an objective listener and observer of the phenomenon while collecting data. While bracketing keeps the researcher in an objective listening mode, it does not serve well when the gathered information needs to be analyzed and interpreted. When coding and categorizing, the researcher has understand the topic as presented by the previewed literature and his or her own expertise on the topic in order to understand what themes and categories to pull from the data. As the primary research instrument, I went over the transcribed data line-by-line to see what responses aligned with the four major research questions. Additionally, I looked for words that repeated themselves, concepts that surprised me or stood out in a particular response, what the respondent stated was important, what might have been stated in the literature review in Chapter 2, and what may have reminded me of the two theories of the study's conceptual framework. I went over each of the 10 individual interviews with these questions in mind.

The method used for coding and identifying themes was a combination of manual coding and verifying with the Nvivo 10 software. After a visual identification of recurrent words and phrases, I used the Nvivo 10 software to do word and phrase frequency queries throughout all of the transcribed data. This dual approach served to confirm or disconfirm some of my findings. An example of this was the words frustrating, frustrated, or frustration as it related to the caregiving experience. I believed that all 10 of the respondents used this concept in describing their experience. A closer look at the data by the Nvivo word query revealed that the frequency in my mind did not match the actual word count frequency in the data. Where I was under the impression that the term was used multiple times and by all caregivers, it was only used by CGs #1, #3, and #5. On the other hand, the term rewarding had a much higher frequency and characterized the ADRD caregiving experience for seven out of the 10 respondents (CGs #1, 3, 4, 5, 6, 7, and 9). This was contrary to the frequency that I had in mind. Such cross checking helped me to understand how I could be biased in my interpreting of the data. In this case, the software revealed a potential preconceived idea on my part that the experience of ADRD caregivers is more frustrating than rewarding when, in reality, the opposite seems was the case.

As I sought to capture the individual and collectively lived and shared experiences of formal and informal ADRD caregivers, it was appropriate for me to look at what was emphasized as important to them in their responses. Field notes containing respondents' observed expressions, and my impressions of what they emphasized, were consulted to give support to what I thought was important. I considered the idea of what their freshly captured insight and experience could add to the existing knowledge of the phenomenon. With this filter and sensitivity, I read and reviewed the data in an unbracketed frame of mind.

I then gathered the various recurrent thoughts, phrases, and concepts highlighted from the text and placed them in nodes within the Nvivo software. Nodes are containers or bins into which identified words, concepts, or themes can be placed or indexed for future retrieval and analysis (*NVivo 9 Tutorial*, 2011). The following are some examples of identified words, phrases, and categories that were highlighted for deeper analysis of their meanings and main themes of the study:

- Needs of formal and informal caregivers
- More information and education
- Respite
- Support
- More resources
- Help for caregivers at different stages of the disease
- Certification and accreditation is needed

Experiences of formal and informal caregivers included the following:

- Difficulty of caregiving
- Each case of ADRD is different
- Frustration/frustrated
- Rewarding experience
- Stress

- Lack of self-care
- Health issues around caregiving
- Financial difficulty or devastation
- CR wants to stay at home

What policymakers need to do to support formal and informal ADD caregivers is included below:

- More information and education
- Help for caregivers at different stages of the disease
- Certification and accreditation
- Policies to keep CR at home in the community

These words and phrases from the transcribed data represent the overall impression of both the formal and informal ADRD caregiver experience and what they emphasized policymakers need to do to support them in their caregiving needs (see Questions 7 and 8 of Appendix E).

Qualitative data analysis does not include firm guidelines related to method of interpretation, coding, or extraction of themes from the data (Creswell, 2007). Therefore, the identified words, phrases, and concepts are a broad representation of the lived and shared experiences of the informal and formal ADRD caregivers interviewed for the study. Table 2 categorizes some of the individual responses to the caregivers’ subjective experiences, barriers to their caregiving, and their thoughts on what policymakers need to do to improve those experiences:

Table 2

Individual Caregivers' Experiences, Barriers/Needs, Policymakers' Responsibility

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG1 Informal	Experiences • Difficulty with ADLs for CR (physical, emotional and financial burden and stress of care) • Decision to keep at home is to improve quality of life (QOL) Barriers/Needs • Has her own medical/mental health issues and no insurance • Does not want to institutionalize CR Government Responsibility • Needs more support from government (e.g., Tax breaks, better insurance, long-term Care funding)	CG was emotional and emphatic often to the point of tears when making these statements.
CG2 Informal	Experiences • Physical burden is decreased but emotional is still high • CG feels as much risk to health as CR • Decision to institutionalize was to improve QOL for both Barriers/Needs • Lack of awareness and education about the disease for CR is needed Government Responsibilities • Facilities and formal caregivers need to be certified-accredited	CG is at peace that CR is in institution but is still emotionally burdened and engaged by CG responsibilities. Emphasis is placed on the need to look at the declining health of the CG relative to the CR.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
G3 Informal	Experiences • Experience is like parenting an old child • Emotionally demanding (frustrating and rewarding) Barriers/Needs • Need for respite even though he is paying for extra help Government Responsibility • Training for agency caregivers needed (that this informal CG is speaking to the need for training for formal CG speaks to where the two overlap)	This is the only male caregiver in the study. CG is relaxed, thoughtful, animated, and engaging throughout.
CG4 Informal	Experiences • Caregiving is difficult and ADLs are time consuming • CG is not trained • Needs more education and knowledge of the disease at various stages • Multiple loss of relatives with attending grief issues Barriers/Needs • CG is concerned that, while her family can cover the 24/7 care needed for CR, there are not enough resources for other caregivers who are stressed because they cannot quit their jobs to care for CR Government Responsibility • It's better to have family members care for CR but there are no incentives	CG is thoughtful but is a bit unsure of how she should respond to questions. She later said she was nervous because of the recording device.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG5 Informal	Experiences • CG's CR has early or younger onset which she feels makes her caregiving different and more difficult than the others in her cohort • She does not want to place him because it would be financially devastating Barriers/Needs • She needs training, education, and information to deal with caregiving at each stage of the disease Government Responsibility • She needs more community and personal care services • She believes there should be more funding for Alzheimer's Association so they can give out more CG respite vouchers • perhaps some sort of tax break	CG is quite distressed and emotional (tearful) throughout the interview. Debriefing with the CG post interview gave her a better sense of direction, hope, and calm.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG6 Formal	Experiences • Formal caregivers are professional, experienced, accountable, and insured • doing good and contributing to others • Putting something in the Karma jar • Giving dignity to Care Recipient • Paid well • Inequity in pay across caregiver continuum • Co-dependencies in both Caregiver and Care Recipient • Maintaining balance to keep Care Recipient trusting Barriers/Needs • Not having enough information for different stages/types of ADRD • More pay for formal Caregivers • Grief Counseling • More free information clinics • Outreach to older Care Recipient • Working w/Medical Team: Doctors, Resources • Limited in what she can tell clients of what would be in their best interest Government Responsibility • Paying Caregiver more for work they do • $7.00-$8.00/hour for back breaking work when employer or Agency gets $5,000/month per Care Recipient	Caregiver was professional, passionate, and confident throughout interview. It is my impression that she is an advocate for certification and higher pay for care.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
G7 Formal	Experiences • It is difficult "When they can't do anymore for themselves as they go through the various stages" • I need to have patience • Watching the progression of decline in ADLs • "Sad, Sad, but rewarding that I'm there to Help" Barriers/Needs • Not knowing what to do as stages progress Government Responsibility • More education needed • More classes, informational material • One-on-one teaching	Caregiver was nervous throughout interview but was sure of her thoughts as they relate to what she felt was needed from policymakers.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG8 Formal	Experiences • Assessing client needs and assisting with ADLs • "I am . . . happy that I work with an agency. . . . They provide training." • Other caregivers are not all trained at the same level • Client's reactions to drugs can influence the way caregiver experiences caregiving Barriers/Needs • "Working with dementia requires a lot of understanding about the disease" • Training needs to be extended beyond classroom • Agencies not matching up caregivers with the right client Government Responsibility • Allow for certification and better training of caregivers • "So, I would say that training is very important!" • Training should be on the job and not just in the classroom	Caregiver is very excited, professional and positive about participating and sharing her insights. She is expressive and gesticulates much.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG9 Formal	Experiences • Assist with ADLs, medication management • Thankful for CNA certification • She feels more experienced than informal caregivers but disempowered because she can't make decisions on the client's behalf as a family member could • She collaborates with other caregivers and asks for help • Experience is rewarding because she is there to give companionship Barriers/Needs • Disempowered since she's not a family member • Can only do what staff at facility tells her Government Responsibility • More funding for respite for caregivers • One-on-one patient to staff ratios needed • More CNA caregivers needed	Caregiver is comfortable and settled in her role as a caregiver. She is thoughtful about her responses.

ADRD Caregiver	Experiences, Barriers/Needs, Policymakers' Responsibility	Field Note Observation
CG10 Formal	Experiences • She lives to empower and give dignity to care recipients • Her clients are well taken care of because her goal is to keep them safe • They need resources • All caregivers are loving, caring and are in it to help someone • She gets more out of giving care. Barriers/Needs • Isolation of older care recipients • Older people living alone in their homes while becoming more demented should be a concern for everyone Government Responsibility • One-on-one care should be expanded (lower staff to client ratios) in facilities • Give care recipients more access to senior centers • Get government agencies like Adult Proactive Services involved in finding isolated ADRD clients	Caregiver is generally happy about the care she gives and personal benefits she gets from giving care. It is my impression that her clientele are older and more isolated. She is also emotionally (tearful) connected to ADRD caregiving because her mother died of Alzheimer's. Caregiver is concerned about clients in and out of facilities.CG is seasoned.

Field note observations are included in Table 2 to capture the emphasis on individual themes where noted. Table 2 is not exhaustive of salient themes, but rather captures some of the statements that respond to the general research query and how the statements aided in the development of the major themes by their connection to the four research questions and the overall phenomenon of ADRD caregiving.

Development of Major Themes

While it is typical for qualitative studies to have many themes emerge from the data analysis process, distilling them down to five or six is the preferred method of theme development (Creswell, 2009). As is typical with qualitative studies, many themes could have been highlighted. However, I narrowed emerging thoughts down to one, which captured the phenomenon of the caregiving experience, and four other themes that were directly connected to the four research questions. The inductive process used to move the codes and categories of Table 2, from their coded units to the larger themes developed from the data, was a combination of the manual DCA method and the NVivo10 software. I placed the response to each of the interview questions in a node container that related to each of the four research questions. For example, all responses to Interview Questions 1 and 2 (IQ1, IQ2) were placed in a node labeled Construct of Informal and Formal ADRD Caregiver. RQ #1 was designed to capture what constituted a formal or informal ADRD caregiver. Likewise, RQ #2, which corresponded with IQ3 and IQ4, was designed to capture responses about the lived and shared experiences of the ADRD caregiver. Similarly, RQ #3 coincided with IQ5 and IQ6, which sought to understand the situations that influenced daily experiences of the ADRD caregiver. Lastly, RQ #4 related to

IQ7and IQ8 to gather responses about what state policymakers could do to improve and support the ADRD caregiver experience. Once these correlations were categorized in the various nodes, I was able to identify the predominant concepts that reoccurred in at least 30% of the formal and informal caregiver respondents. I then coded each outstanding concept as a theme that I felt represented the majority of the respondents' views on the particular RQ. For example, in IQ1 and IQ2, under the RQ #1 construct of what constitutes a formal or informal ADRD caregiver, nine caregivers felt that the caregiving experience included assisting CRs with their ADLs. CG# 2, who had to place her husband in a facility at the latter stage of the caregiving journey, was the only one who did not consider her experience as handling too much direct ADL care. The following statement from CG# 2 is her thoughts on why she is the exception to the ADL construct:

> I don't have to deal with the physical things when he was home. He's 6'2" and a big guy. He was beyond [my ability] and I was hiring 2 people to help me get him up and dressed and fed at home. So that piece is really helpful. I don't have the physical caring part, um ... but I feel that I'm monitoring his care, I'm there when he's … he has some wounds, some pressure wounds. ...I'm there when he's dressed, I take pictures, I keep on top of what's going on. I see what he's been fed; I'm monitoring what goes on, so I'm still very much emotionally caregiving. Physically not so much, it was beyond what I could physically do, but I'm still there in terms of mentally being a part of his life.

With this understanding, I coded this as ADLs and incorporated it into the theme of construct of the formal and informal ADRD caregiver. This process was repeated until the rest of the major themes were developed. The five major themes that emerged from the study were (a) the phenomenon of ADRD caregiving, (b) the construct of an informal or formal ADRD caregiver, (c) shared and lived experiences of formal and informal ADRD caregivers, (d) situations that influence the experiences of formal and informal ADRD caregivers, and (e) what policymakers need to do to improve the experiences of formal and informal ADRD caregivers. These themes, categorized in Table 3, also correlate to the four research questions that came from the main question that I sought to answer and will be discussed later on in the chapter.

Table 3

Five Main Themes and Percentage of Contribution

Main Themes	Respondents	%
Phenomenon of ADRD Caregiving	10	100%
Construct of Formal and Informal (F/I) Caregiver (CG)	10	100%
Shared and Lived Experiences of Formal and Informal ADRD CG	10	100%
Situations that Influence Experience of F/I ADRD CG	10	100%
What Policymakers need to do to Support F/I ADRD CG	10	100%

How Discrepant Cases Factored into Analysis

The presentation of negative or discrepant cases can aid in providing credibility and realistic validity to qualitative research (Creswell, 2009)**.** This occurs as the researcher presents information that is contradictory to the themes and premise of the study (Creswell, 2009). CG #2 in the study said, “Well, what you learn is that if you know someone with Alzheimer’s, you know one person with Alzheimer’s. They’re not the same.” Each case of ADRD is different, and the caregiving experience for each will be likewise different. Each caregiver experience could be a discrepant case. In factoring discrepant cases into the analysis, I looked for those statements that were most different from the majority of respondents and the premise of the study as reviewed in the literature. Moreover, as in real life, multiple individuals do not always have the same perspective about a particular topic and will often share that difference with others. In this study, CG #2, CG #3, and CG #5 all had responses to various interview questions that appeared different in perspective from the other participants of the study. Therefore, the primary criterion for a discrepant case was if one or two respondents out of the 10 gave a contradicting or differing response from the other eight or nine. This resulted in statements that were strongly felt by the respondent as important to them and statements that I felt gave additional or different meanings to the study’s research questions and premise. There will be a further discussion of the discrepant cases with an attending table of statements in the section of the chapter that addresses major themes.

Evidence of Trustworthiness

The trustworthiness of qualitative studies is evaluated by four domains: credibility, transferability, dependability, and confirmability (Creswell, 2007). All four of these domains of reliability and validity are explained here. The data collection and analysis process as presented in the study could be audited to determine if there was any researcher bias or inconsistencies. For credibility, transferability, dependability, and confirmability, I will explain how they are evaluated in the study.

Credibility

The criteria of credibility establishes whether or not, from the participants' point of view, the results of the qualitative study are believable or credible (Onwuegbuzie & Leech, 2007). Because the purpose of this qualitative study was to understand the phenomenon of the ADRD caregiver from the respondents' viewpoint, only the respondents of the study can legitimately confirm the credibility of the results. As presented in Chapter 3, this is the criterion of reliability that was most likely to be violated, and to address that issue, I clarified as many of the respondents' statements during the study as was reasonable. Checking back with participants when there was a concern regarding what they said or information that they may have left out was also done as necessary. For example, I missed asking CG #9 her age in the demographic questionnaire before the interview questions commenced. I was able to call her back to get that information and not rely on my own prediction of her age. All study participants gave me permission to call back and verify their data if I had concerns about credibility. During the analysis process, I was mindful of this open door to check-in with the respondents as needed. By this awareness, my own integrity as a researcher added to the credibility.

Transferability

Transferability is the responsibility of the individual doing the transfer or generalization of the resultant data to another context. In the context of this study, I attempted to enhance the transferability of the study results by giving as rich a textural description of the process and the results obtained as possible (Trochim, 2006). Furthermore, transferability can mean that connections could be made between portions of the experiences of participants of this study with caregivers outside of the study. However, the size of the study sample and the lack of representative sampling make it insufficient for generalizability. Therefore, the rich textural descriptions of the emergent themes and my own ethical concerns as a researcher can serve to make the results transferable (Onwuegbuzie & Leech, 2007, p. 238).

Dependability

There is no research design that can guarantee the trustworthiness of collected data (Onwuegbuzie & Leech, 2007). Dependability, in qualitative research, references the trustworthy repeatability of the research by another researcher. Because qualitative studies are not amenable to repeatability due to the changing context of the research and its participants, it is the responsibility of the researcher to describe and disclose whatever changes have occurred in the research process and setting that may have had an impact on how the study was accomplished. In the case of this study, there was no major change from the proposed methodology in Chapter 3 to the actual data collection and analysis processes. The one change that could be noted is the fact that I proposed to have all of the data transcribed by a paid transcriber. This did not occur completely because the paid transcriber completed four of the 10 recorded data sets, and I completed six of the 10 data sets. While verbatim transcription should not allow for much deviation from original data between transcribers, my understanding of the research topic and my direct involvement in the data collection process could differ from the paid nonresearcher transcriber and could generate some deviation in transcription. To mitigate against this possibility, I went over the four data sets transcribed by the paid transcriber several times, some with the paid transcriber and some by myself, to ensure that what was said by the respondents on the recording did match what was transcribed verbatim. By going over the four pieces of data that were not transcribed by me, and making minor adjustments and corrections to what was on the recording, it gave me an opportunity to further immerse myself in the data and get a more accurate view for interpretation to enhance the dependability of the study.

The study was conducted as approved by the Walden University IRB. The best way to determine dependability at this point is to assess the data gathering and analysis process to verify if mistakes were made in translating raw data into themes. For example, if there were errors made in data transcription that could alter the meaning of a respondent's statements, this could affect dependability. By frequently going over the digitally recorded data in concert with the transcribed data to catch and correct transcription errors, I was able to improve upon dependability.

Confirmability

Confirmability in qualitative research connotes the degree to which others can confirm the study's results as being objective. Steps taken to ensure confirmability in this study included the following: First, during the data collection process, I used the bracketing technique as described in Chapter 3. This was done to isolate my biases, my personal opinions, and my expertise on the topic from the study participants' responses about the ADRD caregiving phenomenon. Additionally, I spent many hours reviewing the audio recordings and going over the transcriptions of each individual caregiver to ensure that the data as captured matched the data as transcribed. Furthermore, I identified, listed, and expounded on the main themes of the study, as well as the discrepant cases. Finally, I used both manual DCA coding and the QDA software NVivo 10 to confirm and crosscheck results, themes, and interpretations. These actions required exposure to the raw data and enabled a certain saturation of responses for me as the primary confirming research instrument.

Results by Main Themes

The main research question was used to explore how public policy (policymakers) can improve the experiences of formal and informal ADRD caregivers. The four subsequent research questions that flowed from the main question were the following: (a) What constitutes the construct of the formal and informal caregiver? (b) What are the shared and lived experiences of formal and informal ADRD caregivers? (c) What situations have influenced the experience of formal and informal ADRD caregivers? And (d) What can state policymakers do to better support formal and informal ADRD caregivers?

The resulting responses to these subsequent research questions became four of the primary themes of the study. The other theme that made up the five is the overall phenomenon of the ADRD caregiving experience. In this section of the study, I will address the phenomenon of the ADRD caregivers’ experiences and each research question. Each theme will be addressed, and a table will follow to indicate what the respondent said relative to the theme and what my interpretation is of what was said. Moreover, the tables will indicate field notes of the respondents' observed nonverbal responses to add further validity to indicate emphasis to the statements.

Phenomenon of Caregiving Experience

The first theme discussed is the phenomenon of the ADRD caregiving experience. This theme captures the overall experiences of the two types of caregivers in the study. Statements from all 10 respondents, as they responded to the eight interview questions, were consulted to capture this theme. Phrases such as difficult, frustrating, need more training and information, rewarding, giving dignity, different in each case, and not wanting to place CR in an institution were instrumental in substantiating this theme. While not exhaustive, Table 4 illustrates some of these thoughts and the impression they made on me in getting a general sense of the ADRD caregiver phenomenon.

The response for the theme phenomenon of ADRD caregiving came out of RQ 1-3 and IQ 1-8. The quotations in Table 4 below capture some of the difficulties that ADRD caregivers faced in their daily giving of care. Issues of their own health failing, the frustration and reward of caregiving, and the need for respite in the caregiving process were prominent concerns in the overall phenomenon of their experiences.

Table 4

Phenomenon of ADRD Caregiving (Interview Questions 1-8)

Participant Statement	Interpretation	Observation
CG #2 responses to IQ4: (Your shared or different experience with other ADRD CGs?) CG: Well, what you learn is that if you know someone with Alzheimer's, you know *one person* with Alzheimer's. They're not the same.	Each experience of caregiving is different and unique to the particular caregiver and any attempt to make the experience a singular one will not be sustainable. This thought seems to be mentioned by other CGs.	Respondent makes direct eye contact when making this statement.
CG #3 responses to IQ3: (Your general daily experience as ADRD CG?) It's simultaneously rewarding and frustrating experience. Um . . . It's got good moments and terrible moments and you go through the whole gamut of feelings I guess. It's pretty much going back to parenting. You're taking care of a child. . . . an old child.	The ADRD CG experience can be Difficult, frustrating, and rewarding.	Respondent is thoughtful, focused and animated. At times he uses humor.
CG #1 response to IQ3: Sometimes it's very difficult and sometimes it's very rewarding in the fact to see him smile and be happy and doing things within his limits of what he can do fun things. Most times it is very hard. The memory is dissipating and his care takes a little bit longer because he cannot remember how to do something. He gets frustrated. I just have to talk him and walk him through it and it usually works out ok. The hard part is he has a tendency at 7 o'clock every evening he rages out for no apparent reason.	This caregiver is more specific about the rewards and difficulty of giving care to an ADRD care recipient.	This caregiver is emotionally labile throughout interview process. I sense a plea for help on many levels.
CG #1 responses to IQ7 and IQ8: Losing my insurance, I have had Bipolar since . . . I was 15. . . . I have been on the same regimen of	CG's compounded healthcare issues adds to the difficulty of	CG is rapidly speaking and may be in a

Participant Statement	Interpretation	Observation
medications for about 12 years and they are working for me. . . . I am pretty stable, have not been hospitalized, haven't [got] nothing except for respite care. When they put him in [the hospital] they let me respite care. . . . That was the only way that my doctor could see that it would work for me to get some respite care. So I can take care of him, if I don't have my bipolar medicines I can't even take care of myself. It's depressive. You know way depressive. Sometimes manic where it's just crazy off to the other end so he needs me here so I can take care of him. . . . So either I'm depressed or I'm gone, you know manic. And I'm not focused or being able to um . . . keep up as much as I do around here. It's really dusty! But there's [there are] other things that interfere too. . . . And I think how can I take care of him if I'm not well? I have other issues. I have a kidney that needs a biopsy I can't get done. There's no way I can afford that. I have injections that need to be in my lower 4, lower 3 vertebrae's in my back from picking him up out of the bathtub because he fell.	caregiving.	manic mode at this time but she is staying on task.
CG #2 responses to IQ2: It was basically the physical aspect of caring that I couldn't do it. . . . I had him in the emergency room a couple of times. I think what we know now is that caregivers are in [health] danger as much as the person and what happened with me is I took him to Share Your Care [senior day care] went back to the car and felt really heavy, yet that was my time to do errands. So I went uptown to pick up a racing shirt for my granddaughter and I started getting woozy so I came home and googled women's heart attacks.	Caregivers are concerned that their health will be failing along with the care recipient's health.	CG is concerned for herself and other ADRD caregiver's health.

Participant Statement	Interpretation	Observation
CG #5 responses to IQ7 and IQ8: So . . . for me it was really difficult because I was at that time too, battling cancer. So . . . what made me realize he was really sick was when I got cancer.		CG is animated and advocating for formal caregivers.
CG #6 responses to IQ7 and IQ8: Yes . . . and I was just thinking about this, like I said before I just lost a client and I haven't been able to talk to my bosses about this. And so I think they would be more than willing to provide this if I would ask . . . but maybe some grief counseling? I do have a counselor that I see but that's on my own . . . for those that don't because I work for an agency, and we barely got health insurance, but for people that don't . . . working through that [grief and loss]. I mean gosh, my boss is a social worker so I'm sure that we could just sit down and talk about this stuff . . . support that way		

The theme of the phenomenon of ADRD caregiving also corroborates the reviewed literature that categorizes the experience of ADRD caregiving as more difficult than caregiving of other chronic disabilities (Miller et al., 2009).

Construct of the Formal and Informal Caregiver

While the phenomenon of ADRD caregiving is a theme that stands alone as a general overview of the respondents' experiences, it also captures the four subsequent research questions that comprise the additional four themes. The theme construct of formal and informal ADRD caregiver was developed out of RQ1 and IQ1 and IQ2. The respondents' quoted statements were selected because they best fit and captured what the other respondents in the study contributed to the ADRD caregiver construct. There might be a temptation to consider the construct of the ADRD caregiver as being the same as the phenomenon of the ADRD caregiver, but a closer look should reveal that they are two different themes. For example, the caregivers quoted in Table 5 all felt that an ADRD caregiver, whether formal or informal, had to assist the client with their ADLs. On the other hand, the phenomenon of the ADRD caregiver was more about the caregiver's general sense of gain and loss around the caregiving experience. The frequency of concepts such as rewarding or frustrating was used in developing the theme and addressed the RCT framework that partially undergirds the study.

The construct of the formal and informal ADRD caregiver came primarily out of my analysis of RQ1, IQ1, and IQ2 responses and the NVivo 10 data and transcripts. This theme not only defines each type of caregiver, but it draws a distinction between the formal and informal ADRD caregiver. Primarily, the formal caregiver group is paid by an agency, and the informal is not compensated monetarily, but often is experiencing added cost and loss of income in order to continue their caregiving. The following quote by informal CG #3 bears this out:

> And I'm not working right now because I'm taking care of her. Right? If I wasn't taking care of her, I would be working and I would be paying taxes and I would be hiring somebody to take care of her who would be paying taxes as well.

The theme also captures the notion that formal caregivers are more trained and supported by the agency they work for than the informal caregiver. Table 5 includes the number of other caregivers who had similar statements and sentiments as the presented participants' statements. Note that only three respondents shared a particular thought or statement. As was mentioned earlier in the chapter, this frequency of at least 30 % of the respondents sharing similar thoughts aided in the process of developing the themes.

Table 5
Construct of Formal and Informal ADRD Caregiver (RQ1, IQ1, and IQ2

Participant Statement	Interpretation	Observation
In response to IQ1 and IQ2 the CGs made the following statements: CG #1: I am not formal; I am not authoritarian or licensed. I am not licensed.	Formal and informal CGs are fully aware of the distinction between each other. Informal CGs are usually family members as the literature suggests.	All CGs are quick in their responses about the difference between themselves and the other type of CG.
CG #3 in response to IQ1: Yes, I consider myself an informal caregiver, I am the son-in-law of the person with the condition and um . . . the way that I pass my daily activities is my time is dedicated primarily to her care. And my roles include everything from um . . . feeding to medicating, help with toilet, dressing, um . . . companionship and just sometimes just sitting there listening, sometimes just sitting there. Just being there. And also, all of the doctor's appointments and hold on one second. . . . I need to get something.	Formal CGs in this study appear to be less stressed and burdened than the informal CGs. Other CGs with similar thoughts: All five formal CG distinguished themselves from the informal and all informal CGs felt their roles were different from the formal CGs.	
CG #5 in response to IQ2: I mean you really need specific training. RR: So you would say that a formal caregiver is more one that's trained? CG #5: Yes. Absolutely!!	Formal caregivers are more trained and supported. Other CGs with similar thoughts: CG #2, CG #4, CG #6 – CG #10.	CG is very emphatic about this response.

Participant Statement	Interpretation	Observation
CG #1 in response to IQ2: My main goal at home is to keep him out of the hospital, keep him at home, comfortable as much as possible and safe.” “He’s going to end up in a home or hospital and that’s not what we want for J-.	Both formal and informal CGs would prefer to care for CR in their home and in their community rather than in an institution.	CGs have no particularly outstanding emphasis.
CG #4 in response to IQ2: Like . . . my mom said that this is her gift to her mom. To take care of her and be there for her – she will never go into a nursing home. Yet my mom has had a lot of struggles to finding her durable medical equipment.	Other CGs with similar thoughts: CG #6, CG #8, CG #10.	
CG #5 in response to IQ2: If he gets very sick and I have to place him in a home, which I don’t want to do, we will be financially devastated because he’s going to run about $4000 or $5000.		

Shared and Lived Experiences of Formal and Informal Caregivers

The theme, the shared and lived experiences of formal and informal ADRD caregivers, captures the things that both groups of caregivers had in common. In reviewing the data for this theme of shared experience, both groups seemed to feel the need to have more oversight and regulation of facilities. For the formal caregivers who may work in facilities, it could be understandable. Informal caregivers, on the other hand, would have infrequent encounters with facilities except when they may put a CR in for respite or if someone was sent from a facility agency to render care in the home. The reason for why informal caregivers desire to see agencies regulated and given more oversight is not clear and is not something that was reviewed in the literature of this study. The trained formal caregiver also felt the need for more training. This is surprising because all formal caregivers acknowledged that they did receive training through their agencies. It is, however, noteworthy that they did not feel the training they received was sufficient for them to do their best at their caregiving tasks.

Table 6

Shared and Lived Experience of Formal and Informal ADRD CG (RQ2, IQ3 and IQ4)

Participant Statement	Interpretation	Observation
CG #6 response to IQ3: Some barriers have been not communicating this [the different types and stages of dementia] properly. Not [giving us an opportunity to shadow] properly [but] throwing us into [a situation] that we don’t know anything about.	Both groups feel they need more training and education, particularly to deal with each stage of their caregiving journey.	CG is Thoughtful and serious. CG makes eye contact.
CG #7 response to IQ3: Some of it can be difficult, challenging, depending on the stage that they are in. . . . But it’s very rewarding, you get to learn from them and from everything going on. Um, I don’t know, it’s just a really good experience.	Other CGs with similar thoughts: CG #4, CG #5.	
CG #10 response to IQ3: I understand that and know that that’s part of the reason it’s like that [smells bad]. But you don’t see that in the [Care recipient’s] homes. RR: So your experience in the home is a much cleaner? CG #10 response to IQ4: Because it’s a one-on-one type of thing. You know, you’re . . . sometimes you might have a husband and wife that you’re together but I’ve still never experienced bad care.	Most feel that care recipients are better off cared for at home in the community than institutionalized. Other CGs with similar thoughts: CG #1, CG #2, CG #3, CG #4, CG #5, CG #6.	CG is animated and emphatic about this point.

Participant Statement	Interpretation	Observation
CG #2 response to IQ3: I think we need to be a little more careful about. . . .I'm looking for the right word . . . accrediting facilities. Being sure they are doing what they say they are doing	A sense that facilities should be better regulated and monitored to see if they are rendering good care to ADRD patients. Other CGs with similar thoughts: CG #3, CG #6, CG #9, CG #10.	CG is thoughtful and serious about this point.
CG #4 response to IQ4: But a lot of people um . . . they can't quit their jobs, they can't lose their health insurance. . . . It causes depression for the other caretakers. Anxiety. Depression. You know everything is stress. Stress is the main key and there's no services other than support groups, but . . . for uh, a caretaker to come in to the home you don't know . . . it's very difficult because the person with the Alzheimer's doesn't understand what's going on so they were not able to tell you if they are not safe.	Stress and the need for self-care is shared by some CGs in both groups. Other CGs with similar thoughts: CG #2, CG #5, CG #7.	CG's posture is concerned and advocating.

Situations that Influence Experiences of Formal and Informal Caregivers

In reviewing the data, this theme surfaced out of the responses of all study participants. The most prominent response by virtue of frequency of respondents was the need for support and self-care. The lack or presence of support and self-care was the primary situation that made the caregiving experiences either positive or negative.

Table 7

Experiences of Formal and Informal ADRD CG (RQ3,IQ5, and IQ6

Participant Statement	Interpretation	Observation
CG #4 in response to IQ6: Definitely resources . . . it's hard to find the durable medical equipment for her . . . a lack of understanding. Um . . . time . . . that's pretty much it. CG#4 reiterated this point in in response to IQ7 and IQ8: Um . . . more support groups, um . . . resources, I mean, there's a tremendous lack of resources for this disease. I feel . . . people that are extremely overwhelmed – they are the main caretaker. What do they do for themselves? [Clarification question from RR]: RR: It sounds like if there were resources that could help you at each stage to help you understand what you could do to help her that would be a good thing? CG #4: Yes!!	Lack of adequate resources, but CGs are not always clear what the resources should be. Other CGs with similar thoughts: CG #6, CG #10.	CGs are thoughtful but not able to come up with specifics of needed resources.
CG #5 in response to IQ6 and alluded to in IQ3 response because of his illness, how are we going to make ends meet? Financially, although he has a great retirement plan and a great social security. I'm unemployed as I'm battling cancer. So mostly the devastation is financial at the moment wondering how we're gonna get through this to get the stability.	Financial devastation does and can impact caregiving. Other CGs with similar thoughts: CG #1, CG #3.	CG is very emotional and expressive throughout the interview
CG #2 in response to IQ5 and reflected in IQ3: So, something has to be [more supportive groups] there has to be more models, more options, options is a good word. . . . Our church has formed	Need for more Support groups and self-care Other CGs with similar thoughts: CG #4, CG #5,	CG is excited to tell of a self-initiated support

Participant Statement	Interpretation	Observation
something called the Memory Café because we saw there were enough people in that church had memory issues that we needed to do something. So, we meet once a month and it's on a model that we found on the computer that was from England actually. Um . . . It's a time that you just say to everyone come and be family with us. And so, husbands and wives, and sometimes children come and we make things together, we sing songs together. It's not heavy at all. It's like a party. But you can be normal; you can come and interact with other people. That's been very helpful.	CG #6, CG #7, CG #8, CG #9, CG #10.	group she started.

What Policymakers Need to Do to Support Formal and Informal Caregivers

After review of the data by the joint method of manual DCA and NVivo software, the theme of what policymakers need to do to support formal and informal ADRD caregivers emerged from Interview Questions 7 and 8. As well as providing data to the study's main research question, Table 8 supplies quotations that capture the sentiments of what all respondents collectively believed policymakers could do to better support them and improve their caregiving experiences. While much more could be added to this table, there is data saturation of the theme by virtue of the number of other respondents who have corroborated the quotes that are present in the tables. See interpretation column for other caregivers with similar thoughts.

Table 8

What Policymakers Need to Do to Support Formal and Informal ADRD CG (RQ4, IQ7, and IQ8

Participant Statement	Interpretation	Observation
CG #1 in response to IQ8: I'd like it to be for my family. It's not. I'd like to tell you that I don't think they are informed about the conditions of him. You know there is a HIPAA law where they can't have this, but if I were to send a pamphlet or anything like that.	CGs needs research-based policies that increase information and awareness of ADRD. Note the statements of both the informal and formal CGs are almost identical in what they think the state could do to better inform them and increase awareness to the general public.	CGs did not have to think too hard to come up with these responses.
CG #7in response to IQ7 and IQ8: Classes would be great! Maybe just some learning pamphlets, books, I don't know . . . everything like that. I mean . . . I think that would be great, some one-on-one teaching, classes, just classes, books, pamphlets, videos.		
CG #5 in response to IQ8: So I think what's most important is the research. Funding that research for you guys at the university so that you guys can figure out what's going on.	CG #5 is suggesting more research to inform and add awareness. Other CGs with similar thoughts: CG #2	
CG #4 in response to IQ7 and IQ8: More support groups, um . . . resources, I mean, there's a tremendous lack of resources for this disease. I feel . . . people that are extremely overwhelmed – they are the main caretaker. What do they do for themselves?	CGs needs policies that increase respite funding. Other CGs with similar thoughts: CG #1, CG #3, CG #5.	
CG #4 in response to IQ7 and IQ8: I've	CGs needs policies that	Support is the

Participant Statement	Interpretation	Observation
learned through the Alzheimer's Savvy Caregiver more than I would have ever known. So I think it's very important to offer education.	increase support for them in their tasks.	main thing needed by CGs.
CG #5 in response to IQ7 and IQ8: I think if the government . . . the state funded the Alzheimer's Association, cause it's a wonderful entity. So that they could have . . . I mean they're a skeleton crew, really. If they could have a lot more specific support and training that is directly related to where we're at.	Training and education by agencies like the Alzheimer's Association. Other CGs with similar thoughts: CG #2, CG #4, CG #5, CG #6, CG #7, CG #8, CG #9, CG #10	
CG #3 in response to IQ7 and IQ8: I'm not sure what kind of regulations they have on these agencies? But to control better how these agencies work and supply the family of the patient with guidance on the selection process.	Policymakers need to increase oversight to agencies that administer ADRD care	
CG #8 in response to IQ7 and IQ8: Probably if they required [certification for CNAs], or maybe for CNAs, add certain sections about dementia [like extra training on dementia would be helpful]. Because, I know that [there isn't a lot you can learn in the class] it's mostly [learned] on the job. But it would help if we know a little bit more before [we go out on the job] and get in to work with those clients.	CGs needs policies that increase and provide better training and certification for CNAs and facilities. Other CGs with similar thoughts: CG #5, CG #7.	
CG #9 in response to IQ7 and IQ8: I would just say, in my experience, going into facilities, Alzheimer's facilities, that I think they need to improve in interacting with these people more. . . .There is not	Policymakers need to work at increasing the certified nurse aids (CNA) workforce.	

Participant Statement	Interpretation	Observation
enough hands-on care. There’s not enough CNA caregivers.		

The caregiver statements in the above table capture several of the recommendations of the participants as to what they believe policymakers could or should do to improve and support their caregiving experiences. There was only one other recommendation that stood apart from the general themes of what most respondents believed should be done. Caregiver 4, in response to IQ7 and IQ8 said, “You know . . . I think law enforcement needs to be [better] trained more. I think everybody needs to be trained more – education.” While most caregivers felt that they should be better trained, CG #4 felt that the training should be extended to all stakeholders including law enforcement. Figure 4 below illustrates the number of respondents who believed the government should take certain steps to support and improve their caregiving situations. When responding to RQ4, IQ7, and IQ8, all 10 of the respondents believed that the government needed to get involved. However, there are variations of what the policymakers’ involvement should entail. The suggestions are not unanimous, but the need for overall support for caregivers by policymakers stands out and was recommended by all participants. Exactly what that support should encompass was not made clear by the respondents. However, recommendations of what support might look like will be discussed in Chapter 5.

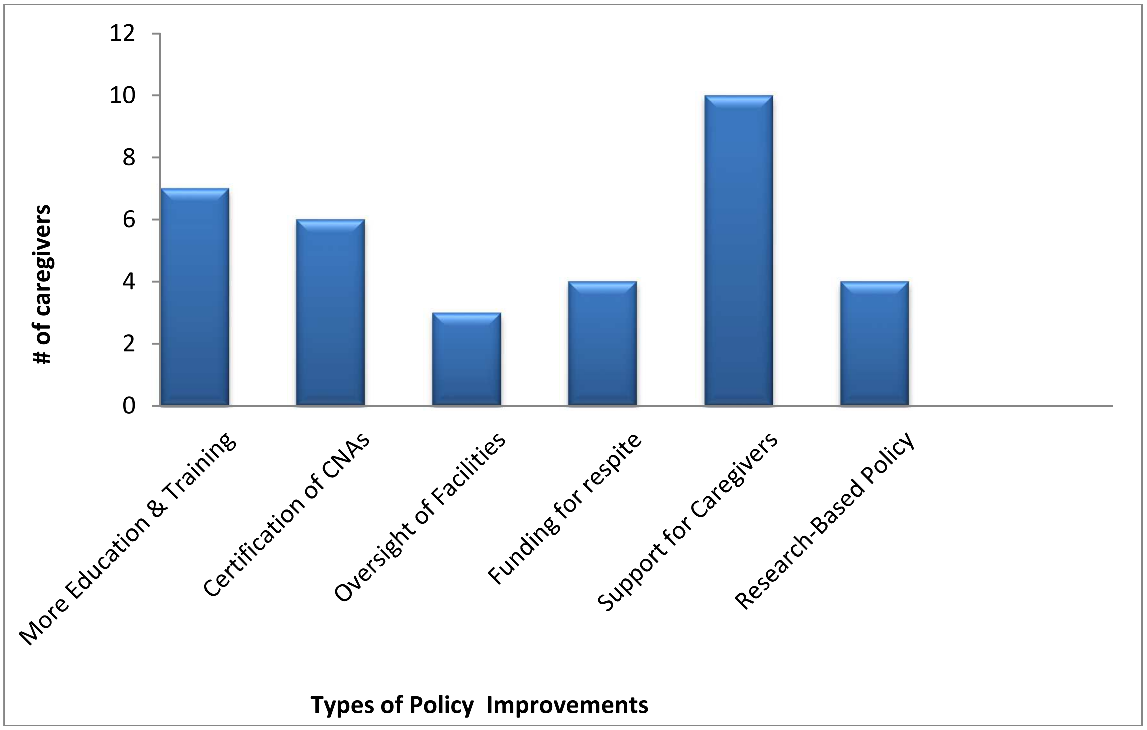

Figure 4. Main steps public policy should take to support ADRD caregivers

Results by Discrepant Cases

If one or two respondents gave a response to an interview question that seemed different from the others, it would be an alarm in the analysis process to determine why it was different or what meaning the different response provided for the overall study. For example, CG #2 did not feel the financial hardship in caregiving as the other four informal caregivers felt because she was able to place her husband in a specialized Alzheimer’s facility at a monthly rate of close to $7,000. This is in stark contrast to CG #1 and CG #5 who struggled to make ends meet and wondered how the cost of their CR’s placement would be met if the need for placement in a facility became necessary. CG #2 also needed to come to a place of acceptance that placement was the best option. She said,

> So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were.

This caregiver's CR passed away less than 2 weeks after the interview, so it is not known if her observed calm and collectedness was due to her being at the end of the caregiving journey compared to the other family caregivers who may still be in the early or middle stages of their caregiver's journey. CG #2 was also a discrepant case because she was the only one of the five informal caregivers who was no longer taking care of her CR in her home.

Another discrepant case was that of the experience of CG #3, the one male caregiver in the study. There was a potential second male caregiver; however, he presented himself as a supporter of his wife who was the primary caregiver and respondent in the study. The experiences of male caregivers should be incorporated in future studies as their perspective needs to be presented to policymakers in proportion to the conventional and predominant female caregiver experiences (Robinson et al., 2009). The experience of CG #3 was discrepant from the other nine formal and informal female ADRD caregivers. One primary difference was that, unlike the female informal caregivers who were caring for a male spouse, CG #3 was caring for his mother-in-law so his wife could go to work. In his description of his experience, he used terms such as emotionally demanding, parenting an old child, emotionally removing your [him] self, Respite is the main thing, tiredness, and frustrating and rewarding. His informal ADRD caregiving experience is additionally discrepant in that, evident by his quote, “I am not putting her in a home.” He seemed to be willing to overcome all of the frustration and difficulty of the task to keep his CR at home through the end of her life. This is contrary to the discrepant case of CG #2 who would not keep her CR at home through the end of life. Yet another discrepancy of this male case was his insistence that formal agency caregivers be trained and certified before they are allowed to assist informal caregivers. This concern of CG #3 addressed the universal need for more training for all ADRD caregivers. These discrepancies of this male caregiver case support Robinson et al.’s (2014) suggestion to have more male caregiver studies done. While the experience of CG #3 may not be generalizable, it is important in the discourse of supportive policy among policymakers and other stakeholders.

Finally, CG #5 was discrepant in that she was the only informal caregiver who was caring for a patient with earlier or younger onset ADRD. This caregiver felt that she was different from the other informal caregivers because the grief of the loss of her CR’s youth and the future plans they were being robbed of as a consequence of the disease was overwhelming and intolerable. While there was nothing in the literature review of this study on the distinction between ADRD caregivers of older versus younger onset care recipients, such a discrepancy does draw attention to the variation of difficulty of this type of caregiving. More will be said about this caregiver’s case later in the Chapter 5 discussion. Table 9 provides a description of the discrepancy of the case, what was said, and my observations during the data collection process.

Table 9
Discrepant Cases

Caregiver and Discrepancy	What was Said	Observations
CG #2 - Less financial problems than other informal (family) caregivers but still wanted to keep loved one at home. - Was forced by circumstances (inability to continue care in the home) to place care recipient in appropriate care facility.	That, you know, and we're not going to get the money we paid in, I mean he's not going to live that long. So I said, we're the good guys, you know you are going to have a lot more money from us than we'll ever use. So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were."	Caregiver was relaxed, calm, collected, and content with her decisions and status.
CG #3 - Only male giving direct care to ADRD CR in the study. - Insists on keeping CR home thru end of life contrary to actions of CG #2. - Informal CG believes there needs to be more training for formal agency	Yes, I consider myself an informal caregiver, I am the son-in-law of the person with the condition and um . . . the way that I pass my daily activities is my time is dedicated primarily to her care. And my roles include everything from um . . . feeding to medicating, help with toilet, dressing, um . . . companionship. In fact I went to the agency yesterday and I complained to	Respondent is happy to be giving care to mother-in-law and relieving his wife of the physical burden of care. Again he is happy to be keeping her home and caring for her.

Caregiver and Discrepancy	What was Said	Observations
CG #2 - Less financial problems than other informal (family) caregivers but still wanted to keep loved one at home. - Was forced by circumstances (inability to continue care in the home) to place care recipient in appropriate care facility.	That, you know, and we're not going to get the money we paid in, I mean he's not going to live that long. So I said, we're the good guys, you know you are going to have a lot more money from us than we'll ever use. So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were."	Caregiver was relaxed, calm, collected, and content with her decisions and status.
CGs who are sent to assist the ICG in the home. The discrepancy is found in fact that an ICG is requiring training not for self but for agency FCG. This is also a point of shared concern for both groups of CGs.	them, you are going to send me somebody that doesn't have any experience? This was the first caregiving job that this woman had. She had no training. . . . . So now we are going to schedule another visit with another caregiver, from the same agency, to see if there is a fit. But to bring it back to the answer. That's what stops me from getting help. There is no good way of getting help. Not that help isn't available. . . . The screening, you know, um . . . I don't think people realize the importance of this job and all that it involves. It becomes very difficult. . . . It's bad enough.	All of this was said with resolute confidence and a bit of anger that agency CGs were not being trained and screened before they were sent to assist the ICG in home.
CG #5	I was pretty lost. I just didn't	Caregiver is almost

Caregiver and Discrepancy	What was Said	Observations
CG #2 - Less financial problems than other informal (family) caregivers but still wanted to keep loved one at home. - Was forced by circumstances (inability to continue care in the home) to place care recipient in appropriate care facility.	That, you know, and we're not going to get the money we paid in, I mean he's not going to live that long. So I said, we're the good guys, you know you are going to have a lot more money from us than we'll ever use. So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were."	Caregiver was relaxed, calm, collected, and content with her decisions and status.
- The only CG with a younger onset Alzheimer's care recipient. - More difficult to deal with the loss of CR's functionality and uncertainty of cost. - Feeling financial and emotional devastation. - Lack of training, information, and support for this type of disease. - More funding for agencies (Alzheimer's	even know what to do. I mean, I called Alzheimer's Association. You know, they have some support. . . . They have, you know you can meet individually but it's really mostly geared towards the elderly. You know all the classes I go to, I'm the only one that's caregiving a younger onset. So my issues and their issues are very different.	tearful and in a state of grieving as she expresses this reality.

Caregiver and Discrepancy	What was Said	Observations
CG #2 - Less financial problems than other informal (family) caregivers but still wanted to keep loved one at home. - Was forced by circumstances (inability to continue care in the home) to place care recipient in appropriate care facility.	That, you know, and we're not going to get the money we paid in, I mean he's not going to live that long. So I said, we're the good guys, you know you are going to have a lot more money from us than we'll ever use. So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were."	Caregiver was relaxed, calm, collected, and content with her decisions and status.
Association who gives respite funding to CG.		

Summary

In this chapter, I presented a review of the study purpose, the setting in which the study took place, and the demographics of the participants. Furthermore, the data collection and analysis process were conducted and contrasted with how they were described in Chapter 3. There were no deviations in data collections and analysis between the two chapters. Evidence of trustworthiness was presented to give credibility, transferability, dependability, and confirmability to the study. The four research questions and how they were answered are summarized here.

The primary research question of the study, how public policy can improve the experiences of formal and informal ADRD caregivers, was answered by four subsequent questions: (a) What is the construct of an informal or formal ADRD caregiver? (b) What are the shared and lived experiences of formal and informal ADRD caregivers? (c) What situations influence the experiences of formal and informal ADRD caregivers? and (d) What can policymakers do to improve the experiences of formal and informal ADRD caregivers? These questions made up four of the five major themes that emerged from the study. The fifth theme that emerged was what is the phenomenon of ADRD caregiving? The results section of the chapter was comprised of these five themes and concepts.

First, the theme of the phenomenon of the ADRD caregiver answered the first part of the primary research question, namely the positive and negative experiences of this group of caregivers as they administer care to people with Alzheimer's disease and related dementias. The respondents answered this overall question collectively, and their responses are represented in quoted form in a table. Second, the construct of what an ADRD caregiver is was answered in the study with formal and informal caregivers seeing themselves as distinct from each other, but also fulfilling the same roles as caring for the CR's ADLs. Third, the shared and lived experiences of the formal and informal ADRD caregiver was answered and presented in a table. Caregivers from both groups shared a desire and need for more knowledge to better inform their caregiving. Fourth, the question of the situations that influenced ADRD caregiving was addressed and represented in another table. The answer to this question indicated that support, or the lack thereof, could positively or negatively influence the outcome of the caregivers in either group. Fifth, another table described what participants thought policymakers needed to do to support them and improve their caregiving situation.

Overall, the results of the study that came out of the responses of the participants was successful in giving a picture of the formal and informal ADRD caregivers' experience. There is an opportunity for much more discussion of the findings in reference to the study's conceptual framework and the literature that was reviewed in Chapter 2. In the next chapter, I will also discuss the interpretation of the study's findings, its limitations, recommendations, and implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Unlike general caregivers of people with other disabilities, ADRD caregivers have a much more complicated and unique set of challenges in their caregiving (Miller et al., 2009). They encounter more stress, can serve longer at their caregiving role, and face health, psychological, and economic consequences as a result of their care provision. When unsupported by policy-driven services, they can prematurely initiate the placement of their CR in nursing homes and other institutional care settings. Such actions on the part of the caregiver could result in a greater cost to the public (Altshuler & Schimmel, 2010; Foster & Kleinman, 2011).

The purpose of this qualitative, phenomenological study was to discover and describe the lived and shared experiences of formal and informal ADRD caregivers. Understanding and categorizing those determined themes and meanings of those experiences gave structure to the supports needed to improve the caregiving process. The study's nature was inductive and expanded on the knowledge of the formal and informal ADRD caregiving experiences by highlighting the meaning and importance of their voices (Creswell, 2009). A qualitative, phenomenological study was the best inquiry design to capture the voice of the ADRD caregiver in a way that legislators might hear it. The fundamental concepts and phenomenon being investigated are

1. The verbalized lived and shared experiences of ADRD caregivers
2. What supports might be lacking that would enable caregivers to continue giving care in the community for a longer period of time

3. How policymakers could improve the caregiving experiences of formal and informal ADRD caregivers.

This study was carried out to examine the unique experiences of formal and informal ADRD caregivers. Additionally, the study needed to be undertaken to address a gap in the literature that indicates little phenomenological insight into the ADRD caregiver's experience. It was the intent of the study to gain insight and add applicable substance to those making policies that support this caregiver group.

Interpretation of the Findings

The results from this study present a new set of insights into the lived and shared experiences of ADRD caregivers in Albuquerque, New Mexico. Additionally, I present information on how the local public policy system can better support and improve caregivers' experiences. The primary research question of how policymakers can improve the experience of the formal and informal ADRD caregiver is what gave structure to the study. In this section, the findings are discussed as they relate to the reviewed literature of Chapter 2. Additionally, findings are presented in the context of the conceptual framework of RTC and PST. The five main themes that emerged from the analyzed data give structure to the discussion of the findings.

Theme 1: The Phenomenon of Caregiving

What is the phenomenon of ADRD caregiving? All of the participants in the study in one form or another answered this question and the theme it represents. Chapter 4 included a table that categorized the overall experiences of caregivers, the barriers and limitations regarding their caregiving, and what they thought were government responsibilities to improve their caregiving situations. These three concepts made up the phenomenon of caregiving in this study. Moreover, the phenomenon as captured by this study was characterized by many of the things that were reviewed in the literature. For example, the comments of informal family CG #3 about the "simultaneously frustrating and rewarding" aspect of this type of caregiving underscores the difficult and challenging nature of giving care to a person with ADRD (Miller et al., 2009; Perdue, 2012). Miller et al (2009) and Perdue (2012) suggested that the family caregiver has a harder time at caregiving than the formal professional caregiver, and this is borne out by the findings of this study. Additionally, 3 out of the 10 caregivers, who happened to be women, were suffering from health crises and were concerned that their health was in jeopardy as a direct result of their caregiving. This indication is equally confirming of the previously reviewed literature. Furthermore, both formal and informal caregivers in the study felt that they could use some more training and information about their caregiving roles and what to expect as the ADRD progressed in their CR. The phenomenon of formal and informal ADRD caregiving is characterized by a need for support, training, respite, and more public policy involvement. This characterization is borne out in both the reviewed literature and the findings of this study.

Theme 2: Construct of Caregiver

The construct of ADRD caregiving requires the caregiver to assist in the ADLs and IADLs. CG #1 captured some of the psychological and physical burdens that may accompany assisting with ADLs and IADLs:

> I don’t think they realize the extent of what all 24 hours a day is. Twenty-four hours a day is cleaning up poop because he had an accident in the store, here, in the car, or anywhere. Having to buy Depends, having so many expenses, and the embarrassment of him having accidents. People look at him and think that he is fine. He looks healthy after having nine strokes. He is still walking. We got him physical therapy back. A lot of work to do that through a lot of determination on my part, and he’s walking with a cane but he is still walking.

Implied in the above statement is the idea of being on duty 24/7 with no relief, which is a contrast from the formal caregiver who can go home at the end of a shift.

For the formal caregiver, the construct is one who is a professional, usually a CNA, who works for a skilled agency or a respite providing agency. In contrast, the informal caregiver is generally a person who is a family member (Davis & Curtin, 2011; Feinberg et al., 2011). I found that the constructs of the formal and informal caregiver were distinct from each other in that the formal group was paid and more supported than the informal group. Another distinction was that the formal group usually rendered service in an institution as the CR had advanced to a higher level of care. Informal family caregivers, on the other hand, were more prone to keep their CRs at home for longer periods despite the lack of additional support and services. Furthermore, I found two instances (CG #2 and CG #3) where the informal caregivers were paying to have their CR placed in a facility. This occurred when the physical ADL part of caregiving became unmanageable and help needed to be brought into the home to give the cargiver some emotional respite. While there are distinctions between the two groups of caregivers in the study literature, there are points of overlap that will be captured in the next theme.

Theme 3: Lived and Shared Experiences of Caregiver

Researchers have discussed common experiences of both the formal and informal ADRD caregiver (Miyamoto et al., 2010; Robinson et al., 2009). Like the literature, I revealed that behavioral and psychological symptoms of ADRD caregiving can influence both formal and informal groups alike. In this study, CGs #2, #4, #5, and #7 all felt psychological stress and increased burden in the form of depression or some anxiety around their caregiving. Additionally, a lack of sufficient information postdiagnosis to aid in the caregiving process was a common shared experience of both the formal and the informal caregiver. The following statement from CG #4 captures this thought as it appears in the literature:

> I just think education, because people don't understand and it's not a visible condition or diagnosis. People don't know you have it you could be walking down the street and all of a sudden they just – don't hit me – don't – you know?

Another shared experience of both caregiver groups was the preference to keep the CR at home, or in a home within the community, where they can receive care with a lower patient to staff ratio. There will be fewer people available to care for this population. The trend of declining ADRD CGs was echoed by the respondents in this study as well (Redfoot et al., 2013). Additionally, CG #2, #5, and #6 all felt that there should be a move in the direction of compensation for the informal caregiver and enhancement of pay for the formal caregiver. The premise of these caregivers' responses were similar to that of the literature, which recognizes the need to place value on this significant (80%) part of the caregiving workforce (Levine et al., 2010). Finally, a sense that facilities and agencies that render ADRD care should be accredited, regulated, and monitored by government was a shared experience as it relates to this theme.

Theme 4: Situations that Influence Caregiving Experiences

Both formal and informal caregivers in the study addressed the need for some type of compensation or increase of pay to caregivers for the work that they do and the potential cost to the public that they can reduce. Caregiving takes a significant financial toll on those who are rendering care. The statement “I’m unemployed as I’m battling cancer. So mostly the devastation is financial at the moment wondering how we’re gonna get through this to get the stability” is an example of how financially damaging ADRD caregiving can be. This is borne out in the literature as well (Langa et al., 2001; Miller et al., 2009). There were some caregivers (CG #2, #3, and #6) who were not as affected or devastated by finances in the caregiving process as the other study respondents were.

Another situation influencing the positive or negative aspects of ADRD caregiving was the presence or lack of adequate supports. Neither the reviewed literature nor the responses of this study’s participants were definitive or consistent as to what constituted supports. In this study, educational and informational materials were often cited as the best supports that could be provided for caregivers. These findings of the situations that influence the ADRD caregiving experience leads to what policymakers need to consider when designing policy to support and improve their conditions.

Theme 5: What Policymakers Need to do to Improve the Experiences of Caregivers

This particular theme is a call from the literature and a response from the caregivers in this study as to how public policy can support and improve the caregiving experience of the caregiving workforce. The answers are varied, but equally substantive because the respondents were thoughtful about their answers. For example, CG #5 said, "So I think what's most important [for policymakers to do] is the research. Funding that research for you guys at the university so that you guys can figure out what's going on." On the other hand, many caregivers (CG #2, 4, 5, 6, 7, 8, and 9) implied or stated that support in the form of funded respite and enhanced education would be the best that policymakers could do. While the thought of more research seems divergent from the more concrete supports that the other caregivers recommended, it is my opinion that research and concrete support services are both a part of a continuum of steps that the government needs to take in order to curtail the public cost of current and future ADRD caregiving. These steps are all supported by the literature reviewed for this study. CG #5 stated that here is the need for tax breaks that would help ease the financial burden that working caregivers have as a result of their caregiving.

One other significant finding, as it relates to what policymakers can do, is the need for more certification and an increase in the ADRD caregiver's workforce. Several caregivers (CG #3, 5, 7, 8, and 9) all thought that there should be an increase in the number of CNAs in the workforce, as well as training for those CNAs. Both formal and informal caregivers recognized this need as they experienced giving care. Acknowledging their need to be more proficient care providers will ultimately enable them to provide optimal care to their CRs. The need for an increase and a more educated ADRD caregiving workforce is represented in the literature reviewed for this study.

Interpretations and Findings by Conceptual Framework

Rational Choice Theory

This study was based on a conceptual framework that encompasses RCT and PST. Research Questions 1, 2, and 3 along with IQs 1, 2, 3, 4, 5, and 6 were all influential in providing the data to address RCT in the study. RCT was instrumental in developing an explanation of the phenomenon of caregiving as it emerged from this study. The premise of RCT as it relates to this study is to explain how rational actors, ADRD caregivers, come to their choices based on the phenomenon they are experiencing. Despite the difficulty, cost, and frustration of ADRD caregiving at home or in institutions, caregivers still found it rewarding to continue rendering care. In addition, it was my expectation that many of the informal caregivers made the rational choices to keep their CRs at home or place them in an institution based on the cost or benefits of their caregiving. On the contrary, while there were conversations about the sustainability of keeping the CR at home, as in the case of CG #1 and CG #5, it would be an overreach of the study findings to say that many of the caregivers made their choices based on cost and benefits as described by RCT. That being said, CG #2 made a rational choice to institutionalize her CR husband based on benefits she was no longer receiving by keeping him at home. CG#2 stated,

> So it was a real wake up call to say you know. . . . I think we all live under the myth that we can pay for caregivers that we can keep our loved ones at home and

> I think that's a myth. You know you have to be very realistic about it. By the time he went to the Retreat, the doctor assessed him there and he took me out in the hall and said I think he has 2-3 days to live. That's how far along we were.

Another example of RCT at work in the study is the following statement by CG #5 as she wrestled with what would determine if she kept her younger onset Alzheimer's CR at home or place him in an institution:

> So to me that's a big barrier. The other barrier to me is the worry again….because of his illness, how are we going to make ends meet? Financially, although he has a great retirement plan, and a great social security, . . . getting back to, he's so young, am I going to have to put him in a place? I don't want to do that. If I bring him in here [back home], I don't know if we can afford that either so I will have to become his caretaker.

Yet another example of RCT at work is seen in the following quote by CG #1:

> I was making $55,000 a year on my own and then his retirement we were set pretty good. I had a 401K, I had insurance through my work and all that stuff which was really good. But I couldn't afford what it cost for somebody to sit with J---- while I was working. So I had to give my 2 week notice. And pay a lot of money the last 2 weeks especially. Um . . . to somebody and it was really expensive, like [$15 an hour] it was a lot, it was a lot of money for me at that time. Even though I made OK money, it was still a lot.

Political Systems Theory

As discussed in Chapter 1 and 2, PST is used to explain the moving parts of a political system. It provides a model for explanation and analysis of the internal and external forces that facilitate transactions and exchanges between policymakers and citizens (Easton, 1979; Prestine, 1991). Research Question 4 and IQ7 and IQ8 are the questions in the study that provided data to address the PST portion of the conceptual framework. A primary motivation for some participants' involvement in this study was based on them feeling that their participation would be an opportunity to represent their voice to New Mexico policymakers. While it is not verifiable, the idea of being a part of the political process motivated them. Their willingness to give information and answers to IQ7 and IQ8 is indicative of such a motivation.

PST is a dynamic systems approach to the formation, implementation, and evaluation of the policy process. The actual dynamics of PST, as it relates to this study and its findings, will not be fully realized until the study is published and disseminated to the policymakers. Policymakers can then act on the environmental stimulus of the ADRD caregivers' responses. The respondents of this study are expecting that results, which included their individual concerns, will make it back to policymakers who can use them in agenda setting or formation of new supportive policies. Finally, CG #2, 3, and 8 all expressed off-the-record desire to get involved in the policy informing process. They saw their participation in this study as a step in that direction.

Limitations of the Study

Limitations to Trustworthiness

As it relates to trustworthiness, the study was limited in that there was much more that could be extracted from the raw data to add to the findings. To do that would require an exhaustive analysis of the data, and because qualitative phenomenological studies do not lend themselves to precise and ordered patterns of analysis, a comprehensive review would have taken much more time. All four aspects of the study's trustworthiness might be called into question because of the study's time constraints. If there was unlimited time, a more thorough review of the data could be done, and trustworthiness could be increased.

In addition, the study was limited in that it was confined to the caregivers only and not some of the CRs who might have been able to corroborate the experiences of the caregiver. While it is understandable that CRs are vulnerable and protected citizens in the research realm, it might have enriched the study to hear from CRs who were able to share their experience about receiving care from their caregivers.

Another limitation was that the study was a qualitative, phenomenological approach that by nature uses a smaller sample size of participants. While phenomenological data do not require more occurrences of the same responses to validate the phenomenon, more responses from a larger sample of this particular set of caregivers might serve to strengthen the data and findings.

Additionally, I only used participants from Albuquerque, New Mexico. New Mexico is a state with vast rural communities that have caregivers and CRs. This study and its results may not have captured the experiences of more of the state's rural caregivers. Because policymakers will be acting from the state level to support caregivers, they would need the findings of studies to be as representative as possible. Finally, all of the caregivers in the study indicated that they received some form of training either by the Alzheimer's Association caregiving course or by the agencies where they worked. Despite that training, they all said they could use more training, education, and information. Because they were all trained in some form or another, this could have additionally limited the study in that completely untrained caregivers were not represented. However, this limitation was mitigated in that some of the informal and formal caregivers were immersed in their roles with a limited understanding of what that role was or how the progression of the disease would influence their caregiving.

Recommendations

Recommendations for Further Research

While this study's findings filled the literature gap of what the ADRD caregivers' experiences are, the results have also created some more gaps that may be filled by further research. Because there is a need for more information and education about the disease for both groups of caregivers, I would recommend more qualitative and quantitative studies that explore the types of training and information that ADRD caregivers need. After listening to the respondents of this study and hearing their plea for more education and information about how to manage their CRs at different stages of the disease progression, I am convinced that various types of educational programs should be explored further. While such studies have been done in the past (Gallagher-Thompson et al., 2003; Llanque, 2011), the dynamic nature of best practice ADRD caregiving warrants new exploration of what is in the best interest of today's caregivers. Furthermore, Title V, Subtitle D, Sections 3302 and 3305 of the ACA has provisions that recommend training for general and geriatric caregivers as a means of enhancing the caregiving workforce (ASPA, 2013; Patient Protection and Affordable Care Act, 2010).

Additionally, I discovered that ADRD caregivers need personal respite. The respondents struggled to explain what suitable respite really means for them. While there is ample literature to describe and emphasize the need for and benefits of respite to caregivers, there are less data on the particular type of respite that would be suitable for today's ADRD caregivers. I recommend that further studies be conducted that attempt to determine what is the most effective respite program for the ADRD caregiver.

Moreover, caregivers often suffer from personal health issues while administering care to their CR. There is little in the literature on the public health cost of not keeping the caregiving workforce healthy. As caregivers' health breaks down due to their caregiving, job loss, surrendered livelihood, or lack of health insurance, they will look to the public health system for their health care needs. It would be a prudent move on the part of policymakers to gather more data on the effect of ADRD caregiving and the caregiving workforce to determine what can be done to minimize that effect. The ACA originally proposed the Community Living Assistance Service and Supports Act (CLASS Act), which intended to initiate a self-funded, voluntary, long-term care insurance that would provide benefits to individuals needing long-term care for chronic diseases. This insurance would have had flexible benefits that would have funded a range of community supports, such as home health care and respite (ASPA, 2013; Patient Protection and Affordable Care Act, 2010). Caregivers of ADRD could benefit from a revisiting of this law that was repealed from the ACA (Bell, 2013).

There was a caregiver who was experiencing the difficulty of giving care to a CR with early or younger onset ADRD. There are approximately 200,000 cases of younger onset ADRD in the United States. This version of the disease is believed to progress more rapidly and could require earlier institutionalization for a variety of caregiving related stressors (Smith, 2014). This version of the disease presents a more unique set of challenges around long-term care financing and the degree of stress and burden more than what standard ADRD caregivers face. For that reason, I recommend further exploratory research to examine the difference between older and younger onset caregivers of the disease. If, for example, scholars indicate that one type of ADRD caregiver suffers more than another, appropriate public policy steps can be made to address the particular needs of the more burdened group.

At least five of respondents in this study recommended that caregivers and caregiving facilities be certified or have more government oversight. Respondents wanted formal caregivers to be trained and certified at the CNA level. The rationale for this is to ensure a valuable and qualified ADRD caregiving workforce. Those in the field and on the frontlines of care recognize the benefits of giving qualified and quality care to the CRs. Policymakers, as a function of the policymaking process, should be invested in sanctioning research that strengthens and supports the need for such enhanced quality in this vital workforce.

Strengths of the Study

This study added to the knowledge base of the experiences and needs of formal and informal ADRD caregivers. Because there are limited phenomenological studies on the actual lived and shared experiences of this niche of caregivers, I recommend that similar studies be conducted to give those making policies a well-informed basis for their policy agendas. An additional strength of this study was its timeliness. The United States and the international research communities are seeking to understand all aspects of ADRD and its impact on those afflicted with the disease and their caregivers. For example, at this writing, the State of New Mexico has authorized, by a House Joint Memorial 4, a Family Caregiving Task Force to address the needs of caregivers of ADRD and other disabling diseases (Salazar, 2014). With President Obama's National 2012 plan to address ADRD, numerous other state plans have been presented with recommendations to deal with caregiving issues. Given this momentum towards finding out how to handle ADRD and support its caregivers, I recommend that policymakers seek out findings from phenomenological studies similar to this, so they can have a real-time understanding of the dynamic phenomenon.

Limitations of the Study

The study was limited in that it was qualitative and phenomenological in nature. As echoed in CG #2 statements, "if you know someone with Alzheimer's, you know one person with Alzheimer's. They're not the same." I recommend that policymakers in New Mexico and nationwide extend studies like this into rural areas of the state. A call for data from rural areas would primarily capture the experiences of as many ADRD caregivers as possible. Such a call for statewide data would ensure that supportive policies are representative of the people they intend to serve. New Mexico's current working Family Caregiving Task Force should be extended to ascertain the needs of caregivers statewide to come up with recommendations to support those needs. Such a task force could benefit from a deeper understanding of the caregiver's experiences and needs.

Reviewed Literature

The major theme of the literature could be summed up in the following thoughts: ADRD is a growing disease that will increase in prevalence and incidence with the aging of the U.S. senior population and throughout the world. With increased incidence and prevalence of the disease, there will need to be a commensurate increase of individuals who are willing and able to give care to those afflicted. The cost of providing ADRD care is predicted to rise exponentially to an estimated $1.5 trillion by the year 2050. At the beginning of this study in 2013, the predicted cost was estimated at $1.2 trillion (Alzheimer's Association, 2013; O'Neill, 2014).

The people who give care to ADRD CRs will also decrease in numbers, which will lead to less formal and informal caregivers being able to support the increase in CRs. The decline in the ADRD caregiving workforce will result in a more and earlier institutionalization of CRs and an increased public cost if nothing is done to better support them and improve their experience around caregiving. Both the reviewed literature and the informal ADRD caregivers interviewed for this study made recommendations that I agreed could support them and improve their caregiving situations. First, support should come in the form of expanded respite funding. The state of New Mexico currently funds the local Alzheimer's Association respite program minimally through its Aging and Long-Term Care Services Division. The state funding translates to a grant of $300 per ADRD household per year. Usually, this grant is used to pay the caregiver who then pays an alternate caregiver to care for the CR while the primary caregiver attends psychoeducational training on how to care for the CR. In evaluating this program, this is not true respite because the ADRD caregiver is still engaged in the caregiving process. It is my recommendation that the state increase funding for this program so that, outside of ADRD training, the caregiver can take time off away from his or her CR and the caregiving process. If ADRD caregivers do not get adequate respite support, they will ultimately succumb to the heavier psychological burden that this form of caregiving produces. In addition, they may institutionalize their CR sooner.

The health toll that a lack of adequate respite will take on the caregiver could come at a much higher cost to the individual and the public. Consider the around the clock engagement of the ADRD caregiver when a CR is progressing towards the end stages of the disease that requires more direct ADL caregiving. This level of care output is not sustainable and will ultimately lead to a total breakdown of the caregiver if adequate respite is not given. Increasing funding for respite programs will incentivize respite for those who might not take it otherwise. Some respondents in this study suggested that caregivers will not take breaks because they cannot afford to pay for respite. A little extra support in the form of additional funding could go a long way in easing the caregiving burden of this unique group.

Additionally, both the literature and the caregivers in this study suggested more education and information about how to render care at various stages of the disease process would be helpful. I recommend that such educating and informing be expanded through agencies such as the Alzheimer's Association and New Mexico Direct Caregivers Coalition. Both increase of respite and education to ADRD caregivers need not be policy acts that start from the beginning of the policy process. As an alternative, existing programs and policies can be revised to optimize their proficiency and output to better support the caregiver.

Implications

Formal and informal ADRD caregivers are experiencing difficulty, frustration, a lack of respite, and a lack of information and education about the disease as it affects their CRs. These deficiencies translate to an overall lack of support. There are many unmet needs of the current formal and informal ADRD caregiver workforce.

Positive Societal and Policy Change

In this study, I revealed a distinction between the formal and the informal ADRD caregivers. Primarily, formal ADRD caregivers have access to more training and better supports through their employers. They are not faced with unending contact with the CR and the attending caregiving burden that such exposure brings. Based on the findings of this study and the literature, the implications of positive social change would be more beneficial to the informal family ADRD caregivers than for the formal caregivers. For positive social change, policymakers should take the following steps to support the informal family ADRD caregivers:

1. Develop policies that would expand existing ADRD educational and informational outreach. Such an action would increase the caregiver's capacity to give better care in the community and keep the caregiver rendering care in the community longer. Benefits of such measures could also reduce the public cost over time as caregivers are supported to institutionalize their CR later in the progression of the disease rather than sooner.
2. Because respite can be beneficial, an increase of funding for existing caregiver respite programs would go a long way in minimizing the burden and stress that ADRD caregivers are currently experiencing. This could reduce the public cost as the health and well-being of the caregiver is preserved for them to give care another day.
3. Be proactive in seeking accurate data that can inform ADRD caregiving policy agendas, implementation, and evaluation. Actions taken now will reduce the harm to society, limit the public projected cost of the disease, and mitigate the suffering of individuals and families who are currently bearing the burden of ADRD.

Conclusions

The essence of this study was to discover how public policy could improve the caregiving experience of an undersupported formal and informal ADRD caregiving workforce. Evident from both the literature and the study findings is a lack of sufficient positive action towards the needed outcome. The following statement by one study participant in response to IQ8, “What can government do to better improve your ADRD caregiving experience?” may capture what policymakers need to do to make the study’s essence an actionable reality:

> Pretty much what I said before, do not turn this into a political issue. This is a very personal health related issue. We are now on the cusp of the baby boomers coming of age. This is only going to increase. The number of people with dementia is only going to increase. If we’re not proactive which I think we are late for it already, we are going to be in deep trouble. We’re not gonna have the conditions, we’re not gonna have the people to take care of the elderly. Um….one of the things I uh….appreciate about the let’s call it religious values, both the Judeo-Christian and the Native American religious values is take care of your elders. And I think that people have forgotten that.

The caregiver is making a plea that the issue of a growing number of ADRD CRs will require an increasing number of ADRD caregivers. With that scenario, there is no time to be political in the process of forming, implementing, and evaluating the proper political strategies to make a difference. Much is at stake as it relates to the needs of the caregivers and their CRs. Having completed this study, and deploying my expertise on the subject, there is not a lack of understanding of what needs to been done to help and support this group of caregivers, but a willingness of policymakers to move on actionable research findings.

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Appendix A: Informed Consent to Participate Form

You are invited to take part in a research study of caregivers of people with Alzheimer's disease and related dementia (ADRD). The researcher is inviting individuals who; 1) Can speak and understand English well 2) Have provided informal care to ADRD patient for at least 6 months
3) The care-recipient is diagnosed with ADRD 4) Caregiver is engaged in daily hands-on caregiving requiring assistance with ADLs 5) Caregiver has been in contact with at least one other person who is or has given care to a person with ADRD, and who wants to share the experience to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

A researcher named Roxroy A Reid who is a doctoral candidate at Walden University is conducting this study.

Background Information:
The purpose of this study is to get an understanding of the lived and shared experience of family and formal caregivers who care for people with ADRD. The results of the study will be provided to you in a 1-2 page summary for your participation. Additional, the researcher hopes to get the study results to policymakers who might be able to provide government policies that are supportive to ADRD caregivers.

Procedures:
If you agree to be in this study, you will be asked to:

- Answer 8 open-ended interview questions about your caregiving experience
- Respond to follow up phone calls to clarify your response from the interview
- The interview should be done in 60 or more minutes but may require a follow-up phone call or email to clarify your answers

Voluntary Nature of the Study:
This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one involved in the study will treat you differently if you decide not to participate. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:
Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming tired, stressed or getting upset as you retell your experience. Being in this study would not otherwise be a risk to your safety or well-being. If you do become adversely and emotionally impacted by the interview process the

researcher will check in with you and may stop the study and direct you to needed assistance.

Some possible benefits of this study are the opportunity for you to indirectly share your concerns for help as a caregiver with State legislators who may be able to enact more supportive caregivers' policy. Additionally, you will have the opportunity assist other caregivers in your community by speaking as a subject matter expert.

Payment:

Participant in this study will not be compensated financially or otherwise. This is a voluntary study

Concerns of Privacy:

Any information you provide will be kept confidential, with certain exceptions. If, during the study, you disclose an instance of possible elder abuse, neglect, or exploitation, the researcher is required by the State of New Mexico to report the instance(s) to the local Adult Protective Services agency. The researcher will not use any information you provide for any purposes outside of this research project. In addition, the researcher will not include your name or anything else that could identify you in any reports of the study. Data will be kept secure by the researcher in a locked safe with access only to the researcher. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. If you have questions later, you may contact the researcher via [redacted] or [redacted]. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 612-312-1210. Walden University's approval number for this study is **<u>IRB will enter approval number here</u>** and it expires on **<u>IRB will enter expiration date.</u>**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant ______________________________

Date of consent ______________________________

Participant’s Written or Electronic* Signature ________________________________

Researcher’s Written or Electronic* Signature ________________________________

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person’s typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

Appendix B: Recruitment Letter Sent to Caregiver Support Agencies

Hello,

My name is Roxroy A Reid and I am a doctoral student at Walden University.
I am conducting a study of informal family and formal caregivers to people with Alzheimer's disease and related dementia (ADRD). I need to recruit 10 participants who meet the following criteria:

1) Can speak and understand English well
2) Have provided informal care to ADRD patient for at least 6 months
3) The care-recipient is diagnosed with ADRD
4) Caregiver is engaged in daily hands-on caregiving requiring assistance with ADLs
5) Caregiver has been in contact with at least one other person who is or has given care to a person with ADRD.

Each participant will be interviewed at a location that is convenient for both the participant and myself. The interview will last 30-60 minutes, and will include some general questions about the caregiving experience, as well as specific questions about how and what you believe policymakers can do to support ADRD caregivers. Would you be willing to post a flyer that I provide to recruit participants for my study?
Please reply to this email with your response. Thank you so very much! Please call for clarity,

Roxroy A Reid
[redacted]

Appendix C: Flyers Posted to Community Agencies

AN OPPORTUNITY TO PARTICIPATE IN Alzheimer's/Dementia CAREGIVING RESEARCH!

A Walden University researcher is conducting a doctoral study of Alzheimer's disease and related dementia (ADRD) informal/family and formal caregivers. Eight to Ten participants will be interviewed in person at a convenient location, over the telephone, or in person, for about 60 minutes. Interview will be recorded and follow up call may be made to verify other information. The ability to speak and understand English is required. Interview questions will include a general description of the caregiving experience, and specific questions about what you think policymakers can do to support formal and informal ADRD caregivers.

Anyone interested in participating in this study should contact me by email or by telephone:

Email address: [redacted]

Telephone: [redacted]

Appendix D: Demographic Information

Please indicate or circle the appropriate response to the following demographic questions:

1. Name (will be coded as caregiver [CG1, CG2 etc.])
____

2. Contact information for follow up (you will not be identified for confidentiality)

Phone #______________ Email_________________

3. Gender (Male/Female)
4. Occupation_______________________
5. Age (under 65/ Over 65)
6. Care recipient has diagnosis of ADRD (Yes/No)
7. Time as an ADRD caregiver (more than 6 months/Less than 6 months)
8. Formal or informal caregiver (working with family member from home and working for or assigned by an agency to home)
9. Relationship to care recipient (spouse, child, friend)

Appendix E: Interview Questions (With Prompts)

The following Prompts will be used to in conjunction with the research questions to elucidate the meaning behind the ADRD caregiver experience: Can you tell me more about that, what is that like for you? Can you give me an example of that?

1: Do you consider yourself as an informal family caregiver to your care recipient and what does your role mean to you?

2: Do you see yourself as a formal ADRD caregiver and if so why?

3: What is or has been your general experience of giving care to a person with Alzheimer's disease or related dementia?

4: In interacting with other ADRD caregivers, what experiences do you feel you share in common with them?

5: What are the main situations (Important, rewarding, bad, burdensome) that influence your experience as an ADRD caregiver?

6: What are some barriers that limit your ability to give good care to care recipient?