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Perceptions of Burden Among Informal Caregivers of Older Adults in Assisted Living

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This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,
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Walden University
2024

Abstract

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Gösta H. W. Schlegel

MPS, University of Connecticut, 2016

BS, Dominican College of Blauvelt, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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Abstract

Few studies have focused on the lived experiences of informal caregivers of residents of assisted living facilities (ALFs) and their perceptions of their caregiver burden, which can lead to decreased physical and mental health, decreased economic status, and negative effects on the care recipient's wellbeing. A considerable knowledge and practice gap remains regarding how public health practitioners relate to informal caregiving. The purpose of this study was to understand what informal caregivers of ALF residents perceive as factors that affect their caregiver burden and the perceived impact caregiver burden has on the caregiver and their eldercare recipient. The social-ecological model provided the organizational framework for this qualitative study. Semi-structured interviews were conducted with 10 participants recruited through convenience sampling. Thematic data analysis resulted in three significant findings: informal caregivers of ALF residents experience varying degrees of caregiver burden, factors that influence the perception of caregiver burden are represented at all five levels of the SEM, and informal caregivers have varied perceptions of how the presence and degree of caregiver burden impacts their care recipients. Implications for positive social change include assisting public health professionals and ALF staff to better address the promotion of health and wellness of informal caregivers and their ALF-dwelling care recipients, encouraging greater multilevel involvement in addressing caregiver burden, and further developing the foundation of knowledge needed to inform evidence-based interventions and policy development.

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Dedication

To all my family members who have supported me during this long but fruitful journey. To my wife and better half, Sheelagh, thank you for your often gentle and sometimes firm encouragement, particularly when I experienced writer’s block: I made it! To each of my children and “acquired” children: TJ, Suzana, Alyssa, Evan, Christian, William, Elijah, Jasmine, and Lukas, I did this for all of you. I hope that in some way, I can serve as a role model. I will now have the time for those honey-do lists, playing those games, and just being there. Again, Sheelagh; no more “not right now!” To all my extended family, friends, and those I didn’t visit quite as often, thank you for your unwavering support and encouragement. Finally, thank you, God, for hearing and speaking to me: I listened!

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Chapter 1: Introduction to the Study

Background of the Study

America is aging. In 2016, 49.2 million Americans were aged 65 and older (U.S. Census Bureau, 2018). By 2019, that number had climbed to over 54 million Americans (U.S. Census Bureau, 2020). Many of these older adults remain healthy and continue to live independently. However, 80% of older adults suffer from at least one chronic condition, and close to 70% have two or more chronic conditions that can impact their ability to live independently (De Biasi et al., 2020). Chronic conditions such as diabetes, heart disease, and dementia can result in older adults losing their ability to be independent and require the care of others (De Biasi et al., 2020). Frequently, older adults choose to continue to live in their own homes and communities with support, while others make the choice to move into assisted living facilities (ALFs) or other residential settings. In 2018, there were 818,000 older adults living in ALFs nationwide (National Center for Assisted Living [NCAL], 2018). Over 70% of ALF residents were women, and most were over 85 years of age (NCAL, 2018). ALFs offer various services, such as tiered formal caregiving, which can include help with activities of daily living (ADLs) and functional mobility (NCAL, 2018). While formal caregiving involves providing care for compensation, informal caregiving is performed by individuals who provide unpaid care to family members and friends with a health problem or disability (Centers for Disease Control and Prevention [CDC], 2021). Despite the variety of paid services available in ALFs, family caregivers frequently remain involved in caring for family members who have moved to an ALF. They continue to provide care similar to what they provided at home, including socialization and emotional support, coordination of medical services, money management support, and transportation to and from appointments and other events (Schulz & Eden, 2016). Whether paid or unpaid, the phenomenon of providing care to someone 65 and older is called *eldercare*, and those providing that care are called *eldercare providers* (U.S. Bureau of Labor Statistics, 2019). According to the U.S. Bureau of Labor and Statistics (2019), 40.4 million people were eldercare providers between 2017 and 2018.

Problem Statement

A few examples of challenges facing informal caregivers include a lack of preparedness for assuming the caregiver role, a sense of obligation for filling in the gaps of formal service provision and adjusting to the variability of difficulty and demand of the caregiving (Lieshout et al., 2020). The multiple challenges that impact informal caregivers are collectively known as *caregiver burden* (Ghazawy et al., 2020; Rodger et al., 2015). Caregiver burden can lead to decreased mental health in caregivers from social isolation, decreased economic status for caregivers and their families because of greater expenses and withdrawal from work, and decreased physical health in caregivers due to the physical burden of caregiving and a neglect of one’s own health needs (Berglund et al., 2015). Caregiver burden has also been associated with negative effects on the care recipient’s wellbeing, such as a decline in function (Stall et al., 2019). The impacts of informal caregiving do not always lessen when older adults transition to ALFs or residential living (Turcotte & Sawaya, 2015, as cited in Hainstock et al., 2017). Care management, resource management, overseeing family access and adjustment, and managing emotions such as guilt emerge as additional factors that can impact caregiver burden following the transition to an ALF (Hainstock et al., 2017; O’Hora & Roberto, 2019).

Public health plays a critical role in addressing the chronic health conditions of older adults (De Biasi et al., 2020), and public health professionals have been charged and continue to be tasked with meeting the needs of the informal caregivers who provide eldercare (Anderson & Egge, 2014; CDC, 2019; Talley & Crews, 2007). The Healthy People initiative has encouraged public health professionals to focus more on informal caregivers by including an indicator that addresses the informal caregivers’ perceptions of available caregiver support services (Prohaska et al., 2012). Additionally, the CDC issued a call to action to address the burdens and needs of informal caregivers (CDC, 2019).

From an epidemiological perspective to best address the needs of informal caregivers and understand caregiver burden, public health professionals must understand caregiver burden prevalence, characteristics, and health effects (Reinhard et al., 2019). From a community health perspective, public health professionals must explore ways to better understand the incidence and distribution of caregiver burden to address the promotion of caregiver burden mitigation strategies and preserve the wellness of caregivers and their frail elderly care recipients (Schulz & Eden, 2016). From a social justice perspective, public health professionals must promote policies to protect and support informal caregivers and preserve autonomy among their care recipients (Almgren, 2017).

A critical step to addressing the important issue of caregiver burden is a better understanding of the depth and impact of the problem. Public health professionals have recognized the importance of a greater exploration of informal caregiving and caregiver burden and have advocated for further research. From an historical perspective, Talley and Crews (2007) advocated strongly for further research by public health professionals into the lived experiences of informal caregivers and their burden as a public health issue. Berglund et al. (2015) discussed that further research into health outcomes among caregivers was needed to learn which factors mediate the caregiver role to the associations of lower health outcomes. Biello et al. (2019) suggested that future qualitative work was needed to explore the perspectives and experiences of caregivers without formal support services. Almgren (2019) posited that further research of the causal relationships between caregiver burden and health status was needed to inform policy makers interested in social justice initiatives. Kent (2020) highlighted caregiver burden as a unique public health challenge and advocated for further research that explored the complexity of contextual factors that affect emerging adult caregivers. Morelli et al. (2019) promoted further public health consideration of location and access to support services for informal caregivers. Rabarison et al. (2018) promoted the importance of informal dementia caregiving as a public health issue and called for future research that highlighted the economic contributions of informal caregiving and the impact of burden. As ALFs continue to emerge as viable options for residential care, researchers continue to express the need to gain a deeper understanding of the phenomenon of informal caregiving to ALF residents (Hainstock et al., 2017; O’Hora & Roberto, 2019).

Purpose of the Study

Both the World Health Organization (WHO, 2017) and the CDC (2019) have expressed the importance of health systems focusing on the needs of informal caregivers and the demands of caregiving. Since this study expressly explored caregiver burden as it relates to informal caregivers providing eldercare to ALF residents, further references to informal caregiving and the role of the caregiver will primarily focus on the caregiving phenomenon as it relates to the provision of unpaid eldercare to older adult ALF residents. Public health researchers have conducted quantitative analyses of caregiver burden, and the CDC has included questions on informal caregiving in a national survey that serves as a secondary data source for researchers (Edwards et al., 2020). While quantitative studies can capture statistical relationships and associations between the various factors related to caregiver burden, and recognize and explore the multidimensional interplay of those elements through statistical analysis, the impact on the greater context of caregiving, especially the deeper exploration of lived experiences, is best explored by public health professionals using a qualitative approach because the researcher can better interpret the narratives to learn what it is really like to be an informal caregiver who is experiencing caregiver burden (Sharif et al., 2020). Few studies of caregiver burden in public health literature are qualitative, and some authors have identified this lack of phenomenological study by calling upon public health researchers to explore the multifactorial characteristics and interplays of caregiver burden through qualitative analysis (Berglund et al., 2015; Riffin et al., 2019). Additionally, few studies have explored family caregivers' perceptions of stressors related to residents of ALFs. Adding this qualitative study to the body of knowledge helps public health professionals better address major functions of public health related to caregiver burden: to promote the health of individuals and their communities, encourage multisectoral involvement, and create the scientific foundation necessary to inform policies and interventions (WHO, 2018).

Research Questions

1. What do informal caregivers providing eldercare to ALF residents perceive as factors that affect their caregiver burden?
2. What impact does caregiver burden have on the caregiver and their eldercare recipient as perceived by the informal caregiver?

Conceptual Framework for the Study

The five-level social-ecological model (SEM) provided the organizational framework for this study. This model addresses not only individual factors, but also interpersonal, community, organizational, and social and policy level factors (Leung et al., 2021). Important constructs of the SEM are that it is multilayered, accommodates complexity and system dynamics, serves as a stimulus for knowledge development, incorporates a biological perspective, and is multidisciplinary. Ecological thinking in public health has identified and continues to recognize the inherent complexity of the factors that shape an experience and provide a means to structure the varying factors and their interplay (Lang & Rayner, 2012; Leung et al., 2021). Using the SEM to explore caregiver burden in the ALF environment not only allowed consideration for the multidimensional intertwining of factors that leads to caregiver burden and the perceived impact that the caregiver burden has on the informal caregiver, the care recipient and their dyadic relationship in this unique environment, but it can also serve as a framework for developing interventions at and across the various levels of the model.

Nature of the Study

This was a qualitative study that explored the lived experiences of informal caregivers providing eldercare and their perceptions of caregiver burden and its effects on their physical health, mental wellbeing, economic stability, and the health and welfare of their care recipients. This type of study was best suited for a phenomenological study design because it allowed for a deep exploration of the interplay of factors within and across the various ecological levels that influence informal caregivers' perceptions of their caregiver burden in ALFs and its impact.

Definitions

Activities of daily living (ADLs): Daily living tasks related to selfcare, which include self-feeding, grooming, bathing, dressing, toileting, and the related functional mobility to include mobility to and from the tasks (Reinhard et al., 2019).

Assisted living facility (ALF): ALFs provide a form of long-term care to older adults and individuals with disabilities. They offer a variety of services ranging from meal service, medical services, recreation and socialization services, and laundry and cleaning (Bagwell, 2019).

Caregiver burden: A concept that represents an attempt to describe a subjective state a caregiver may experience when caring for a care recipient. In the literature, caregiver burden is often described as negatively impacting or burdening the caregiver as to cause excess physical, psychological, emotional social or financial stress as a result of engaging in caregiving (Bastawrous, 2013).

Care recipient, care receiver, family member, loved one, patient: An individual who has a chronic illness or disability requiring ongoing assistance, intermittently or daily (Family Caregiver Alliance, 2016). In this study, the care recipient, family member, or loved one, is the elderly individual receiving the support of a caregiver.

Chronic disease, chronic illness, chronic condition: The CDC (2022) defines chronic disease or illness as a condition lasting over a year that requires medical attention or limits participation in daily living.

Disability: Having limitations in activity due to physical, mental, or emotion factors or requiring adaptive equipment or strategies to complete a task (CDC, 2019).

Eldercare: Formal and informal caregiving specific to elderly individuals or senior citizens (Seniorcare.org, 2014).

Elderly, aged, older adults, seniors: A broad definition would include individuals who have reached old or very old age and who are nearing the end of the human life cycle. Throughout scholarly and popular literature, there is disaccord and ongoing debate over what age should mark entry into old age. Some have suggested that terms such as *elderly* and *aged* are ageist and should be avoided in favor of the term *older adult* (Avers et al., 2011). U.S. government agencies have defined old age as beginning at age 65, and many government reports refer to seniors as adults 65 and older (CDC, n.d.; U.S. Census Bureau, 2018, 2020). In this study, the term *older adult* was preferred and used to refer to individuals aged 65 and older.

Formal caregiving: An arrangement during which individuals providing care to a care recipient are reimbursed or paid (Schulz & Eden, 2016).

Frail, frailty: A clinical state in which an individual is left more vulnerable to internal or environmental factors which may impact health (Proietti & Cesari, 2020).

Frail elderly: Older adults who are experiencing frailty, such as an age-related reduction in physical fitness which makes them more likely to be dependent on others (Åhlund et al., 2020).

Informal caregivers, carers: Individuals who provide unpaid assistance to family members or friends who can no longer care for themselves (CDC, 2019). Talley and Crews (2007) described caregiving as multidimensional and varying in complexity, intensity, and duration.

Instrumental activities of daily living (IADLs): Daily tasks related to maintaining the household to include meal preparation, laundry, shopping, cleaning, money management, and transportation (Reinhard et al., 2019).

Multidimensional, multifactorial, multilayered: Related to the various factors and levels that influence a phenomenon. In this study, used within the context of describing the various elements that contribute to caregiver burden.

Perceive, perception: The phenomenological philosopher Maurice Merleau-Ponty (2012) described perception as offering the lens and framework through which we see every conscious action and experience. Through perception, we assign meaning to the world and everything we experience. For this study, the focus was the meaning informal caregivers assign to caregiver burden and the framework through which they see it.

Wellness, well-being: Often used synonymously; wellness may more closely refer to a good state of health, whereas well-being frequently refers to a greater holistic experience of physical, emotional, or spiritual satisfaction or feeling good. Greater well-being can be associated with decreased levels of caregiver burden (Cosco et al., 2017)

Assumptions

Research assumptions are presuppositions that a researcher holds prior to engaging in research. An assumption can help researchers formulate conclusions from their research (Roulston, 2021). I made several assumptions as I began my research of how informal caregivers providing eldercare to ALF residents perceive caregiver burden. First, I assumed that the transition to becoming an informal caregiver was either gradual with responsibilities growing in intensity over time or occurred with the acute onset of a condition that caused the eldercare recipient to suddenly lose independence. Second, I assumed that the informal caregiver had a previous relationship to the care recipient (e.g., family, friend, or neighbor) in which there was reciprocity. I also assumed that informal caregivers are motivated and committed to offering support to their eldercare recipient or recipients. Finally, I assumed that the perceived benefits and liabilities of living in an ALF played a role in the final decision to transition to one.

Scope and Delimitations

The results of this study provide insights into the lived experiences of informal caregivers of ALF-dwelling older adults and their perceptions of the caregiver burden and the caregiving process. The insights gained can assist public health professionals and ALF staff to better address the promotion of health wellness of informal caregivers and their ALF-dwelling care recipients, and encourage greater multisectoral involvement in addressing caregiver burden, and further develop the foundation of knowledge needed to inform evidence-based interventions and policy development.

I selected a purposive sample that was delimited to unpaid adult caregivers who (a) provided informal eldercare to care recipients ages 65 and older, who were residing in one of several ALFs in southwestern Connecticut, and (b) expressed having increased stress or stressors associated with their caregiver role. Informal caregivers not included in this study were (a) those providing eldercare to older adults not living in ALFs and (b) those providing care to children and young adults. Additionally, informal caregivers not verbalizing caregiver-related stress were not included in this study. I perceived transferability to those informal caregivers rendering support to individuals other than ALF dwelling older adults in southwestern Connecticut as limited due to differences in the patient-caregiver dyad and the variability in the availability of resources and supports in other regions.

Limitations

A potential limitation to generalizability I initially identified was that this study focused on the perceptions of informal caregivers whose eldercare recipients live in ALFs in southwestern Connecticut. Informal caregivers of older adults living in ALFs may have different factors affecting caregiver burden due to the care services offered and the additional coordination and costs resulting from those services.

The ongoing COVID-19 pandemic has affected the nature of contact to informal caregivers resulting in less face-to-face encounters with a variety of family, community, and organizational level actors. The CDC reported that there is little COVID-19 surveillance data specific to ALFs; however, it has offered a variety of recommendations that have resulted in limiting informal caregivers' direct contact with their care recipients (Yi et al., 2020). The result has been a greater leveraging of audio and video conferencing technology to engage in caregiver interactions with their elderly care recipients and support personnel. I anticipated the availability of resources to be limited in two ways: (a) the caregivers' and the care recipients' limited understanding and access to technology and (b) the community and ALF level resource limitations imposed as a response to the pandemic. Finally, for the same reason, data collection for this study also took place using virtual platforms to curb the risk of exposure to infection. Using a virtual platform to conduct semi-structured interviews was expected to yield sound data. In a recent study that took place before and during the pandemic, the researcher saw no differences in results when triangulating face-to-face and virtual data collection (DiLeone, 2021). The author also suggested that participants may have found the online nature of the study more convenient due to decreased travelling and time impositions, which may have allowed for less stress and a greater focus on providing more comprehensive responses (DiLeone, 2021).

Significance

Conducting this study addresses knowledge gaps by providing public health professionals and ALF staff with a greater understanding of the complexity of the phenomena of informal caregiving for older adults living in ALFs and their associated caregiver burden. A closer look at the context of informal caregiving in ALFs helps public health professionals and ALF staff better understand the multifactorial nature of eldercare in this unique setting, how it influences caregiver burden, and how that burden impacts the informal caregiver and the eldercare recipient. Knowledge gained from this study will help public health professionals identify risk factors of caregiver burden specific to ALF residents, assist in the promotion of strategies to lessen the impact of the interplay of those factors, and help informal caregivers providing eldercare avert the negative consequences of caregiver burden to themselves and their care recipients within the ALF context. Additionally, this study can serve to initiate a partnership between public health practitioners and ALF staff and leadership. Although this study approach is exploratory and thus not generalizable, the result is a greater understanding of the unique lived experiences of informal caregivers providing eldercare to older adults living in ALFs, which in turn leads to customized approaches for mitigating caregiver burden and enhancing the wellness of caregivers and their care recipients and serve as a model for further exploratory studies of caregiver burden and its effects within the context of eldercare in facilities and informal caregiving in general.

Summary

Elderly family members, friends, and neighbors may gradually or suddenly lose their ability to care for themselves. Informal caregivers provide eldercare to those individuals. Their health and wellness can be affected by the multiple challenges of caregiving resulting in caregiver burden. Informal caregivers of ALF residents have a unique set of circumstances that may impact their perception of caregiver burden. Mitigating the effects of caregiver burden can lead to positive outcomes of health and wellness for the informal caregiver and the care recipient. ALF staff must be invested in decreasing caregiver burden among the informal caregivers of residents in their facilities. Public health professionals must address caregiver burden by better understanding this phenomenon. The number of public health studies exploring caregiver burden are sparse. The lack of qualitative studies exploring caregiver burden limits the insights of public health professionals into the lived experience of informal caregivers experiencing caregiver burden. To address this knowledge gap, I conducted a qualitative study exploring the perceptions of caregiver burden by informal caregivers of older adults living in ALFs.

In Chapter 2, I offer a thorough review of my choice of conceptual framework, the SEM. I discuss the relevance of the SEM to my study and how its elements align with my research topic of understanding the perceptions of caregiver burden among informal caregiver burden of older adults living in ALFs. Additionally, I provide an exhaustive review of the search process for pertinent literature on informal caregiving, caregiver burden, and the effects of caregiver burden. To do this, I describe related studies of those constructs, their relevance, how researchers have approached caregiver burden, the strengths and weakness of those approaches, and a justification for my conclusion that there remains a knowledge gap related to this problem.

Chapter 2: Literature Review

There have been several recent qualitative efforts to explore the effects of caregiver burden. For example, Lilleheie et al. (2021) explored the phenomenon of informal caregiving in the first 30 days after a perceived early discharge from hospital. They concluded that when caregivers perceived that the discharge of their loved one was premature, the abrupt role adjustments they endured led to strain. In a recent study in Hong Kong, China, using the SEM to identify factors at each level to assess caregiver readiness that impact caregiving outcome, Wang et al. (2020) concluded that at each level, there were modifiable factors such as patient behavior problems, caregiver efficacy, and social support and nonmodifiable factors such as duration of caregiving, gender, and level of education that impacted the informal caregiving experience. The researchers advocated for health professionals to be mindful of those factors when developing caregiver interventions.

In this chapter, I offer a thorough review of the conceptual framework chosen for this study, the SEM. I discuss the relevance of the model and how its concepts and constructs align with my research topic of exploring caregiver burden among the informal caregivers of ALF dwelling older adults. Additionally, summaries of key studies related to caregiver burden are provided. I also offer an exhaustive review of my literature search process to include search terms, pertinent literature related to my study, and how the conclusions of those studies have influenced my research.

Problem Statement

The need to become an unpaid eldercare provider can happen suddenly with little or no warning to the informal caregiver or the eldercare recipient and can result in many life challenges for the caregiver (Kent, 2020). A few examples of challenges facing informal caregivers include a lack of preparedness for assuming the caregiver role, a sense of obligation for filling in the gaps of formal service provision and adjusting to the variability of difficulty and demand of caregiving (Lieshout et al., 2020). The multiple challenges that impact informal caregivers are collectively known as caregiver burden (Ghazawy et al., 2020; Rodger et al., 2015). Caregiver burden can lead to decreased mental health in caregivers from social isolation, decreased economic status for caregivers and their families because of greater expenses and withdrawal from work, and decreased physical health in caregivers due to the physical burden of caregiving and a neglect of one’s own health needs (Berglund et al., 2015). Caregiver burden has also been associated with negative effects on the care recipient’s wellbeing such as a decline in function (Stall et al., 2019). The impacts of informal caregiving changes little when older adult care recipients transition to ALFs or residential living (Turcotte and Sawaya, 2015, as cited in Hainstock et al., 2017). Care management, resource management, overseeing family access and adjustment, and managing emotions such as guilt emerge as additional factors that can impact caregiver burden following the transition to an ALF (Hainstock et al., 2017; O’Hora & Roberto, 2019).

Public health plays a critical role in addressing the chronic health conditions of older adults (De Biasi et al., 2020). Public health professionals have been charged with meeting the needs of the informal caregivers who provide eldercare (Hanson et al., 2019). The Healthy People initiative, sponsored by the U.S. Department of Health and Human Services, has encouraged public health professionals to focus on informal caregivers more directly by including an indicator that addresses the informal caregivers' perceptions of available caregiver support services (Prohaska et al., 2012). Nearly a decade later, the CDC (2019) issued a call to action to continue to address the burdens and needs of informal caregivers.

From an epidemiological public health perspective, to best address the needs of informal caregivers and understand caregiver burden, public health professionals must understand caregiver burden prevalence, characteristics, and health effects (Prohaska et al., 2012). From a community health perspective, public health professionals have directed that public health must explore ways to better understand the incidence and distribution of caregiver burden to address the promotion of caregiver burden mitigation strategies and preserve the wellness of caregivers and their frail elderly care recipients (Goodman et al., 2014). From a social justice perspective, public health professionals have advised that public health must promote policies to protect and support informal caregivers and preserve a degree of autonomy among their care recipients (Lindemann-Nelson, 2012).

A critical step to addressing this important issue of caregiver burden is conducting more research to better understand the depth and impact of the problem. Public health professionals have recognized the importance of a greater exploration of informal caregiving and caregiver burden and have advocated for further research. Berglund et al.

(2015) discussed that further research into health outcomes among caregivers was needed to learn which factors mediate the caregiver role to the associations of lower health outcomes. Biello et al. (2019) suggested that future qualitative work was needed to explore the perspectives and experiences of caregivers without formal support services. Further research of the complex relationships between caregiver burden and health status is needed to inform policy makers interested in social justice initiatives (Swartz & Collins, 2019). Kent (2020) highlighted caregiver burden as a unique public health challenge and advocated for further research that explored the complexity of contextual factors that affect emerging adult caregivers. Morelli et al. (2019) promoted further public health consideration of location and access to support services for informal caregivers. Rabarison et al. (2018) promoted the importance of informal dementia caregiving as a public health issue and called for future research that highlighted the economic contributions of informal caregiving and the impact of burden. In their seminal article, which continues to be widely cited, Talley and Crews (2007) had strongly advocated for research by public health professionals of the lived experiences of informal caregivers and their burden as a public health issue. As ALFs continue to emerge as viable options for residential care, researchers must continue to express the need to gain a deeper understanding of the phenomenon of the informal caregiving to ALF residents (Hainstock et al., 2017; O’Hora & Roberto, 2019).

Purpose of the Study

Both the WHO and the CDC have expressed the importance of health systems focusing on the needs of informal caregivers and the demands of caregiving (CDC, 2019;

WHO, 2017). The purpose of this study is to gain a greater understanding of how informal caregivers of older adults living in ALFs perceive caregiver burden and its effects on their physical health, mental wellbeing, economic stability, and the health and welfare of their care recipients. Public health researchers have conducted quantitative analyses of caregiver burden, and the CDC has included questions on informal caregiving in the Behavioral Risk Factor Surveillance System, a national survey that serves as a secondary data source for researchers studying health behaviors and related risks (Edwards et al., 2020). While quantitative studies can capture statistical relationships and associations between the various factors related to caregiver burden, and recognize and explore the multidimensional interplay of those elements through statistical analysis, the impact on the greater context of caregiving, especially the deeper exploration of lived experiences is best explored by public health professionals using a qualitative approach because the researcher can better interpret the narratives to learn what it is really like to be an informal caregiver who is experiencing caregiver burden (Sharif et al., 2020). Few studies of caregiver burden in public health literature are qualitative and some authors have identified this lack of phenomenological study by calling upon public health researchers to explore the multifactorial characteristics and interplays of caregiver burden through qualitative analysis (Berglund et al., 2015; Riffin et al., 2019). Additionally, there have been few studies that have explored family caregivers’ perceptions of stressors related to residents of ALFs. Adding this qualitative study to the body of knowledge will help public health professionals better address major functions of public health related to caregiver burden: to promote the health of individuals and their communities, encourage multisectoral involvement, and create the scientific foundation necessary to inform policies and interventions (WHO, 2018).

Literature Search Strategy

For this study, I had access to four digital university libraries: Walden University, Quinnipiac University, University of Connecticut, and Sacred Heart University. I also used Google Scholar, PubMed Central, Citation Machine, and Vital Source for textbooks. Frequently, the university libraries were linked to content providers such as EBSCO, ProQuest, and Elsevier. Occasionally, peer-reviewed articles were open access.

The major key search terms I used for my literature review included individual concepts such as *informal caregiver*, *caregiver burden*, *care recipient*, *assisted living facility*, *social ecological model*, *public health*, *well-being, lived experience*, and *qualitative*. I also used combinations of those terms and variations or synonyms of search terms. For example, search engines often suggested that additional terms be included such as *family caregiver* for *informal caregiver*. Recommendations from the Walden University librarian for refining the search process were welcomed and included in the study.

For the search process, I made a list of possible terms after rereading my approved premise. Search terms and their combinations yielded varying results. I then reviewed the suggested articles by reading the abstracts and conclusions. If an article was promising, I added it to my Endnote database, which allowed me to catalog and organize my sources, and formulate the citations. I used the Endnote (Versions 20 and 21) software to read and markup the articles I read. I also followed a similar procedure with textbooks, reports, and pamphlets which I had purchased from Amazon or acquired open source over the internet. Through Endnote, I have had searchable access to my entire article and reference library. I focused on using references from within the past 5 years. Occasionally, when explaining an established concept such as the model I used in my study, I used older seminal works such as *The Ecology of Human Development* by Uri Bronfenbrenner (1979), who first developed the ecological model.

Conceptual Framework

The Social Ecological Model

The SEM is the conceptual framework I have chosen for this study. In a 2007 public health journal article, Eckenwiler discussed using an ecological model when addressing the complexity of caregiving. The author stated that all the forces that shape the context of caregiving should not be considered individually but rather as a whole, to reveal the complex interconnections and their effects. These included the caregiver, the care recipient, nongovernmental and not-for-profit agencies, and policymakers that shape economics and healthcare (Eckenwiler, 2007). Despite being developed in the 1970s, the SEM has continued to be relevant and contextually adaptable. I now highlight several recent public health studies that have used the SEM as a model.

There are several reasons to support the use of the SEM as the underlying model for this study. I had become familiar with the SEM through previous research. However, I was initially interested in using knowledge translation as a conceptual framework to explain the process of how knowledge is modified and adapted to the local context of informal caregiving (Foord, 2021). However, as my study evolved, it became clear that knowledge translation was too linear to describe the dynamic interplay between the many elements that contribute to caregiver burden. Additionally, the focus of my study shifted from providing services to mitigate caregiver burden to exploring the caregivers' perceptions of their burden. Another framework I considered was the health belief model, which recognizes personal beliefs regarding susceptibility, severity, benefits, and barriers related to behavior change (Bishop et al., 2015). I then acknowledged that my research questions had evolved to seek to recognize the factors that influenced caregiver burden and its effects, and not necessarily how to modify caregiver behavior. The health belief model may still be suitable for a study that addresses caregivers and their need to change behaviors to mitigate the impact of caregiver burden once there is understanding about which behaviors and behavioral characteristics contribute to burden.

As a model, the SEM provides a practical and dynamic lens through which to understand the constructs of influencing and being influenced by the multiple levels of the SEM. In Wang et al.'s (2020) study in Hong Kong, China, investigators used the SEM to identify factors at each level to assess caregiver readiness that impact caregiving outcome. They concluded that at each level, there are modifiable factors such as patient behavior problems, caregiving efficacy, and social support and non-modifiable factors such as caregiving duration, gender, and level of education that impact the informal caregiving experience. They advocated for being mindful of these factors when developing formal caregiver interventions by health professionals. I concluded that the SEM offers a sound framework for organizing and explaining the interplay between SEM levels as they relate to the development of caregiver burden, but also offers a practical way to organize responses to mitigate burden through purposeful interventions.

History of the Model

Ecological systems theory was first conceptualized and used by Uri Bronfenbrenner, a developmental psychologist, to help explain how children and their environments interact and how those interactions influence a child's development (Bronfenbrenner, 1979). He detailed the components of his model in the publication *The Ecology of Human Development*. He stressed that roles and contexts evoke the behaviors and tendencies the environment associates with those roles and within those contexts (Bronfenbrenner, 1979). He placed the individual in the middle of gradually larger nesting circles of various contexts or systems of influence (Bronfenbrenner, 1979). He labeled those contexts or systems according to their level of intimacy to the individual resulting in the micro-system, the mesosystem, the exosystem, and the macrosystem, with the latter representing the level of broadest societal influences (Bronfenbrenner, 1979; Onwuegbuzie et al., 2013). As the theory developed into the SEM, the construct of health was more greatly conceptualized in public health resulting in the use of the SEM to describe disease prevention and health promotion. The SEM is now an accepted model for quantitative, qualitative, and mixed-methods research (Kilanowski, 2017). As a framework for illness prevention and health promotion, the SEM can enhance our understanding of the dynamic, interrelated, and multifaceted connections and intersections between individuals and their environment (Leung et al., 2021).

The SEM is very adaptable to various contexts and has emerged in numerous forms. For example, the most widely used version of the model includes the five levels: individual, interpersonal, organizational, community, and societal. However, in some instances, the organizational level and the community level are joined, such as on the CDC website, which has adopted the four-level SEM as a framework for violence prevention (CDC, 2021). Additionally, some experts have also inverted the community and organizational levels, depending on their needs and uses.

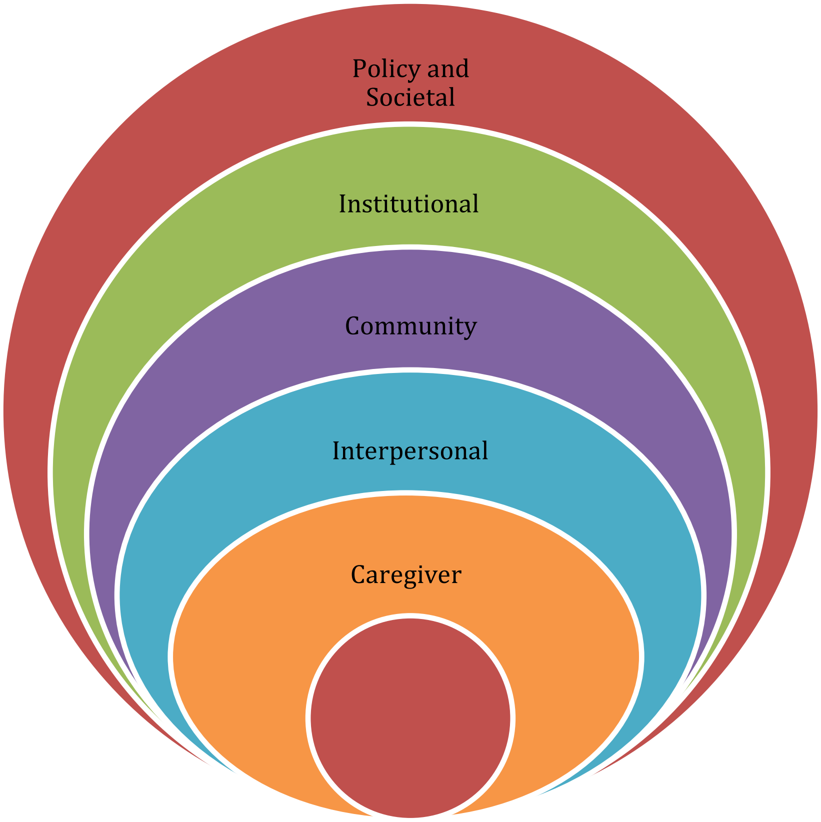
Levels of the SEM

The first and innermost level focuses on the individual. Knowledge, attitude, behavior, self-awareness, and experience are common concepts and constructs associated with the individual level. This is the most basic level for targeted health promotion activities. For this study, the individual refers to the informal caregiver. The second level is the interpersonal level, which Bronfenbrenner called the microlevel. Important concepts at this level are family, friends, and social networks. The perceptions and attitudes of social networks are important influences. The third level is the community level, or meso-level. Relationships between community organizations and their leaders are important concepts and they are strongly influenced by interventions that address health at the community level. The next level, the institutional, organizational level, or exo-level represents relationships between organizations and social institutions. Common considerations at this level are capacity, environment, and service delivery. The final level, the policy or societal level is the macrolevel. Here, relationships with legislation and society are the focus, and influences such as policy, social norms, and the perceptions and attitudes of policy makers and leaders are to be considered (Bronfenbrenner, 1979; Golden & Earp, 2012; Onwuegbuzie et al., 2013; Simpson, 2015).

When considering caregiver burden using the SEM as a conceptual framework, the informal caregiver would be at the middle of the model. Here, the knowledge, beliefs, and self-concept related to caregiver burden are considered. Individual strategies to promote behavior change to mitigate caregiver burden are the aim at this level. At the interpersonal level, the care recipient, other family, friends, peers, and co-workers that surround the individual influence their behavior regarding caregiver burden. At the next level, community factors describe the relationships between community organizations and institutions such as local senior centers and residential facilities. They contribute to community norms. The organizational level includes the workplace, faith-based organizations, and social institutions. They often have formal policies and informal norms regarding attitudes toward caregiving for the elderly. The final policy or societal level influences such things as health care reimbursement, attitudes and policies toward informal caregivers, and culture specific values and attitudes such as filial piety (Simpson, 2015).

Figure 1

Social Ecological Model.



Adapted from "Using the Socio-Ecological Model to Frame Agricultural Safety and Health Interventions," by B. Lee, C. Bendixsen, A. Liebman and S. Gallagher, 2017, *Journal of Agromedicine*, *22*(4), p. 299. (https://doi.org/10.1080/1059924X.2017.1356780)

The SEM recognizes the inherent complexity of the factors that shape a phenomenon and provides a means by which to structure the varying factors and their interplay (Lang & Rayner, 2012; McCormack et al., 2017). Using the SEM to explore caregiver burden not only allows consideration for the multidimensional intertwining of factors that lead to caregiver burden and the perceived impact that the caregiver burden has on the informal caregiver, the care recipient, and their dyadic relationship, but also serves as a framework for developing interventions at and across the various levels of the model.

Literature Review Related to Key Variables and/or Concepts

A historical reference by Talley and Crews (2007) described caregiving as multidimensional and varying in complexity, intensity, and duration. The authors promoted informal caregiving as a public health issue, described informal caregivers as demographically diverse, and identified caregiver burden as a health concern. Most recently, government and nongovernment agencies and researchers have restated the importance of a public health approach to addressing the caregiver burden of informal caregivers (Capistrant, 2016; Centers for Disease Control and Prevention, 2019; Koca et al., 2017; Reinhard et al., 2019; Shiba et al., 2016)

Caregiver Burden

Caregiver burden describes the problems experienced by informal caregivers that can impact the physical, emotional, social, and financial well-being of informal caregivers (Lilleheie et al., 2021). Berglund et al. (2015) discussed the apparent negative implications of caregiver burden on informal caregivers and identified that self-rated health was a significant indicator of poor health outcomes among informal caregivers. This gives credence to the soundness of the relationship of caregiver perceptions of burden and wellness. Kent (2020) promoted the need for qualitative studies of caregiver burden by discussing the importance of understanding the unique needs of young adult caregivers, which supports the notion of the multifactorial nature of caregiver burden.

Assessment of Caregiver Burden

As more patients with chronic conditions were being discharged home and more family members and friends were challenged to provide informal care to older adults, interest in developing caregiver assessments to identify the unique issues, needs, strengths, resources, and utility of caregivers rose (Family Caregiver Alliance, 2012). Measures to assess their knowledge, skills, capacity, and their vulnerability to caregiver burden needed development (Family Caregiver Alliance, 2012). In 2012, the Family Caregiver Alliance released the second edition of their inventory of caregiver assessment measures and cataloged over 200 assessments and measures, many of which address caregiver strain, stress, or burden (2012). One comprehensive assessment that was first developed in 1989, was the Caregiver Burden Inventory. Now called the Caregiver Inventory Assessment, it is a 24-item measure that assesses the caregiver's burden in relation to time restrictions, congruency in development and achievement with their peers, level of perceived physical burden, level of social burden, and level of emotional burden (Family Caregiver Alliance, 2012; Lane et al., 2017; Novak & Guest, 1989). The Brief Assessment Scale for Caregivers is a 14-item standardized measure that focuses on assessing the emotional factors of caregiver burden but also addresses positive aspects of the caregiver dyad (George et al., 2016; Glajchen et al., 2005). A final significant measure is the Zarit Burden Interview (ZBI; Al-Rawashdeh et al., 2016). It is a 22-item self-assessment in which caregivers use a 5-point Likert scale that was recently used in a study to explore caregiver burden in informal caregivers of older adults with chronic conditions. The authors of the study found the ZBI to have good validity. The ZBI focuses on the perceived consequences of caregiving, the care recipient’s dependence, exhaustion and uncertainty, guilt and self-criticism, anger, frustration, mental and emotional burden, and role strain (Al-Rawashdeh et al., 2016). Due to its validity, its breadth, its self-assessment feature, and ease of use (Hagell et al., 2017), I used the ZBI as a tool to screen participants for inclusion in my study.

The large number of available caregiver burden measures characterizes the variety of situations in which clinicians and researchers have sought to gain insight into the instances of caregiver burden; from chronic care recipient conditions such as dementia, to individual constructs such as self-rating of caregiving confidence, and conceptual domains such as context of care, caregiver perceptions, well-being, skills, and abilities and needs. This interest has resulted in the over 200 cataloged measures identified in the 2012 inventory (Family Caregiver Alliance, 2012).

Complexity of Caregiver Burden

Caregiver burden can be classified into two dimensions: objective and subjective burden. Objective burden describes the physical and tangible characteristics of burden such as investment of time and resources. Subjective burden describes the emotional impact of providing care (Lilleheie et al., 2021) Caregiver burden is often also classified by intensity, with the level of burden ranging from low to high and with intensity representing the magnitude of the caregiving by time and effort (Prevo et al., 2018). Capistrant (2016) has suggested that the multilevel, dynamic, and complex factors that influence caregiver burden should be studied using the various levels of the SEM. While the influential factors may identify primarily with one level, they may also extend into other levels and be multilevel. As is characteristic of the SEM, factors at one level can influence those of another to add to the complexity and variability of caregiver burden. I now summarize the key findings from literature of how the various factors interact with the different SEM levels for informal caregiving.

Individual Level Factors

This study has focused on informal caregivers and their caregiver burden. As such, the informal caregiver is positioned at the individual level. The informal caregiver's knowledge, attitude, behavior, self-awareness, and experience are common concepts and constructs associated with the individual level.

Informal Caregivers

Informal caregivers are individuals who provide unpaid assistance to family members or friends who can no longer care for themselves (CDC, 2019). They play a pivotal role in supporting the wellbeing, health, independence, and quality of life of their care recipients (As reported by Plothner et al., 2019 and Schulz & Eden, 2016 in Lilleheie et al., 2021). CDC recognized informal caregivers as an integral part of the health care system, and burden and poor health as possible negative consequences of informal caregiving (CDC, 2019). The CDC (2019) call to action outlined a strategy for addressing the need for informal caregivers to have greater recognition and access to local and system-wide support services. Reinhard et al. (2019) reported on a mixed-methods research study that offered great insight into the context and complexity of informal caregiving. Major findings of the study included the understanding that caregivers provide intense and complex care, that informal caregivers and their experiences are diverse, that social isolation compounds complex care, that increased care complexity increases the level of stress experienced by informal caregivers, and that informal caregivers lack support from health systems.

A recent estimate of the numbers of individuals providing informal care to adults aged 65 and older is 17.7 million (Pristavec & Luth, 2020). This amounts to over $470 billion in unpaid labor annually. Of those, 75% are close family members and over half are female: either the older adult's wife, daughter, or daughter-in-law. The remainder consists of other family members and friends (Pristavec & Luth, 2020). While most informal caregivers are female and middle-aged, informal caregiving is demographically diverse and cross-generational (Reinhard et al., 2019)

In a 2019 special report on caregiving complexity funded by the AARP, the major findings identified that many informal caregivers provide complex medical care to their care recipients, with close to three quarters of them also engaging in pain management (Reinhard et al., 2019). This care has traditionally been exclusively within the scope of care of medical professionals.

Informal caregivers also feel socially isolated and feel they have no choice about whether they should provide the care, often out of a sense of obligation or their presumption that their caregiving will keep their care recipient from needing to transition to a higher level of care, such as a nursing home. In general, informal caregivers are afraid of making mistakes. There is a correlation between that fear and care complexity. Together with fear; stress, worry, social isolation, and financial concerns also increased with the rise in complexity of care (Reinhard et al., 2019). Many informal caregivers have felt they were not ready and ill prepared to assume their new caregiving role. They also felt they were largely on their own, without the benefit of community, institutional and societal and policy support. Finally, the major findings of the report concluded with the informal caregivers' perceptions that the formal health care continuum was not ready to provide them with the needed information and support (Reinhard et al., 2019).

Caregiver Gender

The gender of the caregiver can have an impact on how they experience caregiver burden. In the United States as well as in other countries, women are reported to be the predominant informal caregivers of older adults (Sharma et al., 2016). According to stress and coping theories, there is a greater likelihood that women are exposed to greater caregiver stressors than men (Sharma et al., 2016). Caregiver studies that have focused on gender, have identified that women are more likely than men to take on greater caregiver tasks and tasks that focus on personal care (Sharma et al., 2016). The National Alliance for Caregiving (2020) has reported that 61% of caregivers of older adults are women, with more than a third being daughters (DiLeone, 2021). It has been suggested that as societal roles change and more men take on greater personal care and other caregiving tasks, gender-related caregiver stress perceptions may change (Sharma et al., 2016).

In studies highlighting gender differences, several themes have emerged. For example, many studies have concluded that women spend more time providing care and females are more likely to provide personal care to care recipients (Sharma et al., 2016). This may be explained by considering that men may be less likely to provide personal care to their female care recipients (Evans et al., 2011), who outnumber their male care recipients two-to-one (National Alliance for Caregiving, 2020). Role strain has been more greatly associated with women than men, with women experiencing greater limitations at work and in their social lives because of the care they provide (Sharma et al., 2016). The positive consequence of satisfaction in caregiving has emerged as being inclusive, with several studies concluding that women are less satisfied with their caregiver role, but almost as many studies not noting a significant difference between the genders (Sharma et al., 2016). Sense of obligation to care was more greatly realized by women with constructs such as altruism and self-sacrifice emerging, while some studies described men as experiencing sentiments such as commitment and family responsibility (Sharma et al., 2016).

According to Cloyes et al. (2021) and Valenti and Katz (2014) the lesbian, gay, bisexual, transgender, queer, and otherwise non-straight and/or non-cisgender (LGBTQ+) population has recently emerged in a small number of studies regarding informal caregiving. LBGTQ+ caregivers have described factors leading to their perceptions of caregiver stress as starkly different from their cisgender counterparts. The main constructs leading to increased caregiver burden, that were discussed in two recent studies included the expectation of complications in communicating with health care workers, the lack of LBGTQ+ specific resources, the difficulty with dynamics within the family, the sense of having to alter aspects of oneself to appear more conforming, and an overall expectation of poor treatment and discrimination (Cloyes et al., 2021; Tomás et al., 2016). A conclusion of both studies was that more training of healthcare workers could lead to more knowledgeable staff resulting in a greater sense of comfort and decreased burden (Cloyes et al., 2021; Valenti & Katz, 2014).

Caregiver Race and Ethnicity.

Almost 40% of caregivers of older adults belong to a race or ethnic minority group. Of those, 14% are African American, seventeen are Hispanic, 5% are Asian American, and 3% identified as *other* (National Alliance for Caregiving, 2020). Minority informal caregivers are more likely to be female, single and someone other than the spouse of the care recipient, belong to the sandwich generation; caring for an older adult and children or grandchildren, live with their care recipient and be head of household, and earn less than $50,000 each year (McLennon et al., 2020).

Some studies have concluded that African American informal caregivers experience less caregiver burden that caregivers of other minorities and Caucasians. Cultural factors may play a role in less perceived stress, burden, and depression. In general, African American caregivers rely more on spirituality, practice less avoidance coping strategies, and demonstrate greater resourcefulness (McLennon et al., 2020). Some researchers speculate that African Americans are less likely to express perceptions of caregiver burden: “It’s just part of life.” Cultural female role expectations and the sense of duty to care may also play a role (McLennon et al., 2020). The concept of familism or priority to family has been speculated to be a reason for the lessor degree of experienced caregiver burden (McLennon et al., 2020).

Filial piety as it relates to perceptions of caregiver burden among Asian American informal caregivers has been studied in detail (Pan et al., 2022). Filial piety is transcultural but is predominant in Eastern cultures. It is the concept that early on, children are nurtured to one day *repay* their parents. The sense of commitment to revere and care for one's elders supplants other initiatives such as taking care of oneself and tending to other roles and obligations an adult child caregiver might have (Pan et al., 2022). The consequences of filial piety can result in greater role strain and sacrifice as the caregiver's sense of duty clashes with the influences of Western culture. In contrast, a mild benign effect was noted by researchers conducting studies with subjects who had greater access to societal resources that supported Eastern cultures and norms (Pan et al., 2022).

Two studies that explored Hispanic perceptions of caregiving revealed that familism played a role in outcomes of caregiver burden (Balbim et al., 2019; Smith et al., 2020). Additionally, the concept of fatalism, the belief in the predetermined (Balbim et al., 2019), and Marianismo, the belief in a series of constructs that revolves around the veneration of the female virtues (Smith et al., 2020), influenced informal caregiver perceptions of caregiving (Balbim et al., 2019). Latino caregivers relied less on venting through social outlets for stress relief: they were less likely to seek support from friends and groups. There was a strong sense that supporting family members physically, financially, and emotionally was part of a predetermined path and that it was God's will. Spirituality emerged as not only a strong cultural influence but also a coping strategy that mildened the impact of caregiver-related stressors. One study revealed several themes that mostly female informal caregivers employed as coping strategies. Avoidance was practiced by simply "walking away" when the care recipient became aggressive or overbearing. This served to defuse the situation and the care recipient’s hostility lessoned. Keeping busy was a strategy reported by some study participants. This included work, tending to the needs of pets, and completing chores. Engaging in self-care activities emerged as a strategy for mitigating stressors related to informal caregivers. Rationalization or recognizing that the care recipient is not well, and that the dependencies and behaviors experienced by them are not their fault was raised as a theme. Cultivating meaningful relationships with others and engaging in physical activity where additional themes that were mentioned to mitigate stress related to informal caregiving (Balbim et al., 2019) Overall, both studies agreed that environments that promoted providing care within the cultural context of familism, fatalism, and marianismo had a positive effect on the perceptions of caregiver burden (Balbim et al., 2019; Smith et al., 2020).

Interpersonal Level Factors

The interpersonal level focuses on concepts such as family, friends, and social networks. The perceptions and attitudes of social networks are important influences. One important entity at this level is the care recipient. Together with the caregiver, the care recipient forms a dyadic unit and is often looked at within this context (Meyers et al., 2020). On the interpersonal level, other family members, who may also be caregivers, are considered.

Elderly Care Recipients

In 2019, there were over 54 million Americans aged 65 years and older (U.S. Census Bureau, 2020). The United States population of residents ages 65 years or older has grown 15.1% over the past 10 years, but the total growth of the U.S. population was only 9.7% (Dapice Wong, 2015). The fastest growing segment of the U.S. population is ages 45-64 years (a 31.5% increase from 2000 to 2010), which is primarily due to the aging of the baby boomer generation (Parkman, 2021, June 7). Additionally, the U.S. population is living longer, as indicated by an increase in the median age of the United States population. For the first time in history, the older segment of the population in the United States grew faster than the younger segments, and this trend is expected to continue as people live longer (Dapice Wong, 2015)."

Many of these older adults remain healthy and continue to live independently. However, 80% of older adults suffer from at least one chronic condition, and close to 70% have two or more chronic conditions that can impact their ability to live independently (De Biasi et al., 2020). Chronic illnesses such as diabetes, heart disease, and dementia can result in older adults losing their ability to be independent and require the care of others (De Biasi et al., 2020). Those older adults either transition to a higher level of formal care, such as a nursing home (Hainstock et al., 2017) or an ALF (Parkman, 2021).

Older Adult Transition to Dependency

The transitions of older adults into some level of dependency can be for health or situational reasons. Health-related transitions are the result of changes to the health and well-being of the body, while situational transitions may include changes in the environment or one's roles (Dapice Wong, 2015). These transitions can be considered transactional events that can cause discontinuity and it can be a time of increased stress and changes in personal well-being, environmental imbalance, and role disengagement for the older adult (Dapice Wong, 2015) as well as for the unprepared prospective informal caregiver (Reinhard et al., 2019). Role strain is stress that can occur when the role expectations of the individual exceed the capacity of the individual to meet the needs of the current roles (Olsen & Dapice Wong, 2015). The level of stress experienced by the elderly can depend on the degree of predictability related to the environment or to the fluidity of role transition. The onset of disability can result in an array of unplanned and unpredictable environmental transitions, and in the acute phase of a condition that causes disability, the older adult may experience a variety of transitions within the health care continuum that can cause stress for them and their informal caregiver (Dapice Wong, 2015).

Family Members

Caregiver responsibilities typically fall predominantly onto one person. When other family members are available, they may also be called upon to participate in caregiving. The inequitable dissemination of caregiving duties can lead to conflicts and dissention and can result in an imbalance within the family and increase experienced caregiver burden. The support of the family is a highly desirable quality that can have a positive influence on the wellbeing of both the primary informal caregiver and the care recipient (da Silva-Falcão et al., 2016).

Cohesion, hierarchy, and flexibility are key dimensions in the structure of family relations (da Silva-Falcão et al., 2016). Cohesion can be described as the "emotional bond or connection between family members" (Fleck & Brown, 1961 as cited in da Silva-

Falcão et al., 2016, p. 62). Hierarchy has been described as the sequential levels that denote the authority attributed to each family member which helps define the status, power, and roles held by each of them. Family roles take on social trajectories, and gradually, the lives of family members become interwoven with social roles (Koehly, 2016). A strong emphasis should also be placed on understanding hierarchy as it relates to the family system to allow for greater flexibility in decision-making and a more functional distribution of tasks (da Silva-Falcão et al., 2016). It was noted that family cohesion does not change significantly between the varying degrees of care recipient dependence. Primary informal caregiver children generally hold greater hierarchical power than their siblings, and children often experience hierarchical power commensurate to the disability experienced by their care recipient parents (da Silva-Falcão et al., 2016).

Inevitably, some tension or conflict may arise within the family system, especially among siblings. As the parents become more dependent and the primary informal caregiver assumes more duties, they also experience higher levels of conflict, criticism, and demands. Care recipients then often show favoritism to their primary caregiver children. Favoritism can lead to family system conflict and greater burden and is most often observed between parents and their youngest children, and by parents and their opposite gender children (da Silva-Falcão et al., 2016; Pillemer & Gilligan, 2018).

The dyadic relationship between the caregiver and the care recipient has emerged as a focus of discussion and research. Lilleheie et al. (2021) have discussed the potential to focus mostly on the caregiver when considering caregiver burden. They emphasized the need to also look at the care recipient's everyday experiences and their perceptions of how they contribute to the burden experienced by their caregiver (Lilleheie et al., 2021). Pucciarelli et al. (2017) emphasized the importance of further dyadic-level research, and they made a strong case for addressing the caregiver-care recipient dyad as an entity when addressing health interventions. Meyers et al. (2020) have reported on approaching patients and their caregivers as a dyadic unit rather than separate entities.

Community Level Factors

Relationships with community level entities such as formal caregivers, ALFs and their management, and their parent companies are important concepts, and they are strongly influenced by interventions that address health at the community level. Community level entities can have an impact on caregiver burden by offering paid support services to older adult care recipients and their informal caregivers. However, there can also be increased stress by ALF dwelling care recipients who anticipated aging in their familiar home and their informal caregivers who are tasked with making decisions about and coordinating levels of care within the ALF (Jaschinski & Ben Allouch, 2019).

Formal Caregivers

Formal caregivers are nurses, therapists, and other individuals who offer care to the care recipient and are monetarily compensated (Hajek et al., 2016). In 2017, in recognition of the frequent involvement in the direct care of care recipients by informal caregivers, the Centers for Medicare and Medicaid Services (CMS) revised their conditions of participation to include the education and training of informal caregivers by formal caregivers (Burgdorf et al., 2021). Interactions and supports by formal caregivers with informal caregivers and their care recipients can help to improve the quality of care provided to the patient, which has the potential to decrease caregiver burden (Burgdorf et al., 2021).

Assisted Living Facilities

ALFs are residential facilities for older adults who are no longer able to fully live independently (AARP, 2019). There are nearly 29,000 ALFs nationwide with almost one million available beds. ALF staff can assist or supervise residents with ADLs such as bathing, walking, dressing, toileting, transfers, and feeding. ALFs may also offer recreational and spiritual opportunities, wellness programs, housekeeping services, medication management, and transportation to and from appointments for their residents. ALFs sometimes have special memory care units for individuals with dementia. They also coordinate with health care agencies and clinics to offer a variety of health services to their residents (NCAL, 2018). There are 811,500 ALF residents nationwide, with 71% of them being women (NCAL, 2018). Over half of ALF residents are 85 years or older, 30% are 75 to 84, 11% are 65-74, and 7% are under 65 (NCAL, 2018). Two percent of older adults live in ALFs at an average cost of $4,576 and $9,000 monthly for a private apartment. Added care services come at an additional cost and full-time home health services can become costly. It is expected that over the next two decades, the number of older adults in the United States will continue to grow resulting in the need for an additional one million ALF beds (Parkman, 2021, June 7); more ALF staff will be needed and there will be a greater number of informal caregivers associated with the greater number of ALF residents.

There is growing interest in better understanding the interaction between ALFs and residents and their families. Kemp et al. (2019) have suggested that dynamic care networks should include family and friends. They promoted a health care mosaic that considered informal caregiver factors such as availability, willingness, ability, communication practices, knowledge, expectations, support levels, attitudes and beliefs, and resources (Kemp et al., 2019). Wilson (2019) sought to understand how knowledge influenced the attitudes of African Americans toward ALF living. The study found that most participants initially lacked knowledge about ALFs, but attitudes were generally positive. In her study, some perceptions of lack of trust were noted, which was then alleviated if a family member or informal caregiver began to actively monitor care (Wilson, 2019).

Institutional Level Factors

Institutional level factors look at relationships between organizations and social institutions. Common considerations at this level are capacity, environment, and service delivery. Organizational level factors can impact informal caregivers by mitigating the impact of health conditions through community education about caregiver burden and by lobbying for policy change (Golden et al., 2015). These organizations include special interest groups, community coalitions, and advocacy clusters, but they can also be local and state agencies (Golden et al., 2015) such as local health departments or state departments of aging and disability services. Some larger non-governmental entities can be found at a state and national level, with many national organizations having state or local chapters and all maintaining a robust internet presence. They may primarily address informal caregiving and related caregiver burden, or they may be more disease or condition specific. One such entity is the American Alzheimer’s Association (ALZ). The ALZ offers a wide range of support from educational courses on the characteristics of the disease to how to care for individuals with Alzheimer’s Disease (AD). Informal caregivers can register for courses, attend in-person caregiver support groups at one of their chapters, or attend a virtual support group or discussion. The ALZ also provides support and strategies for supporting individuals from informal caregivers to health care workers. The ALZ has a series of educational pamphlets that are typically displayed in senior residences, ALFs, senior centers, or health care facilities where individuals with AD or their caregivers may be served. The services ALZ provides are free and their helpline is available 24 hours per day (ALZ, n.d.)

Aside from its local and national efforts, the ALZ has also joined with international agencies to research and support individuals and their families in middle-income and low-income countries. This has led to partnerships with WHO, Alzheimer’s Disease International, and the organization’s counterparts in other countries that have reinforced local services for individuals with dementia and their families (Sexton et al., 2021).

Another national group that provides extensive services for informal caregivers is the National Alliance for Caregiving (NAC). As the name implies, the NAC was founded by combining the efforts of several national and federal organizations, some of which continue as their own entities. The NAC has a wide range of partnerships with other organizations to include AARP, that provides services to retired persons. The NAC supports local grass roots caregiver support efforts and is also active in nurturing alliance partnerships internationally (National Alliance for Caregiving, n.d.).

In addition to the national caregiver support entities that provide ongoing resources to informal caregivers, there are many local groups and organizations that focus their efforts within a geographic location. One such group is Caregiver Support Services. It is based in Omaha, Nebraska, and focuses on providing a wealth of resources to local formal caregiving agencies and informal caregivers (Caregiver Support Services, n.d.)

There are also many other examples of local caregiver support by faith-based organizations, ALFs, senior centers, hospitals, and universities. There are also do-it-yourself web sites, workbooks, and multimedia programs. As with the larger national organizations, they can focus on an aspect of caregiving or on a condition or disease. One such effort is a book in its seventh edition, *The 36-Hour Day*. The first edition appeared 40 years ago and has been meticulously updated to include new content about caregiving and caregiver self-help (Mace & Rabins, 2017). I will be offering this book to study participants.

Policy and Societal Level Factors

This level addresses influences such as policy, social norms, and the perceptions and attitudes of policy makers on informal caregivers and the caregiver dyad. Policy makers and social norms have a direct impact on constructs related to informal caregiving. Consequently, policy makers such as CMS and cultural norms also directly impact caregiver burden and its effect.

Societal Implications

Social norms and culture influence the behaviors of informal caregivers (Schulz et al., 2020). For example, there are greater societal and cultural demands on women to more readily adopt the caregiver role (Sharma et al., 2016). It has been suggested that as societal roles change and more men take on greater personal care and other caregiving tasks, the distribution of gender related caregiver stress perceptions and social norms related to that stress may change (Sharma et al., 2016). In contrast, religion, spirituality, and related social support have been shown to positively affect caregiver burden by creating resiliency, especially among women (Koumoutzis & Mehri, 2022) resulting in greater health outcomes among care recipients and their informal caregivers.

Public Health Policy

Talley and Crews (2007) made a strong case for public health initiatives to address research to explore caregiver burden and interventions to address the needs of caregivers. Arai and Zarit (2011) reinforced the need to recognize caregiver burden as a public policy issue, also being borne by society and not only the individual informal caregiver. They spotlighted initiatives in Japan that addressed long-term care insurance that recognized and supported the need for funding caregiving. They concluded that the Japanese efforts let to greater policy and societal recognition of informal caregiving and caregiver burden resulting in decreased caregiver burden (Arai & Zarit, 2011). The authors also highlighted initiatives in Scandinavia that focused on greater public recognition of the potential need for becoming an informal caregiver as part of a greater societal obligation (Arai & Zarit, 2011)

Public Policy and Research

There is a need for further epidemiologic inquiry into caregiver burden because there is a lack of general overview of informal caregivers and caregiver burden – many studies focus on one aspect, but the limited scopes and resulting knowledge are not encompassing enough to warrant a comprehensive overview. For example, Lilleheie et al. (2021) reported that there are few studies that explore the recent trend of “quicker and sicker” discharge in which older adults are discharged for hospital more quickly and with greater, more complex needs (2021). Wang et al. (2020) advocated for further research to identify the impact of aging and chronic disease on informal caregiving. For clarity: caregiver interventions are not to address the act of informal caregiving, but to understand and address informal caregivers’ health and to address the causal pathways that lead to caregiver burden (Capistrant, 2016).

From an epidemiological perspective, to best address the needs of informal caregivers and understand caregiver burden, public health professionals must understand caregiver burden prevalence, characteristics, and health effects (Prohaska et al., 2012). From a community health perspective, public health professionals must explore ways to better understand the incidence and distribution of caregiver burden to address the promotion of caregiver burden mitigation strategies and preserve the wellness of caregivers and their frail elderly care recipients (Goodman et al., 2014). From a social justice perspective, public health professionals must promote policies to protect and support informal caregivers and preserve a degree of autonomy among their care recipients (Lindemann-Nelson, 2012). Berglund et al. (2015) emphasized that further research into health outcomes among caregivers was needed to learn which factors mediate the caregiver role to the associations of lower health outcomes. Biello et al. (2019) suggested that further qualitative work was needed to explore the perspectives and experiences of caregivers without formal support services. Kent (2020) highlighted caregiver burden as a unique public health challenge and advocated for further research that explored the complexity of contextual factors that affect emerging adult caregivers. Morelli et al. (2019) promoted further public health consideration of location and access to support services for informal caregivers. Rabarison et al. (2018) promoted the importance of informal dementia caregiving as a public health issue and called for future research that highlighted the economic contributions of informal caregiving and the impact of burden. Finally, as ALFs continue to emerge as viable options for residential care, researchers continue to express the need to gain a deeper understanding of the phenomenon of the informal caregiving to ALF residents (Dunn Cruz, 2006; Hainstock et al., 2017; O’Hora & Roberto, 2019).

Social Justice as a Driver for Research on Caregiver Burden

In 2011, Buyck et al. emphasized that further research of the complex relationships between caregiver burden and health status was needed to inform policy makers interested in social justice initiatives. Most recently, Jawahir et al. (2021) also reinforced that greater insight into causal relationships between caregiver burden and health status would benefit to further inform social justice initiatives. Public health led social justice initiatives addressing caregiver burden can expose and mitigate the potential for exploiting the vulnerable population of informal caregivers new to caregiving. In his 2012 essay, Lindemann-Nelson described the *practical identities* of caregivers as being at risk. Practical identities can be understood to mean the value that an individual places on their roles and experiences within a given context (Lindemann-Nelson, 2012). The risk family caregivers face is the pressure to devalue their practical identities and therefore put at risk their participation in those established roles. Duration and intensity play a role in the impact on practical identity, which can lead to greater perceived caregiver burden (Lindemann-Nelson, 2012). A third social injustice to informal caregivers that can lead to increased caregiver burden is the perpetuation of patterns of injustice. These include task assignment related gender, imbedded patterns of communication that lack variability based on the characteristics of the informal caregiver (Lindemann-Nelson, 2012) to include race (Noonan et al., 2016). These may include lack of caregiver access to knowledge such as with eHealth and health literacy (Latulippe et al., 2020), lack of resources due to economic status or geographical location, and other social determinants of health (Smith & Braithwaite, 2016).

Summary and Conclusions

In Chapter 2, I reiterated the problem and purpose of my study. I discussed my literature search strategy by discussing search terms and processes. I then reviewed the theoretical foundation for my study, the SEM. I related it to my study and provided literature to support my decision. I then conducted a comprehensive literature review of key concepts related to my study.

I used the SEM as a guide to organize my literature review. This strategy helped in supporting the benefit of the SEM as a model. The various levels of the SEM served as headings and a review of factors influencing caregiver burden assigned to each heading. I was able to offer the support of various authors in concluding that there are a variety of factors that can influence caregiver burden. The complexity, intensity, duration, and frequency of the factors have a strong role in defining each informal caregiver's level of burden. Conversely, some factors defined within the levels of the SEM can serve to mitigate the negative impact of others. The interplay of those factors can also influence the impact of caregiver burden and may serve as a starting point for using the SEM as a model for intervention by addressing the negative factors.

In the next chapter, I detail my research design and rationale. I discuss my role as the researcher. I also outline my methodology, instrumentation, recruitment strategy, and data analysis plan. I discuss any issues of trustworthiness, and I review ethical procedures. Finally, I provide a summary that serves as a segue into the fourth chapter.

Chapter 3: Research Method

The purpose of this qualitative study is to gain an understanding of how informal caregivers of ALF-dwelling older adults perceive caregiver burden and its effects on their physical health, mental well-being, economic stability, and the health and welfare of their care recipients. While quantitative studies can capture statistical relationships and associations between the various factors related to caregiver burden and recognize and explore the multidimensional interplay of those elements through statistical analysis, the impact on the greater context of caregiving, especially the deeper understanding of lived experiences is best explored by public health professionals using a qualitative approach because the researcher can better interpret the narratives to learn what it is really like to be an informal caregiver who is experiencing caregiver burden (Sharif et al., 2020). Few research studies of caregiver burden in public health literature are qualitative, and some authors have identified this lack of phenomenological study by calling upon public health researchers to explore the multifactorial characteristics and interplays of caregiver burden through qualitative analysis (Berglund et al., 2015; Riffin et al., 2019). Additionally, little is known about caregiver burden as it relates to the informal caregivers of older adults living in ALFs. Adding this qualitative study to the body of knowledge can help public health professionals and other professionals better address major functions of public health related to caregiver burden: to promote the health of individuals and their communities, encourage multisectoral involvement, and create the scientific foundation necessary to inform policies and interventions (WHO, 2018).

In this chapter, I outline and explain my study's research design, the rationale for the research design, and the research questions. I also include a description of my role as the researcher, and I address any professional relationships I might have with the study participants. I discuss biases and ethical concerns and provide justification for the incentives to participate in this study. I also discuss the relationship between saturation and sample size. Finally, I discuss instrumentation, procedures, my data analysis plan, and any issues of trustworthiness.

Research Design and Rationale

The following research questions have been addressed in this study:

1. What do informal caregivers providing eldercare to ALF residents perceive as factors that affect their caregiver burden?
2. What impact does caregiver burden have on the caregiver and their eldercare recipient as perceived by the informal caregiver?

I chose phenomenology as a research methodology because in phenomenological research, the investigator seeks to understand the lived experience of their research participants (Bloomberg & Volpe, 2019). This aligns with my objective of understanding the perceptions of informal caregivers of ALF residents. Other qualitative study approaches I could have chosen for this study include the case study approach or the ethnological study approach. However, case studies often focus on the complexity and fullness of a single case over a period of time (Bloomberg & Volpe, 2019), whereas ethnology primarily focuses on the influences of culture (Welz, 2015). In contrast, my intent was to explore the lived experiences of several people at one point in time. One additional methodology I might have selected is narrative inquiry. This type of qualitative strategy uses narration to gain insight into an individual’s experiences and how those experiences are related to their social and cultural constructs. A critique of narrative inquiry is the potential for reflexivity within the narrative, leaving it unclear how influential the investigator’s position is to the narrative (Bloomberg & Volpe, 2019). The research focuses more deeply on the storied experience of the participant than an experienced phenomenon (Bloomberg & Volpe, 2019). In my study, I focused on the perceptions of caregiver burden and their impact rather than on a narrative of a caregiver’s experience.

Finally, to further distinguish my study, I chose a descriptive phenomenological method as opposed to an interpretive method. Matua and Van Der Wal (2015) stated that descriptive inquiry allows researchers to explore, analyze, and describe the phenomena being studied, while the interpretive method’s focus may be on the investigator gaining a deeper understanding of a phenomenon through their interpretation of what they experienced. Because, through my study, I sought to better understand informal caregiver perceptions of their caregiver burden, the perceived origin, and the effects on the caregiver and their care recipient, the descriptive method is better suited. Investigators engaged in descriptive phenomenological research should attempt to diminish the influences their own experiences have on their research so that the study truly captures the study participants’ depictions of the phenomena being investigated. This reduction of preconceptions is achieved through reflexive bracketing (Matua & Van Der Wal, 2015).

Role of the Researcher

My role as the researcher in this phenomenological study was to explore the lived experiences of informal caregivers, who experienced caregiver burden, to answer the stated research questions. As the primary investigator, I have been licensed as an occupational therapy practitioner in Connecticut for 30 years, during which I have frequently worked closely with informal caregivers of older adults. At the time of this study, I worked as an occupational therapist in a home care setting where much of my work included interacting with ALF residents and their informal and formal caregivers.

In this capacity, I have had many meaningful and insightful interactions with older adult patients and their informal caregivers. My professional experience as a therapist and my most recent academic experiences in public health informed my decision to pursue this study topic, and I did not have any prior connection to any of the study participants. To ensure the credibility of this study, I controlled for any potential biases I might have had through meticulous recordkeeping, reflexive bracketing, and developing and adhering to an interview protocol that met the aims of this study.

A potential bias that may have affected the objectivity of my research was that I am the informal caregiver of a frail elderly mother. Early phenomenologists such as Husserl and Heidegger discussed bracketing as a technique to prevent culture and tradition from affecting the outcome of the study of a lived experience (Vagle, 2018). Over time, reflexive bracketing evolved to describe a critical self-analysis by which the researcher is tasked with recognizing and stating their own biases and personal suppositions so that they would not taint the study (Dörfler & Stierand, 2020; Gregory, 2019; McNarry et al., 2019; Weatherford & Maitra, 2019). As McNarry et al. (2019) suggested, I used reflexive bracketing by routinely speaking with mentors and by maintaining a bracketing journal in which I identified and documented my potentially biased thinking. The contents of my journal were explored and discussed during the data analysis stage of my research.

Methodology

Before beginning any part of my study, including finalizing the study flyer and initiating recruitment, I applied for and received approval from Walden University's Institutional Review Board (IRB; Approval No. 11-15-22-0675718). I also received IRB approval for the consent form I developed from a Walden University template. I selected semi-structured interviews to gather data and answer my research questions to further my understanding of the perceptions of caregiver burden among informal caregivers of older adults living in ALFs in southwestern Connecticut. I initially chose asynchronous online focus groups (AOFGs) as I envisioned informal caregivers answering and discussing questions through an online platform. Using AOFGs for data collection would have allowed participants to respond at a convenient time and place (MacNamara et al., 2021). However, after careful consideration of the feedback from the IRB and my mentors, I ultimately chose semi-structured interviews as my data collection strategy, because of the highly sensitive nature of my questions, which may have resulted in issues of privacy and confidentiality.

Semi-structured interviews maintain the qualities of structured interviewing by following a specific list of questions. This leads to greater reliability and validity for measuring key concepts (Bryman & Bell, 2019). Additionally, the semi-structured interviewing technique provides greater leeway for the interviewer to ask follow-up questions, which could lead to deeper insight into how each interviewee or participant interprets the questions. This allows for a richer understanding of how they experienced the phenomenon (Bryman & Bell, 2019). In contrast, during focus groups, the investigator gains an understanding of the phenomenon; however, the emphasis is as much on the interaction and dynamics experienced during the group interview (Hesse-Biber & Leavy, 2006). The result may lack the deep insight that can be gained when an interviewer interacts privately with each participant and can ask direct follow-up questions without the reflections of other participants.

Inclusion Criteria

I used criterion sampling and volunteering to recruit participants for my study. Bloomberg and Volpe (2019) described criterion sampling as a purposive sampling strategy in which study participants are chosen because they meet certain criteria. This sampling strategy was appropriate because participants were vetted for eligibility based on inclusion and exclusion criteria (Patton, 2015, as cited in Bloomberg & Volpe, 2019). Additionally, Rice et al. (2019) described calling for volunteers as a frequently used method of obtaining study participants but stated that a limitation of this method was that only those who wished to volunteer would be included as study participants, limiting the study to only their perspectives.

In my study, the sample selection was delimited to uncompensated adult caregivers who provided informal eldercare to care recipients ages 65 and older, who were residing in one of the seven ALFs owned by a private for-profit agency in southwestern Connecticut, and who self-identified as experiencing stress or stressors associated with their caregiver role. Participants rated their stress by self-administering the ZBI to measure their perceived level of caregiver burden. Individuals who indicated having any degree of burden were selected for the study. Those who perceived no stress would have been excluded from the study.

Informal caregivers were also required to have been in the caregiver role for at least 6 months. Informal caregiving is typically not an isolated occurrence. Rather, caregiving should be considered a trajectory or path (LaManna et al., 2020), with one episode of caregiving needs leading to another with subsequent greater needs. As such, caregiver burden does not suddenly appear; rather, it develops over time. Given this trajectory, a 6-month experience as a caregiver was adequate in a similar study for participants to experience the burdens of caregiving (Wingham et al., 2017). Provided that the individual met all the other inclusion criteria, they were included as a study participant.

Further, groups of informal caregivers not meeting eligibility for this study included those providing eldercare to older adults not living in the seven Connecticut agency ALFs and those providing care to care recipients younger than 65. Finally, informal caregivers needed to verbalize caregiver-related stress to be included in this study.

Procedures for Recruitment, Participation, and Data

The agency ALF wellness directors are nurses familiar with caregiver burden and the unique stressors of being an informal caregiver to an older adult living in an ALF. As one wellness director stated (personal communication, August 17, 2021), wellness directors are typically the point of contact for informal caregivers with questions and coordination of care. During their interactions with informal caregivers, wellness directors were often able to discuss their stressors with them. This led to opportunities to make the informal caregivers aware of the research flyers outlining my study.

The study flyer had information about the study, including a headline identifying the study, a summary of the study, eligibility criteria and study details as bullet lists, a statement of compensation, a description of the online nature of the study, and my contact information. Potential study participants could then contact me via phone or email, during which I further detailed the study and invited them to take the ZBI, which was then explained and sent to them. Once potential participants identified that they had completed the self-assessment, I scheduled an interview time. Due to confidentiality and out of respect for the ALF management, I did not ask at which facility participants were made aware of the flyer.

Sample Size

I actively recruited participants until I had a final selection of 10 study participants that scored at least a little stress on the ZBI, fully met the inclusion criteria, demonstrated a full understanding of the study, and gave written consent.

Creswell and Poth (2018) have explained that in qualitative studies, sample sizes are much smaller than in quantitative research, where a study intends to generalize information to a population. In qualitative research, the aim is to gain a firm understanding of the phenomenon in question as it relates to a set of individuals within a population and their experiences. The research approach drives considerations for selecting a sample size, the level of detail and depth sought (Creswell & Poth, 2018), and when the investigator believes they will achieve *saturation*, a term in qualitative research that refers to the point at which the investigator can expect no new categories or themes to emerge and in which the themes are well-developed (Braun & Clarke, 2021). Braun and Clarke (2021) advised that reaching saturation does not imply that there will be no further development of thematic categories. Rather, the complexity, the interplay and the variations of the themes should be explored when considering saturation. Following counsel from my mentors and the recommendations from an article that discussed sample sizes for qualitative interviewing (Malterud et al., 2015), I set my sample size to 10 interviews.

Instrumentation

To answer my research questions, I used semi-structured interviews as my data collection instrument. Semi-structured interviews differ from structured interviews in that they allow the interviewer to ask follow-up questions (Bryman & Bell, 2019). This often leads to deeper insight into how the participant interprets the questions, which allows for a richer understanding of how they experienced the phenomenon (Bryman & Bell, 2019).

During each interview, I asked the following 10 questions in order. I occasionally rephrased them if the participant asked for clarification.

1. How did you feel about the caregiver burden self-assessment and your score?
2. Did the caregiver burden self-assessment help you better understand the strain you may be experiencing?
3. As you are comfortable, please share some details about your caregiver journey and for whom you are a caregiver.
4. Who is an additional caregiver for this person? Tell me about the dynamics with that person or persons and how you distribute caregiving tasks.
5. Talk more about the difficulty or complexity of the care you provide and how prepared you were when you started on your journey and how comfortable you are now at carrying out those tasks.
6. What support and resources were helpful to have and what would you have liked to have had, both then and now?
7. What impact has the caregiving journey had on your physical and mental health and your success in all the other areas of your life (work, family, social, spiritual, leisure)?
8. Please discuss your perception of the stress you feel that is related to caregiving and the effect it has had and is having on you, your family, and the loved one for whom you are the caregiver.

9. Discuss your level of comfort with being a caregiver from the time you started until now and what things impacted your comfort positively or negatively along the way.
10. Do you know anyone else who may wish to share some of their perspectives on being a family caregiver and the stressors they may have experienced?

Depending on the participants' responses, I used silence to allow additional time for thought, asked probing questions to elicit a richer response, redirected if I felt the participant was not fully answering the question, and validated and empowered the participants as they told their stories.

The COVID-19 pandemic required public health researchers to rethink how data were gathered by considering issues such limiting the risk of virus transmission through wearing masks, maintaining social distancing, and limiting interpersonal contact (CDC, 2021). My safety, the safety of the study participants, and the safety of their care recipients needed to be considered. Subsequently, I made the decision to conduct all data collection virtually, with the participants having the choice between Zoom video, Zoom audio, or via telephone.

Incentives

As an incentive to participate, members received an Amazon gift code toward the purchase of an e-book or hard copy of a caregiver support book. I recognized the commitment of study participants to take the time to complete the self-assessment and participate in the interview. The incentive was not to be considered a reward; rather, it was recognized as an acknowledgment for pledging to reserve time, participate, and follow the established study guidelines and format as detailed on the consent form (Krueger & Casey, 2015).

Privacy

I maintained privacy and confidentiality by only knowing the participants' email addresses. For data analysis, I referenced participants by a number assigned to them when they consented. Any privacy concerns were also directly addressed to IRB satisfaction when I transitioned from AOFGs to semi-structured interviews.

Validating Questions

Glesne encouraged piloting interview questions prior to the first interview (2006). Before conducting the interviews, I informally piloted the ZBI and interview questions with two friends. Pilot respondents should be encouraged to be critical when answering interview questions and providing feedback to ensure the usability of the questions (Glesne, 2006). My informal pilot participants reported taking about 5 minutes to complete the ZBI, and the piloted interviews took over an hour each because there was immediate feedback and discussion. After reviewing the responses and feedback, none of the questions were modified, and I was convinced that the questions were relevant and would lead to a deep understanding of the phenomenon and fully answer my research questions. It was agreed that the final question related to further participant recruitment might not yield tangible results since the participants might not immediately share an additional candidate. Nonetheless, I decided to keep the question for recruitment purposes. Especially since I felt the preceding nine questions were adequately strong to answer the research questions.

Data Analysis Plan

I used thematic analysis as a phenomenological research methodology for content analysis (Bloomberg & Volpe, 2019) with an inductive approach, because I had no pre-established themes, and an established theory was not driving my analysis (Bloomberg & Volpe, 2019). Rather, I anticipated that the emerging themes would develop my understanding of the phenomenon of caregiver burden among informal caregivers of ALF-dwelling adults.

Quirkos is a qualitative data analysis (QDA) software that is offered as a web application or downloadable program. It is unique in that it uses a visual representation called the canvas, to develop themes from codes that are extracted from imported text data. The canvas feature allows the researcher to maintain an overview of the developing groups and themes and rearrange them. I used the Quirkos web application for data coding and analysis and I thoroughly familiarized myself with the software using available online tutorials, guides, and manuals. I also attended a live web event to further deepen my understanding and learn from the questions that other researchers asked. I transcribed the recorded interviews by hand and with the help of the voice-to-text software Audiate by TechSmith or via the Zoom transcription feature.

Issues of Trustworthiness

To address credibility, I used frequent member checking during my interviews. At the end of each interview, I did a more comprehensive member check to confirm the validity of my interpretations. Adams suggested that member checking and respondent validation were effective strategies for upholding standards for trustworthiness (2015).

To address transferability, I considered how this study could be replicated or applied to a different population. I have provided a detailed description of the study tools and strategies within this manuscript so they can be easily replicated or adapted to other populations. For dependability, I maintained an audit trail detailing how I would conduct the study. I also developed a clear strategy for maintaining reflective notes by using a bracketing journal to address the confirmability of my qualitative research study. The bracketing took place in a digital journal on a password protected Remarkable 2 tablet.

Ethical Procedures

Upon gaining Walden University IRB approval, I requested formal permission and support from the engaging ALFs. The research sample for my study was composed of alert and oriented adults and could not be considered a vulnerable population. I thoroughly explained the research study, the interview process, the time commitment, and the ability to withdraw from the study at any time to each participant at the time written consent was given and once again at the beginning of each interview. Prior to the interview, while gaining consent and during completion of the ZBI, I also assessed each participant for health literacy by reviewing their ability to understand the consent form and complete the caregiver burden self-assessment. I also ensured that facility wellness nurses had a thorough understanding of how to identify caregiver burden. Additionally, to maintain research integrity, the recruitment process and ethical considerations were also clearly explained to them.

Summary

In this chapter, I reviewed the purpose of the study. I discussed the research design and gave a rationale for my choice. I discussed my role as the researcher and offered a detailed review of my planned study design including my sampling strategy, recruitment plan, instrumentation, and issues of trustworthiness, credibility, transferability, dependability, and confirmability. I finished with a brief discussion of ethics related to my study. For this study, data was collected from a group of informal caregivers using a convenience sampling method. Candidates who actively engaged in providing care to elderly family members or friends were considered as study subjects. Potential study candidates were made aware of the study by wellness nurses at the ALFs, and data collection occurred remotely through semi-structured interviews. Due to the established social distancing protocols. Interview transcription was done by hand using Audiate and the Zoom transcription feature. The thematic analysis occurred manually and with the Quirkos QDA software.

Chapter 4: Results

The purpose of this study was to gain a deeper understanding of how informal caregivers of older adults living in ALFs perceive caregiver burden and its effects on their physical health, mental well-being, economic stability, and the health and welfare of their care recipients. The results of this study provide insights into the lived experiences of informal caregivers of ALF-dwelling older adults and their perceptions of their caregiver burden and the caregiving process. The insights gained can assist public health professionals and ALF staff in better addressing the promotion of health, wellbeing, and stability of informal caregivers and their ALF-dwelling care recipients, encourage greater multisectoral involvement in addressing caregiver burden, and further develop the foundation of knowledge needed to inform evidence-based interventions and policy development. For this qualitative analysis, my focus was on the following two research questions:

1. What do informal caregivers providing eldercare to ALF residents perceive as factors that affect their caregiver burden?
2. What impact does caregiver burden have on the caregiver and their eldercare recipient as perceived by the informal caregiver?

In this chapter, I present the results of my study by first discussing the setting in which the study took place. Then, I discuss participant demographics, which include the number of participants, where and how data collection took place, and any variations in data collection that were initially planned and presented in the methods section. I then discuss how data were analyzed and explore evidence of trustworthiness. Finally, I present the results by exploring my research questions using the SEM levels as a framework for organizing the codes and themes that emerged from my thematic analysis.

Pilot Study

No formal pilot was done for this study. However, I trialed the caregiver self-assessment tool and my interview questions with two friends as discussed in the Methodology section. The informal pilot validated my perception of the stress scale and reinforced my notion that my instrumentation was effective. As a result, no changes were made to my data collection strategy.

Setting

A worldwide COVID-19 pandemic was occurring while I collected qualitative data through semi-structured interviews. As previously discussed in the Methodology section, physical personal contact was restricted, which resulted in all interviews being conducted via audio or video conferencing. Study participants occasionally mentioned pandemic-related restrictions during the interviews, and the COVID-19 pandemic and its influences emerged as a theme during data analysis.

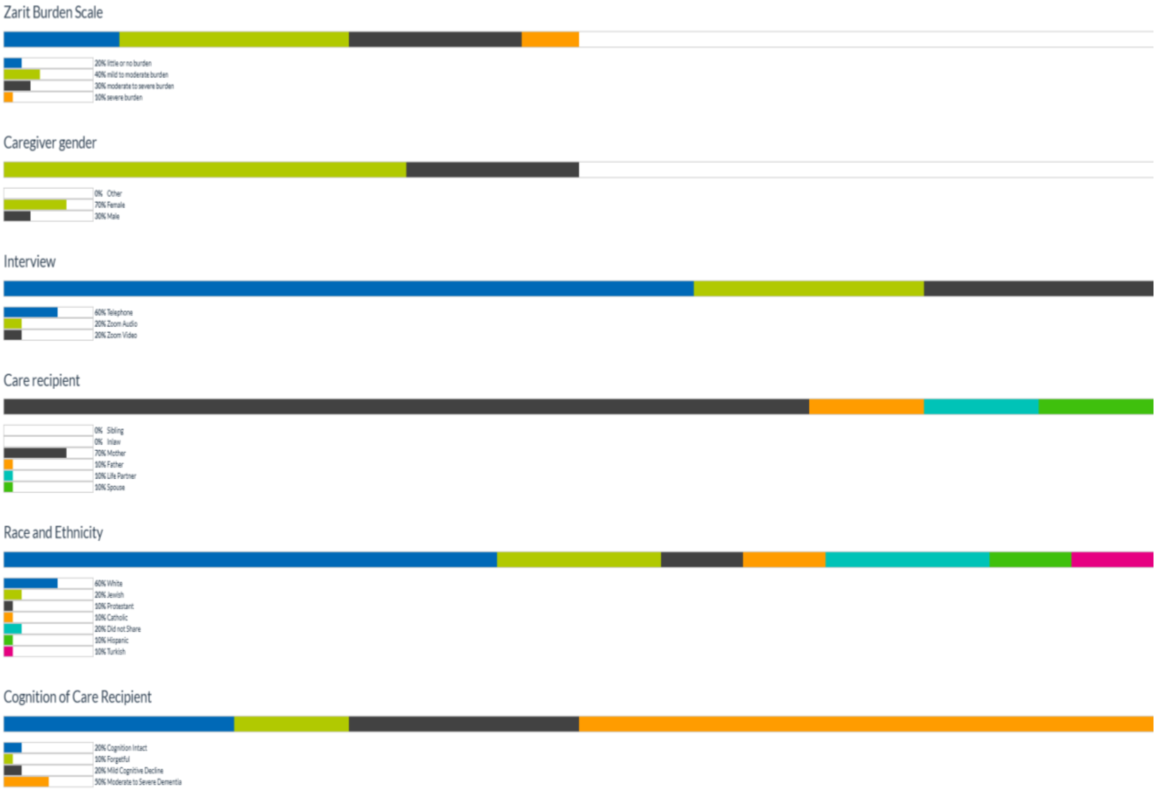
Demographics

Important study demographics included the gender of the caregiver, the gender of the care recipient, and the relationship of the caregiver to the care recipient: seven out of 10 caregivers were female, seven participants were caregivers for their mothers, one was the caregiver for their father, one for a life partner, and one for their spouse. Although I did not specifically ask, when caregivers shared their race and ethnicity, I noted it: six identified as White, one as Hispanic, one as Jewish, one as Protestant, and another as

Roman Catholic. I cannot draw any conclusions from these data other than that the caregivers who volunteered for my study were predominantly White. Figure 2 shows this information in graph form.

Figure 2

Participant Demographics and Properties Summary



Relevant characteristics (see Table 1) included the choice of interview medium, and the rated category of perceived strain based on the ZBI.

Table 1

Participant Characteristics

Participant number	Caregiver gender (CG)	Care recipient (CR) gender	Relationship of CR to CG	Interview medium	ZBI level of burden
1	Female	Female	Mother	Phone	Mild to moderate
2	Female	Female	Mother	Phone	Moderate to severe
3	Female	Female	Mother	Zoom video	Moderate to severe
4	Female	Male	Father	Phone	Severe
5	Male	Female	Mother	Phone	Moderate to severe
6	Female	Male	Life partner	Phone	Mild to moderate
7	Female	Male	Spouse	Zoom video	Little or no burden
8	Female	Female	Mother	Zoom – audio only	Little or no burden
9	Male	Female	Mother	Zoom – audio only	Mild to moderate
10	Male	Female	Mother	Phone – car interview	Mild to moderate

The following is a brief description of further characteristics of each participant and their unique situation.

- Participant 1 – This participant is a retired single female who is one of several daughters caring for their ALF-dwelling mother. She considers herself a primary caregiver 50% of the time, depending on whether she is in town. Another sister takes over in her absence.
- Participant 2 – This participant is the daughter of an ALF-dwelling care recipient with early-onset dementia. The participant has not yet started a

family and shares caregiving duties with her father, who still works and lives in her childhood home. Still, at the beginning of her career, she is attempting to balance her roles.

- Participant 3 – This participant is a middle-aged daughter who cares for her mother, who lives in an ALF. She has raised children and still supports her youngest, just attending university. She manages the household but does not formally work due to a chronic condition.
- Participant 4 – This participant is a single middle-aged woman who is her father's primary informal caregiver. She often hosts her ALF-dwelling father and receives no support from her siblings in caring for her father. She expressed how greatly caregiving has impacted her career and admits to occasionally accepting money from her father as compensation for some services.
- Participant 5 – This participant is an adult male who is the primary caregiver for his mother who has lived in a group home with 13 other residents for 6 months. The participant shared that, at the beginning, his perceived level of stress was in the moderate to severe range, but it has now decreased to mild to moderate.
- Participant 6 – This participant is a retired female who is the primary caregiver for her male life partner of 11 years, who was diagnosed with dementia 3 years ago and now lives in an ALF. They lived together until the

participant felt she could no longer care for him. She shares caregiving duties with her life partner’s son, who is very supportive.

- Participant 7 – This participant is a female who recently retired earlier than planned from a career as a banking executive. She is the caregiver for her husband, who has dementia, is 25 years her senior, and now resides in an ALF. She discussed currently having little to no stress but stated that she experienced greater stress within the past 6 months.
- Participant 8 – This participant is the daughter of an ALF-dwelling female who, until recently, had lived in her own apartment and drove within the community. Her mother realized that it was time for her to go to assisted living after a fall with an injury. Participant 8 stated that her stress and perceived burden dropped significantly following her mother’s move.
- Participant 9 –This participant is a single middle-aged man who works in television production. He is the caregiver for both his father and mother. The father continues to live in the family home together with the participant. The mother has lived in an ALF for 2 years. This participant shared that as his mother declined in function, she came to the realization on her own that she should transition to an ALF.
- Participant 10 – This participant is the primary informal caregiver for his mother. She lives in an ALF on a memory care unit. He is married with children and describes the support from his family as strong. Additionally, he runs his own company and considers himself a strong organizer. His family

support and his own organizational skillset leads him to perceive his caregiver stress as mild.

Data Collection

I conducted semi-structured interviews with 10 participants from November 2022 to April 2023. Before scheduling each interview, the participants were given access to the ZBI and asked to complete it. All interviews were conducted remotely, and participants were given the option of using a Zoom videoconference, a Zoom audioconference, or a telephone interview. Subsequently, six participants chose the phone interview, and four asked to use Zoom. Of those four, two chose audio only, and the remaining two opted for video interviews. Most interviews lasted 45–50 minutes, with one interview lasting 70 minutes and the final interview lasting only 35 minutes.

Data Management

All participants consented to having their interviews recorded. For those using phone interview, the interviews were recorded over speaker phone on a Sony handheld digital recorder in a private setting. For those interviews conducted over Zoom, the interviews were recorded using the built-in recording feature. The Zoom recordings were saved to a thumb drive using the Zoom local storage option. Both the thumb drive and the Sony recorder were stored in a locked safe. The data from the digital recorder have now been transferred to the thumb drive, where they will remain locked in my safe for 5 years. The Zoom interviews were initially automatically transcribed via Zoom technology and then depersonalized and cleaned by hand. Interviews recorded on the Sony digital recorder were initially transcribed using Tech Smith Audiate software and then also depersonalized and cleaned. The Zoom transcriptions had the advantage of having already identified the speaker. The transcriptions made using Audiate required the additional step of also separating what was said by me, as the interviewer, and the participant.

In all but one instance, I was able to schedule convenient interview times for the participant, and I conducted the interviews from my home office. On one occasion, during the final interview, the participant had a difficult time scheduling. He was flying overseas on a business trip but wanted to share his story, so he suggested conducting the interview from his car. This was on such short notice that I, too, was traveling. This led to the interview being conducted while both the participant and I were in our vehicles driving. The interview was conducted by phone and recorded using the Sony recording device. Fortunately, because of the superior microphone, the recording was of adequate quality to be easily transcribed. I feel I gathered sound data from this interview and deviated from taking any handwritten notes.

Data Analysis

I used thematic analysis as a phenomenological research methodology for content analysis (Bloomberg & Volpe, 2019). My approach was inductive because I had no pre-established themes, and an established theory did not drive my analysis (Bloomberg & Volpe, 2019). Rather, the emerging themes helped develop my understanding of the phenomenon of caregiver burden among informal caregivers of ALF-dwelling adults.

I used the Quirkos web application for data coding and analysis. Quirkos is a QDA software offered as a web application or downloadable program. It is unique in that it uses a visual representation called the canvas, to develop themes from codes that I extracted from the adjacent interview transcripts. The canvas feature allowed me to maintain an overview of the developing groups and themes and rearrange them. The categories, or grandparents, represented the five levels of the SEM. The parents emerged as overarching themes that I was able to group together. They represent the main ideas that reoccurred over and over to form patterns. The children represent experiences and perceptions that emerged as the themes extracted from the data which I had identified as codes.

I was aware of and reduced my own preconceptions through reflexive bracketing, which I began while writing the first chapters of this manuscript, by diligently documenting my thoughts and preconceptions using the Remarkable 2 digital notebook. By recognizing my potential bias, I maintained objectivity when exploring the lived experiences of my study participants' caregiver journey (McNarry et al., 2019). Once the interviews were completed and transcribed, I transferred the transcripts of the semi-structured interviews into Quirkos and begin inductive coding using the SEM as a framework, I derived codes from the transcripts and assigned them to the developing themes within the levels of the SEM. I used the data analysis feature in the Quirkos software to identify how often codes appeared and how often various codes appeared together. This helped me understand the interplay between codes, from which I developed themes and interconnections within and across the SEM levels. I used thematic analysis to explore the emerging patterns.

I facilitated the data analysis process by using the Quirkos canvas feature with filters to help visualize how often specific codes appeared. Following my first round of coding, I used a more research-centric approach to identify patterns that emerged, and I explored how well the patterns informed my research questions (Skjott Linneberg & Korsgaard, 2019). To gain a deeper understanding of my data, I also began to develop some visualizations of my data by using a combination of tables and figures using the Quirkos data analysis tools (see Appendices C-G).

I used an inductive approach to engage in a thematic analysis of my data. To organize my data, I used the five levels of my chosen conceptual model, the SEM, to create categories. During the first review of all 10 transcripts, I began developing initial themes. I color coded the themes and organized them into the corresponding categories representing the five SEM levels. During the second round of coding, I identified most of the themes while reviewing the first five interviews but added new ones throughout to the final interview. Once most themes had emerged, coding involved highlighting the coded text and adding it to existing themes. After each interview, I reviewed the themes and occasionally revised them to best reflect the coded text assigned to them. Ultimately, I had 409 codes assigned to 77 themes and organized them within five SEM levels, which I have thoroughly reviewed in the Results section.

I often assigned codes to several themes across more than one level of the SEM. Examples of this include “If we had to do it over again, we might not have done it,” related to the themes positive inter-caregiver relationships, second guessing the decision of the transition to the ALF, which was also linked to the high cost of ALF living linked to the interpersonal level and the institutional level. Another related code was assigned to feelings of being misled by the ALF marketing and the high cost of ALF living, which resulted in this caregiver and other family caregivers wanting to explore other opportunities.

Another code which also spanned the interpersonal and the community level, “Um, and they understand her type of dementia a little bit better, but that’s the point about like, I think we are a little bit calmer too. And not as stressed So. Our time with her. I feel a little bit more meaningful. Yeah” was assigned to positive feelings toward ALF staff, good perceptions of care, and still participating in ADLs. This caregiver and her caregiver father continued to assist her mother with dressing, showering, hair washing, and grooming. The hair management and dressing became a time for collaboration with the ALF dementia care staff and the care recipient. Yet, not all caregivers were as complimentary of the ALF and the system in general, “They just didn't really make any effort” and “they just, you know, like these programs were kind of either shut down or they they're not existing anymore” was a reference by participant 10 to attempting to navigate health care during the COVID pandemic.

The formal education of the caregiver and positive relationships were two overlapping themes in different SEM levels to which codes from several participants were assigned. For example, participant 7’s code related to their preparedness in the management of formal caregivers was also assigned to the caregiver level and community level. Participant 7 asserted that financial stability and preparedness has led them to have a positive perspective of the health system and toward the care their loved one is receiving.

Yet another participant lamented that they were not at all prepared, which led to critic of the health care system, “I would hear you know one doctor say something to me, and then I’d be in the hospital with my mom, and someone would come in and be doing something totally different.” Another code from the same caregiver dealt with the need to transition from a familiar primary care provider, which resulted in a critic of the health care system, critic of the lack of formal institutional level support, and poor perceptions of care.

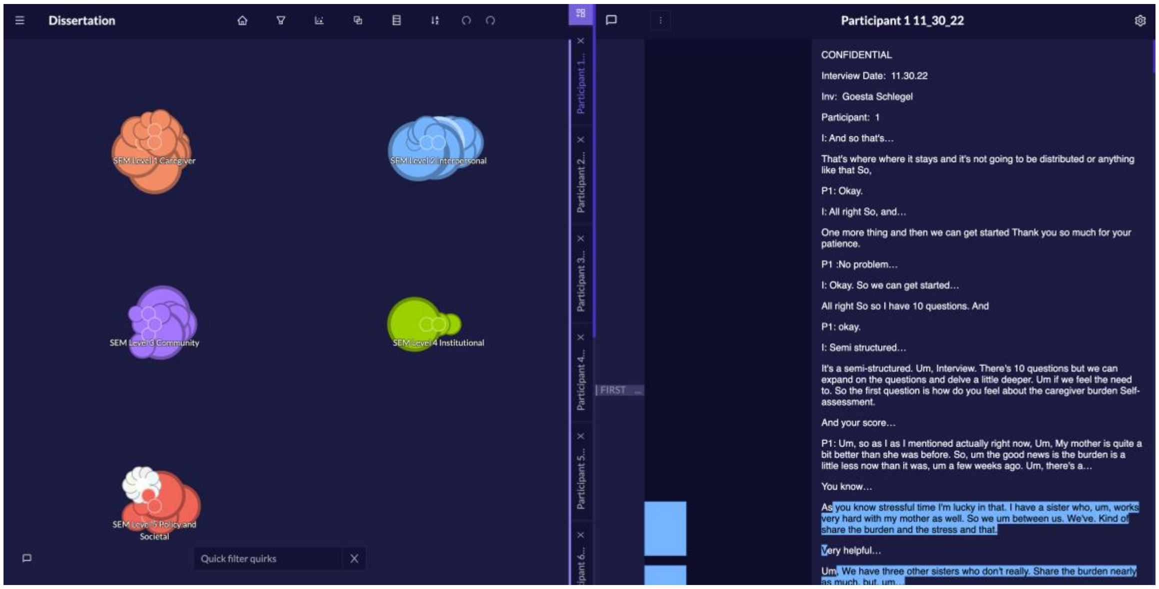
The code “I mean the communication between my family is I'm really stressed out and it would be. It would kind of be nice to be able to talk to 'em. My sister and brother about it” was assigned to the caregiver level and interpersonal level, while “Sometimes I just wish somebody else would step up” was connected to the interpersonal level and the community level because of feelings of unequitable task distribution among the informal caregivers and perceptions of care related to the caregiver’s lack of trust of ALF staff. This caregiver shared that they felt others in the family were not stepping up to pull their weight after they perceived ALF staff were not as participative and present as initially imagined.

Quirkos as a Data Analysis Tool

The Quirkos interface offered a visual display with the transcripts of my interviews in one window and the canvas with emerging themes in the other. I was quickly able to identify codes and drag and drop them to the canvas to develop the themes and thematic patterns and then assign them to the five levels of the SEM. The following is a summary of the SEM categories, overarching themes or main ideas, and a survey of themes that emerged during my data analysis.

Figure 3

Screenshot of Quirkos Webapp With Canvas and Transcripts



CONFIDENTIAL

Interview Date: 11.30.22

Inv: Goesta Schlegel

Participant: 1

I: And so that's…

That's where where it stays and it's not going to be distributed or anything like that So,

P1: Okay.

I: All right So, and…

One more thing and then we can get started Thank you so much for your patience.

P1 :No problem…

I: Okay. So we can get started…

All right So so I have 10 questions. And

P1: okay.

I: Semi structured…

It's a semi-structured. Um, Interview. There's 10 questions but we can expand on the questions and delve a little deeper. Um if we feel the need to. So the first question is how do you feel about the caregiver burden Self-assessment.

And your score…

P1: Um, so as I as I mentioned actually right now, Um, My mother is quite a bit better than she was before. So, um the good news is the burden is a little less now than it was, um a few weeks ago. Um, there's a…

You know…

As you know stressful time I'm lucky in that. I have a sister who, um, works very hard with my mother as well. So we um between us. We've. Kind of share the burden and the stress and that.

Very helpful…

Um, We have three other sisters who don't really. Share the burden nearly as much, but, um…

Evidence of Trustworthiness

To address credibility. I conducted respondent validation throughout the interview process. I encouraged participants to review their ZBI: they were given time to check their answers and then review their scores to ensure the burden category was consistent with their perceived level of stress or burden. Throughout the interviews, I frequently asked for clarification and rephrased their responses to ensure I had understood correctly. At the end of each interview, I again reviewed the main points to confirm the validity of my interpretations.

To address transferability, I have provided a detailed description of the study and the tools and strategies I used so they can be easily replicated or adapted to other populations. For dependability, I have maintained an audit trail with details about how I conducted the study. I also maintained reflective notes by using a bracketing journal to address confirmability of my qualitative research study. The handwritten bracketing journal was maintained on a password secured digital tablet. Additionally, I added my thoughts and observations into Quirkos using the memo function, which allowed me to add them at pivotal points within the transcripts. In Quirkos, those memos became searchable and could also be added codes and themes.

Results

The findings of this qualitative research study address the research questions of what informal caregivers providing eldercare to ALF residents perceive as factors that affect their caregiver burden and what perceived impact the caregiver burden has on the caregiver and their eldercare recipient. Three major findings emerged from this study:

1. Informal caregivers of ALF residents experience varying degrees of caregiver burden or stress, ranging from little or no burden to severe burden.
2. Factors that influence the perception of caregiver burden are represented at all five levels of the SEM. However, the institutional level of the SEM is under-represented as an influential factor among the informal caregivers in this study.

3. Informal caregivers have varying perceptions of how the presence of caregiver burden and the degree to which their caregiver burden impacts them and their care recipients.

Finding 1

Informal caregivers of ALF residents experience varying degrees of caregiver burden or stress, from little to severe burden. Table 2 shows the distribution of categorical ratings from the ZBI, with the average rating for all 10 participants being 2.5, while the most common rating was Mild to Moderate. No participants who took the ZBI identified as not having any burden. Had that occurred, I would have excluded them from the study.

Table 2

Distribution of ZBI Ratings

Caregiver burden rating	Number of participants
Little to no burden	2
Mild to moderate burden	4
Moderate to Severe Burden	3
Severe burden	1

Finding 2

Factors that influence the perception of caregiver burden are represented at all five levels of the SEM. However, the institutional level of the SEM is under-represented as an influential factor among the participants in this study. The following is a review of each SEM level and the associated codes that I identified as potentially contributing toward caregiver burden.

SEM Level 1: Caregiver

Preparedness. This theme contains codes that address how the participants perceived their level of preparedness. Specific codes included not being prepared “it’s, it’s so unpredictable. And, and you know from, from the beginning you weren’t prepared; you weren’t expecting that” (Participant 6), the extent to which another role, typically their career, impacted their preparedness “I was lucky because I was an OT (occupational therapist) so I like knew. And in theory how to do a lot of things” (Participant 2), their transition to identifying as a caregiver “It’s like taking a kid to summer camp. Can you imagine?” (Participant 4), and then the decision that led them to supporting an ALF placement for their loved one “And then, as you start going through the motions, you’ll learn, and you may have to adjust that decision. So, like I made the decision to put [loved one] in a facility” (Participant 7).

Feelings. This theme includes codes that address the array of feelings felt by the caregiver toward the situation, toward the care recipient, and toward others. The following is a representation of the codes added to this theme: empathy or sympathy for the care recipient, feelings of guilt related to the perception that the caregiver is neglectful of the care recipient “I mean there’s still moments of stress. So…or guilt. Like I don’t make it there one day” (Participant 2), despair about the newly perceived lack of spontaneity, and comfort in the perception that the caregiver has insight into the care recipient’s needs.

Roles. This Theme encompasses roles related issues such as lifestyle compromise, adjusting to the new role of caregiver, and the impact of caregiving on other roles: "…and there have been times where I've like sort of had a desire, or, or wished I could do something like a little part time" (Participant 3).

Health and Wellness. This theme included perceptions of the level of stress participants experience, the impact of prior medical conditions and the participant's neglect of their own health, and the physical and mental impacts of caregiving: "I'm like so easily triggered into crying, and that's, you know, stress on your body" (Participant 2) and "Myself, I do not put enough attention or focus on my own health" (Participant 3).

SEM Level 2: Interpersonal

Care Recipient Factors. This theme represents the impact, influence, or control the care recipients' physical, cognitive, or emotional state has on the caregiver or their situation. It includes codes such as care recipient decline, a past dyadic relationship, guilt felt by the care recipient, negative behaviors manifested by the care recipient toward the caregiver, the care recipient missing family events, shared decision-making, and the perpetuation of prior roles held by the care recipient: "I've always had a good relationship with my parents where I've always felt that I have to please them" (Participant 4), "She's still our intermediary a little bit even though she's not doing it in words" (Participant 2), and "She actually said to me, I think I need to go into assisted living" (Participant 9).

Family Member Factors. Family member factors include both positive support and lack of support. Positive support includes help and equitable task distribution among family members, collaboration with non-residential parents, and shared decision-making among family members. Negative family support includes backseat drivers, Monday morning quarterbacking, and lack of engagement by other eligible family members: “You should be doing this. So, you should be doing that and it's like, this is already hard enough” (Participant 2) and “When you get a snarky email from somebody saying, why are you… whatever? And I just was ignoring it because I just didn't want to engage, and then that would make my blood pressure go crazy” (Participant 8) as negative support and “So [my sister] and I, um, I mean by far, we share the decision-making pretty, pretty um…You know, equally” (Participant 1) and “my folks looked far enough into the future that they had long term care insurance. So that's made it possible to have mom in assisted living” (Participant 9).

SEM Level 3: Community

ALF. This theme focuses on positive and negative feelings toward ALFs. A major theme that emerged and was commented on by six of the 10 participants was the high cost of ALF living: “The cost factor is significant. I don't realize, and that's why I'm saying, this is a business” (Participant 7). Two participants felt they were misled by ALF marketing staff, and ultimately, the services offered were misrepresented. This generally related to add-ons such as personal care, medication management, and escorting within the facility, all of which are at extra cost. Additionally, poor care coordination and communication among ALF management was a significant theme that emerged from Participant 1, ultimately resolved by transitioning from one facility to another.

Nonetheless, seven of the 10 participants had positive feelings toward ALF living and their current experience: “He [participant’s father] lives like a king” (Participant 4).

Formal Caregivers. Nine of 10 participants spoke highly of at least some of the ALF direct care staff. They spoke of the positive engagement of their loved ones by ALF care staff and the perceived understanding of conditions by ALF direct care staff, particularly by informal caregivers of ALF residents with cognitive decline (20% of care recipients) or dementia (50% of care recipients). While perceptions were overwhelmingly positive regarding ALF direct care staff, the perceptions of private aides, those hired privately by the family were not as favorable, at least by two caregivers who shared that they were not impressed with their services and that the additional support of private aides was very costly.

Medical Professionals. Participants also expressed their satisfaction with the medical professions that worked with and offered medical or medically related services to their loved one: “I felt like I was getting some, some good, some good advice from people” (Participant 9).

SEM Level 4: Institutional

For this level, only three participants shared that at least at one point or another participated in a support group. Those that did reported seeing a clear benefit: “I would have to say like I'm very lucky that I'm so supported by, um, my therapist and my support group” (Participant 2). All three participants shared that they have loved ones with cognitive delay or dementia. Three additional participants shared that they are not aware of support groups tailored to their needs: “I didn't really care much for the twelve-step program” (Participant 6).

SEM Level 5: Policy and Societal

Societal Implications. This theme focuses on codes in which caregivers discussed their motivation for and dedication to caregiving: “My family is about family” (Participant 3) and “I come from a very family oriented, you know close ties, and of course I mean I don't know any alternative to what I’m doing” (Participant 7). This participant also referenced her European heritage as a societal motivator. Participant 9 stated that he felt compelled to reciprocate for all the love and caring he received from his parents.

Policy. This theme emerged as participants critiqued the health care system with mostly negative observations. It was rife with comments related to fragmented care, difficult navigation of the medical landscape, and the compelling need for the informal caregiver to become an educated advocate for their loved one to ensure adequate care. The reflections categorized here differ from the generally positive view of the medical professionals in that policy was more deeply focused on structural challenges rather than the skillset of individual professionals. Policy also included participant references to the effects and impact of COVID-19 and the public health response to include explicit and implicit limitations and restrictions.

Research. This theme focused on the expressed benefits of this study to include the ZBI and the interview. Codes such as “It does add a bit of clarity” (Participant 1), “The questions were helpful in seeing what areas are more stressful” (Participant 2), and

“Everybody should take the self-assessment” (Participant 9) to gain greater insight. One participant commented that for the first time, they were more fully aware of the extent to which they participated in being a caregiver.

Finding 3

Informal caregivers have varying perceptions of how the presence of caregiver burden and the degree to which their caregiver burden impacts them and their care recipients.

Impacting the Caregiver

Participant 2 commented on the “pretty big toll [the caregiving has taken] on my health”. The participant went on to say that they are easily triggered into crying and commented on the degree of stress on their body. Participant 3 stated that “it’s draining” and the stress from caregiving complicates their ability to care for their care recipient. They furthered the narrative by sharing that their children and spouse were unaware of the toll caregiving is taking on them. Participant 3 also described the caregiving as a “constant weight on my shoulders” because the care recipient is demanding and “there is no one else to be demanding of besides me.” Participant 4 stated that their hair was shedding and thinning. Participant 5 stated that they sometimes feel “numb” because there are so many things to think about. Participant 6 shared that they “lost a lot of weight” and ultimately sought out counseling. Participant 7 shared that they turn to “scotch” or wine at night: “I just want to relax. They also shared that they pursue physical exercise. Participant 8 also referenced having a glass of wine as a means of unwinding and clearing their thoughts. Finally, Participant 9 stated that they were certain that their health was suffering by not getting enough sleep and not eating properly.

Impacting the Care Recipient

Four participants discussed their perceptions that their level of burden had a negative impact on the care recipient. One participant shared that their mother, who noted that the participant had neglected some duties related to their ongoing informal care, yelled at them as they entered through the door. The same caregiver also stated that on other occasions, the mother reportedly felt neglected, which resulted in the care recipient having mental health issues, “She’s been a little down or depressed because she, she feels lonely”. Another participant lamented that when they were visibly stressed, their care recipient father responded by becoming more demanding of them. After further probing and discussion, the caregiver shared that this dynamic has been present in their relationship since before they assumed the role of caregiver and before their father’s transition to an ALF. They attributed it to a life decision in their early adulthood that they made with which the father disagreed.

Another participant shared that they felt guilty leaving their spouse at the ALF when they travel to participate in major family events. On one occasion, they did not bring their husband to their daughter’s wedding because of the strain that being the exclusive caregiver would put on them. They did not feel ready to be responsible for dressing, bathing, feeding, and toileting him. They lamented that the husband was unable to attend and reported feeling guilty. They also stated that transitioning their husband to the ALF was necessary because they were no longer able to manage his ADLs and related mobility.

Other themes related to this finding were that the care giver felt guilty over the decision of the care recipient transitioning to a residential facility because they were no longer able to handle it all. Another caregiver stated that their care recipient was the one who felt guilty for the perceived burden they had caused for the caregiver. Yet others discussed the health and functional decline they have noticed in their care recipient in response to aging and furthering of their chronic conditions.

Discrepant Cases

There were no discrepant or disconfirming cases in this study because the purpose of this study was not to confirm or disconfirm a position. The intent of completing this study was to gain a deeper understanding of the phenomenon of being a caregiver for an ALF-dwelling individual, the caregiver burden and stress those caregivers experience, and the impact that stress has on them and their care recipients.

Each interview generated data that led to codes to further confirm established themes or develop new ones. Perspectives that may have been conflicting served to deepen the understanding of the breadth of variance in perceptions and experiences between the caregivers interviewed.

Summary

In conducting my study, I have been able to answer my research questions about what informal caregivers providing eldercare to ALF residents perceive as factors affecting their caregiver burden and their perceptions of the impact caregiver burden on themselves and their eldercare. My data analysis resulted in three significant findings. I discovered that informal caregivers of ALF residents experience varying degrees of caregiver burden or stress, ranging from little or no burden to severe burden. I found that factors that influence the perception of caregiver burden are represented at all five levels of the SEM, with the institutional level of the SEM being under-represented as an influential factor among the informal caregivers in this study. Finally, I found that informal caregivers have varying perceptions of how the presence of caregiver burden and the degree of caregiver burden impacts their care recipients.

I now transition to the final discussion chapter in which I provide a thorough interpretation of these findings, discuss the limitations of my study, provide recommendations for further research by public health practitioners, and make suggests for interventions by public health practitioners to address caregiver burden among informal caregivers.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to gain a greater understanding of how informal caregivers of older adults living in ALFs perceive caregiver burden and its effects on their physical health, mental well-being, economic stability, and the health and welfare of their care recipients. The results of this study provide insights into the lived experiences of informal caregivers of ALF-dwelling older adults and their perceptions of their caregiver burden and the caregiving process. The insights gained can assist public health professionals and ALF staff in better addressing the promotion of health, wellbeing, and stability of informal caregivers and their ALF-dwelling care recipients, encourage greater multisectoral involvement in addressing caregiver burden, and further develop the foundation of knowledge needed to inform evidence-based interventions and policy development. For this qualitative analysis, my focus was on the following two research questions:

1. What do informal caregivers providing eldercare to ALF residents perceive as factors that affect their caregiver burden?
2. What impact does caregiver burden have on the caregiver and their eldercare recipient as perceived by the informal caregiver?

In this final chapter, I discuss and interpret my research findings using the SEM as a framework. I start by discussing how my own experiences with informal caregiving helped shape my study. I then review and comment on the initial assumptions described in Chapter 1 and how those assumptions were effective in shaping my study. I then discuss the limitations of my study and make recommendations for positive social change, further research, and future practice. I conclude with a strong take home message that draws on my findings, their implications, and how they fit within the public health body of knowledge and practice.

Using the SEM to explore caregiver burden not only allowed consideration for the multidimensional intertwining of factors that lead to caregiver burden and the perceived impact that the caregiver burden has on the informal caregiver, the care recipient, and their dyadic relationship, but also served as a framework for developing interventions at and across the various levels of the model.

Three major findings emerged from my study. I found that informal caregivers of ALF residents experience varying degrees of caregiver burden, from little burden to severe burden, with most caregivers experiencing mild to moderate burden. I also found that factors which influence caregiver burden are represented at all five levels of the SEM. Often, those factors extend across multiple levels, making them complex in nature. Finally, I found that informal caregivers have varying perceptions of the degree to which caregiver burden impacts them and their care recipients.

Interpretation of the Findings

Review of Past Literature

The findings from my study demonstrated that challenges attributed to informal caregiving by Lieshout et al. (2020), such as issues of preparedness for assuming the caregiver role, a sense of obligation for filling the gaps in care, and issues in adjusting to the variability and difficulty of informal caregiving, are experienced by my study population of informal caregivers of ALF residents. Decreased mental health, increased social isolation, a sense of decreased economic status, which are attributed to the general informal caregiver population of older adults (Berglund et al., 2015), are also experienced by my study population. The informal caregivers in my study discussed a decline in function by their care recipients, but no participant felt the decline could be attributed to their caregiver stress such as discussed by Statt et al. (2019).

My research supports the conclusions of prior studies that the impact of informal caregiving changes little when older adult care recipients transition to ALFs or residential living (Turcotte and Sawaya, 2015, as cited in Hainstock et al., 2017). As with prior studies (Hainstock et al., 2017; O'Hora & Roberto, 2019), I found that care management, resource management, overseeing family access and adjustment, and managing emotions such as guilt emerged as additional factors that can impact caregiver burden following the transition of a family member to an ALF.

Current Findings

This is not a comparative analysis where I compared the perceptions of caregiving and associated stressors between caregivers of ALF dwellers and those living at home or in another setting. Rather, in this inductive analysis, I focused on the perceptions of caregivers of individuals living in assisted living. Previous studies and reports in my literature review informed me about the stressors and the phenomenon of caregiver burden among caregivers in general. However, I did not develop themes based on that understanding.

Finding 1

Being the caregiver to a care recipient in an ALF continues to present factors leading to caregiver burden. My study was voluntary for study participants, and I cannot make assumptions of prevalence. However, public health practitioners and ALF management should consider programming that addresses the factors informal caregivers experience that led to caregiver burden and provide them with resources to mitigate the effect of those factors and intervention to address the resulting burden.

Finding 2

The SEM was an effective way of organizing the themes for this study. Using the SEM to explore caregiver burden not only allowed consideration for the multidimensional intertwining of factors that lead to caregiver burden and the perceived impact that the caregiver burden has on the informal caregiver, the care recipient, and their dyadic relationship, but also served as a framework for developing recommendations for positive social change, recommendations for further research, and implications for interventions at the various levels of the model.

Individual Level Factors. Not being prepared was a common theme among study participants. The sudden onset of the need for assistance experienced by older family members, the abruptness of the need to assume the role of caregiver, the changes in the caregiver focus, and the difficulty with juggling established roles all challenge the resilience of the informal caregiver. The informal caregiver often experiences an array of feelings related to the functional decline of the care recipient, the associated role changes of the caregiver. Past experiences and qualifications, both personal and professional, helped caregivers more effectively adjust to their new role. The impact of caregiving on the health and wellbeing of the caregiver is often not addressed in a timely manner and puts the caregiver at risk of physical and mental decline.

Interpersonal Level Factors. There is much research on the caregiver dyad, which has led to addressing the caregiver and care recipient as a unit rather than separately. Occasionally, care recipients continue to contribute equitably to the dyad, which has a positive effect on decreasing caregiver burden. The past relationship to the care recipient, the cognitive and physical state of the care recipient, and the physical and mental state of the caregiver are factors.

Family members or other family caregivers can have either a positive or negative effect on the primary informal caregiver. The past nature of the relationships and dynamics of family members are factors that impact an exacerbation or mitigation of stressors. Informal caregivers in communicative and collaborate arrangements are most positive while perceiving that others are quick to judge but not willing to assist are negative. Informal caregivers should leverage the support of the care recipient in establishing a collaborative and equitable environment.

Community Level Factors. Participants' sentiments toward ALFs, formal caregivers, and medical professionals ranged from positive to negative. Most participants commented on the high cost of ALF living. Two separate caregivers felt the final cost to live in the ALF was misrepresented and should have been more clearly identified. There were variations in the degree of collaboration and communication participants experienced with ALF staff. Past authors have identified networking, collaboration, and including informal caregivers as a vital role of ALF staff (Kemp et al., 2019). This was not always the case and is an area for potential growth in some settings.

Overall, attitudes toward ALFs were favorable among study participants. Especially in relation to staff members. A general observation was that the staff of which participants were most likely to have a less favorable opinion were less educated care staff, and those of whom caregivers had a higher opinion were those with professional degrees. This is likely related to the amount of education and professional investment in customer satisfaction. Additionally, participants voiced greater satisfaction with dementia care staff.

Institutional Level Factors. This level is made up of organizations and social institutions, and references to them were least represented during the interviews. Only through my studies and deliberate attempts to learn about and connect with these entities, am I aware of them. Institutional level resources are lacking regarding informal caregiver support within the ALF context.

Policy and Societal Factors. Participants had a mostly negative impression of support at this level of the SEM. The healthcare landscape is difficult to navigate, and it is fragmented in the sense that agencies and governmental supports are ill equipped to collaborate. The responses of governmental entities to the COVID-19 pandemic were mentioned several times in interviews. My fieldnotes related to the fragmented system include references to the local hospital not having access to my mother’s electronic health record because they use different systems. Additionally, at my level of understanding, navigating the landscape has been challenging, even for me.

Finding 3

This finding relates to informal caregiver perceptions of how their caregiver burden impacts their health and the wellbeing of the care recipient. I was not surprised at the references to neglecting one's one physical and mental health. The comments about perceived stress, lack of sleep, prioritizing care recipient care over their own care, and even exhausting one's own compliment of coping strategies resonated with me in my caregiving situation. Feelings of neglect, guilt, and perceptions that the care recipient was being neglected because the caregiver is overwhelmed were mentioned and are consistent with findings from past studies (Al-Rawashdeh et al., 2016).

Reflexivity

I used reflexive bracketing by routinely speaking with mentors and by maintaining a bracketing journal in which I identified and documented my potentially biased thinking. The content primarily focused on my current experiences with my mother as she gradually transitioned from living independently to first living in supported senior housing and then a nursing home. Often, my experiences closely resembled some of those that the participants in my study described. I was cautious not to influence the participants' narratives with understanding affirmations. Rather, I was deliberate in drawing out a deeper meaning through well-placed statements of empathy, such as "That must have been difficult" or "I can hear the emotion in your voice." On other occasions, I used silence to reinforce an empathetic moment. In any case, my personal experiences with caregiving and caregiver burden helped me come across as authentic and trustworthy. Gair (2012) advocated for conveying a feeling of empathy back to the study participant to facilitate more “enriched, insightful research encounters” but warned against aligning too closely and losing objectivity. This is similar to the phenomenon of countertransference, during which a clinician transfers emotions to a client, which could negatively impact the therapeutic relationship through loss of objectivity and trust (Gabbard, 2020).

Assumptions

I made several assumptions as I began my research of how informal caregivers providing eldercare to ALF residents perceive caregiver burden. My assumptions developed out of my familiarity with my research topic. I was therefore able to ensure that the SEM was an effective framework with which to organize my data and findings, and I was able to develop effective interview questions and techniques that allowed me to answer the research questions.

I assumed that the transition to becoming an informal caregiver was either gradual with responsibilities growing in intensity over time or occurred with the acute onset of a condition that caused the eldercare recipient to suddenly lose independence. Second, I assumed that the informal caregiver had a previous relationship to the care recipient (e.g., family, friend, or neighbor) in which there was reciprocity. I also assumed that informal caregivers are motivated and committed to offering support to their eldercare recipients or recipients. Finally, I assumed that the perceived benefits and liabilities of living in an ALF played a role in the final decision to transition to one.

Limitations of the Study

A limitation of my study may have been that I used volunteering as a recruitment strategy. Rice et al. (2019) described asking for volunteers as a limitation since only those who wished to volunteer would be study participants. In my study, only those who were willing to share their experiences were participants, and I risked not learning from those who may have experienced caregiver burden but were not willing to participate in the study. A focus group with hypothetical questions about caregiver burden may help capture their perspectives.

One additional limitation of the study is the small sample size and the lack of generalizability of the study. Qualitative studies attempt to explore phenomena more deeply within a specific context (Creswell & Poth, 2018). For my study, the relevance of the data and its interpretation are limited to the 10 interviews I conducted within southwestern Connecticut.

Recommendations

The following is a list of recommendations based on my findings related to positive social change, research, and practice. These recommendations relate mostly to my research on the informal caregivers of ALF dwelling older adults but may have relevance with the general informal caregiver population. Using the SEM to explore caregiver burden in the ALF environment not only allowed consideration for the multidimensional intertwining of factors that leads to caregiver burden and the perceived impact that the caregiver burden has on the informal caregiver, the care recipient and their dyadic relationship in this unique environment, but it also served as a framework for developing interventions that address positive social change at and across the various levels of the model.

The promotion of health, wellbeing, and stability of informal caregivers and their ALF-dwelling care recipients requires alliances and participation across the various levels of the SEM. To elicit positive social change, public health officials are well situated to promote greater multisectoral involvement in addressing caregiver burden and further developing the foundation of knowledge needed to inform evidence-based interventions and policy development.

Positive Social Change

I used the SEM as a framework for my study. My study directly addressed the potential impact for positive social change at each level of the SEM. Additionally, the results of this study can assist public health professionals and ALF staff better address health promotion and wellness of informal caregivers and their ALF-dwelling care recipients, encourage greater multilevel involvement in addressing caregiver burden, and further the development of the foundation of knowledge needed to inform evidence-based interventions and policy development.

Caregiver

Public health officials, ALF management, and other related staff and clinicians should invest time to further develop their understanding of informal caregivers, the stress they experience, and the impact of that stress. The emphasis should be on promoting the health, mental well-being, and economic stability of informal caregivers, and working collaboratively, to ensure that informal caregivers feel they are an equal member of the care team.

Interpersonal

A greater understanding of the caregiver dyad and family dynamics could lead to a more positive experience by primary caregivers and their caregivers. Team building, conflict resolution, and reconciliation should be emphasized in self-help literature, and should be made available to informal caregivers at ALFs.

Community

ALF management should focus on ensuring the future resident and the informal caregivers are fully counseled on the costs of ALF living, and that every fee is fully explained. The resident and their caregivers should feel they have a clear understanding of services and related costs. Additionally, ALF staff at all levels should receive training on how to collaborate with caregivers. The emphasis should be on ensuring that the care recipients and residents have their unique needs met, and that the informal caregiver is consulted.

Institutional

Governmental agencies, social institutions, and private organizations at every level should work to ensure that informal caregivers are aware of and have access to the resources needed by the caregivers.

Policy and Societal

From a social justice perspective, public health professionals and other health professionals must promote policies to protect and support informal caregivers and preserve a degree of autonomy among their care recipients (Lindemann-Nelson, 2012). Public health practitioners must use the data presented in this study to further inform health policy at a community, regional, and national level. The prevalence, unique characteristics, and the health effects of informal caregiving as described by Reinhard et al. (2019) should be considered with developing policy briefs by associations and agencies such as Argentum, Assisted Living Workgroup, American Senior Housing Association, CMS, NCAL, and the U.S. Department of Housing and Urban Development. public health professionals must promote policies to protect and support informal caregivers and preserve autonomy among their care recipients (Almgren, 2017).

Implications for Research

The field of public health is unique in that it is multi-professional; with many unique foundations of knowledge and theories to guide its development. As I have mentioned, the SEM is well-suited to capture the multilevel qualities of informal caregiving. Future research should continue to focus on the specific needs of informal caregiving in a variety of settings. Of great interest should be the phenomenon of caregivers tending to their own health and well-being. The health belief model may be suitable to study caregivers and their need to change behaviors to mitigate the impact of caregiver burden now that there is a greater understanding of which behaviors and behavioral characteristics contribute to their burden.

Implications for Practice

Researchers from prior research have concluded that at each level of the SEM, there were modifiable factors such as patient behavior problems, caregiver efficacy, and social support and non-modifiable factors such as duration of caregiving, gender, and level of education that impacted the informal caregiving experience. They advocated for health professionals to be mindful of those factors when developing caregiver interventions (Wang et al., 2020). I have found the SEM to be not only helpful in organizing factors influencing caregiver burden, but also for organizing interventions to address those factors, especially if the implications that span across levels. For example, issues of readiness for caregiving originate at the caregiver level, but also span across the interpersonal level by impacting the care recipient and other caregivers. Community level entities are impacted as the caregiver seeks counsel and support from professionals and from the ALF. At the institutional level, formal governmental organizations, non-governmental organizations, and grass roots entities may be challenged to provide information and support related to their mission. Finally, Policy and societal factors can strongly influence the resources available to the individual caregivers. The dynamic nature of the SEM provides a sound and effective framework for entities at each level when addressing issues of caregiver readiness.

The insights gained from this study can assist public health professionals and ALF staff to better address the promotion of health wellness of informal caregivers and their ALF dwelling care recipients and encourage greater multisectoral involvement in addressing caregiver burden.

Dissemination of Research Findings

The results of my study can assist public health professionals and ALF staff in effecting positive social change, developing further studies, and putting this new knowledge into practice. To disseminate this knowledge, I plan on presenting and writing about my findings locally, statewide, nationally, and globally. I have already presented aspects of caregiving and intervention techniques I learned from my research and from continuing education related to learning theory and dementia care. I have incorporated the need for caregiver support into the health science courses I teach, and I have begun to co-moderate a monthly caregiver support group at an agency ALF.

I am poised to share my finds with others who will read my published dissertation, read subsequent journal articles related to my research, and attend conference presentations on my findings on caregiver burden. I will consider publishing in journals such as the *American Journal of Public Health, American Journal of Occupational Therapy, Health Promotion Practice, BMC Public Health,* and the *Journal of Aging and Health.*

Conclusion

The findings of my study suggest that informal caregivers of ALF-dwelling older adults living in southwestern Connecticut continue to experience varying degrees of stress and burden after their care recipient’s transition to a residential facility. Some factors influencing their stress are like those of informal caregivers regardless of where their care recipients live, while other factors are unique to informal caregiving within the context of residential living.

In this final chapter, I discussed recommendations for specific actions that could be taken by public health practitioners and the impact this study has on the public health body of knowledge, practice, and future research. I used the SEM to outline the impact of positive social change, and I conclude with the thought that a considerable knowledge gap, a substantial practice gap, and a significant knowledge translation gap remains regarding how public health practitioners relate to informal caregiving. An ongoing call for action must be made by public health practitioners to continue to further our understanding of this phenomenon by sanctioning and conducting studies that address the knowledge and practice gaps that exist in a variety of contexts. Additionally, attention must be directed at bridging the knowledge to action gap that prevents the transfer of the available understanding of caregiver burden to translate into practice. America is aging, and often at great expense, informal caregivers are filling a critical role in caring for our elderly.

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Appendix A: Caregiver Burden Self-Assessment

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Caregiver Burden Self-Assessment

The following questionnaire, known as the Zarit Burden Interview, was first developed in the 1980s to help caregivers and mental health professionals evaluate caregiver stress and burnout. While professional psychologists and therapists use this tool to assess clients who are providing care for loved ones, family caregivers who are concerned about their own welfare can use this quick quiz to receive a reliable and objective calculation of the level of strain they are experiencing.

<u>Instructions:</u> Answer the following questions as honestly as possible in order to receive the most accurate assessment of your caregiver burden. Use the following scale to choose a number that best describes how you feel about each question.

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly Always

QUESTION	SCORE
1) Do you feel that your loved one asks for more help than they need?	0 1 2 3 4
2) Do you feel that, because of the time you spend with your loved one, you don’t have enough time for yourself?	0 1 2 3 4
3) Do you feel stressed between caring for your loved one and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4) Do you feel embarrassed about your loved one’s behavior?	0 1 2 3 4
5) Do you feel angry when you are around your loved one?	0 1 2 3 4
6) Do you feel that your loved one affects your relationships with other family members or friends in a negative way?	0 1 2 3 4
7) Are you afraid of what the future holds for your loved one?	0 1 2 3 4
8) Do you feel your loved one is dependent on you?	0 1 2 3 4
9) Do you feel strained when you are around your loved one?	0 1 2 3 4
10) Do you feel your health has suffered because of your involvement with your loved one?	0 1 2 3 4

11) Do you feel that you don't have as much privacy as you would like because of your loved one?	0 1 2 3 4
12) Do you feel that your social life has suffered because you are caring for your loved one?	0 1 2 3 4
13) Do you feel uncomfortable about having friends to your home because of your loved one?	0 1 2 3 4
14) Do you feel that your loved one seems to expect you to take care of them as if you were the only one they could depend on?	0 1 2 3 4
15) Do you feel that you do not have enough money to take care of your loved one in addition to your other expenses?	0 1 2 3 4
16) Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17) Do you feel you have lost control of your life since your relative became ill?	0 1 2 3 4
18) Do you wish you could leave the care of your loved one to someone else?	0 1 2 3 4
19) Do you feel uncertain about what to do about your loved one?	0 1 2 3 4
20) Do you feel you should be doing more for your loved one?	0 1 2 3 4
21) Do you feel that you could do a better job of caring for your loved one?	0 1 2 3 4
22) Overall, how burdened do you feel in caring for your loved one?	0 1 2 3 4
	TOTAL:

Scoring: After answering all 22 questions above, add up the numbers that correspond to your answers. Compare your total number to the scale on the following pages to receive an interpretation of your caregiver burden. On the last page of this assessment, you will find tips, resources and next steps that will help you reduce your burden and see that your loved one receives the care they need.

Your Results

0 – 20: Little to No Burden

Your final score indicates a fairly low and perfectly acceptable level of burden. However, since caring for a loved one is often a long-term commitment, it is crucial for you to stay in tune with your emotions and regularly reassess your stress levels.

Burnout can easily sneak up on family caregivers who are focused on and dedicated to providing care. Learn to be extremely honest with yourself. Recognize your limits early on, get comfortable with acknowledging when you are approaching or have exceeded them, and have a plan in place for these scenarios (because they WILL happen).

While you may think that attending a support group or hiring in-home care for a few hours each week might be excessive at this point, these steps can provide you with a solid foundation for your efforts that can be adapted and increased as your loved one's needs evolve. These supports will enable you to make rational and confident decisions for your loved one and yourself throughout the entire caregiving process.

21 – 40: Mild to Moderate Burden

Moderate caregiver burden sounds like a harmless, normal level of stress, but this particular stage can be the tipping point for many family caregivers. You are already face to face with the difficult realities of your caregiving role. You may not have reached your limits yet, but you are certainly experiencing some stress and strain, even if it is intermittent.

This is an excellent time to assess your care plan and take a realistic look at how much longer you anticipate providing care for your loved one. This is not meant to be callous advice, but conditions like dementia, Parkinson's, and heart and lung disease can worsen over the course of many years. Do you want to continue providing hands-on care for that length of time? Will you be physically, mentally, and financially able to do so? Have you discussed home care services or other long-term care options with your loved one?

Broaching these subjects early on will help ensure that you both are on the same page when it comes to valuing one another's emotional and physical wellbeing. It also gives you ample time to make financial and legal arrangements that are conducive to your plan of care as it evolves.

<u>41 – 60: Moderate to Severe Burden</u>

As your loved one ages and their health conditions progress, things like growing daily responsibilities, financial strain and sleep deprivation begin to add up and have more serious, longer-lasting effects on YOU. Whether you are experiencing a marked change in mood, frequent colds, or the inability to simply focus and think straight, heed the physical and mental warning signs that your body is giving you. You are trying to do too much.

If you still have not felt a compelling need for respite or a support group, take the initiative to seek these things out now. Many caregivers take pride in their work because they do it out of love. The desire to save money is also a common reason for keeping hands-on care within the family. However, by the time most family caregivers ask for assistance, damage has already been done to their health, psyche, relationships and other aspects of their lives.

Make yourself a priority and part of your loved one's care plan in order to avoid these unnecessary complications. It has been proven that the mental and physical stress caregivers endure increase their risk of developing chronic medical conditions and even death. If you were to be hospitalized tomorrow or pass away suddenly, who would care for your loved one?

<u>61 – 88: Severe Burden</u>

You are profoundly burnt out. At this point, your welfare and that of your loved one are at serious risk. Even if you have performed your duties with the best of intentions, you have pushed your limits way too far—and not in a good way.

It is likely that you have reached this point because you haven't heeded your body's warnings or sought out assistance that you truly need. If you haven't already arranged for alternative sources of care, attended a support group, or spoken with your physician about your mental and physical health, NOW is the time to do so. Letting this go unchecked may result in compassion fatigue, depression and anxiety, heart attack or stroke, and even neglect of your loved one.

Caregivers experiencing burnout are incapable of providing adequate physical and emotional care. While you may have promised your loved one that you will be the sole person to care for them no matter what, even temporary respite through a home care agency, an assisted living facility or a nursing home would be a better option for both of you while long-term decisions are made. It may sound backwards, but the top priority right now is YOU. Until balance and wellness are reinstated in your life, your loved one must accept care from someone or somewhere else.

Appendix B: Self-Assessment Resources and Intervention Options

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Resources and Intervention Options

A 2013 study published in the Scandinavian Journal of Caring Sciences concluded that there are four main aspects to “unburdening” a caregiver: information, professional assistance, healthy communication, and public/financial programs. Below we have curated a list of informational and supportive resources in each of these four categories that every caregiver should consider, regardless of their burden level.

1. **Information and Training Materials**
    - Care Plan 101: Set Yourself Up for Success as a Caregiver
    - Strategies for Getting (and Staying) Organized While Caregiving
    - Why Caregivers Refuse Help
    - Relaxing: Why It’s Hard and How Caregivers Can Learn to Unwind
    - Sick with Worry: How Thoughts Affect Your Health
    - Compassion Fatigue: When Caregivers Go Beyond Burnout
    - Getting Caregiver Support When You Have No Time

2. **Professional Support**
    - The Importance of Counseling for Caregiver Burnout
    - Is a Geriatric Care Manager Right for Your Family?
    - Where to Find Respite: Resources for Caregivers
    - 3 Types of Adult Day Care
    - Kinds of Home Care Available for an Elderly Parent
    - Choosing Senior Housing Care Based on Your Parent's Needs
    - Understanding Long-Term Care Options and Finding Providers

3. **Effective Communication**
    - Apologizing After Caregiver Stress Causes a Blowup
    - Getting Your Siblings to Help With Caregiving
    - 11 Ways to Keep Your Relationship Healthy
    - Family Meetings: How to Have Peace and Avoid Arguments
    - How to Discuss Money with Your Parents
    - 6 Ways to Prepare for "The Talk" About Moving to Senior Living

4. **Public and Financial Support**
    - Hidden Money: Overlooked Funds Could Pay for Long-Term Care
    - VA Aid and Attendance: The Basics
    - 19 Free Services for Seniors or Their Caregivers
    - When to Begin Applying for Medicaid
    - Long-Term Care Insurance: How To Use a Policy and File a Claim
    - How to Use a Life Insurance Policy to Pay for Long-Term Care
    - Find Your Local Area Agency on Aging

Appendix C: List of SEM Level 1 Caregiver Themes

Preparedness

- 2nd Guessing Decisions – Second guessing past care decisions
- Formal Ed of CG – Formal training prepared caregiver for new role
- Wasn't Prepared – Lack of preparedness for new role
- CG Prior Role to CR – Personal relationship and roles override formal training
- Identifying as CG – Identifying as caregiver
- Decisions leading to ALF Placement

Health and Wellness

- Lvl of Stress – Response to the caregiver burden self-assessment
- Impact on Wellness – Physical and mental impact of caregiving on caregiver
- Med Condition CG – Existing medical conditions of caregiver
- CG Neglect Health – Caregiver neglecting own health

Roles

- Lifestyle Compromise – Lifestyle compromise due to caregiving -Caregiver role impacts other roles
- Adjust to Role – Adjusting to caregiver role
- Impact on Roles

Feelings

- Caregiver Empathy – Caregiver empathy for care recipient
- Feelings of Guilt – Guilt due to perceived lack of attentiveness – lice for not visiting care recipient

- Insight Into Care Recipient’s Needs
- (-) Spontaneity – Lack of spontaneity
- CG Guilt -> Negativism – Caregiver guilt due to perceived negativism
- Uncertainty about the future

Appendix D: List of SEM Level 2 Interpersonal Themes

Care Recipient Factors

- Seeing Decline – Recognizing decline - health, or functional decline of loved one
- Decision Sharing with Care Recipient
- Still Doing Self-Care - Still involved with pre-ALF caregiving tasks
- CR still in Roll - Care recipient past family member roll still emerging
- CR - Let’s Do It - Care recipient decision to transition to residential living
- CR -> CG: No burden - Care recipient feelings of guilt and remorse due to perceived level of burden on caregiver
- CR tough on CG – Difficulty with care recipient behaviors toward them
- Past Dyadic Relationship

Family Member Factors

- Positive Family Support – Other family members that help
- Family Decision Sharing – Shared decision-making with other family member other parent or sibling
- Unequitable task Distribution - Task distribution with additional caregiver
- Primary Caregiver Supports Others – Participant support of other caregivers
- One Parent in ALF – ALF living of one parent, impacting non-residential parent
- Backseat Drivers/Monday Morning Quarterbacking – Perceptions of input from non-caregiver family members
- Informal Supports – Friends

Appendix E: List of SEM Level 3 Community Themes

Assisted Living Facility

- Negative Feelings Toward ALF – Negative feelings toward ALF
- Overpaying ALF – Paying for a service we don't think we needed or paid for
- Better ALF Options – More logical care alternatives than facility provides
- Misled by ALF - Misled or poorly advised by ALF misled or poorly advised by ALF either with malintent, or without
- High Cost of ALF Living
- Poor Care Coordination – ALF staff perceived lack of care coordination or communication among ALF staff
- ALF Change – Poor facility resulting in switch - positive outcome
- Positive Feelings Toward ALF – Positive feelings toward ALF living
- Other ALF Caregivers? – On the relationship to other family caregivers in ALF.
- Feelings Toward Residence

Formal Caregivers

- Perceptions/Care – Perceptions of provided care
- On Private Aides
- Perceptions/Formal Caregiving

Medical Professionals

- Good Medical Professionals – Praise for medical professional
- Medical Professional -> Good Education of medical professional

Appendix F: List of SEM Level 4 Institutional Themes

How to Choose an ALF

Organizations

- Prior Support – Past formal support gain importance
- Formal Supports - Available formal supports

Appendix G: List of SEM Level 5 Policy and Societal Themes

Societal Implications

- Tradition on Caregiver Role - Values/the impact of family tradition on perceived caregiving role

Policy

- Impact of Covid on Caregiving Day – Caregiver discusses impact of COVID
- Critique of System – Criticism of medical personnel/system

Research

- Benefit of Survey – Questionnaire brought clarity
- Topic and Interview – On the topic and interview process