Spring 4-25-2024

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Recommended Citation

RIvers, Ann, "The Perceived Impact of an "Awareness Toolkit" on Alzheimer Caregivers' Preparedness, Burden, and Posttraumatic Growth" (2024). *Social Work Doctoral Dissertations*. 36.
https://research.library.kutztown.edu/socialworkdissertations/36

THE PERCEIVED IMPACT OF AN “AWARENESS TOOLKIT” ON ALZHEIMER CAREGIVERS’ PREPAREDNESS, BURDEN, AND POSTTRAUMATIC GROWTH

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April 25, 2024

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ABSTRACT

Background

Over 7 million Americans age 65 and older live with Alzheimer's in the United States, and more than 11 million caregivers of people with Alzheimer's disease or other dementias provided an estimated 18 billion hours of unpaid care valued at $340 billion (Alzheimer's Association, 2023). This study implemented a new intervention called an "Awareness Toolkit" for Alzheimer's caregivers comprised of Alzheimer's disease-related education, community resources, and support tailored to the county where care was provided, including caregiver self-care and coping tips. The aim of this study is to evaluate the impact of an Awareness Toolkit intervention and examine its influence on Alzheimer caregivers' preparedness, burden, and personal growth.

Methods

Randomly assigned caregivers in the intervention group were informed about the Awareness Toolkit intervention, supplemented with social work case management services. Conversely, randomly assigned caregivers in the control group received this intervention upon the study's conclusion. A total of 51 completed surveys were returned, comprising 28 surveys from the intervention group and 23 surveys from the control group. Three measurements were used to measure levels of caregiver burden, preparedness, and growth: 1) Zarit Caregiver Burden Assessment (Zarit et al., 2001), 2) Preparedness for Caregiving Scale (Archbold et al., 1990), and 3) Posttraumatic Growth Inventory Short Form (Cann et al., 2010).

Results

There was a significant difference in the preparedness scores between the intervention group (M=2.2, SD=.67) and the control group (M=1.8, SD=.70); $t(47)$=1.9, p=.032. Female caregivers showed a higher level of posttraumatic growth than that of male caregivers (p=.003). The results of the regression analysis indicated the two predictors, burden and toolkit, explained 20% of the variance; $R^2 = .36$, $F(6,43)=3.52$, $p=.007$. It was found that receiving a toolkit intervention significantly predicted caregiver's preparedness ($\beta=.31$, $p=.02$).

Implications

The results of this study underscore the value of an Awareness Toolkit intervention for Alzheimer's caregivers, providing essential preparation and support across the progression of the disease. Provided at the right time and in the right place, this toolkit intervention may help mitigate some of the burden experienced by caregivers, promote personal growth, and enable caregivers to focus on the positive aspects of the caregiving relationship.

Keywords: Alzheimer caregivers, primary care, posttraumatic growth, dementia

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Chapter 1: Introduction

With the expanding growth of the aging population, the number of Americans diagnosed and living with Alzheimer's dementia is rapidly increasing as is the need for caregiving (Alzheimer's Association, 2023; Centers for Disease Control and Prevention, 2019; Julia, 2023; National Alliance for Caregiving, 2020). Approximately 7 million Americans age 65 and older are living with Alzheimer's dementia today (Alzheimer's Association, 2023).

Alzheimer's dementia is an irreversible, progressive brain disease that slowly worsens brain function over time affecting memory, thinking, behavior, and social skills (Mayo Clinic, 2023). It is characterized by changes in the brain that cause the brain to shrink and brain cells to eventually die (Mayo Clinic, 2023). Alzheimer's dementia impacts an individual's ability to care for themselves and perform basic life tasks (Mayo Clinic, 2023). There are several types of dementia; however, Alzheimer's dementia is the most prevalent one, has no known cure, and is ultimately fatal. Given the debilitating nature of the disease, caregiving is critical as those diagnosed live a portion of their life dependent on others for their long-term care needs.

Alzheimer's dementia is a disease that is often under-detected, under-diagnosed, under-disclosed, and mismanaged which results in a domino effect for caregivers who face increased challenges (Alzheimer's Association, 2023; Bernstein et al., 2019; de Levante, 2022; Fernandez et al., 2021). Surprisingly, many individuals, including those diagnosed early with Alzheimer's dementia, are sometimes not even aware they have the diagnosis. Unfortunately, when caregivers do not know the diagnosis, they face greater challenges in managing memory, behavioral and functional changes as they lack knowledge about Alzheimer's disease, available resources, and options, which delays access to services and support. According to the Alzheimer's Association (2020), adults aged 65 and older make up 40% of primary care visits and at least 13% of those patients are diagnosed with dementia. Too often primary care providers (PCPs) delay or refer to specialists for diagnosis leaving caregivers unsupported in dealing with symptoms and behaviors they do not understand nor know how to address. As stated in a 2019 Alzheimer’s Association report, it is not uncommon that a dementia diagnosis occurs in the middle to late stages of the disease or at times of crisis. Data showed that only 45.4% of adults age 45 and older who experienced subjective cognitive decline discussed their concerns with a healthcare professional (Taylor et al., 2018). Constrained by time and frequency of visits limiting their ability to detect subtle cognitive changes, primary care providers often hesitate to initiate conversations and rely on family members to bring it to their attention. Sociocultural beliefs, personal experiences, social and health stigma, insurance coverage issues and a shortage of medical specialists are additional barriers to early diagnosis.

The impact of Alzheimer’s dementia for caregivers is often significant as it affects every aspect of their life and well-being. Due to the unpredictability, intensity of needs, and length of illness, caregivers often experience emotional stress, employment and income issues, financial insecurity, burnout, and fatigue (Alzheimer’s Association, 2023; Bayly et al., 2021; Brodaty & Koschera, 2003; Centers for Disease Control and Prevention, 2019; Cross et al., 2018). A report by the American Association of Retired Persons (2020) found that 26% of Americans caring for someone with Alzheimer’s disease have trouble coordinating care and 23% reported their own health worsened. Little is typically provided to caregivers during their transition to the caregiving role leaving them unprepared to manage and cope with the myriad of issues that arise along the disease trajectory (Ducharme et al., 2011). More than 84% of caregivers preferred more information or assistance with caregiving topics like home safety, stress management and end-of-life decision-making (National Alliance for Caregiving and American Association of Retired Persons, 2015).

Numerous studies in the literature have consistently identified Alzheimer caregivers as a vulnerable and underserved group that warrants attention and intervention to better support them along the care continuum (Bayly et al., 2021; Chang et al., 2020; Chappel et al., 2015; Connor et al., 2008; Cross et al., 2018; de Levante, 2022; Gallagher-Thompson et al., 2020; Gaugler, 2011; Gomez et al., 2020; Henriksson & Arestedt, 2013; Lee, 2019). There is little consensus, however, regarding the type of interventions that would be most helpful for caregivers and when is the right time to implement those services and supports. Many studies promoted a multi-team perspective to be most effective while others suggested a psychotherapeutic approach, behavior management, medication interventions, mindfulness, case management and social support programs. There has been greater emphasis on targeted tailored interventions addressing different aspects of caregiving rather than packaged programs and a growing number of studies underscored the importance of primary-care-led dementia care specific to timing and early diagnosis.

Care models varied by who was assigned the responsibility for providing training, education, and resources including nurse practitioners, nurses, case managers, social workers, and dementia-care specialists. Unfortunately, staffing issues, funding, and lack of stakeholder support often presented as barriers. Many primary care practices in the greater Philadelphia area in Pennsylvania do not utilize any evidence-based practices to support Alzheimer caregivers but instead rely on their care managers and medical providers to disseminate information as needed (S. Sumilat, personal communication, March 14, 2023; M. Horvat, personal communication, March 13, 2023). Providing an educative and supportive intervention, like an Awareness Toolkit, at the right time, in the right place, and in the most prudent way, may promote a sense of empowerment for caregivers and help them feel more confident and more competent in their caregiving role. An Awareness Toolkit is a collection of Alzheimer's disease-related education, care, and community resources and supports specific to the county where care is being provided and includes caregiver self-care and coping tips. It serves as a guide on how best to navigate the dementia journey and provides critical information and options to help caregivers work through difficult problems related to care. Caregivers will concurrently have access to social work case management to educate, facilitate and advocate based on caregivers' individualized needs and provide direction and support as questions arise and challenges increase. If this gap in care is addressed, it may potentially reduce the effect of stressors and improve general well-being for both caregiver and care recipient.

The objective of this study is to assess the aspects of Alzheimer caregivers' preparedness, perceived burden, and posttraumatic growth in the context of an Awareness Toolkit intervention developed for primary care in Southeastern Pennsylvania. Informal Alzheimer caregivers, referred to hereinafter as Alzheimer caregivers, are defined as non-professionals who provide unpaid caregiving.

Scope of the problem

Disease prevalence

A growing public health problem, dementia caregiving creates multiple challenges given the long duration of the illness which is spent in a state of disability and dependence (Alzheimer's Association, 2021). According to the Alzheimer's Association (2023), Alzheimer's remains the fifth-leading cause of death among Americans age 65 and older with the number of deaths increasing over 145% from 2000 and 2019. Worldwide, 55 million people are living with Alzheimer's and other dementias with nearly 10 million new cases every year. Today, more than 7 million Americans age 65 and older are living with Alzheimer's in the United States, 1-9 people aged 65 and older (10.7%) which is expected to more than double to 13 million by 2050 (Alzheimer's Association, 2023). Cases in Pennsylvania totaled 280,000 in 2021 which is projected to reach an estimated 320,000 by 2025, a 14.3% increase (Weuve et al., 2015). Seventy-three percent of those diagnosed are age 75 or older; however, younger-onset Alzheimer's dementia is on the rise in the United States totaling about 200,000, 5-6% of Americans (Alzheimer's Association, 2022). There is a higher prevalence of Alzheimer's and dementia for women estimated at 3.8 million compared to 2.4 million for men (Alzheimer's Association, 2022).

Daughters caring for a parent comprise over one-third of dementia caregivers (Friedman et al., 2015; Kasper et al., 2015). Family caregiving also extends across all generations including Boomers, Gen-X, Gen-Z, Millennials, and Silent (American Association of Retired Persons, 2020). Twenty percent more time is provided by caregivers today than a dementia caregiver a decade ago, which equates to almost six more full work weeks of unpaid care each year (Alzheimer's Association, 2023). A study by Jutkowitz et al. (2020) found that people with dementia initially required 151 hours of caregiving per month which later increased to 283 hours per month over an eight-year period.

Financial burden

As the population ages and families are unable to sustain the long-term cost of services, the system may not be able to support the growing demands associated with Alzheimer's and caregiving. More than 11 million caregivers of people with Alzheimer's disease or other dementias provided an estimated 18 billion hours of unpaid care valued at $340 billion (Alzheimer's Association, 2023). According to Sauer (2023), the total lifetime cost of care for someone with dementia is estimated to be $341,840, with the costs associated with family care to be 70% of the total cost burden or $239,288. The financial burden is staggering, placing a huge financial strain on the healthcare system estimating $345 billion in healthcare costs with $222 billion (64%) paid by Medicare and Medicaid and expected to increase to nearly $1.1 trillion by 2050 (Alzheimer's Association, 2023). Medicare spending per person for those with Alzheimer's dementia and other dementias is more than three times higher than spending across all other seniors (Alzheimer's Association, 2021).

State of caregiving

The most significant finding for caregivers was identified in one study of 1,221 married couples, aged 65 and older, that found those caring for a spouse with dementia were at six times greater risk of developing dementia themselves than those caring for a spouse that was dementia free (Norton et al., 2010). It is estimated that 11 million caregivers, or one in four caregivers, are referred to as "sandwich generation" caregivers because they are caring for an older adult while raising a child or grandchild. Jutkowitz et al. (2020) reported that when activities of daily living (ADLs) and instrumental activities of daily living (IADLs) decrease, five more hours of monthly caregiving is required. Among caregivers who were employed, 57% said they had to go in late, leave early, or take time off, while 18% reduced their work hours, and 13% took a leave of absence (Alzheimer's Association, 2023). According to Hoffman et al. (2016), there are seven potential family caregivers per adult projected to decrease to only four potential family caregivers per adult by 2030. This projection is very compelling because when unpaid caregiving cannot be supported, costly long-term care is often the only other alternative. To compound the situation further, an estimated 1.2 million additional paid care workers will be needed between 2020 and 2030 more than in any other single occupation in the United States (Alzheimer's Association Facts and Figures, 2023).

Primary care

Since primary care serves as the cornerstone in our healthcare delivery system today providing patient-centered care, interventions that support Alzheimer caregivers can facilitate positive outcomes. Primary care is a level of care or setting in which primary care providers such as doctors, nurses, nurse practitioners, and physician assistants provide comprehensive coordinated care and maintain long-standing relationships with their patients. It is often considered the first patient contact within the healthcare delivery system. According to Aminzadeh (2012), primary care providers play a key role in timely diagnosis, ongoing treatment, extensive case management, and support to caregivers and care recipients. Healthcare providers have an important opportunity to learn about their patients' caregivers and connect them early with resources, and support information (Robinson-Lane et al., 2021; Welch et al., 2022).

Impact of caregiving

Without adequate support or knowledge of caregiving tasks and disease progression, caregivers must learn to cope independently with behavioral and cognitive changes associated with the disease, multiple losses, and their new caregiving role. A study by Cross et al. (2018) investigating the experiences, quality of life, and psychosocial impact of caregiving found that caregiver's confusion and difficulty in understanding what was happening to the care recipient was due to a lack of information and limited knowledge of dementia.

Considered to be "the invisible second patients," caregivers' experiences often involve high rates of burden, psychological morbidity, social isolation, poor health, distress, and financial hardship (Brodaty & Donkin, 2009). Koca et al. (2017) perceived the incapacity, despair, loneliness, and exhaustion encountered by caregivers as the invisible aspects of the disease. Many caregivers experience an array of emotions, i.e., irritability, sadness, worthlessness, guilt, grief, social withdrawal, and denial relating to the diagnosis and their role as caregiver. Due to the caustic nature and unpredictable behaviors typical of Alzheimer's dementia, caregiver burnout and fatigue are high. Mental health issues like anxiety and depression often contribute to physical conditions such as high blood pressure and heart disease due to the stress generated by caregiver burden. Sorensen and Conwell (2011) found that dementia caregivers reported higher levels of stress, more depression and anxiety symptoms, and lower levels of subjective well-being compared to non-dementia caregivers. Higher psychological issues are due to the high level of functional assistance needed from caregivers as well as the unpredictable behaviors characteristic of this disease.

This study seeks to determine whether an Awareness Toolkit intervention provided to Alzheimer caregivers helped them feel better prepared, less burdened, and experienced personal growth and some positive aspects of caregiving. The findings may provide valuable insight and contribute to the development of a formalized social work intervention that will educate caregivers and facilitate optimal outcomes.

Relevance to Social Work leadership, education, and research

Acknowledging and understanding the complexities of this disease and the issues faced by Alzheimer caregivers demands the attention of social work professionals who can provide the expertise needed to effect positive change in how we perceive Alzheimer's dementia, how we deliver services and how we support those who are caregivers. Social workers serve a key role in serving vulnerable and underserved groups, including this growing population of caregivers. Only by recognizing the full scope of care challenges along the disease trajectory, can we act responsibly to meet caregiver's needs, help to improve their quality of life, and support their relationships with their healthcare providers.

Chapter 2: Literature Review

Introduction

This chapter examines the literature relating to Alzheimer caregivers and the impact of Alzheimer's disease on the caregiving experience specific to caregivers' preparedness, perceived burden, and resiliency and posttraumatic growth. A review of the literature seeks to provide a clear understanding of the prevalence of the problem, the complexities of the disease, and issues faced by Alzheimer caregivers. Research was conducted during the period from September 2021 through November 2023 using PubMed, Google Scholar, Research Gate, Google Custom Search, ERIC, etc. searching the following keywords: Alzheimer's dementia, caregiving, caregiver burden, resiliency, and preparedness. This chapter also examines the outcomes and implications of existing interventions, which supports the need to provide caregivers with Alzheimer's disease-related information, resources, and support.

Three theories will be discussed: The Roy adaptation model, the Neuman systems model and Uncertainty management theory. The Roy adaptation model considers the negative impact of stress on caregiver's ability to cope and adapt over time to the changing care needs and behavioral challenges (Reuda et al., 2017; Thornbury et al., 1992). The Neuman systems model offers insight regarding the effects of a long-term illness, like Alzheimer's dementia, on the caregiver's role and experiences (Neuman, 1996; Ume-Nwagb et al., 2006) while Uncertainty management theory addresses the uncertainty of health experiences as an illness, focusing on the ambiguity and unpredictability of the situation, and the importance for caregivers to have knowledge of Alzheimer's disease-related information and available resources (Lambert & Loiselle, 2007; Rains & Tukachinsky, 2015).

Importance of intervention timing

According to Gallagher-Thompson et al. (2020), intervention timing has been largely neglected in previous reviews of caregiver interventions although there is increasing evidence that implementation of an intervention directly into the primary care setting can be of significant benefit to the patient-caregiver dyad and their relationship with their healthcare provider. There are wide individual differences in timing and type of interventions, services, and supports needed as caregivers move through the disease continuum (Gallagher-Thompson et al., 2020). They recognized that what might be effective in early stages may not be suitable in middle or late stages of the disease.

De Levante (2022) claimed that high-quality care is synonymous with early accurate detection and diagnosis enabling more effective management of this chronic condition. Early discussions about cognitive impairment at the primary care level can also lead to more timely access to care and treatment, community resources, and support services. Lee (2019) focused on caregiver experiences, needs, and interventions at the time of an Alzheimer's diagnosis and contends that it is a critical time for caregivers to receive information and resources to support their transition into the caregiving role and increase positive outcomes. Providing psychosocial interventions and resources to caregivers of newly diagnosed Alzheimer's may contribute to better adaptations to the caregiver role and reduce stress. Gaugler (2011) argued that challenges during care transitions, such as lack of preparedness in the initial caregiving stage, contributed to negative health outcomes for both caregiver and care recipient hastening the transition to a long-term care setting.

Findings of a review by Bayly et al. (2021) suggested that early-stage intervention, regardless of the type of intervention, had a small positive effect on caregiver's well-being and ability to provide care with the greatest impact on caregiver distress and anxiety. Another study showed that 58 % of family caregivers were in favor of early dementia diagnosis, 50 % needed dementia education, and 23% needed in-home support (Khanassov & Vedel, 2016). Cross et al. (2018) found that caregivers generally welcomed and sought information about dementia but preferred to receive it in a timely manner as needed rather than receiving it all at once at the time of diagnosis. They recommended a person-centered approach to care planning as part of a dementia care package that addressed caregivers' emotional support, coping, resilience, information, and respite care.

Caregiver preparedness

Preparedness in the caregiving role is essential when dealing with a chronic disease like Alzheimer's dementia given the unpredictability of behaviors and needs of the care recipient which can also affect caregiver's resilience. Preparedness implies being in a state of readiness, feeling better equipped, and more confident to handle the demands, stressors, and challenges of caregiving including physical care, emotional support, and access to resources and services. Caregivers' understanding of a dementia diagnosis and its meaningfulness in relation to their coping and perceived manageability influences the quality of caregiving and the caregiver role (Henriksson & Arestedt, 2013).

The literature suggests that many caregivers receive inadequate preparation for the tasks they are expected to assume in their caregiving role. Some studies reported that feelings of preparedness influence the caregiving experience and protect the caregiver from any negative consequences (Chappel et al., 2015; Henriksson & Årestedt., 2013). According to Scherbring et al. (2002), greater preparedness in the caregiving role related to lower levels of burden over time. Likewise, a study of community-dwelling caregivers found greater caregiver preparedness was associated with lower depression and burden which decreased the risk of caregivers' feeling like yelling or screaming at the care recipient (Hancock et al., 2022). The researchers emphasized the importance of providing caregivers with education and training to be better prepared for their caregiving role. They argued that educating caregivers on stress management strategies, access to respite or other support services may help to alleviate caregiver burden. Yang et al. (2014) found that a high level of understanding and preparedness protected caregivers from high levels of role strain, even when caregiving was high. Kasuya et al. (2000) claimed that educating caregivers on what to expect when taking care of an individual with Alzheimer's dementia can increase confidence and performance.

Another study assessing dementia care management in nine southern California primary care clinics stressed the importance of clarifying the service needed and connecting caregivers to agencies for specific services (Connor et al., 2008). It found that assessing the specific needs of caregivers and their care recipients in the home environment was linked to improvements in caregivers' sense of mastery. A study involving veterans diagnosed with Alzheimer's or Traumatic Brain Injury who received an evidence-based collaborative care model for brain care showed significant improvement in the quality of care and management of behavioral and psychological symptoms for patients and their caregivers (Carnahan et al., 2020). It determined that family caregivers spent more time on safety, managing behaviors, advocating, and ensuring access to care and supportive services. These researchers recognized the need for primary care-based interventions given the changing view of primary care as the "hub of care" (Carnahan et al., 2020). Similarly, Callahan et al. (2011) proposed that individualized care facilitated by a care team comprised of a care manager, a primary care physician, and a memory care specialist utilizing information technology resources produced positive outcomes for caregivers.

Caregiver burden

Throughout the illness, caregivers often experience increasing burden as care demands increase and change. Caregiver burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving role (Kasuya et al., 2000; Wennberg et al., 2015). Caregiver burden is linked with distress which negatively influences one's capacity to manage daily care and affects the quality of caregiving. Symptoms of perceived caregiver burnout may manifest itself as stress, anxiety, depression, changes in appetite, weight and sleep patterns, and fatigue. Burden including strain, depression, and other adverse health consequences can be debilitating and overwhelming for caregivers (Reuben et al., 2019). Many caregivers struggle with different emotions like anger, anxiety, irritability, sadness, worthlessness, guilt, grief, social withdrawal, and denial relating to diagnosis or their role as caregiver. Coping with some or all these emotions can further contribute to emotional burden and caregiver stress**.** According to Hellis and Mukaetova-Ladinska (2022), caregiver burden was associated with negative consequences for both caregivers' and care recipients' physical and mental health. The results of 873 caregiver interviews by Chappell et al. (2015) found that daughters experience the highest burden but also the highest self-esteem compared to wives and sons. Norton et al. (2010) determined that the burden for spouses may be even greater due to close emotional ties to their partner, greater risk of fatigue and functional limitations over time, and anticipatory grief associated with caregiver burden. A survey of 200 U.S. caregivers regarding the impact of Alzheimer's disease on caregivers' physical, emotional, and social health found that 58% of caregivers perceived themselves as "incredibly stressed", 65% of caregivers rated the difficulty caring for someone with Alzheimer's dementia as "hard and extremely hard”, 47% of caregivers reported becoming sleep deprived, and 43% of caregivers were more socially isolated (Vu et al., 2022).

According to a study of 85 urban caregivers, 19% reported experiencing subjective strains like worries and uncertainties, balancing multiple demands, and feeling overwhelmed with care, while spiritual and personal growth, and feelings of mastery produced feelings of gain (Sanders, 2005). Similarly, another study examined caregivers’ experiences including emotional strain, increased caregiver burden and poorer quality of life which were attributed to caregiver beliefs, financial strain, and lack of support. Findings suggested that caregiving should be taught as a normal part of adult education so individuals can be better prepared for the caregiving role (Hellis et al., 2022). Caregivers shared that many caregiving challenges are related to the burden of caregiver strain and the transitive nature of the disease (Ashrafizadeh et al., 2021). These researchers proposed a multi-dimensional targeted approach and recommended educational and support packages to minimize challenges and decrease their care pressure. Werner et al. (2012) examined the relationship between caregiver burden and family’s perceptions of being stigmatized by their association with a parent diagnosed with Alzheimer’s and found increased feelings of burden and increased negative caregiving experiences. Findings from an Iranian study revealed that perceptions of caregivers’ role varied as some caregivers experienced burnout and exhaustion while others experienced growth and satisfaction.

According to Jorge et al. (2019), the strongest predictor of quality of life among caregivers was determined by their perception of the caregiving experience as well as other aspects of life, such as family, employment, and caregiver’s emotional and mental health. A qualitative study of fifteen informal caregivers focused on information seeking as a coping strategy to reduce stress and improve quality of life for both the caregiver and care recipient

(Mason et al., 2022). They identified many emotions related to caregiving such as feeling obligated and stuck, stressed, frustrated, overwhelmed, and feeling guilty or like a failure. Some participants even perceived their interactions with healthcare professionals contributed to their stress and frustrations because they lacked an understanding of the caregiving situation.

The significance of healthcare providers to identify caregivers who are under tremendous burden or at risk of burnout in a timely manner can help to prevent and initiate appropriate interventions that result in improved quality of life for both caregiver and care recipient (Kasuya et al., 2000). They also stressed the importance for healthcare professionals to recognize their own burnout in managing this complex disease. Yang et al. (2022) found that an empowerment program focusing on self-care increased quality of life for caregivers and decreased caregiver burden following the implementation of an education program focusing on caregiving. Likewise, a study by Yazdanmanesh et al. (2022) demonstrated that an empowerment program reduced care burden and increased healthcare quality of life for family caregivers of care recipients diagnosed with Alzheimer's disease. Igarashi et al. (2020) found that primary caregivers had poorer health scores, higher caregiver burden, work impairment, and absenteeism than non-primary caregivers. They proposed further investigation to develop specific interventions to reduce caregiver burden and improve quality of life for both caregiver and care recipient. A review of burden and interventions concluded that psychosocial and case management interventions produced modest improvements on caregiver outcomes while respite care and communication technology interventions were ineffective (Schoenmakers et al., 2010). The researchers concluded that a population health approach consisting of individualized, holistic care with tailored mixed interventions and ongoing contact with dyads to be the most effective (Olazaran et al., 2010). Kam-Shing (2005) believed that a social work strengths-based perspective can play a vital role. According to McGovern (2015), when strengths-based social work is applied in practice and integrated into dementia care processes, well being can increase. Likewise, a study by Ostwald et al. (1999) suggested that “a resource-building approach” might help prevent stress-related symptoms. They found that burden and depression were significantly lower among caregivers whose treatment matched their needs and goals and interventions addressed multiple dimensions of caregiving stress.

Sorensen and Conwell (2011) believed that multicomponent interventions addressing specific aspects of caregiving were more effective in delaying nursing home placement and reducing perceived caregiver burden. They looked at the results of various interventions tested in randomized controlled trials in two longitudinal studies. Bakker et al. (2011) showed that an intervention with multiple components designed to meet the specific needs of caregivers and their care recipient, resulted in reduced perceived burden and neuropsychiatric symptoms. Gaugler et al. (2011) focused on the important role that caregiver burden played in mediating the relationship between patient behavioral disturbances and nursing home admission. Their findings supported the need for treatment approaches that incorporate caregiver burden and the behavioral/psychiatric symptoms of the care recipient simultaneously. A multi-dimensional intervention is more effective, according to Zarit and Femia (2008), than a one-dimensional program because they have the potential to address multiple stressors and specific caregiver problems. Skaria (2022) suggested that policymakers and managed care organizations should develop healthcare strategies that enable patients to age-in-place while providing support services to reduce caregiver burden.

Caregiver resiliency and posttraumatic growth

Resiliency helps caregivers maintain their mental and physical stability, fostering caregiving, and providing better health and quality of life for the care recipient. Resiliency refers to the ability to handle difficult or challenging life experiences and to adjust and adapt to deal with stressors and external demands (Babic et al., 2020). It can be considered a protective factor against the negative impact of stressful or traumatic situations that lead to positive outcomes. Resilience represents a coping process that helps an individual to rise above challenging experiences, return to a previous healthy condition, and provide a sense of well-being despite chronic illness (Babic et al., 2020). The researchers regard resilient individuals to be optimistic and social, and tend to view everything as a useful experience and opportunity for personal growth.

One study looked at resiliency among Alzheimer caregivers, specifically its methodological approaches and models, and found lower burden, stress, neuroticism, and perceived control to be the main psychological factors associated with resiliency (Dias et al., 2015). Social support was determined to be a factor of resiliency, and different types of support seemed to mitigate the physical and mental overload caused by stress (Dias et al., 2015). A study by Scott (2013) found a relationship between resilience and caregiver burden, specifically, as resilience in Alzheimer caregivers increases, caregiver burden decreases. The study highlighted the importance of supportive interventions that will increase resilience in Alzheimer caregivers. A survey examining the effects of resilience on caregiver's level of preparedness and compassion from an Asian perspective found that resilience was a significant mediator of preparedness and compassion satisfaction (Sheth, 2020). According to Cross et al. (2018), caregivers' knowledge about the disease and their need for information play an important part in their coping and resilience levels. They identified the need for a "one-stop service or one contact for caregivers" in a healthcare setting to ensure access to information, skills training, or referral to services. The results were mixed as some caregivers reported there was a lack of dementia information provided at the time of diagnosis, while others found the amount of information provided overwhelming. Tailoring interventions to individual preferences regarding timely receipt of dementia-related information and support may be best to ensure caregivers' needs are met.

According to Wilks and Croom (2008), stress negatively influenced caregivers' resilience while social support (i.e., high family support) had a positive effect on resilience levels**.** Findings from a study of 120 caregivers in Badajoz, Spain showed that caregivers with high levels of resilience had moderate signs of burden, and fewer symptoms of depression, anxiety, and somatic symptoms (Brodarty & Donkin, 2009). They believed that having a better understanding of caregiver resilience and its contributing factors could help in designing future interventions to identify caregivers with lower levels of resilience early on to improve caregivers' well-being.

Koivisto et al. (2015) assessed the effect of early psychosocial intervention on disease progression, behavioral symptoms, and postponement of institutionalization but found no effect on caregiver distress, depression, quality of life nor any delay in nursing home placement. These researchers determined that individualized support programs may be more effective than providing psychosocial intervention courses. According to Durán-Gómez et al. (2020), utilization of social support and problem-solving coping strategies influenced caregiver resilience; however, caregiver's own intro-psychic resources showed stronger correlations. Sheth (2020) recommends resilience training that supports problem-solving and conflict-resolving skills and positive thinking to help strengthen one's resilience and well-being. Cognitive behavioral therapy, mindfulness, and antidepressant medications were also suggested to build resilience. Roberts and Struckmeyer (2018) conducted a study addressing caregiver respite programming and resilience and discovered that many participants felt that by reaching out for help they were a failure which decreased resilience over time. The study identified the need to create opportunities for individualized, rather than one-size-fits-all support programming. Walsh (2003) proposed a "family resilience model of adaptation" which included making meaning out of adversity, maintaining a positive outlook, social connectedness, and flexibility. According to Palacio et al. (2020), a resilient coping style can decrease stress and burden while promoting adaptation in the caregiver.

A related concept to resilience is posttraumatic growth. Posttraumatic growth (PTG) refers to positive change experienced as a result of struggling with highly challenging, highly stressful life circumstances that test the adaptive resources of an individual and their perception about themselves, their relationships and the world. This is particularly true for Alzheimer caregivers who are impacted physically, mentally, emotionally, financially, and socially by the exhaustive, caustic, and unpredictable nature of this disease. To mitigate this impact, caregivers may have opportunities for growth by reframing their perception of stress that can add personal value and well-being resulting in more positive outcomes for themselves and the care recipient. It represents an individual's capacity to reflect, grow, and shift one's perspective to achieve a greater appreciation for life, commitment to their values and renewed connection to others (Jones et al., 2020).

Special categories of caregivers

Alzheimer's dementia is not only a major public health crisis in the United States but a growing health disparity. The U.S. Census expects the minority population to rise to 56% of the total population in 2060 with no group having a majority as the U.S. moves closer to becoming a plurality nation of racial and ethnic groups (Wazwaz, 2015). Alzheimer caregivers of disadvantaged groups, particularly those that are racially and ethnically diverse, still face challenges in access to care, services, and support due to continuing inequities (National Academies of Sciences, 2021). The Alzheimer's Association (2023) refers to Alzheimer's dementia as "a silent epidemic" in the African American community since they suffer disproportionately from the disease and are twice as likely to have Alzheimer's dementia than white Americans (Fortune, 2013). According to Alzheimer's Association Facts and Figures (2023), older Hispanics are one and a half times more likely to develop Alzheimer's dementia or other dementias than older white Americans. There are greater risks of Alzheimer's disease and dementia for Black and Latino people and more consequences for their caregivers who face additional barriers to services due to lack of information, limited or no access to community resources and services, as well as other social and economic benefits. These conditions are often referred to as social determinants of health which drive health inequities within different racial communities resulting in poorer health outcomes (Centers for Disease Control and Prevention, 2021).

Another study found that Black caregivers often experience significant emotional, health, and financial challenges and find themselves without adequate support, knowledge of caregiving tasks or disease progression (American Association of Retired Persons, 2020). Many of those caregivers reported feeling less confident in finding respite care and in managing disruptive behaviors. A focus group of Black caregivers agreed that the health system they experience is broken, which results in people slipping through the cracks in respect to care, services and needed resources (Alexander et al., 2022).

A study of 146 family caregivers consisting of approximately 75% African American and 25% Caucasian caregivers focusing on burden and self-efficacy determined that an understanding of the contributing factors is necessary to develop critical strategies to reduce caregiver burden and improve outcomes for both the caregiver and care recipient (Jackson, 2015). According to Nielsen et al. (2020), people from minority ethnic groups may still choose not to accept care and support services due to cultural norms and the fact that formal services are typically not specific to their needs. They underscored the need to develop protocols and interventions that demonstrate cultural awareness and diversity to effectively support caregivers within their communities. Guerriero et al. (2004) developed and implemented nonpharmacologic protocols for the management of Alzheimer's patients and their caregivers in a multi-racial primary care setting which included individualized behavioral intervention strategies, a psychosocial-educational support group with an exercise component for caregivers coordinated by a nurse practitioner. They considered the care management program to be successful based on the large percentage of minority attendees.

Caregivers in the LGBTQ+ community experienced even more prejudice, insensitivity, and lack of support within healthcare due to concern for privacy and legal challenges with estate planning like next of kin rights (Moore, 2002). Individuals with early-onset dementia and their caregivers face additional challenges as younger caregivers are often unprepared and experience increased burden as they serve in a caregiving role for a longer period, have dependent children at home and experience financial hardship. Luscombe et al. (1998) emphasized the need for early referral to services, appropriate day care for this younger group, as well as more information and support at diagnosis for caregivers. Similarly, Latino caregivers of early onset Alzheimer's reported negative experiences with primary healthcare providers because they were not informed about the disease, were insensitive or unsympathetic (Withers et al., 2021).

Praxis

Several primary care practices within the Greater Philadelphia area were contacted by this researcher to determine if there were any formal processes or evidence-based practices to support Alzheimer caregivers. Aside from PENN Medicine's Memory Center which offers a multicomponent approach including an evidence-based educational caregiver class, respite, lectures, and other caregiving programming, there were no consistent processes across any of the other primary care practices contacted. Several of Grand View Health's primary care offices (Grand View Health Primary Care Harleysville, Primary Medical Practice Souderton, and Lederach Family Practice) relied on their care managers who have limited time and knowledge of resources and who were only able to sporadically engage with patients and their caregivers. One of the care managers wished there was one resource to refer to and emphasized the need for more supports like respite. Two of the primary care practices within Doylestown Health system, Tohickon Medical and Buxmont Medical Associates, assign their healthcare providers the responsibility to disseminate information and resources when necessary.

Theoretical framework

This section will review the Roy Adaptation Model, the Neuman Systems Model and Uncertainty Management Theory which provides the theoretical underpinnings to help conceptualize this phenomenon and the need to better support this underserved population of caregivers throughout the disease continuum. Quality care may be delivered by integrating theory-guided perspectives with an intervention toolkit that may produce optimal outcomes for both caregiver and care recipient.

Roy Adaptation Model

The Roy Adaptation Model avers that humans are adaptive living systems who strive to maintain stability and functionality despite stressors (Reuda et al., 2017). Individuals respond to a constantly changing internal and external environment through adaptive coping mechanisms that result in positive or negative responses (Thornbury et al., 1992).

Both the behavioral and physical care needs of individuals diagnosed with dementia cause stress that affects caregivers' ability to cope and manage care effectively which, in turn, impacts adaptation to caregiving and the overall caregiving experience. Over time, it depletes the caregiver's ability to handle difficult and/or challenging life experiences and to adjust coping to deal with stressors and external demands. Caregivers often feel less confident to manage care demands including physical care, emotional support, and their ability to access resources and services. Some of the concepts of systems theory may be relevant to understand how various systems in an individual's life influence their behavior and share their experiences, while striving toward adaptation to protect itself, cope, and maintain homeostasis (Walker, 2019). The emotional upheaval can make it difficult to function and impede caregiver's capacity to maintain quality caregiving given feelings of distress and burden often associated with caregiving. This theory outlines the tools needed to guide healthcare professionals to support and educate for optimal functional and psychological adaptation (Gibson, 2020). The accessibility of knowledge and resources provided by this intervention may offer caregivers the utility of choice and instill a greater sense of control which may help to increase caregiver's confidence, capacity, and resiliency.

Neuman Systems Model

While the Roy Adaptation Model highlights the importance of knowledge and resources leading to choice and empowerment, the Newman Systems Model offers an insightful understanding of the effects of a long-term illness, like Alzheimer's dementia, and its effect on caregivers' experience and role. As an application of General systems theory, this model views individuals in their environment as open systems vulnerable to stressors that disrupt the system (Neuman, 1996). Caring for someone with a long-term illness can influence and disrupt all aspects of life including physical and emotional wellness (Ume-Nwagb et al., 2006). This can wear down a caregiver's physical, mental, and emotional health resulting in fear, worry, sadness, despair, and grief. It emphasizes the need for education and intervention for improved, overall wellness and preparedness for the caregiver journey. From a systems theory perspective, there is an input of energy to the open system in the form of education and intervention that leads to change and positive outcomes for caregivers. Prevention strategies, like an Awareness toolkit, may help to maintain stability by improving caregiver's level of competence and resilience and lessen feelings of burden knowing that information, services, and case management are available to them through this intervention.

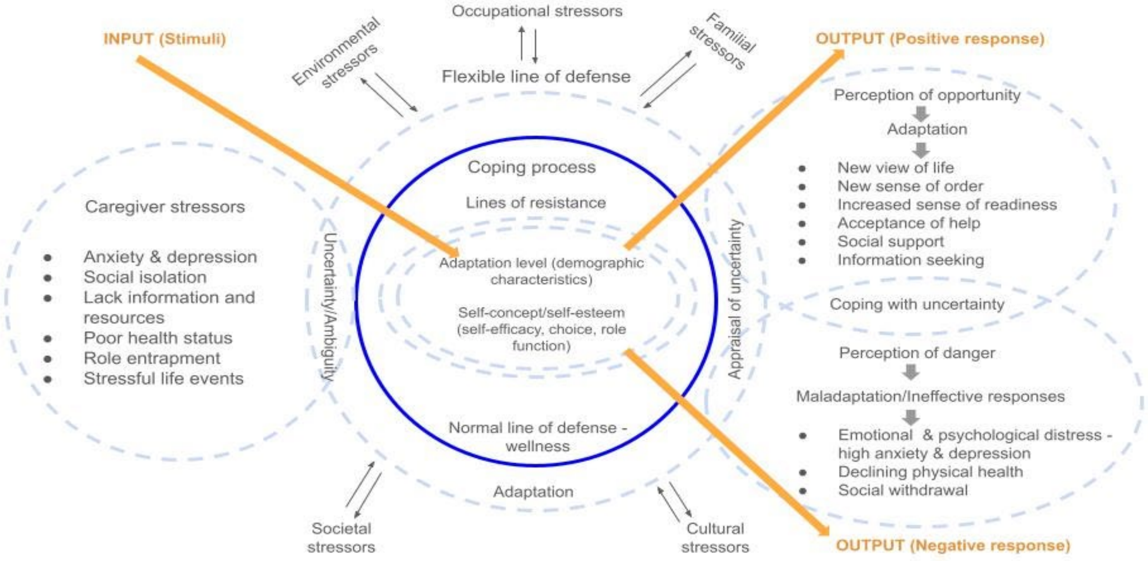
Uncertainty Management Theory

Uncertainty Management Theory can be applied to the uncertainty of health experiences as in illness and caregiving, specifically the ambiguity, unpredictability of the situation and lack of knowledge and information which contributes to feelings of burden. Uncertainty Management Theory outlines the processes through which individuals cope with health-related uncertainty (Rains & Tukachinsky, 2015). This is especially true regarding Alzheimer's disease given the changing needs and unexpected demands throughout the care trajectory. A study by Visser et al.

(2020) found that expressed uncertainty was mostly related to the unpredictability of the future and limits to available knowledge. According to Lambert and Loiselle (2007), managing uncertainty through information seeking may help to minimize emotional stress typically experienced in the caregiving role. Moreover, providing caregivers with a better understanding of the diagnosis through appropriate education, social support, and support from healthcare providers can result in reduced uncertainty (Zhang, 2017). Likewise, information seeking has been considered an important predictor of uncertainty management success (Rains & Tukachinsky, 2015). Therefore, an Awareness Toolkit may equip caregivers with the necessary information to promote readiness to adjust expectations and to better deal with changing care needs and behavioral challenges. Additionally, knowledge of available resources and services may also provide a level of certainty and stability for caregivers within the care situation.

Figure 1

Integrative Chart of the Roy Adaptation Model, Neuman Systems Model, and Uncertainty Management Theory



The Neuman Systems Model offers a systems-based dynamic framework related to stressors, reactions against those stressors and protective interventions that help to maintain balance. Neuman regarded individuals as ever-changing open systems that are in constant interaction with the environment and vulnerable to emotional, physical, psychological, and social stressors. Caregiving, for instance, places emotional and physical stress and strain on caregivers that can affect their personal health, psychological and emotional well-being, as well as interpersonal relationships (Ahmadi & Sadeghi, 2017). Neuman argued that there are variables, such as an individual's circumstances, their physical, emotional, and mental health, genetic makeup, stressor response patterns (depicted in the chart at the center of the client system) which influences how stress is managed. Neuman views an individual as a basic structure surrounded by concentric defensive rings or lines of defense that defend against stressors and help to maintain the systems' stability. The lines of resistance represent the internal factors that help individuals defend against a stressor, the normal line of defense represents the person's state of equilibrium or usual level of wellness, and the flexible line of defense depicts the dynamic nature that can rapidly change over time. When a stressor penetrates the normal protection line, it puts the system at potential risk and causes an adverse reaction triggering the resistance lines to protect the overall system (McAllister & McKinnon, 2009).

The Roy Adaptation Model views the individual as a biopsychosocial being and system that continually interacts with stimuli in the internal and external environment and strives to maintain balance through coping processes and adaptive responses. Adaptive modes such as physical, self-concept, role function and interdependence as well as adaptive responses including adaptive or ineffective behaviors affect the individual's overall well-being (Wang et al., 2020). The chart illustrates how outside stimuli (focal, contextual, and residual) can penetrate the system requiring coping or adaptive responses to lessen its impact. Objective burden such as caregiving duties are considered the most important stimulus (focal) that leads to perceived caregiver stress. Contextual stimuli includes stressful life challenges or experiences other than caregiving, i.e., lack of social support, and social roles. Residual stimuli such as caregiver's race, age, gender, relationship to the care recipient, also influences and contributes to caregiver burden and stress (Tsai, 2003). The challenges of living and dealing with Alzheimer's dementia can drive caregivers to seek new ways of coping to adapt to different care needs and behavioral changes.

Uncertainty Management Theory focuses on uncertainty and information seeking and how individuals respond to uncertainty. Uncertainty results from reduced predictability and control over situations, events, and the world around us, its antecedents and predictors and the strategies employed to manage and reduce uncertainty (Hogg & Belavadi, 2017). Uncertainty Management Theory states that uncertainty can cause a wide range of emotions, from anxiety to stress and distress (Bora et al., 2022). Individuals may choose to reduce, maintain, increase, or adapt to uncertainty by either seeking or avoiding information. An individual's emotional response to uncertainty and lack of the desired level of information determines the range of behavioral and psychological responses to uncertainty. Uncertainty can be perceived as positive, negative, combined, or neutral (Anderson et al., 2019). When perceived as positive, uncertainty is beneficial whereas when perceived as negative, uncertainty is seen as a danger/threat. In combined responses, there are both positive and negative responses and in neutral responses, uncertainty is viewed as inconsequential. This theory provides an understanding of how Alzheimer caregivers, given the long duration of the illness, perceive and manage stress throughout the care continuum. Since Alzheimer's disease is intrinsically ambiguous given its unknown etiology and lack of a cure, it is not uncommon that caregivers encounter uncertainty on a daily basis (Polk, 2005). Uncertainty is dependent upon caregiver's perspective, appraisal and coping of the uncertainty associated with the care situation, the specific circumstances, and resources available in addition to caregiver's emotional response. Those who create a sense of meaning to the caregiving experience or understanding in unpredictable, ambiguous situations may adapt more easily to uncertainty and perceive the outcome as an opportunity with positive benefits rather than a danger or threat resulting in negative implications for caregivers (Kramer, 2018).

Multiplicity of perspectives

Many studies promoted a multi-team perspective to be the most appropriate approach given the multiplicity of issues and needs. UCLA's Alzheimer's and Dementia Care Program which has served 2,619 participants and their caregivers is a successful example of coordination of care using a nurse practitioner, dementia care and physician dementia specialists in partnership with primary care. Designed to specific patient and caregiver needs, participants meet one-on-one to address questions, receive information/community resources and behavioral health support. The program also reduced Medicare costs by $2,400 per person, per year (Reuben et al., 2019). Brodaty et al. (2003) claimed that individually tailored behavior management therapy successfully reduced caregiver distress in both the short and long term. According to Zarit and Femia (2008), effective interventions included a psychotherapeutic, multi-component approach specific to the needs of the caregiver, and of adequate duration. Moreover, Tremont (2011) postulated that regular, individualized contact with a counselor or social worker over time resulted in reduced caregiver distress. Another recommendation was to embed case management and advance care planning in the primary care practice early while cognitive decline is mild and involves all stakeholders, caregivers, patients, family, and family physician (Fernandes et al., 2021). Unfortunately, lack of successful implementation into care teams within primary care, cost and ineffective communication between case management and physicians were problematic outcomes.

The Resources for Enhancing Alzheimer's Caregiver Health (REACH I and REACH II) and REACH OUT programs used care management teams consisting of dementia specialists, primary care physicians, nurses, and social workers, to assess and create individual care management plans for each caregiver-care recipient dyad (Burgio et al., 2009). The primary care educational intervention, REACH VA, involved a trained coach who provided sessions to caregivers relating to self-care, problem solving, and mood and stress management (U.S. Department of Veterans Affairs, 2020). According to Callahan et al. (2006), a collaborative care approach resulted in significant improvement in the quality of care as well as in behavioral and psychological symptoms of dementia among primary care patients and their caregivers. Callahan et al. (2011) in collaboration with community stakeholders developed the ABC Medical Home, a memory care program, implemented in primary care to meet the needs of Alzheimer's patients and their caregivers. This program utilized advanced practice nurses who worked directly with primary care physicians to facilitate care addressing pharmacological and psychosocial interventions, self-management tools, medication and case management, and coordination of community resources to name a few care delivery components of the program. Adding dementia-focused health professionals into primary care, providing information, community service links and ongoing social support proved most effective in building dementia care capacity (Frost et al., 2021).

There are numerous studies emanating outside of the U.S. that present more progressive ideas such as one from New Zealand. This study compared their approach of a systematic, comprehensive pathway in primary care using nurse practitioners who were more proactive to diagnose, manage care and connect families to services than their U.S. counterparts who were reactive and reticent to provide a dementia diagnosis, less certain how to manage care and less knowledgeable of resources (Palumbo & Rambur, 2020). One of the findings of a 2014 Quebec Alzheimer Plan identifying both the met and unmet needs of Alzheimer's dementia patients and their caregivers in primary care, suggested that caregivers would benefit from a separate needs assessment and recommended that community mental health services should extend their support programs to caregivers (Khanassov et al., 2021).

As technology continues to advance and become more accessible and reliable, further development is needed to support technology-based interventions and programs that could reach more families especially those in rural communities where caregivers and their care recipients are often isolated with little access to information and services. Additionally, innovative web-based clinical tools and programs such as the Dementia Management Quality Measurement Set provides metrics physicians can use to evaluate the current level of dementia care and focus on specific areas for quality improvement. Another evidence-based online program for professionals known as TCARE (Tailored Caregiver Assessment & Referral) Support System addresses caregiver burnout by assessing social determinants of health, identifying risk factors, and developing individualized care plans by "surfacing the right interventions, at the right time" (National Council on Aging, 2020). Likewise, Frame et al. (2013) designed a software (eMR-ABC) that facilitates the management of a high-risk population suffering from aging brain disorders such as dementia as well as the burden of family caregivers which provides decision support to care coordinators to create a personalized care plan.

Summary

Review of the literature consistently identified Alzheimer caregivers as an underserved and vulnerable group that warrants some type of intervention. Despite general acknowledgement that caregivers need to be educated about the disease and have knowledge of and access to available resources and services, information is limited, lacking, or inconsistent with no consensus in respect to when, where, and how information should be disseminated to meet caregiver's needs. Providing Alzheimer caregivers with an Awareness Toolkit will address this gap in care early at the primary care level and enable caregivers to better adjust and adapt their coping to deal with the stressors and external demands of caregiving, feel more equipped and confident to manage daily care challenges and focus more on the positive aspects of the caregiving experience. Since primary care is considered the first patient contact within the healthcare delivery system, early discussions with primary care providers may result in more timely diagnosis, treatment, and early-stage intervention, resulting in more positive outcomes for caregivers and their care recipients (Aminzadeh, 2012). This would, in turn, increase capacity for healthcare providers to treat and better manage the multiplicity of issues related to this chronic debilitating disease and improve quality of care.

Given the highly stressful and challenging nature of this disease, these experiences test the adaptive resources of caregivers and their perception about themselves, their relationships, and the world. To reduce the impact, caregivers may have opportunities for personal growth by reframing their perception of stress that adds personal value and improves well-being for themselves and the care recipient (Jones et al., 2020). An educative and supportive intervention, like an Awareness Toolkit, may promote a sense of empowerment for caregivers and help them feel more confident and more competent in their caregiving role. The toolkit is a collection of Alzheimer's disease-related education, community resources and caregiver supports specific to the county where care is being provided, including caregiver self-care and coping tips. It serves as a guide how best to navigate the dementia journey and provides critical information to help caregivers better manage their role and life. Caregivers will concurrently have access to social work case management to educate, facilitate and advocate based on caregivers' individualized needs and provide direction and support as questions arise and challenges increase. If this gap in care is addressed, it may potentially reduce the effect of stressors and improve general well-being for both caregiver and care recipient.

As healthcare continues to embrace a patient-centered, multidisciplinary approach toward care, social workers can serve a critical role in primary care as a one-stop, one-contact expert who can successfully implement this intervention and provide the guidance and expertise needed to effect positive change in how we perceive Alzheimer's dementia, how we deliver services and how we support those who are caregivers. Only by recognizing the full scope of care challenges along the disease trajectory, can we act responsibly to meet caregiver's needs, help to improve their quality of life, and support their relationships with their healthcare providers.

Chapter 3: Methodology and Research Approach

Methods

Research design

A survey questionnaire was developed to determine whether an Awareness Toolkit intervention provided to Alzheimer caregivers helped them feel better prepared, less burdened, and experienced personal growth and some positive aspects of caregiving.

Three hypotheses were explored in this study:

1. An Awareness Toolkit intervention positively affects caregivers' preparedness.
2. An Awareness Toolkit intervention positively affects caregivers' perceived burden.
3. Caregivers who show a high level of posttraumatic growth demonstrate a high level of preparedness and perceived burden.

Discussions with Tandigm Health, LLC and TriValley Primary Care regarding this research study began in March 2022 through August 2023 at which time this researcher had access to TriValley's master list of patients diagnosed with Alzheimer's disease. Participant recruitment and a cross-sectional quantitative study were conducted from August 2023 through January 2024 (IRB #05092023).

Participants

The master list for this study was comprised of adult informal caregivers caring for individuals diagnosed with Alzheimer's dementia. Informal Alzheimer caregivers are defined as non-professionals who provide unpaid caregiving. Potential participants selected met the following inclusion criteria: 1) Caregivers ranged in age from 18 years and older, 2) A caregiver with the primary responsibility for the home-based care of a person diagnosed with Alzheimer's dementia, and 3) The care recipient had a confirmed Alzheimer's diagnosis (ICD-10 G30.9, Alzheimer's Disease, unspecified, ICD-10 G30.0, Alzheimer's Disease with early onset and G30.1, Alzheimer's Disease with late onset) by a medical provider.

Caregivers of all genders, races and ethnicities were included in the master list. According to Flanagin et al. (2021), identifying the race or ethnicity of participants and other socio-demographics may provide information about the participants and the potential generalizability of the study results as well as disparities and inequities. To ensure accuracy, inclusivity and equity, this researcher's reporting of race and ethnicity was accompanied by other sociodemographic factors and social determinants. Other sociodemographic factors were identified as employment, living arrangement and educational level while social determinants included the cost of care, income, access to information/services.

Potential caregiver participants were randomly assigned (using a random number generator) to two groups (intervention group vs. control group) to attain internal validity. Caregivers in the intervention group were contacted by phone and offered an Awareness Toolkit which was mailed or emailed based on their preference. The toolkit is a collection of Alzheimer's disease-related information and community resources specific to the county where care was provided in addition to receiving social work case management services. The toolkit provides education about Alzheimer's dementia, the stages of the disease, symptoms, and common challenges. It offers tips for caregivers on how best to handle communication problems, personality, and behavior changes as well as changes in mood and reality. It gives concrete suggestions to cope and manage hallucinations and delusions as well as agitation and aggression. Caregivers are encouraged to find ways to reduce stress and provided recommendations including relaxation and coping exercises. The toolkit also includes community and care resources for in-home support services, private duty caregiving, adult day care, veterans' services as well as information about additional levels of care. Legal, financial, and end of life planning are addressed. Helpful caregiver websites and some suggested readings are also provided to support Alzheimer caregivers.

Caregivers in the intervention group were also advised of available social work case management services and contacted within 1-2 weeks following receipt of a toolkit and thereafter as appropriate to support and guide access to resources and services. In contrast, caregivers in the control group only had access to traditional social work services and would receive an Awareness Toolkit by mail at the conclusion of this study. Traditional social work services involved working directly with individuals and families when requested to provide support and/or assistance in accessing resources and services.

The process of collecting data involved follow up telephonic outreach to caregivers in the intervention group who were contacted in early September 2023 and in the control group who were contacted in October/November, 2023 to obtain their consent to participate in this research study. Caregivers were initially mailed an Informed Consent and HIPAA Authorization form following their verbal consent to participate in this study. A stamped self-addressed envelope was provided to obtain participants' signatures and timely return of all signed forms to this researcher.

Caregivers in both groups were informed of the study's purpose and the procedures to be used in data collection, its voluntary nature, the protection of confidentiality, the amount of time needed to complete the survey, and their right to withdraw from the study. A contingency statement regarding the handling of situations involving ethical considerations such as concern for elder neglect and/or abuse or if an Alzheimer caregiver or the recipient of care are at imminent risk of seriously harming themselves or others was included in the Informed Consent. They were informed that this researcher is professionally bound by law to report any suspected cases of neglect and/or abuse regarding the caregiver or care recipient to Adult Protective Services (if caregiver or care recipient is 60 years of age or older) in the specific county where care was provided. Caregivers and care recipients 59 years of age or younger suspected of neglect and/or abuse would be reported to local law authority in the county where care was provided.

A subsequent mailing including a follow up letter and survey was sent to recruited caregivers from approximately November 2023 through January 2024 who were asked to complete the survey at home and were provided a stamped self-addressed envelope for a timely return. All surveys requested no identifying information but included an individual code number assigned to protect confidentiality. The survey required about 15-20 minutes to complete and mail back to this researcher in the envelope provided.

Description of the sample

A master list of 260 eligible patients with an Alzheimer's dementia diagnosis and their caregivers was identified. Identification of patients' caregivers, however, was not initially known and required further review of patients' clinical charts. Using a random number generator, 129 caregivers were assigned to the intervention group and 131 caregivers were assigned to the control group. A total of one hundred and seventy-five Alzheimer caregivers were successfully recruited over the course of five months from August 2023 through January 2024. Ninety-four caregivers in the intervention group were contacted by this researcher and agreed to participate in this research study. Caregivers were sent two mailings, the first included a welcome letter and consents and a subsequent mailing included a follow up letter, an Awareness Toolkit, and survey. Caregivers in the intervention group also received periodic telephone calls by this researcher for support and social work assistance. Eighty-one caregivers in the control group were contacted by this researcher one to two months later and agreed to participate in this study. Caregivers were mailed a welcome letter and consent forms followed by a second mailing which included a follow up letter and survey. Caregivers were also encouraged to seek social work assistance if needed and provided contact information. A total of 52 completed surveys (28 surveys from the intervention group and 24 surveys from the control group) were returned to this researcher however one caregiver survey in the intervention group was returned incomplete and excluded from data collection.

The demographic data of Alzheimer caregivers included gender, age, relation to the care recipient, race/ethnicity, marital status, education level, employment status, household income, and living arrangement. Additionally, caregivers who received a toolkit were coded 1 for the intervention group, and caregivers in the control group who did not receive a toolkit were coded 2. The total number of participants in the final sample was 51 when controlling for the following demographic variables.

- Gender was coded 1 for female, 2 for male.
- Marital status was coded 1 for married, 2 for widowed, 3 for divorced, 4 for never married and 5 for other.
- Education was coded 1 for less than high school degree, 2 for high school degree or equivalent, 3 for some college but no degree, 4 for college degree and 5 for graduate degree.
- Caregivers' race and ethnicity were coded 1 for White, 2 for Hispanic Latino Spanish origin, 3 for Black of African American, 4 for Asian, 5 for Middle Eastern or North African, 6 for Bi-racial or Multi-racial and 7 for other.
- Caregivers' relationship was coded as 1 for child, 2 for spouse/partner, 3 for grandchild, 4 sibling and 5 for other.
- Living situation was coded as 1 for living in the same house, 2 for living in the same neighborhood and 3 for living one hour or more away.
- Caregivers' employment status was coded as 1 for employed and 0 for unemployed.

Caregivers' demographics (n=51) indicated that there were 34 females (67%) and 17 males (33%); All caregivers in the sample were White with an average age of 71 years old and a mean income of $65,332. Eighty-two percent of caregivers had Medicare, 36% had commercial insurance and 6% had Medicaid. Sixty-five percent of caregivers identified as spouses/partners, 29% as the care recipient's child, 2% sibling and 4% other. A majority of caregivers were married (90%) and living in the same household as the care recipient (75%), 20% living in the same neighborhood and 6% living an hour or more away. About 75% of caregivers were educated compared to 26% with a high school diploma/GED or less.

Table 1

Sample Demographic Characteristics

Characteristics	n (%)	Mean	Std. Deviation
Gender	n = 48		
Female	32 (66.6%)	3.07	.94
Male	16 (33.3%)	2.20	.83
Other	0		
Category	n = 48		
White	48 (100%)	2.78	.99
Other	0		
Educational Level	n = 48		
Less than H.S	0		
H.S. or equivalent	12 (25%)	3.03	1.09
Some college, no degree	11 (23%)	2.55	1.00
College degree	9 (18.8%)	2.70	.90
Graduate degree	16 (33.3%)	2.78	.99
Marital Status	n = 48		
Married	43 (89.6%)	2.79	1.02
Widowed	1 (2.08%)	2.80	0
Divorced	1 (2.08%)	3.60	0
Never married	3 (6.25%)	2.30	.46
Other	0		
Employment	n = 51		
Employed	14 (27.5%)	.117	.325
Unemployed	37 (74.5%)	.059	.237
Insurance	n = 47		
Commercial	17 (36.2%)	2.63	1.17
Medicare	39 (83%)	2.84	.89
Medicaid	3 (6.4%)	2.40	1.44
Living arrangement	n = 48		
Same house	36 (90%)	2.83	.87
Same neighborhood	9 (18.75%)	2.33	1.36
Living 1+ hour away	3 (6.25%)	3.5	.65
Relation to care recipient	n = 48		
Child	14 (29.2%)	2.79	1.14
Spouse/partner	31 (64.6%)	2.78	.89
Sibling	1 (2.08%)	2.80	0
Other	2 (4.2%)	2.70	2.20

Note: Due to missing demographic data, *n* sizes ranged from 47 to 51.

Risk/benefit assessment

This study may have caused some caregivers in the intervention group to feel uncomfortable by reflecting on and acknowledging their feelings regarding their role and experiences as a caregiver. Otherwise, there were no risks from participating in this research study. Caregivers were provided with this researcher's contact information and given the opportunity to ask questions, discuss this study and/or seek support if necessary. As a licensed social worker in Pennsylvania with many years of mental health and case management experience, this researcher was qualified to provide the necessary support and expertise to connect caregivers to the appropriate mental health resources upon request. Likewise, caregivers in the control group were mailed an Awareness Toolkit at the end of this research study and received the same information. This researcher hypothesized that the benefits to participation in this study may enable caregivers to better adjust and adapt their coping to deal with the stressors and external demands of caregiving, feel more equipped and confident to manage care and behavioral challenges and focus more on the positive aspects of the caregiving experience. This would, in turn, increase capacity for healthcare providers to treat and better manage the multiplicity of health and medical issues related to this chronic debilitating disease and improve quality of care.

Collected data was kept private and stored in an SPSS file maintained on a password protected memory data storage device. Hard copies of completed surveys and signed consents (Informed Consents and HIPAA Authorization forms) were retained in sealed envelope(s) in a locked cabinet with only the researcher having access to them. No identifiable information was shared in any report or presentation and participants' confidentiality was protected. Destruction of all paper documentation containing personal and health information will be properly shredded and all electronic data and information will be permanently deleted after three years following completion of this research.

Ethical considerations

In compliance with the Department of Health and Human Services' (HHS) regulation, 45 CFR 46.115(b) for the protection of human subjects in research, all records relating to this study will be retained for at least (3) three years after completion of this research. HHS regulations require institutions to comply with 45 CFR part 46 before initiating participation in HHS conducted or supported research involving human subjects. The regulations found at 45 CFR part 46 are based on the Belmont Report and were established to offer basic protections to human subjects involved in both biomedical and behavioral research conducted or supported by HHS (U.S. Department of Human Services [HHS], 2021). The NASW's Code of Ethics guided this researcher regarding any ethical issues and this researcher's CITI training and certification on the protection of human research participants provided the education to avoid potential risks and ethical dilemmas.

Measures

Three major variables of burden, preparedness, and posttraumatic growth were measured at an ordinal level in the context of an Awareness Toolkit intervention. The three ordinal level instruments were: 1) Zarit Caregiver Burden Assessment (ZBI) developed by Zarit and Femia (2001), 2) Preparedness for Caregiving Scale (PCS), developed by Archbold et al. (1990), and 3) Posttraumatic Growth Inventory--Short Form (PTGI-SF) developed by Cann et al. (2010).

Zarit Caregiver Burden Assessment

Caregiver burden was measured by the Zarit Caregiver Burden Assessment (ZBI), a twelve-item self-administered questionnaire using a five-point Likert-type scale with response options ranging from 0 (never) to 4 (nearly always). The scale provides a list of statements reflecting how people sometimes feel when taking care of another person which assesses the subjective level of burden experienced by caregivers in a caring situation. Examples include, “Do you feel stressed between caring and meeting other responsibilities?”, Do you feel you have lost control of your life since the care recipient’s illness?” and “Do you feel you don’t have enough time for yourself?” Total scores range from 0-48, with 0-10 indicating no to mild burden, 10-20 indicating mild to moderate burden and greater than 20 demonstrates high burden. This researcher changed the language in this tool from “your relative” to “care recipient” to describe all care relationships whether related or not.

The twelve-item scale is a shorter version of the original twentynine-item self-reported scale and modified twentytwo-item scale which has been found in past studies to be valid and reliable. Bedard et al. (2001) conducted a study to develop a short and screening version of the twentytwo-item Zarit Burden Interview (ZBI) using data from 413 caregivers of cognitively impaired older adults. They produced both a twelve-item version and a four-item screening of the Zarit Burden Interview which produced correlations between the short and full version ranging from 0.92 to 0.97, and from 0.83 to 0.93 for the screening version. The results of a two-way analysis of variance found that it produced identical results to the full version and did not affect the properties of the ZBI (Bedard et al., 2001).

Preparedness for Caregiving Scale

The Preparedness for Caregiving Scale (PCS), developed by Archbold et al. (1990), is a caregiver self-rated instrument that consists of eight items that asks caregivers how well prepared they believe they are for multiple domains of caregiving (Zwicker, 2017). Responses are rated on a five-point scale with scores ranging from 0 (not at all prepared) to 4 (very well prepared). The higher the score, the more prepared the caregiver feels for caregiving; the lower the score, the less prepared the caregiver feels. Examples of questions include “How well prepared do you think you are to take care of his or her emotional needs?”, How well prepared do you think you are for the stress of caregiving? And “How well prepared do you think you are to find out about and set up services for him or her? This researcher replaced the phrase “your family member” with the term “care recipient” to describe all care relationships whether related or not.

Internal consistency has been reported as moderate to high with alphas of 0.88 to 0.93 in several studies (Carter et al., 1998; Hudson & Hayman-White, 2006). A study by Carter et al. (1998), examined the experience of spouses caring for their spouse with a long-term chronic illness and found internal consistency as moderate to high with alphas of 0.88 to 0.93. A longitudinal study by Hudson and Hayman-White (2006), focused on caregivers’ appraisal of their role caring for someone with advanced disease and found moderate to high internal consistency with Cronbach’s alphas ranging from 0.86 to 0.92. Another cross-sectional design study of 156 caregivers of stroke survivors determined the Preparedness Caregiver Scale to be valid and reliable with a Cronbach alpha of 0.94 and test-retest reliability of 0.92 (Pucciarelli et al., 2014).

Posttraumatic Growth Inventory

The Posttraumatic Growth Inventory--Short Form (PTGI-SF) (Cann et al., 2010) is a ten-item scale which measures two items associated with each of the five areas of posttraumatic growth: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life using six-point responses. This scale was designed to increase one’s understanding of how people cope and bounce back from prolonged stress, trauma, or crisis to gain meaning and greater confidence dealing with future uncertainties (Tedeschi & Calhoun, 1996). Similar to resiliency, posttraumatic growth refers to what can happen when an individual who has difficulty bouncing back from prolonged stress or trauma, experiences either personal growth and positive outcomes or distress and confusion requiring personal re-evaluation before they are able to rebound.

This scale is an abbreviated version of the twentyone-item Posttraumatic Growth Inventory (PTGI) developed by Richard Tedeschi and Lawrence Calhoun (1996) which proved to be a reliable instrument. The PTGI-SF displayed adequate internal consistency ($\alpha = 0.86$ to 0.89) and confirmatory factor analyses supported the five-factor structure. Moreover, reliability and evidence of sensitivity and criterion-related validity were also supported (Garrido-Hernansaiz, 2022). A longitudinal study by Hudson and Hayman-White (2006) focused on caregivers' appraisal of their role caring for someone with advanced disease found moderate to high internal consistency with Cronbach's alphas ranging from 0.86 to 0.92.

Caregivers indicated the degree to which they have or have not experienced a particular change using a scale ranging from 0 (I did not experience this change as a result of dealing with ongoing stressors as a caregiver) to 5 (I experienced this change to a very great degree as a result of dealing with ongoing stressors as a caregiver). Examples of statements include: “I discovered that I'm stronger than I thought I was, I'm able to do better things with my life, I changed my priorities about what is important in life”, and “I learned a great deal about how wonderful people are.” A high total score implies a high level of posttraumatic growth reflective of positive change(s) or outcome(s) which for this population of caregivers may reflect a high level of preparedness and a low level of burden. Since caregivers experience multiple stressors over time rather than a single traumatic event, this researcher changed the language in this scale from “as a result of dealing with your crisis” to “as a result of your role as a caregiver dealing with ongoing stressors.”

Chapter 4: Data Analysis and Findings

This research study focused on the impact of a toolkit intervention for Alzheimer caregiver's preparedness, perceived burden, and posttraumatic growth in the caregiving role. Descriptive statistics were applied to demographic data as well as the number, percentage, average, and standard deviation (SD) for each scale. Independent sample t-tests were applied to assess differences between the demographic data/score of each questionnaire and the impact of receiving an Awareness Toolkit. A Pearson's correlation was used to determine the correlation between continuous variables and the impact of receiving an Awareness Toolkit. Additionally, a regression analysis was utilized to identify associations between variables and predict statistical significance. All tests were two-tailed, and $p < .05$ was considered statistically significant. Data were analyzed with IBM SPSS software version 28.0.

A Pearson's correlation coefficient was computed to determine the relationship between an Awareness Toolkit and preparedness, perceived burden, and posttraumatic growth. A marginally significant association was found between a toolkit intervention and preparedness (r=.27, p=.063). No significant correlation was found between a toolkit intervention and perceived burden nor a toolkit intervention and posttraumatic growth. In addition, a positive correlation was associated with perceived burden and preparedness (r=.43, p=.002). There was a positive association between caregiver's relation to the care recipient and preparedness (r=.33, p=.019), and a positive correlation between caregiver's relation to the care recipient and perceived burden (r=.31, p=.032). There was also a significant relationship between gender and posttraumatic growth r=-.42, p=.003. No correlation was found between preparedness and caregiver's education level nor burden and care recipients' cognitive status. The mean score on the Preparedness for Caregiving Scale (PCS) was 2.0 (*SD*=.705); the mean score on the Zarit

Caregiver Burden Assessment (ZBI) was 19.2 (*SD*=8.0); and the mean score on the Posttraumatic Growth Inventory (PTGI) was 27.7 (*SD*=9.76).

Based on caregivers' responses regarding preparedness for caregiving, 60% and above were "somewhat to not at all prepared" to care for the physical needs of the care recipient, to get help and information from the healthcare system, to find out about and set up services for the care recipient, to respond to and handle emergencies, and overall to care for the care recipient. Over 70% of caregivers reported "somewhat to not at all prepared" to handle the care recipients' emotional needs, to make caregiving activities pleasant, and to manage the stress of caregiving.

Over 70% of caregivers felt burdened and reported "sometimes to nearly always" not having enough time for themselves, feeling stressed between caring and meeting other responsibilities, and feeling they could do a better job. Caregivers' responses were almost equally split regarding feeling angry, strained, not having as much privacy, and feeling their social life suffered when around the care recipient. Sixty-one percent of caregivers reported "sometimes to nearly always" feeling uncertain about what to do regarding the care recipient in contrast to over 60% of caregivers who "rarely to never" felt their relationship with others was negatively affected, their health suffered, they lost control of their life, and they should be doing more for the care recipient.

Caregivers experienced change and personal growth in their life as a result of dealing with ongoing stressors in the caregiving role. Eighty percent of caregivers reported a "moderate to very great degree" a greater appreciation for the value of their own life. Over 70% of caregivers acknowledged their ability to handle difficulties and learned how wonderful people are while over 55% developed a stronger religious faith, a better understanding of spiritual matters, discovered that they were stronger than they thought, and changed priorities about what is important in life. More than 50% of caregivers experienced a “small to no degree” of change and growth concerning establishing a new path in life, a greater sense of closeness with others and ability to do better things with their life.

In respect to caregiving activities, 92% of caregivers assisted with scheduling and accompanying care recipients to their appointments while over 82% helped with household chores, finances, transportation and provided emotional care. More than 74% of caregivers helped with grocery shopping and medication management, 63% monitored for safety and 45% assisted with personal care.

Table 2

Summary of Pearson correlation of the variables

Variable	1	2	3	4	5	6	7	8	9	10
1 Toolkit	1									
2 Prepared	.27	1								
3 PT Growth	-.12	.10	1							
4 Burden	-.02	.43**	.09	1						
5 Cognition	-.00	-.12	.01	-.26	1					
6 Resources	.20	.17	.09	-.15	.25	1				
7 Education	.02	.16	-.06	.21	.19	.23	1			
8 Income	.09	-.16	-.18	.02	-.02	.21	.20	1		
9 Living arr	.20	-.04	.00	.09	-.02	.25	.03	.16	1	
10 Relationship	.19	.33*	-.02	.31*	-.01	-.20	.16	-.19	-.36*	1

Note. **Correlation is significant at 0.01 level (2-tailed)
*Correlation is significant at the 0.05 level (2-tailed)

Independent-samples t-tests were run for each of the variables in this study to determine whether there were statistically significant differences between the means in the intervention group and the control group. An Independent-samples t-test was conducted to compare the impact of receiving an Awareness Toolkit intervention on caregiver preparedness for a group of caregivers who received a toolkit (Group 1) and a group of caregivers who did not receive a toolkit (Group 2). There was a significant difference in the preparedness scores with the mean score for Group 1 ($M = 2.2$, $SD = .67$); $t(47) = 1.9$, $p < .05$, $p = .032$ was higher than for Group 2 ($M = 1.8$, $SD = .70$). The magnitude of the differences in the mean (mean difference = 0.38, 95%

CI: -.02204 to .77851) was significant and supported Hypothesis 1 (An Awareness Toolkit intervention positively affects caregivers' preparedness). There was no significant difference in the scores for perceived burden for Group 1 (*M* = 2.4, *SD* = .69); *t*(47) = -.11, *p* = .46 and Group 2 (*M* = 2.4, *SD* = .68). Similarly, no significant difference was found in the scores for posttraumatic growth for Group 1 (*M* = 2.7, *SD* = 1.1); *t*(46) = -.84, *p* = .20 and Group 2 (*M* = 2.9, *SD* = .85). An Independent-samples t-test was also conducted to compare the levels of posttraumatic growth between female and male caregivers. There was a significant difference in posttraumatic growth with the mean score for female caregivers (*M* = 3.0, *SD* = .94); *t*(3.0) = 46, $p < .05$, *p* = .003 which was higher than for male caregivers (*M* = 2.2, *SD* = .82). The magnitude of the differences in the mean (mean difference = 0.85, 95% *CI*: .30097 to 1.41778) was significant and supported Hypothesis 3 (Caregivers who show a high level of posttraumatic growth demonstrate a high level of preparedness and perceived burden). There was no significant difference in the levels of perceived burden between female caregivers (*M* = 2.4, *SD* = .69); *t*(.52) = 47, *p* = .60) and male caregivers (*M* = 2.3, *SD* = .66). Likewise, no significant difference was found in the levels of preparedness between female caregivers (*M* = 1.9, SD = .76); *t*(-.17) = 47, *p* = .862) and male caregivers (*M* = 2.0, *SD* = .59).

The results of a regression analysis shown below indicated the two predictors, burden and toolkit, explained 20% of the variance; R^2 =.36, *F*(6,43)=3.52, *p*=.007. It was found that receiving a toolkit intervention significantly predicted caregiver's preparedness (β=.31, *p*=.02).

Table 3

Analysis of variance (ANOVA) and regression coefficients

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	8.225	6	1.371	3.521	.007[b]
	Residual	14.406	37	.389		
	Total	22.632	43			

a. Dependent Variable: Prepare_Avg

b. Predictors: (Constant), What is your age? , Have you received an Awareness Toolkit which was sent to you in September? , CogStatus, NeededCare, What is your gender?, Burden_Avg

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			Correlations		
		B	Std. Error	Beta	t	Sig.	Zero-order	Partial	Part
1	(Constant)	-.710	.744		-.954	.346			
	Have you received an Awareness Toolkit which was sent to you in September?	.455	.194	.312	2.352	.024	.282	.361	.309
	What is your gender?	-.100	.218	-.067	-.458	.649	.040	-.075	-.060
	NeededCare	.074	.049	.227	1.505	.141	.079	.240	.197
	CogStatus	-.002	.046	-.005	-.037	.971	-.082	-.006	-.005
	Burden_Avg	.457	.157	.432	2.911	.006	.426	.432	.382
	What is your age?	.014	.009	.228	1.545	.131	.333	.246	.203

a. Dependent Variable: Prepare_Avg

Chapter 5 Discussion and Implications

This recent study found those caregivers who received a toolkit demonstrated preparedness which supports the hypothesis that an Awareness Toolkit intervention positively affects caregivers' preparedness. The findings, however, did not indicate that caregivers who received a toolkit experienced any reduced burden which this researcher argues may be attributed to the timing of the intervention and what disease stage best described the care recipient. The long duration of Alzheimer's disease often makes it difficult to definitively identify where the care recipient is along the disease continuum. This researcher contends that the impact of receiving a toolkit intervention would be most impactful and meaningful for caregivers if provided early when the care recipient is either newly diagnosed or when caregivers begin to observe cognitive changes or behavioral issues. Gallagher-Thompson et al. (2020) identified intervention timing to be a critical factor in managing this chronic condition and recognized that what might be effective in early stages may not be suitable in middle or late stages of the disease. For those recruited caregivers managing a care recipient who was more advanced along the disease trajectory, receiving a toolkit may not have been as helpful. This relationship can be further studied longitudinally to determine any causal effects. More research and evidence-based practices are needed to provide education and support for healthcare providers, especially primary care physicians, to feel more confident to conduct early discussions about cognitive impairment, diagnose timely, address on-going issues, discuss treatment options, and connect caregivers early with resources and support information.

The results also showed a relationship between caregivers' preparedness and perceived burden. This may be best explained by the fact that often both physical and emotional burden increases with disease progression regardless of the degree of caregiver preparedness. Increasing care needs as well as behavioral and psychological disturbances are critical factors contributing to increased care burden (Chia-Hui et al., 2020). Disruptive behaviors like agitation, aggression, and disinhibition, followed by delusions and mood disturbances were most predictive of caregiver burden and depression due to the negative impact on the emotional connection between caregiver and care recipient and the increased challenges (Sheung-Tak., 2017). Furthermore, due to the vast amount of resources required to provide adequate care along the disease continuum, greater caregiver involvement is typically expected with less time for themselves, their families and their occupations adversely impacting their overall well-being (Vu et al., 2022). Although many studies cited improved caregiver well-being post placement, others have not experienced the same effects (Paun et al., 2014). Many caregivers continue to feel burdened despite relinquishing care and guilty over the care recipient's transition into long term placement. Kiecolt-Glaser et al. (1991) found that caregiver's immune function remained negatively depressed long after placement. Other studies have found increased feelings of burden and depression in some caregivers following placement of the care recipient into long term care (Gaugler et al., 2009) while others experienced increased physical and psychiatric morbidity long after institutionalization or death of the care recipient (Papastavrou et al., 2007).

This current study also showed that caregivers' relationship to the care recipient affected perceived burden and preparedness. Spousal caregivers in their 70s and 80s comprised about half of all caregiver relationships in this study. It is easy to speculate that spousal caregivers might experience considerable emotional, physical, and financial burden in the caregiving role over the course of the disease as they are often alone or have minimal support managing care and household responsibilities. Carter et al. (1998) focused on spousal perspective by disease stage for Parkinson's Disease, another debilitating, life limiting illness, and found that caregiver strain was experienced across all stages and increased significantly as the disease progressed. To be more specific, the positive quality of the dyad relationship declined early on, the number of caregiving tasks tripled as they moved through the disease process, however, preparedness did not significantly differ across disease stages. This information may be particularly useful in designing evidence-based interventions to provide more effective help for this vulnerable group of caregivers. Recent research led by the University of California, Davis, suggested that couples coping with dementia can navigate the challenges with greater resilience and well-being by working together and supporting each other (Huo, 2024). Relationship quality also played a role according to Huo (2024) who believed that having a beneficial relationship in early stages may help reduce caregiver burden and slow disease progression. Likewise, Lai (2023) reported that spouse/partner caregivers may provide more stable and consistent care that promotes familiarity, predictability, and supports functional well-being.

A significant association was found between gender and posttraumatic growth. Given that there were twice as many female as male caregivers in this current study, this can be explained as gender differences in the conditions of burden (Pearlin et al., 1990). Pearlin and his colleagues argued that women tend to fall into the caregiving role, subjected to greater responsibilities and intensities of stressors than their male counterparts which lends greater opportunity for personal change and growth in the caregiving role. According to one study, females employed more positive reappraisal and positive self-talk than males, despite their experiences of greater stress (Rausch et al., 2008; Tamres et al., 2002). Another study involving 124 dementia caregivers from a memory clinic examined caregiver's gender, relationship with the patient, difficulty balancing financial income and expenditures, and disease severity (Li et al., 2021). A high level of posttraumatic growth was found for female caregivers and spouses who had a balance of income and expenditures in the past month and who cared for patients with severe dementia. Previous studies by Balfe et al. (2016) claimed that caregivers who were unable to balance their finances showed a higher level of posttraumatic growth than those who had a balance of income and expenditures in the past month. They reasoned that caregivers in a good economic state can more readily deal with difficulties during patient care. These caregivers reported a low level of subjective burden, which does not result in high levels of posttraumatic growth. Conversely, other studies indicated that the posttraumatic growth level was not correlated with caregiver gender (Loiselle et al., 2011), or that male caregivers demonstrated high levels of posttraumatic growth (Kim et al., 2007).

Study limitations

There are several limitations that should be considered when interpreting the results of the present study. The generalizability of this research is limited due to the small sample size which restricted the use of additional analyses that may have supported some of the hypotheses. Another significant limitation was the relatively short timeframe to complete this research which if extended might have allowed more time for caregivers who received an intervention to benefit from the information and support resulting in more valued and accurate data. Caregivers were in different stages of caregiving which was an important premise not measured in this study but one that could offer opportunity for further research. Likewise, identification of the care recipients' disease stage would offer critical information to support caregivers' preparedness and provide tailored interventions that would address caregivers' specific needs and challenges.

Gender bias presented as another limitation given there were twice as many female caregivers as male caregivers in this study. Many studies have acknowledged that there are differences in the way that men and women experience caregiving (Swinkels et al., 2019) which may have skewed perceptions in this study by excluding the richness of the male caregiving experience. Because the dominant category of caregivers was Caucasian and not representative of cultural diversity, the findings were not generalizable to all caregivers. This finding is, in fact, reflective of the actual racial population in Bucks County with the absolute majority being White and a population of 548,081 (85.12%) of the total population. Similarly, the largest racial group in Montgomery County is White, with a population of 656,077 (77.10%) of the total population (Neilsberg Research, 2023). Furthermore, a total of 337,374 people residing in Bucks County are married (56.27%) while a total of 438,417 Montgomery County residents are wedded (54.43%) (Yardi, 2024). Additional research should focus on caregivers who identify with different racial and ethnic groups as they experience even greater challenges in access to information, resources, and services.

Response bias may be another limitation given that the instruments used self-reports with no opportunity for verification. The use of structured instruments did not allow caregivers to freely convey their sentiments nor share their care experiences although some caregivers were compelled to do so and returned completed surveys with additional information written all over it. Several caregivers even took the time to contact this researcher directly to tell their story and explain the reason why they were unable to participate in this study. Given the level of caregiver distress at the time of participation and the care recipients’ disease stage, there may also be memory bias in the data collection. Furthermore, selection bias may also exist because the characteristics of the caregivers who participated may have been different from those who chose not to participate in this research. Lastly, caregivers who received an Awareness Toolkit intervention may have had different caregiving experiences than those who did not receive a toolkit intervention. Future studies reflecting changes in posttraumatic growth along each disease stage may offer insight into the caregiving experience and aid in the development of interventions that support positivity in the dyad relationship.

Chapter 6: Conclusions and Recommendations

The findings from this current study support the benefit of an Awareness Toolkit intervention for Alzheimer caregivers to better prepare and support them along the disease continuum. This toolkit intervention was developed to address a gap in care at the primary care level and improve quality of care while building dementia care capacity for both caregivers and healthcare providers. Alzheimer's disease creates a multiplicity of issues and challenges for caregivers given the long duration and caustic nature of the illness. Since there is little consensus regarding the type of interventions that would be most helpful for caregivers, it is anticipated that tailored interventions that provide caregivers with the knowledge and resources needed together with social work support may facilitate more optimal outcomes and allow caregivers to focus on the positive aspects of the caregiving relationship. Provided at the right time and in the right place, this toolkit intervention may help mitigate some of the burden experienced by caregivers and foster reflection and personal growth.

Social workers can serve a pivotal role in primary care as a one-stop, one-contact expert who can implement this intervention effectively and provide the guidance and expertise needed to effect positive change in how we perceive Alzheimer's dementia, how we deliver services and how we support those who are caregivers. Only by recognizing the full scope of care challenges along the disease trajectory, can we act responsibly to meet caregiver's where they are at, help to improve their quality of life, and support their relationships with their healthcare providers. Future longitudinal studies may offer better information about the effects of intervention timing on successful management of this chronic and debilitating disease. Examining changes in posttraumatic growth in each disease stage may aid in the development of interventions that support positivity in the dyad relationship. Further research focusing on caregivers from different racial/ethnic groups may provide richness and address social determinants of health for health equity. It is critical to continue research efforts in the development of evidence-based practices that will support the individual needs of Alzheimer caregivers, ensure greater access to information and services, and enhance the positive aspects of caregiving.

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