

**HONORING THE WHOLE FAMILY: EXAMINING THE EFFICACY OF THE DAWN
METHOD ON DEMENTIA CAREGIVERS**

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Abstract

Introduction/Background: Dementia is a neurocognitive disorder that affects more than 50 million people each year in the United States. Caregivers of people living with dementia (PLWD) are tasked with assisting with activities of daily living (ADLS). The ongoing demands of caregiving may negatively impact caregivers' emotional and physical health. The purpose of this study was to examine the efficacy of the DAWN Method on decreasing caregiver burden and increasing positive perceptions of caregiving.

Methods: Participants were recruited over the course of one month on social media platforms. Participants were screened based on inclusion criteria. Participants attended educational training sessions for eight weeks via Zoom. Pre-test and post-test data were collected via the Zarit Burden Inventory (ZBI) and the Positive Aspects of Caregiving (PAC) Scale. A brief demographics survey and four open-ended questions were also administered following the completion of the study.

Results: Twenty-seven participants completed the pre-test surveys. Twenty participants completed the post-test surveys. The sample included males (n = 4) and females (n = 16). Participants represented four countries including the United States (n = 16), Canada (n = 1), the United Kingdom (n = 2), and Brazil (n = 1). The study represented four ethnicities including Caucasian (70%), African American (10%), Latino/Hispanic (15%), and two or more (5%). A paired, one tailed t-test was used to analyze data. The study found statistical significance in the improvement of scores from the Zarit Burden Inventory (<.05) and the Positive Aspects of Caregiving Scale (<0.01).

Discussion: The findings are similar to those of larger studies on caregiver education intervention have found. Caregiver support has the potential to improve caregiver burden and

perceived positive aspects of caregiving. Although the effect size was small, it contributes to the existing body of knowledge that supports the notion that caregiver support is essential. Social workers, policy makers, and organizational leaders may use the findings to explore how they can further support caregivers in their communities.

Keywords: *dementia, caregiving, caregiver burden, attitudes about caregiving*

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Introduction

Dementia affects more than 55 million people each year, with nearly 10 million receiving a new diagnosis of dementia (World Health Organization, 2022). The current trajectory suggests that there will be more than 78 million people living with dementia (PLWD) by 2030 and more than 139 million in 2050 (World Health Organization, 2022). In light of these numbers, it is vital that we examine our current system of caregiving and how it supports – or denies – adequate care in the community. More than 17 million caregivers of PLWD provide more than 18.5 billion hours of care each year (Centers for Disease Control and Prevention, 2022). Approximately two-thirds of caregivers of PLWD are female while around 34% of caregivers are aged 65 or older (Centers for Disease Control and Prevention, 2022). Caregivers of PLWD have poorer personal health outcomes than those who care for individuals without dementia. Literature suggests that caregivers of individuals with dementia are at higher risks for chronic medical conditions and mental illness. Caregivers may lack the most appropriate information about dementia and caregiving (Peterson et al., 2016). This ultimately demonstrates a gap in the healthcare continuum.

Caregivers of PLWD may find resources and support along numerous avenues. Literature suggests that support groups, psychoeducation, respite care, and supportive services have a positive effect on the mental health and experiences of caregivers. Such interventions may help limit the use of psychotropic medications to manage dementia-related symptoms. Although there is an increasing emphasis on using psychotropic medications for managing symptoms of dementia, the effects vary and may have unintended consequences. Despite many of these medications making it easier for caregivers to provide care to loved ones, the poor side effects generally outweigh the positive effects. This ultimately increases distress for caregivers of

PLWD.

Among other studies examining the impact of caregiving, this study sought to explore how education and support may improve the experiences of people who provide care for PLWD. The principal investigator collaborated with the Dementia & Alzheimer's Wellbeing Network (DAWN) to implement an eight-week intervention that consisted of weekly educational training sessions on dementia and caregiving.

Review of the Literature

Although many individuals maintain good health and independence as they age, others face incurable conditions that negatively impact their psychosocial functioning. One condition that commonly affects older adults is dementia. Dementia is a term that describes neurocognitive disorders caused by abnormal changes in the brain that affect cognitive functioning and may limit independence (Wang et al, 2021). These changes disrupt communication between cells in the brain (Rao, Degnan, and Levy, 2014). As the disease progresses, dementia will diminish an individual's quality of life by interfering with social engagement and increasing psychological or behavioral distress (Wang et al, 2021). Wang and colleagues (2021) report that dementia affects more than 4% of the population aged 60 years or over worldwide.

The World Health Organization (2020) emphasizes that dementia is not part of the normal aging process. It is a chronic illness that derives from multiple causes (WHO, 2020). WHO (2020) estimates that an individual is diagnosed with dementia every three seconds. Nearly 50 million individuals live with a diagnosis of dementia worldwide (WHO, 2020). With more than 10 million individuals diagnosed with dementia each year, it is expected that there will be more than 152 million cases of dementia across the globe by 2050 (Wang et al, 2021; WHO, 2020). Due to the nature of the disease, it is expected that many of these individuals will need

increased care in a variety of settings (Wang et al, 2021).

Despite developments in research and medicine that can aid in the management of the symptoms of dementia, it remains a chronic illness that cannot be cured (Nelson & Tabet, 2015). Alzheimer's dementia is the most common form of dementia (Rao, Degnan, and Levy, 2014). Authors describe Alzheimer's dementia as a disease that progressively affects the brain (Wang et al, 2021; Nelson & Tabet, 2015). Although there is evidence that the brain is impacted prior to the onset of symptoms, it is difficult to detect until the individual begins to experience memory deficits or language issues (Nelson & Tabet, 2015). This typically occurs at or beyond the age of 65 (Nelson & Tabet, 2015). Symptoms occur when neurons in the brain responsible for memory, learning, and thinking are damaged or destroyed due to disease progression (Sato et al., 2018). Individuals with Alzheimer's disease will eventually lose the neurons that aid in managing bodily functions, walking, completing ADLS, swallowing, and breathing (Sato et al., 2018). The end of the disease cycle results in individuals becoming bed bound and receiving around the clock support from family, caregivers, or healthcare providers until death (Thuné-Boyle, 2010). Despite mortality rates declining due to increased prevention efforts and scientific developments between 2000 and 2019, death due to Alzheimer's dementia increased by nearly 145% (Alzheimer's Association, 2021; U.S. Department of Health and Human Services, 2019).

It is estimated that 60% to 80% of cases of dementia are classified as Alzheimer's disease (Sosa Ortiz et al., 2012). Recent studies of autopsies of Alzheimer's-affected brains reveal that more than half of them showed mixed pathologies for cognitive decline (Brenowitz et al., 2017). Although this is not uncommon, it is noted to be difficult to detect early in the disease progress (Sperling et al., 2011). Early symptoms of Alzheimer's dementia may include difficulty remembering names, events, people, or recent conversations (Sperling et al., 2011). Advanced

stage symptoms may include disorientation and confusion, changes in communication and comprehension, poor judgement, behavioral changes, and ultimately issues with ADLS (Sperling et al., 2011). As the disease finishes its course, individuals forget how to speak, swallow, control bodily functions, walk, and breathe (Sperling, 2021).

Mistry and colleagues (2020) examined the progression of dementia by tracking healthcare markers associated with patients receiving primary care. Much of the data collected from their study focused on the number of admissions to the hospital, admissions to palliative care programs, and mortality (Mistry et al, 2020) This study suggested that targeted support and better management of patients at the primary care (family medicine, geriatric medicine, internal medicine, etc.) level may improve outcomes for individuals with a poorer prognosis (Mistry et al. 2020).

Psychopharmacological Interventions

Throughout the history of dementia care, psychopharmacological interventions have been used to address symptoms of dementia. Although pharmacological management of the disease is effective in managing these symptoms, individuals may experience negative side effects (Nordgren & Engström, 2013). In particular, the use of antipsychotics can diminish an individual's quality of life (Nordgren & Engström, 2013). Advocacy organizations have reported that antipsychotics may cause an increased risk of sedation, shaking, infections, falls, blood clots, ankle swelling, stroke, exacerbation of dementia symptoms, or even death (Alzheimer's Society, n.d.). Due to the increasing need for evidence-based practices in dementia care, researchers and clinicians have sought interventions that benefit individuals with minimal side effects. Such efforts have increased attention to alternative or complementary interventions (Nordgren & Engström, 2013).

As of 2021, the U.S. Food and Drug Administration has approved six medications for treatment of Alzheimer's disease: rivastigmine, galantamine, donepezil, memantine, memantine combined with donepezil, and aducanumab (U.S. Food and Drug Administration, 2021). Although the efficacy of these drugs is up for debate, the most recent drug was approved in June of 2021 (U.S. FDA, 2021). Aducanumab is the most recent drug to receive approval from the FDA. The approval is significant because it is the first therapy for dementia to be approved since 2003 (U.S. FDA, 2021). The drug is unique in comparison to the former because it can potentially slow down the progression of Alzheimer's disease (FDA, 2021). One drawback that critics highlight is how the drug was only tested on individuals with mild cognitive impairment or early-stage Alzheimer's dementia (Alzheimer's Association, 2021).

Levels of Care

In Alabama, the projected number of individuals living with Alzheimer's disease is expected to increase by 14.6% this year (Weuve, Herbert, and Scherr, 2015). As the population continues to age, caregiving responsibilities are increasingly needed for PLWD (Xian and Xu, 2019). Individuals have three options for care when it is most needed. First, they may remain at home with a caregiver who can assist with ADLS (Rausch, Caliouw, and Ploeg, 2016). Although this is the most desirable option for numerous PLWD, many family members are unable to fulfill caregiving duties due to their own conflicting roles and responsibilities (Rausch, Caliouw, and Ploeg, 2016). Second, patients may choose to live in residential settings such as assisted or independent living (Hoe et al., 2018). These settings require some level of support from family members or other care providers, but the goal is to allow individuals to remain as independent as possible with assistance from healthcare providers (Hoe et al., 2018). According to Genworth, a financial management company, the average cost for basic assisted living or similar residential

programs is \$51,600 per year (Genworth, 2021). Third, transitioning to long-term care in a skilled nursing facility is an option that many families pursue (Hoe et al., 2018). Skilled nursing care facilities provide care from registered nurses and trained healthcare staff every day of the year (Bowers, Luring, and Jacobson, 2008). Such facilities can assist with bathing, cooking, exercising, socializing, managing medications, and offering a space for end-of-life care (Bowers, Luring, and Jacobson, 2008). In comparison to other residential programs, skilled nursing homes are the most comprehensive (Alzheimer's Association, 2021). This is reflected by data obtained by GenWorth (2021). The average cost for a private room in a skilled nursing facility is more than \$105,000 per year (Genworth, 2021). Semi-private rooms cost approximately \$93,000 (Genworth, 2021). While the cost of care is dependent upon the facility, population, and geographic location, it must be noted that comprehensive care for PLWD is expensive (Genworth, 2021).

Role and Impact of Caregiving

The population of caregivers serving PLWD is expansive and diverse. According to the Alzheimer's Association (2022), nearly half of all caregivers in the United States (48%) provide care for PLWD. Approximately two-thirds of caregivers of PLWD are female and around 34% of caregivers are aged 65 or older (Centers for Disease Control and Prevention, 2022). Data indicates that two-thirds of caregivers are Caucasian, 10% are African American, 8% are Latino/Hispanic, 5% are Asian American, and the remaining 10% represents caregivers from other ethnicities (Alzheimer's Association, 2022). Many caregivers (40%) are highly educated with at least one college degree, 41% have a household income of approximately \$50,000 or less, and approximately 25% of caregivers of PLWD are categorized as the "sandwich generation," which means that they care for a parent with dementia while also caring for children of their own

(Alzheimer's Association, 2022). As of 2022, the number of caregivers aged 18 to 29 has increased by 7% since 2015 (Alzheimer's Association, 2022).

The role and impact of caregiving has become the topic of a plethora of research, programs, and interventions. Caregivers have a challenging role that has been known to have a direct impact on social and physical health (Xian and Xu, 2019). For many caregivers, it is not uncommon to experience increased stress, strain, psychological and physical illness, social isolation, and financial hardship than those who are not caregivers (Xian and Xu, 2019). Financial burden alone is worth noting as more than 90% of patients in the community rely on unpaid caregiver support and more than 80% of patients in residential settings rely on unpaid caregiver support (Kasper et al., 2015). Among those who accept caregiver roles, (Kasper et al., 2015) found that caregiving is most intense in community settings when a spouse, child, or someone who lives with the patient is the caregiver. Intensity was measured by Kasper and colleagues (2015) by calculating the mean hours that someone participated in caregiving activities each month. In 2015, researchers examined studies from 2011 that revealed that nearly six million caregivers were providing approximately 6 billion hours of care per year to PLWD (Kasper et al. 2015). In contrast, the Alzheimer's Association (2021) found that 11 million caregivers provided nearly 15.3 billion hours of unpaid care to PLWD in 2020. Research also identified significant increases in both the number of caregivers and the number of unpaid hours of caregiving between 2011 and 2020.

The ongoing stress and responsibility of caregiving for PLWD has alarmed public health experts (Fonareva and Oken, 2014). A systematic review conducted by Fonareva and Oken (2014) compared physiological indicators of caregivers of individuals with dementia to those of caregivers of persons who did not have dementia. The review found that caregivers of PLWD

have more biomarkers for chronic diseases than non-dementia caregivers do (Fonareva and Oken, 2014). Such biomarkers indicate a higher risk for hypertension, cardiovascular disease, hyperglycemia, immune dysfunction, and premature death (Fonareva and Oken, 2014). This study also revealed that dementia caregivers experience a more active sympathetic nervous system, as demonstrated by changes in blood pressure, catecholamine levels, and adrenergic receptors, than do caregivers of persons without dementia (Fonareva and Oken, 2014). In fact, Fonareva and Oken (2014) found that dementia caregivers appeared to have higher blood pressure levels than non-dementia caregivers, despite taking more medications for hypertension.

Increased levels of burden and distress are noted among dementia caregivers (Wiegelmann and Speller, 2021). When compared to caregivers of individuals with other chronic and terminal illnesses, dementia caregivers' well-being is at an increased risk (Wiegelmann and Speller, 2021). This is likely due to the caregivers offering more hours of care, money for medications and supplies, and assistance with ADLs than non-dementia caregivers (Karg and Graessel, 2018; Brodaty and Donkin, 2009). Ory and Hoffman (1999) and Hiyoshi-Taniguchi, Becker, and Kinoshita (2018) found that negative behavioral changes, particularly aggression and irritability, that are associated with dementia may have a substantial impact on the mental health of caregivers. It is noted that such behaviors can be associated with an increased risk of depression and other mental health issues (Ory and Hoffman, 1999; Hiyoshi-Taniguchi, Becker, and Kinoshita, 2018). In fact, an earlier study examined what factors can influence the likelihood of depression among dementia caregivers. Truzzi and colleagues (2012) found that three dimensions affect caregiver burden -- emotional exhaustion, depersonalization, and reduced personal accomplishment. The study ultimately highlighted that caregiver burden and depression are strongly correlated with emotional exhaustion (Truzzi et al., 2012).

Caregiver distress may lead to caregiver burnout (Hiyoshi-Taniguchi, Becker, and Kinoshita, 2018). Despite many dementia-related symptoms precipitate distress and not burnout, Hiyoshi-Taniguchi, Becker, and Kinoshita (2018) found that patients' aggressive behaviors, irritability, abnormal motor functioning, and hallucinations caused the most burnout among dementia caregivers. Researchers made a clear distinction that distress does not always lead to burnout (physical, emotional, and mental exhaustion); however, higher levels of caregiver distress increase the risk for burnout (Hiyoshi-Taniguchi, Becker, and Kinoshita, 2018).

Numerous studies have examined variables that impact mental stress and caregiver depression. Wiegelmann and colleagues (2021) conducted a review of studies that examined four factors that includes the mental health of caregivers. First, they highlight how gender, relationship, cohabitation, and financial strain had an impact on dementia caregivers' mental health. Second, the researchers examined how health-related variables were related to decreased mental health. The patient's health condition, type of dementia, behavioral issues, inability to complete ADLS, and other psychiatric symptoms impacted caregivers. Three, caregiver variables were closely examined and how they served as a risk or protective factor. In addition, Wiegelmann and colleagues (2021) examined how high levels of neuroticism, increased emotional expression, poor attachment styles, low confidence in caregiving role, isolation, and poor coping strategies were primary risk factors for the development of depression. Four, relationship variable such as quality of relationship and levels of intimacy were explored as risk or protective factors associated with caregiver mental health (Wiegelmann et al., 2021).

Issues and Barriers for Caregivers

PLWD commonly require assistance from friends and family throughout the disease process. Most caregivers have no formal education, training, or experience working with

dementia and its progressive trajectory (Peterson et al., 2016). This is an ongoing issue that is ultimately rooted in gaps in knowledge rather than a reluctance to learn (Peterson et al., 2016). Peterson and colleagues (2016) explored what barriers are in place that affect a caregiver's experience. The data collected highlight that most caregivers receive insufficient information about their loved one's disease, caregiving needs, and resources in the community (Peterson et al., 2016). The study further revealed that caregivers are open to obtaining information from various sources, but often do not know where to begin (Peterson et al., 2016). Caregivers ultimately expect primary care physicians (PCP) to suggest or recommend sources of information that is in the best interest of the patient (Peterson et al., 2016).

Social isolation and poor support systems are concerns for dementia caregivers (Han et al., 2012). Caring for PLWD has social implications that impact how caregivers live, function, and cope (Han et al., 2012). Among social supports in the community, Han and colleagues (2012) found that positive and affectionate social interaction reduced psychological burden through direct and indirect channels. They report that the correlation between caregiver well-being and social support was significant and could reduce psychological burden by up to 20%.

The effects of the COVID-19 pandemic on caregivers of PLWD should not go unmentioned. Although quarantining and isolating were powerful tools to mitigate the spread of the virus, they had unintended consequences for PLWD and their caregivers (Rainero et al., 2021). Rainero and colleagues (2021) examined how isolation and quarantine affected both caregivers and PLWD. Their study found that quarantine was a contributing factor to worsening clinical symptoms among patients and worsening symptoms of burden among caregivers (Rainero et al., 2021). The study found that caregivers experienced a significant increase in psychological stressors due to quarantine (Rainero et al., 2021). Data shows that caregivers

experienced an increase in anxiety, depression, irritability, and distress (Rainero et al., 2021).

Evidence-based Caregiver Interventions

A substantial body of research suggests that caring for PLWD may negatively impact the physical and mental health of caregivers. When examining caregiver distress and its impact on health, it is important to note that education and support interventions have been sought to address such issues. This paper reviews interventions that have been developed to reduce symptoms of mental and physical health issues.

Support groups and education programs

Support groups for caregivers are a widespread intervention that is easily implemented, cost efficient, and has a proven record of success. Chien and colleagues (2011) conducted a meta-analysis that examined the impact of traditional in-person support groups. The meta-analysis found that support groups have a substantial impact on caregiver mental health (Chien et al., 2011). Support groups were found to have the most significant impact on psychological well-being, depression, burden, and social outcomes (Chien et al., 2011; Chu et al., 2010).

With the rise in technology, many researchers and clinicians are offering technology-based support groups to increase access (Lee, 2015). After closely examining studies that sought insight into technology-based support groups, Lee (2015) found that such support groups have a modest positive impact on caregiver burden and improving support networks. Lee (2015) found that these impacts are comparable to face-to-face support groups. A more recent meta-analysis by Armstrong and Alliance (2019) found similar data. Armstrong and Alliance (2019) discuss studies that used technology-based support group interventions. Commonalities among the studies that they examined included the numbers of participants, duration of support groups, and topics covered in support groups (Armstrong and Alliance, 2019). Topics frequently included

coping skills, knowledge, caregiving skills, and resources. Caregivers in the studies expressed benefits from participating (Armstrong and Alliance, 2019).

In addition to using support groups as a means of supporting caregivers, dementia education programs have been developed to address the impact of caregiving (Devor and Renvall, 2008). Devor and Renvall (2008) and Glueckauf and colleagues (2005) discuss how caregivers rarely receive instruction or training about how to be effective caregivers. Devor and Renvall (2008) conducted a study that provided an educational intervention to 300 self-identified caregivers of PLWD. Data highlights how self-reported caregiver burden decreased and perception of competence increased following the intervention. The study also showed that the intervention may have slowed the future burden anticipated by caregivers (Devor and Renvall, 2008). This was assessed at the six-month follow-up.

Control Trials

Two large scale studies that succeeded at supporting caregivers to increase positive outcomes were the Resources for Enhancing Alzheimer's Caregiver Health (REACH) and Care of Persons with Dementia in their Environments (COPE). These controlled trials allowed researchers to assess how well support services helped the overall well-being of caregivers.

REACH

REACH initially studied 495 caregiver-patient dyads across six cities in the United States including Miami, Florida; Boston, Massachusetts; Memphis, Tennessee; Birmingham, Alabama; Palo Alto, California; and Philadelphia, Pennsylvania. (Elliott, Burgio, and DeCoster, 2010). Participants were recruited in June 2004 and were followed until August of 2004 (Elliott, Burgio, and DeCoster, 2010). The intervention group completed a comprehensive assessment that allowed trained interventionists to identify needs and then implement tailored interventions for

each dyad (Elliott, Burgio, and DeCoster, 2010). After completing the assessment and identifying needs, researchers developed interventions to be implemented over nine home visits and three telephone calls (Elliott, Burgio, and DeCoster, 2010). Lykens and colleagues (2014) reported that interventions were primarily counseling-based and covered topics including home safety, emotions, stress, behavioral issues, and community resources. Caregivers also received supportive material that was tailored to their individual needs (Lykens et al., 2014). Supportive material included a notebook that was individualized for each caregiver (Lykens et al., 2014). The notebook helped caregivers track their interactions with counselors and consisted of items that reflected quality of life indicators (Lykens et al., 2014). To increase access to REACH services, a professionally printed notebook was translated to Spanish (Lykens et al., 2014).

Elliott, Burgio, and DeCoster (2010) used numerous assessment tools to measure caregiver health and burden. Their study ultimately found that caregivers reported improved health, sleep, physical and emotional health, and felt less burdened/stressed with caregiver responsibilities after receiving the intervention (Elliott, Burgio, and DeCoster, 2010). The primary measure included health status prior to the intervention and following the intervention (Elliott, Burgio, and DeCoster, 2010). The secondary measure was caregiver burden at baseline versus after intervention (Elliott, Burgio, and DeCoster, 2010). Both primary and secondary measures indicated improvements (Elliott, Burgio, and DeCoster, 2010).

The current author is from Alabama and found it appropriate to discuss specific interventions and outcomes from the site in Birmingham. The location in Birmingham was only one of two sites that served the South. This is significant due to the study's goal of offering education and support interventions to rural, low-income, and racially diverse communities (Pisu et al., 2021; Schulz et al., 2003). Birmingham (42.9%) was second to Philadelphia (47.8%) in

terms of African American participants (Schulz et al., 2003). These percentages were substantially higher than the overall sample size of African Americans in the study (24.2%) (Schulz et al., 2003). While other cities had participants from Hispanic backgrounds, data collected in Birmingham were vital for understanding the efficacy of REACH among African Americans (Schulz et al., 2003). In addition, Birmingham's sample was diverse in terms of income, as 34.6% of participants reported making <\$20,000, 35.3% made between \$20,000 and \$39,999, and 30.1% made more than \$40,000 (Schulz et al., 2003).

Per Schulz and colleagues (2003), interventions at this site were tailored towards caregiving skills. The interventions included primarily of supportive and skill-training activities that helped the caregivers manage behavioral issues demonstrated by individuals with dementia (Schulz et al., 2003). It also appears that these interventions helped caregivers manage and cope with daily stressors associated with caregiving (Schulz et al., 2003). Schulz and colleagues (2003) report that the intervention had different effects on African American and non-spouse caregivers when compared to white and spousal caregivers. The control group received telephone-based interventions with minimal active listening and empathy components (Schulz et al., 2003). Data collected at pre-test and post-test did not indicate statistical significance (Schulz et al., 2003).

COPE

A second study, Care of Persons with Dementia in their Environments (COPE), was conducted in Pennsylvania. Recruitment lasted from 2006-2008. After screening measures were completed, 270 dyads were determined to be eligible for the study. COPE was designed to reduce environmental stressors and to enhance caregiving skills and patient capabilities (Gitlin et al., 2010). The study focused on numerous measures including functional dependence, quality of

life, agitation or behavioral issues, engagement with patients, well-being, confidence in caregiver activities, and caregivers' perceptions of participation (Gitlin et al., 2010).

Participants in the intervention group received in-depth support as demonstrated by receiving 10 home visits from an occupational therapist and one visit from an advanced practice nurse. The support from occupational therapy helped caregivers learn how to adapt the environment for patients to live as independently and safely as possible. The support also helped caregivers learn how to communicate with loved ones more effectively and reduce overall stress (Gitlin et al., 2010). In conjunction to occupational therapy support, nursing services were provided to aid in medication management, providing education to caregivers, and managing care plans (Gitlin et al., 2010). In comparison, the control group received three telephone calls and educational materials.

Gitlin and colleagues (2010) found that each outcome measure had improved significantly for the intervention group. In contrast, the control group had relatively poor outcome measures (Gitlin et al., 2010). Gitlin and colleagues (2010) ultimately validated that living with dementia can be managed by non-pharmacologic interventions such as caregiver support and education, home modifications and safety planning, and routine support.

REACH and COPE were effective due to the increases support experienced by caregivers and patients. They received individualized interventions, in-home support, telephonic support, and appropriate education. Both studies addressed issues that have been noted in literature about dementia. One, both studies avoided pharmacological interventions. As Nordgren & Engström (2013) highlighted, many pharmacological interventions to manage dementia have harmful side effects and can negatively impact quality of life. This ultimately impacts both the patient and caregiver. Two, Peterson and colleagues (2016) report that most caregivers are untrained and

lack education about dementia and caregiving. COPE and REACH addressed this issue by incorporating both written and verbal education to patients and caregivers. Third, the studies addressed isolation that is experienced by many caregivers (Xian and Xu, 2019). Both studies incorporated home visits and telephone calls. Both of which increased human interaction.

The DAWN Method

To help educate and support caregivers and families, Judy Cornish developed the Dementia and Alzheimer's Well-Being Network (DAWN) in 2010. Through her own experiences of working with PLWD, Cornish developed the DAWN Method program to help patients and caregivers develop a sense of security and well-being. The Method is a strengths-based model for providing person-centered dementia care. Cornish hypothesized that caregivers cannot provide person-centered care if they only understand PLWD as they once were, instead of as they are now. Cornish concludes that care for PLWD can improve by understanding what skills they have retained while also being aware of the skills that they have lost. The DAWN Method is simple and can be used by caregivers in the home. By gaining a sense of security and well-being, PLWD may experience less negative behaviors. This ultimately limits caregiver stress.

A full description of the DAWN Method training can be found on the DAWN Method's website (DAWN, 2021). DAWN offers two options for participating in its training sessions. One, families can register to take an online course. This typically takes caregivers about eight weeks to complete. There are eight lessons divided into three areas: introduction, security tools, and wellbeing tools. Each lesson has videos and a quiz. A second option is being trained by the creator or a certified trainer. This option takes the same length of time but is more interactive and offers families ample opportunities for questions and discussion. Identical to the online course,

quizzes are required after each live session. After taking the online course or being trained via live instruction, families are ready to utilize the DAWN Method at home.

The DAWN Method has similarities to other dementia-related care programs. It focuses on educating caregivers about the experiences and barriers that PLWD have. The researchers hypothesize that, by educating caregivers about aspects of dementia, they can better care for their loved ones. This improves the lives of PLWD and it minimizes the stress of caregiving.

Three Modules of the Dawn Method

The DAWN Method was designed with the idea that one topic will be covered each week for a total of eight weeks and eight hours. This allows participants to learn, retain, and practice what they have learned in between topics. To organize the eight topics, the trainings are separated into three modules including introduction, security tools, and well-being tools.

The first category captures a broad overview of dementia and the DAWN Method. Whether learning through live instruction or online modules, the introduction category provides surface-level knowledge to participants. Following the completion of the introduction, participants move forward to the second category in the program. The second category, security tools, focuses on topics that interfere with an individual's sense of self and safety. As dementia progresses, individuals often lose their ability to regulate their mood, maintain a sense of safety due to ongoing confusion, and manage their personal security because of changes in care. The DAWN Method teaches that if an individual feels secure in three domains (mood, confusion, care) they are likely to have better lived experiences. The third category, well-being tools, focuses on increasing well-being by ensuring an individual has a sense of social success, control, value, and the future. Each of these topics are thoroughly taught and explored throughout the DAWN Method training program.

The Dawn Method in Eight Topics

Introduction

1. Introduction to Dementia Care (1 hour)

The first lesson of the DAWN Method training program helps caregivers and families learn how to understand dementia. Throughout the lesson, caregivers learn how many skills, such as intuitive thinking or ability to experience the present, are not lost as dementia progresses. The first lesson helps caregivers obtain the knowledge they need to amplify their loved one's strengths as well as improve their experiences. The education component of this lesson resonates with findings from Terayama and colleagues (2018), who report that education about dementia helps improve experiences of caregivers by decreasing depressive symptoms.

Security Tools

2. Mood Management (1 hour).

The second lesson explores how individuals with dementia oftentimes lose the ability to manage their moods. Caregivers learn about their role in establishing and maintaining a positive mood and environment for the individual with dementia. Desai, Schwartz, and Grossberg (2012) report that issues with mood and mental health lead to behavioral disturbances in almost all cases of dementia. In fact, they group behavioral disturbances into four categories including mood disorders, sleep disorders, psychotic disorders, and agitation (Desai, Schwartz, and Grossberg, 2012). Utilizing the second training session to focus on mood management is vital to long-term success.

3. Security in Confusion (1 hour)

Caregivers learn throughout the third lesson that individuals with dementia become increasingly confused and rely heavily on those around them. The lesson focuses on how many

individuals find security in confusion as it is the only thing that may seem familiar to them. It appears that individuals with dementia often get confused (Walker et al., 2000). It is essential that individuals and families participating in the DAWN Method trainings learn about the role of confusion in dementia and how to mitigate its effects.

4. Security in Care (1 hour)

Throughout the fourth lesson, caregivers learn about the importance of the caregiver-care recipient relationship as the individual is increasingly unable to care for themselves. As the lesson indicates, there is a sense of security when one knows that they are loved and accepted by those caring for them. Heard and Lake (1997, 2019) found that strong support from caregivers is needed despite the strength of attachment. Past and present attachments have been noted to be a protective factor for older adults living with dementia (Brown and Shlosberg, 2006). By acknowledging the importance and role of attachment in care delivery, the DAWN Method helps caregivers have an awareness of how security in care is vital to the care recipient's well-being.

Wellbeing Tools

5. Social Success (1 hour)

Despite losing cognitive functioning, individuals with dementia continue to experience feelings of uncertainty and embarrassment. Lesson five guides caregivers through the importance of helping individuals with dementia feel successful in social situations. Improving social communication and interpersonal interactions ultimately improves well-being and quality of life for PLWD (Acton et al., 2007).

6. Sense of Control (1 hour)

The sixth lesson exposes caregivers to issues that arise when one feels that they do not have control over their bodies, minds, or lives. The lesson focuses on the importance of

enhancing the decision-making ability of individuals with dementia. Despite individuals with dementia experiencing cognitive decline, decision-making and a safe level of autonomy is warranted by the UN Convention on the Rights of Persons with Disabilities (Wied et al., 2019). This lesson is supported by the idea that decision-making strategies are needed to ensure this human right is honored (Wied et al., 2019).

7. Sense of Value (1 hour)

The seventh lesson provides an overview of the importance of feeling valued. The DAWN Method discusses numerous techniques for caregivers to use with individuals to increase feelings of dignity and worth. Steeman and colleagues (2011) discuss how PLWD have difficulty maintaining their identities beginning in early-stage dementia. It was determined that many individuals with dementia struggle to feel valued (Steeman et al., 2011). This lesson provides an in-depth review of the importance of feeling valued by both loved ones and communities.

8. Secure Future (1 hour)

The final lesson teaches caregivers how an individual's inability to plan for the future can cause distress in individuals with dementia. This lesson prepares caregivers for assisting individuals throughout the disease's progression. Despite limited data or literature, securing a plan for the future is becoming increasingly popular around the world (Dickinson et al., 2013). To reduce personal and familial stress, it is important to discuss advance care planning with loved ones (Dickinson et al., 2013). Although many people have heard about advance care planning, they commonly do not have anything formal in place. Dickson and colleagues (2013) found five barriers to discussing advance care planning: lack of knowledge and awareness, difficulty in finding the most appropriate time and place, preferences for informal versus formal plans for the future, constraints about future care needs and settings, and lack of support to make

choices about future health-related needs. This lesson allows families to understand how vital it is to provide a sense of a secure life to those they are caring for.

Theoretical Framework

To help understand the interaction between older adults and their environments, Lawton and colleagues (Lawton, Brody, and Turner-Massey 1978, and Lawton 1983, Lawton 1985) developed the environmental press model. This model explains how interaction between persons and stimuli in their environments can impact behavior and mental health. Lawton described that an individual's behavior is a result of their competence and environmental press. When stimuli in an individual's environment changes, their behavior and experiences are dependent on their level of competence to adapt or cope with that change (Hans-Werner et al, 2012). When an individual's level of competence (abilities) is congruent with stimuli (press), it can cause positive behaviors and experiences for the individual (Lawton, 1989; Ruggiano, 2011). In contrast, when stimuli is incongruent with an individual's competence, it may cause negative behaviors or experiences (Lawton, 1989; Ruggiano, 2011). In addition to his initial model, Lawton described three elements that influences behaviors in older adults based on their environments. These elements include maintenance, stimulation, and support. While Lawton's model was developed for the gerontology community, it can be applied to caregivers of PLWD.

While caregiving itself does not always result in poor outcomes for caregivers, the ongoing demands has the potential to cause burden and distort attitudes about caregiving among individuals serving in that role. These individuals must learn to adapt to such challenges. This study examined how the DAWN Method increased competency among caregivers by providing them with the knowledge and skills to improve care delivery in the PLWD's environment. Through an environmental press model lens, increasing a caregiver's competency ultimately

helps them take better care of loved ones and more effectively address challenges.

Project Rationale and Aims

Caregivers of PLWD experience numerous stressors that impact psychosocial functioning. One of the primary concerns found in the literature is how caregiving impacts mental health. Literature suggests that mental health is negatively impacted by caregiving. Studies have found that interventions to support caregivers alleviate mental health symptoms and improve quality of life. This study sought to utilize the DAWN Method and measure its efficacy.

The purpose of the present study is to assess the efficacy of the DAWN Method in reducing caregiver stress. The greater purpose is to contribute to existing literature about issues that dementia caregivers face and evidence-based interventions for helping address such issues.

The study aimed to achieve three objectives including examining the efficacy of the DAWN Method, educating caregivers about dementia, and providing exposure to another option for caregiver support. The results of the study will ultimately inform helping professionals and beyond about the impact support had on dementia caregivers.

Hypotheses

I. Caregivers who participate in the DAWN Method training program will report lower levels of caregiver burden at the end of the training.

II. Caregivers who participate in the DAWN Method training program will report improved attitudes about caregiving at the end of the training.

Research Question

U. What are caregivers' perceptions of the DAWN Method training classes?

Methodology

Project Design

Recruitment

Recruitment took place during August 2021. Participants voluntarily inquired about the study online. Digital posters were posted on multiple social media platforms, including Facebook, Instagram, and LinkedIn, and e-mail/newsletters accessible to the DAWN Method and the principal investigator. The digital flyer directed participants to visit a webpage on the DAWN Method's website about the study's purpose, risks and benefits, and how to inquire about participating. Inclusion criteria included participants being at least eighteen years old, being an active caregiver for someone living with dementia, and be willing to commit to the eight-week educational trainings.

Screening

The digital poster had a link attached that allowed potential participants to read about the study and directions on how to inquire about participating. An e-mail address was requested during this phase in the event the participant did not meet inclusion criteria and must be contacted. The investigator examined each potential participants' screening questions to ensure that they met inclusion criteria. Those that did not meet inclusion criteria were contacted via e-mail.

Consent

Eligible participants were contacted utilizing the e-mail addresses requested during the screening process. To protect participants' identities, the "blind carbon copy" feature was used when e-mailing all eligible participants simultaneously. Participants received emails that outlined the study, its risks and benefits, confidentiality, and the measurement tools being used for data

collection. They were informed that by completing the pre-test survey they were giving consent to participate in the study.

Training

The training/intervention phase lasted for eight weeks. The DAWN Method was implemented by Judy Cornish via Zoom. Passwords were provided and required to access the trainings. There were eight lessons divided into three areas: introduction, security tools, and wellbeing tools. The trainings included educational lectures and required quizzes. After receiving live instruction, participants were instructed to implement the DAWN method as part of their daily caregiving. Participants were encouraged to review information provided in the training materials and in the DAWN Method's library.

Measurement Instruments

The study sought to measure two variables including caregiver burden and positive attitudes towards caregiving. Level of burden was measured using the 22-item Zarit Burden Inventory (ZBI). Items are rated on a four-point scale from zero (never) to four (nearly always), which are ultimately summed for data analysis purposes. Scores for the ZBI range from 0-88, with a score of 17 indicating high level of burden (Al-Rawashdeh, Lennie, Chung, 2016). Lower scores indicate a lower burden. Attitudes towards caregiving were measured using the 9-items Positive Aspects of Caregiving (PAC) Scale. These items are rated on a five-point scale from one (disagree a lot) to five (agree a lot), with a higher score indicating more positive attitude about caregiving. Scores for the PAC range from 9-45. Both instruments have demonstrated reliability and validity with samples of caregivers of older adults with dementia and other issues impacting older adults (Seng et al. 2010; Siow et al, 2017).

A brief demographics survey was administered at the end of the study. It collected data

about age, gender, ethnicity, country of origin, education level, relationship to loved one with dementia, length of time as a caregiver, housing, community setting, and employment.

In addition to demographic data, participants were asked to answer four open-ended questions about their experiences, observations, or opinions about the DAWN Method trainings. Questions focused on what participants liked about the trainings, what they disliked about the trainings, how it impacted them as caregivers, and how it impacted their loved ones with dementia.

Data Collection Procedures

Data collection was conducted at pre- and post-test intervals via Qualtrics prior to the first training (week 1) and following the last training (week 8). Data were collected via Qualtrics by e-mailing a link to the surveys to participants. To protect the identities of participants among each other, e-mail addresses were used to distribute the survey utilizing the “blind carbon copy” function. In addition, participants were asked to provide their favorite movie title in the pre- and post- survey so that survey data could be matched without identifying the participants.

Data Analysis

Data collected from Qualtrics were coded and imported to Microsoft Excel for analysis. Two columns were created to list the pre-test and post-test scores. A paired, one tailed t-test was conducted by using the data analysis feature.

Protection of Human Subjects

The study was approved by the institutional review board (IRB) at the University of Alabama. The study had minimal risks for participants. Due to the study taking place virtually, additional precautions were taken to ensure confidentiality. First, participant e-mail addresses were securely stored with no identifiable information. When using e-mail to communicate with

participants, the “blind carbon copy” feature was used on Microsoft Outlook. Second, participants were asked to use their favorite movie titles in lieu of their names when completing the pre-test, post-test, and demographic surveys. This provided an additional layer of protection. Third, passwords were required to access the Zoom sessions for each of the training sessions. The passwords were provided to participants prior to each session. Fourth, participants were encouraged to keep all comments and information about peers confidential.

Results

A total of 20 caregivers consented and enrolled in the study. A summary of the sample’s demographics can be found in Table 1. The sample included males ($n = 4$) and females ($n = 16$). Participants represented four countries including the United States ($n = 16$), Canada ($n = 1$), the United Kingdom ($n = 2$), and Brazil ($n = 1$). The study represented four ethnicities including Caucasian (70%), African American (10%), Latino/Hispanic (15%), and two or more (5%).

Twenty-seven ($N = 27$) participants completed the pre-test surveys for the ZBI and the PACS. At post-test measurement, eighteen ($N = 18$) participants completed the ZBI while 20 ($N = 20$) participants completed the PAC Scale. Data that did not have matching movie titles or internet protocol (IP) addresses were excluded from data analysis.

Caregiver Burden

The findings indicated that there was a reduction in burden at the post-test follow-up. Participants’ scores for burden improved from pre-test ($M = 28.14$, $SD = 14.02$) to post-test ($M = 18.38$, $SD = 5.32$). In the pre-test assessment, participants’ scores for caregiver burden ranged from 2 – 74. A total of 23 caregivers had scores greater than 17, which indicates high levels of burden. At post-test assessment, participants scores ranged from 11-31. A total of 11 caregivers had scores great than 17, which indicates a reduction from high burden from pre-test to post-test

measurement. Findings from the t-test demonstrated that this improvement was statistically significant, $t(17) = 2.14, p < .05$.

Sociodemographic Characteristics of Participants

Table 1
Sociodemographic Characteristics of Participants

Sample Characteristics	N	%	M	SD
Gender				
Male	4	20		
Female	16	80		
Age			59.5	13.85
Ethnicity				
Caucasian	14	70		
African American	2	10		
Latino/Hispanic	3	15		
Two or more	1	5		
Education				
Some College	4	20		
Associates	1	5		
Undergraduate	6	30		
Graduate	9	45		
Country				
United States	16	80		
Canada	1	5		
United Kingdom	2	10		
Brazil	1	5		
Home Setting				
Urban	9	45		
Suburban	9	45		
Rural	2	10		
Employment				
Full-time	6	30		
Part-time	5	25		
Retired	7	35		
Disabled	2	10		
Relationship				
Wife	3	15		
Husband	4	20		
Parent	8	40		
Daughter/in-law	2	10		
Other	2	10		
Other non-relative	1	5		
Years as Caregiver				
0 to 1 year	4	20		

1 to 5 years	8	40
5 to 10 years	3	15
10 to 15 years	3	15
More than 15	2	10

Positive Aspects of Caregiving

Scores referring to the attitudes about caregiving also improved. Scores improved from pre-test (M =28.84, SD = 8.44) to post-test (M = 35.5, SD = 6.28). In the pre-test assessment, participants’ scores for attitudes about caregiving ranged from 10 – 45. At post-test assessment, participants scores ranged from 22-45. A total of 14 caregivers had scores increase, which indicates an improvement in attitudes about caregiving from pre-test to post-test measurement. Findings from the t-test demonstrated that this improvement was statistically significant, $t(19) = -4.84, p < 0.01$

Participant Perceptions of the DAWN Method

Participants answered four qualitative questions at the end of the demographics survey that pertained to the DAWN Method trainings. Eighteen participants completed the qualitative questions. Themes were identified and linked to the correlating question.

Satisfaction. Feedback was overwhelmingly positive as it pertained to the DAWN Method trainings. Participants expressed their gratitude for Judy Cornish, complimented the clarity and delivery of information, and spoke highly about having a deeper understanding of how dementia care can be person-centered rather than disease centered. Participants highlighted the DAWN Method’s “philosophy and approach in care,” “conceptual clarity,” and how it helped them “learn new ways of living life with a loved one with dementia.” Participants also expressed the value in obtaining and practicing new skills, learning better ways to communicate with PLWD, and disease-specific information about dementia and its progression.

Data included three recommendations for future DAWN Method trainings. One

participant found the pace of the trainings could have been improved to allow more time for questions and discussion. The participant indicated that they were often “unable to stay after the time allotted to ask questions.” The second participant noted that it would be most helpful if the PowerPoint presentations were provided before each training in lieu of receiving it afterwards. This would allow caregivers time to review the content before each session. The final recommendation highlighted the desire for more role-playing opportunities to help obtain, strengthen, and practice new skills.

Perceived Impact on Caregiving. Participants’ responses varied in content spanning from increased competency to a change in their perspectives about caregiving. The feedback included comments such as it gave participants “hope,” “had a positive impact,” “have more patience,” and “helped me have more compassion.” One participant felt that their “lifespan has been prolonged by the reduction of acute stress and lowering of index of chronic stress that a caregiver has when caring for a loved one.”

Perceived Impact on Care-recipient. Participants provided clear feedback that entailed themes of positive impacts, patience, and compassion. It appears that many participants felt that their loved ones already reaped the benefits of the DAWN Method trainings. One participant commented that “without a doubt my wife is feeling better understood and less embarrassed.” Additionally, one participant reported that their loved one “feels more secure and less stressed and confused about the routine.” Many comments closely aligned with the content of the trainings including emotional and physical security.

Discussion

With more than 58 million individuals living with dementia in the United States (CDC, 2022), research on the impacts of caregiving is valuable to service providers and the populations

they serve. While ample research has been conducted over the last two decades, additional research is warranted as the number of dementia diagnoses increases. This study provides a foundation for future research on the DAWN Method and other caregiver support programs. By contributing to existing literature, this study serves a purpose by providing knowledge to social workers across the practice setting continuum.

The DAWN Method uses an experiential care model rather than the medical or treatment model for working with PLWD. As noted by Nordgren and Engström (2013), the medical model – particularly the use of antipsychotics to manage behaviors associated with dementia – can have detrimental effects to the well-being of PLWD. The experiential care model helps define specific problems and provides a range of solutions. Furthermore, the DAWN Method identifies a pattern in the cognitive skills lost and the cognitive skills retained throughout the progression of dementia. It focuses on psychological aspects of dementia rather than medical perspectives (Cornish, 2022). This allows caregivers to learn how to anticipate, recognize, and meet the emotional needs before they result in maladaptive behaviors. This helps reduce caregiver burden and improves attitudes about caregiving.

This study found that participants experienced a statistically significant reduction in burden and an improvement in attitudes about caregiving following the completion of the DAWN Method trainings. These findings indicate that support and education can positively influence caregivers' perceptions and experiences. The findings align with existing literature that validate the efficacy of dementia caregiver support provided in group or individual settings in the community (Schulz et al., 2003; Devor and Renvall, 2008; Elliott, Burgio, and DeCoster, 2010; Gitlin et al., 2010).

Notable studies that indicate the efficacy of caregiver support include the REACH and

COPE studies. As previously discussed, Peterson and colleagues (2016) highlight how most caregivers lack training and education about caring for someone living with dementia. The DAWN Method, much like COPE and REACH, addressed this issue by providing dementia-specific support and education to caregivers over an extended period.

Implications for Social Work

Over the next several decades, social workers' roles in gerontology will likely increase due to the needs of the aging population. Kunik and colleagues (2017) report a shortage in geriatric mental health providers, especially geriatric psychiatrists. Due to the shortage of geriatric mental health service providers, social workers must learn about the needs of caregivers and PLWD. In lieu of seeing a geriatric psychiatrist, many older adults and their caregivers may see PCPs and social workers for mental health needs. It is vital that social workers are aware of support and education programs that will help alleviate issues that impact mental health. The DAWN Method uses a strengths-based model that is focused on helping caregivers create environments that are aligned with the remaining abilities of their loved ones. The findings of this study highlight how the trainings have decreased burden, increased positive attitudes about caregiving, and how both caregivers and PLWD have benefited.

The findings also allow social workers to contemplate their role in the advocacy process. It is evident that caregiver support programs can be effective in improving the lives of caregivers and PLWD; however, such programs and services are still difficult to locate for many. As advocates at all levels of practice, social workers can advocate for the creation and implementation of caregiver support services in their practice settings. With approximately 60% of the mental health workforce being clinically trained social workers, it is an opportunity for social workers to lead the efforts in person-centered dementia care (College of St. Scholastica,

2017).

Implications for Policy

The findings of this study should help inform public policy and advocacy that impacts caregiving. In 2021, the RAISE Family Caregiving Advisory Council released its preliminary report to Congress about how the federal government can assist Recognize, Assist, Include, Support, and Engage (RAISE) family caregivers (Administration for Community Living, 2021). After conducting a thorough needs assessment about the state of caregiving, the initial report discusses 26 recommendations for enacting change. There are five primary priorities for the RAISE Family Caregiving Advisory Council. These priorities include increasing awareness about caregiving, increasing the integration of caregivers into processes that they have traditionally been excluded from, increasing access to services and support for caregivers, increasing protections for caregivers in financial and workplace settings, and improving research and data collection about issues impacting family caregiving (Administration for Community Living, 2021). As the National Association of Social Workers (NASW) Code of Ethics calls for social and political action, social workers should have knowledge about PLWD and the impacts on caregiving. This knowledge allows social workers to advocate for public policy, such as the RAISE Act, that will have a positive impact on family caregivers.

By advocating for legislation (i.e., RAISE Act), communities and organizations may potentially have access to funding for caregiver support programs in the future. With the number of social workers projected to increase to 790,000 by 2026, advocating for public policy should be a priority at all levels of practice (U.S. Bureau of Labor Statistics, 2022). It is an opportunity for the profession to make significant contributions to the field of gerontology.

Implications for Research

This study specifically examined two variables for a small-scale education program. It was similar to other studies in that it examined burden and attitudes toward caregiving. Future research may examine the extent to which and how caregivers apply what they learn, impact on self-efficacy, and how to effectively implement technology-based interventions for caregiver education. In addition, one variable that was not assessed in this study was outcomes for care recipients. Despite not assessing this variable, qualitative data indicate that the trainings had a positive impact on PLWD as described in the results section.

Future research on the DAWN Method should pay close attention to recruitment efforts that represent a more diverse sample. The study did not measure how the DAWN Method impacted emotional and physical well-being. These elements naturally align with caregiver burden; however, it was not included in the study's design.

Study Limitations

The study had limitations and therefore the findings should be reviewed with caution. First, the sample size was small and a larger sample size is needed to generalize the findings of the study. Second, the sample primarily consisted of Caucasian individuals with high education attainment. The sample does not accurately represent communities of lower education attainment or socioeconomic status.

Another significant limitation was that the study took place during the COVID-19 pandemic. This caused the trainings to take place virtually in place of a traditional setting. This was complicated by having 20 participants each time. Cornish traditionally offers trainings to individual caregivers. It was the first time that the Method had been taught in a group format.

Study Strengths

Despite the COVID-19 pandemic creating limitations for the project, it was found that there were some advantages to using Zoom as a platform for the DAWN Method, such as increasing accessibility to participants. Zoom provides a safe, reliable, and confidential virtual meeting room that can be accessed on most electronic devices. Participants were provided a link to the meetings via e-mail. Participants simply clicked the link, entered the password, and were admitted to the virtual meeting room. While the study did not assess the efficacy of utilizing technology as a means for caregiver support, the findings suggest that virtual support had a positive impact on burden and attitudes about caregiving. Many studies have explored interventions to support caregivers; however, most of those studies have occurred in-person. The principal investigator and founder of the DAWN Method chose to utilize a virtual platform because of COVID-19 and accessibility. Zheng and Phillips (2021) found that providing support via an online format was helpful for participants that were isolated or lacked access to support due to COVID-19. They also found that meeting on a virtual platform allowed participants to problem solve common issues that impact each other and normalize feelings that the community may have (Zheng and Phillips, 2021). The use of technology allowed caregivers in this study to access the trainings from the comfort of their own environments. By completing the real-time trainings on Zoom, participants could remain in the home with their loved ones. Technology also allowed caregivers from across the world to participate. Four countries were represented in the study including the United States, United Kingdom, Brazil, and Canada.

In addition to the use of technology, the DAWN Method provides education and support about the dementia experience. It presents information that helps caregivers understand complex concepts that impact PLWD including an introduction to dementia care (Terayama et al., 2018),

mood management (Desai, Schwartz, and Grossberg, 2012), security in confusion (Walker et al., 2000), security in care (Brown and Shlosberg, 2006; Heard and Lake, 1997 & 2019), social success (Acton et al., 2007), sense of control (Wied et al., 2019), sense of value (Steehan et al., 2011), and sense of the future (Dickinson et al., 2013). Literature suggests that elements of these topics are vital for understanding the dementia experience and providing quality care.

The study's design had three primary strengths. One, the researcher was not the interventionist, which can minimize bias. While the researcher helped with recruitment efforts and collected all data, Cornish interacted with participants and taught each of the eight training sessions. Two, the project had low attrition. Most of the participants completed the intervention and took the post-survey. This provided ample data for a small-scale study. Three, the measurement tools that were used for data collection have strong reliability and validity. This ensured that the data collected were consistent and that it captured data that the researchers aimed to collect.

Conclusion

This study reinforced what is already known about dementia caregiving. It can be a challenging task that generally receives minimal support. The lack of support can cause caregivers to feel burdened and may distort any positive aspects of the caregiver role. The study found that the DAWN Method decreased caregiver burden and improved attitudes about caregiving among participants. The statistical significance observed in both measurement tools is a testament to the positive impact of caregiver support programs. The findings provide the field of social work with additional literature about interventions to help individuals navigate roles as caregivers. The study provides a foundation for future research on the DAWN Method.

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Appendix A

Burden Scale

Participant ID In lieu of using your name or other identifiable information for data collection, we're requesting that you list your favorite movie instead (i.e. The Little Mermaid). Please use the same movie for each survey you take as part of the study.

Q1 Do you feel that your relative asks for more help than he/she needs?

- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)

Q2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)

Q3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q4 Do you feel embarrassed over your relative's behaviour?

- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)

Q5 Do you feel angry when you are around your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q7 Are you afraid what the future holds for your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q8 Do you feel your relative is dependent on you?

- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)

Q9 Do you feel strained when you are around your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q10 Do you feel your health has suffered because of your involvement with your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q11 Do you feel that you don't have as much privacy as you would like because of your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q12 Do you feel that your social life has suffered because you are caring for your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q13 Do you feel uncomfortable about having friends over because of your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q16 Do you feel that you will be unable to take care of your relative much longer?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q17 Do you feel you have lost control of your life since your relative's illness?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q18 Do you wish you could leave the care of your relative to someone else?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q19 Do you feel uncertain about what to do about your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q20 Do you feel you should be doing more for your relative?

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q21 Do you feel you could do a better job in caring for your relative

- Never (0)
 - Rarely (1)
 - Sometimes (2)
 - Quite Frequently (3)
 - Nearly Always (4)
-

Q22 Overall, how burdened do you feel in caring for your relative?

- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)

Appendix B

Positive Aspects of Caregiving Scale

Participant ID In lieu of using your name or other identifiable information for data collection, we're requesting that you list your favorite movie instead (i.e. The Little Mermaid). Please use the same movie for each survey you take as part of the study.

Q1: Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel more useful

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q2 Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel good about myself

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q3 Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel needed

- Disagree a lot (1)
- Disagree a little (2)
- Neither agree or disagree (3)
- Agree a little (4)
- Agree a lot (5)

Q4 Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel appreciated

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q5 Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel important

- Disagree a lot (1)
- Disagree a little (2)
- Neither agree or disagree (3)
- Agree a little (4)
- Agree a lot (5)

Q6 Providing help/care to or ensuring provision of care to (name of care recipient) has... made me feel strong and confident

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q7 Providing help/care to or ensuring provision of care to (name of care recipient) has... enabled me to appreciate life more

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q8 Providing help/care to or ensuring provision of care to (name of care recipient) has... enabled me to develop a more positive attitude toward life

- Disagree a lot (1)
 - Disagree a little (2)
 - Neither agree or disagree (3)
 - Agree a little (4)
 - Agree a lot (5)
-

Q9 Providing help/care to or ensuring provision of care to (name of care recipient) has... strengthened by relationship with others

- Disagree a lot (1)
- Disagree a little (2)
- Neither agree or disagree (3)
- Agree a little (4)
- Agree a lot (5)

Appendix C

Demographics Survey

Q1 What is your age?

Age: _____

Q2 What gender do you identify with?

Male

Female

Non-binary / third gender

Other _____

Q3 What is your ethnicity?

Caucasian/white

African-American

Latino or Hispanic

Asian

Native American

Native Hawaiian or Pacific Islander

Two or More

Prefer not to say

Q4 What country are you located in?

- United States
- Canada
- United Kingdom
- Brazil
- Other _____

Q5

What is the highest level of education that you have achieved?

- Below high school
 - High school/equivalent (i.e., GED)
 - Some college (no degree)
 - Associate's degree and/or trade school
 - Bachelor's degree
 - Graduate school or higher
-

Q6 You are a caregiver. How are you related to the person you provide care to? They are my...

- Wife
 - Husband
 - Partner
 - Parent
 - Daughter/in-law
 - Son/in-law
 - Other relative
 - Other non-relative
-

Q7 How long have you been a caregiver?

- 0 months to 1 year
 - 1 to 5 years
 - 5 to 10 years
 - 10 to 15 years
 - 15 +
-

Q8 How many days per week do you provide care to your loved one?

- Days per week: _____
-

Q9 Do you currently live with the care recipient?

Yes

No

Q10 Would you describe the community you live in as...

Urban

Suburban

Rural

Q10 I am employed...

Full-time

Part-time

Retired

Disabled

Q11 What did you find most helpful about the DAWN Method training classes?

Q12 What did you not like about the DAWN Method training classes and think should change?

Q13 What impact do you think the DAWN Method trainings have had on the experiences as a

CAREGIVER?

Q14 What impact do you think the DAWN Method trainings have had on the experiences of your LOVED ONE?

Appendix D



September 22, 2021

Jeffrey Caldwell
Department of Social Work
College of Social Work
Box 870314

Re: IRB # 21-06-4701 "Honoring the Whole Family: Examining Impact of the DAWN Method on Dementia Caregivers"

Dear Mr. Caldwell:

The University of Alabama Institutional Review Board has granted approval for your proposed research. Your application has been given expedited approval according to 45 CFR part 46. You have also been granted the requested waiver of documentation of informed consent. Approval has been given under expedited review category 7 as outlined below:

(?) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The approval for your application will lapse on September 21, 2022. If your research will continue beyond this date, please submit a continuing review to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Good luck with your research.

Sincerely,



Carpathato T. Myles, MSM, CTM, CLP
Director & Research Compliance Officer

Jessup Building | Box 870127 | Tuscaloosa, AL 35187-0127
256-348-8461 | Fax 205-318-7199 | Toll Free 1-877-820-3066

Appendix E

THE UNIVERSITY OF
ALABAMA

Office of the Vice President for
Research & Economic Development
Office for Research Compliance

September 24, 2021

Jeffrey Caldwell, MSW, LICSW, PIP
Doctoral Student
School of Social Work
The University of Alabama
Box 870314

Re: IRB # 21-06-4701-A "Honoring the Whole Family: Examining Impact of the DAWN Method on Dementia Caregivers"

Dear Mr. Caldwell:

The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your protocol will expire on September 21, 2022.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,



Carpanato T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer

Jessup Building | Box 870127 | Tuscaloosa, AL 35487-0127
205-348-8461 | Fax 205-348-7189 | Toll Free 1-877-820-3066

Appendix F



January 6, 2022

Jeffrey Caldwell, MSW, LICSW, PIP
School of Social Work
The University of Alabama
Box 870314

Re: IRB # 21-06 4701-B: "Honoring the Whole Family: Examining Impact of the DAWN Method on Dementia Caregivers"

Dear Mr. Caldwell:

The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your protocol will expire on September 21, 2022.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,

Carpentale T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer

Appendix G

Looking for Dementia Care Study Participants



For in-home **Family Caregivers**
Receive **FREE** training in
the **DAWN Method®** with Judy Cornish

8-Week Session:
Sept. 23–Nov. 11, 2021

Study overseen by Institutional Review Board at the University of Alabama.
(Details: <https://thedawnmethod.com/call-for-participants-2021/>)

Appendix H

Sociodemographic Characteristics of Participants

Table 1

Sociodemographic Characteristics of Participants

Sample Characteristics	N	%	M	SD
Gender				
Male	4	20		
Female	16	80		
Age			59.5	13.85
Ethnicity				
Caucasian	14	70		
African American	2	10		
Latino/Hispanic	3	15		
Two or more	1	5		
Education				
Some College	4	20		
Associates	1	5		
Undergraduate	6	30		
Graduate	9	45		
Country				
United States	16	80		
Canada	1	5		
United Kingdom	2	10		
Brazil	1	5		
Home Setting				
Urban	9	45		
Suburban	9	45		
Rural	2	10		
Employment				
Full-time	6	30		
Part-time	5	25		
Retired	7	35		
Disabled	2	10		
Relationship				
Wife	3	15		
Husband	4	20		
Parent	8	40		
Daughter/in-law	2	10		
Other	2	10		
Other non-relative	1	5		
Years as Caregiver				
0 to 1 year	4	20		
1 to 5 years	8	40		
5 to 10 years	3	15		

10 to 15 years	3	15
More than 15	2	10

Appendix I

