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A Qualitative Evaluation of Caregiver Support Resources at the Cognitive Disorders Specialty Care Education Center of Excellence at the Atlanta Veterans Affairs Medical Center

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B.S.
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Thesis Committee Chair: Nancy Thompson, PhD, MPH

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

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By Shannon Biello

The Department of Veterans Affairs (VA) administers care to approximately 300,000 individuals with dementia. Projected increases in incidence pose unique challenges to this healthcare system, including how to assist the many informal caregivers who provide long-term, comprehensive support to Veterans. Recognizing the critical role caregivers play in Veteran's health, the Cognitive Disorders Specialty Care Education Center of Excellence (COE) at the Atlanta VA Medical Center implemented a suite of caregiver support services, including both formal programs and resource linkages. This quality improvement project sought to evaluate the effectiveness of COE caregiver support resources, identify any caregiver perceived gaps in these resources, and to explore current caregiver coping strategies that may be leveraged in future COE initiatives. Eleven in-depth, semi-structured interviews were conducted with caregivers of Veterans seen in the COE who have engaged with a caregiver support resource(s). For thematic analysis, codes were generated from the initial interviews, refined into a codebook of eight major codes, applied to the remaining transcripts, and synthesized across all interviews. COE caregiver resources that offered detailed information on dementia, social support, an emphasis on caregiver well-being and caregiver self-efficacy, and methods for behavioral change were positively received by caregivers. Identified gaps include the need for individually tailored resources and for practical support in matters like advanced directives and eligibility for VA benefits. Prominent caregiver coping strategies included individual free time (when the caregiver was not responsible for Veteran well-being), external support groups, and respite care. Findings will inform future improvements to COE caregiver support resources, such as an expansion of the caregiver educational programs' content, as well as efforts to increase the capacity of these resources. These results also highlight opportunities for the COE to interface with internal and external agencies and organizations to enhance existing caregiver services.

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Keywords: dementia, caregivers, support resources

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Introduction

Dementia is a common disorder among elderly populations, affecting approximately 14% of U.S. adults older than 70 (approximately 4.2 million individuals), with prevalence expected to rise as the overall population ages (Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Plassman et al., 2007; Prince et al., 2013). A “dementia” diagnosis encompasses a constellation of disorders characterized by memory decline and the obstruction of other critical thinking skills that influence the ability to perform routine activities, with Alzheimer’s Disease being the most common diagnosis (60-80% of cases) followed by vascular dementia (*2016 Alzheimer's Disease Facts and Figures*, 2016). Dementia is a growing concern in the U.S. health system, since care for dementia is costly and spans years or, in some cases, even decades (Hurd, Martorell, & Langa, 2015). Recent estimates suggest that the annual cost of dementia care may double from its current healthcare cost of $109 billion by 2040, with programs like Medicare and Medicaid shouldering a significant portion of the financial burden (Hurd et al., 2013; Hurd et al., 2015).

To offset the cost of more formal healthcare expenditures, the burden of long-term dementia support also falls on informal care strategies, like uncompensated, non-clinician caregivers. Informal caregivers play a critical role in U.S. healthcare, acting as supplemental support outside of clinical spheres for patients with dementia disorders (*Caregiving in the U.S.*, 2015). Indeed, elderly individuals with neurodegenerative conditions often rely upon informal caregiving to maintain adherence to provider instructions and to perform activities of daily living, with one study estimating that family and other unpaid caregivers provide an average of 91.7 hours of assistance to patients with dementia per month (roughly 23 hours per week) (Kasper, Freedman, Spillman, & Wolff, 2015). Recent calculations have valued the cost of informal caregiving for dementia per person at $56,290 per year (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Hurd et al., 2013).

Informal caregiving may become physically and emotionally taxing as caregivers administer what Samia et al. (2012) refer to as an evolving “trajectory of care” typically prescribed for patients facing years of cognitive decline. Informal dementia caregivers must continuously adapt to the stages of degenerative neurological impairment, a task that requires significant emotional, physical, time, and other resources. Recent studies have identified a number of consequences that are directly linked to extended caregiving for patients with neurodegenerative disorders. More specifically, researchers found that long-term caregiving may lead to psychological distress, decreased work productivity, decreased participation in typical leisure activities like visiting loved ones and attending religious services, and increased caregiver utilization of emergency and other medical services (Moon, Rote, & Beaty, 2016; Wolff, Spillman, Freedman, & Kasper, 2016). With such an array of issues associated with caregiving, it is concerning that only about 25% of caregivers report use of supportive services (Wolff et al., 2016). Since caregivers are integral to the health of the patient, especially for long-term chronic conditions, it is crucial that healthcare providers promote better engagement with support resources to ensure caregiver health and well-being.

Available literature on informal caregivers of patients with dementia clearly articulate the consequences of long-term caregiving, establishing a compelling need for programs that provide supplementary support to this population outside of emergency and routine healthcare visits. In fact, recent work has demonstrated that caregivers of patients with cognitive disorders are better able to manage the daily stressors of caregiving if provided with appropriate educational materials, training, and support (Mittelman et al., 1995; Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). Healthcare providers and other related staff, therefore, can appropriately address caregiver burden through interventions and support groups tailored to the unique needs of caregiver sub-populations (e.g., caregivers of patients with Alzheimer's disease) when these resources are appropriately implemented and evaluated (Samia, Hepburn, & Nichols, 2012). It is critical for healthcare organizations to rigorously assess the perceived benefits of and identified gaps in current caregiver support resources to ensure that informal caregivers are able to continue providing support to patients with dementia while maintaining appropriate quality of life. In the process of evaluating these programs, it is also essential to include the perspectives and opinions of caregiver consumers of these resources to afford this population the opportunity to provide input about the types of support most needed to sustain their work.

The Department of Veterans Affairs (VA) has lately placed a particular emphasis on caregiver support programs, recognizing the intrinsic value of informal caregivers for maintaining patient well-being. One location where caregiver support programs are being assessed and expanded upon is the Atlanta Veterans Affairs Medical Center (VAMC) in Georgia. The Cognitive Disorders Specialty Care Education Center of Excellence (SCE COE) at the Atlanta VAMC administers care to Veterans with various neurodegenerative conditions, and, as such, COE staff often interface with informal caregivers. Recognizing the critical role these caregivers play in the success of patients, the Cognitive Disorders SCE COE has endeavored to implement a suite of support resources for caregivers who attend office appointments with Veterans. At present, the Cognitive Disorders SCE COE offers caregivers appointments with staff social workers, referrals to caregiver resources, and evidence-based interventions, like the

Savvy Caregiver Program, which provide individuals with the knowledge and skills to navigate support for long-term cognitive impairment (Samia et al., 2012). Most recently, the Cognitive Disorders SCE COE has launched a tele-health caregiver support group ("Tele-Savvy") that provides sessions of the Savvy Caregiver program remotely through tablet technology. Given the varied selection of caregiver programming available through the Cognitive Disorders SCE COE, it is useful to explore caregiver perceptions and opinions of these resources to evaluate overall program effectiveness using qualitative methods that capture the unique perspectives of caregivers who have participated in these resources.

Using the Transactional Model of Stress and Coping as a framework, this project sought to evaluate the utility of caregiver support resources currently available through the Cognitive Disorders SCE COE at the Atlanta VAMC. The Transactional Model of Stress and Coping is a well-established behavioral theory developed by Lazarus & Folkman (1987) that assesses how individuals respond to unique stressors in their immediate environment, the coping efforts individuals use to manage these stressors, and the outcomes (e.g., health behaviors, physical well-being) that directly arise from coping. Multiple studies have employed similar stress theories to examine how to best improve caregiver well-being in response to challenging care circumstances, emphasizing the importance of understanding the nuanced relationships among stressors, emotional responses, coping strategies, and health outcomes in caregiver populations (Haley, Levine, Brown, & Bartolucci, 1987; Kneebone & Martin, 2003). The Transactional Model of Stress and Coping and its established constructs were used as a guide when developing interview questions that explored the experiences of caregivers who attend the Cognitive Disorders SCE COE, examined their perceptions of Cognitive Disorders SCE COE caregiver support resources, and identified any gaps in current resources that should be addressed (Lazarus & Folkman, 1987).

The primary evaluation question examined by this quality improvement project is: how do caregivers who provide direct support to Cognitive Disorders SCE COE patients with dementia describe their experiences with the Atlanta VAMC caregiver support resources? Secondary questions explored by this project include: what coping efforts do these caregivers currently employ to manage daily stressors and what additional resources would allow these caregivers to continue to function in their supportive capacity without endangering their own health? The objectives of this project were as follows: (1) to evaluate the effectiveness of current Cognitive Disorders SCE COE caregiver support resources and resource referrals; (2) to identify any gaps in current Cognitive Disorders SCE COE caregiver support resources that would improve caregiver experiences with COE resources as well as COE operations overall; and (3) to explore current coping strategies of caregivers of Veterans who attend the Cognitive Disorders SCE COE. The Cognitive Disorders SCE COE will use data from this project to improve resources for and better administer to the needs of primary caregivers of their patients. Specifically, evaluation findings will highlight any caregiver unmet needs that the Cognitive Disorders SCE COE may want to consider in future iterations of the caregiver support services.

Literature Review

Role of the Informal Caregiver

An informal caregiver functions as a primary support provider to patients with long-term health needs outside of clinical appointments and hospital stays with no formal compensation (*Caregiving in the U.S.*, 2015). In response to an aging population in the U.S., informal caregiving has emerged as an important care mechanism in the national health system, especially for patients diagnosed with neurodegenerative conditions that require years of medical and social support (*2016 Alzheimer's Disease Facts and Figures*, 2016). It is estimated that 34.2 million Americans have provided informal care to a care recipient aged 50 or older in the past twelve months, with unpaid family members or other informal caregivers managing about 90% of residential long term care (Adelman et al., 2014; *Caregiving in the U.S.*, 2015). The relationship between the caregiver and care recipient varies—some caregivers are spouses or partners while others are daughters, nephews, or friends. Depending upon individual circumstances, caregiving responsibilities may be shared among a group of individuals or managed exclusively by a single primary caregiver.

A recent report entitled "Caregiving in the U.S." and generated by the National Alliance for Caregiving and the American Association for Retired Persons (AARP) offers a comprehensive national assessment of caregiver populations. The report found that, on average, informal caregivers provided 24.4 hours of care per week, though 23% of caregivers provided greater than 40 hours of care per week. For spouses, caregiving was often more time-intensive and averaged 44.6 hours per week (*Caregiving in the U.S.*, 2015). The length of caregiving may span years or even decades depending upon the patient's diagnosis, with 24% of surveyed caregivers having provided five or more years of care (*Caregiving in the U.S.*, 2015). Long-term caregiving was found to be especially likely among patients with dementia, since these individuals face years of neurocognitive decline. Among all informal caregivers in the U.S., 26% provided care to patients with memory loss conditions (e.g., dementia) and 21% provided care to patients with Alzheimer's disease (AD), the most common form of dementia (*Caregiving in the U.S.*, 2015).

In general, informal dementia caregivers provide basic assistance with the activities of daily living (ADLs), like eating and bathing, as well as the instrumental activities of daily living (IADLs), which include transportation and grocery shopping (Hurd et al., 2015). These caregivers also offer medical assistance in the form of medication adherence, office appointment scheduling, transportation to appointments, and sometimes treatment decision-making (*Caregiving in the U.S.*, 2015). Depending upon the caregiver-care recipient dyad, the caregiving role may also include emotional support and other coping assistance. The 2015 National Alliance for Caregiving report found that 57% of informal caregivers are also completing tasks that are more often performed by registered nurses and other skilled healthcare staff, including injections and catheter care. It is important to note that most informal caregivers are untrained, particularly in complex medical tasks (*Caregiving in the U.S.*, 2015).

Caregiver Burden

While engaging in such a critical, time-intensive role, it is hardly surprising that informal caregivers often experience physical, emotional, financial, and other strains. For caregivers providing higher-hour, long-term care, like those supporting patients with dementia, these pressures can be even more debilitating. Indeed, as many as 50% of informal caregivers for patients with AD reported feeling emotional stress in response to caregiving (*Caregiving in the U.S.*, 2015).

Caregiver burden has emerged as a major, and often under-acknowledged, health concern, particularly among older populations. Caregiver burden has been refined by many researchers into a multi-dimensional construct, measuring the unique elements that negatively influence caregiver health and well-being (Adelman et al., 2014; Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014; Etters, Goodall, & Harrison, 2008). Perhaps the most comprehensive definition is found in the work of Zarit and colleagues who developed a well-validated Caregiver Burden Scale. Zarit, Todd, and Zarit (1986) classify caregiver burden as "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning" (p. 261). With this definition in mind, it is important to note that caregiver burden manifests differently in individuals, with some caregivers experiencing mild emotional stress while others contend with physical disabilities related to their role and duties (Zarit, Todd, & Zarit, 1986).

Persons at Risk of Caregiver Burden

Much of the last decade of research on informal dementia caregivers has enumerated a number of sub-groups at higher risk of caregiver burden. Certain demographics are more likely to experience caregiver burden when compared with the general caregiver population, specifically, individuals who are of advanced age (Richardson, Lee, Berg-Weger, & Grossberg, 2013), are female (Brodaty et al., 2014; Moon et al., 2016), have a lower educational background (Hughes et al., 2014; Moon et al., 2016; Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006), are of low socioeconomic status (or experience financial stress) (Moon et al., 2016), and/or who reside with the care recipient (Adelman et al., 2014; Kasper et al., 2015). Expectedly, individuals who provide care over longer hours for greater durations of time or who manage complex care needs are also at increased risk of caregiver burden (Kasper et al., 2015). Complex care needs may include medical comorbidities, moderate to severe cognitive impairment, behavioral problems, ADL impairment, and/or decreased mobility (*Caregiving in the U.S.*, 2015; Richardson et al., 2013).

Social isolation has emerged as a risk factor, with research demonstrating that individuals who experience little contact with others or have perceived low social support are at greater risk of experiencing caregiver burden (Hughes et al., 2014; Mitrani et al., 2006). As such, informal caregivers who have limited to no emotional, practical, or guiding support from family members and friends are more likely to be burdened by their role. When caregiving is divided among more than one individual (e.g., among various family members), tensions may arise when sensitive care decisions must be made, endangering critical support networks (Lilly, Robinson, Holtzman, & Bottorff, 2012; Mitrani et al., 2006; Unson, Flynn, Glendon, Haymes, & Sancho, 2015). With increased environmental stressors, like poor perceived social support, caregivers may experience decreased quality of life, which similarly increases the risk of caregiver burden (Takai et al.).

The relationship to the care recipient is also influential—caregivers who report poor relationships to the care recipient are more likely than others to experience strain related to caregiving (Hughes et al., 2014). Similarly, caregivers who report little or no choice in assuming the role of caregiver are also more likely to experience burden (Unson et al., 2015). For caregivers who have a close relationship with the recipient, the visible decline in function of a patient is often emotionally taxing, contributing to psychological strain (Fauth et al., 2012; Unson et al., 2015).

Caregivers who report a perceived lack of information related to caregiving and their role may also be at increased risk of caregiver burden (Lilly et al., 2012). “Care transitions,” during which a patient is transferred from the home to a long-term care facility or from the hospital to the home, are periods of acute stress for caregivers, especially those with limited to no information about how to properly engage in patient transfers (Adelman et al., 2014). Caregiver burden is intrinsically linked to individual self-efficacy, such that caregivers with low self-efficacy for performing the various tasks ascribed to their role are at increased risk of experiencing strain (Etters et al., 2008). Not surprisingly, individual self-efficacy for performing caregiver tasks is often targeted in programs as an effective way to improve caregiver well-being (George & Steffen, 2014; Samia et al., 2012).

Negative Health Outcomes Associated with Caregiver Burden

Informal caregiving is associated with a number of negative health outcomes, particularly if the caregiver dedicates a significant amount of time to providing support to the care recipient and has not engaged in formal caregiver training. Dementia caregiving tasks may be especially challenging for informal caregivers since the care recipient is less able to assist with his or her care schedule over time as the disease progresses (Adelman et al., 2014; de Vugt & Verhey, 2013). Even more, since many patients have other multi-morbid chronic conditions in addition to dementia, caregivers must often manage multiple complex treatment regimens (Poblador-Plou et al., 2014; Zhu et al., 2015).

Due, in part, to strenuous aspects of routine caregiving, such as assistance with ADLs and IADLs, caregivers may experience a number of physical health complications (Schulz & Sherwood, 2008). Most studies address the physical toll of caregiver burden by assessing caregiver maintenance of health behaviors, including physical activity, nutrition, and sleep patterns (Hoffman & Zucker, 2016; McCurry, Logsdon, Teri, & Vitiello, 2007; Schulz & Sherwood, 2008). With the extensive amount of time required for caregiving responsibilities, caregivers may perceive that certain health behaviors are too time-intensive (Lilly et al., 2012). These individuals are also more likely to experience disrupted sleep patterns, particularly in response to the haphazard nighttime routines of care recipients (McCurry et al., 2007). Though caregivers may attend all health appointments with their care recipient, these individuals are significantly less likely to schedule and attend their own health appointments and monitor their own treatment schedules, which may lead to unaddressed health concerns that could worsen over time (Wolff et al., 2016). Perhaps as a coping mechanism, caregivers are also more likely to report increased substance use, particularly of alcohol and prescription drugs (Hoffman & Zucker, 2016). Together, these unhealthy behaviors may lead to caregiver development of chronic health conditions that increase emergency room visits and hospitalizations (Zhu et al., 2015). Though other physical health complications may arise as a direct result of caregiving, very few studies have addressed the physical health impacts of caregiving among informal dementia caregivers.

In response to the challenges of providing intensive support indefinitely, informal caregivers may experience depression or other psychiatric complications (Vaingankar et al., 2016). Some extreme cases of caregiver burden are associated with suicidal ideation, with one study finding that family caregivers of patients with dementia demonstrated higher rates of suicidal ideation (approximately 16% of the sample), especially when coupled with symptoms of depression and fewer perceived reasons for living (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016). Caregivers are also prone to experiencing feelings of social isolation and loneliness since large portions of their time are consumed by caregiving, limiting or precluding outside social interactions (Richardson et al., 2013). Caregiver burden is generally associated with chronic stress in dementia caregivers, which can trigger prolonged high cortisol levels (Richardson et al., 2013). High cortisol, a common response to stress, is associated with a number of negative physical health outcomes, including impaired cognitive function, obesity, hyperinsulinemia, and inflammation (von Kanel et al., 2012).

Caregiver burden may also result in poorer health outcomes for care recipients as caregivers contend with escalating "burnout" (Lilly et al., 2012; Unson et al., 2015). Caregiver burnout may prevent dementia caregivers from being able to provide adequate support to the care recipient, sometimes culminating in earlier care facility placement (instead of remaining at home) (Lilly et al., 2012). As such, the consequences of caregiver burden extend to both the caregiver and the care recipient, resulting in poor health outcomes for both members of the dyad.

Caregiver burden may ultimately impact the quality of the caregiver-care recipient dyad, with some caregivers reporting reduced relationship quality (Unson et al., 2015). Some studies have found that caregivers feel trapped in their role or overwhelmed by responsibilities associated with caregiving (Moon et al., 2016; Unson et al., 2015).

Caregiving for dementia patients, in general, may result in a number of financial consequences, especially since the care recipient requires long-term medical assistance along with informal caregiving and often spends the final years of cognitive decline in assisted living or other care facilities (*2016 Alzheimer's Disease Facts and Figures*, 2016; Lilly et al., 2012). Further, in the midst of complex caregiving responsibilities, caregivers are more likely to report difficulties managing employment responsibilities as well as unexpected absences from work, negatively affecting job performance overall (Hoffman & Zucker, 2016). When caregiving tasks become more intensive towards the later stages of dementia, caregivers must often quit their jobs or retire (Wolff et al., 2016).

Caregiver Coping Strategies

To manage the consequences associated with providing daily support to an individual with dementia, caregivers may engage in personal coping strategies aimed at reducing the effects of caregiver burden. One study found that caregivers of individuals with AD and frontotemporal dementia were most likely to use active coping strategies (e.g., positive thinking) to manage the strains of caregiving, with passive coping strategies contributing to increased burden and lower quality of life (Riedijk et al., 2006). Active coping often refers to an individual's ability to employ his or her own resources to mitigate stressors in the environment, while passive coping refers to an individual's perceived inability to manage a stressor, so much so that he or she relies on others to address the situation (Zeidner & Saklofske, 1996).

Other coping strategies of caregivers found through extensive qualitative work were related to self-care, where participants purposefully engaged in exercise, gardening, or other personally enjoyable activities to relieve stress. Interestingly, some caregivers noted the use of problem solving as a coping strategy, viewing the overcoming of daily obstacles as a measure of personal growth (Unson et al., 2015). Support groups were cited as a favored coping strategy in place of professional counseling, and interactions with social workers were found to be especially clarifying for practical matters like Do Not Resuscitate (DNR) forms (Unson et al., 2015). In some cases, caregivers also rely upon spirituality to cope with the burden of caregiving (Kaye & Robinson, 1994; Rathier, Davis, Papandonatos, Grover, & Tremont, 2015). Unfortunately, many caregivers are hesitant to seek out supportive services and often do not request assistance until their situation becomes exacerbated (Unson et al., 2015; Wolff et al., 2016). Though some studies have attempted to understand the specific coping mechanisms used by caregivers to manage the stress of supporting an individual with dementia, more work is needed to clarify strategies that have been successful in alleviating caregiver burden in this population.

VA Support Policies and Services for Caregivers

In response to the unique challenges faced by informal caregivers and previous studies that detail the negative health consequences associated with this role, recent caregiver work has pivoted towards piloting interventions aimed at reducing caregiver burden and improving caregiver well-being overall. The Department of Veterans Affairs (VA), the largest discrete healthcare system in the U.S., services approximately 300,000 Veterans with dementia (*Projections of the Prevalence and Incidence of Dementias Including Alzheimer's Disease for the Total Veteran, Enrolled and Patient Populations Age 65 and Older*, 2013). Informal caregivers of Veterans who receive care from VA care facilities, like the Atlanta Veterans Administration Medical Center (VAMC), are often eligible for a collection of support services, depending upon the status of the Veteran and the location from which care is administered ("Caregivers Program: Department of Veterans Affairs," 2015). The VA has been specifically working towards the expansion of caregiver support services following the implementation of new policy. In May of 2010, former President Barack Obama signed into law the Caregiver and Veterans Omnibus Health Services Act, which mandates that VA establish support programs for caregivers of Veterans ("Caregivers Program: Department of Veterans Affairs," 2015).

The VA defines a “primary caregiver” as an individual who provides support services and who is designated by the Veteran and approved by the VA ("Caregivers Program: Department of Veterans Affairs," 2015). The VA also defines secondary caregivers and general caregivers, with service eligibility contingent upon a caregiver’s specific classification. For the purposes of this quality improvement project, we will focus specifically on primary caregivers who, based upon recent changes in VA policy, qualify for resources catered to both the caregiver and the Veteran. These include: education and training on caring for a Veteran; use of telehealth technologies; counseling; respite care available for at least 30 days per year (or more if deemed clinically appropriate); Veteran-specific instruction and training; beneficiary travel; ongoing technical support; monitoring; a monthly caregiver stipend; and healthcare coverage (if eligible) ("Caregivers Program: Department of Veterans Affairs," 2015). Specific caregiver programs implemented within VA healthcare, however, may come with additionally eligibility requirements.

Current VA Caregiver Programs

Accordingly, research teams and governmental agencies have implemented a number of caregiver support programs and interventions focused primarily on caregivers of Veterans diagnosed with neurodegenerative conditions. These programs have demonstrated marked successes in reducing caregiver burden and improving caregiver emotional and physical well-being while remaining cost-effective (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; D'Souza et al., 2015; Nichols et al., 2011).

One such program is Resources for Enhancing Alzheimer’s Caregivers Health (REACH), a six-month, evidence-based intervention in which 12 individual home-based and telephone sessions and 5 telephone support group sessions are delivered by trained VA staff and cover a range of salient caregiver topics, including: safety, social support, problem behaviors, depression, and individual health (Burns et al., 2003; Nichols et al., 2011). When this program was implemented at a VA Medical Center in Memphis, results demonstrated significant decreases in caregiver burden, depression, impact of depression on daily life, and caregiving frustrations, as well as reductions in troubling dementia-related behaviors. Most importantly, the program was well-received among caregivers, with 96% of participants indicating that the program should continue to be provided to caregivers of Veterans with AD (Nichols et al., 2011).

Another recent program is the Caring for Older Adults and Caregivers at Home (COACH), which uses a care-coordination framework to provide education and support to Veterans and their caregivers, with the ultimate aim of delaying nursing home placement and reducing caregiver stress (D'Souza et al., 2015). Through this program, caregivers of Veterans are provided with counseling and education on dementia and behavioral management strategies. Participants may also attend a monthly caregiver support group. Initial pilot data demonstrated a 38% decrease in caregiver strain (D'Souza et al., 2015).

Other programs aimed at improving care for Veterans with dementia may also provide ancillary services to caregivers. For example, care coordination initiatives, like the Partners in Dementia Care program, have begun to encourage caregiver participation, allowing these individuals to play a greater role in critical medical decisions as well as integrating them into proposed treatment schedules (Bass et al., 2013). The inclusion of family members and other informal caregivers into care coordination models is often key to Veteran health, as it encourages Veteran participation in care and adherence to medication and other forms of treatment (Bass et al., 2013; Judge et al., 2011). Programs such as these demonstrate how caregiver support mechanisms may be added to existing dementia care frameworks in practical and cost-effective manners that ultimately improve patient health outcomes.

Cognitive Disorders SCE COE Caregiver Support Resources

Within the Cognitive Disorders SCE COE at the Atlanta VAMC, staff have implemented the Savvy Caregiver Program, a 5-6 session psychoeducational training for dementia caregivers aimed at preparing caregivers for the challenges of neurocognitive decline (Hepburn, Lewis, Sherman, & Tornatore, 2003). The program seeks to provide caregivers with "the knowledge, skills, and attitudes needed to mediate their stress situation and more effectively carry out the caregiving role" (Hepburn et al., 2003, p. 909). Previous assessments of the program found demonstrated increases in measured caregiver skills, knowledge, and confidence. Like the REACH program, the majority of Savvy Caregiver participants indicated they would recommend the program to others (Hepburn et al., 2003). Recently, three caregiver cohorts have participated in the Savvy Caregiver program facilitated by Cognitive Disorders SCE COE staff at the Atlanta VAMC. Unfortunately, like many other in-person programs for caregivers, consistent attendance was difficult. The Cognitive Disorders SCE COE has also implemented Tele-Savvy, a tablet-based, remote version of the Savvy Caregiver Program, with three additional cohorts of caregivers to specifically address issues of reach.

In addition to the more formal caregiver support programs, the Cognitive Disorders SCE COE employs social workers who meet with caregivers to conduct assessments, provide support and referrals, and offer assistance with practical matters. Other Cognitive Disorders SCE COE providers, like nurses, neurologists, psychiatrists, and gerontologists, also offer informal, ad-hoc support to caregivers during appointments and via telephone calls.

Use of the Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping, developed by Lazarus and Folkman (1987), is a useful framework for exploring how individuals respond to stressors in their environment (Glanz, Rimer, & Viswanath, 2008). Stressors are defined as "demands made by the internal or external environment that upset balance or homeostasis, thus affecting physical and psychological well-being and requiring action to restore balance and equilibrium" (Glanz et al., 2008, p. 211). In the context of caregiving, a stressor could be anything from an aggressive outburst by the care recipient to an unpleasant conversation with a provider or an expensive medical bill. The model posits that individual responses to stressors are unique and may either encourage or impede healthy behaviors. As such, stress is conceptualized as an interaction between a person and his or her environment. An individual's appraisal of a stressor mediates the influence of the stressor, with primary appraisals being the perceived threat of the stressor and secondary appraisals being the individual's unique abilities to control the stressor (through internal and external mechanisms). Self-efficacy is included as an element of secondary appraisals (Glanz et al., 2008).

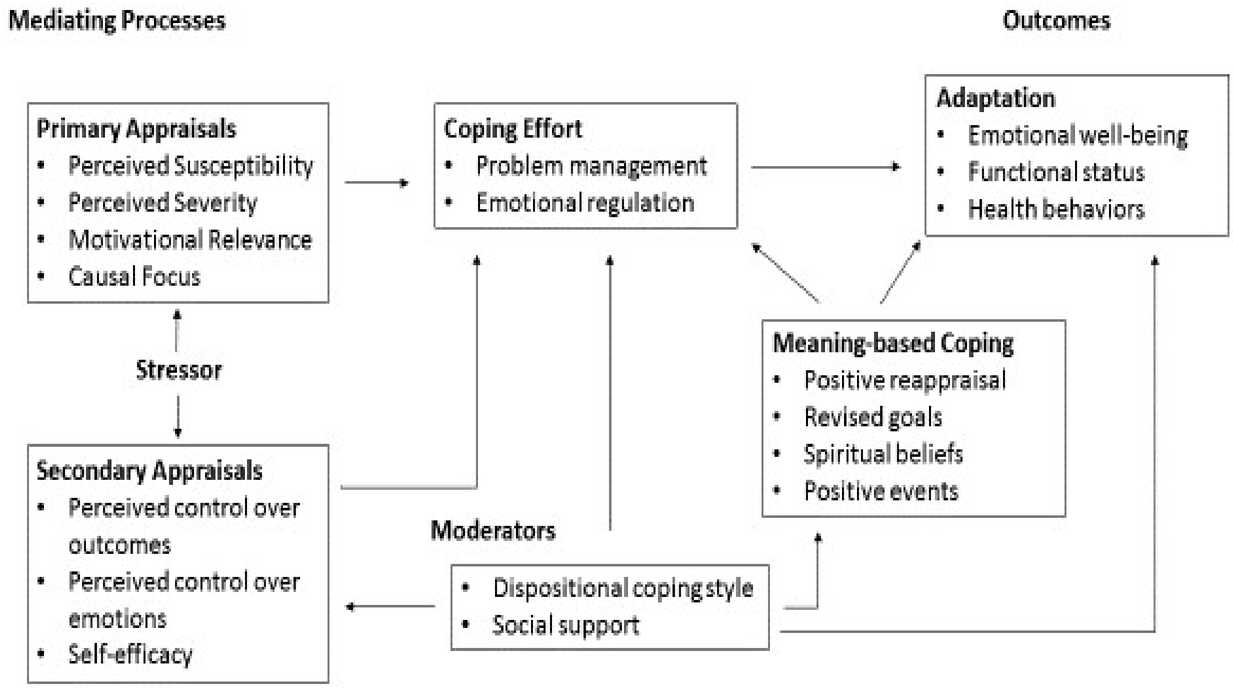

Figure 1. Transactional Model of Stress and Coping adapted from (Glanz et al., 2008, p. 216)

In response to primary and secondary appraisals, individuals may employ coping efforts as strategies to manage stressors. To examine the success of these coping efforts, the theory also measures outcomes of coping, including emotional and physical well-being (Glanz et al., 2008). As a later addendum to the theory, and in acknowledgement of how essential external support may be in mitigating stress and facilitating coping, the model also adopted social support as a construct (Glanz et al., 2008). When using the model as a guide for evaluating interventions, the effectiveness of programs focused on coping efforts may be determined by observing participant outcomes of coping. From further analyzing the relationships between and among the constructs of the Transactional Model of Stress and Coping, the project endeavored to better understand the specific experiences of caregivers taking part in Cognitive Disorders SCE COE caregiver programs of the Atlanta VAMC, to assess the effectiveness of these caregiver support programs in augmenting caregiver coping efforts and improving caregiver well-being, and to identify any limitations of these caregiver support programs that should be addressed in the future.

From interviews grounded in the Transactional Model of Stress and Coping, this quality improvement project sought to evaluate the effectiveness of current Cognitive Disorders SCE COE caregiver support resources and resource referrals; to identify any gaps in current Cognitive Disorders SCE COE caregiver support resources that would improve caregiver experiences with COE resources as well as COE operations overall; and to explore current coping strategies of caregivers of Veterans who attend the Cognitive Disorders SCE COE. Findings from this evaluation will be used to modify and expand current caregiver support resources at the Cognitive Disorders SCE COE. By rigorously evaluating caregiver support resources, the Cognitive Disorders SCE COE hopes to better serve informal caregivers who provide critical support to patients, reducing caregiver burden while improving caregiver well-being.

Methods

A qualitative quality improvement project, aimed at evaluating the effectiveness of caregiver support programs and resources currently available through the Cognitive Disorders SCE COE at the Atlanta VAMC, was conducted under the supervision of COE leadership, Drs. Anne Tomolo and Corrine Abraham, and other staff. This project was given a non-research determination by the Atlanta VAMC and the Emory University Institutional Review Board. It was thoroughly reviewed and approved by all appropriate VA chains of command and privacy committees to ensure quality and ethical standards prior to any project activities.

Participants

The project used a purposive, non-probability, convenience sampling method to identify caregivers of patients diagnosed with a cognitive disorder who were receiving care from the Cognitive Disorders SCE COE. This recruitment method was appropriate, given the project was targeting a very specific population for which the sampling frame is small. Cognitive Disorders SCE COE staff provided recommendations of eligible participants based upon the following criteria: (1) the individual is significantly involved in the outside care and support of a patient with a diagnosed cognitive disorder who receives care at the Cognitive Disorders SCE COE clinic (i.e., is a primary caregiver); and (2) the individual has participated in one or more of the caregiver support programs and resources offered through the Cognitive Disorders SCE COE. The project did not exclude specific caregiving relationships (e.g., spouse, family member) but did prioritize interviews with primary caregivers. For the purpose of this quality improvement project, Cognitive Disorders SCE COE caregiver programs and resources were identified as the following: the Savvy Caregiver Program, the Tele-Savvy Caregiver Program, caregiver visits/telephone calls with Cognitive Disorders SCE COE social workers and other staff, and VA caregiver resource referrals by Cognitive Disorders SCE COE staff. Previous participation in a COE clinic caregiver support program was verified by the Cognitive Disorders SCE COE nurse and social workers through recall of previous interactions with caregivers and Computerized Patient Record System (CPRS) notes. Cognitive Disorders SCE COE staff generated lists of eligible caregivers who had engaged in the support programs, which functioned as the project sampling frame.

Eligible participants were contacted in-person at the Atlanta VAMC or by phone by the investigator (PI) to determine interest in participating (and by Cognitive Disorders SCE COE staff in a few instances). For both in-person meetings and calls, the PI provided a short description of the project before confirming interest in participation. Most interviews were scheduled over the phone, including interviews that coincided with participants attending Cognitive Disorders SCE COE provider appointments with the Veteran. Immediately prior to the interview, participants were given a more thorough overview of the project to ensure participant comprehension of the project's objectives and goals as well as the project's confidentiality practices before being asked for verbal confirmation of participation. Permission to record responses was obtained prior to all interviews through this verbal consent process and also through participant completion of form #10-3203 "Consent for use of Pictures and/or Voice," which was signed and dated by both participant and interviewer (**see Appendix A**). Participants who agreed to be interviewed over the phone were sent form #10-3203 in the mail. Interviews were scheduled and conducted over the phone once a signed consent form was mailed back to the Cognitive Disorders SCE COE. Most project work, including identification of eligible caregivers, participant consent, and interviews, was conducted at the Atlanta VAMC, while transcription, analysis, and writing were completed at the Rollins School of Public Health at Emory University.

Procedures

Confidentiality Practices. Appropriate confidentiality was maintained throughout the entirety of the project. When identifying participants to be interviewed, the PI made sure to explain the purpose of the project and privacy procedures to participants to ensure participant comprehension of project goals and procedures. Prior to beginning the interview, the PI noted that all participant answers would remain confidential and that all recordings would be destroyed upon project completion. Participants were informed that they were not obligated to participate and that they could end the interview at any time without penalty and their answers would be discarded. The interviewer also noted that participants could choose not to answer any and all of questions posed in the interview. Permission to record interview responses was obtained prior to any interview using verbal consent and a specified VA audio consent form. Participants were assigned a unique identifier that was used throughout the project. Other identifying information was removed during the transcription process. All digital data were stored on password-protected computers and kept in locked spaces when not in use. All hard-copy data were also stored in locked spaces at the Atlanta VAMC when not in use.

Interviews. In-depth, semi-structured interviews were conducted by the PI in private rooms in the Neuropsychiatry offices or in other private clinic spaces at the Atlanta VAMC to maintain confidentiality, or by phone if the participant was unable to travel to the clinic within the designated recruitment window. Eleven interviews were conducted between the months of October 2016 and February 2017, and generally lasted 30-45 minutes (with a range of 17-62 minutes). In general, non-participation was due to travel and/or time restrictions. In rare cases, individuals refused to participate due to negative perceptions of the caregiver support programs or because they did not believe the Veteran had a dementia disorder. One consented participant requested the interview be halted for personal reasons and was excluded from analysis. Participants were not provided with incentives for their time.

Recording. The interviewer took brief field notes in a single notebook during the interviews, pending permission from the participants, to record any observations, questions, or comments that further informed collected data. The notebook was kept in a locked space accessible by only the PI when not in use.

All interviews were audio-recorded, with participant consent, using a VA-approved audio recording device and transcribed verbatim by the PI onto a password-protected computer, which was kept in a locked space accessible only by the PI when not on the PI's person. Only project-assigned identifiers were included in the transcripts and any other project-generated documents to maintain participant confidentiality. Any other identifying information from interviews was de-identified during the transcription process. Upon completion of the transcription process (approximately 3 months), the audio files were deleted from the recording device. No copies were made. All other electronic project data were stored on VA and other password-protected computers with access restricted to the PI, the Cognitive Disorders SCE COE clinic Social Work Case Manager, Registered Nurse Care Coordinator, and Directors, and the Rollins School of Public Health Thesis Committee. Other hard-copy data, such as consent forms and participant contact information, were stored in a locked space at the Atlanta VAMC when not on the PI's person.

Participant Support. Upon completing the interview, participants were encouraged to contact the Cognitive Disorders SCE COE clinic social worker to manage any unanticipated emotional responses from participation. Most participants appeared comfortable contacting Cognitive Disorders SCE COE staff with any questions or concerns, but business cards for the social worker were given to participants as needed. Since many participants were enrolled in or had been enrolled in caregiver support programs run by the Cognitive Disorders SCE COE at the time of interviews, these individuals were already in fairly regular contact with staff.

Measures

A standard interview guide, developed by the PI in conjunction with Cognitive Disorders SCE COE leadership, was used for all participant interviews and included questions that were categorized by the following domains of interest: background information, previous/other experiences as a caregiver, caregiver experiences, individual coping strategies, experiences with Cognitive Disorders SCE COE caregiver support resources, and perceived gaps in these caregiver support resources (**see Appendix B**). Questions were informed by constructs in the Transactional Model of Stress and Coping (**Figure 1**) described previously, including: primary appraisals, secondary appraisals, coping efforts (both before and after participation in Cognitive Disorders SCE COE caregiver support resources), outcomes of coping, and social support. The interview guide went through multiple rounds of editing by various project members and experts in qualitative research methods, including: the thesis committee chair, faculty at the Rollins School of Public Health, Cognitive Disorders SCE COE leadership, and graduate students in the Rollins School of Public Health Master of Public Health program. The Cognitive Disorders SCE COE was referred to as the “Cognitive Clinic” during interviews, as this title was well-known among caregivers.

Demographic Data. Demographic data were collected at the beginning of participant interviews. Participants were asked to self-report the following information: age, gender, race/ethnicity, if he/she lived with the Veteran, length of caregiving, and highest level of education obtained.

Interview Guide Data. The interview guide was composed of thirteen questions, each with 3-4 probes. Initial questions specifically focused on relevant background information. Caregivers were asked to describe their relationship to the Veteran to preliminarily define the caregiver-patient dyad, using prompts like: “How long have you known the Veteran?” and “How long have you been providing support/care to the Veteran?” Following this, caregivers were asked to discuss their prior experiences with the Atlanta VAMC, including how often they attend provider appointments with the Veteran as well as how often they otherwise engage with the Atlanta VAMC, to better understand their comfort with VA healthcare structures and resources. Additionally, previous experiences as a caregiver were examined through questions like: “To what extent have you provided caregiver support to another individual(s) with a medical condition and/or disability?” and prompts such as “What types of support did you provide?” Previous and/or concurrent caregiving experience was assessed to determine if this role familiarity functioned as a protective factor for caregiver burden.

Questions also specifically explored routine caregiver experiences. Participants were asked to describe a typical day providing care to the Veteran, including common stressors and demands. Participants were also asked to reflect on any changes in their own health that have occurred since assuming the role of caregiver. These questions were used to examine caregiver emotional and physical responses to caregiving stressors, including health concerns, in an effort to understand primary and secondary appraisals in this population. Present coping efforts were assessed using the following questions: “What types of activities and strategies do you use to manage any changes in your life associated with caregiving?” and “How often do you rely upon other individuals like family and friends to manage the impact of your caregiving role?”

Finally, current Cognitive Disorders SCE COE caregiver support resources were evaluated using questions focused on perceptions of these resources as well as any noted changes in caregiving experiences, self-efficacy, or coping efforts following engagement with a resource(s). Example questions include: “What VA caregiver support resources have you used in the past (e.g., Savvy Caregiver Program, Tele-Savvy)?” with other possible resources included as prompts; “Now, thinking specifically about the time since you started participating in caregiver support resources, how have your experiences as a caregiver been?”; and “In thinking about the time since you started participating in the Cognitive Clinic caregiver support programs, how has your confidence in providing support to [name of the Veteran] been?” Additionally, participants were asked to clarify any gaps they perceived from participation in these resources in an effort to identify areas for improvement. The interview concluded by asking participants if they had any other information that would like to share that had not yet been discussed.

Analysis

Transcripts were imported into and data were analyzed using MAXQDA 12 Base software (VERBI GmbH, Berlin, Germany), a program that the PI had used in the past to analyze qualitative data. Thematic analysis occurred in a concurrent, iterative manner with data collection. This project used a modified Grounded Theory approach, in which the first batch of interviews was used to inform later data collection and analysis strategies (Corbin & Strauss, 1990). Themes that emerged from initial interviews were applied to later interviews and constantly refined with the addition of new data in order to generate meaningful and compelling comparisons among participants and thematic domains. Modifications to the interview guide were made as needed following discussions with the thesis committee chair and Cognitive Disorders SCE COE leadership.

Prior to fully coding the first initial batch of transcripts, the PI read through interviews and recorded initial thoughts. Following an open coding of the initial interviews, a codebook of categories was developed with support from the thesis committee. Intercoder reliability was assessed through a second coder, who read through and coded 20% of the data, and then met and discussed these codes with the PI, refining as necessary until appropriate consensus was reached. The PI then worked to formally define agreed-upon categories and themes in the codebook. The final codebook was applied to the remainder of the transcripts. Coding was then synthesized and compared across all conducted interviews.

Results

Descriptive Results

Data are from a purposive sample of 11 caregivers of Veteran patients with dementia who attended the COE Clinic. Of the 16 caregivers who were asked to participate, four caregivers chose not to participate because of the time commitment (n=2) or because the caregiver did not believe that the care recipient was experiencing symptoms of dementia and, therefore, caregiver support programs were not applicable (n=2). One caregiver consented to be in the interview but then requested that the interview end shortly thereafter.

All eleven caregivers were female spouses of Veteran patients, with an average age of 67 years (SD: 4.56 years; Range: 57-72). Only one participant did not live with the Veteran; instead, the Veteran resided in a Memory Care facility. Caregivers had been providing support to their Veteran for a median length of 6 years (Range: 1.5-24 years). These and other descriptive results may be found in **Table 1.**

Table 1

Descriptive Statistics of Caregiver Participants

Characteristic	
Age	Mean: 67.27 years SD: 4.56 years Range: 57 – 72 years
Female	100% (n=11)
Spouse	100% (n=11)
Race/Ethnicity	
White	63.64% (n=7)
Black/African American	36.36% (n=4)
Level of Education Completed	
Some High School	9.09% (n=1)
High School Graduate	27.27% (n=3)
Some College	36.36% (n=4)
College Graduate	9.09% (n=1)
Advanced Degree	18.18% (n=2)
Length of Caregiving	Median: 6 years Range: 1.5 – 24 years
Live with Veteran	
Yes	90.91% (n=10)
No	9.09% (n=1)

In general, caregivers indicated they were responsible for managing and directing household and hygiene tasks for the Veteran, including: meal preparation, housekeeping, Veteran bathing practices, and Veteran teeth brushing. Participants were also often responsible for managing the Veteran's medical care regimen, which may involve scheduling and attending provider visits, medication management, and enforcing compliance with medical advice. All caregivers noted that they attend all Cognitive Disorders SCE COE appointments with the Veteran, especially if their spouse had middle to late-stage dementia and was no longer permitted to operate a vehicle. Four caregivers also attended other VA "satellite" clinics on a fairly regular basis, mostly for Veteran primary care appointments. At times, caregivers also engaged in simple medical management procedures, like glucose monitoring and incontinence care. Four caregivers described an ever-present responsibility of keeping the Veteran engaged and safe. As one caregiver stated, *"But as you go along on this journey, um, it's a challenge of how to occupy their day so you spend half your time occupying, um, you know, time to—designated time I should say—to keep them busy, um, and staying out of trouble"(P01).* Three other caregivers similarly noted that some of their time went towards ensuring the Veteran remained engaged in activities like gardening or food preparation and in safe spaces where the potential for accidents was minimized.

Nine caregivers described sharing caregiving responsibilities with others. "Shared" caregiving refers to periods of time when the caregiver is not primarily responsible for the safety and well-being of the Veteran and, instead, another individual assumes the role of a temporary caregiver. Commonly, family members like sons, daughters, and siblings assisted with caregiving. Other times, close friends provided additional caregiving support, particularly individuals with whom the caregiver felt comfortable discussing challenges associated with dementia support. Caregivers who did not share caregiving responsibilities with others cited instances when family and friends did not seem to understand the scope of the disease (n=1) or lived too far away to assist with caregiving (n=1). Other caregivers viewed Veteran support as their sole responsibility and, therefore, often refused additional assistance.

Approximately half (n=6) of the caregivers had previous caregiving experience. Three caregivers had supported other individuals with dementia in the past. One caregiver compared her clinical training as a psychologist to career caregiving, explaining, "*No, I'm, I'm a psychologist so I care…I'm caregiver for a lot of people in the past*" *(P07).* Of the caregivers who indicated previous caregiving experience, four regarded these experiences as positive influences, noting how they felt more prepared for the tasks of caregiving and responded with more patience to challenging circumstances.

Caregivers encountered a number of common stressors associated with dementia progression and their supportive role. As dementia patients often manage complex comorbidities, caregivers often faced Veteran health complications that required additional appointments with primary care and specialist providers as well as hospitalizations. Caregivers also contended with disruptions in sleep, exercise, nutrition, and other common health behaviors. As a direct result of caregiving, some caregivers suffered from physical health complications like high blood pressure and mental health complications like chronic stress and depression. Consistently, caregivers noted that the intense time commitment, with most providing 24/7 care to the Veteran, and the corresponding reduction in individual free time contributed significantly to their stress. In response to less free time, one caregiver was forced to retire early and others could only maintain limited responsibility at their place of employment (e.g., work an inconsistent schedule, work from home). Since dementia is associated with increased medical costs and caregiving reduced opportunities for employment, some caregivers acknowledged financial difficulties as a major stressor.

(1) To evaluate the effectiveness of current Cognitive Disorders SCE COE caregiver support resources and resource referrals

The primary objective of this quality improvement project was to evaluate the effectiveness of Cognitive Disorders SCE COE caregiver support resources and resource referrals. The caregiver support resources identified and discussed during qualitative interviews with caregivers included: (1) interactions with COE staff, (2) interactions with COE social workers, (3) interactions with other VA healthcare staff, (4) the Savvy Caregiver program, (5) the Tele-Savvy Program (the virtual, distance-delivered version of Savvy Caregiver), and (6) internal VA and external resource referrals.

Overall, caregivers provided positive opinions of the current caregiver support resources at the Cognitive Disorders SCE COE. One caregiver described available resources as, "*wonderful*" *(P11).* Of the more formal caregiver support programs, one caregiver stated, "*...I was glad they included me in that and it was awesome. The whole course was good. And the people that did attend, was interesting*" *(P01).* Cognitive Disorders SCE COE staff received similarly high praise, with one caregiver stating, "*everybody* [COE staff] *that has been…has been wonderful. They're trying to give us support" (P07).* Those caregivers that specifically interacted with Cognitive Disorders SCE COE providers, nurses, social workers and other staff as a resource (n=8) were pleased with the support that they received.

From caregiver interviews on Cognitive Disorders SCE COE support resources, five major elements emerged as components of effective caregiver support.

Information about Dementia

Caregiver support services that provided comprehensive information about dementia were positively reviewed by participants. For the purposes of this project, information about dementia indicates instances when a caregiver gained knowledge about the disease directly from a COE staff member or caregiver support resource. Provided information included dementia symptoms, progression, management, and treatment options. Most caregivers (n=10) specifically noted the value of dementia information provided by Cognitive Disorders SCE COE resources and how this information may be employed when managing the disease. One caregiver explained:

> *… the class teaches you, you know, to, you know, different stages and levels for dementia and so, um, you could…I was able to see and tell basically what stage he was in, he's in so I know what to expect. So, uh, so I would just, you know, it was something like a health issue other than uh the dementia then I was able to, uh, tell the difference for him so then I…for instance, he's a diabetic, uh, if, if his, uh, you know, sometime his blood sugar go up, you know, he'll get disoriented. So, uh, and then I know with the dementia, most of the time he seems like he's disoriented anyway so, uh, but I know, I knew how to distinguish between the two. (P09)*

Dementia information provided through resources, therefore, improved the ability of the caregiver to administer support to the Veteran. The delivery and specificity of dementia information tended to vary by source. Caregivers who had enrolled in the more formal caregiver support programs (i.e., Savvy Caregiver and Tele-Savvy) were pleased with how the established program curriculum offered a thorough and thoughtful perspective on the disease. Said one caregiver:

> *It had a lot of good information in it. It made me aware of…what stage he was in, you know, and what we've already been through, and what's normal, what's not normal, um. And what to look for as we go on, you know. Um…I think it really helped me. It gave a lot of good advice. Reading materials and all helped. (P03)*

Program materials on dementia provided caregivers with a better understanding of the disease—including the Veteran’s current stage, what is “normal,” and future prognosis—that assisted in tailoring their caregiver routine to the unique symptoms and circumstances of the disease stage.

Additionally, information about dementia also enforced the notion that caregivers have no control over the disease and its progression, reducing feelings of guilt or blame that may exacerbate caregiver burden. One caregiver recalled:

> *So they [staff in the caregiver program] have kind of helped me to know that it’s not my fault that this is happening. It’s nothing I can do about it. It’s nothing that I did wrong. It happens, and we have no control over the disease. And, and we don’t know…it’s, it’s almost like it just sneaks up on you. (P06)*

Thus, knowledge of the disease also prevented caregivers from feeling a sense of inadequacy or responsibility related to the Veteran’s cognitive decline.

Unfortunately, because dementia is characterized by long-term cognitive decline, caregivers of Veterans in the earlier stages of the disease seemed to benefit more from the materials than caregivers of Veterans in the later stages of disease. When asked about her caregiver experiences following participation in Savvy Caregiver, one participant explained:

> *I can’t say they’ve changed a lot. Um, it gives me a way to get a day out—that sounds terrible. Um, but because most of what they’re talking about…I’ve been taking care of VETERAN a long time. I’m toward, more toward the middle to the end of this than I am the beginning. (P05)*

Dementia information provided by the program appeared better suited to new caregivers, with a potential program weakness being the limited provision of information related to the end stages of dementia. The same caregiver further explained that she was compelled to go searching for relevant information on the internet, noting:

> *Researched Alzheimer's on the internet so many times it's not funny. And when you start hearing the things that can happen and how bad it can get, I get petrified, you know? I mean, how am I gonna handle it when he's totally bedridden and I have to figure out a way to diaper him in the bed when he weighs 210 pounds and I weigh 115? (P05)*

Program instruction on dementia, therefore, seemed less constructive for caregivers who are managing late-stage dementia for which care can be more taxing, complicated, and multi-faceted. As such, one caregiver was forced to seek health information from other avenues, like the Internet. For those caregivers of Veterans with late-stage dementia, desired information about the disease was less focused on disease progression and more on palliative and end-of-life measures.

Caregivers also appreciated individual instruction about dementia and dementia care provided by COE staff either during appointments or over the phone. Said one caregiver, "*You know, I can't leave VETERAN to come…it takes three hours round trip to come down here for caregiving, so…I, I do a lot of things. NURSE makes great suggestions for things on the YouTube and I get support that way so…" (P07).* Like the formal caregiver support programs, COE staff offered caregivers useful information about dementia that could be directly applied to their caregiving routine. In contrast to the formal caregiver support programs, which only met at scheduled intervals, staff were often available outside of office appointments to answer dementia-related questions and to provide advice about patient-specific situations, delivering personalized and targeted support to caregivers outside of provider visits.

Social Support

Perceived social support resulting from caregiver group dynamics and from caregiver-provider interactions was an effective element of the Cognitive Disorders SCE COE caregiver support programs. The majority of caregivers who participated in the formal caregiver support programs (n=7) described the emotional benefits of interacting with others who were managing similar caregiving circumstances, noting a shared sense of empathy and encouragement. One caregiver recalled:

> *…that has really helped me a lot, you know, just you can come in, you can sit down, you can talk to them. They know what you're going through. They know, you know, the things that are happening and so it just, you know, I feel like I talk freely and not have to watch what I'm saying or watch how I say it or anything like that so… (P06)*

This collectivism produced by weekly conversations among caregivers, especially in a safe and unbiased environment, meaningfully contributed to the effectiveness of caregiver support resources.

Other caregivers appreciated the opportunity to share and compare experiences as a way to better prepare for their role and to anticipate future challenges. One caregiver explained:

> *Um, they [other caregivers] may have experienced something that I have not done yet. Or my experience may have, you know, if I had shared about it, maybe something they're not going through yet. And it just kind of gives you a, a heads up on what may or may not be coming. Um, you know, what to look for. (P11)*

Through these mechanisms of social support, caregivers are better able to "see what's coming" in terms of disease progression through powerful anecdotes and shared personal experiences.

Another caregiver noted the benefits of personally opening up, recalling, *"And I'm not ashamed of opening up cause I might can help the person next to me. You know? Let 'em know that, you know, when it…my situation little worse than yours or your situation little worse than mine but we still in here together" (P02).* By reflecting on individual challenges, caregivers constructively used their experiences to assist others, facilitating a sense of community and being "in here together." This sense of community is likely critical in the reduction of caregiver burden, since these caregivers noted previous instances where they chose to repress or shield others from the difficulties of dementia support.

Social support was also garnered through interactions with COE staff, when providers would purposefully reach out to caregivers as an informal "check-in." One caregiver noted how a physician called her after an appointment to specifically ask about her well-being, emphasizing, "*that was important because I always feel like no one, they always ask 'how is your husband?' but nobody asks how are you doing?*" *(P04)*. Another caregiver provided a similarly positive review of her interactions with COE staff, relaying:

> *They just give me a lot of support. And NURSE is fantastic. I can pick up the cal…phone and call her whenever, you know, if, if we need something or, um, I don't understand something, um, and she's always there and always got an answer. She even gave me her number for when she was, um, not here one time. (P08)*

Continuous support and a "willingness to help" from COE staff was highlighted repeatedly by caregivers who routinely interacted with providers. Caregivers specifically acknowledged how this strong sense of support from COE staff improved their experiences.

Caregiver Self-Efficacy

Improved caregiver self-efficacy also emerged as an important element of the caregiver support resources. Seven caregivers noted increased self-efficacy, described as feeling more confident and comfortable performing tasks typically ascribed to a caregiver, as a direct result of participation in the Cognitive Disorders SCE COE caregiver support resources. Caregivers recalled moments when they were able to better regulate their emotional responses to Veteran behaviors and caregiving circumstances following participation in the caregiver support programs. When asked about how her caregiving experience has changed following participation in the program, one caregiver explained:

> *Well, I don't feel as overwhelmed. You know, I don't get as anxious as I used to cause now what I try to do is uh first do the things that I know that I can do. If it's something that I know that I can't do, then I don't get overwhelmed about it, you know. I try to find an easier way to get it done. I don't, again, I don't try…I try to handle one stress at a time. I don't try to just let it pile up and then all of a sudden, you know, you just, just….you get so overwhelmed that you just, you just feel the need…it's like you can't…you don't know what to do first and what not to do. (P09)*

Improved caregiver self-efficacy seemed to reduce caregiver burden such that caregivers appeared less overwhelmed by their circumstances and better equipped to address challenges as they arise through strategies like prioritizing tasks. In fact, one caregiver felt confident enough to propose caregiving practices to staff at a memory care facility in an effort to improve her husband's care. She said, "*I feel confident when I go there, cause I, I can make changes still for him even though I'm not 24 hours a day there with him. I'm still able to guide his care*" *(P01).*

Improved self-efficacy, therefore, appeared to enhance caregivers' abilities to manage various stages of caregiving as well, including the Veteran's transition to a long-term care facility.

As with other elements, improved caregiver self-efficacy was more apparent among caregivers who had participated in the formal caregiver support programs in comparison to those who had primarily interacted with COE staff. This finding is expected given that the formal caregiver support programs specifically aim to increase caregiver self-efficacy following the completion of the sessions.

Emphasis on Caregiver Well-being

Another effective component of the Cognitive Disorders SCE COE caregiver support resources was an emphasis on caregiver well-being. During interviews, three caregivers noted the difficulty of prioritizing themselves in the wake of their husband's illness and deteriorating condition. In response to increased demands as a caregiver, participants were likely to neglect their own health and well-being, citing instances of failing to make needed medical appointments, being unable to exercise, and experiencing chronic stress and disrupted sleep patterns. Caregivers noted that support programs encouraged continued self-care (referred to as "caring for the caregiver"), even when faced with difficult caregiver circumstances. An emphasis on caregiver well-being also included the notion that caregivers may struggle to continue supporting the Veteran if they do not prioritize taking care of themselves. One caregiver noted how the program staff improved her sleep behaviors, clarifying:

> *...just the caregiving for the caregiver. Just, just, uh, the information on taking care of yourself, you yourself, you know. Um, 'cause you yourself have to be good to be able to*

> *take care of him, you know? You really do. Which, yeah it's hard to do, but this course really, really zeros in on you taking care of yourself. (P01)*

Interestingly, when caregivers in the support programs were encouraged to focus on their own well-being, it sometimes resulted in sustained behavioral changes, like better sleep management.

An emphasis on caregiver well-being also prompted two caregivers to seek greater external support from loved ones, something that was previously avoided. One caregiver recalled, after participating in a support resource, *"…just trying to get the support system group going and, uh, not being so prideful when I do need help, to ask for help, instead of…trying to do everything myself"(P03).* While primary caregivers tend to manage the larger components of support provision for Veterans with dementia, external support from family, friends, and others in their social network can be integral to maintaining effective caregiver support and reducing caregiver burden.

Altogether, this emphasis on caregiver well-being encouraged caregivers to focus on themselves in discussions with COE staff and other caregivers, rather than on their spouse. One caregiver explained, *"Uh, I think that, that's been another really huge help 'cause now there are a lot of times I'll…instead of talking about VETERAN, I'll talk about me. And they said, no that's what we want" (P06).* This realization that discussing the caregiver's own struggles related to dementia, rather than only the Veteran's condition, is acceptable suggested an interesting tension. Caregivers may routinely default to considering the Veteran's health issues over their own, further neglecting their well-being.

Application of Behavioral Change

Caregivers provided examples of how advice and guidance from staff provided during formal caregiver programs or from other more informal support resources led to substantive behavioral change. Some caregivers described moments when they would consciously alter their behavior to reflect information gained from the Cognitive Disorders SCE COE and its support services, acknowledging popular guidance from modules like “Don’t just do something, stand there.” Said one caregiver who participated in Savvy Caregiver:

> *I had never thought about the fact that, that keeping them engaged, that is better for them. It keeps ‘em busy. And so I have really worked on, you know, trying to keep him engaged in what I’m doing. ‘Cause he’ll get up and he’ll say, you know, what’s the plan for the day? And I’ll say well I need you in the house and this is what I need. So we start off, you know, I can’t give him a whole list. ... I start (Laughs) I start off with one thing, I said now do this and when you get that done come back and I’ll give you something else to do. I had really never thought about, you know, keeping a person engaged. Uh, and doing things at home so…um, and it has also given me a chance to kind of let my hair down around people that understand what I’m going through. (P06)*

About half of the caregivers (n=6) acknowledged how the support resources and proposed behavioral changes assisted them in feeling more capable and patient when providing support to the Veteran. In response to dementia symptoms, one caregiver noted how she altered her reaction: *“And like he…you know like they…sometime like you leave and they follow you and you be in the kitchen and they…’whatever,’ you just relax. It’s, it’s the disease, it’s not him” (P10).* This statement also demonstrated how behavioral change and knowledge of dementia are closely linked, such that improved knowledge of dementia—in this instance, understanding "it's the disease and not him"—coupled with suggestions for behavioral change led to improved caregiver well-being. Another caregiver adopted meditation into her nightly routine after being encouraged to do so during the Savvy Caregiver sessions. She explained, "*A lot…I learned from the Savvy program that uh you need to meditate so uh some after… some nights before I….after I have my bath I'll go ahead and do the meditation" (P09).* From participation in support resources, caregivers were able to successfully adopt healthy behavioral practices with the intent to improve their well-being.

It also appeared that caregivers who had participated in the more formal caregiver support programs were more likely to be aware of appropriate behavioral changes in response to dementia and apply these changes in their routines. This result was somewhat expected, given that the Savvy Caregiver and Tele-Savvy programs included modules specifically focused on behavioral change. Caregivers who did not participate in these formal programs may have received less targeted guidance from COE staff and were, therefore, less likely to note instances of specific behavioral change. However, these caregivers did consistently acknowledge that staff provided guidance in response to challenging circumstances.

(2) To identify any gaps in current Cognitive Disorders SCE COE caregiver support resources that would improve caregiver experiences with COE resources as well as clinic operations overall

Additionally, this project endeavored to pinpoint any gaps in current Cognitive Disorders SCE COE support resources that would improve caregiver experiences in the clinic as well as clinic operations overall. Caregivers identified four major perceived gaps in the available caregiver support resources that might be addressed in future clinic initiatives.

Promote a Better Understanding of Dementia Symptoms and Progression

Although caregivers cited information about dementia as one of the facets of the programs they appreciated, some caregivers seemed acutely aware of limitations in their knowledge of dementia, including symptoms and progression, after engaging with support resources. Five caregivers expressed a desire to acquire more advanced information about the disease and/or disease management following discussions with a Cognitive Disorders SCE COE staff member or participation in the caregiver support programs. When asked about gaps in current caregiver support programs, one caregiver reflected on how she would have wanted:

> *…a little bit more detailed information, uh, a little more uh would have been nice if we could have some hands on experience to be…or something to just enhance the…so that we, when we, when we really start, when we have something to do, uh, we know how to get really dive in there and get it done. (P09)*

In particular, caregivers seemed to desire a clearer picture of the disease and its expected progression as a way to better manage their circumstances, since some did not feel as though they understood the true pathology of dementia.

Requests for more information about dementia also indicated challenges with health literacy, as four caregivers appeared to struggle with the terms and processes associated with the Veteran's illness. One caregiver explained how a more complete understanding of the disease and its related terminology would allow her to better anticipate which symptoms and circumstances may manifest:

> *You know, because I want to call it what it is. I don't want to label something it's not. And…so this is where I'm at with it. And…the stages. How…you know I know people can live for years, you know, with this. Um, when they start getting violent, you know, what happens? You know. I know my husband not violent. Not now. I hope he don't get that way. But some people, that's in there because, might be violent, you know. And how you handle situation 'cause that, you answer this lady question over here about her husband violent, you might be answering a question for me when that time come. (P02)*

Of note, too, was a habit of identifying gaps in understanding based upon other caregiver's experiences. For example, one caregiver may relay anecdotes about her spouse's violent tendencies that prompt other caregivers to pursue other facets of dementia knowledge and care that they may not have considered previously. Therefore, group interactions in Cognitive Disorders SCE COE support programs alerted caregivers about additional gaps in dementia knowledge.

Though a challenging topic, caregivers were also interested in end-of-life care, recognizing a need to talk about this topic but acknowledging that they felt somewhat overwhelmed by the prospect of pursing this discussion in great detail. Two caregivers specifically requested information on the final stages of dementia, with one caregiver clarifying:

> *So, you know, tell me anything that I….well when I get to this final stage, you can expect such and such, you know. And what to, what you can do to make it easier on yourself….how you can, uh, continue to get the self-care that you need in order to be able to withstand that last, that final stage. (P09)*

When promoting the inclusion of end-of-life measures in support resources, the other caregiver emphasized, *"I have no choice but to think about it" (P05)*. As such, caregivers, particularly those of Veterans in the advanced stages of the disease, would benefit from information that specifically addresses late-stage dementia.

Tailor Resources to Individual Caregiver Experiences

More than half of the caregivers (n=7) emphasized a desire for support programs that better address individual caregiver needs. Three caregivers specifically discussed unique and challenging behavioral changes in the Veteran that were likely manifesting as a result of his dementia diagnosis and had been alarming or frustrating to them. One woman recalled her husband's obsessive behavior, explaining how she would have appreciated more targeted guidance on how to manage this unique symptom of the disease. She noted:

> *I'm still…I mean, I was hoping it would help me, um, the obsession he has over the video tapes. That was something I would get some more concrete advice but even the doctors now they don't… (Laughs) I mean they don't even really have any concrete things. Just handling it and…I've tried not to…I'm…one thing that I've gotten most out of is just don't take him where they have videos (Laughs) so. But that's hard to do sometimes. (P03)*

These caregivers expressed a desire for the Cognitive Disorders SCE COE support programs and resources to include time to explore Veteran quirks and to problem-solve as a group, especially since other caregivers may have experienced similar difficulties and since some matters, like increased sex drive or dementia-related infidelity, may be too personal to discuss with family.

Offer Practical/Logistical Support

As a facet of navigating the sometimes complex VA health system, six caregivers indicated a need for increased practical and logistical support. Practical and logistical support references external resource linkages, clarification on VA benefits and eligibility, and guidance on practical and legal matters like advanced directives, financial management, and long-term arrangements. One caregiver suggested:

> *Just uh information on medication and how to matriculate the system. That's the main thing. I didn't know anything about military stuff. I…we, we were… I worked always. I never got involved in…we didn't have VA or need it. We had Blue Cross Blue Shield, and now I'm just worried about being able to do it long term. If VETERAN needs uh more physical care than I can give. (P07)*

Caregivers who are not necessarily familiar with the VA prior to diagnosis appeared to be at a particular disadvantage in terms of navigating eligibility. Another caregiver recommended:

> *…a follow-up of things to come, like, as a caregiver, all of a sudden, especially on a woman, um, lot of the roles that you didn't play, your VETERAN usually would do a lot of the financial things, any kind of dealing in stocks, you know things like that. Um, they were in to that. Um, big decision things. If somebody…or even, um, legal stuff is a lot of things I wish they were call in, maybe, an elder attorney to help describe some of the ways that, things that you need to do to make it easier for you, especially if you need to have the patient's signature ahead of time. Before they get to a part where they can't sign things. So, you have legal stuff set up. Or even to tell benefits that the VA could help you get, like that aide and attendance, some of the different things for that. (P01)*

Not all requested information about caregiving was related to dementia. Some caregivers needed more specific instruction on practical tasks associated with caregiving, like the preparation of a Do Not Resuscitate (DNR) order for the Veteran while he is still able to consent. Further, since the sample was entirely composed of women, some caregivers required supplementary guidance on household tasks that traditionally were handled by a male spouse, like paying bills and overseeing stocks.

Improve Course Availability

Caregivers noted two distinct issues with course availability. First, three caregivers would have liked the course to be extended in some fashion, either through advanced modules or by increasing the length of time over which the course is offered. Extending the course, they perceived, would solve some of the other identified gaps, including the addition of advanced information about dementia. One caregiver noted simply, *"...yeah I wish they would offer continuous on to it, you know. Like another phase of it" (P01).* She explained how these additional sessions would allow for more material to be covered. Two other caregivers requested an extension of the program over longer time intervals, with one caregiver describing how it was difficult to keep up with module readings and individual assignments while acting as a caregiver.

Second, one caregiver found it difficult to attend formal caregiver support resources because of when these programs were offered (weekdays during the day), and requested that these programs be held during other times when those who work or are busy might be able to attend. This result was consistent with retention issues encountered by the Cognitive Disorders SCE COE during implementation of the Savvy Caregiver Program. The caregiver, who works full-time, explicitly noted how she was invited to join the Savvy Caregiver program, but, *"I* *don't get home until like 4 or 5 and then, by the time I get here, it wouldn't be, it would be like 6 or 6:30 because of the traffic coming through. So it would have to be evening. Well then, I can't do too much because he…his confusion comes in the evening" (P04).* This explanation of why the caregiver was unable to participate suggests that the more formal caregiver programs are somewhat self-selective, in that only caregivers who are able to coordinate Veteran care, transportation, and their potential work schedule were able to participate.

(3) To explore current coping strategies of primary caregivers of Veterans who attend the Cognitive Disorders SCE COE

The final objective of this quality improvement project was to explore current coping efforts among caregiver participants. A variety of strategies and practices were identified.

Individual Free Time

Ten caregivers emphasized the use of individual free time as a strategy to cope with stress from their role. Individual free time may refer to a number of activities used specifically to distance oneself from the responsibilities of caregiving, including: spending time outside, exercising, shopping, reading, and watching television. Individual free time excludes completing other caregiver responsibilities outside of direct support for the Veteran, like grocery shopping. It was often used to offset the long hours of support required for caregiving. Nine caregivers noted speaking with or spending time with family and friends in their free time as a method of coping with caregiver stressors. One caregiver listed the many activities she participated in while her husband is under the care of others:

> *I have started going—while he goes to the daycare—I go to the gym now, and do work, like I go to Silver Sneakers and they have, have a little thing they do. They do all these*

> *rounds on all these machines, and so I do that and just go shopping and walk around without having to worry about him, looking at tapes and finding, you know, going through dragging him around. Um, sometimes it's just nice to go back home and sit (Laughs). Play with my dog. You know, not have to worry about what, what he's doing, you know? (P03)*

Free time, therefore, encompassed a variety of activities, including reading, going outside, walking, watching TV, or playing with pets, from which the caregiver was able to successfully separate herself from the responsibilities of providing support to the Veteran. Another caregiver described how she spends her free time when relatives are taking care of the Veteran, explaining:

> *I just shut down. I do. I...I just shut down. I just…I just sit down and watch TV. I don't do anything. I do not do…I sit there…'cause I think 'I need this. I need this.' You know, the house is torn upside down. It's a wreck right now. And I...I'll think when they…you know, they come, well I'll say I'll clean it up. But I don't. I just sit there and do nothing. Because I need that time to just chill and just kind of say, okay, take a deep breath and calm down. (P06)*

Individual free time, then, also referenced moments of "doing nothing," when the caregiver was not necessarily engaged in an activity but was still able to take a meaningful break from her role.

Free time may also occur when the caregiver and Veteran are in the home together but the Veteran does not require immediate attention. One caregiver cited how she uses separate spaces in the house to manage caregiver stress. She noted, "*Yeah, I've got a craft room. I can get away and do that, yeah. And I'm still in the house*" *(P08).* In this manner, caregivers decompressed through purposefully imposed "free time" away from the Veteran in the home without having to worry about securing respite or other care services. Similarly, another caregiver described how she used print and other media to relax while at home with the Veteran: "*Something either on, um, you know, on or I go through Facebook or the social networks. Or I'll read something to kind of unwind me. I have favorite shows that I kind of try to, you know, do" (P04).* She finished her statement with the concession, "*But, um, the one thing that I would really, really like to do is exercise,*" *(P04)* noting her inability to participate in physical activity within these parameters. This clarification emphasized limitations to individual free time for caregivers providing long-term support.

External Caregiver Support Groups

About half of the caregivers interviewed (n=6) were either involved in or pursuing external support group opportunities (i.e., opportunities not offered through the Atlanta VAMC) for dementia caregivers. Many of these support groups were facilitated by places of worship. Two of the caregivers attended more than one external support group, explaining how each of the support groups offered unique dynamics and guidance. One caregiver described the different group dynamics between the two caregiver support groups she attended, noting, "*...I go to once a month, um, at a Baptist church out on LOCATION and, uh, that one's a smaller group. There's like 4-5 people there and it's more, more staged, where it's, um, you can talk as long as you want, you know, whatever. It's more personal, that one*" *(P01).* For another, she explained:

> *The one on Tuesdays is set up to where everybody sits in a circle with a microphone and anything that you really say in there kind of stays in there and people let loose. I mean, on their stress. Sometimes you hear crying, sometimes cursing. They say what's on their mind. What their loved ones are doing, the craziness going on. And it's real…it's crazy*

> *sometimes. But they…and it's….and there's so many people so you'll only get maybe five minutes to say what's going on in that week with you. They like to hear about the stress that you're having. (P01)*

Different groups provided caregivers with disparate yet effective types of support that, together, addressed stressors and burdens as a caregiver**,** showing how certain support group structures fit specific caregiver needs (e.g., smaller versus larger groups). External caregiver support groups also facilitated dementia resource referrals, where members exchanged knowledge about existing services for caregivers, including VA benefits.

Respite Programs

Two caregivers also noted the use of respite programs to manage caregiving tasks. Respite programs were primarily used by caregivers to complete household and other caregiver tasks, like grocery shopping, and to have individual free time. One caregiver used respite services offered through her place of worship. This caregiver also relied upon respite programs to attend the Cognitive Disorders SCE COE support resources, like Savvy Caregiver, highlighting a potential limitation of these support programs. The need to secure respite care for the Veteran may prevent some individuals from participating in caregiver support resources, particularly those programs that include in-person meetings at VA facilities like the Atlanta VAMC.

Other Coping Mechanisms

Additional caregiver coping mechanisms included spirituality. One caregiver relied upon religious beliefs and practices to manage caregiver stressors and burdens. She likened the use of spirituality as a coping mechanism to remaining, *"prayed up" (P02).* Three caregivers described maintaining control of situations as a method of coping. Through strategies like planning ahead (e.g., preparing for a trip to the grocery store) or being less reactive, caregivers were able to better manage challenges associated with caregiving. These caregivers emphasized the benefits of maintaining control by remaining calm and focused to avoid the exacerbation of dementia stressors. This coping strategy, therefore, involved stabilizing their own emotions, so as to not upset the Veteran, or walking away from a situation.

Discussion

The Cognitive Disorders SCE COE at the Atlanta VAMC has made a concerted effort to ensure that caregivers of Veteran patients are receiving appropriate support for their role. A focus on caregiver well-being is a unique and innovative public health approach, especially given that caregivers are not patients of the Cognitive Disorders SCE COE and their health, therefore, is not a direct COE responsibility. It is important for the Cognitive Disorders SCE COE and the Atlanta VAMC to have a clear understanding of the utility of these caregiver support services, particularly since staff, time, and resources are being devoted to these efforts in place of others. Data on program effectiveness is critical when considering how best to modify and sustain these initiatives in the future.

Many of the stressors and consequences mentioned by caregivers corresponded to data on caregiver burden from larger samples and population-based dementia caregiver surveillance (*Caregiving in the U.S.*, 2015). Findings also align with constructs and construct relationships proposed in the Transactional Model of Stress and Coping (Glanz et al., 2008). Caregivers acknowledged a number of stressors in their external environment that impacted their well-being and often necessitated action. Dementia knowledge gained from the support resources appeared to inform primary and secondary appraisals, where caregivers leveraged their evolving understanding of dementia to evaluate the magnitude and controllability of circumstances that arise specifically as a result of the Veteran's diagnosis. Consistent with the conceptualization of secondary appraisals, caregivers were able to use particular information about dementia to understand which stressors fall within their control and to then respond accordingly. Caregiver support strategies aimed at boosting caregiver self-efficacy, an element of secondary appraisals, also appeared to positively influence coping efforts in that caregivers felt more comfortable and confident managing their unique and sometimes challenging circumstances. Findings related to social support are also consistent with the Transactional Model of Stress and Coping as social support played a major role in coping efforts, moderating the ability of individuals to manage common stressors (Glanz et al., 2008). Productive behavioral changes catalyzed by the Cognitive Disorders SCE COE caregiver support resources are related to the construct coping efforts in the Transactional Model of Stress and Coping, as the caregivers adopted certain strategies in response to primary and secondary appraisals of circumstances and experienced positive outcomes as a result. Overall, findings suggest an association between successful coping strategies and positive gains in caregiver well-being, as hypothesized by the theory (Glanz et al., 2008).

This quality improvement project identified several components of the Cognitive Disorders SCE COE caregiver support resources that were effective in addressing caregiver well-being. Caregivers responded well to the dementia information disseminated through the current support resources. This result is consistent with a previous review of caregiver programs that found reductions in caregiver burden and other measures of emotional distress as a result of interventions that focused on providing knowledge of the disease in an interactive format to participants (Pinquart & Sörensen, 2006). Formal caregiver programs like Savvy Caregiver and Tele-Savvy are particularly structured for delivering useful dementia information to caregivers in an interactive and amenable format.

While caregivers acknowledged the benefits of their improved understanding of dementia from the support resources, these individuals consistently requested more "advanced" information about the disease. When determining how to proceed with caregiver support resources in the future, the Cognitive Disorders SCE COE may consider establishing a comprehensive dementia curriculum for caregivers that may be easily applied both in formal caregiver programs as well as in individual settings. An established curriculum would allow the Cognitive Disorders SCE COE to incorporate materials specific to the needs of their caregivers that were identified during these interviews. Materials should address both health and practical matters through modules focused on elements like: a detailed exploration of every stage of the disease (including late-stage dementia); a discussion of end-of-life measures and care; a review of practical caregiver tasks (e.g., safety-proofing a home, making funeral arrangements) and timelines for when these tasks should be completed; and guidance about eligibility for VA benefits. In this manner, the Cognitive Disorders SCE COE would be able to offer requested information on the disease and practical/logistical support through one cohesive mechanism.

It would also be beneficial for the Cognitive Disorders SCE COE to consider alternative methods of delivering this information. Currently, the majority of caregivers seem to obtain information about dementia through individual interactions with COE staff and through formal caregiver education programs like Savvy Caregiver. While the Cognitive Disorders SCE COE is currently in the process of piloting remote-delivery of the Savvy Caregiver program (Tele-Savvy), staff should explore additional strategies to streamline caregiver education, like online modules that may be completed individually, particularly for those caregivers who are unable to attend formal support programs. Past work has demonstrated the effectiveness of internet-based interventions for caregivers of individuals with dementia as an alternative to in-person instruction (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014), especially since this population is often home-bound and managing an erratic schedule. Web-based delivery would also address caregiver concerns about course availability, since individuals would be able to access the materials at their own leisure.

As with any program targeted towards older populations, it is crucial to consider the “digital divide” and the technological self-efficacy of older users who engage in internet-based resources (Hall, Bernhardt, Dodd, & Vollrath, 2015). Using a national sample, one recent study estimated that 47% of individuals over the age of 65 had used email, text, or the Internet in the past month; however, only 15.7% of these individuals had used the Internet to retrieve information about health conditions (Elliot, Mooney, Douthit, & Lynch, 2014). Further, online formats may be challenging for elderly populations of low socio-economic status who are known to be less technologically literate for a number of reasons including limited exposure to computers, with one study finding that only 17% of low-resource, disabled elderly individuals used the Internet (Choi & DiNitto, 2013). Technology-based support strategies may require some form of technical assistance, such as a short in-person or other orientation to the equipment and programs (Hall et al., 2015). For individuals with limited access to technology or low self-efficacy with technological equipment like tablets and computers, it may be necessary to also offer more traditional methods of information dissemination, like booklets and pamphlets of the requested dementia information.

Another important consideration when developing and delivering materials about dementia is health literacy. Indeed, health literacy remains one of the greatest challenges when developing public health educational content for diverse populations, like caregivers, who may differ in demographic characteristics like age and highest level of education obtained (Nutbeam, 2000). Prior research has shown that health literacy is particularly low among elderly populations (Baker, Gazmararian, Sudano, & Patterson, 2000). Other work has shown that advanced health information may also exacerbate caregiver distress if not presented in formats that are accessible to the target population (Proctor, Martin, & Hewison, 2002). Whereas some caregivers interviewed for the project did not experience difficulties mastering the dementia content provided through the Cognitive Disorders SCE COE, other caregivers indicated challenges when reviewing materials on complicated health topics, especially when adhering to the imposed Savvy Caregiver or Tele-Savvy program schedule. In the future, the Cognitive Disorders SCE COE should examine existing dementia materials with a health literacy lens, to ensure that content is accessible for as many caregivers as possible.

Social support also emerged as a beneficial component of available caregiver services. Caregivers appreciated the opportunity to share experiences among individuals managing similar circumstances, citing the value of group dynamics from caregiver support resources offered through the COE. Support group frameworks for caregivers are well-researched, with one meta-analysis finding that support group participants demonstrated marked gains in emotional well-being following membership (Chien et al., 2011). However, the current Cognitive Disorders SCE

COE caregiver support resources are not structured to sustain a long-term support group, since the formal caregiver programs are limited to a certain number of sessions. To promote the continuation of social support and effective group dynamics among caregivers, staff may consider other platforms that do not necessitate the somewhat intensive coordination of an in-person support group. For example, asynchronous and informal online support groups provide a feasible and cost-effective alternative to more traditional in-person formats (McKechnie, Barker, & Stott, 2014). These alternative support group formats, like online groups, also have the potential to be tailored to individual caregiver circumstances, where certain groups or forums may focus on specific experiences associated with caregiving. Recent work has demonstrated significant benefits for dementia caregivers who participate in online support groups and communities (Czaja, Schulz, Perdomo, & Nair, 2014; O'Connor, Arizmendi, & Kaszniak, 2014), including a study on the use of avatars to facilitate the structure of an in-person support group through a web interface (O'Connor et al., 2014).

If these interactive platforms are not possible, the COE should create and maintain a list of caregiver support groups available in Atlanta and throughout Georgia, if one does not already exist, to offer to caregivers who request support services. This list could focus specifically on organizations that facilitate support groups for dementia caregivers in Georgia, like the Alzheimer's Association which provides a list of both in-person and remote support groups ("Support Groups," 2017)

Caregivers also experienced social support through interactions with providers that focused specifically on caregiver well-being. In fact, the Cognitive Disorders SCE COE staff consistently received praise for being attentive to caregiver needs, like assisting in the completion of VA paperwork and in the process of deciding on long-term care arrangements. While staff attention to caregiver support is commendable, the added responsibility of “checking-in” with caregivers of Veteran patients could eventually strain existing COE resources and risk provider “burn-out” (Lamson, Meadors, & Mendenhall, 2014). Future quality improvement efforts should strive to incorporate staff perspectives of caregiver support resources, a useful vantage point when considering program feasibility and sustainability.

An emphasis on caregiver well-being continuously emerged as an effective component of caregiver support programs, especially as a tool to alleviate caregiver burden. Previous work has shown that caregivers are prone to neglecting their own needs in order to ensure the care recipient is receiving continuous and adequate support (Lilly et al., 2012). Findings from this project suggest that an emphasis on caregiver well-being may function as an impetus for behavioral change, with caregivers citing moments when they chose to modify their actions following COE staff guidance to focus on their own well-being—essentially, “caring for the caregiver.” Additional methods to disseminate caregiver well-being strategies should be considered in an effort to promote greater outreach among caregivers of the Cognitive Disorders SCE COE. Information related to self-care may be refined into educational materials that are readily available for caregivers, streamlining the process of support by allowing information to be delivered outside of the scope of formal caregiver programs and extended provider interactions.

Improved caregiver self-efficacy from caregiver support programs was also associated with reductions in caregiver burden and positive gains in caregiver well-being. Self-efficacy is a well-studied concept, and recent work on associations between caregiver self-efficacy and depressive symptoms indicates that self-efficacy should be a target in dementia caregiver interventions to improve emotional well-being (Grano, Lucidi, & Violani, 2017). While the formal caregiver support programs already include improved caregiver self-efficacy as a desired outcome, the Cognitive Disorders SCE COE should consider additional methods to boost self-efficacy among caregivers of Veterans. Since self-efficacy is related to observing individuals successfully complete tasks (Glanz et al., 2008), caregiver self-efficacy may be encouraged through the expansion of social support mechanisms outlined above where caregivers trade information about how to successfully manage their role.

Results identified a number of coping strategies that caregivers currently use to manage any stress associated with their role. Primarily, caregivers used explicit “free time” to disengage from their caregiving role as well as external support groups and respite care. The Cognitive Disorders SCE COE may use these findings on caregiver coping strategies to augment their existing support resources. More specifically, COE staff may incorporate these coping strategies and methods into current caregiver support services and materials.

Any expansion of the Cognitive Disorders SCE COE caregiver support resources would require a critical assessment of which services fall within the purview of the COE and which do not. For example, while some caregivers requested tailoring of the support resources to individual caregiver experiences, these targeted services may not be within the scope of the Cognitive Disorders SCE COE caregiver support program. More than half of the caregivers were aware of or had participated in an external caregiver support resource, highlighting potential avenues for partnerships and resource linkages. Thus, the Cognitive Disorders SCE COE may interface with other VA facilities and external caregiver programs to enhance existing caregiver support resources in a practical manner. Since a number of caregivers indicated that they more frequently used VA satellite clinics for medical care and resources, including caregiver support, the Cognitive Disorders SCE COE should explore how to better coordinate its services with these satellite clinics, allowing for effective resource sharing within the same health system. Long-term, the Cognitive Disorders SCE COE should create a comprehensive resource list for caregivers that includes information on both health (e.g., support groups) and practical resources (e.g., legal counsel). By engaging with other stakeholders in caregiver support, particularly those within the VA system, and maintaining a resource list to provide to caregivers as needed, the Cognitive Disorders SCE COE would eventually establish a standardized and streamlined resource referral process. This process would ideally facilitate caregiver enrollment in other relevant support programs and services, addressing the need for more tailored services. An established resource referral process also would be particularly useful for caregivers who may not know how to access available caregiver resources, since one study found that only 19% of sampled caregivers were aware of how to access community services (Jennings et al., 2015).

Implications

These findings add to an existing body of knowledge that stresses the benefits of supporting dementia caregivers, especially with the current U.S. health system's reliance on informal caregiving. Caregivers provide substantial and intensive services to loved ones, often at the expense of their own well-being. For this reason, it is critical for healthcare settings that regularly interface with caregivers, like the Cognitive Disorders SCE COE, to offer innovative support strategies in an effort to safeguard both caregiver and patient health. Positive results obtained from this quality improvement project justify the continuation of the Cognitive

Disorders SCE COE caregiver support programs in the future. The results also identify effective components of existing Cognitive Disorders SCE COE caregiver support resources that should be preserved and augmented in the future, including the provision of dementia information, caregiver social support, and caregiver self-care guidance. Caregiver-identified gaps in the Cognitive Disorders SCE COE caregiver services indicate areas where the clinic may choose to enhance or expand their programs while ensuring that these services do not overburden existing resources. While these identified gaps are constructive, some suggested improvements may not fall within the desired scope of the Cognitive Disorders SCE COE caregiver support resources. To appropriately address these gaps, the COE should also explore potential partnerships, collaborations, and connections with other caregiver support services and organizations.

When considering the VA in general, these findings demonstrate the importance of caregiver-focused policy in improving health outcomes for Veteran populations. The projected number of individuals over the age of 65 is expected to increase significantly in the next few decades (Vincent & Velkoff, 2010). Since approximately 14% of U.S. adults 70 years or older experience dementia, the prevalence of dementia is expected to rise commensurately in both Veteran and non-Veteran populations (Hurd et al., 2013; Plassman et al., 2007; Prince et al., 2013). Since the number of Veterans diagnosed with dementia is expected to rise proportionately with the general population, the VA will likely rely even more on informal caregiver support in the ensuing decade. As stated above, these results offer support for the continuation of caregiver-focused initiatives within the VA. Thus, long-term, it will be critical for the VA to ensure that caregivers of Veterans with dementia receive appropriate support so that these caregivers, in turn, may continue to effectively care for Veterans.

These evaluation findings suggest that the Cognitive Disorders SCE COE caregiver services may also serve as an example for other VA and external healthcare environments that are interested in implementing effective caregiver support mechanisms. Future work should continue to rigorously evaluate existing support programs to elucidate best practices for caregiver support. Finally, as the findings are also restricted to the perspectives of the caregivers alone, and do not include other key stakeholders, like COE Clinic staff, future work should also explore additional perspectives when considering future iterations of caregiver support services.

Strengths and Limitations

Since the Cognitive Disorders SCE COE used extensive documenting procedures, this quality improvement project capitalized on well-maintained sampling frames of caregivers who had engaged in support services. Staff were instrumental in identifying appropriate caregivers who would provide diverse perspectives on and experiences with support resources, allowing for rich data. As caregiving can be an emotionally-charged topic, particularly as the Veteran's health deteriorates, semi-structured interviews provided caregivers with an appropriate level of privacy to encourage an honest exchange about the support services and the effects these resources had on each caregiver's well-being. The one-on-one interviews also prevented social desirability bias where other caregivers' opinions might have influenced individual responses. Since the PI was not involved in the provision of caregiver support services, pressure on participants for socially desirable responses about program benefits was further reduced. Recall bias was also somewhat reduced, since caregivers had participated in support services in the past few months. Intercoder reliability was used to improve the validity of the findings.

This quality improvement project had a number of limitations. First and foremost, since this project was qualitative and based on a small number of interviews, findings from the evaluation are not generalizable to other caregiver populations or clinic environments outside of the Atlanta VAMC. The themes presented here, therefore, may not be applied more broadly to caregivers in general, although the experiences of this sample did align with existing data on caregiver responsibilities and burden, as noted. Furthermore, qualitative findings are restricted to the perceptions and opinions of the caregivers who were interviewed; however, the purpose of qualitative data is to provide insight, not generalizability.

Despite the efforts to minimize bias described above, since these caregivers and their Veterans rely upon services and benefits administered through the Atlanta VAMC and the VA in general, responses are still at risk of social desirability bias. The findings are also restricted to caregivers who actively engaged in caregiver support resources and who were interested in offering their perspectives on the program—a somewhat self-selected group. At least two caregivers who did not complete the program refused to participate, limiting the range of the results. Future work should seek to gather the perspectives of caregivers who are less actively engaged in these support resources to obtain a more complete understanding of the programs' effectiveness.

Conclusions

The caregiver support resources administered by the Cognitive Disorders SCE COE at the Atlanta VAMC are well regarded among caregivers who use them to better manage the challenges and circumstances that result from providing support to Veterans with dementia. While caregivers noted some important limitations of these programs, in general, the COE clinic caregiver support resources were described as successful in their primary goal of promoting caregiver well-being through mechanisms like increased caregiver understanding of dementia, social support, caregiver self-care, caregiver self-efficacy, and suggested behavioral changes. Findings from this quality improvement project support the continuation and expansion of these resources in the future, as well as demonstrate the clear utility of providing caregiver support resources through VA facilities.

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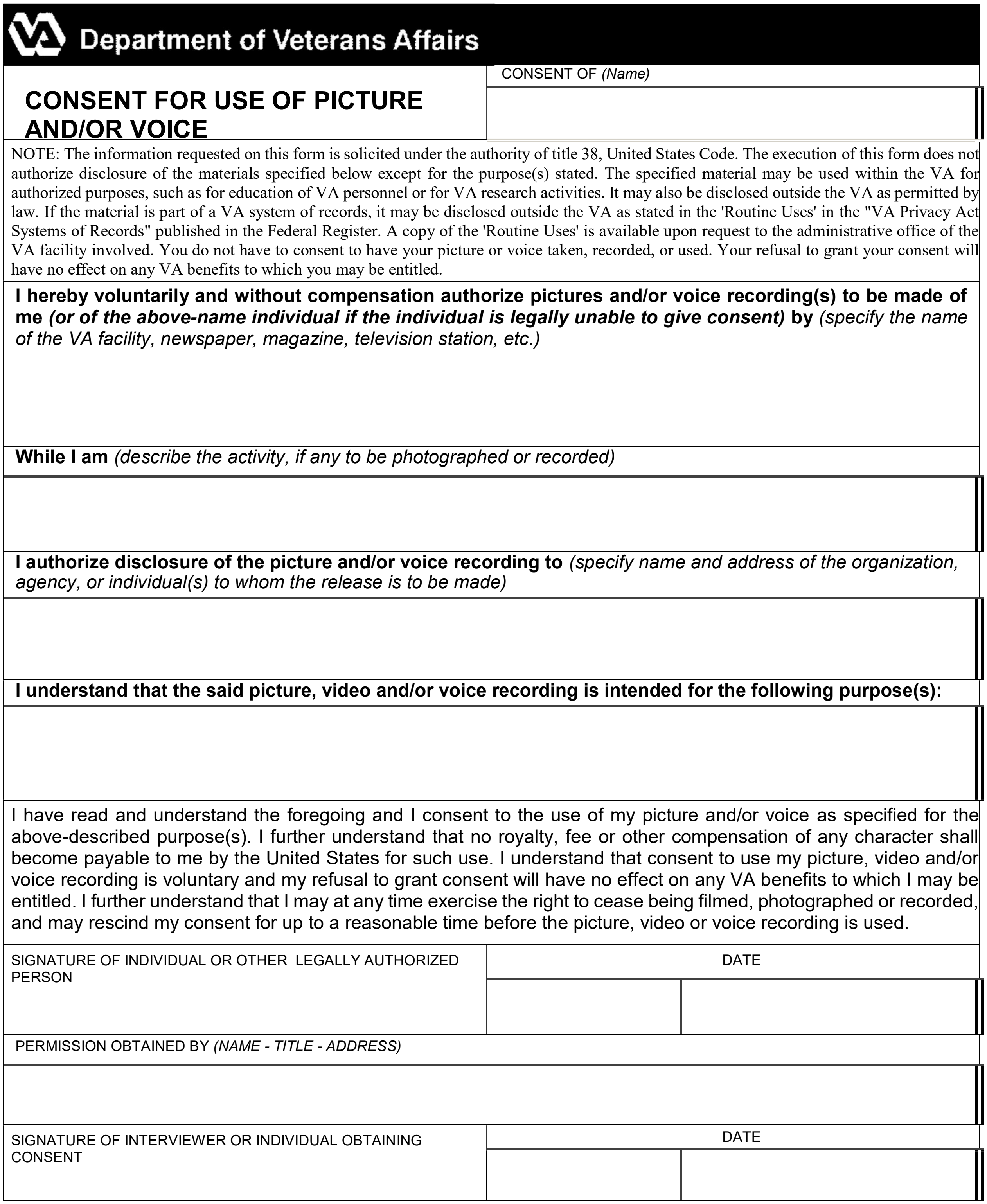
Appendix A. Consent Form



Department of Veterans Affairs

CONSENT FOR USE OF PICTURE AND/OR VOICE	CONSENT OF *(Name)*

NOTE: The information requested on this form is solicited under the authority of title 38, United States Code. The execution of this form does not authorize disclosure of the materials specified below except for the purpose(s) stated. The specified material may be used within the VA for authorized purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as stated in the 'Routine Uses' in the "VA Privacy Act Systems of Records" published in the Federal Register. A copy of the 'Routine Uses' is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.

I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me *(or of the above-name individual if the individual is legally unable to give consent)* by *(specify the name of the VA facility, newspaper, magazine, television station, etc.)*

While I am *(describe the activity, if any to be photographed or recorded)*

I authorize disclosure of the picture and/or voice recording to *(specify name and address of the organization, agency, or individual(s) to whom the release is to be made)*

I understand that the said picture, video and/or voice recording is intended for the following purpose(s):

I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.

SIGNATURE OF INDIVIDUAL OR OTHER LEGALLY AUTHORIZED PERSON	DATE

PERMISSION OBTAINED BY *(NAME - TITLE - ADDRESS)*

SIGNATURE OF INTERVIEWER OR INDIVIDUAL OBTAINING CONSENT	DATE

PRODUCTION TITLE	PRODUCTION NUMBER	
INDIVIDUAL' S NAME AND ADDRESS	IMPORTANT: This form must always be completed prior to the making or using pictures, video or voice recording(s) of any VA patient. If any patient health or demographic information is to be provided or released with the picture, video or voice recording, VA Form 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.	

VA FORM MAY 2005 **10-3203**

Appendix B. Interview Guide

Project Objectives

The purpose of this project is to evaluate the effectiveness of caregiver support resources currently available through the Cognitive Disorders Specialty Care Education Center of Excellence (COE) [**henceforth referred to as the Cognitive Clinic**] at the Atlanta Veterans Affairs Medical Center (VAMC). The objectives of this project are as follows:

- To explore current coping strategies of primary caregivers of Veterans who attend the Cognitive Clinic
- To evaluate the effectiveness of current Cognitive Clinic caregiver support resources and resource referrals
- To identify any gaps in current Cognitive Clinic caregiver support resources that would improve caregiver experiences in the clinic as well as clinic operations overall

Topics

- Current caregiver coping strategies to manage daily stressors of supporting an individual with a diagnosed cognitive disorder at the Cognitive Clinic
- Perceptions of Cognitive Clinic caregiver support resources
- Effectiveness of Cognitive Clinic caregiver support resources in assisting caregivers
- Are there any gaps in available resources?

Interview Guide

To read before beginning each interview to obtain verbal consent:

Hi, (**name of participant**). My name is (**name of interviewer**). I want to take this moment to thank you for agreeing to participate in this interview. We believe your insights are important for better understanding the experiences of caregivers of Veterans who attend the Cognitive Clinic.

This project is being conducted in an effort to evaluate current Cognitive Clinic caregiver support resources. I want to assure you that your answers will remain confidential—only project identifiers will be used in the data, and recordings will be destroyed following transcription. Per the nature of this project, the answers you provide today will be shared only with Cognitive Clinic leadership and Emory University. I anticipate this interview will take approximately 30 minutes total.

If at any time you no longer feel like participating in this interview, you may leave without penalty. Any answers provided will be promptly discarded. I would like to remind you that you are not obligated to participate, nor are you obligated to answer any and all of the questions. If a particular question makes you feel uncomfortable, you may indicate that you do not wish to answer.

Please note that to ensure data accuracy, I would like to record the entire interview using a recording device. To supplement the audio recording, I would also like to take some notes if you do not mind.

For the purposes of this project, I will now request formal verbal consent. Please answer the following questions.

Do you consent to participate in this interview?

CONSENT OBTAINED: ____ Yes ____No

Do you consent to this interview being recorded in its entirety?

CONSENT OBTAINED: ____Yes ____No

Before beginning, do you have any further questions for me?

(After answering any questions, begin interview.)

Interview Questions:

Participant Background Information:

1. How would you describe your relationship to [**name of the Veteran**] receiving care at the Cognitive Clinic?
    - How long have you known [**name of the Veteran**]?
    - How long have you been providing support/care to [**name of the Veteran**]?

    Rationale: Establishing the caregiver's relationship to the Veteran is useful for understanding a particular caregiver-Veteran dyad. This background information will likely inform how involved the caregiver is in providing support to the patient outside of clinic visits.

2. What are your prior experiences with the Cognitive Clinic and the Atlanta VAMC?
    - How often do you attend Cognitive Clinic appointments/other appointments with [**name of the Veteran**] at the Atlanta VAMC?
    - How often do you otherwise engage with the Atlanta VAMC?

    Rationale: Caregivers that are more comfortable operating within the frameworks of the Atlanta VAMC may have a better understanding of available VA resources and how to request support.

Previous/Other Experiences as a Caregiver:

3. To what extent have you provided caregiver support to another individual(s) with a medical condition and/or disability?

- What did you perceive your role was in providing support to this individual(s)?
- What types of support did you provide?
    - i. Emotional?
    - ii. Practical?
    - iii. Financial?
- How do you think this influenced your current role as a caregiver?

Rationale: Previous experiences as a caregiver/providing support may function as a protective factor or may influence how an individual elects to cope with caregiving presently.

Caregiver Experiences:

4. Tell me about a typical day providing care to [**name of the Veteran**].
    - Do you share caregiving responsibilities with others? If so, who?
    - How many hours a day do you spend providing care? How many hours do you have to yourself?
    - Describe some general tasks you perform.
    - Describe some common stressors/demands you encounter.
        - i. Any conflicts with [**name of the Veteran**]?
        - ii. Any conflicts with family members/friends related to caregiving?
        - iii. If none, how do you avoid feeling stressed?

    *Rationale: By having the caregiver describe a "typical" day of caregiving, the interviewer can better understand how involved the caregiver is in the Veteran's health. Additionally, the interviewer may tease out a number of stressors that arise from a typical day of caregiving to inform future caregiving support strategies***.**

5. How was your health prior to taking on the role of caregiver for [**name of Veteran**]?
    - Describe your previous physical and mental health prior to taking on the role of caregiver.
    - Can you describe any changes in physical health? Nutrition? Sleep?
    - Can you describe any changes in mood, energy, or emotional responses?
    - Have family and friends noted any changes in mood and overall health?

    Rationale: By establishing the participant's health status prior to taking on the role of caregiver, the interviewer will have a better understanding of any major health shifts that have likely occurred in response to caregiving responsibilities (addressed in later questions). It is important to establish if caregiving is associated with any changes in physical or psychological health that the caregiver is willing to disclose. By doing so, the Cognitive Clinic may be more aware of typical outcomes and challenges associated with caregiving.

6. How do you think caregiving has contributed to any changes in your health?

- Describe any physical or emotional changes that you think are directly related to caregiving.
- Any increase in health incidents and/or visits to providers?
- In what ways may you have neglected your health since taking on the role of caregiver?
    i. Eating habits?
    ii. Sleep?
    iii. Physical activity?
    iv. Substance abuse?

Rationale: It is important to capture participant perceptions of how caregiving has impacted their overall health. Research has shown that caregivers of individuals with cognitive impairments are prone to neglecting their health and to using more emergency health services.

Individual Coping Strategies:

7. What types of activities and strategies do you use to manage any changes in your life associated with caregiving?
    - How well are you able to personally manage day to day demands?
    - How often do you participate in activities just for yourself?
    - What do you do to take a break or "let off steam"?
        i. Spend time outside?
        ii. Read a book?
        iii. Attend religious services?
        iv. Talk to friends?
        v. Spend time with friends or family without Veteran? (try to get at social isolation)

    Rationale: This question prompts an exploration of current caregiver coping efforts to see how caregivers of Veterans attempt to mitigate the stress of caregiving. Answers will allow the Cognitive Clinic to identify areas for improvement.

8. How often do you rely upon other individuals like family and friends to manage the impact of your caregiving role?
    - Who do you contact for emotional support? How often?
    - Who do you contact for practical/logistical support? How often?

    Rationale: Since research notes that support networks are critical for caregivers, it would be interesting to explore if caregivers at the Cognitive Clinic are engaging with their support networks to cope with caregiving and/or to share responsibilities.

Cognitive Clinic Caregiver Resources:

9. What VA caregiver support resources have you used in the past (i.e.: Savvy Caregiver Program, Tele-Savvy)?

- Any support group participation?
- Any engagement with Cognitive Clinic social workers?
- Any engagement with VA-wide caregiver resources in addition to Cognitive Clinic resources?
- Please describe some of your experiences with these resources. Positive? Negative?
- Describe any referral to community resources. Helpful or not? (trying to get at our connection to non-VA community resources)

Rationale: From this question, the interviewer can assess participant use of COE resources and if use of resources occurred in conjunction with other caregiver support resources offered more broadly through the VA.

10. Now, thinking specifically about the time since you started participating in caregiver support resources, how have your experiences as a caregiver been?
    - Describe any changes in your caregiving experience.
    - Describe any modifications in your behaviors and overall routine.
    - How did your responses to daily caregiver demands change?
    - How did your interactions with [**name of the Veteran**] change?

    Rationale: This question directly address the impact of COE caregiver support programs on caregiving.

11. In thinking about the time since you started participating in the Cognitive clinic caregiver support programs, how has your confidence in providing support to [**name of the Veteran**] been?
    - Has it changed? If so, how has it changed?
    - Tell me about an experience where you felt comfortable using support techniques after participating in a Cognitive Clinic program.
    - How did Cognitive Clinic program influence your comfort with providing support to the Veteran during these experiences?

    Rationale: Caregiver perceptions of self-confidence will assist in determining if COE resources improved caregiver self-efficacy.

Perceived Gaps in Cognitive Clinic Caregiver Resources

12. What are some gaps in current Cognitive Clinic caregiver support resources that should be addressed?
    - Is there anything you have wished was provided that was not?
    - Any experiences with resources that did not address all your caregiver questions?
    - How adequately did these resources address your stress associated with caregiving?

- What are some topics that were not addressed in caregiver support programs that you would have liked to discuss?

Rationale: With this question, caregivers are given an opportunity to evaluate perceived gaps in COE resources, alerting COE staff to elements of programming that may require revision and modification.

Closing the Interview:

13. Is there anything that we have not discussed yet that you would like for me to know?
    Rationale: This question allows the interviewee to provide any other important information about experiences as a caregiver that was not covered in the other interview questions.

(End of the Interview)

Thank you very much for your time. I appreciate all of the insights you have provided regarding your role as a caregiver and your experiences with the Cognitive Clinic caregiver support resources.