

UTILIZATION OF THE SHORT FORM ZARIT BURDEN INTERVIEW TO SCREEN
DEMENTIA CAREGIVERS FOR CAREGIVER BURDEN IN THE CLINIC SETTING

By

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Submitted to the School of Nursing and The Graduate Faculty of the University of Kansas in
partial fulfillment of the requirements for the degree of Doctor of Nursing Practice.

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10 June 2019

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Dementia Caregivers for Caregiver Burden in the Clinic Setting

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Abstract

Informal caregivers of persons with Alzheimer's disease and related dementias (ADRD) are known to have increased caregiver burden. Research has shown caregiver burden places persons with ADRD and their caregivers at increased risk for poor health outcomes. Screening caregivers for increased caregiver burden is essential to identifying caregivers in need of additional support and improving such outcomes. Therefore, the purpose of this project was to conduct a needs assessment to determine if routine screening of informal caregivers of patients with ADRD for caregiver burden would identify increased caregiver burden and the need for intervention at an internal medicine clinic in the upper Midwest. This project utilized the Zarit Burden Interview (ZBI-12) tool to screen informal caregivers over a 6-week period. All caregivers with increased caregiver burden were offered a referral to respite care, counseling, or case management. Results were used to evaluate the need for routine screening for increased caregiver burden. The number of referrals was also evaluated to determine the practicality of the provider in the clinic initiating referrals for additional support services. Of the 22 caregivers screened, 12 (54.5%) were found to have increased caregiver burden. Caregivers with increased caregiver burden were more likely to be female (9, 75%) and college educated (12, 100%). Of those with increased caregiver burden, only 3 (25%) requested referral for support services. These findings indicate that over half of caregivers screened had increased caregiver burden. However, few requested referral for support services. Routine screening of informal caregivers may help identify increased caregiver burden; however, the limited number of caregivers interested in additional support services, requires further investigation.

Keywords: Alzheimer's disease, dementia, informal caregivers, screening, short form Zarit Burden Interview.

Acknowledgments

A special thank you to Teresa Patwell, MSN, APNP, GNP-BC for her continued support and assistance throughout this project. Your knowledge and expertise in the care of patients with Alzheimer's disease and related dementias was invaluable.

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Utilization of the Short Form Zarit Burden Interview to Screen Dementia Caregivers for Caregiver Burden in the Clinic Setting

Alzheimer's disease and related dementias (ADRD) are irreversible, progressive brain disorders that affect more than 5 million adults in the United States (Herbert, Weuve, Scherr, & Evan, 2013). Alzheimer's disease and related dementias are characterized by a slow decline in cognitive function that leads to changes in behavior and functional status ultimately making those with ADRD unable to care for themselves or live independently (Centers for Disease Control and Prevention [CDC], 2017). Family members of persons with ADRD are often faced with the decision to either care for their family members themselves or seek placement for them in a long-term care facility. Whether due to a lack of appropriate long-term care facilities or other religious, cultural, or financial reasons, many families choose to become the primary caregiver for their family members.

Informal caregivers of persons with ADRD are known to experience higher caregiver burden (Etters, Goodall, & Harrison, 2008; Riffin, Van Ness, Wolff, & Fried, 2017). Primary care providers regularly encounter patients with ADRD and their caregivers, however, research indicates that caregivers often become the "invisible patient" with physical and psychosocial needs that go unnoticed by providers (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Schoenmakers, Buntinx, & Delepeleire, 2009). Providing support to informal caregivers of patient's with ADRD is essential to ensuring optimal outcomes for both patients and their caregivers. Thus, primary care providers, must be cognizant of the risk for increased caregiver burden among informal caregivers of patient's with ADRD and be prepared to assess caregivers and provide additional interventions to help decrease caregiver burden when needed.

Statement of the Problem

Increased caregiver burden is associated with poor outcomes for persons with ADRD and their caregivers. Research has shown that caregiver burden places persons with ADRD at increased risk for early nursing home placement, abuse, and death (Gaugler, Kane, Kane, & Newcomer, 2005; Schoenmakers et al., 2009). Caregivers, due in part to the chronic stress of caring for persons with ADRD and the lack of time available to manage their own health needs, are at increased risk for mental and physical health problems. Studies have found that caregivers of persons with ADRD experience higher rates of anxiety and depression (Llanque, Savage, Rosenberg, & Caserta, 2014; Riffin et al., 2017). Caregiver burden has also been shown to increase the risk of cardiovascular disease, hypertension, kidney disease, and obesity among caregivers (Fonareva & Oken, 2014).

In addition to its effect on the overall health of persons with ADRD and their caregivers, increased caregiver burden has significant economic implications. Informal caregivers have been found to utilize more healthcare resources, such as emergency room and primary care provider services, when compared to non-caregivers (Bremer et al., 2015; Goren et al., 2016). Furthermore, in 2017 alone, the total value of care provided to patients with ADRD by unpaid caregivers was estimated to be around \$230.1 billion (CDC, 2017). Failure to provide sufficient support to informal caregivers could result in caregivers seeking placement for their family members in long-term care facilities potentially resulting in increased Medicare and Medicaid spending and further stress on a healthcare system that is already stretched thin (CDC, 2017).

Purpose of the Project

Assessing informal caregivers of persons with ADRD for caregiver burden is essential to ensure optimal health outcomes for persons with ADRD and their caregivers. Currently,

informal caregivers of patients with ADRD at an internal medicine clinic in the upper Midwest, do not routinely undergo screening. Therefore, the purpose of this project was to conduct a needs assessment to determine if routine screening of informal caregivers of patients with ADRD for caregiver burden would identify increased caregiver burden and the need for intervention. The secondary objective of this project was to determine if routine screening of caregivers, using the ZBI-12, and initiating referrals for additional support services for caregivers with increased caregiver burden could be conducted in the clinic setting.

Literature Review

A comprehensive literature review was conducted using CINAHL, PubMed, MEDLINE, Cochrane Library, and ProQuest Databases. Key words used included: dementia, Alzheimer's disease, Alzheimer's disease and related dementias, informal caregiver, caregiver burden, screening, screening recommendations, short-form Zarit Burden Interview, primary care, provider, and nurse practitioner. The review was limited to studies from peer-reviewed journals that were in English and published within the last 15 years. However, the search was ultimately extended to include studies published in the last 20 years to allow for the inclusion of studies necessary to provide a comprehensive review of caregiver burden and the Zarit Burden Interview.

Studies were further limited to those that focused on: ADRD and caregiver burden among informal caregivers, the effects of increased caregiver burden on patients with ADRD and their caregivers, and utilization of the Zarit Burden Interview tool in screening of caregivers for caregiver burden. Databases and other reputable sources including the Alzheimer's Association, Centers for Disease Control and Prevention, National Institute of Health, and U.S. Census Bureau were also utilized to gather statistics on the prevalence of ADRD and caregiver burden

and to further define informal caregivers, characteristics of ADRD, and the financial impact of caregiver burden.

Alzheimer's Disease and Related Dementias

Alzheimer's disease and related dementias (ADRD) are progressive and neurodegenerative brain disorders characterized by irreversible changes in memory, language, cognition, and behavior (Alzheimer's Association, 2018; National Institute on Aging [NIA], 2017). Alzheimer's disease (AD) is the most common cause of ADRD accounting for 60 to 80 percent of cases (Alzheimer's Association, 2018; CDC, 2017). Other causes of ADRD include vascular dementia (VaD), dementia with Lewy body (DLB), mixed dementia, and frontotemporal degeneration (NIA, 2017). Although ADRD is not considered a normal part of aging, as the population of Americans age 65 and older continues to grow, so too does the number of Americans living with ADRD with more than 14 million people projected to be diagnosed with AD alone by 2050 (Herbert et al., 2013; U.S. Census Bureau, 2018). Symptoms of ADRD range in severity and as the disease progresses, ADRD will ultimately render those affected unable to care for themselves leaving them completely dependent on others for all aspects of their daily care (Alzheimer's Association, 2018; NIA, 2017a).

Informal Caregivers

Informal caregivers are defined as persons, often family members, who provide unpaid care to someone with whom they have a personal relationship (Schulz & Tompkins, 2010). Currently, 83 percent of the help provided to older adults in the United States comes from informal caregivers with 48 percent of those caregivers providing care to someone with ADRD (Friedman, Shih, Langa, & Hurd, 2015). In total, more than 16 million Americans in 2017

provided unpaid care to people with ADRD, totaling an estimated 18.4 billion hours of unpaid care (Alzheimer's Association, 2018).

The majority of informal caregivers of persons with ADRD are 50-64 years of age, with 34 percent being 65 years or older (Alzheimer's Association, 2018; National Alliance for Caregiving [NAC], 2017). Two thirds of caregivers are non-Hispanic white while 13 percent are African-American, 13 percent are Hispanic, and 6 percent are Asian (NAC, 2017). Studies indicate that approximately 64 percent of informal caregivers are women with at least one third of those women being daughters (Friedman et al., 2015; Kasper, Freedman, & Spillman, 2014; Riffin et al., 2017). Roughly 40 percent of informal caregivers have a college or graduate degree and 59 percent of caregivers work full or part-time while providing care (NAC, 2017). In addition, 25 percent of caregivers are caring for a child or grandchild under the age of 18 in addition to caring for someone with ADRD (Alzheimer's Association, 2018; NAC, 2017).

Informal caregivers primarily provide assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs); however, it is important to note caregiving tasks are often cumulative with caregivers providing more assistance as ADRD progresses (Roth, Fredman, & Haley, 2015; Shulz & Tompkins, 2010). Initially, caregivers provide assistance with IADLs such as providing transportation, doing household chores, shopping, preparing meals, managing finances, and arranging outside services. Studies indicate 71 percent of caregivers provide help with at least four IADLs while 24 percent provide help with all IADLs (NAC, 2017). As ADRD progresses and disabilities increase, caregivers begin to provide assistance with ADLs such as bathing, dressing, ambulating, toileting, and feeding. Sixty three percent of informal caregivers help with at least one ADL where as 38 percent provide help with three or more ADLs (Kasper et al., 2014; NAC, 2017). In addition, 15 percent of caregivers help

with behavioral symptoms such as wandering, depressive mood, agitation, anxiety, and nighttime disturbances (NAC, 2017).

Caregiver Burden

Caregiver burden is defined as a multidimensional response to physical, psychological, social, and financial stressors associated with caregiving (Kasuya, Polgar-Bailey, & Takeuchi, 2000). The chronic, debilitating, and incurable nature of ADRD makes caring for persons with the disease particularly challenging (Fonareva & Oken, 2014). Recent studies have indicated caregivers of persons with ADRD are one of the more burdened groups of caregivers with 46 percent of caregivers having a high level of burden (NAC, 2017). Several risk factors for caregiver burden among informal caregivers of person with ADRD have been identified including: female sex, residing with the care recipient, a high number of hours spent caregiving, perceived lack of choice in being a caregiver, and low educational attainment (Adelman et al., 2014; Collins & Swartz, 2011; Hirst, 2005). Care recipient characteristics have also been shown to impact caregiver burden with dementia severity, duration of illness, and behavioral symptoms being the most important contributors (Fonareva & Oken, 2014; Pinguart & Sorenson, 2007).

Caregiver burden has been shown to have a significant impact on the health of caregivers. Fonareva and Oken (2014) conducted a systematic literature review to evaluate the effects of the chronic stress of caregiving on the health and well-being of dementia caregivers. The review revealed caregivers had higher systolic and diastolic blood pressures than non-caregivers despite caregivers using more antihypertensive medications than non-caregivers. Caregivers were also found to have a higher risk of developing coronary heart disease over ten years (Fonareva & Oken, 2014). Additionally, caregivers had decreased sleep efficiency, longer sleep latency, and spent less of their time in restful sleep compared to non-caregivers (Fonareva & Oken, 2014).

Sleep disturbance and poor sleep quality among caregivers is particularly problematic as it has been shown to be associated with poorer self-reported physical functioning, reduced quality of life, higher levels of depressive symptoms, and increased caregiver burden (Beaudreau et al., 2008; Peng & Chang, 2013).

Furthermore, several studies evaluating the impact of caregiving and caregiver burden on caregivers' overall health and quality of life have reported significantly lower health related quality of life (HRQoL) and overall health status among caregivers (Bremer et al., 2015; Goren, Montgomery, Khale-Wroblewski, Nakamura, & Ueda, 2016; Pinguart & Sorenson, 2007; Valimaki et al., 2016). Goren, Montgomery, Khale-Wroblewski, Nakamura, and Ueda (2016) assessed how family caregivers of patients with ADRD differed from non-caregivers in health outcomes. Findings from the study that included 53,758 non-caregivers and 1,302 caregivers suggest caregivers have poorer HRQoL and significantly poorer mental and physical health status (Goren et al., 2016). Valimaki et al. (2016) evaluated the impact of ADRD on caregivers' quality of life with similar findings. The authors found caregivers had significantly lower HRQoL and that their well being deteriorated significantly during the three years of follow-up (Valimaki et al., 2016). Moreover, data suggests caregivers' health related quality of life deteriorates earlier than expected during the gradual decline in cognition that occurs with ADRD (Valimaki et al., 2016). None of the studies discussed above were able to provide a definitive conclusion regarding a causal relationship between caregiving, overall health, and health related quality of life; however, 35 percent of caregivers of persons with ADRD report their health had gotten worse due to care responsibilities (NAC, 2017).

In addition to the impact on physical health, caregiver burden has also been shown to impact the psychological well being of caregivers. Specifically, caregivers of persons with

ADRD have been found to have higher levels of psychological distress, anxiety, and depression (Goren et al., 2016; Liu et al., 2016; Pinguart & Sorenson, 2003; Sallim, Sayampanathan, Cuttilan, & Ho, 2015). Sallim, Sayampanathan, Cuttilan, & Ho (2015) conducted a meta-analysis to evaluate the prevalence of mental health disorders among caregivers of patients with ADRD. The results suggested one in three caregivers of patients with ADRD suffers from depression (Sallim et al., 2015). The prevalence of anxiety disorders among caregivers was 43.6 percent (Sallim et al., 2015). Additionally, caregivers with higher levels of caregiver burden were found to be at 11.9 times greater risk of having depression and to be 19.3 times more likely to have anxiety (Sallim et al., 2015). Liu et al (2016) also found that not only were depression and anxiety the greatest challenges facing caregivers of patients with ADRD but that both depression and anxiety were associated with increased caregiver burden. The prevalence of depression among caregivers is particularly concerning as research suggests caregivers at risk for clinical depression are more likely to engage in potentially harmful caregiving behaviors such as screaming, yelling and swearing, withholding food, hitting, and threatening physical force, abandonment, or to send the care recipient to a nursing home (Beach et al., 2005).

The estimated economic value of care provided by informal caregivers of persons with ADRD in 2017 was \$230.1 billion (CDC, 2017). A recent longitudinal study of the monetary value of family caregiving for persons with ADRD found the value of family care increases 18 percent with each additional year of care provided indicating the economic value of care provided by informal caregivers is extremely high and will only continue to increase (Rattinger et al., 2015). Thus, failure to provide adequate support to informal caregivers could have substantial economic consequences for the current healthcare system.

Gaugler, Kane, Kane, and Newcomer (2005) found caregivers that reported unmet needs were more likely to place care recipients in nursing homes. This is of increasing concern as total Medicaid spending for people with ADRD is projected to be \$47 billion in 2018 alone (Alzheimer's Association, 2018). Furthermore, with only 1.7 million licensed nursing home beds in the United States, there simply is not enough room in long-term care facilities for the influx in patients with ADRD that could result if steps are not taken to provide informal caregivers with the support they need to continue to care for patients with ADRD in their homes (CDC, 2016).

In addition, studies suggest caregivers of persons with ADRD have higher rates of healthcare resource utilization when compared to non-caregivers (Bremer et al., 2015; Goren et al., 2016). Bremer et al. (2015) examined the relationship between caregiving intensity, caregivers' health, and health care utilization. A strong and positive relationship between the amount of informal care provided and self-stated health care use was observed among caregivers. Individuals who provided more total hours of informal care reported increased use of health care resources due to their caregiver tasks (Bremer et al., 2015). Goren et al. (2016) also found caregivers reported significantly more visits to the emergency department and healthcare providers when compared to non-caregivers. The findings above highlight the impact caregiving and caregiver burden can have on persons with ADRD, their informal caregivers, the economy, and an already taxed health system and further reinforce the need for screening for and identification of caregiver burden.

Screening Tools

Zarit burden interview. The Zarit Burden Interview (ZBI) is an instrument that was developed to measure subjective burden among informal caregivers (Higginson, Gao, Jackson, Murray, & Harding, 2010). The ZBI measures several different aspects of caregiver burden to

include social, physical, financial, and emotional burden (Van Durme, Macq, Jeanmart, & Gobert, 2012). The original version of the ZBI was a 29-item version published in 1980 by Zarit, Reever, & Bach-Peterson, however, the 22-item version of the ZBI is the instrument most commonly used to measure caregiver burden in dementia caregiving research (Bedard, Pedlar, Martin, Malott, & Stones, 2000).

More recently, researchers have sought to develop a ZBI tool that was less burdensome for caregivers to complete and would allow for more rapid screening of caregivers in often busy clinical settings (Higginson et al., 2010; Lin, Wang, Pai, & Ku, 2017). This has ultimately led to the development of a variety of short-form versions of the ZBI to include the ZBI-12, ZBI-8, ZBI-7, ZBI-6, ZBI-4, and ZBI-1 (Higginson et al., 2010). While all six short-form ZBIs have been found to have good validity and internal consistency, the ZBI-12 has been endorsed by researchers as the best short-form version (Higginson et al., 2010; Lin et al., 2017; Van Durme et al., 2012). See Appendix A for the complete tool

The ZBI-12 was developed by Bedard and colleagues (2001) and consists of twelve items that were selected from the ZBI-22 based on high factor loading and high item-total correlations. Each item or statement on the ZBI-12 is rated by the caregiver using a 5-point Likert-type scale to describe how often the statement occurs with 0 indicating “never” to 4 indicating “nearly always” (Bedard et al., 2001). The ZBI-12 has a score range of 0-48 with the following categories for scoring: 0-10 no to mild burden, 10-20 mild to moderate burden, and > 20 high burden.

Results indicate that when used to evaluate caregiver burden among informal caregivers of persons with ADRD the ZBI-12 has very good validity (ρ 0.95-0.97) and internal consistency (Cronbach alpha 0.85-0.89) (Bedard et al., 2001; Higginson et al., 2010; O’Rourke

& Tuokko, 2003). In addition, when differentiating between low and high burden the ZBI-12 was found to be the short-form with greatest discrimination (Higginson et al., 2010). Bedard and colleagues (2001) defined a score above 16 as suggestive of clinically significant caregiver burden, however, O'Rourke and Tuokko (2003) found this cutoff score limited the sensitivity of the ZBI-12 to 49 percent relative to clinically significant depressive symptomology as measured by the Center for Epidemiologic Studies-Depression Scale. O'Rourke and Tuokko (2003) instead suggested a cutoff score of 10 which increased the sensitivity of the ZBI-12 to 75 percent but decreased the specificity to 68 percent. In contrast, when a cutoff score of 12 was used among 105, 131, and 215 informal caregivers for patients with advanced cancer, dementia, and acquired brain injury the ZBI-12 had a sensitivity of 92 percent and specificity of 94 percent (Higginson et al., 2010).

Although the sensitivity and specificity of the ZBI-12 has been shown to vary significantly based on the cutoff score chosen, the validity and internal consistency of the tool support its use in quantifying caregiver burden. Furthermore, the ZBI-12 has been validated for use with caregivers of persons with ADRD making it an ideal tool for use in this project (Bedard et al., 2001; O'Rourke & Tuokko, 2003). Finally, the ZBI-12 has been found to be quick and easy to use being completed by informal caregivers in five to ten minutes making it optimal for use in a busy clinic setting (Lin, Ku, & Pakpour, 2017; Stagg & Lerner, 2015).

Other tools. Van Durme, Macq, Jeanmart, and Gobert (2012) conducted a literature review to identify an acceptable and appropriate tool for evaluation of the impact of caregiving on informal caregivers of the elderly. One hundred and five scales were identified and included in the review (Van Durme et al., 2012). The authors compared the psychometric properties of each scale and ultimately identified the ZBI-12 as the most useful tool for the evaluation of the

impact of caregiving on informal caregivers. Like the studies discussed above, the extensive validation, conciseness, and user friendliness of the ZBI-12 were the principal reasons for its endorsement (Van Durme et al., 2012).

Screening Recommendations and Barriers

It has been widely recognized that screening, assessment, and monitoring of the degree of caregiver burden among informal caregivers is essential to ensuring optimal outcomes for persons with ADRD and their caregivers (Adelman et al., 2014; Eppers et al., 2008). Despite this finding, screening and assessment of informal caregivers has not been routinely carried out in practice leaving caregivers to continue to suffer in silence (Adelman et al., 2014; Family Caregiver Alliance [FCA], 2006; Schulz & Tompkins, 2010). A lack of definitive recommendations regarding screening of caregivers has led to further confusion regarding implementation of routine screening for caregiver burden in the clinical setting.

In 2006 the Family Caregiver Alliance (FCA) released the report *Caregiver Assessment: Principles, Guidelines, and Strategies for Change* that outlined the importance of routine caregiver assessment and provided general practice guidelines. The FCA identified screening as an essential part of the caregiver assessment process. Ultimately, the FCA recommended any person who self-identifies as a caregiver be offered screening, which should lead to further assessment as appropriate (FCA, 2006). In addition, the FCA recommended regular reassessment to identify any new challenges and assess changes in the caregiving situation (FCA, 2006). While the FCA recommends routine screening and reassessment, they also note there is no set protocol to follow nor is there any single approach that is optimal across care settings (FCA, 2006). The FCA does not provide any further recommendations regarding specific

screening tools to use for assessment of caregiver burden nor do they specify how frequently caregivers should be reassessed (FCA, 2006).

Since the FCA report, the Centers for Disease Control and Prevention (2009) released a critical issue brief highlighting the importance of protecting the health of informal caregivers, however, they did not provide any further recommendations regarding assessment. Moreover, there was no consensus regarding the frequency with which reassessment should occur. Some recommend screening caregivers every six months whereas others recommend periodic assessments (Adelman et al., 2014; Eters et al., 2007). Still others suggest providers simply “stay alert at all times” and screen caregivers when they believe caregiver burden is a concern (Langman, 2016).

In addition to the relatively vague recommendations provided by the FCA a number of barriers exist that prevent screening of caregivers for caregiver burden. The most commonly cited barrier to implementation of caregiver screening was time (Adelman et al., 2014; Collins & Swartz, 2011; Schoenmakers et al., 2009). Schoenmakers, Buntinx, and Delepeleire (2009) conducted a systematic literature review and found providers considered treatment of dementia, with respect to the caregiver, to be time consuming and highly frustrating. Additional barriers identified included the tendency of providers to focus exclusively on the medical problems of the patient and a lack of understanding of and confidence in the management and coordination of care to support informal caregivers (Schoenmakers et al., 2009). Despite the barriers listed above, providers and researchers continue to acknowledge the need to routinely screen informal caregivers for caregiver burden in order to prevent the myriad of complications that can result from unidentified caregiver burden (Adelman et al., 2014; Collins & Swartz, 2011; Eters et al., 2008; FCA, 2006; Schoenmakers et al., 2009).

Treatment

A variety of treatment modalities for caregiver burden have been proposed in the literature to include counseling, case management, psycho-educational interventions, respite care, support group interventions, skills training, and general educational (Wennberg, Dye, Streetman-Loy, and Pham, 2015). Several systematic reviews and meta-analysis have been conducted in an attempt to identify the most appropriate interventions to decrease caregiver burden, however, results are inconclusive. Psycho-educational interventions, counseling, case management, and respite interventions have all been found to have a statistically significant effect on caregiver burden (Corvol et al., 2017; Pinquart & Sorenson, 2006; Van't Leven et al., 2013). Results also suggest multicomponent interventions could reduce depressive symptoms, decrease caregiver burden, and reduce the risk of institutionalization (Laver, Milte, Dyer, & Crotty, 2017; Pinquart & Sorenson, 2006).

Though there does not appear to be one treatment modality that is superior to another in reducing caregiver burden, there is consensus among researchers regarding the importance of interventions being tailored to the specific needs of each caregiver-patient dyad (Corvol et al., 2017; Laver et al., 2017; Pinquart & Sorenson, 2006; Van't Leven et al., 2013). While there are a variety of treatment modalities that providers could effectively use to decrease caregiver burden implementation in a busy clinical setting may not be feasible. Nevertheless, at minimum providers should be screening caregivers for caregiver burden and referring as necessary to case management or social work for further assessment and initiation of appropriate interventions (Adelman et al., 2014; Collins & Swartz, 2011; Langman, 2016).

Summary

Caregiver burden among informal caregivers of persons with ADRD is a common problem associated with a variety of poor health outcomes for persons with ADRD and their caregivers. Furthermore, failure to recognize informal caregivers as integral to the current healthcare system and to provide them with the support they need could have significant economic consequences. Screening informal caregivers for caregiver burden is essential to identifying caregivers at risk; however, current literature indicates informal caregivers are not routinely screened in practice. Research found that a lack of time was the most common barrier that prevented providers from proactively screening informal caregivers. The ZBI-12 has been found to be a valid, reliable, efficient, and user-friendly screening tool for quantifying caregiver burden. This project therefore utilized the ZBI-12 to screen informal caregivers of persons with ADRD for caregiver burden at an internal medicine clinic.

Conceptual Framework

The conceptual framework used to guide this project was the Deming cycle also known as the Plan-Do-Study-Act (PDSA) cycle. The PDSA cycle is a standard quality improvement process commonly used in health care settings to facilitate change (Coury et al., 2017; Reed & Card, 2016). The acronym PDSA stands for the four steps implemented during the cycle: (1) plan how the project will be implemented and data will be collected; (2) do the project and collect data; (3) study the results and analyze the data; and (4) act based on what has been learned (Agency for Healthcare Research and Quality, 2008; Reed & Card, 2016).

The purpose of the PDSA cycle is “to learn as quickly as possible whether an intervention works in a particular setting and to make adjustments accordingly to increase the chances of delivering and sustaining the desired improvement” (Reed & Card, 2017, p. 147).

Plan-Do-Study-Act cycles are by design small cycles including a limited number of subjects that allow for small-scale tests for change making it ideal for use in a single provider clinic such as the one in this project (National Institute of Health, n.d.; Reed & Card, 2017).

Ultimately, this project utilized all four steps of the PDSA cycle. First, the author worked with the nurse practitioner at the clinic and with project committee members to identify the objectives for the project. Next a plan for implementation and data collection was developed. Following approval from the Institutional Review Board (IRB) the project entered the “do” stage of the PDSA cycle during which time the project was carried out and data was collected. The data was then analyzed using descriptive statistics and the findings summarized during the “study” portion of the PDSA cycle. Finally, the findings of this project were presented to the providers at the clinic with further discussion regarding how best to integrate the findings and recommendations into practice.

Assumptions

For this project assumptions included:

1. The ZBI-12 questionnaire is a valid and reliable screening tool for caregiver burden.
2. Patients with ADRD will present to the clinic with their informal caregiver.
3. At least 75 percent of informal caregivers will consent to screening.
4. Caregiver burden will be present, however, to what degree is unknown.

Methods

Design

This project utilized a two-phase approach to assess the need for routine screening for increased caregiver burden among informal caregivers of patients with ADRD. In phase one,

each informal caregiver who accompanied a patient with ADRD to the internal medicine clinic was offered the opportunity to participate in the project. Every informal caregiver who consented to participate was given the ZBI-12 tool to complete. Of note, caregivers were taken to a separate room within the clinic to complete the screening tool while the patient they accompanied was undergoing cognitive testing with the provider. This was done in order to minimize the impact on clinic flow and prevent any delay of care.

Once the screening tool was complete it was reviewed and scored by the investigator. Informal caregivers with a ZBI-12 score of 12 or greater were considered to have increased caregiver burden. Every caregiver found to have increased caregiver burden was offered a referral to respite care, counseling, or case management. The investigator notified the provider, upon re-entering to the exam room, of each caregiver with increased caregiver burden and whether they were interested in referral for additional support services. The provider then spent a few minutes talking with the caregiver to discern if there was anything that could be done to better meet the caregivers needs.

Additionally, all caregivers regardless of ZBI-12 score were given a pamphlet outlining support services within the community that are available to patients with ADRD and their caregivers (See Appendix B). Once the office visit was complete the screening tool was placed in a locked storage box at the internal medicine clinic for further evaluation during phase two. In phase two, data analysis occurred.

Setting

This project was conducted at an internal medicine clinic in the upper Midwest. The internal medicine clinic was a community-based clinic that provided health care services to adults in a large metropolitan area. Patients with ADRD were seen one day per week by the

geriatric nurse practitioner (GNP) at the clinic. Patients were referred to the GNP specifically for evaluation and management of their ADRD and were typically accompanied by an informal caregiver.

Sample and Selection

Participants in this project were individuals who identified themselves as an informal caregiver of someone with ADRD. To be included in this project the caregivers had to meet the following criteria: (1) be at least 18 years of age, (2) identify themselves as a caregiver for a friend or family member with ADRD, and (3) have provided care during the past month. The project utilized a convenience sample to recruit 22 caregivers over a 6-week period. No informal caregivers who presented to the clinic were excluded from the screening process.

Data Collection

Data was collected during phase one of this project. Each caregiver who agreed to participate was given a blank screening tool to complete while the patient with ADRD was undergoing cognitive testing. The screening tool was comprised of: demographic data, one questioning regarding the caregiver's relationship to the care recipient, one question regarding whether or not the caregiver lives with the care recipient, and the ZBI-12 tool. Demographic data collected for this project included age, gender, ethnicity, and education level. Upon completion of the screening tool by the caregiver the investigator scored the ZBI-12 tool. Whether or not the caregiver was referred for additional support services was then documented by marking a check box next to "yes" or "no." Where the caregiver was referred was also documented by marking the appropriate check box next to one of the following: respite care, counseling, or case management. See Appendix C for the entire screening tool.

Once the screening tool was complete, it was reviewed to ensure all questions had been answered in their entirety. Next, the screening tool was placed in a locked storage box in the clinic to assure confidentiality was maintained. The screening tools remained in the locked storage box until data evaluation and analysis occurred.

Data Analysis

Data analysis occurred during phase two at which time all screening tools were removed from the locked storage box and assessed for completion. Descriptive statistics were applied as the primary method to evaluate the data that was collected. To assess whether the implementation of routine screening for caregiver burden, using the ZBI-12, would identify increased caregiver burden the percent of informal caregivers with increased caregiver burden was calculated. The percent of caregivers referred to each of the different support services was also calculated to provide insight into preferred support services among caregivers and whether or not the provider at the clinic would need additional assistance to manage caregiver referrals to such services. Finally, the percent of caregivers that answered “sometimes”, “quite frequently”, or “nearly always” for each of the 12 questions on the ZBI-12 tool was calculated to further understand what aspects of their role caregivers felt were most burdensome.

Human Subjects Protection

Several steps were taken to maintain participant privacy. First, demographic data collected was limited to age, gender, ethnicity, and education level to prevent collection of any identifiable information. Next, screening forms were kept in a locked storage box at the internal medicine clinic with access limited to the primary investigator only in order to ensure privacy and confidentiality. This DNP project was a quality improvement project thus a quality improvement determination request was completed and approved by the Institutional Review

Board (IRB). See Appendix D for a copy of the IRB letter of approval and Appendix E for the collegial letter of support.

Results

Data was collected over a 6-week period during which time 22 informal caregivers were screened. All 22 caregivers completed the screening tool. Caregivers ranged in age from 19 to 91 years with the mean (SD) age being 63.8 (15.5) years. The majority of caregivers were Caucasian (21, 95.5%) and around half of them were female (12, 54.5%). Most had an educational status of college or above (19, 86.4%) and were the spouse (8, 36.4%) or child (13, 59.1%) of the care recipient. Slightly less than half of the caregivers lived with the care-recipient (9, 40.9%). See Table 1.

Table 1
Caregiver Characteristics

	All Caregivers (<i>n</i> = 22)	Caregivers with Caregiver Burden (<i>n</i> = 12)
Age (years), M ± SD	63.8 ± 15.5	68.8 ± 11.6
Gender (women), n (%)	12 (54.5)	9 (75)
Ethnicity, n (%)		
African American	1 (4.5)	1 (8.3)
Caucasian	21 (95.5)	11 (91.7)
Educational Status, n (%)		
High School	3 (13.6)	0
College or above	19 (86.4)	12 (100)
Relationship to Care-Recipient, n (%)		
Spouse	8 (36.4)	6 (50)
Child	13 (59.1)	6 (50)
Other	1 (4.5)	
Living with Care-Recipient, n (%)	9 (40.9)	6 (50)

Of the 22 caregivers that completed the screening tool 12 (54.5%) had a ZBI-12 score of 12 or greater indicating increased caregiver burden. When compared to the other caregivers, caregivers with increased caregiver burden were more likely to be older (68.8 ± 11.6 years), female (9, 75%), and have an educational status of college or above (12, 100%; Table 1). All

caregivers with increased caregiver burden were offered a referral to respite care, counseling, or case management. Three (25%) of the 12 caregivers with increased caregiver burden requested referral for additional support services. All three caregivers requested referral to case management.

Table 2
Caregivers' Responses to the ZBI-12 Questionnaire

	“Never” (0)	“Rarely” (1)	“Sometimes” (2)	“Quite Frequently” (3)	“Nearly Always” (4)
Do you feel...					
1. That because of the time you spend with your relative you don't have enough time for yourself?	6 (27.3%)	9 (40.9%)	4 (18.2%)	3 (13.6%)	0 (0%)
2. Stressed between caring for your relative and trying to meet other responsibilities (work/family?)	3 (13.6%)	7 (31.8%)	10 (45.5%)	2 (9.1%)	0 (0%)
3. Angry when you are around you relative?	10 (45.5%)	8 (36.4%)	4 (18.2%)	0 (0%)	0 (0%)
4. That your relative currently affects your relationship with family members or friends in a negative way?	10 (45.5%)	9 (40.9%)	3 (13.6%)	0 (0%)	0 (0%)
5. Strained when you are around your relative?	9 (40.9%)	5 (22.7%)	7 (31.8%)	1 (4.5%)	0 (0%)
6. That your health has suffered because of your involvement with your relative?	15 (68.2%)	3 (13.6%)	2 (9.1%)	2 (9.1%)	0 (0%)
7. That you don't have as much privacy as you would like because of your relative?	14 (63.6%)	5 (22.7%)	3 (13.6%)	0 (0%)	0 (0%)
8. That your social life has suffered because you are caring for your relative?	11 (50%)	4 (18.2%)	6 (27.3%)	1 (4.5%)	0 (0%)
9. That you have lost control of you life since your relative's	12 (54.5%)	7 (31.8%)	2 (9.1%)	0 (0%)	1 (4.5%)
10. Uncertain about what to do about your relative?	5 (22.7%)	8 (36.4%)	6 (27.3%)	2 (9.1%)	1 (4.5%)
11. You should be doing more for your relative?	2 (9.1%)	8 (36.4%)	9 (40.9%)	2 (9.1%)	1 (4.5%)
12. You could do a better job caring for your relative?	3 (13.6%)	7 (31.8%)	10 (45.5%)	1 (4.5%)	1 (4.5%)

The proportion of caregivers who responded with “sometimes”, “quite frequently”, or “nearly always” to each question on the ZBI-12 tool was also examined to better understand caregiver burden among the caregivers in this project. More than half of caregivers (12, 54.5%) responded with “sometimes”, “quite frequently”, or “nearly always” to questions two, eleven, and twelve (Table 2). Question two relates to the degree of stress caregivers feel when trying to care for their relative while maintaining other personal responsibilities whereas questions eleven and twelve related to how well the caregiver felt they were doing in their role as a caregiver. In addition, 9 (40.9%) caregivers answered “sometimes”, “quite frequently”, or “nearly always” when asked how often they felt uncertain about what to do when caring for the care-recipient. See Appendix A.

Discussion

The main purpose of this project was to determine if routine screening of informal caregivers of patients with ADRD for caregiver burden would identify caregivers with increased caregiver burden, and secondarily, could be conducted in a busy internal medicine clinic. Of the 22 caregivers screened for this project 12 (54.5%) had increased caregiver burden. This number was 8.5% higher than national average of 46%; however, direct comparison across studies is difficult with the many instruments available to assess caregiver burden. It has been suggested that implementation of routine screening should be considered (NAC, 2017). This project found caregivers with increased caregiver burden were more likely to be female, and have a high level of educational attainment. The tendency of female caregivers in this project to have increased caregiver burden was consistent with previous studies that identified being female as a risk factor for increased caregiver burden (Adelman et al., 2014). However, contrary to former studies, low

educational attainment and living with the care-recipient were not found to be associated with increased caregiver burden in this project (Adelman et al., 2014; Collins & Swartz, 2011).

The secondary objective of this project was to determine if routine screening for caregiver burden using the ZBI-12 could be conducted by the GNP in the clinic setting, and if referral to additional support services could be initiated for caregivers found to have increased caregiver burden. Interestingly, while all caregivers with increased caregiver burden were offered a referral to additional support services, only 3 (25%) caregivers requested referral. Notably, when offered a referral to respite care, counseling, or case management all caregivers requested a referral to case management, a service that is currently offered at the clinic. Based on these findings, caregiver referral to case management could effectively be managed by the GNP at the clinic. In addition, all caregivers were provided a pamphlet with available services in the community that may have been perceived as sufficient to meet the caregiver's needs thus making referral to additional support services unnecessary.

Moreover, the results appear to indicate that there are three areas where caregivers felt particularly burdened. The first was in trying to balance their role as a caregiver with their own responsibilities as a parent, spouse, employee, etc. The second was in their uncertainty with how to manage an illness such as ADRD that is progressive, degenerative, and often difficult to predict. The third was in feeling that they could and/or should be doing more in their role as a caregiver. These findings suggest that caregivers felt they were not well prepared to care for someone with ADRD in addition to being concerned that they were not doing enough in their role as a caregiver.

Implications for Practice

The findings from this project provided further insight into the degree to which increased caregiver burden was present among informal caregivers of patients with ADRD. The relatively high percentage of caregivers with increased caregiver burden and the impact of caregiver burden on the physical, psychological, and financial well-being of patients with ADRD and their caregivers makes routine screening integral to ensuring optimal outcomes for both. As suggested in the literature, screening informal caregivers for increased caregiver burden should be considered a routine task during clinic visits for patients with ADRD. Providers should be screening caregivers of patients with ADRD annually at minimum with special consideration given to the rate of decline in the patient with ADRD. Caregiving is often cumulative with caregivers providing more assistance to patients as ADRD progresses therefore a significant change in a patient's condition should prompt reassessment of the caregiver for increased caregiver burden.

Furthermore, data from this project indicates that simply offering caregivers with increased caregiver burden a referral to respite care, counseling, or case management may not be sufficient as the majority of caregivers in this project were not interested in such services. Taking a few minutes to inquire about each caregiver's needs and concerns may prove to be a more worthwhile alternative and allow for identification of interventions and referrals that would better meet their needs. Additionally, the number of caregivers in this project who felt uncertain about how best to care for someone with ADRD highlights the need for additional support and education for informal caregivers. Providers have a limited amount of time while in clinic with which to address a multitude of issues, however, this project reinforces that it is possible for providers to refer caregivers to appropriate support services during the care-recipient's visit.

Finally, while the literature indicated a lack of time was the most common barrier to implementation of routine screening of caregivers it is important to note that the ZBI-12 is a validated, reliable, and easy to use screening tool that can be completed by caregivers in five to ten minutes. Moreover, because the ZBI-12 is a self-administered questionnaire it could be sent to the caregiver prior to the office visit or provided to the caregiver upon arrival to the clinic thus allowing for completion of the screening tool prior to the appointment. Ultimately, screening for caregiver burden can be integrated into an office visit, as was done in this project, and completed without taking time away from the patient. However, when to screen caregivers for caregiver burden during the office visit is contingent on how the provider chooses to conduct the visit and will likely vary from clinic to clinic.

Limitations

The limited number of options for additional support services may have been a limitation in this study. Caregivers with increased caregiver burden in this project may have chosen to forgo referral to additional support services not because they were not interested but because the options offered did not meet their needs. The inclusion of a pamphlet outlining available services in the community may have also played a role in the limited number of referrals as caregivers may have found the list of services sufficient to meet their needs resulting in a decision to decline referral. As such, future evaluation to identify appropriate support services for caregivers with increased caregiver burden should be considered.

Conclusion

Informal caregivers of patients with ADRD are an integral part of the patient-caregiver dyad and a critical component of the healthcare team. Providers must begin to view supporting the informal caregiver as central to providing quality care to patients with ADRD. Screening

informal caregivers for increased caregiver burden is essential to identify informal caregivers in need of additional support and ensuring optimal health outcomes for patients with ADRD and their caregivers. Thus, routine screening for caregiver burden should be viewed as part of providing high quality care to patients with ADRD and implemented accordingly.

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Appendix A

Short Form Zarit Burden Interview (ZBI-12)

	“Never” (0)	“Rarely” (1)	“Sometimes” (2)	“Quite Frequently” (3)	“Nearly Always” (4)
Do you feel ... ?					
That because of the time you spend with your relative you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

Note: Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The zarit burden interview: A new short version and screening version. *The Gerontologist, 41*, 652-657.

*Appendix B***SUPPORT SERVICES FOR PATIENTS AND CAREGIVERS****Aging & Disability Resource Center of Dane County**

2865 N. Sherman Avenue

Northside Town Center

Madison, WI 53704

- Website: www.daneadrc.org
- Stop in, Call, Email, or Request a Home visit
 - Phone: 608-240-7400
 - Email: ADRC@countyofdane.com
- Services:
 - Information and Assistance with: disability and long-term care related services, living arrangements, health, adult protective services, transportation, home maintenance, and nutrition
 - Benefits Counseling: accessing Medicare, Medicaid, Social Security, or other benefits
 - Elder Benefit Specialist Program: legal advice/representation for senior adults (age 60+) residing in Dane County

Alzheimer's & Dementia Alliance of Wisconsin

3330 University Ave.

Suite 300

Madison, WI 53705

- Website: www.alzwisc.org
- Stop in, Call, or Email
 - Phone: 608-232-3400 or 888-308-6265 toll free
 - Email: support@alzwisc.org
- Services: Consultation, Support Groups, Education Programs
- Community Resource Guide

National Family Caregiver Support Program

Area Agency on Aging of Dane County

2865 N. Sherman Ave.

Madison, WI 53704

- Phone: 608-261-9930
- Email: AAA@countyofdane.com
- Services:
 - Information for caregivers about available services
 - Assistance to caregivers in gaining access to supportive services
 - Individual counseling, support programs, and training for caregiver, Respite care

Care Wisconsin: Wisconsin Managed Care Organization

1617 Sherman Ave.

Madison, WI 53704

- Phone: 1-800-963-0035 (toll free)
- Services:

- Matching seniors and individuals with disabilities to healthcare and long-term care support and services they need to remain in their homes

Home Care Services

- Please contact the Alzheimer's & Dementia Alliance of Wisconsin (see above for contact information) for a complete list of home care service agencies in the Dane county area.

Senior Centers

Madison Senior Center

330 West Mifflin St.
Madison, WI 53703

- Phone: 608-266-6581

Middleton Senior Center

7448 Hubbard Ave.
Middleton, WI 53562

- Phone: 608-831-2373

Verona Senior Center

108 Paoli Street
Verona, WI 53593

- Phone: 608-845-7471

Adult Day Care

Adult Day Center

5401 Fen Oak Dr.
Madison, WI 53718

- Website: aduldaycentermadison.org
- Phone: 608-826-8106
- Email: TourADC@ccmadison.org

Benevolence Adult Day Care

914 Laurie Drive
Madison, WI 53711

- Phone: 608-442-0253
- Email: BenevolenceADC@aol.com

SSM Health Adult Day Health Center

2440 Atwood Ave.
Madison, WI 53578

- Phone: 608-249-4450

Respite Care

- Respite care at residential care facilities may be arranged for overnight or multiple day stays. Please contact individual facilities for more details.

Transportation

Area Agency on Aging of Dane County

2865 N. Sherman Ave.
Northside Town Center
Madison, WI 53704

- Phone: 608-261-9930
- Email: AAA@countyofdane.com

Community Living Alliance – CLA Care Solutions

1414 MacArthur Rd
P.O. Box 8028
Madison, WI 53708

- Phone: 608-242-8335
- Email: info@clanet.org

Aging & Disability Resource Center of Dane County

- See above for contact information

Other Charities

Catholic Charities Madison

- www.catholiccharitiesofmadison.org
- Phone: 608-826-200

Jewish Social Services of Madison

- www.jssmadison.org
- Phone: 608-442-4081

Mobile Applications:

- Alzheimer's Daily Companion
- Alzheimer's Caregiver Buddy
- Balance: Alzheimer's Caregiving
- Alzheimer's Manager
- MindMate

Appendix C
Screening Tool

A. Demographic information

Age: _____

Gender: _____

Ethnicity: _____

Highest level of education completed: _____

What is your relationship to the patient? (please circle one)

Spouse/Significant Other

Child

Sibling

Other Family Member

Friend

Do you live with the person you provide care for? (please circle one)

Yes / No

B. Short Form Zarit Burden Interview (ZBI-12)

	“Never” (0)	“Rarely” (1)	“Sometimes” (2)	“Quite Frequently” (3)	“Nearly Always” (4)
Do you feel ... ?					
That because of the time you spend with your relative you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

Note: Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The zarit burden interview: A new short version and screening version. *The Gerontologist*, 41, 652-657.

Total Score: _____

C. Provider Referral

****All informal caregivers with a ZBI-12 score of 12 or greater are considered to have increased caregiver burden and should be offered referral to additional support services.**

Was the caregiver referred to additional support services?

- Yes No

To what support service was the caregiver referred?

- Respite Care Counseling Case Management

Appendix D

IRB Letter of Approval



St. Mary's Hospital
700 South Park Street
Madison, WI 53715
stmarysmadison.com

April 30, 2019

Judith Anderson
University of Kansas School of Nursing Student

Re: DNP Project: Utilization of the Short Form Zarit Burden Interview to Screen Dementia Caregivers for Caregiver Burden in the Clinical Setting

Dear Ms. Anderson

On April 10, 2019, SSM Health Wisconsin Institutional Review Board (IRB) chair and coordinator reviewed your project proposal.

Upon review, your project does not meet the definition of research for IRB purposes. Therefore, it does not need to be reviewed by the SSM Health Wisconsin IRB. With that being said, at any point in which you plan on sharing your project learnings more broadly or plan on expanding, please reach back out to us as it may then meet criteria for IRB approval.

You may use this letter as official notification that your project does not need to be reviewed by the IRB. We want to thank you for reaching out, and wish you all the best in your project and future pursuits. We applaud you in your pursuit of questioning the status quo and dedication to research.

Sincerely yours,

Sarah Donnell, MSN, RN, FNP-BC
Chairperson, IRB

cz
IRB Exempt Letter.doc

Through our exceptional health care services, we reveal the healing presence of God.

Appendix E

Collegial Letter of Support

February 19, 2019

The University of Kansas Medical Center
Institutional Review Board
3901 Rainbow Blvd., MS 1032
Kansas City, KS 66160

To Whom It May Concern:

I am writing this letter to confirm our support of Judith Anderson, RN, BSN in her Doctorate of Nursing quality improvement project. The project titled, *Utilization of the Short Form Zarit Burden Interview to Screen Dementia Caregivers for Caregiver Burden in the Clinic Setting* will take place onsite at the SSM Health Dean Internal Medicine Clinic – West located at 752 N. High Point Rd., Madison, WI 53717. This project will assist in determining if routine screening of informal caregivers of patients with Alzheimer’s disease and related dementias for caregiver burden should be implemented at the clinic. The information collected will be used to encourage further discussion of how to best meet the needs of our patients with Alzheimer’s disease and related dementias and their caregivers. The project is slated to begin in February 2019, with completion after 90 days post education program. Specific dates are to be determined in collaboration with SSM Health Dean Internal Medicine Clinic – West staff and student.

Sincerely,

Gregory Motl, MD
SSM Health - Division Chief of Skilled Nursing Facilities