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## Assessment of Caregiver Burden in a Memory Loss Clinic

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## **Executive Summary**

### **Introduction of the Problem**

In the United States, there are over eleven million family caregivers providing care for persons with dementia (PWD) (Griffiths et al., 2018; Alzheimer's Association, 2022). The caregiver number in Illinois is over 131,000 (Illinois Department of Public Health [IDPH], 2020). The numbers are expected to increase as the number of people inflicted with dementia and memory loss is expected to rise. There are currently over 230,000 PWD in Illinois and that number is expected to grow to 260,000 by 2025 (IDPH, 2020).

The responsibilities of the caregiver can include taking over finances, managing all medical appointments including scheduling and transportation, and grocery shopping or dropping off meals. Care can evolve to feeding, bathing, dressing, and assisting with toileting the person with dementia. This work can range from taking a few minutes each day to 24-hour a day care. The responsibilities of caregiving, combined with the progression of memory loss, can lead to adverse health effects for the caregiver. These effects may include caregiver burden symptoms of depression, anxiety, and perceived stress (Griffiths et al., 2018; Possin et al., 2019; Leng et al., 2020; Hepburn et al., 2021). Caregiver burden can also adversely affect the care provided to the person with memory loss (Stall et al., 2019).

Caregiver burden assessments assist health care providers in monitoring the health of the caregiver and the person with memory loss as well as determining if there are risk factors that would adversely affect their health. In addition, identifying caregiver burden prompts the provider to provide supportive intervention to reduce the burden and improve health. Prior to this project, no formal caregiver burden assessments were completed at a memory clinic in central Illinois. This project aims to identify if current care at the memory loss clinic is controlling

caregiver burden and to determine what process is best for completing caregiver burden assessment.

## **Literature Review**

Caregiving for a person with dementia or memory loss may include assistance with activities of daily living, finances, medication administration, and housekeeping. As the disease progresses, the caregiver may need to determine if additional in-home care is necessary or if placement into a long-term facility is appropriate. Providing this care may lead to isolation for the caregiver and may put strain on physical and financial health. As a result, caregiving can lead to caregiver burden.

There are national and state level plans in place with recommendations for dementia care. Each plan recognizes the interdependence of the caregiver and the person with memory loss and believes each member of the dyad needs care through assessment and support (Department of Health and Human Services, 2021; IDPH, 2020). In addition, the American Academy of Neurology & American Psychiatric Association (2013), Alzheimer's Association (Fazio et al., 2018), and Family Caregiver Alliance (2006) concur with the determination that caregivers' needs are important to assess including their overall health, depression status, emotional stress, and quality of life.

There are multiple assessment tools available for providers to administer and for caregivers to do self-assessments to assess burden. These tools include, but are not limited to, the Alzheimer's Association Caregiver Stress Check (Alzheimer's Association, 2019), the American Medical Association's Caregiver Self-Assessment Questionnaire (American Psychological Association, 2022a), and the Caregiver Reaction Scale (Pearlin et al., 1990). The most widely used caregiver burden assessment is the Zarit Burden Interview (American

Psychological Association, 2022b; Mapi Research Trust, 2022). This tool's questions include areas of stress, strain, anger, financial security, isolation, and burden. Results of the assessment aid health care providers in providing appropriate care and interventions if caregiver burden is identified.

## **Project Methods**

Caregiver burden assessments were completed by a nurse practitioner in a central Illinois memory loss clinic. The purpose of the assessment was to determine if the care currently being provided at the clinic prevented caregiver burden. The assessment was offered over ten clinical days to all caregivers who were accompanying patients scheduled for assessment/treatment in the memory loss clinic. Prior to implementation, approval from SIUE IRB and the memory loss clinic's IRB were obtained. Each IRB classified the project as a quality improvement project.

A Zarit Burden Interview (ZBI), 22-question self-assessment, was offered to each caregiver. A demographic questionnaire requesting information on the relationship to the patient, site of residence of the caregiver, age, sex, marital status, ethnicity, educational background, working status, hours spent providing care for the patient, and how long the patient has had memory loss was provided to each participating caregiver. This questionnaire also included questions related to gerontologist visits, clinic-associated support program participation, and neuropsychological assessment completion. The ZBI and demographic questionnaire were completed while the provider administered the Mini Mental State Exam (MMSE) to the patient. The score of the MMSE was documented on the associated demographic questionnaire.

## **Evaluation**

The ZBI scores, MMSE scores, and demographic information were entered into an EXCEL spreadsheet for further assessment to identify caregiver burden and possible associated

factors for the burden. Any score above 0 (range of 0-88) on the ZBI reveals a level of caregiver burden. A higher score represents a higher level of burden. The total points possible on an MMSE is 30. Scores of 21-29 reveal mild cognitive impairment; 11-20 represents a moderate level of cognitive impairment; scores 10 and below represents severe cognitive impairment. Although a score of 30 is considered normal, overall assessment of a patient is not based on an MMSE score alone.

There was a total of forty-six candidates for inclusion in this project. Of those, twenty-seven chose to participate. Two of the twenty-five caregivers did not fully complete the paperwork and their partial information was not included in the overall assessment. Demographic information revealed 72% of caregivers identified their gender as female and 28% as male. Most caregivers were spouses (72%). Children/children-in-law made up the other 28% of caregivers. Ethnicity was 96% White and 4% Black. Caregiver ages varied: 80s – 32%; 70s – 28%; 60s – 20%; 50s – 16%; 40s – 4%. All caregivers had at least twelve years of formal education and 28% had 16+ years of education. Eighty percent of the caregivers were retired. Twenty percent of the caregivers were still employed and 12% of the total were working fulltime. Caregiver residence was primarily with the person with memory loss, 76%; with the remaining 24% of caregivers living outside of the home. The range of caregiving hours ranged from <1 hour daily to 24-hour daily care. None of the participating caregivers had participated in a family educational session with the gerontologist nor had any participated in clinic associated support programs. There were also no patients accompanying the participating caregivers who had received a neuropsychological assessment.

The patient's MMSE score was reviewed and compared to the caregiver's ZBI score. Although all caregivers had some level of caregiver burden with scores ranging between 10-

63/88, a low score on the MMSE was not necessarily associated with a higher score on the ZBI. The highest level of caregiver burden was from a 53-year-old daughter who was working full time, lived outside of the home, had 14 years of education, and provided 10-15 hours of care weekly. Her ZBI score was 63/88 and the patient's MMSE score was 24/30 (mild cognitive impairment). In contrast, an 89-year-old husband, who was retired, living in the home, and providing care 24 hours daily scored 36/88 and his wife's MMSE score was 0/30 (severe cognitive impairment).

There were limitations during this project due to the COVID-19 pandemic. Staffing issues and clinical schedule changes impacted the original plan of implementation resulting in only one nurse practitioner completing the assessments. There were unanticipated obstacles, including the addition of 5-10 minutes of length on some visits due to implementation of the assessment, the scheduling of medical students, physician assistant students, and residents in the clinic during the August 2022 assessment period, the late arrival of patients, and the occasional difficulty experienced by the caregiver in completing the forms. An unexpected benefit was observed as well. When caregivers were completing the ZBI and demographic questionnaire, they were less likely to interrupt or prompt the patients during MMSE administration.

Due to the project design and limited number of participating caregivers, the data, although helpful, is not generalizable. That does not negate the results that all participating caregivers were experiencing some level of caregiver burden.

### **Impact on Practice**

Formal caregiver assessment is being discussed at an administrative level at the memory clinic. Based on the results of the project, further assessment and interventions need to be implemented and the researcher is seeking support. The obstacles during each visit, including

assessments taking a few minutes longer, impacts the flow of clinic and alternative assessment tools are being explored. Alternative timing of administration may be considered including having the assessment completed during the rooming process.

If caregiver burden assessment is to be implemented throughout the memory clinic, the remainder of the providers will need to be educated and trained on the Zarit Burden Interview score interpretation. A more formal data system vs an EXCEL spread sheet would also be of benefit for statistical analysis. It would also be of benefit to assess caregivers who are participating in clinic-associated support programs to determine if the interventions are effective, and if so, how to expand them to reach more dyads.

## **Conclusions**

Caregiver burden impacts the health of the caregiver and the person with memory loss. As the numbers of people with dementia and memory loss grows, so shall the numbers of caregivers and the potential for caregiver burden. Assessment for caregiver burden is supported by national and state programs, medical associations, caregivers' organizations, and disease associated organizations. Caregiver burden assessment provides health care providers with an opportunity to identify risk factors which may adversely impact the health of the caregiver and the person with memory loss. Assessment provides them with an opportunity to intervene with supportive measures to improve the health of the dyad.

This project was designed based on the Deming's Plan-Do-Study-Act method which focuses on an initial small-scale analysis. The Plan-Do results revealed that 100% of the participating caregivers had some degree caregiver burden. The Study-Act steps may include assessment of caregiver burden over time versus a one-time assessment. After further study on levels of caregiver burden, interventions for burden relief should be assessed.

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