



RSGC  
Royal St. George's College

The Young Researcher

2020 Volume 4 | Issue 1

# The Assessment of Unpaid Dementia Caregivers by Primary Care Clinicians

Asha Kalapatapu

## Recommended Citation

Kalapatapu, A. (2020). The assessment of unpaid dementia caregivers by primary care clinicians. *The Young Researcher*, 4 (1), 220-233. Retrieved from <http://www.theyoungresearcher.com/papers/kalapatapu.pdf>

ISSN: 2560-9815 (Print) 2560-9823 (Online) Journal homepage: <http://www.theyoungresearcher.com>

All articles appearing in *The Young Researcher* are licensed under CC BY-NC-ND 2.5 Canada License.

# The Assessment of Unpaid Dementia Caregivers By Primary Care Clinicians

Asha Kalapatapu

This research study explores the relationship between the mental health of informal dementia caregivers and the assessment of this issue by primary care clinicians. Through the use of a survey, data was gathered to answer the question as to whether primary care clinicians address and identify the needs of caregivers in the outpatient setting, given the high rate of caregivers of dementia patients suffering from caregiver burden and its effect on their wellbeing. This study captures the frequency of primary care clinician identification of caregivers, evaluation of their stress, and referral to outside resources. It hypothesizes that primary care clinicians oftentimes do not address caregiver needs, due to time constraints, the large number of informal dementia caregivers, and the extent of their unmet needs and need for additional aid. After surveying primary care clinicians, the study concludes that while the majority of primary care clinicians identify the informal dementia caregiver, they less frequently evaluate their level of stress or refer them to outside organizations or resources.

*Keywords:* primary care clinician, informal dementia caregiver, persons with dementia (PWDs)

## Introduction

Dementia is defined by the National Institute of Aging (2017) as a loss of cognitive function -- thinking, remembering, and reasoning -- to the extent to which it hinders a person's day to day activities. As the proportion of the elderly diagnosed with Alzheimer's dementia in the United States continues to grow significantly (Khanassov & Vedel, 2016), research indicates 8.4 million Americans aged 65 or older will suffer from the illness by 2030, according to the Alzheimer's Association (2019). Given the "complex interactions between cognitive deficits, psychological symptoms, and behavioral abnormalities" (Muller-Spahn, 2003) that persons with dementia, or PWDs,

endure, the support of a caregiver is essential for bettering the patient's and caregiver's quality of life (Brodaty & Donkin, 2009).

While research shows that PWDs are far more likely to live in a community or care facility than other recipients of care (American Association of Retired Persons), it is nevertheless true that approximately 75% of PWDs receive support from relatives or friends (Schultz & Martire, 2004), often referred to as informal, or unpaid, caregivers. There are quite a few explanations as to why informal caregivers fulfill this role, including "a sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures, or in rare instances, greed" (Eisdorfer, 1991). The AARP reported that 60% of these informal caregivers are female, 57% are married, and roughly 41% are un-

employed. Studies have demonstrated that unpaid caregivers of PWDs often take the role of providing hands-on care, including dressing, toileting, bathing, and feeding, among other daily activities (Brodaty & Donkin, 2009; AARP, 2015). Studies find that the burden of these essential tasks result in emotional and physical stress and puts the caregiver's health at risk (AARP, 2015).

## Literature Review

### The Impact on Unpaid Dementia Caregivers

The strenuous tasks executed by unpaid dementia caregivers often increases their risk for high levels of stress, anxiety, and depression, among other health complications. Research at the University of California at Berkeley found that up to 40% of dementia caregivers suffer from depression, and most experience raised levels of social isolation, anxiety, and irritation (Anwar, 2017). The poor health outcomes caused by the daily stress of caregiver tasks is attributed to what is known as caregiver burden (Litzelman et al., 2015). This conclusion is supported by the *American Journal of Nursing* (2008), which found that "psychological distress, impaired health habits, physiologic responses, psychiatric illness, and physical illness" can be held responsible by the consequence of caregiver burden.

On the other hand, research reveals that playing the role of an informal caregiver could be associated with positive wellbeing. The U.S. National Library of Medicine (2009) reported that between 55% and 90% of dementia caregivers enjoy the feelings of togetherness, reciprocal bonding, increased faith, and the sharing of activities through the time spent with the PWD. However, given the extensive amount of time needed to provide adequate care for the PWD, dementia caregivers tend to experience an influx of negative consequences rather than positive ones. A study surveying 227 U.S. dementia caregivers concluded that almost 25% spent 40 hours or more each week caring for the PWD, in comparison with 16% of non-dementia caregivers (AARP, 2015). Thus, it becomes difficult to balance the responsibilities of work and caregiving, contributing to financial, social psychological and physical stress (Brodaty & Donkin, 2009). Indeed, numerous groups, including the Alzheimer's

Association and the U.S National Library of Medicine (2009), have conducted studies concluding that dementia caregivers experience higher burden rates due to the increased amount of time required to tend to their loved one.

### Available Resources

While the support offered to informal dementia caregivers is tailored to each individual, research consistently demonstrates the positive correlation between the well-being of the caregiver and the amount of support received (Brodaty & Hadzi-Pavlovic, 1990; Cohen, 2004 ). The U.S National Library of Medicine (2009) explains three categories of support: instrumental support (aid with daily tasks and work in the household), informational support (insight from healthcare professionals or those knowledgeable about caregiver burden) and emotional support. A popular resource for dementia caregivers is the Alzheimer's Association, which provides "information, emotional support, practical advice, support groups, training programs, help sheets, toll-free helplines, and useful websites" (Brodaty & Donkin, 2009; Alzheimer's Association 2019).

Yet over 80% of unpaid dementia care-takers state that they could use more information or help regarding caregiving, according to the AARP (2015). More specifically, those caring for PWDs are more likely to undergo emotional stress and furthermore desire additional information pertaining to controlling their stress (49%) and managing difficult behaviors (31%) in regards to the PWD (AARP 2015). Given the plethora of available resources, it is frequently questioned as to why informal dementia caregivers are unaware of free or low-cost services and resources. Many attribute this information gap to healthcare providers, as only 16% of unpaid dementia caregivers report being questioned by a healthcare provider about what they may need in order to improve their well-being (AARP 2015). Consequently, 39% of dementia caregivers believed that discussions with healthcare providers regarding recipient care would be helpful and 27% were intrigued by conversations about self-care (AARP, 2015). The World Health Organization (2012) states that ultimately it will become difficult to intervene in the detrimental symptoms dementia caregivers experience without the consistent involvement of primary care.

## Gap in Research

Despite the abundance of research regarding the impact taking care of PWDs has on a caregiver's health, research on the primary care clinician's assessment of dementia caregivers is minimal. As recorded previously, researchers have gained information pertaining to the unpaid dementia caregiver's belief as to whether or not their needs are being met by healthcare providers (AARP, 2015). However, insight into whether primary care clinicians believe that they are holding such discussions has yet to be fully accounted for. For instance, while Davis et al. (2019) did study the frequency of dementia caregiver assessment and identification by healthcare professionals, its methodology was somewhat limited, as electronic medical records (EMRs), or a digital collection of stored health information, were assessed, rather than direct conversations with healthcare professionals. Conversations regarding the needs of the caregiver may have been held in the outpatient setting, however may not be recorded in the EMRs. After reviewing research about informal dementia caregivers, and the resources that may be directed to them by healthcare professionals, there appears to be a lack of information on whether primary care clinicians hold these essential discussions with the caregivers. The purpose of this study is to explore whether primary care clinicians are adequately identifying unpaid dementia caregivers and directing them to available resources after assessing their level of burden or stress. This leads to the question: Do primary care clinicians address and identify the needs of unpaid dementia caregivers in the outpatient setting<sup>1</sup>? I made the assumption that healthcare providers most suitably fill the role of assessing the needs of unpaid dementia caregivers and directing them to adequate resources, due to their experience and knowledge in the field. Given the large proportion of caregivers of PWDs that believe that further help would be beneficial to improving their mental health, I hypothesize that primary care clinicians in most cases do not address caregiver needs to the extent in which it is necessary.

1 Outpatient care is most frequently provided in medical offices

2 Emails distributed under the supervision of internist Dr. Viswanath Kalapatapu MD at Katy Internal Medicine Associates

## Methodology

### Participants

Participants of this study included primary care clinicians such as nurse practitioners, physician assistants, internists, geriatricians, and family doctors working in the outpatient setting. Although predominantly in practices located in Houston, Texas, participants were surveyed from varying cities across the country. Given the diversity in the race and gender of the participants, results were not skewed to one reigning background. All participants were volunteers.

### Materials

A self-created survey via Google Forms (Appendix A) was required for the participants to complete. Thus, it was essential for the participants to acquire a device, such as a smartphone, laptop computer, or desktop computer, in addition to internet access. The survey link was distributed to primary care clinicians via email<sup>2</sup>. Participants needed to have a regularly checked email address in order to access the survey link.

### Design and Procedure

Methodology employed in the study was a survey due to its ease of use and its flexibility of time to complete the survey. First and foremost, approval from the Campus Review Board was necessary, given the distribution of my survey to outside organizations and research performed on human subjects. The survey examined possible correlations in the identification and assessment of unpaid dementia caregivers by primary care clinicians in order to indicate whether they are adequately providing help to the caregivers. Variables such as race, gender, and number of years in practice of the medical professionals were taken into account. In addition to a direct link to the survey, an explanation of the research project was sent through email. The brief explanation described who I was and what I was studying for my Advanced Placement Research course, given my precursory interest in dementia. The

importance of receiving a high response rate and valid results was also outlined. The participants were told that this was an anonymous survey requiring approximately five minutes, and to complete it within a week of receiving it. A note was provided in the introduction clarifying questions that incorporated a Likert scale. The survey consisted of ten questions, eight of which were multiple choice and two allowed free response. The free response questions inquired about the background of the clinician, including the amount of time they have practiced medicine and the number of patients with dementia they see each week. Two multiple choice questions were interposed regarding the gender and the field of medicine the primary care clinician was in. The four responses pertaining to the background of the primary care clinicians were used to describe the demographics and diversity of the sample participants. Four of the eight multiple choice questions employed a Likert scale, in which participants were asked to rate how often they execute the given action, such as how often they identify the dementia caregiver, evaluate their burden or stress, direct them to an outside resource, in addition to the usefulness of better communication with the Alzheimer's Association. For the two remaining multiple choice questions, the participants were told to "mark all that apply" pertaining to the resources, if any, they directed the caregivers to, and the major factors that have historically hindered this referral.

### Analysis of Data

Given the fact that the survey was created through Google Forms, responses were automatically processed and categorized. Responses were programmed to be transcribed onto a Google Spreadsheet upon its submission by the participants. Furthermore, Google Spreadsheets were essential for the overview of responses. In addition, Google Forms categorized all responses by question and the participants' selected answers through its automation of pie charts and bar graphs in a visually clean manner, providing the percentage and the number of responses for each category or question. For questions utilizing a Likert scale, a high percentage of responses under the "always" category indicated the raised frequency of clinicians properly assessing the caregiver, whereas more responses under the "never" category indicated the opposite.

As for "mark all applicable" questions, the number of boxes checked indicated the extent clinicians' played in directing resources to caregivers. The primary data for my study was furthermore extracted from both the number and the percentage of participants who selected the given response in their survey. It was thus clear to understand the percentage of primary care clinicians that were assessing and identifying the needs of the unpaid caregivers of persons with dementia. Thus, the use of Google Forms for conducting my research was most convenient in its observation and analysis of the data due to its straightforwardness and simplicity.

### Method Advantages

The use of a survey allowed me to easily gain insight into whether primary care clinicians identified unpaid dementia caregivers and their needs. The creation of the survey through Google Forms not only allowed for simple extraction of data, as stated previously, but also enabled participants to complete the survey anonymously and in any length of time. Jones et al. (2013) stated that the use of survey research "allows large populations to be assessed with relative ease." Conducting my research via survey provided the participants with more time to consider their past actions regarding their assessment of dementia caregivers, rather than in person interviews or phone calls. The utilization of a survey also warranted a greater depiction of whether primary care clinicians identify and address the needs of unpaid dementia caregivers than direct observations of electronic medical charts as done in Davis et al. (2019), which stated that it was "quite possible that many providers conduct caregiver assessments routinely without documenting them." Despite the limited amount of questions in my survey, it was concisely able to address my research question, given that my questions were closed ended and directly pertained to my gap in research. My questions specifically inquired about the frequency of dementia caregiver identification and the resources being directed to them by the healthcare professionals, aligning with my initial query as to whether primary care clinicians are addressing and identifying the needs of unpaid dementia caregivers.

## Results

In total, 33 primary care clinicians participated in this research study, with a response rate of approximately 70%. Based on the data extracted from the survey (Appendix A) it is evident that while primary care clinicians overall identify the caregiver (Figure 5), they less frequently evaluate the burden of stress the caregivers may face (Figure 6) and direct them to the proper resources (Figure 7). The majority of participants believed that the insufficiency of direction to the adequate resources is due to a lack of awareness of the available resources (Figure 9); this too was presented in the findings of whether a more concrete system of communication between the Alzheimer's Association and the practices of primary care clinicians was implemented (Figure 10). Furthermore, the results affirm my hypothesis in that primary care clinicians are not identifying and addressing the needs of the caregivers to the extent to which it is necessary.

## Survey Data

### Type of primary care clinician

33 responses

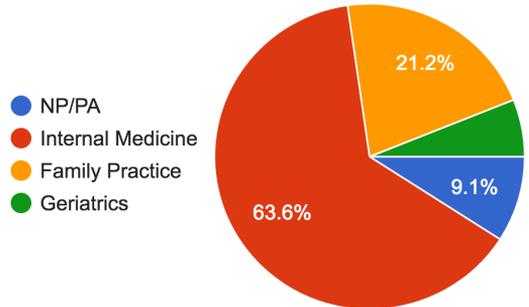


Figure 1. Participant responses regarding the type of primary care clinician they are. 63.6% reported being in internal medicine, 21.2% family practice, 9.1% nurse practitioner/ physician assistant, and 6.1% geriatrics.

### Number of years in practice

33 responses

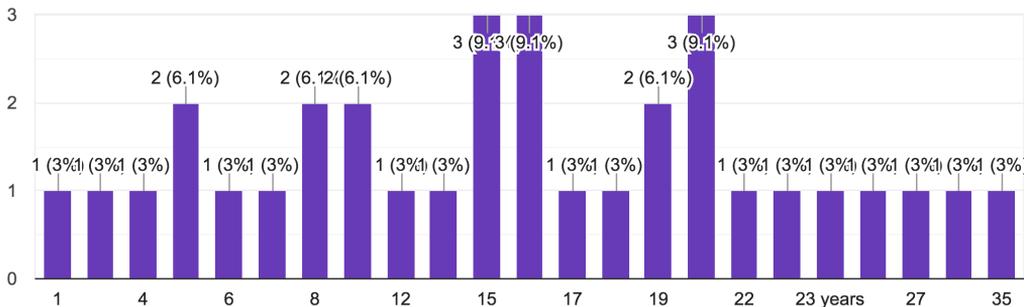


Figure 2. Participant responses regarding the number of years they have practiced medicine. Responses ranged from 1 year to 35 years, with a mean of 15.15 and a standard deviation of 7.94.

# ASSESSMENT OF UNPAID DEMENTIA CAREGIVERS BY PRIMARY CARE CLINICIANS

## Gender

33 responses

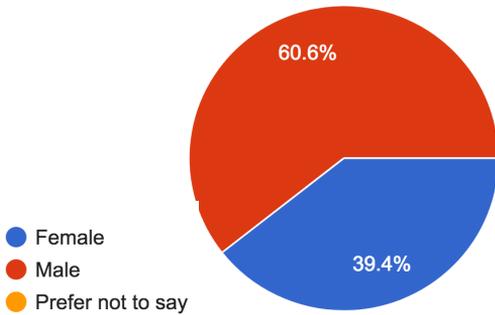


Figure 3. Participant responses regarding their gender. 60.6% identified as male, and 39.4% identified as female. No participants opted out of providing their gender.

## How often do you identify the primary unpaid /family caregiver of your patients with dementia?

33 responses

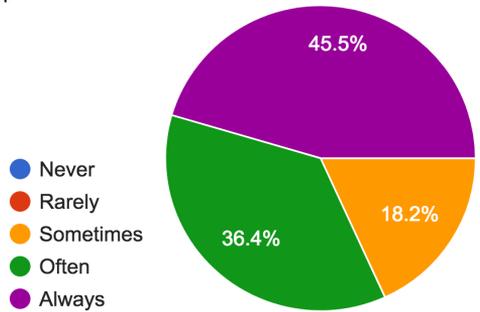


Figure 5. Participant responses to the question “How often do you identify the primary unpaid/family caregiver of your patients with dementia?” 45.5% of participants stated “always,” 36.4% “often,” 18.2% “sometimes,” and no participants reported “never” and “rarely.”

## How many patients with dementia do you see each week?

33 responses

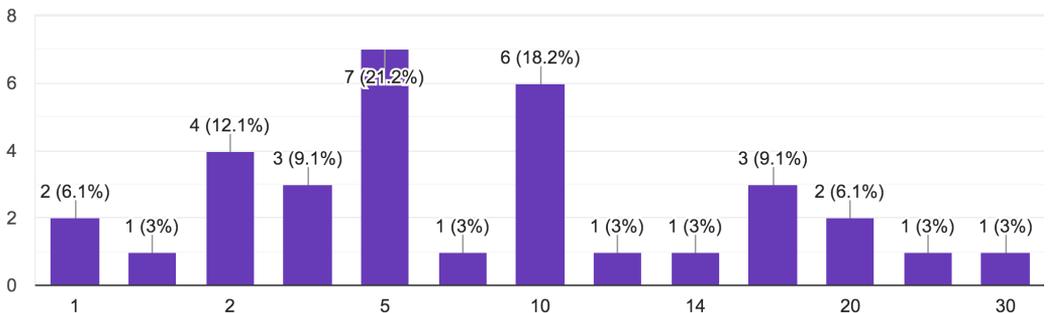


Figure 4. Participant estimates as to how many patients with dementia they see each week. Responses ranged from 1 patient to 35 patients, with a mean of 9.32 and standard deviation of 7.06.

How often do you evaluate caregiver burden and stress?

33 responses

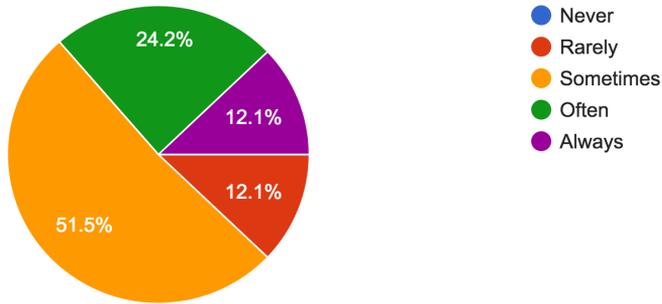


Figure 6. Participant responses to the question “How often do you evaluate caregiver burden and stress?”. 51.5% of participants responded “sometimes,” 24.2% “often,” 12.1% “always,” and 12.1% “rarely.” No participants stated “never.”

How often do you refer caregivers to another provider or organization to address their stress and/or knowledge related to caring for persons with dementia?

33 responses

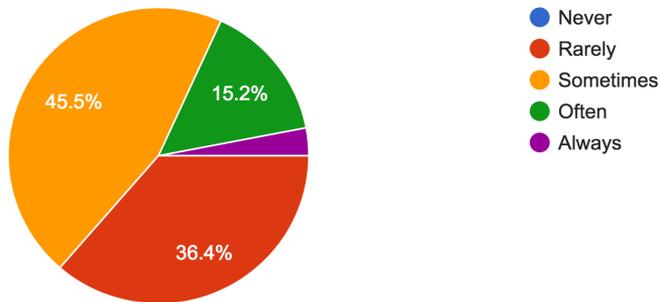


Figure 7. Participant responses to the question “How often do you refer caregivers to another provider or organization to address their stress and/or knowledge related to caring for persons with dementia?” 45.5% stated “sometimes,” 36.4% stated “rarely,” 15.2% stated “often,” and 3% stated “always.” No participants stated never.

## ASSESSMENT OF UNPAID DEMENTIA CAREGIVERS BY PRIMARY CARE CLINICIANS

Which of the following resources do you direct caregivers to? (Mark as many as applicable)

33 responses

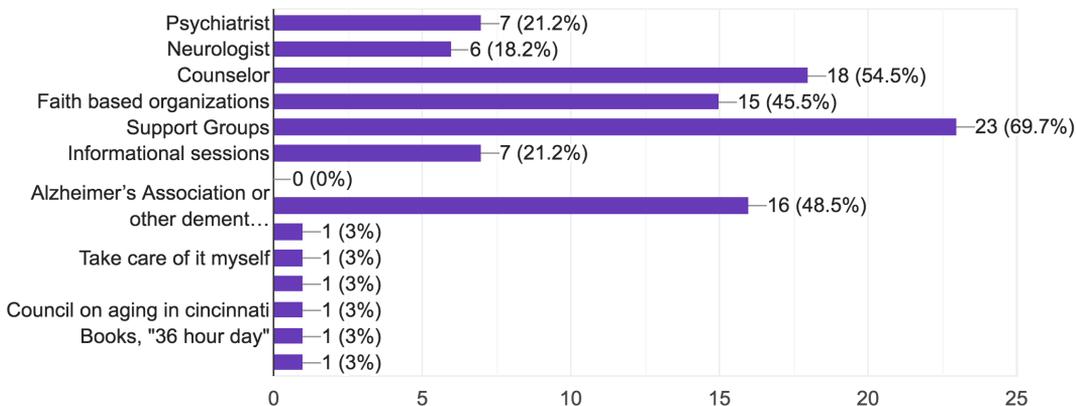


Figure 8. Participant responses to the question “Which of the following resources do you direct caregivers to? (Mark as many as applicable)”. 69.7% of participants direct caregivers to support groups, 54.4% to counselors, 48.5% to dementia-serving nonprofit organizations, and 45.5% to faith-based organizations.

What are the major factors that prevent connecting caregivers with the appropriate resources? (Mark as many as applicable)

33 responses

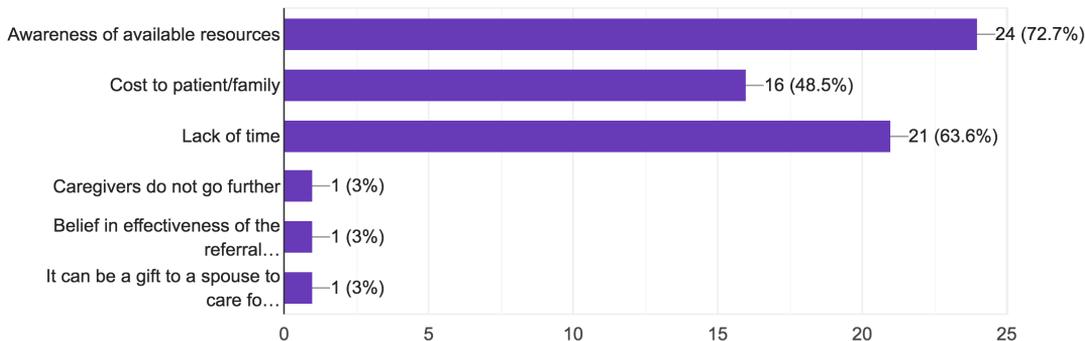


Figure 9. Participant responses to the question “What are the major factors that prevent connecting caregivers with the appropriate resources? (Mark as many as applicable)”. 72.2% of participants believe the lack of awareness of available resources is a major factor preventing the connection, 63.3% stated “lack of time,” and 48.5% stated “cost to patient/family.”

How useful would increased communication from the Alzheimer's Association to your practice be to serving patients and caregivers in your practice?

33 responses

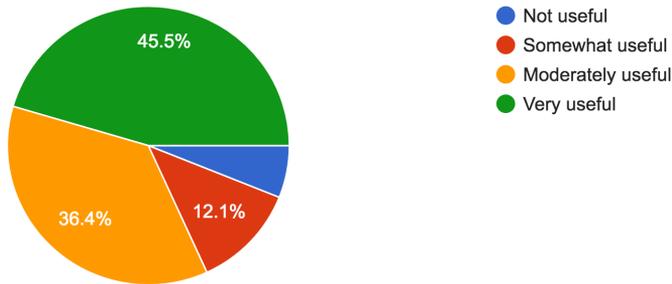


Figure 10. Participant responses to the question “How useful would increased communication from the Alzheimer’s Association to your practice be to serving patients and caregivers in your practice?” 45.5% of participants believe it would be “very useful,” 36.4% “moderately useful,” 12.1% “somewhat useful,” and 6.1% “not useful.”

## Analysis of the Survey

**Identification of Caregivers:** As shown in figure 5, 45.5% of participants stated “always,” 36.4% “often,” 18.2% “sometimes,” and no participants reported “never” and “rarely”. This indicates that overall, primary care clinicians prioritize identifying the caregiver of the dementia patient, given how crucial the aid of a carer is toward PWDs.

**Evaluation of Caregiver Stress:** Though caregivers are commonly identified, the stress that the PWD caregiver endures is less frequently evaluated, according to figure 6. When asked how often they evaluate caregiver burden and stress, 51.5% of participants responded “sometimes,” 24.2% “often,” 12.1% “always,” and 12.1% “rarely”. No participants responded “never”. Seemingly, while primary care clinicians do not give precedence to assessing the mental health of the caregivers, it would be inaccurate to conclude that they never do so.

**Referrals for Treatment:** When asked the question “How often do you refer caregivers to another provider or organization to address their stress and/or knowledge related to caring for persons with dementia?” 45.5% of participants stated “sometimes,” 36.4% stated “rarely”, 15.2% stated “often”, and 3% stated “al-

ways”. No participants stated “never” (figure 7). This indicates that primary care clinicians possibly refer PWD caregivers to outside sources if it seems urgent or if necessary given the circumstances surrounding the health of the caregiver.

**Use of Available Resources:** Shown in figure 8, primary care clinicians were asked to select the given resources, or others not listed, they may direct caregivers to. 69.7% of participants direct caregivers to support groups, 54.4% to counselors, 48.5% to dementia-serving nonprofit organizations, and 45.5% to faith-based organizations. It was evidently less common for the primary care clinicians to refer the caregivers to another medical specialist, as only 21% refer them to psychiatrists, and 18% to neurologists.

**Preventatives of Caregiver Referral:** After being asked what the major factors that prevent connecting caregivers with the appropriate resources were, 72.2% of participants believe it is the lack of awareness of available resources, 63.3% stated “lack of time”, and 48.5% stated “cost to patient/family” (figure 9). Though it is true that not much can be executed on behalf of the healthcare provider to prevent many of these limiting factors, their awareness of available resources can alter. Perhaps, if primary care clinicians further understood the available resources to caregiv-

ers and their benefits, they would take greater consideration in addressing the needs of the caregivers.

**Communication with the Alzheimer’s Association:** Presented in figure 10, participants were given the question “How useful would increased communication from the Alzheimer’s Association to your practice be to serving patients and caregivers in your practice?” . 45.5% of participants believe it would be “very useful”, 36.4% “moderately useful”, 12.1% “somewhat useful”, and 6.1% “not useful”. It is indicated that a better means of communication with dementia-serving organizations would bring recognition to the available resources. This reconfirms the conclusion that increased awareness of the available resources would aid in serving caregivers.

## Discussion

Due to the significant proportion of unpaid dementia caregivers suffering from mental health issues, attributed to caregiver burden (Anwar 2017), it is concerning that primary care clinicians do not take greater initiative to offer them additional resources, considering their insight into the individual’s wellbeing. The primary care clinicians do not often take the supplementary step of evaluating the burden of the unpaid dementia caregiver, as 51% only do so “sometimes.” This supports the 2015 finding that 39% of dementia caregivers believe discussions with healthcare professionals regarding patient care would be beneficial (AARP 2015), and thus further establishes the need for primary care clinicians to play a larger role in diminishing the common side effects of caregiver burden. When asked how often they direct the caregivers to another provider or organizations to ease their stress, nearly 46% of primary care clinicians stated that they do so “sometimes” and 36% stated “rarely,” only 3% stating “always.” The participants may identify the caregiver, and possibly evaluate their level of stress, yet a significant proportion do not take the initiative to resolve the common phenomenon of caregiver burden. However, the finding that they do not direct unpaid dementia caregivers to the appropriate resources could be out of their hands, considering that about 73% of participants stated that the lack of awareness of the available resources is a major barrier, 63.3% stated “lack of time,” and 48.5% believed it was also the “cost

to patient/family.” Additionally, 45% of primary care clinicians “always” and 36% “often” identify the primary caregiver of the dementia patient, demonstrating that they recognize the responsibility of the lives of PWDs the caregivers bear. Primary care clinicians seem to be aware of the task ahead of the caregivers, however multiple factors influence the likelihood of their recognition of caregiver burden.

## Solutions

Given the conclusion that primary care clinicians do not adequately identify and address the needs of the dementia caregivers, there are a number of plausible approaches to diminishing this common issue. One of the major factors preventing the evaluation of caregiver burden is the lack of time with the patient. Furthermore, if caregivers were told to complete a form regarding their level of caregiving-related stress while in the waiting room, primary care clinicians could take it under review when assessing other mandatory medical forms. Questions could include: “How emotionally distressing do you find (patient’s) behavior?”; “How often in the past six months, have you felt like screaming or yelling at (patient) because of the way he/she behaved?”; “In the past month or so has caregiving made you feel overwhelmed or extremely tired?”; or “In the past month, have you felt depressed, sad, had crying spells or felt like you often needed to cry?”. After taking review of the caregiver’s completed form, primary care clinicians would be able to further address the needs of the caregiver and subsequently make referrals to the appropriate resources. However, there is seemingly a gap in knowledge between the primary care clinicians and the available resources. Dementia-serving nonprofit organizations such as the Alzheimer’s Association offer a free 24/7 helpline created to coach caregivers and connect them with the appropriate resources. Resources offered by the Alzheimer’s Association includes but is not limited to: live chats, support groups, online courses, informational sessions, message boards, help sheets, and helpful websites (Alzheimer’s Association 2019). The Alzheimer’s Association or other dementia-serving organizations could team with the healthcare providers to better relay the available resources to the caregivers. I suggest that primary care clinicians attend a seminar on caregiver health, offered by nonprofit de-

mentia-serving organizations, to gain a better understanding of how to treat unpaid caregivers of PWDs. However, out-of-office participation may not be truly feasible given a lack of time medical professionals often experience. If faced with this issue, perhaps they can watch an online video provided by the Alzheimer's Association covering the treatment of caregivers.

### Limitations

As four out of the ten questions inquired about the background of the participants, only six questions were used to determine the identification and assessment of caregivers, due to the low likelihood of participant willingness to complete longer surveys. Furthermore, additional questions may have better gauged whether or not the initial hypothesis was correct, and may have better demonstrated the complexity of the assessment of caregivers. Supplementary questions could include "How aware are you of the available resources to caregivers," and "Do you believe that healthcare providers have an obligation to fulfill caregiver needs." Another prominent limitation may be the number of primary care clinicians partaking in this research survey; I received 33 responses at approximately a 70% response rate, and a greater scope of responses may have adjusted the accuracy of the final results. Additionally I did not poll the city and/or clinic each participant was from, which ignores the question of the extent to which location influences the assessment of caregivers. It should be taken into consideration that it is highly possible that participants may not have been aware of what the Alzheimer's Association provides to caregivers looking for additional support. Perhaps this justifies the large proportion of participants that do not believe better communication between the Alzheimer's Association and healthcare providers would aid in addressing caregiver needs. It may also confirm the reasoning behind the low likelihood of the clinicians directing caregivers to outside resources or organizations (*figure 7*). Another consideration is the social desirability bias of the participants- they may have not completed the form with complete honesty, or may have exaggerated the frequency of executing the given actions on the survey out of a sense of embarrassment or denial. However, the survey was anonymous, so it is unlikely that the participants had any motivation to be untruthful.

Lastly, only one past research study investigated the extent to which healthcare providers assess the needs of caregivers (Davis et al. 2019). Furthermore, my research study cannot be widely compared to past research due to the lack of previous studies.

## Conclusion

### Implications

My research was successfully able to bridge the gap between the mental health of caregivers of PWDs and whether their needs are being met by healthcare professionals. It was previously established that unpaid dementia caregivers are frequently subject to mental health issues due to caregiver burden (*American Journal of Nursing* 2008). Considering the vast amount of resources available to caregivers, it was unanticipated to see that 80% of dementia carers believe they could use additional support regarding caregiving (AARP 2015). Thus, research was conducted on the role primary care clinicians play in the identification and addressing of caregiver needs in the outpatient setting. With the exception of the 2019 American Geriatrics Association clinical study (Davis et al. 2019), research on the identification and assessment of informal dementia caregivers was minimal. Furthermore, I gained insight into whether primary care clinicians were assessing the stress of the caregivers and directing them to the adequate resources, as needed. My research shows that while the primary care clinicians overall identify the caregiver, they do not frequently evaluate their level of burden and direct them to the proper resources, confirming my hypothesis. This implies that the healthcare providers are not playing a major role in resolving the burden caregivers may face; they instead accept that such mental health struggles are present, however may not put in exponential effort into diminishing these common issues. My results align with the finding that a large proportion of dementia caregivers could use more support (AARP 2015), as the lack of involvement of the healthcare providers may contribute to the growing need for additional caregiver help. This may primarily be due to the primary care clinicians' lack of awareness of the resources available to unpaid dementia caregivers. While a variety of resources are available to further aid in dissolving the

stress of caregiving, primary care clinicians have yet to take advantage of these opportunities. If primary care clinicians were to have a better understanding of the resources and their benefits, perhaps they would subsequently direct caregivers to the appropriate resources adequately. Additionally, my results align with those of the American Geriatrics Society (Davis et al. 2019), which concluded that while healthcare providers overall identified the caregiver, they were less likely to assess their wellbeing and needs. Therefore, my hypothesis that primary care clinicians do not address the needs of unpaid dementia caregivers to the extent to which it is necessary is confirmed.

### Future Research

My findings have shown that the majority of participants believe the lack of awareness of the available resources is a hindrance of connecting caregivers with the appropriate resources. Thus, future research can be conducted on the aptitude of primary care clinician knowledge on resources available for caregivers of PWDs. Tackling this question would allow us to further understand the complexity of why the caregivers need additional help. In addition, further research can be conducted on whether increased communication between primary care clinicians and organizations involving the care of dementia patients would help in addressing the needs of caretakers. This will aid in determining whether improving this relationship will increase the proportion of healthcare providers directing informal dementia caregivers to outside resources. Ultimately, the project goal was fulfilled in that I reached the conclusion that primary care clinicians do often identify the dementia caregiver, however do not assess their needs and burden to the extent to which is necessary.

## References

Anwar, Yasmin. "Dementia Patients May Die Sooner If Family Caregivers Are Mentally Stressed." *Research UC Berkeley*, 26 June 2017, [vcresearch.berkeley.edu/news/dementia-patients-may-die-sooner-if-family-caregivers-are-mentally-stressed](http://vcresearch.berkeley.edu/news/dementia-patients-may-die-sooner-if-family-caregivers-are-mentally-stressed).

Brodsky, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, 11(2), 217–228.

Davis, Michelle L., et al. "Taking Care of the Dyad: Frequency of Caregiver Assessment Among Veterans with Dementia." *Journal of the American Geriatrics Society*, vol. 67, no. 8, 2019, pp. 1604–1609., doi:10.1111/jgs.15882.

Jones, T L et al. "A quick guide to survey research." *Annals of the Royal College of Surgeons of England* vol. 95,1 (2013): 5-7. doi:10.1308/003588413X13511609956372

Khanassov, V., & Vedel, I. (2016). Family Physician-Case Manager Collaboration and Needs of Patients With Dementia and Their Caregivers: A Systematic Mixed Studies Review. *Annals of family medicine*, 14(2), 166–177. doi:10.1370/afm.1898

Litzelman, K., Skinner, H., Gangnon, R., Nieto, F., Malecki, K., & Witt, W. (2015). The relationship among caregiving characteristics, caregiver strain, and health-related quality of life: Evidence from the Survey of the Health of Wisconsin. *Quality of Life Research*, 24(6), 1397–1406. Retrieved from <http://www.jstor.org/stable/44849144>

Müller-Spahn F. (2003). Behavioral disturbances in dementia. *Dialogues in clinical neuroscience*, 5(1), 49–59.

NAC (National Alliance for Caregiving) & AARP Public Policy Institute. Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50+; 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/caregivers-of-older-adults-focused-look.pdf>. Accessed October 25 2019

Schulz Ft., Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004;12:240–249

Schulz, R., & Sherwood, P. (2008). Physical and Mental Health Effects of Family Caregiving. *The American Journal of Nursing*, 108, 23-27. Retrieved from <http://www.jstor.org/stable/24466476>

"What Is Dementia?" *Alzheimer's Disease and Dementia*, 2019, [www.alz.org/alzheimers-dementia/what-is-dementia](http://www.alz.org/alzheimers-dementia/what-is-dementia).

"What Is Dementia? Symptoms, Types, and Diagnosis." *National Institute on Aging*, U.S. Department of Health and Human Services, 2017, [www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis](http://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis)

## Appendix A: Survey Questions and Explanation

### The Assessment of Unpaid Dementia Caregivers by Primary Care Clinicians in the Outpatient Setting

My name is [REDACTED] am an [REDACTED] student at [REDACTED] taking an Advanced Placement Research Class. In this course, I must complete a compelling, scientifically valid research study. I am studying primary care clinicians' identification and needs of unpaid/family caregivers of persons with dementia. In order for me to have valid results and a final product for my class, it is essential to receive a high response rate. I hope you can help me. This survey is anonymous and will only take five minutes. Please complete it within one week of receiving it. Thank you for taking the time to help me with my research.

Disclaimer:

For questions on frequency of caregiver assessment, consider how often you conduct these actions out of all interactions with patients/caregivers, not in relation to how often you see an individual patient or dyad (i.e., "Patient A/Caregiver A").

Family/unpaid caregivers are unpaid individuals, such as a spouse, family member, or friend, involved in assisting others with daily living or medical tasks.

"Needs" of caregivers can be psychological, monetary, time, materials needed for care such as medications, modifications to living environment, etc.

\* Required

**1. Type of primary care clinician \***

*Mark only one oval.*

- NP/PA
- Internal Medicine
- Family Practice
- Geriatrics

**2. Number of years in practice \***

---

**3. Gender \***

*Mark only one oval.*

- Female
- Male
- Prefer not to say

**4. How many patients with dementia do you see each week? \***

---

# ASSESSMENT OF UNPAID DEMENTIA CAREGIVERS BY PRIMARY CARE CLINICIANS

**5. How often do you identify the primary unpaid/family caregiver of your patients with dementia? \***

*Mark only one oval.*

- Never
- Rarely
- Sometimes
- Often
- Always

**6. How often do you evaluate caregiver burden and stress? \***

*Mark only one oval.*

- Never
- Rarely
- Sometimes
- Often
- Always

**7. How often do you refer caregivers to another provider or organization to address their stress and/or knowledge related to caring for persons with dementia? \***

*Mark only one oval.*

- Never
- Rarely
- Sometimes
- Often
- Always

**8. Which of the following resources do you direct caregivers to? (Mark as many as applicable) \***

*Check all that apply.*

- Psychiatrist
- Neurologist
- Counselor
- Faith based organizations
- Support Groups
- Informational sessions
- Alzheimer's Association or other dementia-serving nonprofit organization
- Other: \_\_\_\_\_

**9. What are the major factors that prevent connecting caregivers with the appropriate resources? (Mark as many as applicable) \***

*Check all that apply.*

- Awareness of available resources
- Cost to patient/family
- Lack of time
- Other: \_\_\_\_\_

**10. How useful would increased communication from the Alzheimer's Association to your practice be to serving patients and caregivers in your practice? \***

*Mark only one oval.*

- Not useful
- Somewhat useful
- Moderately useful
- Very useful