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Barriers to Utilizing Resources for the Dementia Caregiver

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Barriers to Utilizing Resources for the Dementia Caregiver

By

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A Thesis Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master

In

Aging Studies

Minnesota State University, Mankato

Mankato, Minnesota

December 2019

December 10, 2019

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Aging Studies, Minnesota State University

Mankato, MN 2019

Abstract

The family caregiver of a person with dementia (PwD) provides valuable care and experiences negative health outcomes as a result. These negative health outcomes can be mitigated utilizing resources, however utilization rates remain low. While there is some research on barriers to accessing resources there is very little focused on caregivers of PwD. This study through semi-structured interviews with caregivers of PwD takes a deep look into the experience of first signs, diagnosis, and utilization of resources to better understand what those barriers might be. This study found that because of the healthcare structure caregivers do not learn about resources until much later in their journey and in hindsight agree that using them early on would be beneficial, especially caregiver support group. Agencies and institutions that seek to support caregivers of PwD can take this information and make changes in their approach to increase utilization that will improve the health of both the caregiver and the PwD.

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Barriers to Utilizing Resources for the Dementia Caregiver

Family caregivers of persons with dementia (PwD) are an invaluable source of free care to many in our society. Along with the joys of caregiving they experience stress that leads to negative health outcomes. According to the Life Stress Paradigm theory (Ensel & Lin, 1991; Judge, 2010) these negative health outcomes can be offset by utilizing resources. Some of the community resources that have been shown to improve both caregiver and care receiver health are: adult day care, home care, respite care, support groups, and caregiver training. Utilization of these community resources remains low and much still remains to be understood as to why this is the case. Very few studies have looked specifically at the unique group of PwD that experience a higher load of caregiver stress and account for more than half of caregiving. For these reasons this study examines the experience and barriers of caregivers using community resources. This was done by conducting semi-structured interviews with caregivers of PwD.

This study has the potential to provide valuable information for the many organizations small and large who provide these community resources. Understanding how to tailor a resource to make it more available to those who need it can be beneficial. It is also valuable for organizations that have a vested interest including health care, government, or national nonprofits such as the Alzheimer's Association. While they may not directly provide the service they work as partners in planning, supporting, and funding initiatives that support the caregivers of PwD.

Background

In 2013, unpaid family caregivers provided an estimated 470 billion dollars worth of care to aging adults (Family Caregiver Alliance, 2015). This estimate is significant,

especially when one considers it is more than the 451 billion dollars spent on Medicaid in 2016 (Centers for Medicare & Medicaid Services, 2017). Of the total amount of estimated caregiving that is provided in the United States, more than half was provided to persons with dementia (PwD Link, 2015). Currently there are 46 million people over 65, and that will increase to 98 million by 2060 (Population Reference Bureau, 2016). This is largely due to the baby boomer generation being proportionally larger than the preceding and following generations and increasing life expectancy. Of those aging adults it is estimated that 14 million in 2050 will experience dementia (Population Reference Bureau, 2016). Concurrently, as the number of individuals needing care will grow the proportional number of available family caregivers will shrink. This is due to two main reasons: first, there are fewer children in the generation younger than the baby boomers and second; more of those caregivers (mostly women) will be employed. The amount of care that family caregivers provide without pay is substantial, over half of it is for PwD, and as society ages we will need more care and have less of that free care available.

Caregivers as a valuable resource. Most older Americans value independence and desire to remain in the least restrictive setting that is possible, which is usually their own home (Binette & Vasold, 2018). Remaining at home with a family caregiver to support is often more cost-effective than either an assisted living home or a nursing home. This is something the Minnesota Department of Human Services (MNDHS) seeks to help citizens understand in their Own Your Future Minnesota guide (2016). According to MNDHS, the average cost of assisted living in Minnesota is more than \$4,000 per month, this does not include any services that may be needed like medication

management or bathing assistance. A nursing home costs \$7500 per month on average. Home Care agencies that can provide some help in the home cost around \$26 per hour. The high cost of long-term care and the desire to remain independent likely encourage family caregivers to support their family member in their home. However, as a result of caregiving demands, a caregiver can experience negative health outcomes. Experiencing negative health outcomes increases the risk for nursing home placement (Spillman, 2009). Considering the significant amount of care that is provided, the increasing demand for that care, and the decreasing supply of caregivers it is apparent that the role of the family caregiver is highly valuable both fiscally and socially. It follows that preserving this resource is imperative.

Caregiver burden. Family caregivers experience stress with their role, often referred to as “caregiver burden”. This is especially true with caregivers of PwD (Ying, 2018). Caregiver burden leads to negative health outcomes that can affect both the physical and mental health of the caregiver (Potter 2018; Ruiz-Fernández & Ortega Galan, 2019). Some evidence points to depression rates twice as high in caregivers of PwD compared with other caregivers (Joling, 2012). Caregiver burden increases with length of caregiving and the intensity, or length of time and amount of care (Potter 2018; Ruiz-Fernández & Ortega-Galan, 2019). Caregivers of PwD provide more hours of care per week and for a larger duration of years than other caregivers (Family Caregiver Alliance, 2016). The caregiver burden can be higher with caregivers who are employed (Wang et al., 2018). Spouses with health problems themselves are at a higher risk to experiencing caregiver burden (Chen, Chen, & Chu, 2015). Caregivers of PwD should be an important target for community support as they provide over half of that free family

care and are at greater risk for the negative health outcomes due to caregiver burden. The risk increases even more for those who are employed or have health problems themselves.

Resources. The literature identifies three main types of resources that can help to moderate caregiver burden. They include support from informal social networks, the learned resourcefulness of caregivers, and community-based services. These resources weaken the negative impact of caregiver burden on caregiver health. There are a variety of community-based services that are intended to support the PwD and the family caregiver. Some of them are: adult day care, home care, respite care, transportation, meal programs, support groups, and caregiver training. A growing number of studies are showing the clear positive impact these community-based resources can have on both caregiver health and the PwD (Link, 2015; Castora-Binkley, Noelker, Ejaz, & Rose, 2010). Even though the benefits to using these resources are clear their utilization rates are very low (Mavandadi et al., 2017; Potter, 2018; Mittleman & Bartells, 2014; Hong, Hash, & Lee, 2011). This underutilization of resources raises the questions of “why?” and, “What are the barriers to utilizing these resources?” While these seem like simple and obvious questions there is a surprisingly small body of research addressing the barriers that caregivers of PwD face in accessing resources (Phillipson, Jones, & Magee, 2014).

Literature Review

Barriers

Social/Cultural barriers. In review of the literature, some of the barriers to utilizing caregiver resources that have been addressed are those relating to both social

and cultural factors. One of the major barriers is the caregiver not even perceiving the need for a resource. In a unique qualitative study Dam et al. (2018), the researchers interviewed 10 spousal caregivers and one more member of their social network to understand the barriers. Among the many findings, they discovered one which was that the spousal caregiver did not experience a need for help or in a fear of losing autonomy they would not acknowledge the need. This barrier of unacknowledged need is an important one and something that may be challenging to capture empirically.

Other qualitative studies have uncovered other social or cultural barriers (Dam et al., 2018; Winslow, 2003). One cultural barrier is a self-imposed expectation the caregiver may have that it is their responsibility and their obligation to provide care. They may feel that they want to manage their ‘own tasks’ and not be a burden on others (Dam et al., 2018; Winslow, 2003). Added to this cultural expectation is the reality that acknowledging that they need help can also lead to a loss of control. In Winslow’s (2003) study interviewing 21 family caregivers, they heard remarks about it being a duty as a spouse, or feelings of guilt if they did not take care of their loved one as long as they could. This barrier of perceiving the caregiving role as an obligation that solely falls on the family is of note, especially if it occurs in combination with other barriers.

Another unaddressed barrier is the reality that many caregivers do not utilize resources because the PwD is resistant to the service. In Winslow’s study (2003) it was the most frequently mentioned reason for not using services. In this study it was observed that some PwD did not want to leave the house, some were fearful or embarrassed to have someone else helping them, and others did not want anyone else in

the house. It can become easy to understand the strength of this barrier, especially in combination with the barrier of perceived obligation.

Understanding these significant social and cultural barriers of unacknowledged need, feelings of obligation, and care receiver resistance helps to clarify why services are underutilized. This knowledge may lead to better ways to address such barriers. Having a positive experience with a service can help override feelings of guilt (Winslow, 2003). Knowing that a service is beneficial to the PwD can help overcome the obligation barrier (Winslow, 2003). Open communication with social networks can help caregivers to recognize the need for help (Dam et al., 2018).

Barriers in the healthcare structure. Another set of barriers relates to the health care system or structure. How information about resources is shared, how it is funded, what are the costs, and who qualifies all play a part in creating barriers to utilizing resources. Most medical insurance plans do not pay for caregiver resources or for services that support PwD. The vast majority of PwD have Medicare as their primary form of insurance. The only service that Medicare will pay for in the form of services or resources for a PwD is testing for Alzheimer's disease (one of the main forms of dementia) and care planning regarding treatments and services (Elder Law Answers, 2017). However, this Medicare benefit is very new and it is unclear if PwD and their caregivers are taking advantage of it. If a person qualifies for Medicaid, the national health insurance for the poor, then they may qualify for waiver programs that can help pay for a variety of services. These waiver programs pay for services similar to the list described above, but can also include emergency response systems and homemaker services. An individual qualifies for them based on income and asset guidelines and an

assessment that determines their physical need. It is important to be aware that our current healthcare structure provides little to no financial help with services until you reach a certain financial and physical situation.

The majority of services and resources are either through private organizations that charge by the hour or through nonprofit organizations that are largely grant funded. If an individual is on Medicaid a waiver can pay for the service; limitations and rules apply that can vary from state to state and for each individual's specific eligibility. What is available and the costs can vary considerably from community to community. In addition, eligibility rules can be difficult to understand and inconsistent from place to place and time of application.

Since 2000, the National Family Support Program (NFSP) distributes federal funds to states. They are charged to develop programs that address family caregiver need and there is a great deal of flexibility given to each state on how to spend their allotted funding. The federal budget provides around \$146 million and is 25% matched by non-federal sources (Link, 2015). Compared to the number of caregivers this leaves approximately \$4 per family caregiver; clearly, this is not enough to meet demands, but efforts do help to organize and coordinate services. One initiative, started in 2003, is to provide centers called Aging and Disability Resource Centers (ADRC). These ADRCs provide information and assistance in a wide range of areas and are intended to be a comprehensive resource on many subjects related to aging and disability (Link, 2015). Understanding the variableness of services in what they offer, how one qualifies, and how they are funded is relevant as we study the barriers that exist due to the healthcare structure.

Song-Iee Hong et al. analyzed the 2004 National Long-Term Care Survey and Informal Care-giver Data Set with 1908 participants. This survey reports the prevalence of 10 service barriers related to 10 different services as well as services in general. Utilizing the Behavioral Model of Health Service Hong et al. put caregivers in three categories: light service-users, selective in-home users, and multiple service users. Light service users were those who had lower probability across all 10 services, selective in-home users utilized in-home services like medical equipment, home adaptations, and personal/nursing care, and multiple service users had a higher probability for using all 10 services. This perspective helps to understand the interrelated services. The results showed that the top barriers are awareness, availability, and affordability. In addition for caregivers of PwD privacy and confidentiality was also an important barrier. The analysis also highlighted the reality that those using waivers were more likely to be in the multiple service users group. This is not surprising given that the structure is such that individuals need to pay for services unless they meet the qualifications for a waiver. They also found that cognitive impairment (otherwise known as dementia) was associated with light service use. It was not clear why cognitive impairment was associated with light service use. Clearly awareness and cost are barriers to use, but also highlighted in this study is the realization that additional barriers exist for PwD as utilization is even lower for them.

Macleod, Tatangelo, McCabe, and You (2017) conducted a qualitative study involving semi-structured interviews with 24 family caregivers of community-dwelling PwD and found six barriers and three facilitators to the use of services. Of these barriers and facilitators, over half relate to the healthcare structure. The barriers related to the

healthcare structure were: the inability to find information about relevant services or support, poor quality of services, mistrust of the services, and inflexibility of services. The key facilitator relating to the structure of healthcare was having an “expert” point of contact. The other barriers and facilitators found related to the cultural expectation or beliefs of the caregiver and resistance by the care recipient. From his study it was clear that the lack of assistance to understand both what was available and what was appropriate was a barrier, and that it was overcome by having an “expert” point of contact. This study also found that not having a service in a time or place that works for the caregiver and the care receiver was a barrier. Lack of stimulation and appropriate activities at adult day centers led to perceptions of poor quality. Caregivers felt that staff were not adequately trained and did not trust them with their family member in their home alone. Other qualitative studies conducting interviews with caregivers of PwD echoed the findings of this study. They have found that need for information, need for financial help, the quality of service, and the lack of convenience are all barriers to utilization of services (Vaingankar et al. 2013; Winslow 2003).

In order to address some of these barriers Mavandadi et al. (2017) conducted a study that examined experience of participants in a free program offered through the care receiver’s prescription health care program. Participants were required to be older than 65, be a caregiver 18 or older, live in the community, filled a prescription for an antidepressant, anxiolytic, or antipsychotic in the previous 6 months, and have dementia. This service provided management services including individually tailored education, emotion and problem focused coping skill training, emotional and informational support, and assistance with connecting to community resources. Assistance was provided

entirely over the phone. Half of the participants offered the free service agreed to participate, but only half of those individuals followed through with the assessment and at least two sessions. Importantly they found that caregivers with higher caregiver burden, greater depressive symptomology, and caring for PwD with higher needs had higher rates of enrollment and engagement. This is inconsistent with the findings of previous studies that seem to suggest those with higher caregiver burden are too overwhelmed to participate. These results suggest that the combination of need, convenience, and individual tailoring increased their participation. Another result that was unexpected were the high rates of young caregiver engagement, again this is likely attributable to the convenience of the service. (Mavandadi et al., 2017).

In sum, studies that examine barriers to participation in services designed to aid caregivers and care receivers, it is evident that the healthcare structure plays an important role in utilization. As a whole the system does not do well at providing information about services and paying for them. When it comes to individual agencies the service quality and the convenience or flexibility in how and when it is offered are additional barriers.

Feasibility of availability. Adjacent to the healthcare structure is the platform of how these services are made available. A caregiver may have a grasp on what is available, how they can qualify to use it, are able to pay for it, and what may be appropriate for their situation but they still run into the barriers of when, where, and how it is available. As was discussed in the Mavandadi et al.'s (2017) study making a service convenient in time and place resulted in an increase in participation. Hong et al.'s (2011) analysis of the National Long-Term Care survey pinpointed availability as one of the top

three of the ten barriers they examined. Likewise many of the qualitative studies that interview caregivers cite the inflexibility and accessibility of services as a barrier to use (Vaingankar et al., 2013; Winslow, 2003; Macleod et al., 2017). These studies highlight the reality that when and where a service is offered have an effect on utilization.

Measuring the appropriateness of availability presents challenges. This refers to how relevant the resource is to the individual needs. In healthcare today, a common term used is “person-centered”. Person-centered refers to the idea that care is provided and available in a personalized, proactive, and patient-driven way; it suggests a personalized health plan that fits the specific needs and desires of an individual (U.S. Department of Veterans Affairs, 2017). Knowing that one needs caregiver training, but only receiving that service in a generic way and not in a way that helps in their specific situation is an example of how the way in which a service may be available is a barrier.

It is clear from several qualitative studies that person-centered assistance is desired and the lack of it is a barrier. Help dealing with unique circumstances and individual needs is valued. This was evident in the analysis of the free program Mavandadi et al. (2017) analyzed, when they observed a proportionately higher participation rate in those with higher caregiver burden. In a qualitative study interviewing caregivers in Singapore several unmet needs were found (Vaingankar et al., 2013). Among them was lack of information about the disease, its progression, and services that were designed with the specific needs of a PwD in mind. Many caregivers found themselves not wanting to use services because they were not sensitive to the specific needs of PwD. This was seen either in the inability of staff to deal with behaviors or the lack of appropriate interventions to enrich the lives of the PwD.

In a review of 14 studies of barriers to use of respite services Phillipson et al. (2103) concluded that there is a need for person-centered assessment, matching, and programs that target specific sub groups. This review highlights the reality that use of respite for caregivers of PwD is low and does not appear to match caregiver need. In this review they highlight the reality that behavioral problems are a unique issue and caregivers experience a high psychological burden. Because of this, they propose that a multi-pronged approach is needed to address caregiver beliefs, establish supportive environment for PwD, and provide public education to reduce stigma. Clearly the research suggests that having services that are available at times and places that caregivers need and person-centered appropriate services improve utilization.

Moving Forward

As we consider the life stress paradigm theory, which argues that caregiver burden leads to negative health outcomes, we need to understand where the research fits in and what is there left to be understood. The theory clearly points out that resources, both external and internal (i.e., one's own coping strategies) help to reduce the negative impact of caregiver burden. From this review, we see that barriers impact utilization of these resources. With the many barriers cited, it would be helpful to better understand how access to these services can affect barriers and utilization. There is minimal research on this subject, especially studies focused on caregiver of persons with dementia who provide most of the care and are at greater risk for caregiver burden.

Methods

Theoretical Framework

The stress process model is used to frame the impact of stress on health outcomes; it is derived from the life stress paradigm theory (Ensel and Lin, 1991; Judge, Menne, & Whitlatch, 2010). This theory proposes that resources can moderate the negative impact of stress on health outcomes. Studies suggest that because of the demanding nature of caregiving, especially caregiving to persons with dementia (PwD), stress occurs and negative health outcomes are observed; this experience is referred to as caregiver burden. According to the theory and the research associated with it, access to resources moderate (weakens) the negative effect of stress on health outcomes. These resources can be internal (e.g., individual's coping style), social (e.g., social support or community resources), or material (e.g., funds to pay for services). This study also relies on the Behavioral Model of Health Service Use to explore the relationship of barriers with service utilization. This model recognized that healthcare systems and the external environment effect utilization (Anderson, 1995). This study focuses primarily on how barriers affect patterns of utilization of caregiver services. Utilization rates of community resources are consistently low among caregivers of PwD, they have been found to be as low as 2-11% according to the Department of Health and Human Services, the Alzheimer's Association, and the Administration on Aging (Hong et al., 2011). There are a variety of resources available to caregivers of PwD, such as adult day care, home care, respite care, transportation, meal programs, support groups, and caregiver training, however the availability and types of services vary from community to community. See Diagram A, p.19.

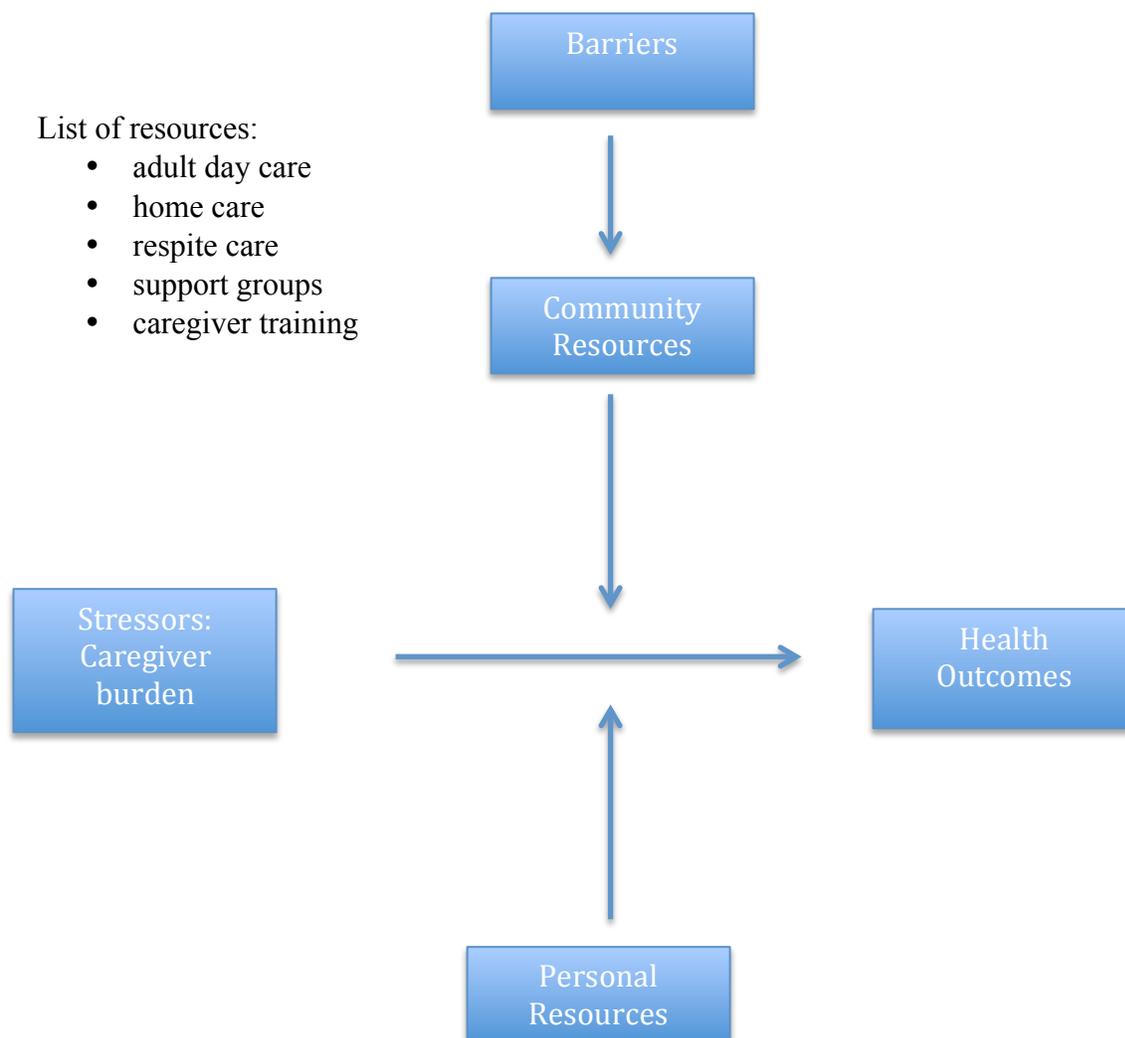
Sample

This study used purposive style sampling. Current or past caregivers of persons with dementia were recruited. They needed to have experience with at least one community resource. They were a mix of both children caregivers and spousal caregivers. They were from both rural (population less than 20,000) and more urban (population greater than 50,000) regions of the state of Minnesota. The reason for recruiting those who had already used resources is to learn how they decided to use services. Interviewing about past experiences gave an opportunity to see the progression, the multiple barriers that may have changed over time, how the caregiver arrived at utilizing a resource, and how they understand benefits of services, if at all, in retrospect.

Recruiting participants. Program Development staff from Minnesota River Area Agency on Aging (MNRAAA) gave contact information of service providers that offer caregiver services in surrounding communities. Participants were recruited by coordinating efforts with these service providers on how to best invite them to participate. They were presented with a simple flyer with contact information to share with possible participants, or they could collect contact information from them to schedule a time later. Another method was the service provider asking permission of potential participants to be contacted directly. If given permission, possible participants were reached out to and informed about the consent form and what to expect with the interview. If the participant was willing to be interviewed a time and a place was scheduled. For the interviews that were conducted over the phone a consent form was sent in advance and signed before proceeding with the interview.

Diagram A
Barriers - community resources - health outcomes

Based on the stress process model this model shows the relationship between stressors and health outcomes. They can be moderated by both community resources and personal resources. Affecting the community resources are barriers to them. These barriers moderate by reducing the utilization of the community resources which then affects the health outcomes.



Data Collection

The consent form was explained to participants and a copy of it was provided. It notified the interviewee what they can expect and that they can discontinue at any time. Once a signed form was received the interview proceeded. The interviews were audio recorded. The interview was conducted either in-person or over the phone. The length of the interview varied depending on responses, but in general were about 30 to 60 minutes.

Demographics. The semi-structured interview covered some demographic details. This included: age, gender, race, and the relation to the PwD. At the end of the interview financial questions were also asked. This information provided a profile of who the caregiver was.

Diagnostic experience. The next set of questions was about the diagnostic process for the PwD. What were some of the early signs, how much time elapsed between that and diagnosis, what resources were provided upon diagnosis? What was the treatment plan? These questions were included to provide a glimpse of timeline from first signs of cognitive deterioration to diagnosis. Certainly knowing when to target caregivers in their journey is helpful, asking these questions sheds more light on that journey. In addition, their experience in this diagnostic process could be a barrier, so understanding this experience was helpful.

Caregiving duties and tasks. Questions about the work the caregiver completed were asked. These questions helped determine how much caregiving was really going on and for how long. Studies have indicated that this is a factor for caregiver burden. It was important in this section to help define what ‘care’ means as some caregivers had the

perception that they are not doing much, they were not labeling some of the care they provided as caregiving.

Community resources experience. In this section caregivers were asked multiple questions about resources including timeline of usage, how they found out about the resource, what prompted them to seek assistance, if it was useful, and more. These questions also explored barriers to utilization.

Lastly in this section were questions relating to hindsight. These questions helped the participant really express what their individual journey has been and what their unique barriers were. The answers offer valuable insight on how to overcome the barriers.

Sample Interview Questions

1. Questions about early indicators of dementia and the diagnostic process
 - a. When did you first notice that something might be wrong with your family member's memory?
 - i. What are some examples of things you noticed that concerned you?
 - b. How long (in years) was it from the time you first noticed changes in memory to the time you sought a medical evaluation for possible dementia?
 - c. What prompted you to seek medical evaluation for possible dementia? Was there a significant or dangerous event that happened (e.g., getting lost in a familiar place, a car accident) or was it a series of minor events that began to happen more frequently?
 - d. What tests were done as part of the person's evaluation? In other words, how was it concluded that your family member had dementia?
 - e. Were you satisfied with the medical care you received while your family member was being evaluated for dementia?
 - f. Once you received the diagnosis, do you feel you were given adequate information from your medical provider about what to do next?
2. Questions about caregiving duties/tasks

- a. How long have you been helping the person who has been diagnosed with dementia? (in months or years)
 - b. How many hours during the day or week do you typically spend helping (name)? This could include providing transportation, managing finances, supervision for safety, preparing meals, cleaning, direct care, and more.
 - c. Describe the kinds of care tasks you complete in a typical day, or week.
3. Questions about the use of community resources
- a. From the time your loved one was diagnosed with dementia, how long did it take (in years or months) before you decided to seek help from outside sources (i.e., agencies other than family members or friends)?
 - b. What was the first service you used and how long ago did that occur?
 - i. How did you find out about this service?
 - ii. What prompted you to seek this assistance?
 - c. Did you find this assistance to be useful?
 - i. Did this initial experience with seeking assistance lead you to seek additional services?
 - d. What additional community resources do you currently use?
 - i. Review over the list of resources including definitions - adult day care, home care, respite care, support groups, information and assistance, and caregiver training.
 - e. Are there any resources you wish you had decide to use, but did not?
 - i. What prevented you from seeking this assistance?
 - f. Are there any resources that you wish you could use right now but are not?
 - g. What were the main difficulties (if any) that you encountered when seeking assistance from outside sources? (Some possible difficulties could be: never heard of it, too far away, too expensive, not available, didn't need it, PWD did not want to use, etc.) Please explain.
 - i. Explore individual difficulties mentioned here.
 - h. If you were sitting with someone that is in the situation you were in 5 years ago what would you want them to know?
 - i. Are there specific resources you would recommend to them?
 - ii. If they were hesitant to consider using these resources, what might you say to them to change their mind?
4. Demographic details
- For the family caregiver
- a. Gender:
 - b. Race:
 - c. Relation to PwD:
- For the PwD
- d. Age:
 - e. Gender:
 - f. Race:
 - g. Relation to caregiver:

5. Income/Assets

- a. What is the monthly income of the PwD and their household?
- b. \$0-\$1300
- c. \$1301-\$2100
- d. \$2101-\$3000
- e. \$3000 or greater

- f. What is the estimated total liquid assets including savings and investments, but not including house, vehicle, or farm land for the PwD and their household?
- g. \$0-\$3000
- h. \$3001-\$10,000
- i. \$10,001 - \$50,000
- j. \$50,000 - \$170,000
- k. \$170,001 or greater

Definitions of resources for clarification purposes:

Adult Day or Community Respite. These are centers where a person with dementia can be left to be taken care of. They often include meals, activities, and bathing if needed.

Home Care. This is where a home health aid or homemaker comes to your home to help with various tasks that can include cleaning, cooking, and shopping or tasks related to direct care to the person with dementia that can include dressing, bathing, and medication management.

Respite Care in Home. This is when a home health aid or a volunteer stays with the person with dementia relieving the caregiver.

Support Groups. These are groups that meet to discuss caregiving and dementia.

Caregiver Training. These are classes or one-on-one instruction on tools and strategies to be an effective caregiver.

Data Analysis

While the overall research design was structured as a qualitative study where responses were coded, it did not fit in to a pure grounded theory approach (Glaser & Strauss, 1967). Instead it was developed with an approach much like Weston et al.'s team with their a priori method (2001). Their approach to qualitative data analysis

incorporates several methods and begins with background research that helps to build a “tentative model of reflection” (Weston, 2001, p.382). This helps to structure the interview process, the questions to ask, and even the framework of coding. As the data is gathered, more detailed coding occurs and better understanding of the phenomenon can be achieved. This a priori approach is described similar to zooming in and out (p.397), where one starts with an overall idea of the phenomenon then moves in to focus on details with the coding then moving out again to see how this new knowledge shapes the big picture understanding. In this research design, the framework of the phenomenon of resource utilization by dementia caregivers is shaped by the research and informs the questions. In analyzing and coding the transcripts we were able to zoom in within this frame, then zoom back out to see how this changed the bigger picture of utilization of resources.

Interviews were transcribed and then coded using a software program called MAXQDA. This software allows the researcher to highlight and organize codes to help recognize patterns. Special attention was paid to topics such as the diagnostic process, timelines, type and amount of care, difficulties or barriers accessing resources, resources used, and what advice would be given to other people in the same situation. Any other recurring topics or themes were noted through coding. As themes and common responses were observed in analysis they were compared to the existing research. Results were also measured against the demographic details of the participants. As common themes were explored deductions could be made in answering the overall question of why are caregivers of PwD underutilizing resources.

Limitations

There are some weaknesses in this research design. First participants were recruited from places that are offering resources, which excludes those who are not currently using any resources. While the interview is intended to gather past experience about barriers, it does assume that eventually the caregiver does reach out and utilize resources. Recruiting caregivers who never used resources is challenging because these individuals are difficult to locate. The small number of interviews conducted is also a weakness because it limits the generalizability of the finding to the broader population of caregivers of PwD. While there may be vast similarities concerning resources, the journey and experience of dementia is infinitely unique.

Despite these limitations, this study has the opportunity to better understand what barriers prevent caregivers of PwD from utilizing resources. This will provide organizations with information that they can apply strategically to address the barriers, increase utilization, and improve caregiver health.

Results

Demographics

Ten interviews were conducted with caregivers of persons with dementia. Six were with spousal caregivers and four were with child caregivers. Five of them lived in a rural area with populations less than 20,000 and five of them lived in a more urban setting with a population over 50,000. One caregiver was a caregiver to both her mother and her mother-in-law and another was caregiver to both her in-laws. Eight participants were female, and two male. All the caregivers identified as White. The ages of the care receivers ranged from 78 to 102, with the average age of 88. Monthly income of the

person with dementia which included the spouse if applicable ranged from \$0-\$1300 to over \$3000, with six participants reporting incomes greater than \$3,000. Assets of the PwD and their spouse if applicable ranged from \$0 - \$3000 to greater than \$170,000, with four participants reporting assets over \$170,000 and the rest evenly disbursed among the other options below that.

Early Indicators and Diagnostic Process

Early signs. There was considerable variability in the answers to “when did you first notice signs that something was wrong?” This varied from interview to interview not only because the progression of dementia varies from case to case but also because the caregivers were interviewed at different stages in the dementia progression process. For example, one participant noticed symptoms six months ago and had no diagnosis while another caregiver had a PwD that died several years ago.

There were several different signs that were initially noticed. Some of them were outbursts of anger, getting lost while driving, finger rolling, not remembering names, actions out of character, not being able to keep up with conversations, unable to keep up with financial book keeping, and forgetting how to cook.

In considering all the different responses, there were three common responses. For example, six reported changes in memory as early signs that were noticed. Specifically, behaviors like taking a much longer time to recall things, unaware of time, forgetting conversations, and forgetting names were reported. Five respondents reported a decrease in their ability to drive as an early sign. This included getting lost, but also included forgetting how to use things such as cruise control and failing to follow traffic laws. In four interviews changes in behavior that were out of character were noticed.

This mostly included angry outbursts, but also included some paranoia, increased stubbornness, and disregard for things that use to matter.

Timeline from first signs to diagnosis. Responses to this question ranged from no signs noticed prior to diagnosis to four years of signs before diagnosis. Five caregivers reported that two years elapsed before diagnosis and the combined average was 1.9 years.

What prompted diagnosis? Four participants reported that a visit to a physician prompted the diagnosis. For three participants outbursts of anger prompted them to find out what was going on and get a diagnosis. Hallucinations, getting lost while driving, and other people pointing out deficits made up the remainder of the responses.

Diagnosis. There was much more consistency in responding to the question about the diagnostic process. Six participants were referred to a neurologist by their primary doctor. Those that met with a neurologist had hours of diagnostic testing. The other four participants reported short evaluations. For example in one case the evaluation was done while the PwD was hospitalized for pneumonia. In another case an evaluation was done during the admission process to a memory care unit.

Satisfied? The results regarding satisfaction with care were mixed, but many more were satisfied than not. Three individuals did not respond to this question. Of the seven who did respond five were happy with the medical care received in the diagnostic process. For those who were not satisfied, a common response was frustration that physicians could not help. For example, one respondent reported “I don’t know . . . that summer I was calling the ambulance all the time because of all the rages” which would cause a hospitalization, a return back home, and would be repeated. For another one the

first neurologist experience was unsatisfactory, but as her mother had to switch (because she gave up driving) the new one, who did different and further testing, they were very satisfied with. Some of the responses for a positive experience were; “Yes, very much so”, and in reference to the neurologist “she was a Godsend for me because she is straightforward”, and after getting details about prognosis from a nurse “I feel more confident that they know what they're doing then the first one”.

Treatment plan. This question garnered the most consistent answer. In 80% of cases, the treatment plan after the diagnosis only involved prescribing medications. One caregiver remarked when asked if they referred you to anything like a support group or the Alzheimer’s Association “oh no nothing like that!” In two of the ten PwD that were diagnosed additional information was given. For example, one caregiver stated, “The neurologist gave us a whole handful of brochures and stuff but I don't think we ever sat down and read them”. For another participant ideas and suggestions of home cares services were discussed.

Caregiving Duties and Tasks

How long have you been a caregiver? Similar to the question about how long ago did you notice the first signs of dementia the answers to this question varied greatly for the same reasons. Dementia progresses at a different pace for different individuals and each is at a different stage of the process. The results ranged from six months to nine years. Those that have been caregiving for shortest time have PwD in the beginning stages of dementia. Two caregivers had PwD that have passed away. The remaining responses ranged from three years to six years. They are in varying parts along the dementia process, but where they are is not necessarily reflective of how many years they

have been caregiving. It is important to note that this question was a bit challenging for many caregivers that were spouses as they did not readily recognize what they were doing as it merged with their role as a spouse. One caregiver remarked, “ well I’ve been helping him for 65 years” we laughed, but the care they provide does come on gradually as they take on more and more of the shared responsibilities.

How long before admitting to Memory Care? Looking at timelines of first signs to diagnosis to utilizing resources, there was additional data concerning the timeline between first signs and admitting to a memory care assisted living. Six of the PwD were eventually admitted to memory care (see Table 1, column E, p.38). The range of time before admitting was from two years to six years.

It is interesting to note that five of these admittances were after an accident or sickness that landed them in the hospital. For three of the five the hospitalization opened a window that helped convince the PwD to accept admittance into a facility. For the other two, their experience was different and much more traumatic as they were dealing with Lewy Body dementia and unsafe behaviors. For one of them there were six different facilities between hospitals and nursing homes before the PwD was stabilized and brought to a memory care assisted living home. Another caregiver had to go against his spouse’s wishes and let them admit her to a specialized facility for dementia. Feeling like it was too much responsibility, he let them admit her and she stayed there for over a month while he searched for a memory care unit that could meet her needs. For the sixth one he was asked by the assisted living they were living in to move her to a memory care unit.

How many hours do you spend as a caregiver? For the four of the six spousal caregivers this was just about 24 hours/day when considering the time spent supervising the individual for safety reasons (before admittance to memory care). For some participants, they are still able to leave their spouse at home for several hours during the day. After admittance to a memory care unit, participants reported that they still spend a significant amount of time with the PwD. For the four children caregivers the amount of time spent ranged from six to eight hours per week to eight hours per day.

What kind of care tasks? When asked about care tasks, most reported assisting with instrumental activities of daily living (IADL). This includes medication management, meal preparation, transportation, housework, telephone use, shopping and managing finances (Minnesota Department of Human Services, 2017). In addition, some caregivers provided help to fulfill social needs. Seven of the PwD received help with all or most of the IADLs.

Three caregivers reported providing some assistance with personal cares, which typically involved providing verbal prompts to bathe, dress, shave and with some, actual hands-on help to bathe and dress.

Community Resources

Time between diagnosis and resources. The participants reported a range of two years before diagnosis to four years after, with an average of 1.6 years between diagnosis and seeking to utilize resources (see Table1, column C). It is important to point out that the one who had negative time was seeking for services for her father-in-law, but was unable to use them because of barriers (discussed later). When looking at Table 1,

column D we see that participants reported that the time from first signs to seeking to utilize services ranged from no time to 4.5 years, with an average of 2.4 years.

What resources did you use and how did you find them? Table 2, column B on page 39 lists the resources utilized in the order they were used. For five of the caregivers, a support group was the first service used. Two started with training, one with meals, one with home health, and one with adult day services. When considering all the resources used (see Chart 1, p.40) there were 26 different resources used. Clearly, support groups are the top resource utilized followed by Memory Care, Adult Day, and caregiver training.

In Table 2, column C we can see how the caregiver found out about the resources. Interestingly, none reported finding initial resources from healthcare professionals. Four of the caregivers found out about their first resource in a random way such as, through a friend, while on a tour of a facility, while doing volunteer work, and seeing a poster in a community center. The other ways that caregivers found out about resources were through their profession (taking a caregiving class as training for their job), from a family member, searching on the Internet, searching on their own, and one could not remember how she found out. Most of the secondary resources used were learned by participation in the first.

What prompted you to use them? For five participants they reported that learning about the service was enough to prompt them to use it. Additional resources like memory care were recommended during a hospital stay that resulted from an accident or illness. For the other resources, it was almost always learned about and prompted through the use of a resource that was already being used. One example of this was a

caregiver who was out doing volunteer work inspecting a meal sight when she learned that home delivered meals were not just for the “people who are really invalid” as she previously assumed. She decided to use this service as she hated to cook and during the intake process, a support group was suggested. She attended the support group and she learned about Caring Connections, which is a resource that provides weekly social visits to help get the caregiver out of the house and doing something of interest. Two caregivers tried out adult day and respite/companionship after learning about it during support group. Another caregiver, in the early stages at this point, has continued to learn about educational opportunities about dementia through her support group.

Were the resources useful? The majority of the answers to this question were “yes” (see Table 2, column E). Of the seven caregivers who participated in support group only one found it unhelpful. It is important to note that five of those caregivers attend a support group with the same organization. Comments like “it saved my life” and “one of the best things that ever happened” and “it was helpful” were said about the usefulness of the support group. Of the list of 27 resources reportedly used, there were four that did not find them useful and one was “so-so”. The reasons given were:

- Home care – the PwD refused
- Homemaker – it was not needed
- Adult Day – it didn’t fit the PwD’s social needs
- Support group – a caregiver complained about the assisted living home the whole time so the attendee felt it was a waist of time.
- Memory care – PwD’s care there is not as good as is desired

The majority of resources used were described as useful. For this group of caregivers 81% of the resources tried were found to be useful and of those the support group received the greatest praise.

What resources do you wish you had used or could use now? There was a lot of variability in the answers to this question however, the majority of them related to the barriers of not knowing and not being available. There were five responses concerning resources that were not available. They were for a specified Alzheimer's support group that fizzled out, an expert to guide through the whole process, caregiver training, homemaker, and expert financial help. There were responses related to not knowing. One was they wish they had known about and started support group sooner and one that they knew about training and education opportunities. There was one caregiver who wished she had started with home care sooner. Three did not feel there were any resources they were missing; one because she tapped into them early and felt well covered and two because they are early enough in the process they do not feel the need at this point.

Barriers and difficulties utilizing resources. Of the 29 barriers mentioned in the interview there were seven related to the PwD refusing to use or cooperate, four because they were not available, four who found the resource not useful, four who mentioned the timing of the resource was inconvenient (see Chart 2 for a list of all barriers). Each of these barriers will be discussed briefly below.

PwD resistant to resource. One caregiver needed to go away for a period of time but was unable to place her husband in a memory care on respite because he refused to go. Later due to his behavior with staff the homecare refused to continue helping the

PwD. Another caregiver made several attempts to hire help but the PwD refused to accept the help. This same caregiver attempted to move him into an accessible apartment after an episode of illness of which he refused. Later after an injury he was admitted to memory care, he still asks to leave most times he is visited. In fact his son will only visit before a meal so that it is easier to say goodbye leaving him in the dining room ready for a meal. Another spousal caregiver runs into a similar problem with his wife initially refusing to move into memory care and daily threatening to leave or pleading with her husband to let her go home.

Resources unavailable. A caregiver that was utilizing an Alzheimer's support group saw it fizzle out and end. She was very disappointed as it addressed her specific needs, provided good information, and was at a convenient time. One caregiver who was a retired nurse felt she needed some training on how to deal with the hallucinations her husband was experiencing she remembers him in tears scared to death and hiding because someone under the stairs wanted to take him away she said "nobody teaches you how to handle things like that". Another caregiver mentioned that she wished there were caregiver training available for her brother and sister-in-law to take, as they are the ones who live close to her mom. The fourth caregiver mentioned that the homemaking service would have been really helpful for her mother but it was not available back then.

Resource was not useful. A caregiver that was about to use a companionship resource anticipated it not being useful as she did not think there would be enough for them to do with her husband, and since she works at home it would be distracting to her. Another caregiver was getting homemaker services that were set up by her son and paid for by long-term care insurance. She did not feel they were helpful as she could complete

this work herself and it felt like they were there all the time. Another caregiver tried out a support group at the facility where her mom was staying after it being suggested by the social worker. She gave it one try but after hearing an individual complain about the facility the majority of the time she told a social worker who asked why she did not attend: “I didn't come here to hear what she liked or didn't like about the facility, that wasn't helpful.”

Inconvenient time of availability. After the Alzheimer's support group ended a caregiver decided to join the general caregiver support group though it was during working hours and so at an inconvenient time. This was the same case for the caregiver who gave the support group one try, because of the negative experience and the inconvenient time (during work hours) she declined to continue to use it. One caregiver in working with the county on financial resources was frustrated by the long wait times to be able to communicate and hear back from the county worker on his case, because of this he stopped the process and is not getting any financial support that his wife very likely qualifies for. Another caregiver attends a support group that meets twice a month, she is unable to make one of the two monthly meetings because it is at the same time as another important monthly event.

Did not know about the resource. Though not implicitly stated by all the caregivers, a lack of awareness of resources was clear in the majority of cases. This was seen in the random way in which the resources were learned about and how the knowledge of it was the only thing needed to prompt them to try it out. We saw this in at least four of the cases. It is also clear in two others that they did not know of resources

like support group until they were informed of it and gave it a try after many years of care and after admittance to a memory care.

Advice

While the advice varied two key themes echoed through the statements. One was that support groups are a very helpful resource. The other is to start using resources early. There were other myriad pieces of advice that included lessons learned like; remember it's the disease your dealing with, the biggest thing you can do is love them, listen, be patient, change your mindset (you are no longer the child), and start educating yourself.

Support group. As was mentioned in the usefulness section support group was found to be very valuable to six of the caregivers. One caregiver when asked are there any resources you would recommend stated "Definitely support group", she said "it was the biggest thing for me . . . in dealing with challenges it helped you think of things you hadn't thought of . . . and it is nice to be able to talk to someone". Another caregiver advised to "start with caregiver support group from there you will quickly discover from others what it is you need". Another caregiver stated to try caregiver support to "get a sample" of what is out there to help. In the fourth example, this caregiver said, "I would definitely say make an appointment with *the person who leads* the caregiver support group". Clearly, this was a valuable resource. Interestingly, all the spousal caregivers that used support groups were very satisfied with it.

Start early. The other common words of advice were to start utilizing resources earlier. One caregiver said she would "get help a lot sooner, that was a mistake I made". This is coming from a spousal caregiver who experienced negative health due to

caregiving. Another adult child caregiver said to get help early so you can love them longer. She talked of the challenge of squeezing in the caregiving tasks with a busy life and still having time to listen and love. With more help she realized that she could take the time and energy to listen and love, whereas before it was hard. Another adult child caregiver recommends to “start early to educate yourself”. She has found it helpful to learn more about her role as a caregiver and ways to approach communication in such a role. Another spousal caregiver recommends seeking out a support group early to get a sample. The last example of a spousal caregiver recommends making an appointment with caregiver support leader right away. He has found their knowledge and advice very helpful in understanding other resources and in better ways to communicate and deal with his role as a caregiver in a very tough caregiver to care receiver relationship. It is evident that starting earlier with resources is recommended by those who have experienced years of caregiving.

Table 1 - Caregiver Timeline

A	B	C	D	E
Interview	How long caregiving? In years	From diagnosis to first resource. In years	From first signs to first resource. In years	Memory care, from first signs to admit. In years
1	6	1	5	5.5
2	3	-2	0	2
3	8	0.33	0.5	3
4	5	3.5	3.5	4.5
5	2	2	4	N/A
6	0.5	N/A	0.5	N/A
7	9	2.5	4.5	6
8	4	not collected	not collected	N/A
9	4	4	4.5	3.5
10	5	1.5	3.5	N/A

A	E	F
Interview	Time spent caregiving. In hours, before Memory Care	Time spent caregiving. In hours, after Memory Care
1	4-8/day	
2	7-10/week	5-8/week
3	24/day	N/A
4	24/day	5-7/day
5	1-3/day	N/A
6	6-8/week	N/A
7	24/day	8/day
8	24/day	N/A
9	24/day	3/day
10	4-8/day	N/A

Table 2 Resources

A	B	C	D	E
Interview	Resource	How found out	Prompted	Useful?
1	Alzheimer support group	by accident while on a tour		yes
1	General support group	word of mouth		yes
1	Memory Care		hospitalized for illness	yes
2	Home Care	Internet		no- PwD refused
2	Memory Care		hospitalized for illness	yes
3	Support group	can't remember		yes
3	Adult Day			yes
3	Companionship			yes
3	Homemaker	son arranged		no-didn't need
3	Memory Care		hospitalized for behavior	yes
4	Support group	friend	friend's advice	yes
4	Respite	daughter		yes
4	Adult Day	support group		no-didn't fit PwD needs
4	Memory Care		referred by assisted living staff	yes
5	Caregiver training	on the job training		yes
6	Caregiver training	on the job training		yes
7	Adult Day	sister		yes
7	Memory Care		hospitalized for accident	yes
7	Support Group	referred by LTC staff		no- not helpful
8	Support Group	posters at Senior Center		yes
8	Education	support group		yes
9	Memory Care		hospitalized for accident	yes
9	Support Group	friend	friend's advice	yes
10	Meals	while volunteering	need	yes
10	Support Group	interview agency that delivers meals	referral from specialist	yes
10	Caring Connection	support group		yes

Chart 1 – Resources

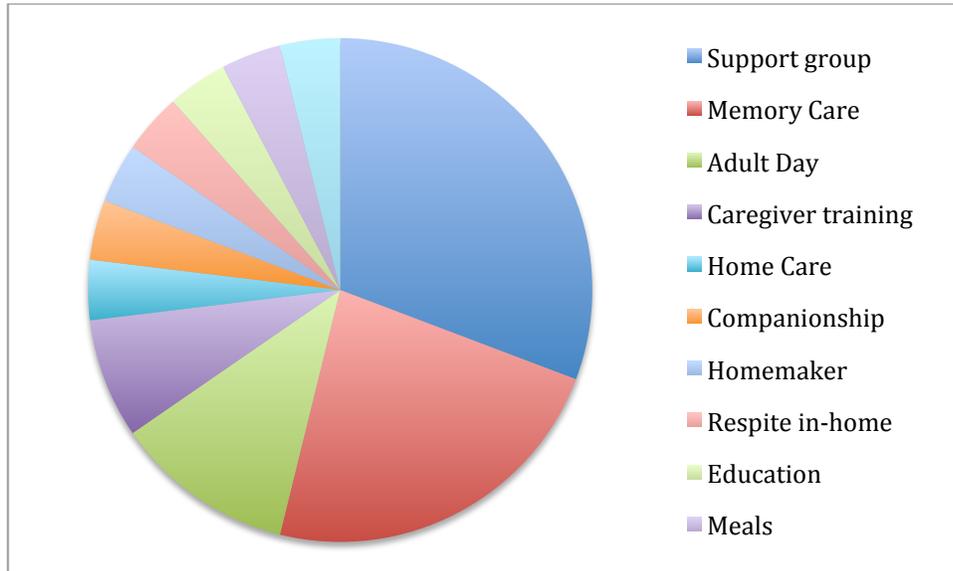
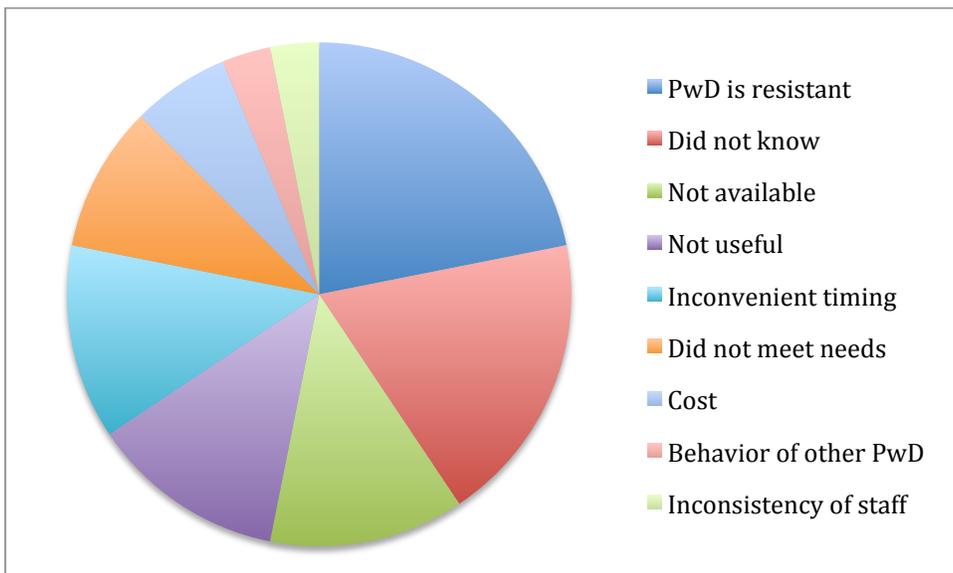


Chart 2 – Barriers



Discussion

Barriers.

As discussed before the top barriers reported were the PwD refused the resource, it was not available, not useful, and at an inconvenient time. All these barriers reflect what is in the literature. In the study by Winslow (2003) the PwD refusing the service was the most frequent reason for not using a resource. In several of the studies discussed inflexibility or lack of convenience reduced participation (Macleoad et al., 2017; Vaingankar et al., 2013; and Winslow, 2003). Making a resource more convenient increased participation in the study by Mavandadi et al. (2017), this was especially true in caregivers of PwD.

Omissions in the Health Care Structure

Participants reported a long period of time between signs of dementia to diagnosis; the average span was two years. The average time from signs to using a resource was 2.8 years with six of them waiting longer than 3.5 years (Table 1, Column D, p.39). This combined with the advice from caregivers of getting help sooner raises a red flag. This becomes especially poignant when considering the diagnosis process and treatment. We have the majority of individuals go through hours of testing to only be given a diagnosis and medications as treatment with little to no recommendations to resources. The average time between diagnoses to using a resource was 1.6 years (see Table 1, column C). The reality that caregivers discover the resources that they end up using by accident further highlights the gap that exists in caregivers even knowing that these resources are available. This is also seen in the literature as there were several studies cited that found not knowing about a resource as a top barrier (Hong et al., 2011;

MacLeod et al., 2017; Vaingakar et al., 2013; and Winslow, 2003). This study not only further validates this barrier, but also exposes the limitations of the healthcare structure in overcoming that barrier.

Most participants reported satisfaction with the diagnosis process and do not seem to realize the omission of a myriad of things that could teach them, help them, support them, and guide them in their journey. They leave thinking they have gotten the top care they can from their healthcare system and that must be all there is. Yet the reality is the healthcare system is not structured to treat chronic care it is structured to treat acute care (Fani & Stafford, 2012). It is not their role to coach and guide, only diagnose and prescribe. It is not as if the healthcare they are receiving is bad, it is just not structured to provide the care they need. It is not hard to stretch the imagination into mitigating some of that void. A one-hour consultation with a social worker, or an invitation to a training course hosted by the healthcare facility, or something else. These ideas reflect what Macleod et al. (2017) found in his study that an expert point of contact increases service use. Winslow's (2003) study found that caregivers need information.

Support Group

There is little in the literature that looks specifically at caregivers of PwD in accessing resources. One important highlight that these interviews expose is the reported benefit of the support group. The literature does state that there are unique and variable needs of the dementia caregiver. It also mentions that they are under greater stress because of the nature and length of their care. Perhaps the blend of learning a variety of problems and solutions from the experience of others combined with some much needed

socialization is why the support group is having high success with this group. This might be a valuable topic of further study.

First Resource Leads to More

Though not overtly obvious the idea that one resource leads to another was evident in the interviews. As was mentioned in the results most of the secondary resources listed were learned about by utilizing the first. This is important to highlight as it can inform agencies seeking to provide services to caregivers.

Admission into Memory Care

It is interesting to note that every single admission into memory care occurred after intervention with a trained medical provider. PwD were admitted to the hospital for a broken ankle, pneumonia, bleeding ulcer, a fall, and behaviors. This leaves one wondering if the event did not occur how much longer before the PwD would be admitted. For several participants they remarked the event was a blessing, because it put into motion the opportunity to move the PwD into memory care. This topic certainly warrants further study.

Limitations

One of the most significant limitations in this study was the small sample size. It was very evident from the interviews that the diagnostic and caregiving journey was different and unique in each case. With this variability the evidence would be stronger with a larger sample size. The homogeneity of race with all participants being White was also a limitation.

Another limitation concerns problems with retrospective reporting. As questions were asked, especially in relation to timing, participants were relying on memory. This

could add some inconsistency with the truth in the timelines of first signs, diagnosis, using resources, and placement in memory care. It also came into play with details surrounding the experience of diagnosis, as it was hard for some to recall the details.

Another obvious limitation is the fact that the participants interviewed are those who have already accessed resources. Not represented are those who never really use resources, so it is unclear if these individuals would report different barriers than the participants who have used them.

Conclusion

Even though this study had some clear limitations it was still able to expose some barriers that caregivers of persons with dementia experience. In short caregivers do not know about these resources until much later in their journey and in hindsight agree that using them early on would be beneficial. This study also illustrated that the healthcare structure is not equipped to help the dementia caregiver in their journey. The finding that PwD were admitted into memory care only after a hospitalization raises questions and is a topic of further study. Another topic of further study was the overwhelming positive experience of the caregiver support group. Could this resource be especially beneficial to the dementia caregiver, and if so why? While there is still much to be understood about the journey of the dementia caregiver in utilizing resources this study has exposed some clear directions to take.

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