

NORTHERN ILLINOIS UNIVERSITY

Barriers And Facilitators To Service Utilization For People With Dementia And

Their Families

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Abstract

According to the CDC, there were 5.2 million Americans living with Alzheimer's disease in 2013. That number is expected to nearly triple in 2050 as the baby boomer generation reaches retirement age. Underutilization of services is something experienced by many demographics and is a considerable issue for individuals with dementia. This study sought to uncover factors correlated with underutilization of services for people with dementia through both a literature review and sit-down interviews with three healthcare professionals. Results indicated that cultural, financial, attitudinal and knowledge barriers exist for PwD (people with dementia) and their caregivers and may interfere with their ability to seek the help they need. By uncovering these barriers and proposing potential solutions to these problems, issues related to health service utilization can be minimized and eventually overcome.

Intro / Aims

According to the CDC, there were 5.2 million Americans living with Alzheimer's disease in 2013. That number is expected to nearly triple in 2050 as the baby boomer generation reaches retirement age (CDC, 2013). Dementia, chronic and irreversible memory loss, is one of the symptoms of Alzheimer's disease, and it affects the quality of life of millions of Americans and their families. As a future occupational therapist (OT), increasing quality of life and participation in ADLs is important to me. This requires the use of formal care, which unfortunately is being underutilized. According to Sayegh et al. (2013), PwD who delay the use of formal care experience greater severity of symptoms upon being diagnosed.

Throughout the semester, I have conducted a systematic review of factors affecting service utilization for people with dementia (PwD) and their caregivers. There are a number of reasons why some people choose not to receive services., and I utilized a variety of databases and published texts in order to uncover why underutilization of services is such an issue. In addition to my literature review, I have also conducted interviews with local practitioners to find more information on the subject at hand. I have analyzed my data and have uncovered various trends in how services are used and have outlined obstacles that may interfere with someone receiving the services they need to live comfortably. These barriers and their corresponding articles can be seen in **Appendix C**. Finally, I have proposed ways in which these barriers can be overcome.

Methods

Systematic Review

Data Collection The databases *Pubmed*, *Web of Sciences*, and *CINAHL* were used to generate peer-reviewed articles relating to dementia, barriers / facilitators and service utilization. Related

terms were searched as well and have been outlined in **Appendix D**. MeSH was used to more efficiently obtain results of *PubMed*, and the majority of articles used in my literature review were obtained from here. Search results were narrowed down based on the year of publication and geographic location of where the study was conducted. Articles were generated from within the past 10 years and were narrowed down based on geographic location. While this particular project focused on the US and westernized countries, some trends were noted from other countries that may be applicable to service utilization in the US. This generated a total of 40 peer-reviewed journal articles, which were later narrowed down a bit further. The second database searched was *Web of Science*. The terms searched in this database were “dementia,” “barriers,” and “services.” A total of 11 results were generated that had been published within the last five years and were US based. The final database searched was *CINAHL*. Dementia, barriers, and healthcare utilization were searched, along with related terms that can be seen in the search term list table. A total of 6 results were found using this method.

Data Analysis After generating relevant articles, each abstract was read to uncover the type of study each was and how the participants in each were generated. Relevant themes from each study were noted and were recorded in a table outlining the type of study and participant demographics from each. Studies that presented strong evidence were retained, while the rest were discarded. See **Appendix C** for more information regarding the peer-review articles utilized. A total of 12 articles were utilized in the creation of this paper. Themes from these 12 articles were condensed into a chart which can be found in **Appendix B**.

Interview

Data Collection Three interviews were conducted with individuals employed at a local skilled nursing facility. These individuals include a nursing home administration, an RN in a dementia

care unit and the Activities Director of the nursing facility. These individuals were picked out of convenience from the facility where I am currently interning. I attended each interview with a list of questions in mind to ask. During each interview, I jotted down some notes. At some points, the content of our interviews veered off topic, which led to additional questions being asked that were not previously planned. After each interview, I took some time to collect my thoughts and to write down whatever themes or relevant information was uncovered. Several trends were uncovered that helped to corroborate information from the systematic review. In addition to this, other themes and subthemes were noted regarding stigma, and financial and cultural barriers. Potential solutions to offset these problems were discussed in the interviews and these, along with interview questions and field notes, can be found in **Appendix A**.

Data Analysis Information obtained from my three interviews was consolidated and rewritten for clarity. While reading through my notes, I drew parallels between the themes found in my interview and the themes found during my literature review. The barriers prominent in both my interviews and my literature review were cultural, financial, attitudinal and knowledge based. Information regarding caregiver involvement was also present in both parts of my research.

Results

Cultural Barriers

A number of minorities communities are susceptible to underutilizing services. This includes immigrants and religious and ethnic minorities. A literature review conducted by Sayegh et al. (2013) reveals that minority ethnic adults experience many cultural barriers which may lead to delays in timely care. Because of these diagnostic delays, they are more likely to display an increase in the severity of their dementia symptoms upon being diagnosed. One of these barriers includes the cultural perception that memory loss is simply a normal sign of aging.

If people do not understand that there is a problem, then they will not seek out help. In addition to this, some orthodox religions believe dementia symptoms are God's will; others believe dementia is a curse or a sign of possession. These people may be less inclined to utilize formal care as they believe everything happens for a reason and do not want to mess with "fate."

Sayegh et al. (2013) points out that many minorities may be wary of seeking treatment due to prior experiences with discrimination. More specifically, they found that minority communities sometimes feel as if their dementia symptoms are being ignored by practitioners. This was especially found in the African American community. Chinese Americans caregivers in their sample felt physicians were not spending adequate time addressing their questions and concerns about the dementia diagnosis, demonstrating a clear lack of trust and communication among clients and their practitioners. When people do not feel listened to and their needs are not being addressed, they are deterred from seeking treatment in the future.

Language barriers may also be an obstacle to timely care for immigrant families. Giebel et al. (2014) conducted a literature review on South Asian adults with memory problems and found that due to the presence of communication barriers, immigrant families are not maximizing the health services available to them. Haralombous et al. (2014) elaborated on this and found that navigating the healthcare system can be relatively complex for immigrant families especially. This can be due to not only language barriers, but having to utilize a new system that they simply are not familiar with. The system in play is simply not user friendly, and those whose primary language is not English will have an especially difficult time navigating it.

An addition barrier faced by minorities with dementia is that they tend to underutilize medication. Diaz et al. (2015) completed a registry-based study on immigrants 50 and older with dementia and found that knowledge of a diagnosis and management of memory problems was

scarce among Norwegian immigrants. When compared with immigrant populations, native Norwegians were 20-50% more likely to utilize medication, which has been shown to slow down the progression of dementia symptoms. This is just one implication of service underutilization that minority populations may experience. By educating practitioners on such barriers and reaching out to vulnerable populations, health care providers can help to make sure PwD and their caregivers are receiving the care they need.

Financial Barriers

Those who are uninsured or of a lower socioeconomic status are less likely to seek out formal care. When Amihzadeh et al. (2012) conducted a scoping review of Western literature published over the past decade, they found that gaps in financial resources may lead to a delay in the onset of care. They went on to suggest that Western countries face challenges in providing care that is both comprehensive and cost effective. In order to progress, the article suggests a coordinated effort and increased levels of commitment would be required to focus on both barriers and enablers to receiving dementia related care.

Limited income and lack of insurance may both lead to a decrease in help-seeking behavior for informal caregivers of PwD, as formal care can be extremely expensive (Phillipson et al., 2013). In the US, formal care is especially costly, even in the presence of insurance. Because of this, people have a tendency to avoid treatment altogether unless it is absolutely necessary. This review goes on to say that the existence of resource barriers must be addressed, as respite services have been shown to extend the PwD remain living. Use of services is low among these people and does not match care needs. Information from the first interview I conducted may help to corroborate this information. When I sat down with the administrator of a local nursing home, we spent some time discussing the demographics of the clients he serves

(Personal communication, B. Becker, Sept. 29th, 2016). He mentioned how a large portion of the clients at his SNF are Medicare recipients. He understands that health care services can be costly and may add up rather quickly--- especially those provided in skilled nursing facilities. He went on to say he believes that the presence of government programs, such as Medicare and Medicaid, greatly increase the number of people who have access to the care they need.

Attitudinal Barriers

A common theme throughout both my interviews and literature review is that stigma and attitudinal barriers can impede someone's use of formal care. In my first interview (with the nursing home administrator), we discussed how there is a great deal of stigma associated with receiving care in such a setting (Personal communication, B. Becker, Sept. 29th, 2016). He believes stigma and media perception can and do affect one's ability to seek needed treatment at nursing homes and SNFs. In my second interview, conducted in a dementia care unit, the RN I spoke with mentioned how the facility she works at acknowledges the existence of such stigma and actively works to reduce it by engaging with the community and inviting them into the facility (Personal communication, Amy Larson, Oct. 27th 2016). She mentioned how she believes this approach helps a lot, and she went on to say that several families inquire about the dementia care unit now through word of mouth. One of the best ways to reduce stigma, she said, is to allow community members to visit and observe the facility firsthand.

Focus group interviews conducted with 28 informal caregivers of PwD found that fear of stigma and low acceptance affect the onset of formal care usage (Boots et al., 2015). Some of these people had difficulty acknowledging a problem existed, while others had trouble coming to terms with the fact that their loved one had dementia. An additional attitudinal barrier uncovered in this study is that some people have difficulty accepting loss and change. What is important to

note, this study mentions, is that early care can prevent overburdening of caregivers, making early care important for not only PwD, but for their families as well.

Diagnoses often serve as labels to people and can bring about a great deal of stigma as well. A methodological review done by Garand et al. looked into the effect that diagnostic labels can have on PwD and mild cognitive impairments (2015). Their review found that diagnostic labels often interfere with a person's willingness to not only seek care but to participate in research studies as well. Therefore, overcoming the stigma of a dementia diagnosis is an integral factor in further dementia-related research. Stigma and attitudinal barriers can and most be overcome to increase formal care utilization for people with dementia.

Lack of Knowledge

Lack of knowledge presents an additional barrier to PwD and their families. Werner et al. (2013) conducted a systematic review of articles published up until June 2013 and found that inadequate knowledge, along with the presence of stigma, are the most common barriers to timely help-seeking. The importance of timely care was emphasized in this study, as it may be associated with better outcomes for PwDs and their caregivers. Phillipson et al. (2013) hints that education levels positively correlate with the tendency to seek help for PwD, indicating that educating communities is important to increase the usage of formal care.

Some misconceptions about what constitutes normal aging may also be to blame for the lack of care utilization. Mukadam et al. (2015) studied South Asian families with dementia and their caregivers in and around the Greater London area. Focus groups and individual interviews were conducted as part of their study. This study found that several people do not seek help for dementia as they feel that nothing can be done to help. In addition, this study found that several people fail to seek care for dementia as they feel it is simply a normal sign of aging. This was

corroborated by Sayegh et al. (2013), who believes that cultural perceptions may lead to the belief that memory loss is a normal sign of aging. The article suggests that education is key to understanding what constitutes normal and abnormal aging. This distinction can help to make sure those who need help can receive it.

Caregiver / PwD Relationship

Through interviews with 243 informal caregivers of PwD, Lopez et al. (2014) was able to determine that a pattern exists in terms of who tends to institutionalize their relatives and who does not. What this team found was that male and non-spouse relatives are more likely to seek external help than their female counterparts. The study went on to say that females typically have stronger attachments to their relatives, which can make institutionalizing them harder to overcome.

On a similar note, Lund et al. (2009) conducted 90 minute in home interviews with family caregivers of those receiving adult day services. Their sample was selected from moderately sized cities in the Greater Salt Lake City area. This study outlines several dimensions of caregiver burden, including physical, social, time and emotional burdens. They found that formal care allows for ample time to tend to personal, household and social needs. Because women and spouses of PwD underutilize services, they may lack the time necessary to care for their own needs. Therefore, increasing formal care can benefit not only PwD, but their caregivers as well.

Discussion and Implications

My interviews and systematic review uncovered that cultural, financial, attitudinal and knowledge barriers exist when it comes to service utilization for people with dementia. It can be fairly difficult for immigrants to navigate the healthcare system in place and minorities often do

not seek treatment out of fear of discrimination. The cost of healthcare and formal care can be extremely expensive, so those who are uninsured or of a lower socioeconomic status may delay receiving formal care. Stigma exists among both PwD and their caregivers, brought on by both a diagnosis and the need to seek an outsider's help. Finally, many people are simply uninformed in terms of that treatment and care options are available to them. However persistent and troublesome these barriers may be, I am confident that through governmental and community based interventions, they can be overcome.

As a student who plans on studying occupational therapy, this project has helped me to better understand difficulties individuals may face in terms of obtaining the services they need. Whether it is minority families or those who lack financial resources--- all who can benefit from dementia care services should be able to obtain them easily and efficiently. Practitioners and care providers must work together to decrease stigma and to increase knowledge on the benefits of formal care for those with dementia. By gaining such knowledge, we can erase the narrative that suggests seeking out formal care is a sign of weakness.

Many minorities lack trust in health care professionals due to fear of discrimination and prior negative experiences. As an OT student and an eventual practicing professional, I can reach out and make a concerted effort to build trust and rapport with minorities. This specific consideration will help this demographic access services that they typically would not have otherwise. In order to ensure these families are receiving the care they need, Giebel et al. (2014) suggests healthcare providers begin culturally tailoring services and employing staff who display demographics similar to those of the population served. As Kathy Vickers noted in our interview, employing CNAs who speak the native language of clients help them to feel more included and welcome (K. Vickers, personal communication, Nov. 1st, 2016). This can help minority

communities feel comfortable and represented, making them more inclined to seek out help they need.

Another main issue regarding utilization of services is the general lack of knowledge of the facilities and programs in place. Education is an imperative tool and powerful way to help people with dementia and family members access the appropriate programs and facilities to increase quality of life. As an occupational therapist, I can ensure that the community in which I live understands and knows about the services we provide. Hopefully, through my concentrated efforts in education, people will be more inclined to access these necessary programs. Providing printed material in group settings may help to offset this issue and can help minority families more easily obtain the healthcare services they need, as Haralombous suggested (2014).

In terms of financial barriers, expanding Medicare and Medicaid may provide families with the necessary capital to seek out treatment if financial barriers had previously been holding them back. As Bart Becker, the administrator of a local SNF stated, several individuals with dementia rely on governmental programs to help pay for their treatment. The presence and funding of these programs is vital to making sure people can afford the care they need.

Continuing to fund these programs and expanding on these efforts may allow families to seek out care without worry of the financial burdens it may cause their families (Personal Communication, B. Becker, September 29th, 2016).

By implementing the previously stated changes, cultural, financial and knowledge barriers can be significantly reduced, leading to an increase in service utilization. The effects of dementia and Alzheimer's disease can be devastating, but the presence of formal care help can help decrease caregiver stress and can help maximize the functioning and activity of PwD, providing them and their families with increased comfort in the process.

Some limitations of my study are that the samples I obtained, in both my interview and my literature review, were convenience samples. My results may have been varied if I had access to more journals and more people to interview. Given the scope of the project only being a semester long, I did not have the opportunity to evaluate and analyze the issue in greater detail. In addition to this, my sample size was relatively small, which may indicate that my data does not fully and accurately represent the population I have studied. Regardless of any limitation, the results of my research are still valuable in defining barriers PwD and their families face. By acknowledging these barriers and proposing potential solutions, practitioners can be better equipped to overcome them and to ensure their clients are receiving the care they need for them and their caregivers to live comfortably.

References

- Alzheimer's Disease. (2015). Retrieved December 6, 2016, from <http://www.cdc.gov/aging/aginginfo/alzheimers.htm>
- Aminzadeh, F., Molnar, F. J., Dalziel, W. B., & Ayotte, D. (2012). A Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care. *Canadian Geriatrics Journal, 15*(3). doi:10.5770/cgj.15.42
- Boots, L. M., Wolfs, C. A., Verhey, F. R., Kempen, G. I., & Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: The paradox between needing and accepting help. *International Psychogeriatrics, 27*(06), 927-936. doi:10.1017/s1041610214002804
- Diaz, E., Kumar, B. N., & Engedal, K. (2015). Immigrant Patients with Dementia and Memory Impairment in Primary Health Care in Norway: A National Registry Study. *Dementia and Geriatric Cognitive Disorders, 39*(5-6), 321-331. doi:10.1159/000375526
- Garand, L., Lingler, J. H., Conner, K. O., & Dew, M. A. (2009). Diagnostic Labels, Stigma, and Participation in Research Related to Dementia and Mild Cognitive Impairment. *Research in Gerontological Nursing, 2*(2), 112-121. doi:10.3928/19404921-20090401-04
- Giebel, C. M., Zubair, M., Jolley, D., Bhui, K. S., Purandare, N., Worden, A., & Challis, D. (2014). South Asian older adults with memory impairment: Improving assessment and access to dementia care. *International Journal of Geriatric Psychiatry, 30*(4), 345-356. doi:10.1002/gps.4242
- Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., . . . Logiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the

Cultural Exchange Model to explore barriers and enablers. *Journal of Cross-Cultural Gerontology*, 29(1), 69-86. doi:10.1007/s10823-014-9222-0

López, J., Losada, A., Romero-Moreno, R., Márquez-González, M., & Martínez-Martín,

P. (2012). Factors associated with dementia caregivers' preference for institutional care. *Neurología (English Edition)*, 27(2), 83-89. doi:10.1016/j.nrleng.2012.03.004

Lund, D. A., Utz, R., Caserta, M. S., & Wright, S. D. (2008). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28(1), 109-131. doi:10.1177/0733464808323448

Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, 5(9). doi:10.1136/bmjopen-2015-007990

Phillipson, L., Jones, S. C., & Magee, C. (2013). A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health & Social Care in the Community*, 22(1), 1-12. doi:10.1111/hsc.12036

Sayegh, P., & Knight, B. G. (2012). Cross-cultural differences in dementia: The Sociocultural Health Belief Model. *International Psychogeriatrics*, 25(04), 517-530.

doi:10.1017/s104161021200213x

Werner, P., Goldstein, D., Karpas, D. S., Chan, L., & Lai, C. (2014). Help-Seeking for Dementia. *Alzheimer Disease & Associated Disorders*, 28(4), 299-310.

doi:10.1097/wad.0000000000000065

Appendix A

Interview Field Questions / Notes

Interview 1: Bart Becker (nursing home administrator)

Describe the demographics of the residents served at your facility?

Have you noted any patterns in who chooses to institutionalize their loved ones?

What are some benefits of formal versus informal care?

What would you say to individuals who are weary of formal care, nursing homes especially?

How does DCRNC reduce stigma?

Notes: Majority over 65, on medicare, mobility issues / fall risk, mostly female

People of all kinds use services, few minorities however

Limited minorities in community and community members are given priority admissions

Formal care reduces caregiver burden, residents are more social and active

Some require constant supervision and nursing services

Care is tailored to each residents needs and is done by practitioners who are trained

Encourage those from community to come in and observe, provide community with brochures and other literature

Education is key to reducing stigma, take time to address concerns

Interview 2: Amy Larson (RN in the Dementia Care Unit)

What services do you provide for patients in the dementia care unit?

Describe the patients you treat in the dementia care unit. Are most of them in the early or late stages of dementia?

Are there benefits in receiving care early? If so, please describe.

What can be done to make sure people are receiving care early?

What are some factors that get in the way of people receiving seeking the services they need?

What can we do to make getting help easier for people with dementia and their caregivers?

Can you think of anything that could help make receiving services easier for those who need it?

Notes: Dispense meds, activities, nursing care, monitor diet / blood sugar

All done in a homelike environment; residents may sleep and wake when they like.
Majority of families visit regularly
Routine is emphasized,
Residents in all 7 stages of dementia
Sun downing = increased confusion
Agitation for some residents
Others, calm yet forgetful
Benefits of music, arts and crafts – keep the mind active
Activities based on abilities, they are not sitting all day
Reduced stress for families
In an environment where people have medical and health care backgrounds
Patients often do not seek out care until a situation becomes too stressful / it starts to affect caregiver's health, sleep. Stigma is also a factor as well as caregiver guilt. Often, promises are made to never use nursing homes.
No one wants to be in a nursing home
Once a resident is placed in the SNF, many people regret not making the decision earlier.
Additional benefits
Example: Wife was taking care of resident who was not active at all
SNF got him walking, talking and participating again.
Activities are geared toward making them successful and enjoying moment
Marketing
educating communities
open houses to the community are offered regularly
invite community families in
give tours - have people observe what's going on
word of mouth

Interview 3: Kathy Vickers (Activities Director)

What activities are provided for residents at DCRNC?

How is participation encouraged?

What are some benefits of participation in such activities?

Describe the cultural demographics of your residents.

What do you do at DCRNC to appeal to minority communities and make their stays more comfortable?

Notes: arts and crafts, exercise groups, history lessons, church services, bingo, Google hour, music group, cooking activities
Residents are asked every morning to participate. Their input is required in choosing activities. They are done in small and large group. Resident council speaks on behalf of what residents want
Mind is kept active, residents socialize, practice autonomy, feel useful, encourage reminiscing

Majority are older and white, some type of mobile disability, most are Christian

Some minorities: Koreans, have housed Jewish residents.

Language barriers for Korean residents, hired Korean CNA

Maintaining cultural ties is important

Fate versus Intervention

Activities are tailored based on resident's culture.

Lessons on Passover, bring in religious leaders from their communities, provide comfort for residents during end of life.

Appendix B

Emerging Themes / Subthemes

- ❖ Minority communities tend to underutilize services
 - Immigrant communities
 - Language barriers
 - Delay in timely care
 - Use of medication
 - Religious minorities
 - Fate / In God's hands
 - Ethnic minorities
 - Fear of discrimination
- ❖ Price of care may lead to underutilization of services
 - Majority of those utilizing SNF are Medicare
 - Lack insurance / limited income lead to underutilization formal care
- ❖ Attitudinal barriers / Stigma
 - Lack of acceptance
 - Lack of trust
 - Stigma of a diagnosis
 - Prior negative experiences
- ❖ Lack of knowledge
 - Limited education or resources
 - Believe it's normal aging
 - Feeling that nothing can be do

Appendix C

| Title | Author | Year | Participants | Geographic Region | Research Design | Results: Identified Barriers / Facilitators |
|--|--------------------|------|--|-------------------|---|---|
| South Asian older adults with memory impairment: improving assessment and access to dementia care. | Giebel et al. | 2014 | 18 articles regarding South Asian adults with memory impairment from Web of Knowledge, Pubmed and Ovid databases | US, UK, Wales | Systematic Review | <ul style="list-style-type: none"> • Lack of knowledge of dementia • Stigma • Culture • Language and communication barriers • Services must be culturally tailored to ensure maximum utilization • Providers should be better informed. • Employing staff with similar demographics to the population served may assist as well. |
| Help seeking in older Asian people with dementia in Melbourne: using the Cultural Exchange Model to explore barriers and enablers. | Haralambous et al. | 2014 | 13 carers of people with dementia, 12 community workers and 39 health professionals who work with Chinese and Vietnamese populations | Australia | Consultation with community workers and health professionals using the Cultural Exchange Model: | <ul style="list-style-type: none"> • Complexity of navigating the healthcare system • Lack of time / travel • Language • Lack of Knowledge • Solutions: Providing printed material in community group settings. |
| Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. | Boots et al. | 2015 | 28 informal caregivers of people with dementia | US | 4 focus group interviews | <ul style="list-style-type: none"> • Fear of stigma and low acceptance affect onset of formal care • Lack of knowledge • Difficulty accepting loss and change |

| | | | | | | |
|--|-------------------|------|--|---|---|--|
| | | | | | | <ul style="list-style-type: none"> • Early care can prevent overburdening of caregivers |
| What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. | Mukadam et al. | 2015 | 53 South Asians with dementia & their caregivers (18-83), mostly female and Bangladeshi | Community settings in and around Greater London | Focus groups and individual interviews | <ul style="list-style-type: none"> • “normal aging” • Spiritual cause • Denial • Stigma • Don’t want help • Prior negative experiences • Hopelessness • Interventions should be targeted at known barriers |
| A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. | Phillipson et al. | 2013 | 14 articles from MEDLINE, CINAHL, ERIC, PRO-QUEST 5000/Central, Science Direct, PsycInfo, Medi- text and Web of Science. | n/a | Narrative synthesis of peer-reviewed literature | <ul style="list-style-type: none"> • Attitudinal and resource barriers exist and must be addressed, as respite services extend time people with dementia remain living • Use of services is low and does not match carer needs • Demographics (older / female caregivers less likely to use services) • Education • Healthcare beliefs • Embarrassment • Lack of trust • Lack of knowledge |

| | | | | | | |
|---|---------------|------|---|---|----------------------|---|
| | | | | | | <ul style="list-style-type: none"> Limited income / no insurance |
| Factors associated with dementia caregivers' preference for institutional care□ | Lopez et al. | 2012 | Informal caregivers of 243 individuals with dementia | Spain | Interview | <ul style="list-style-type: none"> Males and non-spouse relative are more likely to seek external help. Females having stronger attachments which make institutionalizing hard to overcome |
| Help-seeking for dementia: a systematic review of the literature. | Werner et al. | 2014 | 48 peer-reviewed journal articles | Clinical Research from across the globe | Systematic Review | <ul style="list-style-type: none"> Inadequate knowledge & stigma are the most common barriers to timely help seeking (HS) Timely HS may be associated with better outcomes for people with dementia and their caregivers |
| Immigrant patients with dementia and memory impairment in primary health care in Norway: a national registry study. | Diaz et al. | 2015 | Norwegians and other immigrants >50yo with dementia n = 585 for those from high income countries n = 213 for those other from other countries | Norway | Registry-based study | <ul style="list-style-type: none"> Linguistic barriers and challenges should be further investigated Knowledge about diagnosis and management of memory problems is scarce Among people with dementia, native Norwegians were 20-50% more likely to utilize medication than immigrants |

| | | | | | | |
|--|-------------------------|-------------|---|---|--|---|
| <p>Cross-cultural differences in dementia: the Sociocultural Health Belief Mode</p> | <p>Sayegh et al.</p> | <p>2013</p> | <p>Both PsycINFO and PubMed were searched for barriers to dementia care for ethnic older adults</p> <p>No sample size was given</p> | <p>Based in Los Angeles – articles obtained from global databases</p> | <p>Literature Review</p> | <ul style="list-style-type: none"> • Cultural and ethnic barriers may lead to a delay in timely care • Diagnostic delays lead to a delay in care an increase in the symptom severity upon being diagnosed: • Cultural perception – memory loss is a normal sign of aging • Religion – people with dementia are evil or possessed / things are God’s will / • Difficulties navigating the healthcare system. • Fear of racism, lack of trust |
| <p>A review of barriers and enablers to diagnosis and management of persons with dementia in primary care.</p> | <p>Amihzadeh et al.</p> | <p>2012</p> | <p>326 articles about people with dementia / caregivers in primary care</p> | <p>Western Countries (US, Canada, etc)</p> | <p>Scoping review of Western literature published over the past decade</p> | <ul style="list-style-type: none"> • Gaps in knowledge, skills, and resources may lead to a delay of care • Western countries face challenges in providing comprehensive and cost-effective care <p>Proposed solutions:</p> <ul style="list-style-type: none"> • Progress requires a coordinated campaign and increased levels of commitment and effort, focusing on barriers and enablers |

| | | | | | | |
|---|---------------|------|---|--|---|--|
| Examining What Caregivers Do During Respite Time to Make Respite More Effective | Lund et al. | 2009 | 52 family caregivers of those receiving adult day services | Moderately sized cities in the Greater Salt Lake City area | 90 min in home interview with caregiver | <ul style="list-style-type: none"> • Dimensions of caregiver burden are outlined (physical, social, time, emotional) • Respite allows for ample time to tend to personal, household and social need |
| Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. | Garand et al. | 2015 | <p>Individuals with dementia or Mild Cognitive Impairment (MCI) and their caregivers</p> <p>Sample size not specified</p> | USA | Methodological Review | <ul style="list-style-type: none"> • Diagnostics labels are associated with significant stigma that may interfere with a person's willingness to seek care or participate in research. • Overcoming barriers is essential to the research process. |

Appendix D

| Database | Date | Search Terms | Results | Misc. |
|------------------|------------|--|---------|---------------------------|
| PubMed (MeSH) | 10/13/2016 | Dementia AND Barriers AND Healthcare Utilization (related terms searched using MeSH) Dementia, cognition, memory Barriers, obstacles, problems Services, healthcare utilization, respite | 42 | Within last 5 years |
| Web of Science | 11/1/2016 | Dementia AND Barriers AND Services | 11 | US only, last 10 years |
| CINAHL | 11/2/2016 | dementia or alzheimer's disease or cognitive impairment or memory impairment barriers or obstacles or challenges healthcare utilization or health care use | 6 | US only, last 10 years |