2022

Dementia Care Among Somali Elders

Emmanuel Asante Opoku
Minnesota State University, Mankato

Dementia Care Among Somali Elders

By

Opoku Emmanuel Asante

An Alternative Plan Paper Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

In

Aging Studies

Minnesota State University, Mankato

Mankato, Minnesota

December 2022

This Alternative plan paper has been examined and approved by the following members of the student's committee.

Dr. Kathryn Elliott, Ph.D.,
Advisor

Dr. Aaron Hoy, Ph.D.,
Committee Member

Dr. Jeffrey Buchanan, Ph.D.,
Committee Member

ABSTRACT

Caring for persons with dementia is demanding and complicated since there is "no one-size-fits all" formula for dementia care. The care needs to be modified to fit the various stages of the condition and each family's unique situation. Racial and ethnic differences place unique demand on all the forms of dementia care; in-home care (IHC), long-term care (LTC), adult day centers (ADC), short term care (STC) and hospice care (HC).

This paper aimed to study how Somali elders think and interact with dementia care services, from in-home care to hospice care. Some recommendations to study this issue is to do a systematic review on related articles that would aid in understanding how Somali elders perceive dementia care in the US. Challenges and limitations of Somalis being refugees, immigrants and having unique cultural identity were reviewed.

The paper analyzes the Somali cultural and religious norms and evaluates how these have influence on how they utilize dementia care services. Inferences were drawn from over 13 articles on Somali refugee mental health, Somali cultural profile, dementia in Somali community and journal of immigrant health among others.

This paper shows the unique cultural and racial values that Somali elders would want to be incorporated into dementia care services. Challenges associated with Somalis as refugees (post-war), as immigrants, and as people with different cultural and religious norms were found to have direct and indirect influence on how they interact with dementia care services in the United States.

ACKNOWLEDGEMENTS

I would like to thank my advisor, Dr. Kathryn, for her help and guidance during my studies.

Special thanks go to Dr. Aaron for his continued support from admission through graduation.

I would like to thank Dr. Jeffrey for his immense contributions to this paper.

I would like to thank my friends for their encouragement and support: Lenah and Asamoah.

For unconditional love and encouragement: Christabel and Granny.

Table of Contents

CHAPTER 1: INTRODUCTION

The Alzheimer's Association defines dementia as a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life (Kumar, A., Sidhu, J., Goyal, A., Tsao, J. W., & Svercauski, J. 2021). Dementia has several symptoms associated with decrease in cognitive functions that even affects activities of daily living. In addition, patients can show symptoms of emotional problems and decreased motivation. Research done by Mette Sagbakken, Ragnhild Storstein Spilker and T. Rune Nielsen in 2018 emphasized that, Alzheimer's dementia made it to the top list of major public health challenges of the century. Therefore, the need for support and care will increase over the course of the disease, often resulting in physical, emotional, and economic pressures, causing stress to families and caregivers, and leading to increased societal costs (Sagbakken, M., Spilker, R. S., & Nielsen, T. R. 2018).

While immigration seems to give a better life option to immigrants, navigating the health system has been difficult for most immigrants. A study done by Kovaleva, Jones, Maxwell and Long found that, immigrants have a higher prevalence and risk of dementia, including undiagnosed dementia. Older immigrants face unique obstacles in terms of their cognitive health, including language barriers, economic constraints, depressive symptoms, social isolation, low acculturation to the U.S., stigma related to dementia, and lacking education about dementia (Kovaleva M, Jones A, Maxwell CA, Long EM, 2021).

Therefore, there is a need to study factors that would influence preferences for dementia care to inform caregivers, policymakers, researchers and other interest groups. Most institutions are not shaped to accommodate care recipient's beliefs, and cultural values, especially with older immigrants.

Fernández-Shaw and colleagues found that, though family caregivers of loved ones with dementia and other forms of dementia in the U.S. and China have similar coping styles, caregivers in America reported experiencing more depression and anxiety (Fernández-Shaw, C., Marina, A., Cazorla, P., Valdivieso, F., & Vázquez, J. 1997).

Figueredo-Borda, N. (2015) discussed in an article that, there is a need for health care professionals to examine their personal and professional knowledge before approaching a patient from a culture different from their own. This would improve quality of care especially in elderly immigrants. This conscious effort goes a long way to curb confounding issues to clinical iceberg, such as cultural imposition, and help eradicate the patient´s lack of integrity (Figueredo-Borda, N. 2015).

It is therefore needful to do a study on factors influencing preferences for dementia care among Somali elders, which would inform policy makers and caregivers about mostly ignored factors that may have an influence on dementia care. This paper would do an in-depth analysis and evaluation of factors contributing to the choice of dementia care among Somali elders. The study would show the unique cultural and racial values that Somali elders want to be incorporated into their care, and how different their care should be from the standard care.

CHAPTER 2: LITERATURE REVIEW

Aging Demographics

Aging is a natural process that everyone goes through, this process together with several factors have impact on the life course. The fastest growing age group is the older-than-85-year group (National Institute on Aging, 2014), with the life expectancy of this group steadily increasing (United Nations, 2013).

Older African immigrants including Somalis, who migrated to America have a very negligible proportion compared to the general population. However, their numbers are doubling every decade since 1970. Most Somalis who now live in Minnesota came to the United States as refugees fleeing war. Minnesota is home to the country's largest population of Somali residents, which numbered 87,853 as of 2008. International institute (2017) of Minnesota estimates that there may be as many as 150,000 Somalis living in Minnesota, which is likely the highest concentration of Somalis in the U.S. Most Somalis live in the metro area, particularly in Minneapolis (U.S. Census Bureau; Anderson 2020). Looking at the increasing number of older Somalis, the number of dementia patients is expected to rise as well. Older African adults 65 years and older have greater risk of getting dementia (Henderson, J. N. 2015).

Breakdown of Dementia in The United States

The global prevalence of dementia almost doubles every 20 years, with estimations reaching 65.7 million in 2030 and 115.4 million in 2050 (Sagbakken, M., Spilker, R. S., & Nielsen, T. R. 2018). Alzheimer’s Association (2022) estimates that about 6.5 million Americans aged 65 and older are living with Alzheimer's dementia, and this number could grow to 13.8 million by 2060. This means

that ten percent of elders 65 years and older have Alzheimer's dementia (AD), and almost two-thirds of Americans with Alzheimer's are women. Statistics further show that Alzheimer's dementia affects racial and ethnic groups disproportionately. Compared to white elders, African Americans are about two times more likely to have Alzheimer's or other dementias, and Hispanics are approximately 1.5 times as likely (Alzheimer's Association, 2022).

As the American population continues to rise, the proportion of ethnic minorities among the elderly in the United States has also increased. By 2050, the proportion of elders who are white and non-Hispanic will decline from 87 percent in 1990 to 67 percent. It is interesting how the population of Hispanic elders would be 11 times greater by 2050. Of the 80.1 million older adults projected for 2050, 8.4 million (10.4 percent) will be black, as compared to 8 percent of elders in 1990 (U.S Census Bureau).

Such changes would affect ethnic minority populations to also have an increased share of the economic and social problems associated with diseases that affect the elderly, such as Alzheimer's disease (AD) and dementia. At the same time, different racial groups being compared residing in the same environment with similar socioeconomic status and equal exposure to risk factors may help to disclose genetic factors responsible for AD.

It is also estimated that the prevalence of dementia for white women (2.9%) is almost like that for white men (3.3%), but the rate for black women is considerably higher than for black men (19.9% and 8.9%, respectively). Blacks are more likely than whites to have a history of stroke, hypertension, and other chronic disorders that contribute to the development of dementia.

This raises a public health concern because ethnic minorities may be at higher risk for Alzheimer's and dementia than White Americans (Anderson, N. B., Bulatao, R. A., Cohen, B. 2004).

Diagnosis of Dementia

Due to several problems that immigrants face in America, there has been a negative effect on diagnoses of dementia. From language barriers to lack of education, immigrants have hard times navigating the American health system as far as dementia is concerned. A recent study found there was a significant "over and under" diagnosis of dementia in ethnic minorities. Participants were 68,219 persons aged 20 and above. A sum of 174 dementia patients were recorded. The average age at diagnosis was 57.7 years (SD = 16.2). Compare that to the entire population, there was an increased prevalence of dementia among those younger than 60 years, and a noticeably lower prevalence of dementia among those 60 years and older. It was found that, dementia is under-diagnosed to a greater extent among ethnic minorities in the age group 60 years and older but is over-diagnosed in the age group younger than 60 years. Several factors may contribute to this pattern, including cultural differences in help-seeking behavior, and problems in navigating the health-care system. Furthermore, cross-cultural assessment of dementia can be difficult because of language barriers and cultural differences (Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. 2011).

Dementia Among Immigrants

Neurodegenerative disease, such as Alzheimer's and dementia of late life constitute an increasingly growing global problem (National Institute on Aging 2014). Alzheimer's Disease and Related Dementias (ADRD) has greatest lifetime threat with old age and even much worse amongst people that are at risk, for example immigrants. That means as immigrants continue to grow, their chance of getting dementia also grows. This also puts pressure on health system as the rise in the condition calls for increased medical interventions to help curb related issues and,

consequently, it constitutes an unprecedented disparity in the health system (Coreil, Bryant, & Henderson 2001).

Current estimates are that about 5.8 million people in the United States have Alzheimer's disease and related dementias, including 5.6 million aged 65 and older and about 200,000 under age 65 with younger-onset Alzheimer's. By 2060, the number of Alzheimer's disease cases is predicted to rise to an estimated 14 million people, with minority populations being affected the most (CDC, 2019).

Henderson, J. N. (2015) in "cultural construction of dementia progression" explained that ethnic minority populations are likewise living into the ages of greatest risk for ADRD. For example, the American Indian and Alaska Native population aged older than 65 years is expected to grow from 212,605 in 2007 to a projected 918,000 by 2050 (U.S. Department of Health and Human Services 2014). The term ethnic minority was used in reference to sub-groups within larger populations that have significantly different cultural value systems, language, and an ethos separate from the majority group. In real practice, ethnic minority status is highly variable as an intercultural difference, but ethnic minority factors are also present in a great range of intragroup variations as well (Henderson, J. N. 2015).

Furthermore, how ethnic minorities live their lives as far as their norms and values are concerned, play major role in how they receive dementia care (Aranda, M. P. 2001).

Families with someone who has a chronic, progressively worsening cognitive and behavioral conditions such as Alzheimer's dementia needs help from health workers and relatives to be able to handle activities of daily living and continue normal lifestyle (Maki, Y., Sakurai, T., Okochi, J., Yamaguchi, H., & Toba, K. 2018).

Henderson, J.N. 2015 explained that the common cultural construction of the condition is just too static to properly account for progressively worsening mental disease. Immigrants' families would oftentimes seek health help but experience it within the context of their peculiar health beliefs and practices. Henderson further explained that one big issue is the perception of the group about dementia (Henderson, J. N. 2015).

In a study in Denmark done by Nielsen, T. R., Nielsen, D. S., & Waldemar, G. 2021, "Barriers in access to dementia care in minority ethnic groups in Denmark", they found that, culturally stigmatizing beliefs about dementia have major impact on choice of care. Particularly that dementia is a form of insanity, was an issue that prevented or delayed dementia care seeking. Due to the strong stigma, minority ethnic people with dementia and their family caregivers would often try to conceal the symptoms for as long as possible (Nielsen, T. R., Nielsen, D. S., & Waldemar, G. 202).

Among the other reasons affecting the receipt of dementia care among immigrants, Henderson pointed out that, immigrants seem to live together and help each other which could be because of being away from home or due to culture. For immigrants that live together, they are seen to manage both their loved one's chronic, incurable disease and biomedical bias, intentional or not, against unorthodox cultural health beliefs and practices (Henderson, J. N. 2015).

People address disease and disability in life by connecting to their foundational norms of their culture and beliefs to create explanations and forecasts about their predicament (Henderson & Henderson, 2002; Kleinman, 1980; Kleinman, Eisenberg, & Good 1978). Cultural factors as basic as norms and values of family solidarity could directly affect the character of "how, who, when, and where" caregiving for chronic disease occurs (Henderson 1987 & 2009). Cultural concepts of faith referring to what caused the disease, what did the person do and what could be done, may

determine preferences for care and affect the complete process of handling the disease (Henderson, Finke, & McCabe 2004).

On the issue of culture and mental health, people intentionally or unintentionally use their cultural perceptions to deal with all manner of life's difficulties including dealing with a chronic mental disease as an immigrant according to Green (1995). Risk of exclusion and isolation of immigrant communities is heightened by behaving in ways considered nonstandard by the whole population. Protecting oneself, family, and community from the penalties of being seen as too different or too ethnic by the bulk population are sufficient to motivate immigrants to stop seeking help for mental health conditions or to suppress the disease by their own means (Green 1995; Helman 2007; Tseng 2003; Valle 1998).

African immigrants including Somalis rely more on informal care than Whites, especially those with disabilities (Bradley et al.2004). Since dementia is prevalent amongst elders aged 65 and above, it is important to consider at their long-term care (LTC) preference for dementia (Thorne 2020). Nursing homes should be a home away from home as every American would prefer. The vulnerability of such care recipients can increase, especially those who require specific treatment or have special needs alongside cultural preferences. African immigrants have less confidence engaging in future LTC plans compared to their white counterparts (Sörensen and Pinquart 2001). The health system should be modified in a way that immigrants would feel welcome just like an American citizen would. Seminars, training, and workshops should be organized to create awareness and educate caregivers on socio-cultural differences. Caregivers should improve their different skills to increase their work efficiency while caring for immigrant elders with dementia. Health care professionals should examine their personal and professional knowledge before approaching a patient and their families different from their own culture, which would improve

the attention´s quality of care, especially in dementia patients. This conscious effort goes long way to curb confounding issues to dementia care (clinical iceberg), such as medical cultural imposition, and help eradicate the patient´s lack of integrity (Figueredo-Borda, N. 2015).

The population of immigrants keeps increasing which keeps increasing the population of immigrants' elders in America, but immigrant patients are underrepresented in dementia assessment and care (Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014).

All the above-mentioned factors surrounding immigrants and dementia care have direct and indirect relationship with cultural beliefs and values. Also, it may be difficult to form clinical assessments of immigrant group patients who do see a physician for dementia symptoms. This paper aims to expound factors that would influence preference for dementia care among Somali elders.

Somalis and Dementia

Though all immigrants above 65 years are at risk of having dementia, Somali elders are at greater risk due to how they came to United States and their situation back home. Statistics about Somali elders indicate that 50% of Somali elders come to the United States alone. The high prevalence of post-traumatic stress disorder (PTSD) among the Somali refugee population immigrant groups contribute to their burden of disease and affects their quality of life. Post-traumatic stress disorder (PTSD) is common among the Somali refugee population in America (Kurtakoti, S., Kurtakoti, S. S., & Kerzner, L. J. 2010). This paper focuses on dementia among Somali elders due to their risk of having PTSD, depression, and psychosis based on factors of wartime conflict (Kroll, Yusuf, & Fujiwara, 2009).

Somali's culture makes their choice of care and preferences for care unique. A typical Somali home has unique family system which is different from that of American, and research shows that this unique family system has influence on how they perceive dementia and long-term care (LTC). Amongst Somalis, men and women fulfill gender-specified tasks. The women are mostly responsible for household chores including taking care of sick relatives (Lewis 1994). If an elderly male individual leaves his home without his partner, he must adapt and learn to deal with house chores, that means a Somalis elder in nursing a home would be expected to handle his own affair. Due to how their culture respects elderly men, it is highly possible they retain them in their homes instead of letting them choose LTC (Cohen and Menken 2006).

Considering all these factors associated with Somalis and dementia, there should be more research in this area to reveal solutions to help improve quality of dementia care among Somalis. It is rather unfortunate that research on Somali elders and dementia is very limited. Nkimbeng and colleagues mentioned that dementia research with communities such as African immigrants is limited because historically these communities have faced many social and cultural barriers to their participation and inclusion in research (Nkimbeng, Manka**,** Christina E. Rosebush, Kwame O. Akosah, Hawking Yam, Wynfred N. Russell, Gabriela Bustamante, Elizabeth A. Albers, Tetyana P. Shippee, Arundhathi P. Sasikumar, and Joseph E. Gaugler. 2022).

As a response to this knowledge gap: given the limited research on dementia among Somali elders, this paper aims to elaborate on how Somali elders think and interact with dementia care services in the United States. The paper will address the following: How do Somali immigrant elders think and interact with dementia care services in the United States? And how are these shaped by cultural and religious factors?

My Experience

Though studies have revealed the urgency of the need for research on immigrants and dementia, my experience at a nursing home showed how serious the situation is. As a caregiver, I worked directly in contact with elders, assisting them with activities of daily living and instrumental activities. One thing that I have realized at the nursing home is, though the community where the nursing home is situated has a lot of Somali elders, I have not found a single Somali elder in the nursing home (one of the biggest nursing homes in the community). Could this be due to a lack of knowledge about available resources, financial difficulties, the language barrier or as a result of inadequate culturally oriented nursing homes in the community?

As an immigrant and a nursing aide at the facility, the cultural shock and feeling of not belonging was felt in the beginning weeks of my work. I can relate to a Somali elder who will have to live most of their lives in a nursing home they are not familiar with if the need arises. Apart from the stress Somali elders have been through post-war and the fact that they are refugees with their own challenges, Somali elders have their cultural identity which differs from the American culture.

In nursing homes in America, vulnerable adults are respected and treated with dignity. As part of creating “home-like” nursing homes, there are several activities that reflect the American culture, the daily routine, meals, language, values, norms and the atmosphere in the nursing home are designed to fit the American norms. This is different for Somalis elders who have lived all their

lives within the context of their own culture. Even Somali shops and stores in Mankato sell mostly Somali cultural products. The design, smell, food, clothes and everything there reflects their identity.

In the American nursing homes where I work, it is common for residents to order meals from a list of available orders. Interestingly, there is no 'bariis iskukaris' (the most popular Somali dish) on the menu. Special orders are possible but must be done within the scope of the kinds of food available in the nursing home's kitchen. In fact, there is no place to prepare "culture-specific" meals. Interestingly, there are quite a few Somali refugees in the community. There are several reasons why older people in Somalia do not seek nursing home or dementia care services, but cultural differences stand out. When I asked a Somali nurse at a nursing home, she replied, "The Somali elders are being cared for in another home, so they don't want to be here." She said that caring for the elderly in Somali households is widely considered a family duty, especially for the younger generation. She also said, "it's a cultural view that we have to take care of our parents," and "They gave us so much that we have to pay them back."

Somali cultural literacy is indeed essential for dementia care, and cultural engagement in mental health care like dementia requires a great deal of commitment and experience with Somali cultural groups. Therefore, it is a lifelong goal in health care. Regardless, cultural openness and willingness to explain expectations and beliefs may be key to initiating appropriate communication. Positive acceptance, building relationships, and active listening can be effective ways to gain trust and ensure proper service to Somali elders. Also, increasing the ethnic diversity of healthcare providers by providing services through healthcare providers who share the same cultural background as the Somali group, wherever possible, is a shorter and more efficient method and helps ensure cultural competence with less time and in a more efficient way.

CHAPTER 3: METHOD

Inclusion and Exclusion Criteria

To address the research questions as mentioned above, a literature review was conducted using search strategy to narrow down to the topic. The literature review search strategy included journal articles and research papers published up to January 2022. The search was done between September 8, 2022, and October 12,2022. Databases used are EBSCO Host: Academic Search Premier, Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with Full-Text, and Cochrane Database of Systemic Reviews. Health Source: Medline, and PubMed, and google/Scholar as search engines.

Search terms relevant to research question together with Boolean operations were used. The following are the search terms: ‘Immigrants', 'Somali culture’, ‘Somali elders’, ‘Somali refugees’, ‘Somali elders AND mental health’, ‘dementia OR/AND Alzheimer’s’, ‘dementia support programs’, ‘dementia care AND Somali elders’, Somali religion AND dementia’, ‘Somali culture AND dementia’, and ‘Somali language barrier’. Studies of both 'dementia' and 'Alzheimer's disease' related to support programs and care for dementia and Alzheimer's disease are often similar in nature and content, and often the two words are used interchangeably.

The literature review captures the full range of cultural norms that have an influence on healthcare decision or accessing dementia services. The literature review included studies conducted on immigrant population groups that included people with dementia, informal and formal caregivers and dementia services. Studies on challenges to equal healthcare access among other immigrant refugees were excluded from this review.

Search Strategy

Databases searches yielded over 3,000 topics on the broader perspective. The articles were narrowed down to a total of 48 research publications, including peer-reviewed journal articles, e-books, dissertations, and book chapters as of September 8, 2022. Abstracts identified as important to the research question were retained and full-text articles were retrieved for further review. Found references were listed and related articles were screened to prevent double ups. After screening for double ups, nine articles were deleted out of the 48 (n= 48-9).

Critical Appraisal Skills Program (CASP) checklist was further used to narrow down to articles relevant to the research question. At the CASP screening, 19 articles out of the 39 were excluded (n = 39-19), they were not found related to Alzheimer's dementia. Full-text articles were assessed for final eligibility (n = 20), 7 articles were excluded (n=20-7), these 7 articles were not directly related to dementia among immigrants.

A total of 13 articles were included in the final data analysis using thematic analysis method based on relevance for data extraction purposes. The thematic method was used to organize and categorize the qualified articles. The selected articles were categorized initially into sections, and they were further grouped under research setting/location, purpose of the study, design, methods, sample, and key findings in tables form for comparison (Appendix: tables 1,2,3 and 4). Similar data were compared and grouped until the final themes were refined. Results were analyzed and evaluated to identify common themes, methods and research gaps. In addition to the scientific literature, information and insights such as statistical data, current approaches and recommendations were drawn from the Alzheimer's Association of America and U.S Data and Statistics.

CHAPTER 4: LITERATURE FINDINGS

Background of Somalis Culture in the United States

Statistics show that United States is among the world's most ethnically diverse and multicultural nations and has seen massive immigration influx from several countries. It is very important that as the American population continues to grow diversely, the American health system should also change to match the paradigm (Adams and Strother-Adams, 2001).

A study done by Bentley and Owens revealed that, like many other African countries, Somalis have a culture that comprises a clan-based social system that focuses on family and communal bonds. A typical Somali community is made up of several major clans and sub-clans. Statistics show that most Somali refugees residing in the United States are either from the Barawan or Benadir group, and others from other clans such as Hawiyo, Darood, Dir, Digil and Mirif. The Benadir people are mostly traders and artisans that come from the southeast coastal regions of Somalia. Somalis residing around Kismayu are the Barawan clan which is mostly a fishing community. The country has been suffering from inter-clan conflicts and ultimately civil war which may be as a result of the lack of centralized government. Due to the effect of war and the mini cultural clans within the country, a typical Somali identifies more with their clan than the entire society (Bentley J. A., & Owens, C. W. 2008).

Literature showed that the most predominant family structure in Somalia is the patriarchal system, where the father is the head of the household and the “breadwinner” of the family. whereas the women do the household chores with the children. Since the women are responsible for home duties, they also take care of the children and prepare meals. Somalis are found to have an extended family system, due to their extended form of living, the home responsibilities are extended to other relatives and close family friends living with them. Another intriguing finding was that children

are valued in the Somali community, so having many children is highly valued. Somalis live together or stay in touch with extended family members for support, love, and belongingness. With the extended family system, elders in the community are respected and children usually help elders with chores they are no longer able to do. This unique identity of Somalis may be different in Somalis born or raised in America, and there will be a slight cultural change in the younger generations in America (Scuglik, D. L., Alarcón, R. D., Lapeyre III, A. C., Williams, M. D., & Logan, K. M. (2007).

Somalis Cultural Norms

Evidence shows that, the population of American born elders outweighs that of immigrants such as Somali elders, however, studies show that the population of immigrants are increasing at a faster pace. The rise of the number of immigrants and refugees raises concerns that mental health professionals working with immigrants such as Somali elders should be equipped with the necessary services and skills to meet their specific needs. Health care providers need to become familiar with Somali perceptions and cultural understandings of both physical and mental health conditions like dementia. Healthcare workers should understand the Somali culture, that is their food, clothes, spirituality, values and belief system. The study explained that if health services are enriched with cultural norms and values, family caregivers would find it easier to take Somali elders to seek health care services (Lindesay, J. (1998).

It is evident that in nursing homes and elderly daycare centers in United States, the activity structure and daily routine like foods, drinks, songs, music, television and traditional pastimes, and the norms for socialization between genders, would often be unfamiliar to Somali elder. Although caregivers representing some ethnic minority groups are represented in nursing homes and home care services, care providers are not always ready to match these to the cultural background of

residents. According to Czapka, E. A., & Sagbakken, M. 2020, there are several factors that contribute to minority ethnic groups not utilizing dementia care services in the United States. Most of these factors surround cultural norms such as stigmatization, family dependence, religious beliefs, language barrier and lack of knowledge about dementia care services (Hasselkus, B. R. 1992) (Czapka, E. A., & Sagbakken, M. 2020).

Cultural Stigmatizing Beliefs

Data from people with dementia have shown that stigma is a deterrent to seeking needed information and support. Literature reveals that in a typical Somali community, dementia is considered a form of madness, and that is another issue that discourages Somali seniors from seeking dementia care, even when living in the United States. Relatives with dementia and Somali elders often tried to hide their illness from their neighbors. In most cases, Somali women hide mental illness from men in order not to lose their marriages. (Perez, C., Roble, M. A., & Gardiner, L. 2008).

The Somali cultural profile revealed that mental disease is seen as a condition that runs in families and is believed to be genetically linked. That is, if a family member is diagnosed with dementia, the dementia patient's relative may also have dementia in future. This stigma directly and indirectly affects family status and jobs in the community, as well as family marriage prospects. As a result, some Somali elders do not want to know about dementia resources and how best to help.

There were examples of family caregivers who, instead of seeking dementia care, kept people with dementia at home and hid them when behavioral symptoms became apparent. The sense that neighbors know about one's mental illness, coupled with the taboo against putting the elderly in foster care, makes it difficult for Somalis to place their elderly in nursing homes. Evidence also found that Somali families do well in home care but typically lack expertise in understanding

dementia, how to manage dementia-related behaviors, and how to manage caregiver burden that can lead to neglect and abuse (Sun, W., Biswas, S., Dacanay, M., & Zou, P. 2019).

Family Dependence

A study of Somali culture reveals that Somalis live together and depend on each other. This cultural norm is known to be associated with underutilization of dementia care services. The fact that older adults rely on other family members to contact and communicate with health care providers for dementia care services is of great concern. Therefore, when deciding to seek dementia care, Somali elders will consider: Who should know about these intimate and potentially revealing issues? When does the person have time to take them? The literature suggests that in Somali households, access to dementia care is influenced by family decisions, taking into account the needs, desires and interests of both the older person with dementia and, sometimes, immediate family members and extended family members based in Somalia. This gives a clear picture of how complex healthcare decision making would be on the part of Somali elders. The article explained that the Somali family system has hierarchical and gender-specific roles and positions within the family. Decisions about dementia care were dependent on family members who were not the actual caregivers but rather the men. Thus, men are the decision-makers and breadwinners of the household, while women are the caretakers (Bentley, J. A., & Owens, C. W. 2008).

Although it is evident that there are several resources available in the United States to help older adults with dementia, research indicates that these resources are provided against the family system and thus appear useless to Somali elders. Botsford, J., & Dening, K. H. found that Somali elders are not able to benefit from dementia services because these services do not meet their cultural needs. They therefore believe that the available services are inadequate, both in terms of dementia care services that are available and how they are delivered. Most Somali elders prefer options that

help them receive dementia care at home or in culturally friendly nursing homes (Botsford, J., & Dening, K. H. 2015).

Religious Influence on Dementia Care

Given the importance of religion in the lives of Somalis, it is also important to understand the role of religious involvement in determining help-seeking behavior for dementia. A study of African Americans with mental disorders identified a distinct profile of help-seeking behavior. The results showed two classes of help-seekers: low use/informal support (95%) and high use/all support (5%). Low subjective religious engagement was associated with low "use/informal support class" membership. Higher levels of religious devotion outside the organization were associated with membership in high "use/all-support classes". No association between demographic characteristics was found between the two classes. The results highlight the heterogeneity of help-seeking behavior among African Americans and the importance of considering multiple domains of religious engagement that influence this behavior. Findings highlight the importance of collaboration among religious institutions, health and mental health service providers, and family and friendship networks in providing mental health care to African Americans (Hays, K., & Lincoln, K. D. 2017).

According to the Federal Ministry of Endowments and Religious Affairs, more than 99 percent of the Somali population is Sunni Muslim (U.S. Department of State, May 2021). Making inference from literatures, almost all of Somalis population is Muslim, so Islamic practices have become a cultural norm. Therefore, the religious beliefs and practices of Somali elders need to be highly valued to ensure holistic dementia care. Religious practices in the Somali communities are merged with their cultural norms, therefore, it is almost impossible to separate a Somali elder from their religion even when receiving health care.

Language Barrier

Surveys show that of the 291.5 million Americans aged 5 and older, 60.6 million (21%) speak a language other than English. Language influences people's identities and expresses culture by creating boundaries for behavior. Language barriers are known to pose significant challenges to the delivery of effective, quality health care. (Ryan, C. L. 2013).

Although evidence shows that federal and state laws provide a framework to ensure healthcare access for individuals unable to speak English, but there is still a lot to do with regard to incorporating culture into healthcare. Many larger healthcare institutions have access to interpreter services, and the availability of professional translators has been associated with improvements in patient satisfaction, communication, and healthcare access. However, it is not only the availability of professional translators that helps ensure “cultural-centered-care” healthcare (Wolz, M. M. 2015).

Language is a symbol of culture, so it is not enough to have a professional interpreter handle the language. Nurses' cultural competencies are fundamental to reducing ethnic and racial disparities. Wolz's (2015) study of 39 Somali immigrants in London showed that simply having translators is not enough to overcome cultural barriers. Perhaps the most obvious and debated challenge in caring for refugee migrants such as Somalis is the problem of communication due to language barriers. A professional interpreter who understands the patient's culture can help providers identify hidden factors that may affect care, even if the patient understands the language of the host country. Challenges associated with language barriers depend on several factors related to how information reaches the care recipient. All these factors lead to a lack of sufficient knowledge and understanding of dementia services available to older Somalis. Factors such as difficulty with

interpreters (at home and at the health facility), ineffective communication, and lack of appropriate information may prevent older Somali elders from seeking medical services for dementia (Wolz, M. M. 2015).

Literature compared U.S. citizens without language barriers with immigrants with language barriers. Those with language barriers were more likely to report poor health. After years of managing stressors, immigrants with language barriers are less likely to report poor health. However, these immigrants were more likely to report poor health early in their lives in the United States. That suggests that they are more stressed as newcomers into the US. Stress associated with early years as an immigrant, and the language barrier combine to worsen mental health for immigrants (Ding, H., & Hargraves, L. (2009).

Ineffective Communication and Interpretation

A careful analysis of difficulties associated with using interpreters revealed that there is a fair amount of research showing the pros and cons of using interpreting services. Interpreters typically incorporate verbal and non-verbal communication skills and facilitate long conversations by providing opportunities to assist with pre-examination paperwork. However, ensuring the quality of interpreting services is undoubtedly the key to avoiding additional burdens on healthcare providers. Low quality examples can be observed in situations where the interpreter can add his own experience or add emotions. Another interesting aspect of interpreting services for refugees, such as elders in Somalia, is that interpreters tend to take on roles beyond those of medical interpreters. This is usually due to the desperate need of many refugees who need an interpreting relationship based on a long-term care model. Moreover, terms that do not exist in refugee culture are difficult or even impossible for medical professionals to explain (Wolz, M. M. 2015).

Another emerging factor contributing to ineffective interpretation is the lack of cultural inclusion. Despite the enormous benefits that professional interpreting services provide in healthcare, it is emphasized that a high standard of care cannot be guaranteed if culture is ignored. The reason is that interpreters usually only relieve the communication effort to a limited extent by overcoming the language barrier between patients and providers. However, they are unique to Somalis and may not be able to meet the cultural expectations of these refugees beyond speaking Somali. One doctor explained in Wolz's (2015) study that telling his patients they had depression was a big challenge for him because there was no equivalent word for "depression" in her language. It is therefore important that interpreters are properly trained to serve the Somali community in a culturally sensitive manner. As with many other aspects of healthcare, interpretation must incorporate cultural values and norms. For Somali elders, for example, translation services should also consider cultural gender roles. Somali women prefer female custodians and interpreters, while men prefer male services (Wolz, M. M. 2015).

Findings of Roth, D.L. and colleagues suggest that patients report greater satisfaction, participation, and positive impact when interacting with caregivers from their cultural or ethnic group. Dementia care communication requires healthcare providers to prioritize the beliefs and values of care recipients, and information transmitted must be culturally rich. From face-to-face interactions, with or without interpretation, communication must revolve around cultural norms. Cultural communication is an important aspect of the physician-patient relationship that is likely to influence patient outcomes. Therefore, ineffective communication in dementia care services at home and in health facilities is influenced by a variety of factors. This depends on the provider's cultural background and knowledge, the interpretation process and the cultural atmosphere of the facility (Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. 2001).

Jain, P., and Krieger, J. L. (2011) focused on developing an acculturation curriculum for international medical graduates (IMGs). The study found that physicians trained abroad were better at understanding the concepts of patient engagement and patient autonomy. IMGs were found to use several strategies during physician-patient communication to accommodate intercultural and intergroup differences. They do so by repeating information, adjust their speaking style, and using non-verbal communication skills.

However, the study found some communication challenges inherent in cross-cultural interactions between physicians and patients, especially when physicians are foreign-born. The three most common sources of IMG difficulty that were found are language, emotional or affect related issues, and cultural norms of medical interaction. International physicians, undergo a rigorous assessment of their English and communication skills before being accepted into residency programs. These findings are in line with other research on the barriers that IMGs must overcome. This report contributes to the literature by showing the strategies IMG physicians incorporate into their care to minimize cultural differences. Statistics show one in four of U.S. physicians is an Internationally Trained Physician (IMG), and approximately 30% of IMGs are involved in care in a variety of primary care specialties.

The literature shows that all aspects of interacting with doctors are guided by norms and expectations shaped by culturally acquired attitudes and beliefs. For example, US medical privacy standards require doctors to provide medical information directly to patients. A survey of 90 physicians in 20 countries found that physicians outside the United States are most comfortable communicating diagnoses of life-threatening illnesses (such as cancer) to patients' families. Like other common communication challenges faced by IMG, it is unclear to what extent it adapts to the diverse cultural norms of patients across the United States (Jain, P., & Krieger, J. L. 2011).

Lack of Knowledge

From literature above, it is now evident that the lack of knowledge about dementia care services in the US among Somalis may be due to language barriers where information about dementia services is not properly understood. Care providers must have a good knowledge of Somali culture and refugee life in order to provide culture-centered care.

Studies of physician perceptions in private practice show that most residents prefer to care for refugees and immigrants. However, they are concerned about the quality of service. In addition, more than half of residents feel they are not well informed about the health of migrants and refugees. Another study by Medact in the UK shows knowledge gaps among doctors, nurses and non-clinical staff working with refugees and asylum seekers. According to the report, of the 198 national health workers who participated in the survey, the terms "asylum-seeker," "asylum-denied," "economic migrant," and "refugee" were not used with confidence. Only 21% could be defined. Only about 25% were able to explain which groups were entitled to free medical care, and 32% were unaware that denied asylum seekers were entitled to free emergency care. The majority expressed lack of confidence in collecting stories of trauma and torture and called for training on various aspects of refugee health and issues related to asylum seekers and refugees (Asif, Z., & Kienzler, H. 2022).

Lack of knowledge about dementia care services could also be caused by ineffective communication as studies show. Literature further proves that ineffective communication may be caused by the lack of knowledge of Somali culture among healthcare providers and health workers. Studies show that due to limited time to prepare medically for culturally diverse groups and inadequate training opportunities, health workers usually do not have good knowledge of refugee

cultures and are not well trained. As a result, they fear that their encounter will be misunderstood and offend the refugee patient in ways they do not know. This can even lead to accusations of racism due to misunderstandings and lack of cultural understanding.

CHAPTER 5: DISCUSSION

Influence of Cultural Norms on Dementia Care

The above discussed articles, journals and books about Somali culture and how Somalis receive mental healthcare highlight how cultural incompetence hinders appropriate interactions between healthcare professionals and patients, creating challenges for caregivers in their daily work. Out of the 13 articles that were analyzed, eight articles revealed how cultural and religious norms have influence on accessing dementia services.

The articles note that for providers to develop measures to curb these challenges, they should understand the norms and values of Somali elders not just to accommodate for their culture. For instance, in a typical Somali community where most people there are refugees from a patriarchal culture, attempts to obtain detailed medical histories to develop a dementia care plan may be seen as threatening. Health care providers reported to researchers an inability to take a holistic approach to treating health problems in a unique culture of that sort (Kavukcu, N., & Altıntaş, K. H. 2019). Studies have also revealed that challenges with Somali cultural norms within the U.S healthcare system have created other confounding factors inhibiting the receipt of dementia care. We saw that if healthcare providers are not able to take a comprehensive medical history, a quality dementia healthcare plan would be jeopardized. This clearly leads to cases of unknown illnesses such as stress, mental disorders, and cases such as sexual violence that health care providers are unaware of. The stigma makes it particularly difficult in Somali communities as it is difficult to maintain

proper medical communication and thereby obtain an accurate medical history (Kavukcu, N., & Altıntaş, K. H. 2019).

A study of Somali immigrant women's experiences with American doctors provided a good example of how cultural expectations and differing understandings influence the services that health care providers give to culturally diverse groups. The research showed that medical practice varies by culture. Just as dementia care has an individual unique care plan for each person who needs care. Dementia caregiving can be very complicated and frustrating when caregivers overlook the caregiver's cultural norms and expectations as revealed by the articles.

Research has shown that the western medical practice dominates the Somali community in the United States which frustrates Somali elders. The use of a non-patriarchal approach by mental healthcare providers who rely on patient-provider collaboration is not useful to Somali elders who view health care providers as authoritative and expect to be told what to do because their culture has shaped them that way. Mistrust is therefore another culture-related issue that arises the moment health care providers start collecting medical histories using the normal standard of care approach which is non-patriarchal. For example, Somali elders with dementia or relatives would feel that they are asked too many questions during screening, have too many blood tests done, and even fear that their blood will be sold, and this hinders providers from obtaining critical clinical information and from providing the best possible services to refugees (Kavukcu, N., & Altıntaş, K. H. 2019).

Differences in perceptions of healthcare are related to how the terms disease and health are conceptualized across the Somali culture. Conceptualization of mental health and dementia has been seen to be dependent on the level of mental health literacy, the availability and willingness of relatives to educate and seek help, the influence of Islam, and the availability of dementia

services in the Somali community. Cultural norms and beliefs related to gender roles and responsibilities have also generated considerable challenges for health care providers. Somali families have gender roles and gender beliefs that derive from intertwined religious and cultural norms. A study of Muslim refugees and immigrants in Melbourne, Australia, showed that women felt more comfortable with female doctors and that their husbands also preferred female health care providers. A Somali Muslim allows her husband to speak to a health care provider instead and does not want a male worker by her side as she undresses (Kavukcu, N., & Altıntaş, K. H. 2019) (Guerin, B., Guerin, P., Diiriye, R. O., & Yates, S. 2004).

The Centers for Disease Control and Prevention (CDC; Atlanta, Georgia, USA) reported on the health profile of Syrian Muslims. The report showed that Muslim women prefer to put on a long hospital gown and prefer same sex healthcare providers. This is also evident when Somali women wear veils and long dresses in hospitals and public places. The Islamic culture of the Somali community also influences dementia care.

Therefore, in dementia care settings where elders are sometimes confused and have forgetfulness, healthcare providers should create a cultural and "religious-like" routine in nursing homes for Somali elders. For example, allowing imams and sheiks to come and visit Somali elders, adding Somali food to the menu and allowing Somali elders to wear their special clothing. Research shows that creating a daily routine for dementia patients improves their ability to perform activities of daily living (Wehrmann, H., Michalowsky, B., Lepper, S., Mohr, W., Raedke, A., & Hoffmann, W. 2021).

Despite the variety of training and education programs available that provide dementia healthcare providers with a culturally sensitive approach to service delivery, the literature shows that there is more to be done for Somali elders. Providing simple and good service does not always help. The

compounding challenges Somalis face in the United States post-war as refugees together with symptoms of dementia (loss of cognitive functioning) complicate the decision to seek medical care in the United States and put dementia healthcare providers in a complicated position as well. Dementia healthcare providers need to understand Somali elders' mental health issues and enable them to ask questions and express culturally bound health-related expectations.

Recommendations

Somali elders, being refugees and immigrants, have several stressors to deal with in their early years in America. In addition to post traumatic stress, they go through cultural shocks, some barriers and difficulties navigating the American health system. Some of the identified barriers, include lack of knowledge regarding available dementia services, misconceptions and stigma related to dementia.

Due to the lack of culturally competent mental healthcare services, Somali elders find it difficult to navigate through the American health system. The Somali cultural lifestyle coupled with the strain they undergo as immigrants and refugees after escaping war, contribute to their inability to utilize available dementia resources. It is imperative for policy makers to pay attention to their preference for health services especially for vulnerable adults like dementia patients.

Research shows that the consequences of dementia in refugees' communities are influenced by cultural factors leading to a cluster of persistent barriers to accessing dementia care services.

To address all these factors, policy makers, and healthcare facilities together with the government should not only set up dementia services but customize those services culturally to accommodate Somali elder's entire identity.

In a nutshell, researchers and dementia organizations should raise awareness about dementia and the existence of dementia care services in Somali communities, to reduce stigma; create language

appropriate services (at home and in hospital facilities); educate healthcare givers; and to develop culturally appropriate dementia care options. A survey should be done in Somali communities to determine how they would want to receive dementia care services since research in this area is limited.

REFERENCE

1. Ali, A. M. (2008). *Acculturation and the subjective well-being of Somali immigrants in the United States: An explanatory mixed methods investigation* (Doctoral dissertation, Capella University).
2. Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *12*(4), 459-509.
3. Anderson, N. B., Bulatao, R. A., Cohen, B., on Race, P., & National Research Council. (2004). Ethnic differences in dementia and Alzheimer's disease. In *Critical perspectives on racial and ethnic differences in health in late life*. National Academies Press (US).
4. Antelius, E. (2017). Dementia in the age of migration: cross cultural perspectives. *Living with Dementia: Relations, Responses and Agency in Everyday Life*.
5. Antelius, E., & Traphagan, J. (2015). Ethnocultural Contextualization of Dementia Care: Cross-cultural Perceptions on the Notion of Self. *Care Management Journals*, *16*(2), 62-3.
6. Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. The Gerontologist, 37(3), 342-354.
7. Asif, Z., & Kienzler, H. (2022). Structural barriers to refugee, asylum seeker and undocumented migrant healthcare access. Perceptions of Doctors of the World caseworkers in the UK. *SSM-Mental Health*, *2*, 100088.
8. Aranda, M. P. (2001). Racial and ethnic factors in dementia care-giving research in the US. *Aging & Mental Health*, *5*(sup1), 116-123.
9. Barthel, H. R., Petruschke, R. A., Gold, M. S., & Wieman, M. S. (2010). Safety of diclofenac sodium 1% gel for knee osteoarthritis in patients aged≥ 65 years with comorbidities. *Journal of the American Medical Directors Association*, *11*(3), B23.

10. Bentley, J. A., & Owens, C. W. (2008). Somali refugee mental health cultural profile. *Ethnomed. Available at: http://ethnomed. org/clinical/mental-health/somali-refugee-mental-healthcultural-profile (Accessed 3 February 2011)*.
11. Calia, C., Johnson, H., & Cristea, M. (2019). Cross-cultural representations of dementia: an exploratory study. *Journal of Global Health*, *9*(1).
12. Cohen, B., & Menken, J. (2006). *Aging in Sub-Saharan Africa, Recommendations for Furthering Research, National Research Council (US) Committee on Population*. Washington (DC): National Academic Press.
13. Ding, H., & Hargraves, L. (2009). Stress-associated poor health among adult immigrants with a language barrier in the United States. *Journal of immigrant and minority health*, *11*(6), 446-452.
14. Eng, K. J., & Woo, B. K. (2015). Knowledge of dementia community resources and stigma among Chinese American immigrants.
15. Fernández-Shaw, C., Marina, A., Cazorla, P., Valdivieso, F., & Vázquez, J. (1997). Anti-brain spectrin immunoreactivity in Dementia disease: degradation of spectrin in an animal model of cholinergic degeneration. *Journal of neuroimmunology*, *77*(1), 91-98.
16. Figueredo-Borda, N. (2015). Gerontology & Geriatric Research.
17. George, D. R., Whitehouse, P. J., & Ballenger, J. (2011). The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Culture, Medicine, and Psychiatry*, *35*(3), 417-435.
18. Guerin, B., Guerin, P., Diiriye, R. O., & Yates, S. (2004). Somali conceptions and expectations concerning mental health: Some guidelines for mental health professionals. *New Zealand Journal of Psychology*, *33*(2), 59-67.

19. Hasselkus, B. R. (1992). The meaning of activity: Day care for persons with Alzheimer disease. *The American Journal of Occupational Therapy*, *46*(3), 199-206.
20. Hays, K., & Lincoln, K. D. (2017). Mental health help-seeking profiles among African Americans: Exploring the influence of religion. *Race and Social Problems*, *9*(2), 127-138.
21. Hydén, L. C., & Antelius, E. (Eds.). (2017). *Living with dementia: relations, responses and agency in everyday life*. Macmillan International Higher Education.
22. Jain, P., & Krieger, J. L. (2011). Moving beyond the language barrier: The communication strategies used by international medical graduates in intercultural medical encounters. *Patient education and counseling*, *84*(1), 98-104.
23. Kavukcu, N., & Altıntaş, K. H. (2019). The challenges of the health care providers in refugee settings: a systematic review. *Prehospital and disaster medicine*, *34*(2), 188-196.
24. Kitwood, T., & Brooker, D. (2019). Dementia reconsidered revisited: The person still comes first. McGraw-Hill Education (UK).
25. Kovaleva, M., Jones, A., & Maxwell, C. A. (2021). Immigrants and dementia: Literature update. *Geriatric Nursing*.
26. Kumar, A., Sidhu, J., Goyal, A., Tsao, J. W., & Svercauski, J. (2021). Alzheimer Disease (Nursing).
27. Kurtakoti, S., Kurtakoti, S. S., & Kerzner, L. J. (2010). Screening for Post-Traumatic Stress Disorder in Somali Elders through Physician Home Visits. *Journal of the American Medical Directors Association*, *11*(3), B23.
28. Lindesay, J. (1998). Diagnosis of mental illness in elderly people from ethnic minorities. *Advances in Psychiatric Treatment*, *4*(4), 219-226.

29. Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of cross-cultural gerontology*, *23*(3), 283-299.
30. Maki, Y., Sakurai, T., Okochi, J., Yamaguchi, H., & Toba, K. (2018). Rehabilitation to live better with dementia. *Geriatrics & gerontology international*, *18*(11), 1529-1536.
31. Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. (2011). Over-and under-diagnosis of Dementia in ethnic minorities: a nationwide register-based study. International Journal of Geriatric Psychiatry, 26(11), 1128-1135.
32. Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2021). Barriers in access to dementia care in minority ethnic groups in Denmark: a qualitative study. *Aging & mental health*, *25*(8), 1424-1432.
33. Omar, M. A. (2015). Somali Elder Care: A Guide for Healthcare in the West.
34. Pollitt, P. A. (1996). Dementia in old age: an anthropological perspective. *Psychological Medicine*, *26*(5), 1061-1074.
35. Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African American and White family caregivers. *Psychology and aging*, *16*(3), 427.
36. Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer's and vascular types. *BioMed research international*, *2014*.
37. Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: a qualitative study of challenges related to identifying, assessing, and diagnosing Dementia. *BMC health services research*, *18*(1), 1-14.

38. Schuchman, David McGraw and McDonald, Colleen (2008) "Somali Mental Health," *Bildhaan: An International Journal of Somali Studies*: Vol. 4, Article 8.[2]
39. Scuglik, D. L., Alarcón, R. D., Lapeyre III, A. C., Williams, M. D., & Logan, K. M. (2007). When the poetry no longer rhymes: Mental health issues among Somali immigrants in the USA. *Transcultural psychiatry*, *44*(4), 581-595.
40. Sloane, J. K. (2017). *Out of Time: The Perceived Loss of Self in Dementia Patients in the United Kingdom and United States*. University of California, San Diego.
41. Stevnsborg, L., Jensen-Dahm, C., Nielsen, T. R., Gasse, C., & Waldemar, G. (2016). Inequalities in access to treatment and Care for Patients with dementia and immigrant background: a Danish Nationwide study. *Journal of Alzheimer's Disease*, *54*(2), 505-514.
42. Stewart, M., Anderson, J., Beiser, M., Mwakarimba, E., Neufeld, A., Simich, L., & Spitzer, D. (2008). Multicultural meanings of social support among immigrants and refugees. *International Migration, 46*(3), 123–159.
43. Sun, W., Biswas, S., Dacanay, M., & Zou, P. (2019). An examination of factors influencing equitable access to dementia care and support programs among migrants and refugees living with dementia: a literature review. *Redirecting alzheimer strategy-tracing memory loss to self-pathology*.
44. Wehrmann, H., Michalowsky, B., Lepper, S., Mohr, W., Raedke, A., & Hoffmann, W. (2021). Priorities and Preferences of People Living with Dementia or Cognitive Impairment–A Systematic Review. *Patient preference and adherence*, *15*, 2793.
45. Williams, A. E. (2018). *Cross-Cultural Views of Dementia: A Focus on African Americans, Asians, Caucasians and Hispanics* (Doctoral dissertation).

46. Winer, J. P., Forgeard, M., Cardeli, E., Issa, O., & Ellis, B. H. (2020). Factor structure and concurrent validity of the Cognitive Fusion Questionnaire (CFQ) in a sample of Somali immigrants living in North America. *American Journal of Orthopsychiatry*.
47. Wolz, M. M. (2015). Language barriers: challenges to quality healthcare. *International journal of dermatology*, *54*(2), 248-250.

Appendix
Table 1.

Database Search Description

Database/Search Engine	**Restrictions Added to Search**	**Dates included in Database**	**General Subjects Covered by Database**
EBSCO Host, including Academic Search Premier, CINAHL Plus with Full-Text, Cochrane Database of Systemic Reviews	Full Text; English language; Peer Reviewed	2010 through 2022	Academic Search Premier: citations, abstracts, and full text of articles (mental health, and aging). CINAHL Plus with Full-Text: e-books about social service and allied health journals. Cochrane Database of Systematic Reviews: Healthcare articles
Medline	Full Text; English Language; Peer Reviewed	2010 through 2022	Research, clinical practice, administration, policy issues, and health care services.
Google Scholar (Search engine)	Full Text; English Language; Peer	2010 through 2022	Citations, abstracts, journals and full text articles: (immigrants, mental health, nursing homes and more)
PubMed	Free Full Text; English Language; Systematic review	2010 through 2022	Nursing, medicine, dentistry, veterinary medicine, and preclinical sciences

Table 2.

Data Abstraction Process

Data Search	Key Words	Results in EBSCO Host	Results in PubMed	Results in Medline	Results in Google scholar
09/08/2022	"Immigrants"	15	60,309	4,728	3,900,000
09/08/2022	"Somali"	0	1,907	212	375,000
09/08/2022	"Mental health"	34	481,492	44,304	6,300,000
09/11/2022	"Somali elders"	0	12	61	41,000
09/11/2022	"Somali Refugees"	0	375	50	122,000
09/11/2022	"Somali immigrant elders"	0	5	31	21,500
09/12/2022	"Somali elders mental health"	0	2	55	19,600
09/12/2022	"Dementia AND Somali elders"	0	0	33	2,970
09/12/2022	"Somali Culture"	0	770	102	218,000
09/12/2022	"Somali culture and healthcare"	0	326	26	39,100
09/16/2022	"Somali language barrier"	0	66	71	40,800
09/20/2022	"Somali language" AND dementia"	0	0	32	21,160
10/08/2022	"Somali religion and dementia"	0	0	31	2,610
10/08/2022	"Somali culture and dementia"	0	0	35	4,180
10/12/2022	"Somali elders AND Alzheimer's"	0	0	13	2,230

Table 3.

Characteristics of Literature Included and Excluded

Reference	**Included/Excluded**	**Rationale**
Ali, A. M. (2008). *Acculturation and the subjective well-being of Somali immigrants in the United States: An explanatory mixed methods investigation* (Doctoral dissertation, Capella University).	Excluded	The study focuses on some important acculturation issues affecting the well-being of the Somali immigrant.
Omar, M. A. (2015). Somali Elder Care: A Guide for Healthcare in the West.	Included	Discusses Somali culture and elder care.
Anderson, N. B., Bulatao, R. A., Cohen, B., on Race, P., & National Research Council. (2004). Ethnic differences in dementia and Alzheimer's disease. In *Critical perspectives on racial and ethnic differences in health in late life*. National Academies Press (US).	Included	The study highlights the importance of ethnic differences in dementia and Alzheimer's care.
Antelius, E. (2017). Dementia in the Age of Migration: Cross Cultural Perspectives. *Living with Dementia: Relations, Responses and Agency in Everyday Life*.	Included	Discusses cross cultural perspectives of living with dementia
Antelius, E., & Traphagan, J. (2015). Ethnocultural contextualization of dementia care: Cross-cultural perceptions on the notion of self. *Care Management Journals*, *16*(2), 62-3.	Included	Focuses on cross cultural perspective of dementia care

Reference	**Included/Excluded**	**Rationale**
Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, *37*(3), 342-354.	Excluded	Addresses caregiver stress and coping strategies.
Eng, K. J., & Woo, B. K. (2015). Knowledge of dementia community resources and stigma among Chinese American immigrants.	Excluded	This study is specific to Chinese American immigrants
Fernández-Shaw, C., Marina, A., Cazorla, P., Valdivieso, F., & Vázquez, J. (1997). Anti-brain spectrin immunoreactivity in Alzheimer's disease: degradation of spectrin in an animal model of cholinergic degeneration. *Journal of neuroimmunology*, *77*(1), 91-98.	Excluded Excluded	Focuses on immunoreactivity in dementia disease. Focuses on immunoreactivity in dementia disease.
George, D. R., Whitehouse, P. J., & Ballenger, J. (2011). The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Culture, Medicine, and Psychiatry*, *35*(3), 417-435.	Excluded	Discusses the evolving classification and the future of Alzheimer's dementia.

Reference	**Included/Excluded**	**Rationale**
Guerin, B., Guerin, P., Diiriye, R. O., & Yates, S. (2004). Somali conceptions and expectations concerning mental health: Some guidelines for mental health professionals. *New Zealand Journal of Psychology*, *33*(2), 59-67.	Included	Specific to Somali conceptions and expectations concerning mental health.
Kitwood, T., & Brooker, D. (2019). *Dementia reconsidered revisited: The person still comes first*. McGraw-Hill Education (UK).	Excluded	Focusses on the paradigms about dementia.
Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. (2011). Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *International Journal of Geriatric Psychiatry*, *26*(11), 1128-1135.	Included	Discuses diagnoses of dementia in ethnic minorities.
Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: a qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC health services research*, *18*(1), 1-14.	Included	Addresses challenges related to identifying, assessing and diagnosing dementia among immigrants.

Reference	**Included/Excluded**	**Rationale**
Schuchman, David McGraw and McDonald, Colleen (2008) "Somali Mental Health," Bildhaan: An International Journal of Somali Studies: Vol. 4, Article 8.[2]	Excluded	Discusses Somali mental health.
Kovaleva, M., Jones, A., & Maxwell, C. A. (2021). Immigrants and dementia: Literature update. *Geriatric Nursing*, *42*(5), 1218-1221.	Excluded	Focuses on immigrants and dementia.
Wehrmann, H., Michalowsky, B., Lepper, S., Mohr, W., Raedke, A., & Hoffmann, W. (2021). Priorities and Preferences of People Living with Dementia or Cognitive Impairment–A Systematic Review. *Patient preference and adherence*, *15*, 2793.	Excluded	Specific to priorities and preferences of people living with dementia.
Wolz, M. M. (2015). Language barriers: challenges to quality healthcare. *International journal of dermatology*, *54*(2), 248-250.	Included	Discusses challenges to quality healthcare among immigrants.
Hays, K., & Lincoln, K. D. (2017). Mental health help-seeking profiles among African Americans: Exploring the influence of religion. *Race and Social Problems*, *9*(2), 127-138.	Included	Addresses the influence of religion on mental health among Africans.
Sun, W., Biswas, S., Dacanay, M., & Zou, P. (2019). An examination of factors influencing equitable access to dementia	Included	This study examines factors influencing access to dementia care among immigrants and refugees.

care and support programs among migrants and refugees living with dementia: a literature review. *Redirecting alzheimer strategy-tracing memory loss to self-pathology*.		
Bentley, J. A., & Owens, C. W. (2008). Somali refugee mental health cultural profile. *Ethnomed. Available at: http://ethnomed. org/clinical/mental-health/somali-refugee-mental-healthcultural-profile (Accessed 3 February 2011)*.	Included	Addresses Somali mental health cultural profile.
Jain, P., & Krieger, J. L. (2011). Moving beyond the language barrier: The communication strategies used by international medical graduates in intercultural medical encounters. *Patient education and counseling*, *84*(1), 98-104.	Excluded	This study discusses communication strategies used by international medical graduates.
Calia, C., Johnson, H., & Cristea, M. (2019). Cross-cultural representations of dementia: an exploratory study. *Journal of Global Health*, *9*(1).	Excluded	Specific to cross cultural representations of dementia.
Sun, W., Biswas, S., Dacanay, M., & Zou, P. (2019). An examination of factors influencing equitable access to dementia care and support programs among migrants and refugees living with dementia: a literature review. *Redirecting*	Included	Addresses factors influencing access to dementia care among immigrants and refugees.

alzheimer strategy-tracing memory loss to self-pathology.		
Lindesay, J. (1998). Diagnosis of mental illness in elderly people from ethnic minorities. *Advances in Psychiatric Treatment*, *4*(4), 219-226.	Excluded	Specific to diagnoses of mental illness in elderly people.
Pollitt, P. A. (1996). Dementia in old age: an anthropological perspective. *Psychological Medicine*, *26*(5), 1061-1074.	Excluded	Specific to anthropological perspective of dementia in old age.
George, D. R., Whitehouse, P. J., & Ballenger, J. (2011). The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Culture, Medicine, and Psychiatry*, *35*(3), 417-435.	Excluded	Discusses the evolving classification and the future of Alzheimer's dementia.
Stewart, M., Anderson, J., Beiser, M., Mwakarimba, E., Neufeld, A., Simich, L., & Spitzer, D. (2008). Multicultural meanings of social support among immigrants and refugees. *International Migration*, *46*(3), 123-159.	Excluded	This study addresses different cultural meanings of social support among immigrants.
Ding, H., & Hargraves, L. (2009). Stress-associated poor health among adult immigrants with a language barrier in the United States. *Journal of immigrant and minority health*, *11*(6), 446-452.	Included	Focuses on immigrant elders with language barrier in the United States.

Table 4.

Literature Review Table of All Studies Included

Citation	**Purpose of Study**	**Pop (N)/Sample Size (n)/Settings**	**Design/Level of Evidence**	**Variables**	**Interventions**	**Findings**	**Implications**
Bentley, J. A., & Owens, C. W. (2008). Somali refugee mental health cultural profile. Ethnomed. Available at: http://ethnomed.org/clinical/mental-health/somali-refugee-mental-healthcultural-profile (Accessed 3 February 2011).	To evaluate depression, anxiety, and posttraumatic stress disorder (PTSD) within the Somali refugee community; and to share knowledge of common Somali beliefs about mental illness, traditional treatment approaches, and advice for healthcare providers working with this population.	6 interpreters and 7 providers	Systematic Review/Level 1	n/a	n/a	Indigenous religious and cultural views should be incorporated into treatment	Somali cultural views and practices should be respected during physician and patient interaction

Citation	**Purpose**	**Pop (N)/Sample Size (n)/Settings**	**Design/Level of Evidence**	**Variables**	**Interventions**	**Findings**	**Implications**
Sun, W., Biswas, S., Dacanay, M., & Zou, P. (2019). An examination of factors influencing equitable access to dementia care and support programs among migrants and refugees living with dementia: a literature review. *Redirecting Alzheimer strategy-tracing memory loss to self-pathology*.	To examine factors influencing equitable access to dementia care and support programs among migrants and refugees living with dementia	Southeast Asian population	Systematic Review/Level 1	n/a	n/a	"Loss of face" were identified to contribute to stigmatization associated with dementia. The ideology of "caring" was also observed among Asian American migrants.	There is a need for future research to explore the key barriers faced by migrants and refugees with dementia in accessing timely and appropriate dementia care and support programs.
Ding, H., & Hargraves, L. (2009). Stress-associated poor health among adult immigrants with a language barrier in the United States. *Journal of immigrant and minority health*, *11*(6), 446-452.	To evaluate stress-associated poor health among adult immigrants with a language barrier in the United States	Adult immigrants with a language barrier	Quasi-experimental	Unhappiness, Depression, and Anxiety	n/a	Results demonstrated that the three stress-related conditions were significantly associated with a dramatically elevated poor health status.	Healthy migrant hypothesis may not be generalizable to this population.

Citations	**Purpose of Study**	**Pop (N)/Sample Size (n)/Settings**	**Design/Level of Evidence**	**Variables**	**Interventions**	**Findings**	**Implications**
Hays, K., & Lincoln, K. D. (2017). Mental health help-seeking profiles among African Americans: Exploring the influence of religion. *Race and Social Problems*, *9*(2), 127-138.	Exploring the Influence of religion among African Americans	n = 1315 African Americans with mental health disorders	Latent Class Analysis	n/a	n/a	Findings revealed two help-seeking classes: Low Use/Informal Support (95%) and High Use/All Support (5%)	There should be collaborative efforts between religious institutions, health and mental healthcare providers, family and friendship networks in the delivery of mental health care to African Americans
Wolz, M. M. (2015). Language barriers: challenges to quality healthcare. *International journal of dermatology*, *54*(2), 248-250.	Evaluating the influence of language barriers on quality healthcare		Systematic Review/Level 1	n/a	n/a	Cultural competence training programs may help increase awareness among healthcare providers and facilitate good quality care for patients from all backgrounds	Professional interpreters could raise the quality of clinical care for patients with language barriers to approach or equal that for patients without language barriers

Citations	**Purpose of Study**	**Pop (N)/Sample Size (n)/Settings**	**Design/Level of Evidence**	**Variables**	**Interventions**	**Findings**	**Implications**
Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: a qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC health services research*, *18*(1), 1-14.	To explore challenges involved in identifying, assessing and diagnosing people with cognitive impairment/dementia who have different linguistic and cultural backgrounds.	27 health professionals (including 18 women and 9 men)	Qualitative in-depth interviews and focus-group discussions	Participants' own experiences and perceptions	n/a	The study identified four main themes: delayed help-seeking, health professionals lacking experience, lack of knowledge and use of appropriate diagnostic tools, and challenging assessment situations	There are challenges in assessment and lack of knowledge regarding appropriate diagnostic tools among health professionals
Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. (2011). Over-and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *International*	To compare the prevalence of register-based dementia diagnoses in the largest ethnic minority groups in Denmark with the prevalence of register-based	68 219 persons aged 20 and older	Descriptive correlational, Level IV	Prevalence rates for dementia were calculated	n/a	There was a higher prevalence of dementia among those younger than 60 years, and a markedly lower prevalence of	Dementia is under-diagnosed to a greater extent among ethnic minorities in the age group 60 years and older but is over-diagnosed in the age group younger than 60 years

Journal of Geriatric Psychiatry, *26*(11), 1128-1135.	dementia diagnoses in the general Danish population					dementia among those 60 years and older	
Guerin, B., Guerin, P., Diiriye, R. O., & Yates, S. (2004). Somali conceptions and expectations concerning mental health: Some guidelines for mental health professionals. *New Zealand Journal of Psychology*, *33*(2), 59-67.	Evaluating Somalis conception and expectations concerning mental health	30 participants	Meta-analysis, Level 1	n/a	n/a	Study identified five main problem areas: communication differences, medication prescriptions, specialists' services, use of interpreters and community knowledge and involvement	Successful resettlement of Somali depends upon either extending current services to meet these client needs or establishing and developing specialized services.
Antelius, E., & Traphagan, J. (2015). Ethnocultural contextualization of dementia care: Cross-cultural perceptions on the notion of self. *Care Management Journals*, *16*(2), 62-3.	Exploring cross-cultural perspectives on the experiences and interpretations of dementia		Systematic review & Meta-analysis, level 1	n/a	n/a	How we conceptualize care is closely related to how we perceive the construction- and thus deconstruction- of the self.	The notion of care needs to be understood in relation to cross-cultural perceptions of dementia

Citations	**Purpose of Study**	**Pop (N)/Sample Size (n)/Settings**	**Design/Level of Evidence**	**Variables**	**Interventions**	**Findings**	**Implications**
Anderson, N. B., Bulatao, R. A., Cohen, B., on Race, P., & National Research Council. (2004). Ethnic differences in dementia and Alzheimer's disease. In *Critical perspectives on racial and ethnic differences in health in late life*. National Academies Press (US).	Evaluating racial differences in dementia and Alzheimer's	Ethnic minorities in the US. Other ethnic settings: Europe, Asia, India, Israel and South America.	Meta-synthesis, Level V	n/a	n/a	The study observed differences in rates of dementia across ethnic groups. cognitive decline.	There should be more studies to address ethnic differences in these exposures and on factors influencing the differences.
Omar, M. A. (2015). Somali Elder Care: A Guide for Healthcare in the West.	Exploring Somali elder care	Somali elders	Systematic review, Level 1	n/a	n/a	Somali elders have unique culture which should be respected and embraced to aid in proper delivery of care	A health care system that is unprepared to care and treat refugees from different cultures and beliefs needs some awareness and training about the cultural background of the elders.
Scuglik, D. L., Alarcón, R. D., Lapeyre III, A. C., Williams, M. D., &	To identify and explore cultural dynamics	37 members of the	Expert Opinion, Level V	Perceptions of health care	n/a	The study revealed that Somalis rarely	Include alternative health care approaches utilizing family values, `bargaining,' and

Logan, K. M. (2007). When the poetry no longer rhymes: Mental health issues among Somali immigrants in the USA. *Transcultural psychiatry*, *44*(4), 581-595.	influencing the mental health care of immigrant Somalis in the USA	Mayo Clinic Department	(Phenomenological)	professionals		acknowledge mental/psychiatric problems and common traditional treatments have become ineffective in the new context.	educational approaches to acculturation.