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OTs Delivering Culturally Sensitive Care for Dementia Family Caregivers From Diverse Backgrounds

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**OTs Delivering Culturally Sensitive Care for Dementia Family Caregivers From
Diverse Backgrounds**

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A culminating capstone project submitted to the faculty of Dominican University of California in
partial fulfillment of the requirements for the degree of
Master of Science in Occupational Therapy

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San Rafael, CA

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Abstract

As occupational therapists, addressing key cultural barriers that may obstruct access to dementia care and education for individuals with dementia and their caregivers from diverse backgrounds is a priority for client-centered care. Stress, racial discrimination, and distrust may exacerbate symptoms and prevalence of dementia in certain populations such as Chinese-American and Latinx (Quinones, et al. 2020). Immigrants' experiences of aging and health are diverse due to belonging to different socioeconomic, ethnic, cultural and linguistic groups and have varying levels of education and work experience (R. S. 2020). There are existing cultural differences regarding caregiving and family networks, perception and recognition of dementia and associated symptoms, negative experiences with health and care services, and language barriers. Examining how individuals from diverse cultural backgrounds understand dementia and experience the caregiving role can provide occupational therapists (OTs) with an understanding of the importance of cultural sensitivity. We aim to establish educational resources for OT Practitioners (OTPs) on how to be culturally sensitive when supporting caregivers from diverse backgrounds and individuals living with dementia (ILwD) and their particular needs. Providing educational resources to OTPs will contribute to fostering collaborative relationships between OTPs and dementia family caregivers from diverse backgrounds.

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Introduction

Dementia is a general and broad term that encompasses symptoms like memory loss and other cognitive and social interactions. As the population ages, dementia rates are projected to increase proportionally. In 2021, there were an estimated 6.2 million individuals living with dementia (ILwD), and that number is estimated to increase to 12.7 million in the next ten years (Alzheimer's America, 2021). In addition to the increased prevalence of dementia, America has become increasingly ethnically diverse. The United States Census Bureau estimates that 4 out of 10 individuals in America identify with an ethnicity other than white. Culture and ethnicity are significant factors in the occupation of caregiving and the experience of caregivers for individuals with dementia. The perception and stigma surrounding dementia and old age often vary between cultures and backgrounds. Being culturally sensitive is the ability to understand, appreciate and interact with people from cultures or belief systems different from our own (DeAngelis, 2015). Healthcare providers' understanding of the different cultural norms and backgrounds of individuals living with dementia and their caregivers can exponentially impact care. James and Al-Kofahy (2021) found that there are essential cultural similarities and differences in the beliefs and values between mainstream America and other cultural groups about dementia and the role of caregivers. When working with individuals from different ethnic backgrounds, it is crucial to know more than just the dementia diagnosis and stage. Healthcare practitioners who demonstrate an understanding of cultural customs and etiquette can better establish trust and rapport with caregivers. Trust and rapport are essential elements of client-centered care.

Occupational therapy for individuals with dementia and their caregivers is an evidence-based and valuable intervention that includes caregiver education on the use of compensatory or

adaptive strategies to promote independence (American Occupational Therapy Association, 2017). As a part of their intervention, occupational therapists can directly address key ethnic or cultural barriers that may impede client and caregiver access to client-centered dementia care and education. For example, stress, racial discrimination, and distrust in the healthcare system may exacerbate symptoms of dementia in certain populations, such as Asians and Latinx (Quinones et al., 2020). Healthcare providers who are trained in cultural sensitivity and approach clients and caregivers with cultural sensitivity will have a greater understanding of how individuals from diverse backgrounds understand dementia and experience the caregiving role. In addition, culturally sensitive healthcare providers can provide caregiver education and support that is both culturally sensitive and informed. While nurses and other healthcare professionals have training programs that educate practitioners on culturally sensitive practice, there is currently no comprehensive editing program for OT practitioners working with dementia family caregivers from diverse backgrounds. Our goal is to provide occupational therapy practitioners with educational resources to increase understanding of perspectives and best practices for delivering culturally sensitive care to dementia family caregivers from diverse backgrounds. The provided educational resources will be easily accessible and interactive and provide OT Practitioners with opportunities for both knowledge acquisition and reflection.

Background and Review of Literature

Dementia

Dementia is often mislabeled as a disease; however, it is actually a term that embodies a group of symptoms (Mayo Clinic, 2019). As of 2021, an estimated 6.2 million individuals are living with Alzheimer's disease and related dementias. However, that number is estimated to double to 13 million by 2050 (Alzheimer's America, 2021). Hallmark symptoms of dementia include cognitive, psychological, and behavioral changes. While cognitive impairment may be the most recognizable and common symptom of dementia, behavioral and psychological symptoms (BPSD) are an under-discussed experience of individuals living with dementia. BPSDs such as agitation, aggression, sleep disturbances, apathy, and disinhibition occur in up to 90% of individuals with dementia (Chunga et al., 2021). In addition, stress and burnout are amplified for caregivers when caring for a loved one with dementia who experiences BPSD (Chunga et al., 2021).

According to Alzheimer's Association (2021), the rate at which dementia progresses for each individual varies, "On average, a person with Alzheimer's lives four to eight years after diagnosis but can live as long as 20 years, depending on other factors" (Alzheimer's Association, 2021). As a progressive condition, dementia has three main stages: early, middle, and end-stage. Dementia stages may also be referred to as mild, moderate, and severe (Alzheimer's Society, 2021). Each stage is characterized by specific functional limitations, symptoms, and required levels of care (Alzheimer's Association, 2021). As ILwD progresses through stages, the need and resources for more support often cause additional barriers for family caregivers.

Family Caregivers

The term "family caregiver" is used interchangeably with "caregiver" and/or "informal caregiver" and is defined as an unpaid person involved in attending to another individual's well-being and health needs (Alzheimer's Association, 2021). The increasing prevalence of dementia results in an increased need for family caregivers. According to the Centers for Disease Control and Prevention (CDC, 2019), in the United States, each year, more than 16 million individuals are family caregivers of loved ones living with Alzheimer's and related dementias, providing more than 17 billion hours of unpaid care worth approximately \$235 billion. One in three caregivers of ILwD is 65 years or older, and approximately two-thirds are female caregivers (Alzheimer's Association, 2021). Family caregivers play a crucial role in providing care for ILwD. Caregivers act as a support system for ILwD. Additionally, caregiving often includes assisting with activities of daily living (ADLs), such as personal hygiene, and instrumental activities of daily living (IADLs), such as transporting ILwD within the community.

Family caregivers of dementia have twice as many emotional, financial, and physical difficulties compared to caregivers of individuals without dementia (Alzheimer's Association, 2021). Analysis has shown "that dementia family caregivers are significantly more stressed than non-dementia carers and suffer more serious depressive symptoms and physical problems, specifically the overall prevalence rate of depressive and anxiety symptoms is 34% and 44%, respectively" (Bachmann, 2020).

Caregiving Occupation

Major occupational transitions take place in dementia caregivers' lives, including but not limited to the occupations of work, leisure, and social engagement. A qualitative study by Tangelo (2018) explored family caregivers' needs and barriers including access resources that

address mental health, emotional support, social relationships, and personal time. This study also found that a primary barrier for partner caregivers was that they had difficulty in acknowledging their needs (Tangelo et al., 2018). Thus, caregiving becomes a new form of occupation that caregivers want and/or need to do. Although not intentional, caregiving can become a full-time role, especially as the abilities of the ILwD decrease over time and they require more care from their loved one (Tatangelo et al., 2018).

Caregivers from Diverse Backgrounds

Caregivers from diverse backgrounds are increasing as the prevalence of dementia is affecting more diverse individuals. For example, according to Chicago Health and Aging Project (CHAP) study, 18.6% of Blacks and 14% of Latinos aged 65 and older have Alzheimer's dementia compared with 10% of White older adults. Additionally, older Black adults are about twice as likely to have Alzheimer's or other dementias as older Whites adults (Alzheimer's Association, 2021). Some studies indicate older Latinos are about one and one-half times as likely to have Alzheimer's or other dementias as older Whites (Alzheimer's Association, 2021). As such, findings from Dementia Caregiving in the U.S. Report (2017) note that about 66% of dementia caregivers are White, 13% are Latinos, 13% are African American, 6% are Asian American, and 2% are labeled as other.

Experience of Family Caregivers from Diverse Backgrounds

Each ILwD experiences dementia uniquely with personal factors such as life experiences, culture, symptoms, progression, context, and environment. Therefore the caregiving experience of diverse family caregivers is also unique to each individual as well. While this is true, there are also some common experiences among caregivers. Motta-Ochoa et al. (2021) reported that withdrawal and disengagement of ILwD become increasingly frequent as the disease progresses

until the person “is gone” for caregivers of individuals with dementia. This ethnographic study found that the loss impacts the relationship between the caregiver and the ILwD. In the study, caregivers shared metaphors, such as “being lonely together” (Motta-Ochoa et al. 2021).

Additionally, Motta-Ochoa et al., (2021) state how diverse caregivers experience feelings of isolation and social exclusion as they adapt to increasing responsibilities as a caregiver of an ILwD.

Transitions in family dynamics that occur when one moves from being another member of a family to being a caregiver of an ILwD causes feelings of loss for family caregivers. The unmet need for time alone along with the natural development of difficulty in acknowledging their needs demonstrates the difficulty maintaining emotional support for family ILwD (Tangelo et al., 2018). Another common experience of caregivers from diverse backgrounds is feeling forced to follow their cultural obligation of caring for elderly family members. Some caregivers from diverse backgrounds took on the role of caregiving in response to cultural expectations. According to Hughes et al., (2014) caregivers from diverse backgrounds are at an increased risk of mental and physical health issues as demands and levels of stress increase. A research study by Samson et al., (2016), looking at the experiences and needs of African American dementia family caregivers, elucidated feelings of burden, physical and emotional strain, which resulted in the neglect of caregivers' own health and wellbeing. Furthermore, caregiving for ILwD places family members at increased risk of adverse mental and physical outcomes. Napoles, M. A. et al., (2010) additionally found that minority caregivers may be at higher risk because their care recipients have a higher prevalence of dementia-related behaviors and greater physical and functional impairment and they are less likely to use external support resources compared to White caregivers.

Cultural Values Related to Caregiving for ILwD

Although there are common experiences shared by caregivers from diverse backgrounds, there are also experiences that are unique to specific cultures. In both Latinx and Asian communities, culturally derived stigma around persons with Alzheimer's disease and related dementia (ADRD) exacerbate caregiver burden (Hu et al., 2021). The shared elements between these two cultural values both emphasize family members having the primary role of caring for their elders. Often prevalent in the Latinx community, familism refers to an obligation that family members are expected to take care of each other and provide emotional and instrumental support when necessary (Valdivieso-Mora et al., 2016). Specifically, the essence of family outweighs the needs and values of an individual family member. Filial Piety is a cultural belief embedded within Asian culture that can exacerbate the caregiver burden. Filial Piety is a term coined to describe the Chinese virtue of respect toward parents and elders. While this virtue is an essential building block for developing a respectful culture, when it comes to persons with ADRD, it places the responsibility to care for the older parents on the adult children. Sending parents to a nursing home would be considered a failure to fulfill an essential family duty (Thompson et al., 2009). While these virtues may represent strong family values, they exacerbate the pressure placed on caregivers. Over time, the overwhelming pressure and stress can lead to caregiver burnout, resulting in placing loved ones in institutionalized care facilities such as skilled nursing facilities. In addition, the elder abuse risk may be greater with family caregivers who are overwhelmed and unable to provide care (Robinson et al., 2022).

Chinese American Culture

Chinese-Americans view dementia as a form of normal aging. As a result, many families describe difficulties with memory and behavioral symptoms linked with dementia as if it was

associated with normal aging. “One study suggested that due to this belief, some Chinese families do not think that symptoms of dementia represent an illness that requires medical assessment or treatment” (Elliott et al., 1996). Commonly, Asian families relate the psychiatric symptoms of dementia, such as paranoia, hallucinations, and delusions, to other types of mental illnesses.

Two characters represent the Chinese word for dementia; one means crazy, and the other is catatonic (Elliott et al., 1996). The stigma, shame, and negative responses experienced by families and individuals with dementia limit their willingness to seek appropriate medical assessment and treatment in the early stages of the condition. Chinese caregivers have consistently reported burden and stress when caring for family members with dementia. In Chinese American culture, dementia is considered shameful because of the embarrassment that dementia is not normal. Chinese American families may minimize the cognitive/behavioral disorders associated with dementia (Elliott, Di Minno, Lam, et al. 2009). To maintain a strong family connection, Chinese American families will often keep information related to their elder with dementia hidden from non-family members and health care providers. Many families will often curtain their elder with dementia from the public and avoid sharing information with non-family members or health care providers because they may feel that discussing the problems of caring for a Chinese American elder with dementia with strangers would cause the family to lose a sense of family connection (Elliott, Di Minno, Lam, et al. 2009).

When it comes to Chinese Americans' caregiving for family members with dementia, families are expected to take full responsibility for providing care for their elders and aging parents. In Chinese American families, multiple families contribute to caregiving to express their respect for ill family members (Ma, 2020). Traditional Chinese values dictate that the dedicated

caregivers for elders are their oldest son and his wife or other children if the eldest son is unavailable. Chinese cultural family principles value collectivism over individualism and emphasize filial obligation and family kinship ties. When a daughter marries, she becomes responsible for the care of her in-laws and is no longer considered part of the family caregiver network for her family of origin. (Ma, 2020).

In addition to cultural values, the lack of culturally appropriate medical and social support services presents another service barrier that results in service professionals not considering developing culturally sensitive care for ethnic minorities with dementia. While some research has been aimed at identifying cost-effective interventions tailored to Chinese American families, there is still a significant need for culturally appropriate ADRD services for Chinese American families (Sun, F. 2014). Like Chinese family caregiving, Latin family caregivers experience a service barrier in which the younger generation of the family prioritizes caregiving as a sign of respect. From childhood, children are raised with the cultural belief to take care of and take care of family members who raised and cared for them.

Latino Cultures

The cultural value of familism shapes Latin family caregivers' experiences and expectations. In Latino culture, seeking help outside of family relationships is frowned upon. Women in Latino culture learn about caregiving from their experiences within their families; being taught to be a family caregiver depicts a gendered role of labor (Balbim, 2020). There is a psychological importance of being in relationships and caring for others within the context of family relationships. Thus, for women, the issue is not whether one should care for another but how one should care for and deal with caring concerns (Balbim, 2020). Families may seek advice or help from informal sources, which may result in seeking professional help for a family

member as a last resort (Min, 2009). Caregiving usually revolves around familism or "familioso," which refers to the value of the family as an institution and the priority placed on reliance on family members rather than on more impersonal institutions for instrumental, emotional, and material support (Balbim, 2020). A family member is expected to take the primary caregiving role due to values such as loyalty and undividedness between family members. Elders should maintain their former roles within the family to the extent possible, and their autonomy should be respected. These noble aspects of familism emphasize sacrificing individual or personal desires or goals in the service of others, altruism, collectivism, and interdependence (Flores, Y.G., 2019).

In a study of Latinos and community members aging in place, Jacqueline Angel focused on the strengths of Latino families, the underlying problems they face, and how to address their needs. One of the significant issues is that Latinos of Mexican descent in the U.S. spend about two-thirds of their lives after age 65 with compromised health (Jiménez, 2020). Jobs with caregiving leave, resources, and retirement accounts are needed. The Latino caregiver role requires more training, intensive care, and extended periods of caregiving. However, Latinos' high desire to take care of aging parents is rooted in the culture that they can buffer the challenges that they are facing. Even though there are high demands on caregivers in the Latino population, there is a tremendous amount of resilience (Jiménez, 2020).

Role of OT for ILwD and Caregivers

Occupational therapists have the knowledge to identify the remaining abilities of ILwD at all stages. Through OT screening tools and a strength-based approach, OTs can work with caregivers and those in the early stages of dementia to identify strengths, impairments, and functional implications (Schaber & Lieberman, 2010; American Occupational Therapy

Associations, 2019). In addition, OTs can educate caregivers on proper adaptation and compensation, such as cueing, social supports, and coping strategies, to increase the quality of life (QoL) of ILwD and their caregivers (American Occupational Therapy Association, 2019).

Use of Collaborative Model of Care and Support

In order to be culturally sensitive, occupational therapists should utilize a collaborative model of care and provide support for caregivers of ILwD. Existing literature highlights the importance of being culturally sensitive to support diverse caregivers' needs, yet the literature lacks specific resources, and program training that has made a significant difference in supporting caregivers. Additionally, by using a collaborative model of care, OT practitioners are practicing a core value of the OT profession, by being lifelong learners and utilizing therapeutic use of self to support OTP and caregiver relationship. This requires OTs to be aware of their approach and interactions when supporting caregivers from diverse backgrounds. By doing so, OTs are able to engage clients to elicit a significant outcome during the OT process for the client. Thus, a valued aspect of client centered for clients and families in order to support shared decision-making (Moyers et al., 2014).

Understand the Role and Feelings of Caregivers

It is essential that occupational therapists acknowledge diverse cultural experiences and provide culturally sensitive care for diverse caregivers. OT practitioners need to receive training and engage in education to be able to comprehend the role and experiences of diverse caregivers. According to Heng et al., (2021) qualitative study, “the early stages of ‘becoming a caregiver’ can be likened to that of a fledgling learning to fly, where the inexperienced caregivers will face stresses and challenges as they learn to navigate this role. A thorough understanding of the early stages of caregiving would help identify and prioritize areas where these caregivers would

require assistance” (p. 1518). OT practitioners are providing culturally sensitive services to address the needs of ILwD and their caregivers in some regions. During Chan et al., (2021) cross sectional study, the authors indicate family caregivers experience difficulty coping and adjusting immediately upon loved ones dementia diagnosis. For example, “In Asia-Pacific regions, growing dementia incidence has made caregiver burnout a pressing public health issue” (Chan et al., 2021). However, findings reveal the impact OT services and allied services made on caregiver stress for Asian caregivers. Through an occupational profile assessment and initial evaluation, OTs build rapport with caregivers and better understand their occupational needs. By understanding the hardships, feelings, and impact the caregiver role has on diverse caregivers, OTs are able to guide and support caregivers wellbeing while maintaining their role.

Culturally Sensitive Care in Nursing

Nurses often work with individuals from many different cultures and backgrounds. Providing culturally sensitive nursing care is essential in delivering effective and respectful treatment and the utmost quality of care to different patients (Liyan et al., 2021). Building blocks of cultural sensitivity include awareness, knowledge, attitude, skill, desire, and cultural encounters in society (Kaihlanen et al., 2019).

Summary and Conclusions

In order for occupational therapy practitioners (OTPs) to provide culturally sensitive OT services it is important to acknowledge the significance of culture, assess cross-cultural relations, recognize potential cultural impacts and expand cultural knowledge. Dementia does not discriminate, but it affects people of all backgrounds and cultures. Caregiver’s backgrounds and beliefs contribute to their sense of self, their perception of, and reactions to other people and their environment. Each diverse background has its own cultural perception and norms on how to care

for dementia and people in old age. For OTPs working with ILwD and family caregivers, it is crucial to use collaborative models of care and support as well as understand the roles and feelings of family caregivers. Our review of the literature indicates that there is a gap in practice regarding available education on how OTs can be culturally sensitive and gain a better understanding of diverse backgrounds in order to educate family caregivers. Essential parts of culturally sensitive care include “awareness of self and one's value system; an understanding of the concept of culture and its role as a factor in health and healthcare; a sensitivity to cultural issues for each patient; and an understanding and ability to use specific methods to deal effectively with cultural issues in interacting with individual patients, their families, members of the healthcare team, and the wider community” (Reznik et al., 2001).

Statement of Purpose

Providing individualized and culturally sensitive care to dementia family caregivers from diverse backgrounds and ILwD can, in turn, promote quality of life, minimize caregiver burnout and lead to a better patient-caregiver relationship. Unfortunately, many culturally diverse caregivers may not have access to culturally sensitive care due to external barriers such as geographical location, education, and systemic healthcare complications (Gradellini, 2021). Occupational therapy practitioners (OTPs) play an essential collaborative role in the care of ILwD and caregivers. OTPs' understanding of the intricate relationship between person, environment, and occupation required for successful task performance allows them to better support ILWD to retain existing functions as long as possible. Our goal is to establish evidence-informed resources for OTs on how to be culturally sensitive when supporting caregivers of ILwD and their particular needs. The educational resources will be presented as a toolkit, including print resources and online training modules. The educational resources aim to provide specific information on the importance of culturally sensitive care and the two different cultural perspectives of dementia and caregiving. Specifically, our printed resources will summarize information on culturally sensitive care, tips for multicultural collaboration, and cultural sensitivity when it comes to Asian American caregivers.

While nurses and other healthcare professionals have training programs that educate on how to be culturally sensitive, there currently is no existing training material for OTs working with diverse caregivers of individuals with dementia. This project aims to provide an educational toolkit for OTs to use when working with diverse caregivers. Educating OTs on the value and impact of culturally sensitive care, as well as specific skills and knowledge, will create better client/ therapist relationships and more client-centered and culturally-sensitive interventions. In

the initial phases of the project, we predict that our educational toolkit will positively impact OT practices by increasing their knowledge and skills in providing culturally sensitive care. While our educational resources use concepts from Asian and Latinx cultures as specific examples, we will also cover broader concepts of cultural sensitivity that are applicable in general practice.

Theoretical Framework

Through the understanding of dementia family caregivers from diverse backgrounds, experiences, strengths, barriers, and unique needs, OTPs can create a positive impact on supporting caregivers and ILwD. This project will utilize two theoretical frameworks: The KAWA River Model and the Doing-Being-Becoming framework.

The KAWA River Model

The KAWA River Model provides a framework for OTPs to aid individuals in understanding personal barriers and supports in their life. The KAWA River model utilizes a metaphor of a river to illustrate an individual's life journey and to navigate through the river with a continuous and harmonious flow. The river (kawa) represents an individual's life flow and occupations. The riverbank (Kashi) symbolizes an individual's environmental and contextual factors. Factors that inhibit occupational engagement and cause dysfunction are the rocks (iwa). At the same time, driftwood (ryūboku) is classified as a personal attribute and resource that can support or hinder occupations (Iwama et al., 2009). Space between obstructions (sukima) is the gap individuals must navigate through in order to keep going and allow for personal life flow (Iwama et al., 2009). The KAWA River model explores individuals' past, present, and future occupational needs and goals. This model allows caregivers to identify and analyze supports and barriers. Applying the KAWA River model to our project allows occupational therapists to explore and comprehend caregivers' barriers to occupational engagement and find resources and opportunities to enhance the flow of the caregiver's life (Iwama et al., 2009). In our project, we plan to teach therapists how to use interventions supported by the model by providing a hypothetical case study revolving around a client. The KAWA River model informs our project by providing a framework for occupational therapists and caregivers to discuss factors they

perceive as inhibiting and/or supporting personal well-being for both the caregiver and the ILwD.

Doing-Being-Becoming Framework

The Doing-Being-Becoming framework integrates aspects of “doing,” “being,” and “becoming” (Wilcock, 1998). According to Wilcock, “doing” refers to an individual's occupation and occupational performance, which is essential to interact with others and developing self-identity. “Being” allows individuals to sustain their own roles by self-reflection. “Becoming” relates to how individuals redefine values and priorities in preparation for strengthening existing roles and acquiring new ones (Wilcock, 1998). “The ultimate goal of this framework is to guide occupational therapy practitioners to support individuals to do and be, and through the process of becoming” (Wilcock, 1998). This framework supports our project as it allows occupational therapy practitioners to understand caregivers' way of doing and being through individual culture, norms, values, identity, and beliefs to lead to their personal becoming of not only as a caregiver but developing new roles as well. Through the lens of this framework, OTs will be able to guide caregivers from diverse backgrounds to find the best fit for personal wellbeing and support, whether that is access to caregiving services, prioritizing mental and emotional health, or establishing adaptive routines.

Ethical and Legal Considerations

Ethical and legal considerations have been acknowledged for this project, including compliance with copyright laws. To ensure confidentiality of program participant's contact information is to remain confidential with non-disclosure policy. Also, program participants' feedback will only be utilized for the enhancement of this project. Occupational therapy practitioners must follow ethical principles outlined in the Occupational Therapy Code of Ethics (AOTA, 2020). Nonmaleficence, Veracity, and Justice principles are central to this project. Nonmaleficence is the obligation of an OT not to harm their client. Good intercultural communication is demonstrated through perceiving, reacting, and accepting. Ethnocentrism is defined as the attitude or point of view by which the world is analyzed according to the parameters of a person's own culture, which relates to the belief that one's ethnic group is the most important or superior to those of other cultures (Baugher & Estrada, 2015). Ethnocentric perspectives have the potential to cause harm to others.

“Veracity is based on respect toward others, including but not limited to service recipients, colleagues, students, researchers, and research participants” (Occupational Code of Ethics, 2021). The OT workforce incorporates comprehensive, accurate, and objective information to the recipient. The program participant has a right to be in possession of precise information. In addition, the transmission of information is incomplete without also ensuring that the recipient or participant understands the information provided (AOTA, 2020).

The principle of justice relates to the fair, equitable, and appropriate treatment of persons. Occupational therapy organization relates respectfully, fairly, and impartially to individuals and groups with whom they interact while respecting the applicable laws and qualifications of their specialization (Occupational Code of Ethics, 2021). OTs work together to sustain a society.

Individuals have an equal opportunity to achieve occupational engagement as an essential component of their life (AOTA, 2020).

Methodology

Project Design

The two elements of design for this project include curricular design which pertains to what content we decided to include and instructional design which is about how we delivered the instruction. The educational modules are designed to address three key learning objectives. The first learning objective is for program participants to understand the importance of OTPs providing services to dementia family caregivers from culturally diverse backgrounds. The second learning objective is for program participants to identify essential elements of culturally sensitive care. Lastly, the final objective is for program participants to reflect on how they can personally implement culturally sensitive care into their OT practice.

The online-based educational modules consist of six modules and printable resources that will support OT Practitioners (OTPs) understanding of perspectives and best practices for delivering culturally sensitive care to dementia family caregivers from diverse backgrounds. In addition, the educational modules provide OTPs with opportunities for both knowledge acquisition and personal reflection. Furthermore, the educational modules explore two particular cultural groups, that is, Asian and Latinx communities, in order to help program participants apply cultural sensitivity. The design of the educational resources aligns with the KAWA River model concepts, as OTPs can utilize this framework to identify, analyze and address caregiver supports and barriers.

The online modules developed with Articulate Rise 360 are easily accessible, self-paced, free, and interactive. Utilizing an online curriculum design promotes accessibility for program participants who are unable to attend in-person educational sessions due to geographical location, busy schedule or other responsibilities. With this in mind, the modules are designed to

retain saved progress to be self-paced. The modules are designed to be effective and engaging for individuals with varied learning styles and include interactive learning activities such as visuals, carousel displays, case study, matching exercises, flip flashcards and accordions with drag-dwon motions. The printable/downloadable resources support implementation and follow-through, including one-page infographics for specific cultural groups and an evidence table summarizing supporting evidence. By providing an evidence table this is considering that many OTPs lose access and/or have challenges accessing certain databases without a fee.

Agency Description

This project has been piloted with Ensign Services Inc., which supports operations and healthcare practitioners at over 250 Ensign-affiliated skilled nursing facilities (SNFs). Ensign-affiliated OTs work with family caregivers of ILwD who are receiving post-acute care services and plan to return home. In addition, many Ensign-affiliated SNFs have outpatient licenses and have recently been piloting outpatient OT services for community-dwelling older adults with dementia. Partnering with Ensign Services offers access to a broad spectrum of OT practitioners working in skilled nursing facilities and outpatient clinics. Ensign's core values include accountability, passion for learning, loving one another, intelligent risk-taking, and ownership. These core values guide decision-making and our project will facilitate the achievement of their goal of providing clients with the best possible care.

Target Population

The target population for this project are OTPs at Ensign-affiliated skilled nursing facilities, who are working with community-dwelling dementia caregivers from diverse backgrounds. The secondary population is the dementia caregivers from diverse backgrounds,

and ultimately, the tertiary population that will be impacted by this project are the individuals living with dementia (ILwD).

Project Development

The development of this project was informed by an extensive literature review that elucidated a clear gap in available educational resources to support culturally sensitive OT services for caregivers of individuals living with dementia, leading to the design and development of the online-based educational modules. During the program development process, the project development team first conducted a literature review to explore our target population's project development needs. Thus, we discovered a gap in practice, which our project addresses. The literature review was conducted utilizing available databases from the Dominican University of California Archbishop Alemany Library and Google Scholar. Keywords and topics searched included "diverse dementia caregivers experiences," "LatinX cultural values and needs," "Asian cultural values and needs," "family caregivers role," "role of OT," "culturally sensitive care," and "impact of culturally sensitive care." To develop the online educational modules, the project development team learned to utilize an online course-builder software called Articulate Rise 360. The educational modules were designed and implemented using this software. The project development team also created three one-page infographics summarizing key points on specific cultural groups through another online platform, Canva. With full liberties to creatively design on Canva, the team used meaningful images and concise language to convey clear points. Another resource developed by the group was an evidence table summarizing supporting literature. For this, the team revisited the literature to provide relevant summarized evidence.

Project Implementation

The initial pilot of the project occurred in October 2022. Three OTPs who are subject matter experts in dementia care with Ensign-affiliated SNFs were recruited to pilot the online-based modules and provide formative feedback. The final project deliverables will become available for all OTPs at Ensign-affiliated SNFs by the end of November 2022 to utilize through their practice. This project encountered a couple of implementation challenges, such as a limited number of OTPs providing outpatient services for community-dwelling ILwD and their caregivers, resulting in low participation in the initial pilot. Because of these challenges, there was a delayed initial pilot, resulting in a lack of summative findings.

Project Evaluation

In order to obtain feedback from program participants in the initial pilot, the team collected formative evaluation data for each module (six modules total) via Google Forms (See Appendix A). Both qualitative and quantitative formative data were gathered for each module. The formative evaluation questions on, the overall value of the modules, and questions that provided an opportunity to identify, new information learned that is of value to the individual and/or OT practice. Program participants had the opportunity to provide suggestions to improve modules and were also asked to describe what, if anything, was especially helpful in this module. Due to our evaluation being limited to formative feedback, we suggest that future users of the educational program modules expand evaluation and collect summative data. In addition, it is vital to measure the long-term impacts of the post-educational modules for providing culturally sensitive care to dementia family caregivers from diverse backgrounds.

Results

This project was developed to provide educational resources to OTPs that were easily accessible and interactive and allowed for opportunities for knowledge acquisition and personal reflection to deliver culturally sensitive care. In total, three OTPs who are subject matter experts in dementia care provided formative qualitative and quantitative data for each module. We received qualitative data from three subject matter experts, and two (out of three) subject matter experts provided quantitative data. Based on the Likert scale ratings from 1-10 for each module, the value of the modules to the learner's OT practice was a 10, very valuable, for 5/6 modules. Module three, the lowest-rated module, received an average score of 9.5 (See Appendix B). One program participant said, "It was good to identify my own values for caring for our family members and continuing to engage them." Another program participant stated, "Something that was especially helpful from this module was the interactive format of the KAWA method." Also, a participant shared this feedback, "Wow, these [modules] are so beautifully written - I love the images too! I especially appreciate the training on different cultures. It is so important for us to understand these cultures to support our clients and their families". Overall, the formative initial pilot survey results demonstrate positive results, especially as it targets some of the learning objectives of this project.

Discussion

According to the formative initial pilot survey data collected, program participants found the educational modules very valuable to their practice. This program bridges the gap in practice by developing a culturally sensitive care educational program for OTPs working with dementia family caregivers from diverse backgrounds. To address the feedback provided, the team responded to change by revising the flow of content and organization to improve clarity for program participants. This program highlights strengths by having an online format that increases accessibility for OTPs with limited access to in-person sessions. Also, the program includes different modes of learning through a variety of interactive activities. However, while online instructional design promotes accessibility, it also limits opportunities for program participants to have group discussions and learn from each other's experiences. The program is also limited to an in-depth exploration of two specific cultural groups that may affect program participants' transferability of knowledge to other cultural groups.

Implications

This project highlights the importance of providing OTPs with educational resources to increase cultural sensitivity, which has the potential to promote the culturally sensitive delivery of OT services and increase quality of care. Foremost, this educational program could be utilized as a model for other OT practice areas and populations, especially because this project supports OTPs in fulfilling their professional and ethical responsibility of treating individuals holistically, with client-centered approaches that are culturally sensitive and individualized for each client. Although there were a few implementation barriers, this educational project will positively impact the OT profession, and all future OTPs should have the opportunity to learn how to be more client-centered and culturally sensitive.

Conclusion

In order to identify strengths, impairments, and functional implications, OTs must engage in collaboration with caregivers and utilize a strength-based approach for individuals living in the early stages of dementia (Schaber & Lieberman, 2010; American Occupational Therapy Association, 2019). Cultural sensitivity is essential for developing collaborative partnerships with caregivers from diverse backgrounds. While nurses and other healthcare professionals have training programs that educate providers on culturally sensitive practice, there currently is not an existing comprehensive program for OT practitioners (OTPs) working with dementia family caregivers from diverse backgrounds. Limited knowledge of culture can be a barrier for OTPs when working with culturally diverse caregivers. In both Latinx and Asian communities, culturally derived stigma around individuals living with dementia exacerbate the caregiver burden (Hu et al., 2021). This project aims to provide OT practitioners with educational resources to increase their understanding of perspectives and best practices for delivering culturally sensitive care to dementia family caregivers from diverse backgrounds. We developed educational resources that were easily accessible and interactive and provided OT practitioners with opportunities for both knowledge acquisition and reflection.

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Appendix A: Post Training Surveys

Post Training Survey for Module 1

Hello! After completing each module, you will be asked to fill out a short formative survey. Your responses are anonymous and will be used only for our project. Thank you!

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice.
2. Is there something important that we missed to support your learning from this module?
3. What, if anything, was something that was especially helpful from this module?

Post Training Survey for Module 2

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice
2. What, if anything, was something you learned that was valuable to you and/or your OT practice?
3. What suggestions do you have for how we can improve this module?

Post Training Survey for Module 3

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice
2. Is there something important that we missed to support your learning from this module?
3. What, if anything, was something that was especially helpful from this module?

Post Training Survey for Module 4

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice
2. Is there something important that we missed to support your learning from this module?
3. What, if anything, was something that was especially helpful from this module?

Post Training Survey for Module 5

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice
2. What, if anything, did you learn that was valuable to you and/or your OT practice?
3. Is there anything you would like to know more about how to apply culturally sensitive care to different cultures?
4. What suggestions do you have for how we can improve this module?
5. What would help you apply this information to your clinical practice?

Post Training Survey for Module 6

1. In a likert scale of 1-10 (1=not at all valuable and 10= very valuable), this module was valuable to my practice
2. What, if anything, did you learn that was valuable to you and/or your OT practice?
3. What suggestions do you have for how we can improve this module?

Appendix B: Formative Initial Pilot Survey Results

Figure 1 Likert scale rating for each module



Appendix C: Program Handouts


Figure 2 Dementia Caregiver Experience Flyer

DEMENTIA CAREGIVER EXPERIENCE

Caring for someone with dementia can have a cognitive, physical, and occupational impact, with caregivers experiencing changes in their daily lives and relationships with the loved ones they care for. While there are common family dementia caregiver experiences, culture and diversity are added layers that play an impactful role in the caregiver's experience.


1.) IMPORTANCE OF CULTURAL SENSITIVE CARE

- Caregivers from ethnically diverse backgrounds have different values, beliefs, and needs.
- Lived experiences of each caregiver are unique.
- Understanding cultural customs and etiquette allowed for a well-rounded Occupational Profile.



2.) DEVELOPING CULTURAL SENSITIVITY

- Awareness and development of personal cultural values, beliefs, and cultural knowledge.
- Acknowledging and embracing dynamics of cultural differences.
- Adapting service delivery to individuals needs, expectation and context.



3.) PRACTICING CULTURAL SENSITIVE CARE

- Embody sensitivity, respect, and recognition of differences during interaction with caregivers from varied cultural backgrounds.
- Be responsive to the individual's feelings, attitudes, and dynamics and deliver service in an accessible manner according to the individuals needs and cultural preferences





Figure 3 Asian-American Cultural Sensitivity Flyer


Asian-American Cultural Sensitivity

Dementia

Many Asian-American families view dementia as a form of normal aging and do not believe symptoms related to dementia require medical support.

Many Asian families may relate to psychiatric symptoms of dementia such as paranoia, hallucinations, delusions to other types of mental illnesses





Family Caregiving


In some Asian-American cultures, families are expected to take full responsibility for providing care for their elders and aging parents

The risk for elder abuse may be greater for family caregivers who are overwhelmed and unable to provide care.

Filial Piety

Filial Piety is a cultural belief embedded within Asian culture that can exacerbate caregiver burden. Filial Piety describes a Chinese virtue of respect toward parents and elders.

When working with dementia, adult children must care for their elders. Sending parents to a nursing home would be considered a failure to fulfill an essential family duty.



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Figure 4 Multicultural Collaboration Tips Flyer

Multicultural Collaboration Tips for OT Practitioners working with Dementia Family Caregivers from Diverse Backgrounds

Do	Don't
<ul style="list-style-type: none"> Recognize that there are differences in individuals' values, beliefs, perspectives, and norms within a culture that impact the needs of the caregivers that you are supporting 	<ul style="list-style-type: none"> Use generalizations about other cultures to stereotype
<ul style="list-style-type: none"> Try to put yourself in the caregivers shoes and imagine their situation via their cultural lens 	<ul style="list-style-type: none"> Assume that your way of understanding a situation or communicating is the correct or only way
<ul style="list-style-type: none"> Approach cultural differences with a spirit of curiosity, acceptance and accommodation 	<ul style="list-style-type: none"> Give up after one cultural impropriety; ask for feedback and suggestions from lived experiences
<ul style="list-style-type: none"> Be culturally sensitive when working with caregivers 	