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Contextual, Cultural, and Sociopolitical Issues in Caring for Latinxs with Dementia: When the Mind Forgets and the Heart Remembers

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Abstract

Latinxs in the USA continue to be disproportionately impacted by dementia. Despite its prevalence within the Latinx community, there is a dearth of literature that explicitly addresses the unique cultural ways in which patients and families of Latinx descent experience, describe, understand, and manage brain-related diseases such as dementia. This chapter provides a nuanced and complex understanding of the contextual and sociopolitical factors (e.g., racial biases, xenophobia, institutional barriers) that impact the care of Latinx patients and their families. The central elements that characterize the Latinx culture are described, followed by a section about within-group Latinx differences, which underscores the heterogeneity (e.g., nationality, immigration, race) that exists within this population. Systemic challenges and their impact on diagnosis and symptom management of dementia are provided. The chapter concludes with a brief discussion on how Latinx culture and context impacts the caregiving of Latinxs with dementia.

Contextual, Cultural, and Sociopolitical Issues in Caring for Latinxs with Dementia: When the Mind Forgets What the Heart Remembers

Latinxs[1] are currently the largest ethnic minority group, comprising 18% of the U.S. population (U.S. Census Bureau, 2016). The Bureau of the Census reports that, as of 2016, there were approximately 57 million Latinxs living in the country. The growth of the Latinx population is expected to continue in the upcoming decades with projections calculating that by 2030, 20% of the total population will be of Latinx descent (U.S. Census Bureau, 2004). Latinxs also represent the fastest-growing aging population in the U.S., with 3.6 million individuals over the age of

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[1] To include and center the broad range of gender identities present among individuals of Latin American descent, the term Latinx is used throughout the chapter.

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65 (Administration on Aging, 2015). The Administration on Aging reports that between 2008 and 2030, the Latinx aging population will increase by 224% compared to a 65% increase for non-Latinx Whites. Thus, it estimated that by 2060 there will be 21.5 million Latinx elders, totaling 22% of the older U.S. population. In addition to being the fastest-growing aging population in the U.S., Latinxs also have a longer life expectancy than their African American and non-Latinx White American counterparts (Centers for Disease Control and Prevention, 2015). In fact, Latinx life expectancy is projected to increase from 80 to 87 by 2050 (Centers for Disease Control and Prevention, 2015).

With the long life expectancy projected for Latinxs, they will undoubtedly face changes related to age-associated conditions including the loss of cognitive functioning, for example, memory, language, comprehension, and thinking. One of the most pernicious cognitive diseases related to old age is dementia: an umbrella term used to define a group of incurable brain diseases that cause loss of memory and cognitive functioning which impacts daily life and is oftentimes progressive. While there are many different types of dementia (e.g., vascular, Lewy bodies, frontotemporal), dementia of the Alzheimer's type (AD) is the most common, accounting for 60–80% of all dementia cases (Alzheimer's Association, 2016a). The statistics of people with AD are overwhelming. Currently, more than five million individuals are living with the disease, one in three dying with AD or another dementia, and every 66 seconds someone develops AD (Alzheimer's Association, 2016a). These alarming figures make AD the sixth leading cause of death in the U.S., with more deaths than prostate and breast cancer combined (Alzheimer's Association, 2016a).

Over time, dementia results in marked behavioral changes that limit the patient's ability to problem-solve and perform simple, everyday tasks and activities (Wu, Vega, Resendez, & Jin, 2016). With regard to Latinxs, research indicates that this population is disproportionately impacted by dementia. In fact, the incidence of Alzheimer's disease and related dementias has been documented as being much higher among African Americans and Latinxs compared to non-Latinx White Americans (Manly & Mayeux, 2004). For instance, according to figures reported by the Alzheimer's Association (2016b), Latinxs are 1.5 times more likely to develop dementia of the Alzheimer's type (7.5% between ages 65 and 74; 27.9% between ages 75 and 84; 62.9% over age 85) than non-Latinx Whites (2.9% between 65 and 74; 10.9% between ages 75 and 84; 30.2% over age 85).

Despite the prevalence of dementia within the Latinx community, there is a dearth of literature that explicitly addresses the unique ways in which patients and families of Latinx descent experience, describe, understand, and manage brain-related diseases such as dementia. Hence, there is an urgent and sustained need for healthcare providers to integrate culture into healthcare service delivery for Latinxs. This chapter seeks to provide a more nuanced and complex understanding of the contextual and sociopolitical factors that impact the care of Latinx patients and their families. The central elements that characterize the Latinx culture are described, followed by a section about within-group Latinx differences, which underscores the heterogeneity that exists within this population. Systemic challenges and their impact on diagnosis and symptom management of dementia are also provided. The chapter concludes with a brief discussion on how Latinx culture and context impact the caregiving of Latinxs with dementia.

Understanding Latinx Culture in Dementia Care

Latinxs are a heterogeneous group, rich in diversity manifested through differences in generational status, race, socioeconomic status, ethnicity, degree of bilingualism, nationality, level of acculturation, and stage of ethnic identity. Despite these differences, Latinxs are united by a common culture, a history of colonization (Chavez-Dueñas, Adames, & Organista, 2014), and traditional cultural values focusing on interdependence, collectivism, and a group orientation to family unity (Adames, Chavez-Dueñas, Fuentes, Salas, & Perez-Chavez, 2014; Romero, Cuéllar, & Roberts, 2000; Saetermoe, Beneli, & Busch, 1999; Santiago-Rivera, Arredondo, & Gallardo-Cooper, 2002). This section briefly describes the roots of the common traditional cultural values practiced by Latinxs in contemporary society and how such values may impact dementia care.

The Latinx culture is a complex constellation of ancestral Indigenous and African traditions, mores, beliefs, and cultural values combined with European practices and belief systems imposed through the process of conquest and colonization (Adames & Chavez-Dueñas, 2017). Latinx culture serves as the general foundation upon which traditional cultural values are formed. Defined as beliefs and practices, traditional cultural values are considered important among members of an ethnic group (Kluckhohn & Strodtbeck, 1961). In general, cultural values are based on collective experiences believed to influence thoughts, goals, and behaviors, impacting preferred styles of communication (Adames et al., 2014; Añez, Silva, Paris, & Bedregal, 2008; Chandler, 1979; Inclan, 1985; Szapocznik, Scopetta, & King, 1978). Among healthcare providers, it is imperative to understand cultural values since these drive patients' preferences for practices that are considered culturally congruent (Adames & Chavez-Dueñas, 2017). They also play a key role in shaping a person's internal frame, informing attitudes, and promoting behaviors (Miller & Rollnick, 2013). Cultural values have been found to shield against the adverse effects of immigration, acculturation, and oppression, which are common experiences among many Latinxs in the U.S. (Miller & Rollnick, 2013; Villarruel et al., 2009). Research has also revealed that cultural values related to interpersonal relationships (e.g., *simpatía, respeto*) and family (e.g., *familismo*) play an important role in the provision of health services of U.S. Latinxs. Specifically, interventions that take into account a client's cultural values result in better treatment outcomes among individuals from this population (Bernal, Jiménez-Chafey, & Domenech Rodríguez, 2009; Carter, 1991). The integration of traditional Latinx cultural values can also increase treatment retention (Kalibatseva & Leong, 2014). Furthermore, among Latinx families and patients affected by dementia, traditional cultural values may impact how they make sense of the condition; understand, describe, and interpret symptoms; communicate with healthcare providers; and respond to treatment options. Below is a brief review of the literature regarding the most common Latinx cultural values, followed by a discussion on how such values interact with traditional gender role ideologies to produce dementia care that is highly gendered.

Latinx Cultural Values

Familismo/familism continues to be the traditional Latinx cultural value in the dementia literature that is often underscored (Talamantes, Trejo, Jiminez, & Gallagher-Thompson, 2006). The concept of *familismo* involves broad networks of support that extend beyond the nuclear family to include aunts, uncles, grandparents, godparents, and other close family members (Adames et al., 2014). Family structures, processes, and interactions are informed by the collectivistic norms of the Latinx culture (Falicov, 1989), emphasizing obligation, affiliation, and cooperation (Adames & Chavez-Dueñas, 2017). Within Latinx families, individual identity is commonly secondary to family identity, requiring individuals to prioritize family needs over individual ones. Such family-centered socialization creates a strong sense of connectedness and interdependence within its members. *Familismo* also promotes and maintains loyalty, attachment, and a sense of responsibility toward the members of one's family (Falicov, 1989).

Given the strong sense of obligation, loyalty, and responsibility that familism engenders, it is often believed to serve as a protective factor for patients with dementia. Overall, Latinxs are more likely to be cared for by family members when faced with chronic and terminal conditions (Adames et al., 2014). However, research on familism and caregiving has produced mixed results. For instance, some studies demonstrate that familism conveys a perceived availability of support and caregiving satisfaction while assist-ing patients with dementia (John, Resendiz, & de Vargas, 1997; Scharlach et al., 2006; Wallace & Facio, 1987). Thus, higher scores on familism are associated with lower scores on caregiving burden (Losada et al., 2006). However, other studies have not found a relationship between familism and caregiving burden (Crist et al., 2009). Additional studies have concluded that familism is also associated with worse psychological outcomes (Shurgot & Knight, 2005), high levels of stress (Youn, Knight, Jeong, & Benton, 1999), lower levels of perceived support (Schurgot & Knight, 2005), and depression (Rozario & DeRienzis, 2008) among Latinx caregivers. Overall, the role of familism in the care of Latinxs with dementia appears to function as a double-edged sword. On one side, familism serves as a determinant factor in the decision to become the caregiver of a family member with dementia (John et al., 1997; Scharlach et al., 2006). On the other side, familism decreases the perceived burden associated with such care. Such strong sense of loyalty to one's family may also decrease the probability that supportive resources will be utilized, thus increasing the objective burden on the caregiver.

Dementia Care: A Gendered Practice Caregiving is a highly gendered practice wherein the expectation is on women to become the caretaker of patients with dementia (Mendez-Luck, Applewhite, Lara, & Toyokawa, 2016). These findings can also be extended to Latinxs where traditional gender roles including *machismo* and *marianismo* interact and influence caregiving expectations and practices. *Machismo*, defined as a "socially constructed, learned, and reinforced set of behaviors comprising [the] male gender in Latino/a society" (De La Cancela, 1986, p. 291), is comprised of two aspects, including *traditional machismo* and *caballerismo*. The former is often associated with negative behaviors (e.g., firm, domineering, aggressive, stoicism), while *caballerismo* includes more positive aspects of Latinx male behavior socialization (e.g., honor, respect, reliability, courage). The socially constructed, learned, and reinforced behaviors comprising the content of the female gender role in traditional Latinx culture is known as *marianismo*. Latinas who conform to this ideal of womanhood are expected to be long suffering, nurturing, humble, and spiritually stronger than men (Gil & Vasquez, 1996; Santiago-Rivera et al., 2002). When considering how familism and gender ideologies interact with dementia, it becomes clear that while the value of familism holds that "caregiving is a family obligation ... it is predominantly women who enact the care" (Shurgot & Knight, 2005, p. 1057). Moreover, women are expected to accept and fulfill the caregiving role without complaints (Magaña, Schwartz, Rubert, & Szapocznik, 2006). For example, in a qualitative study of caregivers of elderly family members, Mendez-Luck et al. (2016) reported that when it came to caregiving, women of Mexican descent sacrifice themselves to follow the idealized principles of familism (e.g., obligation, loyalty, responsibility). The devotion and sense of responsibility that Latina women experience may propel them to leave their jobs, postpone their personal goals, and sacrifice their needs in order to care for a family member with dementia. However, less research exists examining the relationship between *machismo*/*caballerismo*, familism, and caregiving for patients with dementia. Nonetheless, given the available literature on the male gender roles in Latinx culture, we can speculate that when Latinx men do find themselves as the only viable caregiver, they may face particular challenges that need to be considered by health professionals. In particular, Latinx men may be less likely to express feeling overwhelmed, stressed, or ask for help when unable to provide the level of care required by their ailing family member.

As discussed throughout this section, Latinx cultural values and traditional gender role socialization influence an individual's decision to become the caregiver of the patient with dementia, as well as how they understand such responsibility. Thus, it is essential that healthcare providers become aware of how Latinxs give cultural meaning to caregiving experiences and how such experiences are informed by traditional gender role expectations. However, two additional factors need to be considered when working with Latinxs. These factors include ethnic identity development (Atkinson, Morten, & Sue, 1989) and acculturation (Kohatsu, Concepcion, & Perez, 2010), both of which serve as variables that moderate the extent to which individuals adhere to traditional cultural values and Latinx gender role expectations. Acculturation is defined as the process through which individuals adjust to a new culture, which involves the incorporation of the new culture's beliefs, values, norms, language, and behaviors. Ethnic identity is an aspect of the self that includes a sense of acceptance and congruence regarding one's membership in a socially constructed ethnic group. Furthermore, it involves an individual's perceptions and feelings about members of his/her/their own ethnic group as well as members of the dominant group. Both ethnic identity and acculturation are influenced by the current sociohistorical context and within-group Latinx differences such as nationality, immigration, legal status, and race. While an in-depth review of the literature on acculturation and ethnic identity is beyond the scope of this chapter, readers are encouraged to review several foundational and contemporary publications on acculturation (see Berry, 1990; Capielo Rosario, Adames, Chavez-Dueñas, & Renteria, 2019; Cuéllar, Arnold, & Maldonado, 1995) and ethnic identity theory (see Adames & Chavez-Dueñas, 2017; Atkinson et al., 1989; Helms, 1990; Phinney, 1989). Being well versed in this body of literature will set the groundwork to help providers develop culturally congruent dementia care for Latinx patients.

Considering Nationality, Immigration, and Race: Diversity Within Latinxs

While Latinxs share elements of a common culture including traditional values and beliefs, considerable diversity exists within this heterogeneous population. To illustrate, Latinxs can differ in their nation of origin, history of immigration, legal status, skin color, and phenotype (Adames & Chavez-Dueñas, 2017; Chavez-Dueñas et al., 2014). These differences may impact their sense of connection to the traditional Latinx culture, adherence to cultural values, connection to the dominant culture, as well as their perceptions of themselves and others. Additionally, these areas of diversity are likely to affect access to life-enhancing resources such as formal education and health insurance, factors that are key for early detection and treatment management of dementia (Alzheimer's Association, 2016b). Hence, effective healthcare delivery for Latinx patients with dementia requires providers to develop a nuanced understanding on how Latinxs' intersecting identities impact dementia care.

Nationality

Statistics regarding the incidence of dementia in Latin America are varied. Though it appears that Latin American countries may have approximately half the number of dementia diagnoses than the U.S. (1.8 million compared to 3.4 million, respectively), it is projected that these numbers may become even by the year 2040 (Ferri et al., 2005; Sousa et al., 2010). Overall, urbanized areas in Latin America appear to have a higher prevalence of dementia diagnoses than rural regions (Rodríguez, Ferri et al., 2008; Sousa et al., 2010). Moreover in Cuba, the prevalence of Alzheimer's disease and related dementias is reported to be as high as in developed countries (Rodríguez, Valhuerdi et al., 2008).

In the U.S., Latinxs can trace their origins to 19 countries with their own unique cultures and traditions, with the three biggest groups being Mexicans (64%), Puerto Ricans (9.5%), and Cubans (3.7%; Lopez & Patten, 2015). Each Latinx country has its own history of contact, settlement, and immigration to the U.S. To illustrate, individuals from some Latinx groups have deep-seated roots in the U.S. that date back several generations. This is the case for Latinxs of Mexican descent whose ancestors lived in the southwest part of today's U.S. prior to the Mexican-American War (1846–1848). After the war, Mexico lost over half of its territory, and Mexicans who were living in the new U.S.

territory became foreigners in their own land. This history led to economic and racial oppression, which is still experienced by many of their descendants today. Other Latinx groups (e.g., Guatemalans, Salvadorans, Mexicans) have migrated to the U.S. seeking better economic opportunities and family reunification. Alternatively, Cubans arrived into the U.S. seeking political asylum following the Cuban Revolution (1953–1959), which put Fidel Castro in power. Unlike other Latinxs, Cubans were able to benefit from a wide range of programs created by the U.S. federal government to guarantee their successful adjustment into the U.S. culture. As a result of their history, Cubans enjoy higher levels of education and socioeconomic status. Finally, Latinxs of Puerto Rican descent have a history of colonization resulting from political intervention by the U.S. in the island (Organista, 2007). Today's Puerto Rican community continues to be impacted by their history of double colonization, first by the Spaniards (1492) and then the U.S. government (1898). People of Puerto Rican descent fare worse than other ethnic groups on several indicators of well-being, including lower household incomes and homeownership, and are also more likely to live in poverty (Acosta-Belen & Santiago, 2006; Adames & Chavez-Dueñas, 2017; Brown & Patten, 2013). Puerto Ricans have also been reported to have an earlier age of onset of dementia, higher rates of cognitive impairment, and greater severity even after controlling for educational attainment (Livney et al., 2011).

The diverse histories of Latinxs in the U.S. highlight how the pan-ethnic label can be helpful in describing shared cultural characteristics which are important to consider when working with Latinx patients with dementia. However, knowledge about the complex U.S. history of each Latinx group is also necessary to help providers contextualize the sociopolitical realities that impact families and clients suffering from dementia. Such knowledge can also assist providers to dispel commonly held myths and stereotypes about this population such as all Latinxs are immigrants, all immigrants are undocumented, most Latinxs speak Spanish, Latinxs are a monolithic racial group, etc.

Immigration

Contrary to commonly held stereotypes, the majority of Latinxs in the U.S. (65% or 36 million individuals) are U.S.-born American citizens. The remaining 35% (19 million) are immigrants who have historically traveled to the U.S. for a variety of reasons including better economic opportunities, family reunification, or to escape violence and political turmoil in their countries of origin. However, access to economic opportunities available to Latinx immigrants has fluctuated depending on the economic circumstances and sociopolitical climate of the U.S. at the time of their arrival, as well as the need for cheap labor. To illustrate, during times of economic growth, when the demand for cheap labor is high, immigrants are welcomed and immigration laws become less stringent. However, during times of economic uncertainty, immigrants are vilified and scapegoated while immigration laws become stricter (Cornelius, 2009; Flores et al., 2008). As a result, the experience of many Latinx immigrants in the U.S. has been marked by exclusion, exploitation, and xenophobia (Chavez-Dueñas, Adames, Perez-Chavez, & Salas, 2019). Although there is a growing body of interdisciplinary scholarly work on Latinxs and health, the literature examining the role of immigration and all of its complexities on Latinx patients with dementia remains sparse. However, few available studies suggest that immigration plays an important role. In a study examining nativity status and sources of care among older Latinx immigrants of Mexican descent, Angel, Rote, Brown, Angel, and Markides (2014) posit that elderly Latinx immigrants were more likely to report cognitive impairment, mobility limitations, and difficulties with basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs) compared to U.S.-born Mexicans. Interestingly, children of Latinx immigrants with dementia were less likely to seek support or assistance from other family members and social service agencies. These findings are important to consider when designing support services for caregivers of Latinx immigrants with dementia.

Unauthorized Immigrants Currently 8.5 million Latinxs live in the U.S. without permission of the U.S. government and are referred to as undocumented immigrants. This segment of the U.S. Latinx population is one of the most vulnerable groups that is susceptible to high levels of stress resulting from xenophobia, lack of access to resources, and discrimination. Moreover, due to their legal status, undocumented immigrants are also susceptible to exploitation and abuse from their employers who often deny them the most basic labor rights (e.g., breaks, access to water, restroom facilities) while at times exposing them to dangerous working conditions (Kronick & Hargis, 1998; National Council of La Raza, 1990, 2008; Suárez-Orozco & Suárez-Orozco, 2001; Velásquez, 1993). Overall, undocumented people experience a host of psychosocial stressors that require attention in the assessment, diagnosis, treatment, and outreach of individuals and families dealing with dementia (Chavez-Dueñas et al., 2019). For instance, undocumented immigrants often find it more difficult to secure good-paying jobs that offer benefits (Migration Policy Institute, 2014). As a result, the undocumented population has high rates of financial hardship with approximately 33% living in poverty and 66% earning less than twice the federal poverty line. Moreover, they often have low levels of formal education with only 25% obtaining a high school diploma or General Equivalency Diploman (GED; Migration Policy Institute, 2014). Additionally, with the exception of some emergency care, unauthorized immigrants are not eligible for most federally funded health insurance programs (e.g., Medicare, Medicaid, Affordable Care Act). Thus, it is not surprising that the share of uninsured individuals among this group (60%) is much higher than that of Latinx adults who are permanent legal residents or citizens (25%), and as compared to the general U.S. population (14%; Krogstad & Lopez, 2014; Migration Policy Institute, 2014). The lack of access to health insurance coupled with economic hardship serve as barriers to early detection of dementia. A delayed diagnosis prevents people from receiving treatment that may help slow the progression of cognitive decline. The circumstances that many Latinx immigrant families face leave them with less time to adjust and plan for the life changes and logistics associated with caring for someone with dementia (e.g., costs, medication management, palliative care). Unfortunately, undocumented patients and their families may not be able to afford the services they need, thus requiring healthcare providers to become creative in securing the necessary help. For instance, healthcare providers can help undocumented patients to connect with private medical and community organizations that may provide services at low or no cost.

Medical Repatriation Medical repatriation is the practice wherein hospitals and healthcare facilities send undocumented immigrant patients back to their country of origin without their consent (Donelson, 2015). Unfortunately, medical repatriation has received little attention in the dementia literature. Although unauthorized immigrants are ineligible for federally funded health insurance programs, hospitals are required to provide emergency medical care. Nonetheless, once medical staff deem patients medically stable, the staff are no longer obligated to provide health services (Center for Social Justice at Seton Hall Law School [CSJ] and the Health Justice Program at New York Lawyers for the Public Interest [NYLPI], 2012; Donelson, 2015). However, the Emergency Medical Treatment and Active Labor Act (EMTALA, 1986) mandates that hospitals create discharge plans, which include the transfer of patients to health facilities where continuity of care can be ensured. Lamentably, undocumented immigrants are unable to pay for continuity of care services; as a result, due to their status, centers and long-term facilities refuse to admit them as patients (Donelson, 2015). The lack of facilities that would admit undocumented immigrants, coupled with financial concerns for the level of care needed, often leaves hospitals with few choices regarding discharge planning. As a result, many medical facilities operate as de facto Immigration and Customs Enforcement (ICE) officials, deporting immigrants without their consent and, at times, through coercion (Donelson, 2015). While the exact statistics of undocumented immigrants impacted by medical repatriation is currently difficult to assess given the failure of legislation requiring such monitoring, there are a number of documented cases when undocumented Latinx immigrants have been sent back to Mexico, El Salvador, Guatemala, and Honduras (Center for Social Justice at Seton Hall Law School [CSJ] and the Health Justice Program at New York Lawyers for the Public Interest [NYLPI], 2012). The quote, "Apparently they see us as beasts of burden that can be dumped back over the border when we have outlived our usefulness" (Sontag, 2008, para. 5), captures the sense of frustration, betrayal, and no-win position that undocumented immigrants impacted by medical repatriation may experience. Sadly, given the disproportionate rates of dementia among Latinxs, along with the additional risk factors faced by immigrants, medical professionals will continue to grapple with the realities associated with providing care to people who are unable to afford health services, which, in turn, may lead to unethical practices such as medical repatriation.

Racial Diversity

The literature on Latinxs in the social science and medical fields often uses pan-ethnic terms (e.g., Hispanic, Latino, Latinx) to describe this diverse segment of the population. While pan-ethnic labels have political relevance and provide a sense of unity among individuals who have experienced a history of oppression, discrimination, and invisibility (Adames & Chavez-Dueñas, 2017; Chavez-Dueñas et al., 2014), they can also obscure within-group differences. Of particular relevance to Latinxs are differences in skin color and phenotype, which have been associated with a wide range of variables. Available studies examining how skin color and phenotype impacts Latinxs suggest that being darker and less European-looking can negatively affect their mental health (Montalvo, 2005; Montalvo & Codina, 2001; Ramos, Jaccard, & Guilamo-Ramos, 2003), educational attainment, and wages (Arce, Murgia, & Frisbie, 1987). Despite the diversity in skin color and phenotype that exists within this community, Latinxs are socialized to not identify themselves racially (Adames & Chavez-Dueñas, 2017; Chavez-Dueñas et al., 2014). In order not to succumb to commonly held stereotypes, it is important for health professionals to know that a "typical" Latinx phenotype does not exist. However, Latinxs may be phenotypically Black, Brown, White, and any range of skin color in between. Consideration that variations in skin color within Latinx families can impact family dynamics is important when developing programs and creating treatment protocols for individuals with dementia (Adames, Chavez-Dueñas, & Organista, 2016). Overall, it is imperative that health professionals not only incorporate the Latinx culture but also integrate the patient's racialized experiences into their assessment and treatment. For instance, practitioners working from traditional frameworks are not likely to consider the role that race and ethnicity plays in the lives of their Latinx patients with dementia. Moreover, when culture and race are incorporated, they are often used purely as descriptors. While a patient's background is important, it does not provide sufficient information on how the patient's racialized experience shapes their symptoms and response to care, which may be different among racially heterogeneous ethnic groups such as Latinxs.

Systemic Challenges and Their Impact on Dementia Care for Latinxs

Socioeconomic Status

One of the biggest challenges experienced by Latinx elders is poverty and lack of financial security. Overall, Latinx elders tend to have fewer financial resources such as pensions, housing assets, and retirement funds compared to their non-Latinx White counterparts. Approximately 25% of Latinx elders are reported to live below the poverty line, which represents more than double the rate of non-Latinx White elders (DeNavas, Proctor, & Smith, 2011). Additionally, Latinxs are half (39% vs. 72%) as likely as non-Latinx elders to have additional income from private retirement plans. Consequently, a significant percentage (40%) relies solely on social security benefits as a source of income (Angel & Angel, 2009). Given these grim statistics, Latinxs diagnosed with dementia or other chronic and progressive conditions are more likely to rely on the caregiving provided by their children, spouses, and extended family (Gassoumis, Wilber, Baker, & Torres-Gil, 2010). Latinx elders with dementia are also less likely to afford supportive services (e.g., home healthcare, respite care), putting the burden for all the necessary caregiving on their children and family members.

Xenophobia and the Rise in Anti-Latinx Sentiment

In addition to high levels of poverty, many Latinxs in the U.S. confront increasing degrees of xenophobia and a growing anti-Latinx sentiment (Chavez-Dueñas et al., 2019). While experiences of rejection and hostility against Latinxs are not new, several events have contributed to an increase in the anti-Latinx sentiment. First, the unprecedented changes in the U.S. demographics have made Latinxs more visible in every sphere of society, increasing fears about imminent changes in the social and cultural fabric of the population (Stacey, Carbone-López, & Rosenfeld, 2011). Second, the events that took place on September 11, 2001, resulted in an increase fear and rejection of people perceived as immigrants. In the wake of 9/11, rhetoric describing immigrants as "criminals" who may become a potential threat to the homeland security began to emerge. Although Latinxs were not involved in 9/11, they were deeply impacted by it. Following 9/11, a number of laws and policies opposing immigration, disproportionately targeting Latinx populations, increased dramatically. For instance, in 2005 there were approximately 300 bills related to immigration. This number increased to 1500 by 2009. During the same 9-year period, the number of legislations enacted increased by approximately 500%, from 38 to 222 new laws (National Conference of State Legislatures, 2011). Finally, the anti-Latinx and anti-immigrant rhetoric expressed by Donald J. Trump during the 2016 U.S. presidential election campaign took the anti-Latinx sentiment to new lows (Chavez-Dueñas et al., 2019; French et al., 2019). To illustrate, a hate crime report conducted by the Los Angeles (L.A.) County Commission on Human Relations indicates that hate crimes against Latinxs in L.A. increased by 69% in 2015 (Romero, 2016). These events and the resulting increase in rejection and hostility toward Latinxs have the potential to increase psychological distress and anxiety among individuals, families, and communities of Latinx descent. Among families and patients suffering with dementia, the current sociopolitical context may contribute to Latinxs being more reticent to seek assistance from health professionals.

Service Underutilization and Its Impact on Dementia Care for Latinxs

Studies suggest that Latinxs tend to underutilize formal caregiving services (Crist, Garcia-Smith, & Phillips, 2006) including long-term care facilities (e.g., nursing homes). This pattern of underutilization persists even among patients who have suffered a significant decline in their ability to function independently (Espino, Angel, Wood, Finely, & Ye, 2013). A complex set of factors contribute to the underutilization of mental health services by Latinxs including economic variables, access to health insurance, language barriers, lack of culturally congruent services, and racial/ethnic biases among healthcare providers. Lack of access to health insurance, particularly among low-income and undocumented Latinxs as discussed earlier in the chapter, is likely to delay the diagnosis and treatment of dementia

(Angel, Angel, McClellan, & Markides, 1996). Communication barriers are additional challenges experienced in the healthcare system by monolingual, Spanish-speaking patients (Fortinsky, 2014). Not speaking and understanding English often results in patients or their families not being able to describe the symptoms, signs, onset, and course of cognitive decline in detail, which are core elements of an accurate dementia diagnosis. As a result, communication difficulties often become challenges to treatment compliance. In addition to communication barriers, Latinxs may find that the health services they are offered are incongruent with their traditional cultural values (e.g., placing a family member in a long-term care facility). Thus, they may not follow the recommendations made by health professionals and may keep their family member in the home for longer periods of time, thus increasing their caregiver burden (Adames et al., 2014).

In addition to economic, language, and cultural barriers, racial and ethnic biases existing within the healthcare system are additional factors associated with service underutilization among Latinxs. First, research indicates that racial and ethnic minorities are more likely to receive lower-quality healthcare than non-Latinx Whites, even when access to healthcare and socioeconomic status are controlled for (Smedley, Stith, & Nelson, 2003). Second, healthcare providers have been found to interact less effectively with Patients of Color than with White patients (Cooper & Roter, 2003; Cooper et al., 2003), with racial and ethnic biases contributing to the disparity in healthcare quality received by Latinxs. For instance, scholars Tobin and colleagues (1987) and Van Ryn and Burke (2000) report that healthcare providers hold implicit biases based on patients' race, ethnicity, and other demographic variables (e.g., gender, sexual orientation). Implicit biases impact the ways healthcare professionals interpret signs and symptoms of different conditions as well as their clinical decision-making (Kunda & Sherman-Williams, 1993; Tobin et al., 1987). Moreover, implicit biases may impact how providers relate to patients and how much attention is paid to patient concerns. To illustrate, in a study conducted by Hinton, Chambers, Velasquez, Gonzalez, and Haan (2006), it is reported that while the racial and ethnic disparities in health service utilization between Latinxs and non-Latinx Whites may be attributed to Latinxs not seeking help, a significant percentage (80%) of caregivers reported that psychiatric symptoms related to dementia were not considered even when these were communicated to primary care physicians. In other words, Latinx caregivers reported that medical professionals neglected information related to the management of behavioral problems and as a result they did not provide recommendations for how to manage these symptoms. Thus, contrary to the belief that Latinxs do not seek support from medical professionals, evidence suggests that when they do, their needs are likely to be neglected (Hinton et al., 2006). These negative experiences with healthcare providers result in Latinxs rating their experiences with the medical system as less than satisfactory. In a study by Fortinsky (2014), Latinxs rated their experiences with health professional as fair to poor regardless of socioeconomic status.

Diagnosis and Dementia Symptom Management in the Latinx Patient

As described in the introduction section of this chapter, Latinxs are more likely to be diagnosed with dementia than their non-Latinx White counterparts. Researchers from the Institute of Aging project that the number of Latinxs living with Alzheimer's disease, the most common type of dementia, could show an alarming increase of 832% going from 379,000 in 2012 to 3.5 million in 2060 (Wu et al., 2016). Studies also suggest that, on an average, Latinxs have an onset of Alzheimer's that is approximately 7 years earlier compared to non-Latinx Whites (Alzheimer's Association, 2010). Despite what we know about the prevalence and symptom onset of dementia among Latinxs, there continues to be a dearth of literature examining the biopsychosocial factors that contribute to such statistics. Moreover, few studies have analyzed how systemic barriers, racial biases, and lack of culturally trained health professionals impact the early diagnosis and symptom management of dementia among Latinxs. This section provides a brief overview of the emerging literature on Latinxs, dementia diagnosis, and treatment.

Biopsychosocial Variables and Dementia Prevalence in Latinx Populations

The increased probability of developing dementia for Latinxs is arguably due to the combination of biomedical, environmental, and systemic variables that disproportionately impact Latinxs. Latinxs are more likely to be diagnosed with medical conditions such as hypertension, atherosclerosis, and diabetes mellitus that increase the risk of developing dementia. Interestingly, the disparity in age of onset among Latinxs has been arguably due to a higher prevalence of diabetes mellitus (Alzheimer's Association, 2010). Latinxs are also more likely to live in places (e.g., houses and neighborhoods) where they are exposed to environmental toxins (e.g., contaminated water, air pollution) that increase their risk of developing dementia (Santiago-Rivera, Adames, Chavez-Dueñas, & Benson-Florez, 2016). Finally, Latinxs are more likely to experience systemic barriers including low levels of academic attainment and high levels of poverty, which have been shown to decrease access to high-quality nutritious foods, thus further exacerbating their vulnerability for developing a dementia (Aggarwal, 2013; Killin, Starr, Shiue, & Russ, 2016). While currently no cure exists for dementia, early diagnosis and symptom management can improve the quality of life for both patients and their caregivers (National Hispanic Council on Aging, 2016). Unfortunately, Latinxs do not often benefit from an early diagnosis given that they are less likely to be screened for the condition due to lack of knowledge coupled with distrust in the medical system. Moreover, the percentage of Latinxs participating in dementia research is significantly lower than that of their non-Latinx White counterparts (Gallagher-Thompson et al., 2004; Mehta, Yin, Resendez, & Yaffe, 2005). It is thus imperative that health professionals develop ways to deliver culturally congruent information about dementia. Gallagher-Thompson et al. (2015) and Valle, Yamada, and Matiella (2006) use *fotonovelas*, stories conveyed through photographs and text in a comic book-like fashion, to increase awareness about the symptoms associated with dementia, to increase symptom management, and to teach Latinx caregivers how to cope with stress and depression.

Making a Timely Diagnosis of Dementia

A critical step in the management of dementia is making a prompt and accurate diagnosis. Nonetheless, a correct diagnosis depends on the health professional's ability to understand and accurately interpret the beliefs, values, and behaviors of patients as well as their barriers to early diagnosis (Karlawish et al., 2011). One of the most important facts that health professionals need to understand and consider is that many Latinxs lack basic knowledge about the common symptoms associated with dementia (Cox, 2007; Karlawish et al., 2011). For instance, Latinxs tend to attribute memory loss to the normal aging process, making it less likely that they would seek medical assistance during the early stages of dementia (National Hispanic Council on Aging, 2016; Neary & Mahoney, 2005). As a result, missed and delayed diagnoses are more common among aging Latinxs than non-Latinx Whites (National Hispanic Council on Aging, 2016). Latinxs also experience a longer delay between the time they recognize the signs and symptoms of the condition and the diagnosis of dementia (Connell, Roberts, McLaughlin, & Carpenter, 2009; Dilworth-Anderson, Hendrie, Manly, Khachaturian, & Fazio, 2008). Unfortunately, by the time they receive a diagnosis of dementia, many Latinx patients typically have already experienced a significant impairment in their overall cognitive functioning (Cox, 2007).

The shortage of bilingual Latinx healthcare professionals also contributes to the problem of early diagnosis of dementia (Wu et al., 2016). In 2013, only 4.5% of all practicing medical professionals were of Latinx descent; however, it is unknown how many providers in this group were also bilingual. Some obstacles to an early diagnosis of dementia can be improved by both increasing the number of outreach and recruitment programs that are culturally congruent and language specific and by developing culturally responsive training programs for Latinx-serving health professionals (e.g., primary care physicians, neuropsychologists, nurses). Programs with Latinx-specific foci may assist professionals in gaining knowledge on how to minimize their biases so they can develop *confianza* (trust) with their Latinx patients. Once *confianza* is established, Latinxs may be more likely to see medical settings as places where they can seek help. This assertion is supported by studies that have looked at the role of *confianza* which demonstrate that when Latinxs are encouraged by someone they already trust, they are more likely to engage in health screenings including for dementia (National Hispanic Council on Aging, 2016).

Dementia Symptom Management

After Latinxs receive a diagnosis of dementia, the management of symptoms becomes the main goal of treatment. However, effective symptom management requires that the patient follow the recommendations of health professionals. Among Latinxs, treatment compliance also requires that both the patient and the family understand the biomedical nature of dementia and how treatment can be useful. Thus, providing basic psychoeducation regarding the etiology and treatment of dementia is particularly important for Latinxs, given the lack of information and the persistence of misconceptions that exist about this condition within this community. Evidence indicates that Latinxs believe that dementia can be caused by high levels of stress, thinking too much, and taking things too seriously or that it may be simply the result of destiny (National Hispanic Council on Aging, 2016). It is this type of information and misinformation, combined with the systemic barriers discussed above, that likely contributes to Latinxs not taking advantage of the available treatment options that can help manage dementia-related symptoms and behaviors.

Due to the fact that many people in the Latinx community typically associate dementia with memory loss, they are often unaware of its neuropsychiatric symptoms such as apathy, depression, and irritability. Consequently, Latinx caregivers are more likely to attribute behavioral changes to other factors such as health conditions, interpersonal problems, personality, and stress (Ayalon & Areán, 2004; Hinton, Chambers, & Velásquez, 2009; Hinton, Franz, Yeo, & Levkoff, 2005). When asked what contributes to neuropsychiatric symptoms, less than 30% of Latinxs attribute these symptoms to dementia (Hinton et al., 2009). Unfortunately, when Latinxs recognize the behaviors associated with dementia, they often report that healthcare providers do not provide information on how to manage these symptoms (Hinton et al., 2009). Latinxs often end up having to find their own ways to manage these symptoms which tend to increase caregiving burden. The consequences of not addressing neuropsychiatric symptoms are exemplified by the Sacramento Area Latino Study on Aging (SALSA), one of the most well-known studies examining aging in the Latinx population. In the study, Haan and colleagues (2003) found high levels of behavioral symptoms among older participants of Mexican descent diagnosed with dementia. Despite the high prevalence of neuropsychiatric symptoms in this population, patients and their family members reported not receiving information on how to manage these symptoms. The patients were also not referred to specialists (e.g., psychologists) who could help with symptom management (Hinton, Haan, Gellar, & Mungas, 2003). As a result, the participants in the study were less likely to receive help from professional sources (Hinton, Chambers, Velásquez, Gonzalez, & Haan, 2006). Given that neuropsychiatric symptoms are associated with increased disability among cognitively impaired Latinx elderly (Hinton, Tomaszewski Farias, & Wegelin,

2008) and with symptoms of depression noted among caregivers (Hinton et al., 2003), it is essential that families are provided with ways to recognize these symptoms, so services can be secured.

The Latinx Culture, Context, and Caregiving

Caring for a family member with dementia is a particularly overwhelming task that can have serious adverse health consequences for the caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Zarit, Todd, & Zarit, 1986). Evidence suggests that caregiving is associated with a wide range of negative physical and mental health outcomes including depression and early mortality (Schulz, O'Brien, Bookwala, & Fleissner, 1995). While the literature on caregiving is extensive, most studies focus on non-Latinx White caregivers. At the same time, the study of the interplay between culture, context, and caregiving among Latinx populations remains sparse. This area requires further attention because the proportion of Latinxs who will be expected to become caregivers will grow exponentially. Evercare and the National Alliance for Caregiving (2008) reports that approximately eight million caregivers in the U.S. are of Latinx descent with 1.8 million of them providing care for a patient with Alzheimer's disease, as Latinxs are more likely to provide informal care to their family members than individuals from other racial/ethnic groups (Weiss, Gonzalez, Kabeto, & Langa, 2005). Research suggests that Latinx caregivers often live in multigenerational households where they are responsible for caring for not only a parent with a dementia but also children under the age of 18 (Evercare & The National Alliance for Caregiving, 2008).

Latinx Perceptions of Caregiver Burden

The few available studies on Latinx caregivers have produced mixed results. For instance, some studies suggest that Latinxs view caregiving as an honor and a responsibility, and as a result, these individuals are less likely to describe caregiving as a burden (Coon et al., 2004). Given their views on caregiving, Latinxs tend to perform the duties associated with the role even during challenging circumstances and with little to no formal support (Coon et al., 2004). The strong sense of responsibility for the care of their family contributes to Latinxs finding themselves in intensive caregiving situations where the patient requires constant monitoring and support (Evercare & The National Alliance for Caregiving, 2008). Other studies suggest that Latinxs do perceive caregiving as a burden with 63% of Latinxs caregivers reporting high levels of burden compared to 51% of non-Latinx caregivers (Evercare & The National Alliance for Caregiving, 2008). This group of Latinxs reports feeling anxious and in need of social support. When compared to their non-Latinx counterparts, Latinxs report being more bothered by the caregiving responsibilities such as feeding, dressing, hygiene, and the like (Cox & Monk, 1993; Valle, Cook-Gait, & Tazbaz, 1993). They also reported higher levels of somatic symptoms and stress. Overall, subjective experiences of caregiving burden impact mental health and predict depression among Latinxs (Hernandez & Bigatti, 2010). Interestingly, despite the challenges and burden experienced by Latinx caregivers, research also suggests that they see themselves as having the ability to respond to disruptive behaviors associated with dementia and have more control over negative thoughts related to the caregiving role (Depp et al., 2005).

Contextual and Cultural Beliefs in Caregiving

Systemic challenges related to race, gender, and immigration further complicate the experiences of caregiving among Latinxs. For instance, *marianismo* influences women's attempt to balance a perceived duty to the family (Arévalo-Flechas, Acton, Escamilla, Bonner, & Lewis, 2014). As a consequence, Latinx women are more likely to become caregivers while simultaneously juggling multiple responsibilities (Apesoa-Varano, Barker, & Hinton, 2012). In addition to the challenges they experience when caring for a person with dementia, Latinx caregivers also report difficulties associated with being a member of a racial and ethnic minority group including financial stress, health disparities, low levels of education, racism, and the like (Neary & Mahoney, 2005). Research indicates that immigration status also adversely affects caregivers' assertiveness. For instance, undocumented immigrants report feeling afraid when communicating with healthcare providers (Neary & Mahoney, 2005).

Cultural beliefs also have a central impact on the caregiving experience and decisions caregivers make about their family members with dementia. To illustrate, cultural beliefs influence a caregiver's decision to keep a family member with dementia in the home instead of placing them in a long-term care facility. Latinxs may view placement in a nursing home as abandoning their family responsibilities and resort to such measures as a last alternative (National Hispanic Council on Aging, 2016; Neary & Mahoney, 2005). Additionally, placing a family member in a nursing home can be overly stressful for patients as they are likely to miss aspects of their culture such as food, music, and language which may provide a sense of comfort (Neary & Mahoney, 2005).

The Mind May Forget but What If the Heart Remembers?

As described throughout this chapter, culture facilitates how patients and their caregivers understand, experience, and respond to medical conditions including dementia. Culture also facilitates and impacts how Latinx patients and their families make meaning of their conditions, respond to symptoms, and make decisions about their treatment options. In addition to the undeniable and pivotal role of culture on medical conditions, Latinxs are also impacted by context and sociopolitical factors that may limit access to resources, exacerbate their symptoms, or contribute to their disease's progression. Effective outreach, diagnosis, and treatment of Latinxs with dementia necessitate careful consideration of all of these factors. Without a planned integration of the patient and their family's cultural values, beliefs, and practices, along with the systemic barriers they experience, inferior quality of care is likely to be delivered (Adames & Chavez-Dueñas, 2017; Bosma, Apland, & Kazanjian, 2010). We further posit that even as patients' cognition begins to deteriorate (e.g., memory) as a result of dementia, a thoughtful integration of their culture and careful consideration for how lifelong experiences of oppression have impacted their life can produce healthcare that is truly humane. In order to craft and deliver comfort, dignity, and the best quality of life possible for Latinxs with dementia, healthcare providers must consider the role of cultural values, practices, and a history of oppression on the patient and the family. After all, while the patient's mind might forget, their heart may still remember images, odors, and sounds that are either threatening or comforting.

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