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Integration of Latino/a cultural values into palliative health care: A culture centered model

HECTOR Y. ADAMES, PSY.D.,[1] NAYELI Y. CHAVEZ-DUEÑAS, PH.D.,[1]
MILTON A. FUENTES, PSY.D.,[2] SILVIA P. SALAS, M.A.,[1] AND JESSICA G. PEREZ-CHAVEZ, B.A.[3]
[1]The Chicago School of Professional Psychology, Chicago, Illinois
[2]Montclair State University
[3]Cornell University

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ABSTRACT

Objective: Culture helps us grapple with, understand, and navigate the dying process. Although often overlooked, cultural values play a critical and influential role in palliative care. The purpose of the present study was two-fold: one, to review whether Latino/a cultural values have been integrated into the palliative care literature for Latinos/as; two, identify publications that provide recommendations on how palliative care providers can integrate Latino/a cultural values into the end-of-life care.

Method: A comprehensive systematic review on the area of Latino/a cultural values in palliative care was conducted via an electronic literature search of publications between 1930–2013. Five articles were identified for reviewing, discussing, or mentioning Latino/a cultural values and palliative care.

Results: Only one article specifically addressed Latino/a cultural values in palliative care. The four remaining articles discuss or mention cultural values; however, the cultural values were not the main focus of each article's thesis.

Significance of results: The results of the current study highlight the lack of literature specifically addressing the importance of integrating Latino/a cultural values into the delivery of palliative care. As a result, this article introduces the Culture-Centered Palliative Care Model (CCPC). The article defines five key traditional Latino/a cultural values (i.e., *familismo*, *personalismo*, *respeto*, *confianza*, and *dignidad*), discusses the influence of each value on palliative health care, and ends with practical recommendations for service providers. Special attention is given to the stages of acculturation and ethnic identity.

KEYWORDS: Palliative, Cultural values, Latino, Hispanics, Death, Ethnic identity, Acculturation

INTRODUCTION

The United States (U.S.) has experienced an unprecedented shift in its demographic makeup. Latino/as,[1] one of the groups contributing to this shift, currently represent the largest and fastest growing ethnic minority group in the U.S. The Bureau of the Census (2011) reports that there are currently 50.5 million Latinos/as living in the U.S., comprising 16% of the total U.S. population. The growth in the Latino/a population is expected to continue. In fact, it is projected that by 2030, 20% of the total U.S. population will be of Latino/a descent (U.S. Census Bureau, 2004). Nevertheless, despite the increased representation of Latino/as in the U.S., there continues to be a lack of focus on research that addresses how this community experiences the end-of-life process (Smith, Sudore & Perez-Stable, 2009). Moreover, there is little literature addressing the integration of

Address correspondence and reprint requests to: Hector Y. Adames, The Chicago School of Professional Psychology, 325 North Wells Street, MM-4116, Chicago, IL 60642. E-mail: hadames@thechicagoschool.edu

[1]The term Latino/as refers to individuals that trace their descendance to Spanish-speaking countries of Latin American including: Central America, Cuba, Dominican Republic, Mexico, Puerto Rico, and South America.

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traditional cultural values into the delivery of palliative healthcare (Del Gaudio et al., 2012).

The end-of-life process, as proposed by advocates of palliative care, should focus on creating an environment that allow patients to experience comfort, dignity, and the best quality of life possible (Born et al., 2004). However, the U.S. institution of dying is imbedded in a Western majority culture, which according to some authors, "tends to be composed of monotheistic religion, whiteness, socioeconomic power, and rational scientism" (McCann & Adames, 2012, p. 1). Thus, in order to achieve the aforementioned goals of comfort, dignity, and optimal quality of life, a planful integration of patients' cultural values is critical. We posit that culture should be a core and central element in the service delivery of end-of-life care, as it facilitates how we understand, experience, and respond to death (Becker, 1973). Culture also facilitates and impacts how patients make meaning of their illness, respond to symptoms, make decisions about health care choices, and express affect related to the dying process (Krakauer, Crenner & Fox, 2002). Hence, without a planful integration of the dying patient and their family's cultural values, beliefs, and practices, inferior quality of care is likely to be delivered (Bosma, Apland & Kazanjian, 2010).

As the U.S. continues to become a more multiracial, multiethnic, and multicultural society (White & Henderson, 2008), there is a higher risk for people of color to receive poor end-of-life health care (Fischer, Sauaia & Kutner, 2007). Therefore, it is imperative for palliative care providers to recognize both universal and relative Latino/a cultural factors that influence decision-making regarding the end-of-life care. Some of the specific factors include, traditional Latino/a cultural values such as *familismo*, *personalismo*, *respeto*, *confianza*, and *dignidad*.

STUDY PURPOSE

Although cultural values are experienced and lived on a daily basis, they are particularly critical when considering end-of-life (Smith, Sudore & Perez-Stable, 2009). The purpose of the present study was two-fold: one, to review whether Latino/a cultural values have been integrated into the palliative care literature for Latinos/as; two, identify publications that provide recommendations on how palliative care providers can integrate Latino/a cultural values into the end-of-life care.

METHOD

A comprehensive systematic review on the area of Latino/a cultural values in palliative care was conducted via an electronic literature search of publications between 1930–2013. The following databases were used: Cumulative Index to Nursing and Allied Health Literature (CINAHL®), PsycINFO®, and PubMed®. Only articles published in English were reviewed. The last search was conducted on March 1, 2013.

Search terms included: (1) *palliative* combined with the following words: *familismo*, *respeto*, *dignidad*, *confianza, personalismo*; (2) *palliative* and *Latino/a*; and (3) *palliative* and *Hispanic(s)*. The first two authors, of this article, independently completed the search, reviewed each title and abstract to identify manuscripts that discussed Latino/a cultural values in palliative care. Both independent searches produced a total of 145 articles of which five were identified as relevant to the topic of this manuscript.

RESULTS

Five articles were identified for reviewing, discussing, or mentioning Latino/a cultural values and palliative care. Only one article (i.e., Del Rio, 2010) specifically addressed Latino/a cultural values in palliative care. Del Rio's (2010) article discussed the role that Latino/a cultural values play in the decision-making process related to artificial nutrition and hydration. The four remaining articles (i.e., Gutheil, & Heyman, 2006; Kreling, et al., 2010; Kwak & Haley, 2005; Tellez-Giron, 2007) discuss or mention cultural values; however, the cultural values were not the main focus of each article's thesis (see Table 1).

Latino/a Cultural Values & Recommendations for Their Integration Into Palliative Care

The results of the current study highlight the lack of literature specifically addressing the importance of integrating Latino/a cultural values into the delivery of palliative care. Moreover, no articles have outlined which Latino/a cultural values are most salient or how to integrate the cultural values into the end-of-life care for Latinos/as. What follows is an overview of five main Latino/a cultural values and their integration into the delivery of palliative care. It is necessary to mention that the patient and their family's level of acculturation and stage of ethnic identity influences the extent to which these values are relevant and practiced; hence, these additional considerations are discussed at the end of the manuscript.

Latino/a Cultural Values

Miller and Rollnick (2013) postulate that [cultural] values play a key role in shaping a person's internal

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Table 1. *Latino/a cultural values in palliative care: Results from a systematic review of the literature*

Study	Title	Thesis	Does the article integrate Latino/a cultural values
Del Rio, (2010)	The influence of Latino ethnocultural factors on decision making at the end of life: Withholding and withdrawing artificial nutrition and hydration	Provides a review of the literature on Latino/a beliefs and practices with a specific focus on the values of *familismo*, filial duty, respect for authority figures, and *personalismo* on decision-making at the end-of-life.	Yes
Gutheil & Heyman, (2006)	They don't want to hear us: Hispanic elders and adult children speak about end-of-life planning	Addressed Latino/a elders and adult concerns about end-of-life planning. Themes that emerged through the focus groups conducted included: communication, control, burden, spirituality, religious issues, and importance of family relationships.	No
Kreling et al., (2010)	The worst thing about hospice is that they talk about death: Contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, and non-Latino cancer caregivers	Qualitative study examining hospice decision and experiences among immigrant Central, South American Latino/as, and non-Latino/a cancer caregivers. Results indicated differences in decision-making and caregiver experience. Among Latino/as, cultural values, secrecy about prognosis, and family-centered system influenced decision-making.	No
Kwak & Haley, (2005)	Current research findings on end-of-life decision making among racially or ethnically diverse groups	Reviewed the literature on racial and ethnic diversity and end-of- life decision-making. Results indicated that Latino/as are more likely to prefer family-centered decision making than other racial ethnic groups.	No
Tellez-Giron, (2007)	Providing culturally sensitive end-of-life care for the Latino/a community	Provides a review of the literature regarding end-of-life and Latino/as. Article highlights the need for culturally sensitive health and education services at the end-of-life and provides examples on cultural traditions, rituals, and beliefs.	No

frame, noting that cultural values inform attitudes and promote behaviors. They assert that "to live with integrity is to behave in a manner that is consistent with and fulfills one's core values" (p. 85). Moreover, with respect to Latino/as, Villarruel et al. (2009) recognize the critical role that traditional cultural values play on identity and cultural practices. Interestingly, they have recognized the protective effects of cultural values, suggesting that they shield against the pernicious effects of migration, discrimination, and acculturation.

A Guide to the Integration of Latino/a Cultural Values Into Palliative Care

In this next section we offer three domains (e.g., *que es* [what is it], *como se ve* [how is it observed in palliative care], and *que hago* [what do I do]) to concretely illustrate strategies to understand, asses, and incorporate the five Latino/a cultural values presented earlier (i.e., *familismo*, *personalismo*, *respeto*, *confianza*, and *dignidad*).

Familismo

¿Que Es? *What Is It?*

Familismo is one of the key values that is significant in palliative care delivery to Latino/as patients and their families. *Familismo*, is closely associated with familial ideals; it involves broad networks of support that extend beyond the nuclear family to include aunts, uncles, grandparents, godparents, and other close family friends. Moreover, family structures, processes, and interactions are highly informed by the collectivistic norms of the Latino/a culture

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(Falicov, 1989), emphasizing obligation, affiliation, and cooperation. In Latino/a families, individual identity is commonly secondary to family identity, requiring individuals to prioritize family needs over individual needs. This family-centered socialization breeds considerable connectedness and interdependence. *Familismo* promotes and maintains "solidarity, family pride, and a sense of belonging and obligations to one's blood ties" (Falicov, 1989, p. 163) and to close friends that acquire formal kinship through religious or familial rituals (e.g., godparents).

¿Como se ve? *How is* familismo *Observed In Palliative Care?*

Family members are typically the primary caretakers. Palliative care providers can expect large numbers of individuals whom may all be considered "part of the family" and are involved in the care of the dying person (Smith, Sudore & Perez-Stable, 2009). This devotion and sense of responsibility for the dying person can propel members of the family to leave their jobs and travel long distances to care for the dying individual (Born et al., 2004). Decisions on end-of-life care tend to be made through family consensus (Born et al., 2004) with the father, oldest male, or oldest female (i.e., if no males are present), serving as the spokesperson for the family (Minnesota Network of Hospice & Palliative Care & Comunidades Latinas Unidas en Servicio, 2010). Last, children are not excluded from the care provided to the dying person or the dying process. In fact, in many Latin American countries, wakes take place in the home of the deceased with children often playing around the dead family member. As a result, providers can expect children to be present throughout the palliative care process.

¿Que hago? *What Can Palliative Care Providers Do*?

1. If possible, have conversations with patients regarding the role they would like their family to play in their care; allow patients to decide who is considered a member of their family.
2. Once permission is granted, actively engage family members and allow the family to be involved in the care of their dying loved one.
3. When the patient is unable to communicate, it is important for the practitioner to have a good understanding of the ethical guidelines and legal policies regarding the dying person's protected information. Thus, it is necessary to identify the spokesperson for the family and communicate any changes or needs, regarding the care of the dying person to that individual.
4. In addition to maintaining open communication with the family's spokesperson, it is still important for providers to make time to meet with the whole family to answer questions or address concerns.
5. Providers should offer referrals and provide resources to anyone in the family who may be experiencing significant difficulties (e.g., anxiety, mood, behavioral disturbances) related to the impending loss.
6. If palliative care is taking place in an institution, it would be important to designate a space where family members can congregate. This will facilitate the adherence to institutional policy regarding number of visitors allowed at one time in a patient's room, and the like.

Personalismo

¿Que Es? *What Is It?*

Another Latino value that greatly influences palliative care is *personalismo*; a value that places considerable emphasis on the personal interactions of people. Latino/as tend to be relationship-centered and prefer informal and supportive interactions to formal and professional interactions (Carteret, 2011). According to Falicov (1998), when establishing relationships with professionals, Latino/as require rapport building that includes warmth, informality, and regard. A significant emphasis is placed on professional relationships where the "means" to the professional care is as important as the treatment received.

¿Como se ve? *How Is* Personalismo *Observed In Palliative Care?*

Latino/a individuals prefer communication styles that are pleasant, free of conflict (Añez et al., 2008) and conducive to the maintenance of harmonious relationships. As a result, Latino families may engage in a number of unique and culturally congruent behaviors. For instance, Latino/as are likely to engage in indirect forms of communication by speaking through metaphors known as *dichos* (Zuñiga, 1992). This style of relating can be observed among family members and between the family unit and providers. In fact, it is not unusual for the staff to witness Latino/a families agreeing with each other regarding decisions pertaining to end-of-life care (e.g., respirators, feeding tubes, intravenous hydration, cardiopulmonary resuscitations, hospice care, autopsy). Many providers may leave feeling as if the family unit is in complete agreement with each other and

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that a final decision has been made. However, it is not atypical for families to congregate following such encounter to discuss their options in greater detail. Following such meeting, individual members of the family may approach the staff with differing opinions and requests; hence increasing the likelihood of a different outcome. These divergent messages may be confusing for providers and may thwart the process of coming to a decision regarding a final end-of-life care plan for the patient.

¿Que hago? What Can Palliative Care Providers Do?

1. Palliative care staff should be equipped to provide Latino/a patients and their families with information regarding all viable options. After delivering such information, the staff should provide the dying person and their family with ample time to consider options, emphasizing that there is no need to hurry with their deliberation.
2. With the help of the dying person (if possible), identify the spokesperson for the family while honoring the family's hierarchy.
3. Palliative care staff is encouraged to communicate both verbally and nonverbally in ways that foster harmonious interactions through the use of *personalismo*, which includes: listening, warmth communication, attentiveness, caring, and interacting in ways that are free of conflict.
4. It is critical for palliative care provides to be comfortable managing differing family members' opinions, agendas, ways of coping, and emotions while maintaining a relationship with the family unit as a whole.

Respeto

¿Que es? *What Is It?*

Another highly referenced Latino value, that can inform palliative care ideologies and practices, is *respeto* (respect). The value of *respeto* reveals the hierarchical structures that may exist in Latino/a communities, contributing to differential behaviors toward others based on a number of factors, such as age, gender, social or economic status, and authority. This value becomes highly evident in adult-child relationships, where children are expected to listen to adults (e.g., the elderly, parents, teachers) and comply with their requests (Falicov, 1998). This value can also significantly influence professional relationships, as Latino/as perceive professionals as highly regarded authorities, who are not to be questioned, leading to misunderstandings or non-compliance (Carteret, 2012).

¿Como se ve? *How Is* Respeto *Observed In Palliative Care?*

Respeto may be expressed in palliative care settings through various behaviors. For instance, family members may show deference to authority by not openly questioning recommendations made by palliative care staff. Additionally, families may expect providers to know, understand, and adhere to preexisting hierarchical relationships within the family.

¿Que hago? *What Can Palliative Care Providers Do?*

1. Palliative care staff should communicate respectfully and empathically with the dying person and all members of the family.
2. It is recommended that providers be mindful of their role within the family and respect the family's cultural preferences, which may include rituals, prayers, and beliefs. For instance, Latino/a families may consult with traditional healers, which can include folk healers (e.g., *curanderas/os*, *santero/as*, *hueseros/as*, *shamanes, naturistas*, *sobadores/as*).
3. When communicating with the patient and their family, providers should use formal titles to show *respeto* and establish a more hierarchical relationship. Titles including *doctora/doctor* (doctor), *señorita* (Ms.), *doña/señora* (Mrs.), *dama* (lady), *señor/caballero* (Mr.) are encouraged.

Confianza

¿Que es? *What Is It?*

Confianza (trust) is a value that is characteristic of the Latino culture, where individuals are invested in establishing relationships that are based on reciprocal trust. Moreover, *confianza* can be understood when someone expresses his or her deeper feelings only to an inner circle of familiar confidants. Overall, *confianza* connotes that the other person(s) in the relationship have their best interest in mind (Bracero, 1998; Lewis-Fernandez & Kleinman, 1994).

¿Como se ve? *How Is* confianza *Observed In Palliative Care?*

Building and establishing *confianza* with Latino/a patients and their families is often complicated. Experiences of discrimination, prejudice, and oppression can have a detrimental effect on establishing *confianza* (Smith, Sudore & Perez-Stable, 2009).

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In fact, families may be cautious with the information they disclose to the palliative care staff initially. Such cultural suspicion is normal, expected, healthy, and considered a resiliency factor resulting from strategies employed by ethnic minorities to cope with a long standing history of oppression and discrimination (Boyd-Franklin, 2006; White & Cones, 1999).

Providers may begin to notice a change in the family's behaviors toward them once *confianza* has been developed and established. For instance, patients and family members may attempt to deepen the *confianza* by asking providers questions related to their personal life. Moreover, patients and their family may be more at ease in their comfort level allowing for more direct conversations with palliative care staff.

¿Que hago? *What Can Palliative Care Providers Do?*

1. Given the complexity around building and establishing *confianza*, palliative care providers should be aware that building *confianza* will take time.
2. The establishment of a relationship based on *confianza* would depend on the provider's ability to demonstrate respect and empathy toward the dying person and their family. Thus, it is essential for palliative care providers to consistently follow through on promises.
3. Palliative care providers can demonstrate their own *confianza* (trust) by spending additional time with the patient and his/her family. Providers can engage in *platicas* (personable small talks) with the family unit.
4. Palliative care providers should assess their own level of racial and ethnic identity development in order to understand the experiences of Latino/as and other ethnic minority patients and families. Such work will enable providers to engage in open dialogues with patients and their families around issues of discrimination and prejudice; hence, likely having a significant positive impact in the establishment of *confianza*.

Dignidad

¿Que es? *What Is It?*

Another rather important, but less-referenced Latino cultural value that relates to palliative care is *dignidad* (dignity). Fundamentally, *dignidad* is associated with worthiness (Triandis et al., 1984) and feeling valued (Chochinov, 2002). It is understood as a concept that includes an individual's sense of self-worth, as well as that individual's experience of others valuing them. In short, this value recognizes that individuals are inherently worthy and meant to be respected (Santiago-Rivera, Arredondo & Gallardo-Cooper, 2002).

¿Como se ve? *How Is* dignidad *Observed In Palliative Care?*

Given the inherent challenges and fears likely to surface during the end-of-life process, patients may exhibit a number of behaviors. For instance, as patient's grapple with the anxieties surrounding death and the impending end-of-life, they may also experience the fear of being treated inhumanely. These fears may manifest as patients worry about being ridiculed for their condition, their physical appearance, and their difficulties or inability with basic activities of daily living. Such feelings may be fuelled by concerns regarding who (e.g., family members, palliative care providers) and how (e.g., being fed, dressed, groomed, provided with medications to manage their pain) their activities of daily living would be managed. This fear is likely to be exacerbated as the patient's health deteriorates or when they begin to lose control over their bodily functions (e.g., incontinence). Such experiences may further make patients feel vulnerable and physically exposed. These experiences may have a direct impact on the patient's sense of *dignidad* as they may feel that their worthiness is jeopardized. Family members may experience similar sentiments; as result, they may attempt to protect their loved ones sense of *dignidad* by volunteering to care for the patient's basic needs.

¿Que hago? *What Can Palliative Care Providers Do?*

1. It is recommended that palliative care providers have an open conversation with the patient and their family regarding the progression and sequelae of illness while allowing the patient and the family to exercise as much autonomy as they wish regarding palliative care.
2. Palliative care providers must take time to assess "what humane care" looks like for each patient and their family and incorporate such humane treatment into the palliative care.
3. Providers are encouraged to make counseling services available to address the patients and the family's fears and anxieties.
4. In order to honor patients' sense of *dignidad*, palliative care units can assign the same staff person to assist with basic activities of daily living. Although this may be difficult given the

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realities of staffing at palliative care units, we must find solutions to these challenges if we are truly dedicated to compassionate, culture centered, and human treatment.

TOWARDS CULTURE CENTERED PALLIATIVE CARE: CONSIDERING LEVEL OF ACCULTURATION & STAGE OF ETHNIC IDENTITY

Developing a culture-centered care plan can be an arduous and complex task for most palliative care professionals. This may be attributed to the scarcity of literature regarding the role that traditional cultural values have on the delivery of palliative care services (McCann & Adames, 2012). This article offers one step to address such complexity by providing the reader with some concrete recommendations to integrate Latino/a cultural values into palliative care. The impact that culture has on patients' decision-making processes is better understood by integrating cultural values. However, two additional factors need to be considered when working with Latino/as. 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 cultural values as depicted by the Culture Centered Palliative Care Model (CCPC) in Figure 1.

The CCPC illustrates how the patient and their family's level of acculturation and stage of ethnic identity influences the extent to which cultural values are adhered. In the context of this paper and the CCPC Model (see Fig. 1), 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 congruency regarding one's membership in a socially constructed ethnic group. Furthermore, it involves an individual's perceptions and feelings about members of his/her own ethnic group as well as members of the dominant group.

While an in-depth review of the literature on acculturation and ethnic identity is beyond the scope of this manuscript; palliative care providers are encouraged to review some of the classical literature and studies in these two important areas. Being well versed in this body of literature will set the ground to help providers develop culturally congruent palliative care. Readers are encouraged to review a number of critical foundational publications on acculturation (e.g., Berry, 1990; Cuellar, Arnold & Maldonado, 1995; Ramirez, 1984) and ethnic identity (e.g., Atkinson, Morten & Sue, 1989; Helms, 1990; Phinney, 1989) theory and research.

CONCLUSIONS

In order to truly craft and deliver comfort, dignity, and the best quality of life possible, palliative care providers must consider the role that cultural values have on service delivery. Although culture-centered palliative care may be an arduous and complex task, this process is necessary if indeed we are committed to provide an environment where the patient can live and die with dignity. Culture, when uniquely honored and integrated into palliative care, may be our last act of compassion for the dying other and their family.

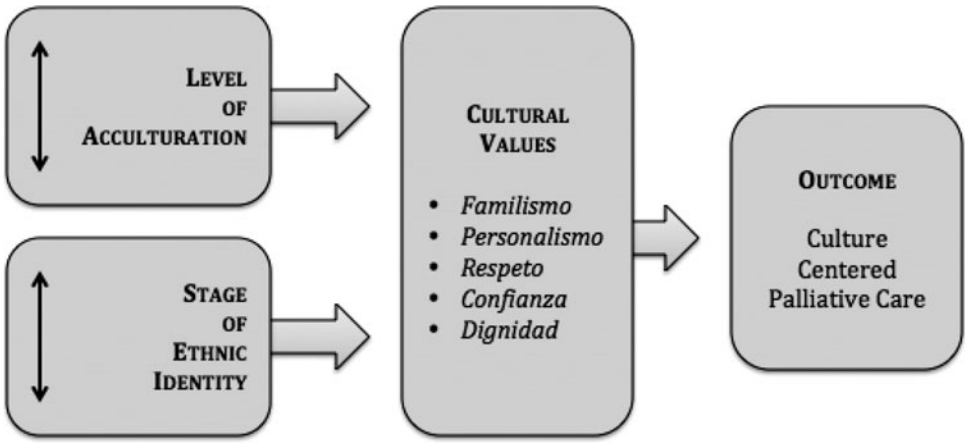

Fig. 1. The Culture Centered Palliative Care Model (CCPC). The patient and their family's level of acculturation and stage of ethnic identity influences the extent to which cultural values are adhered. The CCPC model can be applied to any cultural group by integrating the group's traditional cultural values.

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