

Education for Building Culturally Skilled Health Professionals and Community Health Empowerment: Resources to improve access to palliative care for Latinos

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Abstract

Latinos diagnosed with severe or life threatening diseases are less likely than non-Hispanic whites to have access to palliative care. The reasons for the lack of access to palliative care are numerous and include limited referral to palliative care, cultural and language barriers and lack of patient information about palliative care.

Familias en Acción, a Hispanic serving community organization in Portland, Oregon, found that many of the clients served through their patient navigator program had advanced stages of diseases and thus benefitting from but not receiving palliative care. Limited cultural knowledge by healthcare personnel and lack of patient/family understanding of palliative care served as barriers to patients receiving optimal management of symptoms, psychosocial support, and assistance with decision making.

Familias through funding provided by the Cambia Health Foundation developed and implemented cultural competence training for healthcare professionals and a community based palliative care educational program. Building the cultural knowledge of health professionals and community understanding of palliative care paired with culturally specific patient navigators serve as a model for increasing access for Latinos to palliative care.

Introduction

Latinos/Hispanics are the largest minority group in the United States and comprise over 17% of the total population. (1) However, despite this growth Latinos continue to experience significant health disparities (2) including limited access to culturally competent palliative care. Limited referral to palliative care, assumption that family will care for patients, cultural & language barriers, low levels of patient engagement and lack of patient knowledge about benefits of palliative care are some of the barriers that limit access for Latinos to palliative care. Lack of palliative care for Latinos leads to lower quality of life for patients with severe chronic conditions and higher healthcare costs. The diagnoses of a severe chronic condition and the end of life process should focus on creating an environment that allow patients to experience comfort, dignity, and the best quality of life possible. (3) Limited access to palliative care and hospice indicates Latinos diagnosed with severe or life threatening illnesses are not able to lead the best quality of life possible.

The new report by the Institute of Medicine (IOM), *Dying in America*, (4) states that the U.S. healthcare system is ill equipped to deal with the end of life process. The IOM committee believes a person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life should be a national priority. “*Dying in America* provides a comprehensive assessment of the knowledge gaps, structural problems, and financial disincentives that hamper delivery of optimal care and makes cross-sectoral recommendations to achieve compassionate, affordable, sustainable, and effective care for all Americans.”(4) Responding to the challenges offered by this ground breaking report to ensure effective care for all Americans will require the integration of cultural competence in all strategies for systems change.

Systems change is taking place nationally and in states throughout the country through policies designed to eliminate health disparities. The Affordable Care Act includes specific provisions that address health disparities. The Department of Health and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities (“HHS Disparities Action Plan”) (6) builds on national health disparities’ goals and objectives in *Healthy People 2020*, (7) and leverages key provisions of the Affordable Care Act. The vision of the HHS Disparities Action Plan is “A nation free of disparities in health and health care” providing key strategies to eliminate health disparities.

National and state policy makers have prioritized the need for a health care system that respects the cultural differences of individuals and a workforce that understands how to provide culturally and linguistically appropriate services and uniquely interact with clients from diverse backgrounds. (8) States such as Oregon, in the process of healthcare transformation, have established benchmarks for culturally competent health care that include ongoing training for health professionals to enhance their skills in serving diverse communities. (9)

Familias en Acción, a Hispanic serving health promotion organization in Portland, Oregon, recognizes that culture and palliative care cannot be separated. We use the following definition of palliative care: *Palliative care is a medical specialty but it is also a philosophy or attitude about patients and life. Palliative care offers relief from suffering to patients with serious and complex illness. It addresses the "whole person" and the family (physically, emotionally, and spiritually) honoring their cultural perspective and beliefs.* It does not replace other medical care but works together with it. This means that the patient can experience the best possible quality of life while dealing with the illness. And the family gets the support they need in order to continue to provide care to the patient.

Cultural competence in health care describes the ability of systems to provide care to patients and their families with diverse values, beliefs and behaviors including tailoring delivery to meet their cultural, social and linguistic needs. (10, 11) Rather than separate programs, cultural competence and palliative care, are most effective as the overall culture of healthcare organizations. Culturally competent palliative care need not be set apart as an entity in and of itself. It becomes the philosophical and ethical foundation for all healthcare encounters. Culturally competent palliative care for Latinos links healthcare personnel with community and family supportive resources including patient navigators, community health workers, clergy, clinical staff, social workers, social service organizations and other community resources.

Culturally competent palliative care for Latinos is considered a verb (ongoing action and attitude) not a noun (not always a place or person that patients are referred to).

Despite limited access to palliative care for Latinos, numerous researchers have documented the interest of Latinos in palliative care and how the values of palliative care complement those of Hispanic culture. The cross-cultural research on Hispanics/Latinos demonstrates the importance of developing personal relationships with the population that will lead to trust and an enhanced ability to engage in the dialog with patients and their families about palliative care, hospice and end of life decisions. Cruz-Oliver, Talamantes M & Sanchez-Reilly (12) also found the majority of older Latinos in their study preferred a family-centered, group decision-making model with limited patient autonomy which is contrary to the culture of palliative care in the U.S. which tends to be focused on individual decision making and patient autonomy.

Cultural differences are a significant barrier to palliative care for Latinos and other minority populations resulting in lower quality of life for patients and increased medical costs. (13, 14, 15, 16) Significant cultural differences exist between the U.S. healthcare system which is individualistic, time oriented and focused on treatment of disease and Latinos who are family/group oriented and relationship based. Palliative care with its holistic focus on the person, relationship based care can complement Hispanic culture and yet remains out of the reach of most Hispanic patients and their families.

Culture is central to the end of life process and impacting how patients view their illness, make decisions about their illness and cope with the end of life process. McCann and Adames (17) describe the culture of the U.S. healthcare system as viewing death as a failure of modern medicine, a taboo and an event of unspeakable terror. They describe dying in the U.S. as dominated by Western culture composed of monotheistic religion, whiteness, socioeconomic power and rational scientism. Palliative care, with its focus on management of symptoms, psychosocial support, and assistance with decision making, has the potential to improve the quality of care and reduce the use of medical services. However, Latinos and other minority populations will continue to have limited or no access to palliative care without a health system skilled in providing care to provide care to diverse populations.

For Latinos to receive palliative care the following are important: 1- Culturally competent healthcare organizations; 2- Integrate patient navigators, community health workers or promotores de salud as members of the care team. 3- Ongoing cultural competence and palliative care training for all staff; 4- Community palliative care education and 5-Partnerships between healthcare organizations and community resources to address social determinants.

Patient navigators, community health workers or promotores de salud are increasingly recognized as important “cultural brokers” for Latino patients and their families. Patient navigators originally focused on assisting cancer patients in navigating the U.S. healthcare system. Community health workers and promotores de salud are common in Latin America playing an important role in health promotion and access for underserved population. Building capacity for these community leaders can enhance access for Latinos to palliative care. (18) These trusted leaders have demonstrated success in supporting patients and their families by providing case management, health education and support in health navigation. They can work closely with members of the care coordination team to support access to palliative care for their patients and families. Community understanding of the importance of palliative care can enhance their ability to become more involved in their clinical care and to advocate for patient centered care. (19, 20)

Familias through their patient navigator program identified palliative care services as a need for their clients. Upon referral to their program the majority of their clients had received no palliative care services and often hospice only during the last days of their lives. Familias patient navigators found that healthcare staff had limited knowledge of how to respond to the cultural needs of their Hispanic patients and limited or no knowledge of community resources that could assist them. Most had received limited/or no training in how to care for their diverse patients. Culturally competent palliative care training was not available to healthcare personnel. Cultural competence training for health care professionals is crucial in building their skills to understand the cultural values of their Latino patients and to assist Latino families with end of life decision making for their elder family members.

Palliative care education should happen for all patients diagnosed with a severe chronic condition and in the communities through faith organizations, community organizations and through the media. Palliative care and hospice do not translate well into Spanish and often are equated the same. Community focus groups held by Familias determined limited knowledge about palliative care. Culturally and linguistically appropriate community education is important for Latinos to enhance their skills in patient advocacy and to understand how to become more active in their care. It is important for Latino community members to be aware of palliative care its benefits.

Palliative Care Resources for Latinos

Familias en Acción (Familias) is a Hispanic serving organization serving low income Latinos in Portland, Oregon since 1998. The mission of Familias is to promote holistic family well-being for Latinos through community engagement, education, research and advocacy for social change. Since 2008 Familias has provided patient navigator services to community members diagnosed with chronic diseases including cancer, diabetes, hypertension, HIV/AIDS and end stage renal disease (ESRD). Patients were often referred by hospital social workers, community health centers, primary care clinics and community based organizations. Patients often presented with later stages of chronic diseases that had often been undiagnosed or untreated for extended periods of time due to patients' lack of access to care for reasons including lack of healthcare insurance, no access to a medical home, low levels of health literacy and socioeconomic barriers such as limited income, underemployment, etc. Of particular concern were patients' limited understanding of their disease and their treatment options with limited support for chronic disease self-management. These patient barriers to care were not limited to Latinos who were uninsured but also included *insured patients*.

Client Stories:

Sr. Jose, age 62, was recently diagnosed with an aggressive cancer and had been told treatment would not be beneficial. He described being in severe pain and did not understand why he was not in chemotherapy. Sr. Jose had not been referred to hospice since healthcare providers assumed he would not qualify due to being uninsured.

Sra. Lupe, age 70, had been on dialysis for one year. She had limited understanding of the dietary restrictions of end stage renal disease patients and no understanding of the purpose and dosage of her prescribed medications. She was not able to afford the co-pay for several of the medications. Sra. Lupe believed the dialysis was temporary. She lived with her daughter and her family who struggled economically and were in jeopardy of losing their home. Sra. Lupe did not want to be a burden to her family.

The above client stories are not atypical and demonstrate the significant health disparities faced by Latinos throughout the United States. Advanced stages of diseases are not uncommon for Latinos who often lack access to preventive care, to a medical home with social determinants that impact their health. Healthcare providers, often disease focused with limited cultural knowledge, experience frustration in adequately responding to the healthcare needs of their Latino patients. Latinos may appear “non-compliant” and unengaged in their care when in reality they may be experiencing significant barriers to their care.

However, despite the many challenges for Latinos diagnosed with severe and life threatening diseases they are often sustained by cultural strengths including faith, family and the belief that there is a purpose for their suffering. Faith and family are the lenses through which Latinos view the world and can serve as protective factors despite health disparities that they experience.

In 2013 the Cambia Health Foundation provided funding to Famílias to develop and implement palliative care training resources. The purpose of this project is to develop curricula to train a healthcare workforce to provide care that is sensitive to the culture of their Hispanic patients and to educate Latinos about palliative care ultimately increasing the number of Hispanic patients accessing palliative care.

This project was unique because insights from patients, families and community leaders provided assessment of need and cultural specificity of training materials for both curricula. They were actively involved in curriculum development through content, video production and community palliative care education. Healthcare providers, already experts in palliative care, from all levels (physicians, nurses, hospice caregivers) and social service partners provided expert medical and social content about options for care.

A palliative care advisory council was developed that included patients and health professionals with palliative care, hospice and Hispanic health expertise from throughout the country. Members represented community organizations, academia and healthcare organizations. The palliative care advisory council provided guidance in the design and dissemination of the training resources.

The first palliative care resource to be developed was a community based training, *Empoderate/Empower Yourself: Health Empowerment for Latinos*. *Empoderate* is a two hour training community educational program for Latino patients dealing with chronic disease and their families to promote health literacy, empower them to utilize medical systems and to be introduced to palliative care. (21)

To develop *Empoderate* focus groups were held with community health workers, hospice workers, patient navigators, Latino patients and their families. This information became the basis for developing the educational session, *Empoderate*, which could be provided by patient navigators, promotores de salud, community health workers and other leaders in Latino communities. Four pilot trainings were held and enthusiastically received. The manual was reviewed by members of the advisory group, other professionals, and potential end users. Using their input, the materials were revised and finalized.

The trainer manual was translated into English for use in marketing and accountability to non-Spanish readers. The manual gives clear instruction for leading sessions that use popular education techniques. Participation does not require high literacy skills or expensive materials. Training to use it will be a full day in person train-the-trainer. During 2014 over 200 individuals participated in the *Empoderate* community educational program. The response to the program has been extremely positive. Latino community participants overwhelmingly have expressed interest in the topics of Empoderate.

The second resource to be developed was, *Cultural Competent Palliative Care for Latinos*, (22) an online and in-person training for healthcare professional to their increase knowledge of cultural issues affecting Hispanic patients and build their capacity for cross cultural communication and culturally sensitive palliative care. To develop the health professional training we used the knowledge gained from focus groups, from Empoderate pilot sessions, conducted telephone interviews with healthcare personnel, and convened the palliative care advisory council. We partnered with University of Portland Academic Technology Services to develop technology for the online training which consisted of four modules comprised of videos, discussion, and multi-media with recorded slides. The videos were written, filmed and produced by Familias and the University of Portland and follow the patient and her family from diagnoses of late stage breast cancer through the discussion of end of life decisions for care.

The online training is being offered by California State University Institute for Palliative Care in partnership with Familias. (22) The online training is offered as a two week, instructor facilitated course. Twelve continuing education units (CEU's) are available. A pilot course was completed in early September 2014 with favorable reviews.

The in-person training has been adapted from the online course and is available as a one hour standalone training or as a series. Important components of both the online and in-person trainings are the videos, didactic components and group discussion.

On September 19, 2014 Famílias held a palliative care for Latinos summit. Over 70 participants attended the summit representing diverse disciplines including nursing, medicine, social work, clergy, caregivers, community health workers, patient navigators, administrators and community members. The summit vision was: “A community and health care system that supports the "whole" person (palliative care) including the family, and is able to provide and connect them with care which recognizes, values and works with their cultural base to find culturally appropriate ways to maintain the best possible quality of life...or the best end of life... as defined by the patient and family. Culturally competent and patient centered care is optimal for all patients and their families!” Guided by the summit vision small groups provided recommendations on the following: 1-What can you do to empower your Latino patients and families to ensure they receive the care and support that they may need when they are diagnosed with a severe chronic condition? 2-How does palliative care complement Hispanic culture? 3-What can your organization and the health system do so that palliative care becomes the foundation for all patient and family encounters?

Recurring themes of the discussion groups:

Question 1-What can you (in your role) do to empower your Latino patients and families to ensure they receive the care and support that they may need when they are diagnosed with a severe chronic condition?

Palliative care- Ask for palliative care consultation immediately upon diagnoses.

Patient and family empowerment- Encourage patients to ask questions. Involve family as much as possible. Ensure patient and family understand the breadth of palliative care services.

Health Literacy- Ensure patient and family understanding of diagnoses and treatment options. Utilize culturally and linguistically appropriate audio/visual aids health information. Utilize culturally appropriate models for patient health literacy.

Communication- Ask the patient what is important for them? What gives them joy? Be open to the patient. How can I help you? Humor is important. LISTEN. Determine how the patient and family prefer to communicate.

Cultural humility/cultural competency- Latinos are a diverse population. Determine primarily language of patient and family.

Community Support for Patient and Family- Link patient and family to bilingual/bicultural patient navigators, community health workers, promotores de salud. Partner with community organizations specializing in housing, immigration, employment and other social services.

Question 2-How does palliative care complement Hispanic culture?

Family and Community- Natural fit with family. “Mirrors culture.” Support. Palliative care can be “interpreter” between medical system and patient/family. Warmth, connectedness, openness. Palliative care is like a family; relationship based.

Faith and Spirituality- Part of culture and language. “Vaya con Dios, Si Dios Quiere.” Free to share spiritual beliefs. Gives strength. Faith is healing. Can continually tap into faith while in crisis. Spirituality at forefront. Health organizations with a strong palliative care team brings together medical and spiritual care.

Question 3-What can your organization and the health system do so that palliative care becomes the foundation for all patient and family encounters?

Hispanic health personnel- We need more of us (Hispanics). Hire from the culture not train about culture. Hire or contract with patient navigators, community health workers.

Cultural Competence- Require cultural competence training for all staff. Certification. Educate healthcare providers about the role of interpreters. Establish list of interpreters trained in palliative care and end of life. Recognize different dialects. Not all patients have Spanish as their first language.

Training for Interpreters- Course in palliative care for interpreters so they have the right skills to interface with providers and patients. Prepare interpreters for end of life discussion.

Community Partnerships- Establish partnerships with Hispanic serving community organizations including social services, faith organizations and consulates.

Community Education- Provide palliative care and end of life education to Latino community. Put a face to palliative care. Make it relatable. Use media.

Palliative Care- It's everyone's responsibility-Create the expectation for your team. We (all staff) can be empowering even though we might not be (palliative care) experts

Recommendations for the Development of Culturally Competent Palliative Care for Latinos

The following recommendations are in alignment with strategies provided by The Department of Health and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities and the Oregon Health Authority. The recommendations by Familias integrate recommendations made by patients, families, community leaders with those from health professionals.

1-Culturally competent healthcare organizations-

Culturally competent health systems are dynamic organizations that constantly strive to provide quality care to all patient populations and are positioned to attract diverse patients and market share. Cultural competence in health care describes “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs. To attain *clinical cultural competence*, health care providers must: (1) be made aware of the impact of social and cultural factors on health beliefs and behaviors; (2) be equipped with the tools and skills to manage these factors appropriately through training and education; and (3) empower their patients to be more of an active partner in the medical encounter.” (23)

Recommendations:

- 1-Ongoing cultural competence training required for all health system personnel including the following: Hispanic culture and values, cross cultural communication, culturally sensitive communication, culturally appropriate care and patient health literacy.
- 2-Hire bilingual/bicultural personnel at all levels
- 3-Ensure access to interpreters for non-English speaking patients
- 4-Conduct annual audits to ensure access for non-English speaking patients to health services including communication, signage, forms, clinical instructions.
- 5-Develop and implement policies for a culturally inclusive organization

2-Integrate patient navigators, community health workers or promotores de salud as members of the care team.

Patient navigators, (community health workers or promotores de salud) play an important role in reducing health system barriers for Latino patients and their families. The role of patient navigators can include case management, patient education, psychosocial support and advocacy. Patient navigators also play an important role in addressing any social determinants that may impact patients and their families.

Patient navigators, community health worker or promotores de salud are increasingly being integrated into care teams at community health centers that serve large Hispanic populations. However, within larger health systems their presence is rare.

Patient navigators play an invaluable role in providing access to palliative care and hospice for Latinos. They serve as an important liaison between the patient/family and healthcare system. They provide education to both healthcare providers and to patients and their families assisting in meeting the health and psychosocial needs of patients. They provide culturally appropriate support to patients and families dealing with the end of life process.

The integration of patient navigators into the care team will require ongoing training to ensure that all team members are clear about their roles, to develop an effective communication process and work plan. Ongoing clinical training is important for patient navigators to build their understanding of chronic diseases and to enhance their skills in advocating on behalf of patients and their families.

Recommendations

- 1-Contract with culturally specific community organizations to hire bilingual/bicultural patient navigators, community health workers or promotores de salud.
- 2-Internally hire bilingual/bicultural patient navigators, community health workers or promotores de salud.
- 3-Provide training and support for the integration of patient navigators, community health workers or promotores de salud into care coordination team

3-Ongoing cultural competence and palliative care training for all staff

Ongoing cultural competence is essential for all staff. A culturally inclusive health organization requires that staff at every point of client contact has the skills to interact with patients and their families in a manner that is culturally respectful. Cross cultural communication skills are essential in responding to the unique needs of each patient and are as important as clinical skills. The Californians' Attitudes Toward End-of-Life Issues Report (24) indicates that Latinos express a general mistrust of the medical system that serves them. Health care professionals express frustration with treatment compliance by patients which can be addressed through effective cross cultural communication and cultural knowledge.

For palliative care to be effective for both provider and patient, providers must be aware of, and be able to match their care to, the cultural context that patients bring. (Kagawa-Singer & Blackhall, 2001).

Recommendations

- 1-Implement culturally competent palliative care as an organizational value
- 2-Provide ongoing training for all personnel in culturally competent palliative care
- 3-Include patient navigators, community health workers or promotores de salud in providing palliative care to patients and their families and with the end of life process.
- 4-Provide palliative care and end of life training for interpreters to enhance their skill for interpreting these difficult topics

4-Community palliative care education

Palliative care and hospice are not terms that are commonly understood by many individuals. Palliative care and hospice do not translate well into Spanish. Hospice means orphanage or place for poor people and requires culturally appropriate education to enhance community understanding of the term. Culturally appropriate palliative care education must also be relationship and family based and interactional vs didactic. The integration of palliative care education into existing community programs (faith organizations, schools, community organizations) is an effective strategy for reaching community members.

Recommendations:

- 1-Utilize culturally and linguistic appropriate curricula to enhance community understanding of palliative care and advance planning. Empodérate/Empower Yourself: Health Empowerment for Latinos is available through Familias en Acción. (www.familiasenaccion.org)
- 2-Partner with the Spanish language media to develop palliative care public service announcements
- 3-Partner with faith leaders in palliative care education for their communities

5-Partnerships between healthcare organizations and community resources to address social determinants

Social determinants of health reflect social factors and the physical conditions in the environment in which people are born, live, learn, play, work and age. Also known as *social and physical determinants* of health, they impact a wide range of health, functioning and quality of life outcomes. (Healthy People 2020). Social determinants that can impact health include poverty, transportation, lack of healthcare insurance and substandard housing.

Latinos are often labeled as “non-compliant” when in fact they may be dealing with barriers to their care. Examples of barriers to care can include no access to public transportation, inability to afford co-pays for office visits/medication and lack of family support. Patients may be homeless which for Latinos often means living on a friend’s couch or in an apartment with numerous families. The inability to adhere to a recommended diet may be due to limited income.

The establishment of partnerships with Hispanic serving organizations is important to address social determinants. The partnership must be relationship based so that both the health system staff and community organization staff can directly contact each other to make referrals and to discuss patient/client needs. Patients and their families do not benefit from referrals that are made through providing the contact information for the community organization but rather a “warm” referral must be made through direct contact and follow up to ensure the patient and family have been engaged with the social services. Community organizations should also feel comfortable their needs are being met through the partnership which can include health education provided by health system personnel and referrals for clinical care.

Recommendations:

- 1-Develop ongoing relationships with Hispanic serving social service organizations.
- 2-Develop contracts with community organizations to provide patient navigator, community health worker or promotor de salud services.
- 3-Include patient navigators, community health workers or promotores de salud as members of care coordination team to address social determinants that impact patients’ disease management.

Conclusion

Healthcare transformation in the U.S. provides the opportunity to build health system capacity to serve Latinos and to ensure quality of life for those patients diagnosed with severe or life threatening diseases with access to culturally competent palliative care. The growing Latino population along with the increasing numbers of Latinos ages 50 and older living with chronic diseases will continue to burden a healthcare system already challenged in responding to the needs of diverse patients and their families.

The resources and recommendations of this project are all important components necessary to increase access for Latinos to palliative care. Healthcare professionals who understand Hispanic culture and patients who have received culturally and linguistically appropriate health information can lead to appropriate symptom management, psychosocial support and informed decision making for Latinos diagnosed with severe or life threatening diseases.

Latinos are resilient and spiritual people. (25) Many of them are far from their homeland and family members. They have worked hard often with multiple jobs to provide for their families in the U.S. and in Latin America. When confronted with a severe or terminal illness Latinos deserve care that helps them with quality of life. Care that honors their culture and values. Care that honors the diversity of all patients.

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