

Cultural Humility and Compassionate Presence at the End of Life

by Silvia Austerlic

Setting a conceptual framework: beyond cultural competence, cultural humility

Gabriela Rivera and her family are among the many millions of Latinos who have left behind family and home in search of a better life. As time goes by, though, their "American dream" - better opportunities to live with dignity, earn a living, and provide a good education to their children - becomes harder to achieve, as they encounter a harsh reality that they are not well-equipped to face. The better opportunities are still out there, but access barriers to work, education, and health services often stand in the way of their dreams. External barriers such as poverty, illegal residence, lack of insurance, or lack of culturally appropriate services, give rise to internal barriers, such as fear of deportation and mistrust of the health system. These might explain why many Latinos don't reach out for help until a time of crisis.

Even though illness, death, and dying are universal experiences, the ways people understand and respond to them are shaped by the attitudes and beliefs of their particular culture. Broadly speaking, our cultural background provides a road map or lens of perception through which the world is understood and interpreted. Culture impacts the meaning of health, illness, and dying; relationships between patients and health providers; how end-of-life decisions are made; communication styles; and so forth. The challenge for health care providers is to learn how cultural factors influence patients' health beliefs, behaviors, and responses to medical issues in order to assure high quality care for all.

In Western societies, as Dr. Rachel N. Remen has said, "we have made death into a technological and management issue and robbed it of its holy significance and dignity." Communicating a terminal prognosis to patients and families is much more than a medical conversation, and acknowledging the role played by culture can transform the way both providers and patients understand and relate to each other, in order to deal with the end-of-life situation in a culturally appropriate and compassionate way. *Cultural competence* is a conceptual framework to help providers understand, appreciate, and work with individuals from diverse cultures. Its components are awareness and acceptance of cultural differences between/within cultures, self-awareness, knowledge of the patient's culture, and adaptation of skills (to better accommodate the patient's culturally-influenced needs). *Cultural competence in health care* refers to both the strategy to reduce racial/ethnic disparities in access to health services for all patient populations and the ability of the systems to provide high quality care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs.

Latinos, like some other minorities, are often referred to as an "underserved population," indicating their relative lack of access to social services and their condition as "have-

nots." This designation denotes an intrinsic power imbalance, a relationship in which there is little they can do for themselves, except to ask the "haves" for help. In this light, I'd like to introduce another term, *cultural humility*. This phrase better reflects the complex attitude and sensitive skills required to meet the needs of patients and families in a way that empowers them to participate in a two-way therapeutic relationship, where both patient and provider are understood to have something to contribute. According to Tervalon and Murray-Garcia, cultural humility is "a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues and with themselves" (Tervalon and Murray-Garcia, 1998). In a nutshell, cultural humility invites providers:

- to engage in self-reflection and self-critique
- to bring into check the power imbalances, by using patient-focused interviewing and care
- to assess anew the cultural dimensions of the experience of each patient
- to relinquish the role of expert to the patient, becoming the student of the patient
- to see the patient's potential to be a capable and full partner in the therapeutic alliance

From my perspective as a hospice Latino community liaison, I will here present some observations on cultural dynamics with regard to illness, death, and dying in the Latino community - in particular, reflecting on the provider's difficult role of initiating the end-of-life (EOL) conversation and facilitating decision-making around treatment options. Since an EOL situation is much more than a medical circumstance, cultural humility and a compassionate presence can have a critical impact on the patient's and family's experience; hence the need for providers to gain new understandings, knowledge, and skills.

Cultural dynamics regarding illness, death, and dying in the Latino community

While the demands and needs of a Latino family facing EOL issues may or may not be different from those of any other family, access to care and the quality of care are affected by cultural attitudes, practices, and concepts that are not self-evident to non-Latino caregivers. Gabriela and her son Marcos exhibit many of the general traits described by cultural categorizations of Latino health behavior. The information presented here should be considered very general in nature. Latinos are a diverse group with varied social, economic, and political reasons for being in the States. Not only do they arrive from many different countries, but they also belong to many different cultural groups. Thus, my comments are meant to be generalizations not stereotypes. A stereotype is an ending point; a generalization, a beginning point that can help us understand and anticipate behavior (Galanti, 2000).

The purpose of bringing cultural differences to the foreground is not to create false dichotomy (i.e. us vs. them, good or bad, better or worse), but to acknowledge the unique cultural background of patients and families, and to foster respect and dignity in the exchange. Additionally, health providers must become knowledgeable of their patients' health care models because *principles, practices, and procedures that are beneficial to one cultural group might not be beneficial, and might even be harmful, to other cultural*

groups. For instance, in the United States, it is customary for health providers to disclose a terminal prognosis to patients under the principle of truth-telling, respecting also the perception that the patient has the right to know the truth. However, in diverse Latino cultures, families often oppose the direct disclosure of a terminal prognosis to the patient, in the belief that they are protecting the patient from information that might be experienced as cruel, disrespectful, or killing or giving up hope.

In general, for individual, social, and cultural reasons, many Latinos don't tend to engage in preventive health behavior. Sometimes it is their financial condition or the lack of transportation that makes it difficult to get to medical appointments, or like Gabriela, to take necessary medications. Latinos rely more on home remedies and over-the-counter medications, as well as on advice from friends and relatives on medically-related matters. They also tend to use traditional medicine, and/or to self-diagnose and self-treat initial symptoms, and often they will only seek professional advice if symptoms persist. Regarding the relationship between patient/family and health care providers, a *personal relationship* or *connection* is at the heart of most interactions among Latinos. *Family* is considered to be the very soul of the Latino culture and plays an essential role when making health care decisions. The family has a strong influence regarding the patient's treatment and where the patient will be looked after. Family members ordinarily are very supportive and usually quite involved with care.

Latinos view health care providers as authority figures and treat them with much *respeto*, respect and deference. In turn, they expect a provider to be warm and friendly, to have some appreciation of the Latino culture, and to take an interest in the whole person. Central to this is the level of *confianza* or trust that makes honest communication possible. Its absence means that a patient or family member might not share important health information, such as the use of traditional medicines, or difficulty in understanding medication instruction.

Fatalismo - the sense that what is happening is beyond one's control, and the tendency to accept hardships as the will of God and to endure a certain amount of suffering with dignity and self-sacrifice - sometimes plays a role in health care behavior. This might explain why Gabriela ignores symptoms such as her "increasingly persistent cough, headaches, shortness of breath, and generally feeling ill"; or why Marcos, her son, ignores the doctor's advice to "make a major lifestyle change in order to prevent the worsening of his (diabetes).... He reasons that he will just learn to live with his symptoms, which are still relatively mild."

Death and dying are topics that many Latinos may not be willing openly to discuss, especially when a loved one is seriously ill. As health deteriorates and there is a health crisis, families usually call 911 and/or rush to the emergency room or the hospital, wanting "everything done." Unfortunately, many times patients arrive too late for technology to change the course of an illness that is very advanced. At that time, it might seem obvious to doctors and nurses that death is imminent, and aggressive treatment may look more like medical futility than life-saving technology. For health providers, the line between the time to treat and the time to let go might be much clearer than for patients

and families, who are now turning towards the mainstream health care system to save the patient's life.

Signing a DNR form or making the decision of withholding or withdrawing treatment is not something about which many Latino families feel comfortable. It is difficult for one single family member to be responsible for such a critical decision, and at times continuing treatment may represent "not interfering with God's will." In cases like this, it could be convenient to have a family conference or call a priest to assist the family in making a difficult decision, one aligned to their deepest beliefs and values.

Regarding comfort care, it is not uncommon that hospice (a service that is still neither well known nor well understood in the Latino community) is presented in a way that looks more like withdrawing treatment and giving up hope. The notions of *quality of life* at the end of life and *comfort care*, the patient dying peacefully at home surrounded by loved ones and with his or her pain controlled, are *not* what patients and families have in mind when they rush to the ER. And even though in some cases the patient's life cannot be saved, there is *much* that providers can do to give patients and families the best care possible, along a continuum of care from aggressive treatment to palliative care to comfort care and hospice.

Cultural humility and compassionate presence at the End of Life

At the risk of stating the obvious, it is important to say that a conversation about the end of life is much more than a medical conversation, even when the focus is on bodily condition and treatment options. At a personal level, a terminal prognosis threatens the person's whole existence. For the family members, it is often the worst nightmare. To restore death and dying to a place of dignity and holy significance, providers need not only cultural sensitivity in order to ensure that all patients and families receive the best care possible, but also human compassion, to provide support and guidance at this most difficult time. The end of life is also a time of profound suffering. Patient and family may be the protagonists, but health providers are *not separate* from the suffering. Aside from the patient-provider relationship and the pain of seeing someone we care about suffer, the dying person becomes a mirror of our own mortality. Suffering is a universal condition, and we are part of the equation. When medicine's life-saving technologies and aggressive treatments can't offer a cure, *cultural humility* and a *compassionate presence* can greatly impact the patient's and family's experience.

Cultural humility comes from stepping away from the comfort zone/role of expert and acknowledging when we might not know what else to do. Becoming a student of the patient means learning about who patients are, including their beliefs, expectations, and values, and what "quality of life" would look like to them. By asking questions and listening carefully, we may tap into the patient's potential to be a capable and full partner in the therapeutic alliance, even in the face of imminent death.

Compassion, the capacity to empathize with other people's suffering, is universal and can be felt even in the face of language barriers. Compassion is felt in the heart, an intuitive knowing that someone cares about what one is experiencing, even when nothing can be

done to change the situation. This can look like the right word at the right time, but also a glass of water, holding hands, gentle touch, or silence. Compassion is not about fixing a problem, but rather witnessing and "being there" for the one who is suffering. According to J. Goldstein and J. Kornfield, compassion arises as "the spontaneous response of an open heart to help others be free of their suffering.... For genuine compassion to arise it is necessary to reverse the conditioned tendency of avoidance (of suffering) and to openheartedly experience the full range of our human condition" (Goldstein and Kornfield 2001).

Below, I'd like to present three "**compassionate interventions**" at the end of life, interventions which we can apply to Gabriela's case:

1. To meet the needs and desires of patients and families by presenting choices at the end of life

Meeting patients and families where they are requires learning about and from them, what they believe and understand, what their expectations are, and what they are ready or willing to know. This assessment is essential before definite disclosure of a patient's terminal prognosis. Helpful are the ability to ask open-ended questions (questions that elicit dialogue) and to listen beyond one's own biases and preferences. When disclosing a terminal prognosis, treatment options, costs, adverse effects and benefits, and any other relevant information should be presented in a language that patients and families can understand. If possible, in the face of critical choices, caregivers should assess patients' understanding by asking them to tell what they have understood, and if there is anything else they might need to know in order to make informed choices. *In Gabriela's case, Dr. Parker surely had good intentions when he "gently raised the possibility of foregoing dialysis ... and instead providing hospice care at home." Yet, given Marcos' abrupt and angry reaction, it is clear that he was not ready to accept that his mother was dying. There might not be a way of avoiding that reaction, since anger is a natural response in the grieving process. Maybe there could have been a way to assess Marcos' understanding and to present information in terms of choices they could make as a family - referring to what would be best for Gabriela, considering who she was and what "quality of life" would mean to her.*

2. To enable hope in the face of no more life-saving technologies or aggressive treatments available

Finding hope at the end of life is a paradoxical task. In mainstream culture, hope equals cure. In the hospice culture, hope changes its focus, from finding a cure to trying to make the patient comfortable and pain-free, and improving the patient's quality of life, defined in the patient's and family's own terms. In the Latino community, hope is a vital value, not only from a religious and spiritual standpoint, but psychologically, as a source of inner strength and resilience. Hope at the end of life should not be "false hope," exclusively focused on cure. Hope is to be found by patients in their own terms. Providers can enable hope by showing respect for the patient's beliefs and values, and by creating an atmosphere in which the dying can search for their own meaning. *In Gabriela's case, since*

Marcos has expressed that "God will certainly protect such a saintly woman through this time of trial," it would be important to acknowledge the role that their religion and faith play, and maybe offer to call a priest to assist them at this time. Besides cure, what would their hopes be? If going back to how things were in the past were not possible, what would their hopes be? Would Gabriela want to go home, or would she want to be at the hospital connected to life-prolonging technologies? Besides information, providers offer education and preparation for the end of life, information that may take time for families to assimilate and process.

3. To facilitate healing, even when physical cure is no longer possible

Another paradox: End of life asks us to accept the ultimate loss of a human life, yet healing goes beyond the cure of the body. Healing means "restoring wholeness," a wholeness that includes our bodies, and also our relationships, deeds, and legacies. Healing is about *relationships* - the relationships of persons with themselves, with their illnesses, with their loved ones, with their medical providers, and with their fates. Healing is a personal matter, and can only happen from the inside out. It is vital to ask, directly or indirectly, what does healing mean for this person? It could look like letting go, dealing with unfinished business, asking for or granting forgiveness, a last wish, or coming to terms with one's own death. *In Gabriela's case, part of the healing process would be allowing the family to take in the bad news and to go through the anticipatory grief journey, whatever that might look like for them. Calling a Spanish-speaking priest or chaplain to talk to both Gabriela and/or her family can open the conversation to make room for other dimensions of the patient's experience affected by this terminal prognosis. Inquiring into sources of strength and resiliency would also facilitate healing.*

Lastly, cross-cultural skills for health providers, skills that may help bring compassionate presence, include the following:

- 1. Self-Awareness:** *How do I react to cultural differences? How do I manage my own reactions? How do I negotiate with patients and families in the face of cultural differences?*
- 2. Active Listening:** Listening in (self-awareness) and listening out (to other practitioners, patients and families); listening with our *body* (sensations & body language), *mind* (facts and stories), and *heart* (emotions and feelings);
- 3. Bearing Witness:** *Being present* in a way that communicates that the person is not alone.

I'd like to end with an insight from one of my teachers, Frank Ostaseski, founder and co-director of the [End-of-Life Care Practitioner program](#), whose mission is to provide innovative education on spirituality and dying. He writes "*In being with someone who is dying we need to be completely ourselves. Natural and ordinary. That means to bring both our strength and vulnerability to the bedside. Professional warmth doesn't heal. This is intimate work. We can't serve from a distance. We can't travel with others in territory that we haven't explored ourselves.*"

It's not often our expertise but the exploration of our own suffering that enables us to be of real assistance. That's what allows us to touch another human being's pain with compassion instead of with fear and pity. We have to invite it all. It is an intimacy with our own inner life that enables us to form an empathetic bridge to the other person." (Ostaseski, 2008)

Notes

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