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CHAPTER 5

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CASE DESCRIPTION

Mr. Martinez is a 66-year-old who has late-stage lung cancer. An immigrant from Guatemala, Mr. Martinez worked as a skilled automotive repairman at a major dealership until he retired early at the age of 62, after his cancer diagnosis. He was referred to hospice care by his oncologist who suggested it to his wife and daughters after stating "there was nothing more that medicine could do for him." Mr. Martinez's wife requested services from the hospice but asked the staff to not tell her husband that he is in the final stage of his illness. She also requested that if Mr. Martinez asks where the staff works, they should say they are home health providers and not use the word "hospice." Mr. Martinez is supported by a small but close family including his wife, two married daughters and their families, and a younger brother who is a Catholic priest in the community. Father Joe is well-respected by the hospice chaplain for his pastoral services and devotion to parishioners who have been in hospice care.

STATEMENT OF PROBLEM

Mrs. Martinez made it clear that she does not want her husband to know he is receiving hospice care. How should a hospice respond to a request for nondisclosure when that is posed as a condition for accepting hospice care? Part of the problem in this particular case is illustrated by the oncologist's comment that hospice was appropriate because "there was nothing more that medicine could do for him." Such reasoning, however common, does a considerable disservice to
hospice and palliative care which have much to offer, including pain management, symptom control, holistic and family-centered care, and a team approach to treatment. A better approach would have been to begin with a discussion of the family's hopes and goals for the patient. In that discussion, it would be critical for the family to fully understand and accept that the goal of care now was palliative; medical interventions could no longer offer a cure or an extension of life, but there was much that could be done to ease death. Such discussion should be done sensitively, acknowledging the family's hopes for a different outcome, while affirming much could be offered to make Mr. Martinez's final days more comfortable and to support his family.

ANALYSIS

Nondisclosure requests to hospice are not unusual (Partington & Kirk, 2015). Partington and Kirk (2015) make a persuasive case that granting nondisclosure requests is inimical to effective hospice care. Patient-centered care is central to the hospice philosophy, they argue. In order for care to be effective and suffering minimized, an individual's experience of dying needs to be integrated within his or her life experience. By that, the authors mean patients needing to discuss their impending deaths or review their lives as they face death should be able to do so. This process can only occur in a context where there is open communication—that is, care that is not bound in secrecy.

In addition, Partington and Kirk (2015) acknowledge the ethical argument for disclosure. Truthfulness requires that patients have the requisite information to make decisions; beneficence and sensitivity require, to Partington and Kirk, that the process of obtaining the family's consent for disclosure may involve patience and time, entailing active listening and a shared commitment to benefit the patient, as well as acknowledgment and validation of the emotions of family caregivers. But the end result is that patients should have full knowledge of their state.

However, such a position needs to concede that different cultures have different stances toward disclosure. Years ago, I had the opportunity to do some work around grief and loss with the Inupiat peoples, a Native Alaskan group. The Inupiat place great value on words. One of the ethical issues experienced by professionals working with this population was that many times individuals would refuse to sign advance care directives after a discussion of the possible situations
that can occur during serious illness, injury, or death. In Inuqiat
culture, talk of illness, injury, or death is believed to be a bad omen
that has real potential to cause such adversity to occur.

While there are significant cultural differences, diverse ethnicities,
and varied experiences within the Hispanic cultures, some of the
values common to this culture influence the decision on how to
respond to the Martinez family's request for nondisclosure. First is
the value of familismo, which recognizes the importance of family ties
and relationships and places the locus of decision making within the
family rather than the individual. Second is a value of presentismo,
or an emphasis on the present; one should live in the moment as one
never knows what the future will bring. Within this perspective is a
strain of fatalism expressed by the common expression que sera, sera,
or what will be, will be. Such values can inhibit advance care planning
as well as discussions of death (Houben, 2012; Talamantes, Gomez, &
Braun, 2000).

GOALS OF COUNSELING

Truth-telling is different from truth-offering. It is one thing to
demand that patients face the truth whether they wish to hear it or not;
it is quite another to offer patients information if they wish to hear it.
The goal of palliative care should be one of open communication. Open
communication begins with a goal to keep the conversation going; that
one truthfully responds to questions patients ask in ways that assess
what the patient is really asking, and provides answers in such that
dialogue is not closed.

My own family's experience offers a good example of this. My father
had excellent care in hospice, yet there was one conversation I wish
would have been handled differently. Dad knew both his diagnosis and
terminal prognosis. He understood that he was in hospice care, fully
knowing what that meant. Yet one day, even though he was bedbound,
he asked his nurse when she thought he might drive again. She seemed
shocked by the question and reminded my father that he was dying
and would never be able to drive. My father held his anger but, from
that moment on, conversations with her were merely perfunctory. I
wish the nurse would have not focused so much on “truth-telling,” and
focused instead on addressing his loss (You really must miss driving) or
assess for any unfinished business (If you could drive, where would you
like to go?).
Open communication requires understanding the reality of *middle knowledge* (Weisman, 1972). Middle knowledge means that while most patients recognize that they are dying, responding to both internal and external cues as well as their own knowledge, they often drift in and out of the awareness. Sometimes they will acknowledge the situation, other times they choose to ignore the closeness of death. Understanding middle knowledge means that clinicians recognize that individuals who are dying will choose the times, places, and persons with whom they share their questions and concerns.

**INTERVENTION STRATEGY**

When Mr. Martinez’s family made the request for nondisclosure, the hospice team first convened a meeting with an ethics consult to discuss the family’s concerns and needs. They then invited Mr. Martinez’s family to a meeting with the hospice team. Family members who attended included Mr. Martinez’s wife, two daughters, a son-in-law, and Mr. Martinez’s brother, Father Joe. The family expressed a concern that if Mr. Martinez knew he was dying, he would lose all hope, withdraw from the family, and die more quickly. While Father Joe functioned as the family spokesperson, it was evident that he felt somewhat discomforted by the family’s position.

The hospice team first carefully listened to the family’s concerns and validated their caring. The team then shared their own philosophy of open communication. They assured the family that they would address prognosis only if and when Mr. Martinez brought up the issue, after carefully exploring his questions, and with the aim of continuing a dialogue until his concerns were met. Throughout this process, Father Joe acted as mediator, reminding his family that past work with hospice patients gave him great confidence in the care this hospice could provide. The team suggested a follow-up meeting in two weeks; although tentative, the family agreed, and hospice services were started.

Mr. Martinez politely declined chaplaincy services, proudly affirming that his spiritual needs would be taken care of by his “kid brother, who is also a wonderful priest.” Mr. Martinez was quiet and rarely asked questions or expressed needs to his social worker, nurse, or physician.

Family members seemed guarded around the professional staff; however, the team discovered that Mr. Martinez had had extensive
conversations with Anita, his home health aide, about his concerns for his family after he died. Father Joe later found out that the aide possessed two attributes that facilitated conversation: as a Puerto Rican native, she was fluent in Spanish, and the family often used the time that she was there to do chores, allowing Mr. Martinez and Anita time to talk alone. Father Joe realized that while his brother was aware of his prognosis, he found it difficult to discuss death with his family, and sought to protect them.

At the second meeting with the hospice team, both Mr. Martinez and Anita participated. Hearing this, the family realized that they, too, could more openly address issues related to dying. The hospice also provided a Spanish-speaking nurse, adding another level of comfort. While discussions of death never predominated, it was no longer a taboo topic. In fact, Mr. Martinez and his brother began to plan his funeral, sometimes even making jokes about the plans. Within 10 weeks of entering hospice, Mr. Martinez died peacefully with his wife and brother by his side.

CONCLUSIONS AND REFLECTIONS

The story of the Martinez family reaffirms that cultural issues can play a large role in both the acceptance of hospice care and the way dying is viewed and discussed. The fact that Mr. Martinez accepted hospice care is interesting, as Hispanics and Latinos, especially first generation, are underrepresented in hospice (Talamantes et al., 2000); recent data shows that only 7.1% of hospice patients were of Hispanic or Latino origin (NHPCO, 2015). Having literature, community liaisons, and staff that can communicate in the language of varied cultures within the community, as well as sensitivity to cultural nuances around death and dying, are essential for outreach into underserved populations.

Cultural sensitivity training of hospice teams should include home health aides, often representative of these same underserved populations. As with Anita and Mr. Martinez, home health aides often develop close relationships with patients and may therefore have critical information that the patient has only shared with them. This situation is reflective of the Hispanic cultural value of personalismo, which places a high value on personal relationships and mutual disclosure; families may be intimidated by doctors and nurses, in part because the time they spend with the patient may focus primarily on medical issues and may therefore be perceived as somewhat distant.
Another important point is that there is a difference between truth-telling and open communication. Hospices should train staff in the open communication approach, as it is sensitive to cultural differences and constraints regarding conversations about death. This approach is also consistent with middle knowledge, offering patients control of whether, when, how, and with whom they choose to communicate their fears and anxieties about death.

It seems clear that hospices can function most effectively when there is open communication among patients, families, and staff. If families wish to deny or discourage an open communicative process, it is difficult to see how effective care can be offered. In such circumstances, hospices should decline care in all but the most extraordinary situations, such as a patient's extreme anxiety or diminished capacity to process such information. Open communication, after all, is the gold, silver, and bronze standard of care.

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**REFERENCES**


