Wishes Left Unspoken: Engaging Underserved Populations in End-of-Life Advance Care Planning

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Abstract: The end of life can be a highly emotional and difficult time for patients and their families. Advance care planning for end-of-life care is one option for helping to mitigate the burden of this experience. Despite its advantages, gaps in end-of-life advance care planning participation persist, particularly among underserved segments of the U.S. population who might benefit from it. This column highlights barriers to end-of-life advance care planning among medically underserved populations and discusses opportunities for greater engagement.

The Case of Mr. Martin

Mr. Martin is a 65-year-old patient with hypertension, diabetes, peripheral vascular disease, and end-stage renal disease requiring dialysis. Mr. Martin has had several dialysis access difficulties since starting dialysis 20 years ago. He now has lost his dialysis access; permanent surgical access is not an option for him due to severe peripheral vascular disease. In addition, Mr. Martin has had multiple hospitalizations in the last six months due to line sepsis, which has been complicated by poorly controlled Type 2 diabetes, despite adherence to a restricted diet and medication regimen.

Mr. Martin presents to a health care facility with a fever, an altered mental status, elevated serum creatinine, and peripheral edema. Family—his wife, two daughters, and son—are present at the bedside. There is discord among family members about how to proceed with Mr. Martin’s care. Mr. Martin’s wife speaks limited English. His eldest daughter is adamant that she knows what her father would want, which would be “to let him go.” Mr. Martin’s wife and other children are in sharp disagreement with this and want “everything done to save him.” They have never had a discussion about end-of-life care options with Mr. Martin, among themselves, or with a health provider.
There are countless Mr. Martins in America today. Due in part to the persistence of chronic disease-related morbidity and mortality, health care providers, patients, and families are often faced with tough decisions regarding end-of-life care. A small proportion of Americans have even discussed or reached consensus on these choices prior to the end of life. Mr. Martin's family members were confident that they knew the best course of treatment, but what would Mr. Martin himself have wanted? His wishes were unrecorded. Advance care planning for end-of-life care is one option for helping to mitigate the burden of this difficult experience. Despite its advantages, end-of-life advance care planning is underutilized, particularly among medically underserved segments of the population.

Planning for End-of-Life Care

End-of-life care planning is a process of communication between an individual, his or her family members, and health care providers to ensure end-of-life health care is consistent with the patient's preferences and values. This process typically results in a written instructional advance directive executed by a competent person that reflects his or her values and preferences in the event he or she becomes incapacitated (e.g., do not resuscitate order, health care proxy/health care power of attorney, living will). One advantage of end-of-life advance care planning is the opportunity for patients and their providers to engage in a collaborative health care decision-making process, which empowers patients, giving many a sense of control over their health care decisions. Individuals and their families are also afforded an opportunity to express their culture or religious beliefs, values, and views about treatment before a crisis occurs, which helps in preventing unguided and culturally unacceptable care decisions at the end of life.

Although end-of-life advance care planning offers individuals an opportunity to express their health care wishes, these wishes are left unspoken for 70% of Americans. Despite the passing of the 1990 Patient Self-Determination Act, which requires hospitals, long-term care facilities, and home health agencies reimbursed by Medicare or Medicaid to inquire about and recognize patient advance directives, and practice guidelines encouraging advance care planning, it is a useful, yet underutilized process, particularly among disadvantaged or marginalized groups.

End-of-Life Advance Care Planning among Underserved Populations: Gaps and Barriers

Certain populations who are typically underserved by the health care system—such as low-income Americans, uninsured persons, immigrants, racial and ethnic minorities, and the elderly—experience challenges to accessing patient-centered care. Advanced care planning operates under tenets like those of patient-centered care by affording patients with opportunities to express end-of-life care wishes. Opportunities for such planning should be available equally to all groups.

Gaps in end-of-life advance care planning among racial/ethnic minorities have been attributed to various causes, including a lack of knowledge, language, and other communication deficits, and opposing cultural beliefs and values. People of minority
cultural and linguistic backgrounds engage in advance care planning less frequently than the majority population, prefer family/group decision making as opposed to individual decision making, consider advance directives to be an intrusive legal mechanism that interferes with their responsibilities as family members to care for their loved ones, indicate preferences for life-prolonging treatment to be administered regardless of their illness state, and are less trusting of health care policies and the health care system. Given historical accounts of exploitation, experimentation, and stigmatization in the U.S. medical system, vulnerable populations may fear that the health care system has ulterior motives when raising issues of end-of-life care.

Furthermore, hospice and palliative care, which are valuable end-of-life care and support services, are underutilized by many underserved groups. In 2009, less than half (41.6%) of all deaths involved patients who were under the care of a hospice program and only 19.5% of hospice patients identified themselves as non-White. On average, minority populations use these services less frequently than Whites. Many patients and their families are simply unaware that these services are available, which can result in more costly health care at the end of life. In co-author Dr. Hine's practice experience in Atlanta, more often than not, lack of hospice utilization among her patients is due to unawareness of hospice and palliative care as an option for care and, in some instances, patients and families assuming that this care was reserved for people with certain conditions (e.g., cancer or AIDS). The onus is on health care providers to identify and implement successful practices to educate patients and their families from traditionally underserved populations about hospice and palliative care services when planning for end-of-life care.

The Cultural Challenge

 Approaches to death and dying differ significantly across languages, cultures, ethnicities, and socioeconomic status. Simultaneously, these factors can represent unique expressions of grief and celebrations of life, but can also present themselves as barriers to engaging in end-of-life advance care planning or the utilization of end-of-life care services such as hospice or palliative care. Successful inclusion of these groups in end-of-life advance care planning requires the acknowledgement of key barriers to involvement and the implementation of directed efforts toward a culturally inclusive approach to end-of-life decision making. In order to achieve this, culture must not be viewed as a barrier; instead, practitioners should look to culture for all the richness it can add. Culture and the context of patient experiences deserve acknowledgement, respect and integration into the end-of-life advance care planning process. This is the true meaning of patient-centered care.

To ensure high quality care for all patients, health care providers must actively seek to learn how cultural factors influence patients’ health beliefs, behaviors, and responses to medical issues. Cultural competence in health care refers to both a strategy for reducing racial/ethnic disparities in access to health services for all patient populations, and the ability of the health care system to provide high quality care to patients with diverse values, beliefs and behaviors; this includes tailoring care delivery to meet patients’ social, cultural and linguistic needs. For example, the complexity of
multigenerational relationships in a family of Latino immigrants—often encompassing varying attitudes and beliefs, familiarity with the U.S. health care system, and language needs—can pose challenges to end-of-life planning and care. However, acknowledging and accommodating such variables is a critical part of delivering culturally-competent patient-centered end-of-life care.

Opportunities for Increased Engagement of Underserved Populations in End-of-Life Advance Care Planning

Engaging patients in advance care planning is a responsibility that we encourage all physicians and health providers to readily accept. By planning for care in advance, providers can better avoid over- or under-treating patients, and more efficiently utilize care resources. We can increase engagement by encouraging all patients, regardless of race, ethnicity, age, or health status, to reflect on and express their values and vision of what an acceptable quality of life is, and by ideally initiating such discussions with patients prior to the time of hospitalization, critical illness, or injury. A commitment to open communication by reviewing goals for care and treatment preferences with patients periodically, as well as during times when significant changes in personal or health status occur, is essential. The opportunity to engage underserved populations in this process must be seized.

Practice Considerations

Health care providers often experience an imbalance between time and responsibilities, which can translate into lower quality care for underserved populations. Failure to integrate end-of-life discussions into medical encounters, particularly among those with chronic, life-limiting illnesses, may lead to suboptimal care experiences for patients and their caregivers as their disease progresses. These discussions can and should effectively be integrated into daily patient encounters and transdisciplinary care plan meetings in order to help patients and their loved ones fully understand their options and the implications of their choices.

We offer the following recommendations for better end-of-life advance care planning engagement:

1. Identify easy-to-use, evidence-based resources that can be easily implemented into your practice models. Care models and practice tools have been developed to assist providers with effective implementation. One such tool, PREPARE, is a free, five-step, publicly accessible online advance care planning tool that teaches individuals the skills to prepare for communicating their end-of-life wishes with their families and providers, and how to make end-of-life decisions by taking into account cultural and individual needs, preferences, values, and beliefs. PREPARE was developed based on research that emphasizes the importance of documenting end-of-life preferences. Such documentation is a process that includes 1) identifying an individual’s past experiences with illness and medical decision-making; 2) identifying an individual’s definition of quality of life; 3) helping patients iden-
2. Engage in continuing education and professional development. As clinicians, our professional ethics require us to engage in continuing education to best serve our client populations. Advance Care Planning: An Introduction for Public Health and Aging Services Professionals, is a free, self-paced online course designed to prepare providers help patients and their families understand the advance care planning process and document their end-of-life preferences accordingly. In three modules, providers learn about the importance of advance care planning, are introduced to the essential elements of the advance care planning process, and identify ways to start the conversation with patients and their families. This course also provides an overview about state-to-state laws and requirements. Drawing upon such resources, providers can extend end-of-life advance care planning’s reach to patients unfamiliar with this process.

3. Establish a professional standard for cultural competency. Engaging underserved populations in end-of-life advance care planning in a manner that respects and embraces cultural differences is critical. It would be nearly impossible for any one individual provider to know the cultural mores of every patient s/he encounters; however, we as providers can commit to achieving a level of cultural competence that enables us to have constructive conversations about death and dying in the cultural context of the patient. We can start by asking ourselves these questions: 1) What are the patient’s and family’s views of death and dying? and, most importantly, 2) What are the patient’s wishes for care at the end of life? Other critical questions include What are the cultural rituals for coping with the dying, the deceased person’s body, and for honoring the death? and What are the family’s beliefs about what happens after death? Subsequently, we can execute coordinated efforts to uncover the answers to these questions through patient and family engagement. While no single standard approach to this topic exists, the process of providing services in a culturally competent manner can be initiated by gaining some knowledge about the culture’s health-related beliefs. Further, by considering how our own cultural beliefs and practices may influence the care we provide, not assuming that all patients conceptualize the end of life in the same way, and demonstrating cultural humility, or a long-term proactive commitment to engaging and empowering patients to become active partners, health providers can lastingly connect culture to care.

4. Pay careful attention to language, words, and terminology. Greater attention to detail is needed for the wording of advance care planning forms, as an unintended consequence is having these forms become a barrier to underserved populations due to limited literacy or understandability, or non-inclusivity. Assistance with forms should be provided as needed and adaptations may be necessary to enable the clear expression of wishes based upon religious, cultural, or social preferences. People for whom English is not the primary language require access to end-of-life forms and materials in their native language, as well as to an interpreter. For persons of lower educational attainment or inadequate health literacy, visual...
aids may be a useful communication tool, as they have been shown to increase comprehension and understanding of medical information.\textsuperscript{26}

5. \textit{Use a transdisciplinary, team-oriented approach to end-of-life advance care planning.} Utilizing this approach may help to engage patients from diverse backgrounds. If we assume that only one member of a health care team or one clinical discipline is responsible for addressing this issue with patients, then the risk of marginalization is great. It is important to remember that patients and their families are valuable members of the health care team, and should always be included in care plan meetings.\textsuperscript{27} Additionally, through inclusive and collaborative efforts, such as empowering grassroots community engagement campaigns, health care teams may more effectively promote the initiation of end-of-life care discussions.\textsuperscript{28}

\textbf{Conclusion}

Planning for end-of-life care is indeed a public health issue because of its potential to prevent unnecessary suffering and to support an individual's decisions and preferences related to the end of life.\textsuperscript{29} Throughout his illness, Mr. Martin encountered numerous health professionals, all of whom were aware of his deteriorating health, but never initiated end-of-life advance care planning with him or his family members. The opportunity for Mr. Martin to express his wishes and to develop a plan with his family and health care team was missed entirely. By establishing shared practice goals in this area, along with a shared commitment to actively engaging traditionally underserved populations in end-of-life advance care planning, health care teams everywhere can improve the end-of-life care experiences of countless patients and their loved ones.

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\textbf{Notes}


