

# Cultural diversity and barriers to high-quality end of life care

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*Provenance:* This is a Guest Editorial commissioned by Section Editor Qing Ma, MD (Department of Oncology, the General Hospital of the Tianjin Medical University, Tianjin, China).

*Comment on:* Periyakoil VS, Neri E, Kraemer H, *et al.* Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study. *J Palliat Med* 2016;19:373-9.

Submitted Sep 02, 2016. Accepted for publication Sep 02, 2016.

doi: 10.21037/apm.2016.11.01

**View this article at:** <http://dx.doi.org/10.21037/apm.2016.11.01>

Dying in America, the Institute of Medicine's (IOM) comprehensive report (1), addressed the state of the US health care system regarding end of life (EOL) care, and pointed out multiple deficiencies. While most Americans prefer to die at home and have control over their health care decisions, this is not the case for many patients. The report also pointed out the increasing cultural diversity of the US population and barriers of access to palliative care faced by minority patients and their families. The IOM report put forward many recommendations to improve EOL care, including the provision of patient-centered/family-oriented palliative care, improving communication including advanced care planning, educating clinicians about palliative care and increasing public information/participation in EOL care. The report also recommended the restructuring of the US payment system and policies to support palliative care provision (1).

What constitutes high quality EOL care is not clear. Improving pain and other symptoms, addressing emotional and other distresses of patients and families, and avoiding heroic interventions at the EOL were suggested, but a Cochrane Database systematic review found that there was limited data on what constitutes an effective EOL pathway (2,3). However, there is some agreement that poor care criteria does include dying in hospital, particularly in intensive care units and frequent hospitalizations towards EOL (4).

Over the last two decades, the number of hospices and hospital-based palliative care services has increased. Currently, over 6,000 hospices are functional in the US (3).

However, the time spent receiving palliative care is shortening, and the median length of stay in hospices is less than three weeks. In some conditions such as cancer, this may be due to the availability of more therapies. This short period isn't enough to reap the full benefits of hospice care. Minority patients in particular are less likely to enroll in hospice, and more likely to die in hospitals. There is paucity of research on the reasons for this disparity. However, late diagnosis, lack of insurance and cultural issues could be possible factors.

Periyakoil and colleagues tried to address this problem in their article published April 2016, in the *Journal of Palliative Medicine* (5). They aimed to identify the barriers to EOL care that are faced by multi-ethnic, multi-lingual patients. They conducted a cross-sectional study on people aged 50+ from different racial and ethnic groups including Asian Americans, Caucasians, African American and Hispanics in the San Francisco, California and surrounding areas during the year 2013–2014. Other demographic information collected included marital status and educational level. Medical interpreters were utilized to ensure full understanding of the questionnaire given. The study utilized two cohorts, a development (n=72) and a validation (n=315) cohort. In the development cohort, two open ended questions were asked: whether receiving high-quality EOL care is important to the participant, and to list the top three barriers (if any) the participant or people from their culture have faced in receiving high-quality EOL care. Fifty transcripts were randomly selected, and the codes that emerged were compared to the six initial barriers described

by the development cohort. They conducted qualitative and quantitative analysis to verify and rank the responses. The barriers in receiving high quality EOL care were: financial/health insurance barriers, doctor behaviors, communication chasm between patients and doctors, family behaviors and beliefs, health care system barriers and cultural/religious barriers. However, the study did not compare the responses from the minority patients to those of the Caucasian group. Further analysis of the responses in this study needs to be done to determine if there truly was a divide between ethnic/racial groups.

The study by Periyakoil *et al.* (5) highlighted the major need for research which was represented in the consensus of all patients, identifying that high-quality EOL care is important to them and their communities. Furthermore, 60.6% (n=191) of patients identified that there were indeed obstacles in receiving this care. According to the 2015 National Healthcare Quality and Disparities report (6), although filling the gaps in the disparity between healthcare for minorities is progressing in some areas, these gaps still remain throughout all measures of access. They found that there still seems to be a divide in quality of healthcare, and the largest discrepancy was fundamentally the access to healthcare. In terms of access measures, minorities consistently were grouped in the “worse” category (7), and in terms of quality of care, minority patients report poor care in 40% of measures.

Financial/insurance issues were reported as the main barrier in the study by Periyakoil *et al.*, particularly in patients without formal education. Formal education can be correlated with income level as represented in the National Center for Educational Statistics’ analysis of a report of G-20 countries, which concluded that higher levels of education were associated with higher income (8). This agrees with the 2015 National Healthcare Quality and Disparities report, where one aspect remained the common denominator, the level of income. People in poorer households consistently had inferior quality and access to healthcare. This could also reflect on the premise that many minorities live in poverty or that poverty will reflect the same challenges in any racial circle. This consensus is ironic due to research showing that EOL care, including advanced care planning, can significantly reduce the cost of health-care by avoiding ineffective and unneeded interventions (1). Furthermore, hospice care can be free for those who cannot afford it. As a result of the lower socio-economic status of these patients and their lack of medical care, they present to hospitals at the EOL and receive aggressive care including intensive-

care unit admission which subsequently leads to in-hospital mortality (8).

Communication is a recurring barrier that deals with several aspects of patient relationships in the study by Periyakoil *et al.* Interestingly, doctor behaviors was cited as the most important barrier for patients and families within the educated groups. These behaviors were described as “insensitive” “lacking empathy”, “vague” “unaware”. They conveyed a certain reluctance and frustration on the patient’s part to make what are essentially uninformed decisions influenced by cultural/spiritual beliefs that doctors may not be privy to. On the other hand, what patients perceive as a lack of interest may be the doctor’s own perception of doing no harm, such as the psychological harm (9) that can be caused by untrained individuals initiating these conversations. Consequently, this avoidance on both parts may likely be driving the frustration that patients feel in not receiving the EOL care they desire, and the physician’s similar frustration with ineffectively trying to prolong life (10). Therefore, the EOL care discussion is a crucial part of a physician’s training to handle these situations.

Additionally, religious/spiritual beliefs can be difficult for a physician to navigate through due to these topics being taboo in clinical settings. One’s perception of God and the afterlife or suffering as karma (11) can lead to a tense atmosphere of different backgrounds representing deeply engrained belief patterns of the patient, their family and also the physician (12,13). It is likely that utilization of a well-trained multi-disciplinary team is needed to overcome these cultural and religious barriers.

Furthermore, Periyakoil *et al.* took into account the extreme emotional burden put on patients and their families. These patients expressed lack of control over final decisions and surrogates making decisions for personal reasons such as overriding the patient’s wishes due to a perceived sense of guilt, needed closure, and religious or cultural reasons. The patients in the multi-ethnic study described situations where they underwent ineffective interventions to appease the family members’ wishes of prolonging life, and not their own wishes. Therefore, it is essential to collaborate with patients, doctors and their families to determine realistic and satisfactory EOL care goals, ideally with the patient as the primary decision maker (14).

The communication chasm between doctors and patients was the second most common barrier found between all levels of education in this study, and the third overall biggest barrier (5). In order for patients to take control of their EOL care, there needs to be an atmosphere of shared

decision making (15). Periyakoil *et al.* reflected that the patients in the study stated they were limited by health literacy issues and limited English proficiency (LEP). These are major hurdles to overcome, as complex situations can get lost in translation from the physicians to patients. Silva *et al.* showed that the use of professional interpreters resulted in better quality EOL care to LEP patients (16). However, the fundamental issue is that of doctors not transmitting crucial information, or patients not receiving it owing to the higher likelihood of minorities and people without formal education having poor health literacy (17). These discussions continue to center around the issue of training doctors in communication and health literacy training as part of community health promotion (18).

In conclusion, the study by Periyakoil *et al.* further supports the recommendations in the IOM report, Dying in America (1) and highlights challenges facing the US health-care system. Improving communication could play a major role in improving the care of these patients, preventing costly and wasted resources, decreasing the financial burden on patients and their families, in addition to preventing “false-hope” which further distresses the already difficult predicament of accepting the EOL and dying on their own terms (9). Further studies should address certain interventions to improve care for underserved and minority patients.

## Acknowledgements

None.

## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

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**Cite this article as:** Abunafeesa H, Elsayem AF. Cultural diversity and barriers to high-quality end of life care. *Ann Palliat Med* 2017;6(2):183-186. doi: 10.21037/apm.2016.11.01