

# Quality of end-of-life care: how far have we come in addressing the needs of multicultural patients?

Karl A. Lorenz<sup>1,2</sup>

<sup>1</sup>VA Palo Alto Healthcare System, Palo Alto, CA, USA; <sup>2</sup>Department of Medicine, Stanford University School of Medicine, Palo Alto, CA, USA

Correspondence to: Karl A. Lorenz, MD, MSHS. Department of Medicine, Stanford University School of Medicine, 1265 Welch Road, Palo Alto, CA, USA. Email: kalorenz@stanford.edu.

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

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In an important foundational study, in 1995 Blackhall *et al.*, identified divergent preferences and approaches to decision making among 200 Korean, Mexican, African, and European-Americans surveyed at 31 senior centers in the cultural mix of Los Angeles (1). Participant groups differed with minority groups compared to European-Americans favoring nondisclosure *vs.* disclosure of diagnoses and group *vs.* individual approaches to decision making. Since the 1990's substantial research has delved into many aspects of diversity and patient-provider communication, but there are persistent gaps and challenges in the provision of end of life care across diverse racial and cultural groups (2), and we need a more complete lens for understanding and addressing disparities in end of life care as suggested by a recent publication.

Using similar methods at community centers to conduct open ended surveys of 387 Asian, Hispanic, African, and Caucasian Americans in the San Francisco Bay Area, Periyakoil *et al.*, identified barriers to "effective end of life conversations" with their doctors. These concerns fell into the following domains of financial/health insurance, doctor behaviors, communication chasm between doctors and patients, family beliefs and behaviors, health care system barriers, and cultural/religious barriers. Specific impediments to end of life conversations included being uninsured, out of pocket costs, personal finances, access to physicians, interpersonal communication, language diversity, family dynamics, aggressive medical culture, and religious and cultural preferences (3).

Although there are many and important gaps in the acts of communication (4), a recent informative study of end of life processes and outcomes in the Department of Veterans Affairs (VA) found that the families of African American Veterans reported poorer communication experiences than whites, despite equal processes of care (5). A previous regional study found greater disparity in communication sensitive processes than medically sensitive processes among Veterans (6). The VA in many ways exemplifies equal access to care, and the persistence of end of life disparity points to profound cultural issues that color both delivery and perceptions about end of life care. Other reports show that non-white patients and families rate end of life care differently than whites (7) and confirm that we need not only more communication, but novel, culturally sensitive ways of communicating (8).

Other studies including Periyakoil *et al.*'s, highlight additional, diverse structural and individual dimensions to this problem including low socioeconomic status (9), yet we still lack a well formulated effort to characterize the independent contributions of the full range of these issues. Nearly two decades ago in California, we described variation in the hospice services available to patients that might help to improve access and outreach to ethnically diverse Californians, and similar variation has recently been described elsewhere (10-12). The types and numbers of problems highlighted by existing literature suggests that we should apply comprehensive models like the modified Anderson framework to encompass the complexity and

evaluate the multiple levels and issues that may be salient to promulgating disparities in palliative and end of life care (13). Furthermore, there is likely some finesse in applying these issues depending on context (e.g., challenges in the community *vs.* the hospital).

Not only are there shortcomings in the provision of care among culturally diverse Americans at end of life, but many members of these communities also experience the outcomes of potentially burdensome overuse of care. Studies have generally found nearing the end of life, that minorities compared to whites have more costly care in addition to a greater likelihood of experiencing potentially inappropriate or burdensome care such as prolonged intensive care unit stays or end of life chemotherapy very close to death (14). A series of studies examined intensive end of life healthcare use among patients with cancer and found that controlling for race and ethnicity, positive religious coping was associated with greater likelihood of intensive therapy (15).

Efforts to narrow disparities in palliative and end of life care have received relatively little attention. Our team recently completed a systematic review of randomized controlled trials (RCTs) conducted and published since 2000 that address palliative care or hospice service delivery interventions to improve quality of life relevant outcomes including communication. Despite identifying 124 RCTs from the United States and Europe that addressed these goals during the last decade, none had as a primary aim the goal of narrowing disparities, nor did they report meaningful differences in efficacy or effectiveness among culturally diverse populations (16). We need a significant investment to build evidence based of the highest quality studies identifying, evaluating, and implementing effective interventions to address the problem.

A potentially concerning context for Periyakoil's study and our need for greater understanding and progress in narrowing end of life disparity is the recent institution of the California Aid in Dying Act. This act made access to prescriptions and assistance for ending one's life legal in California as of June 9, 2016. Will this act foster mistrust in palliative care and hospice among diverse communities struggling to achieve equal access to good end of life care? Conversely, will it spur innovation, attention, and efforts to narrow the gap among diverse communities in palliative and end of life care? And how will we monitor the outcomes and impact of this and other policy efforts including the Affordable Care Act on palliative and end of life care in California and other states?

More than ever we need studies that help us to think comprehensively about the complexities of the issue of delivering palliative and end of life care to diverse communities, that identify the most salient, feasible, and culturally acceptable solutions, that elucidate meaningful and effective interventions to improve both processes and outcomes of palliative and end of life care, and that are feasible to implement at the provider, system, and policy levels. The situation is urgent especially as pressures grow to reduce costs, and the risks of social inequity and impacts on patients, families, and caregivers rise. We need to pinpoint the most promising areas to move forward with immediately. The challenges highlighted by Periyakoil's study are likely to become more widespread with growing diversity elsewhere in the United States, and hopefully will be accompanied by growing competence in addressing the accompanying challenges.

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### Footnote

*Conflicts of Interest:* The author has no conflicts of interest to declare.

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