Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study

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Abstract

Objective: The study objective was to empirically identify barriers reported by multiethnic patients and families in receiving high-quality end-of-life care (EOLC).

Methods: This cross-sectional, mixed-methods study in Burmese, English, Hindi, Mandarin, Tagalog, Spanish, and Vietnamese was held in multiethnic community centers in five California cities. Data were collected in 2013–2014. A snowball sampling technique was used to accrue 387 participants—261 women, 126 men, 133 Caucasian, 204 Asian Americans, 44 African Americans, and 6 Hispanic Americans. Measured were multiethnic patient-reported barriers to high-quality EOLC. A development cohort (72 participants) of responses was analyzed qualitatively using grounded theory to identify the six key barriers to high-quality EOLC. A new validation cohort (315 participants) of responses was transcribed, translated, and back-translated for verification. The codes were validated by analyses of responses from 50 randomly drawn subjects from the validation cohort. All the 315 validation cohort transcripts were coded for presence or absence of the six barriers.

Results: In the validation cohort, 60.6% reported barriers to receiving high-quality EOLC for persons in their culture/ethnicity. Primary patient-reported barriers were (1) finance/health insurance barriers, (2) doctor behaviors, (3) communication chasm between doctors and patients, (4) family beliefs/behaviors, (5) health system barriers, and (6) cultural/religious barriers. Age ($\chi^2=9.15$, $DF=1$, $p=0.003$); gender ($\chi^2=6.605$, $DF=1$, $p=0.01$); and marital status ($\chi^2=16.11$, $DF=3$, $p=0.001$) were associated with reporting barriers; and women <80 years were most likely to report barriers to receiving high-quality EOLC. Individual responses of reported barriers were analyzed and only the participant's level of education (Friedman statistic = 2.16, $DF=10$, $p=0.02$) significantly influenced choices.

Conclusion: Multiethnic patients report that high-quality EOLC is important to them; but unfortunately, a majority state that they have encountered barriers to receiving such care. Efforts must be made to rapidly improve access to culturally competent EOLC for diverse populations.

Introduction

TOO LARGE A GULF EXISTS^{1–3} between the health care Americans want at life's end and what actually occurs. A vast majority of patients^{1,4} say that they wish to avoid ineffective, high-intensity care and prefer to die gently and naturally, but their wishes are often overridden. National data^{4–6} show that the end-of-life care (EOLC) patients receive depends not on their wishes or their advance directives (ADs), but rather on local health care system variables like institutional capacity and individual doctors' practice style. Thus a big percentage of the 2.6 million Americans who die every year⁷ spend the last phase of their lives beset with repeated hospitalizations, subjected to ineffective and burdensome high-intensity treatments at great human cost. The cost to the

nation is not trivial either. U.S. health care spending, which is already extremely high, is projected to escalate further.⁸ Better outcomes are not associated with higher costs.^{1,2} Judicious curbing of costs in the end-of-life (EOL) arena, by avoiding ineffective treatments that patients and families do not want, will allow¹ for redirecting of resources toward vital services like caregiver support and other basic care needs specifically tailored to increase quality of care for all seriously ill persons.

Health disparities persist well into EOL^{9–13} with seriously ill ethnic minority patients being disproportionately affected by poor-quality care. The United States is poised to become a minority majority nation in 2044.¹⁴ Thus the need to ensure culturally competent, high-quality EOLC for diverse Americans is not only a national priority but also perhaps the

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largest public health crisis looming over our nation. This multilingual, mixed-methods study¹⁵ was conducted to determine if multiethnic patients and families valued high-quality EOLC and if they had encountered barriers to such care for persons within their racial/ethnic community.

Methods

Study sample

Multiethnic people from five cities (Fremont, Palo Alto, San Francisco, San Jose, and Walnut Creek) in California participated in a cross-sectional survey; data were collected from calendar years 2013–2014 and analyzed in 2014–2015. Participants were recruited from community-based centers using a snowball sampling technique.

Data collection

The questionnaire was administered once. No personal health identifiers were collected in an effort to promote participant confidentiality and honest responses without concerns about individual scrutiny. In order to ensure ease of participation for patients with Limited English Proficiency (LEP), the study was conducted both in English and their primary language. Medical interpreters were available to help LEP patients. Stanford University's institutional review board approval was obtained to conduct the study and analyze the data presented in this paper. These are the open-ended triggers used in data collection:

- Is receiving high-quality EOLC important to you?
- Please list the top three barriers (if any) you and people from your culture, race, and ethnicity face/have faced in receiving high-quality health care at the EOL?

Study phase 1

The objectives of this development phase were (1) to ensure the relevance of the research question to patients and families and (2) to identify common barriers (if any) patients identify in having effective EOL conversations with their doctor with the purpose of code development by qualitative analyses. A sample ($n=72$ persons) of community dwelling persons (23 men and 49 women, 16 Caucasian, 6 Hispanic, 6 African Americans, and 44 Asian Americans) was recruited and served as the development cohort. All participants in the development cohort felt that receiving high-quality health care at the EOL was an important priority for them. Of the development cohort, 27.8% ($n=20$) denied having any barriers and 72.2% ($n=52$) reported encountering barriers to receiving high-quality health care at the EOL.

The open-ended responses by the 52 participants of the development cohort who reported barriers to receiving high-quality EOLC were transcribed, coded, and analyzed using Microsoft Access and NVivo 7 (QSR International Pty Ltd., Melbourne Australia). Grounded theory techniques^{16–17} of intense open and axial coding were used to identify key barriers reported. First, using an open-coding approach, one of the authors (VSP) and a trained research assistant independently coded the transcripts of the development cohort. During open coding, recurrent barriers were identified and characterized. During axial coding, the barrier categories were further defined and the relationships between them were

characterized. Next, the coders compared their assignment of codes, and a third investigator (HCK) mediated any discrepancies between codes assigned until agreement was reached. Efforts to maintain the validity of the qualitative data included the following: to evaluate inter-coder reliability, the exact assignment of codes was assessed for 100% of the development cohort transcripts; agreement was found to be greater than 90%,^{18–19} which was comparable with previous work. After 30 transcripts had been coded, no new codes emerged from the next five transcripts (data saturation had been reached). To confirm data saturation, the remaining 22 transcripts in the development cohort were coded, with no new code labels emerging. At the end of this process, six primary patient-reported barriers to high-quality EOLC were identified. The development cohort was discarded and not used in phase 2 of the study.

Study phase 2: Study sample and data collection

The validation cohort consisted of 315 multiethnic participants 50 years and older (see Table 1 for demographics). The trigger questions (see above) were administered to participants in English or in their preferred language. The questions were translated and back-translated to ensure accuracy by medical interpreters into Spanish and several Asian languages (Burmese, Hindi, Mandarin, Tagalog, and Vietnamese). Trained interpreters were available on site at the community centers to assist participants with Limited English Proficiency (LEP) who needed any help with survey completion. Participants had an option to respond to the survey questions either in their native language or in English. Participant responses in various languages were translated and verified by professional medical interpreters and transcribed. Demographic

TABLE 1. DEMOGRAPHIC CHARACTERISTICS SHOWING VALIDATION COHORT PARTICIPANT GENDER, AGE, AND RACE/ETHNICITY

Demographic	N	%
Gender		
Female	212	67.3
Male	103	32.7
Age		
50–59 years	70	22.2
60–69 years	87	27.6
70–79 years	65	20.6
≥80 years	93	29.5
Race/ethnicity		
African American	38	12.1
Asian American	160	50.8
Caucasian	117	37.1
Education		
No formal education	42	13.3
Elementary school	29	9.2
High school	41	13.0
College	99	31.4
Graduate/professional	104	33.0
Marital status		
Married	125	39.7
Single	18	5.7
Divorced	42	13.3
Widowed	130	41.3

TABLE 2. TOP SIX BARRIERS (WITH EXEMPLARS) TO EFFECTIVE EOL CONVERSATIONS WITH DOCTORS ACCORDING TO MULTIETHNIC PATIENTS

<i>Barrier domain</i>	<i>Exemplar</i>
Finances/health insurance barriers	<ul style="list-style-type: none"> • “Lack of access to affordable medical care” • “Lack of finances” • “Lack of health insurance” • “Do not have funds for out-of-pocket expenses for health care”
Doctor behaviors	<ul style="list-style-type: none"> • “Doctors lack empathy” • “Doctors give vague answers” • “Doctors do not listen” • “Doctors’ cultural insensitivity” • “Doctors very busy, not available”
Communication chasm between doctors and patients	<ul style="list-style-type: none"> • “Difficulty understanding medical terms” • “For seniors, inability to hear or comprehend all conversations” • “Lack of knowledge of EOLC options” • “Doctors usually don’t speak the same language and can’t answer questions directly that patients have”
Family beliefs and behaviors	<ul style="list-style-type: none"> • “Wish to avoid family conflicts (if EOL issues are discussed)” • “Family members get too emotional and do not make good decisions” • “Disconnect between individual and family” • “Family believes patient is not that sick” • “Family members may feel people will blame them that they don’t care enough if they concede death is about to happen”
Health care system barriers	<ul style="list-style-type: none"> • “Do not know where to go. It is hard to get an appointment” • “Lack of help to complete medical directives” • “Hospital staff think that they must resuscitate the dying person” • “Medical system insistence on doing everything possible”
Cultural and religious barriers	<ul style="list-style-type: none"> • “Superstition about discussing EOL issues” • “Cultural beliefs/misconceptions about EOL issues” • “Religious belief that it’s wrong (to discuss EOL issues)” • “Cultural bias towards ‘staying alive’ instead of making someone as comfortable as possible when dying”

EOL, end of life; EOLC, end-of-life care.

data (age, gender, ethnicity, level of education, and marital status) were collected, but personal identifiers were not collected in an effort to promote participant confidentiality and honest responses without concerns about individual scrutiny. There was no repeated contact of participants.

Code validation

Of the 315 transcripts from the validation cohort, 50 were drawn randomly and coded independently by the coders (VSP and project RA) for the presence or absence of each of the six primary barriers identified by the development cohort, as well as for any new codes. The two coders then met and compared codes for each transcript and determined that no new recurrent codes emerged and that the six primary barriers identified earlier were sufficient to appropriately code the entire validation dataset.

Qualitative coding of the validation cohort (n=315 subjects)

Next, the validation dataset responses were coded independently by the two coders qualitatively for the presence or absence of the six primary barriers identified by multiethnic patients in conducting effective EOLC with their doctor identified by earlier qualitative analyses using grounded theory methods. The two coders coded the validation cohort responses independently. All discrepancies in codes were

reviewed by both coders with one of the authors (HCK) and debated until consensus was reached (Table 2).

Quantitative analyses of validation cohort responses

The primary six barriers to high-quality EOLC, as identified by each participant, were rank-ordered according to the response (with tie ranks, particularly for those barriers not mentioned). The data were imported into statistical software SAS (SAS version 9.3; SAS Institute Inc., Cary, NC) for quantitative analyses. A variant of the Friedman test²⁵ was used to compare subgroups (age, gender, ethnicity, education level, and marital status) and determine if any of the six primary barriers was ranked consistently higher or lower.

Results

Group differences between patients who reported barriers to high-quality EOLC and those who did not report barriers

All participants in the validation cohort affirmed the importance of receiving high-quality EOLC. Of the 315 subjects in the validation cohort, 124 (39.4%) did not report any barriers and 191 (60.6%) identified barriers to receiving high-quality EOLC for persons in their culture/ethnicity. There were significant differences between the two groups in terms of age (Mann Whitney Wilcoxon $\chi^2 = 9.15$, $DF = 1$, and

FIG. 1. This graphic shows how patients and families of various education levels rate the relative importance of the six primary barriers to receiving high-quality EOLC. The solid line represents persons with no formal education. The dotted line represents persons with elementary or high school education. The dashed line indicates persons with college/graduate/professional education. Primary barriers in rank order of importance with mean rank and SD are barrier 1 (B1): finance/health insurance barriers (mean rank 2.93, SD 1.62); barrier 2 (B2): doctor-related barriers (mean rank 3.46, SD 1.48); barrier 3 (B3): communication chasm between doctors and patients (mean rank 3.46, SD 1.45); barrier 4 (B4) (mean rank 3.58, SD 1.33); family barriers; barrier 5 (B5): health system barriers (mean rank 3.58, SD 1.33); and barrier 6 (B6): cultural barriers (mean rank 3.96, SD 1.16). Patients with no formal education found financial/insurance issues to be most challenging followed by the communication chasm between doctors and patients and health system issues. Patients with any other level of education (elementary, high school, or more) identified doctor behaviors to be their biggest barrier to receiving high-quality EOLC for persons in their culture/ethnicity followed by communication chasm between doctors and patients and health system issues.

$p=0.003$); gender ($\chi^2=6.605$, $DF=1$, and $p=0.01$); and marital status ($\chi^2=16.11$, $DF=3$, and $p=0.001$). A receiver operating characteristic (ROC) analysis was performed to further understand the group differences (if any) that might identify patients who are more likely to report barriers to receiving high-quality EOLC. The ROC found an age and gender interaction with 74.7% of women <80 years of age being most likely to report barriers to receiving high-quality EOLC for persons within their culture/ethnicity/race compared to 48.5% of men <80 years and 42.2% of persons ≥ 80 years.

Next, individual responses for the 191 patients who reported barriers to receiving high-quality EOLC for persons in their culture/ethnicity were analyzed. Only the participant's level of education (Friedman statistic=2.16, $DF=10$, $p=0.02$) had a significant influence on how the participants rated the barriers to effective EOL conversations with their doctor (Fig. 1). The group with no formal education was statistically significantly different ($p=0.01$) from the group with elementary or high school education. Patients with no formal education found financial/insurance issues to be most challenging followed by

the communication chasm between doctors and patients. Patients with any other level of education (elementary, high school, or more) identified doctor behaviors to be their biggest barrier to receiving high-quality EOLC for persons in their culture/ethnicity followed by communication chasm between doctors and patients. There were no significant differences in how patients ranked the magnitude of the barriers based on gender, age, ethnicity, or marital status.

Discussion

All study participants endorsed the importance of receiving high-quality EOLC for persons in their culture/ethnicity/race and a majority (60.6%) reported struggles in doing so. Women from all ethnic groups who were between the ages of 50 and 79 years reported the most struggles in receiving high-quality EOLC. It is likely that women in this age group are most likely experienced in caregiving²⁰ for the seriously ill in their family circle and thus may be more sensitized to the struggles and barriers in accessing high-quality EOLC.

Six primary, multiethnic patient-reported barriers to receiving high-quality EOLC

Barrier 1: Finance/health insurance barriers. Multiethnic patients identified lack of finances and insurance to be the biggest barrier to accessing high-quality EOLC for persons in their culture/ethnicity. In 2012, an estimated 84 million Americans did not have insurance for the full year or were underinsured and unprotected from high out-of-pocket costs.²¹ Forty-three percent of Americans reported cost-related problems getting needed health care. Lack of basic health access continues to plague the poorest²² in the nation and exacerbates the health disparities triggered by the social determinants of health.

Under the current U.S. health system, patients (and families) are liable for the costs of care in part or in full even if the care was ineffective and irrespective of whether they were informed and consenting recipients of such care. Seriously ill patients, who access emergent care at safety net hospitals, are less likely to have access to primary care,²³ less likely to complete advance care planning, and more likely²⁴ to be subjected to ineffective and burdensome treatments. They may be forced to bear the cost of this care either in part or in full, further depleting their meager resources.

A large national study²⁵ identified medical debts to be the largest cause of personal bankruptcies. Having health insurance is only partially protective against medical bankruptcies, as most medical debtors were educated homeowners in the workforce and 75% had health insurance. While the Affordable Care Act (ACA)²⁶ is trying to promote uniform access to health care, it has also proposed to reduce funding to safety net hospitals where the poorest in the nation get their care. Health care needs to be reformed to ensure that diverse Americans receive high-quality EOLC irrespective of their socioeconomic status.

Barrier 2: Doctor behaviors. Our study participants felt that the doctors were just too busy to initiate EOL conversations, reluctant to listen to their concerns and questions about EOL decision making, and often gave vague responses, making it difficult for the patient to comprehend their choices and make informed decisions. EOL decisions are intensely personal and often influenced by the individual's cultural and religio-spiritual beliefs and biases. Patients felt that the doctors¹⁹ were either unaware of or insensitive to their cultural/spiritual needs. This perceived lack of empathy and sensitivity made patients reluctant to voice their values and preferences, causing them to shy away from EOL discussions. While we need to train doctors¹⁹ to communicate with empathy and cultural effectiveness, this is just one part of the problem. The fragmented health system that mainly reimburses doctors for treatments and procedures is the underlying larger problem in urgent need of an solution. Fortunately, effective January 1, 2016, Medicare will pay for 30 minutes of ACP in a physician's office or in a hospital (CPT billing code 99497). In both settings, Medicare will pay for 30 additional minutes of consultation (add-on CPT billing code 99498).

Barrier 3: Communication chasm between doctors and patients. The third biggest barrier identified by our study subjects was the communication divide that exists be-

tween doctors and their patients. The main reasons¹⁹ fueling the communication gap were (1) health literacy issues for most patients and (2) language issues for patients with LEP. Currently, 36% of all Americans have basic or below-basic health literacy. Older Americans are affected disproportionately by limited health literacy in addition to having visual and hearing deficits that make them extremely vulnerable.

In routine medical encounters, the patient's health literacy level, while important, is not critical, as these encounters often do not require that patients make crucial decisions. For example, when getting an antibiotic for an infection, the patient is faced with limited or no choices and much of the patient education emphasis is on the importance of treatment adherence. EOL situations, however, are different in that they require patients to take an active role, partner with their doctors, and make complex and high-risk decisions in the face of an uncertain future. This is best done using a Shared Decision Making (SDM)²⁶ approach, a fact that is recognized by ACA sections 3506 and 3021. In order for SDM to work, doctors and patients need a common vocabulary to discuss complex and sensitive EOL issues. In the event EOLC decisions have to be conducted through a medical interpreter due to a language barrier, the situation becomes inordinately complex. Doctors need to become skilled at explaining complicated medical issues¹⁹ in simple English without losing the underlying nuances and complexity, so that patients can make informed EOL choices. Patients need both health literacy^{27,28} and numeracy skills to meaningfully comprehend the various options available to them. It is important to make health education an integral part of high school education, so that patients are better informed and able to participate in their care.

Barrier 4: Family behaviors and beliefs. Our study participants identified their own family members as a barrier for the patient receiving quality EOLC. Proxy decision makers (health care surrogates) when they disagree with the patient's choices can and do override patients' stated wishes due to (1) love for the patient and not being able to contemplate the thought of losing the patient, (2) a sense of duty to protect the patient from the health care system and ensure that they receive all possible medical treatments available to them, (3) guilt associated with refusing treatments that attempt to prolong life, (4) the desire to have time to repair their relationship before the patient dies, (5) religious/spiritual reasons that discourage treatment refusal, or (6) secondary gain in some cases. Also, in many states, the primacy of the surrogate decision maker is not protected; i.e., other family members and stakeholders can and do override the decisions both of the patient and the designated surrogate, leading to tremendous conflict. As discussions about EOL between the patient and family led to conflicts, our study participants reported that they avoided these discussions. In other cases, our participants reported instances when the family members persuaded the patient to undergo burdensome treatments that the patient did not want but acquiesced just to please their family.

It is vital that patients learn to take the lead on the issue of EOL decision making. While this is no easy task, the physical, emotional, and fiscal toll of not doing so is very high, as patients are at risk for being subjected to ineffective and burdensome treatments³⁰ and procedures that they do not want.

Barrier 5: Health care system barriers. Patients identified two types of health care system barriers: (1) Difficulties accessing services and support for the care they needed: With the growing doctor shortage, accessing medical care can be challenging, especially doctors with palliative skills. (2) Health care culture that is biased towards high-intensity treatments even if ineffective: Patients and families reported that when hospitalized, they were subjected to tests and treatments at a very rapid pace, and that they did not understand what these interventions were intended for. They reported that the hospital staff often felt pressured to try to prolong life even in the face of obvious terminal illness. This resulted in dying patients being subjected to burdensome treatments³⁰ that were ineffective and took an enormous emotional toll on the patient and family.

The ACA has implemented a pay-for-performance program and the Centers for Medicare & Medicaid Services is changing the way Medicare pays for hospital care by rewarding hospitals for delivering services of higher quality and higher value and reducing payments to acute care hospitals with excessive readmissions. This program should also screen for overtreatment of dying patients³¹ (for example, providing chemotherapy for cancer patients with poor functional status who have progression of disease after receiving three consecutive regimens) and reduce payments for such care. All doctors should be incentivized to become skilled in primary palliative care so that they can incorporate palliative principles into their practice.

Barrier 6: Cultural and religious barriers. In many ethnic cultures, death is a taboo topic,¹⁹ as patients and families fear that speaking about death may invoke it. Patients belonging to certain religious and spiritual groups expressed the sentiment that death and dying are in the hands of God and mere mortals should not be speculating about it or tamper with the dying process. Some families reported believing in religious miracles and refused to entertain withdrawal of life support even in imminently dying patients. Others believed in redemptive suffering. Decreasing lifespan by withholding or withdrawing life support was seen as foregoing a God-given opportunity for redemption,¹⁸ and such actions were deemed to be morally problematic. As EOL issues are complicated by a complex interplay of medical, spiritual, and existential issues, we need coordinated efforts of an interdisciplinary team of experts including chaplains and community faith leaders working in conjunction with medical providers.

Our study is unique, as we used mixed methods to better understand a complex and sensitive research question with multiethnic participants. By conducting the study in seven languages and using medical interpreters we were able to engage an otherwise difficult to reach population of ethnic persons with LEP about the sensitive topic of EOLC, which has never been done before to the best of our knowledge. We are limited by the fact that we recruited participants using a snowball technique from only five cities in one state. Also, our study is in part a qualitative study and thus methodologically challenging to conduct nationally. However, it is to be noted that we have followed the consolidated criteria for reporting qualitative research (COREQ)³² guidelines in conducting our study and in reporting our qualitative findings.

Conclusions

Multiethnic patients report that receiving high-quality EOLC is important to them, but also state that persons from their cultural/ethnic/racial group have encountered barriers to receiving such care. We have empirically identified the six primary barriers reported by multiethnic patients preventing them from receiving high-quality EOLC. As the United States is becoming increasingly ethnically diverse and as ethnic patients have been shown to consume ineffective and burdensome high-intensity treatments at the EOL, there is an urgent need to train and support doctors and allied health professionals in conducting culturally effective EOL conversations early in the trajectory of any chronic and serious illness in order to facilitate dignity^{33,34} at the EOL for diverse Americans. There is an equally urgent need to educate and support³⁵ Americans to proactively participate in EOLC planning. Finally, health care payments should be linked to quality of care at the EOL.

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Author Disclosure Statement

No competing financial interests exist.

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