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End-of-Life Concerns and Experiences of Living With Advanced Breast Cancer Among Medically Underserved Women



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Abstract

Context. Breast cancer morbidity and mortality disproportionately affect medically underserved women. Most studies of the experience of living with advanced breast cancer do not focus on this population. A deeper understanding of racial/ethnic minorities' and low-income patients' experiences is needed to reduce breast cancer health and health care disparities.

Objectives. This qualitative, community-based participatory research study explores the lived experiences of medically underserved women with advanced breast cancer.

Methods. We conducted in-depth, semistructured interviews with low-income patients from a community clinic and safety-net hospital, focusing on issues related to advanced breast cancer and end of life. Six team members independently coded transcripts, jointly reconciled coding differences, and identified key themes.

Results. All 63 participants (83% response rate) had an income $\leq 200\%$ of the federal poverty level; 68% identified as a racial/ethnic minority. Four predominant themes emerged: compounding of pre-existing financial distress, perceived bias/lack of confidence in medical care received, balancing personal needs with the needs of others, and enhanced engagement with sources of life meaning.

Conclusion. Participants resiliently maintained engaged lives yet described extreme financial duress and perceived provider bias, which are known contributors to worse quality of life and health outcomes. Participants downplayed their desire to discuss dying to accommodate pressure to "stay positive" and to mitigate others' discomfort. Improving care for underserved women with advanced cancer will require addressing disparities from screening through hospice, developing personalized opportunities to discuss death and dying, and enhancing access to and affordability of medical and social support. *J Pain Symptom Manage* 2019;58:959–967. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Advanced cancer, breast cancer, end of life, underserved, community-based participatory research, qualitative research

Introduction

Although there is increasing focus on health care for patients with advanced cancer and those requiring end-of-life (EOL) care, little is known about the

experience and EOL concerns of medically underserved patients with cancer. Many factors contribute to disparities in cancer care, with low socioeconomic status (SES) and racial/ethnic minority status being particularly well characterized.^{1–5} We conducted a

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community-based participatory research study to examine the experience of medically underserved women living with advanced breast cancer.

Breast cancer is the most frequently diagnosed cancer and the second leading cause of cancer death among women in the U.S.⁶ Breast cancer morbidity and mortality disproportionately affect underserved women. Women with low SES receive less screening mammography,⁷ present with more advanced breast cancer,⁸ receive less effective treatment,⁹ and have lower survival rates.¹⁰ Similarly, racial/ethnic minority women are more likely to face barriers to cancer screening,^{11–13} present with later stages of disease and have lower survival rates,^{10,14} and experience worse health-related quality of life.^{15,16} Emerging evidence likewise shows that minority patients are less likely to complete advanced directives^{17,18} and to receive proper symptom management and are more likely to receive aggressive care in the last six months of life and to die in the hospital compared with white patients.¹⁹ Recent studies reveal the prevalence of these disparities in the specific context of terminal cancer care.^{20,21} Researchers have also documented gender-based health disparities.^{22,23} Minority and low-income women with advanced cancer are thus subject to intersecting systemic injustices.

Despite the impact of these health and health care disparities, research to date has emphasized the experience of white European American, middle-class patients with breast cancer in hospitals and cancer clinics. Of the few studies examining the illness experience of minority women with breast cancer, key findings include the primary role of family and spiritual beliefs and communities as sources of support, increased risk of financial distress and barriers to care, and instances of culturally inappropriate care.^{24,25} These studies do not, however, focus specifically on advanced cancer or EOL concerns. Researchers and clinicians require a deeper understanding of underserved women's EOL concerns and experiences of living with advanced breast cancer to develop interventions to benefit this population.

Methods

Study Design

We undertook a phenomenological qualitative study to examine and describe the lived experience of underserved women with advanced breast cancer by directly eliciting their personal perspectives. This article represents findings from a component of a larger study evaluating a narrative intervention to decrease suffering at EOL. Findings from the narrative portion of the study will be published separately.

This is a community-based participatory research study. Our partnership is a collaboration between the University of California, San Francisco (UCSF) and Charlotte Maxwell Clinic (CMC), a state-licensed health clinic in Oakland, California, that provides free integrative medicine for low-income women. Our academic and community team members collaborated closely throughout the project, from needs assessment through planning, study design, implementation, analysis, and dissemination.²⁶ The study was approved by the UCSF institutional review board (#10-00302). All participants provided informed consent.

Subjects

Eligible participants included patients with breast cancer who identified as women, were 18 or older, and had an annual family income $\leq 200\%$ of the federal poverty level (a cutoff commonly used in the San Francisco Bay Area to define eligibility for health care services and used nationally to define eligibility for insurance subsidies for the Affordable Care Act). Women who could not be interviewed in English were not eligible, but Spanish-monolingual women were referred to a related pilot study with the same inclusion criteria. Clinic staff at the two sites identified potential participants, who were subsequently mailed a recruitment letter and contacted by telephone for eligibility screening.

Recruitment began with women receiving services at CMC and was extended to include patients at Zuckerberg San Francisco General Hospital, the county safety-net hospital. Our sample was intended to be representative of community-living, underserved women with advanced cancer in the San Francisco Bay Area. Initial selection criteria limited inclusion to hospice-eligible patients and those with histologically or cytologically confirmed metastatic disease. To identify more participants, we expanded recruitment to include patients with progression of disease on chemotherapy, targeted drug therapy, or hormonal therapy. At the close of recruitment, 27% of participants met the expanded eligibility criteria. We compared the responses of participants recruited under the original and expanded criteria and did not find differences between the two.

Interviews

Participants met with a trained interviewer for four 45–60 minutes' interviews spaced one or two weeks apart. Interviewers followed a semistructured interview guide with open-ended prompts. Content domains included the experience of living with advanced cancer and considerations related to EOL. All interviews were digitally audio-recorded and transcribed verbatim.

Table 1
Participant Demographics

Characteristics	N (%)
Age	
20–39	7 (11)
40–59	40 (63)
60–79	16 (25)
Race/ethnicity	
White/European American	20 (32)
Black/African American	18 (29)
Asian/Asian American	9 (14)
Multiethnic	9 (14)
Latina/Latin American	4 (6)
Native Pacific Islander	2 (3)
Native American/American Indian	1 (2)
Relationship status	
Single	22 (35)
Married or partnered	18 (29)
Divorced	11 (17)
Dating	7 (11)
Separated	4 (6)
Widowed	1 (2)
Primary language	
English	55 (87)
Spanish ^a	3 (5)
Tagalog	3 (5)
Cantonese	2 (3)
Farsi	1 (2)
Vietnamese	1 (2)
Religion	
Christian	38 (60)
Spiritual, with no formal religious affiliation	15 (24)
Atheist	6 (10)
Buddhist	3 (5)
Jewish	1 (2)
Children	
Total women with children	42 (67)
Women with children aged ≥18 years	35 (56)
Women with children aged <18 years	13 (21)
Living arrangement	
Living with family	32 (51)
Living alone	20 (32)
Living with others (not family)	5 (8)
Living with spouse or partner only	4 (6)
Living in temporary housing or homeless	3 (5)
Educational status	
Some grammar school	4 (6)
High school diploma or equivalent	15 (24)
Some college	25 (40)
College degree	12 (19)
Some graduate school	3 (5)
Graduate degree	5 (8)
Employment status	
Disability	42 (67)
Retired	6 (10)
Part time	6 (10)
Unemployed and seeking employment	5 (8)
Full time	4 (6)
Income (total household)	
Less than \$10,000 annually	20 (32)
\$10,001–\$20,000 annually	14 (22)
\$20,001–\$30,000 annually	18 (29)
\$30,001–\$40,000 annually	2 (3)
\$40,001–\$50,000 annually	7 (11)
More than \$50,001 annually	2 (3)
Number of participants with dependents	29 (46)
Medical coverage	
Medi-Cal	20 (32)
Medicare	16 (25)
Medi-Cal/Medicare combined	14 (22)
Private insurance	13 (21)

^aThis number is not representative of the eligible population; women whose primary language was Spanish were invited to participate in a related study for Spanish monolingual and bilingual Latinas.

Analysis

Six reviewers conducted qualitative thematic analysis of interview transcripts, independently coding transcripts and meeting to create a comprehensive codebook and reconcile differences in categories. We present representative quotations to illustrate major themes in participants' responses.

Results

We sent recruitment letters to 115 women. 17 women were unreachable, 13 were too ill to participate, and nine were ineligible because of language barriers. Of the remaining 76 potentially eligible participants, four were unreachable after initial contact and nine declined to participate. A total of 63 women were enrolled (response rate 83%). One of the participants died after the first interview; the rest completed all four interviews. Participants identified as white/European American (32%), black/African American (29%), Asian/Asian American (14%), multiethnic (14%), Latina/Hispanic/Latin American (6%), native Pacific Islander (3%), and native American/American Indian (2%). The age range of participants was 29–71, with mean (\pm SD) age of 53 (\pm 9.01) (Table 1).

Qualitative thematic analysis revealed four predominant themes: compounding of pre-existing financial distress, perceived bias/lack of confidence in medical care received, balancing personal needs with the needs of others, and sources of meaning, coping, and heightened gratefulness.

Compounding of Pre-Existing Financial Distress

Participants consistently raised the issue of financial distress, including difficulty meeting basic needs, stress caused by inadequate financial resources, inability to work, and the precedence of financial challenges over illness concerns.

The financial burden and accompanying distress caused by cancer treatment, though relevant to all patients with cancer, were compounded for the women in our study. More than half of the participants struggled with an annual household income of \$20,000 or less (Table 1), and 5% of them were homeless over the course of the study. The cost of medical treatments exacerbated pre-existing financial hardship, often forcing participants to choose between basic needs. Sixty-five percent of participants reported that, in the previous year, they could not meet daily needs, including utilities (54%), food (48%), medical care (41%), and housing (41%). Financial troubles also negatively impacted stress and mood. "Last year ... was the worst financial year ever. We were standing in food lines and going to food banks and having to get assistance with the utility bills. It was

Table 2
 Illustrative Quotations From Participant Interviews

Compounding of Pre-Existing Financial Distress	
Baseline difficulty meeting basic needs	“I always pay [rent]. I always made sure [of] that. We may not have had food, but we done had a roof.” (P92)
Exacerbation due to medical costs	“I always spend a lot of money on medication. That doesn’t leave me any at all to ... buy clothes.” (P96)
Stress caused by financial concerns	“There are days when I get up ... and I feel so happy and so good. But then there are days when I wake up, it’s like, ‘Okay, the [utilities] bill is due. Oh man, let me just pull these covers up over my head ‘cause I don’t have all the money.’ Just taking care of our daily needs, not the wants. Let’s not even go with the wants right now, but just the daily needs.” (P92)
Inability to work	“I am going to have file bankruptcy ... I’ve tried looking for a job, but with my physical disabilities it’s really hard.” (P88)
Continuing to work despite not feeling well to maintain health coverage	“If I can keep going—I don’t know how [coughing]—but if I can stick in there ... I will have made 10 years at [the university], and after 10 years, I get to continue my health benefits.” (P52)
Financial challenges take precedence over cancer	“It’s really terrible to be homeless and have cancer and to be getting radiation ... I don’t have time to think of cancer.” (P2)
Lack of Confidence in Medical Care Received, Perceived Bias	
Concern about quality of care in public facilities	“It’s a county hospital, so it’s an overly stressed system They don’t have resources They have the American Cancer Society pamphlet from 1996. I was told that in a private institute, you were assigned a nutritionist, a social worker ... and a binder that had everything broken down I wish we had a universal medical system and when you get cancer this is what you get.” (P88)
Perceived provider bias	“[My primary care physician] never once examined this or done nothing, and I think it’s time to change him. He think we all ghetto trash and he don’t care, ‘cause we been drug addicts, whatever He may be a good doctor with people with money, but as far as people on [Medicaid], he’s not a good doctor at all.” (P66)
Balancing Personal Needs With Needs of Others	
Not wanting to burden others despite enhanced personal needs	“There were a couple times where I didn’t have even five dollars to pay for my co-pay I would have to have my boyfriend pay for some of my meds, especially when I didn’t get a paycheck ... I can’t even contribute! ... I hate depending on people.” (P88)
Desire to discuss death amidst perceived pressure to stay positive	“A lot of people are just wanting to be positive and upbeat and not think about dying, and that bothers me.” (P75)
Sources of Meaning, Coping, and Heightened Gratefulness	
Family and social relationships	“My kids are my all and being with them keeps me going ... even through what I’m going through now They’re like my sun. I see them, and I light up.” (P115)
Spirituality and religion	“My spirituality and belief in God are so strong and my faith keeps me strong.” (P91)
Altruism	“I like doing things where somebody’s going to be made happy—to help others to the point that you’re just overwhelmed with joy on the inside.” (P29)
Creative outlets	“[Cancer] definitely changed my life, but it changed it for the better. It gave me more of a clarity about myself ... and how that can help me is by me putting it on paper. I can put it in play form, I can put it in book form ... to take it and grow from it, and heal from it, and achieve from it.” (P92)

so stressful for me. I don’t know how I lived through it. The kids thought we were going to be homeless, which we did, too It was not good.” (Participant 29; see Table 2 for illustrative participant quotations, by theme.)

The impact of disease-related disability on work was another major concern. Unemployment and underemployment added to financial struggles. Women expressed concerns about not being “useful” and becoming financially burdensome to family. “I’m trying very hard not be totally alarmed by my complete loss of financial support because I haven’t been able to

go to work ... I’m very dissatisfied with the inability to keep my mind occupied. Doing things that feel useful makes my life feel purposeful” (P80). As another participant explained, when asked about her quality of life, “Financially, that is the only thing that matters right now—that I’m not working and everything else goes down the drain” (P91). Only 16% of participants were able to continue working on a part- or full-time basis. Of these women, half continued to work despite not feeling well to maintain health coverage. Some women described being too well for disability, but not well enough for full-time work.

In some cases, financial concerns were so great that they took precedence over health concerns. One woman described being fully occupied with “the everyday stresses of just trying to keep it together” and the necessity of “dealing with the cancer on top of that” (P14).

Lack of Confidence in Medical Care Received and Perceived Bias

Study participants questioned whether they were receiving the highest quality biomedical care given their insurance status and health care settings, and sometimes perceived provider bias related to their low SES and/or race/ethnicity. Women commented on the quality of care in public hospitals: “My first surgery was at [the public hospital]. I don’t like to stay there I don’t feel that comfortable. I need to wait four or five hours for a vacant room It’s a happier stay at [the private hospital]” (P84). Another participant emphasized uncertainty regarding the quality of care she received at the public hospital: “You’re thrown into a situation with all these strangers coming at you and you’re wondering what they may not be telling you that you should be asking If someone went to a private cancer place, would they be getting any better treatment?” (P74).

Although many participants described positive interactions with health care providers, some reported instances when they felt providers were biased against them. “[My primary care physician] never once examined this or done nothing, and I think it’s time to change him. He think we all ghetto trash and he don’t care ‘cause we been drug addicts, whatever He may be a good doctor with people with money, but as far as people on [Medicaid], he’s not a good doctor at all” (P66).

Another participant, a disabled woman receiving Supplemental Security Income and Medicaid, explained, “Three times at the dental school I’ve literally heard the doctors and students discuss the fact that they did not want to waste their time or money due to my situation But my oncologist was quite firm in saying that he treats everyone equally. It’s a mixed bag ... but people with the money and education and background do quite a bit different” (P14). Overall, patients viewed fewer financial means, lack of access to private insurance and cancer centers, and minority status as barriers to high-quality care.

Balancing Personal Needs With the Needs of Others

Although participants highlighted increased personal needs for practical, financial, and emotional support, they remained highly attentive to the needs

of others and often worked to maintain their care-taking roles. Many women expressed a strong desire not to burden loved ones and felt grief over increased dependence in daily tasks and financial matters. “I’ve been in a wheelchair ... so I don’t have really a quality of life because the main quality in my life is being able to take care of myself and my children ... other people feel like they need to help me more. And that makes me feel worse because I don’t want people to feel that I’m dependent” (P28).

Participants made an effort to attend to practical matters, including culling possessions, to avoid burdening loved ones after their death. One woman explained, “I have been cleaning out my house and I have written out an advance directive I’m doing my husband’s at the same time If something happens to me, he wouldn’t know what to do I’ll handle that” (P29). Another noted, “I want to take care of funeral expenses and stuff like that I don’t want my mom to have to go through that I don’t want to put any burden on anybody” (P35).

Participants also worked to balance their emotional needs with those of others. “There has to be balance but make sure you’re getting your needs met. Like a battery, if you’re not charged you don’t have anything to give anybody else That’s really hard to do because people feel they need to take care of everybody else’s business” (P53). Navigating personal emotional needs and those of loved ones was often difficult in EOL conversations. Many women downplayed their desires to discuss dying to accommodate loved ones’ discomfort. Conversations about death were painful for family members. “Any time you talk about departing ... it’s really hard. I looked at my son’s face. It was difficult for him My daughter-in-law was saying, ‘Do we have to talk about this stuff?’ ... It was a lot of very tender places we had to touch” (P38). Sometimes others simply refused to discuss the subject: “I told my sister what I wanted, in case something happened to me She just screamed, ‘No, you’re not going to leave me! You’re going to be fine!’” (P91). Women expressed frustration at others’ discomfort-based denials of circumstances: “People have the misconception that if you speak about death and you have cancer, that you’re being negative. It’s so unimaginative. They don’t see that it’s a practical reality” (P2).

Sources of Meaning, Coping, and Heightened Gratefulness

Although study participants faced many difficulties, they frequently expressed appreciation for the

meaningful aspects of their lives and described drawing on sources of meaning to cope with circumstances related to their illness. Key sources of meaning included social relationships, spirituality, creative outlets, and altruism. After diagnosis of advanced cancer, participants continued to engage in valued relationships and activities with equal or increased levels of enthusiasm and often described a shift in day-to-day experience reflecting an enhanced sense of gratitude.

Participants identified family and social relationships, particularly with their children, as their primary source of meaning. Spirituality, religious communities and practices, and creative outlets such as writing and music were also significant. Altruism was important to participants both before and during their illness. Women described volunteering, working in service professions, and donating money and often felt a greater commitment to service after their diagnoses. "Due to the cancer maybe I'm more humanitarian. Since the cancer ... if somebody comes and knocks on the door, 'Can you give me a dollar?' I will give him two" (P15). Many women felt motivated to help other patients with cancer in light of their personal experiences. One participant explained, "Once I got involved with [the cancer support group] that's when I started realizing my purpose ... to share with others ... because it will help them to feel that they're not alone ... I want someone else's journey to be better than mine" (P59). Another participant stated, "As a way to pay it forward, I go into the Susan Komen's Web site, and they have chat rooms ... I signed a petition that was going to the White House trying to [give women more time in the hospital after a mastectomy] Medical supplies that I may have, I'll send it right back. You never know—there's always somebody out there that needs help" (P23). Sources of meaning and altruistic causes thus provided women with a sense of purpose and strength that contributed to coping throughout their illness experiences.

Many participants described a primary sense of fear and anxiety at diagnosis that shifted toward acceptance and increased appreciation for the positive aspects of their lives over time. This was particularly true in contemplating EOL. "Since my diagnosis, I pay attention to the fact that I'm actually walking on the earth because previously time didn't seem that fleeting and that precious. At this point, every single thing is. So, the depth of your experiencing that which keeps you motivated and wholesome and trusting increases probably tenfold" (P14). Participants also noted a heightened sense of gratitude in the context of facing their mortality. "I've been thinking a lot about death ... I can't get it out of my head. It makes me realize how the time I have left is a gift and I need to make the most of it and be as kind as I can" (P68).

Discussion

Marginalized individuals with advanced cancer are often diagnosed later in their disease course than patients with more resources, have less social, economic, and political capital to cope with their diagnosis, have greater treatment complications, and receive lower-quality care.²⁷ Our findings contribute to an increased understanding of the struggles and resilience within this population.

Some of our findings are not unique to medically underserved women. Research involving a broader population of patients with metastatic breast cancer, for example, reveals similar experiences regarding life meaning and thoughts about dying, such as the importance of social support and spirituality, and the shifting of focus after diagnosis from fear and loss to acceptance and an emphasis on positive life aspects.²⁸ In contrast, our findings regarding extreme financial burden, lack of confidence in medical care received, and the perception of provider-driven disparities appear to impact underserved women differentially.

Although the cost of cancer treatment applies to women across the socioeconomic spectrum, financial difficulties were compounded for our study participants, who experienced prediagnosis financial insecurity. Loss of employment was a primary concern, and breast cancer patients with low household income and public insurance have been shown to receive fewer employment accommodations and to be at greater risk of job loss after diagnosis.²⁹ In addition, severe financial burden has been shown to contribute to worse physical and mental symptoms and is associated with lower health-related quality of life in patients with cancer.³⁰ Grossly inadequate financial resources force patients to forgo or delay needed medications and medical visits, increasing the risk of poor symptom management and health outcomes, including early mortality.³¹ The underemployment and financial distress voiced by our participants are thus significant and well-substantiated contributors to higher levels of stress, decreased quality of life, and poorer survivorship rates.

The effect of perceptions of race and class bias on health encounters has also been well documented.^{32–34} Although members of minority groups show heightened awareness of nonverbal cues of prejudice,³⁵ white health care providers tend not to recognize their own racially biased actions and to interact less effectively with minority patients than white patients.³⁶ Provider bias, even if implicitly held, produces mistrust in minority patients³⁷ and is correlated with lower quality care.³⁸ Although patients with advanced breast cancer who are not medically underserved also report dissatisfaction with provision of medical care and support,²⁸ experiences of

dissatisfactory care among the women in our study were uniquely complicated by participants' sense that they would receive better care if they had higher social status, more money, better insurance, or access to private cancer centers. These findings align with previous research showing that minority women with breast cancer are less trusting of their medical providers than their white counterparts.³⁹ Trust in medical providers is one of the core components of patient-centered care and influences health-related quality of life and coping in the context of cancer.⁴⁰

Despite facing tremendous adversity, study participants prioritized the needs of others, maintaining a commitment to support family and friends, as well as to altruistic causes. Participants were able to appreciate beauty and experience gratitude in the midst of their illness experience, drawing on meaningful relationships, spirituality, and creative outlets for resilience and strength.

Strengths and Limitations

A major strength of this study is the community-based participatory research partnership between UCSF and CMC, which enabled us to focus on issues of paramount concern to their community. This collaboration enhances the usefulness of our project by aligning it with community interests and addressing the understandable mistrust often exhibited by vulnerable patients in relation to research. Our partnership allowed us to recruit and retain a diverse, representative sample of medically underserved women and learn from their firsthand experiences, which are insufficiently addressed in research.

Limitations of our study include a focus on patients receiving care in the San Francisco Bay Area, a geographic region with many community health care resources, which may not be representative of rural areas or the country as a whole. In regions with fewer resources available to medically underserved women, however, the concerns expressed by study participants may be even more poorly addressed. Our study also does not include a comparison group, making it difficult to determine the extent to which findings are unique to the study population. Our series of in-depth, open-ended interviews with each participant, however, provided the opportunity to hear directly from women who are rarely asked about their perceptions of their own circumstances.

Implications for Future Work

Although recent years have brought improvements in cancer diagnosis and treatment, patients who are uninsured, underinsured, or medically underserved remain susceptible to receiving limited or suboptimal

care and support. Our findings powerfully illustrate the negative and unnecessary impact of the current U.S. system of health care on a group of people with cancer. This crisis has been well documented; the World Health Organization, among many other groups, advocates for progress toward universal health coverage on the grounds that it leads to improvements in population health.⁴¹ Broader health coverage results in better access to necessary care and improved population health for everyone, but particularly medically underserved people.

To ensure an ethical, comprehensive approach to addressing the morbidity and mortality of advanced cancer, it is necessary to continue studying contextual factors influencing the disease's impact on all members of society. Improving care for underserved women with advanced breast cancer, who bear an unequal burden of suffering from this disease, requires enhancing their access to support, decreasing associated costs, and promoting improved quality of life and adaptive coping throughout the illness experience. To do so, we must address health care disparities across the continuum of care, from screening through hospice. In addition, health professions' education and training should include intensified instruction in cultural humility, awareness of implicit bias, and trust-building in the context of cancer care for underserved populations.

With a growing awareness of underserved women's experience of EOL issues, palliative care researchers and clinicians must develop and implement better and more personalized opportunities to discuss dying and death to promote well-being during serious illness and the last stage of life. Changing national demographics and the rapidly evolving field of palliative and hospice medicine make clear the imperative to develop more equitable and inclusive EOL care.

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