“I’m Sitting Here By Myself . . .”: Experiences of Patients with Serious Illness at an Urban Public Hospital

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Abstract

Objective: To describe experiences of serious illness including concerns, preferences, and perspectives on improving end-of-life (EOL) care in underserved inpatients.

Methods: Qualitative analysis of 1-hour interviews with inpatients at a public hospital whose physician “would not be surprised” by the patient’s death or intensive care unit (ICU) admission within a year. Patients who were non-English speaking, lacked mental capacity, or had uncontrolled symptoms were excluded. A semistructured interview guide was developed and used for all interviews. We digitally recorded, transcribed, and conducted a thematic analysis of the interviews.

Results: Twenty patients participated. Difficult events such as estrangement, homelessness, substance abuse, and imprisonment shaped patients’ approaches to serious illness. This influence manifested in interpersonal relationships, conceptualizations of death and concerns about dying, and approaches to coping with EOL. Because patients lacked social support, providers played significant roles at EOL. Patients preferred honest communication with providers and sharing in medical decision-making. A prolonged dying process was feared more than sudden death. Concerns included pain, dying in the hospital, and feeling unwelcome in the hospital. Patients coped by advocating for their own care, engaging with religion/spirituality, and viewing illness as similar to past trauma. Participants suggested that providers listen to their concerns and requested accessible chaplaincy and home-based services.

Conclusions: Providers should consider that difficult life events influence underserved patients’ approaches to dying. Attention to patients’ specific preferences and palliative care in public hospitals and locations identified as home may improve care for patients who lack social support.

Introduction

AT THE END OF LIFE, most Americans suffer from pain and other distressing symptoms and receive medical therapies that are inconsistent with their preferences.^{1,2} Although there is little research about the end of life of patients with underrepresented cultural and disadvantaged educational and socioeconomic backgrounds, limited data suggest that these patients have worse experiences than the general population.^{3–15} For example, studies indicate that ethnic and racial disparities exist in access to opioid analgesics^{6,9,16} and that hospice is underutilized by minorities.^{9,10,17,18} The homeless underuse hospice for financial and logistical reasons and have high rates of mental illness and substance abuse that complicate the dying process.¹⁹

Palliative care services were developed to improve patients’ end-of-life experience by addressing physical, emotional, and existential suffering.^{20–24} Because palliative care is patient-centered, understanding patient experiences is crucial for designing and improving palliative care services. Previous research elucidates elements of a “good death” in insured populations with sufficient social support.²⁵ However, our understanding of what constitutes a quality death for urban underserved patients is incomplete.²⁶ Descriptive studies of the homeless found unique attitudes, end-of-life preferences, and barriers to care, but the study participants did not have life-limiting illness.^{13,14,26–28} Although the disenfranchised frequently receive end-of-life care in the hospital, little research focuses on the experiences of underserved patients in this setting.²² Therefore, we interviewed seriously ill

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inpatients at an urban public hospital and conducted a qualitative analysis to better understand their concerns, preferences, and perspectives on improving end-of-life care.

Methods

Setting and participants

The study was conducted at a university-affiliated public hospital in San Francisco, California, which is a center of care for underserved patients including homeless, ethnic and racial minority, and immigrant populations. During the data collection phase, November 2008 through January 2009, the hospital did not have inpatient palliative care services. We included patients with a terminal illness diagnosis whom the senior housestaff physician would not be surprised if the patient died or was admitted to the intensive care unit (ICU) within 1 year.²⁹ We excluded patients who were non-English speaking, mentally incapacitated, unaware of their diagnosis, or otherwise unable to consent to or participate in the interview process. Patients were recruited from six nursing units that serve the internal medicine and family medicine departments. Senior housestaff were contacted on a daily basis to identify eligible patients, who were then approached in their hospital room and screened for participation. The University of California, San Francisco, Committee on Human Research and the San Francisco General Hospital Dean's Office granted approval for this study and all participants gave written informed consent.

Data Collection

A semistructured interview guide (available upon request) was developed and used for all interviews. The guide consisted of open-ended questions about the patient's life and understanding of his/her disease, the impact of the illness, perspectives on death and dying, and suggestions about how to improve care. A single interviewer (V.D.C.) conducted all interviews, which were approximately 1 hour in length. All interviews were digitally recorded and transcribed verbatim. We collected data and analyzed transcripts concurrently, conducting interviews until themes repeated and new themes did not emerge.^{30–33}

Analysis

We conducted a thematic analysis of all interview transcripts.^{25,30–35} First, two researchers (V.D.C. and J.W.C.) independently read all transcripts to identify attributes. These primary coders then compared attributes, grouped them into preliminary themes, and created an initial codebook by collapsing the themes into categories. The codebook was iteratively modified by applying it to sequential subgroups of transcripts to ensure that each code was explicit and clear, then checked for reliability by another researcher (S.R.A.), who used it to code a subset of transcripts. In a first-pass of coding, the two primary coders independently applied the final codebook to all transcripts, involving another coder (W.G.A.) to resolve discrepancies. During a second-pass of coding, we further explored associations among themes by comparing within and among codes in all transcripts to elucidate conceptual domains. Through this process, the initial categories were collapsed into the format presented in the results section: a description of the participants' lives, how

their past histories influenced end-of-life, and their suggestions about how to improve end-of-life care. Last, we compared domains that emerged from this study to those supported by previous literature exploring end-of-life concerns both in general and underserved populations.^{13,14,25,26} We used ATLAS.ti version 5.2 (Atlas.ti, Berlin, Germany) software for coding and tracking of themes and exemplar quotes.

Results

Of 333 patients who were screened during the data collection period, 32 were eligible. Ten could not be approached because they were discharged ($n = 9$) or transferred to the ICU ($n = 1$). Twenty patients (91% of 22 who were approached) consented and were interviewed. The participants' sociodemographic characteristics are shown in Table 1. Their mean age was 54.5 years (range, 38–78 years); 65% ($n = 13$) were men, 30% ($n = 6$) women, 5% ($n = 1$) male-to-female transgender, 35% ($n = 7$) Hispanic, and 30% ($n = 5$) African American. One third ($n = 7$) were homeless or marginally housed, and 25% ($n = 5$) had active and 60% ($n = 12$) had past substance abuse. Participants' gender, ethnicity/race, living arrangements, and substance abuse profiles represented the English-speaking population served by the study hospital.³⁶ Participants' life-limiting diagnoses were: cancer (55%, $n = 11$), end-stage liver disease (25%, $n = 5$), chronic obstructive pulmonary disease and congestive heart failure (10%,

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS

Characteristic	n = 20
Age, mean (range)	54.5 (38–78)
Gender	
Male	13 (65)
Female	6 (30)
Transgender (M->F)	1 (5)
Ethnicity, n (%)	
Hispanic	7 (35)
Race, n (%)	
Black or African American	6 (30)
White	5 (25)
American Indian/Alaska Native	1 (5)
Other (mixed Latino/Pacific Islander)	1 (5)
Living arrangements, n (%)	
Live alone	5 (25)
Marginally housed	5 (25)
Live with relatives	4 (20)
Live with spouse or partner only	3 (15)
Homeless	2 (10)
Live in health related facility	1 (5)
Diagnosis, n (%) ^a	
Cancer	11 (55)
End-stage liver disease	5 (25)
Chronic obstructive pulmonary disease	2 (10)
Congestive heart failure	2 (10)
HIV/AIDS	2 (10)
Substance abuse, n (%)	
Active	5 (25)
Past	7 (35)

^aDiagnoses sum to more than $n = 20$ because some patients had more than one terminal diagnosis.

$n = 2$), and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS); 10%, $n = 2$).

Difficult life histories

Participants' lives were marked by difficult life events: loss of relationships, homelessness, substance abuse, imprisonment, and assault. A woman addicted to crack with metastatic cervical cancer discussed losing custody of her children after relapsing:

I went to a rehabilitation program to get my kids back, and I got them back, and then all of a sudden I got that big lump sum check . . . and I relapsed . . . so I lost my babies again.

A man dying of alcohol-induced liver failure discussed his life as a convict:

. . . I mean damn near every jail in California . . . I think I've been in every jail there is on this side of the bay. Being a tough guy and all that crap. I loved misery.

A homeless heroin addict with advanced HIV/AIDS shared a traumatic experience when asked if she had finished high school:

[School] wasn't much my thing. My dad went to prison for killing my mom when I was nine.

These difficult life histories manifested at end-of-life in three domains: interpersonal relationships, conceptualization of death and concerns about dying, and approaches to coping with end-of-life.

Interpersonal relationships

Participants who lacked family and friends yearned for company and support at end of life. They expressed regret about estrangement from meaningful relationships and isolation, loneliness, and self-reproach. One participant, who lost her children due to drug addiction, spoke hypothetically to one of her estranged daughters:

Well, yeah, baby, at that moment, I loved the drugs more than I loved you . . . I was in my addiction . . . But I just pray that all my kids find it in their heart to forgive me . . . that would be the most comfort in the world right there for me. I don't care about no pain, no nothing, as long as I have my babies again.

Another participant expressed regret for losing contact with his wife and son because of alcoholism:

I made a horrible life on this earth. I've got no right to even be accepted on this planet. I don't deserve to live . . . I see misery. Nothing happy, nothing sacred . . . it's all blues. I wake up dreaming about death. I go to sleep dreaming about death. I count the days and miss my son. I miss my wife.

A participant from Puerto Rico, who had been living in the United States alone for over 30 years, discussed his loneliness:

I'm sitting here by myself. And just like everybody else, I need the company of somebody and to have the family. I need my family, too.

In the setting of minimal social support, relationships with health care providers were a source of comfort. One participant, estranged from his family and dying of esophageal cancer, described his medical providers and himself as members of one "team" united for a common purpose:

There's good work to be done. It's like a team effort. If you're a team and they're all together working with the patient itself, it's going to work out really good.

Another man credited his survival to his close relationship with his doctor:

I [appreciate him]. He is the man as far as I'm concerned. [He helped me by] just being there . . . just being himself. If he wouldn't have been that kind of person, odds are I wouldn't be here right now . . . probably dead or something.

Conceptualization of death and concerns about dying

Participants described previous exposures to death as sudden and violent in nature. Sudden death was the expected and thus, less frightening way to die. Because a prolonged, painful dying process went against this conceptualization of death, it was terrifying. One man discussed the attributes of sudden versus prolonged death:

I guess it depends on what disease you have, if it's a long drawn out thing or if you die fast. Cancer to me is kind of a medium thing . . . it doesn't kill you fast but it kills you slowly . . . live fast . . . it's kind of like almost you die fast. I've almost died already a couple times . . . you die fast. That's good.

This participant illustrated the agony of a prolonged dying process:

Cancer is the worst thing that can happen to a man . . . especially when he can't do nothing about it except hope and pray that he either gets well or dies . . . I cry like a little baby. I worry.

Pain was a concern in the dying process, and patients were aware that their past histories could worsen their pain and symptom management. One heroin addict dying of HIV/AIDS expressed:

I don't see any reason why I should be in pain. They ain't got it under control. They keep thinking because I'm a heroin addict I'm trying to get more pills . . . I can go buy my own shit, you know? If I wanted to get drugs from them, I would have did it in a little bit more of a sophisticated way than this . . .

With regard to the location of end-of-life care, participants discussed dying at a place identified as home, which might be marginal housing, but were resigned to dying in the hospital. Although he preferred dying at home near his estranged family, when asked if dying in the hospital was acceptable to him, one man said:

Not something I planned on, no. But it's pretty much going to be inevitable. I don't got too much ways to look at it.

Those with family felt that dying in the hospital would be less burdensome for their loved ones. Another participant discussed how dying in the hospital would be better for his family, but had not yet clarified his preferences with them:

It would be more convenient for my family if I was to pass away here [the hospital], because then they could start my funeral arrangements going . . . No [I haven't talked about these things with them].

Participants also discussed concerns about treatment of their bodies after death. One woman expressed her concerns for the placement of her remains:

I don't even have a casket, or even where they're going to bury me or nothing. That's also essential too, because then if you don't have that, they're going to pick out anything. I mean, you don't know if they're going to put you close to, I don't know; maybe the garbage.

Approaches to coping with serious illness

Patients coped with serious illness by comparing it to past experiences, advocating for themselves, and relying on religion or spirituality. They viewed serious illness as similarly or less challenging when compared to prior struggles. One woman shared the moment in her life that changed her perspective on "bad news":

I was 11 years old and my mother dropped dead. So after that, when news comes, news comes. Nothing can't [affect] me after that.

Participants also voiced the need for self-advocacy in meeting their goals of care. One woman discussed a health care encounter during which she engaged in self-advocacy:

She was screaming at me, and I didn't like that. But I told the doctor about it... afterwards, the nurse was nicer to me; she realized I speak up, that I wouldn't keep my mouth shut.

Others described how their disempowered social standing manifested as helplessness in the hospital. For example, one man did not speak up when he felt uncomfortable during bathing by staff:

... Better to be thought of as a fool than to open your mouth and remove all doubt, I ain't trying to make nothing out of it... [they were] acting more like kids than professionals... like they weren't looking at the whole person.

Another man commented on his concern for disempowered patients and the role of self-advocacy in the hospital:

I think there are a lot of patients who are either not well enough to do anything about [their care], or not smart enough to do anything about [their care], don't voice their opinions and they just take it. But I'm not one to take it.

Religion and spirituality played a significant part in the repertoire of coping strategies. One homeless woman described how important her belief in God and Heaven was in her daily life and the dying process:

[God] keeps me safe and sane. Keeps me from jumping over a bridge... and I tell him how I feel. I feel a little terrified... the only thing I'm going to miss is the streets. I'm going to miss my buddies. Most of them died, so most of them are going to be up there waiting for me.

Suggestions for improving care

Participants suggested improved relationships with providers (doctors, nurses, and aides), accessible chaplaincy services, and home-based services. Regarding relationships with providers, participants described feeling unwelcome in the hospital:

I can see where the wheels are turning and people are thinking should he be here? Is he costing us too much? Is he an outpatient? Or is he a hospice patient? Don't make him too comfortable. If he wants to be bathed, cleaned, he's not supposed to

be in a hospital. That's not what we do—I can feel it from the staff. Their job is not to wipe my butt.

Another patient echoed this concern:

Some of these people look at me like I'm over here trying to rent a room. Well... this is not a hotel. This is not like just calling up room service, or saying, "Can you make my Jacuzzi, sir?"

They felt the experience could be improved by a more humanistic approach. One woman expressed:

I think every patient deserves to be treated with love and respect... think of them not that they're just kind of specimens, but they're human beings... ask the patient what they feel... I want to talk to somebody maybe about what I'm feeling that day, just to have a conversation with them.

Participants voiced their perception of a therapeutic effect of being listened to in the context of the study interview. When asked how the doctors could make him more comfortable, one participant said to the interviewer:

Talk to me like you're doing. That makes me happy.

The need for more accessible chaplaincy services was also a suggestion for improvement:

... they could bring the father here more often so you get communion. Because they want people going downstairs [for mass]... if you go in a wheelchair, usually you don't have underwear on—when you get up to get communion... everybody's looking at your rear end.

Last, patients desired home-based medical services, regardless of whether this "home" was on the streets, or a single-room occupancy (SRO), a form of marginal housing. One woman requested medical/ palliative services at her SRO:

I need a doctor to come see me... a nurse or whatever. I'm getting too weak to [take care of myself]. It's coming... the end. I can tell it's getting to where I'm not going to be able to do anything... help me once, twice a week. Just help me brush my hair... make [me look pretty again].

Discussion

To better understand the end-of-life experience of urban underserved patients we interviewed 20 English-speaking seriously ill patients at a public hospital. We found that difficult life histories impacted end-of-life experiences and patient-provider interactions in the domains of interpersonal relationships, conceptualization of death and concerns about dying, and approaches to coping with end-of-life.

Participants felt improving relationships with providers, accessible chaplaincy services, and home-based services would enhance care. These results contribute to understanding the experiences of serious illness and frame the provision of palliative care services in this population.

Our participants identified factors similar to those in the study by Steinhäuser et al.²⁵ of what constitutes a "good death" (that study did not focus on underserved patients): pain and symptom management, clear decision-making, preparation for death, completion, and affirmation of the whole person. Our participants' life-situations often compromised actualizing these values. Drug addiction often complicates pain management, and our participants perceived providers' reluctance to provide adequate pain

medication because of drug abuse histories.^{37–40} Similar to Steinhäuser and coauthors²⁵ findings, this cohort preferred open communication with providers about diagnosis/prognosis and participation in medical decision-making. However, at times communication with providers felt rushed, and lacked focused listening. Preparation for death was seen as important, but there was little action to plan for death with respect to location of death and disposal of remains. The desire for completion involved estrangement and loss of relationships, but participants lacked opportunity or resources to make amends and attain completion. Finally, patients wanted affirmation of the whole person, treating each patient as a unique, complex person in the context of their histories and values, but some felt unwelcome in the hospital and as though the whole person was not considered.

We identified themes similar to Song and associates^{13,14,26,27} work with homeless persons who were not seriously ill: a desire to discuss end-of-life concerns, seeing death as a sudden and often violent phenomenon, concerns about dying alone, fear that the body will not be respected after passing away, poor social support, poor provider attitudes causing barriers for care such as pain management, and the importance of religion. We confirm how lacking or strained relationships are common in this population and greatly influence the end-of-life experience. Patients that live estranged lives did not necessarily want similarly isolated deaths. This influences both completion and interaction with providers. Our participants saw providers as “family” or “team” members who could provide support and focused listening. Ostensibly, due to minimal social support the role of the provider is more intimate than one might find in the general population.

Some of our findings diverged from Song and coworkers. Whereas Song’s participants feared a violent death, our participants feared a prolonged death—painful, alone, and muddled with regrets. For our participants, the experience of prolonged illness contradicts a possible conceptualization of death in this population. Whereas sudden death, normally observed in everyday life, is not feared, dying of terminal illness is terrifying.

Perceptions of “unwelcomeness” in health care encounters have been discussed involving nonseriously ill participants recruited at homeless shelters.⁴¹ Our study reveals that feeling “unwelcome” remains true while hospitalized and can be even more intense during the dying process. Patients often felt burdensome and undeserving of care, specifically regarding assistance with activities of daily living. This must be remedied for underserved patients for whom the hospital and staff may be the last “home” and relationships experienced before death.

While our participants’ histories often decreased the quality of their end-of-life experiences, they also provided coping strategies. Serious illness was another obstacle for our participants, piling in comparison to loss of relationships, personal violence, and addiction. This led to an acceptance of death as a “what happens, happens” phenomenon—just another difficulty to overcome. The importance of self-advocacy to achieve preferences for care was a prominent theme. Many of these patients are self-reliant and resourceful for every-day survival and use these techniques to navigate the health care system while hospitalized. However, the opposite was also seen; those “beaten down” by life feel powerless to advocate

for their well-being in the hierarchical hospital system. We encourage providers to be aware of this phenomenon, check-in with patients, and be prepared to be patient advocates.

Our study provides hope that the experience of seriously ill patients in public hospitals can be improved. Patient-suggested improvements, including better communication with providers, home-based medical services, and chaplaincy access, are targets of hospice and palliative care services.^{20–23} With regard to relationships with providers, patients requested that someone sit and listen to them; this had a therapeutic effect and is a primary component of palliative care.

Prominent despair and hopelessness at end-of-life may reflect frequent psychiatric comorbidity in this population and managing psychiatric illness is another way interdisciplinary palliative services can improve care. Additionally, chaplaincy services are an essential component of palliative care, and, given the importance of religion/spirituality for our participants, can provide a huge measure of comfort. Similar to past studies,²⁵ though our participants accepted passing away in the hospital, many preferred to pass away at home, even though the “home” they identified was often marginal housing or the streets. Providing home-based medical services can be challenging for homeless or marginally housed patients, but may be key to improving the quality of dying for patients whose identity and social support are in these locations.

Other literature supports the idea that inpatient and home-based/shelter-based palliative care at public hospitals can fulfill a gap in care and address unique needs in these populations.^{19,22,42} These services can help providers attend to the “welcomeness” perceived by patients, the great interpersonal needs, and preparing for a relatively prolonged dying process in comparison to conceptual expectations of death. Having interdisciplinary palliative care services in these settings can facilitate more personal, less rushed communication with these patients, who may view the hospital staff as a more significant part of their end-of-life experience than the general population.

Our study has limitations. First, we focused on the English-speaking subset as a starting point, but non-English speakers are a significant segment of the urban underserved and face distinct barriers to communication and provision of care. Second, caregiver and provider perspectives were not elicited and are important aspects of end-of-life care. Future studies should include the experiences of non-English-speaking patients, providers and caregivers to further understand cross-cultural and multiperspective aspects of end-of-life care. Additionally, our study enrolled more men than women for unclear reasons. Although the public hospital reports serving equal numbers of men and women (of all languages³⁶), it may be that the English-speaking population or patients with serious illness at this hospital are predominantly male. Nevertheless, our study sufficiently represented women. Finally, our study was conducted at one location, which limits the diversity of end-of-life experiences that are represented. Larger studies at more locations are needed to confirm our findings. Our results could be used to design surveys or patient satisfaction instruments that are sensitive to the needs of the subset of underserved populations represented in this study.

In conclusion, when caring for underserved inpatients at end-of-life, providers must consider the ways in which

difficult histories influence the patient experience. Although each end-of-life experience is unique, there are established “universal” components of a quality death.²⁵ Underserved patients may require more intensive, tailored approaches to care given prolific difficult life events and minimal social support. Good communication, attention to patients’ specific preferences and inpatient/home-based palliative care services in public hospitals may improve the experience for marginalized patients with serious illness.

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