

Everyday Struggling to Survive: Experiences of the Urban Poor Living With Advanced Cancer

Anne Hughes, RN, PhD, FAAN, Maria Gudmundsdottir, RN, PhD, CT,
and Betty Davies, RN, PhD, CT, FAAN

ONS Excellence in Cancer Nursing Research Award

Purpose/Objectives: To understand the meaning of dignity to the urban poor and to describe their experiences living with advanced cancer.

Design: Qualitative approach using interpretive phenomenology.

Setting: Various community residential and clinical sites in a western city in the United States.

Sample: 14 patients (6 men and 8 women) with stage III or IV solid tumors who ranged in age from 45–69 years; 50% were people of color.

Methods: Patients were recruited from providers caring for the urban poor. Data were collected from in-depth interviews that were audiotaped and transcribed. Patients were interviewed as many as three times. Interview transcripts and field notes provided data for the analysis, which was part of a larger project. Researchers identified and analyzed themes within and across cases.

Findings: Many of the urban poor had difficult backgrounds prior to being diagnosed with cancer. Most patients, even those only weeks from death, focused on living not on dying. Participants' descriptions of their experiences focused on indignity not dignity. Indignity stories, such as being talked down to, not being listened to, and the embarrassment of fecal or urinary incontinence, were described in vivid detail.

Conclusions: This research confirms the importance of cancer care that recognizes patients' humanity regardless of their psychosocial circumstances.

Implications for Nursing: Nurses need to expediently meet hygiene and toileting needs to decrease threats to patient dignity.

Key Points . . .

- The urban poor with advanced cancer struggle to survive both life and cancer.
- The urban poor living with advanced cancer focus more on living with cancer, even when days or weeks from death.
- For the urban poor living with advanced cancer in this study, particularly when they were hospitalized, interactions with healthcare providers frequently were perceived as disrespectful, impersonal, or uncaring.

Vulnerable populations such as the urban poor are disproportionately affected by cancer. The poor face barriers accessing high-quality cancer care and frequently experience insensitivity to their plight. Untangling the effects of poverty distinct from race and ethnicity on cancer disparities is difficult; in the United States, race and ethnicity often serve as proxies for socioeconomic status (Koenig, 1997). Nevertheless, the National Cancer Institute concluded that poor individuals, regardless of race and ethnicity, are diagnosed with more advanced cancer and have lower rates of survival than those living in more affluent communities (Singh, Miller, Hankey, & Edwards, 2003). That disparity is evident even after controlling for the stage of



Anne Hughes, RN, PhD, FAAN, is an advanced practice nurse in palliative care in the Laguna Honda Hospital and Rehabilitation Center in San Francisco, CA, and an associate clinical professor in the Department of Physiological Nursing at the University of California, San Francisco (UCSF); and Maria Gudmundsdottir, RN, PhD, CT, is an assistant adjunct professor and Betty Davies, RN, PhD, CT, FAAN, is a professor, both in the Department of Family

Health Care Nursing at UCSF. Funding was provided by an American Cancer Society doctoral scholarship in nursing; a National Institutes of Health/National Institutes of Nursing Research Individual Predoctoral Training Grant (F31NR079923); an ONS Foundation Small Research Grant Award; an Oncology Nursing Society Doctoral Scholarship; a UCSF Alpha Eta Chapter, Sigma Theta Tau, Research Award; and a UCSF Graduate Student Research Award. This article is based on Hughes's dissertation research. As the recipient of the 2007 Oncology Nursing Society (ONS) Excellence in Cancer Nursing Research Award, Hughes presented this article at the ONS 32nd Annual Congress in Las Vegas, NV.

Digital Object Identifier: 10.1188/07.ONF.1113-1118

disease at diagnosis (Singh et al.). Poor people are more likely to die of cancer. Few accounts appear in the literature about the everyday lives of the poor living with advanced cancer and the psychosocial and existential consequences of illness and treatment (Hughes, 2005, 2006; Moller, 2004; Williams, 2004).

The original purpose of the research reported in this article was to understand the meaning and experience of dignity in the urban poor with advanced disease, as part of a larger study that used mixed methods and also included people living with advanced HIV. Dignity is a ubiquitous concept in bioethics and theology and often is mentioned in the context of caring for older adults, the disabled, and those who are dying. Dignity has been studied in patients facing the end of their lives (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Enes, 2003; Hack et al., 2004; Turner et al., 1996), but no research was located about dignity and the urban poor with advanced disease in the United States.

Many but not all individuals interviewed could not and did not relate to the concept of dignity and were unable to articulate its meaning. That sentiment was stated eloquently by Sally, a 55-year-old Caucasian woman with advanced ovarian cancer who lived in a single-room occupancy hotel: "What does dignity mean? I got to know what it means before I can answer the questions." Instead of dignity, many participants spoke about respect.

Benner (1994) and Crist and Tanner (2003) noted that qualitative researchers must be willing to modify lines of inquiry according to what is revealed or uncovered in the text. Thus, rather than attempting to answer a research question about dignity that was not meaningful or understandable to the participants, what seemed of greater importance was to understand the everyday lives of a vulnerable population. As a result, the purpose of this qualitative research was modified to also describe the experiences of the urban poor living with advanced cancer.

Methods

Interpretive phenomenology served as philosophical background and analytic methodology for this clinical ethnography. The philosophical framework of interpretive phenomenology is based on the writings of Heidegger (1927/1962), as interpreted by Dreyfus (1991) and further elucidated by Benner (1994); Benner, Tanner, and Chesla (1996); and other interpretive nurse scientists (Gudmundsdottir & Chesla, 2006; Leonard, 1994). Interpretive phenomenology seeks to understand, rather than explain or predict, participants' worlds—their concerns, habits, and practices as they are revealed in narratives; interpretive accounts are always contextualized (Benner). Clinical narratives uncover the practical know-how of symptom recognition and management, help-seeking patterns, and self-care practices for those living with a chronic illness or who are recovering from an injury or illness (Benner; Doolittle, 1994).

Procedures

The study was approved by a university institutional review board, a comprehensive cancer center review committee, and healthcare facility review committees in a western U.S. city. Patients were recruited from providers caring for the urban poor, including an oncology clinic in a public hospital, case managers, and home healthcare clinicians and other social service providers working with the poor. Potential participants were eligible

for the study if they were 18 years of age or older, able to speak and understand English, able to provide informed consent, poor, diagnosed with advanced cancer, and aware of the seriousness of their illness. Healthcare providers informed eligible patients about the study; those who were interested in learning more were asked whether the researcher could contact them.

The data collection procedures and resulting interpretive accounts were monitored carefully throughout the study to ensure scientific rigor. Strategies employed to promote rigor included prolonged and persistent field observations to build trust and appreciate cultural nuances, debriefing by the principal investigator (PI) with the research team to review observations and impressions, comparing and contrasting interpretations of the data, recognizing the researcher's position that may have influenced what was unseen and unheard, providing rich and thick descriptions for readers to verify the trustworthiness of the claims, and member checks with participants about preliminary impressions (Creswell, 1998).

Data Collection

Interview transcripts and field notes provided the primary qualitative data for the analysis. Informal interviews of health and social service providers working with the study population and observations regarding environments where patients lived or received care were recorded in the field notes. Fourteen patients were interviewed as many as three times, for a total of 32 interviews; two patients with advanced cancer who were domestic partners asked to be interviewed as a couple. Interviews were conducted wherever convenient for participants: single-room occupancy hotels, housing projects and other residences, hospital rooms, coffee shops, a residential hospice, or building lobbies. Participants were asked to describe their experiences living with cancer, provide narratives of interactions with healthcare providers, and discuss what dignity meant to them. Data were collected from January 2006 through January 2007.

Data Analysis

Interviews and field notes were audiotaped and transcribed verbatim and later verified for accuracy. Transcripts were read and reread, and interviews were compared and contrasted within and across cases. Identifying paradigm cases is an analytic strategy to begin to understand a text; paradigm cases are "strong instances of concerns or ways of being in the world" (Benner, 1994, p. 113). Thematic analysis allows cross-case comparisons of distinctions and patterns; not infrequently, the incongruities and inconsistencies of human beings emerge (Benner). The PI drafted and redrafted interpretive memos of themes and exemplars that were discussed and revised with the research team to develop an interpretive account. All participants' names used in this article are pseudonyms.

Findings

Sample

The sample was racially diverse and reflective of the city's English-speaking population of the urban poor with cancer (see Table 1). Fourteen patients, six men and eight women, with stage III or IV solid tumors participated. The sample ranged in age from 45–69 years, and 50% were people of color (five African Americans and two Hispanics or Latinos). Seven patients had a history of homelessness. Of note, seven

Table 1. Sample Characteristics

Characteristic	n
Age (years)	
X = 56	–
Range = 45–69	–
Gender	
Female	8
Male	6
Race or ethnicity	
African American	5
Caucasian	7
Hispanic or Latino	2
Education	
Less than high school	3
High school or GED	1
Some college	7
College or graduate school	2
Unknown	1
Tumor type	
Lung	3
Breast	3
Colorectal	3
Ovarian	2
Prostate	1
Liver	1
Head and neck	1
History of homelessness	
Yes	7
No	7

N = 14

patients died by the completion of data collection, some within days or weeks of being interviewed.

For everyone, rich and poor alike, being diagnosed with cancer occurs in the middle of a life, within the context of pre-existing challenges and possibilities. The urban poor with cancer in this study struggled with concerns about housing, personal safety on dangerous streets and neighborhoods, transportation to appointments, limited money for medication copayments, and healthcare systems where many previously felt unwelcomed and avoided “unless dying.” Some believed that their illness was not taken seriously because they did not have the right insurance; all were dependent on overburdened public healthcare systems or faith-based community clinics for care.

All informants discussed ways in which cancer had become an ongoing story in their lives; sometimes their stories were recounted in the linear classic medical history style and other times in a more circular fashion that placed cancer in the context of what was happening in their lives at the time of diagnosis, sometimes at the edge and sometimes nearer the center of their lives. Their stories taken together and representing only a portion of the rich qualitative data provided evidence for the everyday struggle to survive, which is central to the experience of the urban poor living with advanced cancer.

Those who are poor and living in a city are not a homogeneous group; individual experiences with poverty, illness, and life differ from one another. Although most participants had experienced lifelong poverty, others working as artists or in part-time jobs without benefits were uninsured when they were diagnosed and had no source of income. Poverty was exacerbated as a consequence of being ill and no longer able to work. If participants continued to work even part-time,

they risked losing all of their benefits, including medical care, because their income exceeded the eligibility criterion. Many, especially those who had lived in chronic poverty, had difficult or compromised backgrounds that led to being without home and family as adults.

Difficult Backgrounds

Most participants had struggled from a young age. Danny was born in jail, and Sally, who had been placed in foster care at the age of six, repeatedly commented, “I have no family.” Very few participants described close relationships, if any, with their families. Some recalled the deaths of their mothers at a young age and the resulting family disruption and the dissolution of home. Eddie, a 64-year-old Caucasian Vietnam veteran with advanced lung cancer noted,

She passed away [when I was 20 years old]. . . . That was a tragic thing for me because . . . my father went to pieces and . . . I had nothing to come back home to. . . . My mother was the family. . . . [We went our] separate ways. The family just split up. This happened like that, overnight. And within six months, I didn’t know where anybody was at.

Drug and alcohol problems were common and persisted for some, even when they were seriously ill and dying. Danny, a 53-year-old African American man with liver cancer and end-stage heart disease, spent time in a Texas penitentiary where prisoners were expected to pick cotton. A week before his death, Danny had a positive toxicology screen for cocaine; as a result, he was not accepted back at the residential hospice program he had once left to smoke crack. Half of the informants had been homeless, and some remained marginally housed.

Not all participants who were homeless lived on the streets. Rachel, a 64-year-old Caucasian woman with stage IV ovarian cancer, was uninsured and working as a live-in nanny when she was diagnosed. She continued to work part-time for the same wealthy family in an affluent city neighborhood and, in exchange, received room and board with one condition: She could not have any visitors. As a result, Rachel was forced to meet with friends at a local coffee shop that she walked to, but after chemotherapy, she was sometimes too tired to walk the several blocks. Rachel resented her employer but felt she had no other options.

Many participants recounted experiences of trauma, including rape, domestic violence, wartime military service, the death of a mother at an early age, and the murder of a child or other relatives and friends. They told of those traumas as incidental to another story and often in a matter-of-fact tone. Sally mentioned that she stopped working years ago after having been brutally raped and requiring intensive care for months. To the researchers, Sally’s diagnosis seemed a cruel irony. Participants’ stories often were extremely difficult to hear, and the PI who conducted all of the interviews experienced vicarious trauma from listening to and realizing the amount of trauma that many participants had endured and survived. The emotional impact for the PI (the lead author) required routine debriefing with the research team (the second and third authors) and consultation with a mental health professional specializing in multiculturalism and health disparities.

Living Not Dying of Cancer

Cancer, once regarded a terminal diagnosis, now is considered a chronic illness as a result of early detection and treatment

advances. Several participants had been diagnosed with cancer years before its progression. Some, like Terry, a 62-year-old Caucasian divorcee with metastatic colorectal cancer, spoke assuredly of having been declared “cancer-free.”

I was diagnosed with lung cancer about four months ago as a result of the colon cancer. I was operated on. The doctor said I am 100% cancer-free at this point. But they are still putting me through chemotherapy just, I guess, ‘cause they want to [laughs].

Terry was proud of having been declared 100% cancer-free by her surgeon. She claimed the success after a thoracotomy for removal of a metastatic lung lesion, a partial colectomy, and chemotherapy for her initial colon cancer diagnosis, all while still receiving chemotherapy. Patients diagnosed with cancer are called “cancer survivors,” regardless of whether they have curative or even controllable disease (Sontag, 1978). Perhaps Terry considered herself a survivor; at least she was unwilling to consider herself a “cancer victim.” In *Illness as a Metaphor*, Sontag observed that the war rhetoric of cancer is harmful because it requires or even demands that those with cancer fight no matter what the curability of the disease. Terry was faced with an incurable disease, yet she was declared cancer-free by her doctor and thus a survivor. The war rhetoric may limit possibilities during the advanced or terminal stage of cancer as victimhood becomes the only alternative when surviving is no longer possible.

Few patients discussed the possibility of death, even when it was only days or weeks away. Pedro, a 46-year-old Latino man with colorectal cancer and liver metastasis, characterized his health as “up in the air” six days before his death while hospitalized.

PI: So what would you say your health is like now?

Pedro: Well, it’s still up in the air.

PI: [pause] So, “up in the air,” meaning?

Pedro: Um, when I leave this time, I need to reevaluate my . . . decision on whether I choose to fight it or not.

PI: Uh-huh. And the fighting “it” is the cancer?

Pedro: Yeah.

“Up in the air” suggests the unknown, the uncertain. Metaphorically, “up in the air” is not on this earth. Pedro described how he felt he was coming to a crossroads and needed to evaluate whether to keep fighting. Previously, he had not perceived he had a choice about accepting chemotherapy because he was always fighting. He had never been at that place before—so close to the end of his life.

Pedro did not constantly think about cancer. Putting cancer aside was evident even to Pedro’s neighbors in the boarding house where he lived, who encouraged him to go to the hospital when his weakness and jaundice had increased; they even called 911. Despite being quite ill during the interview, Pedro wanted to continue. When he spoke about his cancer support group and its theater project for which he mixed the music, he became animated. His eyes sparkled as he described the fun in selecting each note of music and then combining them to create the right accompaniment for a production.

Three participants acknowledged that they might die as a result of cancer. All three have since died as well as four others who did not speak directly about their deaths. For those who did

not speak about their deaths, some vaguely inferred its possibility whereas others rejected it outright as a possibility. Danny believed he would live forever, and although he found comfort in the idea of an afterlife, he “wasn’t ready to find out yet [about it].” Danny died nine days after making that statement.

Gretchen, a 63-year-old European-born small-business owner, did not have medical insurance when she was diagnosed with stage IV breast cancer. She spoke unemotionally about her death from brain metastasis as a “horrible way to die.” However, according to the nurses who administered her multiple courses of “salvage” chemotherapy, Gretchen never accepted her dying despite her self-appraised poor quality of life.

Eddie saw death as a relief from worries—the worry of paying the rent, getting to appointments, and managing on a fixed income. He was grateful that he was alone and not leaving any family behind to worry about. At the same time, Eddie regretted that he was alone, had never married, and had never had a home or a family.

Sylvia, a 45-year-old Caucasian performance artist with advanced breast cancer, spoke most plaintively about the possibility of her death. Her work was just receiving recognition in the competitive art world.

‘Cause I’m only 45 years old [crying] and having to be a lot older right now. And I just really wanna be well again. . . . I want my next 20 years. You know? 30 years. I want time . . . [to] do my work and enjoy my life. You know?

Culturally, dying is accepted as a normal part of growing old and becoming frail. At younger ages, death cuts off promising careers and possibilities of life. Sylvia died a month after she made her plea.

Struggling With Healthcare Systems and Providers

Participants spoke most vividly about their struggles with healthcare providers and systems, including being sent home alone to a single-room occupancy hotel after cancer surgery while too weak to care for oneself, needing to “jump through hoops” to receive benefits, experiencing delays in diagnosing advanced cancers even after reporting symptoms to primary care doctors for more than a year, and having incomplete cosmetic surgery after mastectomy that left one woman without a breast nipple. One provider was unwilling to confront a powerful surgeon who dismissed a patient’s needs; that same provider secretly encouraged the patient to change surgeons. Inexperienced doctors were involved in inpatient care, and the seeming lack of coordination among specialists often resulted in contradictory assessments of what was wrong and what treatment was indicated. Patients also experienced standing and waiting in very long lines to drop off and pick up medication refills at outpatient pharmacies. In addition, communication with staff in ancillary departments at times was perceived as demeaning, insensitive, dismissive, and “downright rude,” if any communication even occurred.

Several participants encountered nursing care problems during hospitalization that resulted in them feeling frustrated, ignored, and, in some instances, neglected. Two patients experienced problems related to fecal incontinence and were ashamed to tell their stories. One experienced acute diarrhea as a medication side effect, whereas the second had malodorous stools and fecal urgency as a complication of colon cancer. Both put their call lights on for assistance, and both were told a nurse would assist them as soon as possible. After waiting

what seemed like more than an hour, a nurse told one patient that she had forgotten about him. The other patient reported that he became angry and “cussed” at the nurses, who scolded him and told him to “act nice.”

Both of the male patients subsequently avoided hospitalizations, sometimes at their own jeopardy. Ozzy, a 56-year-old divorced African American veteran with metastatic colon cancer living in a single-room occupancy hotel, acknowledged swearing at the nurses. He tried to problem solve and told the nurses to bring him “some big ol’ [diapers]” and washcloths, so he could take care of himself. Not trusting that he would receive help from the nurses in cleaning after his malodorous bowel movements and persistent diarrhea, Ozzy concluded that he must take care of himself while in the hospital. He even told the doctors of his difficulty getting help from the nurses, but he doubted they spoke up for him as they said they would. Ozzy had to take care of himself; he could not trust the nurses in the hospital. Trusting others may have been difficult for Ozzy, who lost his mother at a very young age. He was a loner who kept people at bay and never trusted that others would be there when he needed them.

Gracie, a 59-year-old widow with invasive cancer of the mouth, jaw, and neck who had disfiguring cancer surgery followed by six weeks of radiation therapy, described the discrimination she had experienced as an African American woman receiving care at a university medical center when she was fitted for her mouth prosthesis. She was certain that as soon as the chief of the service saw that she was an African American woman, he lost interest in her case. She was subsequently reassigned to a less-experienced provider. When asked how she felt about race interfering with the care she received, Gracie said,

Gracie: Sometimes I laugh about it. . . . Being from down South . . . I’ve had way worse than that happen.

PI: What happened down South that was worse than this? ‘Cause this seems pretty bad to me. What would’ve been worse than this?

Gracie: When I was demonstrating down South and the Ku Klux Klan burned a cross in my yard and said they were gonna kill me, and I had to leave. They had to get me out of [the South] at night when they set up to kill me. And they sent me to [another state] to save my life.

She went on to explain how a cousin who had been a mortician was murdered because he tended to the body of an African American man who had been lynched. Gracie had seen it all; racism was not new to her whether in the South or in a university medical center.

Danny spoke about being labeled and how that shaped his interactions in the healthcare system. Being labeled as an African American man and as a drug user characterized him in ways that he felt were unfair and dehumanizing. Danny did not want to be remembered only as he had been labeled. According to his social worker, Danny had a long history of difficult or challenging encounters with healthcare providers, resulting in his leaving without receiving care, being lost to follow-up, or becoming quite angry. When Danny perceived he was not heard or was being labeled as “less than,” he reacted in ways that frequently alienated healthcare providers, and their relationships seemed doomed for failure. Danny and four other participants suggested that being treated like a

human being, not being spoken to like a child, and not being treated like a number or an animal but as a person could make patients feel cared for and comfortable.

Discussion

Living with advanced cancer—the threat of death, distressing symptoms, and treatment side effects as constant reminders and dealing with multiple healthcare providers and inflexible, fragmented systems—is not easy for anyone. For the study participants, the experience of advanced cancer occurred in the context of lives that, in most cases, were already challenged and wanting. They had been struggling with life; cancer was at times just one more burden to endure. That conclusion also was reached by Song, Ratner, and Bartels (2005) in a study of end-of-life care beliefs among homeless men in the Midwest. When people lack safe housing, nutritious food, transportation to go where they want, money to meet personal needs, and competent and accessible health care, they struggle to live.

Being poor, being a person whose skin color evokes conscious and unconscious discrimination, and living in an area where the costs of living, particularly housing, are exorbitant perhaps reveal participants’ resilience and will to survive. Cancer survivorship is a social construction in common parlance. According to a report by the Institute of Medicine (Hewitt, Greenfield, & Stovall, 2006), “An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life” (p. 483). Participants in the current study were struggling to survive both life and cancer.

Not all individuals with the same type of cancer have the same odds of surviving. In cancer, just as in life, race and income matter. Cancer disparities are evident throughout the entire cancer care continuum from prevention to survivorship or end-of-life care (Freeman & Chu, 2005; Ward et al., 2004). Most participants presented with advanced disease, which compromised their chances of “beating cancer.” Few spoke about their impending deaths. Most, even those who were days or weeks from death, talked about the future and living.

Participants’ experiences with overburdened systems and providers with more patients than time, were often, but not always, less than satisfactory. For hospitalized patients, not having nurses to attend to hygiene needs was the most serious care problem described in the study. Shame, embarrassment, and frustration resulted when the participants were unable to self-manage elimination needs and when nurses were perceived as nonresponsive. Ensuring adequate staffing to meet all nursing care needs, including basic hygiene, is a challenge for nursing administrators, given the nursing shortage, but is critical nonetheless.

Many African Americans in this study experienced mistreatment by the system and perceived discrimination in their relationships with healthcare providers. The racist legacy of Tuskegee has resulted in a sense of betrayal and mistrust in clinical care and biomedical research by some African Americans (Crawley et al., 2000; Smedley, Smith, & Nelson, 2003). As a result, trust must be earned. Social workers and nurses already serving as case managers, advocates, and patient navigators through the maze of the healthcare system seem to be a possible solution and bridge for the disenfranchised and marginalized. All providers must be prepared to advocate for those whose voices often are unheard or even silenced.

More research is needed to identify the ethical issues of studying the poor who are dying, such as ensuring informed consent when payment is an undue influence and articulating how qualitative researchers may serve as therapeutic interventionists. Additional ethnographic research will allow examination and description of care structures that are respectful and disrespectful with the ultimate goal of modifying them.

Caring for a person with advanced cancer regardless of economic resources or geographic setting requires knowing the patient as a human being with a life story prior to the disease. Participants in this study had difficult personal biographies, sometimes resulting in their lack of trust toward healthcare providers and healthcare systems. Nurses who seek to understand patients' stories and appreciate their lives convey respect and caring and begin to earn their patients' trust. Listening to a patient's story allows nurses to identify that individual's information and support needs, including access to the most basic resources, such as stable and safe housing, food, transportation, income for medication copayments, and access to care. Understanding the everyday lives of patients is necessary to develop realistic and practical self-care plans and to identify needed community resources. Comprehensive cancer care for the urban poor must include intensive social services to access basic services (food, shelter, clothing, financial entitlements, and medical care), mental health care, and substance-abuse services. Cancer

nurses working with the urban poor will be called on to serve as patient advocates in negotiating systems and dealing with other healthcare professionals.

This study raises the question about how nurses might best communicate with their patients about their end-of-life wishes. Most participants in this study did not want to speak about dying—even those days or weeks from death—and instead were focused on how to live, how to survive. Insisting on discussing end-of-life care wishes may be perceived as insensitive, disrespectful, or even harmful.

For nurses practicing in acute care settings, expediently meeting basic hygiene needs, such as toileting, may decrease threats to dignity. Sometimes a patient will have to wait for nursing care. However, nurses who apologize for delays in care acknowledge their patients' humanity and recognize their suffering. Nurse administrators are responsible for providing sufficient staffing so that patients' needs are met. In times of nursing shortages, staffing problems interfere with the relationships of patients and their nurses. In the final analysis, however, improving cancer care for the urban poor will require nothing less than public policy reforms that redress underlying racial and ethnic discrimination, economic inequities, and a healthcare system that well serves far too few.

Author Contact: Anne Hughes, RN, PhD, FAAN, can be reached at anne.hughes@sfdph.org, with copy to editor at ONFEditor@ons.org.

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