

“Can You Give Me Respect?” Experiences of the Urban Poor on a Dedicated AIDS Nursing Home Unit

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In this interpretive phenomenology study, 10 impoverished adults with advanced HIV disease, ages 35 to 58 years, described their understanding of dignity and their everyday experiences in an urban AIDS-dedicated nursing home unit. Three group interviews, along with field notes, were audiotaped, transcribed, and analyzed. For most, dignity meant respect received by others and respect for oneself; some did not understand the word dignity. Receiving respectful care enhanced a sense of dignity for some, and for others, difficulties with caregivers led to feeling unrecognized or disrespected. Everyday experiences of living on the unit included narratives about how they got there, taking antiretrovirals, escaping, the unit as a community of caring, witnessing deaths, relationships with nurses, the unit as a place of safety, and knowing when to leave. This study contributes to knowledge of marginalized minority groups with advanced HIV disease whose experiences often remain silenced.

Key words: *dignity, health disparities, HIV, homeless, marginalization, minorities, nursing home, palliative care, qualitative research, race, respect, substance abuse, urban poor*

In the third decade since HIV was first recognized in the United States, the global pandemic has become associated with poverty and racial/ethnic inequities (O'Neill, Romaguera, Parham, & Marconi, 2002).

Despite overwhelming evidence of the success of antiretroviral (ARV) therapies in reducing HIV-associated morbidity and mortality, stigma and discrimination persist, undoubtedly in part because of the cultural taboos of sex and drug use and their links to viral transmission. Since the widespread use of ARVs in the mid 1990s and the technological ability to monitor serum viral loads and detect drug-resistant genotypes, the illness trajectory of HIV infection and its end-stage complication, AIDS, has been changed from one that was acute and terminal to one that is chronic and manageable (Selwyn & Forstein, 2003). Consequently, recognizing the end stage of HIV presents difficulties because HIV biomarkers such as plasma viral loads and CD4+ cell counts do not predict end stage disease (Brechtel, Patrick, Visintainer, & Brand, 2005). Prognostication challenges using objective biomarkers, however, are not unique to HIV (National Institutes of Health, 2004).

As a result of treatment successes, more individuals are living with advanced HIV disease decades after their initial infection. This success has also

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contributed to a misperception that all persons living with HIV (PLWH) who have access to ARV therapy are well and living full lives. Selwyn et al. (2000) believe that the success of ARV treatment in decreasing mortality may also contribute to more HIV-related disability, thus resulting in greater need for nursing home and other long-term care and requiring further integration of palliative care into HIV care (Selwyn & Forstein, 2003). Little is known about what matters to PLWH with advanced disease who are receiving care in long-term care settings. Indeed, their experiences in long-term care, just like their very existence, are often pushed to the margins.

Background and Significance

In the United States, decreasing health disparities has become a health policy priority (Smedley, Stith, & Nelson, 2003). An uncontroversial disparity in HIV is its epidemiology; HIV disproportionately affects vulnerable and marginalized populations, groups that are already at risk for adverse health outcomes (Aday, 2001) and whose experiences are invisible to the mainstream. African Americans account for almost 50% of all AIDS cases in the United States while making up only 13% of the population; Non-Hispanic Whites account for 30% of the AIDS cases and represent 68% of the entire population (Centers for Disease Control and Prevention, 2007). Disparities, however, persist beyond race and HIV epidemiology. In the United States, African Americans are three times as likely to be economically impoverished as are Whites; one in four African Americans meets the federal criteria for poverty, which is generally believed to underestimate the number who are poor (DeNavas-Walt, Proctor, & Lee, 2006). Clearly, poverty is not restricted to communities of color; nonetheless, poverty and HIV are disproportionately felt by these groups.

In an unpublished pilot study conducted by the first author, persons with advanced cancer and advanced HIV disease were asked about their hopes, concerns, and expectations about end of life (EOL) care. Several informants discussed the importance of being treated with dignity when hospitalized or of the “dignity of the Black man.” This finding brought about an exploration of dignity at EOL initially through a literature review, briefly synthesized below.

Dignity is a construct discussed in relation to international human rights, disability, aging, bioethics, and EOL care most specifically in the United States, in the context of physician-assisted suicide for persons with terminal illnesses such as cancer or AIDS (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Jacobson, 2007). Whereas dying with dignity is frequently mentioned as an outcome of good EOL care, there is little consensus about its definition (Field & Cassel, 1997; Leung, 2007; Street & Kissane, 2001). Consequently, the Institute of Medicine’s report on EOL care recommended as a goal, “death dignified by care that honors and protects—indeed cherishes—those who are dying.” (Field & Cassel, 1997, p. 25).

Researchers studying dignity at the EOL have used quantitative (Chochinov et al., 2006; Hack et al., 2004; Turner et al., 1996) and qualitative (Chochinov et al., 2002; Enes, 2003; Rogers, Karlsen, & Addington-Hall, 2000; Street & Kissane, 2001) approaches. Almost all included persons with cancer and presumably similar disease trajectories. None of the studies were conducted in the United States, and almost all patients in these studies were receiving hospice or palliative care services in countries with nationalized health care systems. Income information and racial/ethnic data were generally not provided. However, most EOL research in the United States has not identified nor addressed the needs of communities of color (Krakauer, Crenner, & Fox, 2002). Some research has suggested that inpatient care threatens a patient’s dignity (Chochinov et al., 2002; Enes, 2003; Rogers et al., 2000). A recent German study explored dignity at the EOL among elderly nursing home residents (Pleschberger, 2007) and concluded that these residents (patients) were at particular risk for threats to or loss of dignity because of limited support systems. Furthermore, Pleschberger (2007) noted that in most nursing homes there are insufficient numbers of caregivers to meet basic care needs, let alone recognize their patients as human beings. No studies exploring dignity among PLWH with advanced disease, living in the community or receiving care in an institution such as a nursing home, were located.

Few nursing homes in the United States in either urban or rural areas provide specialty care for PLWH (Pearson & Hueston, 2004); in the early part

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