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# "Can You Give Me Respect ?" Experiences of the Urban Poor with Advanced Disease

by

Anne M. Hughes

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

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So many have helped me realize this dream. Thirty one persons living with advanced cancer or advanced HIV disease shared their experiences with me; for some, these conversations occurred days or weeks before their deaths. Their generosity and willingness to entrust me with their stories made this research possible.

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This dissertation contains work originally published in other journals and is reprinted here with the generous permission of those publishers. Chapter two, my review of the literature, "Poverty and palliative care in the U.S: Issues facing the urban poor," was originally published in 2005 in *International Journal of Palliative Nursing* and is reprinted here with the permission of the MA (Mark Allen) Healthcare publishing group of the United Kingdom. Elsevier Limited generously granted permission for the reprinting of Table 2 Dignity Model, from a paper published in 2002 in *Social Science and Medicine,* authored by H.M. Chochinov and colleagues, entitled. "Dignity in the terminally ill: A developing empirical model." Permissions from the publishers are included in the appendix.

## ABSTRACT

"Can you give me respect?" Experiences of the Urban Poor with Advanced Disease

Anne M. Hughes

Poverty is a global public health problem with profound moral implications about what it means to be [a]part of the human community. In the United States, one in eight persons lives below the federal poverty line, a metric widely believed to underestimate the scope of the problem. While several ethnographies have described communities affected by poverty, far less research has focused on the personal toll of being poor in an urban area while struggling with a serious illness. Dignity is a concept addressed in human rights declarations, discussed in theological and philosophical descriptions of personhood, and described in clinical contexts relating to end of life care, physician assisted suicide, aging and disabilities. The purpose of this primarily interpretive study was to describe the meaning and experiences of dignity to the urban poor with advanced disease using a mixed methods design. First person in-depth accounts through individual or group interviews and field notes were primary data sources; a survey examined Chochinov's inductively derived model of dignity. Participants included 31 adults, with an average age of 52 years, who were living with cancer, HIV disease or both illnesses. Participants had multiple vulnerabilities: almost 75% were from communities of color and approximately two thirds had histories of homelessness, substance abuse, or other co-morbidities. Ten participants died during data collection. Many participants discussed respect rather than dignity, respect given to and received from others, and self-respect. Most narrated difficult personal biographies that included the loss of beloved family members and other traumas. While describing their illness experiences, difficulties with health care systems and health care providers were noted frequently and described in vivid detail. Participants were significantly ($p < .001$) more likely to report a severe loss of dignity as a result of illness than advanced cancer patients in Canada; many also reported a severe loss of dignity prior to illness. Understanding the everyday lives of the urban poor with advanced disease is essential for providing care that appreciates their humanity and recognizes their struggles to manage illness and treatment demands, as well as for creating environments that are more responsive to their needs.

Work count: 349

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# CHAPTER ONE: INTRODUCTION AND STATEMENT OF PROBLEM

"You matter because you are you and you matter to the last moment of your life. We will do all we can do to help you, not only to die peacefully but to live until you die."

Dame Cecily Saunders, *Nursing Times*, 1974

We see them and yet they are invisible, they live at the margins of society. Thirty-seven million Americans (one in eight) live below the poverty line, the federal household annual income level, an absolute measure of poverty, which defines who is poor (DeNavas-Walt, Proctor, & Lee, 2006). Most of the poor live within urban areas, rather than in communities outside of metropolitan areas, or in suburbs (DeNavas-Walt et al., 2006); although rural poverty is also a significant public health and social problem. The poor are a vulnerable population, an epidemiological and health services term used to describe groups of people at risk for adverse health outcomes (Aday, 2001; Flaskerud & Winslow, 1998). Little is known about what happens when the poor are seriously ill with a lifethreatening and progressive illness, such as cancer or HIV disease (Hughes, 2005, 2006; Moller, 2004; Williams, 2004).

The goal of this chapter is to provide a framework for this dissertation which includes four chapters that have been or will be submitted for publication. The chapter describes aspects of the researcher's biography that situates this research, presents the background and significance of the problem, states the research question, discusses methods and procedures used to address the research question, and includes some of the key findings, some of which modified the original line of inquiry. The chapter concludes by introducing the organization of the remaining chapters.

## Researcher’s Biography

Qualitative research acknowledges that the researcher is an integral part of the research process (Denzin & Lincoln, 2000). Researchers cannot assume some distanced, objective or uninvolved stance when conducting research but bring their own experiences and expectations of the project that inform not only the questions that they ask, but also influence their ability to hear answers that may differ from their expectations. Reflexivity, or self-reflection about one’s relationship to a project, is necessary to appraise a researcher's representation of a phenomenon (Schwandt, 2001).

I grew up in an Irish Catholic working class family, in a neighborhood in Philadelphia with blocks of row homes. My maternal grandparents were born in Ireland. My father was a construction worker who installed and repaired elevators and my mother, who worked most of my childhood, worked in blue-collar jobs such as packing foods on a conveyor belt line or answering telephones. During the Depression, my father's family was poor; he and his siblings often went to bed hungry and cold. One of the values my father instilled in me was a concern for those who were less fortunate, in his words, "the underdog" and a tolerance for difference. Two uncles were Catholic priests; my dad’s brother, Uncle Joe taught me to think, to question, and always to learn.

My first nursing position after completing a two-year Associate Degree nursing program at Gwynedd-Mercy College outside of Philadelphia was in a Catholic hospital in a very poor, black community in west Philadelphia. In the early and mid-70s, and even today 30 years later, gang wars were killing many black youth; in Philadelphia the police department had a reputation for excessive use of force. I witnessed first hand the plight of

the urban poor and the effects of racism and violence on communities that were struggling to survive.

Almost all of my 33 years of practice as a nurse has been caring for the urban poor, in a variety of clinical settings—acute care, home care, hospice and most recently long term care. My career included several stints as a visiting nurse including one in a walking district in south Boston, "Southie," where I cared for poor families living in dilapidated public housing projects.

In the early 1980s, I moved to Seattle to complete a family nurse practitioner (FNP) master's degree program at University of Washington (UW). While in graduate school, I completed an extraordinary elective with Jeanne Quint Benoliel called," Death Influence on Clinical Practice," which profoundly affected me. The course and Dr. Benoliel's teaching approach marked a transition point in my career with the recognition of a passion to work with persons who were dying. After completing the FNP program, I completed a second program at UW called Oncology Transition Services that prepared clinical nurse specialists to care for patients and families affected by progressive and life-threatening illness, such as cancer. In the early 1980s, a deadly virus was infecting gay men, Haitians and hemophiliacs; we now call this global pandemic, HIV/AIDS. I decided to work with persons with AIDS in part due to a sense of responsibility I felt, as a lesbian, to care for persons who were not always accepted because of being different.

Since completing my master's degree at the UW in 1985, my practice has centered on caring for persons with AIDS, cancer, and more recently with other debilitating conditions. For the past 18 years, I have worked for the San Francisco Department of Public Health in health care institutions that serve the poor, San Francisco General

Hospital (SFGH), an acute care teaching hospital and Laguna Honda Hospital (LHH) an 1100 bed skilled nursing facility.

My commitment to caring for persons facing the end of their lives dates back to that first job caring for those adolescents who were dying senselessly from gunshots and stab wounds, and to poignant personal experiences. In my personal narrative, my mother showed me how to love, to care about others and to make them feel at ease. She became very ill and was diagnosed with leukemia while I was in nursing school; my mother died one year after I became a nurse. As a young nurse, I tried valiantly and naively to save her. In the process of my mother's illness and dying, I observed first hand, how families are affected when a loved one is seriously ill and dying. At the same time, Elizabeth Kubler Ross was lecturing throughout the world about the needs of the dying; I was inspired by her work. Consequently, the living and dying transition have been among my personal and professional interests ever since. In addition, my commitment to caring for persons who are vulnerable because of poverty is part of the legacy of my father who died 9 years ago. My biography has shaped my background understandings of the world and what matters, namely that caring for the dying has taught me so much more about living.

## Research Question: Background and Significance

The original aim of this dissertation research was to understand the meaning and experience of dignity to the urban poor with advanced cancer or advanced HIV disease. Dignity was important to understand for several reasons. First, in the discourse about death and dying, a hope expressed by many is to die with dignity. Dying with dignity has been cited as requisite for good death, is memorialized in advanced directives, and

offered as rationale for requests for assisted suicide. Secondly, an inductively derived model of dignity based on interviews with 50 palliative care patients in Canada (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002) was published as my research question was being formulated. Chochinov's program of research has extended to test the dignity model with existing quantitative measures (Chochinov, 2002; Chochinov, Hack, Hassard et al., 2002; Hack et al., 2004), design a dignity intervention (Chochinov et al., 2004) and most recently, validate the original conceptualization of the model (Chochinov, 2006; Chochinov, Hack, McClement et al., 2002).

Third, in the nursing literature the concept of dignified dying has been proposed as an outcome of palliative care nursing suggesting that dignity at the end of life is important to nursing care, and is measurable (Doorenbos, Wilson, & Coenen, 2006; Maas, 1998; S. A. Wilson, Coenen, & Doorenbos, 2006). Finally, in a pilot study in an advanced qualitative research methods course, two of the 5 patients I interviewed commented about dignity in their narratives about their hopes and concerns regarding the end of life. Julie, a 58-year-old white woman with advanced lung cancer discussed "being treated with dignity" in the context of inpatient hospital care, and Jose, a 73-year-old self-described, "black Puerto Rican" with prostate cancer and AIDS spoke about dignity as it related to the personhood of the black man. Listening to these patients and appreciating the discourse about dignity led me to focus my research on dignity and to review and critique the literature in this area.

Studies that examined dignity at the end of life differed in the epistemological assumptions of the researchers. Some treated dignity as an objective and measurable phenomenon while others regarded dignity as a subjective and lived experience.

Moreover, while none of the studies were conducted in the US, all were conducted in English-speaking countries with nationalized health care systems (Chochinov, 2002; Chochinov et al., 2004; Chochinov, Hack, McClement et al., 2002; Enes, 2003; Rogers, Karlsen, & Addington-Hall, 2000; Stienstra & Chochinov, 2006; Street & Kissane, 2001; Turner et al., 1996). Almost all patients had cancer, most were in hospice, and all were conducted in countries with a longer tradition of palliative care than is the case in the United States. The role of place or setting (inpatient versus community) in supporting or detracting from dignity was evident in studies that did not include the urban poor. An inductively derived model of dignity (Chochinov, Hack, McClement et al., 2002) was used as framework for several studies and guided selection of instruments to measure the conceptualization (Chochinov, 2006; Chochinov, Hack, Hassard et al., 2002; Hack et al., 2004), and to develop and test an intervention (Chochinov et al., 2005).

Moller (2004) described the indignities encountered by poor cancer patients who lived in a Midwestern city in the US, but the meaning and experience of dignity were not described. Whether Chochinov's model is applicable to experiences of the urban poor in the U.S. and whether the instruments used to measure dignity would capture what is important about dignity to this population were unknown and untested. Based on my synthesis of the literature, specific research questions were developed to guide the study and are described in the following section on methods.

## Methods

### *Design*

Mixed methods, the use of both qualitative and quantitative approaches, were selected to answer the research question, “What is the meaning and experience of dignity

to the urban poor with advanced disease?" Mixed method approaches are grounded in the belief that combining qualitative and quantitative data creates a more complete and complementary understanding of a phenomenon of interest (Creswell, 2003; Foss & Ellefsen, 2002; Sandelowski, 2000). The rationale for the use of mixed methods was based on the state of knowledge regarding dignity at the end of life.

Voices of the urban poor in the U.S. with advanced disease were virtually silent in the existing literature; therefore a qualitative approach, such as interpretive phenomenology provided a first person account and thick description of the phenomenon. Specific questions which guided the interpretive phenomenological inquiry were:

1. What are the meanings of dignity and indignity at the end of life (EOL) for the urban poor?
2. How are dignity and indignity experienced in the everyday lives of the urban poor?
3. Does the meaning of dignity change as illness progresses?
4. What are the differences in how dignity is experienced when receiving care in an institution?
5. How does dignity affect the experience of living with a life-threatening illness?

However, the emergence of a dignity model, its empirical testing and the recent development of an intervention, presented a unique opportunity to examine the relevance of Chochinov's dignity model in a vulnerable and marginalized population in the US, the urban poor (Chochinov, 2006; Chochinov & Cann, 2005; Chochinov, Hack, Hassard et al., 2002; Chochinov, Hack, McClement et al., 2002; Chochinov et al., 2006). Furthermore, using a quantitative approach, such as a survey, gave me with the

opportunity to learn a method more commonly used in nursing research while being mentored by Dr. Anita Stewart, a member of my dissertation committee. No hypotheses were tested as this work was considered descriptive concept development. Specific questions which guided the survey portion of this research were: (1) What is the acceptability of using selected self-report instruments with this population? and (2) How do informants respond to investigator-developed items to measure dignity based on Chochinov's model?

Creswell (2003) argued that one method, either qualitative or quantitative, must be the primary approach in answering the research question when using mixed methods. In this study, interpretive phenomenology was the primary methodology. The philosophical framework of interpretive phenomenology is based on the writings of Heidegger (Heidegger, 1927/1962), as interpreted by Dreyfus (Dreyfus, 1991) and as methodologically applied and further elucidated by Benner (Benner, 1994; Benner, Tanner, & Chesla, 1996) and other interpretive nurse scientists (Gudmundsdottir & Chesla, 2006; Leonard, 1994). Interpretive phenomenology seeks to understand, not to explain or to predict participants' worlds- their concerns, habits and practices as they show up in narratives; interpretive accounts are always contextualized (Benner, 1994). Interview transcripts and field notes provided the primary qualitative data for this analysis.

The research questions and my clinical experience further shaped the design of this study. Given my 20 years of practice caring for persons with HIV disease and cancer, I was curious about what differences, if any, might appear in their experiences of dignity; as a result, both groups were sampled. The literature suggested that persons in institutions

were at risk for loss of dignity; this guided the decision to collect data from persons living in a dedicated AIDS nursing home unit. Nursing home residents are considered a vulnerable population; to minimize this vulnerability, I conducted group interviews which had the added effect of stimulating participants' conversation with the researchers. To address whether dignity experiences changed over time, and consistent with interpretive phenomenology, patients living in the community were interviewed several times. Procedures and data collection schedules are described briefly in a following section and are more fully outlined in Appendix A. Informed consent documents are included in Appendix B; the study recruitment flyer is contained in Appendix C.

### *Ethical Concerns*

Some anticipated and unanticipated ethical concerns were encountered during the conduct of the study and after the research had been approved by the UCSF Committee on Human Research (CHR), UCSF Comprehensive Cancer Center Protocol Review Committee and SFGH Data Governance Committee and LHH Data Governance Committee. Others reported similar ethical questions among clinical researchers (DuVal, Gensler, & Danis, 2005), specifically, as was the case in this study, related to informed consent and end of life concerns.

Subjects were paid $15 per interview as a recruitment and retention strategy; this decision was consistent with a body of research ethics literature (Dickert, Emanuel, & Grady, 2002; Dickert & Grady, 1999; Grady, 2005; Macklin, 1981) and the practice of other research conducted with the same population. Paying subjects was a token of respect for their contribution. For some participants, however, $15, the average hourly rate in San Francisco, was considered a lot of money and undoubtedly influenced their

participation in this research. Nevertheless, to not pay them because they are poor while expecting their voluntary participation would have been exploitive.

Voluntary consent to participate in research is a core principle of research ethics. The ability of persons who are seriously ill or bereaved to give informed consent, presents some particular challenges (Casarett, 2005; Casarett, Knebel, & Helmers, 2003). When I met with persons with HIV/AIDS who were cared for on a dedicated HIV/AIDS nursing home unit to describe the study and obtain their consent, I assessed their decisional capacity informally. Two assessments indicated a lack of ability to give voluntary consent; these two individuals were excluded from participation in the study. During the group interviews, all participants were engaged in the discussion; however, two participants' comments at times were tangential and non-responsive and I wondered about their cognitive function. Patients (residents) on the AIDS unit who qualify, are eligible for medical cannabis these two participants may have used marajuana before the group interviews as its use was individually managed by the patients. Likewise, some inpatients and outpatients with no apparent cognitive impairment, had difficulty answering some of the survey questions.

Four participants were interviewed days or weeks before their death. When a participant's dying was recognized and acknowledged by staff (either in a single room occupancy hotel [SRO] or in a clinical setting), I asked the staff member to reaffirm the patient's acceptance of my scheduled visit. During these conversations with staff members, I acknowledged my awareness that dying was a particularly sensitive time and my intent not to be intrusive. During the interview with terminally ill and actively dying participants, I reminded them that they did not have to answer any question that they did

not feel like answering, that we could shorten the interview. All insisted that they wanted to continue with the interview and some even asked me to stay with them for a while after the interview had been completed. To avoid fatiguing these participants, I nevertheless shortened some interviews.

### *Procedures and Data Collection*

The original data collection plan (see Appendix A) was to interview all informants before the administration of a survey. The interview guides for both individual and group interviews are included in Appendix D. Some informants (n = 15) would be interviewed in a group to describe the impact of institutionalization on dignity; others (n = 15) would be interviewed individually and followed over time. This plan was modified however because of difficulty recruiting advanced cancer patients living in the community for a group interview; consequently, the cancer patient group interview (n = 5) originally proposed did not occur. In general, cancer patients living in the community were too sick, too busy with other medical appointments, and without transportation to attend a group interview. Seven of the 14 (50%) cancer patients interviewed died during the data collection period. With the approval of my committee, more cancer patients were followed individually than was originally planned.

The procedures resulted in an ethnographic intensity that is illustrated by the description that follows. All interviews were audiotaped, transcribed verbatim and checked for accuracy. Participant observations, including informal conversations with health and social service providers, were recorded in field notes that were also transcribed verbatim. Ten participants (34%) died by the end of the 13 months of data collection.

Following the initial interview, a survey based on Chochinov's model was administered to each participant. Researchers using mixed methods must decide the sequencing of data collection measures (Creswell, 2003; Creswell, Fetters, & Ivankova, 2004). To avoid influencing the participants' narratives about dignity, the survey was administered after the initial in-depth individual or group interview with each participant. To minimize measurement concerns related to literacy, the survey was read to each participant and responses were recorded by the researcher (see Appendix E for survey).

The survey had six sections. Section 1 had 33 dignity items, which I developed to measure themes and sub themes from the Chochinov model and a single item used by Chochinov to measure loss of dignity, or "fractured dignity" (Wilson et al., 2000). This single item was asked twice, once to measure loss of dignity related to illness and a second time to measure loss of dignity experienced prior to becoming ill. The Symptom Distress Scale (McCorkle & Young, 1978) was used by Chochinov and colleagues (Chochinov, Hack, Hassard et al., 2002; Hack et al., 2004) to measure part of the Illness Related Concerns aspect of the model. The Control Preference Scale (Degner, Sloan, & Venkatesh, 1997) is an inductively derived instrument and was used to measure the autonomy/control aspect of Dignity Conserving Repertoire. The QUAL-E (Steinhauser et al., 2002), which is a 26-item inductively derived instrument for measuring quality of life at the end of life, replaced a two item scale measuring quality of life used by Chochinov. The Enforced Social Dependency Scale (Benoliel, McCorkle, & Young, 1980) [ESDS] was used to measure functional status, which is a part of the Illness Related Concerns aspect of the Chochinov dignity model rather than the Katz IADL measure used in Chochinov's earlier study because the ESDS measures additional aspects of adult role

capacity that may be compromised as a result of illness. The demographic information included self-assessment of present financial status and the financial status of the family of origin. See Appendix F for organization of questionnaire and source of investigator developed items.

### *Data Analysis*

Narrative analysis based on interpretive phenomenology was used to analyze three group interview transcripts and field notes of in-depth interviews of 10 informants living in a dedicated AIDS nursing home unit to understand the impact of an institutional setting on the experience of dignity. Groups of three-to-four English-speaking patients with advanced HIV disease, as determined by a health care provider, and able to provide informed consent, were interviewed one time only in a group that was co-facilitated by an African-American female multicultural consultant and me. The consultant co-facilitator also served to decrease the researcher-clinician role confusion related to the dedicated AIDS nursing home unit group interview, because I had worked in the facility.

"Clinical ethnography" is a term coined by Benner (1994) to describe the use of interpretive phenomenology for studying the illness experience. Interview texts and the researcher's participant observer field notes provide insights into the practical knowledge of living with a chronic illness, self-care practices, health seeking practices, the meaning of illness and coping patterns of the person in the situation, (Benner, 1994, p. 122). In addition to the 10 informants living in the dedicated AIDS nursing home unit, 21 persons with advanced cancer or advanced HIV disease were interviewed and followed in the community. These interviews conducted over time uncovered the experiences of living with two progressive illnesses with distinctly different trajectories, and how dignity was

experienced. Interview guides for both group and individual interviews are included in Appendix D. However, consistent with qualitative approaches, conversations flowed naturally based on the concerns raised by the participants and were not constrained by questions or probes in the interview guides.

The intensity of ethnographic work is apparent not only in the actual time spent conducting 3 group interviews, 50 individual interviews, and administering 29 questionnaires, but also in my repeated observations of care settings, participants' residences and neighborhoods, and of patient-provider-system interactions. The emotional impact of this project on me as researcher, as clinician in one of the study sites, and as a human being will remain a part of me long after this dissertation is completed. Indeed the trauma, despair and the poignancy of participants' narratives were so distressing that I sought professional counseling to further debrief what I was witnessing and experiencing during data collection. Appendix G includes excerpts of field notes from interview visits that reveal the emotional valence and moral distress associated with this research.

In the dedicated AIDS nursing home unit, I spent almost 40 hours making the consent visits, arranging and conducting group interviews, and administering individual surveys. These were conducted on weekends or on holidays. I spent additional hours during my work week on the dedicated AIDS nursing home unit during the study in my clinical role as palliative care consultant. One patient who had participated in the study was referred for consultation for pain management after data collection had been completed. The father of a second informant was referred to me in my work role for support related to his adult child's progressive illness and subsequent death.

In a public hospital's outpatient oncology clinic, I devoted approximately 75 hours identifying and recruiting potential participants, observing patient flow in the clinic, and listening to providers discuss individual cases or the problems they experienced in caring or obtaining services for their patients. I observed for 20 hours in hospital or hospice inpatient units while interviewing four participants with cancer who were receiving care in these settings. I also observed in neighborhoods, housing projects and SROs where participants lived; these observations were conducted in association with 120 hours of scheduled interviews, as well as serving as patient educator during an outpatient cancer patient education program (3 hours) attended by 20 patients. Finally, I conducted formal interviews which I audiotaped and transcribed, with a medical oncologist who had many years of caring for this population; a social worker and a nurse who both work with substance using patients with AIDS and cancer; and the interdisciplinary care team at the dedicated AIDS nursing home unit (total of 8 hours).

What is not captured in the almost 270 hours of field work and interviews are the many hours contacting and tracking community dwelling informants to schedule follow up interviews. Interviews with community dwelling participants were planned for a total of four interviews (including the survey visit) approximately 4 weeks apart. Several informants did not have phones or if they did, did not have answering machines to leave messages; for those without phones, messages left at hotel front desks may or may not have been given to the informants. As a result, multiple visits were attempted to locate some participants; in some cases, the contact persons whose names were given by the informant were enlisted to locate the participant. While I was trying to locate an informant, I found myself worrying about their wellbeing.

Informant interviews produced a total of 1,116 pages of transcribed text for analysis. Ten patients died during the 13-month data collection period; four died within 2 weeks of their last interview. All four, while clearly dying, insisted on continuing the interview and contributing to the study. The median time from last interview until death was 37 days and the range was 6 to 181 days.

For purposes of this dissertation, the analysis of survey data was limited to the items which were developed to measure aspects of Chochinov's (2002) dignity model and the single item used to measure loss of dignity that resulted from illness and the loss of dignity that preceded the diagnosis of cancer or HIV/AIDS. In a recent paper by Chochinov (2006), his research team reported items that they developed to measure themes and sub-themes of their dignity model; unfortunately, this paper with their items to measure dignity was published more than midway through my data collection. However, Chochinov's dignity items (2006) are compared with my items to examine his model.

## Key Findings

The racially and ethnically diverse sample included 31 persons living with either advanced HIV disease (n = 14), advanced cancer (n = 14) or with both illnesses (n = 3). Most participants had multiple vulnerabilities in addition to poverty that affected their ability to access and to receive care, such as homelessness, other medical co-morbidities, substance abuse, trauma histories or were members of communities of color that historically have experienced racism and discrimination.

Table 1 describes the sample demographics. Ten of the 31 participants were interviewed one time in a group while receiving care in an AIDS dedicated nursing home

unit. The remainder of the participants (n = 21) were interviewed individually from one-to-three times for a total of 50 individual interviews. Data collection was stopped before all interviews could be completed, with the approval of my committee, because sufficient data had been collected to complete the analysis. Interviews were conducted in the participants' single room occupancy (SRO) hotel rooms or other residences, in coffee shops, in building lobbies, in hospital rooms, and in a residential hospice unit. All interview locations were in the San Francisco Bay Area, most in two or three impoverished neighborhoods in San Francisco.

Participants described the impact of living with HIV or cancer, experiences with health care providers, challenges faced and sources of support. Figure 1 lists key findings from this study; however, it is beyond the scope of this dissertation to discuss all of the findings. Rather, the most salient findings are presented in three separate chapters of this dissertation; each of these chapters is a manuscript that has been, or will be submitted for publication.

An unexpected finding was that many participants interviewed did not relate to the concept of dignity. An example can be heard in the words of Sally, a 55-year-old white woman with advanced ovarian cancer who lived in an SRO, "What does dignity mean? I got to know what it means before I can answer the questions [survey visit #2]." One participant in a group interview went to the dictionary to learn the definition of this "new" word dignity. Several commented that they had not heard of the word dignity, or never thought about it, until I introduced it during the interview. This latter observation is curious given that the consent forms clearly discuss dignity and none of the participants had any questions about the study or its procedures when they were asked during the

consent process. Despite the observation about dignity being an unfamiliar concept for some informants, most participants responded to survey items about loss of dignity without any difficulty. One of the challenges of mixed method design is reconciling qualitative and quantitative findings; data from this study underscores some of this complexity.

Survey data is missing for 2 of the 31 participants; one participant with AIDS was lost to follow up after leaving the nursing home unit and the second participant with advanced cancer died within a week of the initial interview. Despite the possible conceptual confusion about dignity, participants in this study responded without hesitation to a question about illness related loss of dignity and 55% (n = 16) reported most severe or what Chochinov referred to as “fractured dignity” compared with 5.3% (n = 11) of Chochinov’s sample of 211(Chochinov et al., 2006). Furthermore, 15 of the 29 participants in this study reported a severe loss of dignity occurring before their illness.

Rather than dignity, more informants talked about the importance of respect, and described a lack of respect or disrespect as problematic. Respect as described by these informants was generally synonymous with what has been written about dignity i.e., the recognition of personhood and membership in the human community. Vicky, a 56-year-old African American woman living in the community with AIDS and severe COPD observed that hip hop, or rap, music uses the term “dis” to represent disrespect. She believed that these lyrics underscored the importance of treatment with respect. Consistent with interpretive phenomenology, lines of inquiry evolved over the course of a study to reflect what was meaningful and experienced by the informants (Benner, 1994;

Crist & Tanner, 2003) rather than being constrained to the original research question that may not have seemed relevant to the participants' lives.

## Organization of Chapters

The dissertation is organized into five remaining chapters. The second chapter is entitled "Poverty and Palliative Care in the US: Issues Facing the Urban Poor." The text of this chapter is a reprint of a journal article as it appears in *International Journal of Palliative Nursing* (Hughes, 2005) and is published here with permission (see Appendix H). The paper reflects a focused review of the literature that described the problem of poverty in the U.S., identified challenges providing palliative care to the urban poor, and articulated implications for nursing research and nursing practice. An appendix to this already published paper highlights the limited pertinent literature published since 2005.

Chapters 3 to 5 present study findings and each will be or have been submitted for publication. The co-authors listed in the publication directed and supervised the research that forms the basis for the dissertation. The third chapter is entitled, "Can You Give Me Respect: Experiences of the Urban Poor Living on a Dedicated AIDS Nursing Home Unit." This paper presents a narrative analysis that uncovers the everyday experiences of living on a dedicated AIDS nursing home unit and how participants described dignity and respect. The fourth chapter entitled, "Everyday Struggling to Survive: Experiences of the Urban Poor Living with Advanced Cancer," describes the everyday struggle of persons living with cancer and has been submitted for publication to the *Oncology Nursing Forum*. The fifth chapter, "Measuring Dignity in the Urban Poor with Advanced Disease," compares the attitudes, beliefs, and values related to dignity as theorized by Chochinov of this urban poor sample (N = 29) with a Canadian sample using related but

not identical items (Chochinov, 2006) and reports on the loss of dignity using quantitative measures.

The final chapter summarizes the research presented in this dissertation, discusses implications of the key findings for practice and research, and identifies questions for further research.

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Table 1
Sample Demographics (n = 31)

| **Characteristic** | **N (%)** |
|---|---|
| Illness Group | |
| Advanced HIV | 14 |
| Advanced Cancer | 14 |
| Both HIV and Advanced Cancer | 3 |
| Gender | |
| Male | 15 (48) |
| Female | 14 (45) |
| Transgender | 2 (7) |
| Age | |
| Mean | 52 years |
| Range | 35-69 |
| Race and Ethnicity | |
| African American/ Afro-Caribbean/ African | 16 (52) |
| Caucasian/European | 8 (26) |
| Hispanic/Latino | 3 (10) |
| Multiethnic | 3 (10) |
| Native American | 1 (3) |
| Education | |
| Less than high school | 9 (31) |
| High school or GED | 7 (24) |
| Associate degree/some college | 10 (34) |
| College graduate/graduate school | 3 (10) |
| Informants by interview type | |
| Group | 10 |
| Individual | 21 |
| History of Homelessness | |
| Yes | 21 (68) |
| No | 10 (32) |
| Co-morbidities # | |
| Yes | 19 (65) |
| No | 10 (35) |
| History of Substance Abuse | |
| Yes | 20 (64) |
| No | 11 (36) |
| Completed survey # | 29 |

*Note*: # = missing data

Table 2

Key Dissertation Findings

Dignity and Respect

- Dignity was a concept that few understood or found meaningful.
- More patients related to respect (given to and expected from others, and respect for self) than they related to the concept of dignity.
- Significantly more patients in this sample reported an illness-related loss of dignity than in Chochinov's samples (2002, 2006) using the same measure.
- Many reported a loss of dignity prior to their diagnosis with AIDS or cancer.
- Narratives of indignity in the health care system included feeling talked down to, perceived racial discrimination, being forgotten, feeling labeled, and experiencing shame when personal hygiene needs were unmet in a timely manner.
- The loss of dignity was easier to describe than its presence.

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For All Participants

- Family support was limited.
- Spirituality was a source of support and comfort for most.
- Pain and other disease and treatment related symptoms were commonly experienced and reminders of being sick.
- Significant trauma exposures, such as rape, homicide of loved ones, domestic violence, military war experiences, and loss of parents or home at a young age, were common.
- Isolation and loneliness were prevalent especially evident in community dwelling informants.
- For some, illness was a foreground concern while for others illness was an inconvenience that was worked around like other life inconveniences.
- Very few spoke about the possibility of their dying, even days or weeks prior to death.
- Histories of homelessness were common and a source of shame for some.
- Current or past substance abuse and related co-morbidities (such as liver disease related to hepatitis C, or pulmonary disease due to tobacco or crack use) were prevalent.

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Living in a Dedicated AIDS Nursing Home

- The experience of living in a nursing home was shaped by relationships with nursing staff, other care providers and other patients (residents).
- HIV/AIDS stigma remains a powerful cultural background more than 25 years into the pandemic.
- Persons living in a dedicated AIDS nursing home unit were well informed about antiretrovirals (ARVs) and the importance of adherence to treatment; some were convinced that ARVs prevented death.

Living in the Community with Advanced Disease

- Participants spent much of their time and energy identifying, accessing and attending to benefits and resources and basic survival needs like housing, food, medical care, and transportation to appointments.
- Persons with advanced cancer were often sicker than those receiving care in an AIDS dedicated nursing home unit.

Health Care Professional Relationships and Systems

- Information needs related to illness, treatment and prognosis varied widely.
- Most patients preferred to share responsibility for medical decisions with their doctors, rather than being expected to assume responsibility for making decisions.
- Support needs varied; some appreciated support groups while others found them non-responsive to their needs for one-on-one support.
- Substance abuse and mental health co-morbidities frequently complicated patients' interactions with health care providers and systems and their ability to attend to illness related needs.
- Continuity of care was problematic in teaching hospitals where medical residents and attending physicians change often, medical students or interns overseeing care are not always trusted by the patients, and multiple specialists were involved and frequently gave conflicting information.
- Some persons with cancer believed that not having the right insurance resulted in their symptoms not being taken seriously, delays in diagnosis, and the likelihood of their not receiving the most effective treatments.

# CHAPTER TWO: POVERTY AND PALLIATIVE CARE IN THE U.S.: ISSUES FACING THE URBAN POOR AND ADDENDUM 2005-2007

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Hughes, A. (2005). Poverty and palliative care in the US: Issues facing the urban poor. *International Journal of Palliative Nursing, 11*, 6-13.

## Abstract

Poverty is a significant public health and social problem in the US. The urban poor who are living with life-limiting illnesses are a particularly vulnerable population. The literature related to the experiences of the urban poor at the end of life is sparse. Most relates to the experiences of patients with cancer. The purpose of this literature review is to describe the problem of poverty in the US, to identify challenges providing palliative care to the urban poor, and lastly, to articulate implications for nursing practice and nursing research.


Key Words: urban poverty, health disparities, end of life care, palliative care, access

## Background

Poverty affects the well being of persons, families, communities, countries and continents. In 2001, the World Bank estimated that over 1 billion people lived in significant poverty around the globe (World Bank, 2001). Recognizing the unequal burden of ill health experienced by the poor, the International Council of Nurses (ICN) has called for anti-poverty policies and for programs that target populations most vulnerable including women, children, the aged, indigenous people, refugees and internally displaced persons (International Council of Nurses, 2004b).

Although the burden of poverty is disportionately carried by developing countries, even in resource rich countries, such as the US, poverty is a significant problem that affects the quality of life and the manner of dying of the seriously ill (Moller, 2004). Persons who are poor in the U.S. have shorter life expectancies than the non-poor regardless of race or ethnicity (Lichter & Crowley, 2002; Lynch, Davey Smith, Harper, &

Hillemeier, 2004b). Indeed, some have noted that the economic, political and cultural deprivation of those who are living in an inner city (i.e. urban poor) in the U.S. may be comparable to those who are living in developing countries (Hall, 1999). For example, men in Harlem (in New York City) have life expectancy rates equivalent to persons living in Bangladesh (Freeman, 2004). The purpose of this literature review is to describe the problem of poverty in the US, to identify challenges providing palliative care to the urban poor and lastly, to articulate implications for nursing practice and nursing research.

## Understanding Poverty

### *Prevalence and Definition of Poverty in the US*

In 2003, according to the U.S. Census Bureau, the annual incomes of 35.9 million fell below the federal-government defined poverty line (DeNavas-Walt, Proctor, & Mills, 2004).This absolute measure of poverty was set at $9573 a year for a single adult under 65 years of age (DeNavas-Walt et al., 2004) . This statistic suggests that one in eight Americans (12.5%) are poor (DeNavas-Walt et al., 2004). This federal poverty definition is believed to underestimate the number of Americans living in poverty because it fails to take into consideration regional differences in costs of living and is based on a formula devised in the 1960's (Hilfiker, 2002). Persons living in the inner (or central) city have the highest rates of poverty (17.5%) in the U.S. (DeNavas-Walt et al., 2004).

Poverty is not confined to urban areas. States with the highest rates of poverty, e.g. Arkansas and New Mexico, have significant rural populations. Nevertheless surviving on an annual income of less than $9,573/year in Little Rock, Arkansas (a city in a rural state in the Midwest) is undoubtedly different than trying to survive on this same income in San Francisco, California where housing costs are considerably greater.

A recent report by the United Way**,** a nonprofit charity organization (Johnson, 2004) provided a perhaps more accurate picture of poverty in the San Francisco Bay Area. Using a relative measure of poverty, the self-sufficiency standard, it was found one in four (26.2%) working adults/families in San Francisco are poor. The relative poverty standard is based on the assumption that persons and families should not be forced to make such impossible choices of which basic need will be met, i.e. food, housing, child care, medical expenses or transportation.

*Health Care Insurance and the Poor*

According to a federal report, 15.6% of Americans (45 million people) were without health insurance in 2003 (DeNavas-Walt et al., 2004). Of that number, over 16 million of the uninsured live in inner cities and more than 15 million (1/3 of all uninsured) Americans live in households whose annual income was less than $25,000 (DeNavas-Walt et al., 2004).

Less than one-third of those living in poverty in the U.S. are eligible for Medicaid, the state-federal health insurance for the most impoverished who are under the age of 65 years (Hilfiker, 2002). Even if persons have Medicaid, not all medical care providers accept this insurance as payment for services. There is a sizable gap between the care is theoretically available and covered by Medicaid, and what is actually accessible to persons in need (Hilfiker, 1994). Faced with stretching few dollars, the poor spend whatever income they have on food, housing and transportation leaving little left for health care (Lichter & Crowley, 2002).

The urban poor, including those who are employed, are likely to be uninsured or underinsured. These conditions present enormous barriers to accessing preventive,

primary care, chronic and palliative care. For all of these reasons and more, the Emergency Department is often the place where poor people seek medical care (Kiefer, 2000; Moller, 2004).

*Urban Poor as a Diverse Community*

The urban poor are a heterogeneous group that includes individuals and families, racial and ethnic minority groups, children and older adults, and others living solitary lives (Hilfiker, 1994). As noted by Hilfiker (2002), most poor people do not abuse alcohol or drugs and are not criminals. Nonetheless urban poverty in the U.S. has become a byword for black ghetto, drugs and crime. Because some of the urban poor are undocumented immigrants, who avoid contact with social and health institutions fearing deportation, the actual numbers of urban poor are likely further underestimated. Urban poverty is associated with inadequate housing, unsafe and run down neighborhoods and the constant threat of crime which often results in self-imposed isolation (Klinenberg, 2001). However the understanding the role of poverty in contributing to inequalities, independent of race and ethnicity, is difficult to decipher as class and race in the U.S. are closely intertwined (Freeman, 2004; Koenig & Gates-Williams, 1995).

## Disparities and Palliative Care

The Institute of Medicine's (IOM) report on health disparities in the U.S. (Smedley, Stith, & Nelson, 2003)summarized a body of research that compared clinical outcomes according to race and ethnicity**.** The IOM report did not examine the role of poverty in health disparities per se, and discussed only one disparity related to palliative care, i.e. pain management. African-American nursing home residents with cancer were 63% less likely to receive pain medication than were white nursing home residents with cancer.

Minority outpatients with cancer were less likely to receive adequate pain management compared with whites. However, the researchers' failure to assess the ability to pay for medications was noted as study limitation.

Freeman (2004) argued that the poor bear a heavier cancer burden. His editorial described a report on poverty and cancer published 15 years ago, which described a collaborative project of the American Cancer Society, National Cancer Institute and Centers for Disease Control. The key findings from that report are listed in Table 1. Clearly, the link between poverty and cancer has been established (Bradley, Given, & Roberts, 2001; Marcella & Miler, 2001; Ward et al., 2004)**.** How individuals experience the burden of cancer, when poor compared with the nonpoor, has not been reported as thoroughly.

*Challenges of Providing Palliative Care to the Urban Poor: Environment as Barrier to Palliative Care*

Most of the urban poor live in environments that are racially segregated, economically disadvantaged, crime-ridden and dilapidated (Hilfiker, 2002; Kiefer, 2000; Kozol, 1995). As a result, access to health services is frequently compromised. Many social and health programs fearing for the safety of their staff, limit services in central cities including hospice care (Foley & Gelband, 2001).

Pain management, a key component of palliative care is one example of how where people live influences the care available to them (Morrison, Wallenstein, Natale, Senzel, & Huang, 2000; Soares, 2003). In their survey, Morrison et al (2000) randomly called 30% of local pharmacies in New York City to determine the availability of opioids for pain management (Morrison et al., 2000). Pharmacies in primarily poor, non-white

neighborhoods were significantly less likely to stock opioid analgesics than were pharmacies that served more white and affluent communities. Soares (2003) also reported geographic barriers to pain management for persons with life-threatening illnesses. Persons living in neighborhoods marked by poor social conditions, criminal activity and the threat of violence had less access to adequate pain management at home and often required hospitalization for symptom management (Soares, 2003).

Palliative care for the urban poor often includes community health interventions such as harm reduction, nutrition and housing programs as well as advocacy for services, such as pharmacy. In the US, palliative care day programs are generally nonexistent. Most palliative care services not provided in the hospital are provided at home. If the patient is homeless, i.e. does not have a home or if their housing is unstable or unsafe, providing palliative care is difficult at best. Table 2 lists the challenges of providing and receiving palliative care when the patient is poor.

Support systems for many of the poor are fragile. There may be no friends or family able to provide in home care when the person is dying. Some patients are estranged from families; this is often the case when there was a history of substance abuse or domestic violence. Some have no one to act as surrogate decision maker when the patient lacks decision making capacity (related to delirium, dementia, brain-injury or intoxication) and has not previously expressed their wishes for end-of-life care. Under these circumstances, health care providers may need to obtain legal authority from the court to treat the patient. In some cases, health care institutions' ethics committees are available to provide consultation and to ensure that the patient's interests are taken into consideration.

Many of the poor have encountered rejection or shame when accessing health care services. This reaction is more likely if the patient has exhibited behaviors regarded by health care providers as provocative or disruptive, such as selling prescriptions, being intoxicated or threatening violence to the health care providers. Furthermore, many do not have an ongoing relationship with a primary care provider; as a result their care tends to be episodic and is often fragmented.

## Research and EOL Care

Limited research is available to guide care at the EOL for the urban poor (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Moller, 2004; Tarzian, Neal, & O'Neil, 2005; Williams, 2004). Born and colleagues (2004) conducted focus groups of poor, inner city African-Americans and Latinos to identify barriers to hospice use among this population and to understand preferences for EOL care. Barriers to hospice utilization included: 1) lack of awareness of hospice services, 2) prohibitive cost of health care, 3) language barriers for non-English speaking Latinos and 4) mistrust of the health care system related to historical abuses and concerns about quality of care provided to persons of color (most particularly true for African-Americans)**.** Preferences for end of life care included: 1) the central role of the family in providing and directing care, 2) the desire to decrease the burden to families of caregiving responsibilities, 3) spirituality as a primary means of coping with progressive illness and 4) concern that their loved one (the patient) be cared for holistically, as a person (Born et al., 2004).

Williams' (2004) used grounded theory and phenomenology to analyze the interviews of 33 patients, living-dying with cancer, followed in an oncology clinic of a public hospital serves the poor. Most informants were interviewed once, although for

some, the interview occurred in two sessions to reduce patient fatigue. Most informants were female (70%), black (70%), less than 59 years old (76%), unemployed (91%), uninsured (73%) and had an annual household income of less than $9,000 (67%), (Kvale, Williams, Bolden, Padgett, & Bailey, 2004).

Some whose behaviors may have played a role in the development of an illness, such as smoking and cancer, or unprotected sex or injection drug use with HIV infection, felt responsible for dying young. Williams (2004) noted that for many of the poor, serious illness threatens their livelihood and when they are also caring for others who are dependent on them, they cannot afford to take the time off from work for medical care. Williams believes this may explain the late stage cancer presentation of many of the poor. Poor patients cannot take the time away from work and other responsibilities to take care of their own health. As the poor became sicker, Williams observed that their worlds shrunk and they became more isolated.

Williams noted that of greatest concern to her informants was the need for affirmation of their personhood in the ways others treated them. How they were viewed in the eyes of others became reflections of their personal and social continuity—they were still alive, still the persons they had been, still part of families, friendships and communities, and still with the biographies they lived (Williams,2004). The vulnerability to being invisible, Williams (2004) concluded was the greatest threat to their personal dignity.

A further study that directly addressed the experiences of the urban poor at the end of life is described in an elegant ethnography by Moller (2004). Using careful descriptions of place along with narrative text, Moller paints vivid portraits of the living

and dying of the patients he follows and their relationships with family, friends, home, pets, health care providers, social institutions and their own spirituality.

Their stories begin long before the diagnosis of cancer and illustrate how cancer and its treatment fit into the rest of what are often complicated and at times contradictory biographies. Moller describes the lives of his informants even before cancer as often chaotic, neglectful, struggling and disempowered. Poverty was their past, present and future. Much of their energy, Moller explains, was spent trying to get by. The dying poor are the "quintessential violators of the American dream" living in the shame of poverty and the messiness of dying (Moller, 2004, p.10).

Universal human experiences of the dying, according to Moller, include: disease concerns, threats to body integrity, anxiety, concern about loved ones and the need for hope. The need for hope is particularly salient among African Americans patients because of betrayal, rejection and neglect by a primarily white health care system, and because of the role of faith and religion in their lives. Consequently, many African-Americans demand every possible disease-directed intervention fearing abuse by medical providers and researchers, as has been their historical legacy. Spirituality serves as both a source of support and foundation for hope.

Little research has been conducted in the U.S. on the urban poor living with a lifethreatening illness to provide an evidence base for practice. The urban poor in the U.S. who are dying tend to be younger in age. Most studies focused on the experience of persons with cancer, which is not the only progressive illness that the poor must endure and may not be translatable to understanding the experiences of persons dying of other causes. For many of the poor, lifethreatening illness is just one more burden to be carried

## Examples of Palliative or End of Life Care Programs Serving the Urban Poor

Several programs have been developed in the U.S. to address the needs of the urban poor at the end of life (Campbell & Frank, 1997; Hayley, Muir, Stocking, Hougham, & Sachs, 2001; Kvale et al., 2004; Ryan, Carter, Lucas, & Berger, 2002; Selwyn et al., 2003). Some are disease or injury specific and institutionally based (Campbell & Frank, 1997; Selwyn et al., 2003). Others were designed to meet needs that could not be met in other programs, such as hospice (Hayley et al., 2001; Kvale et al., 2004). At least one program (Ryan et al., 2002) which was part of the recent U.S. trend to develop hospital based palliative care teams (Meier, 2002; Ryan et al., 2002), was discontinued despite positive clinical outcomes because of funding difficulties. Two of the most well known programs are described briefly.

The longest program in existence is a nurse-directed collaborative practice, Comprehensive Supportive Care Team, at an inner city Detroit trauma center (Campbell & Frank, 1997). The program provides support to critically ill patients, not expected to survive the hospitalization, and to their families. A primary motivation for the development of this program was to “decompress” ICU beds filled with hopelessly ill patients; a secondary motivation was cost savings. Patients referred to the program have been diagnosed with severe neurological insults (38%) or multiple organ system failure. Most die in the hospital. This program has documented economic savings, greater family support, and has provided a valuable educational experience to medical students and residents (Campbell & Frank, 1997).

The Balm of Gilead program in Birmingham Alabama developed to provide community centered, culturally sensitive comprehensive end of life care to “safety net”

population (Kvale et al., 2004)**.** (Safety net population is a phrase often used in health policy in U.S. to indicate low income and other vulnerable populations.) Components of the program include a palliative care inpatient unit, support to local nursing homes and boarding homes caring for dying patients, and a community-based volunteer program. Additionally, the inpatient unit serves as a teaching unit for medical students and residents. The needs assessment for the Balm of Gilead program identified barriers to home hospice services for the primarily poor, African-American community: homelessness, lack of family caregiver, financial constraints, or caregiver inability to manage because of their own health status, confidence or willingness (Kvale et al., 2004).

Patients who received care on the inpatient unit in the Balm of Gilead were primarily male (56%), African-American (67%), 60 years of age and more often died in the hospital (56%) than at home. The most common diagnoses included: cancer (47%), HIV related illnesses (9%), cardiovascular disease (8%), Alzheimer's disease/other dementias (7%) and other unspecified illnesses (14%). Challenges noted by the this program in providing palliative care to the poor included: unanticipated media and public interest after the program was included in a television documentary, difficulty maintaining volunteer and outreach programs, and funding problems (Kvale et al., 2004).

*Hospice*

In the US, the term hospice refers to a philosophy of care for the dying, to residential settings caring for the dying, and to a formal program of care for terminally ill. Most hospice services in the U.S. are provided at home where most Americans, given the choice, prefer to die. Since hospice programs are licensed and receive reimbursement for their services, there are a number of regulations and policies that shape the nature of the

services provided; some of which, present barriers for accessing hospice care for the urban poor.

Hospice care (program of services) is reimbursed very differently than most other medical care services in the US. Hospice providers are paid a daily rate to pay for all covered services, whereas most other medical services in the U.S. are paid a fee for each service provided (as long the service was evaluated as medically indicated). As a result, hospice providers by necessity must ensure that the services they provide will be compensated so that the program does not overspend and risk financial insolvency. Caring for poor persons who are homeless or those who are actively abusing drugs or alcohol is clinically and financially challenging for many programs. As a result, some hospice programs have concluded that they are unable to provide hospice services to these patients (Jennings, Ryndes, D'Onofrio, & Baily, 2003).

In addition to admission policy restrictions that may limit hospice, the regulations that hospice programs are governed by also present barriers to the urban poor. By regulation, in order to participate in a hospice care program, the patient needs to have an identified family member or friend who is willing to serve as the informal caregiver. In the past, this requirement was sometimes interpreted as needing to be a person actually living with the patient. For some of the urban poor, even if they had a stable home where they could receive care, they do not have a person who is able or willing to serve as caregiver and assume all the responsibility that is associated with that role. Another regulatory requirement of hospice is that a physician must certify that the patient has a prognosis of six months or less and the patient must agree to withhold all potentially curative or disease-directed therapy and instead agree to palliative interventions only.

This latter requirement for many patients, not just the poor, may be viewed as giving up before they have been given a chance at aggressive medical intervention (Tarzian, Neal, O'Neil, 2005). As a result of the many barriers to hospice care for the urban poor, most of the poor do not receive hospice. Most of the poor (like most of all Americans) die in the hospital or in a nursing home in non-palliative care units.

## Implications for Nursing Practice and Nursing Research

The urban poor in the U.S. with life-limiting illnesses are at risk for inadequate, if not negligent palliative care, given the inadequacy and neglect they frequently experience in their day to day lives (Hughes, 2006 #919; Moller, 2004 #595). As previously noted, the urban poor are not a homogenous population. The poor are a risk for a bad death (Hughes, 2001). Bad deaths according to the Institute of Medicine Report (Field, Cassel, 1997) are characterized by neglect, violence and unnecessary medical interventions.

A State of the Science Consensus Conference sponsored by the National Institutes of Health in Washington DC, the leading governmental body that funds research projects (Grady, 2005; National Institutes of Health, 2004) was convened to examine the evidence base for palliative and end of life care. What seemed clear from this meeting was that although much research has been conducted in persons with cancer, little investigation has been directed to the palliative care needs of patients with other chronic and life-limiting illnesses. Furthermore, although pain has been studied extensively and clinical practice guidelines to manage this symptom developed, implementation of best practices to address pain has been inconsistent, at best. The experiences of persons who live at the edges of society in the US, such as the poor and ethnic/racial minorities are

underrepresented in research and our understanding of their experiences and concerns is limited.

Given the challenges of providing palliative nursing care to the urban poor and the absence of evidence to guide practice, the question can be asked as to what nurses caring for patients should do. Some recommendations from the author are as follows:

- Recognize that earning a patient's trust will require more time if the patient has perceived rejection in the past from other health care providers (Hughes, in press).
- Demonstrate respect for the resilience of the patient and an interest in his/her life and priorities.
- Understand that a patient's priorities (for money, food, housing, or substances) may differ from those of health care professionals.
- Serve as a bridge for the care team. Consult with social workers, mental health professionals and substance abuse specialists if available when planning care or trying to manage challenging behaviors.
- Recognize that caring for the person with respect and acknowledging the patient's inherent dignity may be the most therapeutic nursing interventions that can be offered.

Given the paucity of research in the EOL experiences of the urban poor, there are many implications for nurse researchers**.** Kvale (2004) identified a number of research questions, such as clarifying the distinction between racial and socioeconomic barriers to end-of-life care, the need to develop and test culturally specific interventions, and the

need to describe institutional impediments to symptom management and advanced care planning.

Work by Tarzian (2005) highlighted methodological issues, (such as sensitivity in collecting demographic information, use of focus groups and use of community outreach worker in subject recruitment), that researchers need to consider when studying this marginalized population (Hall, Stevens, & Meleis, 1994). Virtually nothing is known about the experiences of urban poor with illnesses other than cancer (and our knowledge of cancer patients is not complete). Questions yet to be answered include: how the problems of the urban poor in relation to end of life care differ from the many problems with EOL care noted in general, what are the barriers to symptom management for community dwelling urban poor and how can these be eliminated, what are the spiritual, social and emotional resources are used by the urban poor with lifethreatening illness use to cope with their situation.

Finally, Moller (2004) noted that some EOL experiences, such as their encounters with health care providers and/or institutions, and the universal experiences with dying, are not unique to the poor. It should be remembered that strength, pride and resilience are evident in the everyday lives of the dying poor alongside the chaos, suffering and neglect (Moller ,2004).

## Conclusions

Poverty poses many risks to the personal health of those who living without healthy food, adequate housing, access to medical care and support, and sufficient income to meet personal and family needs. Consequently, the poor have high rates of lifestyle related chronic life-limiting diseases, such as cancer and HIV/AIDS, and high rates of

environmental related illnesses (e.g. asthma, and injuries related to crime related violence). In addition to the role the environment plays in contributing to illness and injury, access to health care services and other supportive services is often limited. This article has highlighted some of the barriers and outlined possible areas for future research for those who ‘don’t have enough to get by.’

Table 1
Cancer and the Poor in the U.S.

| |
|---|
| • Poor people are more likely to die of cancer than are the nonpoor in part because of lack access to quality health care. |
| • Poor people endure greater pain and suffering from cancer. |
| • Obtaining and using health insurance are barriers to accessing health care. |
| • Poor people and their families make extraordinary sacrifices to pay for health care. |
| • Cancer education and outreach efforts are insensitive and irrelevant to the lives of many poor people. |
| • Fatalism about cancer often prevents the poor from seeking health care. |

*Note*. Adapted from Freeman, 2004.

Table 2.

Challenges to Providing and Receiving Palliative Care when Patient is Poor

| |
|---|
| • Unstable or unsafe housing with inadequate basic facilities (phone, private bathroom, refrigerator and cooking facilities). |
| • Lack of transportation for clinic appointments. |
| • Fragile or nonexistent support system (no primary caregiver, caregiver who is unable to provide necessary care, caregiver also sick, no surrogate or proxy decision-maker, estranged from family, history of family violence or abuse). |
| • Many poor people having encountered rejection or shame when accessing health care services avoid contact and are slow to trust even well-meaning health care professionals. |
| • Poor people who obtain health care usually do so without benefit of a long term relationship with a primary care provider, or case manager who can help them navigate a complex care delivery system, and knows them as a human being with a life story. |
| • Most health care or specialized palliative care services are geographically remote from where poor people live; some providers curtail services to the poorest communities because of concerns about staff safety. |
| • Behavioral problems (e.g., drug hoarding, selling prescriptions, hostility, psychiatric illness, substance abuse) can affect their relationships with health care providers and the care available. |
| • Patient's goals may be difficult to assess if cognitively impaired, intoxicated or brain-injured. Many patients, including the poor, are asked to make treatment decisions without sufficient information about the implications of the decisions and in the context of a patient-provider relationship with enormous power imbalances |
| • Lack of evidence to base therapeutic interventions as this population is not included in clinical trials. |

*Note*. Adapted from Hughes (2006).

## Addendum to Literature Review: 2005-2007

In the past 2 years since this review was published (Hughes, 2005), little research was found about the urban poor and palliative care; none was located that studied seriously ill persons who were poor and living in a city.

A comprehensive review of the challenges providing end of life care to the homeless was published in the *Journal of the American Medical Association (JAMA),* which underscored the limited research available to guide practice (Kushel & Miaskowski, 2006). Two case studies documented the problems the uninsured or chronically homeless face when dealing with medical care systems (Edelman & Adams, 2004; O'Connell, 2005). Evaluation projects described a cost analysis of providing shelter-based palliative care to terminally ill homeless persons in Canada (Podymow, Turnbull, & Coyle, 2006) and challenges to providing end of life care to low income elders with advanced chronic illnesses in a Midwestern city in the U.S. (Kramer & Auer, 2005).

Two research groups studied homeless persons, living in a city, about their views on end of life care (Song, Bartels et al., 2007; Song, Ratner, & Bartels, 2005; Song, Ratner et al., 2007) and their preferences for resuscitation and surrogate decision makers (Norris, Nielsen, Engelberg, & Curtis, 2005).

Song and colleagues (2005) conducted focus groups with homeless men living in a shelter and with social service providers working with this population, to explore participants' experiences, concerns, and observations about death and dying and end of life care. Subjects were paid for their participation. Eleven men and 9 social service workers participated in the interviews; no other demographic or health status information

was provided. Key findings from this qualitative study were: sudden and often violent deaths were common occurrences, several expressed concerns about dying alone and on the streets and about what would happen to their body after their death. Spirituality and religion were important sources of support, family relationships were generally poor, and a number of barriers to end of life care were identified such as the judgmental views of health care providers and mistrust of the health care system. More recently, Song and colleagues (2007) published two research reports of focus groups of 53 homeless persons recruited from social service agencies to describe their experiences with and attitudes toward death and dying and their concerns about dying on the street. Health status data about the diverse sample were not provided; however, several participants described acute illnesses and hospitalization experiences. Researchers suggested that participants' experiences of loss early in life may have served to justify some of their risky behavior or homelessness (Song, Ratner et al., 2007). Song concluded that the homeless were generally overlooked in EOL research and that some of the requirements for end of life care, e.g. stable housing, supportive family and positive relationships with health care system were absent among this vulnerable population (2005).

Using a quantitative cross-sectional survey design, Norris and colleagues (2005) asked 229 homeless men and women about their preferences for resuscitation and intubation in their current state of health, if suffering from severe dementia or permanently comatose, or if bedbound and dependent on others for care. Their responses were compared with those of 226 physicians, and 111 oxygen-dependent patients with COPD who were not homeless. All subjects were given the same survey to complete. The investigator administered the survey to the homeless subjects to avoid problems

related to illiteracy. Homeless participants were recruited from shelters and received a food or coffee coupon for their participation.

The homeless sample included 135 men and 94 women; 59% of the men and 43% of the women were from communities of color. Homeless men were older (mean 56 years) than the women (mean 44 years). More than half of the sample had at least some college or trade school education beyond high school. Homeless men and women were significantly more likely to want resuscitation than physicians or patients living with COPD. Eighty percent reported having no family or not wanting family to serve as surrogate decision maker and instead preferred a physician to decide if they lacked decisional capacity. Norris concluded that homeless persons wanted more aggressive treatment than either comparison group, and if they were unable to speak for themselves or were without a surrogate decision maker, the homeless may not receive the treatment they would prefer.

In summary, in the past two years no research has been located that describes the experiences of the urban poor with advanced disease. There is a growing awareness that persons who are homeless or marginally housed present unique challenges for health care professionals providing end of life care and that the wishes and concerns of this vulnerable and marginalized population have not usually been solicited or heard.

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# CHAPTER THREE: “CAN YOU GIVE ME RESPECT?” EXPERIENCES OF THE URBAN POOR LIVING ON A DEDICATED AIDS NURSING HOME UNIT

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# "Can You Give Me Respect?" Experience of the Urban Poor Living on a Dedicated AIDS Nursing Home Unit

More than 25 years after HIV/AIDS was first recognized in the U.S. (Gottlieb et al., 1981), the global pandemic has become associated with poverty and racial/ethnic inequities (O'Neill, Romaguera, Parham, & Marconi, 2002). Despite overwhelming evidence about the routes of transmission of the human immunodeficiency virus (HIV), and the success of antiretroviral (ARVs) therapies in reducing HIV-related morbidity and mortality, stigma and discrimination persist. Since the widespread use of ARVs in the mid-1990s and the ability to monitor serum viral loads, the illness trajectory of HIV infection and its end stage complication, AIDS, has been changed from one that is acute and terminal to one that is chronic and manageable (Selwyn & Forstein, 2003). As a result of treatment successes, more and more persons are living with advanced HIV disease, years and even decades after their initial infection. Selywn et al. (2000) believe the ARVs success in decreasing mortality may result in more HIV-related disability resulting in the greater need for nursing home and other long term care.

## Background and Significance

In the U.S., concern about health disparities has become a policy priority (Smedley, Stith, & Nelson, 2003). One uncontroversial disparity in HIV is its epidemiology; HIV disproportionately affects vulnerable populations, groups at risk for adverse health outcomes (Aday, 2001; Flaskerud et al., 2002). African Americans account for almost 50% of all AIDS cases in the U.S. while comprising only 13% of the population; whereas Non-Hispanic whites account for 30% of the AIDS cases and represent 68% of the entire

population (CDC, 2004). Disparities persist beyond race and HIV epidemiology however. Poverty affects personal health (McDonough, Amanda Sacker, & Wiggins, 2005) although the interaction of economic effect with race/ethnicity is complex. In the US, African Americans are three times as likely to be economically impoverished as are whites; indeed 1 in 4 African Americans meets the federal criteria for poverty (DeNavas-Walt, Proctor, & Lee, 2006) which is generally believed to underestimate the number who are poor.

Dignity is a construct that appears in literature related to international human rights, disability and aging, bioethics and end of life care, and most specifically in the U.S., in the context of physician assisted suicide (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov et al., 2006; Jacobson, 2007). Eight studies were found that examined dignity at the end of life, four of these (Chochinov et al., 2002; Chochinov et al., 2006; Hack et al., 2004; Turner et al., 1996) used quantitative approaches. The qualitative studies used a variety of approaches: discourse analysis (Street & Kissane, 2001), grounded theory (Chochinov et al., 2002), phenomenology (Enes, 2003) and content analysis (Rogers, Karlsen, & Addington-Hall, 2000). Almost all patients studied had cancer and presumably similar disease trajectories. None of the studies were conducted in the US; all patients were receiving hospice or palliative care services in countries with nationalized health care systems. Income information was not provided. Experiences of dignity, or indignity, of the urban poor living with advanced HIV disease have not been described and surely not in the voices or through the stories of persons living with HIV/AIDS, who are receiving care in an institutional setting, such as a dedicated AIDS nursing home unit.

The purpose of this study was to describe the meaning and experience of dignity to the urban poor with advanced HIV disease receiving care in an institutional setting, a dedicated AIDS nursing home unit.

## Method

Interpretive phenomenology is the philosophical framework and methodological approach used for this narrative analysis, which is part of a larger study. The philosophical framework is based on the writings of Heidegger (Heidegger, 1927/1962), as interpreted by Dreyfus (Dreyfus, 1991) and as methodologically applied and further elucidated by Benner (Benner, 1994; Benner, Tanner, & Chesla, 1996) and other interpretive nurse scientists (Gudmundsdottir & Chesla, 2006; Leonard, 1994). Interpretive phenomenology seeks to understand, not to explain or to predict participants' worlds- their concerns, habits and practices as they show up in narratives; interpretive accounts are always contextualized (Benner, 1994).

Narrative is a description of informants' understanding and interpretation of the world and what is meaningful to them (Seymour & Clark, 1998; Wiklund, Lindholm, & Lindstrom, 2002). The phenomenologist gathers data in minimally intrusive ways such as facilitating narratives or stories that capture the experience (Benner, Tanner, & Chesla, 1996; Kleiman, 2004; Seymour & Clark, 1998; Van Manen, 1990). Phenomenology is particularly well suited to understanding the profound human experience of living with a serious illness and facing one's death (Seymour & Clark, 1998). Benner (1994) noted that participants' narrative descriptions of their everyday life give access to their practical worlds (p. 112).

### *Procedures*

The study was approved by a university institutional review board and facility review committees. English speaking patients (residents) living together in an HIV/AIDS dedicated nursing home unit with advanced HIV disease (operationalized as the clinician intermediary would not be shocked if the patient were not alive in 2 years) and poor (operationalized as receiving Medicaid, Supplemental Social Security Income or otherwise considered indigent) were approached by a clinician intermediary to participate in a study to understand the meaning and experiences of dignity.

### *Rigor*

Validity and reliability, as understood in quantitative research designs, play no meaningful role in evaluating the quality of research that relies on narrative and personal accounts of human experiences. A variety of alternatives have been suggested to evaluate the quality of qualitative research (Beck, 1993; Giacomini & Cook, 2000; Lincoln & Guba, 1985; Seale, 2004; Sparkes, 2001). Seale suggested that paradigmatic changes in the social sciences has resulted in a trend to "search for new ideals (and) seek to substitute moral values and political positions as guarantors of (qualitative research) standards: promoting dialogue, emancipating the oppressed, empowering the weak (as) goals of social research (2004, pp 409)." Within this context, Seale (2004) offers not a formula for ensuring quality qualitative research but rather ideals that guided this project:

> …a general sense of the value of careful scholarship, commitment to rigorous argument, attending to the links between claims and evidence, considerations of all viewpoints before taking a stance, asking and answering important rather than trivial research questions (2004, pp. 409-410).

### *Data Collection*

For this analysis, data were collected in three group interviews (n = 10 informants) which were co-facilitated by the first author who is a white nurse employed by the facility, although not a staff member of the dedicated HIV/AIDS unit, and by an African American woman who is a consultant in multiculturalism and group dynamics. Participants were interviewed one time only. Each group met for approximately one hour and included 3-4 different participants (for total of 10 informants) plus the facilitators. Participants were paid $15 in cash for their participation. Refreshments were provided. After the first group, ground rules were established to assure all participants were heard and the discussions were non-attacking. Participants were asked to describe their experiences living on the unit, to provide narratives of care situations in which they felt recognized and not recognized by staff, and to describe what dignity meant to them. Interviews were conducted from December 2005 to March 2006.

### *Data Analysis*

Interviews and field notes, which included observations of interviews and unit milieu, were audiotaped and transcribed verbatim and later verified for accuracy. Transcripts were read and reread and interviews compared and contrasted with one another to identify salient narratives or stories. The primary author drafted and redrafted interpretive memos of particular narratives. Exemplars, considered a form of interpretive "operational" definitions, were identified that demonstrated the concerns of the participants within a particular context (Benner, 1994). Memos were then discussed and revised with the research team to develop an interpretive account. All participants' names in this paper are pseudonyms.

# Results

## *Setting*

The HIV/AIDS dedicated nursing home unit was situated in a publicly owned skilled nursing facility (SNF) in a western city in the US; most of the care is reimbursed by Medicaid with some additional funds provided by the city government. Unlike typical nursing home populations, the patient mix on the unit was younger, more male, racially and ethnically diverse, and frequently had histories of substance use, chronic poverty, homelessness and criminal histories. The institution had adopted a harm reduction philosophy, a public health strategy commonly used to change harmful lifestyle behaviors by modification of the associated harm. Other HIV/AIDS patients whose care needs were considered less complex were relocated to other non-specialized units in the facility.

Patients on this unit lived in a physically confined space with low ceilings and narrow corridors in the hallway to the main patient care area which are open wards. The unit had a small town community feel. Patients recognized others who live on the unit, even if only by sight. There were three semi-private rooms, one private room and a six-bed room for female patients. All staff members (including the two physicians) were civil servants. Seventy percent of the nursing staff (RNs, LVNs and C.N.As) were Filipina; the ethnicity/racial composition of other clinical staff were more representative of city's population. During the study period there was a public discourse that included a policy debate which directly affected the study nursing home. Some neighborhood leaders, primarily white, believed that the institution should return to serving only the elderly and disabled persons and not continue to serve younger persons with histories of substance

use who were perceived to be at risk for violent behavior. Study participants were well aware of this discourse and mentioned it privately away from the group interviews.

### *Sample*

The sample from the three group interviews included 10 participants: five men, three women, and two male-to-female transgendered persons. All were persons of color: seven African-Americans, one Native American, and two mixed race/ethnicities. The mean age was 45 years; participants ranged in age from 35 to 58 years. Four of the participants had less than high school education, four completed high school or a GED equivalent, and two participants had 1-2 years of college/university education. Four participants had lived on the unit for less than 6 months; three for 6-18 months, and three lived on the unit for more than 3 years. One participant had lived there for most of 11 years with brief interruptions. Two participants died within 6 months following their interviews. All participants had histories of drug and/or alcohol abuse. Some had sex with other men; some had worked as sex workers. Several voluntarily reported periods of incarceration and most revealed histories of trauma (child abuse, domestic violence or assault).

## Findings

Interviews and observations of the participants in their environment resulted in numerous narratives of concerns of this vulnerable population. For this analysis, data specifically illuminating dimensions of their everyday living and their meanings of dignity were selected.

## *Living on the Unit*

All participants described what it was like to dwell and receive care on this HIV/AIDS dedicated nursing home unit. For some, the experience offered the possibility of care, safety and a home. Others perceived their existence on the unit as respite before they returned to the community. Living on the unit included stories about: how they got there, taking antiretrovirals (ARVs), escaping, dealing with boredom, community of caring, witnessing deaths, relationships with nurses, and knowing when to leave.

### *Getting There*

For some participants, living on this unit was in large part defined by their life experiences prior to admission. Jackie, a 35-year-old African American transgendered person who is paraplegic as a result of HIV neurological complications, was on the unit because she had no other choice, no one else wanted her. Her arrival on the unit followed a journey of living on the streets, living in single room occupancy (SRO) hotels , being a patient in at least two different hospitals, short stays with two different siblings, criminal charges for loitering while homeless, and leaving a residential hospice care program because "(she) wanted to live," and was not there "to fucking die."

> Jackie: "…. It's- all around it's a good place. I never wanna come back again… the only reason why I'm still here is because I have bad wounds. If it wasn't for that, I would've been out of here like within a week of getting here. If I have a choice, but I don't have a choice… Because I didn't have anywhere else to go. They didn't want me, you know."

Unfilled beds are rare. For persons unable to manage in the community because of impairments in cognitive function, mobility, toileting or managing complex medication regimens, the unit is the only option when 24 hour care is not available at home or in a

community residential care setting. For most informants, getting to the unit followed periods of being homeless or marginally housed, “messed up by drugs,” leaving or being discharged from other residential care programs, brushes with the criminal justice system, being intoxicated and feeling they had no place else to go. The unit was not only a place of last resort but also a supportive community that opened up possibilities. On the unit, Maryellen discovered her ability to write, to imagine a future, to know she can love again. For Matthew, the unit “brought him back from hell,” the hell of life on the streets and using drugs.

*Taking Antiretrovirals*

Receiving care on the unit created the possibility of taking antiretrovirals, because the structure facilitated adherence as nurses were responsible for administering and monitoring medications. For Danielle, a 43-year-old transgendered Native American, these medications improved her immune function; for Willy, a 58-year-old African American man with end stage renal disease who goes to hemodialysis three times a week, these medications were a matter of life or death. At the time of Danielle’s admission, her HIV disease was untreated, and laboratory tests indicated an increased risk for opportunistic infections and other HIV complications. Danielle agreed to initiate ARVs because her immune system biomarkers (e.g., CD4 count or T-cell count) indicated severe impairment. She felt pressure to accept treatment and for some reason “gave in” this time when undoubtedly she had been offered and refused treatment in the past. It is not clear why she acquiesced this time or why she had refused in the past although Danielle mentioned being “in and out of jail for the 20 years.” While ARV therapy was

successful in increasing her CD4-cell count, she experienced side effects which required treatment so that she could tolerate the therapy.

Willy was adamant about the need to take ARVs for life. He had watched others discharged from the unit on treatment, who believed that the medicines would protect them from getting sick and allow them to "do their thing," i.e., use drugs. However, when these patients presumably stopped taking ARVs, they became sick and were readmitted to the unit and died shortly thereafter. For Willy, taking the ARVs "keeps you alive" and postpones death. He is convinced that if you "slip up" the virus will mutate and the ARVs may no longer be effective, if you stop taking ARVs "you will die."

> A lot of people think because you're taking that medicine, like, "Oh good, it's okay." And no it isn't. Like- it's like life or death, you know? And if you slip up, you know what I mean? And stop taking those little pills, *you will die*. (his emphasis) I don't care what you think, you will die. And that's the only thing that keeps you alive. So like I get up in the morning, take those pills. I do whatever they tell me to do whether I don't feel like I want to. I just do it. And if I get out, I'm gonna continue doing it. 'Cause I've seen too many people be healthy, go out, come back. Next thing you know, they're dead…That virus will mutate. It's a tough nut to crack. Let me tell you. But if you slip up for the slightest and think, "Oh, I'm healthy. I don't need them," the next time you take them pills, they might not work. I'm serious. It's not like a cold that you get over with…

Willy's comments reflect being well informed about the role ARVs have played in decreasing mortality and about the importance of adherence in preventing viral mutations. His passion about adherence, however, seemed more personal than aggregate-based data would suggest, and more emotional than some detached intellectual analysis. Willy was talking about his life and his death.

*Escaping*

Carl, a 42-year-old African American flamboyant gay man who was non-ambulatory and incontinent of bowel and bladder, began the interview by describing his escapes from the AIDS unit. While he said that he both likes and dislikes the place, his actions and other remarks suggested only his dislike. Indeed, when asked what it was like to be a resident on the unit, he seemed to have interpreted the word "like" as positive affirmation and disputed this description. Later in the interview, Carl revealed that his escapes were related to his wanting to use drugs, have sex, and to be a part of society.

> Anne: So when you escaped-
>
> Carl: I was doing drugs then.
>
> Anne: You were doing drugs?
>
> Carl: Crack.
>
> Anne: So you escaped to do some drugs?
>
> Carl: Yeah. I went to go to society and visit my friends, my gay friends, and shit like that… I just wanted to have sex.

Escape is a word used when speaking about leaving intolerable situations, breaking out of –jail or prison, or some other form of captivity. So, was being a nursing home resident for Carl a form of imprisonment? Listening to Carl's stories, we wondered if the escape he was hoping for was not just an escape from the AIDS unit, but also escaping from being unable to walk and living in a wheelchair, escaping from being unable to manage the most intimate of bodily functions like toileting on his own, and escaping feelings of being unrecognized or unappreciated that doing drugs, having sex and being in the community, outside of an AIDS unit, blunted.

*Dealing with Boredom*

Several informants described dealing with boredom on the unit and had specific suggestions for activities, like drawing and knitting classes, which would engage and stimulate them. In the words of Martha, a 51-year-old African American woman without obvious residual impairment from a stroke who lives with chronic pain secondary to having been raped 30 years ago:

> We need more activities – she's right – like maybe knitting class, 'cause it's very boring. Okay? Uh, some… anger management classes would be nice to get. You know… I mean short classes … Like maybe three-week or, six-week or something like that so we could get little certificates, you know?

Some informants focused on the scheduled bus trips arranged by the unit's activity therapist. They felt that the places selected for the trips at times reflected more the staff person's recreational interests rather than their own. Going to restaurants, however, were favorite excursions into the world outside of the unit. Learning new skills or classes on how to cope with anger (which were offered at the facility usually as part of a behavioral management program and awarded certificates on completion of the classes) helped to manage participants' boredom. Most had used drugs in their past as one way to manage their boredom. Some participants mentioned experiencing unfamiliar feelings, like boredom, since they had become clean and sober. Earning certificates for completed courses were valued as recognition for their accomplishments.

*Community of Caring*

Living on the unit was also characterized by the community of caring that the residents created with one another, separate from the formal therapeutic relationships with the staff. Rita, a 39-year-old African American with end stage renal disease

receiving peritoneal dialysis, described how other residents were there for her when she was feeling suicidal because of menopausal symptoms. She described how the other residents responding to her despair, rallied around her. They talked to her in a way that made her feel that there was something worth living for, things for her to do, including reconnecting with a son who was placed in foster care years before.

> But then when this menopause stuff started to hit me, oh Lord, I wanted to die. I just wanted to die… all my friends and everybody heard me in the room crying and stuff, talking about I'm tired, I don't wanna deal with this (menopausal symptoms) no more, I wanna die. And she [pointing to Martha] came in the room and talked to me. ..And she came in the room and talked to me and told me I got too much to live for. .. I better come up out of that shit [giggles]. You know? And then Bill came and talked to me. And then other people I didn't know here came and talked to me

The encouragement of other residents gave Rita a will to live by suggesting that she could choose to "come up out of that shit" of depression and despair. However, living in a community was not always associated with caring. Some informants commented about the lack of privacy and intrusiveness of other residents "into (their) business."

*Witnessing Death*

Willy discussed the deaths he witnessed on the unit and their impact on him. He has lived on the unit for 5 years and understandably had seen many residents coming and going. Willy had watched others get better, be discharged, and come back only to die shortly after returning.

> "And if you stay here long enough, you see enough people pass away, you know? Like it's something you gotta stick in your head. I've seen people just give up. I mean, really give up. And they just make them comfortable. The next thing you know, they're dead. You know, and you can never get used to that. At least I can't".

Witnessing death is something Willy cannot get used to or ignore. Other informants commented on the deaths they had observed and gave a number count; they linked patients' dying to giving up, not fighting to live. Interestingly, none of the participants linked deaths to illness progression or treatment failures.

*Relationships with Nurses*

Many narratives focused on participants' relationships with nurses, some describing the roles nurses played in saving their lives and helping them recover. However, the more vivid narratives were about difficulties experienced with the nurses responsible for their care. Difficulties with nurses included allegations of insincerity, favoritism, laziness, lying, stealing, feeling scolded like a child and talked down to, being ignored, becoming frustrated and angry when nurses spoke in the main Philippine language Tagalog, and one instance in which a patient died because they believed the nurses had not come quickly enough to their calls for help.

> Rita: "And they have a lot of favoritism, which I kind of got wrapped up into. You know? And they don't wanna do nothing. They don't wanna do nothing. You know, you need somebody in the day time. If you- if you get your light on, pay attention to the light and come in and check on who it is. You never know, that person might be having a heart attack."
>
> Martha:: "… like I fell a few times 'cause they wasn't there like they were supposed to be. You know, like- like she said. They're lazy. I've watched them going from one end to the end of the ward hiding, you know, to keep from doing work, playing too much favoritism... I don't care what you do or how you do it. Just help, just give me mine stuff… they're getting my money. I got Blue Cross, Blue Shield *and* Medicaid. So I want what I'm supposed to due to me."

Complaints ranged in severity from the annoyances of gossiping and staff complaining about one another to favoritism, nurses' failure to recognize the humanity of

their patients, and to possible negligence. All participants in one group described some difficulty with nurses that they were forced to endure. Martha commented about wanting justice, getting what is due her. Martha noted that the hospital, which employs the nurses, is receiving payment from Blue Cross, Blue Shield, and Medicaid. In point of fact, only Medicaid typically pays for long term care, but Martha's point was about justice, receiving what was due as a consumer of health care. Martha also acknowledged the lifesaving role the staff played in her care:

> " ...when I first got here, I loved them (staff) so much. They happened to save my life, right? And then as- as time went on- 'cause I- it's gonna be three months soon for me. They- I asked questions and I learned a lot… when you ask them questions, they do tell you things that you need to know, you know, like explain stuff to you….Cause at one point, I had to depend on each and every last one of them nurses. And I have to admit that that time that I really needed them, they were there. They helped…"

Isaac, a 51-year-old Filipino/Mexican man and Willy observed that nurses are often are mistreated by patients:

> Willy: "… a lot of people, you know, act as though like the nurses owe them something. A lot of people, you know, speak abusive or curse or something like that…"
>
> Isaac: "...I see it like (that act as if) they're the only patients here. They act like, you know, "Hey nurse, come here." And the nurse might be changing somebody's bed or something."

Nurses manage the care environment, administer medicines, assist with activities of daily living, report symptoms or problems to other care team members, and are the only care providers present on the unit 24 hours a day. Therefore, some difficulties might be expected, but the apparent lack of trust that some informants had in the nurses

responsible for their care was surprising. Few of the nursing staff members are African American.

Many of these residents' lives were marked by being in trouble with authority figures. Their experiences with nurses (who play the role of enforcer for care team decisions) suggest that their experiences in a nursing home are shaped, influenced and defined by their relationships with the nursing staff, perhaps more than any other discipline, even though most informants clearly articulated their physician's authority for overseeing their treatment.

*Leaving the Unit*

Participants spoke about when they would be leaving the unit to return to the community. Jackie was ready to leave immediately, were it not for severe wounds. Maryellen, a 58-year-old Native American/white woman and self-identified "dope fiend," was learning how to take better care of herself to manage her parenting responsibilities.

> "I've got four children. So right now I need to be here, but as soon as I can without harming myself, I need to be back in their lives, you know?...They're angry with me 'cause I'm here instead of with them. But like I explained to them, I can't leave right now 'cause alls I'd be doing is hurting myself, you know? And I can't take care of them. I take care of my room."

Matthew, a 39-year-old African American man who is wheelchair bound because of weakness and pain secondary to neuropathy, was more circumspect about when he would be ready to leave. He also acknowledged that he was learning how to take care of himself, which for most of these participants was about not using drugs. Matthew expressed his social responsibility when he said, "If someone else needs my bed more than I do, I would leave."

*Not Living*

To Rita a 39-year-old African American with end stage renal disease who uses a wheelchair to get around, being on the unit was not living, was not having a life. She did not want her son to visit or to reconnect with her on this dedicated AIDS nursing home unit, in an institution.

> "I'm not too much ready to leave. You know, but I got to because I got a life out there, you know? And I got, I got a son that I just reconnected with. You know? And he wants to see his mama. And I really too much don't want him coming up here…."

At the same time, Rita saw the unit as a place where she won't overdose or get killed, offering her a "safety zone" from life on the street. Rita felt "institutionalized" after long stays in an acute hospital, at this SNF and interspersed with periods of incarceration. For Rita, outside of the AIDS nursing home unit is where life and living occurs. If living only occurs outside, what happens inside dedicated AIDS nursing home units---existing, surviving, being safe, or being on hold and waiting until life begins again?

*Meanings of Dignity*

Most, although not all, participants believed that dignity was important to them as human beings and to their care, and sought to describe their understandings. Jackie had never heard the word and could not relate to the notion of dignity at all; another admitted looking up the word in the dictionary because he was not certain of its meaning. Rita doubted that health care providers or researchers could ever understand how dignity was experienced by the residents on this AIDS dedicated unit; others in the group suggested that some experiences were unknowable to those who were uninfected. Dignity was

related to understanding another human being's experience, how one treated oneself, and how others treated them.

Most participants, like Martha and Bill, believed that being treated with dignity was being treated with respect, which includes meeting care needs in a timely manner, and not being ignored or put off to other staff members. Being treated with respect was conveyed in how patients were spoken to by staff members. Bill, a 41-year-old African man who is paraplegic, appreciated when he was addressed more formally, such as "Mr. Smith," and regarded this as a demonstration of respect. He commented, "That's all we're asking, Can you give me respect?"

Respect was taken away when participants felt not listened to or misunderstood, when they were made to look bad or felt ashamed. Dignity was also related to self-respect as Isaac said, "Well, it's uh- you begin with yourself. And it's self-respect to have dignity. And once you have that, the other (respect from others) will fall in place." Isaac, a man with a long history of drug use and various drug treatment programs, described his efforts to "show maturity," by quitting his drug use by going "cold turkey."

Matthew said, "Well, my dignity is not about how much money I have …- or where I'm from, [but] what I do." He challenged the cultural links of dignity to money, privilege or social status. For him, dignity is about what he does, who he is and how he treats himself. For Matthew, dignity was also reciprocal, "(he) give[s] and demand[s] respect" in return.

Dignity was also related to the stigma of HIV/AIDS. Willy's experience on the AIDS unit suggests the role that an AIDS dedicated unit may play in supporting dignity.

> "And a lot of people that wouldn't be treated with dignity
> say, on the outside, that they're treated with more dignity

> here because there are more people, say, in similar categories as they are. So they don't- like a lot of people, so they don't seem so out of place. You know? So without this hospital, you know, a lot of them might be, like more felt like they're outcasts or something like that. I've learned a lot of dignity by being here, which I don't really think I had a lot of… I definitely wanna live and I definitely care about me. You know what I mean? So I have to have a little dignity to carry."

Counter intuitively, receiving care in an institution enhanced, rather than detracted from, the dignity Willy experienced. Indeed, being outside of the institution, an outcast of society, isolated from others, feeling out of place, all detracted from a person's sense of dignity.

## Discussion

The lived experiences of the urban poor with advanced HIV disease receiving care in an institutional setting, and the meaning of dignity, were poignantly described in the narratives of these participants. Admission to an urban AIDS dedicated nursing home often followed being homeless. Receiving care on the unit created the possibility for participants to receive ARVs, to avoid problems related to drug and alcohol use, and to develop talents and skills. This latter finding is consistent with a study of African American men receiving care in a dedicated AIDS nursing home unit (Fields & Jemmott, 2003) who believed they were better able to face life outside the facility given the care and support they had received.

However some participants had difficulty enduring the constraints of the unit and they described escaping and other acts challenging the unit's rules and the intrusiveness of others. Their acts of resistance were similar to what some African American elders described to cope with life in a nursing home (Groger, 2002). Those no longer using drugs or alcohol to self-medicate were especially challenged by boredom and managing

unfilled time. While the widespread use of ARVs has decreased the immediacy of HIV related deaths, participants were well aware of the possibility of death and maintained hope that ARVs would forestall, if not completely eliminate, that eventuality.

The experience of being marginalized partially situates the informants in this study; marginalization is an important background social construct to understand their experiences. Margins serve many functions (Fullilove, 1999; Kleinman, 1995; Zerwekh, 2000). They establish boundaries or set borders; they define place and space; they separate the inside(rs) from the outside(rs); they set up possibilities for inclusion or exclusion. Being marginalized is a metaphor for being excluded from the human community, living on the edge, or being an outcast. Marginalization is the process by which individuals are peripheralized on the basis of identities, associations, or experiences and environments (Hall, 1999, 2004; Hall, Stevens, & Meleis, 1994).

Certain stigmatizing illnesses, such as HIV/AIDS, mental illness and drug addiction contribute to marginalization. Nursing home patients live at the margins of society, invisible to those who are healthy, able bodied, and independent. Nursing home placement is a future few of us imagine for ourselves. Indeed, in the well known study which documented poor EOL care in the U.S. (SUPPORT, 1995), patients were asked to express their care wishes related to hypothetical circumstances believed potentially unacceptable and perhaps even intolerable. Among these situations was living in a nursing home. And yet for some in this study, life on the margins, in an AIDS dedicated unit offered safety and removed them from the “hell of the streets.”

Nurses and other caregivers working in nursing homes can create opportunities for their patients to move away from the margins and to be part of the human community.

Programs which focus on community reintegration, such as supporting linkages with cultural or religious groups, or promoting classes in the community help to move nursing home patients, like the participants in this study, from the margins of the society. However, compounding the marginalization experienced by many nursing home residents is the shame and stigma associated with HIV/AIDS of these informants.

In a recent paper analyzing AIDS-related stigma, Castro and Farmer argued that AIDS-related stigma has been used to justify the inadequate responses to the pandemic, and focuses too much on the attributes of an individual that disqualifies him/her from society, rather than looking at the underlying structural causes that sanction discrimination (Castro & Farmer, 2005). Several participants in this study discussed their shame at having AIDS and wondered what would happen if their illness was found out by others. Narratives about the stigma of AIDS and internalized shame and self-imposed isolation were particularly poignant and consistent with findings reported by other researchers (Duffy, 2005). While some participants voiced dissatisfaction with their care, none described feeling devalued, ignored or ostracized as a result of having AIDS on this dedicated unit. AIDS dedicated units and services may buffer the shame and stigma, on the other hand they also label their clients as persons living with HIV/AIDS.

When asked about dignity and how it was experienced, persons in this study typically spoke about respect. Dignity was defined as respect; for some, dignity had no inherent meaning while respect was considered important for almost all informants. Respect is reciprocal—between patients and staff, and between patients and other patients, and respect is what one owes oneself. In a recent qualitative study of nursing home residents in Canada, being treated with respect by their caregivers was the most

important indicator of quality of life for the informants (Robichaud, Durand, Bedard, & Quellet, 2006). If dignity means respect, is the concept of dignity useless as has been recently argued (Macklin, 2003)? Macklin contends that dignity has become a slogan in bioethics which substitutes for respect for personhood and autonomy; these principles, according to Macklin, are evident in the practice of informed consent, confidentiality and protection from abuse. Findings from this study corroborate Macklin's assertion that dignity is synonymous with respect for personhood; informants provided narratives when they felt unseen and unheard and pleaded for respect from their caregivers. However, these findings reveal more about dignity being jeopardized by threats to personhood than Macklin's discussion of dignity within the context of autonomy-based rights.

Caring for patients with respect and providing opportunities for choice in their care are hardly revolutionary ideas. The challenges for nursing homes are daunting given the cultural image of nursing homes as places of last resort. Nursing homes are underfunded, have limited numbers of staff, and a workforce which is often culturally dissimilar from their patients. Furthermore, caring for younger disabled persons with AIDS in a nursing home setting is quite different from caring from elderly patients. The rates of mental illness and substance use disorders are significant co-morbidities in persons with AIDS requiring nursing home care (Goulet, Molde, Constantino, Gaughan, & Selwyn, 2000) and yet some facilities lack the specialists that are needed to manage the complex care needs. Clinical consultants, such as advanced practice nurses, can help staff nurses address patients' complex care needs. They can also assist staff in examining their own concerns about working with individual whose lives differ so much from their own and about how such concerns affect the provision of care. A larger policy issue raised by this

study is the need to develop meaningful programs that address the cultural differences between staff and patients, beyond addressing basic communication needs such as translation services and signage. If nurses feel uneasy or even intimidated by their patients, giving care is at best strained. Foreign born nurses and even some U.S. born nurses are frequently unaware of the racist legacy of Tuskegee and the breach of trust many African Americans experienced with the health care system (Crawley, 2000).

Dignity was violated or threatened when the participants felt spoken down to, when their requests were ignored, and when their hygiene needs were not addressed timely. Ohlen (2004) reported a hermeneutic analysis of narratives of care-related violations among palliative care patients in Sweden. Participants described the suffering they experienced when they perceived a violation in care (e.g., unmet need, frustration, poor care, lack of caring) which were experienced as abandonment, hopelessness and being further wounded (Ohlen, 2004). Similarly, some patients in this study described unmet care needs. However, living on an AIDS dedicated unit mitigated feelings of shame and consequently enhanced rather than violated their sense of being cared for, of being human.

Several limitations are germane when considering the findings of this study. Participants were interviewed one time only. Caregivers were not interviewed so the narratives offer a partial but incomplete account of patient-caregiver interactions. Participants had prior relationships with one another outside of the group interviews; hence, group dynamics at times were more akin to a family interview than a group interview of strangers. The first author (AH) experienced role conflict as both clinician at the facility and researcher; efforts to mitigate this tension included having a group co-

facilitator who was not associated with the facility and the other interpretive team members (BD, MG) who discussed the findings and their emotional impact. However, one participant who was referred to the researcher (AH), in her clinical role commented, “is this a $15 day or are we just going to talk?” Finally, and perhaps most important, was the race and class privilege of the researchers. Group interviews were co-facilitated by an African American woman with expertise in multiculturalism and group dynamics. However, all members of the interpretive team are white, highly educated and female. Understanding the human experiences of persons who have experienced racial oppression, economic disadvantage, and social marginalization requires recognition that the interpretive accounts can only be partial understandings of the life worlds of the participants.

## Conclusion

The AIDS dedicated nursing home unit provided an opportunity for patients to feel accepted for who they are and not ostracized because of their illness. For most persons in this study, dignity was defined as respect, respect received from others and respect for self. Experiences that affirmed their humanity whether with caregivers, or other residents often helped to buffer the shame and the isolation.

Understanding the lived experiences of urban poor receiving care in an AIDS dedicated nursing home is essential if we are to recognize how persons with HIV live with everyday demands related to treatment and their caregivers, and if we are to design and implement care environments which do not inadvertently violate the dignity of their patients and may even enhance it.

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# CHAPTER FOUR: EVERYDAY STRUGGLING TO SURVIVE: EXPERIENCES OF THE URBAN POOR LIVING WITH ADVANCED CANCER

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# Everyday living and struggling: The urban poor with advanced cancer

## Background

Vulnerable populations such as the urban poor are disproportionately affected by cancer. Poor persons face barriers accessing quality cancer care and even when receiving care, frequently experience insensitivity to their plight. Untangling the effects of poverty distinct from race and ethnicity on cancer disparities is difficult at best; in the U.S., race and ethnicity often serve as proxies for socioeconomic status (Koenig, 1997). Nevertheless, the National Cancer Institute concluded that poor persons, regardless of race and ethnicity, are diagnosed with more advanced cancer and have lower rates of survival than persons diagnosed with cancer living in more affluent communities (Singh, Miller, Hankey, & Edwards, 2003). This disparity is evident even after controlling for the stage of disease at diagnosis (Singh et al., 2003). Poor people are more likely to die of cancer.

Few if any accounts appear in the literature about the everyday lives of the poor living with advanced cancer and the psychosocial and existential consequences of their illness and treatment. With few exceptions, little is known about the lives of the urban poor living with advanced cancer (Hughes, 2005, 2006; Moller, 2004; Williams, 2004).

The original purpose of this research was to understand the meaning and experience of dignity to the urban poor with advanced disease, as part of a larger study which used mixed methods. Dignity is a ubiquitous concept in bioethics and theology, and is often mentioned in the context of caring for older adults, the disabled, and those who are dying.

Dignity has been studied in persons facing the end of their lives (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Enes, 2003; Hack et al., 2004; Turner et al., 1996); however no research was located about dignity and the urban poor with advanced disease in the U.S.. Dignified dying has been proposed as a nursing phenomenon (Doorenbos, Wilson, & Coenen, 2006; Maas, 1998; Wilson, Coenen, & Doorenbos, 2006). Of late, some have questioned the usefulness of the concept of dignity (Macklin, 2003) and have argued that its use is merely a substitute for the ethical principles of respect for personhood and autonomy. This study adds to these voices of critique.

Many, although not all, persons interviewed could not and did not relate to the concept of dignity and were unable to articulate its meaning. This sentiment is eloquently stated by Sally, a 55 year old white woman with advanced ovarian cancer who lives in a single room occupancy hotel (SRO), "What does dignity mean? I got to know what it means before I can answer the questions (visit #2)." Instead of dignity, many participants spoke about respect.

Benner and others have noted that qualitative researchers, particularly interpretive phenomenologists, must be willing to modify lines of inquiry according to what is revealed or uncovered in the text (Benner, 1994; Crist & Tanner, 2003). 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 this vulnerable population.

Therefore, the purpose of this qualitative research was to 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 (Benner, 1994; Benner, Tanner, & Chesla, 1996) which studied the cancer illness experience of the urban poor. The philosophical framework of interpretive phenomenology is based on the writings of Heidegger (Heidegger, 1927/1962), as interpreted by Dreyfus (Dreyfus, 1991) and as methodologically applied and further elucidated by Benner (Benner, 1994; Benner, Tanner, & Chesla, 1996) and other interpretive nurse scientists (Gudmundsdottir & Chesla, 2006; Leonard, 1994). Interpretive phenomenology seeks to understand, not to explain, or to predict, participants' worlds- their concerns, habits and practices as they show up in narratives; interpretive accounts are always contextualized (Benner, 1994). Interview transcripts and field notes provided the primary qualitative data for this analysis.

Clinical ethnographies uncover the practical know-how of symptom recognition and management, help seeking patterns, and self care practices for persons living with a chronic illness or those who are recovering from an injury or illness (Benner, 1994; Doolittle, 1994). As Doolittle commented, "because clinical ethnography focuses on the experience of human illness as well as biomedical disease processes," both personal and biomedical perspectives can be explored along with the relationship of one to the other (1994, pp.212)."

### *Procedures*

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

Eligibility criteria for study participants included: 18 years of age or older, able to speak and understand English, able to provide informed consent, poor (operationalized as receiving Medicaid, Supplemental Social Security Income or otherwise considered indigent), diagnosed with advanced cancer (operationalized as a provider would not be shocked in the patient was not alive in two years), and the patient was aware of the seriousness of their illness. Patients were approached by a third party to gain their permission for the principal investigator (AH) to contact them.

### *Scientific Rigor*

Both data collection procedures and the resulting interpretive accounts were carefully monitored throughout the study to assure scientific rigor. Strategies employed to promote rigor included: prolonged and persistent field observations to build trust and to appreciate cultural nuances; debriefing by principal investigator (AH) occurred with the research team to review observations and impressions; negative case analysis permitted contrasting interpretations of the data; recognizing the researcher's position which may have influenced what was unseen and unheard; providing rich and thick

descriptions for readers to verify the trustworthiness of the claims and members checks with participants about preliminary impressions (Creswell, 1998).

### *Data Collection*

Data sources were in-depth interviews and field notes. Informal interviews of health and social service providers working with this population, and observations regarding environments where patients lived or received care, were recorded in field notes. Fourteen patients were interviewed 1-3 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: SROs, housing projects and other residences, hospital rooms, coffee shops, in residential hospice, or lobbies of buildings. Participants were asked to describe their experiences living with cancer, to provide narratives of interactions with health care providers, and to 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 compared and contrasted both within and across cases to identify paradigm cases and themes. 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, pp 113)." Thematic analysis allows cross case comparisons of distinctions and patterns; not infrequently the incongruities and inconsistencies of human beings emerge (Benner,

1994). The primary author drafted and redrafted interpretive memos of themes and exemplars. Memos were then discussed and revised with the research team to develop an interpretive account. All participants' names used in this paper are pseudonyms.

### *Sample*

The sample was racially diverse and reflective of the city's English-speaking population of the urban poor with cancer. Fourteen patients with stage III or IV solid tumors participated. The sample of 6 men and 8 women, ranged in age from 45-69 years; half of the sample (50%) were persons of color (5 African Americans and 2 Hispanic/Latinos). Half of the sample had a history of homelessness. Of note, 7 of the 14 (50%) patients died by the completion of data collection, some within days or weeks of being interviewed. See Table 1 for demographic characteristics of the sample.

## Findings

Hearing the word cancer commonly evokes dread and fast forwards the listener to think about the possibility of death. This association of cancer with death is ever present in the background, even as scientific discoveries have increased hopes for cures, or at the very least, promised more effective cancer treatments. This background meaning is evident when public figures' cancers are announced and their decisions related to the illness, and carrying on public lives, are judged for their appropriateness. Cancer and how persons and families respond are part of the everyday experiences of many, much as most hope to avoid it.

For everyone rich and poor alike, being diagnosed with cancer occurs in the middle of a life, within the context of preexisting challenges and possibilities. Particular

struggles faced by urban poor with cancer in this study included: concerns about housing, personal safety on dangerous streets and neighborhoods, transportation to appointments, having enough money for medication co-pays, and the necessity of relating to health care systems where many previously felt unwelcome and avoided "unless dying." Some believed their illness was not taken seriously because they did not have the right insurance. All were dependent on overburdened public health care systems or faith-based community clinics for care.

Fourteen informants discussed ways in which cancer had become an organizing narrative in their lives, sometimes their narratives 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, not the center of their lives. Their stories taken together provided evidence for the 'everyday struggling to survive' as central to the experience of the urban poor living with advanced cancer.

Persons who are poor and living in the city are not a homogenous group; individual experiences with poverty, with illness and with life differ from one another. While most participants had experienced lifelong poverty, others working as artists or in part time jobs without benefits, were uninsured when they were diagnosed with cancer and had no source of income. Poverty was exacerbated as a consequence of being ill and no longer able to work. If persons continued to work even part time they risk the loss of benefits including medical care, if their income exceeded the eligibility criterion for some entitlement programs. Many, especially those who had lived in chronic poverty, had

difficult or compromised backgrounds which set up the possibilities to be without a home, and alone without family.

*Difficult Backgrounds*

Most participants in this study had difficult personal biographies. Danny was born in jail. Sally had been placed in foster care at the age of six and repeatedly commented, "I have no family." Very few participants described close, if any, relationships with their families. Some recalled the deaths of their mothers when they were young and the family disruption and the dissolution of home that resulted. Eddie, a 64 year old white former Viet Nam vet with advanced lung cancer noted:

> "She passed away [when Eddie was 20 years old]…. that was a tragic thing for me because… and then my father went to pieces and.., I had nothing to come back home to….Because my mother was the family… (We went our) separate ways, you know. The family just spilt up. This happened like that, overnight. And within six months I didn't know where anybody was at…"

Drugs and alcohol problems were common and persisted for some, even when seriously ill and dying. Danny, a 53 year old African American man with liver cancer and end stage heart disease, had spent time in a Texas penitentiary where prisoners were expected to pick cotton. Because Danny had a positive toxicology screen for cocaine a week before his death, he was not refused readmission to a residential hospice program where he had previously walked out of to smoke crack. Half of the informants had been homeless and some remained marginally housed. One participant, who had been homeless for several years, shared a poem about homelessness written by a San Franciscan poet which vividly captures the experience.

It's not what it's like to see
It is what it's like to be,
And such is the title and meaning of homelessness.
Some us who've got nothing at all would sleep outside on the pavement and walls,
with no place to leave the things we own.
We are the ones that have no home.
And some, yeah, we panhandle for change, and
Hope we're not taken for the mentally deranged.
Though some earn theirs by playing a song,
until some authorities says, "Hey move along.'
But where are we all going to go?
So many streets now look like Skid Row.
And when I wake up under someone's stairway,
It's me that feels walked on the rest of the day.
Carrying all my belongings around, looking for Help Wanted signs in town.
But when they see my bags and bedroll,
They say they're not hiring and ask me to go.
So I walk all day chasing charity meals
Knowing this is how low the bottom feels.
Some oatmeal, a sandwich or a plate of slop.
It's back to the streets with no place to stop,
No place to stop,
No place to stop,
No place to stop.

©Daniel Wood, San Francisco Poet

As the poem says, being without a home, without a place where a person belongs, closes off basic human needs and, "is how low the bottom feels." Not all persons who were homeless live on the streets, however. Rachel a 64 year old white woman with ovarian cancer experienced another type of homelessness.

Rachel was uninsured and working as a live-in nanny when she was diagnosed with stage IV ovarian cancer. She continues to work part time for the same wealthy family in an affluent neighborhood in San Francisco, and in exchange, receives room and board with one condition, that she cannot have any friends or guests visit her at their home. At a result, Rachel must meet friends at a local coffee shop that she walks to, but

after chemotherapy Rachel is sometimes too tired to walk the several blocks. She resents her employer but feels she has no other options.

Many participants recounted experiences of trauma including: rape, domestic violence, war time military service, death of a mother at an early age, and the murder of a child or other relatives and friends. They told their stories of trauma as incidental to another story and in a matter of fact tone. Sally stopped working years ago, after having been brutally raped and requiring intensive care for months. Sally's ovarian cancer diagnosis is a cruel irony. Vicarious trauma exposure affected the researchers, particularly the principal investigator (AH), who was overwhelmed at times by the amount of trauma that many had endured and had survived.

*Living Not Dying of Cancer*

Given the chronic nature of most cancers diagnosed beyond the earliest stage, several participants had been diagnosed with cancer years before its progression. Some, like Terry a 62 year old white divorcee with metastatic cancer lived with a cherished cat, 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 percent cancer-free at this point. But they are still putting me through chemotherapy just- I guess 'cause they want to [laughs].

Terry is proud of having been declared 100% cancer free by her surgeon. She claims this success after a thoracotomy for removal of a metastatic lung lesion, and a partial colonectomy and chemotherapy for her initial colon cancer diagnosis, and while still receiving chemotherapy. Susan Sontag in *Illness as a Metaphor* years ago observed that the war rhetoric used with cancer is harmful, as persons with cancer are required to fight.

Cancer treatment liberates those diagnosed with cancer; but can it make Terry and others free? Persons diagnosed with cancer are called cancer survivors, regardless of whether they have curative or even controllable disease (Sontag, 1978). Terry did not accept all of the war rhetoric used with cancer when she commented, "I don't consider myself a cancer victim." If patients are not survivors of cancer must they automatically become its victims?

Few patients discussed the possibility of their death, even when only days or weeks from death. Ozzy, a 56 year old divorced, African American man and veteran diagnosed with metastatic colorectal cancer, lived in an SRO. Ozzy was unclear about the details of his illness, the location of his tumor, and what treatment he was receiving intravenously at an outpatient infusion center every month. He associated his cancer diagnosis to a pneumonia he was hospitalized and treated for that occurred at the time he had been cleaning streets as part of a welfare work program. Six weeks before his death, Ozzy was most disturbed when he was not able to go out:

> "Well, I'm doing very poorly now. I don't feel worth a damn no more. I'm just tired of sitting around in this room doing nothing. I'm tired of my legs being like this here. I can't go nowhere hardly. I can't do nothing. I just get bored…. (INT #2)"

For Ozzy, living was equated with being able to be active, to be able to go where he wanted to go, and not being trapped in his room and feeling bored. Having to sit around in his immaculately maintained room limited Ozzy's ability to maintain his pattern of drinking alcohol and using drugs.

Pedro, a 46 year old Latino man with colorectal cancer and liver metastasis, six days before his death while hospitalized, characterized his health as being "up in the air."

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

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

Anne: [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.

Anne: Uh-huh. And the fighting "it," is the cancer?

Pedro: Yeah.

"Up in the air" suggests the unknown, the uncertain and also conveys a less predictable course, like a kite floating in the wind, not on this earth. As Pedro continued, he described feeling that he was coming to a crossroad, a decision point where he needed to reevaluate whether to keep fighting the cancer or not. Prior to this point, he hadn't had a choice about accepting chemotherapy, because he was always fighting. He had never been at this place before, so close to the end of his life.

Pedro did not constantly think about the cancer, but put it aside from time to time. Putting cancer aside was evident to even Pedro's neighbors in the boarding house where he lived, who encouraged him to go to 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 theatre project he mixed the music for, Pedro became animated and his eyes sparkled. He described the fun of being creative and having to select each single note of music and putting them together to create the right accompaniment for the production.

### *Sources of Support*

Two other participants described the meaning of a cancer support group in their lives. Rachel described how her group gave her a sense of belonging with others who

understood what she was going through, unlike her employer who insisted she continue to work for her room and board and seemed insensitive to how chemotherapy and cancer altered her energy level.

Ozzy had a distinctly different opinion of this popular psychosocial intervention for cancer patients. He found it unhelpful. Even during the consent visit, Ozzy mentioned feeling uncomfortable in the cancer support group and his unease in a group where other cancer patients talked about their illness. He repeated this theme in each of two subsequent interviews.

> "It wasn't meant for me. It wasn't my thing. 'Cause everybody- in the community circle everybody talks about their cancer or what they- what kind of cancer they have. I'm not into to what they have. I'm on to what I have. I just wanna talk to a person one-on-one about me. I don't wanna hear everybody else's problems about their cancer and stuff like that. I feel like this here. I do not fit in that category."

Ozzy had a long history of alcohol and drug use, and participation in treatment groups in which persons shared in a group their personal experiences with drugs and alcohol. "Community circles" are a common strategy to build therapeutic communities but Ozzy wasn't having any of it as "(he) was on to what (he) had" and was not interested in others' experiences.

Support needs clearly varied among the participants in this sample, and in cancer patients in general. For some, a group intervention promoted a sense of belonging, fostered creativity, and mitigated the aloneness of their experience. For others, the support group was at least unsupportive and at times disturbing.

Participants discussed two other sources of support which helped them live with the struggles of cancer and of life: spirituality and seeking information. Almost all

participants spoke about the importance of faith, religion or other abstract spiritual beliefs in their lives. Sally spends a lot of her time everyday studying religious audiotapes, CDs and written materials that she sent away for from a television minister whose sermons she enjoys. The minister's show is on all night long and Sally enjoys going to sleep to the minister's sermon because "you sleep so nice." In the our interview, Sally spoke about how cancer has brought her closer to God and how much she enjoyed learning more about her Christian faith. Religious studies offered Sally a way to not feel trapped staying at home all the time because she did not feel safe on the street. Religious studies also became a way for Sally to manage being alone.

For Maria, a 52 year old Latina with metastatic lung cancer living with three other generations of her family, faith in God has always been a central part of her life. The same evening as my first interview with Maria, she was expecting a visit from a pastor. She described his church as always warm, welcoming and "makes you feel like family, not stranger." Faith provided a feeling of family, of home, and of belonging for Maria and several others in this study. Maria is certain that only God has the power to cure her if it is not her time to die.

> "At one point I told him (God), "Well, if you gave me a heart attack and you saved me, I know you could save me from this if it's your will." But then I said, "If you ain't gonna save me, why didn't you just take me then?" You know? I don't know. I don't know that answer. You know, it's an answer that I'll never know. But that's the only time I ever questioned Him. The rest of it is all in His hands. I can't change anything."

While Maria speaks about God's ability to cure her, she seems to have some doubts and looks for a rational explanation for why she didn't die when she had the heart attack. She repeats "I don't know the answer," hoping for an explanation for a matter of faith, a

matter of suspended belief. She is fatalistic about her future and believes she cannot control her fate, she "can't change anything" as it is "in His hands." Her suffering causes her to question the wisdom of God's timing if she is not to recover. The ambiguity of her situation throws her back on her faith.

Some found support in learning as much as they could about their illness, its treatment and what might lie ahead in their future. Others resisted obtaining information or patient education, and relied solely on what their doctors advised. Danny regretted asking for detailed information:

> "And then I asked the doctors uh, you know, to give me a blow by blow description of what was wrong, right? And uh [chuckles]…yeah, and uh…hmm, anyway, yes, I won't do that anymore."

Just like support needs, information needs of cancer patients differed; one size fits all patient education approaches are never helpful. Terry chafed at health professionals' efforts to educate her about doses and names of chemotherapy agents and questioned, "so knowing a 5mg change in Adriamycin dose has some meaning to me?" Terry indicated that she liked control, just not information and responsibility for involvement in decision making about chemotherapy. Terry was "pissed off" when she lost control by having to use and "drag" an oxygen tank at home after her lung resection. Terry's need for control but resistance to information may seem contradictory; however the control Terry lost was the encumbrance, the lack of freedom of movement she experienced having to use oxygen tank.

*Speaking or Not Speaking About Death*

Three participants acknowledged that they may die as a result of cancer. All three have since died along with four others who did not speak directly about their deaths. For those who did not speak about their deaths, some vaguely inferred its possibility while others rejected it outright as a possibility. Danny believed he would live forever and while 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 this statement.

Gretchen, a 63 year old European born small business owner, was without medical insurance when she was diagnosed with stage IV breast cancer. Gretchen was one of only two participants who brought up "quality of life" in their interviews. Gretchen wished physician assisted suicide was legal. Without much emotion, she spoke about her death from brain metastasis as a "horrible way to die." And yet, 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, managing his "fixed" income. He was grateful that he was alone and not leaving any family behind that he had to worry about. At the same time, Eddie regretted that he was alone, had never married, and never had a home and or a family.

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

> "Cause I'm only 45 years old [crying] and- 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 …do my work and enjoy my life. You know?"

Dying may be more familiar territory to those who are older. At younger ages, death cuts off promising careers and possibilities of life. Sylvia died about a month after she made this plea.

*Struggling with Health Care Systems and Providers*

Participants spoke most vividly about difficulties encountered with health care providers and systems. Difficulties included: being sent home alone to an SRO after cancer surgery when too weak to care for themselves, "hoops" needing to be jumped through to receive benefits, delays in diagnosing advanced cancers even after reporting symptoms to primary care doctors for more than a year, incomplete cosmetic surgery after mastectomy that left one woman without a breast nipple, providers' unwillingness to take on a powerful surgeon who was dismissive of a patient's needs while secretly encouraging her to change surgeons, inexperienced doctors involved in inpatient care and the seeming the lack of coordination among specialists who gave contradictory assessments of what was wrong and what treatment was indicated, having to stand and wait in very long lines to drop off and then stand and wait again to pick up medication refills at outpatient pharmacies, communication with staff in ancillary departments that at times was perceived as demeaning, insensitive, dismissive and "downright rude," if any communication even occurred.

Several participants encountered nursing care problems during hospitalizations that resulted in their feeling frustrated, ignored and in some instances, neglected. For two

patients, the problems were related to fecal incontinence and they were ashamed to even tell their stories. One experienced acute diarrhea as a medication side effect; the second had malodorous stools and fecal urgency as a complication of colon cancer. Both put their call lights on for assistance; both were told the nurse would get to them as soon as possible. After waiting what seemed like more than an hour, one patient was told by a nurse she had "forgotten about (him)" and the other reported that he became angry and "cuss" and was scolded by the nurses to "act nice."

Both of these two male patients subsequently avoided hospitalizations sometimes to their own jeopardy. Ozzy who acknowledged "cussin" the nurses, tried to problem solve and told the nurses to bring him, "some big ol'pampers " and wash clothes and he would 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 doubts they spoke up for him even though they said they would. Ozzy had to take care of himself; he can not trust the nurses in the hospital, and at a far too young age, Ozzy learned that he could not count on his parents to protect him as his mother died when he was less than seven years old. Ozzy keeps people at bay, he is a loner who "does his own thing," not trusting that others would be there for him when he needed them.

Gracie, a 59 year old African American widow born in Louisiana, completed six weeks of radiotherapy following disfiguring surgery to her jaw, face and neck for an invasive cancer three years ago; part of her tongue and the top of her mouth were

removed so she has a prosthesis that prevents food and fluid from entering her sinuses. Gracie was very angry when her minister from the pulpit asked her church congregation to pray for Sister Gracie. Gracie told the congregation to pray for themselves she did not need their prayers as she no longer had cancer. She lives in her recently deceased 90 year old aunt's home in poor and working class, primarily African American neighborhood. She had been the fulltime live-in caregiver of her aunt for many years. Her male cousin, who owns the home where his mother lived, threatened to evict Gracie and sell the home until her white primary care doctor called him and described how sick Gracie was.

Gracie described the discrimination she has experienced as a black woman receiving care at a university medical center when she was fitted for her mouth prosthesis. She is convinced that as soon as the chief of the service laid eyes on her and saw she was black woman, he lost interest in her case. She was reassigned her to a less experienced provider. When asked how she felt race interfered with her care, Gracie commented:

> Gracie: Sometimes I laugh about it. … Being from down south… I've had way worse than that happen.
>
> Anne: 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 Louisiana at night when they set up to to kill me. And they sent me to Illinois to save my life.

Gracie went on to explain how a cousin who had been a mortician was murdered because he tended to the body of a black 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 in a liberal western city.

Danny spoke about being “labeled” and how that shaped his interactions in the health care system. Being labeled as a black 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 has had a long history of difficult or challenging encounters with health care providers resulting in his leaving without receiving care, being lost to follow up, or his becoming quite angry. When Danny perceived he wasn’t heard or was labeled as “less than,” he reacted in ways that frequently alienated health care providers and their relationship seemed doomed for failure. Danny and others participants commented that being treated like a human, not spoken down to like a child, nor treated like a number or an animal, but as a person was how health care providers could make patients feel cared for and comfortable.

## Discussion

Living with advanced cancer—the lurking threat of death, distressing symptoms and treatment side effects as constant reminders, schedules organized around medical appointments, dealing with multiple health care providers and inflexible, fragmented systems— is not easy for any human being regardless of class or income. For participants or informants in this study, the experience of advanced cancer occurred in the context of lives that, in most cases, were already challenged and already wanting. Difficult backgrounds were common and created possibilities and posed challenges (Moller, 2004). Informants had been struggling with life; cancer was, at times, just one more

burden to be endured. When safe housing, nutritious food, transportation to go where a person needs to go, money for personal needs, and competent and accessible health care cannot be taken-for-granted, a person struggles to live (Song, Ratner, & Bartels, 2005).

Besides lacking access to basic resources however, informants in this study were younger in age when they were coping with cancer compared with most facing this diagnosis. The average age of patients in this study was 56 (range 45-69 years of age). According to the National Cancer Institute, the median age for cancer diagnosis in the U.S. is 67 years and average age at the time of death is 73 years (SEER, 2007). Participants in this study were living with-dying from cancer at an age comparable to those in a developing African country (Murray, Grant, Grant, & Kendall, 2003). Dying out of sync was a finding in a study of mostly African American persons with advanced cancer in a Southern U.S. city, a 37 year-old- woman with breast cancer lamented, "This is a young life we're talking about here. I don't want to die young….before I've even had a chance to live." (Williams, 2004). Persons who are poor are living with/dying of cancer at a younger age, 'out of time' from when serious illness and death can be typically expected and before having "a chance to live."

Being poor, being a person whose skin color evokes conscious and unconscious discrimination, and living in a city where housing costs are astronomical, is a testament to the survival of the participants in this study. These life survivors were also trying to survive cancer. Cancer survivor is a social construction in common parlance in cancer care. According to a recent 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 (pp.483)." Survival is a term used for those with endure, who live through catastrophic events that claim lives such as natural disasters and war. Cancer survivor is consistent with the metaphoric language of war that Sontag found problematic for those living with this serious illness (Sontag, 1978). Nonetheless, participants in this study were struggling to survive their life's hardships as well as to survive cancer.

Not all persons 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/end of life care (Freeman & Chu, 2005; Ward et al., 2004). Determining the role of race in explaining these disparities distinct from poverty is impossible (Freeman, 2004). Most in this study presented with advanced disease and their chances of 'beating cancer' were already compromised.

For those who had avoided contact with health care system until "almost dying," their experiences with overburdened systems and providers with more patients than time, were often, but not always, less than satisfactory. Some responded with anger and left after "cussin" staff members. Others learned to cope with the inconveniences and worked around them. Some resorted to not trusting care that would be available and instead relying on themselves. The fortunate few encountered staff members who saw them and listened. Studying the experiences of terminally ill cancer patients in Canada, researchers also discovered that paradoxically, health care services and providers may increase the suffering of their patients (Daneault et al., 2006). Overburdened systems and

overworked providers resulted in patients feeling neglected, alienated and not seen as human being requiring care (Daneault et al., 2006).

Few in this study spoke about their impending death. Most, even those who were days or weeks from death spoke about living. Researchers, examining the existential concerns of advanced cancer patients in Israel, noted that almost half of the 40 patients interviewed reported not thinking about dying since the time of diagnosis (Blinderman & Cherny, 2005). These findings present interesting challenges for clinicians and researchers. How will clinicians assure patients' wishes for care at the end of life are known and are honored if many patients do not want to talk about dying and only wish to talk about living? How will researchers study EOL care if many patients choose not to talk about it? Might researchers' attempts to even raise this topic be viewed as coercive or possibly harmful?

Spiritual practices and religious beliefs were important sources of support, providing a sense of belonging and of community for participants in this study. This finding is consistent with other studies of advanced cancer patients (Blinderman & Cherny, 2005; Moller, 2004; Williams, 2004). In an ethnographic study of urban poor in a Midwestern city, Moller noted that "faith plays a prominent role in providing strength and resilience" throughout the living-dying process (Moller, 2004, p.xiv). Similarly in a southeastern city in the U.S., Williams reported that as patients followed in an oncology clinic of a public hospital became sicker and their ability to be part of a church community diminished, private spiritual practices and televangelism became more common (Williams, 2004). In Israel, Blinderman and Cherny (2005) reported that

spiritual wellbeing was important for most regardless of whether they held orthodox religious beliefs or self-identified as secular Jews.

Information and support needs varied widely within this sample. Not all patients wanted "blow by blow" descriptions of what might lie ahead. Others appreciated being informed and had even sought out information on their own from the American Cancer Society or the web. The clinician is left to determine how much information the patient wants, to assess learning needs and preferences, and then to educate the patient about his/her illness and its treatment. Some patients will refuse information regarding it as irrelevant; others will consider it burdensome. This refusal of illness and treatment related education presents an ethical challenge given the toxicities of many cancer therapies and the emphasis of many patient safety initiatives to promote well informed patients (National Patient Safety Foundation, 2003). For some patients, nurses will be faced with the unsettling issue of how to safely care for the patient who elects not to be informed about cancer treatments.

Informants varied in their response to a support group intervention, a psychosocial intervention frequently used in cancer care (Cella & Yellen, 1993). Some perceived such groups as providing support, companionship and fostering creativity. Other informants, self- described "loners," did not appreciate hearing about others' experiences with cancer, wanting instead to remain focused on their own situation. Some reported feeling uneasy or self-conscious in a group setting. How to best meet the support needs of persons who are uneasy in a group remains a challenge given the limitations of resources and staffing of all programs serving the poor. Social workers or nurses already serving as case

managers, advocates and navigators through the byzantine systems of care seem a too fragile possible solution and bridge for the disenfranchised and marginalized.

For nurses working in hospitals and other inpatient care settings not attending to toileting needs was the most serious care problem described by study participants. Shame, embarrassment and frustration resulted when informants were unable to manage their own elimination needs and when nurses were perceived as non-responsive. In the hectic pace of acute care units when priorities are understandably based on criticality of illness, some patients will be required to wait for help with toileting assistance. This delay in nursing care may be perceived by the patient as neglectful and inhumane. The personal and social meanings of neglect on this level of bodily care are demoralizing and humiliating. Ensuring adequate staff to meet all nursing care needs, including basic hygiene needs, is a challenge for nursing administrators. Responding to patients who feel overlooked or neglected will require skillful intervention by the nurse at the bedside. However, meeting the most basic of care needs is critical nonetheless when human bodies and spirits are broken.

Nurses play important roles as interpreters of medical information, evaluators of functional status and continuing care needs, and as educators for care required at home or in the community. Another finding of this study was the more limited role nurses play for persons living with advanced cancer in the community, where most of cancer care is provided, and where living with advanced cancer is situated. Participants' contacts with nurses were often confined to telephone advice or interactions in outpatient infusion centers. While limited, patients' interactions with nurses in these settings were typically

perceived as very positive, supportive and accommodating. In contrast to these experiences with nursing care were their hospital experiences. When participants were hospitalized and more vulnerable and dependent, their experiences with nursing care were generally, but not always, negative as was previously described. Nurses in inpatient care settings were seen as busy, insensitive, untrustworthy, and often seemed more interested in their work colleagues than their patients. Some American-born participants expressed their frustration when foreign-born nurses were speaking other languages to one another in the patient's presence.

Finally, the research implications of this study are numerous. Most informants in this study were appreciative of the opportunity to participate in this research. Some insisted on being interviewed when they were very near the time of death. This was also reported by other researchers who interviewed terminally patients and their caregivers about the stress and helpfulness of participating in research (Emanuel, Fairclough, Wolfe, & Emanuel, 2004). Participating in research was not considered stressful (89.7%) and even characterized as helpful by the 46.5% of terminally ill patients interviewed (Emanuel et al., 2004).

For those who are not so seriously ill, engaging them in asking what are the important research questions to be answered are important is critical. Designing studies to address their questions engages them as active partners rather than passive "subjects." Without their voices, their lives and their experiences will continue to be marginalized. More research is needed to identify the ethical issues of studying the poor who are dying, such as assuring informed consent, analyzing when payment serves as undue influence,

and articulating how qualitative researchers as human beings may serve as a possible therapeutic intervention. Ultimately since most informants in this study described respect as meaningful, ethnographic research will allow examination and description of care structures of care that are respectful and disrespectful, with the goal of modifying them.

Table 1.
Sample Demographics

| **Characteristic** | **Number (%)** |
|---|---|
| Gender | |
| Female | 8 (57) |
| Male | 6 (43) |
| Race/ethnicity | |
| African American | 5 (36) |
| Caucasian | 7 (50) |
| Hispanic/Latino | 2 (14) |
| Age | |
| Mean | 56 years |
| Range | 45-69 years |
| Education | |
| Less than high school | 3 |
| High school or GED | 1 |
| Some college | 7 |
| College/graduate school | 2 |
| Unknown | 1 |
| Tumor Type | |
| Lung | 3 (21) |
| Breast | 3 (21) |
| Colorectal | 3 (21) |
| Ovarian | 2 (14) |
| Prostate | 1 (7) |
| Liver | 1 (7) |
| Head and Neck | 1 (7) |
| History of Homelessness | |
| Yes | 7 (50) |
| No | 7 (50) |

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# CHAPTER FIVE: MEASURING DIGNITY IN THE URBAN POOR WITH ADVANCED DISEASE

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# Measuring Dignity in the Urban Poor with Advanced Disease

One in eight Americans lives in poverty (DeNavas-Walt, Proctor, & Lee, 2006). Poverty poses many risks to the personal health of those living without healthy food, adequate housing, and access to medical care and community support, or sufficient income to meet personal and family needs. Consequently, the poor have high rates of lifestyle-related chronic life-threatening diseases, such as cancer and HIV/AIDS, and environmentally-related illnesses (e.g., asthma, and injuries related to violence). Little is known about their everyday lives when they are seriously ill and facing the end of their lives and what is meaningful (Hughes, 2005, 2006; D. W. Moller, 2004; Williams, 2004).

Dying with dignity is axiomatic to good end-of-life (EOL) care and to what constitutes a good death (Kaufman, 1998; Proulx & Jacelon, 2004). Indeed, violations, threats, or losses of dignity are associated with bad deaths (Agrawal & Emanuel, 2002; Enes, 2003). When the hope for cure is no longer realistic, many persons at the end of their lives hope for dignity in their dying (Sullivan, 2003). However, the meaning of dignity is assumed to be consensual and unproblematic (Street & Kissane, 2001) and until quite recently, was not measured (Chochinov, Hack, Hassard et al., 2002; Chochinov et al., 2006; Hack et al., 2004). The urban poor are believed at greater risk for bad death and presumably more threats to or losses of dignity (Hughes, 2006).

## Conceptualizations of Dignity

Dying with dignity is thought to be responsive to clinical intervention and therefore observable and measurable (Brant, 1998; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Doorenbos, Wilson, & Coenen, 2006; Rankin et al., 1998; Stewart, Teno,

Patrick, & Lynn, 1999; Turner et al., 1996). Occasionally, dying with dignity is undefined and mentioned only in the title of a paper. Most frequently, dying with dignity is discussed in the context of autonomy-based requests for physician-assisted suicide and euthanasia (Evangelisto, 1996; Field & Cassel, 1997; Hack et al., 2004; Reagan et al., 2003).

For some, death with dignity implies a death free of the encumbrances of medical technology that serve only to prolong dying (Field & Cassel, 1997; Jacobson, 2007; Kaufman, 1998; D.W. Moller, 1990; Proulx & Jacelon, 2004). The Institute of Medicine [IOM] noted problems defining dignified death and instead recommended that the dying be treated in ways that conveys respect for inherent dignity of the person.

> Death dignified by care that honors and protects- indeed cherishes- those who are dying, that conveys by word and action that dignity resides in people, not physical attributes, and that helps people to preserve their integrity while coping with unavoidable physical insults and losses. (Field & Cassel, 1997, p.25)

Discussions of dignity are not limited exclusively to the dying, however, although dignity seems most often raised in this context. Dignity has been studied in other vulnerable populations, including the elderly, the disabled, and the homeless (Jacelon, 2003; Jacelon, Connelly, Brown, Proulx, & Vo, 2004; Miller & Keys, 2001; Stienstra & Chochinov, 2006; Toombs, 2004). Families (Enes, 2003), health care professionals (Enes, 2003; Turner et al., 1996 ) and care delivery systems (Jacelon, 2003) have been studied to describe how dignity is preserved when providing care.

## Research Related to Dignity at the End of Life

Turner and colleagues (1996) conducted one of the earliest studies to examine dignity at the end of life (EOL). These Australian researchers described intrinsic factors (such as symptom management) and extrinsic factors (such as dying in the emergency

room) believed to influence the dignity of terminally ill patients receiving inpatient palliative care. Fifty medical records of deceased patients were reviewed retrospectively and health care professionals who cared for the patients were interviewed within days of the patient's death. Health care professionals rated the dignity of the patient's dying on an eleven point scale (0 = totally undignified dying and 10 = dignified dying). Most patients had at least one symptom in the last three days of life. What was surprising to the researchers was the difficulty expressed by health care professionals in assigning a dignity rating to the patients' dying; both physicians and nurses questioned what the rating was actually measuring (Turner et al., 1996).

Rogers and colleagues (2000) reported bereaved family members' dissatisfaction with hospital care of cancer patients who died in London. The aim of this British study was to describe family members' concerns regarding hospital care in the last year of the patient's life. Family members described a number of threats to dignity of their loved ones: lack of individualized care, placing bureaucratic needs over patients' needs, and perceptions that their loved had been treated in ways that were dehumanizing, devaluing and disempowering.

Street and Kissane (2001) completed a discourse analysis of dignity at the end of life. In their search of professional and lay literature, as well as a review of the qualitative research which they have conducted, the researchers concluded that the meaning of dignity is not universally agreed upon and is conceptually imprecise. Bad deaths and requests for physician-assisted suicide had been linked to lack of dignity. Their analysis further identified a number of definitions and descriptions of dignity at the EOL such as autonomy and self-determination, personhood and self-worth, spiritual or transcendent

experience, embodied, and relational. Dignity as embodied refers to how dignity is experienced or felt; aspects of shame and an abject body are evident in this construction. Dignity as relational suggests its reciprocal nature, and importance of relationships to dignity at the EOL. These researchers believed their unique contribution to the discourse about dignity at the EOL was their conceptualization of dignity as embodied and dignity as relational (Street & Kissane, 2001).

Chochinov (2002) proposed an empirically derived model of dignity at the EOL based on interviews with 50 terminally ill Canadian cancer patients. Patients were asked how they defined dignity, what experiences supported or undermined their sense of personal dignity, and their perceptions of the role dignity placed in requests to hasten death. Researchers used latent content and constant comparison analysis to analyze audiotaped and transcribed interview data from 27 outpatients and 23 inpatients receiving palliative services(Chochinov, 2002).

The sample was primarily over 65 years old (62%), with slightly more females (54%). Most informants (90%) died within one year of the interview. Patients had the following cancers: lung (36%), breast (20%), gastrointestinal (20%), prostate (10%), and other (14%). Race/ethnicity and income data were not reported. Almost half (47%) of all patients approached to participate in the study refused; the most common reason cited by those refusing was not being interested (41%).

Three major categories and related themes and sub-themes emerged from the data: illness related concerns, dignity-conserving repertoire, and social dignity inventory. Illness-related concerns included two themes: level of independence, i.e., cognitive acuity

and functional capacity, and symptom distress, i.e., physical and psychological distress (see Figure 1).

Dignity-conserving repertoire, the second category in the dignity model, was the term used to describe internally held beliefs (called dignity-conserving perspectives) and actions/techniques (referred to as dignity-conserving practices) used by the patient to bolster dignity. Eight sub-themes of dignity-conserving perspectives were described: continuity of self, role preservation, generativity/legacy, maintenance of pride, hopefulness, autonomy/control, acceptance and resilience/fighting spirit. Three sub-themes described for dignity-conserving practices were: living in the moment, maintaining normalcy and seeking spiritual comfort.

Social dignity inventory referred to social concerns that enhance or diminish a person's dignity. Five themes were proposed for this category: privacy boundaries, social support, care tenor, burden to others and aftermath concerns.

The researchers depicted the interrelationships of the three categories (illness related concerns, dignity conserving repertoire, and social dignity inventory). In their model, dignity was identified as the outcome variable. Illness-related concerns and social dignity inventory affected dignity; their effects are modulated however by dignity-conserving repertoire.

Perhaps one of the most intriguing findings was the influence of place on dignity. Outpatients most often reported that dignity is internally held and cannot be taken away; whereas, two-thirds of the inpatients believed others could take dignity away. Institutionalization seemed to compromise dignity. Additionally, the researchers noted that for some patients, a life without dignity was a life not worth living. In this regard, the

researchers noted possible overlap with other concepts, such as quality of life, hope, and self-respect (Chochinov et al., 2002).

Chochinov identified limits to the model that may affect its generalizability: patients' age (most were older), disease status (all had advanced cancer) and data were collected one time only. Because of the cross-sectional design, the researchers noted that changes in how patients defined dignity and factors that influenced dignity over time are not explained in this model (Chochinov et al., 2002). The dignity model's relevance in understanding the experiences of dignity and indignity among the urban poor in the U.S. is uncertain. Since Canada has a nationalized health care system, issues related to access to care are different than in this country. Since race/ethnicity and income data were not provided, it is unclear how, or if, the main components of the model (illness concerns, dignity-conserving repertoire and social dignity inventory) contribute to our understanding of dignity among the urban poor living with a life-limiting illness. Further, whether dignity is defined differently by patients who are living with life-threatening illnesses other than cancer is unknown.

In a follow up study, Chochinov and colleagues (2002) surveyed 213 terminally ill cancer patients to assess the extent to which they were able to maintain sense of dignity and to identify demographic and disease variables related to dignity based on the model previously described. Researchers used existing instruments to measure selected aspects of the model, such as the Symptom Distress Scale (McCorkle & Young, 1978), Katz Index (functional assessment scale), single item measure of loss of dignity (Wilson et al., 2000), Mc Gill Pain Questionnaire, Quality of Life (Graham & Longman, 1987) and items developed by the researchers or used in prior work. A single item was used with 7

possible responses to measure loss of dignity as an outcome variable, in which 0 = never felt a loss of dignity and 6 = extreme loss of dignity. This measure was originally used to examine attitudes of terminally ill patients about euthanasia and physician assisted suicide and has an intraclass correlation between two raters of r=.92 (Wilson et al., 2000). Using a cut off score of 3 or more, a patient was considered to have experienced a severe loss or fractured dignity, the term coined by Chochinov to describe severe loss of dignity.

Surprisingly, most patients (93%, n = 197) reported no, minimal or mild loss of dignity, measured on the single item, 7-point scale. Sixteen patients (7%) reported moderate-severe loss of dignity. All patients reporting moderate or severe loss of dignity were hospitalized and tended to be of a younger age. These 16 patients described as experiencing fractured dignity, were more likely to feel hopeless and depressed. Using multiple logistic regression statistical analyses, several factors predicted fractured dignity: appearance concerns, feeling a burden to others, needing assistance with bathing, pain intensity and location of care (Chochinov et al., 2002).

Enes (2003) used a phenomenological approach to explore the meaning of dignity to terminally ill cancer patients (n = 8), family members of other terminally ill patients (n = 6) and health care professionals (n = 7) in an inpatient hospice in United Kingdom. Each informant was interviewed one time for between 35 to 65 minutes. Four dimensions of dignity emerged from the data: relationship and belonging, having control, being human, and maintaining the individual self. Negative instances in which persons experienced a lack of dignity were described more often than were affirmative instances in which their dignity had been enhanced. Relationship and belonging included: being heard and understood, giving and receiving love, being included, as well as self and

others' perceptions. Informants reported that “having control” over decisions, their body, their behavior and what was happening were important. The concept of “being human” included: feeling worthy of respect, having worth, value and esteem and having rights. The final theme, maintaining the individual self, included: independence, individuality, space and privacy, having needs met, appearance and body image, role and position, maintaining a normal life and the freedom to be. Enes (2003) noted that symptom control enhanced dignity. Finally, the significance of dignity seemed to change or adapt over time (Enes, 2003).

Hack and colleagues (2004) completed a secondary analysis using factor analytic techniques to define dignity in 213 terminally ill cancer patients in Canada (same sample as used in Chochinov et al., 2002). Researchers selected instruments, previously used and tested in other studies, to measure selected concepts in Chochinov’s inductively derived dignity model (2002) and to understand what variables contributed to loss of dignity. Dignity was measured by the single item as previously described.

In this secondary analysis, 16 (7%) patients who reported moderate or severe loss of dignity were included in a factor analysis. Six factors explained 40.5% of the variance of dignity scores in the sample: pain, dependence in activities in daily living, hopelessness/depression, informal support, formal support (i.e. marital status and income) and quality of life. The most significant correlates of dignity were quality of life, hopelessness/depression, and dependency. The authors concluded that dignity may serve as the moral compass to guide care at the end of life (Hack et al., 2004).

Chochinov and colleagues (2006) recently published a study to validate the inductively derived model. The researchers developed 22 items to measure sub-themes

from the model's three major categories (2002). In the past, these researchers used already existing instruments with established psychometric properties to measure the model. Some items were intended to measure more than one sub-theme. Some sub-themes from the original model were not measured, such as acceptance and aftermath concerns.

Subjects indicated their agreement or disagreement as to each item's importance to dignity on a 5-point scale (strongly agree to strongly disagree). For their analysis, strongly agree and agree responses were collapsed and the percentages and frequencies reported. With the exception of one item, thinking about how life might end, 50% or more of the sample agreed that the other 21 items were important to dignity. As was true of earlier studies by Chochinov, few patients (5.3%, n = 11) reported a loss or fractured dignity as measured by the single item (Wilson, 2000) that was scored as a dichotomous variable, no or minimal loss of dignity versus fractured (severe loss of) dignity.

In summary, of the eight studies which examined dignity at the end of life, four (Chochinov, Hack, Hassard et al., 2002; Chochinov et al., 2006; Hack et al., 2004; Turner et al., 1996) used quantitative approaches. The qualitative studies used a variety of approaches: discourse analysis (Street & Kissane, 2001), grounded theory (Chochinov et al., 2002), phenomenology (Enes, 2003) and content analysis (Rogers et al., 2000). Almost all of the patients studied had cancer and presumably had a similar disease trajectory. All patients were receiving hospice or palliative care services. Income or economic resource information was not provided in any of the studies (although was measured in Hack's factor analysis). Experiences of dignity, or indignity, of the urban poor living with a life-threatening illness were not described.

The purpose of this research report is to describe the beliefs and attitudes of economically disadvantaged individuals living with advanced cancer and advanced HIV disease about dignity based on Chochinov's model and to measure the loss of dignity in this vulnerable and marginalized group. This analysis is part of a larger study using mixed methods, qualitative in depth interviews and quantitative survey approach, to understand the meaning and experience of dignity in the urban poor.

## Methods

The study was approved by a university institutional review committee, a cancer comprehensive cancer center review committee, and by facility institutional review committees at a public hospital and publicly owned nursing home.

### *Subject Recruitment*

Patients were recruited from providers working with the urban poor in a western city in the US, including an oncology clinic in a public hospital, a dedicated AIDS nursing home unit, home health providers and social workers. The principal investigator (AH) visited the recruitment sites frequently to consult with providers about potential subjects. Subject eligibility criteria included: 18 years of age or older, able to speak and understand English, poor (based on eligibility for entitlement programs), diagnosed with advanced cancer or advanced HIV disease (operationalized as provider would not be shocked if the subject was not alive in 2 years) and patient aware of the seriousness of his/her illness (verified by provider's report). Potential subjects were asked by their provider if the principal investigator (AH) could contact them. Only after obtaining the patient's name and contact information from the provider would the PI contact the patient to discuss the study and to obtain consent.

### *Data Collection*

The investigator administered the questionnaire to avoid problems related to illiteracy, following an in-depth qualitative interview. The qualitative analysis is reported elsewhere (Hughes, in progress). Data collection included demographic information and twenty-two investigator-developed items to measure Chochinov's model since his items had not been published. In addition to the 22 dignity items developed for this study, a single 7-point item used by Chochinov to measure loss of dignity was used twice to measures dignity lost as a result of illness and loss of dignity that preceded the illness. Data were collected from December 2005 through January 2007.

### *Measures*

The PI wrote 22 items to examine the specific themes and sub-themes of the three main categories of the Dignity Model: (1) Illness related concerns, (2) Dignity Conserving Repertoire and (3) Social Dignity Inventory (2002). Items were based on the descriptions of the sub-theme in the original paper or as reflected in interviewed patients' quotations (Chochinov, Hack, McClement, et. al 2002).

To determine whether a sub-theme of the illness related concerns, cognitive acuity, affected dignity, subjects were asked, "How important to your sense of dignity is being able to think clearly." Subjects were asked to select from 5 possible responses: not at all important, a little bit important, somewhat important, quite a bit important, and extremely important. To examine a sub-theme of dignity conserving repertoire, resilience/fighting spirit, subjects were asked to indicate if, "Having a fighting spirit maintains a person's dignity," was definitely true, mostly true, mostly false or definitely false. To examine the social dignity inventory sub-theme, care tenor, subjects were asked to indicate how

important were two items (on 5 possible responses from not at all important to extremely important), “How important to your sense of dignity is being treated like a person? How important to your sense of dignity is being treated with respect?” Items which reflected values about aspects important to their dignity were scored on a 5-point scale (not at all important to extremely important). Responses for items reflecting beliefs about dignity, such as “Dignity is lost when a person needs help with bathing or toileting,” were scored on a 4-point scale (definitely true, mostly true, mostly false and definitely false).

In addition to the dignity items developed by the investigators, subjects were asked to rate loss of dignity related to illness and the loss of dignity that occurred before becoming sick.

*Data Analysis*

Descriptive statistics were used to describe sample demographics and to calculate frequencies of participants’ responses to the dignity items. Responses were collapsed to indicate agreement about its importance (quite a bit important and extremely important) or endorsement of a belief as stated (definitely true and mostly true). Some of our items were remarkably comparable to Chochinov’s items (2006) and some items were not. Two research team members (AH and AS) reviewed our items and determined their comparability with Chochinov’s (2006) items in measuring the theme or sub-theme. Using the same scoring used by Chochinov, subjects who reported (3) moderate, (4) strong, (5) severe, or (6) extreme loss of dignity were considered to have fractured dignity and those with scores $\leq 2$ were grouped as not having experienced a loss of dignity.

# Results

## *Sample*

Twenty nine subjects are included in this study. Demographics are described in Table 1. The sample included 14 men, 14 women and 1 transgendered person. Age of participants ranged from 35 years to 69 years, with a mean age of 52 years (sd = 8.8). Fifty five percent (n = 16) of the sample were of African American, Afro-Caribbean or African origin and 27% were Caucasian (n = 8). Fifty five percent (55%) had a high school education or less. Fourteen subjects had advanced HIV disease, 15 subjects had advanced cancer. Three of the 29 subjects had both HIV and cancer; they were assigned to a group (cancer vs. HIV) based on whether or not the cancer was HIV-related.

## *Dignity Measures*

Fifteen of our items were comparable to Chochinov's items (see Table 2). For example, to examine cognitive acuity sub-theme of illness related concerns, we asked the importance of "being able to think clearly," whereas Chochinov's group asked their agreement with the statement of "not being able to think clearly," to their sense of dignity. To measure control/autonomy, we asked "having control," and Chochinov asked "feeling you do not have control over life." An example of a non-comparable item measuring social support was our item, "support you receive from others," and Chochinov's item "not feeling supported by your community."

Our sample ranked feeling pride (96.4%), have a chance to help others (93.1%), having a fighting spirit (93.1%), and having a life worth living (92.9%) as the four most important dignity items. Whereas for Chochinov's sample, being treated with respect or understanding (87.1%), feeling like a burden on others (87.1%), feeling like you do not

have control over your life (83.7%), and not feeling you made a meaningful or lasting contribution (83.3%) were the most highly ranked dignity items. In our sample, the four items ranked least important to dignity were: planning for what happens after your death (44.8%), dignity is lost when (you) need help with bathing/ toileting (64.2%), support you receive from others (64.3%) and living in the moment (65.5%). Whereas in Chochinov's sample, the four dignity items ranked as least important were: thinking how life might end (41.7%), experiencing distressing symptoms (53.1%), uncertainty regarding illness (59.2%) and feeling depressed or anxious (59.7%).

Our sample rated physical symptoms as affecting dignity (82.7%) more than in Chochinov's sample (53.1%). Our sample endorsed knowing what to expect with their illness in the future (75.8%) as more important than the comparable item used in Chochinov's sample (59.2%).

*Fractured or Severe Loss of Dignity*

Our sample was significantly more likely to report fractured dignity than Chochinov's sample (55% vs. 5.3%, p-value <.001). Fifty two percent of our participants also reported fractured dignity prior to becoming diagnosed with cancer or HIV disease. There was a weak relationship between those who reported an illness-related loss of dignity with those reporting loss of dignity prior to becoming ill (Pearson's r = 0.10). In other words, patients who indicated fractured dignity resulting from illness were not likely to be the same as those who indicated fractured dignity that preceded illness. Twenty-four percent of patients reported no loss of dignity, 21% reported loss of dignity only before illness, 24% reported loss of dignity only as a result of illness, and 31% reported loss of dignity both before and as a result of illness. Loss of dignity did not

differ significantly by primary illness group in our sample, 64% of the AIDS/HIV group and 47% of the Cancer group reported loss of dignity as a result of illness. Forty-three percent of the AIDS/HIV group and 60% of the cancer group reported loss of dignity before illness.

Dignity items of the 16 subjects with illness-related fractured dignity were compared with the 13 subjects whose dignity was intact. Subjects with fractured dignity were significantly more likely (93.8%) to report that physical symptoms or emotional upset can affect dignity than those whose dignity was intact (69.3%). Knowing what to expect about their illness was significantly more important to those with fractured dignity (87.6%) than those whose dignity was intact (61.6%). Planning for what happens after death was significantly more important to those with fractured dignity (56.3%) than to those whose dignity was intact (30.8%). Conversely, three items were significantly more important to those with intact dignity compared to those whose dignity was fractured: living in the moment (77% vs. 56.3%), having control (84.6% vs. 68.8%) and having a life worth living (100% vs. 84.6 %).

## Discussion

Dignity is challenging to define, let alone measure (Jacobson, 2007; Leung, 2007). Measuring dignity in the urban poor by developing items to measure a model is surely difficult, all the more so because of abstractness of the concept and the very small sample. Nevertheless, this work contributes to the exploration of the concept of dignity and examines its importance in the lives of persons who are poor, scarcely surviving in a city, and coping with serious illness that may well claim their life.

This survey was designed to complement qualitative research. The aim of the larger project using mixed methods, qualitative and quantitative, was to understand how dignity is experienced and what dignity means to the urban poor with advanced disease. The qualitative findings are reported elsewhere (Hughes, in process). However, of particular relevance for this discussion is the finding that many of the urban poor in this study did not understand the concept of dignity and did not find it meaningful to describe their experience.

Some reported having never heard the word dignity, and had never considered the concept until asked by the researcher. Indeed, when administering the survey to Sally, a 55-year old white woman with advanced ovarian cancer living in a single room occupancy hotel, she asked, "What does dignity mean? I got to know what it means before I can answer the questions." Another patient mentioned having gone to the dictionary to look up the meaning of dignity. Rather than dignity, more patients in the qualitative study endorsed the concept of respect as meaningful to them and described in vivid detail instances where they felt they were not respected by health care professionals or others in their lives. In this quantitative analysis, being treated with respect was rated as being important to almost 90% of patients but was not the most highly rated item. Chochinov and colleagues (2002) suggested some conceptual overlap with pride, self-esteem, hope and quality of life with dignity when they proposed their model. This observation may explain our finding about pride being more important than being treated with respect. Nonetheless, in a recent study of the concerns of homeless persons about end of life care, lack of respect in their interactions with health care professionals increased their fear of dying (Song et al., 2007).

Despite a tendency to speak about respect more often than to speak about dignity, a troubling finding in our study is that persons who are poor and living with advanced disease reported significantly more fractured, or severe loss of, dignity than has been reported in Chochinov's studies (Chochinov, Hack, Hassard et al., 2002; Chochinov et al., 2006; Hack et al., 2004). Chochinov's samples included only persons with cancer, whereas our sample also included persons with AIDS. The higher rate of fractured dignity in our sample may be due in part to HIV-related stigma. Nine of the 16 patients (56%) with fractured dignity had HIV/AIDS. However, clearly not all of the difference can be explained by HIV/AIDS. Our sample was younger; the average age of our subjects was 52 years whereas Chochinov's was 67 years. Illness may be more of a threat to dignity when the patient is younger. Ultimately, this finding is not surprising given the limited resources, strained family relationships, unstable housing, and unsafe neighborhoods of the urban poor. Of importance in considering our results is that Chochinov's studies were conducted in Canada, a country with nationalized health care, which raises the question of how health care policy affects patients' interpersonal interactions with health care professionals and their negotiations with health care systems. Many of the poor in the qualitative study described incidents of being mistreated, ignored, and marginalized by the larger society.

An unanswered question remains: How can health care professionals help patients recover from such profound assaults to who they are as human beings? In a controversial essay about the uselessness of the concept of dignity, an ethicist argued that dignity had become a slogan and was a mere substitution for respect for personhood. Findings in this study support this assertion (Macklin, 2003). Recognition of the personhood, the

humanity of persons who are marginalized in society may well be the most supportive psychosocial intervention that clinicians can provide. Such actions may or may not enhance dignity, a concept that health care providers may find more meaningful than do some of their patients. Lastly, health policy changes that eliminate barriers accessing care and provide a range of services in the community, such as housing support, may also serve to recognize the humanity of the urban poor.

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Table 1.

Dignity Model

| Major Dignity Categories, Themes and Sub-Themes | | |
|---|---|---|
| **Illness Related Concerns** | **Dignity Conserving Repertoire** | **Social Dignity Inventory** |
| *Level of Independence*<br>• Cognitive Acuity<br>• Functional Capacity<br><br>*Symptom Distress*<br>• Physical Distress<br>• Psychological Distress<br>Medical Uncertainty<br>Death Anxiety | *Dignity Conserving Perspectives*<br>• Continuity of self<br>• Role preservation<br>• Generativity/legacy<br>• Maintenance of pride<br>• Hopefulness<br>• Autonomy/control<br>• Acceptance<br>• Resilience/fighting spirit<br><br>*Dignity Conserving Practices*<br>• Living in the moment<br>• Maintaining normalcy<br>• Seeking spiritual comfort | • Privacy boundaries<br>• Social support<br>• Care tenor<br>• Burden to others<br>• Aftermath concerns |

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Table 2**.** Sample Demographics (n = 29)

| **Characteristic** | **n (%)** |
|---|---|
| Illness Group [&] | |
| Advanced HIV | 14 (48) |
| Advanced Cancer | 15 (52) |
| Gender | |
| Male | 14 (48) |
| Female | 14 (48) |
| Transgender | 1 (3) |
| Age in Years | |
| Mean | 52 (sd = 8.8) |
| Range | 35-69 |
| Race | |
| African American/ Afro-Caribbean/ African | 16 (55) |
| Hispanic | 2 (7) |
| Caucasian | 8 (27) |
| Multiethnic | 3 (10%) |
| Education | |
| Less than high school | 9 (31) |
| High school or GED | 7 (24) |
| Associate degree/some college | 10 (35) |
| College graduate/graduate school | 3 (10) |
| History of Homelessness | |
| Yes | 20 (69) |
| No | 9 (31) |
| Co-morbidities | |
| Yes | 19 (65) |
| No | 10 (35) |
| History of Substance Abuse | |
| Yes | 19 (65) |
| No | 10 (35) |

[&] = 3 subjects had HIV and cancer and were reassigned to only one group based on primary diagnosis

Table 3.

Fractured or Severe Loss of Dignity Related to Illness

| Illness-related fractured dignity | | |
|---|---|---|
| | N | % |
| AIDS/HIV | 9 | 64 |
| Cancer | 7 | 47 |
| Total | 16 | |

| Fractured dignity preceding illness | | |
|---|---|---|
| | N | % |
| AIDS/HIV | 6 | 46 |
| Cancer | 9 | 63 |
| Total | 15 | |

**Symmetric Measures**

| | | Value | Asymp. Std. Error[a] | Approx. T[b] | Approx. Sig. |
|---|---|---|---|---|---|
| Interval by Interval | Pearson's R | .110 | .186 | .574 | .571[c] |
| Ordinal by Ordinal | Spearman Correlation | .085 | .188 | .443 | .661[c] |
| N of Valid Cases | | 29 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

c. Based on normal approximation.

Table 4

Comparison of Agreement with Items, Overall Rank Order Presented by Categories of Chochinov's Model

| **Our Sample (n=29)** | | | **Chochinov's Sample (n=211)** | | | |
|---|---|---|---|---|---|---|
| Rank Order* | Items | Our sample % Agree | Chochinov sample % Agree | Comparable Item | Not comparable Item | Rank Order |
| **Illness Related Concerns** | | | | | | |
| 5 | Being treated with dignity decreases anxiety person feels when facing their death | 92.6 | 41.7 | | Thinking how life might end | 22 |
| 9.5 | Being able to think clearly | 86.2 | 77..3 | Not being able to think clearly | | 10 |
| 12 | Physical symptoms or emotional upset can affect dignity * | 82.8 | 59.7 | | Feeling depressed or anxious | 19 |
| 12 | Physical symptoms or emotional upset can affect dignity * | 82.8 | 53.1 | Experiencing distressing symptoms | | 21 |
| 14.5 | Knowing what to expect with illness in future | 75.9 | 59.2 | Uncertainty regarding illness | | 20 |
| 16.5 | How body has changed as result of illness | 75.0 | 66.4 | Changes in physical appearance | | 17 |
| 21 | Dignity lost when need help with bathing/ toileting | 64.3 | 82.9 | | Not being able to independently manage bodily functions | 5 |
| | NA | | 79.6 | | Not being able to carry out tasks of daily living | 8 |

| Our Sample (n=29) | | | Chochinov's Sample (n=211) | | | |
|---|---|---|---|---|---|---|
| **Dignity Conserving Repertoire** | | | | | | |
| Rank Order* | Our Items | Our sample % Agree | Chochinov sample % Agree | Comparable Item | Not comparable Item | Rank Order |
| 1 | Feeling pride in who I am and what my life has been about | 96.4 | 74.4 | | No longer feeling like who you were | 14 |
| 2.5 | Having a chance to help others | 93.1 | 83.3 | | Not feeling you made a meaningful or lasting contribution | 4 |
| 2.5 | Having a fighting spirit | 93.1 | 74.5 | Not being able to mentally fight | | 13 |
| 4 | Having a life worth living | 92.9 | 75.1 | Feeling life no longer has meaning or purpose | | 11 |
| 7 | Comfort received from your faith or spiritual beliefs | 89.3 | 73.7 | Not having a meaningful spiritual life | | 15 |
| 8 | Being able to fulfill my responsibilities to family, friends and other | 88.9 | 78.5 | Not being able to carry out important roles | | 9 |
| 11 | Accepting what life brings | 85.7 | 71.6 | Not being able to accept things the way they are | | 16 |
| 14.5 | Having control | 75.9 | 83.7 | Feeling you do not have control over your life | | 3 |
| 16.5 | Keeping your normal day to day routines | 75 | 74.9 | Not being able to continue with usual routines | | 12 |
| 19 | Living in the moment | 65.5 | 74.9 | | Not being able to continue with usual routines | 12 |

| Our Sample (n=29) | | | Chochinov's Sample (n=211) | | | |
|---|---|---|---|---|---|---|
| **Social Dignity Inventory** | | | | | | |
| Rank Order* | Our Items | Our sample % Agree | Chochinov sample % Agree | Comparable Item | Not comparable Item | Rank Order |
| 6 | Being treated with respect | 89.7 | 87.1 | Not being treated with respect or understanding | | 1 |
| 9.5 | Treated like a person | 86.2 | 81.4 | Not feeling worthwhile or valued | | 6 |
| 13 | Feeling like a burden on others | 78.6 | 87.1 | Feeling like a burden to others | | 1 |
| 18 | How important to sense of dignity is privacy | 72.4 | 65.9 | Feeling your privacy has been reduced | | 18 |
| 20 | Support you receive from others | 64.3 | 80.3 | | Not feeling supported by your community | 7 |
| 22 | Planning for what happens after your death | 44.8 | | NA | | |

# CHAPTER SIX: CONCLUSIONS

Understanding the experiences of the urban poor who were living with advanced cancer or with advanced HIV disease, a marginalized and vulnerable population, was the aim of this dissertation. The study used mixed methods, primarily interpretive phenomenology and secondarily a survey to address the research question. The research evolved however from its original aim, which was to describe the meaning and experience of dignity to the urban poor with advanced disease, because many participants could not relate to or did not understand the concept of dignity. This finding became apparent after the study had been approved by institutional review boards, after the research had been funded as originally proposed, and after data collection had begun. Participants were much more apt to define respect as meaningful to them than dignity. Does it matter if respect is the term used to define the experience of recognizing the humanity of the other and of self? Dignity may be the philosophical concept for what was experienced and named as respect by most participants in this study.

## Reconciling Qualitative and Quantitative Findings

The qualitative findings uncovered in the group interviews describing the everyday experiences of those living on dedicated AIDS nursing home unit (Chapter 3), and in the individual interviews of those living with advanced cancer in the community describing their experiences over time (Chapter 4), may or may not be incommensurable (Chesla, 1992) with the quantitative survey findings (Chapter 5) measuring Chochinov's model of dignity ((Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002)). Nonetheless, both qualitative and quantitative data shed light on what is often unseen, the experiences of those who are seriously ill and living at the margins of society.

## Immorality of Poverty

According to the US Census Bureau in 2005, 37 million Americans (12.6%) live in poverty (DeNavas-Walt, Proctor, & Lee, 2006); most experts believe these numbers underestimate the number of Americans who "go without." In 2004, almost 2.4 million deaths were reported by the National Center for Health Statistics (NCHS, 2007). Even without adjusting for the higher mortality rates noted among the poor, at least 300,000 deaths in 2004 occurred among the poor. Countless live with chronic and progressive illnesses that will claim their lives, if violence, injuries or other environmental hazards don't first (CDC, 1987; Klinenberg, 2001). In 2004, the age life expectancy in the U.S. was calculated as 77.8 years (Miniño, Heron, Smith, & Kochanek, 2006). Participants in this study ranged in age from 35-69 years; none had reached the 7$^{th}$ decade of life. Shamefully, the urban poor in the U. S. have life expectancy rates comparable to developing countries (Freeman, 2004; Murray, Grant, Grant, & Kendall, 2003; Williams, 2004).

For some of the poor, poverty is their past, present and their future (Moller, 2004). When poverty is all you know, all that you expect, and being without is all that you have experienced, illness may not be as central a concern as it is for those whose lives are not so tenuous. Indeed, for many of the urban poor in this study, cancer or HIV occurred in the context of lives filled with the challenges of homelessness, substance abuse, unemployment, loneliness, criminal histories, trauma exposures, and fragile if existent family relationships.

Similarities and Differences among Persons with HIV/AIDS and Persons with Cancer

Participants living with HIV/AIDS tended to be more optimistic about their future given the success of antiretrovirals (ARVs) in extending their lives but often described the harm, the chaos, the "hell" caused by their drug use. Many spoke about the shame and stigma of AIDS and how these influenced both their self-perception and their relationships with others. Many believed that adherence to ARVs and self-determination would prevent their death, unless they "slipped up" and started using drugs again.

Cancer patients were more acutely ill than persons with advanced HIV disease, whether as a result of advanced disease or side effects of therapy. The cancer illness trajectory was decidedly different than the illness trajectory of HIV/AIDS. Cancer patients were more likely to have died during the 13 months of data collection. Eight of the ten deaths, which occurred in the sample of 31, were among persons with cancer; one of the 8 also had HIV in addition to terminal lung cancer. Despite the lethality of their illness, some cancer patients commented that having cancer was preferable to having HIV, as the virus never left the body and was like "a chameleon hiding" to later wreck havoc; whereas cancer could be "cured."

Despite their awareness of the seriousness of their illness, whether cancer or HIV/AIDS, most participants described their everyday efforts to live and were unwilling to speak about dying as a possibility. These findings have interesting implications when caring for persons with lifethreatening and progressive illness. Recent efforts to improve care at the end of life have included the development of primarily inpatient palliative care programs (Meier, 2002) and practice guidelines to assure quality palliative care (National Consensus Project, 2004). Most of these efforts have as their goal preparing persons and

their families for death. However, some have observed the difficulty for many persons to speak about their dying which is considered requisite to prepare for one's death (Drought & Koenig, 2002), and to articulate wishes for care at the end of life in autonomy-grounded advanced care directive (Jennings, Kaebnick, & Murray, 2005). Recent research by Song and his colleagues (2007) suggests otherwise. In interviews with homeless persons interviewed in the Midwest, participants appreciated being offered the opportunity to articulate their end of life care wishes. Most had little if any contact with family and lacked an alternate surrogate decision maker. What homeless persons feared most was an anonymous death on the streets (Song, Bartels et al., 2007; Song, Ratner, & Bartels, 2005; Song, Ratner et al., 2007). In the end, I believe that clinicians are left to elicit the preferences of individual patients to participate or to not participate in speaking about the end of their lives and in expressing their hopes, concerns and expectations for care delivered at the end of life.

## Interactions with Health Care Professionals

Interactions with health care professionals whether in the acute care hospital or on a dedicated AIDS nursing home unit, were often problematic. This was not generally the case when participants were interacting with health care professionals in outpatient settings. Difficult hospitalization experiences included: dealing with physicians who were in training or perceived as inexperienced strangers and "too young" to be trusted; feeling talked down to or labeled because of their race or drug use history, nurses who were perceived as not responding to requests for toileting assistance resulting in the shame and embarrassment of being incontinent leaving the patients to have "messed myself and the bed;" the number of medical specialists involved in the inpatient management often

resulted in the sense that providers were not talking with one another when they gave contradictory information about the plan of care; for the few who had outpatient primary care providers, their providers unavailability to coordinate the patients' inpatient care was difficult; and finally, being sent home alone too soon after surgery to manage in an SRO even when limited home care was arranged. Very few people relish the prospect of hospitalization; participants in this study were no different. Therefore, sorting out hospital experiences unique to the urban poor who were seriously ill is not so easy. For example, other researchers studying dignity among patients who are hospitalized have noted patients' or their loved ones' reports of threats to, or loss of, dignity were not uncommon when receiving care in institutions whether in the U.S, Canada or United Kingdom (Chochinov, 2002; Jacelon, 2003; Rogers, Karlsen, & Addington-Hall, 2000; Walsh & Kowanko, 2002). By their very nature, institutions may create structures that make caring practices difficult. Fundamentally caring is grounded in recognizing and understanding the other(Frank, 1991; Taylor, 1991) Caring is experienced when a patient feels known as a person (Benner & Wrubel, 1989; Tanner, Benner, Chesla, & Gordon, 1993). Expert nursing practice is realized when the nurse knows her patient(Tanner et al., 1993).

For those living in a dedicated AIDS nursing unit whose lives prior to admission frequently included homelessness, drug use and brushes with the law, the structure and rules of the unit environment challenged their freedom. In response, some rebelled and others tried to "escape" or simply left. Several felt frustrated, ignored, dismissed or "treated like children." Many interactions with nursing staff were complicated by racial tensions; many patients were African American and many nursing staff foreign-born and

spoke with an accent or in their own language, most frequently Tagalog, sometimes when patients were present. These actions by nurses lead some patients to feel excluded or to express anti-immigrant statements. Other patients witnessed nurses being spoken to "abusively" by their patients. Patients frequently screamed, "cussed" and "carried on" when challenged; this response undoubtedly frightened and in some cases, threatened the staff. Occasionally, these incidents resulted in calls to security staff to intervene to assure safety and to restore calm.

## Examining Chochinov's Dignity Model

Survey findings described our efforts to measure dignity based on an inductively derived dignity model (Chochinov, Hack, McClement et al., 2002) which had been tested in a palliative care samples in Canada (Chochinov, Hack, Hassard et al., 2002; Chochinov et al., 2006; Hack et al., 2004). A very recent review article on dignity and health (Jacobson, 2007) criticized some of the clinical and research applications of dignity because they fail to examine theoretical and historical understandings about dignity before situating their projects.

Twenty nine participants completed a questionnaire to explore their values and beliefs about dignity based on Chochinov's model, and to measure loss of dignity experienced as a result of their illness. Patients were also asked to rate the loss of dignity that occurred before being sick (Chochinov, Hack, McClement et al., 2002). Using the same item and scoring used by Chochinov to measure loss of dignity, patients were assigned to two groups, 1) none or minimal loss of dignity or 2) fractured (or serious loss of) dignity. In Chochinov's (2006) study of 211 cancer patients, 5.3% (~11) experienced fractured dignity whereas in our sample 55% (16 out of 29) reported fractured dignity as

a result of illness and 52% (15/ 29) reported fractured dignity before becoming ill. This finding suggests that seriously ill urban poor are at even greater risk of threats to their humanity, their dignity than are other terminally ill patients.

## Cultural Implications

While there has been a lot of talk about cultural competency in health care settings and national standards exist to promote linguistic and cultural competency (Office of Minority Health, 2001), few programs have successfully addressed how racism and other forms of oppression (such as sexism, homophobia, class differences, ageism, and negative stereotypes about those who are homeless or substance abusers) affects health care delivery, how these effects can be examined and their scars healed. The authors of the Institute of Medicine Report on health care disparities, did not use the term racism to explain blatant inequities in access to care, screening, diagnosis and treatment outcomes (Smedley, Stith, & Nelson, 2003) but rather described care processes that were negatively influenced by "bias, stereotyping and uncertainty." Failure to address oppression in clinical settings is all the more pressing when nursing administrators faced with filling vacancies created by nursing shortages and the increased care needs of their patients, are depending on foreign born nurses to fill positions. To be sure, while foreign born nurses and patients from communities of color encounter interpersonal racism and experience their own internalized racism, institutional and cultural racism, and the other forms of oppression are far more pervasive, far less invisible, and far more resistive to change.

## Implications for Practice

Just like patients with economic resources living with advanced cancer or advanced HIV disease, needs for support and information differed among the urban poor living

with these life-threatening illnesses. But what did not differ was their universal need for advocacy in negotiating systems and dealing with health care professionals. For nurses practicing in institutions responding to patients is recognition of their humanity; failure to recognize is dehumanizing and increases their suffering. Persons who were seriously ill and poor are at much greater risk of severe loss of dignity than were others with advanced disease. Improving care for the urban poor will require recognition practices that know the patient as a person and his/her usual patterns of response to illness (Tanner et al., 1993). Kiefer proposed that human beings behave or act in ways to meet five needs: security, love, respect, stimulation and meaning (Kiefer, 2000). If nurses used this needs framework as a model, their patients undoubtedly would become recognized as persons.

## Implications for Research

Ethnographic research would allow us to examine care in institutional settings to identify structures that impact delivery of person-centered care for urban poor who are seriously ill. Further testing of Chochinov's dignity model would serve to evaluate its relevance in understanding the experience of dignity to other seriously ill populations. Research is needed to examine differences and similarities in EOL care for chronically impoverished versus those who were situationally impoverished. For persons with HIV/AIDS, the impact of stigma on dignity/respect needs further exploration. Finally participatory action research designs would engage this population in identifying care priorities when seriously ill or dying.

## Implications for Policy

Lastly, policy reforms which mitigate poverty, address racism and create supportive community care options will likely enhance dignity. When designing care environments

to humanely address the needs of the urban poor who are seriously ill, or when developing research to describe and to improve their care, simple modifications targeted solely at the level of patient –clinician interaction however will be insufficient, frustrating and misleading. What will be required is nothing less than policy and system changes so that those on the margins are invited inside, closer to the center.

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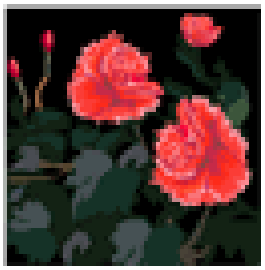
# APPENDIX A: ORIGINAL PROCEDURES PLAN

| | **Advanced Cancer [C]** | **Advanced HIV Disease [H]** | **Total** |
|---|---|---|---|
| Sample size | 15 | 15 | 30 |
| Inclusion Criteria | 18 years of age or older<br>Able to speak and understand English<br>Able to participate in individual or group interview<br>Diagnosed with advanced cancer and/or advanced HIV disease by health care provider (HCP) who attests that HCP would not be shocked if patient died within 24 mos.<br>Has MediCal, Supplemental Social Security Income, or otherwise designated indigent<br>Lives in urban area<br>Has been institutionalized at hospital or nursing home since diagnosed (GROUP interview only) | | |
| Exclusion Criteria | • Unable to give informed consent.<br>• Does not acknowledge (denies) diagnosis of serious illness. | | |
| Recruitment Sites | Public Hospital Oncology Clinic<br>Public Hospital Cancer Patient Education Program | AIDS Nursing Home Unit<br>Public Hospital HIV/AIDS Program<br>HIV Nursing Network | |
| Recruitment Methods | • Discuss study with Oncology Clinic staff to identify potential patients and make initial contact<br>• Flyer for staff with study aims, inclusion criteria and data collection procedures<br>• Attend 2x/wk oncology clinic to identify potential informants<br>• Describe study to patient education program coordinator who will discuss project with cancer patient education group<br>• Snowballing from initial participants | • Discuss study with nursing home unit staff to identify potential patients and make initial contact<br>• Flyer for staff with study aims, inclusion criteria and data collection procedures<br>• Describe study to HIV Nursing Network to identify potential patients and make initial contact<br>• Snowballing from initial participants | |

| | Advanced Cancer [C] | Advanced HIV Disease [H] | Total |
|---|---|---|---|
| Retention Strategies for Individual Patients Interviewed Overtime | • At time of study enrollment, obtain all possible contact information including friends/family who would always know how to reach patient if moved/evicted/relocated.<br>• Make routine check in telephone calls (~ 2-3 wks) to determine any changes in condition or start of new treatments and to maintain relationship.<br>• Provide self addressed stamped postcards to return to Co-PI if change in residence, telephone or situation, if indicated.<br>• Consider providing phone card with Co-PI voicemail number to contact with any changes, if without phone. | | N=15 (10 with cancer & 5 with HIV/AIDS) |
| Data Collection Approaches | • Interview: Individual (Ind) and/or Group (Grp)<br>• Participant Observations: patient's residence, care settings while patient present; and care settings and patients' neighborhoods when study patients are not present<br>• Questionnaires (See data collection protocol)<br>• Interpretive Memos and Field Notes<br>• Documents and other media related to care of patients<br>• Demographic Information<br>• Medical Record Information | | 15 Ind I= 10 C +5 H<br>15 GrpI= 10 H + 5 C |
| Data Analysis Plan | • Qualitative Data: Interpretive Phenomenology<br>• Quantitative Data: SPSS | | |

APPENDIX B: RECRUITMENT FLYER FOR HEALTH CARE PROVIDERS



# Dignity Study

Do you have any patients who might be interested in participating in a study to understand the meaning and experiences of dignity to the urban poor with advanced disease?

Inclusion criteria:

- Poor (MediCal, SSI eligible or otherwise considered indigent)
- Live in San Francisco or Oakland
- Have HIV and/or Cancer
- Health care provider *would not be shocked* if the person was not alive in 2 years
- Able to speak and understand English
- Not in absolute denial about the seriousness of their condition, however does not have to "accept" their eventual terminal condition
- Able to give informed consent
- May have other co-morbidities that are more lifethreatening than either HIV or cancer diagnosis.

What's involved for your patients?

- Interview[s] either individually or in group to hear patients' stories
- Administration of survey instrument
- Payment $15/interview
- Health care provider mentions study to patients and obtains their permission for investigators to contact them.

QUESTIONS/REFERRALS:

- Please contact Anne Hughes, RN, MN
- Tel. 415-759-4569 OR
- Email: anne.hughes@ucsf.edu

# APPENDIX C: STUDY CONSENT FORMS

## UNIVERSITY OF CALIFORNIA SAN FRANCISCO
## CONSENT TO BE A RESEARCH SUBJECT
## Meaning of Dignity to Persons with Serious Illness: Individual Interviews
## UCSF CHR Number: H10976-27604-02

### A. PURPOSE AND BACKGROUND

Dr. Elizabeth (Betty) Davies and Anne Hughes, R.N., a doctoral student in the Family Health Care Nursing Department, University of California San Francisco, School of Nursing are doing a study to understand the meaning of dignity to persons living with a serious illness, who live in a city and do not have a lot of money. You are being asked to participate in this study because you are living with a serious illness, reside in the city and do not have a lot of money.

### B. PROCEDURES

If you agree to be in the study, the following will happen:

- You will meet privately with Anne a total of three to four times for about 1 hour per visit over 4-6 months.
- At three of these meetings, you will be asked about your experiences and thoughts about dignity and the interview will be audiotaped.
- The private interviews will be done at a time and a place that is convenient for you and will last no more than 60 minutes.
- During the 2nd interview only (or if you prefer at the first meeting), you will be asked a number of questions from a questionnaire that are believed related to dignity. This meeting will not be audiotaped.
- Anne will make check in calls to you about once a month and to schedule interviews.
- In order to be able to reach you, she will ask for your contact information (telephone numbers and address) and also phone numbers and names of others who can always reach you if you move.
- Anne may provide you with a phone card so that you can reach her if needed.
- Anne may contact you at later time to clarify your interview responses.

### C. RISKS/DISCOMFORTS

Some of the interview questions may make you uneasy. You are free to not answer any question that you don't wish to or to stop the interview at any time. If you become tired or fatigued you may stop the interview and the interview will be scheduled at a time and place convenient for you. If you become worried, uncomfortable or upset, you can talk with Anne Hughes or your social worker about your reactions. A list of free mental health services will be provided should you like additional support.

Confidentiality Participation in this research will involve a loss of privacy. However, your information will be handled as confidentially as possible. Only project staff will have access to the study records and audiotapes. After the study is complete, the tape will be destroyed. The investigator will retain the transcripts. Your name or other information from the study that identifies you will not be used in any reports or publications that may result from this study.

D. BENEFITS

There will be no direct benefit to you from participating in this study. It is possible that the findings from this study will help health care professionals to provide better care to persons who are living with a serious illness.

E. COSTS

There will be no cost to you for participating in this study, except for the loss of your time.

F. PAYMENT

You will be paid fifteen dollars ($15) in cash for participating in this study immediately after you have completed each interview. . If a subsequent interview is required to clarify your responses an additional $15 will be paid in payment for your time.

G. QUESTIONS

This study has been explained to you by Anne Hughes, RN. If you have any other questions you may call Anne at 415-759-4569 or Dr. Davies at 415-476-4433. If you have any comments or concerns about participation in this study, you should first talk with Anne or Dr. Davies. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach Committee office between 8:00 and 5:00, Monday through Friday by calling 415-476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA. 94143.

H. CONSENT

You have been given a copy of this consent form to keep.
PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline or to withdraw from this study at any time. Your decision to participate or not to participate in this study will have no influence on your care at San Francisco General Hospital or at Laguna Honda Hospital or other health care provider.

If you agree to participate in this study, you should sign below:

_____ _____

Date Signature or Mark (X) of Study Participant

_____ _____

Date Signature of Person Obtaining Consent

UNIVERSITY OF CALIFORNIA SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT
Meaning of Dignity to Persons with Serious Illness: Group Interview
UCSF CHR Number: H10976-27604-02

A. PURPOSE AND BACKGROUND

Dr. Elizabeth (Betty) Davies and Anne Hughes, R.N., a doctoral student in the Family Health Care Nursing Department, University of California San Francisco, School of Nursing are doing a study to understand the meaning of dignity to persons living with a serious illness, who live in a city and do not have a lot of money. You are being asked to participate in this study because you are living with a serious illness, reside in the city and do not have a lot of money.

B. PROCEDURES

If you agree to be in the study, the following will happen:

- You will be asked to come to a place to participate in a group discussion with other patients about dignity.
- An audiotape will be made of the group interview.
- After the focus group, you will meet privately with Anne at a time and place convenient to you. You will be asked a number of questions from a questionnaire related to dignity. This meeting will not be audiotaped.
- Your participation in this study will take a total of 2 meetings, or 3 hours and will happen over one month.
- Anne may contact you at later time to clarify your interview responses.

C. RISKS/DISCOMFORTS

By being part of a group interview, your privacy and confidentiality may be lost. All members of the group will be asked to respect the confidential information shared by others but there this cannot be guaranteed. Some of the interview questions may make you uneasy. You are free to not answer any question that you don't wish to or to stop the interview at any time.
If you become tired or fatigued you may stop the interview and the interview will be scheduled at a time and place convenient for you. If you become worried, uncomfortable or upset, you can talk with Anne Hughes or your social worker about your reactions. A list of free mental health services will be provided should you like additional support.
Confidentiality Participation in this research will involve a loss of privacy. However, your information will be handled as confidentially as possible. Only project staff will have access to the study records and audiotapes. After the study is complete, the tape will be destroyed. The investigator will retain the transcripts. Your name or other information from the study that identifies you will not be used in any reports or publications that may result from this study.

D. BENEFITS

There will be no direct benefit to you from participating in this study. It is possible that the findings from this study will help health care professionals to provide better care to persons who are living with a serious illness.

E. COSTS

There will be no cost to you for participating in this study, except for the loss of your time.

F. PAYMENT

You will be paid fifteen dollars ($15) in cash for participating in this study immediately after you have completed each interview. If a subsequent interview is required to clarify your responses an additional $15 will be paid in payment for your time.

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This study has been explained to you by Anne Hughes, RN. If you have any other questions you may call Anne at 415-759-4569 or Dr. Davies at 415-476-4433. If you have any comments or concerns about participation in this study, you should first talk with Anne or Dr. Davies. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach Committee office between 8:00 and 5:00, Monday through Friday by calling 415-476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA. 94143.

H. CONSENT

You have been given a copy of this consent form to keep.
PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline or to withdraw from this study at any time. Your decision to participate or not to participate in this study will have no influence on your care at San Francisco General Hospital or at Laguna Honda Hospital or other health care provider.

If you agree to participate in this study, you should sign below:

_____ _____

Date Signature or Mark (X) of Study Participant

_____ _____

Date Signature of Person Obtaining Consent

# APPENDIX D: INTERVIEW GUIDES

## Individual Interview Guides: Initial and Follow Up Interviews
## Sample Questions and Probes

Initial Interview

1. What is your health like?
2. What lies ahead for you as far as your health? What do you wonder about or maybe even worry about?
3. What has it been like being a patient and receiving care at _____(clinic/ hospital/ED or nursing home)?
4. Can you tell me a story that describes a time when you felt you were treated well or felt cared for? What happened? Who was there? What about the story made you feel like you were treated well?
5. Can you tell me a story when you felt as if you weren't treated well or weren't cared about? What happened? Who was there? How did you feel?
6. I'm trying to understand what it feels like to be a person who lives in a city, doesn't have a lot of money and is coping with a serious illness. What is it like for you? How would you like it to be different?
7. For some people, it is important to be treated with dignity, have you ever thought about that?

Follow Up Interviews Guides: Sample Questions and Probes

1. Since I saw you, what's been happening?
    - Have you been in the hospital? Or nursing home? Or ED?
    - Have there been any changes in health or treatment?
    - How have you felt treated by those taking care of you?
2. When a person has a serious illness like you do, what is most important?
3. In times of illness, we often think about who we are now and who we've been in the past, --- how do you think (cancer/HIV) affects how you see yourself? Can you give me an example of how it has changed?
4. Do you feel there is someone in your life that understands what you're going through? What tells you that he/she understands? Can you tell me about a time when you felt understood? Or not understood?
5. Can you tell me about a time when your spiritual or religious beliefs affected your experiences living with cancer/HIV disease? OR your non-spiritual/religions beliefs affected your experience?
6. How does having money or not having money affect
    - your illness?
    - how you are treated?, and
    - how you feel about yourself?
7. What can doctors, nurses and social workers and others do to provide respectful and attentive care?
8. What should doctors, nurses, social workers or others NOT do when working with seriously ill patients who don't have a lot of money?

Group Interview Guides: Sample Questions and Probes

Prior to group meeting:

1. All participants meet individually with Co-PI to learn about study, answer any questions and provide written consent.
2. Participants are advised that in a (focus) group respect for confidentiality is essential so that people feel safe to speak. What others say in the group cannot be shared outside the group.
3. Participants will be advised that the hope is that most, if not all, persons have the opportunity to say what they want and to be heard by others.
4. Interviews will be taped so only one person can speak and be heard at a time.
5. Group interview will last about 1-1.5 hours.
6. If at the time of the interview, the participant does not feel up to the interview or the interviewer is concerned about the participant's ability to participate, the participant will be excused and the interview will be rescheduled for another time.

Beginning of Focus Group

1. Welcome and thank participants for being willing to share their experiences. Introduce self and co-facilitator.
2. Review ground rules:
    a. Respect confidentiality of others outside of group.
    b. Do not share what anyone else said or did not say outside of the group.
    c. Interview will be audiotaped.
    d. Only one person can speak and be heard at a time.
    e. Hope that everyone will feel comfortable sharing their experiences and thoughts; will try to give everyone a chance to have their say.
3. Interview will last about one and a half hours.
4. Co-PI will check in with everyone in the group within a week or two.

Sample Questions and Probes (actual questions and follow up will be guided by group dynamics)

1. What is it like being a patient at AIDS nursing home unit OR inpatient at hospital (if relevant)?
    - How does (being a patient in a nursing home/hospital) affect your illness?
    - How does (being a patient in a nursing home/hospital) affect how you are treated?
    - How does (being a patient in a nursing home/hospital) affect what you think about yourself?
2. Can you tell me a story about a time when you received care that respectful and attentive to you? Can you tell me a story about a time when you received care that was disrespectful or not attentive to you?
3. If you could be any place at all, where would you like to be? What's special about this place? What do you miss about this place?
4. In what way, if any, do your religious or spiritual beliefs affect your experiences living with cancer/HIV disease?

5. When a person is nearing the very end of their life, what do you think matters most? What would you like to have happen for you when you're nearing the end of your life?
6. I'm trying to understand the meaning of dignity to people who live in a city, don't have a lot of money and are coping with a serious illness.
    - Have you given much thought to what dignity means?
    - Can you tell me about a time when you felt you experienced dignity? When you did not experience dignity?

# APPENDIX E: SURVEY INSTRUMENT

**Interviewer Script to Read aloud to Participant:** This survey is about what dignity means to a person who is living with a serious illness and who doesn't have a lot of money. It also includes topics that may be related to dignity. This information will help us understand what dignity means in order to provide better care. Some questions may seem alike but they are actually trying to understand different ways that you might think about dignity.

- There are **no right or wrong answers**. The questions are designed to get your opinions and impressions.

- There are six parts to the questionnaire. The first part asks about your beliefs and values about dignity. Second part asks about symptoms you may or may not be having. The third section asks about how you make medical decisions. The 4th part, asks about your quality of life. The 5th part asks about your day-to-day activities. The last part asks some general questions about you.

- This questionnaire may take about **45-60** minutes to complete. If you are uncertain about how to answer any question, please ask for help as some of the ways these questions are asked, may not be so clear. You will be helping to make the questions better.

**Thank you for participating in this study.**

Today's Date: _____/_____/_____

MONTH DAY YEAR

Family Health Care Nursing Department
University of California San Francisco

YOUR VALUES AND BELIEFS ABOUT DIGNITY

Directions: The first group of questions asks about your values about dignity, in other words what is important to you, or matters to you about dignity. After hearing the question, select the response from this set **of <u>PINK</u> colored cards** that is closest to your own. The possible responses are: Not at all important (1), A little bit important (2) , Somewhat important (3) , Quite a bit important (4) and Extremely important (5).

*** = follow with cognitive interview question**

**How important to your sense of dignity is:**

| | | |
|---|---|---|
| 1 | Privacy | * |
| 2 | Being treated as a person | * |
| 3 | Planning for what happens after your death | |
| 4 | Having control | * |
| 5 | Being treated with respect | * |
| 6 | Being able to think clearly | |
| 7 | Knowing what to expect with your illness in the future | * |
| 8 | Comfort received from your faith or spiritual beliefs | |
| 9 | Keeping your normal day-to-day routines | * |
| 10 | Support you receive from others | |
| 11 | Having a life worth living | * |
| 12 | Living in the moment (not worrying about the past or future) | |
| 13 | How your body is handled by others when you are sick | * |
| 14 | How your body changes as a result of illness or treatment | * |

*Q1. When answering this question, what did the word privacy mean to you?*

*Q2. When answering this question, what did the phrase "being treated like a person" mean to you?*

Q4 *When you answered this question about having control and dignity, what were you thinking about*?

Q5. *What does the phrase being treated with respect mean to you*

*Q7. When you answered this question, what information were you thinking about?*

*Q9 What routines were you thinking about when you answered this question?*

*Q11. What does having a life worth living mean to you?*

*Q13/14. What went through your mind when you answered the question about how your body was treated as being important to dignity? What kind of care to a person's body shows dignity? How does illness or treatment affect dignity?*

This next set of questions asks at what times, in a person's life, is dignity is important. After hearing the question, select the response from this set **of PINK colored cards** that is closest to your own. The possible responses are: Not at all important (1), A little bit important (2), Somewhat important (3), Quite a bit important (4) and Extremely important (5).

Dignity is important...

| | | |
|---|---|---|
| 15 | When a person is dying | * |
| 16 | When a person is sick | |
| 17 | All the time | * |

Q15*. Can you please help me understand what you were thinking about when you answered ( give informant's response) about the importance of dignity when a person is dying?

Q17*. Can you please help me understand what you were thinking about when you answered __ about the importance of dignity all the time?

Directions: We're about half way done with this section. These next questions focus on your beliefs about dignity, in other words what you think is true or false about dignity. After hearing each question, **select the YELLOW card** with the response that is closest to your own. The responses are: Definitely true (1),Mostly true (2), Mostly false (3) and Definitely false (4).

18. People are only treated with dignity if they have **money**:_____

19*. Dignity **can be taken away by others**: _____ * (if answer 1 or 2)
** Q19 What would be an example of how others can take dignity away?*

20. Giving to others or **having the chance to help others,** contributes to a person's sense of dignity ____

21. Dignity is **something that all people have** _____.

22. Being treated with **dignity decreases the anxiety a person feels when facing their death** ____

23. Being treated with dignity **means having my treatment wishes following** _____.

24. Dignity **is lost when a person needs help with bathing or toileting** _____.

25. Being a **patient in a nursing home is a threat** to a person's sense of dignity_____. ( *if answered 1 or 2) * Q25 *What do you think it is about being a patient in a nursing home that threatens a person's dignity?*

26. Being a **patient in a hospital is a threat** to a person's sense of dignity _____. (*if answered 1 or 2) *Q26 *What do you think it is about being a patient in a hospital that threatens a person's dignity?*

27. **Feeling like a burden on others threatens** a person's sense of dignity _____. (*if answered 1 or 2) *Q27 When you answered this question, what did the phrase "feeling like a burden on others" mean to you?

28. **Accepting what life brings**, contributes to a person's sense of dignity _____.

29**. Having a fighting spirit** maintains a person's dignity _____.

30. **Physical symptoms or emotional upset** can affect a person's sense of dignity _____. (if answered 1 or 2) *Q30 *What symptoms or upset do you think might affect a person's sense of dignity?*

31.**Feeling pride** in who I am and what my life has been about, contributes to my sense of dignity ____.

32. **Feeling hopeful** supports a person's sense of dignity _____. (if answered 1 or 2)
* Q32 *In what way do you think hopefulness and dignity are related?*

*33.* Being **able to fulfill my responsibilities** to family, friends and others helps me maintain my sense of dignity _____.

Directions: These last two questions in this section ask about your experiences of feeling a loss of dignity. The questions ask you to rate when and how severe you may have experienced a loss of dignity. Please select **the BLUE colored card with the response** that is closest to your own. The responses range from: Never felt a loss of dignity (0), minimum loss of dignity (1), mild (2), moderate (3), strong (4), severe (5) and extreme loss of dignity (6).

34. **Since you have been sick** have you ever felt a loss of dignity and if so, how severe was it?

| | |
|---|---|
| Never felt loss of dignity | 0 |
| Minimum loss of dignity | 1 |
| Mild | 2 |
| Moderate | 3 |
| Strong | 4 |
| Severe | 5 |
| Extreme loss of dignity | 6 |

35. **Before you got sick**, did you ever feel a loss of dignity and if so, how severe was it?

| | |
|---|---|
| Never felt loss of dignity | 1 |
| Minimum loss of dignity | 2 |
| Mild | 3 |
| Moderate | 4 |
| Strong | 5 |
| Severe | 6 |
| Extreme loss of dignity | 7 |

*Q 34/35. When you answered these last 2 questions about loss of dignity, what were you thinking about?*

***Other Cognitive Interview Question for Dignity Items***

*What questions or issues about dignity do you think were missing or not covered enough?*

*Were there any questions that you think just didn't belong when talking about dignity?*

## SYMPTOMS

**Instructions** Below are 5 different numbered statements. Pick the one that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number one indicates no problem and number five indicates the maximum amount of problem with the symptom.

Degrees of Distress

**36. Nausea**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I seldom if ever have nausea | I have nausea once in a while | I have nausea fairly often | I have nausea half the time at least | I have nausea continually |

**37. Nausea (2)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| When I do have nausea, it is very mild | When I do have nausea, it is mildly distressing | When I have nausea, I feel pretty sick | When I have nausea, I usually feel very sick | When I have nausea, I am as sick as I could possibly be |

**38. Appetite**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I have my normal appetite and enjoy good food | My appetite is usually, but not always, pretty good | I don't really enjoy my food | I have to force myself to eat my food | I cannot stand the thought of food |

**39. Insomnia**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I sleep as well as I always have | I occasionally have trouble getting to sleep and staying asleep | I frequently have trouble getting to sleep | I have difficulty getting to sleep and staying asleep almost every night | It is almost impossible for me to get a decent night's sleep |

**40. Pain**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I almost never have pain | I have pain once in a while | I have pain several times a week | I am usually in some degree of pain | I am in some degree of pain almost constantly |

**41. Pain (2)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| When I do have pain, it is very mild | When I do have pain, it is mildly distressing | When I do have pain, it is usually fairly intense | The pain I have is very intense | The pain I have is almost unbearable |

**42. Fatigue**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I seldom feel tired or fatigued | There are periods when I am rather tired or fatigued | There are periods when I am quite tired and fatigued | I am usually very tired and fatigued | Most of the time, I feel exhausted |

**43. Bowel**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I have my normal bowel pattern | My bowel pattern occasionally causes me some discomfort | My present bowel pattern occasionally causes me considerable discomfort | I am usually in considerable discomfort because of my present bowel pattern | I am in almost constant discomfort because of my bowel pattern |

**44. Concentration**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I have my normal ability to concentrate | I occasionally have trouble concentrating | I occasionally have considerable trouble concentrating | I usually have considerable difficulty concentrating | I just can’t seem to concentrate at all |

**45. Appearance**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| My appearance has basically not changed | Occasionally I am concerned about the worsening of my physical appearance | I am not often concerned that my appearance is worsening | Most of the time I am concerned that my physical appearance is worsening | The worsening of my physical appearance is a constant, preoccupying concern |

**46. Breathing**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I usually breathe normally | I occasionally have trouble breathing | I often have trouble breathing | I can hardly ever breathe as easily as I want | I almost always have severe trouble with my breathing |

**47. Outlook**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I am not worried or frightened about the future | I am slightly worried but not frightened about things | I am worried and frightened about things | I am very worried and frightened about things | I am terrified by thoughts of the future |

**48. Cough**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I seldom cough | I have an occasional cough | I often cough | I often cough, and occasionally have severe coughing spells | I often have persistent and severe coughing spells |

**HOW YOU MAKE MEDICAL DECISIONS**

DIRECTIONS: Think about the last decision that your doctor asked your opinion, it may be about starting or stopping a treatment, or having a test. For the rest of these questions please keep this decision in mind when you are making your selection.

There are 5 WHITE cards that contain statements with drawings about how people prefer to be involved in decision making about their health. I will show you 2 cards at a time that describe different ways people want to be involved in medical decisions. Please tell me which card is closest to how you want to be involved in decisions.

A= I prefer to make the decision about which treatment I will receive.

B = I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

C= I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

D= I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E= I prefer to leave decisions regarding my treatment to my doctor.

Order of card sort comparison when administered by hand (Degner, Sloan, & Venkatesh, 1997):

49. AB_____
50. BC_____
51. CD_____
52. DE_____
53. AC _____
54. BD_____
55. CE_____
56. AD_____
57. BE _____
58. AE_____

Your Quality of Life

Directions: I'd like you to think back over the last month. Please tell me the three physical symptoms or problems that have bothered you the most during that time. Some examples are pain, nausea, lack of energy, confusion, depression, anxiety, and shortness of breath.

Symptom #1_____ Symptom #3_____

Symptom #2_____

- If no symptoms were elicited, then state the following:
  **So, just to be sure, over the last month, you have had no physical or emotional symptoms that bothered you.**

If correct, skip to question #5.

Which of these symptoms or problems has bothered you the most this past week?

59. During the last week, how often have you experienced _____?

| *Rarely* | *A few times* | *Fairly often* | *Very often* | *Most of the time* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

60. During the last week, on average, how severe has _____ been?

| *Very mild* | *Mild* | *Moderate* | *Severe* | *Very severe* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

61. During the last week, how much has _____ interfered with your ability to enjoy your life?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

62. How worried are you about _____ occurring in the future?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

63. In general, how important are your PHYSICAL SYMPTOMS OR PROBLEMS to your overall quality of life?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

***Below is a list of statements that other people with a serious illness have said may be important. Please tell me how true each statement is for you.***

64. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

65. I participate as much as I want in the decisions about my care.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

66. Beyond my illness, my doctor has a sense of who I am as a person.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

67. In general, I know what to expect about the course of my illness.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

68. As my illness progresses, I know where to go to get answers to my questions.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

69. In general, how important is feeling like an ACTIVE PARTICIPANT in your HEALTH CARE to your overall quality of life?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

70. I worry that my family is not prepared to cope with the future.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

71. I have regrets about the way I have lived my life.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

72. At times, I worry that I will be a burden to my family.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

73. Thoughts of dying frighten me.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

74. I worry about the financial strain caused by my illness.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

75. In general, how important are CONCERNS ABOUT THE FUTURE to your overall quality of life?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

76. I have been able to say important things to those close to me.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

77. I make a positive difference in the lives of others.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

78. I have been able to help others through time together, gifts, or wisdom.

| *Not at all* | *A little bit* | *moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

79. I have been able to share important things with my family.

| *Not at all* | *A little bit* | *moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

80. Despite my illness, I have a sense of meaning in my life.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

81. I feel at peace.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

82. There is someone in my life with whom I can share my deepest thoughts.

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

83. In general, how important is the feeling that your LIFE IS COMPLETE to your overall quality of life?

| *Not at all* | *A little bit* | *A moderate amount* | *Quite a bit* | *Completely* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

Now, I have one last QOL question.

*84.* How would you rate your OVERALL QUALITY OF LIFE?

| *Very Poor* | *Poor* | *Fair* | *Good* | *Excellent* |
|---|---|---|---|---|
| *1* | *2* | *3* | *4* | *5* |

**Your Day-to-Day Activities**

DIRECTIONS: In general, I would like to know how your present activities differ from before you got sick. I'm interested in what effects your illness has had on your day-to-day living. To make sure I find out as much about this as I can, I'm going to ask you a number of specific questions about what a typical day is like for you.

85. Eating

What about eating, for example? How are your present eating habits?

a. Does it take you more time to eat during the last week?
b. Do you eat at the same times as you used to? Do you eat in the same place (e.g., at the table)?
c. Do people bring food to you more often?
d. Are you able to cut your own food?
e. Is pouring milk or coffee a problem for you?

(OPTIONAL)

Are there any special eating utensils, such as enlarged fork handles or non skid plates, that you use and find helpful?

86. Dressing

What about dressing (e.g., bending to put on shoes, stretching to pull something over your head).

a. Does it take more time to get dressed within the last week?
b. Do you need help in putting on some of your clothes—fastening buttons, for example, or lacing your shoes?
c. Do you wear special clothes, or use special equipment, to make dressing easier?
d. Are there days you don/t get dressed, but wear your bed clothes? About how many days a week, would you say?

87. Walking

Do you walk and get about?

a. Does it take more time to walk somewhere? Is your walking more deliberate (i.e., cautious or careful)?
b. Are you ever assisted in getting about?
   Has the doctor restricted your walking in any way? (e.g., do you need to be accompanied when you go on walks)?
c. Do you use special equipment to help you walk?
   e.g., Do you use a cane or a crutch?
   Do you wear braces or special shoes?
   Do you take elevators more than you used to?

88. Travel

What about your travel and transportation patterns within the last week?

a. How do you presently get to the doctor for your medical appointments?
b. Do you drive a car or take a bus as often as you used to?
c. What kinds of places do you drive to (or go to)?
d. Are there places you used to drive to (or ride to), you don't go to as often now (non-essential trips, e.g., going out for dinner, shopping, etc.)? within the last week?

89. Bathing

How about your present bathing patterns within the last week?

a. About how often—how many times a week—do you bathe now?
b. How do you bathe? Of the___ times a week you bathe, how many are tub baths? Showers?___ Sponge baths?___(e.g., washing yourself down with a close or sponge)?
c. Does it take you more time to bathe?
d. Are you assisted in bathing by other people? e.g., Are water and equipment brought to you? Do you need help in getting in and out of the tube or shower? Do you need help in washing hard-to-reach areas, such as your back?
e. Are there special devices or equipment that you use and find helpful?
f. What about shaving? Do you shave as often? Or have you changed how you shave (e.g., manual razor to electric)?
g. How do you care for you hair? Number of times washed? (e.g., barber shop or beauty shop)?

90. Toileting

What about your present bath room habits?

a. Have your habits changed within the last week? e.g., are you having trouble with constipation or diarrhea?
b. Do you need to get up more often at night?
c. Do you need help to get up more often at night?
   e.g. Does someone assist you in walking to the bathroom or in the bathroom?
d. Do you need special equipment, such as grab-rails or a raised toilet seat, portable commode, bedpan or urinal?

91. Role in the Home

Can you describe what your primary responsibilities have been in your home now?

a. Who prepares the meals? If the patient does, ask if within the last week.
b. Who does the shopping? If the patient does, ask if within the last week.
c. Who does the laundry? If the patient does, ask if within the last week.
d. Who cleans the house? If the patient does, ask if within the last week.
   Who does repairs around the house? If the patient does, ask if within the last week.
e. Who does the yardwork? If the patient does, ask if within the last week.
f. Who runs errands? If the patient does, ask if within the last week.
g. Are there some things you used to do that you are not doing now?

92. Work Role (Complete a or b or c)

a. Do you work? That is, do you receive pay for the work you do? If yes:
   1. Are you presently working? What kind of work are you doing?
   2. Are there some things at work you used to do that you aren't doing now?

b. If you don't work, did you stop working for pay because of your current illness? If yes:
   1. What kind of things do you do <u>now</u> that you think of as work (that is, things you are responsible for, such as chores around the house, volunteer or club duties)?
   2. Are there some things you used to do that you aren't doing now?

c. If you have never worked for pay or have not worked for pay for a considerable period of time unrelated to current illness:
   1. What kind of things have you done that you consider work (that is, things you are responsible for, such as chores—yard work, repairs, cooking, cleaning, shopping— or volunteer work)?
   2. Are there some things you used to do that you aren't doing now?

93. Recreational and Social Role
    a. What kinds of things do you do for recreation or just for fun? What about TV?
    b. What have you done within the last week?
    c. How much contact do you have with people not a part of your family within the last week, and where does this occur?
    d. Do you keep in touch with your friends?
    e. Are there things you'd like to do in the way of recreation or entertainment that you aren't doing right now?
    f. What do you do (do you plan to do) on the most recent (upcoming) major holiday?

94. Communication—Consciousness scale: Interviewer completes
    a. Patient responds to interviewer in normal, coherent fashion.
    b. Patient responds to interviewer's questions but adds much tangential or irrelevant information.
    c. Patient does not respond directly to interviewer; requires much prompting to elicit any answer or maintain attention.

Demographic Questions

| Directions: This is the very last section of the questionnaire and asks some general questions about you. |
|---|

95. Age:_____

96. Gender: Female _____ Male _____ Transgender _____

97. Race/ethnicity:
Latino/Hispanic _____ African American _____ Chinese _____ White _____
Native American _____ Other Asian/Pacific Islander _____ Multiethnic _____

98. Which of these statements best describes your present financial status?

| | |
|---|---|
| I go without | 1 |
| I have barely enough to get by | 2 |
| I feel secure most of the time | 3 |
| I am very comfortable | 4 |

99. When you were growing up, how would you describe your family's financial status:

| | |
|---|---|
| We went without | 1 |
| We barely had enough to get by | 2 |
| We felt secure most of the time | 3 |
| We got everything we wanted | 4 |

100. Are you currently working? No ____ Yes_____
If not working when did you last work? _____
What kind of jobs did you have? _____

101. What was the last grade in school that you finished? _____

# APPENDIX F: ORGANIZATION OF SURVEY CONTENT AND SOURCE OF DIGNITY ITEMS

| Concept | Measures | Source of Data | Data Points | Item # on Survey | Number of Scores of Scales | Source of Measure | Published Avg. Time to Complete |
|---|---|---|---|---|---|---|---|
| Dignity | 33- item researcher developed 2-items modified | Self-report | Visit 2 | 1-35 | 3 subscales<br>a) Items 1-17: 5-point scale (1=not at all important…5= most important)<br>b) Items18-33: 4-point scale (1= definitely true…. 4= definitely false)<br>c) Item 34-35: 7-point scale (0= never felt loss of dignity …6=extreme loss of dignity) | See Dignity Item Source Table | N/A #1-33<br><br>Not reported NR #34/35 |
| Symptom Distress | Symptom Distress Scale | Self-report | Visit 2 | 36-48 | 13 items: 5 point scale<br>Lower score= lower distress | McCorkle, Young, 1978 | 5 min. |
| Decision-making preference | Control Preference Scale | Self-report | Visit 2 | 49-58 | 5 preference styles are written on individual cards with cartoon depiction; asked to select preferred of 10 pairs. | Degner, Sloan, Venkatesh, P. (1997). | 5 min |
| Good Death | QUAL-E | Self-report | Visit 2 | 59-84 | 26 item scale: 5-point scale (1= not at all, 5=completely) 5 factors | Steinhauser et al. (2002) | 15 min |
| Functional Status | Social Dependency Scale | Self-report | Visit 2 | 85-94 | Four items per capacity on 6-point scale. Range of scores for entire scale 12-72 | Benoliel, McCorkle, Young, 1980 | 10-20 min |
| Demographic Data | N/A | Self-report | Visit 1 | 95-97 | Age (Years), Gender (Dichotomous), Race/Ethnicity (Categorical 1-7) | | N/A |
| Clinical data | N/A | Medical Record | Visit 1 | | Date of diagnosis, stage of illness, treatments, complications, prognosis, advance directive | | N/A |
| Socioeconomic status | 4-items | Self-report | Visit 1 | 98-101 | Financial status 4-point scale (current & family)<br>Work status (if current, last employed and type of work)<br>Education (last grade completed) | | N/A |

| **Item #** | Concept | Source/Rationale | **Item #** | Concept | Source/Rationale |
|---|---|---|---|---|---|
| **1** | Privacy | (1) SDI privacy boundaries | **19** | Can be taken away | (1) Question in Chochinov's interview |
| **2** | Being treated as a person | (1) DCR continuity of self | **20** | Having the chance to help others | (1) DCR generativity/legacy |
| **3** | Planning for what happens after your death | (1) SDI aftermath concerns | **21** | Something all people have | Theoretical/philosophical issue |
| **4** | Having control | (1) DCR autonomy/ control | **22** | Decreases death anxiety | (1) IRC death anxiety |
| **5** | Being treated with respect | (1) SDI care tenor | **23** | Having treatment wishes followed | (1) DCR autonomy/control |
| **6** | Being able to think clearly | (1) IRC cognitive acuity | **24** | Needing help with bathing/toileting | (1) IRC functional capacity |
| **7** | Knowing what to expect with your illness in the future | (1) IRC medical uncertainty | **25** | Being patient in nursing home | (1) Dignity fractured was reported more by inpatients |
| **8** | Comfort received from your faith or spiritual beliefs | (1) DCR finding spiritual comfort | **26** | Being patient in hospital | (1) Dignity fractured was reported more by inpatients |
| **9** | Keeping your normal day-to-day routines | DCR maintaining normalcy | **27** | Feeling a burden on others | (1) SDI burden to others |
| **10** | Support you receive from others | (1) SDI social support | **28** | Accepting what life brings | (1) DCR acceptance |
| **11** | Having a life worth living | (1) Chochinov's rationale for his study i.e. concern re. requests for physician assisted suicide | **29** | Fighting spirit | (1) DCR fighting spirit |
| **12** | Living in the moment (not worrying about the past or future) | (1) DCR living in the moment | **30** | Physical symptoms or emotional upset | (1) IRC physical and psychological distress |
| **13** | How your body is handled by others when you are sick | (1) SDI privacy boundaries | **31** | Feeling pride | (1) DCR maintenance of pride |
| **14** | How your body changes as a result of illness or treatment | (1) SDI privacy boundaries | **32** | Hopeful | (1) DCR hopefulness |
| **15** | Importance when dying | Theoretical/philosophical issue | **33** | Fulfill responsibilities | (1) DCR role preservation |

| **Item #** | Concept | Source/Rationale | **Item #** | Concept | Source/Rationale |
|---|---|---|---|---|---|
| **16** | Importance when sick | Theoretical/philosophical issue | **34** | Loss of dignity score (since sick) | Chochinov used (2) Wilson's item as DV with terminally ill pts |
| **17** | Importance all time | Theoretical/philosophical issue | **35** | Loss of dignity score (before sick) | See #34, unclear if poor experience loss of dignity before ill |
| **18** | Money | Relevant to this study of poor | | | |

# APPENDIX G: ETHNOGRAPHIC FIELD NOTES EXCERPTS

Below are samples of field notes that illuminate the ethnographic intensity of this study. These field notes document my emotional response to informants who were actively dying, my role conflict as researcher collecting data in my work site, the clinician-researcher role confusions I experienced, and the issues of race for a white researcher studying persons of color. The first excerpt is field notes from my last interview visit with Danny in the hospital nine days before he died. The second excerpt describes the third group interview conducted on the AIDS dedicated nursing home unit, in the facility where I work; all participants in this group interview were African American. The last field note excerpt documents my last interview with Ozzy in his hotel room days before his death.

## Hospital Visit Excerpt "Danny"

My visit with Danny this evening was very poignant and painful in some ways, and certainly emotional. I went to hospital at the arranged time 7 o'clock after I had interviewed another patient late in the afternoon. I learned from his social worker that Danny had been hospitalized about six days ago and was critically ill at the time of admission and his death was believed imminent. The emergency room physician said that Danny was in liver, heart and renal failure. I called Danny at the hospital earlier today and was surprised that he answered the phone. He recognized my voice and was very happy and actually seemed animated that I called and glad that I contacted him. He readily agreed to my appointment this evening. When I entered the hospital unit and walked in through doors that I had gone through many times in the years I had once worked in this hospital, on this unit, it was nostalgic, sweet and unfamiliar all at the same time. Some parts of the unit were identical; some of the paintings and prints on the walls, the case where patient education materials are kept, were very familiar. I recognized one of the nurses who was giving report. It was very noisy and loud at the nurses' station.

When I walked into Danny's hospital single room, he was lying in bed with a hospital gown on. His legs were not covered, although it had been very hot this afternoon. His eyes were not completely closed and he was breathing in an irregular pattern. I thought he was dying and might even die while I was there. He had a very large abdomen with ascites. His legs were very edematous. He had an IV lock in his left arm. He didn't have oxygen on, but his face was relaxed and he was breathing very infrequently. I checked his respiratory rate and he was breathing 8-9 times per minute. He was having 30-second apneic periods. He was in an adult diaper. His gown looked stain at the borders. He had an unopened 3 Musketeers candy bar in his left hand and his right hand was holding on to the railing, like not letting go. This pose with the 3 musketeers and holding onto the rail, seemed almost like the metaphor for how Danny was in the world. When the night nurse came into the room, and loudly called his name Danny woke up, looked at me and asked "when did (I) get there?"

During our conversation, Danny's mind seemed to wander and I wondered if it was ethical to continue the conversation. I asked him if he were ok to continue the interview

and he said yes. But the issue of decision making capacity with the extremely ill patients is not so simple to sort out. I felt sad leaving him. I mentioned that it was our fourth and last visit. But I realized I was trying to say goodbye to him. When I turned off the tape recorder, he asked me to sit down and stay longer with him. Danny was lonely in this single room. He told me that I brought joy to him and joy to his heart and that he loved me. There was just a genuine human connection that was profound and tender and sad all at the same time. I was tearful by this point. I commented about Danny's kindness and his depth. I told him that similar to other poets, he was a man of few words, but I was confident there many- many deep insights inside. He smiled at this statement. And I told him that I loved him and that I was grateful not only for his participation in my research project. I was grateful for having met him….I was also struck with the conflict and the confusion of my once presence there in this hospital room as expert clinician, and my presence there now in this role as novice researcher.

Field Notes Group # 3 Interview

This group interview began with a very unusual start. Carl had a white ambulatory resident, who was his friend push Carl's wheelchair to the area where the group interview was being held. Carl then told me in the hallway in a loud voice, before we even entered the private interview space, "Anne, he (referring to his friend) has AIDS and I invited him to the group (interview)." I spoke privately with the man and explained why I could not include him in the group interview, i.e. he had not consented and according to IRB protocol I could not have direct contact with patients to recruit them into the study. He seemed disappointed but accepted my explanation. Research as way to get money when desperate was surely a theme here. Can I really get informed (voluntary) consent for research when people are desperate and the incentives seem to provide some relief? Am I taking advantage of the disadvantaged?

This group interview was the most difficult one for me. As the only white person, I felt uncomfortable at times. I felt the need to resist defending nursing, defending (the facility), and defending white people. The four African American patients had difficult stories to share. Rather than speaking of dignity, too often they spoke of indignities. In seeking to obtain clarification, at least once I agitated one participant without intention. I began to feel what it might be like to not be seen when Martha directed most of her comments to my African American co-facilitator. Inadvertently, by seeking further clarification of what dignity "might look like", I failed to recognize what was being said. When Martha challenged me had I ever been in the hospital, ever been a patient there, and insisted I could not know what she and the others felt, I felt humiliated and ashamed.

Indeed, how could I understand what she and the others felt? I am a white woman with privilege. I come and go from (the facility) as my place of work, this place is not where I live or receive care. I would not want to live at (facility or in any other institution for that matter), so in my heart of hearts I wonder how anyone can. Rita spoke about having a life outside of here, at the time in my mind I wondered, is there no life here? Is there no living here?

There were contradictions in their remarks however. Bill seemed high at times and incoherent. Carl, in many ways childlike, uninhibited, and I now suspect with some degree of dementia, said some poignant and tender statements. During the interview, Carl became agitated, and needed to leave in order to be toileted. He had had a bowel movement. I helped push him in his wheelchair return to the nursing unit for assistance. He returned to the interview room angry and agitated when the nurses would not help him immediately. The shame and humiliation of being dependent on others, being put off, being ignored, was all too present on all of their faces. I was embarrassed too.

My efforts to get at the dignity questions that I was hoping to get answered from this focus group, were frustrated. When I attempted to clarify and explore these issues in more detail, I only seemed to confuse or disrespect the people I was asking. My guilt as a white person, was all to present and all too hard. As Françoise reminded me, perhaps because it was an all African-American group, the participants felt more at ease to share their difficult stories than they would otherwise. I am anxious about reading this transcript, and seeing my own racism and feeling my own inadequacy again. Having the focus group in the new area was at least less distracting and less noisy than a dining room. On a less serious note, the group liked the range of refreshments more than the other groups and the hoarding of cookies once again occurred. Having the ground rules helped managed the group dynamics.

Ozzy Last Interview in SRO

I contacted Barbara, the nurse who oversees care of residents living in the Castle Hotel to set up an appointment with Ozzy. When I had called the hotel two days earlier, the front desk person told me that Ozzy was too sick and he wasn't answering the phone. So I was mindful that I did not want to intrude if Ozzy was terminal. I did not want to see him unless it seemed right. I did not want my visit in any way to be exploiting the situation or interfering with this very sacred process of dying. I left a message with these concerns for Barbara and asked her advice. Barbara left me a message that Ozzy wanted to see me, which she said was "very tender because Ozzy had not wanted to see too many other people," and that I could come and see him anytime today. Ozzy's hotel room door was unlocked (which was never the case on my prior visits) and I walked in after knocking and hearing Ozzy say "come in."

Ozzy was sitting in his underwear at the far side of his twin bed; he had always been fully dressed in the past. The bed was very neatly made (as always) but had chucks pads on it. There was a bedside commode next to this bed with a cover on it. Ozzy was sorting through files. He recognized me. Ozzy's appearance had changed a lot in the five weeks since I had seen him. He had lost so much weight. His body was almost like a skeleton with dark skin covering it. His legs were very edematous. The skin around his eyes was sunken in and it was clear he was very dehydrated and very weak. His voice was hard to understand and I had to say, "Excuse me" several times. The interview was brief because I felt like I was intruding, and because his concentration and ability to give very detailed answers were limited.

I suspect he's days away from death. But Ozzy didn't want to talk about death. He described his health as up and down and seemed to say that having a lot of people (caregivers and perhaps others) bothered him. During the visit his sister came and knocked on the door. She was dressed in what looked like scrubs from a nursing assistant or nurse, and said that she was on the way to the dentist and she'd heard his nurse was here. Ozzy had never really spoken much about his family and their present involvement in his life. I asked Ozzy's permission to explain why I was seeing him and said that he was in a study that I was conducting and that's why I was seeing him. I did not want her to mistake my role as his home care nurse who was responsible for his care. His sister was pleasant and warm; she said she would call him later in the day to check in on him.

As I was settling to give his $15 payment for the interview, Ozzy said to me he wasn't thinking about the payment, that was the last thing in his mind with my visit. I had wondered prior to his visit if that was why Ozzy had agreed to see me and felt guilty about my suspicion. I was touched somehow by this comment of not wanting to see me for the money, although would have understood that motivation. I had the feeling that Ozzy was telling me that he enjoyed our visits, and I told him I certainly enjoyed my visits with him and what I'd learned from him. It was very tender. He was thanking me. And I was thanking him. We were terminating our relationship in a way. He also said that he would see me again and when would I be back. I will check in with Barbara.

After I turned the machine off, Ozzy said he was feeling nauseous and thought he would vomit. I helped to reposition him in his bed on his right side, put the chucks underneath him, looked for washcloths and then sat next to him, and told him to breathe deeply. I was coaching him with breathing to relax. He regurgitated a little saliva. He didn't vomit. And then his breathing settled down, he became more relaxed and he fell asleep. I stayed at his bedside for a little bit longer before I got up to leave when I saw that he was resting comfortably. That's when Ozzy asked when would I be back to see him.

At that moment, I realized some of my conflict about the researcher and the clinician role. It was natural to go into the clinician role when a patient was nauseous and might vomit in his SRO alone, positioning, preparing for his emesis, reassuring him and deep breathing --- this what I've always done when someone's having uncontrolled symptoms. These are my automatic, unreflexive embodied interventions as a nurse. And here I was in this other role that I'm still learning and trying to understand. When you are the researcher trying to understand human experiences such as illness, how and when is it appropriate to turn off your clinical skills? I went downstairs then, and on my way out I wanted to tell someone how I'd left Ozzy, to give report.

Elena his case worker in the hotel said that several years ago Ozzy had had lung cancer and had part of the lung taken out. She also said that he didn't want anyone to see him last week. They (all hotel staff) felt that he was very close to death. This week he was eating a little more, a little more willing to have people see him. Last week Ozzy said to her that because he had been shitting all over himself and just dirty and that he said that he lost respect and he had lost his dignity and he couldn't go on like this, without respect,

without dignity. She said the odor and having stool was so embarrassing to him, that he doesn't want anyone to see him. And he's very aware of his odor and frequently has said that he's losing his dignity. And she told me that she said to him he wasn't losing his dignity, that she was there to help clean him up and no one could take your dignity away. I had never heard Ozzy use the word dignity as much as Elena described that he had.

She also told me that the home health nurse was very frustrated because the medical supply company hadn't delivered the supplies in three weeks to the hotel (in this poor neighborhood). And I'm wondering why aren't they delivering in three weeks? And I wondered if it was their own concern about coming to the Tenderloin and bringing equipment there.

I asked whether hospitalization had come up, and Elena said that one of his sisters wanted Ozzy to go to the hospital. Another sister understood that Ozzy did not want go to the hospital. But apparently the one sister said, well, she was going to take him to Oakland, to Kaiser and they would give him the right medicines and that he was dehydrated and they would give him the right treatment. I wondered if that meant that the family thought that his care through the public health care system was inadequate and that he'd get better care at an HMO, interesting. Elena told this one sister that if Ozzy was alert and oriented and he told the doctors at the hospital that he wanted to go home to die, they would listen to him, and so why put him through that? This sister seemed to understand.

This was a very touching visit. In addition to my questioning my role as the nurse clinician and the nurse researcher, I also was very mindful of when is interviewing intrusive when someone's so close to death? Are there times that are so sacred that questions and inquiries should be not part of that story? I don't know. I believe Ozzy wanted to see me and I believe he wanted to participate, to share his experiences and to contribute as he had said in the past. So I am torn.

# APPENDIX H PERMISSIONS

Subject: RE: Obtain Permission
Date: Mon, 18 Jun 2007 16:06:52 +0100
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I request permission to include table 2 in my dissertation (Chapter 5, Measuring Dignity) from the University of California San Francisco which describes my study one of whose aim was to examine Chochinov's dignity model in the seriously ill persons who were poor and living in an urban area in the US. The dissertation will be managed by UMI so that other students and scholars may view in the future.

Additional Info:
I hope to publish some of the findings. I will of course request permission from you again in the future any and all times that I would want to use table 2

***Kerry Holmes <kerry.h@markallengroup.com>*** wrote:

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Date: Tue, 6 Mar 2007 10:25:45 -0000
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To: "Anne Hughes" <ahughes194@sbcglobal.net>

Dear Anne

You are of course very welcome to include a copy of your article in your dissertation. Please just include details of its first publication in IJPN.

Good luck

Tom Pollard
Editorial Director

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From: Anne Hughes [mailto:ahughes194@sbcglobal.net]
Sent: Fri 2/23/2007 1:33 AM
To: Candy.Cooley@sworcs-pct.nhs.uk; Kerry Holmes
Subject: Question about getting permission from Int Journal of Palliative Nursing for dissertation

Dear Kerry and Candy:

I am a doctoral student of Betty Davies at the University of California San Francisco (UCSF). I am very much hoping to graduate in June 2007.

The UCSF School of Nursing has been encouraging students to consider publishing papers as an alternative to the traditional dissertation. I was most fortunate to have published in the IJPN in January 2005, part of my review of the literature related to Poverty and Palliative Care in the US .

I would like your permission to include this paper in my dissertation with full acknowledgment of its original publication in the journal. All dissertations at UCSF are indexed in UMI and may be copied if requested by others. Thank you for considering this request.

Sincerely,
Anne Hughes

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Anne M. Hughes 9/11/07

Author Signature Date