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Dignity Matters: Advance Care Planning for People Experiencing Homelessness

*Dianne M. Bartels, Nancy Ulvestad, Edward Ratner,
Melanie Wall, Mari M. Uutala, and John Song*

Dianne M. Bartels, RN, MA, PhD, is Associate Director of the Center for Bioethics and an Assistant Professor in the Department of Medicine at the University of Minnesota in Minneapolis, barte001@umn.edu.

Nancy Ulvestad, BSN, MART, was a Consultant on this project when this article was written, and is now Project Director at the Center for Bioethics at the University of Minnesota.

Edward Ratner, MD, is an Associate Professor in the Department of Medicine at the University of Minnesota.

Melanie Wall, PhD, is an Associate Professor in the Division of Biostatistics at the School of Public Health at the University of Minnesota.

Mari M. Uutala, MA, was a Student Research Assistant for this project at the Center for Bioethics, University of Minnesota.

John Song, MD, MPH, MAT, is an Assistant Professor at the Center for Bioethics and Department of Medicine at the University of Minnesota. ©2008 by *The Journal of Clinical Ethics*. All rights reserved.

INTRODUCTION

Despite efforts to elucidate good end-of-life (EOL) care in the U.S., there are many aspects that remain poorly understood. The needs of those whose daily lives are tenuous, and for whom the end of life is most uncertain, are rarely addressed. Homeless people have the highest mortality rates in developed nations and often die prematurely.¹ Yet their concerns have generally been ignored, as most research on end-of-life care has focused on concerns of the White middle class.² Homeless people have been found to be very willing to describe their preferences and concerns, and they wish to have a voice in what the future might bring in the event of serious illness or death.³ They have considered how life might end because they frequently witness death on the streets. Many of these deaths occur suddenly or violently. A unique concern for people who are homeless is dying anonymously and without memorialization.⁴

Moller found similar concerns when he recorded the stories of urban poor dying people. From these stories he concluded that neglect in dying can reflect neglect in life. "Perhaps the crowning indignity of a life lived in poverty about which no one cares is death died in poverty while the culture smiles indifferently."⁵ A sense of disempowerment, fear of disrespect, and continued marginalization often pervade thoughts about death.⁶ Indignity is a part of daily life on the streets and raises fear of even greater indignity as homeless people look at the prospect of death. Although "death with dignity" has become a slogan for end-of-life care, the meaning for a given individual remains nebulous.

Unique Concerns of Homeless People

Previous research has reported that homeless people share many concerns with others about end-of-life care, including a desire for treatment of pain and concerns about being tethered to machines.⁷ These studies also found unique concerns based on experiences on the street and in healthcare systems. For example, homeless people have described fears of undertreatment or lack of respect in response to the stigma of being homeless. In addition, distance or alienation from families raised specific concerns about whether, in the case of serious illness or death, their bodies would be recognized or their lives and deaths acknowledged. They also described concerns related to both locating loved ones in case of serious illness or death as well as concerns about people they would *not* want contacted.⁸

In response to these findings, an investigational meeting was convened to specify and prioritize interventions to address the end-of-life concerns of homeless people. Participants included relevant stakeholders such as homeless individuals, shelter providers and street caseworkers, hospice providers and experts in end-of-life care, and representatives from state health departments and medical examiner's offices. Five participants were homeless — two women and three men (age range 38 to 67 years); three Native American, one African-Americans, and one White.

After a review of end-of-life concerns of homeless persons identified in previous research, these constituents were assigned to small groups that were asked to identify and prioritize possible interventions to address end-of-life concerns. They described barriers to end-of-life care that were both systemic and structural and then suggested interventions to address them. Participants suggested that relationships between homeless people and healthcare providers could be enhanced by setting aside assumptions, being honest, and investing time in building trust. Each small group supported opportunities to create advance directives as a primary effort to support improved end-of-life care. They also indicated that standard living wills do not address the unique concerns of homeless people or the indignities they may encounter in healthcare and social service systems. In addition, they suggested creating various forms of identification (cards, bracelets, and so forth) and documenting contact numbers or the existence of living wills.

Because many of these concerns described indignities encountered in healthcare situations as well as the ultimate indignity of unacknowledged death, the investigators sought a way to address dignity concerns in the context of advance care planning. Chochinov and colleagues have developed a model to conserve dignity as a way to concretely address dignity-related concerns.⁹

A Care Model that Conserves Dignity and the Development of an Advance Directive

Chochinov and colleagues conducted research with people who were dying in order to explicate the meaning of dignity at the end of life.¹⁰ Participants in their study described concerns related to the effects of terminal illness in terms of level of independence and control of their medical symptoms. Dignity-specific themes included:

1. Generativity: the sense that one's life has stood for something
2. Continuity of self: a sense that one's essence is intact despite advancing illness
3. Role preservation: a sense of identification with previously held roles
4. Maintenance of pride: ability to retain positive self-regard
5. Hopefulness: ability to maintain a sense of meaning or purpose
6. Concerns regarding the aftermath of death: worries or fears about the challenges or burdens that one's death may impose on others
7. Tenor of care: the attitude and manner with which others interact with the patient that may or may not promote dignity.¹¹

These authors used these empirically derived themes to develop *dignity therapy*, an approach that invited imminently dying people to identify their concerns, tell their stories, and describe how they would like to be remembered. The responses of terminally ill patients were recorded and shared with their loved ones. This opportunity to share thoughts about things that engendered pride and respected dignity was found to

bolster a sense of meaning and purpose while reinforcing a continued sense of worth.¹² Patients who initially reported the most psychosocial despair seemed to especially benefit from dignity therapy. These participants experienced an increased sense of purpose as they approached death, even when their pain wasn't well controlled.¹³ Addressing dignity in this manner within hospice and palliative care programs can assuage the spiritual and emotional suffering that may be associated with the dying process.

Because many of the themes generated in Chochinov's model are similar to themes reported in previous empirical work exploring concerns about EOL care among homeless persons, a novel advance care planning process was designed to honor end-of-life care preferences by building in themes from Chochinov's model along with recommendations from empirical work with homeless people.¹⁴

The format expanded on the recommended language for legal sufficiency of advance directives in Minnesota state statutes. The standard Minnesota advance directive includes contact information for proxies, one's preferences regarding treatment and organ donation, and one's preferences regarding the disposal of one's body. Questions were added that captured the unique concerns of homeless persons, such as physical features (for example, tattoos) that might help with identifying one's body, preferences for disposition of one's body after death, and the designation of people who should and should *not* be notified in the case of serious illness or death. Questions concerning dignity were adapted from Chochinov and colleagues' domains and were incorporated into the process of completing the advance directive (see table 1 for specific questions).

This article describes the results of a content analysis of advance directives completed by homeless persons during a pilot study conducted at a drop-in center in St. Paul, Minnesota. The advance directive was developed as a tool for this pilot, which tested whether homeless people would complete advance directives under two conditions: (1) a "minimal intervention" that included education about end-of-life issues and dissemination of the advance directive form for self-completion, and (2) a "guided intervention" that included education and an opportunity to complete the advance directive in a one-on-one session with an investigator (doctor, nurse, or counselor) who assisted completion of the advance directive.¹⁵ The current study describes the content of the advance directives completed by homeless people who participated in the guided intervention arm.

METHODS

After approval by the University of Minnesota's Institutional Review Board, a convenience sample of 59 subjects was recruited at a homeless drop-in shelter. Volunteers were randomized into two intervention arms: minimal intervention and guided intervention. Compensation was provided to all participants for their study participation (for example, completion of pre-intervention survey tools), but was not linked to returning for follow up or for completing an advance directive.

The 29 individuals assigned to the guided intervention group were invited to return on subsequent days to meet with an investigator to complete the advance directive. On return, an investigator met privately with the subject to answer questions about end-of-life care and to assist in documenting the subject's preferences on a legally signed and witnessed advance directive, using the tool developed for this study. Depending on an individual participant's preference, either the participant or the investigator actually wrote the responses on the living will form as well as the participant's responses to the questions regarding dignity. In either case, the participant reviewed the written responses on completion.

After this review, the form was witnessed by two people (investigators or shelter staff). The intervention averaged 30 minutes per subject; none lasted more than 45 minutes. Participants were offered copies of the form to keep or send to their designated agent and others of their choice. Investigators retained a copy of completed advance directives in order to assess the utility of each question and for qualitative content analysis. The results section below describes responses of participants who elected to participate in the guided intervention.

ANALYSES

The number of participants who responded to each question in the advance directive was tallied as a measure of the utility of the item. No quantitative analyses

TABLE 1. Dignity Questions Included in the Advance Care Planning Process

-
- I. Concerns related to illness
 - A. Current illnesses/health challenges that concern me
 - B. Symptoms of greatest concern
 1. Physical distress
 2. Psychological distress
 - a. Things I worry about related to death
 - b. Concerns I have about being recognized in case of emergency or death
 - c. Relationships that cause me concern or worry
 - d. Possible actions that would relieve any of the above concerns
 - C. Concerns about level of independence
 1. Worries or concerns I have about my ability to think, communicate, or act
 - II. Concerns related to dignity
 - A. Continuity of self
 1. Roles or relationships which are important to me
 2. Person(s) I want to make medical decisions in case I am unable to make them (primary decision makers)
 - B. Maintenance of pride
 1. I am proud of these things
 2. I want to be remembered as a person who . . .
 3. People who care for me could do the following to respect my dignity
 - C. Finding spiritual comfort
 1. After death, what should happen to my body
 - a. Burial (where)
 - b. Cremation and ashes put where
 - c. A memorial service (where/by whom)
 - d. Other
 2. My concerns related to religion of spirituality are:
 - a. Who should be notified for assistance with these needs (name, address, phone, or other contact information)
 - b. Who could be helpful in making arrangements/notifying others (name, address, phone, or other contact information)
 - D. Other values that should influence my care in the event of serious injury or death

Note: Each prompt was presented as an open-ended statement with blanks for responses. Adapted from H.M. Chochinov, "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life," *Journal of Clinical Oncology* 23 (2005): 5520-5.

were planned because of the small number of respondents. All responses to each question on the advance directive were recorded verbatim on a master tally sheet by study number of the participant to maintain anonymity. The results section includes verbatim responses of participants in response to individual questions. Responses to open-ended questions that specifically related to maintenance of pride (#2B in table 1) were collated and independently coded by two investigators. After analysis, two themes were identified to describe the content, and items were re-coded until full agreement on the items included in each theme was attained.

RESULTS

Of a possible 29 participants, 17 who were offered guided intervention returned to the drop-in center to meet with an investigator to complete an advance directive with assistance. Of these 17 participants, 14 were men, 11 were Black, four were non-Hispanic White, and two were Native American. In terms of education, six had finished at least some college, six were high school graduates, one had not finished high school, and four did not answer the education question. Religious affiliation included: four Baptist, three Roman Catholic, six Christian (three specifying nondenominational), one Jehovah's Witness, one Jew, one non-response, and one "none." Of the 17 respondents, 12 were veterans. Over the last year, two people had lived exclusively on the streets, while others had moved among a variety of settings including homeless shelters, hotels, apartments, and rehabilitation facilities. Descriptions below include participants' responses to individual items in the advance directive. Frequencies of response to each question are included with content analysis as a description of the utility of the question.

Identification and Body Disposition

When asked about "things that would help healthcare staff to recognize you in case of emergency or death," 13 respondents described scars from surgeries or injuries and/or tattoos. Examples of responses included:

- Check the I.D. he always carries

- None
- "C-section scar — bikini cut"
- USMC tattoo on right shoulder.

Three left the query blank. Several respondents described both scars and tattoos.

In response to the query regarding "wishes regarding care of my body when I die," eight participants indicated burial and six designated a specific site. Three indicated that they would want to be cremated. Six people indicated that a specified friend or relative could decide what should happen to their body. Four responses added written caveats describing a wish for the lowest cost option to avoid financially burdening relatives, for example, "Burial if financially independent, cremation if dependent. . . ."

Appointment of Primary Decision Maker and Notification of Others

Of 17 participants, 16 identified a specific person to be a primary decision maker for them in the event of serious injury, illness, or death. Six appointed family members (mother, brother, sister, or a combination of these relatives). One of the appointed proxies was from a health plan; two were staff at the drop-in shelter. Eight participants supplied names and contact information, but a relationship was not identified. Five people also identified other people, including friends, a sister, a stepmother, an aunt and brothers, a brother and mother, in addition to decision makers who should be notified in the event of serious injury or death. Three wrote "no one" and nine respondents did not answer the question. Two identified individuals by name who should *not* be notified and another wrote, "Don't notify family."

Stated Wishes for Treatment

In response to the query, "what I would want for my healthcare if I am seriously ill or dying and unable to decide for myself," eight people indicated that they would want all measures taken and one indicated that (s)he would want all measures with the exception of a blood transfusion. Six participants indicated that they would prefer limited treatment, with specifications: "Yes, no Quinlan situation," "if brain dead, no treatment," and "don't keep me alive for a long time." Two participants indicated a desire for no treatment. One person did not answer this question.

Dignity-Specific Concerns

In response to a query regarding "current illness/health challenges that concern me," 13 of 17 people described specific illnesses about which they were concerned. Individual responses included:

- Heart disease and open-heart surgery
- Schizophrenia and multiple broken bones
- Dizziness and bronchitis
- Mental illness and gastritis
- Schizophrenia, depression, affective disorder
- Anxiety, two bad knees, lower bad back
- Bottoms of feet turn yellow, back and hip pain secondary to work injury, hearing voices over the air-waves
- Throat cancer, chronic obstructive pulmonary disease, posttraumatic stress disorder (PTSD)
- Dental: "always bad teeth"
- High blood pressure, hepatitis C
- Bipolar and schizophrenic tendencies
- Hernia, allergies that bother eyes all year long
- High blood pressure and concern about developing multiple sclerosis.

Four had no current illness-related concerns.

Related to "symptoms of greatest concern," 11 people indicated concern about *physical distress* related

to their illnesses. Six described specific pain, one reported allergies, one reported sleep apnea, and one reported high blood pressure. One person indicated "none" and four did not answer the question.

Only two responses indicated concern about *level of independence*, one indicated depression while another was concerned about the possibility of a "manic episode."

Concerns about *psychological distress* included:

- Worrying about four children
- Fear of the unknown, depression, schizophrenia, bipolar disorder, and PTSD
- Boredom due to inability to work
- Concern about being off medication
- Worries or concerns about being homeless (reported by three persons)
- Concern about lack of insurance: "treatment is based on insurance — not on need as a human being."

Participants' responses regarding "things I worry about related to death" included:

- Family not being notified
- Leaving a wife and children behind
- Being a burden to family
- Lack of resources to cover burial costs (family or friends would be responsible)
- Being alone
- One person indicated that he/she didn't want to die: "felt like giving up in the past, but not now."

Five respondents indicated that they had no death-related worries.

Responses to a query regarding "relationships that cause me concern or worry" included:

- Spouse
- Brother who is an alcoholic
- "Relationship with self"
- Not keeping in touch with family
- With nearly adult kids — "sometimes don't get along with my daughter"
- Not spending quality time with family — would like to be more self-sufficient
- "Just interpersonal"
- "What relationships? Everyone wants one and I won't get into one. I am alone . . . but planning to stay and not go home to 'meth'."

Seven respondents wrote "none."

Only three people had suggestions in response to a query regarding "possible actions that would relieve any of my concerns":

- Get work or housing and to notify sister about proxy appointment
- Continue to think positively
- Completing a living will.

Three people indicated "none," and others did not answer the question.

Maintaining Pride

There were 18 responses to a query regarding what "I am most proud of" (see #2B in table 1) that were grouped into two themes: (1) accomplishments and (2) elements of character. Accomplishments described activities that made a contribution including:

- Taking care of oneself
- Ability to work
- Returning to or completing college
- Completing alcoholism treatment

- Taking care of one's health by seeing a doctor regularly
- Serving in the military
- Special skills like building a house or speed skating.

Only one person's source of pride was his/her family. Character items were personal attributes that created a sense of pride including:

- Honesty,
- Compassion and understanding,
- Holding high morals, for example, "I am a good guy, helpful to other people."

Indications of how one *would like to be remembered* were invariably about dimensions of character, with the exception of one person who would hope to be remembered as "a congressman or alderman . . . who created programs for homeless persons." Elements of character included:

- Liking and enjoying life
- Being optimistic in the face of adversity
- Happy
- Helpful
- Believing in God
- Being open-minded
- Able to function in spite of struggling with addiction
- Having a "good spirit."

One person stated, "I lived life to the fullest, loved all people, and was always a helper and listener." Another wrote, "Fair, open-minded, believe in God. Honest, reliable, and unselfish. I know myself and am not ashamed."

Responses addressing *how providers could respect dignity* reflected basic concerns:

- "Treat me like I treat others"
- "Try the best to keep me alert and tell me who I am if I am confused"
- "Don't judge a book by its cover, but from within" and "accepting me for who I am and not telling me what to do."

Additional responses included telling the truth and respecting privacy.

Responses regarding *spiritual comfort* primarily related to specifying post-death plans including burial, cremation, or memorial services. One person indicated that calling clergy would be helpful. Another indicated, "I know who my maker is." Seven people indicated that they would want a memorial service and designated a place. Some gave specific instructions about services and pallbearers. One indicated, "Yes, sing a song . . . 'He keeps his eye on the sparrow' so I know he is watching me."

A unique answer was from a person who wanted his ashes poured into a fishing spot on the Mississippi River. He told the investigator that there was a place under the bridge where he had been fishing since he moved to the state, and indicated that the catfish knew him. He directed that his ashes be taken to the river by the fishing spot so that the catfish could provide "a free trip to [his hometown]."

DISCUSSION

This pilot project built on prior research into end-of-life care concerns among homeless people and the results of a working group focused on the development of interventions to improve such care. The process resulted in development of a unique advance care planning process specifically designed for homeless individuals. The first and possibly most significant finding was that homeless people not only said they would like to complete advance directives, but actually came at a specified time to complete an advance directive

with assistance. The high number of people who returned for voluntary, uncompensated guided intervention demonstrates a high level of interest in advance care planning in this population.

Appointment of a healthcare agent or proxy occurred in almost every advance care planning process. In addition, more than half of the participants named additional individuals whom they wished to be notified. Homeless individuals may not be in contact with their relatives, so it is often not obvious who should be notified when they become sick, or die. Some participants solved this problem by naming homeless shelter staff as healthcare agents, while one specifically stated that family should *not* be notified. Without such an advance directive, notifying family members would likely be the first response of careproviders. Earlier research reported that homeless individuals expressed a concern regarding unacknowledged and unmemorialized death; when homeless people are able to appoint a healthcare agent or another to notify, this concern is addressed.¹⁶ Thus, the advance directive in this population takes on a relatively important role in understanding and potentially honoring patients' preferences. Stated priorities for end-of-life care and post-death care can provide direction for shelter staff, healthcare, or morgue personnel to perform actions that would respect the person's wishes even in the event that no proxy is identified in the form.

In terms of dignity-related concerns, homeless people shared many concerns with hospice patients. They reported few concerns about level of independence and more concern about psychological than physical distress. This distress frequently related to severed relationships or concern about imposing a burden on survivors. Dignity-related questions elicited responses that suggested options for individualized end-of-life and post-death care. For instance, even a proxy who has known someone from childhood would be unlikely to know that a trip down the river with the catfish, or a particular funeral song, would be a source of solace. Participants' thoughtful responses gave voice to the level of anticipation and concern about illness and death that is a part of everyday life for people without a home. Respondents were not hesitant to describe illness-related concerns, things for which they would like to be remembered, or what kind of treatment would respect their dignity.

Learning of homeless persons' deep level of concern about morbidity, premature mortality, and decisions they might confront as they approach the end of their lives should increase clinicians' empathy and ability to best provide care for this vulnerable population. The most difficult challenge a clinician may face would be to respect the wishes of those people who want no one notified. However, this is the situation in which an explicit expression of wishes is most important in guiding clinicians to make decisions that respect autonomy and dignity. Designated agencies or agencies that provide public burial services could be notified regarding preferences for after-death care. Responses to this pilot project suggest a strategy for enhancing advance directives that can have positive implications for homeless people and for clinicians who provide care for them.

Strengths and Limitations

In this study, physician and nurse investigators who had no prior relationship with the study participants provided assistance with completion of written advance directives at the study site. It is unknown whether the expertise of the investigators in end-of-life issues, the ability to focus on advance care planning without the distraction from other clinical concerns, or the familiarity of the setting to the participants affected the rates of completion.

Responses to this intervention may not generalize to other homeless populations because of the limited number of participants and the fact that it was conducted in one site at one time period. However, many of the concerns identified by these participants reiterated themes from previous research.¹⁷ Participants found the format understandable and the questions helpful for advance care planning. Investigators who worked with people in the guided intervention group were impressed with the sophistication and forethought shown in understanding of the relevant treatment options and consequences of various choices.

It was obvious that life circumstances, including the ubiquity of death in the streets, made concerns about what might happen in the event of serious illness or death an important issue that needed to be addressed. However, lack of longer term follow up precluded the possibility of assessing the impact of the

advance care planning process when serious illness or death actually occurs. Although participants responded to the dignity-related questions, this intervention did not specifically ask them about whether the process enhanced their dignity.

Summary and Recommendations

Addressing the themes concerning dignity and asking questions about things like identification of one's body and one's wishes for postmortem care appear to have positive results for people who are homeless. This process can provide direction for healthcare providers and proxies who would make arrangements for cremation, burial, and memorial services. Inquiries regarding dignity invited unique responses that would not have been identified using standard advance directive formats. In future studies, it would be wise to address a larger population of homeless people and to formally measure a sense of dignity to verify whether participants perceive the process to be dignity-enhancing. A logical next step in the process would be to work with emergency systems and healthcare providers to ensure that advance directives are available in the medical record. Analysis of those records would answer the next important question about whether written directives actually influence the outcomes of end-of-life and post-death care.

Linking dignity items and after-death concerns to the process of creating an advance directive provided relevant information for end-of-life and postmortem care. Because the questions about dignity yielded such useful information, the authors plan to include these questions in the body of the advance directive in future explorations.

This project has demonstrated efficacy of a unique advance care planning process that included identifying the dignity concerns for people who are homeless. Other people who are disenfranchised face similar challenges and may benefit from this approach. Chochinov and colleagues report that most of the people who participated in dignity therapy research in palliative care settings in Canada and Australia said they were satisfied with their experience with the study.¹⁸ Their successes, and the positive responses of these participants who are vulnerable but not imminently dying, suggest that it may be wise to assess in more settings whether dignity concerns will add value to the process of creating advance directives and end-of-life decision making.

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