

# Creation and the Empirical Validation of the Dignity Card-Sort Tool To Assess Factors Influencing Erosion of Dignity at Life's End

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## Abstract

Patients often experience erosion of dignity as they cope with the dying process. Preserving patient dignity is a sentinel premise of palliative care. This study was conducted to gain a better understanding of factors influencing erosion of dignity at the end of life. We conducted an open-ended written survey of 100 multidisciplinary providers (69% response rate) and responses were categorized to identify 18 themes that were used to create a card-sort tool. The initial 18-item tool was administered to nurses ( $n = 83$ ), nonhospice community-dwelling subjects ( $n = 190$ ) and hospice patients ( $n = 26$ ) and a principal component analysis (PCA) was used to identify the 6 primary factors. The key item in each factor as identified by the PCA was used to create the final 6-item dignity card-sort tool (DCT). The DCT was also administered to physicians caring for palliative care patients ( $n = 21$ ). For each of the final 6 items, the correlation between the respondents (nurses, physicians, nonterminally ill subjects, and subjects receiving hospice care) was calculated using the Spearman's correlation coefficient. The nurses were very highly positively correlated with the physicians (correlation coefficient = 0.94) and the community-dwelling nonterminally ill subjects were highly positively correlated with the subjects receiving hospice care (correlation coefficient = 0.67). More importantly, both the nurses and physicians were negatively correlated with both community dwelling nonterminally ill subjects and the subjects receiving hospice care. The health professionals in the study felt that treating a patient with disrespect and not carrying out their wishes resulted in erosion of dignity. In contrast patients thought that poor medical care and untreated pain were the most important factors leading to erosion of dignity at life's end. The DCT is a promising tool that may help clinicians identify key factors resulting in perceptions of erosion of dignity in adult palliative care patients.

## Introduction

THE WORD DIGNITY, derived from Latin *dignita* can be traced back to the thirteenth century and is defined by the *Merriam-Webster Dictionary* as "the quality or state of being worthy, honored, or esteemed." There is clear societal consensus that we want to facilitate dignity in aging and end-of-life for all Americans as evidenced government initiatives about "aging with dignity"<sup>1</sup> and "death with dignity,"<sup>2-4</sup> as well as organizations called Aging with Dignity,<sup>5</sup> Death with Dignity National Center,<sup>6</sup> and Dying With Dignity.<sup>7</sup>

Pioneering work by Chochinov<sup>8-14</sup> and others<sup>15-21</sup> has shown that the concepts of dignity and "dying with dignity" are considered to be very important by patients approaching life's end, their families, and their health care providers and that dignity-conserving care<sup>8-14</sup> is an overarching framework

that may guide health care providers, patients, and families in defining the objectives and therapeutic considerations fundamental to the care of aging and dying patients.

Despite the numerous initiatives that have been introduced to facilitate good palliative care in this country, terminally ill patients continue to be vulnerable to erosion of personal dignity during life's final chapter.

In order to best facilitate a sense of dignity and dignified deaths, for all patients, first of all, perceptions of the concept of dignity and death with dignity must be first better understood. This concept is a very subjective one and much influenced by an individual's personal, cultural, social and spiritual constructs. Patient dignity does not exist in a vacuum.<sup>22-29</sup> It is also subject to great influence by the perceptions and behaviors of the health professionals caring for them. Both quality of care and care tenor can either augment or erode patient dignity.

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We argue that the first step in fostering patient dignity is to avoid behaviors that lead to loss of patient dignity.<sup>22–28</sup> In fact the abstract concept of dignity at the end-of-life might be better understood when one attempts to define factors leading to its loss.<sup>27–30</sup> If such factors are identified, it then may be easier for health care providers caring for aging and dying patients to structure care in a manner that will avoid eroding<sup>31,32</sup> and thereby facilitate augmentation of patient dignity.

Using a cross-sectional approach, this study was undertaken to explore both patients (hospice and nonhospice) and multidisciplinary health professionals perspectives of factors influencing loss of dignity at the end of life and then to create and validate the dignity card-sort tool (DCT). All phases of this study were approved by the Stanford University Institutional Review Board.

## Methods

### Phase 1: Preliminary work—open ended surveys of health professionals

Early exploratory work involved conversations with multiethnic patients and families about the concepts of dignity, death with dignity, and erosion of dignity at life's end. They endorsed the need for this line of research and stated that health professionals' perceptions and behaviors are likely to have a significant influence on patients' perception of their dignity. In order to gain an initial understanding of their perception of dignity at the end of life, we conducted an open-ended written survey of 100 multidisciplinary providers (nurses, physicians, psychologists, social workers, and chaplaincy) working in the VA Palo Alto Health care System in Geriatrics and Palliative Care with the following questions:

1. What is dignity? When does a person lose dignity?
2. When does a dying patient lose dignity?
3. Have you cared for patients who died without dignity? Please explain.

Of the 100 professionals contacted, 69 responded (response rate, 69%). The survey responses were transcribed and analyzed using the QSR -N7 (QSR International Pty Ltd. [QSR] ABN 47 006 357 213). Using an open coding approach, themes and subthemes were identified independently by two of the authors (V.S.P. and A.M.N.) and any conflicts were resolved by a series of discussions mediated by another author (H.C.K.). Based on frequency of occurrence and salience, 8 key themes (first-order categories) and 18 subthemes (second-order categories) were extracted from the open-ended survey responses. The 16 of the 18 subthemes were subclassified under the key themes of "respect," "acceptance," "self-image," "quality of care," "connectedness," "autonomy," "comfort and "other." Two subthemes ("when s/he loses control over toileting functions" and "when s/he loses her/his mind") relating to physical disabilities and bodily functions were identified and classified under the theme name "other." Actual words and phrases used by participants were used to name themes and subthemes<sup>34</sup> (Table 1).

### Phase 2: Quantitative phase—creation of the "loss of dignity rank order card sort tool"

The 18 key subthemes identified by participants to be influential in the perception of loss of dignity at the end of life were used to create a loss of dignity rank order card-sort tool (DCT).

**Pilot 1.** Initially, we created a rating scale and asked a small group of pilot participants to rate each of the 18 items on

TABLE 1. FACTORS INFLUENCING PERCEPTIONS OF LOSS OF DIGNITY AT THE END-OF-LIFE DEATH: KEY THEMES AND SUBTHEMES QUESTION: IN YOUR OPINION, WHEN DOES A DYING PATIENT LOSE DIGNITY?

| <i>Factor identified by principle component analysis</i> | <i>Items identified to be influential in perceptions of loss of dignity at life's end (used to create the card sort tool)</i> | <i>Key themes identified by qualitative data analysis</i> |
|--|---|---|
| Factor 1 <sup>a</sup>                                    | When others treat her/him without respect   | Respect   |
| Factor 1   | When others treat her/him like and object   | Respect   |
| Factor 1   | When not honored as a worthy person   | Respect   |
| –(Factor 1)  | When s/he does not accept that s/he is dying  | Acceptance  |
| –(Factor 1)  | When s/he loses control over toileting functions (loss of control over bowel and bladder)                                     | Other   |
| Factor 2 <sup>a</sup>                                    | When her/his wishes are not carried out   | Respect   |
| –(Factor 2)  | When s/he loses positive self image   | Self image  |
| Factor 3 <sup>a</sup>                                    | When s/he is medically mismanaged   | Quality of care   |
| –(Factor 3)  | When s/he dies alone without loved ones   | Connectedness   |
| Factor 4 <sup>a</sup>                                    | When she loses ability to choose  | Autonomy  |
| Factor 4   | When s/he loses her/his mind (cognitive impairment)   | Other   |
| –(Factor 4)  | When s/he is not given emotional comfort  | Comfort   |
| –(Factor 4)  | When s/he is not given spiritual comfort  | Comfort   |
| Factor 5 <sup>a</sup>                                    | When s/he feels ashamed   | Self image  |
| Factor 5   | When s/he has lost self respect   | Self image  |
| Factor 6 <sup>a</sup>                                    | When s/he dies in pain  | Quality of care   |
| Factor 6   | When s/he is not given physical comfort   | Quality of care   |
| –(Factor 6)  | When others violate her/his privacy confidentiality   | Quality of care   |

<sup>a</sup>Indicates the primary item (the item that weighed most on each factor). Items in parenthesis indicate items that those items weighted negatively on the factor.

TABLE 2. DEMOGRAPHIC DATA: AGE RANGE AND ETHNIC BACKGROUND OF STUDY SUBJECTS

| Age range                       | Health professionals | Patients |
|---------------------------------|----------------------|----------|
| 20–29 years                     | 2.8%                 | 1.3%     |
| 30–39 years                     | 21.7%                | 3.2%     |
| 40–49 years                     | 32.1%                | 27.2%    |
| 50–59 years                     | 37.7%                | 32.9%    |
| 60–69 years                     | 5.7%                 | 15.8%    |
| 70–79 years                     | —                    | 14.6%    |
| 80–89 years                     | —                    | 5.1%     |
| Ethnic background (self-report) | Health professionals | Patients |
| Caucasian                       | 41.1%                | 50.4%    |
| African American                | 4.7%                 | 8.1%     |
| Asian                           | 4.3%                 | 31.1%    |
| Hispanic/Latino                 | 2.8%                 | 5.9%     |
| Other                           | 8.4%                 | 4.4%     |

a 5-point Likert scale with choices ranging from “strongly disagree” to “strongly agree.” It was noted that pilot participants rated all 18 tool items as “agree” or strongly agree.”

**Pilot 2.** In an effort to stratify the tool items, we opted for a ranking strategy and accordingly created a rank order paper survey with the 18 items and piloted it on another small group of subjects. Subjects were instructed to rank the 18 items in the order of importance from 1 (most important) to 18 (least important) and to not assign tie ranks. However, results showed that many subjects assigned tie ranks (sometimes even rating all tool items as 1) and items listed first in the written survey typically received higher ranks.<sup>35</sup>

**Card sort tool.** In order to create a random order of items and to have study subjects prioritize among the list of 18 items, we opted to create a card sort rank order tool. Accordingly, each tool item was written on a separate card and the 18 cards were shuffled thoroughly to create a random order. Each participant was then requested to arrange (stack) the cards in the order of most important factor (top-most card) to least important card (bottom-most card) influential in perception of erosion of dignity at the end of life. This was done with the following cohorts: VA nurses ( $n = 83$ ), non-terminally ill community-dwelling subjects ( $n = 190$ ), and terminally ill hospice patients ( $n = 26$ ). Participant demographics are shown in Table 2.

## Results

### Factor analysis

A principal component analysis with varimax rotation was performed on the nurse cohort as well as the patient cohorts to identify 6 main factors that accounted for 63 % of the variance. For each of the 6 factors, a key item (specific item within each factor with the largest weight) was selected (listed below and indicated in Table 1 by an asterisk) to reduce the instrument to a 6-item card sort tool:

- When others treat her/him without respect (Factor 1).
- When her/his wishes are not carried out (Factor 2).
- When s/he is medically mismanaged (Factor 3).

TABLE 3. COMPARISON OF PATIENT AND PROVIDER PERCEPTIONS OF FACTORS INFLUENTIAL IN LOSS OF DIGNITY AT THE END OF LIFE

| Cohort                      | Measured similarity among cohorts (Spearman's correlation coefficient)<br>0 = random correlation; 1 = 100% positive correlation and -1 indicates 100% negative correlation |        |                             |                  |
|-----------------------------|--|--------|-----------------------------|------------------|
|                             | Physicians   | Nurses | Community dwelling subjects | Hospice patients |
| Physicians                  | 1.0  | 0.94   | -0.60                       | -0.38            |
| Nurses                      | 0.94   | 1.0    | -0.31                       | -0.23            |
| Community dwelling subjects | -0.60  | -0.31  | 1.0                         | 0.67             |
| Hospice patients            | -0.38  | -0.23  | 0.67                        | 1.0              |

- When s/he loses ability to choose (Factor 4).
- When s/he feels ashamed (Factor 5).
- When s/he dies in pain (Factor 6).

### Comparison of ratings

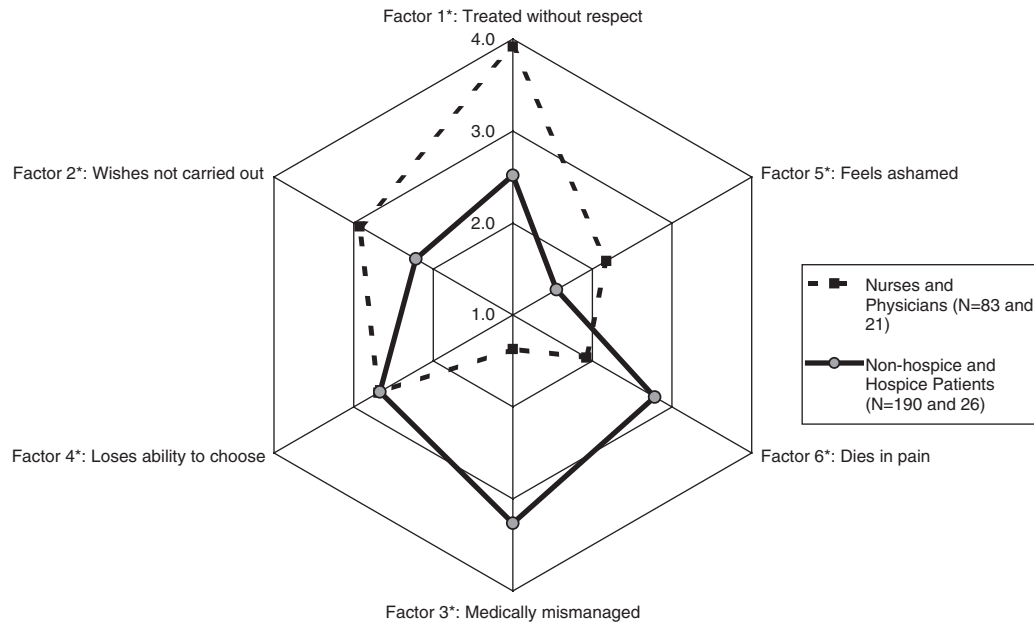
The refined 6-item loss of dignity rank order card sort tool was administered to a cohort of physicians caring for palliative care patients ( $n = 21$ ). Next, for each item, the correlation between the respondents (nurses, physicians, non-terminally ill subjects, and subjects receiving hospice care) was calculated using the Spearman's correlation coefficient (Table 3).

The nurses were very highly positively correlated with the physicians (correlation coefficient = 0.94). The community-dwelling nonterminally ill subjects were highly positively correlated with the subjects receiving hospice care (correlation coefficient = 0.67). More importantly, the nurses were negatively correlated with both community-dwelling nonterminally ill subjects (correlation coefficient = -0.31) and the subjects receiving hospice care (correlation coefficient = -0.23). Similarly, the physicians were negatively correlated with both community-dwelling nonterminally ill subjects (correlation coefficient = -0.60) and the subjects receiving hospice care (correlation coefficient = -0.38).

Nurses and physicians ranked Factors 1, 2, and 4 as the most important factors influencing perceptions of loss of dignity at the end of life. In stark contrast, both cohorts of patients (hospice and community dwelling non-terminally ill subjects) ranked Factors 6 and 3 to be the most important factors (Fig. 1).

## Discussion

In summary, we have empirically explored the concept of loss of dignity at the end of life with both patients and multidisciplinary health professionals. We have developed and initially validated a rank order card sort tool to assess perceptions of factors influential in the loss of dignity at the end of life. It is to be noted that the perceptions of health professionals (nurses and physicians in this study) were significantly different from the perceptions of patients (community



**FIG. 1.** Rank order radar plots comparing patients (hospice and nonhospice) and health care providers (nurses and physicians) ratings of the final six primary factors: comparison of patients' and health professionals' perceptions of factors leading to loss of dignity at life's end.

dwelling persons and hospice patients) that they are caring for. The health professionals felt that treating a patient with disrespect and not carrying out their wishes resulted in greater erosion of patient dignity. In contrast patients felt that receiving poor medical care and dying in pain led to erosion of their dignity. It has been acknowledged that the behavior and the care tenor of health professionals greatly influences patient dignity and it is indeed true that respect<sup>33</sup> is a very important determinant of quality of care. However, from a patient perspective (both hospice and nonhospice patients), practical aspects of care that augmented their physical comfort like access to quality medical care and good pain control out-ranked more abstract concepts like respectful care. The apparent discrepancy between patient and provider perceptions may be due to the following reasons:

1. It is possible that health professionals (nurses and physicians alike) may have felt that the basic needs of dying patients like quality palliative care and good pain control are "a given" and thus may have focused on more abstract concepts like "respect" and "ability to choose." It is well known that many dying patients in this country suffer moderate to severe pain<sup>36</sup> and that most do not have good access to quality palliative care. The opinions of the patients in our study sounds a resounding wake-up call to all clinicians that failure to treat pain effectively and failure to provide quality care to palliate distressing symptoms will result in erosion of dignity at life's end. Going further, we can extrapolate that facilitating access to quality palliative care will prevent erosion and possibly augment dignity of all patients with serious life-limiting illnesses. In addition, noble concepts like "respect" on the part of clinicians may be comparably less important in patients' hierarchy of needs and relatively meaningless in the face of

intense pain and other physical suffering that is not effectively alleviated.

2. Even though the dignity rank order card sort tool asked the question "In your opinion, when does a dying patient lose dignity?" the differing responses from patients and providers may possibly reflect more the role and relationship of the respondent to the question and also their proximity to the dying process. The patients (especially the cohort of hospice patients) who were actually faced with the physical reality of the debility and vulnerability that usually accompanies a chronic terminal illness were likely in a different frame of mind compared to the health professionals who were probably responding to the question somewhat hypothetically.

Furthermore, we acknowledge that perceptions of dignity and its loss at the end of life are very personal issues and subject to influence by various factors like the presence (or the absence) of physical, emotional or spiritual distress, ethnic, cultural and religious/spiritual background, socioeconomic status, functional status, and perceptions of connectedness and social support. Also the construct of dignity and its loss at the end of life is likely to be altered as patients' journey through the dying process (although one of our samples was a cohort of dying patients). Thus it behooves all health professionals to routinely and systematically check in with patients with serious life limiting illnesses to ensure that care provided is tailored to augment and avoid erosion of dignity in the final chapter of life.

Our study is noteworthy for the following reasons. First, to the best of our knowledge, our study is the first to systematically identify the factors thought to lead to erosion of dignity at the end of life from the perspectives of community-dwelling nonhospice subjects, hospice patients, and health professionals. Second, we have compared the perceptions of health

professionals to that of patients and we have empirically determined that patients and health professionals differ significantly in their perceptions of factors leading to loss of dignity at life's end. Third, we have a mixed study population of both hospice and non-hospice patients as well as subjects from various ethnic backgrounds and thus we hope that our rank order card sort tool will help health professionals elicit all patients' hierarchy of preferences related to factors influential in loss of dignity at life's end.

This study is limited by the fact that it was conducted in a single VA facility. Furthermore this is a cross sectional study and we acknowledge that the perception of factors leading to loss of dignity may be subject to change depending on proximity to death and better studied longitudinally through the trajectory of serious life limiting illness. However, in our study, we found that the responses of non-hospice community dwelling subjects in our study was greatly positively correlated (correlation coefficient + 0.67) with that of hospice patients. Finally, it is to be noted that dignity at the end of life is experienced within a complex web of cultural meanings<sup>37-42</sup> and thus this concept and the rank order tool needs to be further validated in cross-cultural cohorts. Additionally, the concept of "respect" that was one of the six key factors influencing dignity according to our study is also a very culturally defined construct and further studies are needed to explore culturally sensitive ways of providing respectful care.

In summary, our study offers valuable preliminary data that should be influential in guiding future advances in the study of factors influential in perceptions of erosion of dignity at the end of life. The dignity card sort-tool is a very short and simple tool that can be used to explore patients' perceptions. The DCT is easily administered, not time-intensive (typically takes a patient about 5 minutes to rank order the six DCT cards, once they understand what is asked of them) and can be used either as a self-report measure or can be administered by clinicians. Before recommending the DCT for more general use, it should be tried by others in various clinical settings and on larger samples to test the generalizability of our results. It would also be desirable to track the changes in the patient responses over time as well as concurrently tracking variables like pain, non-pain symptoms, functional status, and quality of life, and emotional and spiritual distress. Furthermore, it is crucial to ascertain whether the determination of patients' perceptions of factors influential in the loss of dignity is of any clinical utility and whether such information would lead to changes in care that will augment (and avoid erosion of) self-perceived dignity in patients with serious and life limiting illnesses.

## Conclusions

In conclusion, both patients and health professionals recognize and value the concept of dignity and dying with dignity. The dignity card-sort tool is a promising tool that may help clinicians identify key factors resulting in perceptions of loss of dignity in adult palliative care patients. We hope that such identification will lead to quality care that will help augment and avoid erosion of patient dignity at life's end.

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## Author Disclosure Statement

No competing financial interests exist.

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#### APPENDIX A. DIGNITY CARD-SORT (DCT) TOOL USER INSTRUCTIONS

Please take a set of eight identical 4x6 size index cards. Listed below is the tool trigger question, the six items in the final tool. Write one item per card. Keep the cards that state "most important factor" and "least important factor" separately. Shuffle the other six cards a few times to create a random order.

Instruct the subject to rank (stack) the six cards in the order of importance with the most important factor to be placed first, the next one second and so on. Finally instruct the subject has to place the card that states "most important factor" on the top of the stack and the card that states "least important factor" at the bottom of the stack and hand it to the health professional. Care should be taken not to misplace the "most important factor" and the "least important factor" cards as this will lead to errors.

Question: In your opinion, when does a dying patient lose dignity?

Most important factor  
 Least important factor  
 When others treat her/him without respect.  
 When her/his wishes are not carried out  
 When s/he is medically mismanaged  
 When s/he loses ability to choose  
 When s/he feels ashamed  
 When s/he dies in pain

Please note the patient's preferred ranking order and then consider asking exploratory questions about each of the items as appropriate (e.g., What can clinicians do to demonstrate respect to you?) and note down the patient's responses. Subsequent care given to the patient should be responsive to the patient's stated wishes and designed to optimize patient's sense of dignity.