

Dignity and the Eye of the Beholder

Harvey Max Chochinov

From the Department of Psychiatry, University of Manitoba and the Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, Manitoba, Canada.

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Address reprint requests to Harvey Max Chochinov, MD, PhD, FRCPC, Manitoba Palliative Care Research Unit, CancerCare Manitoba, Room 3021, 675 McDermot Ave, Winnipeg, Manitoba R3E 0V9, Canada; e-mail: harvey.chochinov@cancercare.mb.ca.

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Here's the Case

Mr. J was a 67-year-old man with an end-stage gastrointestinal malignancy. Having decided he no longer wished to go on living, he had gone on a hunger strike, precipitating an admission to an inpatient tertiary palliative care unit. He reported that, aside from some minor discomforts, his symptom management was quite reasonable. Psychiatric consultation was initiated to determine if depression might be a factor influencing his wish to die. While he was not overtly suicidal, and in fact seemed ambivalent about his wish to die, he did state, "if I were in a European country where I could 'press the button now,' I would." After careful evaluation, it was determined that rather than depression, the driving force behind his desire for death was a sense that life no longer held purpose, meaning, nor hope. While he spoke of a lingering wish to participate in various life activities, he bemoaned the fact that his body was simply too weak and too ill to allow him to do so. That being the case, he expressed the conviction that living had become redundant, his life had no worth, and there was little reason for him to carry on.

How can we offer comfort to patients whose distress is primarily in the realm of the existential, or beyond the reach of an easily administered psychopharmaceutical or analgesic drug? While these matters are often deferred to the expertise of pastoral care professionals, there is a growing movement—particularly in reference to dying patients—for physicians to expand their caring with attentiveness to psychosocial, existential, or spiritual suffering.¹⁻³ In the absence of a clinical depression or formal

psychiatric disorder, the paucity of therapeutic options or formatted approaches can leave oncology practitioners at somewhat of a loss. There may be aspects of despair toward the end of life that may be inherent to the dying process itself. If such distress is not primarily an aberration of neurochemistry, but rather reflects a paucity of hope, meaning, and self worth, what can be done to safeguard or enhance those life-sustaining attributes? And if loss of meaning, hope, and self-worth are the essence of such despair, what implications does this have for palliative care providers?

The Wish to Die

The expression of a desire for death, or of a loss of will to live, is often misconstrued as being synonymous with a request for euthanasia or assisted suicide. There is good evidence, however, that in the context of advanced illness, desire for death can be thought of along a continuum. At its most extreme, desire for death is synonymous with suicidal intent and preoccupation with the wish to die. Far more common, however, are the many patients who, over the course of their cancer illness, experience occasional and fleeting thoughts that not awakening to another day might offer the kind of escape and comfort they perceive life can no longer provide.^{4,5} People tire of pain, disability, changing roles, mounting losses, and fewer prospects for remediation. In the face of depression, poor symptom control, and lack of appropriate supports, these thoughts can become overwhelming. Conversely, in response to appropriate palliation and the rallying of a community

of support, thoughts about the wish to die can dramatically recede.⁴⁻¹⁰

A variety of studies over the last decade have attempted to profile those patients whose distress has led to a request for hastened death.^{4-9,11,12} The social policy implications of these studies aside, the implications for practitioners attempting to provide quality end of life care are substantial. This literature has provided clear evidence that patients expressing a consistent wish to die are most often burdened by various physical symptoms (particularly pain, dyspnea, and fatigue), psychological symptoms (especially depression), lack of social support, along with various existential concerns (especially worries about being a burden to others), losing control, hopelessness, and general concern that the future only holds a worsening of their distress.

But what does it mean to be hopeless in the face of a hopeless prognosis? Several studies have reported that hopelessness is an ardent predictor of suicidal ideation, even among the terminally ill, and that hopelessness is usually most pronounced in patients meeting criteria for major depression.¹³⁻¹⁵ While depression is present in a minority of dying patients (10% to 25%, depending on what criteria are used and the manner in which they are applied), neither hopelessness nor depression define the experience of most individuals nearing death.¹⁶ If hopelessness is not based on prognostic expectation, how is it then to be understood?

Dignity in the Terminally Ill

To broach the question of hope in patients with advanced illness, we must look toward the broader notion of what it means to die with dignity. Several studies have drawn a connection between loss of dignity toward the end of life and a wish to die. Some Dutch studies have reported that loss of dignity, according to physicians, is the most highly cited reason why patients seek out and receive assistance hastening their death.¹¹ The topic of dignity, however, has not been extensively researched, and most often enters palliative care discourse within the context of social policy and philosophical or religious considerations. Thus, while many caregivers give lip service to the idea of providing care that preserves dignity at the end of life, few specifically target maintained dignity as an objective standard of quality end of life care.

Over the last 5 years, some of the first studies have been published regarding the issue of dignity among the dying.¹⁷⁻¹⁹ One such study examined a cohort of 213 terminal cancer patients, with a life expectancy of less than 6 months, asking them to rate their sense of dignity.¹⁷ Of these patients, only 16 patients (7.5%) indicated that loss of dignity was a significant concern. These patients were far more likely to have significantly increased pain, decreased quality of life, difficulty with bowel functioning, heightened

dependency needs (bathing, dressing, incontinence), loss of will to live, increased desire for death, depression, hopelessness, and anxiety. This report also noted that the issue of appearance seemed to highly correlate with perceptions of personal dignity. For those near the end of life, the notion of appearance extended beyond mere looks, and included their own perception of how they are seen by others.

Mr J, being a man with an end-stage bowel malignancy, had many of the various medical problems that go along with this diagnosis. However, to have known him only in this capacity would have overlooked his core identity, and placed his sense of dignity in jeopardy. If care provider perception is limited to gastrointestinal considerations, then the patient's perception of how he is perceived—accurately—is as an advanced bowel malignancy. Therefore, appreciation and acknowledgment of his personhood or core identity as father, grandfather, husband, and someone with a diverse range of interests, can serve to alter the perception of those looking after Mr J, offering him the comfort of knowing that his core identity has been acknowledged and affirmed.

The Dignity Model

An empirically based model of dignity in the terminally ill has been developed (Fig 1).^{18,19} This model provides caregivers a therapeutic map, incorporating a broad range of physical, psychological, social, and existential issues that may affect individual perceptions of dignity. While many palliative care clinicians provide empathic care, the Dignity Model offers a broad framework that can be used to inform dignity-conserving care.

Three major categories have emerged from qualitative analysis of dying patients' perceptions of their sense of dignity,^{18,19} including: (1) Illness-Related Issues; (2) Dignity Conserving Repertoire; and (3) Social Dignity Inventory. These categories refer to broad issues that determine how individuals experience a sense of dignity in the course of their approaching death. Each of these categories contains several carefully defined themes and sub-themes, serving as the foundation for a model of understanding dignity amongst the dying.

Illness-Related Issues and Concerns

These are issues that derive from the illness itself, and threaten to, or actually do, impinge on the patients' sense of dignity. The defining characteristic of these issues is that they are illness mediated, and very specific to the patient's illness experience. The two broad themes subsumed within this category consist of "Level of Independence" (which is determined by one's ability to maintain cognitive acuity, as well as functional capacity, referring to the ability to perform daily living tasks), and "Symptom Distress." Symptom distress was further divided into the subthemes of

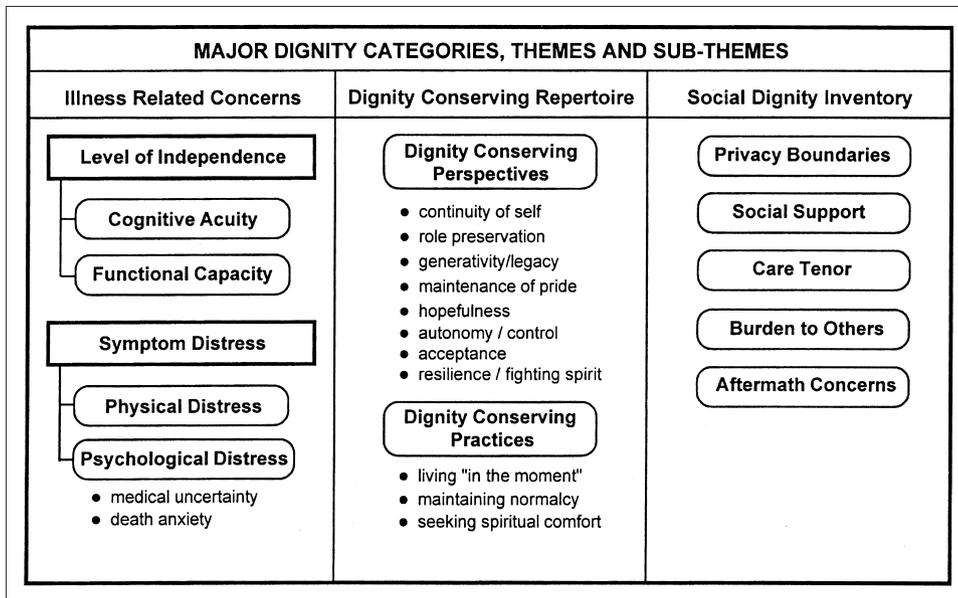


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physical distress and psychological distress. Psychological distress was divided into the following sub-themes: (1) uncertainty (ie, the distress associated with the uncertainties of one's health status) and (2) death anxiety (ie, worry or fear specifically associated with the process or anticipation of death and dying).

Dignity Conserving Repertoire

The second major category that emerged was the Dignity Conserving Repertoire. This category was divided into two major themes, including Dignity Conserving Perspectives and Dignity Conserving Practices.

Dignity Conserving Perspectives are internally held qualities, or a world view consisting of eight sub-themes, including (1) continuity of self (a sense that the essence of who one is continues to remain intact, despite one's advancing illness), (2) role preservation (the ability to continue to function in usual roles, as a way of maintaining a sense congruence with prior views of self), (3) generativity/legacy (the solace and comfort in knowing that something lasting of oneself will transcend death), (4) maintaining pride (the ability to maintain a positive sense of self regard or respect), (5) maintaining hope (an ability to see life as enduring, or having sustained meaning or purpose), (6) autonomy/control (a sense of control over one's life circumstances), (7) acceptance (the internal process of resigning one's self to changing life circumstances), and (8) resilience/fighting spirit (the mental determination to overcome illness-related concerns and optimize quality of life).

Dignity Conserving Practices refer to a variety of personal approaches or techniques that patients used to bolster or maintain their sense of dignity. Three components of

these practices were identified: "Living in the Moment" (focusing on immediate issues or tasks in the service of not worrying about the future), "Maintaining Normalcy" (continuous or routine behaviors, which help individuals manage day-to-day challenges), and "Seeking Spiritual Comfort" (turning toward or finding solace in one's religious or spiritual belief system).

Social Dignity Inventory

This refers to the quality of interactions with others that enhance or detract from one's sense of dignity. The defining characteristic of this inventory is that it refers to external sources or issues that nevertheless impinge on a patient's sense of dignity. Five primary inventory themes were identified, including: (1) "Privacy Boundaries" (the extent to which one's personal environment is encroached on during the course of receiving care or support), (2) "Social Support" (the presence of an available and helpful community of friends, family, or health care providers), (3) "Care Tenor" (the attitude others demonstrate when interacting with the patient that may or may not promote dignity), (4) "Burden to Others" (the distress engendered by having to rely on others for various aspects of one's personal care or management), and (5) "Aftermath Concerns" (the worry or fears in anticipation of the burden or challenges that one's death will impose on others).

This Dignity Model provides an empirically derived theoretical framework, helping us understand the notion of dignity in those nearing death. Furthermore, it provides a foundation on which to both understand how a dying patient may experience a waning of their dignity, and, in turn, provides direction for how to construct dignity-enhancing

Table 1. Dignity Psychotherapy Question Protocol

Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other(s))?
Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future?
In creating this permanent record, are there other things that you would like included?

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interventions for patients nearing death. One such intervention, for example, is a brief psychotherapeutic intervention called Dignity Psychotherapy. This approach is comprised of tape-recorded sessions, which gives patients the opportunity to speak to aspects of life of which they feel proudest, things they feel are, or were, most meaningful, and their personal history they would most want remembered. They are also able to speak about what they might provide in the service of helping to look after their soon-to-be bereft loved ones (Table 1). These sessions are transcribed, edited, and returned to the patient, thereby bolstering the patient's sense of purpose, meaning, and worth, while tangibly experiencing their thoughts and words as having continued value, and satisfying their generativity needs.

Mr J was invited to participate in the Dignity Psychotherapy clinical trial. From the moment he agreed to do so, he indicated that he would defer any decision to “push the button, at least not until this task was completed.” He used this therapeutic trial, mere days before his natural death, as an opportunity to share recollections about his own parents; the trials of living through a devastating war; life as an immigrant; getting married and developing a vocation; the deep and tragic losses that continued to weigh heavily; and the joyful pride he took in his children, grandchildren, and extended community. The role of the therapist was to gently facilitate these poignant disclosures, and to convey the message that Mr J's words, thoughts, and feelings were important, and that the task of sharing these disclosures was profoundly meaningful.

In the absence of such a trial, how might a health care provider otherwise attend to Mr J's distress? While his suf-

fering is considerable, it does not appear to solicit a specific medical response. Intuitively, what might be done? Likely, little time would pass before a care provider would take a seat at the bedside and begin to talk, or perhaps simply listen. And what might be said or heard? The first words would likely be questions about what is happening to him, what matters to him, how he understands what is taking place. Perhaps the care provider might find himself or herself listening to some personal or intimate thought or reflection. In either case, the provider's presence holds tremendous therapeutic power; by taking a place at the bedside, whether asking questions about what matters, or listening to heartfelt disclosures, the provider becomes the beholder. By listening to patients, our perception of who they are extends beyond the confines of their illness, thereby shifting the patient's perception of how they are seen and heard. Validation of their concerns and ascribing meaning to their experience, according to the Dignity Model, can bolster hope, even for those whose illness has long since extended beyond the reach of cure. The reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder.

Author's Disclosures of Potential Conflicts of Interest

The author indicated no potential conflicts of interest.

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