

PERSPECTIVES ON CARE

AT THE CLOSE OF LIFE

Dignity-Conserving Care— A New Model for Palliative Care Helping the Patient Feel Valued

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THE PATIENT'S STORY

Mr S is a 62-year-old man with primary lung cancer diagnosed 18 months ago, with metastases to the liver, brain, and adrenal glands. He has recently developed severe weakness of the left upper and lower extremities with an inability to bear weight, likely related to his brain metastasis. He recently discontinued steroids because of unpleasant adverse effects and completed a 2-week course of antibiotics for pneumonia. His symptoms—which include shortness of breath, seizures, constipation, and occasional agitation—are controlled with ipratropium, phenytoin, senna, haloperidol, and clonazepam, respectively. He now receives comfort care only.

Mr S is a thoughtful and articulate man. He had an unhappy childhood and was later troubled by alcohol abuse associated with extensive difficulties sustaining meaningful, lasting relationships or vocational commitments. He states his life “turned around” 30 years ago, after meeting his wife and joining Alcoholics Anonymous; he has been sober ever since. He and his wife describe a close, trusting relationship. They do not have children. While he had a variety of jobs over the years, “none of which I liked,” he worked most recently as a truck driver. His finances are “difficult,” but he indicates that he and his wife manage to make ends meet. Mr S is participating in a study of “Dignity Psychotherapy,” a new intervention designed to preserve dignity at the end of life. He, his wife, and his physician, Dr F, were interviewed for this article by the author.

PERSPECTIVES

MR S: Dignity is a state of the soul. Dignity is the sense of peace that passes all understanding. I am sure that there is something beyond this lifetime. As a matter of fact, I believe the consciousness goes on from here. Now what the big plan is, nobody has ever got back to me on that, but I am sure it is wonderful . . . because in this lifetime, I have been groping around in the dark and making choices; some of them good and some not so good.

MRS S: Our dignity has been maintained because of the care we have been receiving in the hospital. The staff has been marvelous. They have been helping us as much as they can. I think part of dignity is trying to make him feel that he is still of value.

DR F: I think that individuality and dignity may be the same thing in the end. It ends up being what you see as dignity for

The basic tenets of palliative care may be summarized as the goal of helping patients to die with dignity. The term “dignity” provides an overarching framework that may guide the physician, patient, and family in defining the objectives and therapeutic considerations fundamental to end-of-life care. Dignity-conserving care is care that may conserve or bolster the dignity of dying patients. Using segments of interviews with a patient with advanced lung cancer, his wife, and his palliative care physician, this article illustrates and explores various aspects of dignity-conserving care and the model on which it is based. Dignity-conserving care offers an approach that clinicians can use to explicitly target the maintenance of dignity as a therapeutic objective and as a principle of bedside care for patients nearing death.

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yourself, doesn't it? It is trying to preserve the person as they are; you know, the sensible things like keeping them clean, keeping them comfortable, but also enabling their way of being, what made that person that person.

Why Is the Notion of Dignity Important?

The basic tenets of palliative care, including symptom control, psychological and spiritual well-being, and care of the family, may all be summarized under the goal of helping patients to die with dignity.^{1,2} Considerations of dignity are frequently invoked as the ultimate justification for various, even diametrically opposite, approaches to the care of dying patients, whether in reference to euthanasia and assisted suicide, hydration and nutrition, terminal sedation, or basic symptom management.³⁻¹⁰ In many circles, the term “death with

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dignity" has become synonymous with the right to assisted suicide and euthanasia, removing it from its place as a principle of bedside care for patients nearing death. When the preservation of dignity becomes the clear goal of palliation, care options expand well beyond the symptom management paradigm and encompass the physical, psychological, social, spiritual, and existential aspects of the patient's terminal experience. Systematically broaching these issues within discussions of end-of-life care could allow patients to make more informed choices, achieve better palliation of symptoms, and have more opportunity to work on issues of life closure.

Dignity is defined as "the quality or state of being worthy, honored, or esteemed."¹¹ Despite its unfortunate politicization by the physician-assisted suicide and euthanasia movements, dignity does not relate exclusively to considerations of assisted dying.^{5,7,8} As exemplified by the statements of Mr S, Mrs S, and Dr F, individuals are likely to ascribe their own unique meaning or importance to the notion of dying with dignity, including practical matters such as basic comfort, the tone or quality of care, and considerations of the "soul" or spirit. Dignity provides an overarching framework that may guide the physician, patient, and family in defining the objectives and therapeutic considerations fundamental at the end of life.¹²

A Model of Dignity in Dying Patients

If the preservation of dignity is to be a targeted goal of palliation, the patient's sense of dignity must first be thoroughly understood. Few studies have addressed this issue directly, although several have examined it from the vantage point of a "good death," or a "quality of life" paradigm.^{13,14} Stewart and colleagues,¹³ for example, reviewed the literature to develop a conceptual framework that outlines various domains of influence on the quality of life of dying persons in the context of health care. This framework was meant to guide the development of a comprehensive set of outcome measures, and to evaluate the quality of life of dying persons and the care they require. Others have identified important domains of quality end-of-life care, listing both physical and psychosocial sources of influence.¹⁵⁻¹⁷ The latter domains are variably described as "support of function and autonomy" and "patient and family satisfaction";¹⁵ "overall quality of life" and "psychological well-being and functioning";¹⁶ and "achieving a sense of control" and strengthening relationships.¹⁷ However, without a careful examination of what satisfaction, psychological comfort, or feeling in control and supported means to the dying patient—and because of a paucity of intervention strategies that specifically target these sources of distress—achieving them as therapeutic outcomes remains challenging, and all too often beyond reach.

The notion of a "good death" has been studied in a variety of ways.^{14,18-20} Emanuel and Emanuel¹⁹ described a detailed framework for a good death. While not empirically validated, it does synthesize the dying experience as a process with 4 critical components, including the fixed pa-

tient characteristics, the modifiable elements of the patient's experience, the various interventions that are available, and the overall outcome. Steinhauer and colleagues²⁰ invited patients and caregivers to cite factors that they consider most important at the end of life. These factors included pain and symptom management, preparation for death, decisions about treatment preferences, and being treated as a "whole person." However, these were not further explicated, nor were clinical strategies provided.

Payne et al¹⁴ indicated that "dignity" was often deemed important by patients describing a "good death." Without further clarification, however, the term remains vague and implications for therapeutic responses ambiguous. One study asked members of the patient's care team within 24 hours of the patient's death to rate the deceased's level of dignity during their last 3 days of life.²¹ A list of factors generated by the investigator and health care staff were used as criteria against which to make dignity score ratings. The authors concluded that they were unable to shed light on the deeper meaning and personal relevance of patient dignity, describing it as "an elusive concept" that needed to be studied from the vantage point of patients themselves.

One of the few studies to specifically examine the construct of dignity using patient informants provides a model that helps to describe the notion of dignity-conserving care.²² This study analyzed qualitative interviews of 50 patients in an advanced stage of terminal cancer, and documented their understanding and perceptions of dignity. The dignity-conserving model of care considers 3 broad areas of influence on individual perceptions of dignity: *illness-related concerns*, ie, those things that directly result from the illness; the *dignity-conserving repertoire*, ie, those influences related to the patient's psychological and spiritual resources or makeup; and the *social dignity inventory*, ie, those environmental influences that can affect dignity (TABLE). This model is empirically based on patients dying from cancer, and bears further validation in other specific illnesses or special populations to confirm its generalizability. In addition, this study was conducted in Canadian patients and should be evaluated in other settings to determine whether components such as autonomy are as salient among individuals from other cultures.²³ Although notions of dignity may be influenced by the nature of one's illness, or culturally bound by issues such as religion or ethnicity, the proffered model may be sufficiently broad to encompass these various considerations. Acknowledgment of personal attributes, unique differences, and the essential or even subtle qualities each person embodies is fundamental to the preservation of dignity. As such, although further testing of the model will be required, it appears elastic enough to support its consideration for broad application among patients nearing death.

Illness-Related Concerns

Illness-related concerns refer to those things that result from the illness itself, and threaten to, or actually do, impinge on

the patient's sense of dignity. These concerns are directly related to the patient's illness experience, described in the model as *symptom distress* and *level of independence*. For many patients with an advanced illness, symptom distress (denoting

the experience of discomfort or anguish related to the progression of one's disease) is a defining characteristic of the dying experience.²⁴⁻²⁸ According to this model, symptom distress can be further characterized as *physical distress* and *psy-*

Table. A Model of Dignity and Dignity-Conserving Interventions for Patients Nearing Death

Factors/Subthemes	Dignity-Related Questions	Therapeutic Interventions
Illness-Related Concerns		
Symptom distress		
Physical distress	"How comfortable are you?" "Is there anything we can do to make you more comfortable?"	Vigilance to symptom management Frequent assessment Application of comfort care
Psychological distress	"How are you coping with what is happening to you?"	Assume a supportive stance Empathetic listening Referral to counseling
Medical uncertainty	"Is there anything further about your illness that you would like to know?" "Are you getting all the information you feel you need?"	Upon request, provide accurate, understandable information and strategies to deal with possible future crises
Death anxiety	"Are there things about the later stages of your illness that you would like to discuss?"	
Level of independence		
Independence	"Has your illness made you more dependent on others?"	Have patients participate in decision making, regarding both medical and personal issues
Cognitive acuity	"Are you having any difficulty with your thinking?"	Treat delirium When possible, avoid sedating medication(s)
Functional capacity	"How much are you able to do for yourself?"	Use orthotics, physiotherapy, and occupational therapy
Dignity-Conserving Repertoire		
Dignity-conserving perspectives		
Continuity of self	"Are there things about you that this disease does not affect?"	
Role preservation	"What things did you do before you were sick that were most important to you?"	Acknowledge and take interest in those aspects of the patient's life that he/she most values See the patient as worthy of honor, respect, and esteem
Maintenance of pride	"What about yourself or your life are you most proud of?"	
Hopefulness	"What is still possible?"	Encourage and enable the patient to participate in meaningful or purposeful activities
Autonomy/control	"How in control do you feel?"	Involve patient in treatment and care decisions
Generativity/legacy	"How do you want to be remembered?"	Life project (eg, making audio/video tapes, writing letters, journaling) Dignity psychotherapy
Acceptance	"How at peace are you with what is happening to you?"	Support the patient in his/her outlook Encourage doing things that enhance his/her sense of well-being (eg, meditation, light exercise, listening to music, prayer)
Resilience/fighting spirit	"What part of you is strongest right now?"	
Dignity-conserving practices		
Living in the moment	"Are there things that take your mind away from illness, and offer you comfort?"	Allow the patient to participate in normal routines, or take comfort in momentary distractions (eg, daily outings, light exercise, listening to music)
Maintaining normalcy	"Are there things you still enjoy doing on a regular basis?"	
Finding spiritual comfort	"Is there a religious or spiritual community that you are, or would like to be, connected with?"	Make referrals to chaplain or spiritual leader Enable the patient to participate in particular spiritual and/or culturally based practices
Social Dignity Inventory		
Privacy boundaries	"What about your privacy or your body is important to you?"	Ask permission to examine patient Proper draping to safeguard and respect privacy
Social support	"Who are the people that are most important to you?" "Who is your closest confidante?"	Liberal policies about visitation, rooming in Enlist involvement of a wide support network
Care tenor	"Is there anything in the way you are treated that is undermining your sense of dignity?"	Treat the patient as worthy of honor, esteem, and respect; adopt a stance conveying this
Burden to others	"Do you worry about being a burden to others?" "If so, to whom and in what ways?"	Encourage explicit discussion about these concerns with those they fear they are burdening
Aftermath concerns	"What are your biggest concerns for the people you will leave behind?"	Encourage the settling of affairs, preparation of an advanced directive, making a will, funeral planning

chological distress, with the latter including the anguish associated with not knowing, or being unaware of, aspects of one's health status or treatment (*medical uncertainty*), and the worry or fear associated with the process or anticipation of death and dying (*death anxiety*).^{29,30} Level of independence reflects the degree of reliance an individual has on others and is often determined by the ability to maintain *cognitive acuity* and perform tasks of daily living (*functional capacity*).³¹

Dignity-Conserving Repertoire

The dignity-conserving repertoire incorporates those aspects of patients' psychological and spiritual landscape that influence their sense of dignity. This is often based on pre-existing personality characteristics and on internal resources that patients bring to their illness experience.^{32,33} According to the model, the dignity-conserving repertoire includes *dignity-conserving perspectives*, ie, ways of looking at or coping with one's situation, and *dignity-conserving practices* that can be invoked to bolster or reinforce one's sense of dignity.

The dignity-conserving perspectives include 8 subthemes, each describing a particular influence on a patient's sense of dignity. These perspectives are not hierarchical. No one of them is more potent than any other; one or a few may be as effective for one patient as invoking many or all may be for another. *Continuity of self* refers to a sense that the essence of who one is remains intact, in spite of an advancing illness.^{34,35} *Role preservation* is the ability of patients to function or remain invested in their usual roles, as a way of maintaining congruence with a prior view of themselves.³⁵ *Maintenance of pride* is the ability to maintain a positive sense of self-regard or self-respect.³⁶ *Hopefulness* is seeing life as enduring, or as having sustained meaning or purpose.^{37,38} *Autonomy/control* is the ability to maintain a sense of control over one's life circumstances.³⁰ *Generativity/legacy* is the solace or comfort of knowing that something of one's life will transcend death.^{39,40} *Acceptance* is an ability to accommodate to changing life circumstances.^{41,42} Finally, *resilience/fighting spirit* is the mental determination exercised in an attempt to overcome illness or to optimize quality of life.^{43,44}

Dignity-conserving practices refer to the variety of personal approaches or techniques that patients use to bolster or maintain a sense of dignity. These include 3 subthemes: *living in the moment* to focus on immediate issues in the service of not worrying about the future; *maintaining normalcy* to carry on usual routines and schedules in spite of changing health circumstances; and *finding spiritual comfort*, which is the dignity-sustaining effect of turning toward or finding comfort within one's religious or spiritual beliefs.^{45,46}

Social Dignity Inventory

The defining characteristic of the social dignity inventory is its reference to social issues or relationship dynamics that enhance or detract from a patient's sense of dignity. This facet of the model describes influences on dignity that derive from the patient's environment, and consists of 5 subthemes: *pri-*

vacy boundaries, which is the extent that dignity can be influenced by encroachments on one's personal environment during the course of receiving care or support⁴⁷; *social support*, the presence of an available and helpful community of friends, family, or health care providers⁴⁸⁻⁵⁰; *care tenor*, the attitude others demonstrate when interacting with the patient⁵¹; *burden to others*, the distress engendered by having to rely on others for various aspects of one's personal care or management^{29,52}; and *aftermath concerns*, the worry or fear associated with anticipating the burden or challenges that one's death will impose on others. Unlike burden to others, aftermath concerns refer more specifically to worries about the impact that one's death will have on those left behind.

Differing Notions of Dignity

While the model covers general influences on dignity, each individual will ascribe varying degrees of importance to each of its components. The notion of dignity will vary from individual to individual, and between one circumstance and the next. The difference in how Mr S and Mrs S view the notion of dignity is both striking and illustrative. For Mr S, dignity refers to something from within, and seems to resonate with his core spiritual identity. In other words, his conception of dignity is not dependent on physical or environmental factors (ie, illness-related concerns or the social dignity inventory), but rather seems related to his ability to maintain a positive sense of self-regard (maintenance of pride), a feeling that the essence of who he is remains intact (continuity of self), along with an ability to invest in and gain strength from a rich spiritual life (finding spiritual comfort).^{45,46} For Mrs S, on the other hand, the maintenance of dignity is connected to how she and her husband are treated, and the extent to which they are valued (ie, care tenor). Although it is often argued that palliative care must be philosophically rooted in an acknowledgment of the inherent dignity of individuals, this example illustrates that the question, "what is death with dignity?" requires the important corollary, "according to whom?"^{1-4,24}

For some patients, a sense of dignity is indivisible from their core being or essence. The notion of "basic dignity" has been described as referring to a universal moral quality that is internally held, and inherent in and inalienable from life itself.^{3,53} From this philosophical vantage point, as long as there is life there is dignity. On the other hand, "personal dignity" is frequently invoked in reference to the potential indignities of death and dying.^{3,53,54} Loss of dignity is one of the most common responses given by physicians in studies examining why patients select euthanasia or assisted suicide.^{8,9,53-55} Personal dignity is a construct that is more individualistic, transient, and tied to personal goals and social circumstances. As such, illness-related concerns or components of the social dignity inventory may infringe on personal dignity, perhaps mediated by the resiliency of one's dignity-conserving repertoire. Depending on one's internal resources, individual autonomy may be conflated with

the notion of dignity, and the inability to maintain independence while dying may be experienced as a fundamental loss of dignity, undermining the value of life itself. The experience of other cultures that do not emphasize individual autonomy may provide insights into perspectives in which dignity without independence is possible.²³

Dignity-Conserving Interventions

MR S: *I have been there for other people and it has really done me so much good to be of service. Well, now it is my turn. Somebody may feel as good about taking care of me as I did when I was being of service to other people.*

The physician's challenge in palliative care is to understand how a particular patient and his or her family perceive dignity and create interventions that enhance it. Without adequate strategies to address either terminal distress or suffering for which there is no apparent effective intervention, physicians providing end-of-life care can become demoralized and nihilistic.⁵⁶ Thus, dignity-conserving care, with its expanded range of therapeutic possibilities, has implications for the well-being of patient, family, and care provider alike. According to Sulmasy,⁵⁷ "to treat oneself or others with less than the proper esteem is to behave in an undignified manner." Therefore, delivering care that bestows dignity on others confers and safeguards the dignity of the provider.

Every facet of the dignity model offers guidance on how to provide care that may conserve or bolster the dignity of dying patients. If thought of as a therapeutic map, the dignity model points to directions for care that include biomedical, psychological, psychosocial, existential, and spiritual considerations (Table). Each of these components may be applied to Mr S' experience to better understand the care characteristics most important to him to maintain his dignity.

Managing Illness-Related Concerns

DR F: *If symptom management isn't well handled, discomfort can get in the way of people being themselves, and therefore get in the way of maintaining their dignity.*

MR S: *You know these people wouldn't allow my lights to go out without keeping me as comfortable as possible.*

The illness-related concerns component of the model speaks to the need for attentive management of physical and psychological symptoms. Steinhauser et al²⁰ reported that patients, families, and physicians all agree that pain and symptom management is important at the end of life and integral to the success of improving care for the dying. Symptom distress is a central concern to many patients with an advanced malignancy, because pain is positively associated with depression, anxiety, mood disturbance, and psychological maladaptation.^{26-28,32,58,59} Vigilant symptom management is clearly a cornerstone of quality palliation, and an integral feature of dignity-conserving care. Medical uncertainty and death anxiety, both specific types of psychological distress, suggest that providing information about treatment options or the anticipated unfolding of an illness may further help conserve the

dignity of patients and families plagued by not knowing sufficiently what the future holds in store.^{29,30}

Bolstering Independence

MR S: *I am so angry when I have only one side that works, when I have been a hands-on person all my life. I get angry and frustrated because I can't do things that used to be so easy for me to do.*

The model suggests that the degree of reliance on others can usually be understood in terms of how much one is able to do for oneself (functional capacity), and the patient's degree of mental intactness (cognitive acuity).^{16,31} As such, therapeutic strategies should attempt to bolster the patients' sense of autonomy and their ability to function as independently as possible. Judicious application of orthotic devices, along with physical and occupational therapy, can often bolster functional capacity and the patient's overall level of independence. For patients who are able to be cared for at home, arranging main-floor access, appropriate medical accoutrements (eg, special bedding if required, commodes, braces, orthopedic supports), and sufficient home care and family respite supports can allow patients to remain at home and maximize autonomy within the constraints of their deteriorating health.³¹

Dignity-Conserving Strategies

MR S: *If somebody has to go and wipe off my private parts, well, that is what they do and I am sorry, I didn't do it on purpose but that is their job and I can allow them to do it. I don't see that as having anything to do with my dignity. I have other things to be proud of.*

The dignity-conserving repertoire facet of the model speaks to the internal resources that a patient brings to an illness, based on past experience, psychological makeup, and the richness of their spiritual life. Many of the subthemes within the dignity-conserving repertoire focus on the patient's sense of continued worth, and approximate Cassell's notion of suffering.³⁴ According to Cassell, to the degree that personhood is threatened or compromised, suffering will be proportionate. However, it can be difficult to maintain one's sense of essence (continuity of self) or self-regard (maintenance of pride), or to believe that prior roles are still worthy of investment (role preservation) in the face of deteriorating health circumstances.³⁴⁻³⁶

Even though Mr S was no longer able to work or anticipate a prolonged life span, having him participate in discussions about his treatment options, care planning, and financial issues affecting his wife's future seemed to enhance his sense of being an active and vital participant in a life that was not yet completed. Dignity-conserving strategies should attempt to reinforce the patient's sense of self-worth by adopting a therapeutic stance that conveys steadfast respect for the patient as a whole person with feelings, accomplishments, and passions independent of the illness experience. This is supported by Cassem's notion that dying patients

Box. Dignity Psychotherapy Question Protocol

Can you tell me a little about your life history, particularly those 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 (eg, family, vocational, community service) you have played in life?

Why are 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, in order to provide them with comfort or solace?

In creating this permanent record, are there other things that you would like included?

derive self-respect from a sense that others value them for what they have done and for who they are.⁶⁰ It is no coincidence that patients who feel more appreciated are less likely to have considered euthanasia or physician-assisted suicide.⁶¹ Ascribing importance to the things that the patient holds dear acknowledges individual personhood, while at the same time strengthening the empathic, therapeutic connection between the patient, the patient's family, and the care provider (Table).

Hopefulness, an ability to see life as enduring or having sustained meaning or purpose, is another subtheme of the dignity-conserving repertoire.^{37,38} According to Viktor Frankl,⁶² "what matters is not the meaning of life in general, but rather the specific meaning of a person's life at a given moment." For dying patients, such meaning can derive from visits with loved ones, reviewing lifetime photographs or stories, bequeathing gifts to loved ones, or engaging in meaning-engendering projects (such as organizing photo albums, writing journals, or even preparing one's own obituary).⁶³ In each instance, these activities provide the patient with a sense that they continue to serve a vital function, and that life maintains its purpose and dignity.

Several studies have reported that the undermining of autonomy has the potential to undermine the value patients ascribe to life, with hopelessness and loss of control correlated with a heightened interest in death-hastening measures.⁶³⁻⁶⁸ Therefore, strategies that bolster autonomy and control are paramount to the conservation of dignity. One basic strategy is to ensure that patients are involved in their care and treatment decisions, if they wish. Dr F indicated that when Mr S was first admitted, he was medicated because of an apparent problem with insomnia, disruptive to the ward routine. This resulted in him becoming more confused and agitated. In an attempt to heighten his sense of autonomy and self-reliance, and to facilitate a return to his normal routines, Dr F and Mr and Mrs S decided that reducing his nighttime sedatives and spending time outdoors would be helpful. Loss of autonomy and control is a pervasive experience for patients with an advancing illness. Measures that return control to the patient should be considered and instituted whenever feasible.

For some patients, the preservation of dignity can be achieved by a connection to a spiritual or religious practice or community (finding spiritual comfort).^{45,46} Facilitating these connections and enabling the expression of culturally held beliefs or denominationally appropriate practices constitute dignity-conserving care. For others, ensuring that some aspect of life may transcend death (ie, the generativity/legacy subtheme) holds the key to a maintained sense of dignity.^{39,40} For these patients, participating in a life project such as making an audiotape or videotape, writing letters, keeping a journal, or engaging in dignity psychotherapy (as described below) can offer the comfort of knowing that something of their essence or personhood will survive beyond death.

Dignity Psychotherapy

MRS S: *Being able to read his words will be a way of helping me to remember him, and to think of him. I didn't always understand him, because he was a free spirit and I was the worrier. Maybe I didn't trust God enough. I'm glad I'll have his words to comfort me.*

For many patients, the maintenance of dignity seems connected to the notion that something of their essence will survive beyond the event of death itself (ie, the generativity/legacy subtheme). The psychotherapy clinical trial in which Mr S participated is based in part on this premise. In dignity psychotherapy, patients dying of any cause and thought to be within the last 6 months of life are asked to speak on tape about various aspects of life they would most want permanently recorded and ultimately remembered. Patients are asked a series of questions, based on the dignity model, which focus on things that they feel are most important and that they would most want their love one(s) to remember. Whether or not they feel they have made an important contribution in life, this intervention can engender a sense that they will leave something of value, whether to thank loved ones, ask for forgiveness, leave important information or instructions, or provide words of comfort (BOX).

Dignity psychotherapy interviews are transcribed and then edited so that they read like well-honed narratives. The "life manuscript" is returned to the patient, in most instances to be left for surviving loved ones. This therapeutic process is intended to enhance a sense of meaning and purpose for dying patients. In providing a lasting legacy for their loved ones, patients may sense that their dignity has been duly honored and therefore enhanced.

The Social Dignity Inventory

MRS S: [The staff] have showed an interest in us and that is very important. They have been open to my coming to them and exploring [every] possibility. They have just been so helpful . . . that is really appreciated. I really admire them.

DR F: If all you see when cleaning someone up is excrement, that patient's dignity will suffer. If, on the other hand, you can see the whole person, that person's dignity is more likely to stay intact.

The social dignity inventory component of the model points to environmental or contextual influences on the patient's sense of dignity. Studies find that dying patients' perceptions of support are significantly related to psychological adjustment.^{48-50,69} As such, measures that use the social support network—involving family, friends, health care providers, other patients, spiritual practitioners, and others—fall within the realm of dignity-conserving care. This must be balanced by each individual's wish or need for maintaining stricter privacy boundaries, with sensitivity toward both personal and social boundaries (Table).

Burden to others can be a particularly difficult source of distress for patients, with some studies reporting that it is highly associated with an interest in physician-assisted suicide and euthanasia.^{55,61,64} When patients perceive that their illness is weighing heavily on their support network, or that death will continue to inflict a burden on those who will be left behind (ie, aftermath concerns), clinicians should encourage open, frank discussion about these issues. Fears often can be allayed, and patients reassured that burdens are usually counterbalanced by the privilege of others' being able to be with them, or look after them, in the little time they have left. Aftermath concerns can most readily be addressed by encouraging patients to settle their affairs, write an advance directive, name a health care proxy, make a will, or even—should they so wish—be involved in funeral planning.

Burden to others can be accentuated when patients perceive that their personhood or net worth has been reduced to their illness and its associated encumbrances.^{28,52} One of the most potent dignity-conserving strategies lies in understanding the notion of care tenor.⁵¹ This denotes the affective and attitudinal tone of care and, if dignity is to be maintained, must convey respect and an affirmation of the patient's continued worth. While this can sometimes be achieved by inquiry into the things that have mattered and still matter most to the patient (see "Dignity-Conserving Repertoire"), it is most fundamentally based in the ability to see the patient as a whole

person, deserving of honor and esteem. Maintaining dignity goes beyond what one does with or to a patient, and often resides in how one sees the patient.

CONCLUSIONS

Although dignity-conserving care should be evaluated and validated in diverse populations, the concept of conserving dignity in end-of-life care should become part of the palliative care lexicon, and the overarching standard of care for all patients nearing death. Such care should encompass a broad range of interventions, based on an understanding of the many sources of distress that may infringe on a patient's sense of dignity. What defines dignity for each patient and his or her family is unique and should be considered by clinicians to provide the most comprehensive, empathic end-of-life care possible. The model of dignity offers a framework by which clinicians can consider this task, enabling dying with dignity to become an explicitly targeted outcome.

Dignity-conserving care comprises not only what one does to patients, but how one sees patients. Affirmation can "re-
mind the dying of their dignity . . . [which] is precisely what it means to comfort the dying."⁵⁷ When dying patients are seen, and know that they are seen, as being worthy of honor and esteem by those who care for them, dignity is more likely to be maintained. In turn, caregivers are imbued with the dignity rendered by their actions, better enabling them to provide care and comfort to those nearing death.

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Other Resources: For a list of relevant Web sites, see the JAMA Web site at <http://jama.ama-assn.org/issues/v287n17/abs/jel10003.html>.

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REFERENCES

1. Abiven M. Dying with dignity. *World Health Forum*. 1991;12:375-381.
2. Madan TN. Dying with dignity. *Soc Sci Med*. 1992;35:425-432.
3. Pullman D. Dying with dignity and the death of dignity. *Health Law J*. 1996;4:197-219.
4. Kade WJ. Death with dignity: a case study. *Ann Intern Med*. 2000;132:504-506.
5. Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon: the second year. *N Engl J Med*. 2000;342:598-604.
6. Chater S, Viola R, Paterson J, Jarvis V. Sedation for intractable distress in the dying: a survey of experts. *Palliat Med*. 1998;12:255-269.
7. Quill TE. Death and dignity: a case of individualized decision making. *N Engl J Med*. 1991;324:691-694.
8. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342:557-563.
9. van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet*. 1991;338:669-674.
10. van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med*. 1996;335:1699-1705.
11. *Webster's International Dictionary*. 2nd ed. Springfield, Mass: Merriam; 1946: 730.

12. Quill TE. Perspectives on care at the close of life: initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA*. 2000;284:2502-2507.
13. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage*. 1999;17:93-108.
14. Payne SA, Langley-Evans A, Hillier R. Perceptions of a "good" death: a comparative study of the views of hospice staff and patients. *Palliat Med*. 1996;10:307-312.
15. Lynn J. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc*. 1997;45:526-527.
16. Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.
17. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281:163-168.
18. Cohen SR, Mount BM. Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *J Palliat Care*. 1992;8:40-45.
19. Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet*. 1998;351(suppl 2):S1121-S1129.
20. Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-2482.
21. Turner K, Chyle R, Aggarwal G, Phillip J, Skeels A, Lickiss JN. Dignity in the dying: a preliminary study of patients in the last three days of life. *J Palliat Care*. 1996;12:7-13.
22. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002;54:433-443.
23. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "you got to go where he lives." *JAMA*. 2001;286:2993-3001.
24. Wanzer SH, Federman DD, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients: a second look. *N Engl J Med*. 1989;320:844-849.
25. Breitbart W, Jaramillo J, Chochinov HM. Palliative and terminal care. In: Holland J, ed. *Textbook of Psycho-oncology*. New York, NY: Oxford University Press; 1998:437-449.
26. Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.
27. Caraceni A, Portenoy RK, for the International Association for the Study of Pain IASP Task Force on Cancer Pain. An international survey of cancer pain characteristics and syndromes. *Pain*. 1999;82:263-274.
28. Portenoy RK, Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Res*. 1994;3:183-189.
29. Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliat Med*. 1999;13:19-35.
30. Hinton J. Sharing or withholding awareness of dying between husband and wife. *J Psychosom Res*. 1981;25:337-343.
31. Tigges KN. Occupational therapy. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. New York, NY: Oxford University Press; 1999:829-837.
32. Lichter I. Some psychological causes of distress in the terminally ill. *Palliat Med*. 1991;5:138-146.
33. Cherny NI, Coyle N, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care*. 1994;10:57-70.
34. Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306:639-645.
35. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996;12:237-252.
36. Byock IR. When suffering persists. . . . *J Palliat Care*. 1994;10:8-13.
37. Chochinov HM, Wilson KG, Enns M, Lander S. Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics*. 1998;39:366-370.
38. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284:2907-2911.
39. Lichter I, Mooney J, Boyd M. Biography as therapy. *Palliat Med*. 1993;7:133-137.
40. Fisher BJ. Successful aging, life satisfaction, and generativity in later life. *Int J Aging Hum Dev*. 1995;41:239-250.
41. Taylor SE. Adjustment to threatening events: a theory of cognitive adaptation. *Am Psychol*. 1983;38:1161-1173.
42. Wool MS. Understanding denial in cancer patients. *Adv Psychosom Med*. 1988;18:37-53.
43. Greer S. Fighting spirit in patients with cancer. *Lancet*. 2000;355:847-848.
44. Nelson DV, Friedman LC, Baer PE, Lane M, Smith FE. Attitudes of cancer: psychometric properties of fighting spirit and denial. *J Behav Med*. 1989;12:341-355.
45. Holland JC, Passik S, Kash KM, et al. The role of religious and spiritual beliefs in coping with malignant melanoma. *Psychooncology*. 1999;8:14-26.
46. Daaleman TP, VandeCreek L. Placing religion and spirituality in end-of-life care. *JAMA*. 2000;284:2514-2517.
47. Nemceková M, Ziakova K, Mistuna D, Kudlicka J. Respecting patients' rights. *Bull Med Ethics*. 1998;13-18. No. 140.
48. Katz JS, Sidell M, Komaromy C. Dying in long-term care facilities: support needs of other residents, relatives, and staff. *Am J Hosp Palliat Care*. 2001;18:321-326.
49. Andershed B, Ternstedt BM. Development of a theoretical framework describing relatives' involvement in palliative care. *J Adv Nurs*. 2001;34:554-562.
50. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care*. 1996;12:10-20.
51. Barthow C. Negotiating realistic and mutually sustaining nurse-patient relationships in palliative care. *Int J Nurs Pract*. 1997;3:206-210.
52. Kinsella G, Cooper B, Picton C, Murtagh D. A review of the measurement of caregiver and family burden in palliative care. *J Palliat Care*. 1998;14:37-45.
53. Pullman D. Human dignity and the ethics and aesthetics of pain and suffering. *Theor Med Bioeth*. In press.
54. Kant I. *The Fundamental Principles of the Metaphysics of Morals*. Abbott TK, trans. Buffalo, NY: Prometheus Books; 1987.
55. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338:1193-1201.
56. Portenoy RK, Coyle N, Kash KM, et al. Determinants of the willingness to endorse assisted suicide: a survey of physicians, nurses, and social workers. *Psychosomatics*. 1997;38:277-287.
57. Sulmasy DP. Death and human dignity. *Linacre Q*. 1994;61:27-36.
58. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152:1185-1191.
59. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet*. 1999;354:816-819.
60. Cassem N. The dying patient. In: Hackett T, Cassem N, eds. *The Massachusetts General Hospital Handbook of General Hospital Psychiatry*. Littleton, Mass: PSG Publishing Co Inc; 1987:332-352.
61. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*. 2000;284:2460-2468.
62. Frankl VE. *Man's Search for Meaning*. New York, NY: Simon & Schuster; 1963:171.
63. Block SD. Perspectives on care at the close of life: psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*. 2001;285:2898-2905.
64. Wilson KG, Scott JF, Graham ID, et al. Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med*. 2000;160:2454-2460.
65. Back AL, Wallace JJ, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington state: patient requests and physician responses. *JAMA*. 1996;275:919-925.
66. Seale C, Addington-Hall J. Euthanasia: why people want to die earlier. *Soc Sci Med*. 1994;39:647-654.
67. Block SD, Billings JA. Patient requests to hasten death: evaluation and management in terminal care. *Arch Intern Med*. 1994;154:2039-2047.
68. Ganzini L, Johnston WS, Hoffman WF. Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*. 1999;52:1434-1440.
69. Dobrzt MC. Causal influences of psychological adaptation in dying. *West J Nurs Res*. 1993;15:708-729.